



JUNE 22 TO 24, 2016

Hosted in Sault Ste. Marie, Ontario on the Traditional Lands of the Anishinabek Peoples of Baawaating.

The Northern Ontario School of Medicine's Indigenous Affairs Unit and Office of Research wish to thank **Sue Chiblow of Ogamauh annag Advising Services from Garden River First Nation** for participating in the Indigenous Research Gathering, taking notes, reviewing the discussions, and compiling the content in this report.

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ACKNOWLEDGEMENTS

First and foremost, it is important to acknowledge the Elders, the community leaders, the pipe carriers, the fire keepers, the drummers, and the delegates for making this Gathering a success.

It is also important to acknowledge the planning committee, 1 the keynote speakers, and the presenters for sharing their knowledge and contributing to the purpose and objectives of the Gathering.

The Planning Committee would like to specifically thank Chief Dean Sayers, Batchewana First Nation; Chief Paul Syrette, Garden River First Nation; and, Dr. Craig Chamberlin, Algoma University for their help and guidance.

Lastly, Northern Ontario School of Medicine (NOSM) requires a special acknowledgement as they provided a safe space for this Gathering to take place. NOSM has contributed to the well-being of Indigenous Peoples and truly understands the concepts of collaboration as they continue to break barriers for Indigenous Peoples by building and maintaining a healthy relationship with its partners including the Indigenous Peoples of Northern Ontario.



¹ The members of the planning committee included Dr. Sheila Cote-Meek, Associate Vice President, Indigenous Programs, Laurentian University; Erica Perkins, Health and Social Services Director, Bilgtigong Nishnaabeg; Tina Armstrong, Director, Indigenous Affairs, NOSM; Dr. Penny Moody-Corbett, Senior Associate Dean and Associate Dean, Research, NOSM; and, Dr. Sheldon Tobe, Heart and Stroke Foundation NOSM Chair in Indigenous and Rural Health.

MESSAGE FROM NOSM'S ASSOCIATE DEAN, RESEARCH

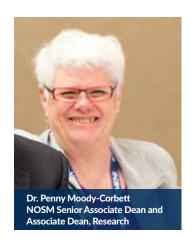
The Northern Ontario School of Medicine (NOSM) was proud to host the Indigenous Research Gathering 2016 on the Traditional Territory of the Anishinabek Peoples of Baawaating and where the Métis have lived for generations. It was amazing to see over 100 delegates, speakers, and community members come together to discuss research and research practices and talk about building research programs in a respectful way—that will have a positive impact on the health of Indigenous communities. We are grateful to have the opportunity to work in the community and on this important Traditional Territory.

NOSM has hosted a number of Gatherings, however this was only the second Gathering that was held specifically to talk about research. The Indigenous Research Gathering 2016 was part of a week of research and educational activities hosted by NOSM and provided an opportunity for attendees to share time and thoughts with other researchers from around the world and highlight some of the research being conducted by Indigenous researchers in Northern Ontario. The Gathering featured presentations and talks by Indigenous researchers, which focused on research having a positive impact on communities and the practical approaches that have facilitated this research. We heard the importance of research being led from the community and about the importance of education, language, Traditional Knowledge, and ceremony all components of successful research programs.

The Gathering was also an opportunity to reflect on the past and hardships related to both research and educational practices. Algoma University hosted an evening at the former Shingwauk Residential School, with a traditional meal and presentations by Chiefs Paul Syrette and Dean Sayers, Métis Councilor Ernie Gatien, and Health Canada Executive Director, Robin Buckland. Chancellor Dr. Shirley Horn gave a keynote address in which she talked about her personal experiences. The Research Gathering also followed closely on the release of the Truth and Reconciliation Commission Report and we were pleased to have Commissioner Dr. Marie Wilson share her thoughts on the report and encourage us to address the Calls to Action from the Report.

As the Associate Dean of Research, I was particularly pleased to plan for and participate in the Indigenous Research Gathering. Planning for the Gathering was as amazing an activity as the event itself. Over the months leading to the Gathering, Tina Armstrong, NOSM's Director of Indigenous Affairs, and I met regularly with the Indigenous Reference Group and the planning committee. We took a number of trips to Sault Ste. Marie and met with members of Garden River and Batchewana First Nations and Algoma University to prepare both a cultural and academic event for the delegates and invitees to the Gathering. For me this was an opportunity to listen and learn from the many people and communities I met and to understand the importance of ownership, respect, and trust. I was honoured to be part of this event and look forward to working with communities to support their research programs and strengthen and improve health outcomes that will have a meaningful and positive impact.

We would like to thank the organizing committee, speakers, and delegates for their contributions to the Indigenous Research Gathering 2016. The lessons learned from the Gathering will be invaluable as NOSM continues to strive towards its vision of Innovative education and research for a healthy North.



EXECUTIVE SUMMARY

Research has often been conducted on Indigenous Peoples and communities with little or no apparent return to the community or people involved causing negative experiences with researchers (Dr. Marion Maar and Ms. Lorrilee McGregor's presentation). Typically, researchers develop their research focus and contact communities to do the research with limited knowledge on Indigenous protocols, the community, and its Peoples or intellectual property rights. This type of approach has not benefited the Peoples or the communities as the dissertations provide limited recommendations or an action plan to implement the recommendations. These types of short term relationships have caused apprehension by the Indigenous Peoples and communities to become involved in research.

More recently, transformative change has begun as communities take control of the research and work in a true collaborative fashion with the researchers to accomplish mutually set goals. The Northern Ontario School of Medicine (NOSM) has recognized this needed shift leveraging on opportunities by providing a space for continued dialogue on relationship building between researchers and Indigenous Peoples.

The Indigenous Research Gathering was held in Sault Ste. Marie, Ontario on June 22 to 24, 2016 in the territory of the Anishinabek (Ojibway) Peoples of Baawaating which includes both Garden River and Batchewana First Nation and land on which the Métis have resided for generations. The purpose of the Gathering was to gather Indigenous Peoples to review the past and current research practices and begin to develop guiding principles that build inclusive and culturally respectful research programs that can have an impact on health in Indigenous communities.

In keeping with Anishinabek traditions, the Indigenous Research Gathering began with ceremonies specific to the Anishinabek of Baawaating including a Sunrise Ceremony and Opening Prayers. The Gathering provided keynote addresses by Chancellor Shirley Horn, Dr. Cynthia Wesley-Esquimaux, and Commissioner Dr. Marie Wilson. Presentations provided delegates with information on research that is having an impact on Indigenous Peoples, in communities and changes to policy. Throughout the presentations, three key themes formed: relationship building, funding, and culture and language.

Researchers—both from communities and working with communities—described their research and their approach to research that has resulted in meaningful outcomes for the communities. Although each presentation was unique, a consistent and resounding message from all the speakers was building relationships and establishing trust.

Delegates were afforded the opportunity to gather in groups focusing on four questions to assist NOSM with feedback on lessons learned, a path forward, priorities, and guiding protocols and principles. Delegates shared lessons learned specific to their experiences with researchers and also from the presentations. Common and key themes from the delegates included: community control; inclusivity, transparency and accountability; respect, relationships and reciprocity; and, the Seven Grandfather Teachings.

Communities and researchers need education to better understand each other, to understand research questions of common interest, and how research can benefit both. Delegates mentioned several different protocols such as OCAP (Ownership, Control, Access, and Possession) for best practices in research and expressed the need to have tools that will assist them in working with researchers. Two examples of models developed to assist Indigenous Peoples and partners such as researchers are the Chiefs of Ontario Environmental Assessment Toolkit and the First Nations Environmental Health Innovative Network.





BACKGROUND

Indigenous Peoples are often the first to feel the effects of toxic environments that are harmful to human health and community cohesion. Many institutions have been structured and operationalized in ways to favour certain populations causing long term systematic problems for Indigenous Peoples and their communities. More recently a shift has begun to emerge where institutions are inquiring how to form meaningful relationships and re-establish historical alliances. This shift is utilizing research-based evidence to inform policy development, including research based on Traditional Knowledge.²

Typically, researchers develop their research focus and contact communities to do the research with limited knowledge on Indigenous protocols, on the community and its Peoples or intellectual property rights. This type of approach has not benefited the Peoples or the communities as the dissertations provide limited recommendations or an action plan to implement the recommendations. These types of short term relationships have caused apprehension by the Indigenous Peoples and communities to become involved in research.

Indigenous Peoples and communities have repeatedly stated the need to be the lead working in true collaboration with researchers in order to address their concerns. They have indicated the need for long term relationships that would benefit both the researchers and the Peoples. Indigenous Peoples and communities have had numerous health studies or research done on them and are left with extensive reports that are difficult to interpret and/or implement causing frustrations within the community, with leadership, and with researchers.

In September 2005, NOSM welcomed its first medical students becoming the first new medical school in Canada in over 30 years, and only the second new medical school in North America during a similar period. It is the first Canadian medical school hosted by two universities, over 1,000 kilometres apart and serves as the faculty of medicine for Lakehead University in Thunder Bay and Laurentian University in Sudbury. NOSM prides itself on the development and deliverance of a distinctive model of distributed, community-engaged, and socially accountable, medical education, with all of Northern Ontario serving as the campus of the School.

