

The Development of Biological Sampling Guidelines on Mnidoo Mnising

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Northern Health Research Conference
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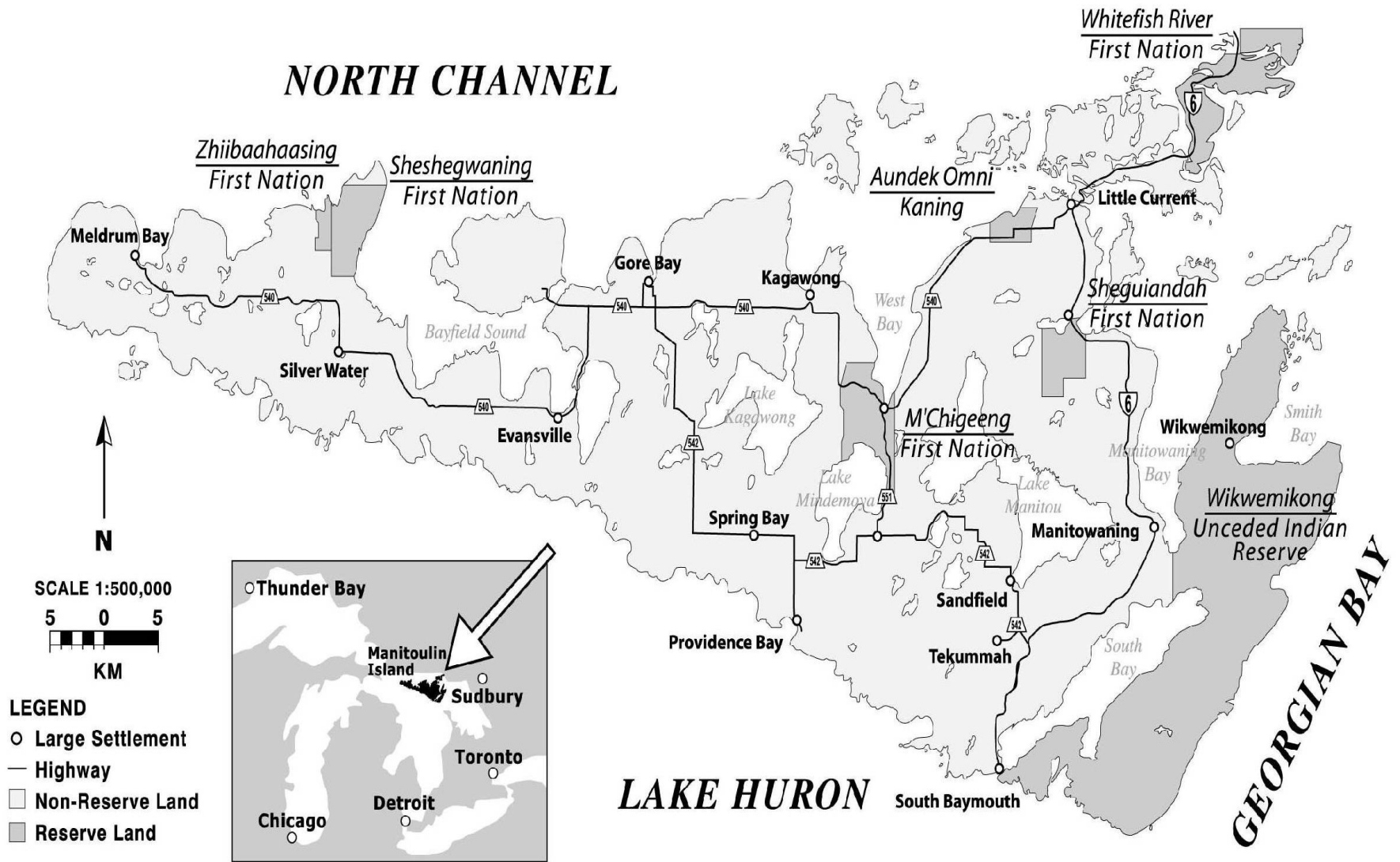
Disclosure of Affiliations, Financial Support, and Mitigating Bias

Speaker: Dr. Lorrilee McGregor

Affiliations: As the Chair of the MARRC we have an arms-length relationship with Noojmowin Teg Health Centre, a not-for-profit organizations.

