



Northern Ontario
School of Medicine

École de médecine
du Nord de l'Ontario

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Partnership
Opportunities
in Research

GATHERING

Report



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Message from NOSM Dean and Associate Dean of Research

It was an honour for the Northern Ontario School of Medicine (NOSM) to host the Partnership Opportunities in Research Gathering. Research is a critical component of medical education at the School, and this unprecedented forum was a unique opportunity to address challenges of Aboriginal peoples and their historical relationship with research methodologies and practices.

From the very beginning when NOSM was still a pan-Northern dream, Aboriginal communities supported the development of a medical school that would address the health-care needs of Northerners. Significantly, this timely event functioned both as a learning forum and as an expression of the School's intent to reinforce relationships with Aboriginal communities through ongoing dialogue.

Aboriginal peoples, community representatives, researchers, organizations, and government representatives came together to listen, share perspectives, and attempt to understand divergent world views – essential steps in the recognition and acceptance of difference. The Gathering featured a candid exchange of opinions from Aboriginal community members affected by unsatisfactory research practices, presentations calling for new research approaches, and working group sessions, which together comprised invaluable contributions to the unfolding dialogue.

On behalf of everyone at the Northern Ontario School of Medicine, we sincerely thank all presenters, participants, and organizations for attending this forum, and look forward to reengaging with Aboriginal peoples in collaborative partnerships aimed at improving the health of the people and communities of the North.



Dr. Roger Strasser
NOSM Dean



Dr. Greg Ross
NOSM Associate Dean,
Research



Dr. Roger Strasser with Gathering Participants

Conference Details

Aboriginal peoples, researchers, policy makers, and faculty and staff from the Northern Ontario School of Medicine gathered together in Thunder Bay for an historic opportunity to discuss research issues affecting Aboriginal peoples.

Over 100 representatives from Aboriginal communities, NOSM, Cancer Care Ontario, Laurentian University's School of Rural and Northern Health, the Heart and Stroke Foundation of Ontario (HSFO), the Institute of Clinical Evaluative Sciences (ICES), and other health research organizations took part in the Partnership Opportunities in Research Gathering at Thunder Bay's Da Vinci Centre from November 4 – 6, 2008.

The first of its kind in Canada, the 'Gathering' was organized to provide a forum for the discussion of Aboriginal grievances over historical research practices in First Nations communities. Identifying differences and similarities in world views was considered to be the foundational step in establishing common ground upon which future collaborative and equal partnerships can grow. The Partnership Opportunities in Research Gathering is a significant step in an ongoing process of re-engagement intended to benefit the health of Aboriginal peoples, research participants, and the Northern Ontario School of Medicine.

Partnerships

The Northern Ontario School of Medicine gratefully acknowledges the participation and contribution of its attending partners. In addition to the dozens of First Nations communities, representatives from Cancer Care Ontario were on hand to apprise participants of the advances in research, and to convey the importance of traditional knowledge in healing initiatives.

"To see the diverse opinions expressed here has been an eye-opening experience. This is an opportunity to share the many different viewpoints about traditional knowledge and spirituality."

Sue Commanda, Nipissing First Nation



Gathering Participants

General Overview

The Partnership Opportunities in Research Gathering was an unprecedented occasion that brought together Aboriginal communities, research organizations, and the Northern Ontario School of Medicine. This three-day forum presented a platform that engaged stakeholders in meaningful dialogue over research strategies which have adversely affected the well-being of Aboriginal Peoples and communities.

“The most significant impact of this Gathering is that the School has the confidence to give the communities the opportunity to provide constructive input. NOSM recognizes what communities can actually contribute to research.”

Chris LaFontaine, Gathering Moderator

The contributions of over 100 Aboriginal community representatives, researchers, administrators, and NOSM faculty and staff were critical to the arrival of meaningful outcomes. Indeed, the Gathering uniquely highlighted NOSM as a frontrunner in addressing long standing inequities, first by identifying the differences that have historically led to contention and distrust, and then by working toward collaborative approaches and understandings upon which research can proceed in a way that benefits all participants.

Widespread discontent over research methodology and protocol historically undertaken in many First Nations communities was a central concern for participants. It was noted that, in some cases, researchers have studied subjects, collected data, published reports and received benefits for their work without acknowledging the contribution of their Aboriginal hosts. Research, moreover, was also perceived by many in attendance to lack direct relevance to the health determinants of the participants and communities involved in these studies.

Of critical importance to the richness of the Gathering’s discussions was the acknowledgment of divergent world views between researchers and First Nations. Though Aboriginal peoples and communities are uniquely defined by language, tribe, custom, and location, they share a fundamentally holistic view of the world in which events and processes are connected to, and influenced by, innumerable factors. Similarly, time may be perceived as circular, as symbolized in the medicine wheel that turns in endless rotation, and is commonly embraced as a teaching tool. Aboriginal approaches also incorporate the physical, mental, emotional, and spiritual dimensions of life in all areas of enquiry and practice. In contrast, conventional researchers subscribe to the ‘scientific method,’ a framework of enquiry that relies on clearly delineated processes of examination and measurement.

Significantly, delegates used the presentations, small group sessions, discussions and interviews as tools by which to explore the uniqueness of each world view, and to confirm the importance of assigning equal value to all models. Appreciating difference and examining similarity was the first step, many concluded, in identifying common ground upon which new research initiatives may grow.

The Gathering also addressed the need for full participation of Aboriginal peoples in the research process by ensuring that:

- Prevailing methodologies be revised to accommodate the demands of host subjects;
- Provision of free and informed consent be provided by individuals, communities, and band councils, where appropriate;
- Compensation be made for the investment of time and energy of research participants; and,
- Retention and ownership of research findings remain in Aboriginal communities.

“The difference in world views has been articulated very clearly at this conference. I was struck by the fact that much of what has been described as First Nations world views represent a new ideal to which we are aspiring.”

Dr. David Henry, President and CEO,
Institute for Clinical Evaluative Sciences

Delegates concluded that the Partnership Opportunities in Research Gathering was the first crucial step in undertaking relevant and meaningful collaborative research dedicated to improving the health and prosperity of Aboriginal peoples.



Lorrilee McGregor



Gathering Participants

Highlights

The richness of the Partnership Opportunities in Research Gathering is owed to the heterogeneous mix of ceremony, distinguished speakers, delegate participation, a candid exchange of views, and fundamentally, respect for people and divergent opinions and beliefs. Aboriginal Elder Josias Fiddler set the tone for each day's proceedings with a smudging ceremony and prayer, invoking blessings to be bestowed on the Gathering.

"This has been an interesting forum, but more such gatherings are needed so we can establish greater contact. You can't reach an understanding in two or three days. The best way to learn about Aboriginal communities is to spend time in them."

Ron Wakegijig, Elder, Wikwemikong First Nation

In his opening address, NOSM Dean, Dr. Roger Strasser, thanked delegates for their interest and cooperation, reiterated the importance of open sharing, and promptly urged participants to immerse themselves in the breadth of subject matter. There were only three days to explore the many dimensions of the historically diverging relationship between Aboriginal and academic history and culture.

Participants, therefore, wasted no time turning their attention to the content of presentations, and later to impassioned discussions over themes directly relevant to Aboriginal Peoples and communities. Of chief interest were the working group sessions in which delegates shared their experience of cultural engagement, issues and barriers, cancer research, ethics, bio-prospecting and mutual benefits. Participants were encouraged to investigate and discuss each topic from several perspectives that would lead to an increased awareness of the complexity of each theme, and the consideration of remedial solutions.

The effectiveness of the many working sessions was enhanced by speakers from diverse constituencies whose contributions helped to establish a robust tempo that sustained a heightened level of engagement. Among the principal speakers was former Nishnawbe Aski Nation (NAN) Deputy Grand Chief Goyce Kakegamic who proposed alternative methods to establish meaningful relationships with Aboriginal peoples and to secure their input on research topics. In doing so, respect, cooperation and a reciprocal relationship that includes the enhancement of community capacity must be secured. Mr. Kakegamic's message to the wider research community called for a greater understanding and appreciation of Aboriginal world views, considered a foundational principle for constructive working relationships.

“We believe it is possible to conduct research in which ownership, control, access and economic benefits remain in Aboriginal communities. Agreements can be made that enable NOSM to work with First Nations in the search for new compounds that could have medicinal properties and benefit the health of Northerners.”

Dr. Greg Ross, Associate Dean, Research,
Northern Ontario School of Medicine

Dr. Greg Ross, Associate Dean of Research at the Northern Ontario School of Medicine, introduced the critical role of research with references to the unique opportunities and responsibilities the School has taken on as a major research and medical education institution. NOSM is in a privileged position to function as a link between researchers and communities.

The School’s mandate to be socially accountable to the people of the North calls for a mechanism by which communities are apprised of research opportunities and are given the option to fully

participate in future initiatives that answer community needs. Dr. Ross encouraged delegates to consider the economic benefits rising from participation in research partnerships, while reassuring the audience that NOSM fully welcomes the holistic Aboriginal world view toward healing.

