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A Regional Model for Ethical Engagement: The First Nations Research Ethics Committee on Manitoulin Island

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Introduction

As do many Indigenous people and cultural minority populations worldwide, Aboriginal¹ people in Canada have, on average, poorer health status and lower income and education levels in comparison to the broader population. For Indigenous people and minority populations, the roots of this inequality are generally found deep within an existing socio-economic and political power imbalance (Geiger 2001, 1699). Ongoing research is necessary to gain a better understanding of how best to address this reality.

In the health sector, the circumstances that lead to poor health in Aboriginal communities need to be understood in order to develop appropriate services and programs that will address local health issues effectively. Aboriginal communities, government agencies, and academic institutions all require good data sources in order to develop effective interventions; however, conducting research on Aboriginal health issues has become an immensely complex endeavour that requires special knowledge and training in the areas of Aboriginal health, participatory research methodology, and research ethics. In order to address pressing and immediate health issues properly, researchers must also consider the effects of colonization on Aboriginal community health, including societal power imbalances, the loss of culture and a traditional way of life, and the experience of forced assimilation; many of these health determinants are still poorly understood in the health sciences. The historical circumstances that have shaped Aboriginal health issues also have had a profound impact on acceptable approaches to Aboriginal community research and contemporary Aboriginal research ethics.

A Century of Aboriginal Health Research

Much research has been conducted on the health of Aboriginal people in Canada over the past century, but the results generally have had only a limited positive impact on Aboriginal health and social conditions. As early as 1907, Peter Bryce,

the general medical superintendent of the Department of Indian Affairs (DIA) conducted an investigation into Aboriginal health, which revealed deplorable conditions (Waldram, Herring, and Kue Young 1997, 156). While his report documented extremely high rates of child mortality and infectious diseases, and of a lack of medical care for Aboriginal people, there was no follow-up on the report, or any expansion of service provisions to improve the Aboriginal health situation (Bryce 1914). In fact, evidence shows that while considerable rates of infectious disease continued to exist in Aboriginal communities, funding for Aboriginal health services underwent significant financial cutbacks during this time (Kue Young 1988, 87–88). Many government reports documenting poor Aboriginal health status² have followed on the general medical superintendent's report; however, the collected information has, arguably, never been used to develop a comprehensive strategy to deal more effectively with Aboriginal health and mental health issues.

Just as with government-sponsored research, much of the existing academic research on this subject has also failed to impact positively on Aboriginal community health.³ It is not surprising that most of the government-sponsored and academic research that has been conducted over the last century has had little impact on poor health conditions for Indigenous Canadians, since Aboriginal people have had little or no involvement in the research projects conducted in their communities. Rather, outside experts, often with little knowledge of the realities of Aboriginal community life, were commonly in a position where they controlled all aspects of the Aboriginal research projects. These experts decided which research questions warranted investigation, which methods should be used to collect data, and how the data should be interpreted and disseminated. The resulting research projects gave little consideration to the insider perspective of Aboriginal community members, existing Indigenous knowledge, the cultural competence of the research methods used, or to collaborative interpretations. Data and results were rarely accessible to community members. Knowledge transfer strategies geared to support community action on a particular problem were absent. Commonly, at the end of a project, outside experts would recommend inappropriate or unworkable solutions to community problems.

The health profile of Aboriginal people has changed dramatically over the past century. Chronic illnesses such as diabetes and heart disease, as well as health conditions related to the consequences of colonization such as mental health problems, family violence, addictions, and unintentional injuries, have emerged as major health concerns; unchanged, however, is the fact that the Aboriginal population has much poorer health status in comparison to the broader Canadian population. Increasingly, it has come to be accepted that, in order to improve Aboriginal health, Aboriginal people must be actively involved as leaders and collaborators in the development of solutions to local health problems. In light of this situation, it is encouraging to know that some successful collaborative

health research projects have been documented in the literature, mainly since the 1990s.⁴

Addressing Aboriginal Concerns Related to Research

The shortcomings of past research have resulted in extreme research fatigue in many Aboriginal communities, which often have come to see government and academic research as an extension of mainstream colonialism, seen as the cause of much ill health in Aboriginal communities. Consequently, it now is common for Aboriginal people to resist participation in research projects. Research initiated by outsiders raises many concerns, some of which were succinctly summarized during the feasibility consultation workshops for the 1996 First Nations and Inuit Regional Health Survey (FNIRHS).

