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LETTER OF INTRODUCTION

March 2003

On March 5th and 6th, 2001 Noojmowin Teg Health Access Centre sponsored a community-based health research conference to provide a forum for participants to discuss their experiences with health research on Manitoulin. Approximately 45 people attended this workshop, which brought together health care workers, community members, elders and local as well as university based researchers and students. Participants brainstormed about what makes research ethical from a First Nations perspective and how the goal of ethical research could be realized. Conference participants then created a **Vision** for ethical health research on Manitoulin.

Since Noojmowin Teg Health Access Centre services all seven First Nations as well as the off-reserve population in the Manitoulin district and also had a Research & Evaluation Program in place, it became the lead organization in forming the Research Review Working Committee. The committee was a collaboration among Noojmowin Teg Health Access Centre, Mnaamodzawin Health Services, Wikwemikong Health Centre, M'Chigeeng Health Centre and the Kenjgewin Teg Educational Institute. Presentations were made to the respective boards and committees and it was unanimously supported. The committee developed research and ethics guidelines based on the perspectives of local First Nations and this manual is based on those guidelines.

This manual was developed by the Research Review Working Committee to promote ethical health research in First Nations communities in the Manitoulin district. The manual outlines strategies to assist agencies to make informed decisions about health research in their community by providing guidelines for the review and evaluation of proposed research projects.

The working committee would like to thank all the First Nations agencies who helped to create this manual through their support:

- Kenjgewin Teg Educational Institute
- M'Chigeeng Health Services Committee
- Mnaamodzawin Health Services Inc.
- Noojmowin Teg Health Centre
- Wikwemikong Health Services Committee
- United Chiefs and Councils of Manitoulin
- Za-geh-do-win Information Clearinghouse
- Northeastern Ontario Medical Education Corporation

Through research we can identify our strengths and weaknesses, and produce information that will help to improve the services in our health centres and keep track of the health priorities in our communities. It is our hope that this manual will help to identify research that is useful and empowering to the First Nations communities.

Respectfully submitted by the members of the Research Review Working Committee:

- Cheri Corbiere, Community Health Representative, Sheshegwaning First Nation
- Donna Debassige, Executive Director, UCCM Tribal Council
- Barbara Erskine, Psychologist, Noojmowin Teg Health Centre
- Steven Fox-Radulovich, Information Technology Analyst, Kenjgewin Teg Educational Institute
- Joyce Helmer, Director of Education & Professional Development, Northeastern Ontario Medical Education Corporation
- Phyllis Kinoshameg, Researcher, Wikwemikong Health Centre
- Diana Lariviere, Chair Person, Noojmowin Teg Health Board
- Marion Maar, Research & Evaluation Coordinator Noojmowin Teg Health Centre
- Lenore Manitowabi, Program Support Worker, Noojmowin Teg Health Centre
- Niki Naponse, Executive Director, Za-geh-do-win Information Clearinghouse
- Peggy McGregor, Executive Assistant, Noojmowin Teg Health Centre
- Mariette McGregor-Sutherland, Executive Director, Noojmowin Teg Health Centre
- Marjory Shawande, Traditional Coordinator, Noojmowin Teg Health Centre
- Christina Taibossigai, Nurse Manager, Mnaamodzawin Health Services

The Research Review Committee would also like to thank Northeastern Ontario Medical Education Corporation (NOMECE) for sponsoring the printing of this document.

OVERVIEW

The Research Guidelines Manual outlines tools and strategies designed to help agencies and communities make informed decisions about developing and managing health research in their communities. Included in this manual are:

1. **Background information** on why and how this document was developed.
2. A **vision** for community-based Aboriginal health research based on Aboriginal values and promoted by the Research Review Committee in the Manitoulin District.
3. **Ethical Research Guidelines** for community-based health research in First Nations in the Manitoulin district to ensure research projects respect local Aboriginal people and culture as well as adhere to high scientific standards.
4. **Guidelines for the review process** of research proposals by community agencies.
4. Using a **steering committee** to guide implementation of research projects
5. **Appendices** include a glossary of terms, sample research contracts and forms and references for additional reading.

The guidelines were developed from the perspective of health research, however the Research Review Working Committee was advised by community members and leadership repeatedly that the guidelines should be applicable to any kind of research projects in the First Nations in the Manitoulin district. We hope that the ideas shared in this document are useful for agencies, community-based researchers and external health researchers in their efforts to conduct meaningful and action oriented research with First Nations agencies and communities.

BACKGROUND

Past experiences with research in the Manitoulin District

Over the past years, local First Nations communities were often contacted by academic researchers or other agencies to participate in health research projects. Despite these research activities many community agencies did not have access to relevant community health information to plan and develop community programs. At the community level, many people felt that their First Nations were being “researched to death”; however, there was no noticeable benefit to their community. Research activities were not designed to benefit the community and rarely lead to action or change. Community agencies were also becoming increasingly concerned about the ethics of some of the research projects that were conducted locally, particularly the lack of community control over the research projects.

While “research fatigue” is growing among community members, First Nations agencies and leadership are under increasing pressure to conduct their own research to provide funding agencies with reliable data to support community-based initiatives. As communities are taking over the delivery of their health services, agencies are also in need of reliable research data on the health status in their communities and the effectiveness of their health programs.

Creating a vision for community health research

On March 5th and 6th, 2001 Noojmowin Teg Health Centre sponsored a community-based health research conference in M’Chigeeng to provide a forum for participants to discuss their experiences with health research on Manitoulin. The workshop was advertised in local papers and in the health agencies. Approximately 45 people attended this workshop, which brought together health care workers, community members, elders and local as well as university based researchers and students. Participants brainstormed about what makes research ethical from a First Nations perspective and how the goal of ethical research could be realized and thus created a vision for health research.

Recommendations from the first research workshop

Following the recommendations from this meeting, a working committee was formed to facilitate collaboration among the following First Nations agencies: Noojmowin Teg Health Centre, Wikwemikong Health Centre, M’Chigeeng Health Services, Mnaamodzawin Health Services, UCCM Tribal Council and Kenjgewin Teg Educational Institute. This working committee for health research was to develop ethical research guidelines. Participants identified Noojmowin Teg as the agency responsible for coordinating this phase, since this health centre already had a research mandate and a full time position for a research coordinator. During the summer and fall of 2001, committee members made presentations to the local four health boards and the UCCM Tribal Council and received their support for the development of ethical research guidelines and a research review committee.

