Seminar Proceedings

2nd seminar
on the ethics of research with Aboriginal peoples

Aboriginal peoples and researchers dialogue: How to work better together

Held on Tuesday, September 20, 2011
Université du Québec en Abitibi-Témiscamingue (UQAT)
First Peoples Pavilion, Multipurpose Room
675, 1st Avenue, Val-d'Or, Quebec

First Peoples Pavilion at Université du Québec en Abitibi-Témiscamingue, opened in 2009.

Bienvenue
Welcome
Mino Pijak
Wachiya

Photo : UQAT

Preamble

In memory of William Commanda, spiritual leader of the Anishnabek

(November 11, 1913 – August 3, 2011)

Organizing Committee Members:

Hugo Asselin, professor, Canada Research Chair in Aboriginal Forestry, Department of Humanities and Social Development, UQAT

Suzy Basile, aboriginal Project Manager, UQAT

Manon Champagne, professor and Researcher, Department of Health Sciences, UQAT

Nancy Julien, professor, Department of Health Sciences, UQAT

Thanks to the *World Café's* facilitators:

- Hugo Asselin
- Barthélemy-Hugues Ateme-Nguema
- Suzy Basile
- Nancy Crépeau
- Janet Mark

- Nancy Julien
- Vincent Rousson
- Bruno Sioui
- Marguerite Gaudreau-Mowatt

It is also possible to obtain the proceedings of the Seminar at the following web addresses:

http://www.uqat.ca/recherche/?menu=premierspeuples

http://web2.uqat.ca/recherche/

http://uqat.ca/services/premierspeuples/?m=recherche

The Seminar was possible thanks to the contribution of the following organizations:

Summary

Introduction

The *Université du Québec en Abitibi-Témiscamingue*'s *Comité d'éthique de la recherche avec des êtres humains* (CÉR-UQAT) (UQAT's research ethics board) is very pleased to present the proceedings of the second seminar on ethical conduct for research with Aboriginal peoples, held on September 20, 2011 in Val-d'Or, and involving some 65 participants.

This activity was a follow-up to the first seminar on ethical conduct for research with Aboriginal peoples, which was organized by CÉR-UQAT in May 2009. The second seminar took place in an especially stimulating context as the second edition of the *Tri-Council Policy Statement* (TCPS 2) had been published in December 2010, with Chapter 9 focusing on ethical conduct for research involving Aboriginal peoples (*Research Involving the First Nations, Inuit and Métis Peoples of Canada*).

There was all the more reason for holding a second seminar in view of the continual increase in research activities conducted in partnership with First Peoples (representing nearly a third of UQAT's research projects), as well as Aboriginal peoples' own growing needs in regard to research. Added to this was CÉR-UQAT's desire to include a section specifically concerning ethical conduct for research with Aboriginal peoples in its new *Politique d'éthique de la recherche avec des êtres humains* (Ethics policy for research involving human beings), which had come out in June 2011.

In this context, the seminar's objectives were to:
- enable participants to share their points of view, needs, knowledge and ideas relating to research with Aboriginal peoples;
- examine Chapter 9 of the second edition of the *Tri-Council Policy Statement*[1] (TCPS 2) dealing with ethical conduct for research involving Aboriginal peoples in Canada;
- contribute to the general reflection about adding a new section on research with Aboriginal peoples in UQAT's ethics policy for research involving human beings;
- develop some concrete ways of following the principles of research ethics in respecting the needs and wishes of Aboriginal communities and organizations.

The participants at this seminar included:
- members of Aboriginal communities who participate in research projects or are interested in research;
- leaders and decision -makers in Aboriginal communities who have to respond to requests from researchers and universities;
- university professors, researchers and students who are involved in research with Aboriginal peoples;
- representatives of regional organizations who are interested in research with Aboriginal peoples.

The day-long seminar was led by Suzy Basile, UQAT Aboriginal project manager, and Nancy Julien, UQAT professor and member of CÉR-UQAT. After an opening ceremony by an Anishnabe elder from Lac Simon, the first part of the morning was devoted to examining Chapter 9 of the TCPS 2. This was presented by Dr. Marlene Brant Castellano, originally from the Bay of Quinte Mohawk community and emeritus professor at Trent University. As a member of the Interagency Advisory Panel on Research Ethics, Dr. Brant Castellano led the work of the working group on Chapter 9 of the TCPS 2 and, during her presentation, shared with us her passion about the ethics of research with Aboriginal peoples and

her extensive knowledge on the subject. Next, Bruno Sioui, UQAT professor and member of CÉR-UQAT, reviewed the findings of the first seminar held in May 2009. An interactive activity in the form of a World Café[2] was then proposed. In the afternoon, Nancy Gros-Louis McHugh, research sector manager for the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC), presented the research activities carried out by this organization. This was followed by an overview of UQAT's *Politique d'éthique de la recherche avec des êtres humains* (Ethics policy for research involving human beings) by Manon Champagne, UQAT professor and CÉR-UQAT chair. At the end of the day, Hugo Asselin, UQAT professor and member of CÉR-UQAT, led a discussion sharing the findings of the World Café.

Included in these proceedings are presentations by Dr. Marlene Brant Castellano, Bruno Sioui and Nancy Gros-Louis, and a summary of the ideas that came out of the World Café. We hope that these different texts will contribute to the general reflection on this topic and serve as a reference for Aboriginal communities and for professors and students who conduct or intend to conduct research with Aboriginal peoples. Enjoy your reading of these proceedings!

Manon Champagne

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1 Social Sciences and Humanities Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Canadian Institutes of Health Research (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

2 The "World Café" is a creative process designed to foster constructive dialogue and the sharing of knowledge and ideas, with the goal of creating a network of discussions and actions. The process reproduces the ambiance of a café, where participants discuss an issue or topic in small groups around a table. At regular intervals, the discussion leaders change tables. At the new table, the discussion leader summarizes the conversations at the previous table with the participants. The new conversations enrich the earlier ones. At the end of the process, the main ideas are summarized during a plenary session, and the possibilities for follow-up are then discussed.

Enabling respectful relationships : the policy approach of the TCPS, Chapter 9

by Marlene Brant Castellano, Professor Emeritus, Trent University

Greetings
Good morning, Bonjour, Shé:kon,

First of all I bring respectful greetings to the Anishnabe people who are the traditional keepers of this territory, to the University of Québec Abitibi-Témiscamingue for the invitation to be with you today, and the organizers who have made my visit very comfortable. I especially want to thank the Elders for their opening, for bringing our minds together to remember the sacred nature of what we are doing. It was very moving even though my knowledge of French is little, and my knowledge of Anishnabe is even smaller. I share the prayer to give thanks for the gift of life and the natural world that supports our feet and to remember the responsibility to use the gifts that we have to make life good for those who are close to us and those for whom we have responsibilities. The opening ties in very well with a session on ethics, remembering the values that instruct us through our traditional teachings, whatever are our traditions, about how to live a good life, a long life. I feel as if I can shorten my talk because you had such a fine introduction to ethics already.

Defining Ethics
Ethics is not a word that I have been accustomed to use over the course of my work. Then, 20 years or so ago, my brother, Dr Clare Brant who was the first psychiatrist of Aboriginal origin in Canada, wrote a paper about native ethics or rules of behaviour. More recently, 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, in a 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. This is what my brother Clare was doing in his writing, as a physician of the minds, bringing into words things that we take for granted the kind of values that the Elders were talking about this morning. In professional communities, like lawyers and doctors, they are written as a code of conduct. And these go back thousands of years: the 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 such terrible damage to other human beings. We need codes, we need ethics 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 after my biography. This picture of a tree that I

designed was my way of presenting my understanding of native ethics and how they fit into the world of Aboriginal people.

Figure 1
Native Ethics

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 were talking 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 way of understanding 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 that you work with.

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. Beyond and underneath everything is the earth which supports our feet and is our first teacher.

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 balance in the four directions, the four colors of humankind. For so many years in Canada decision-making, policy, planning, understanding, teaching, services 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. It is a great pleasure to walk into the Pavilion of First Peoples and to see that hearing what First Peoples have to say, restoring balance, is now part of the education in which you are engaged in. So thank you for asking me to join you.

The TCPS

The *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) is the set of rules for researchers' behaviours that has been jointly adopted by three agencies: the Canadian Institutes of Health Research (CIHR) of which the Institute of Aboriginal People's Health forms a part, the Natural Sciences and Engineering Research Council (NSERC), which is responsible in particular for environmental research, and the Social Sciences and Humanities Research Council (SSHRC). The three councils together distribute close to 3 billion, not million, dollars per year from the federal government to research institutes, universities and scholars for research in Canada. The TCPS, Tri-council policy statement, is the policy which is the guidance document binding on all research institutions who want to be eligible to receive any of that money. So it is quite an important statement.

In addition to being binding on institutes who receive the research money from the federal granting councils, the TCPS is also used by other agencies in Canada and around the world as a reference, as a guide, and quite a number of federal government agencies also look to the TCPS.

The overarching purpose of the TCPS is to ensure respect for human dignity in research, to prevent the kind of violations which were revealed in Nuremberg and have occurred again and again over the last forty years. And if violations happen, then penalties should follow.

Because respect for human dignity is such a broad term, we broke that down into three principles: *respect for persons*, *concern for welfare* and *justice*. These are the principles which advance or protect respect for human dignity. It became evident early on in the work of the panel in which I was involved drafting the 2010 update, that the general ethic in the framework of the TCPS required clarification when it applies to First Nations, Inuit and Métis contexts.

I just want to say a few words about the core principles. The principle *respect for persons* recognizes the inherent value of human beings and the respect and consideration that they are due. It incorporates the dual moral obligations to respect personal choice, which is always referred to as autonomy, the right to make your own choices, and to protect those with developing, impaired, or diminished autonomy. In plain language, that is children, disabled persons or persons who are ill or can't make choices independently.

Concern for welfare: I argued against using the term welfare, because the word welfare has some bad associations for Indigenous peoples. With clarification it stayed in. We defined welfare as protecting the welfare of participants in view of any foreseeable risks associated with the research. So researchers aren't there to protect people from drunk drivers; they are there to protect them from risks involved in research. Welfare refers to all aspects of a person's well-being including physical, mental and spiritual health, physical, economic and social/cultural dimensions of their environment. Concern for welfare is really very inclusive. Well being is used more often in work with First Nations peoples.

The third principle of *justice* is the obligation to treat people fairly and equitably. It entails treating all people with equal respect and concern. It requires distributing the benefits and burdens of research

participation in such a way that no part of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from research.

Challenges in Writing Chapter 9

There are challenges in trying to write a policy that incorporates respect for persons, respect for welfare and justice for First Nations, Inuit and Métis. The first thing is that there is such diversity among First Nations, Inuit and Métis peoples, urban and rural, traditional and acculturated. It was a big struggle even to move away from the constitutional protection language of "Aboriginal" and respect diversity. Second is the distrust resulting from past experiences of research that was not just. It did not distribute benefits and burden equally or fairly. It did not respect persons in the way they wanted to be respected. They were treated as objects. Like the horrible example of measuring the head to see whether Aboriginal brains were big enough to be really educated.

Then there were the multiple constituencies involved in research. We could write a policy that spoke to First Nations, Inuit and Métis peoples in all their diversity, but if it did not speak to researchers and institutions and policy makers and granting agencies; we would be off in another kind of reserve, a research reserve where rules applied only in the tiny little corner where we were operating. So, we had to find a balance, speaking to many, many different constituencies.

There are the language differences in ethics, the difference between a written code and a felt obligation to behave in a certain way because of the sacredness of life. How do you speak in a way that crosses those language barriers? There is a rapidly changing environment of research, and UQAT is such an example of this. Thirty years ago I was welcoming Cree students from James Bay communities to Trent University, where I taught. At that time it was not possible, at least in their view, to find a place to study at an advanced level where their culture and their language and their values and their understanding of the world were given proper attention. So they came to Trent which was one of the first, no, the first and now one of many, many universities across the world, across the country that are making a space, a welcoming space like the Pavilion for First Nations and Inuit and Métis.
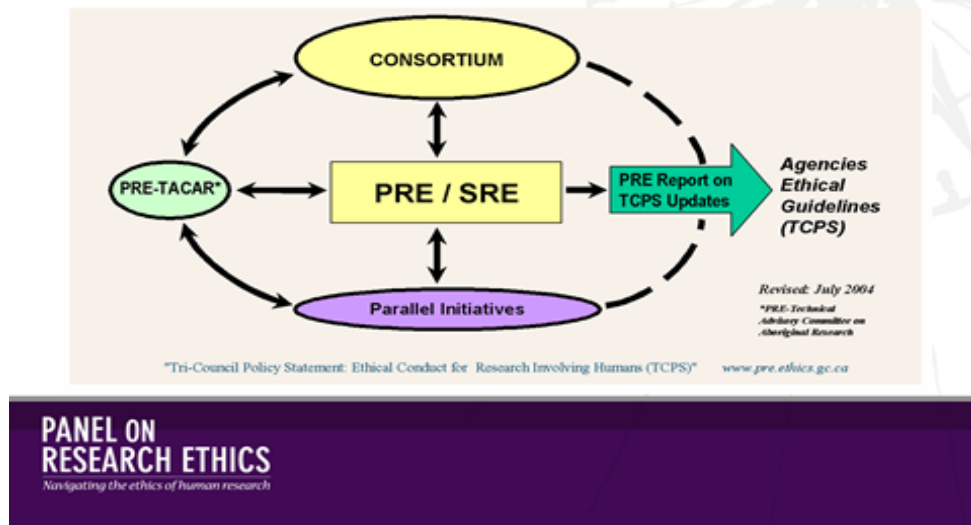
I think one of the changes in research environment is that there are many more First Nations, Inuit and Métis researchers themselves wanting to expand their knowledge, their understanding and their effectiveness in serving their own communities, their own nations. In fact, what is required is not going off on our own track in research but forming partnerships so that we balance that circle and bring the wisdom and the strength and the resources of our own environment and create knowledge for the next generation.

I don't pretend to list all of the challenges but one of the really awkward one was the contestation over the definition, the interpretation of rights. Just to give you an example, there was the Haida-Weyerhaeuser decision on the obligation of public agencies to consult with First Nations communities when anything affecting their rights was going to be developed and that was particularly around forestry. The Supreme Court said that there is an obligation to consult. So the Indian Affairs Department, which sat in one of our advisory group said: "You can't use the word consultation." We answered: "But that is what we are doing in writing the new policy statement on ethics! We are consulting!" They maintained: "You can't use consultation because consultation has been legally mandated by the Supreme Court. And as soon as you use that, then First Nations are going to start litigating with us that we are endorsing a policy of a federal agency without real consultation". So you will see that we find other language.

Collaborating to Find a Balance
To respond to these many challenges, we developed and set up the collaborative process to find a balance, represented in Figure 2.

Figure 2
Collaborating to Find a Balance

"Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)"   www.pre.ethics.gc.ca

PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

I will try to unpack this. At the center there is PRE, Panel on Research Ethics, twelve specialists on ethics from across Canada, including medicine and engineering. We had an engineer who was president of a firm working on artificial intelligence and I learned a lot from the way he approached things. There were sociologists and anthropologists and so, the whole range of researchers in every domain of the tri-councils sat on PRE. I was the only First Nations or Aboriginal person there. When colleagues were telling me: "This position is open; you should put your name forward!", I was saying: "But these are the most expert people in ethics and I am just learning what ethics means and I really think about ethics from a First Nations point of view". And they said, "Marlene, you have been working on ethics your whole teaching life, your whole life as a researcher. Go for it!"

