

Researched to Life: a Report on the IHRDP Northern Aboriginal Health Research Workshop October 4 & 5, 2011, Valhalla Inn, Thunder Bay, Ontario

Background

For the past two years, the IHRDP has been discussing ways to better engage communities and researchers in the Northwest. One of the suggested mechanisms was to undertake a Northern Ontario Health Research Workshop. The workshop was aimed at giving First Nations and Aboriginal health



organizations an opportunity to share research knowledge and experience, and to answer questions or concerns about research that might exist among Northern Ontario participants.

The purpose of the Northern Ontario Health Research Workshop is to build health research capacity or research readiness in selected Northern communities and organizations. The workshop was also used to inform Northern communities of the work of the IHRDP and the IAPH, and to increase research readiness so that communities

are able to engage in health research, develop research partnerships, and ensure that

research is conducted in an ethical manner, with respect for local needs and Indigenous ways of knowing. One of the objectives of the workshop will be to establish relationships between specific researchers and community contacts so that sustainable university-community relationships are begun.

"It's another piece of a puzzle being fitted together..."

Feedback from participant

Specific Objectives

- To Inform participants about IHRDP objectives, student scholarships and community based research funding
- To make participants aware about other NEAHRs, in particular NAMHR
- To outline the implications of CIHR's Guidelines for Health Research involving Aboriginal peoples.
- To facilitate networking between Aboriginal communities who have experience in health research, and those who do not
- To determine if community based priority areas for health research exist in specific communities
- To develop Nation to Nation mentoring for First Nations who may wish to engage in research

Introduction to the Workshop

The Indigenous Health Research Development Program (IHRDP) Aboriginal Health Research Workshop was held in Thunder Bay on October 4th and 5th, 2011. The meeting Elder was Joseph Morrison from Longbow Lake, near Kenora, Ontario. The workshop was facilitated by Mariette Sutherland. The IHRDP was represented by co-investigators Kristen Jacklin, Marion Maar, Bruce Minore and Wayne Warry and

by IHRDP Board members Kim Anderson and Paulette Tremblay, and the IHRDP Coordinator, Valerie O'Brien. There were 30 participants representing First Nations, communities and organizations from across the North, including those from Treaty Three and NAN, ONWA, the Ontario Métis Association, Aboriginal Health Access Centres, as well as academic researchers from Lakehead University, and Ingeborg Zehbe of the Thunder Bay Regional Research Institute. A full list of participants is attached as Appendix 1.



The workshop opened with introductions, a review of the agenda, and an overview of the Indigenous Health Research Development Program. The agenda is attached as Appendix 2.

Day one was organized around the sharing of information about the IHRDP, the NEAHR network, and the Institute of Aboriginal Peoples' Health. Manitoulin Island community representatives Mary Jo Wabano, Health Director of Wikwemikong Unceded First Nation and Lorrilee McGregor, a consultant and PhD student who Chairs the Manitoulin Research Ethics Committee were guest presenters. They shared their experience with research partnerships and the creation of a regional Aboriginal Ethics Committee that now reviews and approves most health research in the region. These presentations were followed by a panel discussion highlighting different types of research and the rewards and challenges of community based research. Day One ended with small group discussions aimed at identifying key research priorities for the communities in Northwestern Ontario and James Bay.

Day Two began with a member-checking review of the key research priorities identified the previous day and then moved to focused small group discussions concerning research readiness and capacity building. Day two included presentations by Annette Schroeter, Aboriginal Research Facilitator from the Lakehead University Research Office; and, by Dr. Wayne Warry, McMaster University and IHRDP,

"We have needed to learn about this for a long time!"

Feedback from participant

who discussed how research is funded by the major granting agencies, such as the Canadian Institutes of Health Research, federal and provincial governments, and Foundations. The workshop ended with a large group discussion on next steps and on how individuals could maintain connections and support each other in developing better communication and capacity about research.

Day One

Guest Presenter - Lorrilee McGregor

Lorrilee McGregor gave a presentation on the Manitoulin Anishinaabek Research Review Committee and the Guidelines for Ethical Aboriginal Research (GEAR).

The presentation included an overview of how and why the communities moved towards formal research procedures, for example, some previous researchers not reporting back, or not consulting with

community prior research. She also reviewed the 5 R's of research: respect, relevance, reciprocity, responsibility (Kirkness and Barnhardt 2001) and relationships (Wilson 2001), finally discussed how they went about the



development of their community-run ethics board. Many workshop participants were interested in the possibility of the development of a Northwestern Ontario-based Aboriginal community-based ethics review process. Co-investigators of the IHRDP indicated that they would be available to help in the development of a research ethics process for NW Ontario. The Manitoulin Ethics Guidelines, and the form and questions that researchers answer is posted on the IHRDP website at: www.ihrdp.ca

The presentation generated discussion on a number of topics. These included relationship building and community partnerships. The idea that research is a journey was discussed, as it can be unpredictable, and in the long term can grow in unexpected ways. Lorrilee McGregor's presentation slides are attached as Appendix 3, the Manitoulin Anishinaabek Research Review Committee, Guidelines in Ethical Aboriginal Research can be found at:

http://www.noojmowin-teg.ca/SitePages/MARRC.aspx

and is also found as a link on the www.ihrdp.ca website.

Guest Presenter – Mary Jo Wabano

Mary Jo Wabano, Health Services Director of the Wikwemikong Health Centre, gave a presentation on the development of research projects over a ten-year period at Wikwemikong. She provided advice on what makes research successful. Mary Jo described the process of building relationships with university-based researchers, and how one research project can naturally lead to another over time. She stressed some of the difficulties from a management perspective in freeing up staff time and human and financial resources that are necessary when research occurs. She also noted that researchers should be expected to bring resources to the community, and to train staff or volunteers in research methods.

Both presenters took questions from participants. Questions focused on the practical process of how an

Ethics Board might be established. In the ensuing discussion it was noted that preliminary consultations would have to be held with Chief and Council or relevant leadership. The possibility of research training for Health Directors was also mentioned.

