

Engaging in Aboriginal Health Research Partnerships: A Booklet for Communities and Researchers



A Collaboration Between Mamaweswen,
the North Shore Tribal Council,
the School of Rural and Northern Health and
the School of Education and Human Kinetics
at Laurentian University
and the
Northern Ontario School of Medicine.
Funded by the Indigenous
Health Research Development Program.

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Preface

Health studies can provide valuable insight into the wellness of individuals, families, and communities. The information gained may be used to work towards positive changes. The participation of First Nations and Aboriginal people* in health studies is vital to the building of healthy communities. This booklet provides helpful suggestions for Aboriginal communities and researchers who engage in health studies.

* "First Nations and Aboriginal" applies to wherever "Aboriginal" is used in this document.

It is about:

- (1) how to work together,
- (2) how to identify types of health studies, and
- (3) how to recognize good research

This booklet bears the insights of people from many Aboriginal communities, including Garden River, Serpent River, Whitefish Lake First Nation, and the Indian Friendship Centre in Sault Ste. Marie, a team from the North Shore Tribal Council, Laurentian University, and the Northern Ontario School of Medicine (NOSM).



The Seven Living Teachings

(<http://www.anishinaabemdaa.com/grandfathers.htm>)

All health research involving Aboriginal communities should adhere to the Seven Living Teachings:

Wisdom (Nbwaakaawin):

To cherish knowledge is to know wisdom.

Love (Zaagidwin):

To know love is to know peace.

Respect (Mnaadendmowin):

To honour all the Creation is to have respect.

Bravery (Aakdehewin):

Bravery is to face the foe with integrity.

Honesty (Gwekwaadziwin):

In facing a situation is to be brave.

Humility (Dbaadenizwin):

Humility is to know yourself as a sacred part of the Creation.

Truth (Debwewin):

Truth is to know all of these things.



A. Information For Aboriginal Communities

Communities can choose to take part in any study that they find relevant. In choosing a research partner, it is important to undertake high quality and relevant studies. Before you get involved, the researchers have the duty to tell you what kind of questions you will be asked. You can refuse to answer some or even all of the questions. You can stop taking part at any time.

How do You Know a Researcher is Ready to Work with an Aboriginal Community?

Researchers are ready when they:

- Want to learn about the community and its history
- Show interest in community partnerships and team work
- Work with the community to make sure that the study is desired and can be done
- Have a process to get community study approval
- Identify research ethics committee(s) to review study benefits and risks, and obtain their approval
- Consider funding options
- Plan to spend some time in the community
- Consider and address key community concerns
- Take the time to do the study

What the Community Can Expect from the Researchers?

- They have the obligation to protect your private information
- They will provide adequate training for community co-researchers
- They are accountable to organizations that employ them and to the funding sources
- They share what they know with others



Some Questions Worth Asking:

- Do we trust the researchers?
- Do they show respect?
- Do the researchers provide opportunities for the desired level of community involvement?
- Do they have previous experience with what they want to study?
- Can we look up their names and previous work?
- Do we clearly understand the benefits this research project will have in improving the health of our families and communities?
- What is in the study for us and for our community?
- Do we know who is paying for the research study to be done?
- Have the researchers explained the main questions to us clearly?
- Have they described how they will protect our personal information?
- Do we know how many people will be involved in the study and how they will be selected and asked to take part?
- Do we know when the study will take place, and how long it will last?
- Have we developed a process to review the study findings before publication?
- Do we know where the results will be presented and published?
- Do they indicate how the information collected will be analyzed?
- Are we able to discuss concerns about the study with the researchers?
- Based on study findings, will the researchers continue to work with us to improve the situation?
- Do they have ethics approval? Researchers must go through an ethics committee to make sure there are benefits and they do not harm anybody.



Medicines pictured: Left - Sage, Top - Sweetgrass, Right- Tobacco, Bottom - Cedar

Questions Worth Asking after the Study:

- What we liked and did not like about the study?
- What we liked and did not like about working with the researchers?
- Were the study expectations met?
- Is the study helpful?
- Are there things that need further study?
- Who will do the work?

About Research Ethics:

Here are some of the ethics boards/review committees in northeastern Ontario:

- Manitoulin Aboriginal Research Review Committee
- Laurentian University Research Ethics Board
- Sudbury Regional Hospital Research Ethics Board

For people who agree to take part in a study, the researchers should provide each one with a letter of information and a consent form to sign. Even if you have signed a consent form, you still have the right to stop.



B. Information for External Researchers

How Can Aboriginal Communities & Health Researchers Work Together?

I. Recognize the Context:

- Given their history, Aboriginal communities are often wary of outside “experts” and health research.
- A key cultural norm in Aboriginal communities is the gift of silence. It is not necessary to fill the space with conversation. Give people time to think about what they want to say.
- Another key cultural norm in Aboriginal communities is the gift of humour.