A Proactive Approach to Research

Since the first research workshop in March 2001 the working committee on research has been meeting on a monthly basis and accomplished the following:

- Ongoing presentations about the work of this committee at the 4 local First Nations health boards/committees and to the UCCM Tribal Council
- Development of terms of reference for the committee
- Gathering of information on research guidelines and ethics, from Aboriginal and academic perspectives
- Development of ethical guidelines based on local First Nations perspectives and culture based on the guidance of a traditional advisory group
- Development of research guidelines to encourage sound and credible research practices that respect Aboriginal culture and values

Main Function of the Research Review Committee

The main ongoing function of the research review committee is to evaluate research proposals on the basis of two interrelated guiding principles:

1. **Ethics review** determines if the proposed research project respects Aboriginal customs and culture in the Manitoulin area. The committee will use the Aboriginal ethical research guidelines as a guide (page 5). The evaluation also takes into consideration ethical guidelines provided by the Tri Council Policy Statement (page 8).
2. **Research review** determines if the research project follows the vision for culturally appropriate Aboriginal health research on Manitoulin (page 4).

Future services provided by the committee can include:

Based on recommendations of the first research workshop and feedback from health board and tribal council information sessions the following future activities have been identified for this committee:

- Reviewing and evaluating research proposals, proposed for implementation in local communities and community-based ethics review for research
- Ethical review of research proposals
- Strategic planning for health research
- Keeping a library of past and current local research

OUR VISION FOR CULTURALLY APPROPRIATE ABORIGINAL HEALTH RESEARCH ON MANITOULIN ISLAND

All health research conducted in First Nation communities should reinforce and respect the cultural values of the First Nation organizations and communities. Research should be owned by the local First Nation communities and organizations. Health research should be designed to enhance information for decision making and development of local health programs. Under no circumstance should research lead to harm, violate the privacy and confidentiality of the clients that we serve, or the community as a whole. Research proposals should be reviewed for their ability to respect communities and reaffirm First Nations values and ethics, particularly adherence to:

- The mission and values of First Nations communities and agencies in the Manitoulin area
- Ethical research standards developed by the Aboriginal Health Research Review Committee in collaboration with a traditional advisory group
- Research protocols and guidelines so that research will lead to an improved capacity for knowledge-based decision making and community empowerment
- Ethical standards outlined in the Tri Council Policy Statement: Ethical Conduct for Research Involving Humans established jointly by Canadian Institute for Health Research (CIHR), Social Sciences and Humanities Research Council of Canada (SSHRC) and National Sciences and Engineering Research Council of Canada (NSERC)
- Ethical and professional standards relevant to the respective professions and disciplines of the researchers (e.g., Canadian Medical Association Code of Ethics)
- Guidelines and policies regarding the respectful treatment of indigenous and traditional knowledge
- Government legislation pertaining to privacy and freedom of information

To contribute to community empowerment through research, proposed research projects should focus on ethical and respectful partnerships with Aboriginal communities:

- 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

ETHICAL RESEARCH GUIDELINES FOR COMMUNITY-BASED HEALTH RESEARCH IN FIRST NATIONS IN THE MANITOULIN DISTRICT

As outlined in the previous section, the community-based research conference held in March 2001 in M'Chigeeng, brought together Elders, health care workers, community members and academic researchers to discuss a vision for health research. From these discussion groups people reached consensus on a vision for research in local First Nations communities:

- Research must emphasize a direct benefit to local community health
- Research projects should have the guidance of a local steering committee
- Issues surrounding the protection of traditional knowledge must be addressed
- Research methodologies must be culturally acceptable at the community level
- Research should incorporate traditional values into the research approach

During August 2002, the Research Review Committee asked for further advice from community members to provide more specific guidance in the development of Aboriginal research guidelines, based on the directions from the March 2001 meeting. This process resulted in the development of the Guidelines for Ethical Aboriginal Research (GEAR).

Aboriginal Ethical Research Guidelines

These guidelines are intended to help researchers and ethics review boards to ensure that research conducted with the First Nations on Manitoulin is ethical from a First Nations perspective. A brief summary on the process for the development of these guidelines is provided below:

Peggy McGregor, (Executive Assistant, Noojmowin Teg) initiated a process to conduct several discussion groups with respected community members, considered to be knowledgeable in local Aboriginal culture and community health issues. The groups involved Marjorie Shawande (Traditional Coordinator, Noojmowin Teg), Leona Nahwegahbow (Health Portfolio Holder, UCCM tribal council), Genevieve Jacko (health board member and mental health worker), Stella Corbiere (Registered Nurse). The participants in this group emphasized that the knowledge they shared was based on their own unique experience, and other community members may be able to add different points of view to this discussion. The discussion groups were facilitated, recorded and summarized in a draft document by Marion Maar (Research Coordinator, Noojmowin Teg). Participants were then invited to review the draft document and suggested changes were made to produce the final document.

The guidelines are based on the seven grandfather teachings of 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, some interpretations are provided below. The interpretations are examples which were shared during the discussion group. They are practical examples of the actions and attitudes that are required for ethical research in local communities. While many aspects of research are covered, these guidelines are not meant to be exhaustive. Rather, it is important for researchers to make every effort

to work within the spirit of the seven grandfather teachings in all aspects of the research process. As research projects are designed, evaluated and implemented, reviewers and researchers are asked to keep in mind the seven grandfather teachings and how these teachings apply to research. Below we give more detail on how the spirit of these teachings can be respected in research:

Respect

- Respect the diversity in spirituality, beliefs and values of First Nation people within each of their communities
- Need to look at all aspects of health in a holistic way
- Ensure participants know outcomes of study
- Be clear what is to be done with data and what is not to be done with it. For example: ensure that participants know that although a housing survey is conducted, it does not necessarily mean that there will be improvements to housing conditions in the near future
- Spend 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.
- Spend sufficient time to develop a comfortable environment. Do not ask people about concepts that are outside of their knowledge base.
- Find out how one should approach a person appropriately
- Avoid intrusive or probing questions, but rather design the questions to be open-ended
- Researchers need to interact at the participants own pace and level of understanding. Do not rush things. Respect people for their own individuality. 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.
- Similarly to the way that the seven grandfather teachings are interconnected and can not be separated, human beings are interconnected with the environment and the animals. Therefore, the same respect should also be extended to the environment and animal and plant life in the research process, ensuring a holistic approach to the research project.