Aboriginal people have become highly critical of governmental or university interests behind the research on their communities. Participants in the workshop had the perception that, despite decades of research on social problems in Aboriginal communities, not much has been improved as a result. They also expressed the concern that the research seems to benefit non-Aboriginal researchers alone by advancing their careers, for example, and providing them with employment. Additionally, participants felt that much of the research on Aboriginal people over the last several decades has asked questions that seem inappropriate in the community context (First Nations and Inuit Regional Health Survey National Steering Committee 1998, A-45).

Aboriginal people commonly see the lack of collaboration and community focus in research design and implementation as an ethical issue. Researchers who work in Aboriginal communities often come in contact with communities and individuals who have participated in research projects and have felt harmed or violated as a result, despite the fact that the research protocols for the projects received ethics approval from a university or hospital-based research ethics board (REB). Clearly, appropriate models for ethical Aboriginal research based on Aboriginal values need to be established and monitored through ethics review processes.

Over the past decade, the mainstream research community has become increasingly aware that ethical review of research topics and methods and dissemination strategies related to Aboriginal research must go beyond what is normally required for academic study in order to address issues like power imbalances and Indigenous knowledge in the research process (First Nations and Inuit Regional Longitudinal Health Survey National Steering Committee 1998, A-45). The Royal Commission on Aboriginal Peoples (RCAP) had a profound impact on raising awareness. The RCAP was established to conduct an in-depth investigation into the issues faced by Aboriginal people in Canada in 1991. The commission's work began against a backdrop of anger and upheaval: an ongoing national

debate about the place of Aboriginal people in the Canadian Constitution; First Nations' blockades and protests over resources and rights-based agendas; and, most significantly, the armed conflict between Aboriginal and non-Aboriginal forces at Kanesatake (Oka) a year earlier, which drew international attention to the situation of Aboriginal people in Canada. The media began to focus more attention on the disturbing inequities in many Aboriginal communities. Statistics portrayed high rates of suicide, substance abuse, incarceration, unemployment, welfare dependence, low educational attainment, poor health, poor housing, and family breakdown. On the positive side, for many Aboriginal people, it was also a period of renewed hope as more and more people were openly reconnecting to their cultural heritage and identity as the foundation upon which to build solutions to community problems.

The RCAP completed its work in 1996, with over 350 research projects commissioned as part of this work (Royal Commission on Aboriginal Peoples 1996a). New ethical guidelines for research had been adopted by the commission as a best practice in order to help ensure that, in all research sponsored by the RCAP, appropriate respect was given to the cultures, languages, knowledge, and values of Aboriginal people (Royal Commission on Aboriginal Peoples 1996b). This was an important national turning point for the processes by which research was conducted within Aboriginal communities. Also, the RCAP report strongly supported the growing recognition that Aboriginal cultures, values, and world views differed fundamentally from the organizing principles of mainstream North American society, and, consequently, that Aboriginal people must formulate their institutions in ways consistent with these values. The RCAP gave voice to what had been a long-held understanding among Aboriginal people: that all Aboriginal people have the right of self-determination by virtue of international law and basic principles of morality.

The RCAP, thus, has had a strong influence on further national developments pertaining to the recognition of Aboriginal research ethics and respect for Aboriginal knowledge.⁵ The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS), adopted by the Canadian national research councils in 1998, acknowledged that research with Aboriginal people requires special consideration and that consultation needed to take place in order to establish policy in this area (Medical Research Council of Canada (MRC), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC) 1998, Section 6). In 2002, the Interagency Advisory Panel on Research Ethics (PRE), with the mandate of supporting the development and evolution of the TCPS, "identified as a priority the development of TCPS guidelines for research involving Aboriginal people, based on respect for Aboriginal knowledge, research modalities, and rights and needs" (Government of Canada 2006). The Aboriginal Research Ethics Initiative was expected to complete these guidelines in 2006, but they are currently still in draft form. Through a parallel process, the Canadian Institutes of Health Research

(CIHR) began development of Aboriginal-specific health research guidelines through consultations with Aboriginal communities and researchers in 2004, and published a set of draft guidelines in 2005 (CIHR 2005).

