

# Ganono'se'n e yo'gwilode'

One Who is Full of Our Traditional Knowledge



## Ethical Guidelines for Aboriginal Research Elders and Healers Roundtable

**A Report by the Indigenous Health Research Development Program  
To the Interagency Advisory Panel on Research Ethics**

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**Forward:**

The Indigenous Health Research Development Program is excited to present to the Interagency Advisory Panel on Research Ethics (PRE) our report, “Ethical Guidelines for Aboriginal Research: Elders and Healers Roundtable.” This work is the compilation of a multitude of voices representing Aboriginal and non-Aboriginal academics, Elders, Chiefs, Faithkeepers, Healers, students and youth.

We utilized a two-step process in order to best access a variety of perspectives surrounding Aboriginal research ethics. First, a roundtable was gathered in order to hear the current practices and policies in place for Aboriginal research, and to develop a list of concerns regarding these current practices. Second, we gathered as a consensual group to a vetting based on the report from the roundtable, which resulted in this submission.

The results from this process are invaluable. The concerned participants demonstrated their ongoing commitment to the protection of Indigenous Knowledge and the health of Indigenous communities. The Elders and Healers chosen to participate in this process have a seven, and in some cases, ten-year commitments to collaborative work on these important issues.

Moreover, Aboriginal and non-Aboriginal participants, Western and Indigenous researchers and practitioners worked cooperatively to develop these guidelines in a most equitable manner. The report follows the organic nature of the two-step process utilized and is the consensual agreement of all participants on the development of ethical guidelines for Aboriginal research.

## **Acknowledgments:**

The Indigenous Health Research Development Program would like to acknowledge the great efforts put forth by the members of the roundtable in their support of this project. To the Elders and Knowledge Keepers, Birgil Kills Straight, Elize Hartley, Francis Thunderhawk, Judy Swamp, Hubert Skye, Norma General, Sara Smith, Tom Deer and Kevin Deer, thank you. To the Chiefs, Allen McNaughton, Arnie General, Jake Swamp and Arvol Looking Horse, thank you. To the Healers and Traditional Practitioners, Elva Jamieson, Katsi Cook, Louise McDonald and Verdie Bennet, thank you. To the researchers and ethics boards' members, Liliana Madrigal, Ruby Jacobs, Pat Hess, James Lamouche, Valerie O'Brien and Rauna Kuokkanen, thank you. To the graduate students, Bonnie Freeman, Rick Monture and Theresa McCarthy, thank you. To our youth, Ali Darnay, Jacob Pratt and Jason Whitebear, thank you. To the non-Native researchers, Brian Thomas, Carl Rothfels, Kate Oxley, Wayne Warry, Micheal Wilson and Gary Dunbrill, thank you.

We would also like to acknowledge and honour our Elders for sharing their wisdom and guidance with us. Your voices are important to us and we thank you for your words and language. We would also like to extend our words of pride for the thoughtfulness and passion of our youth. Ethical research, Indigenous Knowledge and issues of ownership, control, access and permission are of paramount importance to this work and the presentations put forth by the National Aboriginal Health Organization, the Amazon Conservation Team, Royal Botanical Gardens and Six Nations Health Service are appreciated and valued.

And, to Six Nations Polytechnic for housing this event, nya:weh!

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**Background:**

This report is a response to the call for research ethics guidelines in Aboriginal research by the Canadian Institute of Health Research, Institute of Aboriginal Peoples' Health. The Indigenous Health Research Development Program is an Aboriginal Capacity and Developmental Research Environments (ACADRE) centre awarded to McMaster University and the University of Toronto in 2002. One of our offices is situated within the community of Six Nations and is uniquely positioned to conduct community-based consultations in the thematic area of Aboriginal health research. The focus of this report is on a dialogue of cultural values in biomedical and traditional health research ethical principles. Traditional medicine and spiritual healing have been increasingly recognized as central components to any culturally-relevant system of care. In Ontario, for example, traditional medicine is recognized and promoted in the Aboriginal Health Policy (Ontario 1994)<sup>1</sup>, and holistic approaches to health have been incorporated into healing lodges, health access centres and other initiatives under the Aboriginal Healing and Wellness Strategy (AHWS). These institutional approaches raise questions about the relative compatibility or complementarities of Indigenous and biomedical research ethics and approaches to health care research and health promotion.

Indigenous Knowledge incorporates both traditional and contemporary health systems and beliefs as well as the appropriate Indigenous methodologies for accessing and disseminating health information.<sup>2</sup> This project has brought together Aboriginal researchers, community members and, specifically, Elders and traditional healers, to discuss, document, plan and evaluate Indigenous health beliefs and practices that can be developed into a set of ethical principles.

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<sup>1</sup> Ontario Ministry of Health. *New Directions: Aboriginal Health Policy for Ontario*. Toronto: Queens Printer for Ontario. 1994.

<sup>2</sup> Linda Smith, *Decolonizing Methodologies: Research and Indigenous Peoples* (New York: St. Martins Press, 1999).

We have built upon pre-existing relationships between Indigenous Studies, Lakota, Cree, Haudenosaunee, Métis, Anishnabe and Navajo Peoples. The National Aboriginal Health Organization (NAHO) has worked closely with Six Nations on previous projects and agreed to collaborate on this initiative. These developed relationships demonstrate the strength of building a network of Elders and leaders working in a multi-cultural environment. The levels of research that different Indigenous communities have been exposed to and/or engaged, in the area of Indigenous health research varies; however the engaged participants were pleased with having the opportunity to learn from each other and share their views.

**Introduction:**

The collaborators of this project have previously conducted research in the area of Traditional Medicine. NAHO, an organization governed by five national Native organizations, is dedicated to the production of health knowledge and is a partner in the facilitation of ethical guidelines. Both NAHO and the Indigenous Health Research Development Program (IHRDP) supported and participated in the roundtable of Aboriginal health research ethics. Furthermore, the roundtable incorporated the Six Nations community in the development of ethical principles and guidelines.

One aim of the project is to account for the diverse range of Aboriginal experiences with Indigenous medical knowledge. Aboriginal peoples' orientation to Indigenous Knowledge is influenced by a variety of factors, and we recognize that community experience differs with population size, traditional cultural orientation, service levels, local historical relations and contemporary health care utilization.

Together, Elders and Healers shared their ideas about current Aboriginal research ethics practiced, identified best practices of ethical conduct and articulated appropriate protocols, as outlined in this report. The second phase of the project was a vetting process, which allowed for

the critical dissection of the drafted report on guidelines and practices. The accumulation of findings listed within this report as well as the concrete direction put forth by the vetting process has led to this formal report.

### **Methodology**

Both the roundtable and vetting process were held at Six Nations Polytechnic, located on Six Nations of the Grand River. Elders, Healers, youth and Aboriginal academics and researchers had the opportunity to share their ideas about the ways Aboriginal research ethical values are practiced. They identified good ethical conduct, and discussed how to develop protocols which incorporate ethical values. Preliminary research findings and reports were made available for discussion and commentary at a second workshop involving, again, NAHO, IHRDP, Elders, community members and professionals. The vetting process also engaged health researchers and Aboriginal student researchers in discussions. The collaborators were responsible for overseeing the development of ethics and protocol guidelines, providing feedback and disseminating the findings.

The timeframe was very short. Both the roundtable and the vetting were executed within a four-month period. The roundtable consisted of two full-day meetings held at Six Nations Polytechnic in November. The first day engaged Elders, Healers, Traditional Knowledge carriers, community members, Aboriginal students, researchers and Aboriginal health organizations in a dialogue about ethic protocols in Aboriginal communities. On this day, there were presentations from four organizations that have conducted research in and with Indigenous communities. Discussions continued into the second day, when the participants had an opportunity to respond to the issues arising from each research project and provide feedback on the presentations that were made. The Elders and Healers requested that the roundtable allow for

a space where they could discuss amongst themselves sacred knowledge. This request was honoured in respect of traditional protocols.

A report of the roundtable findings was distributed one month later. In February, the entire group of thirty-nine met again at Six Nations for a vetting, during which they evaluated and analyzed in detail the draft report on ethical guidelines. This second phase provided participants of the roundtable an opportunity to verify and expand upon issues and points most relevant for the report. Prior to the vetting, the members of the roundtable were given draft copies of the report, providing them an opportunity to comment upon the roundtable findings. A key principle originating from the vetting process was the recognition of language as the foundation upon which guiding ethical principles are founded. The roundtable therefore supported the translation of this document into an Indigenous language, namely, Mohawk.

The objective of the roundtable and vetting process was to help facilitate a dialogue among diverse participants on ethics and the extent to which the concept of ethics is abstract and carries different meanings and understandings for different people. How one person may understand ethics and protocols is not to say that it will be understood in the same manner by all people. For Indigenous people, knowledge is constructed and disseminated in the teachings of the people to which it speaks and the land to which they belong. Knowledges produced within a group or community dealing with land, the spiritual and the ceremonial, as well as the economic, political and social, are mutually dependent on each other.

### **Consent**

Consent was given by all participants, permitting us the opportunity to freely integrate their words – at points, as one consensual voice. Traditional Western practices of confidentiality and the use of pseudonyms to conceal the identity of informants were seen as dehumanizing, colonial and patronizing. By identifying the Elders, strategically chosen for their expertise, their

knowledge was honoured. The recognition of their wisdom and knowledge is appropriate within this context.

Further, we as a research team, agreed to submit a draft for approval of release and to provide each member of the roundtable a final bound copy of the report. The entire process was documented through audio taping and written record upon approval of all participants. Prior to our final submission, the report was sent for a second time to the participants for their final approval.

Representation from Indigenous and non-Indigenous communities included academics, graduate students and McMaster University's research ethics board, each of whom indicated their expectations for the roundtable. Most of the community people stated that they were there to share their experience and knowledge with respect to sacred medicines, Traditional Knowledge and intellectual property rights.

The thirty-nine members of the ethics roundtable represented a variety of communities, universities and research organizations involved with research, ethics, Traditional Knowledge, medicine and health. From the traditional Aboriginal community, we had fourteen persons including Elders, Chiefs and Knowledge Keepers. Additionally, our group comprised of six Aboriginal members of the health field including researchers, practitioners, and persons in policy and/or administrative positions. Moreover, Aboriginal researchers, graduate students and academics comprised another six members of our roundtable, with another three members representing youth. Additionally, seven non-Aboriginal academics were invited who conducted research in the area of Aboriginal health and/or traditional medicine or were members on university ethics committees.