Both these presentations emphasized the appropriate approach to research is community-based research and participatory action research. This is the model of research promoted by the IHRDP where communities are priorities, are central to the process, and communities are full partners throughout the research process. This style of research allows for community control over the end products of research and is in keeping with Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, "Research Involving The First Nations, Inuit and Metis Peoples of Canada', with the CIHR Guidelines on



Health Research with Aboriginal peoples, and with the principles of Ownership, Control, Access and Possession (OCAP) promoted by the National Aboriginal Health Organization. These documents were provided as an electronic resource (USB key) to participants at the workshop. The links for these are:

Panel on Research Ethics, Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans

http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter9-chapitre9/

Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research http://www.naho.ca/documents/fnc/english/FNC OCAPCriticalAnalysis.pdf

and are also found at the IHRDP website <u>www.ihrdp.ca</u>. Mary Jo Wabano's presentation slides are attached as Appendix 4.

Panel Discussion: Community-based Research: Challenges and Successes

Panel: Lorrilee McGregor, Chris Mushquash, Marion Maar

Dr. Chris Mushquash gave an overview of his history as a graduate student researcher, and IHRDP funded scholar, and his recent appointment as Assistant Professor at Lakehead University. He discussed in detail his PhD research which included the development of culturally relevant interventions for alcohol abuse in Aboriginal youth.

Lorrilee discussed her current role as a graduate student, and IHRDP funded scholar, and the process she undertook to arrive at her research questions for her PhD thesis. Her interests included physical activity and nutrition in youth. Her community engagement process included consulting with community members, health staff, Elders, and youth to confirm whether this was a relevant research area for their community. Her research proposes to focus on children, and the concerns around low levels of physical activity and nutrition choices.

The challenges of being an Aboriginal researcher or living in the community were discussed by the panelists. It was felt that there is more pressure to do a good job and that being in the community



might give you the opportunity to be listened to but you still have to build the relationships. Researchers also have challenges with maintaining relationship with the community and the different requirements within the university. Ethics boards don't always understand there may be different protocols necessary when doing research in Aboriginal communities.

The issue of confidentiality was also discussed. As a local/insider researcher, there is the potential to be interviewing someone you know. The issues around data storage and confidentiality were also discussed. The idea that OCAP may be taken too far was expressed as a concern. It was suggested that if all raw data must be stored in community it would be possible that participant data may be accessed by fellow community members in future, for example, when there is staff turnover. It was suggested that participants need to be told the risk of having their information shared or seen by community members and that there is a need for to discuss a protocol that would have summary data stored at the community but not the raw data, in order to protect the privacy of participants.

Dr. Marion Maar recounted her experience as a researcher at Noojmowin Teg Aboriginal Health Access Centre prior to her coming to the Northern Ontario School of Medicine. She stated how her research there was not academic or aimed at publication and made the point that research is very complex -- one

research project can have multiple topics and research questions. She noted that communities may have many different research priorities and that community based research could produce information that allowed communities to be prepared to respond to the funding opportunities that arise. She provided examples of diabetes research which focused on improvements in clinical care and health promotion.

The panelists then responded to questions from workshop participants. These questions concerned a range of issues related to research capacity and readiness, including how "Would be great to see more examples of research partnerships between researchers and Aboriginal peoples and showcase results."

Feedback from participant

research topics were determined and projects were started; relationships between communities and researchers; the challenges researchers' faced and what lessons were learned. It became clear that community engagement and relationship building was a time consuming but necessary part of the research that needed to be done 'up front' of specific projects.

From the discussion, it became clear that there are hidden costs of research for health directors or communities that want to be involved with research. These include staff time, the time to set aside for

meetings, and training. Outside researchers, especially graduate students, commonly have small amounts of money to train community members and to pay for researchers, who may be staff on secondment or who continue to work part time. Without adequate compensation, research is not sustainable and taxes the time and energy of existing workers. Dr. Chris Mushquash noted that research methods can be adapted to minimize the time of research or interventions and that by working with existing community partners, research can be sustainable.

The discussion also acknowledged many challenges with knowledge translation and the difficulties of getting research results back to communities in a way that was useful, positive, and productive.

Lorrilee McGregor notes that participation in research, particularly on sensitive topics such as mental health, require that researchers put supports in place such as referrals to mental health professionals, so that participants are protected should the research questions be difficult or troubling. The panelists noted that in their experience the real 'payoff' from research was the personal impact of research — the creation of relationships and learning from the community that were sustained over time. Dr. Maar suggested that outside researchers often provided communities with technical knowledge and could assist in bringing together different types of knowledge pieces of the research that could helps communities to figure out solutions to various health care issues.

Northern Research Needs and Priorities: Small Group Discussion

In the afternoon of Day One, four small groups met with the aim to identify research priorities within their communities. Many ideas were brought forward and they are summarized below into 8 broad priority areas.

Research Priorities

1. Environmental Health

- Care for Mother Earth/ Indigenous understandings
- Baseline health and social surveys, especially concerning contaminants mercury and gold
- Water quality monitoring Rainey Lake Ring Of Fire
 - Safety and health of fish -social impacts, family issues, financial issues
- Housing, mould, asthma, allergies



A lot of the small group discussion focused on specific issues that would broadly be labelled Environmental health. This included specific issues around contaminants in the food chain that result from Industrial pollution and impact on hunting, fishing and other aspects of people's everyday lives and subsistence. There were concerns also about the social impacts of employment in the Ring Of Fire, and the difficulties that large scale economic development potentially bring, in terms of family relations, financial relationships, alcohol use and so forth. There was a need expressed for baseline research that would allow communities to see these impacts over the long term. Participants also suggested that Indigenous ways of knowing and understanding the environment and Mother Earth must be built into research concerning Environmental health and wellbeing.

2. Addictions

- Prescriptions/Street drugs/alcohol use
- Severity impact and solutions
- Lifestyle –treatment off reserve social and lifestyle impacts
- lack of access to facilities in the
 12-14 years age group
- Dry communities lack of literature about how to implement it
- Solvent use increase?
- Smoking and Smoking cessation/Band Policy



Small group discussion included many topics that could be labelled "mental health" but specific issues also concerning addictions —both of prescription drugs (a concern across the North and more broadly) and a potential increase or return to Solvent use among youth. Participants mentioned that there was a shortage of programming on addictions, including a lack of smoking cessation programs, and a lack of treatment spaces in the 12-14 year age category. The need for leadership, including Band By laws and policies around smoking, alcohol and other substances is a priority for action and research.