Sitting on this panel of experts on PRE, I found that the first thing they acknowledged: "We don't know anything about the challenges, the contexts or what needs to be done to write ethical rules affecting research with First Nations, Inuit and Métis, but we want to learn." Their attitude was: How does this work for First Nations? What do the Inuit mean when they say this? I had the background of five years working with the Royal Commission to have confidence to say: "This is what I think they say or what they want to do". And I just want to say that this panel of experts on ethics was so respectful, without being "wishy-washy". I mean, they didn't just say: "Well go ahead and write it your way". They said: "Why? What does it mean? How does it fit with the rest?" And this is the way we worked, in a very respectful way.

It was our responsibility as PRE, supported by a secretariat, to send a report to the agencies which what would eventually become policy, in December 2010. We also set up a consortium; we brought together in a kind of a council five national Aboriginal organizations, the senior representatives, often the vice-president of each of the councils, and several federal government ministries. I was surprised that the Aboriginal representatives said: "We want federal ministries to be on the consortium because

we want them to be educated in how we are doing this". Federal ministry representatives were participants in discussions but non-voting. So, this was the consortium that advised PRE. We also convened a researchers committee and this was made up of First Nations, Inuit and Métis researchers and non-Aboriginal researchers who had experience working with communities. That was our technical advisory committee on Aboriginal research, PRE-TACAR.

And then, there were parallel initiatives, the Institute of Aboriginal Peoples Health and CIHR had been forging ahead to write ethical guidelines for health research. NAHO was doing educational work on ethics. The Aboriginal health survey guided by the First Nations Information Governance Committee was working on OCAP: ownership, control, access and possession. They were implementing that and the practice of community-based research in the Aboriginal health survey. There were things going on in universities as well. We kept in touch with people working on parallel initiatives and we brought all this knowledge and advice together in PRE interacting with the perspective of the general research community. I actually worked for seven years on this, from 2003 to 2010. A friend said: "Seven is a perfect number; you can retire now".

I want to emphasize that because CIHR guidelines had been out about two years in advance of the TCPS2 we were very careful to integrate all of the provisions in the CIHR guidelines within the broader TCPS. If communities are comfortable with the specifics and examples of the CIHR guidelines, those can still apply. If you want to see how CIHR guidelines fit into a larger frame beyond health, how they fit with the new rules and research, you can see that in TCPS 2, chapter 9.

One of the things I learned working with the Royal Commission on Aboriginal Peoples (RCAP) from 1991 to 1996 was that I had the privilege of being part of an historic process, a generation-long historic process. I did some travelling after the Royal Commission report was published, interpreting and explaining what it was saying. People in the community were very clear about who was driving the process of change. For example, one person said: "My grandfather was working for years on these issues of justice for First Nations peoples. Don't say the Royal Commission did it!" George Erasmus, who is a fantastically gifted and wise person, when we got hung up on something very difficult in the Royal Commission, said: "People were working on this long before the Royal Commission and they will continue working on these questions long after we are gone, so let's not get too absorbed with how important we are".

The ethics process of guiding researchers to respectful relationship is intimately tied up with reclaiming lands and territory. The process includes the Supreme Court decision, in Delgamuukw, saying you must pay attention and you must give equal weight to oral testimony and oral history along with documentary evidence. Fantastic! The Haida decision says there must be consultation when development on lands under claim is involved and the federal government is saying, well, this applies to just this little part of reality. But what we did in TCPS2 was to say: not consultation but *community engagement* is an ethical obligation across the whole spectrum of research. It is not mandated by the Supreme Court, it is an ethical obligation to sit down and engage with, and listen to, and find the balance with the people in whose lives you are interfering. So the TCPS is part of asserting our rights to survive and thrive as peoples. Not as poor individuals on the margins of society, but as peoples with history, with lands, with a future, with rights which are constitutionally protected. There is one sentence in Chapter 9 that says: It is because of constitutional protection for Aboriginal rights that attention must be paid. Because we did get the question: The accommodations you are making with respect to Native people, why not do the same for Chinese and Ukrainians and East

Indians? Because First Nations, Inuit and Métis have protection to live in this land as peoples, not as immigrants who adjust to everybody else, to the prevailing culture, but to live as peoples with dignity.

To have that presence of First Nations, Inuit and Métis explicitly respected in the TCPS, the policy governing all researchers supported by public funding, federal funding in Canada, means that reclaiming the territory of the mind now has a base, now has a policy base for researchers who wish to respect the human dignity of Aboriginal peoples as they themselves define it. It's a reflection, it's not the beginning or the only statement but it's a reflection of the work we have been doing to renew language and culture, to insert relevant cultural based education, to recognize the power and the wisdom of oral tradition and teaching.

An Elder in Alberta calls what is in progress "researching ourselves to life." In the first seminar like this that we convened with the Royal Commission, not on ethics but on the RCAP research program, my colleague, my co-director of research introduced the agenda and we got the usual complaint: "We have been researched to death. We don't trust researchers." And then an elder who had opened the meeting, stood up from the side of the room and said: "If it is true that we have been researched to death, maybe it's time we start researching ourselves to life."

Here was an Elder who spoke as little English as I speak French and he was respectful of research, he was respectful of what we were going to do in the Royal Commission. And he was saying, in effect: "Are you that dead, really? Research is a tool which we can use to nourish our life." And that saying, *researching ourselves to life*, has become a kind of a mantra out West. You hear it at the beginning of a great many presentations. I have a biased point of view because RCAP absorbed more than 5 years of my life, but I think that the Royal Commission on Aboriginal Peoples wrote the first code of ethics reflecting First Nations, Inuit and Métis expectations of research. It was a turning point in breaking down the mistrust and the bad history changing the attitude that First Nations, Inuit and Métis had about research. They saw that it could be a tool for researching ourselves to life.

The TCPS Chapter 9 is part of a long historic process and it is not finished yet. It is meant to be a living document. First Nations, Inuit and Métis contributors have had a very strong presence in shaping TCPS 2 and there is a statement written into the document that this involvement, having a place at the table, having a voice in the refinement of research ethics in Canada, will continue.

Research Involving First Nations, Inuit and Métis Peoples
I will talk a bit about Chapter 9 specifically. The way to think about Chapter 9 in the TCPS is a dedicated chapter in an integrated document. That decision was made in 2003 or very early on. The first version of the TCPS in 1999, was the first comprehensive document on research ethics in Canada. The document declared that not enough consultation had been done by 1999 to make rules about research with Aboriginal peoples. The TCPS referred researchers to the Royal Commission ethics document and the Inuit Circumpolar Conference statements and a few others. PRE made the decision that attention to Aboriginal research would be 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. We decided not to go that route because we wanted every researcher to know that part of their obligation as a researcher was to give the attention required to be ethical 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."

The fact is that you can't photograph ceremonies such as the one this morning without consent. The fact that there is no person at the door, or that as the ceremony is held out in the wood and there is nobody preventing you access with your camera does not mean that you can just go in and photograph ceremonies. You have to talk with, consult with people about when it's appropriate to take pictures, to record things. When I say that Chapter 9 is a dedicated chapter I mean that we tried to anticipate the kind of issues that might arise and how to deal with them and then make sure that those provisions are reflected in every chapter of the TCPS.

The key provision in Chapter 9 is: Where the research is likely to affect a First Nations, Inuit or Métis community or communities to which potential participants belong, researchers shall seek engagement with the relevant community. So that means that if someone comes into Northern Quebec and is doing research which is likely to have an impact on First Nation or Métis people in the area, they must consult, they must engage with the relevant community. The nature and extent of community engagement in a project is to be determined jointly. It's not sufficient to say, well I asked the Chief and she said it was fine, so we are going ahead. The engagement should be appropriate to community characteristics and the nature of research.

A working paper that PRE published in February 2008 elaborates on background issues leading up the text of Chapter 9 in TCPS2. It is still available in the archives section of the PRE website (www.PRE.ethics.gc.ca). To reach the working paper you can search the PRE website for "Research involving Aboriginal peoples 2008" or for a file "AREI" which is Aboriginal Research Ethics Initiative. Appended to the 2008 working paper are four case studies illustrating ethical research in practice. One is a case study from the Aboriginal health survey, one is on homeless youth in Edmonton, one is a case study of housing in the Arctic Inuit community and the fourth is a case study on language reclamation among the Métis in Manitoba. Also on the PRE website is a tutorial for people who are teaching or learning about ethics and the TCPS.

Community Engagement
Community engagement is the key requirement and, just a word about why we chose that. It is an inclusive term that covers a broad range of relationships. It does not impose restrictions on community processes, so for example, if a community is using the CIHR guidelines and those are the rules that they want to use, the engagement process says that is fine. One of the parallel documents we consulted was the *First Nations of Quebec and Labrador Research Protocol* which is very full and complete and helpful. If that is the document that First Nations of Quebec and Labrador, or a

particular First Nation, want to use for reference, that can be used because engagement says that the guidance and the TCPS are not to override or restrict community processes. So the TCPS provides the guidance of how to resolve the variations, the differences and contradictions, even conflicts between community codes and the TCPS. There will be differences in language, in interpretation and even some basic rules, most of which can be worked through in respectful relationship to allow research to proceed.

The types of community are varied, for example: a territorial community like a First Nation; an organizational community such as a Tribal Council or a Friendship Center; or a community of interest which has fluid boundaries and shared interests such as a network to conserve an Aboriginal language. The case study in the 2008 document concerns homeless youth who obviously don't have an organisation that a researcher can engage with but there are other ways. In this case, the Native Counselling Services of Alberta which provided housing support became the ethical body that the youth who were engaged in the research referred to in order to protect their interests.

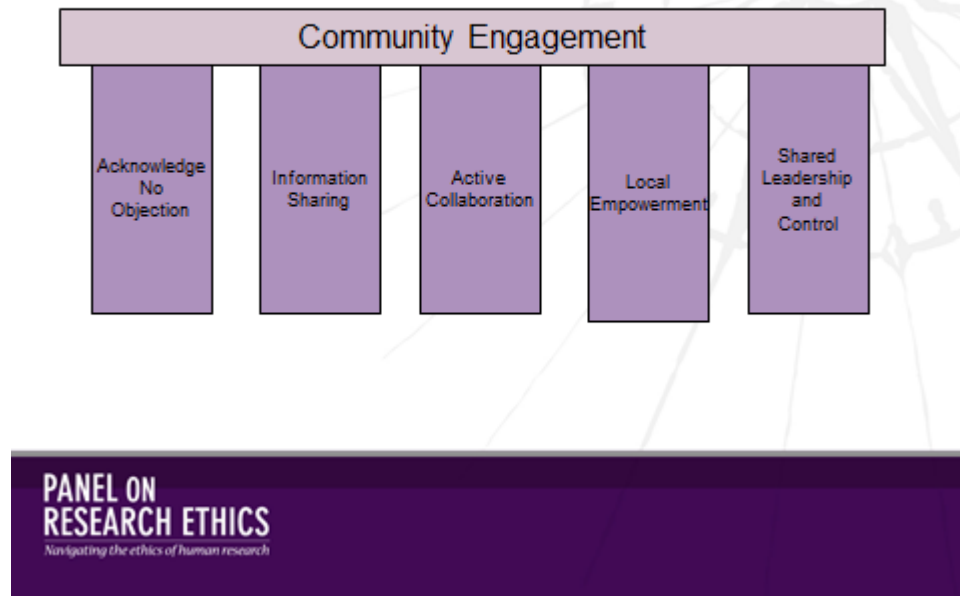There are different forms of engagement illustrated in Figure 3.

Figure 3
Forms of Engagement

Community Engagement

| Agreement of leaders | Joint planning with responsible Agency | Partnership Agreement | Expert Advisory Group |

PANEL ON
RESEARCH ETHICS
Navigating the ethics of human research
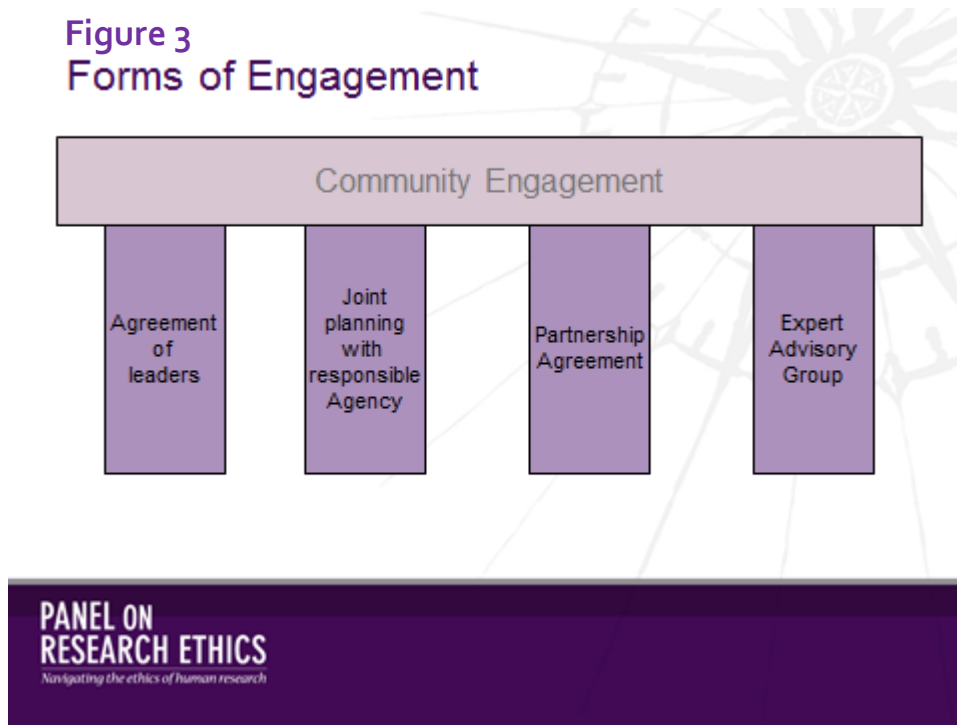
It can be an agreement with leaders; it can be joint planning with the responsible agency, like the Health and Social Service Committee of a Tribal Council or a community. It can be a full partnership agreement, such as the First Nations of Quebec and Labrador have mapped out in their ethical policy. It can be an expert advisory group. In the case study of homeless youth in Edmonton, it was Native Counselling Services who understood the situation of the youth and what kind of risk might be entailed in research involving them. Native Counselling Services provided liaison with the youth and advice to the University of Alberta in carrying out the research on transition from homelessness.

Levels of engagement also vary as illustrated in Figure 4.

Figure 4
Levels of Engagement

Community Engagement				
Acknowledge No Objection	Information Sharing	Active Collaboration	Local Empowerment	Shared Leadership and Control

PANEL ON RESEARCH ETHICS
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There are situations where a community acknowledges the research and has no objection. The example which comes to mind was when the Mohawks of Akwesasne believed that their animals and gardens were being poisoned by fluoride from the regional aluminum plant. The government and the industry were saying: "There is no problem. There is no problem!" The Mohawk community said: "Our animals are dying and the fish are dying. There is something wrong here." They went to Cornell University in Ithaca, New York and recruited scientists. They said: "We believe our lives are at risk. We want an absolutely unquestionable scientific study about pollution." The scientists at Cornell University said: "Yes we will do that." So the Mohawks of Akwesasne said: "We do not want to direct this research. We want scientists to come in and to do it and to provide the results so that nobody can challenge the results." So, that is an example where a community acknowledges that research needs to be done but does not want to be involved in the execution of it.