In 2008, NOSM held a Partnership Opportunities in Research Gathering, which was organized to provide a forum for the discussion of Indigenous 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 was an unprecedented occasion that brought together Indigenous communities, research organizations, and the School. The three-day forum presented a platform that engaged stakeholders in meaningful dialogue over research strategies which have adversely affected the well-being of Indigenous Peoples and communities. The goal of the Gathering was "...to create and sustain working research partnerships within Northern Ontario."

It is not our job, no matter who we are outside of the confines of the community itself, to fix the Indigenous community. It is our job to stop perpetuating the damages we have wrought through our constant interference, and take action only when required, asked, and directed.

If we are not working together, we are not working well."

Dr. Cynthia Wesley-Esquimaux

[&]quot;We have been helped almost to death. What the Government needs to do is get out of the way, cease to help, and learn to respond when asked for assistance for the very things requested—and only those things. They cannot fix anything and this has been the most difficult understanding to impart.

² Traditional Knowledge has several different definitions. Traditional Knowledge in this document will refer to the knowledge that communities hold based on their language, connection to the lands, and knowledge of their how their Peoples function within families and the community

Some of the highlights from the 2008 Gathering included properly engaging Indigenous Peoples and their respective cultures as it would benefit researchers to learn and implement the communities' pedagogy and methodologies; respecting the customs of Indigenous Peoples to expand the potential for new relationships and trust for new partnerships; the "studied-to-death" syndrome, which resulted in those who felt they have been exploited for many generations without any of the data being shared; identifying Intellectual Property (IP) rights that need to be protected and appropriated to Indigenous Peoples; cancer research that must be useful to the Peoples and communities; and, mutual benefits that should be discussed more on an individual community-to-community basis, as not all communities are looking for the same benefit.





INTRODUCTION

Through NOSM's vision and social accountability mandate, it is imperative to move forward to address the continuing disparities and inequitable access to culturally safe health and social services for Indigenous Peoples. NOSM recognizes through research that it must be meaningful to the Indigenous communities in which it is being conducted and to work towards achieving outcomes that have a lasting impact on the health of Indigenous Peoples and their communities. It is NOSM's intention to develop a Declaration of Guiding Principles for research that will begin to close the gap in the disparities and inequitable access to health and social services Indigenous Peoples encounter.

Across the region, NOSM learners (medical students, residents, and learners from other health disciplines such as rehabilitation sciences, dietetics, and physician assistants), are gaining relevant clinical experience under the guidance of health professionals in community hospitals, clinics, and family practices. The School brings together over 90 community partners, over 1,400 clinical, human, and medical sciences faculty, and more than 200 employees.

NOSM's success is very much a result of many partnerships and collaborations with individuals, communities, and organizations including Indigenous and Francophone communities, hospitals and health services, physicians and other health professionals, universities and colleges, information communication technology organizations, and other medical schools.

The Indigenous Research Gathering 2016 was held in Sault Ste. Marie, Ontario in the territory of the Anishinabek (Ojibway) Peoples of Baawaating on June 22 to 24, 2016. The territory is shared with two First Nation communities and a Métis community. This Gathering provided opportunities to enhance relationships by recognizing and acknowledging past grievances and reviewing current research practices Indigenous Peoples and communities may have encountered through research. The Gathering was a community consultative process and in keeping with Indigenous traditions, ceremony was a critical component throughout the Gathering providing delegates with opportunities to restore the relationships with themselves, with each other, and with NOSM.



PURPOSE AND OBJECTIVES

The purpose of the 2016 Gathering was to have Indigenous Peoples from partner communities to review the past and current research practices and begin to develop guiding principles that build inclusive and culturally respectful research programs that can have a positive impact on health in Indigenous communities. The guiding principles will form the basis of a statement of principles to assist researchers in engaging in research that makes a difference and has a positive impact on the community.

The primary objectives of the Indigenous Research Gathering were the following:

- To acknowledge the painful past on research conducted on Indigenous Peoples;
- To build-on and support strong, culturally safe research partnerships to serve the Indigenous Peoples and their communities into the future; and,
- To build inclusive and culturally respectful research programs with the development of specific guidelines that will form the basis of a Declaration of Guiding Principles for research that is truly beneficial to Indigenous Peoples and their communities.



OVERVIEW

Wednesday, June 22, 2016

In keeping with Anishinabek traditions, the Indigenous Research Gathering began with ceremonies specific to the Anishinabek of Baawaating. On the lawn neighbouring the Delta Hotel, members of the Batchewana First Nations raised a teepee, which served as a place of reflection and quiet over the three days of the Gathering. It was here that Chief Dean Sayers of Batchewana First Nation welcomed delegates and shared a teaching on consultation—speaking of the cultural similarities, spirituality, and relationships we have with the world around us, including our human neighbours. A smudging ceremony was performed to cleanse ourselves, bringing our minds together in a good way for the following days. A water ceremony was performed where teachings on the strawberry was shared to remind us of the young taking care of older peoples.

A drum song was offered to the spirits in all directions including above us, on the other side, and from within us. The Sacred Fire was lit with a teaching of the flint sounds calling in the spirits to be with us during the Gathering. Chief Dean Sayers shared knowledge on how his Chief's bonnet connects him to the spirits through the Grandfathers in his bonnet. He expressed the importance of our relationships and that Anishinabek are willing to share their knowledge when asked. Elder Harvey Bell welcomed the delegates to Baawaating sharing knowledge of how Baawaating was a historical gathering place during fish spawning season. He expressed the importance of language and the dialect that is specific to the area of Baawaating. He shared information on how the Anishinabek pharmacy is in the woods and all around us and Anishinabek have always been in this area governing themselves and living off the lands. A pipe ceremony was performed by the pipe carriers welcoming delegates and sharing some of their knowledge about the responsibilities Anishinabek people have. The teepee was also the place for Sunrise Ceremonies on Thursday and Friday mornings to welcome the day, give thanks and reflect on the activities.

The delegates attended a tour of the Shingwauk Residential School and Archives. Delegates gathered for a traditional meal where Dr. Craig Chamberlin, President of Algoma University, welcomed the delegates. Chief Paul Syrette of Garden River First Nation provided opening remarks with a focus on the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the Truth and Reconciliation Calls to Action. Ernie Gatien of the Métis Nation of Ontario spoke of the loss of the land and the historical relationships between the First Nation Peoples and the Métis. Robin Buckland, Executive Director, Office of Primary Health Care, First Nations and Inuit Health Branch, Department of Health, referred to the steps being taken by the Government to address the atrocities of the residential school systems and mentioned that a renewed relationship is needed through reconciliation. Dr. Penny Moody-Corbett, Associate Dean Research, welcomed the delegates and thanked the organizers, the Chiefs, and all the others who made this Gathering a success.

The keynote speaker, Chancellor Shirley Horn, shared her story of being in residential school. This was a very moving story of how a young girl was taken from her family at the age of seven and placed in the residential school system where she was forced

"We have an important relationship with everything around us that has given us a special knowledge and we are willing to share — if you ask"

Chief Dean Sayers

"What we do as individual people, to do our part to change the world for the better, is important."

Chancellor Shirley Horn

to forget Anishinabek ways. She stated the hurts have taken many years to heal and how those hurts don't actually go away. She spoke of the importance of relationships and that everybody has a role in making changes to institutions in a true collaborative manner.

Elder Eleanor Pine spoke briefly of the importance of relationships and that healing oneself is part of learning from experiences. She reiterated that life experiences are part of healing, learning, and moving forward. Following the meal and tour of Shingwauk, delegates were invited to attend a Sweat Lodge, conducted by Mike Hodgson, Batchewana First Nations.

Thursday, June 23, 2016

The day began with a Sunrise Ceremony including the drum and the pipe carriers. Elder Harvey Bell provided a prayer mentioning the importance of water for life. The Chiefs from Batchewana and Garden River First Nation with the Elders sang a song on the drum to start the Gathering in a good way.

Chief Dean Sayers welcomed the delegates to the Gathering and mentioned the spirit room in the Sault Ste. Marie Hospital and how the hospital is working with Anishinabek, providing the example of the placenta ceremony. He shared how Anishinabek still utilize medicines maintaining the relationship to the lands, the winds, and the waters. He also reminded the delegates of how the Anishinabek don't truly feel comfortable going to the hospital, but also shared how he is hopeful that this relationship will change for the positive over time.

Chief Paul Syrette welcomed the delegates, speaking of the many variables contributing to the decline of Anishinabek health. He shared his thoughts about how ceremony will bring healing and reconciliation to the Anishinabek. Chief Syrette spoke of Mino Bimaadizwin leading a balanced life to lift each other up for a healthier Peoples and a healthier community.

Ernie Gatien welcomed the delegates to the Gathering reminding the delegates of how the First Nation and Métis people went to jail together because they stood beside one another to protect the lands. He mentioned a future report to be released soon which will provide insight into relationships between Métis and First Nation Peoples. Mr. Gatien reminded the delegates of the Daniel's Decision, reaffirming Métis as Indigenous Peoples.

Dr. Roger Strasser, NOSM Dean, addressed the delegates reminding them that the Northern Ontario School of Medicine is their school. He reminded the delegates that this Gathering and their participation will guide NOSM's research endeavours.