**Elders/ Knowledge Keepers**

Birgil Kills Straight	Elder	Lakota	Pine Ride, SD
Elize Hartley	Elder	Métis	Hamilton, ON
Francis Thunderhawk	Elder	Lakota	Kyle, SD
Judy Swamp	Elder	Mohawk	Akwesasne, NY
Hubert Skye	Faith Keeper	Cayuga	Six Nations, ON
Norma General	Faith Keeper	Cayuga	Six Nations, ON
Sara Smith	Elder	Mohawk	Six Nations, ON
Tom Deer	Confederacy Secretary	Kanienkeha:ka	Ohsweken, ON
Kevin Deer	Knowledge Keeper	Mohawk	Khanawake, QC

**Chiefs**

Allen McNaughton	Chief	Mohawk	Six Nations, ON
Arnie General	Chief	Onondaga	Six Nations, ON
Jake Swamp	Chief	Mohawk	Akwesasne, NY
Ernest Sundown	Chief	Cree	Joseph Big Head, SK
Arvol Looking Horse	Chief	Lakota	Cheyenne River, SD

**Healers/ Traditional Practitioners**

Elva Jamieson	Traditional Healer	Cayuga	Six Nations, ON
Katsi Cook	Midwife	Mohawk	Akwesasne, NY
Louise McDonald	Cultural Carrier	Mohawk	Akwesasne, NY
Karen Hill	Medical Doctor		Six Nations
Verdie Bennet	Traditional Healer	Navajo	Albuquerque, NM

**Researchers/ Ethics Members.**

Dawn Martin-Hill	Acad. Dir. ISP, McMaster/ Co-investigator-IHRDP	Mohawk	Six Nations, ON
Liliana Madrigal	Amazon Conservation Team	Spanish	Arlington, VA
Ruby Jacobs	Six Nations Health Director		Six Nations, ON
Pat Hess	Royal Botanical Gardens	Cayuga	Six Nations, ON
James Lamouche	Policy Analyst- NAHO	Cree	High Prairie
Valerie O'Brien	Research/ Training Coordinator-IHRDP	Cree	Northern Ontario

**Graduate Students**

Bonnie Freeman	Graduate Student Social Work ethics committee	Mohawk/Algonquian	Six Nations, ON
Rick Monture	Graduate Student	Mohawk	Six Nations, ON
Theresa McCarthy	Graduate Student /Instructor	Onondaga	Six Nations, ON

**Youth**

Ali Darnay	Student	Anishnabe	Garden River, ON
Jacob Pratt	Student/Apprenticing Healer	Dakota	Sioux Valley, MB
Jason Whitebear	Youth Coordinator-NAHO	Cree	Whitebear

**Non-Native**

**Researchers**

Brian Thomas	McMaster Ethics Board	Canadian	North Carolina
Carl Rothfels	Royal Botanical Gardens	Canadian	Hamilton, ON
Kate Oxley	Royal Botanical Gardens	Canadian	Hamilton, ON
Wayne Warry	Assoc. Prof. McMaster/ Co-Investigator-IHRDP	Canadian	Hamilton, ON
Micheal Wilson	Secretary- McMaster Ethics Board	Canadian	Hamilton, ON

Danielle Soucy	Research Ethics & Knowledge Transfer Projects Coordinator - IHRDP	Canadian	Hamilton, ON
Gary Dunbrill	McMaster Social Work Ethics Committee	Canadian	Hamilton, ON

The roundtable was conscious of gender equally of participants. All participants of the roundtable had an interest in, dedication too, or role in the production and/or protection of Indigenous Knowledge.

### **Cultural Framework – Indigenous Knowledge**

Indigenous pedagogy acknowledges diverse ways of knowing and respects the pluralism of knowledge. It is an acknowledgment of geographic and cultural diversity as a part of Indigenous knowledge, and their difference as the contribution to our knowledge base. As defined in the *Report on the Protection of Heritage of Indigenous People*, written by Dr Daes for the United Nations, “Indigenous knowledge is a complete knowledge system with its own epistemology, philosophy, and scientific and logical validity... which can only be understood by means of pedagogy traditionally employed by the people themselves.”<sup>3</sup>

Mohawk scholar Marlene Brant Castellano suggests that Indigenous Knowledge has a multiplicity of sources, including traditional, spiritual, and empirical.<sup>4</sup> Indigenous Knowledge engages a holistic paradigm that acknowledges the emotional, spiritual, physical, and mental well-being of a people. The cultural diversity of Indigenous Peoples is addressed through the recognition that Indigenous Knowledge is attached to the language, landscapes, and cultures from which it emerge. However, pluralistic Indigenous paradigms have been undermined by more hierarchical and linear Western approaches. Scholar Vandana Shiva argues that,

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<sup>3</sup> Quoted in Marie Battiste & J. Youngblood Henderson, *Protecting Indigenous Knowledge and Heritage: A Global Challenge* (Saskatoon: Purich Publishing Ltd., 2000), 41.

<sup>4</sup> Marlene Brant Constellano. “Updating Aboriginal Traditions of Knowledge” in George Dei, Budd Hall and Dorothy Goldin Rosenberg, eds. *Indigenous Knowledges in Global Contexts: Multiple Readings of Our World* (Toronto: University of Toronto Press, 2000), 23-30.

*under the colonial influence the biological and intellectual heritage of non-western societies was devalued. The priorities of scientific development...transformed the plurality of knowledge systems into a hierarchy of knowledge systems. When knowledge plurality mutated into knowledge hierarchy, the horizontal ordering of diverse but equally valid systems was converted into vertical ordering of unequal systems, and the epistemological foundations of western knowledge were imposed on non-western knowledge systems with the result that the latter were invalidated.*<sup>5</sup>

This report uses an Indigenous Knowledge framework and seeks to address critical issues of Indigenous authority, the appropriation and misrepresentation of Indigenous Knowledge, and the marginalization of Indigenous ways of knowing through Western empirical research.<sup>6</sup>

Marie Battiste and J. Youngblood Henderson describe the principles articulated within an Indigenous Knowledge framework. They argue:

*Indigenous peoples regard all products of the human mind and heart as interrelated within Indigenous knowledge. They assert that all knowledge flows from the same source: the relationships between global flux that needs to be renewed, the people's kinship with the spirit world. Since the ultimate source of knowledge is the changing ecosystem itself, art and science of a specific people manifest these relationships and can be considered as manifestations of people's knowledge as a whole.*<sup>7</sup>

Indigenous people, in all their diversity, have a common set of assertions about Indigenous reality which, when put together, form an epistemological foundation and a collective paradigm. Indigenous, for the purposes of this report, is defined as she/he who: a) is born into lands with which she/he maintains an intimate and spiritual relationship; b) belongs to a distinct

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<sup>5</sup> Quoted in Dei, Hall and Rosenburg, *Indigenous Knowledges in Global Contexts*, vii.

<sup>6</sup> Dei, Hall and Rosenburg, *Indigenous Knowledges in Global Contexts*; Battiste and Henderson, *Protecting Indigenous Knowledge and Heritage*; and Smith *Decolonizing Methodologies*.

<sup>7</sup> Battiste and Henderson, "Protecting Indigenous Knowledge and Heritage." 43.

linguistic cultural group; c) has maintained a collective oral memory reaching as far back as creation; d) has unique customs and ceremonies that sustain her/his cultural survival and well-being; and e) has maintained the view that Elders are the knowledge carriers and cultural historians.<sup>8</sup>

Indigenous methodologies are best summed up by Marlene Brant Castellano. She finds that the “knowledge valued in aboriginal societies derives from multiple sources, including traditional teachings, empirical observation, and revelation... Aboriginal knowledge is said to be personal, oral, experiential, holistic, and conveyed in narrative or metaphorical language.”<sup>9</sup>

The development of an Indigenous discourse and creating a greater presence of the community in research methodology, design, priorities and implementation, makes Indigenous people more than mere “collaborators” in Indigenous research. They are the intellectual investigators and contributors. It is crucial that Indigenous peoples have the space and support to initiate an Indigenous research agenda that will move forward the agenda of self-determination and nation building.<sup>10</sup>

Gregory Cajete coined the term “ethnoscience” in his book, *Look to the Mountain*. (1994) Cajete articulates that Indigenous epistemology is tied to the land and the spiritual laws that govern that land. It also recognizes how animal, plant and human life interrelate in a collective balance. He explores how ethnoscience reflects the uniqueness of place and is thus inherently tied to land and expressed through language and cultural practice. He states, “Native community is about a ‘symbiotic’ life in the context of a ‘symbolic’ culture, which includes the natural world as a vital participant and co-creator of community.”<sup>11</sup>

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<sup>8</sup>Dawn Martin-Hill, *Indigenous Knowledge-The Lubicon*. Toronto: University of Toronto Press, Forthcoming, 2005. 13.

<sup>9</sup> Marlene Brant Castellano, “Updating Aboriginal Traditions of Knowledge”, 25.

<sup>10</sup> Smith, *Decolonizing Methodologies*, 139-140

<sup>11</sup> Gregory Cajete, *Look to the Mountain: An Ecology of Indigenous Education* (Kivaki Press: Durango, Col, 1994), 95.

These authors have begun to construct an inclusive discourse for Indigenous research. The justification for the validity of Indigenous knowledge is founded on Indigenous universal natural law; as such, knowledge is spiritually-based and ecologically-derived.

Indigenous peoples' justification of their distinct relationship to their natural environment has been difficult (if not perilous). Indigenous people bring with them a knowledge system that is both distinctive and dynamic: it is able to recreate itself and resist dominant hegemony. The Indigenous societies of North America hold a specific fundamental awareness about their relationship to the universe. This knowledge is undoubtedly spiritual. It includes a fundamental understanding that humans beings are not endowed with rights to dominate others or to destroy that which is around them. The animistic belief that all life forms have spirits, and should be respected, contradicts the dominant ideology based on 'man dominates nature.'

The past, present and future inform everyday actions in political, social, economic and spiritual spheres, all of which are a related whole. Ojibway scholar James Dumont states:

*It is important to understand that it is not confined to a certain group, but is a comprehensive, total viewing of the world and is essential for a harmony and balance amongst all of creation. This is, then, a primary kind of vision... What is essential is not an impossible cross-the-cultural leap of understanding but rather a return to a primal way of seeing. ... During this time, White Man and Red Man found themselves walking together along the same road. At some point in their journey, they came to a division in their path. One of the two possible roads before them offered knowledge and growth through accumulation and mounting of all that could be seen ahead (a one-hundred-and eighty-degree vision). This is what the White Man chose and he has developed in this 'linear' and accumulative fashion ever since. The other road appeared less attractive materially and quantitatively, but offered a whole comprehensive vision that entailed not*

*only vision before but also vision behind (a three-hundred-and-sixty-degree-vision). This is a circular vision that sought to perceive and understand the whole nature of an object or event - its physical reality as well as its soul. The Red Man chose this road and he has developed in this circular and holistic way ever since.... In modern times, especially, it is the one who chose the straight-ahead vision who must recognize the ultimate value of the all-around-vision, and, must see the necessity of returning to this more primal and total way of 'seeing the world.'*<sup>12</sup>

The experiential nature of Native knowledge fosters a rich and total sense of the understanding process. Individuals are recognized as being 'wise and experienced' and are respected by their community as 'keepers of the culture.' The Indigenous mode of learning is holistic and cumulative, not deconstructive. The subjective, human nature of inquiry is defined by several truths that an individual must be prepared to accept. James Dumont elaborates on the significance of placing historical events within Native historical constructions.

The recognition of 'ordinary' and 'non-ordinary' realities within the Native experience enables a deeper appreciation for Indigenous consciousness. We must go beyond ideology and grounding events in ordinary and non-ordinary realities to truly represent Aboriginal history.

### **Literature Review**

Based on the abundance of literature reviews being conducted by sister ACADRES we felt it redundant to repeat this exercise. Given this fact and our original mandate, to incorporate Indigenous Knowledge into the very roots of research projects, we are therefore retaining our focus on the voices of the Elders and Healers with a limited focus on the current works discussing Aboriginal research ethics.

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<sup>12</sup> James Dumont, "Journey to Daylight Land: Through Ojibwa Eyes", *Laurentian University Review* 8/2 (1976). 32.

To understand the numerous ethical considerations essential for Aboriginal research it is first important to note the current literature surrounding Aboriginal research and the methods used through the Western lens, and the field of Indigenous methods. The following is a brief sampling of such literature and sets the precedent to which the need for ethics is necessary. To comprehend ethical concerns in Aboriginal research, it is essential to examine current methodological practices both Western and Indigenous. The following review will argue for the need for ethics to be embedded within an Indigenous paradigm, and serves as a framework for our discussions in this report.

There is a recent debate in academia over the emergence of Indigenous and decolonizing methodologies. For many in the traditional disciplines, this new field has provoked numerous questions with few answers. Namely, how does this work within the traditional Western academic landscape? While Indigenous methodology is considered “new” in terms of a Western perspective: the field has existed since time immemorial in Indigenous cultures. Indigenous methodologies are a way of being and integral to Indigenous worldviews. Some Indigenous scholars perceive the need of Indigenous research and methodology as a way to compensate for the past treatment of researched Indigenous communities. Bryan McKinley Brayboy and Donna Beyhle suggest that,

*just as the exploitation of American Indian land and resources is of value to corporate America, research and publishing is valuable to non-Indian scholars. As a result of racism, greed, and distorted perceptions of native realities, Indian culture as an economic commodity has been exploited by the dominant society with considerable*

*damage to Indian people. Tribal people need to safeguard the borders of their cultural domains against research and publishing incursions.*<sup>13</sup>

This statement contends that Indigenous methodologies can serve to benefit both Western and Indigenous researchers and those societies they study. With Indigenous methodologies, we can move past the often-flawed research methods of the ethnocentric past practices to research methods that are beneficial for all. This dialogue can serve to bridge the often-dichotomous relationships by working towards research implements, such as ethics, that are decolonizing in their practices.