Dr. John McLaughlin is Vice President of Population Studies and Surveillance at Cancer Care Ontario and a distinguished professor at the University of Toronto. He is responsible for introducing new types of health research across Ontario. Dr. McLaughlin supports NOSM’s inclusion of a holistic, spiritually-imbued approach to healing typical of Aboriginal beliefs. Though he remains committed to ensuring that research continues to be of the highest scientific quality, he welcomes alternative approaches that improve health. Cancer Care Ontario, in fact, has an Aboriginal Unit that drives initiatives consistent with holistic views. Broadening parameters to include alternative methods of healing, he says, can only lead to a better understanding of health issues.

Through the candid sharing of individual and collective experiences, the Partnership Opportunities in Research Gathering opened channels of communication and increased understanding of divergent perspectives. Delegates expressed optimism in the School’s attempt to engage communities in meaningful dialogue and research initiatives that will benefit Aboriginal peoples and communities.

Next Steps

The Partnership Opportunities in Research Gathering represents a major advance in identifying Aboriginal research priorities, acknowledging differences, and moving toward greater cooperation among stakeholders engaged in the research process.

The Northern Ontario School of Medicine recognizes that this is one step among many initiatives that will lead to cultivating relationships with its Aboriginal partners, researchers and hosting institutions. In the wake of a historical legacy of distrust, this is an ambitious, but essential undertaking, and one that NOSM is fully prepared to embrace, according to NOSM Dean, Dr. Roger Strasser. "We cannot underestimate the challenge we have taken on. For centuries researchers have been taking Aboriginal knowledge and giving nothing in return. Establishing and maintaining trust will be a long term process."

The Northern Ontario School of Medicine looks forward to building future research relationships based on the achievements reached at this first Gathering.

Call to Action

NOSM welcomes Aboriginal Peoples and communities to participate in research initiatives. Please contact us to advance research proposals and to begin a tradition of collaborative research excellence with the Northern Ontario School of Medicine.

Contact Information

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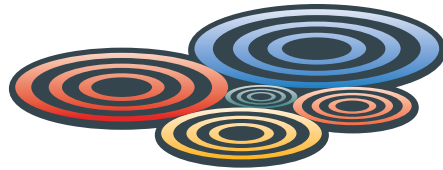
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From left to right: John Gagnon, NOSM Dean Dr. Roger Strasser, and Chris LaFontaine, Gathering Moderator



Partnership
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GATHERING

Report

Acknowledgement

I would like to begin by acknowledging the Elders, leaders, staff, and community members for their willingness to participate in this Gathering. Without participants, there would be no Gathering. They shared their knowledge and insights and made a valuable contribution to this work.

At the same time, I would like to acknowledge the Northern Ontario School of Medicine (NOSM) for its insight and leadership. NOSM leaders understand that they must take risks in order to grow; and they understand that success is best achieved in partnership. NOSM management and staff have a vision to which they are committed. You see it in their planning and organization.

I would also like to acknowledge the workers and volunteers that organized this event, those who booked venues, organized the transportation, registered the participants, prepared the kits, found the gifts, etc. They are often overlooked, but without their effort, this work would have not been possible. Lastly, I would like to express my gratitude to John Gagnon. Without his vision and work, I would have not had the opportunity to participate in this event.

Participants at the Gathering said it was a success and it was a direct result of the combined effort of many, many people who worked tirelessly. Their efforts inspired me to become involved in a project that will have a long-term positive impact in our community.

Christopher Lafontaine
Moderator

Executive Summary

Research at the Northern Ontario School of Medicine (NOSM) is part of the School's mandate "...to be socially accountable to the diverse cultures of Northern Ontario." The School's research program is unique as it targets research questions related to improving the health of people and communities in Northern Ontario. The Partnership Opportunities in Research Gathering was part of an ongoing process "...to get things right" as NOSM investigates areas of research that have a direct relevance to Northern populations.

The goal of the Gathering was "...to create and sustain working research partnerships within Northern Ontario."

First Nation and Métis leadership are growing in capacity and confidence, and as a result, are beginning to question the effectiveness of relationships. Our leaders are "...reading the fine print, they are ever so much more vigilant and asking to formalize benefits and costs so decisions are made benefiting the next seven generations. Our community members desire to protect traditional knowledge because traditional knowledge is integrated with our sense of value and worth – who we are." (Mary Richards, 2008)

Relationships with First Nation and Métis communities are important to NOSM. This meeting was part of a long-term commitment to NOSM's ongoing strategy to identify what is working and the issues and concerns that need to be addressed for a long term relationship to be sustained.

This report is a summary of what was said during the Gathering utilizing a particular approach – the Fault Tree (Steven's 1988). It is not meant to make conclusions, judgments or recommendations about what was heard. Every effort was made to be accurate and not to reinterpret what was said; however, the statements were recast to create Fault Tree statements and to organize the statements into themes or grouping. It is important to note that the Gathering was just the start of a process that will be ongoing.

Background

- The Partnership Opportunities in Research Gathering was organized and sponsored by the Northern Ontario School of Medicine and held November 4, 5, and 6, 2008 in Thunder Bay, Ontario. This Gathering was an exploratory event to open dialogue and seek information on better ways to enhance research opportunities consistent with NOSM's mandate.
- The Gathering was held in collaboration with the Aboriginal Reference Group (ARG) which is made up of members from the Nishnawne Aski Nation, Treaty # 3, Anishinabek Union, Métis Nations of Ontario, Ontario Native Women's Association, Ontario Federation of Indian Friendship Centres, Lakehead University, and Laurentian University.
- Invitations were sent to a number of key stakeholders throughout the region NOSM serves. Over 100 people attended, including: Elders, community leaders/politicians, Chiefs and Councillors, Health Directors, NOSM staff, volunteers, students, community citizens, Aboriginal academics, Aboriginal Cancer Care Unit (ACCU), Cancer Care Ontario (CCO), Heart and Stroke Foundation (HSF), and Institute for Clinical and Evaluative Studies (ICES). The goal was to invite a cross-section of individuals.
- The Ministry of Natural Resources of the Ontario Government also attended to present the Government of Ontario's position and describe their work on a number of the key issues, concerns and questions.

Why was the Gathering held?

- NOSM's social accountability mandate requires the School to create and maintain working relationships with existing and potential partners. NOSM management and staff know that in any relationship there are issues and concerns, and unless these issues and concerns are identified, prioritized and acted on, research initiatives will not benefit the School or the communities.
 - In response to questions regarding NOSM research brought forward from various Aboriginal communities, the NOSM Aboriginal Reference Group recommended to the School that better communication should be developed.
 - Under the direction of Dr. Roger Strasser, NOSM's Founding Dean, and Dr. Greg Ross, NOSM's Associate Dean of Research, a proposal was made to the Aboriginal Reference Group (ARG) on October 5, 2007. The proposal identified a potential engagement process that would focus on basic research, community based research, drug discovery, chronic disease, etc., with involvement from Cancer Care Ontario, the Heart and Stroke Foundation, and research participants, which would interface with the communities. The result was the Partnership Opportunities in Research Gathering.
 - The Gathering was created to be an enhancement of NOSM's ongoing strategy to work with First Nation and Métis communities. This event marked the beginning of a number of proposed activities to create and maintain working relationships.
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Who advised NOSM to hold a Gathering?

- A working committee was created and that group designed the format for the Gathering. A key suggestion from the ARG was to incorporate into the agenda "...an open dialogue with regards to research."
- The NOSM Aboriginal Reference Group recommended that the consultation forum "...focus on partnerships in research opportunities" and the concept was born.

What was the purpose of the Gathering?

- The main purpose of the Gathering was to open dialogue with First Nation and Métis people regarding the "...creation of research partnerships, capacity building, and looking to join future research initiatives."
- First Nation and Métis peoples were invited to articulate: their issues and concerns; their support of what is being done right; and, what it will take to create and maintain future research relationships. The Gathering provided an opportunity to continue the dialogue regarding existing and future relationships.
- The consultation process would also initiate collaborative processes and identify ethical approaches to conducting research.

Design of the Gathering

- Commitment from NOSM is to move from one meeting to a longer term process, and to travel from dialogue exchange to consultation.
 - The agenda and the flow of the meeting was an open forum, although presentations were made on the following topics: Cultural Engagement, Pedagogy, and Methodology; Research Ethics and Etiquette; Issues and Barriers; Bio Prospecting; Community Engagement for Cancer Care Research; and, Mutual Benefits. The presentations were used to stimulate discussion; however, participants were continually encouraged to discuss their immediate and future issues and concerns, and the strengths with the existing processes. Speakers gave a brief ten-minute presentation, which was followed by a brief question period. After the question period, participants were asked to break into small groups to provide everyone with an opportunity to comment. There were two speakers for each topic in order to have two perspectives introduced. By choosing the speakers, the organizers were able to introduce the Anishinaabe and researcher perspective related to these topics.
 - Discussion topics focused on the issues and concerns of the First Nation, and Métis people. For those who were new to the topics being presented, the format introduced participants to the concept of research, gave some instruction, identified an overview, and introduced questions for the discussion.
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- The meeting room was set up with break out tables to accommodate ten to fifteen people. Each group had a facilitator and a note taker to record information on flip charts. Small groups provided the opportunity for everyone in the group to have an opportunity to speak. Participants were further probed with engaging questions: What are the strengths of NOSM? What are the issues? What would issues be in the future? What would you do if you were in position to make decisions?
- General sessions provided opportunities for participants to ask questions of the presenters.
- The working committee investigated a number of models to accomplish their goals and objectives, and decided on a moderator and independent chair – Mr. Christopher Lafontaine.