Dr. Penny Moody-Corbett provided an outline of the purpose and objectives of the Gathering, including the opportunity to draft a declaration of protocols for research that will have a positive impact in Indigenous communities. She also encouraged delegates to develop a tool for research in their respective communities.

"Ceremony will bring healing to the Anishinabek, it is about Mino Bimaadizwin, lifting each other up for a healthier people and community."

Chief Paul Syrette

Elder Dot Beaucage-Kennedy, Chair of NOSM's Indigenous Reference Group shared her role and involvement with the School. She shared a few of her favourite quotes: "health is wealth" and "you are what you eat." Ms. Beaucage-Kennedy referred to the path we travel, which is led by the Creator and that trusting that path to be where you need to be is important for all Peoples.

Keynote speaker Dr. Cynthia Wesley-Esquimaux, Vice Provost Aboriginal Initiatives at Lakehead University addressed the delegates with an address titled Acknowledging the Past.

Dr. Wesley-Esquimaux's address reflected her experiences as a researcher providing recommendations on a path forward. She reminded the delegates of her learning experiences in the current education system in terms of what had been missing in the teaching: "They did not speak to the emotional impact of environmental isolation, the spiritual and mental consequences of Indigenous suicide, or the letting go of inappropriate biases and beliefs prior to my on-site arrival." She spoke of past grievances, "Government, and scholarly and social decisions framed in injustice and arrogance by those who think they know better." Dr. Wesley-Esquimaux posed questions for the delegates to reflect on when considering research in Indigenous communities. She referred to the 94 Calls to Action in the Truth and Reconciliation Commission Report and closed by challenging researchers "to tread the road less travelled, and work hard to find a new lens through which to view your research questions. Include the worldviews and deep understandings of the Indigenous community, because if the prophesies are correct, it is they who will lead us all home, back to the land, back to relationship, and back to a future with hope and health for everyone."

After the keynote, a sacred healing song was rendered by the traditional drum to acknowledge the healing that needs to take place as people move forward.

"Indigenous Peoples have nurtured and maintained an incredible amount of Traditional Knowledge into the present and we must continue to ensure as educators, as students, as lifelong learners, and as Indigenous Peoples that there is very good reason to remember and practice the wisdom in living close to the land and respecting the value and sacredness of those lands and waters."

Dr. Cynthia Wesley-Esquimaux



PRESENTATIONS

Building Research Relationships with First Nation Communities Ms. Lorrilee McGregor and Dr. Marion Maar

The power of silence and humour is important when working with First Nation communities.

Ms. Lorrilee McGregor is an Anishinaabe (Ojibway) from Whitefish River First Nation and a doctoral candidate in the Interdisciplinary Ph.D. program in Rural and Northern Health at Laurentian University. Ms. McGregor's doctoral research focuses on Indigenous children and youth. Dr. Marion Maar is an Associate Professor of Medical Anthropology with NOSM at Laurentian University. She has worked in the area of health promotion and illness prevention focused on Indigenous Peoples and First Nations communities since 1995.

This presentation shared experiences from conducting research in First Nation communities specific to Manitoulin Island. A committee was established for the First Nation communities on Manitoulin Island to review research proposals and ensure the research is conducted and adheres to their protocols. The presenters stressed the importance of the researcher being ready in terms of understanding the community, the effects of colonization, the "power of silence" and humour, and being able to collaborate in a good way. The presenters also stressed the importance of the community being ready for research in terms of support for training. Are people willing to get trained? Are people willing to participate in the research? Understanding and knowing what the research is going to do for the community and being able to articulate that information is imporant to the community. Is the community willing to assist in data analysis and interpretation? Researchers must understand that many communities have research fatigue and typically band staff are overwhelmed with their day-to-day jobs so may not be able to assist in research activities. The presenters also shared information on the need to protect Traditional Knowledge and capacity building within the communities. There are several challenges to doing the research including funding. Typically there is not enough funding to truly engage the communities and build capacity, and timelines associated with funding often do not take into consideration the time to develop relationships and build trust, which results in several challenges for the communities.

Specific to Manitoulin Island, the presenters shared information on the experiences they have encountered with researchers. A community health forum was held with all the First Nations on Manitoulin Island which determined the need to build local capacity, to be more proactive in research, and to develop a process to take control of the research. A committee was established to be the "gate" for researchers to ensure both communities and the researchers are ready. The committee took a few years to establish, along with developing guidelines which ensures questions are answered regarding the researchers' proposals: what is going to be studied; how it is going to be studied; and, who is going to interpret the data collected. The committee is comprised of community representatives, cultural advisors, and Indigenous academics.

The guidelines and a policy developed are based on the Seven Grandfather Teachings³ and the Tri-Council Policy Statement,⁴ Chapter 9, which states the following:

- respect for human dignity;
- respect for free and informed consent;
- respect for vulnerable persons;
- respect for privacy and confidentiality;
- respect for justice and inclusiveness;
- balancing harms and benefits; and,
- · minimizing harm and maximizing benefit.

Researchers must complete the application process established by the committee, which asks several questions specific to the research and the committee will review the application informing the researcher of recommendations in order to be able to conduct the research.

Relationship building is key when working with First Nation communities.

The key messages from this presentation are the community will make the decision on moving forward with research and the importance in taking time to build relationships with universities.

The presentation also offered the following for further reading:

- Chapter 9 Research Involving the First Nations, Inuit and Métis People of Canada of the TCPS2 Ethical Conduct for Research Involving Humans
- First Nations Information Governance Centre online OCAP course
- Cancer Care Ontario: Aboriginal Relationships and Cultural Competency online courses.

Communities and Research: Delivering Change for Pregnant Women Dr. Naana Jumah and Mr. Sol Mamakwa

Dr. Jumah's research and clinical practice focus on Indigenous health and addiction in pregnancy in Northwestern Ontario. She combines her rich academic background and training in medicine and engineering to focus her research on Indigenous women's health, substance use during pregnancy, cervical cancer screening, and the treatment of uterine fibroids. Mr. Sol Mamakwa is from Kingfisher Lake and is the Health Director of Shibogma First Nation Council. Unfortunately, he was unable to attend the conference to present.

This presentation was about the partnership and friendship developed with Shibogma Health Authority with the goal of the First Nations taking control and administrating their health programs. The First Nation communities involved in this project are: Kasabonika First Nation, Wapekeka First Nation, Wawakapewn First Nation, and

³ The Seven Grandfather Teachings are: Nibwaakaawin-Wisdom; Mnaadendmowin-Respect; Aakdehewin-Bravery; Gwekwaadziwin-Honesty; Dbaadendizwin-Humility; Debwewin-Truth; and, Zaagidwin-Love.

⁴ Information on the Tri-Council Policy Statement Chapter 9 can be found at:

Wunnumin First Nation, which are all remote communities located north of Sioux Lookout. The project was developed because in the past, mothers would have to be flown to either Sioux Lookout or Thunder Bay to deliver their babies and would have to stay in these cities for up to three months leaving the communities and families wondering what has happened to both baby and mother. Funding was accessed by Shibogma Health Tribal Council for the project.

The first step in this project was the establishment of a committee and the hiring of an individual to do an environmental scan with the intent of developing an integrated Pathway for the mother and her child so the community could support the mother and her child. The committee wanted to ensure the Pathway was functioning effectively by doing an evaluation which led to Dr. Jumah coming on board to assist with the evaluation.

"When you invest in spirituality, you have hope, belonging, meaning and purpose."

This project is an excellent example of the communities identifying a problem, working together, and developing a solution based on their needs. As with so many other projects First Nations are working on, this project began with the challenges of a colonial approach of funding and constraints including the timelines. The colonial approach enforces deliverables with strict timelines with no consideration for the approaches First Nations need to take to address problems. These types of funding opportunities also pit First Nations against one another in a competitive approach to access funding not allowing for collaboration among First Nations. Shibogma Health Authority decided to reach out to researchers in an attempt to access different funding approaches and provide the communities with opportunities to access researchers based on their needs.

Key messages from this presentation include the importance of relationship building with the communities and the understanding to support the First Nations including the understanding of stepping away from projects when asked. The relationship building is key in working with First Nations and needs to include constant communication, a shared goal, and ensuring roles are clearly defined.

Culture as an Intervention in Addictions Treatment Ms. Carol Hopkins

Ms. Carol Hopkins is Delaware First Nation of Moraviantown, Ontario and was the Co-Chair, First Nations Addictions Advisory Panel whose mandate was to develop a renewal framework for the national Native Alcohol and Drug Abuse and the Youth Solvent Abuse programs. Ms. Hopkins now co-chairs the Leadership Team whose mandate is to implement the renewal framework based on Indigenous Culture as the foundation of the framework. This presentation discussed the development of the framework and the importance of culture in all aspects of research and in health.

The approaches for the framework development were culture-based with a clear vision of establishing a framework to encompass all aspects of health. The first step in this process was to gather Elders, knowledge holders, people from health fields, and Chief and Councils to discuss what their culture says about wellness. The literature search for the framework provided information that focused on deficits and not wellness which lead to the understanding that the framework must rely on Indigenous Knowledge.

