

Ethics of Research Involving First Nations, Inuit and Metis Peoples
Nipissing University April 16, 2014
By Marlene Brant Castellano

First of all I extend thanks and greetings to the Anishnabe people who were the traditional stewards of the land on which we are meeting and to Nipissing University for the invitation to be with you today.

(Traditional Mohawk opening)

It is appropriate to begin a conversation on ethics to remember the values that instruct us through our whatever are our traditions, about how to live a good life, a long life.

Defining Ethics

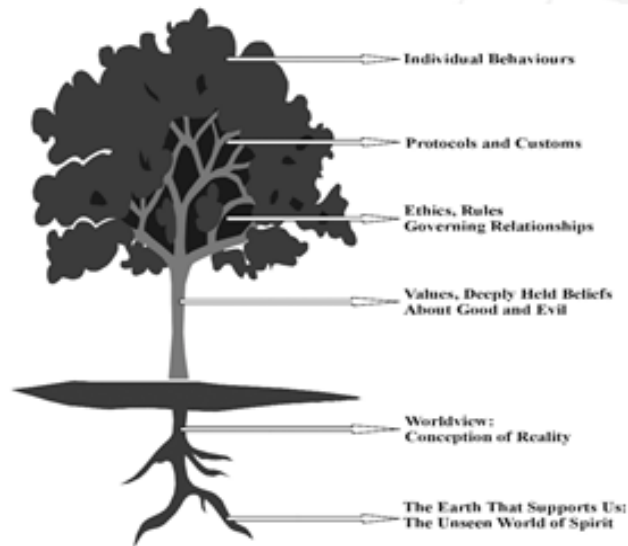
Ethics is not a word that I have been accustomed to use during much of my years in university teaching. Willie Ermine, who is a Cree from Saskatchewan who helped with shaping the Tri-Council policy on research ethics said, " Ethics is the way we treat one another." We all know about ethics, but we use different language.

In a close-knit community such as many of us come from, ethical rules are there but they are not written down. Often they are not even talked about. In professional communities, like lawyers and doctors, ethics are written as a code of conduct. And these go back thousands of years: for example the physicians' ethic of "do no harm".

Codes of ethics, the rules of behaviours that govern researchers are very recent in origin. They go back to the Nuremberg trials of 1946-48 in Germany where it was revealed to the world that doctors and researchers, in the name of science, were doing inhuman things to other human beings. People around the world said: this is terrible that professional people who have power over other people's lives can do mortal injury to other human beings. We need ethical codes for researchers and that was the beginning, the first development of ethical codes for research, at first in the field of medical research. In the last 60 years, those codes of ethics have been refined, further defined, extended to sociology and politics and history and so on, so that eventually all professions developed ethical codes.

I was persuaded in 2004 to write a paper on ethics for the National Aboriginal Health Organization (NAHO), and that paper is listed in the program. This picture of a tree was my way of presenting my understanding of native ethics and how they fit into the world of Aboriginal people.

Native Ethics



**PANEL ON
RESEARCH ETHICS**
Navigating the ethics of human research

(slide 1)

Leroy Little Bear, who is a Blackfoot lawyer and researcher, has written that scientists, anthropologists and sociologists have done a pretty good job of describing behaviours, individual behaviours that go on in native communities, but they really have missed the boat in understanding what lies underneath those behaviours. Scientific papers even describe the protocol and customs that tie together the individual ways of personal behaviour. Behaviours are like the leaves of a tree and protocols are the small branches. But there are larger branches of that tree, which are the rules governing relationships, ethics rooted in the values that the elders talk about. The ethic of sharing goes very deep, so that you see people giving away their food, sharing their food when they have very little of it. It's because they have rules, that are deeply rooted in their understanding of what is right and what is wrong. Values are deeply held beliefs about good and evil and what is required of a human being. They are like the trunk of a tree. Those values are being uncovered in the teachings which are being revived in each of our traditions, the Mohawk traditions that I come from, the Anishnabe of this region.

What is not talked about and what we hardly have the words to explain is where those values come from. Why do we share when we have little? Why do we give away our last bowl of soup? Values originate in our worldview, the conception of reality that says that all of life is sacred. This obligation to share or to

offer respect is because we are sacred beings. The worldview in which our values are rooted is out of sight, like the system of roots that stabilize and nourish a tree.

And beyond and underneath everything is the earth which supports our feet and is our first teacher. The earth which nourishes us like a mother, and embodies the laws of life which we must learn and adhere to if we are to live well.