3. Mental Health

- Mental health all age groups, adult children and youth
- Residential school abuse
- Suicide
- Physical, sexual, and emotional abuse
- Lack of mental health programming/policy

Mental health is a priority area of Aboriginal health research and the small group discussion noted many issues that are well identified in the literature, including Residential School Syndrome and Historical Trauma, and the impact of these on the mental health of children and adults. There is a need for applied research that can lead to long term policy change – the development of Aboriginal specific, mental health policies and programs for all age groups, but particularly for children and youth who are at increased risk of suicide and risk taking behaviours.

4. Health Systems, Quality of care and Access to Care

- Racism and different standards of care,
- For Elders
- Health care provider patient information
- Lack of access to traditional healers/care
- Cultural Competence and Safety
- Continuity of Care, after care and discharge, interrupted care, early discharge
- Diagnostic services screening, children going into foster care only way to get assessed
- Federal Provincial and LHINS jurisdictional issues
- Travel and Transportation
- Telemedicine
- Access to specialty and diagnostic/screening care
- Health Human resources
- Health programs and service required at local level
- How to interest youth in health careers

Almost all of the topics mentioned above and below are connected to a major theme that came out of each of the groups —the poor access to quality health care that Aboriginal people face when compared to mainstream Canadians. This problem was clearly identified as stemming from racism within the health care system and differential access to resources and to culturally specific or appropriate care for Aboriginal patients and their families. A number of specific examples of problems concerning access or barriers to care were mentioned across all age groups. This "research theme" was dominant in many ways during small group discussions and suggests the need for comprehensive inquiry or research into health systems and health care delivery for Aboriginal peoples in the North.

5. Chronic Disease

- Cancer, Diabetes, Heart Disease, High Blood Pressure
- Knowledge Translation, communication and health education
- Direct service care, Elder Care

Small group discussions also focused on the continuing need to understand chronic disease in the Aboriginal context, in terms of the causes of illness and patterns of co morbidity (patients who have multiple health concerns) and with the aim of conducting research that can lead to better health treatment, prevention and health promotion for these diseases.



6. Health Promotion and Education

- Prenatal
- Breastfeeding and nutrition early child development
- Sexual Health
- HIV STIs promotion and prevention and follow up after care
- Knowledge Translation, adapting existing resources
- Children's care, preventative care and education
- Dental and oral care
- Recreational opportunities
- Healthy foods and nutrition,
- Traditional food

The small groups noted the need for research that would generally be understood as focused on health promotion, education and knowledge translation. There is a need to adapt mainstream health promotion materials in a way that they are relevant to First Nations and urban Aboriginal communities. Knowledge translation and 'intervention studies' are increasingly a priority with the Canadian Institutes for Health Research, so that this type of research may present opportunities for northern communities and researchers.

7. Social Determinants of Health

- Education and health
- Food security, gardens, access to nutritious foods
- Community food vouchers, food access, food security

- Healthy food and nutrition
- Traditional foods
- Housing

Much of the small group discussion noted the (w)holistic nature of health and how health was so closely connected to people's social, spiritual, economic and political needs. These discussions can be summarized as acknowledging the importance of what in the literature is known as the social determinants of health. Specifically, there is an awareness that many issues tied to nutrition and healthy lifestyles are linked to the need for sustainable economic environments, improved access to traditional foods or issues of "food security "as they are known in the health literature. Some research on community gardening is already taking place at Lakehead University. The need for research into these issues is seen as another priority for North.

8. Research - How to

- Community health surveys
- Access resources and training
- Have research as benefit rather than a burden
- Sustainability and knowledge translation
- Access to information advocacy for existing information
- Use of own data

The final area of common concern across the small groups was "research readiness" and the lack of knowledge, resources and training that are available to communities who might wish to conduct research. This of course was the focus of the workshop itself, and so many of these comments were mentioned throughout the two days. One challenge is getting information that already exists about key health research to communities. Another is that communities often gather information by way of reporting requirements that goes to government — but never is returned to the community in a meaningful way. Advocacy is needed to have various government agencies provide good information

"Learned a lot from community presentations about how IHRDP funding and relationships makes a difference in community."

Feedback from participant

that might be of benefit to First Nations or Aboriginal organizations.

As a result of these discussions, the IHRDP will explore ways of following up with communities, and with Lakehead University, to promote ways to increase training and capacity for research including exploring the possibility of holding additional workshops or training that might increase research readiness in the North over time.

Day Two

Day Two began with a summary of Research Priorities from Day One given by Drs. Kristen Jacklin and Wayne Warry. This was an opportunity to "check-in" and reflect as a group. This whole group review led to some revision and clarification of the key points listed above.

This presentation was followed by a break out session involving two large groups, one involving participants from Lakehead University and Thunder Bay Aboriginal Organizations, and a second involving representatives from First Nations in the NAN and Treaty Three areas. The Group discussions focused on research readiness and capacity building and specifically, what local communities and organizations could do, or needed assistance in accomplishing.

These conversations are summarized below:

Group One - First Nations and Community Perspectives

The group discussed the possibility of having an inventory of research and researchers in the north, with a comment that there are not a lot of experts in NW Ontario, so they should have a wide scope. They agreed there would be benefits to having a network of people who do Aboriginal research, from the university, hospital, the medical school, Thunder Bay Research Institute and Confederation College as well, and that it would be important to include First Nations, Metis organizations, PTOs, and NAN, Treaty 3, etc. in the network.

It was acknowledged that a barrier to networking and working together is that organizations are competing for the same funds. Then sharing information becomes difficult. It was suggested that if a network were in place, collaborative projects would be more likely and possible; perhaps the network could facilitate such projects.