Wisdom

- Appreciate the silence; silence may mean that people are figuring out things. If you rush people, a barrier will come up.
- Researchers have to become aware of the wisdom of elders and children
- Be aware that the meaning of off-beat remarks by research participants can be easily misinterpreted. The same can also be true for humor in general. Make an effort to appreciate people's humor!

Love

- Have kindness in your approach to research. "We all have the responsibility to be mindful of the benefit of research to all"
- Have a vision and think ahead
- Sharing and generosity in research means to keep in mind the following concepts:
 - How will the research benefit the community?

- How will it benefit future generations? “Are the arms reaching out for the future, just like ancestors arms have done?”
- Is the obtained information shared in a way that will benefit the future 7th generation. Does it reflect our love for the future generation and their survival?
- Does it ring a bell? Is it what our ancestors wanted? Remember the ancestors, you were blessed with their care and their outreach for this generation. Our ancestors had us in mind when they signed the treaties, our generations can have the same mindful thinking for future generations

Honesty

- Within the history of 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, then 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?”
- Honesty of the relationship between researcher and participant. The community and the individuals need to be (and feel) part of the purpose of the project and part of the team. There should be an acknowledgement of their contribution.

Humility

- Researchers should try to get rid of any preconceived expectations. Preconceptions will show! For example if interviews are done in the home of people, don't be judgmental of peoples' homes. Rather show humility in another person's home and conduct yourself without making assumptions about a person.
- Do not be intrusive with questions, there are ways of approaching subjects in a non-threatening way.
- Ensure that it is the right/good time to conduct the interview with a person
- Research participants are helping the researcher when they share information. It is a good practice to acknowledge their contribution by saying things like: “Can you **help** us with this work?”

Truth

- When the answers to the questions start flowing, people speak through the heart. Speaking from the heart means that a response is given in hope for the benefit of everyone. Things that really matter - the truth - comes out. This must be honored. “When the research turns bad, it is like you threw their words away, that is how serious it is!”
- Truth translates into action and benefit from research, without causing harm

Bravery

- It takes courage to let people into an aspect of your life and to participate in research; to do our best to make things right and be a role model to others

- Courage is needed to speak the truth, to stand by the information that has been gathered and to be a part of the process to create change.
- It takes courage to conduct research and to adhere to all other teachings that were mentioned in these guidelines.

In addition to adhering to traditional Aboriginal ethics, it is also necessary that research projects adhere to standard guidelines for ethical research set by Canadian research councils. These standards are outlined in the following section.

Tri-Council Policy Statement Ethical Guidelines

The following guiding ethical principles for research are outlined in the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (see bibliography). These statements are based on the guidelines of the Councils (Social Sciences and Humanities Research Council of Canada, Medical Research Council of Canada, and the Natural Sciences and Engineering Research Council of Canada), recent statements by other Canadian agencies, and statements from the international community. As stated in the Tri-Council policy, these principles have been widely adopted by diverse research disciplines. As such, they express common standards, values and aspirations of the research community. The guidelines are as follows:

1. Respect for Human Dignity: The cardinal principle of modern research ethics is respect for human dignity. This principle aspires to protecting the multiple and interdependent interests of the person - from bodily to psychological to cultural integrity. This principle forms the basis of the ethical obligations in research listed below.

In certain situations, conflicts may arise from application of these principles in isolation from one other. Researchers and research ethics boards must carefully weigh all the principles and circumstances involved to reach a reasoned and defensible conclusion.

2. Respect for Free and Informed Consent: Individuals are generally presumed to have the capacity and right to make free and informed decisions. Respect for persons means respecting the exercise of individual consent. In the ethics review process, the principle of respect for persons translates into the dialogue, process, rights, duties and requirements for free and informed consent by the research subject.

3. Respect for Vulnerable Persons: Respect for human dignity entails high ethical obligations towards vulnerable persons - to those whose diminished competence and/or decision-making capacity make them vulnerable. Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination. Ethical obligations to vulnerable individuals in the research enterprise will often translate into special procedures to protect their interests.

4. Respect for Privacy and Confidentiality: Respect for human dignity also implies the principles of respect for privacy and confidentiality. In many cultures, privacy and confidentiality are considered fundamental to human dignity. Thus, standards of privacy and confidentiality protect the access, control and dissemination of personal information. In doing so, such standards help to protect mental or psychological integrity. They are thus consonant with values underlying privacy, confidentiality and anonymity respected.

5. Respect for Justice and Inclusiveness: Justice means fairness and equity. Procedural justice requires that the ethics review process have fair methods, standards and procedures for reviewing research protocols, and that the process be effectively independent. Justice also concerns the distribution of benefits and burdens of research. On the one hand, distributive justice means that no segment of the population should be unfairly burdened with the harms of research. It thus imposes particular obligations toward individuals who are vulnerable and unable to protect their own interests in order to ensure that they are not exploited for the advancement of knowledge. On the other hand, distributive justice also imposes duties neither to neglect nor discriminate against individuals and groups who may benefit from advances in research.

6. Balancing Harms and Benefits: The analysis, balance and distribution of harms and benefits are critical to the ethics of human research. Modern research ethics, for instance, require a favourable harms-benefit balance - that is, that the foreseeable harms should not outweigh anticipated benefits. Harms-benefits analysis thus affects the welfare and rights of research subjects, the informed assumption of harms and benefits, and the ethical justifications for competing research paths. Because research involves advancing the frontiers of knowledge, its undertaking often involves uncertainty about the precise magnitude and kind of benefits or harms that attend proposed research. These realities and the principle of respect for human dignity impose ethical obligations on the prerequisites, scientific validity, design and conduct of research. These concerns are particularly evident in biomedical and health research; in research they need to be tempered in areas such as political science, economics or modern history (including biographies), areas in which research may ethically result in the harming of the reputations of organizations or individuals in public life.

7. Minimizing Harm: A principle directly related to harms-benefits analysis is *non-maleficence*, or the duty to avoid, prevent or minimise harms to others. Research subjects must not be subjected to unnecessary risks of harm, and their participation in research must be essential to achieving scientifically and societally important aims that cannot be realised without the participation of human subjects. In addition, it should be kept in mind that the principle of minimising harm requires that the research involve the smallest number of human subjects and the smallest number of tests on these subjects that will ensure scientifically valid data.