Why did NOSM go through this process?

- Due to the social accountability mandate in the letters of patent for NOSM, the School has self-declared this social accountability mandate for the purpose of working with First Nation and Métis people.
- NOSM is working towards a future of collaboration, inclusion, and capacity building with First Nation and Métis peoples. In order to ensure proper relationship building, NOSM respects and follows due diligence in all consultations.
- NOSM has worked with the Nishnawbe Aski Nation (NAN) for a few years. NAN has been a strong supporter of NOSM's efforts and has played a role in helping to secure meaningful community participation in the NAN territory. NAN also acknowledges the commitment of NOSM in taking this initiative to "...do the right thing" with research projects and incorporating the First Nation world view, principles, and methodologies into research projects.
- By NOSM incorporating a First Nation and Métis world view into its policies, the School ensures that researchers, working within the First Nation and Métis communities, will respect the world views of those communities.
- NOSM understands that First Nation and Métis knowledge is sanctioned by First Nation and Métis citizens.
- This was an opportunity to engage decision makers in a frank and open dialogue.

The Methodology

- The collection and organization of data uses an adaptation of Roe's (1994) Rural Participatory Appraisal using Steven's (1988) Sage Analysis. This is one way to identify the other perspectives, especially other cultural perspectives. Introducing perspectives enables one to structure policy questions originating in that culture. The moderators and/or facilitators focused on understanding the participants' perspectives using open-ended questions to encourage them to express themselves.
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- In the analysis of the interviews, the moderator used Roe's dis-aggregation process to identify the participants' perspectives about "...creating and maintaining opportunities in research."
 - To organize the many issues, the moderator used Steven's (1988) Fault Tree Analysis to re-define and/or re-cast the issues into themes that can be prioritized into policy problems for presentation back to the group for policy development.
 - The primary data for this report was gathered at the Partnership Opportunities in Research Gathering on November 4 – 6, 2008. Participants were asked to identify, from their point of view, their issues, concerns, and strengths, as well as their perception of "...creating and maintaining research partnerships with NOSM."
 - The participants knew their culture and many were fluent in their first language.
 - All materials collected were formulated into problem statements. There was some grouping and combining of similar problem statements.
 - At this stage, the moderator built a chart using Stevens' (1988) Fault Tree process to organize all problem statements into the chart. The wall chart is used to report back to the groups issues and concerns and the relationships between problem statements.
 - The statements were then organized to show probable cause-effect relationships. For ease of reading the wall chart (Appendix 1), the reader was instructed to insert identifying letters before each statement. To identify the position of the problem statements on the wall chart, each statement is labelled with descriptors A, AA, AAA, AAB, AAC, etc. The labels identify the position of the statements and relationship between them.
 - The next steps included: a review by the group to determine if the statements were clear and reflected what was said; identification of new items that could be included; and the rating of priorities. The review, additional items and rating have not been completed.
 - The moderator also organized a Strength Chart to identify principles to guide future action.

Strength Tree Principles to Guide the Action

Future activities need to focus on the priorities which are identified, but the activities need to be guided by the principles established by the Strength Tree. The Strength Tree identifies those resources and guidelines available to communities for action. The principles are critical because all NOSM efforts should ...build on the strengths while remediating weakness and not violating strengths.

The Strength Tree suggests that NOSM consider principles to guide the development of strategies of "...creating and sustaining working research partnerships." Participants at the Gathering suggest NOSM is "...

on the right track and has a number of strengths to build on.” From the evaluation responses, the following highlight some of NOSM strengths shared by participants:

1. Continue to Listen and Learn:

- NOSM’s strategy of spending time listening and learning is a strength; however, NOSM needs to continue its effort by going out to the communities. When doing research, have First Nation and Métis people work with researchers before communities are engaged.
- Seek to have communities drive the research and continue to encourage NOSM students to learn traditional ways in communities. Use Aboriginal workers in community placements and research to teach. When dealing with communities, establish relationships, protocols, and encourage the establishment of an Aboriginal research committee.
- Seek after and find responsible Aboriginal representatives to oversee research issues and possibly ethics committees. Keep Aboriginal people at the front in activities, and where possible, provide employment (i.e., local surveyors). Use similar approaches that are currently used in retaining Aboriginal staff/faculty/researchers across the School.
- Build on the strengths rather than focus on the weaknesses, for this is the key to building relationships. NOSM has a unique opportunity to lobby for/on behalf of communities as part of the partnerships, while having communities connect NOSM with rural and remote communities. Actively re-define partnerships using ongoing community dialogue. Facilitate the organization of research activities by providing access to political and ethical place to take proposals. NOSM research is useful for local people in the community.

2. Protecting traditional knowledge

- NOSM can develop a strategic partnership with communities that protects traditional knowledge by expanding Elder involvement and reaching out to involve Elders and communities with the intent to increase their role in NOSM, social networking, and Elders on campus.
 - When approaching the community always go to the Elders first. Continue encouraging staff to be open minded and receptive to the Aboriginal ways. Utilize Elders groups. The prophecies suggest that natives and non-natives one day would ask the other for help.
 - Continue seeking to learn and understand the community’s world view, perspectives, and understandings. One is not inferior or superior, they are just different.
 - Continue to reach out and enhance opportunities for Aboriginal students in medical studies. Promote First Nation and Métis languages, ceremonies, and culture. Focus your time and energy on the youth.
 - The creation of NOSM’s Aboriginal Affairs Unit early on to communicate and identify health issues with Aboriginal researchers demonstrates sincerity and the desire to deal with communities.
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3. Trust is earned; building and gaining trust takes work.

- NOSM has demonstrated sincerity and a desire to deal with communities by putting teaching sites in Aboriginal communities, engaging people, taking science camps to the communities, and being aware of the community's needs.
 - NOSM needs to continue to actively develop relationships in research projects and identify research questions following proper protocol.
 - NOSM is taking the time necessary to identify and deal with issues. Do not rush. After each activity, a project debrief will assist in sustaining community approval. When this Gathering creates a plan it needs to be implemented.
 - Facilitate opportunities for local, national, and international Aboriginal people to work together.
 - Encourage research that is solution based. Current projects need to focus on First Nation and Métis priorities. Students that attend communities need to be ambassadors for the School and need to refrain from certain activities that may not be respectable within the community. If they do not they need to be taken out.
 - NOSM needs to assist with the development of community capacity. NOSM should make sure that everything is discussed, engage faculty, senior leadership, and the Board, and ensure all are trained in its policy and approach.
 - Continue to work with all stakeholders as NOSM is ahead of other schools. NOSM's articulated vision includes direct involvement of the community. The vision has to be shared and needs to be enhanced by continuing to work with communities to identify their role in research.
 - NOSM sees the benefit of working with communities and has taken steps to show others that they mean it. This means they need to continue being inclusive. Nishnawbe Aski Nation (NAN) representation on Board is advised.
 - NOSM is a new organization that can be different in form and shape. NOSM needs to share its philosophy that it is working on building relationships, and not as a result of legal requirements. The potential is for a strong, political/cultural group to influence the mandate of the School. NOSM has knowledgeable employees and has in place protocols that allow for open discussions.
 - The School is actively targeting Aboriginal and Francophone youth, as well as Aboriginal and Francophone staff. Share the successes.
 - Share examples of successful bio-prospecting initiatives. Set new standards by using those successes to influence and impact other institutions: internationally, Laurentian University, Lakehead University, the Heart and Stoke Foundation of Ontario, etc., and continue to seek partnerships to enhance relationships and collaborations.
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Tree Themes and Recommendations

- The data provided by participants was recorded by facilitators and note takers after statements were verified by the participant. After each session, the information was transcribed.
- A Fault Tree was constructed using the method described. The chart provides a structuring of relationships between statements that can be used to identify themes. These groupings of problem and strength statements become the other perspectives or themes to explore for further policy development and analysis.
- The original list had 521 items provided by participants. The information was organized into a chart that has 284 issues and 81 NOSM strengths. The issues chart was organized into five major areas or themes. These themes are broad statements of concern which identified the complexity of the problems as seen by the community.
- The Mission of this project is "...create and sustain working research partnerships and relationships with First Nation, Inuit, and Métis people in Northern Ontario." The undesired event would be the failure of the mission to "...create and sustain working research partnerships and relationships with First Nation, Inuit and Métis people in Northern Ontario because..."
- The five broader statements of concern identified on the chart are:
 1. The lack of communications.
 2. The lack of good relationships.
 3. The lack of community involvement.
 4. Studies have not helped the Aboriginal population better themselves; it has been their own initiative.
 5. Fear that NOSM approach is a continuation of Treaty agreements that took advantage of peoples' inability to speak English.
- The organization of the chart allows a description of the perspectives of the people interviewed. The following descriptions from the chart conceptualize the perceptions of the people interviewed around these five general themes. It is important to note that these issues may be real or perceived and because they are not rated, they are not prioritized.