The following questions are crucial to Indigenous research: 1) What is Indigenous methodology? 2) Who is it designed for, Indigenous or non-Indigenous researchers? 3) What is the practical application of Indigenous/decolonizing methodology across disciplines? 4) What role does cultural protocol play for the researcher? 5) How do researchers use Indigenous knowledge and methods in quantitative and qualitative research? Out of these questions, a clear understanding of the organic nature of methods will emerge.<sup>14</sup>

Kaupapa Maori methodology carries many of the commonly found principles of Indigenous methodology, whether in Canada, Australia or the United States. Ella Henry and Hone Pene state, “Kaupapa Maori methodology, as a set of methods and procedures, is shaped by our assumptions about what is ‘real’ and what is ‘true,’ which in turn shapes our perceptions of what is ‘science’ and how we do it.”<sup>15</sup> This perception of what is real and true is a fundamental concept found across the literature. Real and true as defined by Indigenous scholars is not necessarily the same as defined in a Western context. Unlike Western ideologies of science,

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<sup>13</sup> Bryan McKinley Brayboy, Donna Dehyle, “Insider-Outsider: Researchers in American Indian Communities,” *Theory into Practice* 39:3 (2000), 163.

<sup>14</sup> Ella Henry and Hone Pene, “Kaupapa Maori: Locating Indigenous Ontology, Epistemology and Methodology in the Academy,” *Organization: Speaking Out* 8:2 (2001), 238.

<sup>15</sup> Henry and Pene, “Kaupapa Maori,” 238.

most Indigenous societies see the world – plant, animal, human and forces of nature – as living and interacting in a related whole. It is within this realm that the conflict and barriers are most strong. One of the greatest barriers experienced by Indigenous methodologists is aptly described by Leah Lui-Chivizhe and Juanita Sherwood, who suggest,

*they [westerners] perceive that Indigenous academics are bringing forth a paradigm never practised before in this country. This is not the case. We are simply articulating, as we must in the academic and western world constantly, a textual construction and practice utilising Indigenous knowledge that has always been present.*<sup>16</sup>

However, we are now seeing a trend in Western science to acknowledge this “revolutionary” approach and an effort to begin to learn from centuries-old epistemologies and methods in order to understand how and why the world works. While Western scholars are more receptive to this new form of theory and practice, for the Indigenous scholar, the meaning has a different context founded on the principles of their existence.

Lester Irabinna Rigney, in his article “Internalization of an Anti-colonial Cultural Critique of Research Methodologies: A Guide to Indigenous Research Methodology and its Principles,” critically addresses the necessity of Indigenous methodologies. Rigney speaks to the overlooked and often silenced conditions of Aborigines in Australia and parallels this experience to other oppressed and colonized Indigenous peoples. Rigney suggests that current Western methodologies are not completely without use. Indeed he acknowledges that they have, at times, emancipated Indigenous peoples. Nonetheless, for the most part the current methodologies in use were created by and for non-Indigenous Australians, which serve to keep the Aborigines in their

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<sup>16</sup> Leah Lui-Chivizhe and Juanita Sherwood, “Indigenous Research Ethics and Methodology” in. Michelle Blanchard, Anthony McKnight, Leah Lui-Chivizhe, Debbie Wray, Kath French, Juanita Sherwood, Sharon Galleguillos and Arthur Smith, “Creating an Optimistic future for Indigenous Research in Education: Re-Visioning both Outcome and Process.” Panel Presentation Report, Australian Association for Research in Education (AARE) Conference, “Educational Research: Towards an Optimistic Future.” University of Sydney 4-7 December, 2000. Internet: [www.aare.edu.au/00pap/bla00530.htm](http://www.aare.edu.au/00pap/bla00530.htm), p 3. Accessed 04/10/2005.

current conditions and do little to aid in the goal of self determination and continue to treat Indigenous epistemologies and methodologies as irrelevant.<sup>17</sup>

For Rigney, “the Indigenous context of knowledge production and research methodologies is about countering racism and including Indigenous knowledges and experiences for Indigenous emancipation.”<sup>18</sup> This sentiment is echoed by Lui-Chivizhe & Sherwood who argue that the “utilisation of this methodology is essential for self-determination and to carry us beyond mere survival. It is undertaken in order to assist communities in enhancing social change, cultural maintenance, and revitalisation, rather than to fill libraries and sustain even more conferences.”<sup>19</sup> Therefore, Indigenous methodology is about the movement towards autonomy for Indigenous communities and is a means by which to better understand and acknowledge ideologies and practices that are different from and equally as important as Western perspectives.

Indigenous methodologies are based on key fundamentals. Research that is being conducted in, by or about Indigenous peoples should first have the research project approved by the community and its chosen form of leadership. The researcher has to establish a community contact and develop a relationship of respect and reciprocity.

The next step in an Indigenous framework is to establish a place within the community. This would arrive by spending time with the people and developing a sense of the landscape and the general structures in which that particular society exists. The researcher during this process

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<sup>17</sup> Lester Irabinna Rigney, “Internalization of an Indigenous Anticolonial Cultural Critique of Research Methodologies: A Guide to Indigenist Research Methodology and its Principles,” *Wicazo SA Review* 14: 2, 115-129. Cora Weber-Pillwax “What is Indigenous Research?” *Canadian Journal of Native Education*. 25:2 (2001), 170; Henry & Pene “Kaupapa Maori,” 237.

<sup>18</sup> Rigney, “Internalization,” 125; Meredith Gibbs, “Toward a Strategy for Undertaking Cross-cultural Collaborative Research,” *Society and Natural Resources* 14 (2001), 675-677, Mary Hermes, C. Hermes, M. (1998). Research methods as a situated response: Towards a First Nations' methodology. *International Journal of Qualitative Studies in Education*, 11:1, Hermes 2.

<sup>19</sup> Lui-Chivizhe and Sherwood, “Indigenous Research Ethics and Methodology,” 4.

would spend the majority of the time listening; learning from the people is key throughout the whole relationship.

From establishing a relationship and data gathering up to and including the stages of writing, reporting and storage of data, the researcher must at all times adhere strictly to the protocols of that particular community. This applies to all communities including urban ones. It is also necessary for the researcher to maintain a relationship of reciprocity with the community. The process must be equal regarding what is shared with the researcher and how the researcher gives back to the people with whom he/she is working.

Research within Indigenous communities involves a long time commitment. Elders have long criticized those researchers who study communities briefly and are never heard from again. Thomas Peacock contends that “American Indian communities have endured inaccurate and damaging findings in research studies because of (among other reasons) unrestricted access, questionable methodologies, broad cultural generalizations and a disregard for the cultural and spiritual beliefs of tribal communities.”<sup>20</sup>

A common problem found in past and current “Indigenous” research is a one sided presentation of the material/data found either for or against the community or nation studied. This occurs when a research project fails to examine past and current work in the area to see what has been done and what needs to be done or redone. Another problem arises when researchers do not adhere to the protocols of the community/nation they are working in, thus leading to the closing of that community from future researchers. Some researchers are unable or unwilling to make a commitment to those he/she has worked with. Intellectual property rights are another major issue currently being discussed in a global context. Intellectual property rights are concerned with issues of ownership, control, access and permission, and are at the forefront of

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<sup>20</sup> Thomas Peacock “Issues in American Indian Research: The Perspective of a Reservation Indian,” paper delivered at American Indian Research Symposium, Orcas Island, Washington, 1996. 4.

current debates regarding research with Indigenous people.<sup>21</sup> John Tresch, in discussing Kuhn's work on the researcher in non-Western cultures, states, "a study of the accounts and reception of researchers who have undertaken such investigations [the inclusion of Indigenous methods] could provide a series of exemplars by which the concept could be redeemed and developed, while pointing out the particular paradigmatic commitments that have given such criticisms force."<sup>22</sup> This supports one of the fundamental notions of Indigenous methodology, which is the recognition of past tools embedded in research paradigms that can be utilized to decolonize Western methods. However, it still must be conceded that while the researcher can be sensitive to and knowledgeable of Indigenous methodologies, they are still presenting their views as perceived, interpreted and produced through their own lens. As Suggested by Lui-Chivizhe & Sherwood, it is the responsibility of the researcher/research project and approving committee to,

*ensure cultural safety; foster Indigenous employment where possible; establish partnerships and equitable outcomes for participants and researcher, and enable the sharing of information in a way that recognizes Indigenous concerns about knowledge ownership and respects the way knowledge is transferred by Indigenous peoples.*<sup>23</sup>

Thus, Indigenous methodology, while focussing on the bridging of Western and Indigenous thought is also about the mending of the relationships between the two. In understanding the principles of Indigenous methodology, its procedures and intent, it is now time to turn to the following question: Who is Indigenous methodology, designed for-Indigenous or non-Indigenous researchers?

All cultural protocols must be strictly practiced when doing community-based research.

Each culture has its own set of guidelines and it should not be assumed that one set of protocols

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<sup>21</sup> See Battiste and Henderson, *Protecting Indigenous Knowledge and Heritage*.

<sup>22</sup> John Tresch, "On Going Native: Thomas Kuhn and Anthropological Method," *Philosophy of the Social Sciences* 31:3 (2001), 316.

<sup>23</sup> Lui-Chivizhe & Sherwood, "Indigenous Research Ethics and Methodology," 4.

is applicable to all. While an umbrella approach to Indigenous research provides a framework, it is the duty of the researcher to search out the guidance and support of the community it wishes to work with in order to ensure that all cultural protocols are met. Likewise, it is necessary to understand Indigenous protocols when doing research but not sufficient to ignore the subtleties of each nation. Protocols for the Cree nation are not the same as for the Mohawk nation, nor are there generalized guidelines covering First Nations, Métis people alike. As stated by Battiste and Henderson, “academic disciplines have been drawn from a Eurocentric canon, an ultra theory that supports production-driven research while exploiting Indigenous peoples, their languages, and their heritage.”<sup>24</sup> Overall, literature in this field has now begun to question previous notions of Aboriginal research from a Western context and is more receptive by Western researchers, of the inclusion and foundation of Aboriginal research from an Indigenous paradigm.

#### **Elders and Healers Roundtable: November 2005, Six Nations**

There were four presentations by organizations that are engaged with Indigenous people. Each represented innovative approaches to ethical research, programs and initiatives. Each presentation was fifteen-minutes in length and based on current projects in specific areas such as intellectual property rights, the over-use of data and protocols of research projects. The first organization was the Amazon Conservation Team. This was followed by presentations by the National Aboriginal Health Organization, Royal Botanical Gardens-Six Nations Ethnobotany Project and Six Nations Ethics Committee representative and Health Director, Ruby Jacobs.

#### **Traditional Medicine & Ethnobotany-The Value of Indigenous Knowledge Research**

Liliana Madrigal is the Executive Director for the Amazon Conservation Team (ACT). Ms. Madrigal explained how ACT works in partnership with Indigenous peoples to conserve biodiversity, health and culture in tropical America. In summary, ACT is guided by the

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<sup>24</sup> Battiste & Henderson , “Indigenous Research Ethics and Methodology,” 133.

following values: the integration of culture, nature and health into a framework that allows for the systematic analysis of life; biological and cultural diversity; supporting and strengthening shamanism; and maintenance and distribution of traditional health systems. Furthermore, ACT seeks to create a forum for dialogue between Indigenous and Western knowledge holders and advocates for Indigenous rights. ACT respects the intrinsic value of nature, does not engage in bioprospecting, and believes in social and environmental accountability.<sup>25</sup> ACT has a long-term working relationship with the Union of Yagé Healers of the Colombian Amazon Union-Unión de Médicos Indígenas Yageceros de la Amazonía Colombiana (UMIYAC). ACT began their work with the Amazon tribes by assisting with mapping traditional territories and using Indigenous languages to name places and define boundaries. The tribes agreed to lead the project by healing and not by political agendas.