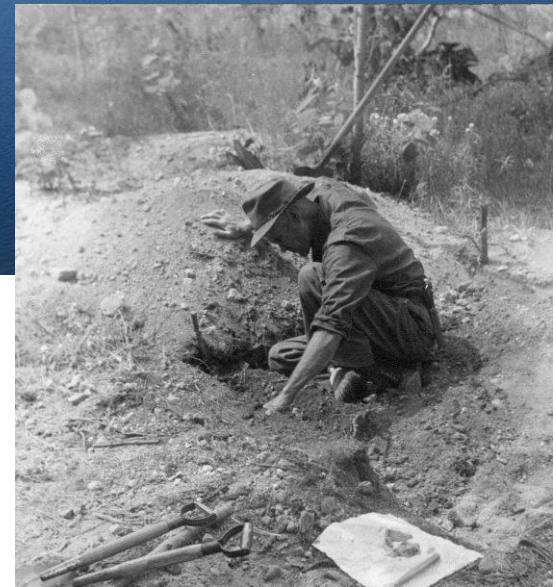
Financial Support: Funding for the community engagement sessions was provided by the Secretariat for the Responsible Conduct of Research

NORTH CHANNEL



First Nations in the Manitoulin district with estimated Aboriginal on-reserve population size as of 1998 in parentheses: Aundek Omni Kaning (320), M'Chigeeng First Nation (800), Sheguiandah First Nation (120), Sheshegwaning First Nation (100), Wikwemikong Unceded Indian Reserve (2,600), Whitefish River First Nation (340), Zhiibaahaasin First Nation (35).

Wagaskinaga Mnising



Unethical research

- Increasing concerns about the uncoordinated approach to health research and lack of involvement of communities
- In 2000, two research projects initiated by outside researchers:
 - Residential schools
 - Arthritis study in Wiikwemkoong

What was wrong with these studies?

Residential school study:

- Lack of community consent
- Potential harm to participants (no support for trauma)

Arthritis study:

- Linkage of collected personal data with patients' health information
- Did not return results in a timely manner
- Gave biological samples away to another researcher

Community response to unethical research

- Concerns about research were discussed at First Nation health agency meetings on Manitoulin Island/Mnidoo Mnising
- March 2001 - two day conference to share experiences with research and to create a vision for Indigenous health research in the Manitoulin area.

Proactive in research

Conference participants stated they want to:

- Become proactive in research
- Develop a process to take control of research
- Build local research capacity
- Form a committee to develop community-based ethical research guidelines for the Manitoulin area

Two year development process

Recommendations from the conference:

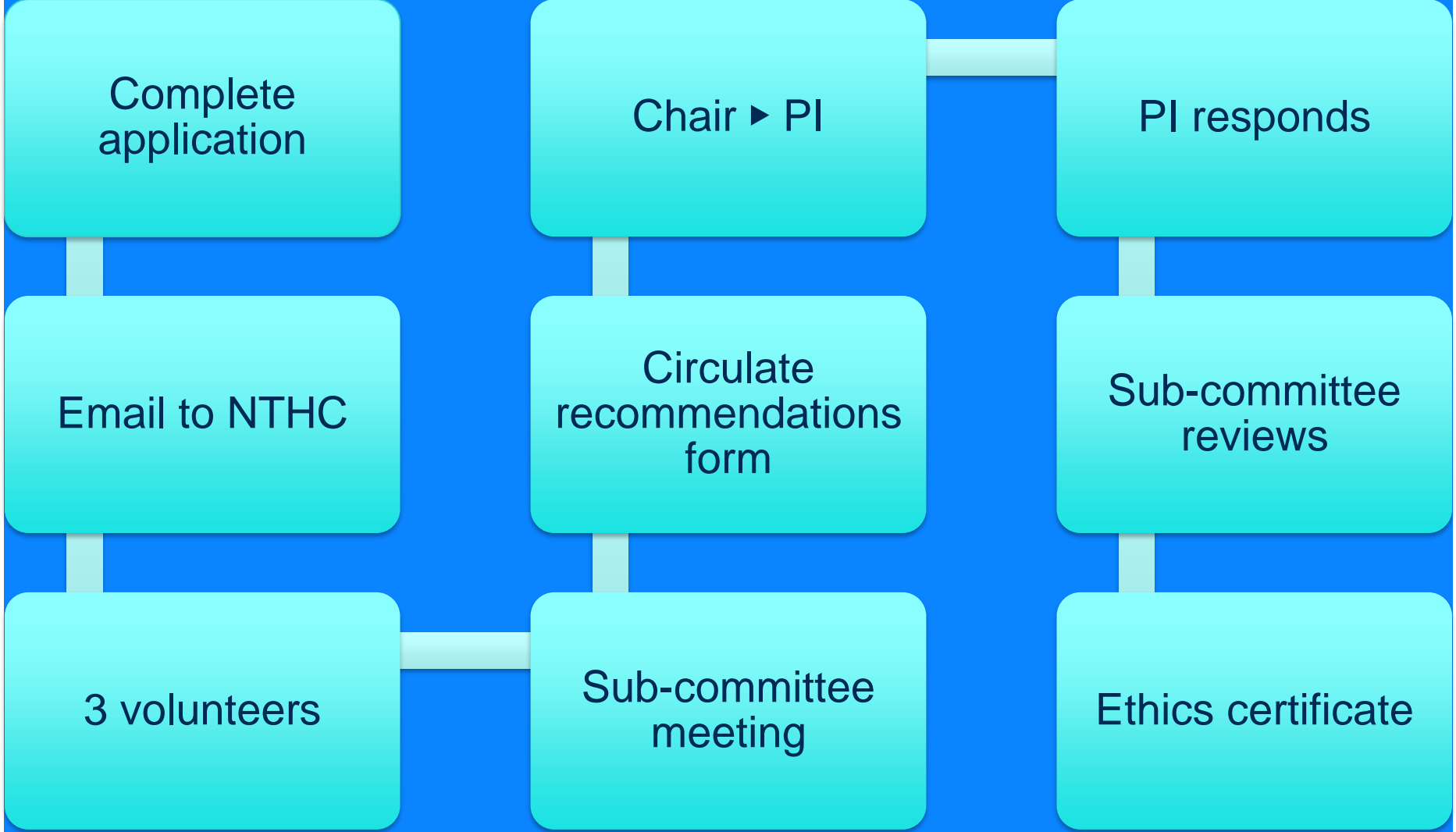
- 1) to continue community consultations
- 2) to develop ethics guidelines
- 3) to develop a process to review health research
- 4) to promote the research review initiative with local decision makers