The idea of an annual conference for Aboriginal health research was suggested and that champions who are conducting research and who have Aboriginal health research experience could be invited. The conference could become a mechanism to understand research needs. A job fair analogy was used. It was also mentioned that a lot of organizations have data from Health Transfer and other sources, and these data have potential to be analyzed in other ways. For example, ONWA just collected a large amount of data on sex trade worker, which is a wealth

Community perspectives

- "Spend time with participants to appreciate and respect the person's level of knowledge to ensure a mutual understanding"
- "Do not rush things. The data researchers are collecting in a survey will not be accurate if they do not respect people in this way, because often community members will go off on a tangent on purpose when they feel the researcher is not respecting them."
- "Always have an interpreter for Elders who are more comfortable in their language."
- "Be aware that meaning of off-beat remarks by research participants are easily misinterpreted. The same can also be true for humor in general. Make an effort to appreciate peoples humor!"
- Appreciate the silence; silence may mean that people are figuring things out. If you rush people a barrier will come up.

hoto by Wayne Warry (IHRDP/McMaster

of information. However, there are not always resources to analyze the data, or to get it to people in a way that facilitates its use.

Having a database that includes graduate students could provide good opportunities for research. Students could partner with Aboriginal organizations to address issues of concern. The point was made that graduate students have only 2 years or so to finish their research but that it could still be a very rich source of information.

Further comments on the benefits of a database or inventory of research and researchers included the comment that what is needed is a better formal process for linking organizations with researchers, and a listing of what faculty members are interested in. The idea of a website to post RFPs or calls etc, it could act as a virtual clearinghouse.

There was some discussion of the role of Annette Schroeter and about what the Lakehead vision of Aboriginal Research Institute was. The group hopes to follow up with the IHRDP to explore ways the IHRDP could collaborate with Lakehead to keep Aboriginal Health research as an ongoing priority.

Group 2 Treaty 3 and Fort Francis, Kenora

The group discussed their communities and the overarching leadership within their regions, the role of Treaty three to the communities, and that they would like to have someone who knows about all the research going on in their region, perhaps a centralized data base. The idea of a checklist and protocol for researchers was discussed.

Issues of ownership and government control over data that is relevant to Aboriginal communities and not giving back the information to the community were discussed. They stressed the importance of having the raw data stay in the community. Terms of reference should be developed from the bottom up so that researchers understand the process of engagement and appropriate protocols for conducting research in their communities.

In the ensuing discussion it was also mentioned that under Health Transfer First Nations can usually expect to receive up to \$20,000 for evaluation of their Health programs, and that if the evaluation is at the Tribal Council level then there may be \$60,000 available depending on population sizes. Finding an Evaluator who is sensitive to community needs or to community based research is important. It is sometimes possible to have specific research needs met by building them into these Health Canada evaluations. Most evaluators are accredited or recognized as members of the Canadian Evaluation



Society http://www.evaluationcanada.ca.

The Kenora Group indicated that they would like to develop structure and guidelines for research, and again expressed an interest in developing their own Ethics Committee. They acknowledged that there are already resources available, surveys that have already been done, and that they would like to develop overall guidelines for the region, and then communities can use that to individualize for each community if they choose to. But the group also

expressed concern that it would be difficult to find funding for this kind of development work and it wasn't clear who would or could take on a leadership role. The group also discussed the need for advocacy around research and taking research to leaders to be advocates for change. The IHRDP will be following up with Treaty Three about a possible workshop in 2012 and will try to help to move the idea of an Ethics committee forward. Annette Schroeter at Lakehead indicated that they are looking at protocols, ethics and guidelines so she may also be able to facilitate some of those activities.

The Group also noted a number of concerns and potential risks associated with research. These included questions of how research gets approved and community control over interpretation, and how communities are represented. Community interests sometimes are different than researcher's agendas and researchers need to publish. There is a need to develop protocols between communities and researchers before the research begins, and to talk about publication and other ways of using research data that can be easily misrepresented.

The group expressed a need for empowerment at the community level with a suggestion that a way to achieve this might be through the development of community research plans.

The importance of maintaining connections and supporting communities was discussed, along with the idea of a coordinating research group and what that might look like. Because there is such a large geographical area, there is a need to think about a number of things, including regional differences. The Independent First Nations Alliance includes First Nations belonging to three different Treaty groups, so it was suggested that the wider the scope of a data base the more it would benefit their group.

It was suggested that one of the positive aspects is that there are some communities that are further along in that they have participated in research and that others could learn from them, and perhaps a database could be created including the research they have completed, and thus, a template of sorts is developed so that other communities interested in participating in research wouldn't have to reinvent the wheel.

The group discussed the issue of ethical conduct of researchers and that there should be a way communities for learn about how well (or un-well) researchers worked have with Aboriginal communities in the past. They suggested that there should be a "Rate your researcher dot com."



Dr. Kristen Jacklin advised that communities should ask researchers for references. For student researchers, ask about their supervisor's experience with communities. The group had questions about how to read an academic CV, and how to interview researchers. It was suggested that the Manitoulin and Six Nations Ethics documents should be shared with communities. The idea of the need for a template, and overall research guidelines that can be adapted to different communities was discussed. Communities could adapt ethics guidelines that have been used at Six Nations and on Manitoulin Island. The links to these guidelines are:

Six Nations Council Research Ethics Committee Protocol http://www.sixnations.ca/admResearchEthicsProtocol.pdf

Manitoulin Anishinaabek Research Review Committee, Guidelines in Ethical Aboriginal Research http://www.noojmowin-teg.ca/SitePages/MARRC.aspx

and are also listed on the IHRDP website at www.ihrdp.ca.

Because the IHRDP investigators have an awareness of a wide number of researchers, they could potentially assist communities in helping them assess researchers CVs or experience.

"...let's do more and keep reaching out to leaders and 'champions' in communities."

Feedback from participant

Following the reporting back of these groups, Annette Schroeter gave a presentation of the roles and responsibilities of her position as Aboriginal Research Facilitator at Lakehead University. Annette Schroeter's presentation slides are attached as Appendix 5. Annette is new to her position but expressed interest in working with communities and through Lakehead to follow up on some of the issues raised at the Workshop and will also continue to communicate with the IHRDP on activities that may result from the workshop discussions.

Day Two also included a presentation on Research funding by the Canadian Institutes of Health Research and a discussion of research from the perspective of university-based researchers. CIHR presentation slides are attached as Appendix 6. Aboriginal Health is now a priority for all of CIHR's Research Institutes in addition to the focus of the Institute of Aboriginal Peoples' Health. The other major social science funding agencies, The Social Science and Humanities Research Council (SSHRC) funds a variety of research on education, culture, heritage and other issues that may also be of interest to communities. The IHRDP funds "seed" projects which allow communities to work with university based researchers or students to begin the research process and over time to potentially leverage larger funding from the major government agencies or from Charitable or Health Foundations.