While all of this work is currently underway at a national level, it is important to stress that Aboriginal cultures in Canada are very diverse and much work remains to be done at the Aboriginal community level to develop regional, culturally specific Aboriginal frameworks for community-based research and ethical research conduct.

Aboriginal Community-based Research

In concert with the growing respect for Aboriginal research ethics, there has been a strong movement towards Aboriginally defined and Aboriginally controlled research approaches, along with the increased politicization of Aboriginal research, over the past decades (Jackson 1993, 49). This is especially true in the area of health services, where “researchers, government officials, and corporations (including those that are Aboriginal) may or may not understand, support, or even be aware of the aspirations of First Nations. They may not prioritize and may even be at odds with community interests (Schnarch 2004).” Thus, in order to advance their own communities’ interests, Aboriginal people have begun to initiate more of their own research projects in an effort to better inform and support the effectiveness of decision making, advocacy efforts, and program design and management.

Among the First Nations of the Manitoulin Island area in Northern Ontario, there was a growing realization during the 1990s that it was important for First Nations to lead the development of all community research projects. To do so would, first and foremost, require the development of a local vision for research, and of locally developed guidelines to steer research. In the following section, we will discuss the development of a community-based Aboriginal research ethics committee on Manitoulin Island, the work of this committee, and the necessary support mechanisms required to support such a committee.

Mobilizing Community Resources on Manitoulin

Manitoulin Island is a large, fresh-water island located on Georgian Bay, in Lake Huron, in Northern Ontario. The closest urban centre, Sudbury, is about 160 kilometers away. The Manitoulin district is home to about 11,000 residents, made up of approximately 4,500 Aboriginal people and 5,500 non-Aboriginal people. The largest community, Wikwemikong Unceded Indian Reserve, has an on-reserve population of about 2,800, while the smallest community, Zhiibaahaasing First Nation, has an on-reserve population of less than 50 people.

On Manitoulin, many Aboriginal people who were working in the health sector had concerns for years about the uncoordinated approach to health research in the

area and the lack of knowledge at the community level about research projects that were being run by outside researchers. Community frustrations culminated in 2000, when the two First Nations on Manitoulin Island who were involved decided to terminate two research projects initiated by academic researchers after ethical concerns about them were raised. The concerns expressed were significant and included problems such as the lack of free and informed consent of research participants, unauthorized linking of collected interview data with patient health information, potential psychological harm to research participants, culturally inappropriate research methods, a lack of community consultation, and the lack of a strategy for knowledge uptake. These serious ethical flaws were present despite the fact that these academic studies had received clearances from hospital and university-based research ethics boards (REBs).

In the aftermath of the terminations, local health agencies took the lead to mobilize and sponsor a regional community workshop (M'Chigeeng First Nation on Manitoulin Island, March 2001) to discuss local Aboriginal attitudes towards research, to create a vision for Aboriginal research, and to take control of local research initiatives. The ensuing two-day event brought together community members and leaders, health care workers, Elders, traditional healers, Aboriginal and non-Aboriginal researchers, and university students. On the first day, participants were invited to share their experiences, their concerns, and their views of potential benefits and drawbacks of health research among First Nations. Informal presentations were made by health care workers, community members, Elders, practitioners of Aboriginal medicine, and Aboriginal and non-Aboriginal students and academics. On the second day, participants broke into small groups and brainstormed about what makes research ethical from a First Nations perspective and how the goal of ethical health research could be realized for the Manitoulin area.