Talking about ethical rules is like pulling out just one branch of the tree without understanding where it is rooted. That is why it is so important to talk about the circle that encompasses all of life, the balance in the four directions, the various gifts carried by the four colors of humankind. For many years Canada decision-making, policy, planning, understanding, teaching, service have been governed by one part of the circle, one direction, one color and all of the richness and the truth and the values that come from the other parts of the circle have been neglected. Hearing what First peoples have to say, restoring balance, is now on the research and education agenda in universities across Ontario and elsewhere in Canada.

Restoring Balance

In December 2010 the federal agencies that distribute research funding to universities, institutes and researchers across Canada adopted a revised and updated code of ethics called the Tri-Council policy statement: ethical conduct for research involving humans – TCPS2. TCPS2 sets out guidelines for research which recipients of funding are required to follow. Chapter 9 of TCPS2 deals specifically with research involving First Nations, Inuit and Metis peoples but the policy covers all domains of research – social sciences and humanities, health research, natural sciences and engineering. TCPS2 is one part of an ongoing process to restore balance and respect in relations between Aboriginal peoples and Settler society. Willie Ermine from Saskatchewan coined the term “creating ethical space” to describe what we were trying to achieve.

(Slide 2) Separate worlds of knowledge

I have talked about the ethical systems and world views that enabled the original peoples of this land to survive for thousands of years.

(Slide 3) Colonized space

As Aboriginal peoples were displaced from their lands and colonial systems of government, education, economic development came to dominate their lives, Indigenous knowledge was dismissed and overshadowed. The expectation that Aboriginal people would be absorbed into colonial society and

disappear, that they were backward and had nothing of value any more to contribute, led to devastating abuses of power. Residential schools were just one expression of the notion that Settler society was doing Aboriginal people a favour by erasing their connections to their histories, languages and lands.

Academics are relatively modest about the influence they have on public policy, especially when the policy turns out to have been bad. In fact, we have a huge influence on what is accepted as true and reliable knowledge, as reflected in textbooks and taught or not taught in schools.

(Slide 4) Research Collaboration

For generations Aboriginal peoples have pushed back against colonialist definitions of who they are. They have maintained: We are nations. We are peoples of this land. We have never given up our right to benefit from our traditional territories. Those assertions have been reinforced by some critical events.

In 1973 the Supreme Court of Canada ruled on a claim by the Nisga'a of British Columbia to an Aboriginal right over their traditional territories which had never been extinguished. The decision was split for and against the Nisga'a, and the deciding vote on which the claim was rejected, was based on a technicality. Nevertheless the recognition of the existence of Aboriginal rights led to change in negotiations over lands and further Supreme Court rulings. In 1982 protection of Aboriginal and treaty rights was enshrined in the Constitution of Canada. First Nations, Inuit and Metis are assured by the highest law of the land that they will have a continuing place in as peoples not just scattered individuals on the margins of Canadian.

There was another critical event in 1992 – the Earth Summit in Rio and the resulting United Nations Convention on Biodiversity. To sustain earth's environment, signatory nations undertook to “respect, preserve and maintain knowledge, innovations and practices of Indigenous and local communities...relevant for the conservation and sustainable use of biological diversity.”

So, the constitution affirms that we have a right to continue as peoples. The Rio convention affirmed that Indigenous knowledge is of value. A third critical event, in my view, was the launch of the Royal Commission on Aboriginal Peoples on which I served as Co-Director of Research.

In 1992 the Royal Commission on Aboriginal Peoples convened a meeting of some 75 Aboriginal people engaged in research, most at the community level and a few in universities., to assist in designing the research program of the Royal Commission. David Hawkes and I were Co-Directors of Research and as David attempted to begin the workshop he was almost drowned out by loud complaints from the assembly about the evils of invasive research. “We have been researched to death” they cried. David turned to me to take over the chair but I was not the one who brought order and focus to the exchange.

The Elder who had opened the gathering with prayer and ceremony spoke from the corner of the room in a gentle voice that nevertheless commanded the attention of everyone. “If it’s true that we have been researched to death” he said, “maybe it’s time we started researching ourselves to life.” There was silence for a moment and a visible shift in the mood of the crowd. I was not only vastly relieved that our conference was not going to turn into a disaster. I was in awe at the depth of awareness in what I had just heard.

The Elder challenged the powerlessness being voiced by the younger, more educated members of the meeting. Is it true that we are dead? He was open to the possibility that we might be in a unique time when the history of oppressive research could be changed. He recognized the power of research to enhance life and he challenged the assembly to take charge of the tools and do something life-giving. And he included himself and the knowledge of his generation as part of the research enterprise.