Closing Session

The workshop ended with Mariette Sutherland leading a whole group session she called "Requests, Offers and Commitments". Participants were asked to share what they requested by way of follow up or hopes for the future and were encouraged to offer specific ideas or make commitments that would move Northern research or specific research initiatives. There was considerable recognition that building research readiness or capacity for research is very difficult, particularly given the lack of financial and human resources available in the north. As one person said, there is a need for

communities and researchers to go forward safely, to take our time, and to walk and not rush ahead. Participants also framed many comments in the context of future generations. We need to question who most benefits from research, and change the environment so that communities, and not university researchers, are the ones who benefit and to continue to think of the benefits of research for our children and grandchildren's generation.

We consider the workshop a success because it provided the opportunity for Aboriginal people across Northwestern Ontario to connect with researchers at Lakehead University, McMaster University, and the Northern Ontario School of Medicine who might potentially partner in research in the future. It facilitated the exchange of knowledge and provided practical information and tools such as electronic resources on research, research ethics and practice that may be of use to communities and organizations. Several individuals committed to staying in touch or maintaining connections. There is the hope that Lakehead researchers will pursue means for more regularly sharing information and through the Aboriginal Research Facilitator's office, will attempt to build on existing community connections.

In closing comments one participant expressed a desire to see put in place rules to "protect our people" and mentioned that communities often felt "researched to death." Research should not be a burden on communities and people should not be taken advantage of by outsiders. In the words of this participant, there was hope that communities could really control research and that they could gain information that would help their people so that instead, their communities would be "Researched to Life."

Examples of requests, offers and commitments that were made at the conclusion of the workshop

"Community empowerment in research" suggested as topic for future workshop

Feedback from participant

included a request from Treaty Three to hold another workshop focused specifically on health research guidelines and research ethics. The commitment of the IHRDP is to sustain contact with Treaty Three and to hold a Research Workshop specifically designed for their communities in 2012The IHRDP also committed to sustaining contact with key workshop participants in order to keep northern issues a priority ("high on our agenda")

and assist, whenever possible, students and researchers in the development of projects. The IHRDP also agreed to follow up on discussions at the workshop by making available for example, e-links to the Manitoulin Anishinaabek Research Review Committee and the application forms that are used to assess "outsider" research. The IHRDP has posted inks and documents given at the Workshop on its website at www.ihrdp.ca. Other links, for example, to the Canadian Evaluation Society, the CIHR and NEAHR Networks are also available at the IHRDP website.

The IHRDP would like to thank all of those individuals who participated in the workshop for taking the time out of their busy schedules to contribute their thoughts and experiences. A special thank you to Elder Joseph Morrison for his guidance and his words, and to those who presented: Annette Schroeter, Dr. Marion Maar, Lorrilee McGregor, Dr. Chris Mushquash and Mary Jo Wabano. Finally, our special thanks to Mariette Sutherland for her facilitation of the workshop.

Appendix 1

Researched to Life: a Report on the IHRDP Northern Aboriginal Health Research Workshop October 4 & 5, 2011, Valhalla Inn, Thunder Bay, Ontario

Participants

Name Community/Organization

Connee Badiuk Waasegiizhig Nanaandawe'iyigamig AHAC

Jason Beardy Nishnawbe Aski Nation

Marlis Bruyere Fort Francis Community Clinic Gizhewaadiziwan AHAC

Karen Drake Metis Nation

Jocelyne Goretzki Kenora Chiefs Advisory

Edna Hodgkinson Gull Bay

Wayne Hyacinthe Grassy Narrows

Melanie Hyatt Anishinaabeg of Naongashiing (Big Island)

Mary Lou Kelley Lakehead

Betty Kennedy Ontario Native Women's Association

Christina Linklater Moose Cree First nation

Lynda Lynch Lake Nipigon

Noella Mandamin Anishinaabeg of Kabapikotawangag Resource Council

Lorrilee McGregor Manitoulin Research Ethics Committee

Chris McLeod Métis Nation of Ontario Rosie Mosquito Oshki-Pimache-0-Win

Chris Mushquash Lakehead Erica Perkins Pic River

Georgina Redsky Dilico Anishinabek Family Care
Allen Sailors Moose Cree First Nation

Annette Schroeter Lakehead

Terry Skead Wauzhushk Onigum

Cheri Stanley Gizhewaadiziwin Health Access Centre

Tyrone Tenniscoe Seine River
Mary Jo Wabano Wikwemikong

Gail Winter Independent First Nations Alliance (IFNA)
Stephanie Wrolstad Fort Frances Tribal Area Health Authority
Ingeborg Zehbe Thunder Bay Regional Research Institute

Fay Zoccole Lakehead

Joseph Morrison Elder Mariette Sutherland Facilitator

Kim Anderson IHRDP

Kristen Jacklin IHRDP/NOSM Marion Maar IHRDP/NOSM

Bruce Minore IHRDP/Lakehead/CRNHR

Valerie O'Brien IHRDP Paulette Tremblay IHRDP

Wayne Warry IHRDP/McMaster

Appendix 2



Northern Aboriginal Health Research Workshop

Valhalla Inn, Thunder Bay

October 4th, 2011

Day One

8:00-9:00	Meet and greet, continental breakfast – Viking room
9:00-9:45	Opening Prayer (Joseph Morrison, Elder) and Introductions
	Review and Discussion of Agenda
9:45-10:15	Overview of IHRDP: Wayne Warry - Examples of Funded Research
10:15-10:30	Nutrition Break
10:30-11:30	Sharing Our experience: Research and Research Ethics on Manitoulin Island Mary Jo Wabano and Lorrilee McGregor
11:30-12:00	Q and A session
12:00-1:00	Lunch
1:00-2:00	Panel Discussion: Community Based Research: challenges and successes Panel: Lorrilee McGregor, Manitoulin Research Ethics Board Chris Mushquash, Assistant Professor, Lakehead University Marion Maar, Associate Professor, Northern Ontario School of Medicine
2:00-2:15	Nutrition Break
2:15-3:00	Northern research needs and priorities: small group discussion
3:00-4:00	Large group forum: reporting back and discussion
6:00 Dinner:	Bistro 1, 550 Dunlop Street