The presenter shared information by Mr. Rupert Ross and Mr. Jim Dumont about truly understanding culture and that everything has a spirit affecting all aspects of life. She shared that we need to decolonize ourselves and spiritual intelligence can be used in all aspects of life to become healthy.

Key messages from this presentation were the importance of language and culture; connecting wellness to culture and Indigenous knowledge sources; and, to invest in social determinants as a basis of wellness.

The Strengths of a Community-Based Approach to Research Dr. Sheila Cote-Meek and Ms. Fern Assiniwe

Dr. Sheila Cote-Meek is the Associate Vice-President, Academic and Indigenous Programs at Laurentian University where she is responsible for university faculty relations, as well as leading the development of Indigenous academic development across various disciplines including the development of an Indigenous Education Centre dedicated to Indigenous learning, culture and scholarly pursuit at Laurentian University. Ms. Fern Assiniwe holds a Master of Social Work from Laurentian University and is a consultant with Assinewe Consulting, which provides management support, training program evaluation and research. She is also the Community Wellness Director with the Sagamok Anishnawbek First Nation-Massey and the Vice President, Nogdawindamin Family and Community Services Board of Directors.

The community has to be the lead on research in their communities.

Dr. Cote-Meek and Ms. Assiniwe shared their knowledge on conducting research in communities. The first step was to develop a research team consisting of Elders, youth, and community members which were all chosen by the community. The community was the lead on the research and made the decisions such as the content of the surveys. The presenters expressed the importance of relationship building, community capacity building, and the importance of the final research product being useful for the community.

The presenters shared lessons and strengths from their experience listed them as follows:

- Flexibility is needed.
- Community-based research takes time so you can respond to the community timelines.
- · Capacity building.
- Youth engagement early in the project is needed.
- Youth survey community teams developed these surveys.
- Community engagement is important and needed for all components of the research.

Lessons learned:

- Positive experience working with the communities.
- Research guide was developed and can be used as a reference for the community.

- Venue-based methodology, which utilizes the different venues located in the community such as going to the school to engage the youth.
- Retention poses issues in communities as people change jobs.
- Working sessions are needed for training, sharing issues and solutions, and constant communication.
- Writing reports based on funding agreements can be intimidating for communities.

Key messages from this presentation related to funding constraints and timelines; the importance of networking when working with more than one community; the pressures from funders and universities to publish are an issue; and, ensure community involvement in all aspects of the project including the community teams presenting the results to the communities.

The Best of Both Worlds Ms. Mary Jo Wabano and Dr. Kristen Jacklin

Ms. Mary Jo Wabano is the Health Director at the Wikwemikong Health Centre where culturally appropriate programs and services for Indigenous Peoples, combining traditional health and Western medical practices aims to improve the social supports and conditions that affect long-term health. Dr. Kristen Jacklin is an Associate Professor, Medical Anthropology, Northern Ontario School of Medicine at Laurentian University collaborating on the project. Unfortunately, Dr. Jacklin was unable to attend the Gathering.

Ms. Wabano shared information on both the establishment of the health centre and on working with researchers. She explained how visionaries assisted with how the health centre was designed and how the community made recommendations so the continual listening to the voices of the Peoples was established. Specific to researchers, the presentation provided information on funding limitations; how to ensure the research has a community champion; the need to respect both cultures; establishing a research advisory group consisting of Elders and community members; and, communication.

Ms. Wabano shared how long-term relationships take time and the responsibility lies with both parties in developing and maintaining the relationship. Learning from both cultures is a shared responsibility and assists with successful research projects but it must be in equal forms in order to be effective. She shared how her community hosts a community day with all researchers presenting back to the community as part of the accountability to the community citizens.

Challenges from her experiences included funding constraints and timelines; and research is generally driven by academia. She shared the challenges in retaining staff due to project based funding. Key messages included the importance of using previous research to determine future research needs; the research belongs to the community; and, the research can improve practices in the community when it is community driven.

Our Health Counts - Working Together to Advance Urban Indigenous Health Services Dr. Janet Smylie and Ms. Cheryllee Bourgeois

Dr. Janet Smylie is a Métis family physician and researcher. Through her work with Well Living House, Dr. Smylie's goal is to ensure that every child born in Canada has the opportunity to live a full and healthy life. Ms. Cheryllee Bourgeois is a Cree-Métis registered midwife at Seventh Generation Midwives Toronto, a practice that focuses on serving the city's urban Indigenous community.

This presentation shared information on working together to improve health services in urban settings, which included supporting the growth of Indigenous midwifery. They built partnerships and established a council of grandparents who developed the concept of "research as a gift exchange." The partnership established with St. Michael's Hospital was critical in the development of the Indigenous midwifery program and communication through many meetings assisted with the partnership. The establishment of the Seven Generations Midwives Centre in Toronto has provided research opportunities and was able to use the research to provide better opportunities for urban Indigenous populations in relation to health.

The key messages from this presentation included the importance of partnership building; conducting research that is applicable; working together to produce knowledge; communication; and, visioning.



PANEL DISCUSSION

All presenters were invited to participate in a panel discussion with the delegates. A question from the delegates about the suicide epidemic among Indigenous youth was posed to the panel. Discussions on this topic included the importance of promoting life as opposed to just focusing on suicide prevention and informing the delegates of a Youth Forum as an opportunity for promoting life in young people. This discussion lead into understanding that the health of a child relates to the health of the parents, the grandparents as it is about intergenerational trauma. Some discussion also focused on the spiritual connections to suicide and how this needs to be addressed and further discussed in communities.

Keynote Address Dr. Marie Wilson, Commissioner for the Truth and Reconciliation Commission

The keynote address started with a short video of Indigenous Peoples talking about their experiences in the residential school system. Many of the delegates were moved to tears from the speakers in the video sharing the atrocities brought on by the system. Dr. Wilson stated that everyone has learnt from hearing the experiences of the children forced to attend and grow up in the residential school systems. She spoke of the intergenerational trauma that continues to plague Peoples and the communities. Dr. Wilson reminded the delegates that a great number of children from all of Canada attended the residential schools and that many of these children died there, that this was a deliberate plan by Canada with the intent to separate children from their families in order to minimize and weaken family ties and cultural linkages, and to indoctrinate children into a new culture. The residential schools were in existence for well over 100 years and the existence of these schools were hidden for most of Canada's history.

Dr. Wilson explained the process of the Truth and Reconciliation Commission including information from the class actions and the Indian Residential Schools Settlement Agreement. The Commission spent six years travelling to all parts of Canada to hear from more than 6,000 witnesses, most of whom survived the experience of living in the schools as children. The information gathered by the Commission will be valuable for generations to come in understanding the history of the Indigenous Peoples and Canada. She explained that a National Centre has been established with a website that will continue to function and provide information long into the future.

Dr. Wilson shared that the principles of reconciliation include language, culture, are land based and need on-going dialogue. She explained that many people came forth to stand with First Nations such as holocaust and Rwanda survivors.

This address explained holistic health and what happens when components are taken away such as social and physical space, mental health, the heart, and how the spirit becomes damaged when health is not approached holistically. Dr. Wilson spoke of how the family and community health are disrupted when individuals are not healthy. She explained there is still a continued brokenness in Canada and the current health of First Nation Peoples is a direct effect of Canadian policy and residential schools. She

"A great number of children from across Canada attended the residential schools, and many of these children died there. This was a deliberate plan by Canada, with the intent to separate children from their families in order to minimize and weaken family ties and cultural linkages, and to indoctrinate children into a new culture."

Dr. Marie Wilson

also stated that we need to stop doing things and making policies without one group being involved. She explained that anger is a spiritual sickness and forgiving makes you free and these are needed to move forward in a healthy way.

94 Calls to Action in the Truth and Reconciliation Report with seven specific to health.

Dr. Wilson stated there are 94 Calls to Action in the Truth and Reconciliation Report with seven specific to health, but stressed the value of Indigenous healing practices and being able to utilize these practices. She explained the importance of establishing a National Council for the Truth and Reconciliation so the Calls to Action will be implemented but reminding us we need to expect a slow recovery.

In closing, she wished the delegates vision, courage, and stamina in their journeys ahead.





REFLECTIONS

Throughout the presentations, four key themes occurred. The following is a summary of the key themes:

1. Relationship Building

All presenters including keynote speakers expressed the importance of relationship building with the communities and how these relationships will evolve into a long term friendship with people in the communities.

2. Funding

Presenters expressed challenges with funding as the timelines provided by funders do not meet the needs of the communities. They also expressed challenges with how funding opportunities pit communities against one another and the need for a different funding mechanism.

3. Culture

Several presenters expressed the need for understanding Indigenous culture. Also expressed was the need for researchers to understand the differences/diversities between communities, to understand humour, understand silence and understand how colonialization has affected Indigenous Peoples.

4. Language

Presenters expressed the importance of the language and the need for researchers to understand some of the basics from each community as dialects do change from community to community.



GROUP SESSIONS

Friday, June 24, 2016

The day opened in the Anishinaabek way with Sunrise Ceremony followed by an opening prayer by Elder Harvey Bell.

The organizing committee and Sue Chiblow facilitated a breakout session with the purpose of obtaining feedback on the following questions:

- What are the important lessons learned about research practices?
- What are recommendations for moving forward with research?
- What are your priorities?
- What are guiding protocols/principles?