At a greater level of engagement there is information sharing with the community. With more engagement still, there is active collaboration of the community with recruitment, collecting data and interpreting the results. There is local empowerment where advancing the capacity of the community to do their own research is part of the agenda; and then there is the shared leadership and control which is outlined under OCAP (ownership, control, access and possession). Community engagement can mean any of those things.

Scope and Limitations of the TCPS
The TCPS applies to institutions which want to maintain eligibility for funding from the federal granting councils. If a pharmaceutical company is doing its own research, the TCPS does not apply, except if the company hires a researcher affiliated with a university bound by the TCPS.

Ethics review is required at the university or research institute to which the researcher is attached AND by the research ethics board or similar body if one exists in the community involved in the

project. Researchers are required to advise the Research Ethics Board of their institution how they have engaged or how they propose to engage the First Nation, Inuit or Métis community. If researchers submit that engagement is not required, they have to present a rationale of why it is not required. For example, if research on wildlife is going on in Northern Quebec and the researcher is gathering samples only from animals and no data from humans, then the TCPS does not apply. In such a case other protocols under the Northern Quebec Agreement would come into play and the TCPS could provide useful advice on how to engage the community respectfully.

Research agreements are used when a community has formally engaged with a researcher and there is a designated representative. It clarifies and confirms mutual expectations and commitments, including the ethics review. It precedes participant recruitment, and consent of individuals is required in addition to community agreement.

Some examples of issues that need advance consideration are:
* How community codes fit with the TCPS.
* The privacy of individual participants in small communities, because this is often a concern; If I give you information, who is going to see it?
* Processes for review of findings prior to publication; Do we have a chance to see how you are interpreting this and did you get it right?
* Sharing the benefits of research.
* Bringing the results back to the community.
* Recognizing the contribution of individuals. Protecting the identity of participants is required in many types of research but sometimes in Aboriginal research naming participants is appropriate for giving proper respect to a person who contributes knowledge.
* Recognizing the unique role of Elders.

Other issues that need advance consideration include: intellectual property; ownership and control of research data, reports and publications; secondary use of data beyond the specific purpose of research. This has been contentious - health researchers collecting blood samples for arthritis research and then using the blood components to argue that the people did not come from where they said they did; they actually came from Asia. In a particular case, the Nuu-chah-nulth in British Colombia were saying: That is a violation of our human rights to take our blood and then to try to destroy the history and traditions of our communities.

The TCPS, Chapter 9 has 22 specific articles, with examples, to enable communities and researchers to engage in respectful relationships, for mutual benefit.

Good as it is, having taken years to develop the TCPS has limitations. This is a policy statement on ethical conduct involving humans, that is, persons who provide information or biological materials. TCPS does not cover research on the environment or wildlife, although other policies may apply and researchers are directed to check all the other policies that may apply.

TCPS is not a funding document. It does not determine how funding will be distributed by CIHR, NSERC and SSHRC. However, since the policy has been adopted by the governing councils of all the agencies fitting the funding policies to ethical requirements is a logical next step. Researchers argue that: "We cannot engage with communities if we don't have any funding available to do that and there is no line in the funding application for preparatory work for developing relationships." There will be a need to push to open that door. That will be done through your university and professional

associations saying, "If you want us to be ethical in accordance with the TCPS, you have to make provision in the funding rules that apply."

TCPS is a guidance document for implementation by institutions sponsoring research and the institutions are the bodies responsible for dealing with violations of the guidelines. What we are doing here today, contributing to UQAT's development of their own institutional policy is the next step required in order to make the TCPS2 a reality. Effective local policies will make TCPS2 a tool for enabling respectful relationships.

Nia:wen, thank you!

Additional Resources

- TCPS2 available at: www.pre.ethics.gc.ca ; www.ger.ethique.gc.ca

- Castellano, Marlene Brant : « Ethics of Aboriginal Research » in *Journal of Aboriginal Health*, 1(1), 98-114 . Available at: http://www.naho.ca/journal/2004/01/08/ethics-of-aboriginal-research/

- Marlene Brant and Jeff Reading: "Policy Writing as Dialogue: Drafting an Aboriginal Chapter for Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans" in *International Indigenous Policy Journal*, Vol. 1, Issue 2. Available at <http://ir.lib.uwo.ca/iipj/vol1/iss2>

PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

Marlene Brant Castellano

Question period
Question 1 Thibault Martin
I am Thibault Martin, I am from the University of Quebec in Outaouais. I have a question, I have been thinking about this question since a long time because it is something that happened to me, it is about community engagement. What if there is a disagreement within the community? What if a group of people ask for research to be conducted in the community and if the Band Council is not supportive of the research? They might not say no, but even if you don't say no, if you don't say yes, it is a kind of an indication that you are not supportive of the research. So what shall we do if it is happening? Sometime it is simply students, they want to do a research, they have connections and people are supportive but not the Band Council.

Marlene Brant Castellano
You have heard about all the smart phone applications, there is an "app" for that. Among the 22 articles in the chapter there is an article addressing this question. It recognizes that there are communities within communities and that there are some segments who are disadvantaged in terms of gaining the support from authorities who speak for the community. We present some strategies for resolving the problem. We used the example of women, especially women who have been reinstated under Bill C31 who may not have a voice and we talked about some alternatives for how to deal with that without widening any divisions that may exist in the community. It is a difficult thing and we suggest ways of getting around it without actually setting up a conflict with the local authority. For example, two spirited homosexual people are sometime targeted in the community. It is a very important element for research but to start a conflict could actually make their situation more risky. So it's a complex situation and you try to strategize and find a way through. We have some suggestions in Chapter 9 about how to go about it.

Thibault Martin
Thank you!

Question 2 Hugo Asselin
Thank for your presentation, very complete and interesting. You talked in your presentation about the Haida judgement by the Supreme Court that said that the Crown and other bodies have an obligation to consult, but the judgement also said there is an obligation to accommodate after consultation of course and to me the problem is they don't say who judges if the accommodation is sufficient or not. Do you have clues on that?

Marlene Brant Castellano
That was why we weren't allowed to use the word consult. Whenever we put consult in the ethics document, people who reviewed it in the Ministry of Justice struck it out. It is one of the areas that will continue to be contested. I am not a litigating person; I am not a good fighter, I am a good arguer but not a good fighter and I am extremely grateful in the work that I have done over the last forty years in education and health and now ethics and research, that there are people who push to the Supreme Court to get a judgement. Delgamuukw was a step in gaining legal recognition for oral history and oral tradition and now the Haida decision says governments and developers must consult and must accommodate. The next step of how to make this really work still has to be done. This is the work of political people, creating space and enabling us to do ethical work as researchers and educators. It is always difficult. The Nuu-chah-nulth gave their blood for arthritis research and found out that it was used for purposes contrary to their interest. They went everywhere. They went to the University of British Colombia, they went to the University of Utah, they went to Cambridge and Oxford, and to

wherever the blood went and protested, saying "This is wrong, this is wrong, give us our blood back", and nobody acted. The TCPS is sort of one more tool to try to enforce ethical behavior just as the Haida decision is one more step in building a legal base of Aboriginal rights. I am grateful to the political people and the leaders and the lawyers who continue to push the envelope, extend the boundaries to make this recognition that we obtain in words, make it real in experience.

Question 3 Bruno Sioui
Thank you Mrs Castellano! Actually would you say that new Chapter 9 provides sufficient guidelines and protection for Aboriginal living in an urban setting?

Marlene Brant Castellano
It was the situation of urban Aboriginal people which led us to make the more expansive definitions of communities because the majority of Indigenous people now live off reserve and off designated territories. The recognition of organisational communities can be the partners with whom you engage so that a Friendship Center or housing association can be a partner. There are other communities of interest who don't have organisational structures to whom you can relate but to whom you nevertheless have ethical obligations. We commissioned a case study on such a community of homeless youth to try to clarify what were the issues. Native Counselling Services which provided housing, became the contact point and then the individual youths were asked "Are you agreeable to having Native Counselling Services act on your behalf to oversee the research?". So we tried to give examples to help people think through these issues. For example, if there were a study of Friendship Center and there is a dissident group that says: "We don't like the board and we want your help to get evidence to prove that they are not doing a good job", you would have to examine the context of the request, the players and the possible impacts. The dynamics of communities within communities are complex. There are situations where critical research is warranted and ethical and there's an article to help navigate that. There is an "app" for that. Critical research is not prohibited by the way we have structured this but we advise caution because so often things appear different from outside the community. I have to give you an example. There is this young man who carries my family name, Shawn Brant, who stopped the VIA train, the CNR train track adjacent to our reserve because he did not like the way a local land claim was going. He was arrested and he appeared in court and a lawyer was acting on his behalf pro bono called me and said: "Would you come and testify, give a character reference for Shawn Brant?". I had to answer: "But Shawn Brant's actions offend many in the community and it is all we can do to keep those good citizens from becoming vigilantes to stop him. He is announcing good motives and doing things which are counter to the welfare of the community." This is an example of how people from the outside, with very good motives, don't always understand the dynamics of what is going on on the ground. This is why you look for the appropriate agency or contact or advisory group to help you understand how to engage in a helpful, ethical and respectful way.

I don't suppose that Chapter 9 answers all the questions that will arise. This is why the TCPS is announced as a living document on which we need your input for the ongoing work of the panel - from which I have retired. PRE will continue to give interpretations that go beyond the text now available. Tutorials and case studies will be available through the website and the policy itself will be reviewed and revised in time. Many of the questions that you have as you try to implement the policy can be resolved through conversation with the people involved at the ground level. Things will improve!

Thank you.

Overview of the Findings of the First Seminar in May 2009
by Bruno Sioui, UQAT

Kwé / Good Morning / Bonjour tout le monde,

My mission today is to summarize the seminar held here, in Val-d'Or, on May 27 and 28, 2009. It was the first seminar on ethical conduct for research with Aboriginal peoples—and note that I say with, and not on, Aboriginal peoples. Another aspect to note is that we didn't talk too much then about First Peoples, but rather about Aboriginal peoples and First Nations. Luckily enough, you are in the First Peoples Pavilion, so I'll also be talking about First Peoples, even though I began by talking about Aboriginal peoples. For me, and for the people who inscribed "First Peoples" on this building, First Peoples means First Nations, status Indians, Métis and Inuit, and it also means Indians—some of whom are here in Abitibi-Témiscamingue—who aren't registered anywhere, who don't belong to a Band, but who are still part of the First Peoples. We're talking about the first peoples who came here, some fourteen thousand years ago.

This first seminar was held over two days, with 37 participants. I'm very glad to see that there are more of you here today. The question behind the activity wasn't exactly the following, if you look at the official documents, but since I'm doing a summary, I'm taking a few liberties! The question was: Does research with Aboriginal peoples have a future in Abitibi-Témiscamingue? This was the question, as I've been on the UQAT research ethics board since 2007, and along with a few other colleagues, we review all research projects involving Aboriginal peoples, non-Aboriginal peoples, and other topics involving humans. There was a time, and maybe we're still in that time, when people wondered whether researchers really had the green light to do research with First Peoples. Or, in other words, do First Peoples really want to work with researchers? Hence the issue that was raised as an open question at that time: is there a future for research with Aboriginal peoples?

Researchers have been interested by First Peoples for a very long time: that was the first observation we made in 2009. But how is their approach perceived? What kinds of guidelines do these researchers follow? And that's another issue! The approach taken by researchers has often been perceived negatively. And then there are the guidelines that they follow. These guidelines are laid down by the TCPS[1]. We also talked about the Canadian Institutes of Health Research (CIHR) document. In 2005, the AFNQL established a research protocol[2] here in Québec as well. It soon became clear that there were guidelines, that there were specific documents guiding researchers in their approach with Aboriginal communities. And this was undoubtedly what we first tried to make people aware of during the 2009 seminar.

In 2009, the participants were asked six questions. The idea was to better understand the problems— because there are many, there were many, and there still will be many problems—as well as the benefits associated with research in the communities. We are casting our net much wider in 2011 than we did in 2009. At that time, we had people from Lac Simon, Kitcisakik and Pikogan. There were of course some people concerned with the question of research in urban areas, but, basically, everyone was from the eastern Abitibi region. That was one of the shortcomings of the first seminar, that we weren't able to receive people, whether they were Cree or Inuit, who speak English and who have needs that aren't necessarily the same as those of the communities around Val-d'Or. That was perhaps the first shortcoming.

By answering the six questions, we tried to provide UQAT with a series of recommendations, since the question was: Is there a future for research? Everyone at UQAT wants there to be a future for research with Aboriginal peoples. What we needed were some recommendations.

We also learned during the first seminar that some communities are literally being besieged. It isn't just UQAT doing research; other universities are also approaching the communities, approaching First Peoples here in Abitibi-Témiscamingue, so we wanted these recommendations to be of a general nature.

The six questions concerned the perceived problems and benefits; it wasn't called that at the time, but I'm calling it here a wish list addressed to researchers. This is what happened: in terms of the problems, yes, the communities—and especially, if my memory serves me well, the community of Kitcisakik—said they were besieged by researchers who wanted to successfully accomplish what they had planned to accomplish. So here already, what we became aware of in 2009 was that almost all, if not all, the researchers were coming with very specific research proposals. They were coming with a method of doing research that had been agreed upon with their funding agency, that is, with a method of collecting data. There wasn't really any room for consultation, for cooperation. Ms. Brant Castellano spoke a little while ago about Chapter 9[3]. I feel that one of the strengths of Chapter 9 lies in the question of research agreements. It is the idea that researchers are partners with Aboriginal people. The idea back in 2009 was that researchers were doing research on Aboriginal peoples; so they were coming with a well-defined project, a funded project, and there wasn't any room for discussion about the project. There were some other problems emphasized, but the most important point, the one that stood out the most, was that there was no collaboration: First Peoples were being subjected to people who were coming to do the work the way they had planned and the way they had promised their funding agency that they would do it.

Over the course of that day, we nonetheless asked Aboriginal peoples in the region: Do you see any advantages to research being done in the region? Are there any benefits to having researchers land on your doorstep? We clearly understand that it isn't being done in the best way possible, but is there something to get out of research? And people answered that, yes, research does develop knowledge and skills.

Firstly, in terms of knowledge: contrary to what most people think, Aboriginal peoples—and I include myself here—are not so very conscious of their identity, of their culture, of their heritage, and of the richness of that heritage. I could go off on a long tangent here about residential schools, and, in my case, I didn't even go to a residential school but to the elementary school in my community. I could tell you that we were told so often in residential schools that we had nothing and that what little we had was bad, so that we somehow very quickly got the idea that we didn't have any culture, and that we didn't have anything good to offer. So we had a very big identity problem: who are we, and what do we have? One advantage that was emphasized during the first seminar was that research helps to answer some of these questions.

The other advantage, in terms of skills, is that research also fosters the hiring of research assistants, of a certain number of people who maybe didn't go to school for very long. This allows them to participate in the research, the data collection, the analysis, etc. Maybe they'll even become experts, and become part of an advisory committee. The participants told us that these people develop very substantial skills and may become future graduates in the community. They may become researchers, and take the place of the current researchers.