II. What Researchers Should DO:

(i) Attitude

- Respect people and communities as participants (not as objects or subjects).
- Honour their ideas and respect their interests.
- In order to work together, communities and researchers must be open and honest with each other.
- Be aware of your own biases and feelings.

(ii) Get Ready

- Take the time to visit, listen, and learn about the community, its people, history, traditions, cultures, order, and politics.
- Build trust and partnerships by first introducing yourself as a person.
- Establish friendly long-term relationships with the community and the participants.



Pictured: Wintergreen

- Approach the Health Director as your primary contact.
- Create a community-based steering committee in consultation with the Health Director.
- Be prepared to make presentations to various groups, including Chief and Council.
- Offer a pouch of tobacco to the steering committee and Chief and Council. If the tobacco is accepted this creates a spiritual contract and acceptance to proceed with the study.
- Discuss the benefits of health research: i.e., what is in it for the person, their family, the community, and the researcher(s).
- Convey what funding agencies and employers expect of you.
- Learn what the community expects of you.
- Ensure the community and the researcher reach a consensus regarding the study and its implications.
- Accept the value of traditional medicines, practices, and community knowledge.
- Show genuine concern for those who take part in the study.
- Consult the community often and at appropriate times. Community awareness is the key ingredient for successful research. Talk to as many community people as possible. Use the community's media tools such as newsletters, flyers, local TV cable station, radio, pamphlets, posters placed in public places, to communicate key messages about the research project.

(iii) The Study

- Create a comfortable atmosphere (greet everyone individually, treat everyone as an equal, dress casually, and be comfortable with silence).
- Use participatory research and be flexible about the research methods.
- Qualitative studies may be preferred because they complement Aboriginal worldview, storytelling, and oral tradition.
- Review and collaborate on study questions (objectives) with a community-based steering committee.
- Communicate using everyday words and limit technical terms.
- Listen and observe attentively.
- Be truthful; avoid putting words in peoples' mouths.
- If the study uses interviews, hire and train community co-researchers and value their input.



Pictured: Wild Rose

- Respectful practices include ensuring transportation for study participants, providing refreshments, and providing possible honoraria, or gifts (e.g., traditional tobacco, food, money, etc.).
- Data collection conducted in homes should initially require a community co-researcher in attendance.
- Recognize that the information provided belongs to the participants.
- Protect the confidentiality of the information.
- Come to a consensus with Aboriginal communities on ownership, control, access, and possession of information.
- Present a community report and convey the study benefits. If elders participated in the study you may want to personally take study findings back to them with the assistance of a trusted community helper.
- Collaborate with the community-based steering committee on next steps.
- It would be helpful to have a step by step guide for leadership about how to implement the findings.
- It is highly recommended that thank you letters or appropriate ads be taken out to thank study participants (i.e., community newsletters).



III. Suggestions for Researchers:

- Dress casually and respectfully.
- Be flexible with time by not imposing overly restrictive deadlines.
- Limit the number of questions to be specific and to the point.
- Too much eye contact may make some people feel uncomfortable.
- Avoid leading people to their answers.
- Avoid showing judgement of people's health and life styles.

Good Versus Not So Good Research

Good	Not So Good
Focuses on what is said and what more is to be said	Cares only for "numbers" and "facts"
Tries to be free from stereotyping and to understand broader relationships that affect health	Uses stereotypes, labels and generalizations
Uses a participatory approach	Uses a non-participatory approach
Respects privacy and keeps names separate from the results	Disregards confidentiality and privacy
Presents and provides results back to communities	Does not share results with communities
Emphasizes why the research is so valuable in moving the health of the community ahead	Emphasizes only the research criteria for the study



Pictured: Tobacco

How to Get Information from People Successfully

- Give clear explanations and let people offer their stories, but do not lead them.
- Use everyday words rather than complex terms.
- Discuss how people will be invited to take part in the study.
- Recognize participants as a gesture of gratitude (The community understands that not all research projects have large budgets).
- Host a feast or celebration.

How do You Know a Community is Ready/Not Ready to Do Research?

Ready	Not Ready
Communities show interest by asking questions	People may speak or use body language to show that they are not interested
Community members take the time to meet or talk with you, considering their commitments	People may avoid you, don't make eye contact, don't answer the phone, and don't show up for meetings



Community Interest in Research

Aboriginal communities are interested in health research done in respectful collaboration. Researchers must respect their knowledge and work together to improve health and health care. Partnerships generate more ideas and outcomes.



Pictured: Sumac

C. Types of Health Studies

Each type of health study design has its advantages and disadvantages.