The UMIYAC was created by the peoples of the Colombian Amazon to protect and preserve their medicine, forest and territories. The seven tribes; the Ingano, Kofán, Siona, Kamsá, Coreguaje, Tatuyo and the Carijon known as the Taitas, Sinchis, Curacas or Payés, formed a committee in June 1999 to develop a *Code of Ethics*. The Union sought to define “who may work legitimately as an authentic traditional healer” and “to determine when and under what conditions an apprentice may begin the learning process, and when he may be authorized to perform a healing.”<sup>26</sup> Further ethical components state that enforcement is done in the territories and if outsiders do not respect the code of ethics, they are punished. The Union has an agreement with ACT that articulates that ACT must; “support their decisions; listen to and respect the

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<sup>25</sup>Liliana Madrigal. Power Point Presentation. Aboriginal Research Ethics Guidelines Roundtable. November 18, 2004. Ohsweken, ON.

<sup>26</sup> UMIYAC: Union of Yagé Healers of the Colombian Amazon. *The Beliefs of the Elders: Code of Ethics for Indigenous Medicine of the Colombian Amazon* (Amazon Conservation Team, 2000), 7.

authority of Elders; engage in and accept ceremony; not take plants, pictures or videos.”<sup>27</sup> Copies of their book *Code of Ethics* were distributed to each of the participants.

Ms. Madrigal elaborated on the concept of Traditional Knowledge in academia, stating that “Shamans are becoming University professors. They plan to “‘infiltrate academia’ by getting academics to understand the value of ethno-medicine.”<sup>28</sup> Noteworthy is the significant statistic that some 80% of the Indigenous people in the Colombian Amazon are off Western medicine; moreover, they support and use a medicine garden to deal with their health needs. Other initiatives of ACT include the development of the *Shamans and Apprentice* programs and the training of primary healthcare providers, to name but a few. A discussion ensued for an hour after the presentation.

### **Ethics, Research and Traditional Knowledge**

The next presentation was by the National Aboriginal Health Organization (NAHO) which is an organization, as previously stated, that is governed by five national Native organizations which include the Assembly of First Nations (AFN), the Congress of Aboriginal Peoples (CAP), the Métis National Council (MTC), the Native Women’s Association of Canada (NWAC) and Inuit Tapirisat of Canada (ITC). “The National Aboriginal Health Organization, an Aboriginal designed and controlled body, will influence and advance the health and well-being of Aboriginal Peoples through carrying out knowledge-based strategies. ... NAHO is respectful and inclusive of all Aboriginal Peoples including urban, rural, men, women, children, youth, and the elderly.”<sup>29</sup> NAHO was represented by policy analyst James Lamouche. NAHO states;

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<sup>27</sup> UMIYAC, *The Beliefs of the Elders*, 8.

<sup>28</sup> Madrigal, Power Point Presentation.

<sup>29</sup> Internet: [www.naho.ca/english/about\\_naho.php](http://www.naho.ca/english/about_naho.php). Accessed 04/10/2005.

*Through our scoping document, the National Aboriginal Health Organization (NAHO) will articulate its roles with respect to research in relation to Aboriginal peoples. These roles will be further defined through a research framework that will include a protocol statement, ethic guidelines, and best practice approaches.*

*NAHO recognizes that health research for Aboriginal people is not limited to the physical well-being of the individual. Research needs to include the cultural, the social and the emotional health of the individual, their families, their extended families, and the community. Research needs to also include the historical context and determinants of health, such as education, housing, employment and community infrastructure.<sup>30</sup>*

NAHO works extensively in the area of ethics relating to Aboriginal health. The substantive issues of NAHO fall under the five following objectives: to improve and promote health through knowledge-based activities; promote understanding of health issues affecting Aboriginal Peoples; to facilitate and promote research and develop research partnerships; to foster participation of Aboriginal Peoples in delivery of health care; and to affirm and protect Aboriginal traditional healing practices.

The focus of the presentation was *Object 5*: “the protection and promotion of traditional healing practices. Lamouche stated, “the key pillars that form the foundation for ethics are: land; languages; relationships. Ethics is all about relationships. We need to know the boundaries if we are to foster good relationships.”<sup>31</sup> They are further working towards a code of conduct that is referred to as “a good path, know it, walk it” in addition to an inventory of Healers and Elders. NAHO has also developed ethic/research *Tool kits* for distribution that provide a foundation upon which our dialogue can be built. Notably, NAHO believes in abiding by the direction of our

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<sup>30</sup> Internet: [www.naho.ca/english/research\\_aboriginal.php](http://www.naho.ca/english/research_aboriginal.php). Accessed 04/10/2005.

<sup>31</sup> James Lamouche, Transcripts. Aboriginal Research Ethics Guidelines Roundtable. November 18, 2004. Ohsweken, ON.

Elders in the restoration of language, land and relationship. Again, the roundtable responded to the values embedded within Indigenous ideas of ethics.

### **Acknowledging Our Environment**

The afternoon was dedicated to discussions on community-based partnerships, agreements and ownership and control of data. The Royal Botanical Gardens (RBG) presented on their *Ethnobotany Research and Botanical Inventory of Six Nations* project,<sup>32</sup> a project that is building capacity in partnership with the Indigenous Studies Programme at McMaster University and Six Nations Polytechnic. This is a three-year project to provide a community intern in Indigenous Ethnobotany and to conserve and preserve Indigenous Knowledge.

The project intern addressed the multiple processes she had to adhere to in regards to the Traditional Knowledge component of the project. Protocols she described included: seeking advice from the Hereditary Confederacy Council at Six Nations; developing a steering committee including traditional medicine people who would advise her on the documentation process; and protocols addressing the natural environment. Other processes necessary for permission to conduct this research included: receiving approval from the Six Nations Council Ethics Committee; developing a Memorandum of Understanding; holding a community meeting to discuss the purpose and intent of the project; seeking a letter of permission to access band-owned lands; and agreeing to a publication ban until materials are approved by the steering committee.

Ethical considerations for the project were to establish trust, transparency, reciprocity and natural wellbeing between the project, community and environment. Notably, the researcher went to the Band Council's ethics committee for permission to work in the territory but stated she would have preferred going to the Traditional Confederacy Council and working with them

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<sup>32</sup> Pat Hess, RBG Presentation, Aboriginal Research Ethics Guidelines Roundtable. November 18, 2004. Ohsweken, ON.

to develop Traditional Knowledge protocols. One suggestion put forth to the researcher was to become engaged with the Haudenosaunee Environmental Task Force.

Fragmentation of communities was a concern for roundtable participants. Who has authority in the area of Traditional Knowledge? The participants suggested Elders, not political organizations; however this creates difficulty when obtaining appropriate permission. Local community researchers expressed a level of stress as insiders. As ‘insiders’ the individual researcher is exposed to immeasurable levels of scrutiny by the community and this is compounded by the academy’s scrutiny. The surveillance is occurring first by their community members who are hesitant, if not sceptical, of their research agenda, then by the academy who question their levels of reliability and impartiality within their work. As an ‘insider,’ the individual is also subject to laws of the nation, beyond the requirements imposed institutionally by granting agencies’ ethics, band council ethics, and research ethics boards.

Clear direction was given from the participants in the case of community fragmentation. In addition, key concerns emerging from this discussion were the ensuing debates about:

1. Which governing body should be approached, and can bodies work jointly?
2. Who had the right to regulate Traditional Knowledge? This discussion led to the recommendation that an ethics board/committee external to the governing bodies, but representative of the community, be created and that funds should be allocated to the creation and maintenance of community committees.
3. How do ‘insiders’ negotiate between their values and beliefs systems and those imposed upon them by outside agents?

The practical complexity of ethics was clear in the RBG presentation. When communities are fragmented, who do you ask? Where do you get data? Again, the participants responded with some insights to these questions.

To address the researchers' concerns with the term "research" and the often loaded meaning of such a word for an insider-researcher, a fellow roundtable member suggested, "to change their thinking about the word by explaining that it meant, simply, 'to look again'.... [and] not to let the limitations of language or the limitations of our communities' experience with it discourage her in any way; to reframe the language of it so that she could empower herself and others with its potentials."<sup>33</sup>

### **Working with Biomedical Knowledge in Indigenous Communities: What Guidelines are needed?**

The final presenter at the Roundtable was the Director of Six Nations Health Services. Ruby Jacobs is a member of the newly-established Six Nations Ethics Committee. This department is frequently approached by numerous researchers and organizations wishing to conduct bio-medical research on Six Nations. Due to this influx of requests, Six Nations Health Services created a guideline for accessing biomedical knowledge in their communities. These guidelines were developed by Six Nations Band Council Ethics Committee in consultation with McMaster University's Ethics Board. The guideline consists of ten protocols. They are as follows:

1. Community consent;
2. Clear understanding and control at the outset of research;
3. Equal partnership with the community and equal control of process structure and function;
4. Respectful of community life and customs;

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<sup>33</sup> Katsi Cook, Transcripts. Aboriginal Research Ethics Guidelines Roundtable. November 18, 2004. Ohsweken, ON.

5. No commercialization of the information or products or unauthorized use or misuse of samples;
6. Transparency of research to the community;
7. Risk management controls for participants-properly trained researchers and financial obligations are the responsibility of the team;
8. Regular reporting of progress to the community;
9. Projects must mirror the gold standard of research, both Aboriginal and Western;
10. Anonymity and confidentiality of client information must be maintained.<sup>34</sup>

These principals govern Six Nations Health Services and are the basis upon which decisions regarding the granting of Aboriginal medical research are made.

### **Traditional Protocols for Guiding Research: Roundtable Recommendations.**

#### **A: Philosophical Statement of Research Ethics**

Six Nations Polytechnic is a community-based, community-operated, post-secondary institute located on Six Nations. Six Nations Polytechnic approached the late Haudenosaunee Chief, Harvey Longboat to write their philosophical mission statement. Mr. Longboat had a lifelong commitment to education and Indigenous Knowledge. The participants requested revisiting this statement, which expressed Six Nations Polytechnic philosophies. The following excerpt is from that statement.

*If a people do not keep pace with others, perhaps it is because they hear a different drummer. Allow them to step in harmony to the music with which they hear, however measured or far away. Our cosmology places Native people in a balanced familial relationship with the universe and the earth. In our languages, the earth is our mother, the sun our eldest brother, the moon our grandmother, the plants and animals our*

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<sup>34</sup> Ruby Jacobs, Six Nations Health Services Presentation. Aboriginal Research Ethics Guidelines Roundtable. November 18, 2004. Ohsweken, ON.

*brothers and sisters. From this view, our people believe that all elements of the natural world are connected physically and spiritually and are to inter-relate to each other to benefit the whole. The responsibility then falls on the people to peacefully maintain nature's delicate balance to ensure that unborn generations can enjoy what we enjoy today.*<sup>35</sup>

The participants also suggested, and unanimously agreed, to adopt his words as their philosophical statement. Indigenous people's guiding philosophical principles are found within the languages. Three core principles are our cosmology, language and relationships. Language embodies the fundamental principles embedded within the ideas and the meanings of Indigenous worldviews.

The following list of expressions was provided by the six cultural groups represented at the roundtable. Each person reflected on their nation's philosophies and felt that the words listed below were the best way to convey their philosophies. Notably, Indigenous philosophies often lose their original meaning when translated into English. However, they provided the concept and translations, which represent a diverse understanding of Indigenous philosophies and the commonalities between them.

**Navajo:** *Linabidiq' saadaqdo lina bindii q' aq'eq'h:* "the rules/protocols of our life language convey."

**Lakota:** *Mitakuye Oyasin:* "we are all related."

**Lakota:** *Wicoicage:* "that the generations may continue."

**Cayuga:** *Ėdwusra sógwihwagyónē sógwuyudēsó:* "follow the ways given to us by our creator."

**Cree:** *Nihiyawewin:* "four parts of humans, physical, spiritual, mental, emotional. Life is a gift, accountability."

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<sup>35</sup> Roundtable Transcripts, February 2005.

**Mohawk:** *Skennen*: “peace,” *skanikonra*: “one mind,” *kasatshtensera*: “righteousness.”

**Ojibwa:** *Hozhóó náh hásdtii*, *miigwech kina gegoo gii miizhoyannng*: “beauty way,” *Mashkikii waawayaanarny*: “strength.”

Ethics were introduced through Indigenous languages. The principles highlighted were integrity, honesty and respect. The participants demonstrated that Indigenous ways of knowing are framed as relationships to all things, lived through our language, and evident in our cosmologies. Grounding in Indigenous Knowledge (IK), therefore language, is vital to ethical research with Indigenous communities.