8. Maximizing Benefit: Another principle related to the harms and benefits of research is beneficence. The principle of beneficence imposes a duty to benefit others and, in research ethics, a duty to maximize net benefits. The principle has particular relevance for researchers in professions such as social work, education, health care and applied psychology. As noted earlier, human research is intended to produce benefits for subjects themselves, for other individuals or society as a whole, or for the advancement of knowledge. In most research, the primary benefits produced are for society and for the advancement of knowledge.

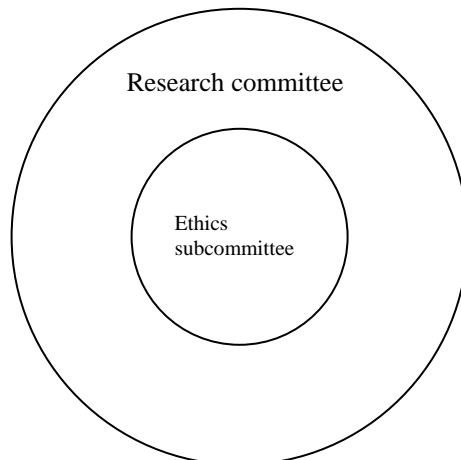
THE ETHICS AND RESEARCH REVIEW PROCESS

In this section we suggest a process for the review of research proposals at the community level. Proposals should be reviewed with a focus on two areas:

1. **Aboriginal ethics review** – this process will determine if the research is ethical
2. **Research review** – this process will determine if the proposed research fits within the local research agenda and will also make suggestions for maximizing community benefit.

1. Ethics review:

The first step in the review process is the ethics committee's review of the proposal. The ethics review committee is a **subcommittee** of the health research review committee. The ethics committee is composed of people with a special interest and training in research ethics. This subcommittee is composed of a chair person and 2 to 3 additional members. Ethical review team members sign a confidentiality form.



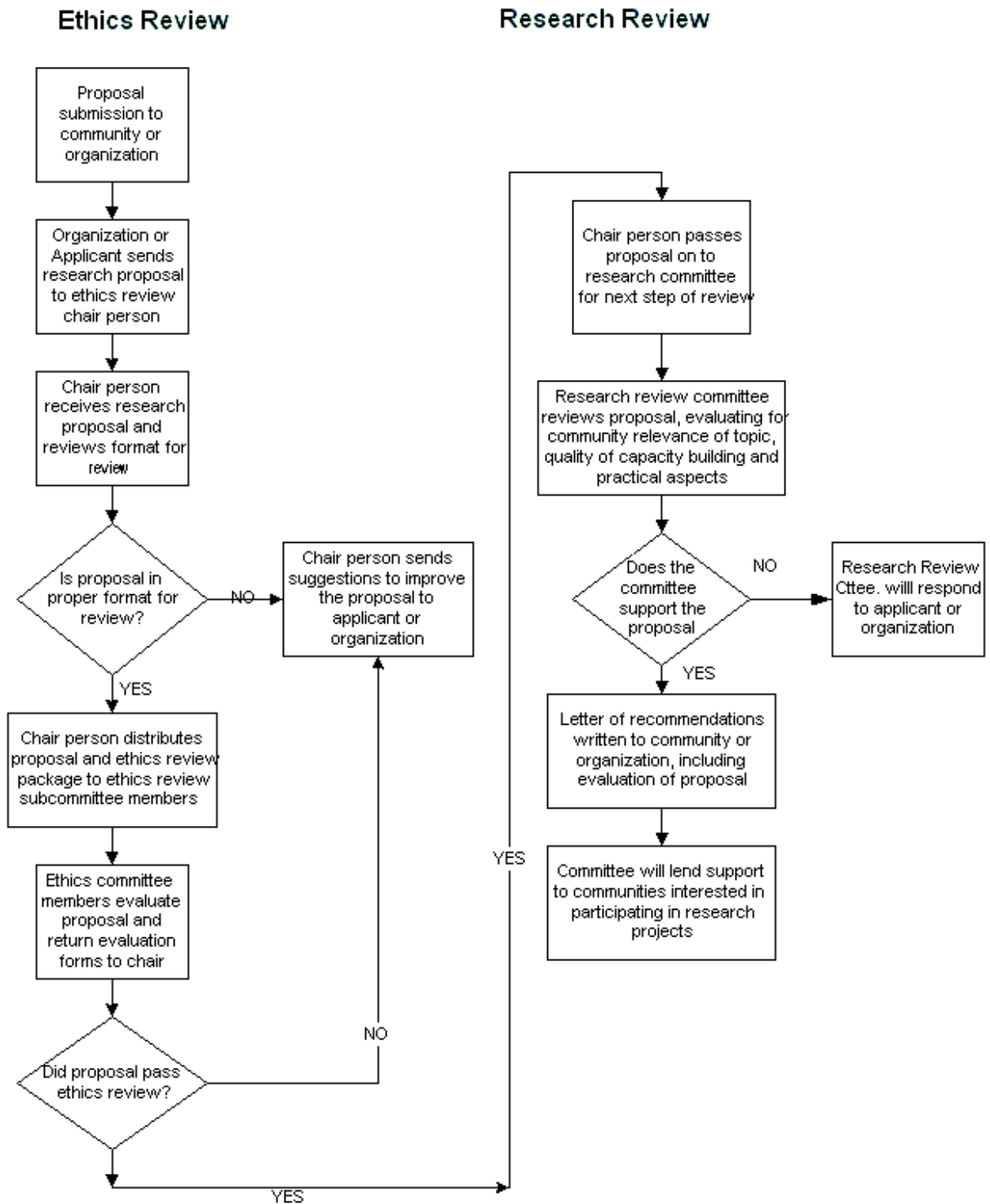
The ethics committee is a subgroup comprised of members of the research committee

The ethics committee determines if proposals are ethical from a First Nations perspective. Based on the ethical research guidelines in this manual, the ethics committee will develop a standard score sheet to evaluate proposals. The chair of the ethics committee is responsible for receiving proposals, acting as a lead contact for applicants, distributing materials to other subcommittee members and communicating results to community agencies and research committee members. Successful ethics review does not automatically result in an endorsement of a research project from the research review committee.