We had a wish list for the researchers too. The participants said—and this surprised us a bit—that they don't want researchers to be prompted by a feeling of pity. Back in 2009, everyone was interested in the residential schools, sexual abuse, alcohol and drug consumption, and parental neglect. Researchers landed at Kitcisakik, Pikogan and Lac Simon and everyone came to rub salt in the wounds. In 2009, the participants came to tell us: It would be really interesting if researchers didn't always keep harping on the same subjects and tried to talk about something else with the communities. It may be therapeutic to talk about your experience in residential school once, twice, three times, but when you've been telling your story twenty times because the researchers seem to be only interested in that, it's a little less therapeutic. So the participants said that we have to be careful about that!

The other point that the participants felt was very timely and of considerable interest was to tell researchers to avoid making comparisons between different groups of Aboriginal people and producing research reports that highlight the relative strengths of one community and weaknesses of another. Avoid making those comparisons, which don't lead anywhere and don't help anyone.

Another element in the wish list was that researchers need to take enough time when they're doing research. We know a lot of researchers who landed in our respective communities with their research proposals, and their good intentions, and left one or two research assistants in the community. The assistants did a data collection. Quite often, this was a very cold data collection, and then we received a research report. In some communities, people didn't even receive a report. In short, the researchers never came back to the community. Of course, many of these researchers were working with grants from organizations that we are all aware of, the SSHRC[4], the FQRSC[5], etc. So they had a deadline for producing their research. Everything's always needed for yesterday, everything's always in a rush. What Aboriginal communities want is people who take the time to come and meet them, who take the time to live in the community and understand the context in which they'll be doing their research. We want people who will come back and stay in the community because we Aboriginal people are very welcoming and sociable people. We mainly want people—and this is very important—who will come to deliver the results to us themselves, and who will deliver them to us on a priority basis, and not after having presented them in ten or twelve conferences here and there across Québec and elsewhere in the world. I call this wish: take enough time.

So, as I've just noted, people told us that they didn't want researchers to be always working on the same topics, to be always rubbing salt in the wounds. What did the participants want? In 2009, they told us that it would be interesting to have more research on identity issues, on culture and traditions. In the communities that were questioned at that time, people were also very curious about land protection and environmental protection issues. And of course about education, in the context of a dropout rate of 70% or more. And about the overall health of First Nations peoples, and not just their physical health. A little while back, Ms. Brant Castellano referred to the different dimensions of health: physical health, of course, but also cognitive health, spiritual health. First Nations peoples believe very much in balance, so we need research on people's overall health. And on quality of life, which Ms. Brant Castellano also talked about. There are also the issues of Aboriginal governance, and negotiation, on the level of land claims and other levels. All these issues are very important. There is a demand, there was a demand in 2009, and I think there will always be a demand for research on those topics.

So let's continue with the recommendations, since that's what UQAT was looking for in 2009. Note

that Chapter 9 hadn't been published yet and that we weren't talking about research agreements between First Peoples and researchers yet, but in Val-d'Or, we were already talking about developing lasting partnerships between people in the communities and researchers. This is linked to what I was saying before: we need to take the time to sit down together, to develop something together. That whole question was raised and was considered very important. We were also asked to put together a list of research projects. Requests are coming from everywhere outside the communities, and in the communities, people don't know if research has already been done on the topics being proposed by researchers, so they'd very much like to have access to a list. This was done at UQAT; we did prepare such a list, but the demand at that time was much more in terms of an overall list, a list for Quebec as a whole. At that time, such a list wasn't feasible, but the people from FNQLHSSC[6] who are here today might just be able to respond to this need!

We were also asked to take some steps to help communities become able to recognize good research projects. One of the problems in the communities is that when researchers come and submit their project to the community, it's very often submitted to the Band Council. So who is this council? It's made up of people who don't necessarily have all the knowledge needed to judge what a good research project is. We were asked to find a way to train people in the communities, people who would be able to assess the relevance and acceptability of research projects proposed by researchers.

Of course, what we recognized here is that the university's ethics board (REB[7]) has to fulfill its role as a trainer, since one of the REB's functions is to train people. We're not here to judge research projects, we're not here to send them to the recycling bin; we're here to train people. We were already asked how we could fulfill our role as a trainer, and we thought—more on the second day—about the appropriateness of having one or two people from the communities on the university's research ethics board. And we did that: we welcomed Marguerite Mowatt and Julie Mowatt from Pikogan, who have now been sitting on the ethics board for almost a year. They're in the process of becoming experts in assessing research projects, and we hope that this trend will continue to grow and that we'll eventually be able to have other people on the board. These people will become knowledge multipliers in their communities, and will be able to support Band Council members in drafting resolutions for or against a given research project.

The last recommendation that was made was that research has to really prove useful to the community. We work on that a lot on the university's research ethics board, on the idea that good research is research that's going to give something to the community. And when I say community, I mean community in a broad sense. There's the community in the city: it's a community as well. There are communities on reserves, and in Indian settlements. So that's the first criterion of good research. More and more, when researchers come to a community, that's the question they're asked. Your research, Bruno: what's it going to give us? What's it going to do for us? That was one of the recommendations at the 2009 seminar.

Okay, I've kept to my twenty minutes, and I wish you a very good rest of the seminar.

Bruno Sioui

1 Social Sciences and Humanities Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Canadian Institutes of Health Research (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*

2 AFNQL (2005). *First Nations of Quebec and Labrador Research Protocol*. Wendake. Assembly of the First Nations of Quebec and Labrador.

3 This is Chapter 9 of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (2010), entitled *Research Involving the First Nations, Inuit and Métis Peoples of Canada.*

4 SSHRC: Social Sciences and Humanities Research Council of Canada

5 FQRSC: Fonds québécois de recherche sur la société et la culture

6 FNQLHSSC: First Nations of Quebec and Labrador Health and Social Services Commission

7 REB: Research Ethics Board

Presentation of the Research Activities of the First Nations of Quebec and Labrador Health and Social Services
by Nancy Gros-Louis Mc Hugh

Kwé / Good Afternoon / Bonjour,

First of all, let me thank the committee that organized this second research ethics seminar for inviting me to come and present the research activities of the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC).

I'd like to start off by showing you some pictures of the community of Wendake, which is my own community and the place where the First Nations of Quebec and Labrador Health and Social Services Commission is located. The community is situated along the Kabir Kouba River, better known as the Saint-Charles River. It has a wonderful waterfall in both winter and summer. Here we see the winter landscape of the Kabir Kouba River, and here, the community of Wendake's church in winter, during the Christmas period.

This is the plan for my presentation. I'll begin by presenting the FNQLHSSC: who we are, where we're located, and our main activities. I'll also tell you a bit about the Assembly of First Nations of Quebec and Labrador (AFNQL), which is part of the environment that we work in. I'll outline the history of the development of the FNQLHSSC Research Unit, the various research tools that we work with, our partners, publications and work in progress, and the challenges that we face.

The FNQLHSSC was created in 1994 by a resolution of the Chiefs' Assembly of the First Nations of Quebec and Labrador. Its mission is to improve the physical, mental, emotional and spiritual well-being of the First Nations communities, families and members while respecting their local autonomy and culture. The Commission is made up of several sectors: administration, health, social services, early childhood, the Social Development Office, and the Research Unit. About 60 employees overall work at the FNQLHSSC, with some 5 to 10 people per sector.

What is the *2007-2017 Blueprint*? It's a collective tool developed by all the Quebec First Nations communities. It mainly consists of observations made in the area of health and social services, which focus on the objectives to be achieved to correct the disparities and close the gaps over a ten-year period. It's a guide to be used for local and regional planning. The FNQLHSSC develops its three-year strategic plan based on this tool, which was created by all the communities so that we can help them meet the objectives that they have targeted.

The Blueprint has also identified certain problem areas related to research and access to information. One major challenge that has been identified is the whole question of the production of new data, whether quantitative or qualitative, that is used to enlighten decision making for various health and social service programs. Another is the exclusion of Aboriginal people from certain research initiatives at both the federal and provincial government levels. Another problem concerns the use of ethnic identifiers in various databases. There are often very few or no distinctions made between First Nations, Inuit and Métis. The term "Aboriginal people" is widely used, but when one wants to define actions for a specific target population, this is very difficult to do.

Among the other problems mentioned in the Blueprint is the fact that there have been few, if any, benefits for First Nations in the various research initiatives carried out in the past. There is the First Nations' exclusion from the planning process and from identification of the research topics prioritized or emphasized by either academic institutions or funding agencies. Various First Nations ethics protocols have not been respected, especially the *First Nations of Quebec and Labrador Research Protocol* and the OCAP principles: ownership, control, access and possession of information and the management of information.

As I mentioned, the FNQLHSSC has developed a strategic plan. In the 2011-2014 strategic plan, some of the main themes and actions highlighted concern research and development. More specifically, one main intervention strategy is to increase analysis and planning skills, and another targets enlightened decision making. Another focus is to foster access to and repatriation to First Nations of information and data that might be held in various government departments. And also, to expand research and development efforts on the part of First Nations. Now that I've given this overview, I'd like to explain the context that we're working in.

The FNQLHSSC was created by the Assembly of First Nations of Quebec and Labrador, which is made up of chiefs from each First Nations community, democratically elected according to the local process in that community. The Chiefs' Assembly meets several times a year to deal with various subjects. Under the Chiefs' Assembly is, as well as the AFNQL secretariat, the FNQLHSSC. There are also the First Nations of Quebec Human Resources Development Commission, the First Nations of Quebec and Labrador Economic Development Commission, the First Nations of Quebec and Labrador Sustainable Development Institute, and the First Nations Education Council. Most of the FNQLHSSC's mandates come from the Chiefs' Assembly or from health and social services directors for Quebec First Nations communities.

Now I want to look at where we've come from to see where we're going. Historically, there were several events and circumstances that led to the creation of the FNQLHSSC Research Unit, and this dates back to 1997 with the development of the *First Nations Regional Longitudinal Health Survey*. The origins of this survey coincided with two events, the Royal Commission on Aboriginal Peoples, and the second being Aboriginal peoples' exclusion from three major national surveys that the federal government had commissioned at that time.

In terms of the setting up of the Royal Commission on Aboriginal Peoples, I'd like to quickly read you some excerpts and conclusions regarding the collection and management of information. The first is: "The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it."[1] The second quote says that: "The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters."[2]

The second event that coincided with the development of this national survey, by and for First Nations, was the exclusion of Aboriginal people from three major Canadian surveys: the *National Population Health Survey,* the *National Longitudinal Survey of Children*, and the *Survey of Labour and Income Dynamics*. At that time, the federal government deliberately excluded Aboriginal people from those three surveys. We obviously need to have information for decision making and the planning of actions, on the local level in the communities, and on the regional and national levels. So, in order to

remedy this situation, a First Nations national committee was set up to develop the regional longitudinal health survey. It was called the First Nations Information Governance Committee.

To follow this same timeline, in 1998, we saw the emergence of the First Nations principles: Ownership, Control, Access and Possession (OCAP) of information and the management of information. These principles were developed by Catherine Georges, who was also working on the First Nations Information Governance Committee at that time.

Then, in 2001, here in Quebec, the AFNQL Chiefs passed a resolution in support of the boycotting of any survey or research not respecting OCAP principles. In 2003, the AFNQL Chiefs passed a new resolution to adopt the *First Nations of Quebec and Labrador Consultations Protocol*. In 2005, the AFNQL Chiefs passed a resolution to adopt the *First Nations of Quebec and Labrador Research Protocol*. I'll come back to this: they are two separate documents. In 2006, at the Socio-Economic Forum in Mashteuiatsh, all the various AFNQL regional organizations made a common commitment, which was presented to the different levels of government, to consider the possibility of creating a First Nations regional research institute, here in Quebec. This didn't go any further at the time.

In 2007, the Canadian Institutes of Health Research developed their *Guidelines for Health Research Involving Aboriginal People*. In 2008, a new resolution by the AFNQL Chiefs gave the FNQLHSSC the power to receive, upon request, and directly from federal ministries and agencies, any data gathered from First Nations. In 2010, the AFNQL Chiefs adopted a resolution ensuring regional support for the creation of the First Nations Information Governance Centre, which was set up on April 22, 2010. This is a national research centre that works closely with regional organizations like the FNQLHSSC to produce credible and significant data relating to First Nations in Canada. This centre is accountable to First Nations leadership on both the national and regional levels across Canada. The Centre is located in Ottawa. In 2010, work was begun to revise the *First Nations of Quebec and Labrador Research Protocol*. This work will be ongoing for the next two years. A multidisciplinary group of experts has been set up to examine what currently exists and is available in the field of ethics. The work is progressing well. Some of the people here in fact belong to this work group.

In 2010, the First Nations Information Governance Centre was officially inaugurated in Ottawa, and in December 2010, Chapter 9 of the *Tri-Council Policy[3] Statement* was made public and official.

In short, I wanted to give you an overview of all the events that, over time, led to our developing the FNQLHSSC Research Unit. As you can see, it's very closely linked to the Assembly of First Nations of Quebec and Labrador leadership, which gave us support during all those years so that we could develop the Research Unit.

Our research team at the FNQLHSSC has been in place since 2004, and it's a multidisciplinary team. We work on three main focus areas. The first is social research, the second, evaluation of the programs and initiatives that have been set up with the communities, and the third is a new area that was added in 2009: public health surveillance. The Research Unit is asked to collaborate on various research projects and works with different partners on the level of both the scientific community and First Nations communities in the Quebec region.

The role of the Research Unit varies depending on the research projects that it is asked to work on. We are at times partners, collaborators, co-researchers, and sometimes the principal investigator. In terms of social research, our mandates come primarily from the FNQLHSSC operations sector: early

childhood, the Social Development Office, social services, and health. These sectors have resources that work closely with the communities and determine whether we need to come up with new knowledge. People call upon our services as needed, and that's how our projects are developed. We obviously favour a participatory approach, and the *First Nations of Quebec and Labrador Research Protocol* is central to every project that we undertake. I'd also like to mention that we have a Quebec First Nations Regional Research Committee, which is made up of members of First Nations communities and organizations that work with us regarding the *First Nations Regional Health Survey*.

In terms of the evaluation of programs and initiatives, the same dynamics are involved. Mandates come from the FNQLHSSC operations sector. What we're trying to promote in this focus area is the development of a culture of self-evaluation in the communities. As we know, after the implementation of a three- or five-year program or initiative, we have to do an evaluation. So we work closely with the communities to develop evaluation initiatives. We use the same philosophy as for our research projects: we ask representatives from the communities to sit down with us, with our groups of experts, and we develop things in a participatory way. There's a dialogue set up with the communities from the beginning of the project right to the end. We also want to ensure that there's a transfer of knowledge. We make sure that we take a long-term view and see to it that the community can reuse the research tools developed in the context of the evaluation over time. For example, we'll work with the community over a three-year period. If we do a process evaluation, it ends after three years when the funding ends. But, in reality, the community then has the tools to evaluate itself if it wants to know whether the service is still appropriate and still meets its needs, whether the clientele is still satisfied, etc.

Now, in regard to public health surveillance, we've been working on developing this area since 2009. What does surveillance mean? It's a continual assessment of the population's state of health and the determinants of this state of health, focusing on the entire First Nations population and based on permanent and recurrent data collection systems, including the major surveys. It's like setting up a warehouse of all the data on state of health and determinants for each Quebec First Nations community. What we'd like is to develop a tool that communities health managers could refer to for accurate information on health determinants, ranging from biological and genetic predispositions to life habits, living conditions, living environments, the physical environment, and the organization of and access to health and social services, the physical and mental state of health—all the health determinants in fact. So we're working on developing a series of indicators. One of the objectives is to keep the indicators that we develop updated. We'll thus be able to obtain an overall profile of the situation of the First Nations' state of health. The primary goal is to make the information available to the communities so that they can better orient, plan and identify their priorities.