Despite the diversity of the participants' background, many common themes emerged. The most important theme was that community members wanted to become proactive in the area of research, build local research capacity, and develop a process to take control of research in their community. The main recommendation of this meeting was that a regional research committee be formed to bring community representatives together on a regular basis to advance these goals. Thus, a working committee was formed to facilitate the development of community-based research ethics guidelines for the Manitoulin area. Noojmowin Teg Health Centre, a regional Aboriginal service organization, was charged with coordinating this work, since this health centre had a research mandate and research staff.⁶

Over the following months the research committee began to meet on a regular basis to draft the guidelines, to plan further community consultations as necessary, and to promote the initiative with local decision makers. Committee members presented the initiative to health boards and Band Councils,⁷ seeking formal support for the work of the committee and to incorporate feedback from local First Nations leadership into the development of the guidelines. During these

follow-up consultations with community leaders, common themes emerged once again. Recommendations were made that the research committee should do more than evaluate research proposals, and that their work should include:

- To review and evaluate research proposals for cultural competence and the potential to create credible results; and to determine whether the research fits with local research priorities and Aboriginal values
- To create a strategic plan for research that encouraged research on topics relevant for the planning of local services
- To create a library of locally conducted research in order to discourage duplication of research and to identify gaps in research
- To support ongoing community capacity building in research
- To expand the health research focus to include other research areas that are of interest to local communities

A shared vision for Aboriginal research on Manitoulin Island began to emerge. People agreed that all health research conducted in First Nations communities should reinforce and respect the cultural values of First Nations organizations and communities, and that all research should be owned by the local First Nations communities and organizations. People also agreed that health research should have practical value for First Nations peoples, and should enhance information for decision making and development of local health programs. Under no circumstances should research lead to harm, or violate the privacy and confidentiality of patients or the community as a whole. Research proposals should be reviewed for their ability to respect communities Aboriginal and traditional knowledge and reaffirm First Nations culture, values and ethics; additionally, people stressed the importance to adhere to national guidelines such as the TCPS and privacy laws as well (Manitoulin Area Aboriginal Health Research Review Committee 2003).⁸ There was also consensus that any proposed research projects should contribute to First Nations community empowerment and include the following properties:

- Be designed to 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
- Respect traditional Aboriginal knowledge and culture
- Build local capacity for research
- Research topic should fit into a local strategic plan for research and/or be directly relevant to local communities

Operationalizing Community-based Aboriginal Ethics Review

After community support for this project was established, the committee began a process to develop community-based guidelines for health research,

established on the information collected during the consultations. To implement these guidelines, two important tasks had to be completed: first, documenting local Aboriginal values related to research; and second, developing a fair and empowering process for reviewing, evaluating, and monitoring research projects at the community level.

Documenting Aboriginal Values Related to Research

To document local Aboriginal values related to research, the committee conducted several discussion groups with respected community members and Elders to discuss their views on Aboriginal research values. The Elders emphasized that the Indigenous knowledge they shared was based on their unique culture and experience and stressed that these values were part of the local Aboriginal culture in the Manitoulin area and not intended to apply to other Aboriginal communities. Because Aboriginal cultures are unique and diverse, it is not appropriate to transplant local ethics and values and apply them to other Aboriginal nations.

Aboriginal research values for the Manitoulin area are based on the Seven Grandfather Teachings: respect, wisdom, love, honesty, humility, bravery, and truth. These teachings are interconnected, and it is difficult to separate them into individual “categories.” However, in order to share the meaning of these teachings with respect to research, the Elders decided to provide interpretations by discussing concrete examples of how these values can be incorporated into research projects. These practical examples describe how the spirit and intent of the teachings can be actualized through specific actions and attitudes to achieve ethical research in local communities. The interpretations of the Seven Grandfather Teachings with respect to research became an important part of the Manitoulin research guidelines and a teaching tool for culturally appropriate research on Manitoulin. Two examples of the Elders’ discussion on respect and honesty respectively are provided below:

Respect the diversity in spirituality, beliefs, and values of First Nations people within each of their communities ... Being clear on what is to be done with data and what is not to be done with it ... Spending time with participants, to appreciate and respect the person’s level of knowledge to ensure a mutual understanding of the proposed collaboration. Always have an interpreter with Elders who are more comfortable in their language. (Manitoulin Area Aboriginal Health Research Review Committee 2003)

The teaching of honesty brought on the following discussion and interpretation:

Within the history of our communities, trust has been broken many times. As a result one often encounters reluctance towards research. The researcher needs to work towards a trust-based relationship with the community and the individuals and families who participate in research. To do this, you may have to visit more often than just once to do a survey. Particularly with Elders, gather the information bit by bit. It may not be appropriate to write things down continuously or tape record. This may be different for

the younger generation. Again it is important that the researcher is aware of the diversity in the community. Approach Elders with tobacco to build a relationship when appropriate. Ask yourself: “Were people happy that you have come to them?” (Manitoulin Area Aboriginal Health Research Review Committee 2003)