Appendix 2



Northern Aboriginal Health Research Workshop

Valhalla Inn, Thunder Bay

October 5th, 2011

Day Two

8:00-9:00	Meet and mingle, continental breakfast – Viking room
9:00-9:30	Day One Review
9:30-9:45	Aboriginal Health Research Funding Structures (IHRDP, NEAHR, CIHR/IAPH, Foundations, other)
9:45-10:15	Small Group discussion: Research readiness and capacity building - in your communities - In organizations (universities, hospitals, etc.)
10:15-10:30	Nutrition Break
10:30-11:30	Reporting Back and general discussion
11:30-12:00	Small Group Discussion: Next Steps: maintaining connections, supporting communities
12:00-1:00	Lunch
1:00-2:00	Large Group forumReporting Back
2:00-2:15	Nutrition Break
2:15-3:00	Large Group discussion, key messages and final thoughts
3:00	Closing Prayer





Aboriginal peoples and research

- First Nation communities are often contacted by academic researchers to participate in health research projects.
- Many First Nations conduct their own research to gather reliable data to support communitybased initiatives.
- Health services are now being delivered by First Nation communities who need data on health status and program effectiveness.

Concerns about research in First Nation communities

- Numerous research activities cause community members to experience 'research fatigue'
- Research results not shared with the participating First Nation communities.
- Research did not lead to any changes or actions and has not led to improved community health
- > The ethical conduct of some researchers has been questionable.

Indian Tribe Wins Fight to Limit Research of Its DNA



http://www.nytimes.com/2010/04/22/us/22dna.html?ref=health

Proactive approach to research

- A community-based health research conference was held on Manitoulin Island in March 2001.
- Brought together health care professionals, community members, Elders as well as local and university-based researchers
- Participants created a vision for ethical health research on Manitoulin. A working committee was formed to make that vision into a reality and the Guidelines for Ethical Aboriginal Research (GEAR) were developed.

Our Vision for Culturally Appropriate Research

> To contribute to community empowerment through research and to ensure proposed research projects focus on ethical and respectful partnerships with Aboriginal communities within the Manitoulin Island District.

Development process

- Summer and fall of 2001 working group sought support for the development of ethical research guidelines from 4 health boards and the tribal
- > In 2002, discussion groups were held with community members who were knowledgeable about local Aboriginal culture and community
- > In 2003/2004 draft guidelines were presented to the health boards and the 7 band councils for review and support.

Guiding Values

- > Research topic should be relevant to the First Nation communities.
- > Research must have a direct benefit on community health.
- > Research projects should be a collaboration with the First Nation community and have the guidance of a local steering committee.
- Build local capacity for research.
- Researchers should respect the diversity among and within First Nation communities.

Guiding Values

- > OCAP Ownership, Control, Access and Possession: Understand that First Nation communities will want to protect the collected data. Ownership and publication will need to be agreed upon.
- Produce documents which are useful for communities and agencies.
- > Traditional knowledge must be protected.
- Research methodologies must be culturally acceptable to the First Nation communities.
- Traditional values should be incorporated into the research approach.

Seven grandfather teachings

- Respect
- Bravery
- Truth
- Humility Honesty
- Love
- Wisdom

Community perspectives

- "Spend time with participants to appreciate and respect the person's level of knowledge to ensure a mutual understanding."
- uncerstanturig:

 not rush things. The data researchers are collecting in a survey will not be accurate if they do not respect people in this way, because often community members will go off on a tangent on purpose when they feel the researcher is not respecting them."
- "Always have an interpreter for Elders who are more comfortable in their language."
 "Be aware that meaning of off-beat remarks by research participants are easily misinterpreted. The same can also be true for humor in general. Make an effort to appreciate peoples humor!"
- "Appreciate the silence; silence may mean that people are figuring things out. If you rush people a barrier will come up."

Manitoulin Anishinaabek Research Review Committee (MARRC)

- The main function of the committee is to evaluate research proposals and to build capacity for ethical Aboriginal research in the Manitoulin area
- Try to ensure representation on the committee from three different groups.
- Committee members are dedicated volunteers.



Review process for research projects: Medicine wheel Western Downwy Completion of Project - The East represents the birth of a research project which is shared with the First Nation community and/or organization - Research proposal is referred to the Manitoulin Anishinaabek Research Applicant either receives approval or receives recommendations for changes to enhance the project which is shared The research applicant either receives approval or receives recommendations for changes to enhance the project - The project begins it's poumey from the Eastern to the Western Doorway (signifying the project from beginning to end)

Tri-Council Policy Statement

Research projects are also expected to adhere to the TCPS

- > 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 harm and benefits
- Minimizing harm
- Maximizing benefit

CIHR Guidelines for Health Research Involving Aboriginal People

- 1. Reconciliation of ethical spaces
- 2. Sacred space and traditional knowledge
- 3. Community control and approval process
- 4. Participatory research
- 5. Community and individual consent
- 6. Confidentiality/privacy
- Inclusion and protection of cultural knowledge in research

CIHR Principles of Ethical Aboriginal Health Research

- 8. Intellectual property rights and indigenous knowledge
- 9. Benefit sharing
- Empowerment and research capacity development
- 11. Cultural protocol, language and communication
- 12. Biological samples
- 13. Interpretation and dissemination of results
- 14. MOUs and research agreements

5 R's of Research

- > Respect
- > Relevance
- Reciprocity
- Responsibility (Kirkness & Barnhardt, 2001)
- > Relationships

(Wilson, 2001)

Other Aboriginal community driven research ethics processes

- Akwesasne Environmental Task Force
- Cree Board of Health and Social Services of James Bay Research Ethics Policy Advisory Committee
- First Nations Environment Health Innovation Network
- Kahnawake Schools Diabetes Program Code of Research Ethics
- Kwanlin Dun First Nation
- Mi'kmaw Ethics Watch
- 2008 North American Indigenous Games

Where are we now?