I. Studies with Numbers (Quantitative Studies)

These studies involve counting people, diseases, potential causes of diseases, treatments, etc. Often these studies involve comparing one group with another. These types of studies can describe factors related to poor health, what drug works, what program can help, and more.

Sometimes these studies focus on learning about individual people and sometimes they want to find information about groups. Researchers may want to know about what is going on right now, what happened in the past, or what is happening now and in the future.

II. Studies with Words (Qualitative Studies)

Researches what people have to say and what stories they have to tell.

For example,

- (1) describe a health experience that happened to you,
- (2) tell a story about an experience related to healthcare,
- (3) talk about your view or your culture, and
- (4) work with a group to develop a research plan.

The information provided can help researchers to find common patterns. They can distill the wisdom to empower the community.

III. Studies with Numbers and Words (Mixed Methods Studies)

Some studies may use a mix of both words and numbers to get the best results.



D. What to Consider When Evaluating a Research Proposal?

Quality of Research

- Does the proposal provide convincing justification of the need to do the study?
- Is the research topic of interest to the community and to the participants?
- Is the type of research study design specified?
- Are these research questions clear?
- When will the study take place and how long will it last?
- Is the number of study participants needed for the study specified?
- How do prospective participants consent to take part in the study?
- Does the proposal give sample letters of information and consent forms?
- Is there a detailed data collection, entry and analysis plan?
- Where will the proposed research study undergo ethics review?

Credibility of Researchers

- Do the researchers have previous experience with the research topic?
- Do the researchers have previous experience working with Aboriginal communities?
- How does the research team keep the information collected confidential?
- How long is the information stored, retained, and how will it be disposed?
- Where and when will the researchers present the study results back to the community and academically?



Pictured: Queen Anne's Lace

Relations with the Community

- Will the study involve community-based researchers and assistants?
- How will the community research assistants be selected and trained?
- Who will be asked to take part in the study?
- Is the selection process clearly explained?
- Where will the participants take part in the study (e.g., at home, at the Aboriginal health centre, etc.)?
- Is the community comfortable with the type of study, the questions asked, and the proposed methods?
- Is the community input valued, respected and included?
- What are the benefits for the participants, the community, and the researchers?
- How and when will the researchers provide the results to the participants and the community?
- Is there a process established for community review and endorsement of the study results (e.g., reports, presentations, and potential publications)?
- If there are differences in interpretation of the results, will the various perspectives be presented?



Closing Thoughts

It takes effort by both communities and researchers to complete successful health research. In true partnership, they need to get to know each other, find common ground, consider the previous research, identify the study objectives, develop method(s), conduct the study respectfully, communicate the results, and plan what to do next. In each step, it is always important to keep the Seven Living Teachings in mind: Wisdom, Love, Respect, Bravery, Honesty, Humility, and Truth.



Pictured: White Birch

Appendix : Overview of Health Study Designs

Some types of quantitative studies are described below:

- 1) **Case (patient) report studies:** This type of study usually describes the characteristics of a disease (or health-related incident, e.g., lung cancer) or small collection of such events in an individual or small group of individuals.
- 2) **Case (patient) series studies:** This is similar to a case report but is a larger collection of cases of disease, often close in time, and which lists the common characteristic of the cases (affected patients).
- 3) **Cross sectional or survey studies:** This is one of the most common types of studies that describe health. It obtains information from individuals and information is collected at one point in time. It is the 'right now' study that often examines the relationship between diseases (or other health-related characteristics) and other variables of interest as they exist in a defined population at a particular time. However, we don't know which came first the factors or the disease.
- 4) **Ecological studies:** This type of study, usually describes (but can be observational where the researcher passively observes health events without controlling study exposure(s)), and examines information about groups, not individuals. It is often used to explore what factors (or exposures) are associated with a type of disease, but information about groups may not represent what happens to individuals. Also, we don't know what came first the factors or the disease.



- 5) **Case-control studies:** This type of observational study is used fairly commonly. This is the 'looking back or can you remember study' that obtains information from individuals with a disease and those without a disease and asks them to think back (so it relies upon having a good memory) about many factors (or risk factors, or exposures) to find out if they are related to developing a disease. This type of study is used to determine the causes of a particular disease.
- 6) **Cohort (or longitudinal) studies:** This type of observational study is the 'looking ahead' study. It follows people forward in time to find out if they develop certain disease(s) and asks them questions about various factors (or risk factors or exposures) at two or more times during the period to find out if the factors are related to disease development. This type of study is used to determine causes of a particular disease(s).
- 7) **Clinical trial:** In this type of experimental study, some individuals with a disease randomly receive a certain (or new) drug (or treatment) and others do not (or may receive a standard treatment used before) to see if they live longer or have a better quality of life. This could be called the does this drug make me better or worse study.
- 8) **Community trial:** In this type of experimental study, communities are randomized to receive a certain intervention (e.g., educational, behavioral, etc.) or not, to see if they do better or not. This type of study could be called the does this help one group more than another group types of study.