2. Research Review:

If a proposal has passed the ethics review process, it is then reviewed by the larger Research Review Committee. This committee evaluates the proposal based on the suitability of the topic and appropriateness of research methods. A standard assessment form addresses how well the proposal matches local research priorities and makes practical recommendations for improving the project to maximize community benefit. Suggestions can also be made for implementation of the project to ensure that the core values for research are upheld. The Research Review Committee communicates their recommendations back to the community agency. The flow chart on page 12 suggests a step by step guide for the review process. Page 13 provides a diagram to show the traditional approach and explanation for the research review process.

Flowchart for Ethics and Research Review



Medicine Wheel for the Research Review Process



Medicine Wheel Research Review Process

To the Ojibwe people, the Eastern Doorway represents the beginning of life and anything new. It is here where the birth of the research project begins. The proposal is presented for review by either the Researcher **through the** Community/Organization or directly **by the** Community/Organization.

The first available option / step for the community is to use the GEAR process for review. If the GEAR process is chosen, the proposal is forwarded to the Ethics Review Committee (ERC). The ERC reviews the proposal to ensure it is ethical according to GEAR. If it is ethically approved, it is then forwarded to the Research Review Committee for final review. Next, the evaluation of the proposal is returned to the researcher or community organization as requested. It may include recommendations for changes. The community or organization will make the final decision to either accept or reject the research proposal.

This process ensures that the proposal has come full circle and that all parties involved had the opportunity to evaluate the proposed project. The journey from the Eastern to the Western doorway represents life from beginning to end. The research project begins its journey from the East to the West during the GEAR review process. The West represents the completion of the Research Review process whether the proposal has been accepted and the research project is completed or if the proposal has been rejected.

STRATEGIES FOR FORMING A COMMUNITY BASED RESEARCH STEERING COMMITTEE

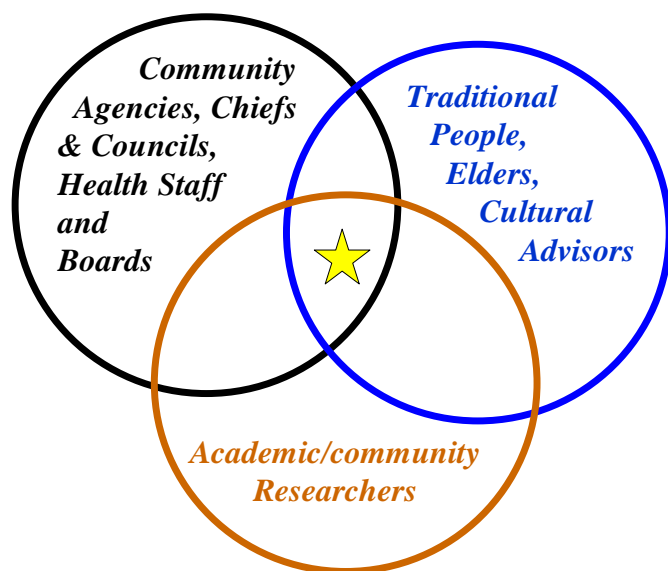
The implementation of each research project should be guided by a community-based steering committee. The function of this committee is to ensure that ethical values are upheld and that the expectations of the organization, the community and the researcher are aligned. Some First Nations may already have policies to guide steering committees. The guidelines below are not intended to replace existing policies in First Nation communities. The purpose for including them in this document is to assist First Nation communities who do not have such policies in place. Forming a steering committee will allow communities to manage the day to day activities of the research project and respond to concerns in a timely fashion.

Who should be on the community research steering committee?

Research Steering Committees should involve of community stakeholders such as:

- Key agency or organization staff
- Board representation
- Band Council representation
- External community representation
- Members with traditional knowledge
- Members with appropriate research background.
- Members with appropriate program expertise.

There is no ideal number of members for such a steering committee. However, organizations may wish to strive for a diversity of perspectives and expertise as well as community representation. Committee members should have an interest in research and the proposed project. A minimum of three members is advisable and up to seven members is manageable in terms of coordination of meetings.



As illustrated in this diagram, the ideal research approach combines three areas of knowledge:

1. knowledge of community and health issues in local First Nations
2. traditional and cultural knowledge
3. academic and community health research expertise

Meetings of the Steering Committee

Meetings will depend on the timeframe of the project but should allow for ample input into the initial design of the study or project, ongoing collaboration throughout the course of the project and final review and approval of any study or project reports and recommendations.

In most instances a research steering committee tasked with overseeing a project, will wish to communicate regularly through periodic updates with the organization's governing body or board. This can be accomplished through the board representative on the committee or the designated chair or relevant program manager.

Decision making process of the steering committee

Key decisions may be brought back to the appropriate governing body, board or committee for their input. The research steering committee should also submit final reports and recommendations for approval to the appropriate governing body.

The committee's role is to guide, review, monitor and support the research project or study and recommend reports, findings and decisions to the board. Final approval would ultimately rest with the organization's board or other governing body.

Procedures for Meetings

A chair and recorder will be selected from amongst the organization's program staff involved in the project. The chair's role would be to convene the meetings, set the agenda, keep meetings on track and ensure tasks are followed up on. The recorder will ensure that a record of key decisions or minutes are recorded and circulated in advance of each meeting.

The meetings schedule should be aligned with the relevant committee members. Committee members should be given ample notice concerning meetings as well as adequate time to review materials and information.

Program budgets permitting, honoraria and/or expenses should be offered to external committee members for their time and expertise.

APPENDIX A:

GLOSSARY OF DEFINITIONS RELATED TO RESEARCH AND ETHICS

Community health research may take place at different levels in the community. The focus of the study may be on clients, service providers, programs or services, organizational structures, comparing several health centres or health systems. Described below are some useful definitions related to research and ethical review.¹

1. Types of Research:

Experimental Research: generally involves a well-focused research question and is restricted to topics for which the situation can be manipulated (Neuman, 1991). Experiments include true experiments with the random assignment of subjects to treatment conditions. In health research, clinical trials fall into the domain of experimental research.

Quasi-experimental research: In quasi-experimental research, control and experimental groups are used in the study, but subjects are not randomly assigned to the groups. An example of quasi-experimental research may involve a comparison of the health status of individuals who have received a treatment/service to individuals on the waiting list.