Here are the tools that we work with. First, the *First Nations of Quebec and Labrador Research Protocol*, adopted at the Chiefs' Table in 2005, is truly at the core of all our initiatives. Why the protocol? Because several recommendations from First Nations were forwarded to the FNQLHSSC and other organizations like the First Nations of Quebec and Labrador Sustainable Development Institute, and to the AFNQL. The communities needed support and a tool to address the various requests that were forwarded to them related to research. After that, discussions were undertaken among the AFNQL organizations and a mandate was given to develop a research protocol. The Chiefs adopted the protocol in 2005. The document includes a long version and a much shorter version. It's available in French and English. The short version is also available in Spanish. All these documents can be found on the FNQLHSSC website, as well as on the website of the First Nations of Quebec and Labrador Sustainable Development Institute.

The protocol is a tool, a living document. It's a tool for reflection bringing together the key criteria for developing a research policy that reflects the position of the Assembly of First Nations of Quebec and Labrador. It's also a reference guide that enables the communities to better regulate the activities and requests related to all types of research carried out on their territories. The protocol's aim is to promote ethics, the carrying out of which respects the wishes of the First Nations involved. It provides various tools that can be found in the document's appendixes, such as a glossary, an example of a research permit, and a consent form template. Some of these appendixes have also been translated into First Nations languages. I'd like to reiterate that this is a living document in the same way as the *Tri-Council Policy Statement* that Ms. Brant Castellano told us about this morning. We're currently in the process of revising the content of this protocol.

Another tool that I wanted to mention is the *First Nations of Quebec and Labrador Consultations Protocol*, which was developed by the First Nations of Quebec and Labrador Sustainable Development Institute. This document is also available on our website, in English and French. This protocol outlines the main elements of a real consultation, be it a healthy and open dialogue between two parties.

Now, let's look at the various partners that the Research Unit works with. We have partners on both the regional and national levels. These of course include the First Nations communities and the various First Nations regional organizations that we work closely with, the AFNQL, the Cree Board of Health and Social Services, Quebec's Ministère de la Santé et des Services sociaux (health and social services department), and Health Canada through the First Nations and Inuit Health Branch. We also work with the Institut national de la santé publique du Québec (National Public Health Institute of Quebec) and the Infocentre. They are responsible for the Québec surveillance plan. We also work with Aboriginal Affairs and Northern Development Canada. Various universities: Laval University, Montréal University, Université du Québec à Trois-Rivières, and McGill University. We also work with Ste-Justine Hospital and the Montreal Jewish General Hospital. On the national level, we have the First Nations Information Governance Centre, the Assembly of First Nations in Ottawa, and the Public Health Agency of Canada. These collaborations and partnerships have developed over the years. As much as in the beginning, in 2002-2003, we had a hard time finding collaborators or partners who were prepared to embark on research projects with us, it's the opposite situation today. Today we get many requests from everywhere to get involved in or collaborate on or go ahead with various research initiatives. I think that it all started to open up after certain changes happened with the *Tri-Council Policy Statement*, the CIHR[4] *Guidelines for Health Research Involving Aboriginal People*, which also really got things moving. It was a series of events that meant that today, the situation has really changed.

We have a number of publications at the Research Unit, as you can see. Many topics which are of course always related to health. We should mention our collaboration in developing the *First Nations of Quebec and Labrador Research Protocol* in 2005. And also in developing the *First Nations Regional Longitudinal Health Survey*, a pioneering survey that opened to the OCAP principles. The first wave was carried out in 1997, the second in 2002, and the third in 2008. The report for this third wave should be available in the winter of 2012. This survey is a big part of what the Research Unit does. Some 23 communities are involved in this research project and our objective is to ask all the communities to participate in the next wave in four years. We also carried out an assessment in the area of continuing care. We developed a portrait of accidental and intentional physical injuries in the communities. And a report on alcohol, drugs and inhalants: a portrait of users and consumption habits. We also have a the *Research on the Health of Quebec First Nations and Inuit: An Overview*, and

the report on *Community Characteristics: Birth Outcomes and Infant Mortality among First Nations in Quebec*. We've also just completed a study on sexual behaviours, attitudes and knowledge related to STBBIs[5] among youth and adults. A portrait of diabetes in First Nations communities. And an evaluation of the pilot project implementation of first-line social services in four Quebec First Nations communities. All these documents and reports are available and accessible on our website.

Among the projects that we're working on, besides the regional health survey, is the surveillance plan on the state of health. We're currently also doing a research project on Aboriginal mediation. And another research project on the trajectories of young people in the youth protection system, and several other evaluations. I'm thinking of the evaluation of the implementation of the diabetic retinopathy distance screening pilot project. The evaluation of the implementation of the mental wellness pilot project in two communities. The evaluation of the implementation of the prevention of violence and aggression project for children aged 0 to 6 years old, and the evaluation of the training project for Quebec First Nations early childhood programs and services.

Upcoming in 2012, we wishe to develop a research strategic plan. We currently respond to requests and mandates from our own internal operations sector, but we need to have a long-term vision of the communities' health and social service research priorities that we should be focusing on. The communities have also recently expressed needs that are linked to the discussions that we had this morning in the World Cafés in regard to support and consulting report. The communities managers that we have ties with when we begin research projects would like us to help and support them in their own research agreements developments that they might develop with external researchers. The communities are getting a lot of requests and they're often asked to participate in research projects, and sometimes people feel helpless because they don't necessarily know all the research jargon. What should an agreement or protocol include? How can they ensure that the First Nations principles OCAP or the Quebec and Labrador First Nations Research Protocol will be properly reflected in this agreement. In the end, they asked us to help them, so that they can respond to the various needs that have been expressed in the areas of both research and evaluation.

And of course we're continuing to revise the Quebec and Labrador First Nations Research Protocol. We also have other projects that we've discussed at the Commission. We want to continue with a feasibility study for setting up a First Nations Research Centre — that's another project that's dear to our hearts—and maybe eventually also look at the question of having a First Nations regional ethics committee. These are needs to which there are a number of constraints and challenges. We also have a training on quantitative analysis methods that was developed for First Nations managers. It's all very well to collect information, to process information, to go back and validate it with people, but there's also a need for help in interpreting this information once it's been collected. So the Research Unit has developed a training that will be offered to all the communities this fall through videoconferencing.

There are currently many challenges. For the moment, in order to keep a small research unit in place, there's always the question of funding. At this time, we don't have any recurrent funding, so we work from project to project, and we're not affiliated with any university. We're completely independent, so it's up to us to see that we can keep the experts we currently have in place. Another challenge is the hiring of Aboriginal human resources for our team. It's not that there aren't any. There are, but they've often been hired elsewhere. There's the whole question of the different research priorities. This was also discussed during the World Cafés, the fact that research priorities are identified by the majority government in place or by the funding agencies. This means that First Nations' research priorities and research topics aren't necessarily reflected in those. So there's still a lot of work to do in

that area.

In conclusion, it is imperative that First Nations acquire infrastructures in the area of research and development on the local, regional and national levels in order to support the various First Nations regional organizations and communities in the transfer of new knowledge and expertise, and ultimately to move toward self-determination. Ms. Brant Castellano outlined it all well, all the issues regarding relations between researchers and the communities. It is essential to establish relationships of mutual trust between First Nations communities and organizations and the scientific community and governments, as well as a healthy and respectful dialogue in the area of research and governance. And everything to do with the repatriation of existing data that First Nations and other organizations don't have access to. This is mainly quantitative information that's held here and there in various federal and provincial government departments. This needs to be pursued. There's also the strengthening of local autonomy, and thus working in support of the communities and responding to a wide range of needs. Every community is structured differently, and every community has different needs. Respond to such wide-ranging needs: that's a challenge in itself.

Megwetch: that was my presentation on the First Nations Québec and Labrador Health and Services Commission's Research Unit, and do you have any questions or comments.

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1 Royal Commission on Aboriginal Peoples. (1996). *Report of the Royal Commission on Aboriginal Peoples*, Vol. 3, Chapter 5, section 8.3, Ottawa.
2 Royal Commission on Aboriginal Peoples. (1996). *Report of the Royal Commission on Aboriginal Peoples*, Vol. 3, Chapter 5, section 8.3, Ottawa.
3 Social Sciences and Humanities Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Canadian Institutes of Health Research (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.*
4 Canadian Institutes of Health Research
5 Sexually transmitted and blood-borne infections

Question Period
Question 1
You said just before that you didn't have any statutory funding to ensure the continuity of the Research Unit. Would you like to send any particular message to potential partners?

Nancy Gros-Louis McHugh
I'd say that this is a question that we're considering at the Commission. Strategically speaking, there are perhaps several different ways of tackling this issue. We clearly have to knock on some doors and see whether there's any openness to this. I feel that this is an opportune time given the change in relations and the way that research is being carried out involving First Nations, so I think that we just have to go out and knock on the right doors. I'm mainly talking about the departments that we work with: Health Canada and Indian Affairs and the *Secrétariat aux affaires autochtones* (Quebec Aboriginal Affairs Secretariat) to see whether there might also be some openness in terms of supporting a minimal infrastructure for the Research Unit at the Health Commission.

Question 2
This isn't a question, but rather a comment. I noticed, as maybe other people in the room did, that UQAT isn't one of your partners: UQAT isn't there. Well, maybe I do have a little question. Do you intend for us to become partners?

Nancy Gros-Louis McHugh
Of course! Why not? UQAT has actually been working with the Commission quite a lot in connection with the work on revising the Research Protocol, so yes, we'll add you as well.

Question 3
Thank you very much for the presentation. It was really very impressive: I don't know how you're able to do all that. It's really fantastic. What I found especially interesting was when you talked about the importance of developing self-evaluation in the communities. You mentioned, among other things, that you encourage the communities to continue to use the tools that have been developed, but I'd like to hear more about that because I feel that it's important to ensure continuity So maybe you could just say a bit more about that, about how you go about this... Is this in fact capacity building?

Nancy Gros-Louis McHugh
Yes, it does mean working to support building capacities, as you said; so for each project mandated to the Research Unit, whether it's a research project or an evaluation, there's always a group of experts associated with project development. The communities concerned are also committed to sit down with the other partners throughout the entire process for the development and to achieve the assessment. Of course, the communities must also give us their views, especially in terms of evaluation.

As you know, federal governments funded program or initiative in community and requires the accountability assessment. The community has to perform this exercise. What we try to explain when we work with the communities is that, aside from the fact that they have to meet the project sponsor's criteria by performing this exercise, it can also be extremely beneficial for the community if we can look together at what they want to document. Are there other elements than the project sponsor's requirements, other issues that the community would like to look at together in connection with the clientele that they serve, in connection with the services in place? There are so many aspects that can be examined, so it's a matter of discussing with the community and seeing what they'd like to

explore and document. Then, we revealed the project results for validation to the various actors concerned in order to validate with them that we've properly understood the context, that we didn't miss anything. We emphasize the different tools that we've developed, created, tested and put in place are tools that will be left with them. So, we spread a few seeds during the exercise so that they can reuse, and adapt these tools for their own needs. That's a bit about how we work with the communities to gradually inculcate this culture of self-evaluation, of reflecting about the service or initiative that's in place on a longer term basis for the project. So that's it!

Question 4

Could you go back to a bit more information on the boycotting of the Statistics Canada survey and where we are with that today? Could you please tell us what's been happening in the past few years?

Nancy Gros-Louis McHugh

What's been happening since then, yes, I'll refresh my memory a bit. At the time, it was very hard for us to get funding to carry out our First Nations' regional health survey. Health Canada funded the first wave and when we had discussions about the second wave, Health Canada said that it might be a good idea to sit down with Statistics Canada and see whether they could contribute to the process. That was done on the national level, and ultimately the results weren't very conclusive. No agreement could be made at the time with Statistics Canada because they were subject to the Statistics Act, which meant that the First Nations principles couldn't be respected. When Statistics Canada does a survey, when they collect information, it belongs to them. They're the ones who subsequently handle the processing and nothing is allowed to go back to First Nations. So there couldn't be any collaboration for our health survey. Statistics Canada was also preparing to launch a survey on the health of children in First Nations communities. Since, we have our own initiative to collect information about children through the First Nations health survey. So, at that point, the matter went to the Quebec Chiefs' Assembly, and a resolution was adopted to boycott any survey that was carried out without respecting the First Nations principles, including the OCAP principles. That's how the boycott came about. And today, there are still discussions at the national level. Some committees were created to study the possibility to work together, and nothing has really come out of that to this day.

Question 5

At one point in your presentation, when you were talking about your organization's work, you mentioned, I don't know whether it was a guide or a protocol, but it set out what a real consultation was. Do you have some examples of consultations that are not real consultations?

Nancy Gros-Louis McHugh

Yes, the consultations protocol was developed by the Sustainable Development Institute. The consultations protocol was put forward and adopted by the Chiefs at the time, very much in connection with the various initiatives and activities being carried out on First Nations territory, developments, forestry, but I remember that it was in connection with the territory. The government at that time very often tended to send a letter to the communities' Band Councils telling them that it wanted to do a consultation to discuss a project that might have repercussions on the communities' territory. They set a cut-off date; they said you have two weeks to either send us a memorandum or come to us and say what you have to say, and, as we know, the communities don't always have the human resources or qualified people to be able to answer as quickly as that. So the message that was being sent was that the government has consulted and unfortunately First Nations communities and leaders didn't necessarily have the opportunity to express their views because they weren't being

given an appropriate time period to do so. After the deadline, the government said, we consulted, we did our part of the work, but in reality, there had never been any exchanges or discussions as such. So, in order to counter this type of practice, which was quite common, the Consultations Protocol was put forward with a few very clear principles regarding what a real consultation was and how it should be carried out so that each party could properly express their views on the issue. Suzy, I don't know whether you wanted to add something.

Suzy Basile

I just wanted to add, if you don't mind, that at the time I was involved in this matter, that this protocol was also adopted by the Chiefs' Table sometime after the most important, well, not the most important, but some very important Supreme Court decisions, that is, the *Haida* and *Taku* and *Delgamuukw* decisions, so that this protocol was confirming and backing up the Supreme Court decisions. But it didn't solve all the problems; this protocol was, and still is, very much ignored by the main parties involved, that is, by governments and companies that do pretty much what they like, and in response to this, the Quebec government put in place an interim consultation protocol in the years that followed.

Nancy Gros-Louis Mc Hugh

Sharing the Findings of the *World Café*, Identifying Possible Solutions, and Recommendations for the Development of a Policy on Ethical Conduct for Research With Aboriginal Peoples at UQAT
by Hugo Asselin, UQAT

Hugo Asselin
Okay, thanks for the presentation. I'll ask the discussion leaders for the various World Café themes to come up here, and we'll take turns summarizing the discussions that took place at the two round tables we each participated in.

Marguerite Mowatt Gaudreau
Theme 1: The need to obtain the community's participation in research projects involving Aboriginal people

Question: How do we obtain the community's participation (or agreement) when projects involve Aboriginal people in urban areas?
Typical situation:
A researcher is conducting a laboratory research about pain. Healthy people aged 18 to 50 are invited to participate. One of those interested in participating is an Aboriginal man. Does this individual need to have his community's agreement to participate? (Note: the researcher isn't necessarily interested in cultural differences in pain perception.)
Same project, but this time the researcher is interested in differences between Aboriginal and non-Aboriginal people with regards to pain perception.

My question focused on how to obtain the community's participation or agreement when projects involve Aboriginal people in urban areas. My question concerned individuals on their own that we meet in, let's say, a laboratory situation. Does this person need to ask for the community's consent? There were two answers in response to our typical situation: yes and no! No, we don't need the community's agreement when individuals present themselves on their own, because this person is just one citizen among many and prefers to be seen as such. Nor is it necessary when the results don't involve the community, when it's a case of someone living on their own in an urban area. Another no is when the person has fewer ties with the community, if he/she has decided to live far away from his/her community and doesn't want to deal with people from that same person's community. Yet another is the case of a person who is sharing his/her knowledge of the urban environment. That person is talking about his/her life experience and not necessarily about life in the community.

I also had some people who said yes, but under certain conditions... If the community comes up with strategies, like asking representatives of populations of a village or community. Again, yes, if it's really... How should I put it? If the person is in an urban area, is he or she a real Indian or not? Maybe they say they're Indian and it's not even true. We need to check with the community whether the person is Indian, because communities have band lists and you're registered on the list. One can also consult Indian Affairs to find out whether this person is really of the Anicinape race.

And also, having the person in an urban area agree to participate in the research depends on the individual wanting to have the research done. What is the researcher looking for? Some are looking for very personal information and the outcomes of that research, the data, are never published. So that's about it, that's a summary. Several questions were repeated because some said, it's an individual outside the community, and I repeat, he doesn't need to have consent; he doesn't live in the community any more. That's what came out of our discussion this morning. Thank you!

Bruno Sioui
Theme 2: The OCAP principles: Ownership, Control, Access, Possession

Questions: What do you think about the OCAP principles? How can they be taken into consideration?

I'll start with a quiz question: anyone here who can tell me what the famous OCAP principles are, please raise your hand. That's not too bad! So, in fact, that was the first finding that came out of the *World Café*. We had to answer questions like: are the OCAPs relevant? How should one lead discussions on the OCAPs? Except that the people who took part in the two cafés that I led, I had to describe what the OCAP principles were to them, because they couldn't tell me what they were. Luckily, they took notes, so that's the good news.

With the remaining time left for discussion after, the presentation was over, we once again asked a very relevant question: do researchers who work hard in big universities, in big research units, who have five or six big research projects on the go besides their teaching and administrative duties, do they really have time to spend time with the communities? Do they really have time to go and negotiate research agreements? Do they have time to regularly go back to the communities, to see that people are appropriating these principles, which are moreover not very well known, it would appear, in the communities?

It was interesting to see that the group didn't have any answers to that for the time being. So, if researchers don't have a lot of time, let's say, let's make the hypothesis that researchers don't have a lot of time, first, to train the communities on what the OCAP principles are, and then to be sure to support them in this respect, who can do this? Can our academic institutions give us the necessary support so that we can help our participants appropriate these principles? I'll now briefly reiterate them: to help our participants maintain access, maintain control, maintain possession, and maintain ownership. Not individual ownership, but collective ownership of research data. This of course raises questions in regard to our contacts in the communities, who are very often Band Council members, and very often, in urban areas, people that work at Native friendship centres, as Ms. Brant Castellano said. Does the fact that it's a small group that has access to the data, does this go in the direction of the community's well-being? Here again, people didn't have any answers, but had to content themselves with asking questions about this. And finally, since I can't summarize everything, someone in the first group said: "OCAP in theory is great, but in terms of application, in practice, that's a whole other thing." We may find that there are a number of stumbling blocks in our path.

Suzy Basile
Theme 2: The OCAP principles: Ownership, Control, Access, Possession (continued)

Okay, thank you: I'll take over at this point because I had the same theme as Bruno, the OCAP principles. Without repeating what Bruno has just said, these principles are indeed little known, and should be more effectively presented both in the communities and to researchers.

The validation and outcomes of research are extremely important issues for which better guidelines are needed. What happens after the research is just as important as the research itself, and there must be consultation with the communities concerned throughout the research process. We need to start with a partnership, in fact, which should be established from the beginning of the research project.

To conclude, two wishes were expressed. Greater control, indeed, over the entire process involved in research projects. Education and training on the OCAP principles are clearly needed, and a presentation like the one Ms. Brant Castellano gave this morning should be mandatory in every good university education program, and for Aboriginal communities that feel the need for such a presentation.

Hugo Asselin
Theme 3: Research agreements between researchers and communities

Questions: What should research agreements between researchers and communities include? How should they be negotiated (at what point, using what tools, with whom, etc.?) Is this the researcher's or the community's responsibility? Are such agreements absolutely necessary? Is the consent form approved by the UQAT research ethics board sufficient?

This was the question of research protocols or research agreements. How do we do this, who should do it, whose responsibility is it, what elements should be included, do we need such agreements, etc.

I'll summarize some of what the two round tables said. Everyone agreed that there should be protocols, but what we need first, the first step, is for researchers and the community to develop a relationship before they can think about signing a protocol. So researchers shouldn't come with their protocol on the very first day and ask people to sign. There was also the question of whether protocols should be written or verbal or both, and we agreed that it was preferable to have them in writing in order to leave a record and in view of the fact that teams sometimes change along the way.

Protocols must be developed together to reflect each party's needs, roles and responsibilities. Protocols are especially important and helpful for "first-timers," that is, for researchers and communities that have never worked together. They're always important, but even more so in such cases. The protocols that are signed, even if they're based on somewhat general rules like the TCPS[1], must take into consideration each project, topic, or community. All of this is needed, because, of course, it's always different each time. There was an excellent suggestion, which was to have a mentor, or even mentors, to guide the process. These could be Elders, on the communities' side, for example, or senior researchers on the universities' side.

Protocols can take different forms. They don't always have to be the same. Some people talked about a *Memorandum of Understanding (MoU)*, or framework agreements. We also need to work with people who want to move forward, on either side; some people always have their foot on the brake, you could say. Sometimes it's better not to involve those people right away; they'll get on board once everything is moving ahead.

We also need to clarify how the project will help to strengthen capacity in the communities. It's important to put this in the protocol; it's something we sometimes forget. We say that we're going to do this at the end, and we ultimately never do it. And sometimes, we need to step back and sign an

umbrella agreement to avoid conflict. I'll explain this: sometimes we have a project that is a little too specific and is likely to exacerbate latent conflicts existing in a community or in the university, or things like that. At such times, we can step back and say: we'll do a much broader project that will incorporate more aspects and thus answer that specific question, but also other questions as well. In that way, everyone will get something out of it, so that there won't be any squabbling.

Barthélemy Ateme-Nguema
Theme 3: Research agreements between researchers and communities (continued)

So, we worked on the theme of "research agreements between researchers and communities." In the two groups that I led, the key word that really came out was "partnership." So the question was: who should initiate the request for an agreement or for collaboration? That usually depends on who's proposing the research topic. Is it the researchers or is it community members?

Another thing that also came out was the fact that research is generally evolving in nature, so that we should try to set up mechanisms to guide this evolution in terms of outcomes. So, does the community want to appropriate something, and, if so, we should try to establish a certain level of control between economic rights and intellectual property rights; that's something that came out of the discussion. In the outcomes, there are of course the various clauses, all the follow-up, all the renegotiating of the initial agreements.

At one point, someone asked the question: does the partnership precede the establishment or putting in place of the protocol or vice versa? We said, okay, the most important thing is usually the agreement between two partners, whether this is two individuals or two entities. Let's go back to the terms of the agreement and leave them quite open, so that they can of course remain flexible over time. And finally, let's try to set up ethical principles that in fact not only allow the community to better frame its participation in a study or research, but also help researchers not to overstep their obligations. So that's it, that's more or less what came out in regard to agreements between researchers and communities. Thank you!

Nancy Julien
Theme 4: Remuneration and recognition

Question: How should Aboriginal participants' involvement in research be recognized by research teams (gifts—tobacco (in what form?), payment, mention of the person's name in the research report (with their permission), certificate of participation, offering the person the status of a co-researcher, etc.)?

All right, I'll talk about theme 4, which was about remuneration and recognition. We asked how Aboriginal participants' involvement in research should be recognized by research teams. The answer that emerged was: it depends on the type of research, it depends on the type of participants, the budget, the researcher. One really important thing that came out was that researchers and student researchers have to realize that doing research is a very valuable thing; it's not free. There has to be something, some form of remuneration.

So researchers should think about this when submitting funding applications and also discuss this when partnership agreements are developed; and, at that point, it's a good time to discuss the various possible options. I'll list some of these possible options. One possibility is a knowledge transfer

activity, for example, at the end of the research; and one example of a knowledge transfer activity is a "Scientific Café". Another important aspect, if the research lends itself to this, is the recognition of Elders who significantly participated in the research. This recognition could take the form of a co-authorship in a research report, or if this isn't possible, at least a description of the person's participation in the "Acknowledgements" section of a scientific article. Researchers can also offer gifts, which ideally should be linked to the research themes. One participant from the forestry or fishing sector, I don't exactly remember which, gave us the example of gifts or participation prizes that could be, for this sector, a fishing rod or other kinds of things that effectively represent the theme. It could be a lunch at the beginning of the research to explain what it will involve, or a lovely banquet at the end, to thank everyone who participated in any shape or form in the research. People also mentioned the idea of giving grocery store gift certificates. One new idea, for me at least, was that of a trade. For example, if the budget is limited, the researcher or student researcher could offer their expertise to help the community in some way.

Vincent Rousson
Theme 5: Recruitment

Question: How do Aboriginal people want the recruitment of participants to be done? What are some good and not so good ways of approaching people to ask them to participate in research in an Aboriginal community?

In the groups that I had the pleasure of leading, we worked on the recruitment of participants. We asked ourselves what were some good and not so good practices or ways of recruiting people. The consensus we very quickly arrived at was to say, look, not many Aboriginal people participated in the two groups, so the first reaction was, "let's consult the communities, and people will be able to tell us."

Aside from this consultation, the unanimous answer was that the communities or Aboriginal people should work together before the research starts. They shouldn't wait for the researcher to arrive with a fully formed project so that they are already limited by certain constraints. It would be much simpler to work with researchers or research teams before the research gets underway, that is, as soon as the seeds are sown in terms of people's interest in a research topic. Our discussions focused on two aspects: research conducted in a community, and research conducted outside the communities.

The Band Council seems to be the natural place to address requests for participants in the communities. The Band Council doesn't become an entity that ratifies the decision, that says yes or no, if such and such person should or should not participate, but would instead serve as a transmission mechanism. The researchers or the research teams, would transmit their request to the Council. So, for example, they'd say, we need participants for a health study, and then the Band Council would convey the information through the various organizations or partners present in the community and return with the reply. The place to address such requests would be the Band Council, in this sense.

In the urban environment, we found it much harder; we asked questions like: "Would Native friendship centres be natural places to address requests for participants? What do we do in places where there aren't any friendship centres?" The urban milieu in Val-d'Or is different from the urban milieu in Montréal or British Columbia. In Val-d'Or, there are maybe two, three or four different communities. In larger centres, we can multiply this two or three times, depending on the size of the municipality: so people were asking questions like that. Another question that people asked was,

when dealing with research topics in the communities, what do we do when there's more than one community or nation involved? Should all the Band Councils be involved? And if so, and here we had a little digression on the previous theme, that is, what do we do when a community agrees or doesn't agree to our request? Can they help us to find participants if they refused our request? What do we do when a community agrees, but no participants from that community are ultimately involved in the research? A lot of questions, and very little time; so people left with many more questions than answers, but this does leave room for more activities like the one held here today.

Nancy Crépeau
Theme 5: Recruitment (continued)

My question was exactly the same as Vincent's: we wanted to know how Aboriginal people would like the recruiting of participants to be done, and so, some good and not so good ways of asking participants to become involved in research, particularly in an Aboriginal community. We talked a lot about everyday appropriate behaviours. Here are some of the elements that were highlighted. First, we talked about the importance of having a contact, a reference person on the Council, a person designated in regard to research, and having that contact's name so that a committee could be set up. We could then discuss recruitment methods with that committee, which would come from the community. The idea was in fact to reach an agreement with people about a way of recruiting participants and also to agree on a way of operating.

Another aspect that we talked about was knowing how to listen to the needs of the people who will be involved in the research. We need to take time to properly explain, in plain language, to explicitly define the goals of the research, the objectives, the processes and the results, from the beginning to the end. We also talked about taking time to meet people in their living environments, to be there, for example, in the area of education, to be there in places where young people gather. It's important to make ourselves known in the community, to interest people in research, especially interest groups, through different means, to get them to understand and find meaning in research. To participate in various events. To be there in the community in order to observe and also identify needs. To take time to get to know the culture or to immerse oneself in community life.

Another element, and we did talk about this today, is to use oral means, to speak to people directly instead of only using lengthy, formal written materials, because this can often impede the process. We also talked about taking time to validate what the participants or partners understand about the research process, in terms of how it will be carried out and the expectations, because we sometimes have to go over things again. Because people's perceptions and interpretations of the research may sometimes vary, and we need to adjust to this. When possible, we can make it easier for people to understand by using demonstrations or experiments. We also talked about ensuring the representativeness of the groups targeted in the research, because influential community members may sometimes refer certain people instead of others who could be representative for the research. We talked about transparency, integrity, and openness to continual adaptation of the research process.

In terms of practices that aren't so good, the fact of using only one contact person to recruit participants may in itself represent a bias. Another attitude that we should pay attention to is that when we gain a community leader's support for a study, that doesn't necessarily mean that individuals should feel obligated to participate in the research: this must be clearly explained. Another practice that's not so good is to present oneself as an exclusive expert who knows everything and feels that

things should only be done one way.

Janet Mark
Theme 5: Recruitment (continued)

For me also, it was about recruitment. One of the typical situations was mainly about Aboriginal people in urban areas. And ultimately, about good and not so good ways of asking people to participate in research. What people said was that it depends on the type of research. Whether, for example, it's a study involving fetal alcohol syndrome or homelessness, it's a very different matter. On the medical level, there are somewhat stricter protocols.

When we're talking about Aboriginal people in urban areas, one of the ways of looking for participants is to get the researcher to visit the different milieus, such as the Québec Native friendship centres. Here in Val-d'Or, for example, we talk about La Piaule, which is a place for the homeless, but where there are a number of Aboriginal people. There are organizations like Habitation Métis du Nord, Waskahegen. And, someone said, researchers can go through the university itself, because we know that there are many Aboriginal students here.

What people also said about all this was that one of the problems these organizations or institutions encounter is that they're often called upon, asked, solicited to find participants, and, as we know, the Aboriginal milieu here is a pretty small world. People know each other, whether here in Val-d'Or, or whether one comes from Quebec City or elsewhere, we know each other and this becomes difficult for the institutions. A good example is that one year in Kitcisakik, there were five studies: five research topics in a community of less than 500 inhabitants. So it might always be the same people that are being interviewed or that complete the surveys, and this is one of the problems.

Researchers also need to take time to listen, and not just to listen with their ears, but also to look with their eyes, and observe. Pay attention to silences too, because silences sometimes say a lot, and we shouldn't bombard people with question after question. Some researchers tend to ask a question, and if the person doesn't reply within three seconds, they start on a second question, and a third, and people haven't answered anything yet; they get a little lost with all those questions.