- MARRC members have made 19 presentations to various organizations and conferences.
- MARRC has reviewed 30 research proposals since August 2005.
- Terms of Reference and Work Book have recently been revised. A Strategic Planning session was held in July 2009 and a consultation with Elders was held in August 2009.
- Planning a research conference to celebrate 10 years of ethical research on Manitoulin Island.

Manitoulin Anishinaabek Research **Review Committee**

- mmittee Members:
 Cheri Corbiere, Sheshegwaning First Nation
 Donna Debassige, Band Councillor, M'Chigeeng First Nation
 Susan Manitowabi, Native Human Services, Laurentian University
 Lenore Mayers, Administrative Program Support, Nocjonowin Teg Health Centre
 Lorrilee McGregor, Research Consultant, Community Based Research
 Marjory Shawande, Traditional Coordinator, Nocjmowin Teg Health Centre

- Resource Members:

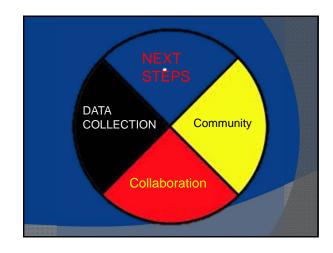
 > Joyce Helmer, Chair, Wabnode Institute, Cambrian College

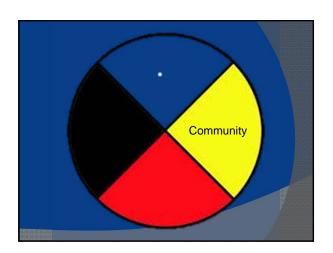
 Niki Naponse, Executive Director, Za-geh-do-win Information Clearinghouse

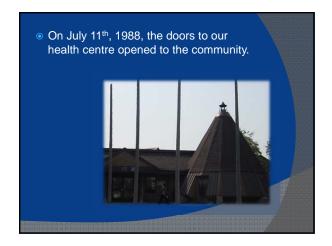
Visit our website at

www.noojmowin-teg.ca





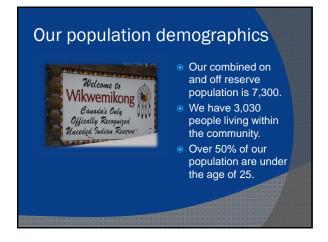




Our Mission: To provide access of all opportunities of traditional and western health to the community

Our Programs and Services: * Health Services Committee * Health Services Director * Administration * Children's Services 0 to 6 Years * Wassa Naabin Community Youth Services Centre * Nadmadwin Mental Health * Community Health Primary Care * Medical Transportation * Home & Community Care/LTC







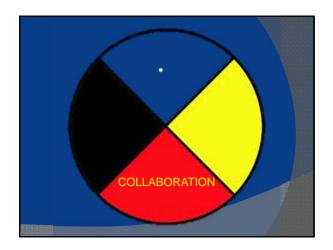
1.NEWAAKAAWIN Children need to know traditional knowledge to help them in their life long journey to live a life that reflects 3. MNAADENDIWIN the 7 Grandfather teachings: 4. AAKDE'WIN S. GWEKWAADZIWIN 1. Wisdom S. DBASENDIZWIN 2. Love 3. Respect **Bravery** 5. Honesty 6. **Humility** 7. Truth

What makes research successful? Present topic of research to appropriate agency/organization Is it a priority within the community? Presentation to respective committee/board and obtain committee motion. Presentation to Chief/Council for support through BCR Respecting community values Following protocols Financial & human resources to support research? Application to Manitoulin Anishinabek Research Review Committee for ethics approval. Ensure respective ethics received from Principal Investigator

Success..... Recruitment of interested & committed individuals from the community as part of advisory committee Community consultations to keep members informed on research to date Determine if translator is required/fluent speaker Report on findings/recommendations Tangible products Use of report to improve services Financial & human commitment

Success

- ☐ Training and support of the 'team' capacity building
- Development & maintenance of a detailed plan
- Opportunity of community members to voice their beliefs/concerns/recommendations through guidance of elders (TC)
- □ Empower community members
- Accountability to community



In 2001, a Youth Needs Assessment was carried out by Kristen Jacklin and Mary Jo Wabano, under the direction of Chief and Council which was a direct result of CHP report of 2001.

Participatory Research Design: community making the decisions; controlling data; designing the questionnaire

Process:

Youth Involvement/Focus Groups/Pre-testing:

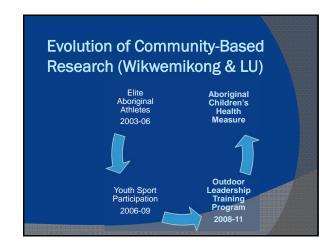
- Focus groups with youth (male; female groups separated) to find out types of Q youth wanted to be asked, willing to answer and issues they face within community
- Pre-test with youth; modifications made and re-implementation

Community Involvement:

- ✓ Focus groups with frontline staff to generate Q for survey that will provide direction on programs/services required for youth; information to support proposal writing
- Review of survey by community resources (Nadmadwin, Psychologist)





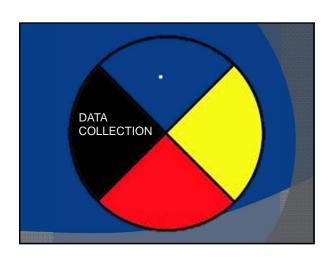


February 11, 2011:
Research Presentations to Community
1. Diabetes
2. Alzhiemers & Dementia
3. Children's Health Research Priorities
4. AHMP – HSFO
5. Nutrition and impacts of RS
6. OALE
Each PI was provided with 45 minutes to present to the community the status of the research; findings; recommendations.