### **Principles of Indigenous Knowledge**

The following are nine primary philosophical principles of IK as agreed upon by the participants.

1. Cosmology
  2. Language
  3. Integrity/Honesty
  4. Respect
  5. Reciprocity
  6. Quality of life
  7. Protection
  8. Acknowledgement of Traditional Protocols
  9. Intent
1. COSMOLOGY

Cosmology generally refers to the study of the universe in its totality and the ways in which we understand all that is encompassed within it. For Indigenous Peoples, a nation’s cosmology is more than the study of the stars and planets. It is an understanding of the

foundation from which their creation stems. It is inclusive of not only the stars, moon and sun, but also the plants and animals and all beings that contain a spirit and are animated. Cosmology is understood as a related whole, rather than in parts. As stated in the roundtable, “[a] key component to our whole cosmology is that we are related to the whole universe in kinship.”<sup>36</sup> It is often this process of kinship that is the most difficult for researchers to internalize. This notion of kinship is one of importance to Indigenous Knowledge (IK), particularly for the researcher, as “[o]ne of the tenets of IK is that the knowledge arises from the place where you live.”<sup>37</sup> Western cosmologies do not often recognize the life force of rocks, stars and plants, let alone recognize their relationship with humans. Thus, research within this Western paradigm of understanding affronts on many levels Indigenous peoples and communities. A research agenda that is sensitive to Indigenous cosmologies will best serve the people. One participant stated, “[a]s Indigenous people, the directions for our actions is advised by the knowledge contained in our ceremonies and oral traditions. It is this spiritual relationship to a land that provides our moral guides and can help achieve or maintain harmony.”<sup>38</sup> This statement recognizes the relationship between ceremony, oral tradition and cosmological beliefs.

It becomes clear that they are articulations of a nation’s cosmology, which in turn provide the foundation to which ceremony and tradition exist. The following story was shared by a Haudenosaunee Faith Keeper during the roundtable.

*My mother... says do you carry the great peace. When you shake hands with someone, that is part of the natural law of saying this is who you are and do you remember where you came from and do you remember to carry those values and those belief systems? Everything about who you are takes place. That is part of our thinking as Indigenous*

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<sup>36</sup> Roundtable Consensus, February 2005.

<sup>37</sup> Roundtable Consensus, February 2005.

<sup>38</sup> Deer, Transcripts, March 2005.

*people. To not only be a part of this moment, but we are a part of the past and all of those stories and we are reminded of that with all of our actions that we do on a daily, on a regular basis. Whether speaking our language, participating in our ceremonies, looking from the past to the present to the future, that's who we are. And we are ensuring that with our ceremonies, with our speeches and with our language – those children of the future are going to be able to show their face and do well. They will be able to have life and to have the abundance of life that we have had. We are going to give them the same we had – the plants, the medicines and food. All of those things that we recite in the Thanksgiving.*<sup>39</sup>

This story keenly demonstrates the differences between Indigenous ethics and those of a non-Indigenous person. Furthermore, it once again reinforces the necessity of language.

## 2. LANGUAGE

Language is open to interpretation and a multitude of meanings. As agreed upon by the group, “[o]ur sounds [language] are a powerful consciousness which conveys the legacy of our knowledge.”<sup>40</sup> It is indeed this legacy that needs to be incorporated into an ethical research design, regardless of whether the researcher is an insider or outsider. As agreed upon by the participants, “language is central and research being done in Indigenous communities should respect the Indigenous language and the local languages, and include them in the process.”<sup>41</sup>

Cultural survival was of critical concern to the participants. They felt all research conducted in their communities should incorporate a language component, a form of reciprocity from researcher to researched. The following statement from the roundtable demonstrates the claim of language as a powerful tool in Aboriginal communities. Responding to participants’

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<sup>39</sup> Norma General, Transcripts, February 2005.

<sup>40</sup> Roundtable Consensus, February 2005.

<sup>41</sup> Roundtable Consensus, February 2005.

view that Aboriginal people who do not know their language are not really “Ongwehonwe,” one person stated,

*I've had students literally cry when what you just said was said to them, feeling completely and utterly shattered in their soul because they don't know their language. And I believe that our language was stolen from us through government policies of assimilation and genocide. So if we're going to talk to our people about not knowing their language, then we also have to acknowledge their pain and their suffering. Because I think the [Haudenosaunee] Great Law is about compassion and having compassion. So I think that before we go into admonishing people for not having or possessing something that utterly a whole generation is walking around, not knowing that. It was never made accessible to us. ...People grew up in a home where the language was spoken, that is really beautiful, but 90% of us did not have access to our own language. That is the crime.*<sup>42</sup>

The research participants agreed that language is paramount in any research agenda. Research should find ways to both revitalize language and create a space in which non-speakers have an opportunity to learn and evaluate it. We recognize the need to discuss research plans in a language most used by a community because this enables Indigenous people to more fully understand the purpose of the research and whether it meets a community's ethical standard. Research should be a reciprocal process that respects the community and broadens the avenues of knowledge-transfer of the research findings.

During an interview with a language speaker and advocate, the following recommendation was put forth:

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<sup>42</sup> Dawn Martin-Hill, Transcripts, February 2005.

*I think I would like to see things translated. ... if there was a report that was part of the final whatever – publication or whatever – in the language, even if it was a synopsis in the language for the community to have. I think that would be a good thing. I'm not saying that they would have to publish the whole thing that would be adding so much extra work on but there should be something in the language for the community. I think that would be a good idea.*<sup>43</sup>

The inclusion of language in research is necessary for the creation of reciprocal space in which both researcher and researched can achieve equilibrium. It is also necessary in order to root the research within the broader cosmology of a nation. The lack of recognition of Indigenous language by researchers is unacceptable. After all, would they do research in Quebec and not pay homage to the French?

### 3. INTEGRITY/HONESTY

The principles of integrity and honesty apply not only to those proposing to conduct research but also to those who wish to participate. As the group has stated, *“all things must be done in a truthful and honest way with integrity.”*<sup>44</sup> The group acknowledged, *“our people participate in just...good research...that holds these values. These values are truthfulness, integrity, honesty, compassion, acknowledging life as a gift, acknowledging cultural survival must be central, as well as spirituality.”*<sup>45</sup> These two statements clearly define values of ethical conduct that are to be applied to the research design.

### 4. RESPECT

One of the most frequently misconstrued components of research is the ideological notion of respect. Literature, case studies and ethnographies are riddled with examples of the

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<sup>43</sup> Tom Deer, Transcripts, February 2005.

<sup>44</sup> Roundtable Consensus, Transcripts, February 2005.

<sup>45</sup> Roundtable Consensus, Transcripts, February 2005

misinterpretation of this word. Upon reflection, many researchers have stated that they followed all the protocols of respect but when revisiting their work from an Indigenous interpretation, instances of disrespect became apparent. This is not to say that the initial work was purposefully neglectful, but that it was not in accord with Indigenous ethics.

The perceived right of access to knowledge is an important point of contention. There are some who would argue that there can be no control or ownership of ideological notions or ways of knowing, that all knowledge once transmitted in the public sphere is open to free access and interpretation. However, within the parameters of Indigenous Knowledge, a 'right' is not freely given, but is an opportunity that must be merited. As stated by one participant, "*[t]here is the element of earning the right to knowledge which is embedded in respect. You must earn the right to the knowledge in the community, and then you demonstrate by respecting the wishes or the agenda of the community.*"<sup>46</sup> The participant added, "*you want your people, or the people in the community, to be treated fairly and decently. All of the things like privacy and confidentiality are going to be honoured and respected.*"<sup>47</sup>

The participant further articulated a common problem of research: "*the knowledge that people are giving you – one of the things that you need to be made aware of – in research, there is always going to be [a] putting forth [of] a thesis and [the] want to come to some kind of conclusion based on that thesis. That's where I have a difficulty sometimes.*"<sup>48</sup> Presumably, once a researcher has attained the knowledge requested he/she will then produce a document with a proven thesis. The problem then, as stated by the participant, occurs in the right to the knowledge. Do the researchers then have the right to use these findings as their own, or is the right to discuss these conclusions still subject to the approval of the community and/or subject?

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<sup>46</sup> Deer T. Transcripts, February 2005..

<sup>47</sup> Deer T. Transcripts, February 2005.

<sup>48</sup> Deer, T. Transcripts, February 2005.

This is one of the questions that must be negotiated in the initial research design in order to satisfy the ethical requirement of respect.

## 5. RECIPROCITY

Relationships comprise one of the three main principles of Indigenous philosophy. Relationships are interactions between beings, symbolic gestures and words in a process of exchange. It was stated by the group that the principle of reciprocity is mandatory for a mutually beneficial and respectful exchange to occur. The participants stated,

*we encourage giving and receiving....reciprocity is understood by the community or the people who are being asked to share their knowledge or whatever the case may be – when someone is about to approach a subject and they have a research project – when they read the philosophy statement, that that is very much a part of it. In the very beginning, you have to understand that it is a two-way process.*<sup>49</sup>

This two-way process is more than a demonstration of diplomacy; it is a fundamental code by which people must abide. The group agreed, “[p]eople working with Indigenous peoples should start articulating an understanding of how they’re going to reciprocate with them in the community – not defined by them but defined by the community.”<sup>50</sup> A key aspect of this declaration is the phrase “defined by the community.” It is necessary, but not sufficient, for the researcher to define what they will give back. The researcher has to acknowledge that the community is best able to define what their needs and wants are, and what will be most beneficial for them. Thus, this series of textuality and dialogue is framed within the Indigenous notion of reciprocity.

## 6. QUALITY OF LIFE

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<sup>49</sup> Roundtable Consensus, Transcripts, February 2005.

<sup>50</sup> Roundtable Consensus, Transcripts, February 2005.

It has been persistently noted by Indigenous peoples that Indigenous communities have been ‘researched to death.’ Given the truthfulness of this statement why then would a community or individual agree to be the “subject” yet again? One answer lies in this principle, the quality of life. Through the process of the roundtable and vetting, this concept was returned to repeatedly, signifying its importance.

*After centuries of colonialism that resulted in the loss of our cosmological environment and relationships, the content of research must be integral to our people’s restoration, health and well being. All research must reflect those ethics. We acknowledge our own participation in our health and well-being. ... [We] want the statement to reflect that it is not just researchers coming in that have this ethical responsibility, but it is our own people [that] have this responsibility to take on themselves....we acknowledge the distrust inherent in our communities toward research; however, we encourage our people to participate in the process of research.<sup>51</sup>*

Thus, not only do the researchers have an ethical responsibility in the process, so too do the people or community agreeing to the research project. Both must view the project as addressing the values found within their own cultures. As a group, it was understood that “*unless research is able to include the quality of life or the health and well being of our people, ... it is not worth it.*”<sup>52</sup>

## 7. PROTECTION OF INDIGENOUS KNOWLEDGE

It was simply stated that the “*protection of IK, [is] the protection of spirituality and ceremonies,*” and this principle is non-negotiable. Thus, protective measures must be instilled in all research projects and all agreements reached must stipulate this measure to be from signing to time immemorial.

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<sup>51</sup> Roundtable Consensus, Transcripts, February 2005.

<sup>52</sup> Roundtable Consensus, Transcripts, February 2005.

## 8. ACKNOWLEDGEMENT

Research must respect the traditional protocols of the nation from design to implementation to dissemination to storage. In order to do this, the researcher must actively seek out members of the community in which they wish to conduct research and develop a relationship in order to gain the knowledge necessary to acquire traditional manners of respect. A common mistake made by researchers is to assume that the protocols of one nation are applicable to all nations. While they share some commonalities, Indigenous nations are distinct and unique and have their own creation stories, social systems, laws, and so forth. Researchers are encouraged to use the protocols of the territory in which they work. Researchers should be forthright in their approach and explain to the community contact or representative their desire to learn the appropriate manner to begin the research project negotiation. Participants at the Roundtable unanimously agreed to the following statement, *“there must be respect for the observation of traditional protocols. Research is about gathering knowledge and in order to participate within a community, you should observe the traditional protocols. Find out what they are!”*<sup>53</sup>

The acknowledgment of Indigenous worldviews, perspectives, pedagogy and epistemology is key to overcoming intellectual barriers in research. When researchers acknowledge this intellectual space and actively engage in its interpretative framework, they are able to understand traditional protocols. Roundtable participants agreed that,

*any research should observe traditional protocols of the community they're in and it is rooted in holism, that the creation stories are the narratives of how families and research about relationship and families. This has to be acknowledged. IK – Indigenous*

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<sup>53</sup> Roundtable Consensus, Transcripts, February 2005.