Developing a Process for Review

The research committee members recognized the importance of supporting and emphasizing the autonomy of all First Nations when choosing to engage in research projects. For this reason, it was decided that researchers must gain the support of local Aboriginal leadership or organizations before they request an ethics review of a research protocol. As the first part of the review process, the research committee would determine if any proposals under consideration were unethical from an Aboriginal perspective. After the ethics review process, the committee would be encouraged to review the proposal with an eye to the suitability of the research topic and how it fits in with current community priorities. The committee would also provide recommendations on how to maximize community benefit from the project, and the results would then be communicated to the Band Councils and other local leadership.

The evaluation process is designed to help communities to make an informed decision about their involvement in a research project. The committee also offers to provide support to communities during the implementation process by helping to form a local steering committee to guide the day-to-day operation of projects.

In order to ensure a well-functioning and transparent review process, the committee members developed an ethics application workbook with standard questions to be completed by researchers (Maar and McGregor 2005). Committee members have all received formal REB training from the National Council for Ethics in Human Research (NCEHR).

Lessons Learned

The process of documenting Aboriginal research values and developing a community-based REB is rewarding, yet very time consuming. In the Manitoulin area, it took four years to build community support, to develop guidelines and a review process, and to train committee members to review research proposals. Commitments from committee members and support from many community stakeholders are required to establish the process, and the process undoubtedly benefits from a community champion who is able to consistently allocate time to this project to coordinate activities.

It is very important to keep community organizations updated on the process and milestones **achieved through ongoing presentations**. **Gaining and maintaining** community support has been the key to the many accomplishments of the Manitoulin research committee. Throughout the research process, it was important to have knowledgeable community participants who had an interest in research

methods and research ethics. Fortunately, a number of resource persons and individuals on the committee had post-graduate educations, health services experience, and/or traditional Aboriginal knowledge. Recruiting Aboriginal people with these types of expertise and experience was essential in making it possible to provide Aboriginal perspectives on research processes and ethics. These individuals also helped to build confidence and credibility in the committee's work within the First Nations communities on Manitoulin. Representation from First Nations communities and organizations was another key consideration in developing the research committee. Many of the representatives participating on the committee were appointed by their respective communities' Band Councils or health boards. These individuals were instrumental as a voice within each community and health agency by being the committee's "ears to the ground." Most importantly, they were experts on topics like community issues, demographics, community and leadership dynamics, as well as the overall priorities and aspirations of the community. They also understood their communities' experiences with research projects in the past and their communities' vision for research in the future. An important issue that was emphasized was that all conducted research must lead toward or result in a tangible benefit or action within the participating communities.

Linkages across sectors within the community were also very important because health issues are intertwined with many other social and economic determinants within communities. Representatives from the local band administrations, Band Councils, and the local tribal councils, were involved in a working group to provide broad policy perspectives. This political representation also helped to raise awareness of the importance of the guidelines and the potential benefits to all sectors in the community.

Ongoing consultation with the seven First Nations communities on Manitoulin Island, through presentations to leadership and health boards, was another key success factor in the development of these guidelines. It was important to continually inform, engage, and seek endorsement from all these groups by seeking their input, advice, and feedback throughout the development of the guidelines. When organizing community information sessions, the research committee felt strongly that community ownership of this process would be reinforced if the local community representatives of the committee were involved in presentations in their communities. This approach worked very well because the local community representative had an intimate understanding of local issues. The community representative was able to illustrate the issues and benefits of the initiative with local examples and could answer questions pertaining to the particulars of that community's situation. The presentations to community leaders were invaluable in terms of the advice and direction provided to the committee's work and the guidelines. Without exception, all presentations were well received and later supported with official Band Council resolutions. More importantly, communities began to see the research guidelines as the beginning of an evolving process

of taking charge of research, rather than an endpoint. The following feedback illustrates this:

Can you make sure that training is provided to our people and include our health staff and board members—We want to make sure they understand how this works and how it benefits the community and we want the skills and knowledge to be provided to our people as well as our committee representative.