Exploratory Research: An attempt to examine a topic or issue in order to learn about it or to formulate more precise research questions. Exploratory research is an attempt to break new ground in our understanding or to yield new insights. Exploratory studies are generally undertaken to: (1) develop our understanding of a topic or issue, (2) to examine the feasibility of undertaking a more care study, and (3) to develop methods to be employed in a follow-up study (Babbie, 1992). Exploratory research may be conducted in a CHC/AHAC to help to understand a specific phenomenon (e.g., barriers experienced by Somali women in accessing health care services in the community), or to understand the factors underlying the success of a program or service.

Participatory Action Research (PAR): a methodology for an alternate system of knowledge production based on the people's (e.g., clients, community members) role in setting the agendas, participating in the data gathering and analysis, and controlling the use of the outcomes (Tandon as cited in Reason, 1998, p. 271). PAR can be used to both advance knowledge and solve community problems. The PAR methodology may incorporate both qualitative and quantitative methods. As applied in CHCs/AHACs participatory action research means that either (1) members of the community or other groups are involved in the research processes of the CHC/AHAC, or (2) representatives of the CHC/AHAC are involved in decision-making, data collection and/or data analysis in research studies that are initiated by researchers from outside the CHC (e.g., students and faculty members from Universities, physicians and researchers from hospitals etc.) (See also the "Emerging International Principles for Protecting Indigenous Knowledge" in Appendix II.)

¹ The definitions are largely borrowed from the manual *Research Readiness in Community Health Centres and Aboriginal Health Access Centres*, by the Research Advisory Sub-Committee, Association of Ontario Health Centres, 2001.
GEAR - Guidelines for Ethical Aboriginal Research in the Manitoulin Area

Program Evaluation: a process of determining whether a program or service produced the intended result; in other words, it addresses the question “Did it work?” Program evaluation has been used to determine the effectiveness of a program and in relation to continuous quality improvement approaches of an organisation (Health Communication Unit, 2000).

Qualitative Research: research with “an emerging research design, uses the natural environment, focuses on determining the meaning attached to phenomena, acknowledges the researcher as an instrument in interaction with the phenomena being studied, and uses words as the primary symbols for generating theory specific to the context in which the research occurs” (Henderson, 1991, p. 11). Qualitative research generally involves the analysis of written or spoken data collected from interviews with individuals, focus groups or archives (e.g., statements written in medical charts).

Quantitative Research: involves the analysis of numerical data. The analysis may be descriptive in nature and produce a “picture” of a group or aggregate (e.g., number of patients served, number of participants in a program, incidence rates of specific medical conditions) or the analysis may involve a comparison of the similarities or differences between two or more groups (e.g., differences in the incidence rates of medical conditions among individuals participating in a treatment program compared to non-participants). Quantitative research may focus on statistics gathered for individuals (e.g., participation in a program, client satisfaction with a service received) or on analysis of a component part of the individual (e.g., heart rate, analysis of the composition of a tissue sample). Quantitative research generally involves the testing of theory, use of controlled data collection, and analysis using statistics (Henderson, 1991, p. 11).

2. Terms related to Research Ethics

Anonymity: Researchers protect privacy by not disclosing a participant’s identity after information is gathered (Neuman, 1991). A respondent may be considered *anonymous* when the researcher cannot identify a given response with a given respondent (Babbie, 1992, p. 467). Example: a mail survey in which participants do not indicate their names or identification numbers on the questionnaires before they are return them to the researcher.

Confidentiality: In a confidential survey or interview, the researcher is able to identify a given person’s responses but essentially promises not to do so publicly (i.e., in reporting the results of the study) (Babbie, 1992). Confidentiality is maintained when the identifiers for respondents are removed from questionnaires and interview transcripts and replaced by numerical identifiers. A master identification file that links numerical identifiers to actual names is then kept separately. In addition, confidentiality is maintained in the reporting of the results by ensuring that where verbatim quotes are used they do not reveal the identity of the individual/organisation, and where demographics are reported they are done so only at the aggregate (group) level.

Deception: occurs when a researcher disguises the true intentions of the research, or uses covert research methods for legitimate methodological reasons (Neuman, 1991). In research, deception is used under two main conditions: (1) in instances where if the subjects knew the true purpose of the research they would modify their behaviour, and (2) access to the research site would not be possible if the true nature of the study were revealed. A researcher who uses deception should obtain informed consent (describing the basic procedures involved in the study and concealing only information about specific hypotheses being tested or examined), never misrepresent possible risks, and always debrief the participants following the study.

Harm: may include emotional, psychological distress and physical harm. “Potential for harm varies by research methods; it is more likely in experimental studies where the researcher manipulates or does something to the subject than in observational or survey research” (Babbie, 1992, p. 471). Emotional distress is possible in all research studies in which questions are asked that elicit anxiety, dredge up unpleasant memories or cause individuals to evaluate themselves critically (Babbie, 1992). Harm may be reduced by using anonymous, self-administered questionnaires, trained interviewers and/or by working questions carefully.

Informed Consent: emphasises the importance of both accurately informing your subject or respondent as to the nature of your research and obtaining his or her verbal or written consent to participate (Babbie, 1992). Requires that coercion is not used to force participation and subjects may terminate their participation in the research at any point in time without fear of recrimination. Informed consent is violated in covert research (where subjects are unaware that they are being studied) and when deception is used (where subjects are under the impression that the research focuses on a different topic or issue). General statements of informed consent provide the following information: (1) brief description of the purpose and procedure of the research, (2) statement of any risks and discomforts associated with participation, (3) guarantee of anonymity and the confidentiality of records, (4) identification of the researcher and where to receive information about subject’s rights or questions about the study, (5) a statement that participation is completely voluntary and can be terminated at any time without penalty, and (6) an offer to provide a summary of findings (Neuman, 1991, p. 445). (See sample Letters of Introduction in Section 5).

Privacy: Privacy can be maintained through the use of self-administered questionnaires that are anonymous and confidential, or in which the identity of the person or group is disguised in publication (Babbie, 1992). In most research methods, analysis and reporting of the data should be at the aggregate (group) level. Violations occur under the right to privacy when researchers identify members of groups that they have studied, release or share an individual’s data or responses, or covertly observe behaviour (Babbie, 1992).