This Elder was not intimidated by the mystique and the protocols of research – constraints that academics are so familiar with. He spoke out of a place of wholeness and integrity, knowing what he knew and opening himself to “the unknown unknowns” the things that we don’t know that we don’t know, to paraphrase the American politician Donald Rumsfeld. What was unknown to the academic world for centuries was the depth of awareness, conserved by Indigenous knowledge-keepers, of the complexities of the world at large and the inner reaches of the human spirit.

What we tried to do from the outset in RCAP research was to marry the most meticulous, credible documentary and academic research with Indigenous Knowledge through the voices of First Nation, Inuit and Metis persons and collectives across the country. I believe that the experience of hundreds of Indigenous and non-Indigenous researchers across Canada in principled, respectful collaboration, with RCAP and with each other, had a huge impact on the confidence that First Nations, Inuit and Metis people now have that research can be an instrument for good in their lives. Research collaborations have been increasing over the past 20 years but the terms of collaboration are still contested. Colonial assumptions are persistent.

(Slide 5) Ethical Space

The guidelines presented in TCPS2 are designed to make collaboration easier, but more than that, the guidelines are inspired by a vision of creating ethical space for research – extending the boundaries of knowledge. In ethical space people come together from different directions, with different experiences, knowledge and perspectives. They undertake to set aside preconceived notions and explore common

purpose and expectations of each other. They acknowledge differences , resolve them where possible and withdraw respectfully where their goals or methods are incompatible.

TCPS and Chapter 9

Chapter 9 of the TCPS is a dedicated chapter in an integrated document. The Inter-agency advisory panel on research ethics (PRE) was mandated in 2001 to revise and update the policy on ethics of human research that was adopted in 2010 by SSHRC, CIHR and NSERC. Early in its life PRE made the decision that ethics of Aboriginal research would form part of the whole document and not a separate code. In Australia, they had been working on Aboriginal research ethics, in health especially, and they have their main policy document and then they have another set of ethical guidelines respecting Aborigines and Torres Strait Islanders. PRE decided not to go that route because we wanted every researcher to know that part of their obligation as a researcher is to give the attention necessary to act ethically in Aboriginal contexts.

For example in the chapter on consent there is a rule against paying people for consent to participate in your project. I said, there has to be an adjustment there. It is not appropriate in many situations to ask Aboriginal people to sign a paper saying I give you consent to take my blood, take my story. It is too much like a treaty. What am I giving away? What am I losing on this? If you are going to treat me properly, respectfully, why do we need this paper?

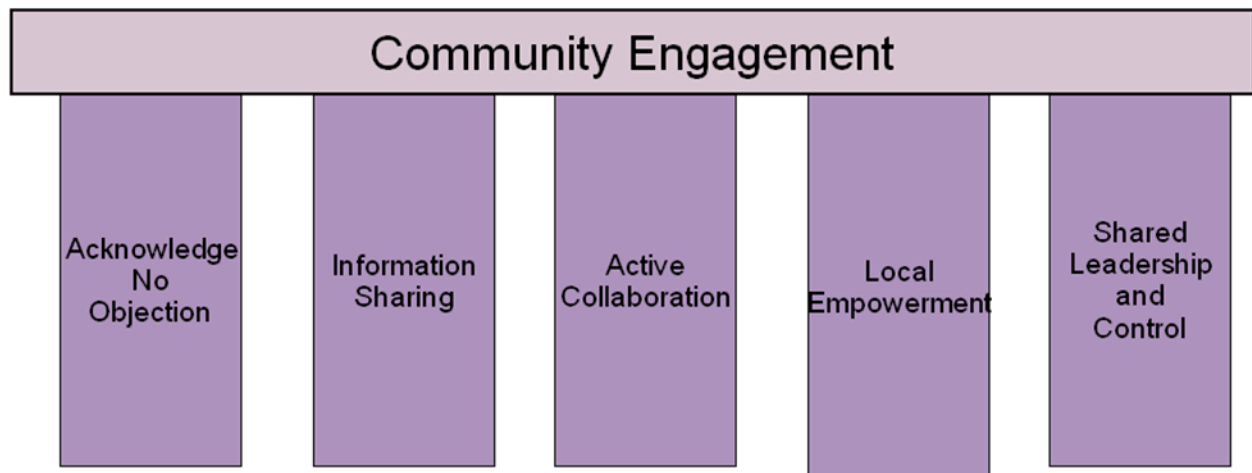
It is proper, however, to give gifts. If you go see an Elder and you are asking to set up a relationship, it is proper to give gifts: a blanket, food to feast people and that represents consent. There have to be provisions that giving gifts, exchanging gifts is one way of sealing consent to research, not just signing a paper that says you understand the research and you agree. So each time we wrote something in the main document about consent or privacy or any of the other things contained in the policy it was my job to say: "In an Aboriginal situation, it works this way, so we have to have this kind of clause put into the general chapter."