Theme # 1 — The Lack of Communications

- The lack of clarity of documents shared with communities; papers are not always the best way to report back; translator may not be effective in other communities because of different dialects
 - No clear statement of what communities want from NOSM in the next five years
 - Little effort to report issue resolutions back to communities (i.e., annual Northern Health Research Conference) -- knowledge and information not shared through community health professionals, leadership etc.
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- Communication materials are not written in laymen terms
 - Obligation to consult cannot be discharged by "...bringing in a couple of people"
 - There is no communication strategy that reports to the communities
 - Communities not aware of NOSM specific research project benefits

Theme #2 — Lack of Good Relationships

- Government contributes to lack of trust by sending mixed messages: they bring in toxins, but fail to take them out of the environment people are forced to live in, and in turn people get sick
 - Historically there is mistrust and no openness; lack of healing process for past problems with relationships
 - Relationships take time and commitment to see positive results; lack of initiative to inform people/ communities of their rights with regards to research; compromising on both sides for betterment of all parties is not encouraged;
 - Bio prospecting should not be at the forefront of relationship building; lack of promotion of research using formal linkages to government departments
 - Limited effort promoting and strengthening traditional values in the community; Traditional and Christian views split communities and families; lack of awareness and/or acknowledgement of other cultural methods and healing practice; the lack of acknowledgement that our survival comes from the land and our relationship to Mother Earth
 - No partnership projects which share ownership and access to information; no acknowledgement of all those in community who participated and assisted; no clear statement regarding ownership of data; follow-up on results of the conference is required to build relationships
 - Ethnocentric cultural arrogance; the Western researcher goal is to dominate the environment using manipulation and studying object independently; people feel they are studied to "...death;" lack of continuity of people and activities – events, gatherings, workshops
 - Lack of resources; financial resources for communities' consultations not available.
 - Number of Aboriginal students accepted into MD program is low.
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Theme #3 — Lack of Community Involvement

- Limited active participation of communities, and individuals from the communities; a few community reps hired; not bringing any infrastructure or economy to community; bio-prospecting is not a high priority compared to health disparities First Nations people are facing today
- Failure to fully include communities in development of relationships; no resources to distribute information in communities; important people missing from these forums
- Limited advice on ethics from the communities
- Community members do not feel comfortable that they contribute to discourse
- Consultation needs to be undertaken with individual communities
- Cultural differences often lead to cultural clashes; an inadequate effort studying specifics of a community before going into the community; communities should not let NAHO and certain people speak for community and call it consultation; lumping into one, Aboriginal-First Nations, Inuit, and Métis decentralizes groups; demographics, diversity of communities, culture has been lost, due to the influences of historical events
- How research will be used is not shared; Western research will not share all information
- Resources decision to address health issues are political
- Researchers come into the environment rather than living in the environment - students shown lifestyle skills at communities

Theme #4 — Studies have not helped the Aboriginal populations better themselves; it has been their own initiative.

- Researchers not trusted by community members; no long term goals in partnership work between communities and researchers
 - No acknowledgement of First Nations who work to provide information to researchers
 - Researchers in bio-prospecting question knowledge of plant properties not knowing combinations; plants do the healing, not the healer
 - Other research models outside health are not being looked at
 - Asking First Nations communities to embrace bio-prospecting without acknowledging spirituality is unacceptable; the spirit of the plant of traditional medicine cannot be manufactured
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- Lack of recognition that traditional knowledge is valid
- Cultural ignorance and acknowledgement of Aboriginal world view; the lack of two-way relationship of cultural learning leading to cultural ignorance/arrogance
- Biases in education Western vs. Traditional
- Lack of acknowledgement that Elders' direction and Traditional Knowledge is actually a way of life
- Lack of thinking of ways to share wisdom so that it stays alive and well in our culture; elder dying with the knowledge; researcher and community objectives often do not match; the lack of native role models
- Abuse of Western medication is extreme (criminal activity), what will happen with traditional medicines that are protected now - will they be mass produced?

Theme #5 — Fear that NOSM's approach is a continuation of the Treaty Agreement that took advantage of the peoples' inability to speak English

- NOSM and government are going to sell community medicines; involvement with Ontario's Ministry of Natural Resources (MNR) is not an asset for NOSM's relationship with communities
 - Insufficient involvement of communities in NOSM and government policy development
 - Follow-up may not use information from Gathering for growth and improvements of NOSM
 - Historically NOSM presence in the communities meant that NOSM wanted something
 - NOSM takes credit where credit is NOT due, when person brings insight to NOSM, the School takes credit as an institution
 - Lack of policy by NOSM to be true to its word – policies with consequence
 - Lack of an Aboriginal curriculum
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Conclusion

The Strength Tree identifies a number of potential principles that can be used to guide the development of research activities. The issues chart identifies themes that should be considered to build relationships. Utilizing these principles and issues grouping in strategic planning will help achieve the mission "...creating and sustaining working research partnerships:"

A typical research and planning process for project development usually includes the following components: a statements of need, introduction of organization;

- vision statement;
- value and principle statements;
- mandate and authority;
- mission;
- the strategy analysis;
- environmental scan;
- the strategy formulation;
- long-term objectives;
- describing the implementation plan;
- the operational plan; and,
- individual work plans.

The written planning document includes a detailed description of each of these components. In this case, the written document will be a proposal for action.

This report provides environmental scan information. The information is a composite of the discussion; however, it is not in the form that will be useful for planning until a group reviews the material and validates the statements. This is a simple exercise where statements are judged on contributory position on the chart. In other words, is the statement clear and does it contribute to the next level? Once the validation is complete then the chart should be shared with participants to make sure it is also complete. As they review the chart, they will begin to identify other issues that can be added to the chart. Once the chart is reviewed then it should be rated. The process to do this is described in the Abacus Chapter in the book. Once it is rated, the group will have a strategic direction which will build on the strengths and remediate the weaknesses of the present relationship.

The Committee members recognize that in order to change present trends they will need to "...build on strengths of the NOSM people, community people and organizations" in their communities. Change will not be imposed, but embraced by members of the community if they participate. These strengths in strategic planning models are called principles and they guide relationship development. In all projects, we want to build on "our strengths and remediate our weaknesses" because if we inadvertently destroy our strengths, we have nothing to build on. The mandate for this project or the authority for action began from NOSM and the School's Aboriginal Reference Group (ARG); however, encouraging community involvement has resulted in some community ownership over this project. This is evident in the interest of getting source data used to build this report.

The central question for all project developers is:

- What activities will have the most potential to help this project achieve the mission?
- How do we get the most benefit for our expenditure of time and resources?

This process contributes to the planning process by identifying the priority issues and principles from the perspective of the stakeholders.

The Partnership Opportunities in Research Gathering opened the door to dialogue exchange and the start of creating a true and genuine relationship amongst NOSM, First Nation and Métis citizens. NOSM and other research institutions such as Cancer Care Ontario, Heart and Stroke Foundation of Ontario, and Institute for Evaluative Sciences have learned a great deal with this venue. There has been a brief introduction of the disparities with which First Nation and Métis citizens and communities have been dealing with for far too long.

NOSM has learned that, due to past improprieties with research and non-consultation, First Nation and Métis citizens have lost a lot of trust in dealing with governmental and research institutions. The need to build relationships and partnerships, and put genuine interest into capacity building, will garner the much needed trust to move forward with research initiatives. There has been more insight given to NOSM in dealing with First Nation and Métis citizens and communities such as: protocol and procedures, traditional knowledge, and values and principles, while the School listens and learns.

Although NOSM is growing in a positive and proper way with regards to First Nation and Métis citizens and communities, there is still much work to do. This will develop with further Gatherings as well as individual community consultations, which will in turn further develop the relationship between NOSM and First Nation and Métis citizens and communities. Primordial care needs to be given to foster trust and build further on the trust NOSM has gained to date.

To say that NOSM has learned much from the Gathering is an understatement. The many aspects of the Gathering were very positive to the dialogue exchange. As a beginning, this Gathering has helped a lot of people learn and has also provided a venue for people to voice their opinions, issues and concerns. Further events of this nature will look to move the dialogue forward and uncover more needs of First Nation and Métis citizens and communities. The intent of the Gathering was to bring forth First Nation and Métis issues and concerns with research, bring together cultures on a human level in a healthy environment, and to learn about one another. A beginning to dialogue exchange, the Partnership Opportunities in Research Gathering was successful in creating an opportunity for NOSM and First Nation and Métis communities to build capacity, partnerships, and relationships.

Appendix 1 — Gathering Topics and Participants Comments

Cultural Engagement, Pedagogy and Methodologies

To properly engage First Nations and Métis peoples and their respective cultures it would benefit researchers to learn and implement the communities' pedagogy and methodologies. The pedagogy of First Nation and Métis people have separate sets of values, principles and systems in comparison to that of mainstream populations. By uncovering the methodologies, researchers can engage the community at a higher level. This act alone would inspire First Nations and Métis peoples by showing due respect, which in turn opens a path to further partnerships.