*Knowledge is acknowledged. We also talked about any research being done from our point of view should have some components of the continuance of identity which then means that research should then be available in our language.*<sup>54</sup>

## 9. INTENT

According to the participants, “*research must benefit the community ... it must abide by our philosophical statement and it must be done within this value system.*”<sup>55</sup> As well, “*the outcomes of the research have to include the physical, mental, emotional and spiritual.*”<sup>56</sup> If research encompasses the values found within the philosophical statement, then its intent is ethical.

Concerns regarding intent arise when research attempts to alter that which is given by the Creator.

*To challenge the natural law and [research] tries to achieve that or be better than that which has already been assigned responsibility. Those are the things that I think are unethical to be greater than the creator. How can we do that? Because you look around and see what beauty that we live in, where everything knows what it is supposed to do at a certain time of the year because of its assignment that came directly from the Creator. I don't understand how... whatever field of work that you're in without acknowledging the Creator. Then you could become unethical and try to change and be the Creator ourselves, and then it is understandable. But it makes no sense to me. It is almost like trying to recreate a model that is of our own making, trying to make it better and it's not being made better. It was better in its original form, which provided freedom in education, and philosophy and it was in balance. Everything was in balance, from the*

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<sup>54</sup> Roundtable Consensus, Transcripts, February 2005

<sup>55</sup> Cook, K. Transcripts, February 2005.

<sup>56</sup> Roundtable Consensus, Transcripts, February 2005.

*animals to the – even the ones that were hunters, the wolves; they're there to keep the balance. Now we have different organizations trying to do it from a man made model and it's making everything more off balance.*<sup>57</sup>

As so eloquently stated above, a researcher's role within creation is to work in harmony with that which the Creator has given and not to dominate it in ways that create an imbalance within creation. Research should be beneficial, and not oppressive.

In conclusion, everyone has to follow laws that are embedded within Indigenous Knowledge, our oral histories and ceremonies. As Indigenous Peoples, intent is entrenched within ceremonies and the land. It is this relationship to the spiritual realms and to the physical land that provides our moral guide and can help achieve and/or maintain wellness. Within our collective Indigenous Knowleges, there is an ethical framework. We can look to the Haudenosaunee *Great Law* or *Thanksgiving Address* or to kinship roles and responsibilities as best practices of how research should be conducted. Our guides are our Elders and the future is within the youth.

## **B) Who is Knowledgeable: Elders/ Knowledge Carriers?**

In order to protect Indigenous knowledge and knowledge carriers, there is a need to know how to define their roles. What criteria need to be in place before we can confidently suggest an individual as an Elder or Knowledge Keeper? Is this person traditional? How does a community or nation decide the extent to which they are traditional? Once an Elder or Knowledge Keeper is identified, do they as an individual have the right to share cultural property such as medicines?

It was suggested that each community should identify their Elders. It was made clear that political organizations should not be sole partners in research. Participants discerned that political organizations may be biased and prevent certain research projects. For example, it was

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<sup>57</sup> General, N. Transcripts, February 2005.

noted in one community the band council rejected a study on the impacts of smoking. The Chief at the time and two council members owned and operated tobacco companies. Needless to say they rejected a study that the community (had they been notified) may have benefited from.

Partisan research is unacceptable in the scientific community, yet, is acceptable in research with Aboriginal peoples. Several participants identified the need to broaden community participation in ethics boards. Elders should be involved in ethics committees. The question is, who is an Elder?

As previously stated, to understand who is knowledgeable and able to discuss culture, we can turn to language. When asked to translate ‘Elder’ into their respective languages, the group stated that many nations do not have a word for Elder as it is understood in English, but have expressions that characterize people who are able to speak about Traditional Knowledge and the ways in which it is expressed. The following is a list of those conceptual paradigms discussing the idea of “Elder,” starting from the language and working our way back.

**Lakota:** *Iyeska* - which is interpreter...I understand that when they would speak, it would bring tears to your eyes, it is so emotional. It is beyond just those kinds of words. This is where we lose it in the English interpretation and that there is no words really to describe it.

**Navajo:** *Hane’bi Nant’ani* - that would mean the person who knows the creation stories or of the beginning of life. You have to describe it, there is no such word. The only thing is that certain ceremonies that are done, they each have a person that does it and we have names for those, but we don’t have a word just for Elder or faith keeper. For each ceremony, it is different.

**Cree:** *Kitiyayuk* - Elder-worthy. *Kiseyew*- it is an older person like what we were just talking about with all that knowledge, language and wisdom, ceremonies and songs. He/she embodies all that, almost like a title.

**Sámi:** *Moaidi* - It is usually an older person and I guess the closest translation is a Shaman. It's not a shaman in the cultural sense, but it is loosely translated. It is a person who central to an extended family or a community and communicates with the animal and spirit world. And who is also a healer.

**Navajo:** *Alk'id dq'a' hane' dóó lináh yé'é' yaa ahwiinisiniigi* - Person with knowledge of life through culture and the traditional way.

**Cayuga:** *Ganono'se'n e yo'gwilode'*-One who is full of our traditional knowledge.

If we look to these words and we think of the questions posited we see that there is no one clear, simple definition, but many definitions. It is not up to us to define Elders and Knowledge Keepers but to accept that the definition is there, embodied in heritage and culture. The following excerpt addresses the question of who is knowledgeable:

*I think that comes back to what we said about after centuries of colonialism, and this taking away of, we're at this point we're taking responsibility and taking things seriously. Taking things back respectfully. And that's how we want research to flow out of that statement. You have a responsibility and we have a responsibility and we are now moving forward. We are who we are because that's who we were created to be. Not because of whether I drum, not because of whether I know my language or not. Those are important to my culture which is separate from who the Creator made me to be. That is another thing that can't be put under the microscope. And that's why we're having a hard time trying to explain it because there is no way to explain it. We are who we are because we were created that way. And we believe in creation. We don't believe in this first come monkey come whatever thing and that's a very strong statement that we need*

*to say. This is it. This is who we are. This is where we're at and that's why we're ready to embark on research on these conditions.*<sup>58</sup>

Upon reflection we can see where authority lays. Interpreters of the sacred are people who know the beginning of life, have the knowledge of ceremonies and songs, and they are people who are the centre of the community.

### **Key Concerns**

A concern expressed by our Elders and Knowledge Keepers is the difficulty in compartmentalizing traditional medicine. By nature, traditional medicine is imbued with animism, and it governs creation. Also addressed by the Elders and Knowledge Keepers was the underlying principle of the ethical self. The Elders state, “[i]n our teachings it tells us to evaluate ourselves.”<sup>59</sup> The philosophy of ethics is grounded in creation stories and traditional laws.

The roundtable also expressed concern in regards to the homogenization of Indigenous peoples. The following describes this problematic trend.

*I think the way that scholars talk about Indigenous people is not plural. So participant A is Cree, and he has a creation story that is different from participant B who is Haudenosaunee and from Participant C who is Navajo. When Participant C tells me her creation story, Participant A doesn't stand up and say, excuse me that is not how it happened. Therefore, the Navajos will abide by our view of the world and they will have to – or we could do the Cree, which I'd like to do, is say that women are – your identity flows through the women's line. I would usurp the whole creation if I did that, right? Because all of their bundles and different things follow a certain set of laws.*<sup>60</sup>

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<sup>58</sup> Cook, K. Transcripts, February 2005.

<sup>59</sup> Roundtable Consensus, Transcripts, February 2005.

<sup>60</sup> Martin-Hill, Transcripts, February 2005.

Therefore, it is necessary for research projects to recognize the differences between nations and to adjust their projects to be reflective of the world view of that particular community.

Another concern put forth by the roundtable was in regard to access to research funds. It was agreed that funds must be made available to community people for all forms of research, whether by an academic institution or a community initiative.

*The Native people in general have been locked out from accessing those [research] monies. In a way, we are speaking to those particular people. Not out of racism but because they are the privileged group of people to get money to do research on us. We, on the other hand, have to beg, borrow and steal to do things to save our culture.*<sup>61</sup>

This current exclusionary practice of research funding will be further addressed in the access to revenue section of this report.

The discussion addressed three key principals in our treatment of our Elders and Knowledge Keepers in research – validation, recognition and responsibility. Judy Swamp noted that we need a network of Elders to share knowledge. It is the Elders' responsibility to pass on knowledge but they need support.

The following are items deemed important by the Roundtable in regards to our Elders and Knowledge Carriers:

- The practice of placing Elders' needs before those of knowledge seekers. It is no longer permissible to expect Elders to travel to a researcher's location. The individual or group seeking the knowledge of Elders should go to their preferred location.
- Elders and youth must continue to work together in the transmission of knowledge.
- Capacity-building resources should be made available in order to ensure the continuation of knowledge transfer between Elders and youth.

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<sup>61</sup> Martin-Hill, Transcripts, February 2005.

- Research must include Elders in the planning and implementation stages. Moreover, Elders guide the research in all phases and participation is on their own terms from their own premises.
- Elders need to be part of the reviewing and decision-making process.
- There must be a member of the research project or a mediator who is able to interpret and explain the process to Elders.
- Elders should provide support for each other, intellectually and spiritually.
- Elders must be recognized as not only advisors, but as valid experts in their field.
- An Elder should be widely recognized if not appointed by the community for the research project.
- We need to protect these very valuable people in our community from any forms of unethical treatment or manipulation by researchers.
- The Elder will represent the voice of the community.
- Elders are recognized as our greatest cultural resource.

These items should be treated as non-negotiable and become integral to the design and implementation of research projects. Aware of this, one participant offered the following analogy: “they [researchers] were coming in and pulling the roots up when they’re picking the medicine. In my view, we’re doing that to our older people. We’re just yanking them around and they’re dying.”<sup>62</sup>

Elders are often marginalized in the community. In order to understand how this happens, we need to examine ourselves, and others, in the type of treatment Elders receive. Like researchers, Elders respond to the needs of their community, however, unlike researchers, Elders are not supported by the institutes which profit from them. They are exploited. What can

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<sup>62</sup> Martin-Hill, Transcripts, February 2005.

we do to stop these processes of marginalization and exploitation of Elders and Knowledge Carriers? Researchers in Aboriginal communities have a responsibility to consult Elders.

### **C) Youth**

The youth participants agreed that the current guidelines for conducting research with Aboriginal peoples are unacceptable due to the lack of respect for Elders and IK. How do we incorporate the views of the youth and recognize that capacity building is intrinsic to research ethics? The Amazon Conservation Team (ACT) apprenticeship model provides youth with the opportunity to learn, participate in, and be acknowledged by their communities. The youth, in reference to the *Shamans and Apprentice* program, suggested a parallel program in North America. They emphasised a need to develop apprenticeship and mentorship opportunities where connections between youth and mentor could be made in reciprocal ways meaningful for both parties.

The youth should be linked to research projects. The current research practice by academics encourages only graduate students to perform research, and community youth are left out of the process. An essential component of capacity building is to provide youth, who would be identified by the community or Elder; the opportunity to take part in the research process. This would not only build research capacity and training in the community, but it would also develop apprenticeship and mentorship opportunities. Research should include undergraduate students as well as partners with community youths.

Community youth, especially those who are trying to learn Indigenous Knowledge, should be included in any research process. When academics receive grants, many create jobs for their graduate students with these funds. The roundtable disagrees with their process, since it privileges university-trained English-speaking youth over youth from the community. The youth who are dedicated to their language, culture and Elders are underprivileged.

Right now, youth who want to learn their language, their culture and ceremonies – in short, IK – are forced into poverty and unemployment and they are marginalized in their own communities. Youth should be provided access to resources and the means to pursue Indigenous Knowledge through research, so that they can begin to be given support and incentives. As one participant reflected upon the status of youth today:

*Because the younger people now are coming with that wisdom, and how are they going to channel, it's not going to be in the classroom. They are coming with the sacred gift of knowledge and wisdom. They are enlightened individuals and we have to provide financial resources for them in order for them to do that [learn culture and research]. That is our traditional [way] – if you want to call it traditional – is to allow the individuals their natural gift, not to cram everything inside of them, but to allow that natural gift to flourish and come out of them. Rather than sitting in square box classrooms at these square desks and square tables, we need to recognize that we are circular people. The youth know that and they're frustrated by having to sit in a classroom. Where are we making the traditions for them to accomplish their dreams and their visions? If we leave them out, they are no longer our dreams and they are no longer our visions. They carry their dreams and they're cut off them by the time they're 7 years of age.<sup>63</sup>*

Our communities have already suffered health disparities from being under-represented in the sciences. The exposure the youth are getting to Indigenous Knowledge should include training which connects IK and Western sciences.

The participants determined that Elders will identify the youth to participate in research. Resources should be provided to conduct research, then it follows that they would also determine

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<sup>63</sup> Sara Smith, Transcripts, February 2005.

the youth from that community who would be supported in that research as well. Additionally, in recognition of those youth who did not grow up in a traditional home, or were not exposed to their culture until much later, “we [as Haudenosaunee peoples] extend an invitation [to those raised outside of their culture] to go back to the tree of peace and say, “those that desire to learn come under the shelter of this knowledge.”<sup>64</sup>

The youth participants expressed other areas of concern, which included the transmission of language. Obviously, this concern coincided with the need to transmit knowledge, and to develop and strengthen a respect for Aboriginal knowledge within the youth cohort.

Ownership, Control, Access, Permission (OCAP) was also raised by the youth participants. A subsidiary of OCAP issues was the need to protect their sacred items and articles, and find ways to end the commoditization of the sacred. They articulated that they wanted to see the regulations further developed and become more reflective of what Aboriginal people would want. Notably, ACT was also highlighted as an example of knowledge transmission for children. They currently have a publishing program in which children’s books are written in their language about their culture. This program to date has been highly successful.

#### **D) Restoration of Respect: Peace, Power and Righteousness**

Value needs to be placed on our own knowledge and language. One hereditary leader expressed, “All of the various Indigenous cultures have something to offer but we must take care of the carriers of the knowledge, like the Japanese whose Elders are considered ‘national treasures.’”<sup>65</sup> Knowledge Keepers are part of communities, kinships and clan leaders, and their roles should be acknowledged and respected by researchers. Traditional Iroquoian teachings were articulated by participants. The ‘Peacemakers’ Great Law, which embodies peace, power

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<sup>64</sup>Sara Smith, Transcripts, February 2005.

<sup>65</sup> Arnie General, Transcripts, February 2005.

and righteousness, leads to good medicine and a good mind. The dilemma research poses is the need to allow access to communities and open up our culture at the same time to protect it.

Respect is a principle that must be integrated into all spheres of research. As one participant stated,

*I think that we need to stand back and realize our culture – our people as a people are on the brink of extinction. That’s a crisis. Now for you to walk in here and not do anything to help us survive as a people is unthinkable. That’s like going over to the Tsunami survivors and saying, by the way, I got a research project, and I want to check your diabetes level under stress. Really!! I’m serious. This is what we as a people have not been allowed to look at ourselves as people who have not only experienced genocide but have survived it. So if we come from that place, then I think we can be very vocal about saying our cultural survival is paramount to any research that might be done. They don’t get it. They say, what’s wrong with them? Why are they so uppity about language and culture? And I think we really need to point out that you can’t come here in a community under cultural stress that could add more stress to that culture’s survivability.<sup>66</sup>*

Recognition of the historical legacy of colonization needs to be ideologically embedded within any research paradigm. If researchers are unable to recognize a history of colonialism, then they are also unable to work within the ethical considerations put forth in this report. Consequently, they should be denied access to the community or individual. Participants felt strongly that research must benefit the community.

Researchers must also be flexible and broad-minded in their thinking. As argued by the group:

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<sup>66</sup> Martin-Hill, Transcripts, February 2005.

*No matter whether you're an insider or outsider, you may not know or participate in the ceremony but you have to respect it and protect it. So that is guardianship. If you are speaking with somebody sharing that knowledge, you have to take it and treat it the same way as if you were an insider. Regardless if you were an Indigenous or non-Indigenous person, the same level of respect and attention has to be paid. There is no scapegoat because I am an Indigenous person and you are non-Indigenous person.<sup>67</sup>*

It is allowable to disagree with the philosophy of a nation but it is not allowable to exploit, demean or disrespect processes unlike your own.

### **E) Central Partnerships**

Before research can occur, it is necessary to establish partnerships between the researcher and the parties of interest. Partnerships should be based on open, inclusive and equitable relationships that are rooted in trust. They should be reciprocal regardless of the position of the parties, whether land owners, knowledge holders or stewards of the environment. To understand the ethical framework that underpins reciprocity, there is a need to examine historical agreements such as the *Kahswentha* (Two Row Wampum). The *Kahswentha* represents two boats, one Ongwehonwe and one European, and states conceptually that two nations shall exist beside each other, but never interfere with each other. Two boats travelling the same path are stable, but if a person has a foot in one boat and a foot in the other, the boat will then become unstable. We can use this concept as a means of interpreting ethical issues that have occurred in the political, social, spiritual, environmental, health and economic aspects of each nation, when researchers have placed a foot in the Indigenous boat.

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<sup>67</sup> Roundtable Consensus, Transcripts, February 2005.



(photograph courtesy of wampum shop)

It is necessary that any research plan put forth clearly outlines how the outcomes and process will benefit the community. The plan needs to address issues of validity, accountability and the extent to which it will enhance current relationships. To date, there lies a conflict of interest within the guidelines in regards to Aboriginal people. The guidelines need to be contextualized for Aboriginal Peoples. Research must engage individual communities' needs.

A final point made in regards to partnerships was that partnerships between Indigenous nations on a global scale should be developed. More specifically, an exchange/ apprenticeship program between the *Ongwehonwe* and the Amazon tribes was suggested, so that we can learn from one another. Research that is inclusive of Indigenous peoples and their goals should result in rich, broadened and excellent results.

#### **F) Research Funds & Revenue from Findings**

Money received to conduct research should be shared with the people. Elders who are sharing their knowledge and being interviewed or questioned in any manner should receive compensation for their time. Elders and Knowledge Keepers, as the source of Indigenous Knowledge and as experts, should receive recognition both financially as well as intellectually.

Granting agencies should develop a fund solely for the purpose of community-based research, thus data collection can and should be done by community people to help their own development and capacity building. Further, money from institutions needs to be allocated for the design and development of an ethics council that is community-based. Allocation of research funds should assist Indigenous communities to design their own research agendas and train their

own investigators. In this way, Elders, who are in demand by communities and researchers, can share responsibilities with youth as well as graduate students.

Elders are interfaced with research at all levels which further ethics issues such as; Elders are in demand by communities and researchers with no thought of the financial, physical and intellectual drain, they endure from demands of people and institutions. Research should integrate building Elder and youth capacity. Resources should be made available to community as well as graduate students.

Revenue that is created through research publications could be shared with the community. A researcher's payment is received through recognition and prestige of the work. Financial gains must be directed to the source. Thus, grants, royalties, and honorariums given to the researcher should be linked to the community in an appropriate proportion.

Any and all research conducted with Aboriginal people or communities must clearly adhere to a research agenda and contract that is both non-exploitative and non-commercial. Thus, any research conducted must be transparent in its entirety. Aboriginal communities should influence research agendas. The research must be cognizant of partisan politics in their ethical approvals of research projects. Traditional medicine practitioners should have equitable resources that are comparable to those of university researchers.

#### **G) Traditional Medicinal Knowledge**

“Bioprospecting” refers to outsiders mining Indigenous Knowledge in Indigenous territories in order to appropriate them and/or use them for profit through the commercialization of new chemicals, drugs and medicines. “Biopiracy” involves taking plants without the permission of the Indigenous people who occupy the territory.

Bioprospecting and biopiracy raise vital issues of power within Indigenous communities. In the roundtable, concerns were expressed in regards to bioprospecting, especially when

knowledge or specimens were obtained in a deceitful manner. Moreover, it was argued that Indigenous people rarely benefit from this pursuit to expand scientific, genetic, somatic and cultural knowledge. Pharmaceutical companies are sponsoring collectors of plants, seeking information to expand their knowledge of scientific, genetic, somatic, and cultural knowledge. The problem exists within the Western agreement for the ‘good of mankind’. However, globally the 300 million Indigenous people are impoverished and do not have access to Western medicine. According to Richard McNeil and Michael McNeil, the legal and moral grounds for Traditional Knowledge can be argued in the following ways:

*[L]about theory of ownership, which argues that we owe nothing to the original discoverers of the medicinal qualities of plants because huge investments-in education, equipment...have created great value where none or almost none exists; Asymmetry in positions, ... are readily apparent. In contrast with the tribal representative, the ethnobotanist has far greater wealth, power, information [sic]. The latter has many choices that the former do not. Fraud and misrepresentation, ...it may be the case that the transfer of information is the product of deliberate fraud....There is some cases, however, which allow recovery for negligent misrepresentation....[lastly,] Constructive trust, [states] the law of equity may be used to assist recovery once a wrongful transaction is found, and recourse and new institutions.<sup>68</sup>*

Thus, it is important to our discussion to know and discuss these current issues.

The following excerpt stems from a follow-up conversation with a roundtable member who works within traditional medicinal knowledge. The member recalls:

*After introducing myself, I remember talking about the centrality of intent in research practice, comparing it to the same level of concentrated effort and conscious*

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<sup>68</sup> Richard J McNeil & Michael J. McNeil, “Ownership of Traditional Information: Moral and Legal Obligations to Compensate for Taking” *Northeast Indian Quarterly* (Fall 1989), 32-34.

*aim required for the ceremonial handling of tobacco. To tie up a bundle of prayers with tobacco in any context is a lonely thing, not of big crowds, but specifically useful in the human things inspired by love of a child, friend or one's People, for purposes of healing and protection. In this same way, why else do research, but to heal and protect our People?*

*In my own experience, the power of the research process – from hypothesis to interpretation of "the data" and extrapolations of its clinical significance to community interventions – rests upon the relationship-building and communications over time with institutions inside [ethical research] and outside the community. Scientific networking is also social networking, increasing power both inside and outside through mechanisms such as shared authorship, community ownership of data, and shared equity. Done properly, the complexity involved increases capacity in all quarters of the scientific research hierarchy and community circles. Increasing the number of Native students pursuing basic research in graduate school, for example, is one way scientific hierarchy benefits. But Aboriginal scientists must achieve different levels of cultural competency, sensitivity, and relevance in the applications of their work just as primary care providers in clinics must, so that the community benefits.<sup>69</sup>*

Further to this conversation, a member of the roundtable commented on their relationship with a traditional medicine practitioner. The participant stated, “[a]s Aboriginal people, our guiding principles emerge from ceremonial space and our ways of knowing within culture - within family- and not just social contracts that guide the legal practice of controlled acts.”<sup>70</sup>

Researchers must again acknowledge the cultural framework in which their data is gathered. As stated by a participant:

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<sup>69</sup>Cook, via personal correspondence regarding roundtable issues.

<sup>70</sup> Cook, via personal correspondence regarding roundtable issues.

*There are traditional healing practices that are of the spiritual world that are not going to be able to be evaluated under any sort of microscope or any sort of research process. You're taking something like the research process which is totally foreign – it is not spiritual in any nature – and you're trying to look at something spiritual. It's like wearing sunglasses at midnight when there's no moon out. You're not going to see anything. And there was concern about people embarking upon that kind of research. Some of the healers were saying, "I don't even know how it works, I'm just the tool. It is something that comes through me from the Creator."*<sup>71</sup>

Historically, a limitation such as the one noted above has been disregarded by the Western approach. However, it is exactly because of this practice that any guidelines developed around ethical research with Indigenous communities must contain this concept of spirituality for overcoming such disrespectful oversights.

Notably, a participant drew upon a concept put forth by the World Health Organization. She stated,

*The World Health Organization has a statement on traditional medicine and I like it. It goes something to the effect – we acknowledge the validity of traditional medicine. It works. We as human society know it works. But we don't need to know how it works. As I say, this area does not need to be engaged in a scientific manner – leave it alone. We don't want research in the sacred. We want to respect the sacred.*<sup>72</sup>

Respecting the sacred is part and parcel of the philosophical statement. Researchers must recognize the limitations of research within Indigenous communities. Ethical research of Traditional Ecological Knowledge (TEK) and Indigenous Knowledge recognizes the following principles: our cosmology places us in a familial relationship with plants and animals and the

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<sup>71</sup>Cook, via personal correspondence regarding roundtable issues.

<sup>72</sup>Karen Hill, Transcripts, February 2005.

sustainability of our culture is dependent on plants; bio-prospecting and biopiracy are not acceptable practice, and we're not going to give permission to do that; and ethics transcend human beings. Moreover, the participants wanted the Elders Summit Declaration submitted as their position. The Elders' statement on environmental issues that is contained in the Declaration "Kindling the Fire" states,

***First Environments Last:***

Environmental assessments must include the traditional ecological knowledge of Indigenous peoples.

Mother Earth and everything she holds including water, plants and animals must be acknowledged and protected. A consciousness of waste management is necessary.

Genetic engineering is not acceptable.

Sacred sites, artefacts, and lands must be honoured, protected and restored.

Benefits derived from natural resources must be shared equally with Indigenous peoples.<sup>73</sup>

**H) Control over Knowledge**

Once research is completed, there are the questions of ownership, who controls the knowledge and who has the right to disseminate this knowledge, both as an educational tool and as a commodity. These decisions need to be built into the agreement prior to the research being conducted. Agreements should also be carefully monitored so that any ambiguous language or terms within the research agreement can not be subjected to legal scrutiny should the researcher or research-granter seek agency over the material. This language also has to be mindful of local control. Will the findings belong to the community as a whole? To Traditional Knowledge

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<sup>73</sup> See Appendix B Elders Declaration.

Keepers/ Elders? Or to Band Council or Traditional Councils? Can offspring, siblings or spouses claim ownership of the material once the original speaker has passed?

The agreement should stipulate that prior consent from the community must be obtained before research findings can be shared. This is inclusive of published materials, lectures and/or discussion with colleagues and peers. Further, access to this research must be predetermined. What, if any, are the limitations stated by the community or group?

There must be shared control over data collected or knowledge collected from Indigenous communities. The control over information collected should be negotiated in agreement and collaboration with the community. Authorship should also be shared.

In regards to biomaterials, the immortalization of cell lines must be prevented. Researchers are not allowed to take any liberties with the materials gathered whether through duplication processes or the selling of biomaterial as a commodity. We support the current practice of “the chain of custody,” which refers to a practice by which a chain of custody document which can be tracked legally through a court of law is attached to every tissue sample that is ever drawn in a research project, all genetic material should be stored and destroyed by the community and its use negotiated by the community in the proposed project agreement.

## **D) Questions Regarding Insider and Outsider Research**

### **a) Insider Research**

How do we access our people? We are in institutions with our own money and are still encountering problems in accessing and sharing those funds with the communities in which we work and live. Internalized colonialism is effectively fragmenting the community in terms of its research needs. For many researchers the work is about the betterment of the community and nation. Work is framed within the researchers’ personal commitment to counter the disruptive discourse present in many communities. For these researchers “it is not about the money.”

The insider researcher, while seemingly having an easier time accessing a community, is in reality bound by greater accountability. Aboriginal researchers need to obtain consent on multiple levels as previously discussed. One component of research that is integral to community work is the ability of the researcher to work within the language of the community. Language is critical to the survival of the people regardless of research. Research in the community needs to address language through its design and include language retention and dissemination within its objectives.

#### **b) Outsider Research**

Further discussion surrounding outsider research dealt with principals of cooperation and respect. It was felt that any outsider researcher working in a community should be accompanied by a community member or “helper.” Moreover, the community or Aboriginal persons engaged in the project need to be involved at the design phase through to implementation. The researcher needs to formalize their relationship and obligation to both the academy and the community.

Ruby Jacobs, Director of Six Nations Health Services, noted that the Band Council developed an ethical screening process because they were being bombarded by research requests by both insider and outsider researchers. The principle underlying the screening process is that research “must be of benefit to the community.”

#### **Elders Meeting:**

In response to the Elders’ request, the last component of the ethics roundtable was inclusive of traditional persons only. This request was honoured to allow the Elders the freedom to discuss ethics, ethical conduct and prior research freely without feeling stifled either directly or indirectly, by the other committee members. Overall, it was stated that much was needed to be done and the group was thankful for the discussion on a “spiritual level.”

There were four statements arising from this discussion.

1. Elders should be conducting research within the community.
2. Respect should be a guiding principle. Research ethics are manifested in natural law.
3. Youth must be included in all aspects of research. Research must be capacity-building in nature, and youth should be provided the opportunity to learn the research skills both as researcher and the researched. This must be a principle of all projects, even biomedical ones.
4. Language must be included in research projects.

To conduct research with or about Aboriginal Peoples or communities without addressing these outcomes is to conduct unethical research.

**Summary:**

One of our main objectives in this process of researching and reporting was to explore the area of Aboriginal Peoples' experiences with Indigenous medical knowledge, and Indigenous knowledge in-of-itself; and the ethics surrounding those researchers wishing to access their experiences and knowledge. This objective was met through a two-way process, first, we held a roundtable with a diverse group of Elders, healers, youth, Aboriginal and non-Aboriginal researchers as well as health practitioners, which included four presentations by organizations intimately involved with research ethics, totalling thirty-seven people. This was followed with a written report submitted to the roundtable for consent and dissection, before holding a vetting session within a two month period. The second step was hosting the vetting session, which created a space for the participants to gather together and critically analyze the findings from the roundtable and to put forth recommendations on ethical guidelines in Aboriginal research. Both stages of this two-way process were recorded and transcribed, consent was given by all members of the roundtable having been clearly explained the reasons for the documentation as well as being provided copies of the draft report at both stages.

The work itself was based within a cultural framework of Indigenous knowledge. This framework created a discursive space in which the diverse epistemologies and pedagogies of the multi-national participants could be explored equilaterally and woven into a set of consensual recommendations and principles for ethical guidelines on Aboriginal research. In the development of these guidelines a survey literature review was conducted on Aboriginal research and the questions that arise from such research as both an ‘insider’ and ‘outsider’ researcher. This review was brief in its discussion due to the literature reviews conducted by fellow ACADRES.

The outcomes of this process are seen in the formation of the following key areas discussed by the roundtable, they are; Philosophical statement of research ethics, who is knowledgeable: Elders and knowledge carriers, youth, restoration of respect, central partnerships, research funds and revenue from findings, traditional medical and ecological knowledge, control of IK and questions on insider and outsider research. Further to these key areas was the development of nine principles of Indigenous knowledge. They are cosmology; language; integrity/honesty; respect; reciprocity; quality of life; protection of IK; acknowledgment, and intent.

The roundtable emphasised within these areas and principles three major themes. The first addressed was Language, it was stated throughout the two-step process that language must be incorporated into a research project when ever possible. This means a researcher must, to the best of their ability, access language speakers to help in the negotiation stage, potentially act as a liaison throughout the process, and aid and direct in the dissemination of the findings. As noted, ethics are embedded within creation and cosmology, thus, ethics are embedded in language.

Second, cultural protocols were flagged as an important theme for this report. This includes the recognition of Elders as knowledgeable, the allocation of funds to Elders and

building youth capacity under the auspices of Elders was deemed highly important. It was stated that research projects must not be limited to the use of graduate students but must be inclusive of youth who are apprenticing with Elders and Healers within a cultural context. It was further articulated that Elders/ knowledgeable people play an active, decision making role within research projects, that the past practice of Elders as figureheads is not acceptable.

Third, further to the relationships between Elders and researchers, cultural protocols must be adhered to by the researcher, this necessitates a commitment by the researcher to actively inquire and work within the protocols of the community or nation to which they working. Within the concept of cultural protocols and Indigenous knowledge are premises of acknowledgement, recognition and control, and the extent to which the community dictates the manner and methods to which data is gathered, controlled and disseminated, inclusive of Indigenous knowledge integration and interpretation. Partnerships must be developed and maintained within the researcher and researched relationship.

### **Conclusion:**

For research to be ethical whether it is investigating health, traditional knowledge or other areas of inquiry, the researcher and research project must recognize and accept the validity of Indigenous knowledge in its own right. Moreover, the researched must be involved from concept to dissemination. It is the community appointed representatives, Elders, or whom ever, as the case may be, that the research project must negotiate with, include within the research design, and be accountable to.

The issues of ownership control, access and permission (OCAP) are inherent within Indigenous cosmologies, thus the research team must acquiesce to these principles. Language, Elders, youth, and cultural protocols are the fundamental principles to which a researcher or research project must be inclusive off, if the research project is to be considered ethical.

Indigenous knowledge cannot be separated from the spiritual, thus, western-based research must be mindful of Indigenous spirituality when conducting research and act accordingly.

### **Appendix A: Cover Picture**

Photograph by Jacob Pratt 2005.

Persons will be identified from left to right.

Back row: Sara Smith, Bonnie Freeman, Seneca Sundown, Michael Peters, Raymond “Stuff” Murdock, Michael Wilson.

Middle row: Valerie O’Brien, Rauna Kuokkanen, Dawn Martin-Hill, Gail Whitlow, Verdie Bennet, Alexandra “Ali” Darnay, Pat Hess.

Third row: Makasa Looking Horse, Katsi Cook, Louise McDonald.

Front row: Chief Ernest Sundown, Chief Arvol Looking Horse, Chief Arnie General, Chief Hubert Skye and Birgil Kills Straight.

## **Appendix B: Elders Declaration**

International Indigenous Elders Summit 2004  
The Decade of Indigenous Peoples

**Elders Declaration: Kindling a Fire**

**DRAFT**

Elders from North, South and Central America gathered on Haudenosaunee territory for six days to share our achievements and future prospects on peace and unity. We reflected on the effects of historical trauma and the path towards decolonization for Indigenous Peoples of the Americas. A common sense of history binds us while oral traditions, lived experiences, gathered knowledge and re-found wisdom build bridges among us. Our heart rests on our kinship with one another

and with all beings of the universe and the cosmos. Our spirits are no longer homeless. We are grounded on Mother Earth. We are connected to and responsible for those who are here, those who are yet to come and those who have been. Our authority flows from these sources. They set the nature, direction and pace of action. We will set the agenda, we will move it forward, we will do it now and we will monitor and measure its progress. Our collective minds and hearts hereby declare the following:

***Women Give Life:***

Violence against Indigenous women must cease.

Women are the mothers of our nations and their authority must be recognized within and outside Indigenous nations.

***Living Treaties Make Healthy Nations:***

Historical treaties must be recognized and interpreted from our perspective.

Nationhood is ours to keep and exercise.

International treaties must secure our future and that of future generations.

***Education is Right:***

It must be made available to everyone.

It must include our own languages and the resources to support this goal.

It must include traditional teaching practices, cultural practices and history from our perspective.

***Tradition Must Lead:***

Indigenous leaders who hold traditional values, beliefs and cultures must be recognized and respected as leaders in their own right and by the world.

***Roots run deeply:***

Indigenous forms of determining who our people are must be acknowledged.

Assimilation policies and practices being forced on our people must stop.

New forms of colonization must stop and decolonization must begin in earnest.

***Laws Exact Justice:***

Traditional laws and forms of justice exist and must be respected.

International tribunals must deal with the persecution and murder of our people.

***First Environments Last:***

Environmental assessments must include the traditional ecological knowledge of Indigenous peoples.

Mother Earth and everything she holds including water, plants and animals must be acknowledged and protected. A consciousness of waste management is necessary.

Genetic engineering is not acceptable.

Sacred sites, artefacts, and lands must be honoured, protected and restored.

Benefits derived from natural resources must be shared equally with Indigenous peoples.

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