General invitation to community members, leadership, committee members, participants, and members of MARRC were invited.
 Acknowledgement of community champions
 Q/A opportunity
 Annual event

Collaboration

- Steering Committee/Advisory group which includes academics, frontline staff and community members
- 'Champion' within the community
- Principle Investigator gaining trust with community members
- PI understanding protocols within the community



Survey Implementation: YNA

- WBE/WHC approval: review and approval of survey
- Staff training (2 days) & Safety net established
- > 75% of students in grade 7 12 were reached = 189 (ages 12 -15)
- Data Analysis consultant
- Findings/Report: 3 priority areas MH, School safety and Risk Behaviours; overall with 31 recommendations made

- 1. Diabetes testing in schools as part of regular health maintenance schedule.
- 2. Programs aimed at youth empowerment and increased S/E; student councils
- 3. Implementation of suicide intervention strategies - ASIST/MHFA
- 4. Training for youth PH/ASIST
- 5. Improve school safety
- Referral on/off reserve to access traditional and western services
- 7. Aim to reduce smoking rates amongst youth

The OALE Program (2009)

Development

- 3 Goals
- 6 Leadership Training Modules
- 4 Implementation Phases
- 14 Programming Principles
- 7 Grandfather
- Teachings
- 10 day canoe expedition

Implementation

- 2 Weeks Staff Training (June)
- 3 Canoe Expeditions (2 in July; 1 in August)
- 6 Travel Groups (2
- Groups per Expedition)
- 43 Youth Participants 1 Celebration Pow Wow
- F/U Programming

6 Leadership Training Modules

- 1. The Essence of Leadership
- Connecting to Aboriginal Roots and Culture
- 3. Creating a Personal Vision
- 4. Cultivating Persistence and Success
- 5. Working Effectively With Others
- 6. Leaving a Legacy

4 Implementation Phases

Phase 1 - Preparation: Training & Planning - Goal Setting / Training / Research (1 Day)

Phase 2 - Outdoor Adventure Leadership Experience: Journeying & Reflecting - Experiential training while traveling on expedition (9-10 Days)

Phase 3 - Community Welcome: Committing & Celebrating - Personal commitments & experiencing community love & support (1 Day – arrival day)

Phase 4 - Celebrating Youth Success:
Recognizing& Transitioning - Sharing stories & recognizing accomplishments (1 Day - end of

Resilience & Wellbeing

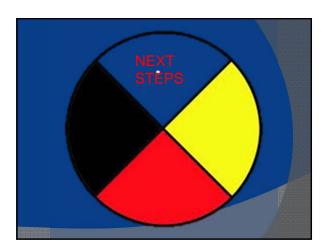
- Qualitative: participant interviews, daily focus groups & talking circles; participant journals; film, video and PI journal/observations
- Quantitative: Self-report Questionnaire (9) -scales / 4 dimensions / 78 items)
- Pre & Post (4wk) administration
- ✓ One year post questionnaire

OALE - Into the future...

- > Ongoing research
- > Secure long-term funding
- > Documentary video 2010
- > Enhanced staff training
- > Involve clinicians
- > Expand to other clinical populations
- > Partner with other communities

Significance & Relevance

- > At-risk population
- > Mental Health Priority
- > Holistic Approach
- Community Driven: C/C, WCRSC; youth population, homecoming celebration
- Comprehensive Research Design: qualitative/quantitative and participatory/capacity building



Community-University Collaboration

Currently and into the future:

- >Enabling children to identify their health needs
- Developing local research capacity wto enable on-going monitoring and evaluation of children's health
- Ultimately to guide health service delivery »by identifying groups in need of services
 - »by matching services to local needs



Mii gwetch
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Appendix 4 04/10/2011







 Collaborate with University researchers (faculty and students) and Aboriginal community partners for the development of research projects. • Provide researchers with information relevant to the pursuit of Aboriginal research.

Ethics

 Marlene Brant Castellano – Tri-Council Policy Statement 2 (Chapter 9)

Methodology

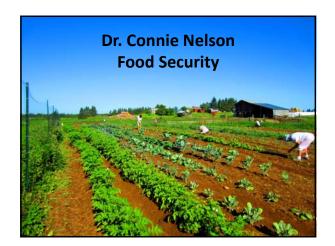
- Collaborative approaches in research
- The National Congress of American Indians Policy Research Centre
- Indigenous Child Welfare Research Network

Cultural Protocols

Funding Opportunities

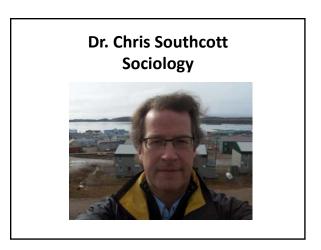
- Promote Aboriginal Research to encourage its development and growth at the University.
 - Aboriginal Partnership Research Award
 - Research and Innovation Week
 - Bi-annual newsletter
 - Facebook group
 - Letter campaign to Aboriginal leaders

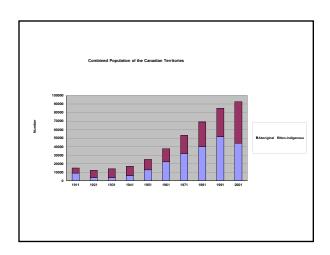
















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How research funding works

- Major Granting Agencies
 - · Priority announcements
 - · Trend to intervention and collaborative grants
 - Researchers chase money
 - · Contact communities, letters of support
 - Other researchers, universities (collaborative and multi-disciplinary research)
- Government
 - Specific relationships to research orgs, PTOs and RFPS to consultants

05/10/201

How research should work (how some of us try to work)

- · Establish community needs
- Find sources of funding that fit those needs
- Find researchers who are experts in those areas
- Prepare proposals with communities

05/10/2011

Funding Sources

- Your Band/First Nation; Tribal Council
 - You can be an advocate for research and knowledge needs
 - Establish Partnerships
- Provincial and municipal government
- Foundations
 - Ontario Mental Health Foundation
 - · Hospitals (Sick Kids)
 - Asthma Society, Alzheimer's Society etc

05/10/201

Major Granting Agencies

- NSERC
- SSHRC social science, education, heritage, indigenous knowledge
- · CIHR all health research
 - · IAPH, Institute of Aboriginal Peoples' Health
 - Standard grants
 - Knowledge translation
 - Special calls –national partnerships, local sites

05/10/2011

Research is competitive

- IHRDP
 - Scholarships 20-30%
 - CBR grants 30-50%
- · Foundation grants
 - 25-30%
- SSHRC
 - 。20%
- CIHR
 - · 15-18%

05/10/2011

An example

- Wikwemikong
 - Band funding youth needs assessment
 - IHRDP funding CBR Grant
 - · Outdoor education, experience -Stephen Richie
 - Need for youth health assessment tool -Nancy Young
 - CIHR application
 - · High ranking and rejection
 - · Reapplication
 - Sustaining relationships

05/10/201