- Looking for advice from the community on subjects such as culture, ethics and research initiatives improves the creation of partnership opportunities.
 - Having key informants from the community working for NOSM to get things done helps in creating trust and shows that NOSM is sincere about future relationships and partnerships.
 - NOSM has created strengths by placing undergraduate medical students in Aboriginal communities to learn lifestyle skills and community perspectives, most of which have been accomplished by the creation of an Aboriginal Affairs Unit.
 - Incorporating spiritual ceremonies and practices into the relationship is a good way to progress this partnership and build on trust.
 - Issues and concerns can be viewed from the community as: trust, past treatment, and cultural differences.
 - The imposition of colonialism.
 - Lack of healthy lifestyles.
 - Environmental toxins are a direct result of the exploitation of the land, medicines (natural resources), animals and water. The health of the people is equalled to the health of the environment.
 - Mistrust needs to be overcome and this can be done, in part, by the sharing of information.
 - People feel that researchers have studied the people to death; almost literally.
 - Historically there has been no openness - First Nation and Métis are more worried if they will see the results of any research studies which have been undertaken for some time now. Will there be a policy created for information sharing?
 - Is NOSM trying to take and utilize Traditional Knowledge?
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- Is there accommodation for profits or dollars to go to the communities?
 - Will there be concessions made for language and culture, as there is not very much understanding of terminology by medical people and researchers?
 - Will NOSM investigate multi-generational values and outlook on life? Then versus now?
 - Following protocol is important: Grand Chiefs, Regional Chiefs, and that it is the community that decides how things happen.
 - Language Barriers are an issue; for example there is no word for “cells” in the language or translating the word “cancer” creates barriers for people who speak only in the respective regional language.
 - There is a feeling from the communities that industrial progress creates illness, private sectors do not want to change old ways of conducting business, and that researchers are silenced by the private sector.
 - Future issues may grow if ownership knowledge is not determined.
 - There is a real lack of knowledge of higher priorities to quality of life and medical care in the community.
 - The people from the communities feel that there is a lack of respect, no open mindedness, and only just documenting problems - no true improvement of general health.
 - The people feel that there needs to be real incentives to participate in research initiatives and it must be known that it is different for each autonomous community and demographics.
 - Success would be seen as: an agreement with both sides not to use prescribed research methods, to ensure that there is no breakdown in communications with communities, and understand that there is a time - and timing - when things need to get done.
 - NOSM can educate other researchers on protocols for approaching communities for research, political correctness, treaty rights, and land issue resolutions.
 - Sensitivity training for researchers regarding being respectful in the community is required. Promote the learning of the culture before engaging research.
 - With utilizing and hiring community reps for research projects, implementing a holistic approach in terms of research, and advertising future career paths in research, a lifelong partnership can be created with communities.
 - Using the local languages for surveys and questionnaires will attract communities for research projects.
 - By participating in more community events, NOSM and researchers will be able to get to know First Nation and Métis peoples and build relationships.
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- Researchers can achieve community “buy-in” by having flexibility in the design of research projects and having a healthy respect for the balance of environment and health.
- Chiefs need to be involved in the decision making process of research projects, then we can benefit together.
- Do not use and abuse the people or participants but instead maintain the relationship.
- There needs to be research guidelines in place.
- NOSM and researchers should conduct research on how to work with First Nation and Métis people.
- Working together to create protocols in conjunction with host universities and not relying on legal requirement to consult would help build the relationship.
- Encourage the creation of a better climate for trust and partnership by fulfilling the duty to consult.
- Communities should have the right to say NO if there is something about the project which creates discomfort.
- Combine environment and health issues together.
- Policies should be principle based (i.e., respect), direction should come from interaction of NOSM and the community.
- Research studies cannot be too prescriptive; researchers should enter communities with a blank slate of “how to do it” and become involved as a part of the community.
- Jointly develop research objectives and methodologies.

Research Ethics and Protocol

First Nation and Métis citizens have been observing the land for millennia, and this must be seen as research. Learning and implementing these historical ethics will confer respect to First Nation and Métis peoples and their intellectual abilities, as well as respecting the land and environment. Understanding the protocol enshrined in an alternative world view will enhance researchers’ abilities to learn cultural protocol. First Nation and Métis peoples have many types of ethics and protocols which differ from that of the mainstream population. Respecting the customs of First Nation and Métis peoples with which researchers are involved expands the potential for new relationships and trust for new partnerships.

- Participants of the Gathering viewed NOSM as having much strength in regards to ethics by engaging the communities, opening the doors to dialogue exchange, and asking First Nation and Métis citizens how to build on the ethics of research.
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- This Gathering held by NOSM to seek input and guidance from First Nation and Métis communities has also done wonders for future partnerships.
 - NOSM strengths are also seen in the Elders Handbook and community engagement with rural/remote communities.
 - Retaining First Nation and Métis administration, faculty, and researchers within the School. Reaching out and being inclusive of elders and community citizens is viewed as positive progress.
 - To continue to participate and engage the communities in activities and events will only enhance relationships and networking.
 - NOSM is viewed as an organization that embraces culture, respecting and understanding of knowledge of culture in relation to enhance non-native knowledge induces the feeling that First Nation and Métis citizens are starting to be acknowledged.
 - NOSM is realizing that First Nation and Métis people's ethics are different and it is good that NOSM is trying to find out what those ethics are exactly.
 - NOSM has put in place proper protocol and the resulting dialogue with communities to identify their role in research has begun the positive process toward partnership. Going to the community to develop relationships and research questions is assisting with strengthening community relationships.
 - The Gathering participants brought forward certain documents which declare ownership such as the National Aboriginal Health Organization's Ownership, Control, Access and Possession (OCAP).

This document proves to be an integral document for all researchers and institutions to read and understand and is meant as follows:

The principles of Ownership, Control, Access and Possession (OCAP) enable self-determination over all research concerning First Nations. It offers a way for First Nations to make decisions regarding what research will be done, for what purpose information or data will be used, where the information will be physically stored and who will have access. This piece of work was sanctioned by the First Nations Information Governance Committee (FIRST NATIONIGC) and the First Nations Regional Longitudinal Health Survey (RHS). In First Nations' world view, the Regional Health Survey (RHS) and its processes and principles of OCAP "come from the people". Rooted in self-determination and inherent rights, within the context of data and information management, the cultural framework of this project was the foundation from which many tools, documents, theories and mechanisms emerged and developed.¹

1 http://www.naho.ca/firstnations/english/documents/FNC-OCAP_000.pdf

Issues exist with regards to ownership of knowledge. Past relationships have been strained because western ideology has not made concessions for First Nation and Métis knowledge and ownership.

- First Nation and Métis communities are not united on the research issue because one size does not fit all.
- NOSM and researchers must uncover, with autonomous community consultations, what differs from community to community in consideration of terminology, research awareness, and long-term commitment to communities, funding, and continuity of research projects.
- Researchers need to comprehend community diversity, dynamics, needs, and values.
- Some research studies will invariably have barriers and extracting data will be difficult as it is very personal; some individuals do not want the data commercialized or do not want it in print.
- Another barrier to research initiatives is the cultural arrogance or perception of our way (western ideology) is the best way, and this can lead to moving away or losing track of partnerships and the eventual loss of respect.
- As not all communities have ethics committees it is imperative to create an overarching ethics committee at the Provincial and Federal level.
- Participants recommended that political leaders from First Nation and Métis communities should support and address the protection of intellectual property with newly proposed legislation and the preparation of Memorandums of Understanding (MOU's) for knowledge sharing.
- There should be a venue to address possible complaints. Where do the people go to lodge complaints regarding a researcher in their community?
- NOSM should serve as brother between researchers and communities in order to ensure research is conducted in an ethical manner. There also exist misleading questions such as: Are researchers studying what they say they are studying?

The community needs to determine whether the research should be done and if it would provide capacity building in research projects. It is the responsibility of Canadian Institute for Health Research (CIHR) to address an Aboriginal Ethics Policy. The policy as an overview is as such:

The CIHR Guidelines for Health Research Involving Aboriginal People were recently presented to the CIHR Governing Council and have been unanimously approved. These guidelines offer the kind of safeguards that have long been missing for Aboriginal people participating in research. The ultimate result is the development of health research ethics guidelines that respond to the pressing needs of the Aboriginal community and the Aboriginal Capacity and Developmental Research Environment (ACADRE) centres, and help CIHR and its Institute of Aboriginal Peoples Health meet its fundamental obligation of accountability to Canadians. The resulting ethics guidelines for health research will contribute to the work of the Tri-Council National Consortium to revise section 6 of the Tri-Council

Policy Statement: Ethical Conduct for Research Involving Humans, which addresses research involving Aboriginal people.

In 2004, CIHR initiated a project to develop Aboriginal specific health research guidelines to ensure adequate protections for Aboriginal research participants. CIHR's Aboriginal Ethics Working Group (AEWG) was established in March 2004 as part of this broad national endeavour. The AEWG is representative of Aboriginal interests and disciplines necessary to provide advice and support for the development of ethics guidelines for health research. The AEWG met over the course of 2004 for in-depth analysis and deliberation of Aboriginal and research issues. A series of background papers were commissioned to inform the deliberations of the AEWG. The drafting of research ethics guidelines occurred over the winter of 2004 and early spring of 2005.²

- To ensure that ethical boundaries are not crossed collaborative research efforts and a committee to review research proposals must be reached for the community and researcher/research institutes benefit.
- The outline of expectations in research studies and the implementation of due diligence to protect both parties involved in research must be critical.
- Privacy issues must be explained to First Nation and Métis citizens and community leaders. It should be explained on what level the privacy policies work.

Issues and Barriers to Research

Many issues and barriers lay amid productive research initiatives. By understanding these issues and barriers, First Nation and Métis peoples and researchers can break down these obstructions and mark a new path for research initiatives. One example is the “studied-to-death” syndrome. There are those who feel as though they have been exploited for many generations without any of the data being shared. By removing these barriers and dealing with the issues, we can enhance today's methods and ideologies of research.