Researchers should have a resource person in the city and in the organizations. We talked about different approaches, about maybe putting up posters in those places to try to recruit people, or organizing events to present the research. Researchers could first present their research to young people. And also, researchers shouldn't work on a topic without knowing anything at all about a particular nation or who the Aboriginal people who live in Val-d'Or, Quebec City or Montréal are, for example.

Researchers can also invite participants from the communities; it all depends on the research topic. If you're in a town like Val-d'Or, you know that there are Algonquins in Lac Simon, Kitcisakik and Pikogan, and why should you limit yourself to Aboriginal people living in urban areas when people living in the communities might be interested?

In the groups of experts from the milieu, people talked about a steering committee, and about having Aboriginal people who are experts on those topics. Aboriginal people can do the initial recruiting. Finally, we also talked about the issue of confidentiality: we can't give names, or lists. Do you have some names? Do you have a list of people? We can't really get involved in that.

Researchers also need to be aware that organizations and institutions are very often asked for help in such and such study. People also talked about using every means of visibility, such as, for example, the newspapers here in Val-d'Or: at the friendship centre, there is the Centre's Notebook, a small paper that comes out every three or four months. So that's it: learning to get to know the communities, to create a good impression, and to be welcoming. We also talked about the idea of preparing something including snacks, or entertainment, in order to develop bonds with people. Respect people's rhythms: researchers are sometimes in a rush. They want to move quickly; there are deadlines, and so on. If you want it all to work, you have to give it some time. It's important for participants to feel that they've contributed to something important as well.

I'll wrap up now. We talked about a process of empowerment for people, for the community, for people to feel important in the process. We also talked about the need to explain things to participants. You could maybe even give some training on "what is research, and what does it involve?" Sometimes people don't know whether they have the right to say no or yes, so it's the idea of really giving some training at the beginning, in a language that's accessible for everyone. Researchers have some homework to do before they start. They have to consult their university's ethics board. We also talked about elders, about getting to know who the elders in that community, or in the city, are. What are their values? We talked about better coordination between universities as well, because sometimes there are studies that repeat the same thing. We also made the link with the fact that Aboriginal people, Elders for example, use oral transmission a lot, and we said that researchers should avoid scientific language and use accessible language. And another thing too, avoid making people read a lot of material: avoid asking them to read it two days before an upcoming meeting. That's really something to avoid!
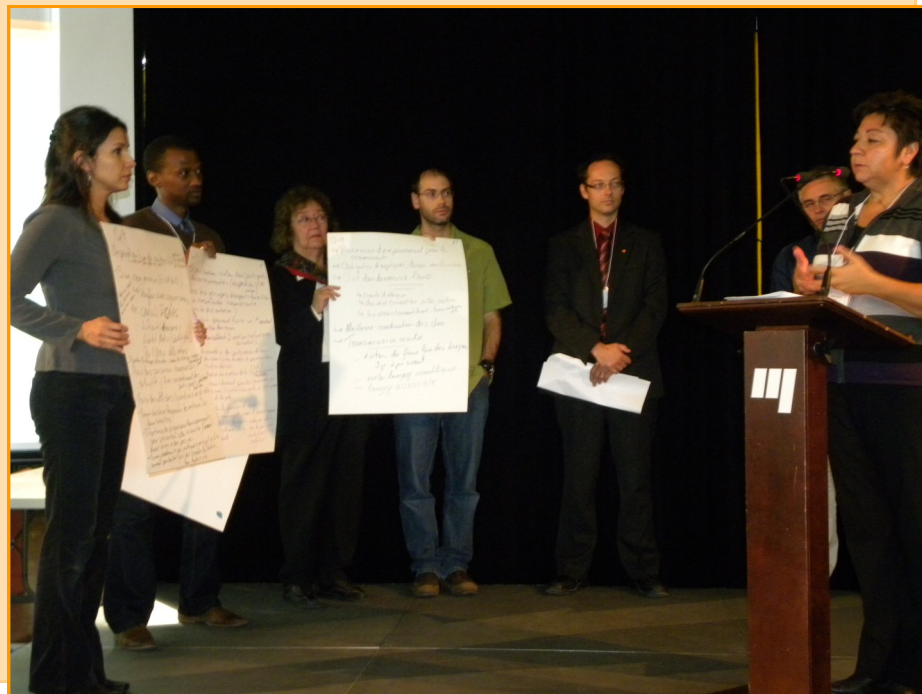
Nancy Crépeau, Barthélemy-Hugues Ateme-Nguema, Marguerite Gaudreau-Mowatt, Hugo Asselin, Vincent Rousson, Bruno Sioui, Janet Mark

Plenary session
Hugo Asselin

Okay, we have some time now; it's the plenary, and it's your turn to speak. If you heard something during the presentations that you don't necessarily agree with, if your comments were misrepresented, if you forgot to talk about a particular topic and want to mention it, now is the time. And I'd like to say that what we have in mind now is coming up with approaches to use in the field. How do we concretely apply the TCPS recommendations and the various research protocols in real life? In our milieu, in your milieu, how do we put them into practice? They're often rather general principles. You understand the principle, but you say to yourself: "Yes, but with my project, I don't know. With the community that I'm working with, how can I really put that into practice and be sure that that's what I need to do?" So, you have the floor.

Observation

This might not be a question; it's more of an observation, because I find that we're talking a lot about research coming from the academic milieu toward the communities, and we haven't talked very much about research projects coming from the communities toward the academic milieu. I wonder how much influence that has on recruitment, on all this, when it comes from the community.

Hugo Asselin

Good, that's an excellent observation! While you're thinking about your questions, I'm going to talk about what this lady has just said. Unfortunately, there is still, indeed, some reluctance in the academic milieu about working like that, but I feel that this is the path that we should take: to listen to the communities, to people, etc., and to turn their needs and questions into research projects. And, at that point, we are then assured of the legitimacy of our work, of people's participation to it, etc. And especially, we're sure that what we're doing is relevant. Besides, researchers don't even need to have ideas anymore! (Laughter)

Reflection

This is actually a reflection. In Kitcisakik, we had a very good research experience with UQAM (Université du Québec à Montréal), which was supposed to last five years but in fact lasted nearly eight years. The researcher had to adapt during the process, and the community also had to adapt along the way. It was a complex study. Many of you here know about her. So, my experience tells me that if I saw a lot of interest on the community's part, it was because the researcher made sure she understood the participants' needs so that she could be sure of understanding what they said and so that afterwards, she could accompany them during the research. She shared the results with small interest groups in the community along the way. Seven, eight years is a long time for research. At a certain point, the community has a work plan and wants to practically test out certain hypotheses or conclusions. It's important to be able to share as the results emerge, not to wait until the certificate or doctorate is completed, but rather during the process, when the community and researcher are collaborating and when there is a relevant result, which enables thinking to be deepened, tools to be developed, and staff to be trained. Of course, this isn't always possible, depending on everyone's agendas, but it was a very positive experience in Kitcisakik.

I see something else happening in the coming years. The communities have, to a great extent, appropriated the language of the specialists in question. That language is evolving over time; it's changing. There's been a new reform in the forestry sector, and the department will have a new language associated with all of that. The community must now start again; it had developed a language and now has to adapt to a new one. This leads me to say that the interest of research is such

that we absolutely must develop tools in order to be able to put research results into practice. It isn't up to the university to do this, but it may happen through education and training. There are different aspects to research; it is multidisciplinary. We must try to balance research efforts so that the community gains operational tools as quickly as possible because there aren't many resources, and the needs are great. I expect that in the coming years, it will be hard to finance fundamental research given the difficult context. Critical needs will be addressed first.

Hugo Asselin

I find it interesting that you're talking about fundamental research and, consequently, applied research. I feel that this is a false division that was created by academic researchers. In fact, as for myself, and I'm not alone in this and I'm not inventing anything new, I'd rather talk about whether research is relevant or not. There's an interesting book called *Real World Research*, about research in the real world, which is a way of saying that there is a research approach that helps to move things forward and that helps to meet needs—in this case, the needs of the communities that we work with. To provide this help, this may mean that we need a bit more fundamental research, because we're starting further behind. And sometimes the research is very much applied and that's all right too, so we might even be able to get funding from agencies that focus a lot on applied research, and this way we can get them to fund some fundamental research projects. At least we can try!

Comment

As I listened to the results, I got the impression that there was one theme that was often reiterated: the theme of research with Aboriginal people in urban areas. We know that there are more and more Aboriginal people in urban environments, so there are probably going to be a lot of research needs in that area as well. If we think about the general concept that research should be done from the beginning with Aboriginal communities, should be initiated in partnership with Aboriginal communities, there's a problem in the urban milieu. All the groups said the same thing. Who do we work with? Who do we contact? Who is the Aboriginal community in an urban area? I feel that the thinking about research ethics should focus on that subject. In the communities, we often talk about the Band Council, and not just the Band Council, but often the institutions are well known, are easy to approach, and sometimes even approach us. In urban areas, how do we go about this? I think that this is really the key issue at this time.

Suggestion

I'm going to suggest something because what the lady brought up just before is something I find very important. I find that today it was a question of partnerships; we talked a lot about partnerships. I find that we also asked a lot of questions about how we should approach Aboriginal communities, whether in an urban area or on a reserve, an Indian settlement. I personally don't think that that kind of partnership is going to happen automatically. It's more of a marriage of convenience than a love match. What I want to suggest, ultimately, is an idea linked to what our institutions and universities could have. What shouldn't we do? How do we structure the partnership? What do they do in other places? For example, think of career days in highschools. What do they do? They bring in people from the CEGEPs and put them in contact with students, and say: "See if you can produce something together." What do they do in other kinds of days, in "speed dating," for example; do some of you know what that is? You take women and put them in contact with men, and say: "See if you can make babies together." Me, I'm saying maybe, and I'll let you react to this, maybe UQAT or the other universities should take that kind of initiative. Bring Aboriginal people from Abitibi-Témiscamingue here, or we go there, and ask the question directly. You have a university there, you have researchers; here they are: these people are interested in doing research. How do you plan to use your university?

And maybe we could do this every six months, every year, I don't know, but it seems to me that we should structure all that, because for me, it's not the most natural of partnerships.

Hugo Asselin

In one of the discussions we had at one of the tables that I was at, we looked at something like that, but indirectly. On the one hand, universities do have strategic planning, and even research groups within universities do planning. They know a bit beforehand the direction they want to take and the topics they want to explore. Despite the lack of resources, it would be important for the communities to do a sort of planning like that. To ask themselves what the priority issues are, or, in any case, those on which they'd like to have research done at the moment. And after that, the universities would indeed need to consult the communities or nations or organizations or all of them at the same time to see what their needs are and then adapt the kind of research projects offered, so that this would be a way of creating partnerships. This is something like what's already being done for research that's partnered with industry, in some sectors. Industrial partners involved in the big research chairs—and we have some at the university in forestry and mining—say: "What we're interested in are the following subjects, and that's what you should do your research on." If researchers want to be relevant, they work on those topics. The model does exist, so it's not that complicated to set up.

Charlie Papatie

Hello. My name is Charlie Papatie: I come from the community of Kitcisakik. I just have a few thoughts to share. I've been working with researchers for ten years. I've learned a lot about the kind of science that students learn at school or in the universities, on resources, health, or economic development. But I'm also going to talk about the knowledge held by Aboriginal people. Aboriginal people's knowledge is often at the oral level, and it's much more oral than written because it's always been handed down from generation to generation, even with history. When we look at the history of Québec or Canada, Québec has been around for 400 years, 400 years that it's been doing development. It's also been 400 years that it's been doing the work of science, in terms of research.

So we often forget about First Nations in relation to their land, in relation to their natural resources. When we talk about natural resources, we shouldn't forget aquatic resources as well, species that live in water. There are also species that fly, species that walk on land. These are the concepts that people reflect on when researchers come to work in different areas. And when we talk about work that needs to be done, this also means getting to know the nation, how people live in relation to the land, in relation to the community. As members of a community, in Kitcisakik, we're still living in a situation that I would call difficult. This is a community that doesn't have running water, that doesn't have electricity, that doesn't have infrastructures, but the community still does a lot of work on the needs expressed by the community.

So, for me, it's still important to want to understand the link between science and Aboriginal knowledge. We need to strengthen that link to be able to build something in terms of living together. Living together is often expressed by the Abitibi region and from other regions, but we mustn't forget as well that it was First Nations that lived on that territory. We see other Aboriginal nations, from east to west, and to the south as well: there are many nations on the territory as a whole. So I learned a lot on the level of science. What we need to understand in science, what the methodology of science is. . . . So we still had to learn this field, on the level of science, and we learned it.

And I'm going to repeat myself, but we also learned your language. People who work in the Aboriginal milieu, we certainly ask them to learn the First Nation's mother tongue. At least a few words, so they

can understand what people are talking about. Because it often happens that at some point, there's clearly a certain limit. When a community member doesn't want to answer any more, it means that there's a certain limit for that man or woman. One has to stop, take time out, and come back another time. Sometimes, it's too many things, or a lot of emotions, because sometimes you meet people who are feeling a lot of discontent inside.

When you're explaining something, there are often misunderstandings in the process, in the approach as such. When we work in a sector like, for example, the forestry sector where I work, and a researcher comes and we talk about the land, about different types of cutting, the person who knew that job, those types of cutting, that person clearly knew them through his experience, because he worked with certain forestry companies. So, in his imagination, in his understanding, he certainly understands why we're now in the process of destroying our Mother Earth. It took him a while to understand because he had to work to support his family. And then came the revolution that changed things. We too, at a certain point, we changed because we had forgotten the concept of being an Aboriginal person. Today, we can be much more of a guardian of the Earth. That's why, with all the capacity that people passed on to us in relation to knowledge, and to research, this also helped us to understand the researchers' way of life and also the forestry companies' way of life.

Now, to be able to understand, they now need to listen to First Nations. What they'd like to pass on in regard to the health of Mother Earth. People often forget the health of the Earth. Because we now see what's happening on the land worldwide. We're now asking ourselves questions in our work environment. It's for the present, for the future, for the future of our generations, our children, your children. It's still important to raise questions: where are we heading now on the level of research? Is it for people's welfare, people's health, and the welfare of our resources, our lakes? It is all of this. We're in the process of killing what we have. Because I don't think it is Mother Earth that will die first; I think it might be us. Some animal species are starting to disappear. One member of my community saw crows, 200, 300 crows, above a village, and I said to myself, it's not normal for birds to gather in such large numbers: we have to ask ourselves, why?

Hugo Asselin
Thank you. There were many relevant and important elements in what you said. There are two things that I'd like to go back to. There's often a concern to the effect that research claims to validate Aboriginal knowledge, as though it needs to be validated, while research does not. This implicitly places research above traditional knowledge or Aboriginal knowledge, whereas they should both be on an equal footing. We never hear people say: "Do your research and we'll validate it with traditional knowledge." Why is that? I think it should go both ways, and that when we write our protocols, when we think about our projects, we should keep this kind of thing in mind, that we're going to go and explain things that the people we'll be working with don't understand. In fact, we often learn more ourselves than the other way around. I think that, in any case, that's a really important element.