Vision for research on Manitoulin

- Respect for Anishinaabek culture, knowledge and values
- Adhere to local Indigenous ethics and TCPS guidelines
- Research should directly benefit the community
- Respect the diversity between and within communities
- Produce documents which are useful for communities and agencies
- Respect that the collected data is owned by local communities and agencies
- Build local capacity for research
- Research topic should fit into a local strategic plan for research and/or be directly relevant to local communities
- Research should assist with decision-making and development of health programs

Guidelines are based on Seven Grandfather Teachings

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



Complete application

Chair ► PI

PI responds

Email to NTHC

Circulate recommendations form

Sub-committee reviews

3 volunteers

Sub-committee meeting

Ethics certificate

Key milestones:

- 2001 – First research conference in M'Chigeeng
- 2003 – Guidelines for Ethical Aboriginal Research
- 2005 – Training from the National Council for Ethics in Human Research
- 2005 – Ethics and Research Review Workbook
- 2005 – reviewed the first ethics application
- 2007 – Terms of Reference for the committee (MARRC)
- 2009 – Strategic planning session in Manitowaning
- 2013 – Research conference # 2 in WRFN
- 2017 – committee reviewed 60 ethics applications

Impact of Guidelines for Ethical Aboriginal Research

- Capacity building – more Indigenous researchers on Mnídoo Mníising
- Better collaborations between researchers and communities
- Communities are initiating research and getting the researchers to find the \$
- Attracts researchers to Mnídoo Mníising because we have this process to conduct ethics reviews

Inquiries from researchers interested in biological sampling

2016 – Community engagement on biological sampling (grant from the Secretariat on Responsible Conduct of Research)

2017 – Elder engagement on biological sampling guidelines

2018 – seeking support for biological guidelines: “Anishinaabe Naagdowendiwin – We are Taking Care of Each Other”

Guidance for researchers:

- Meet with community leadership to determine whether proposed research is a priority.
- Researchers must be aware of Indigenous knowledge, culture, traditions, and beliefs before they come to our communities
- Relationships are in constant flux (Band Councils, staff)

Importance of relationships

- “Researchers must establish or build upon relationships with community partners premised on reciprocity, mutual respect and equal partnership. Mutual understanding must be sought along with an understanding of roles and responsibilities. The relationship between the researcher and the community must be reciprocal so that there is a respectful exchange for mutual benefit.”

Despite the risks and challenges, biological research is considered important because...

- “This is about healing.” Leona Nahwegahbow
- Ethics guidelines are based on the idea of Anishinaabe naagdowendiwin: “we are taking care of each other”

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Folks who contributed to the development of these guidelines

- Kari Aguonia-Smith – Sheguiandah
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- Gord Waindubence – Sheguiandah
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Miigwetch! Merci! Thank you!