- NOSM is viewed in a positive light due to the ability that NOSM has to be formed and shaped, and includes in its goals opportunities such as this Gathering and the opening of dialogue.
- NOSM is viewed as a leader due to consulting and developing resource capacity to improve its relationship with the communities.
- NOSM must provide more venues such as this and declare up front at future events that the Gathering is indeed consultation and not dialogue.
- What happens to ongoing research when there is a change of leadership? If the same Chief and Council are not the same governing body after an election this may have a barrier on research.

- The lack of spiritual understanding and the insincerity of some people and researchers may hinder the relationship, and ultimately the research process.
 - Studies have not helped the First Nation and Métis populations in the past - what will change? Advancements in the communities has been a result of First Nation initiatives to better the community and social life.
 - Institutions such as NOSM must respect that researchers are encroaching on the community's life and reality and some communities find it hard to be disturbed.
 - Logistical issues exist which could be a barrier to research projects such as: isolation of communities, weather, time of year, travel costs, and redundancy of surveys.
 - Entering into communities and asking how it will work as opposed to working together, will be a barrier.
 - Participants asked questions such as where does the "researcher's rights" come from, and what is academic freedom? Ethics cannot be viewed solely as academic freedom.
 - There is a perception that researchers are given permission from someone else other than the community, and it is an imposition of academic rights on the community which disrespects protocol.
 - There needs to be further engagement of the communities through steering committees.
 - Working together on information sharing and assisting the First Nation and Métis communities to understand the values of research would remove some barriers to research.
 - The focus should be the building and solidifying of the relationship with which NOSM has begun, by educating the communities about research and its benefits.
 - With the declaration of joint ownership of knowledge and information, this relationship with NOSM can be fostered with new meaning.
 - If researchers addressed community issues before the actual research takes place, and acknowledged the respect and sacrament of medicines and traditional values, barriers would no longer exist.
 - The participants of the Gathering had strong feelings that there was a real need to protect First Nation and Métis ways of life and teachings.
 - The best way to remove barriers is for NOSM and the First Nation and Métis communities to collaborate on research initiatives.
 - The participants wanted to know what will come of the information that has been collected at the Gathering, and when will they see it.
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Bio-Propecting

This initiative is in no way meant to take away or utilize Traditional Knowledge, nor encroach on the sustainability of the environment. Many of today's most important therapeutic agents are derived from biological sources. The Boreal Bio-Propecting Initiative (BBI) is a collaborative research program which aims to derive new chemical compounds from natural sources. The School uses a random sampling approach to screening new chemicals by testing the biochemical make up of natural products. The program is a joint initiative between a number of Federal, Provincial, academic, industrial, and community groups. NOSM is seeking partnership with First Nation and Métis people's communities and their involvement in research programs.

- First Nation and Métis people are more concerned with the health of citizens and communities and believe these issues should be dealt with before medicines and Traditional Knowledge is discussed. It is believed by the people that medicines cannot be sold.
- The fear of obstructing the sustainability of the forest to collect plants also creates worry.
- There is the concern that Traditional Knowledge will be taken, like the land, the culture and the language. Traditional Knowledge is the final frontier which has not been altered or taken and the First Nation and Métis people are holding onto the idea that Traditional Knowledge must be protected.
- The word itself, Bio-Propecting has a very negative connotation, as it derives from the ideology of Bio Piracy which has been affecting indigenous peoples throughout the world.
- Intellectual Property Rights (IP) needs to be protected and appropriated to First Nation, Inuit and Métis peoples.

The United Nations has recognized the rights of Indigenous peoples and Intellectual Property Rights and states, "The Declaration does not represent solely the viewpoint of the United Nations, nor does it represent solely the viewpoint of the Indigenous Peoples. It is a Declaration which combines our views and interests and which sets the framework for the future. It is a tool for peace and justice, based upon mutual recognition and mutual respect."³ In particular Article 31 states:

1. "Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions."

2. "States, in consultation and cooperation with indigenous peoples, shall take effective measures to facilitate the exercise and ensure the implementation of this right."⁴

Another document which was distributed at the Gathering was the Chiefs of Ontario's resolution on Traditional Knowledge which specifically touches on Traditional Knowledge. Ensuring a solid partnership would mean that NOSM would respect any resolution from First Nation and Métis citizens and its political organization for self-appropriation and self-determination. The resolution is as follows:

Whereas First Nations sovereignty and self-government flow from the Creator;

Whereas the First Nations in Ontario have the right to self-determination and, in exercising that right, must be recognized as the exclusive owners of their Traditional Knowledge;

Whereas the First Nations in Ontario insist that the first beneficiaries of Traditional Knowledge must be the First Nations;

Whereas Canada, Ontario and Research Institutions must recognize that First Nations are the guardians of their knowledge and have the right to protect and control dissemination of that knowledge;

Whereas the flora and fauna are inextricably bound to the territories of the First Nation communities and governments, and research institutions and industry must recognize First Nation guardianship;

Whereas any commercialization of any traditional flora and fauna, including medicines of the Ontario First Nations, must be managed by the communities that have inherited such knowledge;⁵

Community Engagement for Cancer Care Research

Cancer Care Ontario is leading a partnership with other agencies, including the Ontario Institute for Cancer Research and the Canadian Partnership Against Cancer, for the upcoming launch of the Ontario Health Study. This is an innovative, province-wide research initiative that aims to improve our understanding of the risk factors that lead to cancer, heart disease and other important chronic diseases. This knowledge will help to develop new and better ways of predicting and preventing disease. The study will follow 150,000 volunteers from across Ontario, aged 35-69, for more than a decade, and will involve the collection of information about individuals, their environment and their communities. The Study also aims to encompass the cultural, ethnic, and geographic diversity of the province.

While the Study will be conducted across all of Ontario, NOSM is working closely with its partners to enable and ensure the engagement of people of rural and urban Northern Ontario, with special focus on First Nations, Inuit, and Métis peoples and communities. It is essential that all prospective research partners are fully aware of the realities involved with researching in First Nations, Inuit, and Métis communities. Any research projects relating to First Nation, Inuit, and Métis health must be initiated by First Nation, Inuit, and Métis people communities.

4 <http://iwgia.synkron.com/graphics/Synkron-Library/Documents/InternationalProcesses/DraftDeclaration/07-09-13Resolution-textDeclaration.pdf> (p.4)

5 Chiefs of Ontario Resolution, 34th All Ontario Chiefs Conference June 3-5, 2008 Red Rock Indian Band

There were many points of discussion and dialogue regarding the new cohort study, as well as other health research and medical services:

- NOSM is on the right track by bringing in First Nation and Métis workers in community placement and research.
 - Cancer research must be useful to First Nation and Métis citizens and communities; it must enhance the health of the people.
 - The future generations must be on the forefront of the initiatives, knowing that the decisions we make today are going to invariably affect all future generations. Engaging the youth will be the beginning to engaging the future generations.
 - Issues which may become barriers in cancer research are lack of long-term funding and apathy for research due to lack of information sharing in the past, lack of follow up, and ownership of information.
 - Damage to the environment is invariably affecting the people.
 - David Mathews, who has passed on now, participated with a national study and was deemed the most polluted man in Canada, so it raises a point that life in the north or remote areas are being affected by environmental factors.
 - In some way there must be a simultaneous research project which looks into the pollution of the lands and correlates that to the high rates of cancer disease in and around the areas of industry.
 - Clear cutting and mining create pollutants which get into the water, therefore affecting the system, which in turn affect the deer, moose and other wildlife and plants which are then consumed by the people in the affected areas. The Gathering participants had questions for the government:
 - Will the government admit that the harms committed by industries which they allowed to harvest the forest and mine the minerals in the land is the greater cause?
 - Will they take responsibility?
 - Could they ever be humble enough to admit fault?
 - Could these environmental issues be dealt with and addressed as a priority?
 - There is a need to develop awareness and education about cancer, and this will also help the formulation of Cancer research.
 - Education for preventative health measures should be put in place.
 - Community information sessions about questionnaires should be used to deliver more information on the methods of studies. Consultation can bring awareness to researchers with regards to useful First Nation and Métis community information.
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- Materials and presentations should be made available in a format conducive to understanding at the community level.
- First Nation and Métis citizens could help Cancer Care Ontario and other research institutions communicate to the people.
- Be consistent with who is sent to the communities, do not allow new people who have not dealt with the communities; be honest, and most of all just listen. This could be done by employing people from the communities to deliver information.
- The Cancer cohort study must convey that this is for the benefit of future generations. Cancer research must have a clear purpose of benefits communicated in order to set patients and/or participants minds at ease with treatment and care.
- Ensure that there is care for the spirit as much as for the physical body.

Mutual Benefits (MB)

Mutual Benefits must be viewed on multilateral levels and must incorporate new ideologies. Benefits, such as accumulative wealth arising from collaboration in research initiatives, would solely be utilized at First Nation and Métis people's discretion. With this collaboration comes the mutual benefit of sustaining the environment for all future generations to enjoy. Integral to the cumulative benefits is the acknowledgement of Traditional Knowledge, as well as the possibility of amalgamating The People's ideologies with that of Western ideologies.

- NOSM utilizing First Nation and Métis workers would be a mutual benefit as it creates role models for First Nation and Métis youth to aspire to in the future.
 - If NOSM were to use First Nation and Métis workers, there would be a streamline into the community and additionally give NOSM a First Nation and Métis face.
 - Mutual benefits should be discussed more on an individual community to community basis, as not all communities are looking for the same benefit.
 - On a general note there is a definite need for community infrastructure and economic gain. Employment would help communities climb out of poverty and alleviate economic inequalities.
 - The most influential community benefit would be the enhancement of societal health within the communities.
 - Creating partnerships and allotting due respect to First Nation and Métis citizens, culture and language is also viewed as a large benefit.
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Partnership
Opportunities
in Research

GATHERING



Northern Ontario
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École de médecine
du Nord de l'Ontario

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Da Vinci Centre
340 South Waterloo Street
Thunder Bay, Ontario
November 4-5-6, 2008

Program

Welcome to Partnership Opportunities in Research



Creating and sustaining working research partnerships and relationships within Northern Ontario, including First Nation, Inuit and Métis peoples, is of primary importance to researchers. We are confident in a research process which respects protocol and all information sharing which may enhance both

researchers and research initiatives. We have an excellent opportunity to travel forward with research endeavours in a genuine manner and with a respectable commitment for all of Northern Ontario.

NOSM understands that there is a fine line between sharing information and exploiting Traditional Knowledge. We hope this gathering can assist all involved with truly understanding this boundary. We would expect that one rule of engagement is adhered to; that is to respect one another. As this gathering will have diverse attendance, we must consider that all discussions are to be conducted with dignity for all.

Research at NOSM is reflective of the School's mandate which is to be socially accountable to the diverse cultures of Northern Ontario. The School's unique research program targets areas that have a direct relevance to Northern populations. The key theme of NOSM research is tackling the questions of importance to improving the health of the people and communities of the North.

We would like to sincerely thank all who are participating in the Partnership Opportunities In Research and those on the organizing committee that have dedicated many hours to ensure that each of us enjoys an exceptional conference over the next three days. Please enjoy the conference and the networking opportunities that it has to offer!

Sincerely,

Dr. ROGER STRASSER
NOSM Founding Dean

Dr. GREG ROSS
NOSM Associate Dean,
Research



Northern Ontario
School of Medicine

École de médecine
du Nord de l'Ontario

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Introduction

Research initiatives in Northern Ontario potentially include a broad range of topics, including studies into cancer and lifestyle, remote geophysical analysis to determine mineral potential, sampling of boreal plants for medicinal properties, or the impact of internet-based technologies on remote First Nations. Fundamental principles for all types of research have been identified, but have yet to be universally understood, accepted or implemented. We need to delve deeper into First Nation, Inuit and Métis, herein known as *The People*, issues and concerns pertaining to research partnerships.

The Northern Ontario School of Medicine (NOSM) has a social accountability mandate which includes a commitment to research focused on improving the health of people and communities in Northern Ontario. NOSM medical students begin learning about *The People* in their first year, during the course Module 106, which includes 32 northern host communities. The communities invite students to stay for a month to learn *The People's* methodologies.

By definition, the NOSM Research Unit is focused on generating new knowledge and are somewhat aware of *The Peoples* needs. We are invited at times to participate in research activities (initiated by funding partners, other academic organizations, non-governmental sponsors, and others) and work to ensure that these activities are relevant and appropriate when *The People's* communities are involved.

NOSM has a duty as a medical school in Northern Ontario to work collaboratively as a partner with communities to increase knowledge and awareness so that research issues affecting *The Peoples* communities or their traditional territories are determined by the communities. As a result, NOSM intends to use a partnership/collaborative approach early on to engage with communities.

Principal Objectives for A Pan-Northern Gathering “Partnership Opportunities in Research”

- The primary mission of this gathering should be for all participants to engage in the exchange of dialogue;
- Increase awareness of research types/topics, potential benefits, advantages and disadvantages, research ethics as presently understood, as well as best practices for Aboriginal peoples responding to or participating in research initiatives;
- Increase awareness of medical research at NOSM;
- Collaboratively discuss and determine acceptable framework of how NOSM can serve as a partner and assist Aboriginal communities in the design and development, and benefit-sharing and implementation of research projects;
- Discuss ways to increase awareness of partnership opportunities in research for communities;
- Present specific research opportunities for consideration, including existing projects, as well as new initiatives being proposed;
- Researchers need to learn from Aboriginal people how best to conduct research involving Aboriginal communities. Hopefully, partnerships will be created with Aboriginal communities and organizations for suitable research initiatives.

Desired Key Outcomes of Gathering

- New partnerships which provide benefits to participating communities.
 - Enhanced existing partnerships (Laurentian University, Lakehead University, Métis Nation of Ontario, Nishnawbe-Aski Nation, Ontario Native Women’s Association, Oshki-Pimache-O-Win, Union of Ontario Indians, Treaty 3, Independent First Nations).
 - Better recognition and understanding by all parties of the meaning of research and research terms.
 - Better understanding of perceived benefits of research and how benefits can be shared.
 - Increased understanding of the risks and negative aspects of research.
 - A series of events which will contribute to an ongoing process.
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Agenda

ARRIVAL - November 3, 2008		
3:00 p.m. to 7:00 p.m.	Gathering Sign-In Travelodge Airline - Lobby Landmark Inn - Fireside Room	
AGENDA		
DAY 1 - November 4, 2008 - Da Vinci Centre, Michelangelo Room		
7:30 a.m.	Breakfast / Gathering Sign-In	
8:30 a.m.	Opening Prayer	Josias Fiddler
	Welcoming/Opening Remarks	Greg Ross
	Gathering Opening Moderator	Chris LaFontaine
9:00 a.m.	Topic 1: Cultural Engagement, Pedagogy and Methodologies	Goyce Kakegamic Ernie Kwandibens
10:30 a.m.	Health Break	
10:45 a.m.	Return to Topic 1	
12:00 p.m.	Lunch - Address from the Founding Dean	Roger Strasser
1:00 p.m.	Topic 2: Research Ethics and Etiquette	Marion Maar Ron Wakegijig
2:30 p.m.	Health Break	
2:45 p.m.	Return to Topic 2	
4:00 p.m.	Closing Prayer and Adjournment for Day 1	Josias Fiddler
5:00 p.m.	Dinner	

DAY 2 - November 5, 2008 - Da Vinci Centre, Michelangelo Room		
7:30 a.m.	Breakfast / Registration	
8:30 a.m.	Opening Prayer	Josias Fiddler
9:00 a.m.	Topic 3: Issues and Barriers	Lorrilee McGregor Peggy Smith
10:30 a.m.	Health Break	
10:45 a.m.	Return to Topic 3	
12:00 p.m.	Lunch	
1:00 p.m.	Topic 4: Bio-Prospecting	Greg Ross George Duckworth
2:30 p.m.	Health Break	
2:45 p.m.	Return to Topic 4	
4:00 p.m.	Closing Prayer and Adjournment for Day	Josias Fiddler
5:00 p.m.	Dinner	
5:30 p.m.	Entertainment: <i>Comedian Don Burnstick</i>	
Day 3 - November 6, 2008 - Da Vinci Centre, Michelangelo Room		
7:30 a.m.	Breakfast	
8:30 a.m.	Opening Prayer	Josias Fiddler
9:00 a.m.	Topic 5: Community Engagement for Cancer Care Research	John McLaughlin Nancy Lightfoot
10:30 a.m.	Health Break	
10:45 a.m.	Return to Topic 5	
12:00 p.m.	Lunch	
1:00 p.m.	Topic 6: Mutual Benefits	Bev Sabourin David Henry
2:30 p.m.	Health Break	
2:45 p.m.	Return to Topic 6	
4:00 p.m.	Closing Remarks Closing Prayer and Adjournment of Gathering	Roger Strasser Josias Fiddler



Goyce Kakegamic

A retired Deputy Grand Chief of the Nishnawbe Aski Nation, Goyce Kakegamic is one of NOSM's formative visionaries. Born in Keewaywin First Nation and raised traditionally on the land, Mr. Kakegamic is a talented artist whose work can be viewed in art galleries and private collections around the world.



Ernie Kwandibens

(Migisi Keewayunh,
Loon Clan)

Mr. Kwandibens is a Traditional Elder and is an Advisor to Northern Ontario School of Medicine. He has been instructed to conduct Traditional Ceremonies, as well as Cultural Teachings in healing practices.

Cultural Engagement, Pedagogy and Methodologies

To properly engage *The People's* and their respective cultures it would benefit researchers to learn and implement the communities' pedagogy and methodologies. The pedagogy of *The People's* has separate sets of values, principles and systems in comparison to that of mainstream population. By uncovering the methodologies, researchers can engage the community at a higher level. This act alone would inspire *The People's* by simply showing due respect, which in turn opens a path to further partnerships.



Marion Maar

Dr. Marion Maar is a medical anthropologist and assistant professor at the Northern Ontario School of Medicine. Her teaching and research focus is in the area of culturally competent care, e-health and Aboriginal community health issues.



Ron Wakegijig

(Shawani-biness Bear Clan)

Mr. Wakegijig was instrumental in organizing the first Medicine Persons Gathering/ Healing Conference at Dreamer's Rock, Whitefish River First Nation. He has been instructed as a Pipe Carrier and Ceremonial Leader by the Plains Cree Elders from Saskatchewan. He routinely lectures at Universities throughout Canada.

He lectures or presents on various topics including the collaborative use of Traditional and Western Medicine and continues to participate as Guest Presenter in various Medical School events, including the Summer Science camps

Research Ethics and Protocol

The People's have been observing the land for millennia and this must be seen as research. Learning and implementing these historical ethics will confer respect to *The People's* and their intellectual abilities, as well as respecting the land and environment. Understanding the protocol enshrined in an alternative world view will enhance researchers' abilities to learn cultural protocol. *The People's* have many types of ethics and protocols which differ from that of the mainstream population. Respecting the customs of *The People's* with which researchers are involved expands the potential for new relationships and trust for new partnerships.



Lorrilee MCGregor

Lorrilee McGregor, M.A., is an Anishinaabe-kwe from Whitefish River First Nation, where she lives and works. Ms. McGregor earned an undergraduate degree from the University of Toronto, focusing her studies on environment and resource management. Her Master of Arts degree is in Environment & Community from Antioch University in Seattle, Washington where she focused on Indigenous Knowledge.



Peggy Smith

Peggy Smith is mixed blood, with Cree ancestry from the James Bay area in northern Ontario. She is an Assistant Professor in the Faculty of Forestry at Lakehead University and a member of the LU Research Ethics Committee and Aboriginal Management Council which are jointly working on an Aboriginal Research Ethics Protocol for LU researchers.

Issues and Barriers to Research

Many issues and barriers lay amid productive research initiatives. By understanding these issues and barriers, *The People's* and researchers can break down these obstructions and mark a new path for research initiatives. One example is the "studied-to-death" syndrome. There are those who feel as though they have been exploited for many generations without any of the data being shared. By removing these barriers and dealing with the issues, we can enhance today's methods and ideologies of research.



Greg Ross

Dr. Greg Ross is the Associate Dean, Research, for the Northern Ontario School of Medicine. His research is focussed on Health and the Environment, with a particular interest on degenerative diseases. He has an active drug discovery program.



George Duckworth

George Duckworth is employed as a policy officer with the Aboriginal Relations branch of the Ministry of Natural Resources. In this capacity, he has been developing a strategy for the MNR that addresses the consideration of Aboriginal Traditional Knowledge in natural resource based decision making.

Bio-Prospecting

This initiative is in no way meant to take away or utilize Traditional Knowledge, nor encroach on the sustainability of the environment. Many of today's most important therapeutic agents are derived from biological sources. The Boreal Bio-prospecting Initiative (BBI) is a collaborative research program which aims to derive new chemical compounds from natural sources. The School uses a random sampling approach to screening new chemicals by testing the biochemical make up of natural products. The program is a joint initiative between a number of Federal, Provincial, academic, industrial and community groups. NOSM is seeking partnership with *the People's* communities and involvement in research programs.



Nancy Lightfoot

Dr. Nancy Lightfoot is the Director of the School of Rural and Northern Health at Laurentian University and is an epidemiologist trained in community health who is interested in: a) cancer surveillance, aetiology, survival, and program evaluation, b) Aboriginal health, c) occupational health related to resource industries, d) environmental health.



John McLaughlin

Dr. John McLaughlin, Vice President of Population Studies and Surveillance at Cancer Care Ontario is Scientific Director of the Ontario Population Cohort Study.

Community Engagement for Cancer Care Research

Cancer Care Ontario is leading a partnership with other agencies, including the Ontario Institute for Cancer Research, the Heart and Stroke Foundation of Ontario and the Canadian Partnership Against Cancer, for the upcoming launch of the Ontario Population Cohort Study. This is an innovative, province-wide research initiative that aims to improve our understanding of the risk factors that lead to cancer, heart disease and other important chronic diseases. This knowledge will help to develop new and better ways of predicting and preventing disease. The study will follow 150,000 volunteers from across Ontario, aged 35-69, for more than a decade, and will involve the collection of information about individuals, their environment and their communities. The Study also aims to encompass the cultural, ethnic and geographic diversity of the province. While the Study will be conducted across all of Ontario, NOSM is working closely with its partners to enable and ensure the engagement of people of rural and urban Northern Ontario, with special focus on First Nations, Inuit and Métis peoples and communities. It is essential that all prospective research partners are fully aware of the realities involved with researching in First Nations, Inuit and Métis communities. Any research projects relating to First Nation, Inuit and Métis health must be initiated by First Nation, Inuit and Métis people communities.





David Henry

Professor David Henry is a physician and clinical pharmacologist. He is an authority on cost effectiveness in drug selection processes. He was a member of the Australian Pharmaceutical Benefits Advisory Committee (PBAC) and Chair of the Economics Sub-committee of PBAC 1993-2001. Professor Henry was instrumental in establishing the Pharmaceutical Benefits Scheme (PBS) evaluation process now in use. Professor Henry is currently the President and CEO, of the Institute for Clinical Evaluative Sciences (ICES) in Toronto; Professor in the Department of Medicine at the University of Toronto, and an Adjunct Professor at the University of Newcastle, Australia.



Bev Sabourin

Beverly Anne Sabourin is a First Nations Ojibwe from northwestern Ontario with extensive professional and volunteer experience in aboriginal communities and cross-cultural environments across Canada.

Mutual Benefits (MB)

Mutual Benefits must be viewed on multilateral levels and must incorporate new ideologies. Benefits, such as accumulative wealth, arising from collaboration in research initiatives, would solely be utilized at the people's discretion. With this collaboration comes the mutual benefit of sustaining the environment for all future generations to enjoy. Integral to the cumulative benefits is the acknowledgement of Traditional Knowledge, as well as the possibility of amalgamating *The People's* ideologies with that of Western ideologies.



Thank You

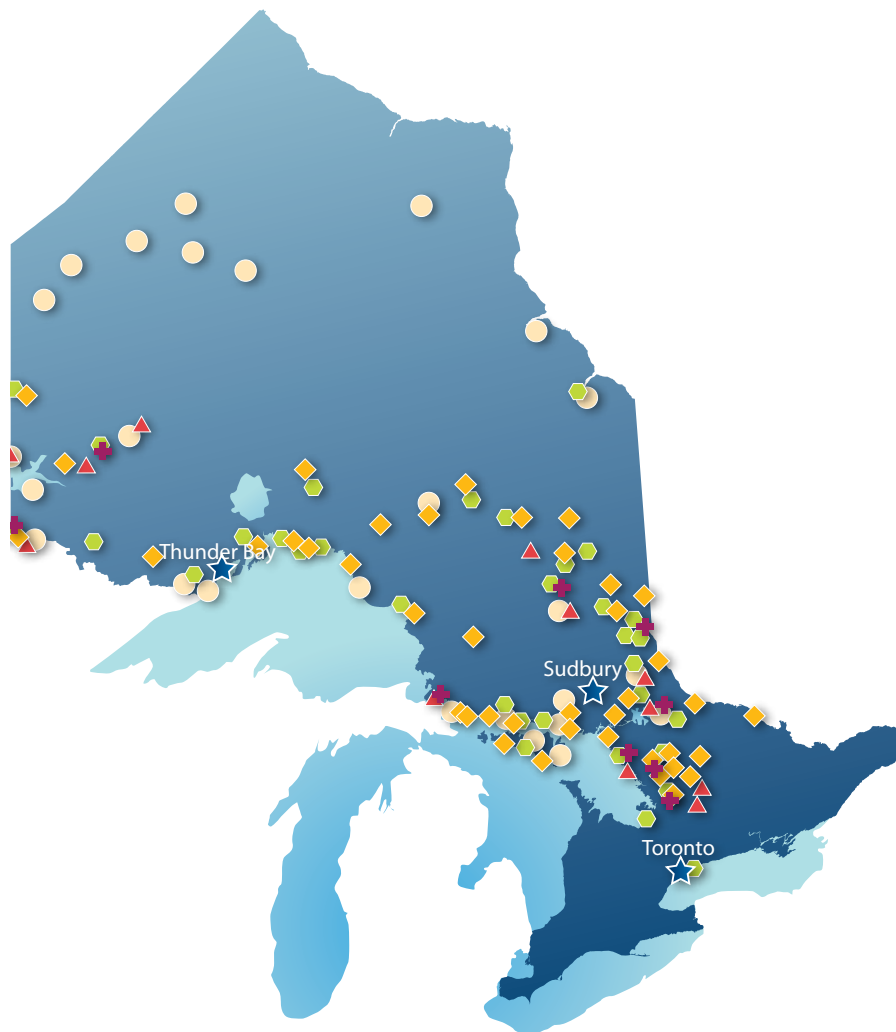
A sincere thank you to all who contributed to making this gathering a reality. Your participation and thoughtful input is the first step on the road to an ongoing process of sharing knowledge in research endeavours in the north. Participants at the Gathering were from the following communities:

Attawapiskat
Balmertown
Big Trout Lake
Birch Island
Cat Lake
Cornwall
Cutler
Fort Albany
Fort Hope
Garden River
Garden Village

Goulais River
Kenora
Kingfisher Lake
Little Current
London
M'Chigeeng
Massey
Matheson
Moose Factory
Muskrat Dam
Naughton

North Bay
Ohsweken
Ottawa
Peterborough
Rama
Red Lake
Sandy Lake
Sault Ste. Marie
Sioux Lookout
Sioux Narrows
Sturgeon Falls

Sudbury
Summer Beaver
Thunder Bay
Toronto
Wallaceburg
Weagamow Lake
Whitedog
Wikwemikong





Northern Ontario
School of Medicine

École de médecine
du Nord de l'Ontario

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