And maybe I'll send the ball back to Ms. Gros-Louis McHugh, because in her presentation she said that in cases of projects that concern the land or animals, and no human beings, it's as though there is no way for the community to have a say in the research. As though there were no need for an ethics protocol if there were no human beings involved. But can't we expand the definition a bit and say that there's a link between the land, animals and human beings, and everything? It seems to me that if somebody decides to go and do a research project on a territory, for example, on the caribou herd in Val-d'Or (there are about twenty or even fewer left), and that if in this project it is a question of capturing them, I don't know whether Aboriginal communities would agree with that. Shouldn't they

have their say in this? How could we go about putting all this into practice, as someone else said?

Nancy Gros-Louis McHugh
I'd like to maybe just clarify, in terms of the *First Nations of Quebec and Labrador Research Protocol*, that it applies to all types of research on First Nations territory, whether this is currently occupied territory or traditional territory. Normally, the communities, the First Nation, should be involved in the entire process. The distinction here, if I correctly understood Dr. Brant Castellano's presentation this morning, is that Chapter 9 of the TCPS only concerns humans and doesn't consider other species and the land.

Hugo Asselin
So that's very important. That means that this doesn't exempt researchers from signing protocols or, in any case, from having an agreement with the community. Okay, so everybody has taken note of this?

Comment
I'd just like to mention, when we were talking before about forging links between the communities and researchers, that at UQAM, we have what we call the Service aux collectivités (community services), which plays precisely this role. So, for example, it might be working in the community kitchens and wonder whether this is really helping our participants. So I'll go and knock on the door of UQAM's community services, and say: "I'd like you to put me in touch with a researcher or researchers who would accept to come and realize an evaluation of the community kitchens program". I know that UQAT is a very small university, but I'm suggesting this idea and I think that it could be not just with Aboriginal communities but with all communities; it could be a way of facilitating contacts between researchers and members of different communities that would like to be able to take advantage of these researchers' expertise.

Hugo Asselin
I think that the director of the Val-d'Or campus wants to say something about this.

Vincent Rousson
Yes, hello, well one possible solution might rest with M. Pierre-André Bélanger. He's the director of BLEUM (bureau-liaison-entreprise-université-milieu) (corporate-university-community liaison office), which might play a similar role to the one that you describe.

Hugo Asselin
Are there any other questions? We still have time. If there haven't any other questions, maybe you'd like to share some of the research experiences that you've had, good or bad.

Marguerite Mowatt Gaudreau
What I'd like to say is that you said a little while ago that there were no Native researchers. I work in the field of education. I've questioned Indians and it seems to me that it was easier for me to question Indians, Native, than when it was a stranger coming to the house and knocking on the door without any other form of introduction. More and more, this is getting better, but I said to myself that it would be interesting to encourage the next generation to take over from us. I know that this isn't your role, but we need to encourage research by Native participants. I find that they have a great deal to offer, and I think that it would be interesting, if we have the opportunity to encourage someone that we meet to do research, to have research done by a Native person. That's what I observed when I did my

research with students. I went to Lac Simon, and I felt this when I was there. The students were being taught by non-Aboriginal people. There were black people, white people, and Hindu people when I went to that school. And the young people were saying: "What are they doing coming here to show us their knowledge; we know what we want." It's true that they were teenagers, but I said to myself that it was easier to have Aboriginal staff. At our school, where I teach, there are a lot of Aboriginal staff in the classrooms and so on. It's a good asset for teachers to be aware of the Aboriginal mentality. In some places, there's a significant staff turnover. You don't have time to get used to someone before they leave and are replaced by someone else. My priority is to have other Indian men and women doing research. So that's my point of view. I have a lot of other things to say, but I'll stop here because I could go on until tomorrow morning.

Hugo Asselin

It's true that this is important, and it also testifies to the concerns that several people have expressed about capacity building. Capacity doesn't always mean learning how to use a tool or software, for example. It also means learning how to do research yourself. I see this myself in the communities that I'm lucky enough to work with; sometimes, after several months or years—it depends, everyone is at their own level along the research path—at one point, the communities themselves undertake research projects. They sometimes come to see me for guidance. Then, there's often nothing for me to do; I tell them, "your project is a good one; do it, then let me know the results: I'll be interested to hear!" That's wonderful, when realize that a community can do its research projects itself and no longer needs outside researchers from the universities or elsewhere; that's the best thing. In any case, researchers will always have work. There aren't enough people in the communities, so we don't have to worry about that, and I think that this is the direction we should be heading. I think that the process needs to be open and transparent so people can see how the mechanics of research work, and appropriate them for themselves. We shouldn't just go and do interviews and then hide in our office and come back at the end with the report. That's the worst thing to do. So, if some Aboriginal people want to be trained to do research, we're always looking for masters' and doctoral students. Just register!

Comment

Yes, that's because I think that we are often able to identify our problems. The need that we have is that once the problems have been identified, we'll turn to the universities for support. Myself, I work in education, and so we turn to the universities with the problem areas that we've identified, and this is where we try to set up agreements so that we can work. What I'd also like to say is that in education, research is often done with the help of teachers, and the problem we're seeing more and more is that it's getting expensive to take teachers out of classrooms. I think that there may not be a lot of money for research, so it's becoming harder and harder. And there's another aspect as well, which is teachers' reluctance to have researchers come into their classrooms. So, doing research in this area isn't so easy; there are all sorts of things like that that we have to take into consideration.

Hugo Asselin

I'd like to ask you how we could not necessarily overcome, but rather diminish, this reluctance. Is there a trick, or some tricks, to this?

Suggestion

I think that we need to be aware of this reluctance. I thought that the teaching milieu was a milieu where, and I'm not from that milieu, I'm a sociologist, so I thought that the teaching milieu was very open. I always thought that to be able to teach, you needed to be on the leading edge of the latest

developments, because with young people nowadays, you have to be very open. I also think that teachers are afraid of change. So I think that by taking this into account, we'll be able to find ways of approaching teachers to simply be able to enter their classrooms. But we still haven't found the solution.

Hugo Asselin

Sometimes, it may be a fear of "top-down" approaches. People say, they're going to come from the government or who knows where and tell me what to do in my classroom, whereas I'm the one who knows this best. So maybe just by working more closely with teachers, the doors will open more easily.

Suggestion (continued)

It's because we had some great research projects, but they could never be completed because the researchers were never able to go into the classrooms with teachers.

Hugo Asselin

Okay, so change researchers! (Laughter)

I'll take advantage of the silence to slowly begin to wrap up the day. I think it's very important to have days like today. Maybe we even waited too long before doing the second seminar, since the first one already dates back to 2009. I'm hoping that there's going to be a third seminar and maybe even others after that. They are special places for exchanging ideas, and I think that it's fun to have everyone together in the same room like this. To take a day to stop and reflect on our practices, on both sides, and to try to find ways of coming closer together. I especially liked the fact that today, even if we're at a university, we don't have our head in the clouds and we try to connect with realities in the field. Sometimes we get lost in our principles; they may look great on paper but then, because of a lack of knowledge and of ways of applying these principles, we sometimes don't apply them even though we may believe in them, but this doesn't translate into real life. Many things came out of today's seminar. We're going to try to compile all this into a report that will be available on the university website or some other way. And I invite those of you who are continuing to reflect on these issues to consult with members of the UQAT research ethics board or with the researchers, whenever you want. We have to keep up the dialogue. Thank you, everyone.

Conclusion

For many years now, there has been more and more research in Aboriginal milieus across the country. However, some approaches have not always benefited the communities, nor have they contributed to the advancement of knowledge. UQAT has always made every effort to work in partnership with Aboriginal peoples. During this second seminar on ethical conduct for research with Aboriginal peoples, Aboriginal communities and organizations, researchers, professors and students have worked together to identify possible solutions responding to the proposals in Chapter 9 of the second edition of the *Tri-Council Policy Statement* (TCPS 2).

The objectives of this second seminar have been achieved. The work accomplished during the day made it possible to develop concrete ways of following the principles of research ethics in respecting Aboriginal communities' needs. The participants came up with some very enlightening observations. What we need to retain from this seminar is that research must be relevant to the people primarily concerned. Aboriginal peoples must therefore have the opportunity to speak about research priorities that concern them. Preparatory work must be done before a research project in the Aboriginal context is developed. Moreover, identifying and mobilizing partners in and outside the communities is still a considerable challenge. Researchers and Aboriginal organizations that decide to participate in a research project must in each case demonstrate openness to mutual understanding. Every community and every project calls for particular conditions: hence the importance of establishing a dialogue of equals. All research partners must also encourage greater knowledge of the OCAP principles (ownership, control, access and possession of information). It is therefore vital that researchers and Aboriginal peoples receive training on the main principles of research ethics and the tools that are available to apply these principles. The approach developed during the seminar will be extended with the addition of a section on ethical conduct for research with Aboriginal peoples in UQAT's *Politique d'éthique de la recherche avec des êtres humains* (Ethics policy for research involving human beings)[1]. So the "Aboriginal Peoples and Researchers Dialogue" truly remains open!

Maryse Delisle, Hugo Asselin, Marlene Brant Castellano, Suzy Basile, Nancy Gros-Louis Mc Hugh, Manon Champagne et Nancy Julien

1 It is noteworthy that CÉR-UQAT created a seat for an Aboriginal representative following a recommendation that came out of the first seminar on Research and Ethic with Aboriginal Peoples, held at UQAT in May 2009.

Suggested Reading

Asselin, H. and Basile, S. (2012). Éthique de la recherche avec les Peuples autochtones : qu'en pensent les principaux intéressés? *Éthique publique*, Vol. 14, No. 1, pp. 333-345. http://ethiquepublique.revues.org/

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Basile, S., Champagne, D. and Crépeau, N. (2009). Summary of the seminar "Les Premières Nations : recherche et éthique," held in Val-d'Or on May 27 to 28, 2009. Unpublished. Université du Québec en Abitibi-Témiscamingue. To obtain a copy (in French), please contact: suzy.basile@uqat.ca

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First Nations Centre. (2007a). *Considerations and Templates for Ethical Research Practices.* Ottawa: National Aboriginal Health Organization: http://www.naho.ca/documents/fnc/english/FNC_ConsiderationsandTemplatesInformation Resource.pdf

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Politique d'éthique de la recherche avec des êtres humains. (2011). Université du Québec en Abitibi-Témiscamingue. Consulted May 10, 2012 at: http://web2.uqat.ca/recherche/Politique%20ethique%20recherche%20avec%20etres%20humains.pdf

Appendix
Biographies of the Guest Speakers

Marlene Brant Castellano

Marlene Brant Castellano is a Mohawk of the Bay of Quinte Band and Professor Emeritus of Trent University. She held a faculty appointment in Trent's Native Studies Department from 1973 to 1996, providing leadership in the development of the Department and in the emerging discipline of Native Studies. From 1992 to 1996 she served as Co-Director of Research with the Royal Commission on Aboriginal Peoples (RCAP) with particular responsibility for drafting the integrated research plan, directing social-cultural, historical and community-based research, and editing and writing major portions of the final report under the direction of Commissioners. She facilitated the work of the Aboriginal subcommittee which drafted RCAP's Ethical Guidelines for Research now widely used as a reference for ethical research in Aboriginal contexts. As a member of the Interagency Advisory Panel on Research Ethics she led the working groups drafting Chapter 9 of the second edition of the TCPS adopted in 2010.

Professor Castellano's formal education is in social work (MSW 1959) and adult education (OISE/UofT 1980-81). Her teaching, research and publications are deliberately bicultural, promoting discourse between the worlds of Aboriginal knowledge and experience and the language and protocols of academics and policy makers. In recent years her writing has focussed on respectful treatment of Aboriginal knowledge in research. The inaugural issue of the *Journal of Aboriginal Health* published by the National Aboriginal Health Organization (NAHO) in 2004 includes her paper "Ethics of Aboriginal Research."

Professor Castellano has served on the Institute Advisory board of the CIHR Institute of Aboriginal Peoples' Health and the College of Reviewers for Canada Research Chairs. She has been honoured with LLDs from Queen's University, St. Thomas University and Carleton University, induction into the Order of Ontario and a National Aboriginal Achievement Award. Dr. Castellano was named an Officer of the Order of Canada in 2005.

Dr Marlene Brant Castellano has published the two following articles :
Brant Castellano, Marlene and Reading, Jeff (2010) "Policy Writing as Dialogue: Drafting an Aboriginal Chapter for Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans," *The International Indigenous Policy Journal*: Vol. 1: Iss. 2, Article 1.
Available at: http://ir.lib.uwo.ca/iipj/vol1/iss2/1

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Available at : http://www.indigenous.ca/docs/ethics%20of%20aboriginal%20research.pdf

Nancy Gros-Louis McHugh

Huronne-Wendat from Wendake, Nancy Gros-Louis McHugh studied and graduated from Laval University in communications. She has worked abroad which allowed her to be more aware about health issues affecting North America's Aboriginal people.

Since 2002, she has worked for the First Nations of Quebec and Labrador Health and Social Services Commission in the social research area. Responsible of a multidisciplinary research team, she coordinates several community research projects on various topics all related to health, and advocates

a holistic approach.

Mrs Gros-Louis Mchugh was actively involved in the development of the Assembly of First Nations Québec and Labrador research protocol. She was also involved in the foundation of the First Nations Governance Center.

Biographies of the Organizing Committee Members

Hugo Asselin

Mr. Asselin holds a B.Sc. in biology with a speciality in ecology from Sherbrooke University (1997), a M.Sc. in biological sciences (forest ecology) from Montreal University (1999), and a Ph.D. in biology (palaeoecology) from Laval University (2005). He was postdoctoral fellow in palaeoecology at UQAT between 2004 and 2007, before joining the department of humanities and social development as a professor. He holds the Canada Research Chair in Aboriginal Forestry and is a regular member of the NSERC/UQAT/UQAM Industrial Chair in Sustainable Forest Management. His research interests focus on integrated and sustainable management of natural resources, social and aboriginal forestry, forest ecology, and palaeoecology. Since 2009 he is a member of UQAT's Research Ethics Board.

Suzy Basile

Suzy comes from the Atikamekw community of Wemotaci, she has a Bachelor degree and a Masters degree in Anthropology (Tourism entrepreneurship in an Aboriginal environment). She is the Aboriginal Project Manager with the *Université du Québec en Abitibi-Témiscamingue (UQAT)*, at the Val-d'Or campus. She is also currently enrolled in the Environmental sciences Ph.D. program of the UQAT and is interested in the role and the place of Aboriginal women in land and natural resource governance. Mrs Basile was involved in the development process of the Assembly of First Nations of Quebec and Labrador's research protocol as well as the revision underway.

Manon Champagne

After having worked for 10 years as a child life specialist in a pediatric setting, mainly with children who had been diagnosed with cancer and their families, Manon Champagne received a Ph.D. in education from the Université du Québec à Montréal (UQAM). She is a Professor in UQAT's Health Sciences Department, where she teaches courses on end-of-life issues, communication, qualitative research and research ethics. As a researcher, she is particularly interested in the psychosocial aspects of pediatric palliative care, in volunteerism in palliative care, in action research and in participatory research. She has been Chair of the UQAT Research Ethics Committee since June 2009.

Nancy Julien

Ms. Julien has completed a Ph. D. in clinical sciences in 2008 [a program of the Université de Sherbrooke offered by extension at the Université du Québec en Abitibi-Témiscamingue (UQAT)]. She is an associate professor in the Health Sciences Department of the UQAT. Her research focuses mainly on endogenous pain control mechanisms. She is currently interested by the chronic pain burden among Aboriginal peoples. She is a member of the UQAT's Research Ethics Board since 2007.