The delegates were divided into nine groups to ensure all delegates had a chance to share in the discussions. Each group assigned one individual to present to all the delegates. The reflections and responses to the four questions of each of the Groups are provided in Appendix 2.

Lessons learned from the breakout groups were similar with the focus being on community driven research, ownership and clear understanding of the research including the entire process. The lessons learned reflected information provided by the presentations and keynote addresses such as the importance of relationship building and the necessity of understanding the communities being researched.

The path forward offered suggestions, which include relationship building, the need for respecting communities, the need to be inclusive of the entire community and protocols. The groups also mentioned the issues related to funding for research but offered solutions that funding options including timelines need to be changed to meet the needs of the communities.

Priorities varied with some groups listing actual research priorities such as diabetics and water. These specific research priorities can be shared with researchers to address what the communities want researched but needs to include an action plan that the community can implement when the research is completed. Other groups focused on what the researcher needs to do in order to effectively work with communities such as inclusion of Elders, creating advisory groups, sharing data and knowledge and the importance of youth involvement.

The guiding principles listed by the groups had many similarities such as the Seven Grandfather teachings, the development of a standard research template, the need for the researcher to be educated about the community prior to research being conducted and the sharing of research models and practices/protocols between communities.

The responses from each of the groups were reviewed and the concepts that emerged were identified and summarized for each question.



The responses from the nine groups could be grouped into seven broad themes: Community Involvement, Culture, Funding, Ownership, Ethics, Timing, and Procedure.

Community Involvement

The community needs to be involved in the research and the research needs to benefit the community. Researchers need to be accountable to the community and the community needs to have a say in publications stemming from the research. There needs to be development of a relationship with members of the community and this relationship needs to facilitate learning in two directions and include educating the community members in research practices and educating the outside researchers about the research practices of the community. The leadership of the community (Chiefs, council and committees) is important and they need to play a role in the research endeavor.

Timing

Timing is an essential component of doing research and this is even more important when time is required to build and maintain a strong and trusted relationship with community.

Culture

Engaging in research requires an understanding of the history, culture, ceremonies, and beliefs of the community. There are different faiths and beliefs, and researchers need to be aware of these differences. The researcher needs to take the time to understand the community and its protocols, views, beliefs, and values and to take the time for cultural training and awareness. Understanding the history and impact of colonization and on-going crises that exist in community is essential. Language is important and understanding silence is important. There needs to be respect for culture and researchers need to understand communities can be suspicious of research.

Procedure

The groups noted research is a shared responsibility, procedures are important, and the community has to be ready to engage in research. Doing research requires researchers to rely on good data that meets the community needs. Researchers need to be aware of past practices and best practices.

Protocols need to be followed and not changed part way through data collection. Raw data needs to be properly archived. Confidentiality agreements need to be in place and researchers need to have proper credentials. Using a checklist for communities regarding protocols, researchers need to be trained on how to ask and understand questions and responses and this may require translation, in particular in the far north. There needs to be appropriate follow-up from data collection, interpretation of results, following through with results, and following up with NOSM students. There also needs to be consideration of support teams for issues that arise.

Consent and Ethics

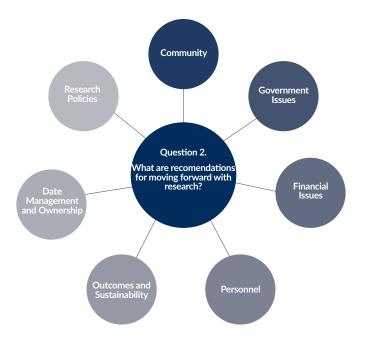
The research needs to consider ethics as it relates to the First Nations communities. There needs to be protection for vulnerable. Researchers need an orientation on research ethics policy accompanied by a First Nations person or community member. Free and informed consent must be given before research is undertaken and if there are problems of not complying there must be sanctions in place to deal with this.

Ownership

Ownership of the data is important and each of the tables repeated the OCAP message of the importance of Ownership, Control, Access, and Possession. The significance is how the community benefits and who ultimately owns the data.

Funding

Appropriate funding for the full spectrum of the research enterprise needs to be considered; funding does not currently align with research timelines (which need to consider relationship building in community) and the expense of travel and access of technology in remote communities is not adequate. Budgets need to be flexible and this needs to line up with community timelines, not the funders' timelines. Community members need to be compensated and monetary incentives need to be in place to participate in research. Funds must be available to pay Elders and cover costs of specialists. There needs to be a consideration of how funding will be provided with following up on research.



The recommendations for moving forward fell into seven broad categories: Community, Government Issues, Financial Issues, Outcomes and Sustainability, Personnel, Data Management and Ownership, and Research Policies.

Community

In order to move the research forward we heard again the importance of community. The research needs to be relevant to the community and be based on priorities of the community, respecting the time commitment required. The research should be driven by the community and must involve informed consent by the community as well as individuals in the community. This requires involving Elders and youth, having approval from Chief and Council, understanding the traditional practices, and knowledge of protocols and community dynamics. Researchers need to understand that communities are diverse and different and not all the same. Researchers need to be mindful and respectful of Indigenous worldviews and need cultural training. Participating in community events, working together and sharing and forming closer connections with communities would benefit research in the future.

Government Issues

In order to move forward there has to be an understanding and respect of Treaties and how the Indian Act and other Government policies have affected communities. There was a view that researchers should be involved in building legal cases and negotiating liabilities. In partnership with communities' leadership, researchers need to advocate and lobby Governments for more funding. The Governments need to understand health priorities and should not consider Statistics Canada as the best data when it comes to Indigenous communities.

Financial Issues

In order to move research forward there has to be adequate and transparent funding and the funds need to be used wisely. Resourcing must consider the full cost at all levels, including costs of community input and participation, collecting data from Government, and where appropriate, how costs should be shared with tribal councils and Indigenous Health Access Centres. The community needs to be able to access funding for research, not just through academia, they need to be aware of funding opportunities. There needs to be local community resources such as post secondary and graduate students and resources need to be available to address specific and urgent concerns such as addictions. NOSM needs to have resources to address the challenges of promoting the school in the far north and bringing together students.

Personnel

In moving research forward, there has to be an opportunity for capacity building, hiring community members, and allocating staff for specific programs such as youth programs. Community members need mentorship in how to conduct research and there has to be involvement of translators when necessary. It is important to establish collaborations and partnerships.

Outcomes and Sustainability

In moving research forward, it has to be based on past results, lead to something, and be beneficial and impactful for the community. There has to be outcomes and followup and the researchers have to be held accountable. The positive benefits of research need to be promoted and the implications of the research outcomes considered. The interpretation of results needs to be understood both within the community and to the researchers, and the community should have the option to edit and change draft documents. Recommended changes need to be identified and implemented to make them sustainable. Research needs to be action-oriented and lead to positive change.

Data Management and Ownership

Data management and ownership is important and OCAP must be respected. The researchers must be accountable with reports, providing community with information from the outset, sharing with stakeholders and adhering to clear deadlines. Data should be shared across communities or pooled with nearby communities where possible. There must be a plan for data ownership and governance.

Research Policies

Policies need to be in place to understand community process, approvals, protocols, and education. Establish protocols to share, understand, and respect traditional and cultural ways, including Anishinabek protocols. Policies should be shared in particular helping communities develop ethics boards and best practices. Standard templates should be considered. There should be strategic plans in place and MOUs with all steps of the research outlined. The research community needs to understand the teachings of natural medicines and include Indigenous knowledge and action.



The groups identified the importance of Community engagement, understanding, and incorporating Culture as major priorities. In addition, the groups identified priorities related to Health and Disease, Governance, Ownership, Benefits and Revenues, and Procedural Issues in conducting research.

Community and Culture

Community and culture are important priorities in how research should be conducted in the future. The communities need to be included in all aspects of the work, understanding the community needs, building relationships, ensuring community members are included, and that the research is beneficial to community needs. The researchers need to understand traditional and cultural history, and protect and respect the history and knowledge of community and the land. It is important to understand the language, and develop a cooperative approach to the research. Understanding the traditional worldview, respecting and engaging the Elders and youth, and understanding medicine people of the community is also important.

Health and Disease

The importance of a good life for all Peoples based on the Seven Grandfather Teachings was identified as a priority. Chronic diseases were recognized as priorities for study in particular: cancer, heart disease, hypertension, diabetes, skin conditions, and mental health. Addictions research is a clear priority for the Indigenous communities, addressing issues of methadone addiction and the long term effect of opiates on children. Access to primary health care and health-care providers within the communities is a major priority, as are issues of basic infrastructure, housing, and access to clean water are priorities. Understanding health issues related to child, youth and maternal issues, including addictions, social programming, and parenting is also key. Research priorities need to include health issues specifically related to the Elderly. Issues surrounding traditional foods versus processed foods and the relationship with disease such as diabetes, and the addictive properties of food were identified as priorities.

Governance

The role of governance in the process of research was an important priority. The groups spoke about the need for buy-in from the political leaders, the importance of self-determination, reconnecting with Elders, and the use of the Seven Grandfather teachings. It is important to have professionals as role models in the communities. Human rights watch and sharing policies specific to this was included as a priority. Ethics boards and the need to consider ethical and cultural sensitivities and work together in future research were also important priorities.