Will there be training that our post-secondary students can take part in as well? We should be building this knowledge in our budding scholars so that they can be the ones taking on the research projects for us. There are already many who are graduating with advanced credentials whom we can start calling on as resource people and researchers.

Engaging leadership in this manner was important to the overall process, not only in setting the direction for the committee's work, but also as a reminder of the importance of building local capacity and setting strategic directions for research topics.

After receiving many requests, the committee began to share its research on Aboriginal research ethics more widely through conference presentations and publications with the purpose of both educating researchers and health service providers and providing information to help other Aboriginal communities to take control over research projects in their communities. These dissemination activities have brought greater awareness to the work of the committee, both locally and nationally.

Funding to support this kind of initiative was difficult to find. The committee had to find creative ways to access funds and relied frequently on the support of local organizations. Sustainability is an ongoing issue for discussion at committee meetings.

The most important attribute of the Manitoulin research guidelines is their embodiment of traditional values and teachings of Aboriginal people in the Manitoulin Island area. The guidelines were built on a framework of original ethics or "teachings" passed down from generation to generation, which could only be gained from personal discussions with traditional knowledge keepers. Cultural sensitivities had to be carefully observed when this perspective was researched.

The work of the committee has had a tremendous impact on local research capacity. A fully functioning, community-based REB now operates on Manitoulin Island. Guidelines and a workbook have been developed that serve as educational tools for researchers, research participants, and community members. The committee has also been able to network and exchange knowledge with other Aboriginal research committees outside of their region and with Aboriginal researchers and health professionals.

Future Areas of Development

The development of a community-based research ethics committee, research guidelines, and an ethics review process are not end points; ongoing policy and

community research is necessary to keep this process alive and to ensure that it continues to evolve and respond to First Nations needs. In the case of Manitoulin Island, the committee has identified several future initiatives. They include the development of resource materials about ethics, participants' rights, and confidentiality in the Anishnaabe (Ojibwa) language. These materials are required to empower Elders who participate in research projects by eliminating the language barrier and informing them of their level of involvement and rights related to research.

Another long-term goal is to continue to build research capacity by forging academic partnerships based on community research needs and providing ongoing training opportunities. The committee is also interested in developing a model for long-term sustainable funding for this committee by assessing various funding sources and exploring diverse operational models. Most importantly, the committee recognizes that guidelines are living documents and will continue to evolve to support the changing needs of local First Nations communities.

Acknowledgements

This paper is based on the work of many people over the past five years, including the members of the research ethics committee, the Chiefs and Councils of the First Nations on Manitoulin, the four area health boards and the Elders Advisory Committee. This research received financial support from the Indigenous Health Research Development Program, the Interagency Advisory Panel on Research Ethics, the National Council on Ethics in Human Research and Noojmowin Teg Health Centre on Manitoulin Island.

Endnotes

- 1 The terms “Aboriginal” and “First Nations” are not used interchangeably in this paper. The term “Aboriginal” is defined in the Canadian Constitution Act and includes all people of Indigenous descent: Status Indians, Inuit, and Métis. The term “First Nations” is used to refer to Status Indians and their communities since it is preferred by many Aboriginal people.
- 2 See, for example, the report of the Ewing Commission (1934); T. Berger(1980). the Royal Commission on Aboriginal Peoples National Round Table on Health Issues (1993); and the Royal Commission on Aboriginal Peoples (RCAP)(1996a).
- 3 For a more detailed review of this topic, see M. Maar (2005).
- 4 Some examples of collaborative projects can be read in S. Abonyi (2001), A.C. Macaulay et al. (1999), and S. Peressini et al. (2004).
- 5 For example, see National Aboriginal Health Organization (NAHO) (2003).
- 6 The position of research coordinator was filled by one of the authors (M. Maar).
- 7 A Band Council is a council made up of the elected officials of a nation of Status Indians.
- 8 Manitoulin Area Aboriginal Health Research Review Committee. 2003. Guidelines for ethical Aboriginal research within the First Nations communities of Manitoulin, Document on file at Noojmowin Teg Health Centre, Aundek Omni Kaning, Ontario.

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