Power: The relationship between the researcher and the subjects involves power and trust; and that power is legitimated by credentials, expertise, training and the role of science in modern society (Neuman, 1991). The potential for ethical abuse is greatest where there are major status and power gaps, or ‘social distance’ between publics. Participatory approaches to research (e.g., PAR) have the potential to decrease this social distance and to reduce power gaps. Where power differentials remain, the researcher has the responsibility to guide and protect the interests of the people being studied.

3. Terms Related to Intellectual Property

Authorship: Refers to the individual or individual(s) that are given credit for reports, journal articles, presentations or products that may emerge from the research study. Authors of a publication are listed in the order of the significance of their contribution, and should include all, and only those individuals who have made a significant intellectual or scholarly contribution to the work reported, and without whose contribution the work would not be complete. All contributors to scholarly works should be recognised, regardless of their status at a University. (Source: University of Waterloo, Policy 73-Intellectual Property Rights. Available on-line: www.uwaterloo.ca/).

Collaborative Relationships- Collaborators should specify, in advance and in writing, how the process by which the rights to Intellectual Property arising out of the collaboration will be determined. The determination of rights should be based on the extent and nature of the contribution, and not on differences in power. Any waiver or modification of rights requires informed consent.

Publication Credit

The American Psychological Association discusses authorship in terms of “publication credit”, as described in the following excerpt from the Ethical Principles of Psychologists and Code of Conduct.

- (a) [Researchers] take responsibility and credit, including authorship credit, only for work they have actually performed or to which they have contributed.
- (b) Principal authorship and other publication credits accurately reflect the relative scientific or professional contributions of the individuals involved, regardless of their relative status. Mere possession of an institutional position, such as Department Chair, does not justify authorship credit. Minor contributions to the research or to the writing for publications are appropriately acknowledged such as in footnotes or in an introductory statement.
- (c) A student is usually listed as principal author on any multiple-authored article that is substantially based on the student's dissertation or thesis.
(Source: American Psychological Association, 1992, Ethical Principles of Psychologists and Code of Conduct. Available on-line: <http://www.apa.org/ethics/>)

Ownership: Ownership refers to the ownership of data and records that are collected in the context of the research study. This could include completed surveys or questionnaires, transcripts and tapes from interviews, medical records etceteras.

Ownership of Records and Data- Recognising that ownership of records and data is governed by legal principles, psychologists take reasonable and lawful steps so that records and data remain available to the extent needed to serve the best interests of patients, individual or organisational clients, research participants, or appropriate others. (Source: American Psychological Association, 1992, Ethical Principles of Psychologists and Code of Conduct. Available on-line: <http://www.apa.org/ethics/>)

Intellectual property: The term “intellectual property” means different things to different people in different contexts and environments. In a legal sense, the emphasis is on ownership and legal protection for something that has real or potential commercial value (the concern is patents, copyrights, trademarks etceteras). In general, common law and certain statutes and acts (e.g., Canadian Patent and Copyright Acts) are the legal means by which IP is defined and through which IP rights can be protected. In an academic community where the emphasis is on the word “intellectual” and includes the peoples ideas and scholarly activity (reports, articles, course materials etceteras). The academic community values openness, sharing of ideas, and scholarly activity, and its primary goals are to increase and disseminate knowledge. Depending on the particular situation, however, there may be a tendency to keep one’s ideas to one’s self. Commercial considerations, as well as potential academic recognition, can influence decisions to share ideas and results with one’s colleagues. While recognising that such tensions can exist, the University encourages an atmosphere of openness to the greatest practical degree. (Source: University of Waterloo, Policy 73- Intellectual Property Rights. Available on-line: www.uwaterloo.ca/)

APPENDIX B:

BIBLIOGRAPHY – ABORIGINAL RESEARCH RESOURCES

Useful Articles and Books

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- National Aboriginal Health Organization; www.naho.ca
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- Canadian Institutes of Health Researchers, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (1998). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Available from the website of the Natural Sciences and Engineering Research Council of Canada: www.nserc.ca/programs/ethics/english/policy.htm
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APPENDIX C:

SAMPLE RESEARCH AGREEMENT FORMS

The agreements provided in this appendix are samples used as Noojmowin Teg Health Centre for contract and partnership-based research. Agreements should be adjusted to each specific community and research project.

Standard Research Agreement Form 1

A copy of the research proposal should be attached to this form.

Title of the study:

1.1 This research agreement establishes the basis of the relationship

1.2 between _____
(Name of the principal researcher)

1.3 of _____
(Institution of the principal researcher.)

1.4 and _____ **Noojmowin Teg Health Centre** _____

In signing this document, the principal researcher and the representatives of Noojmowin Teg Health Centre acknowledge the following:

- (i) All research activities and reports or publications arising from research at the Centre will conform to the **research principles** outlined in the Guidelines for Ethical Aboriginal Research, and the **code of ethics** corresponding to the professional body most closely related to the area of study of the research project (e.g., Canadian Medical Association Code of Ethics, Canadian Occupational Therapy Association Code of Ethics), as well as the draft ethical guidelines for Aboriginal health research on file at Noojmowin Teg.
- (ii) All data obtained from, or collected at, the Centre shall be coded in a manner that guarantees the **anonymity and confidentiality** of the research participants; that is, data will be coded in a way that does not allow for identification of individual research participants.
- (iii) Data from the study will be stored in a secure location. Audiotapes and interview notes will be labelled with pseudonyms. Transcripts, surveys and other raw data will only be seen by members of the research group.

- (iv) Upon completion of the study, data and records that are collected in the context of the research study remain the property of Noojmowin Teg Health Centre. This could include completed surveys or questionnaires, transcripts and tapes from interviews, medical records etceteras. The analysis and interpretation that arises from the raw data will remain the property of the researcher(s), the research steering committee and Noojmowin Teg Health Centre.
- (v) Authors of a publication (community reports, journal articles, presentations or products etceteras) will be listed in the order of the significance of their contribution to the writing of the publication and will include all, and only those individuals who have made a significant intellectual or scholarly contribution to the work reported, and without whose contribution the work would not be complete. Authors of a piece may include the researchers, Noojmowin Teg staff persons, volunteers and Board members who have made contributions to the writing of the publication. Members of the steering committee and other individuals instrumental to the project will be acknowledged in all publications.
- (vi) Any reports or publications arising from the research shall be submitted to the Executive Director prior to distribution to communities and agencies or submission for publication. Noojmowin Teg Health Centre will then have the right to accept or reject the distribution or publication of the report.
- (vii) The Centre shall be provided with copies of all reports/papers derived from the research project.
- (viii) The researcher shall report on an ongoing basis to the Executive Director and the Research Steering Committee or designate on the development, planning, implementation and results of the research.
- (ix) The data collected and stored may not be made accessible to other researchers and/or used for research purposes other than those agreed upon without the Centre's knowledge and consent and without informed consent of participants.