Community engagement is the core ethical requirement set out in Chapter 9, where research involves Aboriginal participants and the well-being of their community is likely to be affected. There are 22 clauses in Chapter 9 and 21 of them provide guidance on when, where, how and with whom community engagement can be carried out. In effect the Policy says: Create space for respectful relationships and here is advice and here are examples for resolving questions that may arise.

Types of engagement:



Levels of engagement



Community engagement was chosen because it is inclusive, flexible and can apply in diverse community environments. The key is that parties engaged in the research agree on what is appropriate.

Some the issues that probably should be discussed in advance are:

- How community codes of conduct, whether oral or written, fit with TCPS requirements
- Protecting the privacy of individual participants in small communities
- Processes for review of findings prior to publication
- Anticipated benefits of the research and how they will be shared

- Recognizing contribution of individuals
- Unique role of Elders
- Intellectual property, i.e. ownership and control of research data, reports and publications
- Secondary use of data beyond the specific purpose of the research

Results of these discussions may be set out in a research agreement or recorded as mutual understanding of expectations which can be added to or revised as the research progresses.

Five Reasons for Making Ethical Aboriginal Research a Priority at Nipissing U.

1. Recognizing and affirming Aboriginal and treaty rights is a constitutional commitment on the part of Canada and arguably an obligation of all public institutions.
2. Standards of ethical practice specific to research involving First Nations, Inuit and Metis peoples have been adopted by SSHRC, CIHR and NSERC with responsibility for implementation devolved to NU and other universities eligible for research funding.
3. High quality research requires prior, informed consent and active collaboration with Aboriginal populations. Anything less risks repeating misconceptions of the past.
4. There is increasing recognition that relations with Aboriginal peoples represent the most important and pressing human rights and economic challenges facing Canada.
5. Nipissing University is strategically placed to play a critical role in facilitating education and research that engages Aboriginal peoples particularly in mid- and northern Ontario to enhance a vibrant and harmonious society.

As Chief Justice Lamer wrote in the 2004 Supreme Court decision on *Delgamuukw*: “Let’s face it. We are all here to stay!”

Additional Resources

- TCPS2 available at www.pre.ethics.gc.ca ; www.ger.ethique.gc.ca . Full tutorial and Ch.9 webinar accessible on line.
- Castellano, Marlene Brant : « Ethics of Aboriginal Research » in *Journal of Aboriginal Health*, 1(1), 98-114 available at www.naho.ca/journal

Traditional Opening Words (Mohawk)

In Mohawk tradition whenever a gathering was convened, whether to strengthen bonds of friendship or to conduct business, certain words that come before all others were to be spoken. The purpose was to bring those present to one mind, in thankfulness for the gifts that sustain and guide our life and to reinforce our responsibilities to the earth itself, and to one another.

We look to the right and the left and acknowledge and greet one another, giving thanks that we have been able to come together from different distances, in good health and with good mind. We also acknowledge and send greetings to the Haudenosaunee and Anishnabe peoples who carried special responsibility from ancient times as stewards of the lands on which we meet today.

Then we are instructed to give thanks to our mother the earth who supports our feet and who brings forth all manner of life upon the earth. So we give thanks and greetings to our mother the earth who is carrying out her responsibilities given at the foundation of the world. Flowing through and around the earth are waters that bring cleansing and renewal, without whom no life could exist. So we give thanks and greetings to the waters and to the thunderers who bring the rains to cleanse and replenish the earth.

On the earth are a multitude of living creatures, the grasses and grains and giant trees that provide nourishment and shelter, the animals that provide food and clothing, the birds that bring joy to our hearts with their songs, the winds that bring the changing seasons. All these are carrying out their responsibilities and we give them thanks.

Our Elder brother the sun marks the days with his daily round and Grandmother moon has special care for women and the coming generations. We believe also that unseen forces also have responsibilities that support life and we give thanks to them .

Having named our relations from the earth to beyond the sky we bring our minds together as one and reach deep in our hearts to find the finest words to give thanks to the Creator, the source of life, whose face we cannot see.

And now, the words that come before all others have been spoken and the work of this meeting may begin.