Ownership

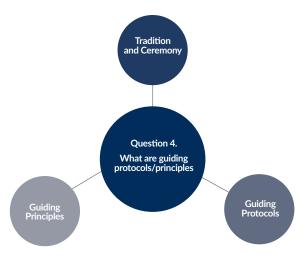
In addition to governance was the topic of ownership as a priority. Understanding the importance of community ownership and the responsibility that Indigenous communities have as stewards of the Turtle Island. In pursuing research copyright, trademarks, patents must be clearly defined and ownership of the data and how it can be used must involve community.

Benefits and Revenues

The groups identified a number of priorities related to revenue generation and community benefits. There needs to be revenue sharing agreements in place and funds available for the community to engage in its own research. The resources must be accessible and distributed equally. The community must see benefit of the research, including capacity building, hiring community members, incentives in terms of bursaries or scholarships, funding increases, and support groups.

Procedural Considerations

How research is conducted, procedural considerations, was also identified by the groups as a priority. Rebuild trusting relationships and making sure that there is follow through on research. Transparency, accountability, quality assurance, and elimination of silos are priorities in research projects. Establish community advisory groups and committees, which are utilized and increase engagement especially when competing with technology. Practical issues such as interpreters, good communication, and following protocols are all important. There must be safety and protection for the community and the knowledge and confidentiality needs to be maintained. It is important to follow the guidance of the Seven Grandfathers teachings and eliminate silos. Having community champions and keeping the research simple were seen to be important priorities.



The groups provided guidance for both protocols and principles and also included the importance of recognizing and incorporating the importance of traditions and ceremony.

Tradition and Ceremony

It is important to recognize the importance of spirituality and incorporate traditions and ceremonies where appropriate, including bringing asema (traditional tobacco).

Guiding Protocols

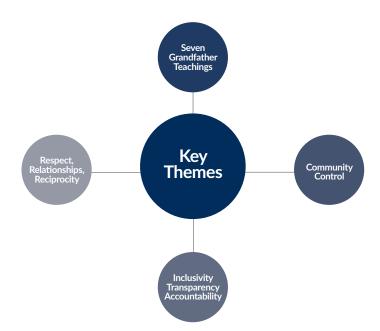
The guiding protocols and procedures need to include OCAP, Seven Grandfather Teachings and local community ethics committees such as the Manitoulin Anishinabek Research Review Committee (MARRC). Standard templates for research should be developed and used, including research ethics protocols and where possible combine or pool data. Identify ownership and how data can be used; clearly identify how costs are to be covered. Plans for follow through need to be developed. Elders and community advisors need to be used as resources.

Guiding Principles

The principles for moving forward with research in community included the role of community, Elders and youth and the importance of utilizing the expertise of local health-care centres, health professionals, and staff. Research needs to be based on community acceptance, trust, and engagement and guided by the community and its needs and the research must lead to action, which is sustainable for the community. Improvements should be incorporated into policy and impact health programs. In order for research to proceed, researchers must build relationships with the community and the research team needs to be part of community. Researchers have a huge responsibility to community, they need to build trust, the work cannot be rushed. The guiding principles also need to include those of the Métis Nation of Ontario.

The key themes from the group sessions can be categorized into the following:

- Community Control For both the research and data.
- Inclusivity, Transparency, and Accountability The researchers need to ensure everyone is included in the research that they are transparent of the research including outcomes and finances, and need to be accountable to the community.
- Respect, Relationships, Reciprocity.
- The Seven Grandfather Teachings.



RECOMMENDATIONS

The two-day Indigenous Research Gathering, preceded by an afternoon and evening of ceremony and reflection provided many opportunities for the delegates, invited guests and organizers to interact and talk about how research can be better incorporated and be more meaningful for the communities of Northern Ontario. One approach is the development of a document that includes two separate but intertwined documents one to assist communities and one to assist researchers. This document needs to encompass education for both the researchers and the communities. Delegates expressed the diversities and differences, in particular between North and South, but also similarities in communities and the importance of sharing. Funding and timeline challenges were expressed in the presentations and by the delegates in the breakout groups and the need to address these challenges. Indigenous Peoples are willing to work with researchers, but it must be on their terms and in order for researchers to better understand this, education and understanding needs to happen for both communities and researchers.

- 1. Research Toolkit: to develop a Research Toolkit that encompasses the educational needs of the communities and the educational needs of researchers with sections to include best practices, research protocols/guidelines and examples of successful research projects. It is important to note that delegates requested follow-up as far too often documents are developed and end up on shelves with no applicable actions for the communities. It is therefore important to ensure training on the Toolkit takes place for communities and providing ownership to the communities through a train the trainer type program. This Toolkit should include a scan of current research models, best practices, information on communities, examples of successful research practices including protocols and processes, and descriptions of the Seven Grandfather Teachings. An example of a Toolkit that has been compiled specific for Indigenous Peoples is the Chiefs of Ontario Environmental Assessment Toolkit. This Toolkit can be utilized by the Chiefs, the community members, Governments and industry as a learning tool with sections specific to each. The Chiefs of Ontario office has provided training on the Toolkit to several First Nations and Tribal Councils.5
- 2. Web-based Network: to develop a model or system where researchers and communities can connect on priorities, but also where communities can find researchers that have been successful in conducting research with Indigenous communities/Peoples. One example of a model that could be adapted to assist communities with partnering with researchers is the First Nations Environmental Health Innovative Network (First NationEHIN) which was developed by an Advisory Group of First Nation Peoples from across Canada in partnership with the Assembly of First Nations.⁶ This type of model could be added to NOSM's website providing both researchers and communities easy access.

⁵ More information on the COO EA Toolkit can be accessed at http://cooeatoolkit.org/

⁶ More information on First NationEHIN can be accessed at http://www.fnehin.ca/

The Delegates also offered some specific advice to NOSM in considering its role in research, which involves Indigenous communities of Northern Ontario. The School should publish how Elders are utilized in the School and how their voice is incorporated within the School. NOSM should consider advertising on APTN and the native media, Wawatay. There should be an encouragement for NOSM students to return to community and incentives for graduating MDs to practice in the North.





APPENDIX 1

Speaker Biographies

Ms. Lorrilee McGregor and Dr. Marion Maar Title: Building research relationships with first nation communities

Ms. Lorrilee McGregor is a research consultant from Whitefish River First Nation in Northeastern Ontario. For the past 20 years she has been working with First Nations, Indigenous organizations, and federal and provincial departments on various health research and evaluation projects. Ms. McGregor has an MA and is doing her Ph.D. in the School of Rural and Northern Health at Laurentian University in Sudbury. The focus of her research is Indigenous children's health - specifically physical activity and nutrition. Since 2002, Ms. McGregor has been a member of the Manitoulin Anishinaabek Research Review Committee (MARRC), a communitybased research ethics review committee. She has served as Chair of this committee since 2004 and has delivered numerous presentations and co-wrote key documents for this committee. Her recreational interests include playing hockey and competing in triathlons. In addition, Ms. McGregor coaches cross country running, hockey and soccer.

Dr. Marion Maar is an Associate Professor in Human Sciences at the Northern Ontario School of Medicine. She has a Ph.D. in Medical Anthropology from McMaster University in Hamilton, Ontario. Dr. Maar has been with the Northern Ontario School of Medicine since 2005. She has conducted research on health issues with a focus on Indigenous community health, including areas in diabetes care and prevention; Indigenous cancer care; combining inter-professional collaboration between traditional Indigenous and clinical health-care providers. Dr. Maar's approach is grounded in medical anthropology; in line with Indigenous understandings of health. She uses a holistic participatory action approach to examine the interplay of history, the health system, culture, traditional medical beliefs on health and mental health, in order to find solutions to current community health challenges. Dr. Maar also focuses her attention on issues related to Indigenous research ethics and is the Chair of NOSM's undergraduate research ethics board.

Ms. Carol Hopkins

Title: Culture as an intervention in addictions treatment

Ms. Carol Hopkins is the Executive Director of the Thunderbird Partnership Foundation (division of the National Native Addictions Partnership Foundation Inc.) since 2009. Ms. Hopkins came to this position from Nimkee NupiGawagan Healing Centre Inc., a youth solvent abuse treatment centre that is founded on Indigenous culture and life ways. She holds a Masters of Social Work Degree from the University of Toronto and holds a degree in Sacred Indigenous Knowledge equivalent to a Ph.D. in western based education systems. Ms. Hopkins has co-chaired various national initiatives and is known for developing best practice in national policy review and development.

These initiatives have resulted in the development and implementation of the

- First Nations Mental Wellness Continuum Framework,
- Honouring Our Strengths: A Renewed Framework to Address Substance Use Issues in Canada
- best practice guidelines for culturally based inhalant abuse treatment.

Ms. Hopkins has also led in partnership, a national research project funded by the Canadian Institutes of Health Research (CIHR) that has resulted in the Native Wellness Assessment and an Indigenous Wellness Framework. In recognition of this work, Ms. Hopkins received the Champions of Mental Health Award 2015 for Research/Clinician. She has taught social work courses for various post secondary institutions and currently is a sessional faculty in the school of social work at Kings University College at Western University.

Dr. Naana Jumah and Mr. Sol Mamakwa

Title: Communities and research: delivering change for pregnant women

Dr. Naana Jumah is an Obstetrician Gynecologist and Clinician Researcher at Thunder Bay Regional Research Institute and an Obstetrician Gynaecologist at Thunder Bay Regional Health Sciences Centre. She is also an Assistant Professor, Northern Ontario School of Medicine and a native of Thunder Bay, Ontario. Dr. Jumah holds a Bachelor's degree in Chemical Engineering from the University of Toronto and a Doctor of Philosphy in Medical Engineering from the University of Oxford, which she completed as a Rhodes Scholar. Following her doctorate, she graduated from Harvard Medical School and then completed her residency in Obstetrics and Gynaecology and specialization in Addiction Medicine at the University of Toronto.

Dr. Jumah's research and clinical practice focuses on Indigenous health and addiction in pregnancy in Northwestern Ontario. She conducted a pilot study into the curriculum needs of Obstetrics and Gynaecology residency programs in the area of the social determinants of Indigenous women's reproductive health. Through a series of integrated research studies, Dr. Jumah seeks to determine how to organize a model of care that addresses the needs of opiate dependent pregnant women in the region. Ultimately, this research aims to improve maternal and neonatal outcomes by developing a comprehensive and integrated care pathway for women with opiate dependence in pregnancy in Northwestern Ontario.

Mr. Mamakwa has recently taken a position as the Health Advisor with the Nishnawbe Aski Nation, who required him to attend a meeting in Winnipeg today and had to cancel earlier this week. Mr. Mamakwa had been the Health Director with Shibogama First Nations Council in Sioux Lookout for almost eight years.

Dr. Sheila Cote-Meek and Ms. Fern Assinewe

Title: The strengths of a community-based approach to research

Dr. Sheila Cote-Meek is the Associate Vice-President, Academic and Indigenous Programs at Laurentian University. She is responsible for university faculty relations as well as leading the development of Indigenous academic development across various disciplines including the development of an Indigenous Education Centre dedicated to Indigenous learning, culture and scholarly pursuit at Laurentian University. Dr. Cote-Meek is a full professor in her home department, the School of Indigenous Relations and has developed expertise in Indigenous relations in the areas of health, education and research. Dr. Cote-Meek is a member of the Teme-Augama Anishnabai.

Ms. Assinewe holds a Master of Social Work from Laurentian University. She is a Consultant with Assinewe Consulting, which provides management support, training program evaluation and research. Ms. Assinewe is the Community Wellness Director with the Sagamok Anishnawbek First Nation—Massey and she is also the Vice president, Nogdawindamin Family and Community Services Board of Directors.

Ms. Mary Jo Wabano and Dr. Kristin Jacklin

Title: The Best of Both Worlds

Ms. Mary Jo Wabano is the Health Service Director with Nahndahweh Tchigehgamig Wikwemikong Health Centre and holds a Masters degree in Human Kinetics. Ms. Wabano has been working with Indigenous youth for over 30 years to look at issues of self-esteem and building self-confidence. She understands the life challenges faced by First Nation youth, which has helped her understand the potential they have in terms of striving to become successful young adults. Ms. Wabano strives to implement programs and services that foster holistic well-being and works with local academic partners to meet the goals and needs of local community health plans.

Dr. Kristin Jacklin is an Associate Professor, in Medical Anthropology, with the Northern Ontario School of Medicine, she is also a member of the School of Rural and Northern Health at Laurentian University and a Faculty Investigator for the Centre for Rural and Northern Health Research, CRaNHR. Dr. Jacklin has a Ph.D. in Medical Anthropology from McMaster University. Her research focuses on Indigenous Health. She works collaboratively on a number of research projects including The Canadian Consortium on Neurodegeneration in Aging and more recently is a collaborator on a National Strategy on Patient Oriented Research project Reducing the burden of diabetes on First Nations people in Ontario: Using population-level data to inform policy and practice.

Dr. Janet Smylie and Ms. Cheryllee Bourgeois

Title: Our Health Counts - Working together to advance urban Indigenous health services

Dr. Janet Smylie is a Family physician and public health researcher. She is an Associate Professor in the Dalla Lana School of Public Health at the University of Toronto. She holds a CIHR Applied Public Health Research Chair in Indigenous Health Knowledge and Information. Dr. Smylie currently works as a research scientist in Indigenous health at St. Michael's hospital, Centre for Research on Inner City Health (CRICH), where she directs the Well Living House Applied Research Centre for Indigenous Infant, Child and Family Health.

She maintains a part-time clinical practice with Inner City Health Associates at Seventh Generation Midwives Toronto. Dr. Smylie is a member of the Métis Nation of Ontario, with Métis roots in Saskatchewan. Her research interests are focused on addressing the health inequities that challenge Indigenous infants, children, and their families through applied health-services research.

Ms. Cheryllee Bourgeois is a Registered Cree Métis Midwife and partner at the Seventh Generation Midwives Toronto. She is a Sessional Instructor in the Midwifery Education Program of Ryerson University, Toronto. She serves as the President of the Board of Directors for the Toronto Birth Centre.

She sits on the Core-Leadership circle of the National Aboriginal Council of Midwives, is a member of the Association of Ontario Midwives Clinical Practice Guidelines Sub-Committee and has been a community supporter and knowledge user on several CIHR grants. Ms. Bourgeoisworked as the Midwife Co-Lead in the establishment of a Midwife-Led and Indigenous governed Birth Centre in Toronto. She is an active supporter of aspiring and current Indigenous midwifery students and is a proud mother of three children.

APPENDIX 2

Group Session Responses

The delegates were divided into nine groups and asked to discuss the following four questions and to ensure all delegates had a chance to share in the discussions. The table below provides the responses from each of the nine groups.

- 1. What are the important lessons learned about research practices?
- What are recommendations for moving forward with research?
- 3. What are your priorities?
- 4. What are guiding protocols/principles?

Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols /
				Principles
1	Past practices from research	Relevant to community and beneficial	We have stewardship of the Turtle Island	Based on Seven Grandfather Teachings, the Great Law,
	Follow protocols Benefits community not	Review MARC policies and protocols	Buy-in from political leaders (Chief and Council/PTO/AFirst	Original Instructions, and the good book – the bible
	researcher	Determine community	Nation)	OCAP, MARC
	Community buy-in	priorities	Prioritize community needs	
	Input from community members	Respect OCAP	Understand traditional/cultural history (pre- and post-contact)	
	Respect OCAP	Respect Anishinabek protocols	Protect traditions, oral, history and knowledge	
	Consent	,		
	Understand and respect Community input throughout treaties entire process			
	Ownership of results	Don't re-invent the wheel	Copyright/trademark/patent	
	Follow thru with results	Sharing with stakeholders	Revenue sharing agreements	
	Don't just go thru the motions	Community driven research		
	Accountability to the community	Understand how Indian Act affected communities		
	Properly archive raw data	Hold researchers accountable		
	Publishing to be determined by the community	How many Government policies affect research in communities		
	Author determined by community	Researchers to include costs of community input, buy-in and participants		
	Confidentiality agreements			
	Respect community views, beliefs and values based on community individuals			
	Cultural training and awareness			
	Involvement of PTO/First Nation/province			

Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols / Principles
2	It was community driven	Help communities develop ethics boards	Ethic boards – community research protocols	Community research needs and how it benefits
	Takes a long time to research/ process	Informed consent for community and individuals	Follow through	Type of community engagement
	Be aware of different faiths/ beliefs	Mindful and respectful of Indigenous worldviews	Community engagement/ involvement/ driven/ beneficial / what are	OCAP – define for community/researchers
	Researcher needs to understand the community and their protocols	Beneficial and impactful to the community	community research needs Interpreters	Research results must lead to action, sustainability for the community
	Focus on strengths instead of deficits	Results lead to something Interpreters to be involved	A good life for all Peoples (Seven Grandfather Teachings)	Research is community controlled
	Interviews can take a long time	Community involvement	Capacity building for researchers and what research	Controlled
	In far North, interpreters are needed	Opportunity for capacity building	is as an on-going practice/ process (collecting data)	
	Understand Indigenous world view Sharing results-follow through	Ensuring that the community is benefiting for the research process (funding, timeframes)	Understanding process of research and availability and benefits on how it would work/benefit them	
	Checklist for communities regarding research protocols	Community driven	(community students) Rebuilding trust = win win	
3	Participation from community members - lack of, disclosure, Elder advise, youth (wanted	Results – community follow up, how does the community benefit, protection for the	Protecting youth for social programming	Building therapeutic relationships with communities
	and needed), ownership, positive opportunities	children (positive for the children)	Funding increases Research process is guided by	Seven Grandfather Teachings (guidance)
	Recognizing signs (negative vs positive), issues	No movement forward when research is completed – there	Seven Grandfather Teachings	NOSM students returning to the communities
	(circumstances), why waiting so long to address	is no follow up Due to results – further hiring	Medical access within the community – MD – home visits, walk-in clinics	Research team becoming part of the community – learning,
	Follow-up (NOSM students – where are they)	of staff for youth programs Need best practices	Protect culture and traditions (respect language)	understanding, participating, building friendships, gaining/ earning trust
	Support teams for issues happening	Need resources to address addictions within the	Good communication	Ensure youth participation – provide opportunities
	Promote NOSM more in communities – support and awareness	communities Use funding wisely and where	Community ownership of results	Have a conversation
	Research results – how does	to access Strategic plan in place	Support groups Elimination of silos (more	
	the community benefit and who owns the results		integration) Primary health care provided	
	Now with research being done - what's going to be done with it; who's going to do it; who's going to pay for it		for community members (number of individuals with no family MD)	
	Opening a can of worms when doing research – who's going to address that (community, big or little research company)		Confidentiality	

Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols /
				Principles
4	Go thru leadership as a harm reduction tool, safety reasons	Share policies with each other	ALL OF THE ABOVE (see previous groups)	Asema (tobacco) first
	Proper credentials (outsiders)	Not all communities are the same – no one size fits all	Self-determination	Seven Grandfather Teachings
	Research ethics policy – orientation, accompanied	- recognize diversities and differences	Community driven	First Nation vision statements Ceremony, spirituality
	by a First Nation person/ community member	Researcher to help build legal cases	Ethics, protocols and working together	Know protocols, traditional medicines, teachings of the
	Kindness and support	Negotiate liabilities	Safety and protection	area
	OCAP	Option to edit/change draft documents	Knowledge protection	Encourage leadership to guide, share info, strategies, inform
	Respect for culture	Ensure Elders and youth are	Transparency	each other about red flags
	Protocol and preparation-it takes time and planning	included in entire process	Community dialogues (build relationships)	Incorporate improvements into policy
	Flexible budget	Transparency (access to budgets, salaries, how NOSM is benefiting	Ensure community members are included (Elders, youth,	Do not rush (anticipate long wait times and plan
	Listening (language and translation)	Accountability – reports	traditional people, land base knowledge)	accordingly)
	How can you collect info/the spirit and intent will direct the	on daily activities, have community initial information, clear deadlines (mutual	Use grandfather teachings	Expertise of health-care centres, heath professionals, staff
	research	responsibility)	Respect each other	
	Free, prior and informed consent (waivers, liability)	Hire community members to help	Hire community members	
	Present research to community	Mentorship for community members to do research	Prepare (have all info, respect for culture	
	Relationship building		Share policies specific to this (human rights watch)	
	Signs not to 'solicit' info			
	Buffer between researcher and community			
	Sanctions			
	Payments for Elders			

Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols / Principles
5	Research that is inclusive and	Develop a standard template	Chronic diseases	Develop standard template for
	respectful	Share models of research	Mental health	research
	Community involvement – research team, language of	ethics	Addictions	Sharing models of research ethics
	the people, priorities, advisory group, research assistant, history of communities,	Pooling data with nearby communities	Child/youth/maternal health	Pooling data with nearby communities
	knowledge keepers	Sharing costs (tribal councils, AHAC's)	Elderly health checks	Practicing traditional protocols
	Contact Chief and Council (BCR)	Understanding health priorities	Connection to the lands	Continue with the
	Contact appropriate	Local community resources (grad students, post secondary, data base)	Language maintaining and learning	representation of community Elders and members in NOSM
	departments		Education	
	Identify specialists costs	Lobby Governments for more	Professionals as role models	
	Involve champions and stakeholders	funding Translators	Incentives/bursaries/ scholarships	
	Shared responsibilities of protocols/policies		Housing/infrastructure	
	Understanding the community (history, ceremonies, community practices)		Water	
	Good understanding of issue			
	'Keep it simple"			
6	Let community have its own voice (stop interfering, dictating)	Interpretation (both ways) Resourcing at every level	Make sure community benefits (information, employment, hall rental fees – all reflected in budgets)	Reciprocity - "A mutual or cooperative interchange of favours, privileges especially the exchange of rights or
	Let community chose and learn from experiences	Knowledge of protocols (they differ, flexible, Christian practices, Traditional practices)	Mutual or co-operative interchange	privileges between nations" Worldview - "A recognition
	Listen to what the priorities are	Collaboration (cross collaboration, partnering,	World views	and acceptance of different views of the universe and our - place in it"
	Take time to build relationships		Reciprocity	- place in it
	Location matters (urban, rural, remote)	Making leadership aware	Understand mutual interests	
	Remote communities may	Understanding community dynamics	Protocols (do your research)	
	miss opportunities due to complex research needs (expense of travel, access,	Making leadership aware	Clear understanding of benefits derived from research (is it measureable, tangable,	
	technology) Community readiness	Approval from Chief and Council and how it is expressed (be flexible, good	does the community walk away with something they can use) Establish a community	
	Suspicious of research	communication, agreements vs no agreements)		
	Interpreted back to the	Understand community	advisory group	
	community	approvals/process	Community champion	
		Participate in community events	Keep it simple	

It has to be valuable and matter to the community Community has to know what 'research' is – education on research and its implications Promote the positive benefits of research Data governance Community advisory committees Requirements for any research going into the community Community advisory community advisory community already has the answers - how this is shared with the broader group -	Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols / Principles
Redistribution of funding so it's more equitable for the community OCAP Making sure community		Starting where community is right now It has to be valuable and matter to the community Community has to know what 'research' is – education on research and its implications Respect community protocols Research takes time Funding does not line up with research timelines Education on the impacts of colonization and ongoing crisis that exists in communities Trust is key Inclusive and protect the vulnerable We have always done research Research has to be community driven Redistribution of funding so it's more equitable for the community OCAP	Community protocols and education Promote the positive benefits of research Data governance Respect time commitment required Implications of research Importance of cultural protocols Learn about the community Learn priorities of the	Full time Indigenous faculty with tenure track Requirements for any research going into the community Community advisory committees Follow advise when given by advisory committees Transparency, accountability, quality assurance, flexibility	Principles Researchers have a big responsibility to the communities and their work so need to – educate themselves about the community – the entire research team - they need to understand that the community already has the answers - how this is shared with the broader group – need to be aware of political, geographic, treaties, PTO's Impact of policy on health

			5.	
Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols / Principles
8	Stats Canada is poor data – collect good data to meet the needs of the community Community collects the data Importance of collaboration Takes time to build good relationships Change the policy and rules of funders Push forward faster with appropriate levels of Governments (what can we do to push forward) Good understanding of culture and history Respect for responses and Traditional Knowledge and not to make own responses Training on how to ask and understand questions and responses (translate into community language) Importance of ethics in research Clear guidelines on what happens with data and who owns it Understand if there is a benefit to the community Still a big differences between north and south communities Be sensitive to the type of research (some areas are not willing to share – specific to certain areas – specific to do the specific to the type of research (some areas are not willing to share – specific to certain areas – specific to the type of research (some areas are not willing to share – specific to the type of research to go hand in hand with Go	Teachings/understandings of natural medicines Implement the changes that are recommended Leadership needs to lobby Government Establish protocols with community in regards to traditional and culture Community driven research Sharing venue for data with other communities (central location, accessible, online portal) Open funding streams for research to communities not just academia Ensure active participation in research by Elders and youth Encourage youth to get involved not only in research by all areas Engage closer connection with community clients served Get the word out that stats Canada is not the best data to use \$ in the research to collect data from Governments Equality between communities when it comes to programming funding as a result of research projects (duplicate programs in other communities) Share information on funders for programs Working together and sharing NOSM needs funds to promote the school in the far north (too much segregation between non-Indigenous and Indigenous students) Cultural training for researchers	Resources (human, funds) equal distribution and accessible Elders are our resources – most valuable so capture their knowledge) Connecting Elders with youth Take the time to understand the Elders Understand medicine people Reconnecting our leaders with our Elders Ethical and cultural sensitive research in our communities Funds available to communities for research Clearly define who owns data and what can be done with it Engage youth – more active in all processes	Seven Grandfather Teachings Community acceptance and engagement Clearly spell out who owns data and what can be done with it Who is going to pay for it Develop a plan for follow through Use of community advisory groups Make funding accessible by communities Specific for NOSM Publish how Elders are utilized and what are their voice within NOSM Advertise NOSM on APTN and Wawatay (native media) Incentives for graduating MD's to practice in the North

Group	Lessons Learned	Moving Forward	Priorities	Guiding Protocols / Principles
9	Get the results back to the community in an understandable way Culturally relevant Community involvement at all stages Leaving people out causes confusion and negative feelings Community understanding of entire research process and what will be done with the data Monetary (extrinsic) incentives to participate in research can be offensive Language is important	Data ownership Community driven (relevant to what's actually happening in the community) Community meetings (leadership, membership, participants) Identify potential outcomes and how to make it sustainable Action oriented (must lead to actions and positive changes) MOU with all steps of research (including Indigenous knowledge and action) Capacity building	Long-term effects of opiates on children whose mothers used during pregnancy Effects of parent behaviours on children (parents leaving children alone) Traditional medicine as a replacement for methadone How to transition off methadone How to increase engagement when competing with technology Cancer screening Phone addiction Diabetics Heart disease Hypertension Skin conditions Traditional foods vs processed foods Addictive properties of foods Processed foods and diabetics	Trust and how to develop relationships Seven Grandfather Teachings Include Elders in approval processes Métis Nation of Ontario guiding principles (statement and primary purpose)





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