Signature of the Principal Researcher

Date

Signature of the Executive Director

Date

Signature of a Research Steering Committee
Appointee

Date

Research Agreement Form 2

*A copy of the research proposal
and a copy of the publication strategy should be attached to this form.*

Title of the study:

1.5 This research agreement establishes the basis of the relationship

1.6 between _____
(Name of the principal researcher)

1.7 of University of _____
(Institution of the principal researcher.)

1.8 and _____ **Noojmowin Teg Health Centre** _____

In signing this document, the principal researcher and the representatives of Noojmowin Teg Health Centre acknowledge the following:

- (i) All research activities and reports or publications arising from research at the Centre will conform to the **research principles** outlined in the Research Guidelines for the Development of Ethical and Culturally Appropriate Health Research within the First Nations Communities on Manitoulin, and the **code of ethics** corresponding to the professional body most closely related to the area of study of the research project (e.g., Canadian Medical Association Code of Ethics, Canadian Occupational Therapy Association Code of Ethics), as well as the draft ethical guidelines for Aboriginal health research on file at Noojmowin Teg.
- (ii) All data obtained from, or collected at, the Health Centre shall be coded in a manner that guarantees the **anonymity and confidentiality** of the research participants; that is, data will be coded in a way that does not allow for identification of individual research participants.
- (iii) Data from the study will be stored in a secure location. Audiotapes and interview notes will be labelled with pseudonyms. Transcripts, surveys and other raw data will only be seen by members of the research group.
- (iv) Upon completion of the study, data and records that are collected in the context of the research study will be destroyed or remain the property of Noojmowin Teg Health Centre. This could include completed surveys or questionnaires, transcripts and tapes from interviews, medical records etceteras. The analysis and interpretation that arises from the raw data will remain the property of the researcher(s) and the research steering committee as appropriate.
- (v) Authors of a publication (reports, journal articles, presentations or products etceteras) will be listed in the order of the significance of their contribution to the writing of the publication and will include all, and only those individuals who have made a

significant intellectual or scholarly contribution to the work reported, and without whose contribution the work would not be complete. Authors of a piece may include the researchers, Noojmowin Teg staff persons, volunteers and Board members who have made contributions to the writing of the publication. Members of the Steering Committee, the Noojmowin Teg Health Centre and Health Board and other members instrumental to the completion of the project will be acknowledged in all publications.

- (vi) Results of community research shall be distributed as widely as possible within participating communities, and reasonable efforts shall be made to present results in non-technical language and Aboriginal languages where appropriate.
- (vii) Any reports or publications arising from the research shall be submitted to the Noojmowin Teg Health Centre Executive Director prior to distribution to communities and agencies or submission for publication. The Centre will review the proposed publications for adherence to this research agreement within 20 days.

Types of report or publication which will require further review:

1. Reports or publications which are identified in an approved publication strategy will **not** require further review. This research can also be presented orally at conferences without further review or consent.
 2. Reports or publications which are not identified in a publication strategy will require further review by a committee appointed by Noojmowin Teg Health Centre. Requests for changes will be made in writing by the appointed committee within 30 days. If the researcher accepts these changes no further review is required. If the researcher does not accept the changes the review process will proceed as outlined above. In all cases, the provisions within this contract must be adhered to for the purpose of publications. If the researcher and the committee can not come to an agreement on issues unrelated to the provisions in this contract, the researcher must at least include a disclaimer stating “the views expressed herein do not reflect the views of the Noojmowin Teg Health Board nor the views of the Noojmowin Teg Research Steering Committee who collaborated on this project”.
- (viii) The Centre shall be provided with copies of all reports/papers derived from the research project within 30 days of publication.
 - (ix) The researcher shall report on an ongoing basis to the Executive Director and the Research Steering Committee or designate on the development, planning, implementation and results of the research.
 - (ix) The data collected and stored may not be made accessible to other researchers and/or used for research purposes other than those agreed upon without the Noojmowin Teg Health Centre's knowledge and written consent.

Signature of the Principal Researcher

Date

Signature of the Executive Director

Date

APPENDIX D:

AGENCY BOARD AND COMMITTEE MOTIONS IN SUPPORT OF GEAR

The Guidelines for Ethical Aboriginal Research (GEAR) were presented to various community agencies and all of the Band Councils. This appendix provides a list of the Board and Band Councils in the Manitoulin district who support these Guidelines.

April 16, 2003 – Wikwemikong Health Board Meeting

- Recommendation to present to the Inter-Agency

May 21, 2003 – Wikwemikong Inter-Agency Meeting

May 28, 2003 – Noojmowin Teg Health Centre Board Meeting

- Motion carried to accept the GEAR document in principle

June 5, 2003 – M'Chigeeng Health Committee – GEAR Presentation

June 9, 2003 – UCCM Chiefs Meeting – GEAR Presentation

June 18, 2003 – Mnaamodzawin Health Services Board Meeting

- Motion carried to accept the Research Review Committee guidelines as presented

January 26, 2004 – Wikwemikong Band Council

- Motion carried to endorse the GEAR document developed by the Aboriginal Research Review Committee

June 28, 2004 – Whitefish River Band Council

- Motion carried to support the GEAR document developed by the Aboriginal Research Review Committee

July 12, 2004 – Sheguiandah Band Council

- Motion carried to support the GEAR document developed by Aboriginal Research Review Committee

September 9, 2004 – Sheshegwaning Band Council

- BCR of support dated November 22, 2004.

October 4, 2004 – Aundek Omni-Kaning Band Council

- Motion carried to support the Guidelines for Ethical Aboriginal Research (GEAR) developed by Aboriginal Research Review Committee.

October 14, 2004 – Zhiibaahaasing First Nation

- Community presentation took place followed by a BCR of support dated October 15, 2004.

November 29, 2004 – M'Chigeeng Band Council

- BCR of support dated November 29, 2004.