Pictured: Boneset

Some types of qualitative studies are described below:

- 1) **Participatory Action Research (PAR):** PAR is actually an approach to research rather than a methodology. PAR acknowledges that there is important knowledge at the community level. Using PAR, community members are collaborating with researchers at all stages of the research, from developing research questions and methods to interpreting and writing up the results. Research methods can really be any qualitative or quantitative approach. The process often involves steering committees, community discussions, and community-based researchers working alongside academic researchers.
- 2) **Narrative / Life story:** This is a story as told by a participant, perhaps an elder telling his entire life history or a person sharing how one is living with an illness. Emphasis is placed on understanding the experience from the point of view of the storyteller. A narrative is often used in health studies when one wishes to provide an example of a story of inspiration or hardship, such as the journey of a community member through cancer.
- 3) **Ethnography:** In this type of study, the researcher makes a long term commitment to immerse oneself into the culture or organization in order to gain a first hand, holistic understanding. This type of immersion is called participant observation and the researcher also conducts many key informant interviews.
- 4) **Vignette:** Vignettes are a form of narrative and storytelling but shortened to a few paragraphs for the purpose of providing an example. The vignette can be either removed from an individual person's example or provide a brief glimpse into one person's experience.



- 5) **Grounded Theory (GT):** Grounded theory is often used when there is limited previous knowledge about a certain topic. Instead of using existing theories to design the study, the research is used to generate new theories from “the ground up.” Theories are usually developed from individual interviews with participants. The goal is to conduct as many interviews as required until little new information is obtained from additional participants. From the interviews, the researchers initially code the data for common meanings and from the coding, eventually develop themes.
- 6) **Case studies:** A case study attempts to describe and understand a specific group, organization or event. The researchers may review documents, program data and interviews and any other methods that are suitable to the topic.
- 7) **Indigenous research methods:** Some Aboriginal scholars have employed indigenous research methods to come to know and understand research from their perspective and place.

Some types of *mixed methods* studies are described below:

There are studies that combine both *quantitative* and *qualitative* methods. When there is a combined method, researchers may state that the approaches are *sequential* or *concurrent*. Sequential means that one method is emphasized more than another; concurrent means both will be done at the same time.



Pictured: Blue Verrain

For Further Reading

1. Benton-Banai E. 1988. The Mishomis Book: The Voice of the Ojibway. Indian Country Communications: Hayward, Wisconsin. p. 114
2. Crombie IK. 1996. The Pocket Guide to Critical Appraisal: A Handbook for Health Care Professionals. BMJ Publishing Group: London, UK.
3. Endacott R. 2008. Clinical research 4: qualitative data collection and analysis. International Emerg Nurs 16:48-52.
4. Friis RH. 2010. Chapter 4: Descriptive Epidemiology: Patterns of Disease – Person, Place, Time. Chapter 6: Analytic Epidemiology: Types of Study Designs. In: Epidemiology 101. Jones & Bartlett Publishers: Sudbury, MA; Boston; Toronto; London; Singapore. pp. 65-85, 105-120.
5. Heller RF, Verma A, Gemmell I, Harrison R, Hart J, Edwards R. 2008. Critical appraisal for public health: A new checklist. Public Health 122:92-98.
6. National Aboriginal Health Organization. OCAP: Ownership, Control, Access and Possession. 2007. NAHO: Ottawa.
http://www.naho.ca/firstnations/english/documents/FNC-OCAP_001.pdf
7. Atlantic Health Promotion Research Centre (AHPRC). 1999. Guidelines for preparing research proposal.
http://www.ahprc.dal.ca/pdf/publications/1999_ResearchGuidelines.pdf
8. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. 1998 (with 2000, 2002 and 2005 amendments).
<http://pre.ethics.gc.ca/eng/policy-politique/tcps-eptc/>

Acknowledgements

We are grateful for all those people who took their time to contribute to this study.

We thank the Indigenous Health Research Development Program for providing funding from the CIHR Institute of Aboriginal Peoples' Health Network Environments for Aboriginal Health Research (NEAHR) grant.



Medicines pictured: Left - Sage, Top - Sweetgrass, Right- Tobacco, Bottom - Cedar

Daybutch G, Lightfoot N, Toulouse P, Maar M, Cheu H, Strasser R, and Schinke R. 2010. Engaging in Aboriginal Health Research Partnerships: A Booklet for Communities and Researchers. Unpublished report for the Indigenous Health Research Development Program.

Booklet Designed by:

