First Nations Centre des Premières Nations

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Health Information, Research and Planning

Under the *Canadian Constitution Act, 1982,* the term Aboriginal Peoples refers to First Nations, Inuit and Métis people living in Canada. However, common use of the term is not always inclusive of all three distinct people and much of the available research only focuses on particular segments of the Aboriginal population. NAHO makes every effort to ensure the term is used appropriately.

If you have questions or comments about this guide, please contact us at:

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Introduction

Health governance is a crucial component of self-determination, and will ultimately lead to improved health status for First Nations Peoples. As part of its mandate to build First Nations capacity to govern, manage and deliver health services, the First Nations Centre (FNC) develops and disseminates information resources on various topics related to health research and planning.

Health Information, Research and Planning defines fundamental concepts in health research and public health, and explains them in a manner that is relevant to First Nations health planners, administrators and leadership. This information is intended to get readers thinking about how health information can be used to support and enhance the development and delivery of community health programs and services.

By demystifying health information and research, we hope that readers will be empowered to initiate some of these practices in their communities. Also, a solid understanding of these concepts can ensure that First Nations are equipped to enter into inclusive, fruitful research partnerships that meet community aspirations and health needs.

This document provides an overview of health research and planning, but it is not comprehensive. Readers are encouraged to follow up on particular topics of interest. Please refer to the list of "Additional Resources" on page 24, or contact the FNC to obtain copies of other documents in this series, including:

- **Understanding Research;**

- **Health Surveillance;**

- **Privacy;**

- **Ethics in Health Research;**

- **Considerations and Templates for Ethical Research Practices;**

- **Understanding the Principles of Ownership, Control, Access, and Possession (OCAP);**

- **Assessment and Planning Tool Kit for Suicide Prevention in First Nations Communities;**

- **Health Careers; and**

- **Sacred Ways of Life: Traditional Knowledge.**

Part I – First Nations Community Health Needs

Health Information

"Without healthy, socially developed youth, we have no leaders for the future. Without available, high-quality care for the elderly, we have no guidance or wisdom from the past. Without strong, committed people acting today to champion our rights and to further our nations' interests, we have no guarantees for anyone beyond today… If we are to survive as a vibrant culture, and as strong and independent Nations, we must attend to the health of our people."

Tom Iron - Fourth Vice-Chief, Federation of Saskatchewan Indian Nations

Although First Nations do not all view health in the same way, there are recurring themes. Health is often described as a balance between various elements. These include the physical, mental, emotional and spiritual realms as well as the environment, culture, family, and community. Well-being "flows from balance and harmony among all elements of personal and collective life."[1] It is fundamentally understood that all things are interconnected. Elder Jim Dumont captures this concept when he speaks of "the total health of the total person in the total environment." [2]

In the past, western medicine and medical science seemed very different from traditional First Nations health knowledge and practices. While First Nations understand health within the principles of holism and interconnectivity, western health science tended to view illness and health as purely physical states, and studied them in relative isolation from social, emotional or environmental contexts.

However, for the past several decades, western health science has been gradually moving toward a more holistic understanding of health. There is now abundant medical research which demonstrates that mental and emotional factors can have major impacts on our physical health. Further, the "social determinants" of health – which include things like governance, income, and education – are widely accepted as significant factors that influence the health of populations and communities. So, you might say that western medicine is moving closer to a traditional First Nations understanding of health.

First Nations have always had extensive knowledge and a profound understanding of health and wellness. Traditional healers had the most knowledge about health, healing and medicines, compiled over generations through careful observation and analysis of all the factors that influenced individual and social health. In this sense, health research and information have always existed within First Nations cultures.

For First Nations, health information today may not be that different than it was in the past. But the nature of modern technology and the structure of the Canadian health care system have changed the ways that health information is gathered, recorded and used. We hope that this document will assist you, not in changing the way that your community understands health, but in enhancing your ability to collect and use health information in order to take full advantage of health programs, services and funding opportunities.

What is Health Information?

Although they are often used interchangeably, "data" and "information" mean slightly different things:

- **Data:** facts or figures from which conclusions can be drawn.

- **Information:** data that has been recorded, classified, organized, related or interpreted within a framework so that meaning emerges.[3]

Health Information – Any information, whether oral or recorded in any form, that is created or received by a health care provider, public health authority or health researcher; and relates to the past, present, or future physical or mental health of an individual, or the past, present or future provision of health care to an individual.[4] In other words:

- Health information is made up of data about individuals;

- Health data becomes health information when it is gathered, organized and interpreted for a particular reason; and

- Health information is collected and produced by people or agencies that have responsibilities or interests related to health.

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Why is health information essential for community health planning?

In every aspect of our lives, we use information to plan and make decisions. The type of information that is required will depend on the decisions to be made. A hunter might plan a hunting trip based on the weather conditions and seasonal movement of animals; a business owner needs information about the demand for products and services. Similarly, health planners need information about health needs and priorities in order to plan and implement effective health programs and services.

The ability to access and use health data and information is the first step toward effective community health planning. Health research encompasses a variety of ways to collect, organize, analyze and interpret existing or new health data, for purposes that are directly related to health planning and decision-making. Figure 1 depicts the health information, research and planning sequence.

Figure 1: Health Information, Research, Planning
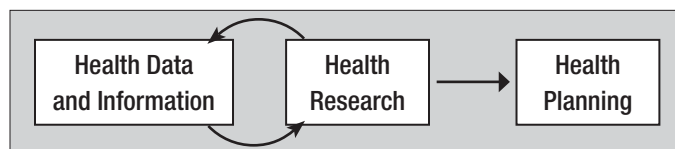
Health information and research can help First Nations leaders and health planners to:

- **Raise awareness of health issues**
  Example: Inform local leadership that rates of accidental injury in the community are on the rise.

- **Set priorities, make plans and allocate resources for the health sector**
  Example: Based on this information, band councils could decide to target injury prevention as a health priority.

- **Lobby for government funding or strengthen funding proposals**
  Example: Rates of accidental injury are cited in a funding proposal for an injury prevention program.

- **Target and design effective health programs or interventions**
  Example: Community health planners design an injury prevention program aimed at youth because statistics show that accidental injuries are most frequent among this group.

- **Evaluate the performance of a health program or intervention**
  Example: Rates of accidental injury will be measured again in two years to see if the injury prevention program is having an effect.

Where can I find health data and information?

The Assembly of First Nations (AFN) has stated that, "to achieve a state of wellness, it is essential that a community have access to information about itself… [but] health data is not available to communities in many circumstances."[5] First Nations health data and information are easier to find at the national and regional levels, where various agencies are mandated to collect and analyze health data. Some national and regional sources for First Nations health data and information are:

- The *First Nations Regional Longitudinal Health Survey* (RHS), now hosted at the Assembly of First Nations, offers unique First Nations data (http://rhs-ers.ca/english/);

- The *First Nations and Inuit Health Branch* (FNIHB) of Health Canada manages and analyzes First Nations health data (http://www.hc-sc.gc.ca/home-accueil/contact/fnih-spni/hiad-disa_e.html);

- FNIHB also publishes *A Statistical Profile on the Health of First Nations in Canada*, which reports on a wide range of health status indicators and determinants (http://www.hc-sc.gc.ca/fnih-spni/pubs/gen/stats_profil_e.html);

- Indian and Northern Affairs Canada (INAC) maintains a number of Aboriginal databases and produces reports and community profiles (http://www.ainc-inac.gc.ca/pr/index_e.html);

- Provincial and territorial health ministries collect and analyse health data for all clients using their services (www.hc-sc.gc.ca/hcs-sss/delivery-prestation/ptrole/ptmin/index_e.html);

- Numerous statistics are available from *Statistics Canada* (www.statcan.ca), including "community profiles" and "Aboriginal community profiles";

- Provincial and territorial statistical agencies provide a wide range of statistics and reports (www.vs.gov.bc.ca/contact/vs_provinces.html); and

- NAHO provides health information reports on its web site (www.naho.ca).

At the local level, health data may be available from a variety of sources but it is more likely to be "raw data"; that is, it has not been previously organized, analyzed or interpreted for health-related purposes. Local sources for health data may include:

- Nursing stations or health centres (statistics extracted from health records);

- Administrative data from community health programs (information generated through monitoring, reporting, evaluation);

- Sales records from local stores (e.g. sales of fruits, vegetables, alcohol, cigarettes, junk food);

- Treatment centres (statistics);

- Community meetings, feasts, cultural events, training sessions, health promotion activities, etc. (frequency, number of participants);

- Schools (dropout statistics, absenteeism); and

- Community-based health research (NEW DATA).

Research

What is research?

Research is an organized and systematic way of finding answers to questions. It is a process whereby data is gathered and information is produced in order to answer a question or set of questions. Four key elements should always be present in research:

- QUESTIONS: questions drive research. Research is focused on relevant, useful, and important questions. Without a question, research has no focus, drive, or purpose;

- SYSTEMATIC: there is a definite set of procedures and steps which you will follow. There are certain things in the research process which are always done in order to get the most accurate results;

- ORGANIZED: there is a clear structure or method to the research. It is a planned procedure, not a spontaneous one. It is focused and limited to a specific scope; and

- FINDING ANSWERS: this is the goal of all research. Whether it is the answer to a simple question or evidence that proves an assumption, research is successful when we find answers. Sometimes the answer is no, but it is still an answer.

There are two main types of research: **Primary** and **Secondary** research. Although it might seem a bit backwards, secondary research is usually done first.

Secondary research

Also known as desk research or a literature review, this type of research involves finding and reviewing research and information that already exists about a particular topic. If you are planning to conduct in-depth research on any topic, it is typical to start with secondary research.

There are several important reasons to do secondary research:

- **It brings you up-to-date with the most current** research and information on a topic;

- **It allows you to see the "bigger picture" by** learning about similar research in other communities or populations;

- **It may show you new ways to interpret an issue** or develop a research question;

- **Learning about other research methods might** give you new ideas on how to design your own project; and

- It helps you to ensure that your research question or topic is addressing something that is not already known.

Secondary research is generally cheaper and faster than primary research. In the past, it was difficult to do secondary research unless you had access to a good library. Now, there is so much information available from the Internet that all you really need is a desk and a computer. Good sources for First Nations, Aboriginal or community health research are described below.

Where can I find health research?

Academic journals – Although health research can be highly technical and scientific, there is lots of First Nations, indigenous and community-based health research that is accessible and useful to non-scientific audience. The following journals, indexes, and full text articles are available on-line:

- *Journal of Aboriginal Health* is published by the National Aboriginal Health Organization (http://www.naho.ca/english/journal.php);

- *Pimatziwin: A Journal of Aboriginal and Indigenous Community Health* is published by the University of Alberta (http://www.pimatisiwin.com/);

- *Canadian Journal of Public Health* is published by the Canadian Public Health Association and has many articles that are relevant to community health planning (http://www.cpha.ca/english/cjph/cjph.htm);

- *Canadian Medical Association Journal* includes medical science research, but also has lots of good articles on First Nations and Aboriginal health (http://www.cmaj.ca/);

- *Health Promotion Practice,* published by the (U.S.) Society for Health Promotion, is a good source for research on health promotion and disease prevention (http://hpp.sagepub.com/); and

- The Assembly of First Nations Health and Social Secretariat conducts research to support its policy work; publications are listed under corresponding "Health Policy Areas" (http://www.afn.ca/article.asp?id=103).

Journals Related to Traditional and Nature-Based Medicine:

Ethnobotany Research and Applications: http://www.ethnobotanyjournal.org/

Phytotherapy Research: http://ca.wiley.com/WileyCDA/WileyTitle/productCd-PTR.html

Journal of Medicinal Food: http://www.liebertpub.com/publication.aspx?pub_id=38

Journal of Herbs, Spices and Medicinal Plants: http://www.haworthpress.com/store/product.asp?sku=J044

Evidence-based Complementary & Alternative Medicine: http://ecam.oxfordjournals.org/

Journal of Herbal Pharmacotherapy: http://www.haworthpressinc.com/store/product.asp?sku=J157

Canadian Journal of Herbalism: http://www.herbalists.on.ca/journal/back.html

HerbalGram (American Botanical Council): http://abc.herbalgram.org/site/PageServer?pagename=Herbal_Library

Herb Quarterly: http://www.herbquarterly.com/

British Journal of Phytotherapy: http://www.phytotherapists.org/journal.htm

Medical Herbalism: http://www.medherb.com/MHHOME.SHTML

International Journal of Phytotherapy & Phytopharmacology: http://www.accessmylibrary.com/coms2/browse_JJ_P043

Alternative Therapies in Health and Medicine: http://www.alternative-therapies.com/at/index.cfm?page=about

The Journal of Alternative and Complementary Medicine: http://www.liebertpub.com/publication.aspx?pub_id=26

Ethnobotany Research and applications: http://www.botany.hawaii.edu/era/default.htm (free online journal)

Australian Journal of Medical Herbalism: http://www.nhaa.org.au/index.php?option=com_content&view=section&layout=blog&id=17&Itemid=57

Protocol Journal of Botanical Medicine: http://www.centerfornaturalhealing.com/gaia/books.html (Back Issues)

The Journal of Science & Healing: http://www.explorejournal.com/

Government publications – Various departments within the federal government conduct and publish health and health-related research, and most of it is available on-line:

- Health Canada (FNIHB) offers reports and publications on many health topics that are of particular concern to First Nations (http://www.hc-sc.gc.ca/fnih-spni/pubs/index_e.html);

- The Public Health Agency of Canada is a good source for research and information on mainstream health and health-related issues (http://www.phac-aspc.gc.ca/publications_e.html#a); and

- Provincial, territorial, regional and tribal health authorities may also have research and publications available that is relevant or useful to your needs; check their websites or contact them directly.

Health databases – There are excellent on-line databases for health and/or Aboriginal health research. These databases can save a lot of time because they give you access to a large amount of information (including journals and governments publications), while limiting your search for information to one broad category (e.g. "health") that can be searched by more specific keywords (e.g. "diabetes"). The only limitation of databases is that you will find references to articles/books that are not available on-line or cost money (however, many articles can be sent by email for a small fee).

- Aboriginal Health Collection and Information Services at the University of Manitoba provides access to the library's catalogue, as well as relevant on-line journals and databases; it is an excellent resource for secondary research (http://www.umanitoba.ca/libraries/units/health/aboriginal/index.html); and

- The Native Health History and Native Health Research databases are provided by the University of New Mexico Health Sciences Centre. The library has access to about 80% of the materials and it will send them to you (electronically) free of charge (http://hsc.unm.edu/library/nhd/index.cfm).

And last but not least, don't forget about the FNC, NAHO! We have a growing collection of research and information about health priorities that have been identified by First Nations people. Please visit us at http://www.naho.ca/firstnations/english/welcome_page.php, and you can access all NAHO publications at http://www.naho.ca/english/publications.php.

Primary research

Primary research is the *collection of new data or information,* to answer a specific research question or shed light on a particular topic. If you are interested in learning about one or more aspects of health within your community, you are likely planning to do primary research. Primary research methods fall into one of two categories:

Quantitative	Qualitative
• Data comes from records, surveys, questionnaires	• Data comes from interviews, focus groups, talking circles
• Results are expressed as numbers or statistics	• Results are not numerical, but expressed as words
• Results are measurable	• Results are descriptive
• Results are specific & focused	• Results tend to be broader, open-ended
• Outcome oriented	• Process oriented
• Understanding based on numerical calculation	• Understanding based on people's views, knowledge, and experiences

Quantitative and qualitative research produces different types of information. For example, quantitative data could tell you that:

- 1 in 4 Elders report loneliness and depression;

- 58% of parents report that they feed their children a healthy diet; or,

- 37% of women over age 45 have never been screened for breast or cervical cancer.

On these same topics, qualitative information could tell you that:

- Many Elders say that they are lonely because activity limitation prevents them from visiting friends or attending community events;

- Some parents say that they would like to feed their children a healthy diet, but they can't afford to buy healthy foods; or,

- Most women said that they don't feel comfortable being screened for breast cancer by a male nurse or physician.

Quantitative data is an effective way of assessing and measuring health status in your community. Qualitative data can reveal why people behave a certain way, or how they feel about health issues. Together, both types of data can paint a comprehensive picture of not only health status, but also of your community's hopes and values about health and well-being.

How is research done?

There are generic steps to conducting a research project, regardless of the specific research methods that are to be used.

1. Develop Research Questions

You probably already have a topic (e.g. childhood asthma) in mind, so now you need to decide more specifically what you want to know. Formulating your research question(s) will depend on what you are planning to do with the information. For example, if you simply want to know the extent of the problem, your research question might be: *How many children in our community have asthma, and is it worse than in other communities?* On the other hand, if you already know that childhood asthma is a serious problem and you want to develop a strategy to reduce childhood asthma in your community, your question might be: *What are the causes of childhood asthma in our community?*

2. Review existing information

This means conducting some level of secondary research. Some of the information that you need may already exist. Make sure that you are aware of research that has been done on similar topics, locally or elsewhere, so that you don't duplicate efforts. Even if there

has not been any research done on a particular health issue in your community, learning about similar research in other communities is important. For example, you might find out that other studies have proven a link between childhood asthma and exposure to second hand smoke and mould; this means that your research project should investigate whether these are prevalent risk factors in your community as well.

3. Develop primary research methods and tools

Data collection methods that are commonly used at the community level include:

- Surveys and polls;

- Administrative data (e.g., extracting information from existing sources such as health records);

- Interviews; and

- Focus groups or talking circles.

The research methods that you choose will largely depend on your research question(s). For example, if your question is, *"what are the causes of childhood asthma in our community?",* you might decide to measure the prevalence of various known or suspected risk factors among children with asthma in your community. Measurements are expressed as numbers or percentages, so your methods should be quantitative. Or, you might decide that interviewing health care staff and parents of asthmatic children is the first step so your research would be quantitative. A combination of methods is often ideal, so you can view the topic from different angles. You can also use one method to refine another. For example, many researchers hold focus groups to explore a topic before they design a questionnaire about it.

Please refer to the FNC's *Research Tool Kit: Understanding Research* (2003) for a more detailed discussion of research methods and tools. Additional sources of information on research methods are also provided at the end of this document.

4. Organize and carry out data collection

The size and capacity of your research team will depend on data collection methods and scope. Be sure that the research team is well-prepared and has some training

in survey/interview/focus group techniques and is familiar with ethics and confidentiality protocols.

Ensure that community members are informed in advance of the purpose and scope of the project. Try to conduct the data-gathering phase of the project during a time when community members are likely to be available and not distracted by other priorities.

The community should have the opportunity to provide feedback on the research methods, instruments and ethics.

5. Analyze the data

Analysis of quantitative data involves:

- Identifying the most common issues/needs based on numerical measurements;

- Turning numbers into rates, percentages, or averages; numbers often don't mean much on their own, so they have to be expressed as a proportion of a total. This also allows you to compare your results to those of other studies or groups; and,

- Using graphs and charts to show patterns; this is usually more effective in passing on information than reading a table of numbers.

Analysis of qualitative data involves:

- Identifying common themes based on transcripts of interviews or focus group discussions;

- Combining similar responses and organizing these around recurring themes;

- Examining how the results differ between groups of respondents (e.g. by gender, age group, etc.); and,

- Pulling out good, clear quotations to support the analysis and interpretation.

6. Prepare the report

A good report is as important as good data. It is the primary record of the project, and its results can be very useful for leadership, community members, and funders. A research report should always include the following elements:

- Statement of research question/objective;

- Description of research methods, including any limitations that were encountered;

- Description of the nature and source of data that was obtained (e.g. how many people participated, or how many records were used);

- Explanation of how data was analyzed; and,

- Interpretation and results.

7. Share the results

Before you finalize the report, you may want to review the first draft with leadership, or even with community members. This step is referred to as "verification of findings." This step will allow you to correct any misinterpretation of findings, and will enhance community support of the outcomes.

In addition to the full report, you may also want to report findings to the community in another way that is language and culture-appropriate. Research results can be made public using:

- Reports;

- Fact sheets, flyers, leaflets;

- Presentations to meetings or community forums;

- Radio or TV interviews;

- Articles in community newspapers;

- Presentations at conferences; and

- Workshops.

How can research results improve community health?

Generally, research alone is not enough to improve health. If you want to use your research results to raise awareness or educate community members, some health-promotion experts have suggested the following approach:[6]

1. Define the desired impact of the information – for example, a change in eating and exercise habits;

2. Identify the target groups – for example, women/men, Elders, youth;

3. Identify "go-between" people or groups that can help you achieve the desired impacts - for example, health care staff, parents, community groups;

4. Develop the message – how can the information be communicated to achieve the impacts you want; and

5. Decide on the best format for communication, such as a video, meeting or a flyer.

Research results can also be used to plan community health strategies or programs. Using the example of childhood asthma, let's say that your research revealed that the most common risk factor among children with asthma in your community was exposure to mould. Therefore, it is decided that a program must be initiated to address this problem. Any health program should have the following elements: goals, objectives, activities, outcomes and indicators. The table below shows how these elements would be expressed using the example of childhood asthma and mould.

Use of research results: a success story[7]

In 1987, researchers at Kahnawake First Nation found high rates of diabetes in the community and unhealthy dietary patterns. They publicized the results in one-hour sessions for various community groups and during a talk show on the local radio station. The results were dramatic:

• The number of people showing up for diabetes screening increased;

• The dietician was swamped with people seeking advice on weight loss, diet change, and exercise; and,

• Teachers at the local schools banned junk food and started a daily exercise period for staff and students.

Table 1 – Elements of Program Planning

Issue	Goal	Objectives	Activities	Outcomes	Indicators
Childhood asthma	To decrease the incidence of risk factors associated with childhood asthma	By December of 2009 to reduce the amount of mould in homes occupied by children	1) Inspections of home occupied by children to identify homes with mould 2) Implement a home repair program to remove mould and prevent recurrence	Reduction in the amount of mould in homes occupied by children by December 2009	The percentage decrease in the number of homes of children with mold or mildew

Public Health Research and Practice

"Public health" is the science and practice of protecting and improving the health of **communities** (as opposed to individual patients). We will be discussing some key concepts in public health that are relevant to community health planning.

The essential functions of public health are:

- **Health protection:** includes the assurance of safe food and water, control of infections diseases, protection from environmental threats and regulation of food and drug safety;

- **Health surveillance:** enables health authorities to identify chronic and infectious diseases patterns and causative factors, which allows for earlier interventions and reduced impact;

- **Disease and injury prevention:** the development and implementation of evidence-based health promotion programs to prevent or delay disease and injury;

- **Population health assessment:** the ability to measure and understand the health of populations and the factors that influence health, leading to more effective services and policies; and

- **Disaster response:** planning to minimize the impact of potential natural and man made disasters, for the health sector and society at large.[8]

Community health planning is a smaller scale version of public health. This section will provide a basic understanding of three methods used in public health research: indicators, surveillance and epidemiology. First, let's look at the very first phase in the long-term process of community health planning: the community health needs assessment.

Community Health Needs Assessment

A Community Health Needs Assessment (CHNA) is a variation of a population health assessment. It is a process for identifying your community's health needs and resources in an organized way. It involves the collection, organization and analysis of a broad range of health information about your community and its members.

Conducting a CHNA is the first step in the Health Services Transfer process. Whether or not your community or regional is planning on initiating this process, a CHNA is an important step toward putting First Nations in charge of planning and delivering health services that will meet the needs of their communities. It provides baseline information about your community's collective state of health, and the resources and gaps that are relevant to addressing health.

A CHNA typically gathers and reports the following types of information:

- demographics (e.g., numbers and ages of community members);

- the elements that make up your community health system;

- the kinds and levels of health issues members of the community are experiencing (including physical, mental, social and environmental);

- the circumstances that are factors of these health issues;

- the resources that are available to address these health issues (e.g., current programs, community expertise, other strengths and assets);

- the community members that have the most urgent needs;

- the best way to meet the needs of community members; and

- the training needs of health care personnel to help them meet the health goals and objectives.

A CHNA addresses multiple research questions about health and health-related issues of a community, and typically employs both qualitative and quantitative research methods. Rather than investigating one particular aspect of health, the CHNA is intended to provide a comprehensive snapshot. The results of the CHNA can also be used to identify areas for more focused health research in the future. Please refer to "Additional Resources" (p. 24) for links to more information on the Transfer process and CHNA.

The results of a CHNA can be used to identify health priorities, resources and gaps. This facilitates the planning of health programs that meet community needs.

Remember, the collection and use of health data should be an ongoing process. The path to health and wellness is just that…a path, not a destination. Deciding what information needs to be collected day by day, as well as planning how that information should be organized, kept and used, will keep your community on the path to health and wellness.

Indicators

Indicators are the primary tool in health surveillance, and the most commonly used type of health information. Indicators are numerical (quantitative) measurements of specific aspects of health within a community or population. Indicators tell you how many people, or what proportion of people in your community, are experiencing specific health or health-related conditions. One of the goals of the CHNA, described above, is to identify and/or measure relevant indicators of community health and well-being that can be tracked over time to assess progress. Whereas the CHNA is a process for assessing all aspects of community health, specific indicators can be selected to measure and monitor a particular issue or problem.

Health Canada is required to report to Parliament on health outcomes and to officials at the federal/provincial/territorial levels. It reports on 14 categories of indicators referred to as the PIRC* (Performance Indicator Review Committee) Indicators: [9]

– Life expectancy;
– Infant mortality;
– Low-birth weight;
– Self-reported health;
– Change in life expectancy;
– Improved quality of life;
– Reduced burden of disease and illness;
– Waiting time for key diagnostic and treatment services;
– Patient satisfaction;
– Hospital re-admissions;

– Access to 24/7 first contact health services;
– Home and community care services;
– Adequacy of public health surveillance; and,
– Health protection and promotion activities.

Health Status indicators are measurements of specific aspects of health (e.g. rates of injury and disease, low-birth weight, life expectancy). **Health Determinant** indicators are measurements of factors that influence health status (e.g. diet, smoking, access to health services).

When deciding what indicators are important for your community, it is helpful to understand the relationship between health status and health determinant indicators. In public health research, the relationship between health determinant and health status indicators is generally understood as one of cause and effect. This is reflected in the Population Health model (Figure 2) used widely by public health authorities, which situates health determinants as the foundation for health status.

Figure 2: Population Health Model [10]
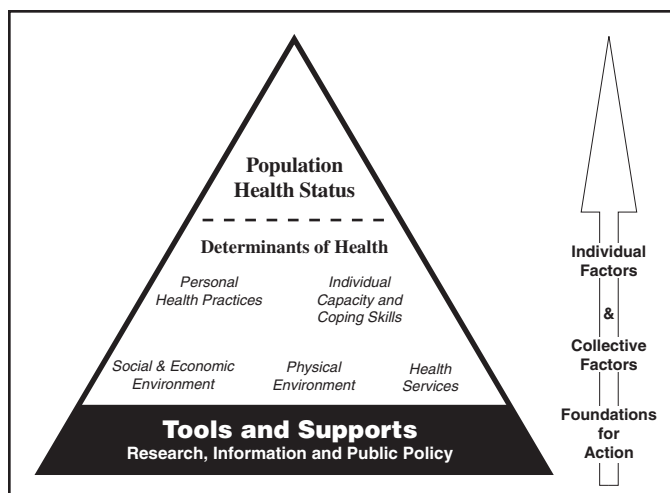
While the Population Health framework and other western models tend to highlight cause and effect, First Nations models often reflect balance and interconnectivity. This is evident in the health determinants model (Figure 3) used in the AFN document, *The Development of a First Nations Health Reporting Framework:*

Figure 3: First Nations Health Determinants Framework [11]
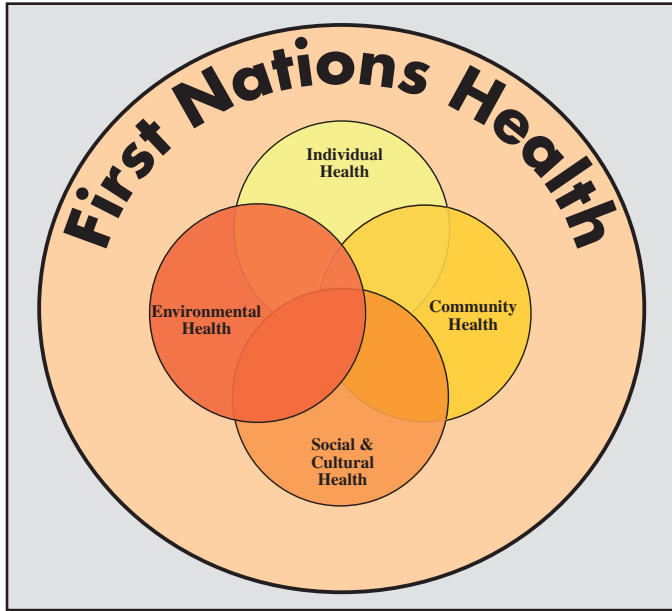
Indicators developed for the Canadian population are not always effective for First Nations because Canadian indicators often miss issues that are important in First Nations communities (e.g. water quality). The AFN places more emphasis on non-medical determinants of health, reflecting the belief that "many of the factors influencing health lie in the complex social, economic and physical environments in which people live." [12] The AFN health policy and planning model (Figure 4) is unique in that "it emphasizes the significance of self-government as the underpinning framework for First Nations health determinants." [13]

First Nations can develop their own indicators for understanding health and well-being. There are several examples of First Nations projects that developed new and unique indicators. For example, the Aboriginal Community Health Indicator Project – a collaboration between the Mohawk Council of Akwesasne, Little Red River Cree Nation, Miawpukek First Nation and the Institute of the Environment at the University of Ottawa – developed unique community health indicators based on First Nations community perspectives. These included: [15]

- Number of hunters in the community;
- Catch rate of ungulates (e.g. deer);
- Ungulate population;
- Number of community or group celebrations;
- Size of forest area;

- Extent and types of forest usage;
- Number of drums in community;
- Number of drumming occasions per year; and,
- Number of religious spaces (e.g. churches, sweat lodges) in community.

Indicators can help you to assess and monitor the health of your community and the effectiveness of health interventions.

For a more detailed discussion of First Nations indicators and indicators in general, please refer to the FNC resource *Understanding Health Indicators* (2007).

Epidemiology

Epidemiology is the branch of health research that investigates the distribution and causes of disease and injury in populations. It is based on the observation that most health effects do not occur randomly, but are related to environmental, behavioural or genetic factors. Thus, the objective of epidemiological studies is usually to investigate, at the level of groups or populations, causes or risk factors for diseases and other health issues.

Epidemiology has led to major advances in our understanding of the transmission of communicable diseases, as well as factors that influence the risk of chronic diseases like cancer, heart disease and diabetes. Also, by tracking the impact of screening and other preventative programs, epidemiology allows us to evaluate what types of programs are effective in reducing diseases, injuries, etc.

An epidemiological study often compares two groups of people who are alike except for the presence of an identified health effect. Let's say that Group A has high rates of diabetes, while Group B has average rates. The study would assess, for both groups, the presence or level of factors known to be associated with diabetes such as poor diet, sedentary lifestyle, and impaired glucose tolerance. It is found that both groups report similar activity levels and blood tests did not reveal any significant differences in glucose tolerance. However, Group A tended to consume less country food but consume more store-bought foods that are high in fat and sugar. Therefore, it could be concluded that poor diet is the primary cause of excess rates of diabetes in Group A.

Figure 4: Proposed First Nations Holistic Policy and Planning Model[14]
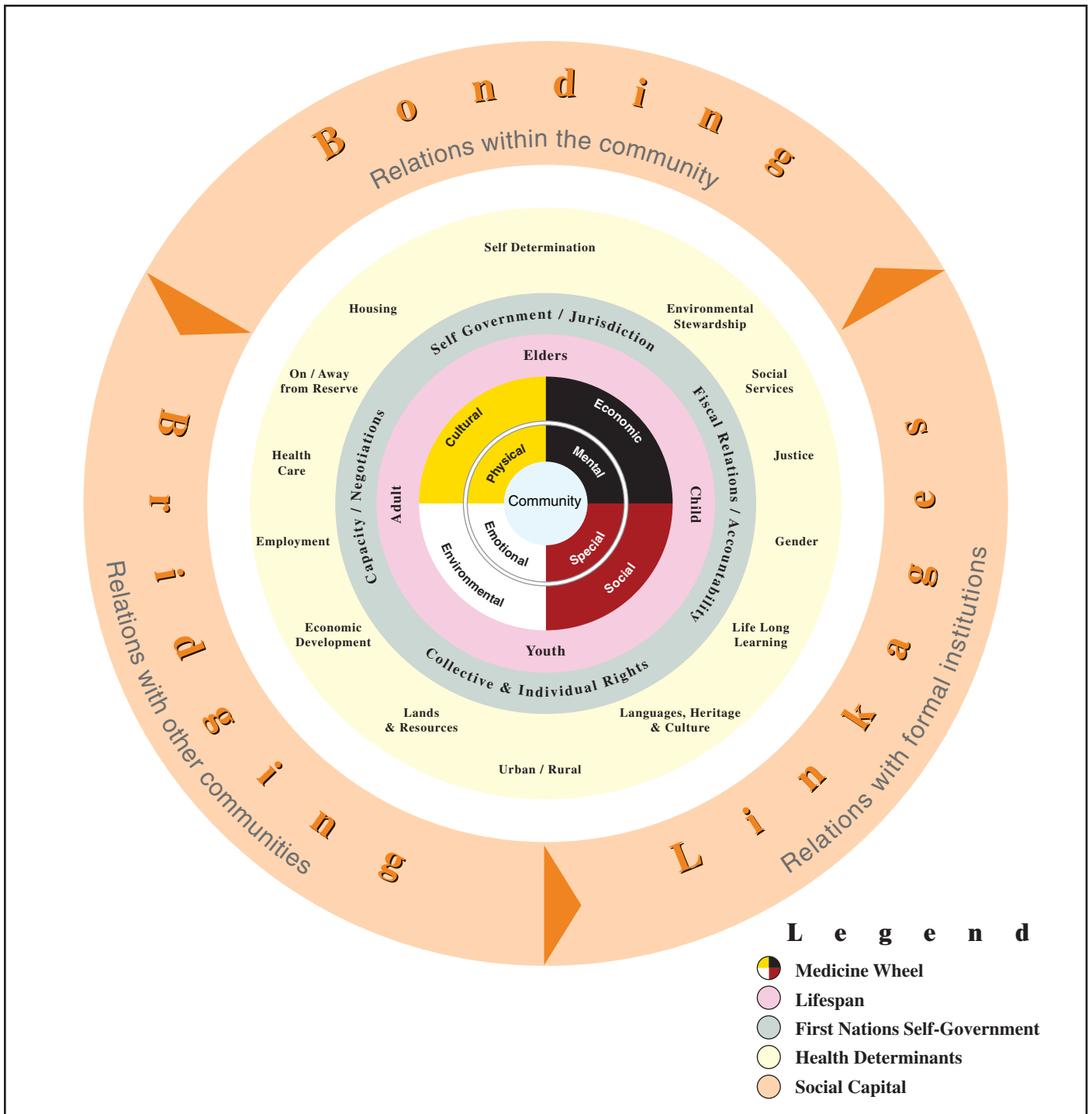
The example described above is simplified for explanatory purposes. In reality, epidemiology uses mathematics and statistics to demonstrate cause and affect relationships. For this reason, epidemiology studies require fairly large "study samples" in order to generate conclusions. Simply put, with larger numbers, it is less likely that the results are skewed by chance or fluke. Epidemiology research teams always include someone with expertise in statistics.

However, it is possible to conduct simple quantitative or even qualitative health research that addresses similar research objectives. For example, talking circles or focus groups with individuals who have a particular health problem may reveal important, previously unknown information about the underlying causes of that health problem, and potential preventative measures. While such a project could not therefore be properly

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described as "epidemiology", it could be very useful for community health planners.

Barriers to Community Health Development

There is a great desire of First Nations people to improve the health and wellbeing of their communities and many initiatives are being taken by dedicated individuals and groups to these ends. Unfortunately, In order to realize their goals, First Nations often have to confront barriers to appropriate community health development, including jurisdictional issues, lack of knowledge of available programs and resources, local or regional capacity, and resource fragmentation and scarcity. Some of these barriers are specific to First Nations in Canada, such as those explained in Section II of this report on the principles of Ownership, Control, Access and Possession (OCAP). Other barriers First Nations encounter are similar to those experienced throughout the world.

A study of community participation in a proposed self-help water project in West Africa, Ambe J. Njoh (2002) identified nine factors that can "hinder and indeed constrain the promotion of participatory development. These factors can be discussed under two broad categories, namely external and internal obstacles. External obstacles include factors residing outside of the beneficiary community but can inhibit or prevent meaningful participation. Internal obstacles comprise factors located within the beneficiary community."

The nine factors can be summarized as:

Paternalistic posture of authorities
Externally planned projects are often doomed to fail, particularly because of the many erroneous assumptions they make about local conditions and needs. Perhaps the most disheartening aspect of externally induced projects is the tendency for outside bureaucrats and experts to dominate the decision-making process.

Prescriptive role of the government
Development project planning and implementation is like most activities in society, very political.

Frequently, a government's interest in community participation has goals that differ from those of the beneficial community. For the government, it is often the case that the main aim of community participatory programs is less about improving conditions for the poor than it is about maintaining existing power relations in society and ensuring the silence of the poor.

Embellishment of successes
There is a tendency to focus on the successes of projects to the exclusion of their failures. This means, among other things, that development planners are deprived of the opportunity to learn from past mistakes.

Selective participation
Some members of a project's beneficiary communities either tend to exclude themselves, or are excluded, from the project development process. Consequently, the voices of self-appointed individuals are erroneously perceived as reflecting the views and perspectives of the larger community or society. The challenge for community development planners is therefore, to encourage the involvement of members of the 'silent majority' in the development process.

Hard-issue bias
'Hard-issues', such as questions relating to technology, finance, and physical resources, tend to dominate discussions on any given project. Consequently, questions relating to 'soft' matters such as community participation, decision-making procedures, community empowerment, effectiveness, and institutional development are put in a secondary position.

Intra/Inter-group conflicts
In diverse communities, internal group conflicts may result from perceived or real differences in culture, language, or socioeconomic status. Ways to avoid conflicts between members of native and non-native populations should be planned for.

Gate-keeping by local leaders

Quite often, a local organization, almost always the dominant one in a beneficiary community, may insert itself between the funding agency and the beneficiaries. One of the dangers here is that community-level decision-making may be hijacked and monopolized by a small and self-perpetuating clique, acting in its own, as opposed to the greater community's, interest.

Excessive pressures for immediate results

Pressures for immediate results coming from higher level authorities have the tendency to overemphasize the importance of delivery (product), while neglecting other worthwhile objectives such as community participation (process), particularly poverty reduction and institution-building.

Disinterest within beneficiary community

One reason for project failure relates to the unwillingness of potential project beneficiaries to become involved. The urgent task for planners is therefore to understand the factors contributing to such unwillingness. In some cases, the cause of this problem may simply be the failure of the government or funding institutions to build community participation into the project design. In other cases, the cause may not be so simple.

First Nations communities will have to be imaginative and innovative to overcome the particular obstacles to effective community health programs and services that they may encounter.

Surveillance

Surveillance is a fundamental activity in the field of public health. Health surveillance refers to the tracking and forecasting of community or population health through the continuous collection of data. It is about monitoring health information at the community or population level and applying this data to disease prevention and control. An effective surveillance system includes data collection, analysis and dissemination linked to public health programs.

Public health surveillance systems are designed to monitor specific public health concerns. They are not the same as a community health assessment which gathers data on a broad range of health and health-related topics. The Public Health Agency of Canada maintains data surveillance systems for a wide variety of health conditions and concerns such as HIV/AIDS, injury, most types of cancers, cardiovascular and respiratory diseases, influenza, West Nile Virus and birth defects.

Surveillance is like an early-warning system for potential public health emergencies. Surveillance was originally developed to alert health authorities to cases of highly contagious diseases (e.g. TB) so they could initiate measures to prevent the spread of the disease. It is now also used to detect changes in patterns or rates of non-contagious conditions (e.g. diabetes, injury). Surveillance systems do not conduct complex research; they collect only enough information to send a warning signal. For example, surveillance may show a sudden increase in cancer rates in a certain area. This would trigger further epidemiological studies to discover the cause, or spur preventative actions (if the cause is already known).

Surveillance can help to detect health problems or patterns as they emerge, so that health authorities can plan proactive measures to address them.

The most well developed system of surveillance in Canada is for communicable (i.e. contagious or infectious) diseases. Many communicable diseases are 'notifiable', meaning that health care workers are legally obligated to report incidence of these diseases to public health authorities. Decisions regarding which diseases are notifiable are made at the provincial/territorial

level, but these decisions are influenced by national consensus through scientific bodies.

Provincial/territorial jurisdictions can use different mechanisms for data collection, analysis and reporting. For example, in some provinces laboratories routinely submit reports of positive tests for notifiable diseases. Health Canada maintains national databases for many communicable and chronic diseases, relying primarily on reports from the provinces and territories as the source of data.

Most surveillance systems collect only de-identified personal health information, in accordance with federal and provincial/territorial privacy laws. However, identifiable personal health information can be released to public health authorities if it relates to certain infectious diseases that pose a serious risk to public health.

Health surveillance for First Nations is affected by jurisdictional issues. While most notifiable disease surveillance systems are maintained by provincial/territorial governments, responsibility for data collection and public health interventions in First Nations communities has generally been the responsibility of the federal government (FNIHB). It has been noted that "this situation can lead to a disconnect between surveillance and public health practice, and quality control in surveillance systems can be compromised."[16]

At a national level, surveillance takes places in five major areas: births, deaths, hospitalization, notifiable diseases and immunization. Regional FNIHB offices generally gather data and negotiate data-sharing with provincial/territorial health authorities. Identifying First Nations patients from administrative health records can be problematic, since not all provinces/territories record First Nations or even Aboriginal status. Sometimes records are cross-referenced with other data sources such as the Indian Status Registry to identify First Nations clients. In either case, it is often difficult (if not impossible) to separate on and off-reserve data.

If First Nations want to access surveillance data on their regions or communities, they should contact regional FNIHB offices.

The transfer of health services to the control of First Nations adds another level of jurisdiction to the surveillance cycle. In the pre-transfer environment, FNIHB had responsibility for the regional and national monitoring of health conditions in First Nations communities. The transfer process shifts these responsibilities to individual communities or regional First Nations organizations. The following passage describes some of the complexities and challenges inherent in First Nations health surveillance:

> Historical, geographic, cultural, epidemiological and socioeconomic factors together account for significant disparities between First Nations and the Canadian population in issues of public health generally, as well as considerable diversity within the First Nations population. Therefore, addressing the information needs in the public health domain among First Nations is a complex task. The task is further complicated when factoring in the issue of scale. Many communities are small, over 30% are remote or isolated. Since each First Nation has its own unique public health situation, it will be important for public health information to be community-specific to the extent possible. Therefore, this raises the need to achieve a balance in decision-making and the distribution of resources between national and regional/Treaty First Nations jurisdictions, and individual First Nations.[17]

The development and maintenance of First Nations health surveillance and public health infrastructure is a long-term process that will require a long-term investment of funding, training and dedicated human resources. The AFN recently developed a policy document entitled First Nations Public Health: A Framework for Improving the health of our People and Our Communities (2006), which argues for a distinctive First Nations model comprised of "regional autonomous networks and a central advisory body that feeds communities relevant, useful and non-identifiable information about the health of their communities."[18]

Part II – Transfer of Health Services to the Control of First Nations

OCAP

"The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters."[19]

The principles of Ownership, Control, Access and Possession (OCAP) emerged in response to First Nations' concerns about the negative aspects of externally driven research. These include:

- lack of meaningful community involvement in the research process;

- lack of individual and community benefit from research (irrelevant research, lack of compensation to participants and no local hiring);

- lack of informed community consent (communities not informed of potential risks to health and safety or negative impacts of research);

- research agendas dictated by personal or academic interests rather than First Nations priorities or interests;

- lack of community ownership of data and research results (no control over analysis, interpretation or reporting; no review or say in who has access to data);

- community stigmatization and stereotyping of First Nations; and

- lack of respect towards First Nations culture and beliefs, including misinterpretation of traditional knowledge and practices.

OCAP, as we call it today, was originally expressed as "OCA"[20] in 1998 by the National Steering Committee[21] of the First Nations and Inuit Regional Longitudinal Health Survey (RHS), a body which is now known as the First Nations Information Governance Committee (FNIGC).[22] As a result of heightened interest in the issue of First Nations ownership of information, the OCAP principles were developed during the inception of the RHS, but also apply to all research, data or information initiatives that involve First Nations. For more information on the context, background and significance of OCAP, please refer to the FNC's OCAP: Ownership, Control, Access and Possession (2007).

As was acknowledged by the Royal Commission on Aboriginal Peoples, "capacity building and control in the areas of research and information are clearly linked to Nation re-building, the implementation of self-government and the assertion of First Nations rights to self-determination."[23]

OCAP is self-determination applied to research.

The OCAP principles are defined as follows:[24]

Ownership: Refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship [or possession].

Control: The aspirations and rights of First Nations to maintain and regain control of all aspects of their lives and institutions include research, information and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion.

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

Possession: While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breach or misuse.

What does OCAP mean for First Nations health research and information?

With respect to health research that is proposed or initiated by an external partner, there are steps that your community can take to ensure that OCAP principles are respected. These include:

- Establish a research committee in your community to ensure careful and consistent consideration of all proposed research activities;

- Identify community priorities for health research and choose to participate only in projects that are relevant to these issues;

- Develop criteria for reviewing research proposals;

- Develop a community code of research ethics, or a code of conduct for external researchers; and

- Insist on meaningful participation in all aspects of community-based research.

These and other suggested strategies for asserting OCAP are described in more detail in the FNC document, *OCAP: Ownership, Control, Access and Possessions* (2007). The FNC's Considerations and Templates for *Ethical Research Practices* (2007) contains templates for developing a code of research ethics, a collaborative research agreement and a data-sharing protocol.

The application of OCAP principles to health information is a tricky issue. Provincial, territorial and federal departments with health and health-related responsibilities routinely collect health information recorded during the course of health care delivery. This information may feed into regional or national surveillance systems, or it may be necessary to process payments for health services.

Although health information that identifies an individual can generally not be released without that individual's written consent, First Nations communities or regions can often access community or regional level health information by making a request to the health agency or authority that holds it. However, it remains true that most First Nations do not own, control or possess "their" health data and information.

To further complicate matters, the situation differs between transferred and non-transferred First Nations communities. In transferred communities, the First Nation does own health records that are produced through the delivery of health care in that community. However, health professionals may still be obligated to submit health information to regional or national registries, usually for surveillance purposes. In non-transferred First Nations communities, the federal government owns the health records that are generated in that community.

It should be emphasized that federal, provincial and territorial governments collect and use health information for important, legitimate purposes. However, many First Nations believe that the ability to collect and use their own health information is crucial to self-determination in health and will lead to better health outcomes for First Nations people.

Building First Nations Health Research Capacity

"Capacity development is more than just computer training and knowledge and use of the Internet; it is building capacity in self-determination and governance in health care that builds upon an individual and community development process. It is developing and applying abilities to govern and manage, solve problems, respond to new

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situations, make informed, evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to effectively and efficiently manage resources (human and fiscal) and to take responsibility for the success or failure of health interventions."[25]

For many years, First Nations people have lived with health programs and services that were designed and delivered by people who did not understand First Nations cultures or aspirations. To put it mildly, this has been bad for our health. We now know that control of social services, particularly health and education, is crucial to health and wellness in our communities. In order to be able to plan effective health services, First Nations also need to have the capacity to gather, record, store and use health information. We need to be able to define our own priorities and needs for health research, and to conduct this research on our own terms.

"Creating and sharing knowledge that authentically represents who you are and how you understand the world is integral to the survival of a people's identity."[26]

Another important reason for First Nations to become more active in the field of health research and information is that the quality of existing First Nations health information is generally poor. First Nations-specific data is often fragmented or unavailable, due to the lack of data infrastructure in First Nations communities, lack of First Nations identifiers in provincial/territorial health databases and lack of shared national standards. Often, First Nations, Inuit and Métis data are combined into pan-Aboriginal statistics that are less useful to all of these groups.

The First Nations Regional Longitudinal Health Survey (RHS) is a national survey of health in First Nations communities. Data-gathering for the 2002/03 phase of the project was highly successful, achieving an 82% participation rate across ten regions with more than 20,000 individuals living on-reserve. It is overseen by the First Nations Information Governance Committee (FNIGC) mandated by the Chiefs Committee on Health, with strict adherence to the OCAP principles. The AFN states that:

"The RHS survey provided, for the first time, a detailed picture of the health of First Nations people across Canada and is considered the most comprehensive study of First Nations health and living conditions in Canada. As such, the RHS was established as an invaluable resource for First Nations health care workers, non-Aboriginal health care providers and federal provincial and territorial policy makers among others."[27]

The RHS signifies a major step in the developing field of First Nations health research and information governance. This process can and should involve community level health information and planning. That is the purpose of this information resource, and of the entire FNC series on health research and information, is to increase First Nations capacity to meaningfully participate in all aspects of health research and to increase First Nations capacity to conduct health research on their own terms.

Research Ethics and Privacy

Ethical research principles apply to all research involving human beings. Communities may conduct their own research or they may be involved in research projects with external partners. Either way, it is important for First Nations to have an understanding of research ethics.

Ethical guidelines are meant to ensure that research processes respect the rights and dignity of the people being researched. They can be divided into two broad groups – respect for individuals and respect for communities.

Respect for individuals

Ethics about how to protect people who participate in research are based on the following principles:

1. Informed consent and voluntary participation

This means making sure that research participants know what they are being asked to do, what the information they provide will be used for and that they are freely agreeing to participate. Consent forms are often used but are not always necessary.

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2. Protection of privacy and confidentiality

When collecting health information, it is particularly important to ensure that personal information is not revealed without consent. Please refer to the following section on privacy for more information about this topic.

3. Risk-benefit assessment

This involves assessing probable risks and benefits of the research in advance, as well as setting up the process so as to produce the least risk and the most benefit to research participants.

Examples of risks associated with a health research project might include: invasion of personal or community privacy, discussion of sensitive or painful issues or the contribution of unpaid time. Benefits of health research projects should include the following: direct economic benefits to community members (e.g. payment for community researchers and participants), training or education for community members, and, perhaps most importantly, the potential for research results to improve community health.

4. Valid research design

Be sure that the research can produce the results it promises so that participants are not wasting their time or being exposed to risk for no reason.

Respect for Communities

In recent years, there has been a movement to broaden research ethics so that they protect the rights of communities or groups, not just individuals. First Nations communities have actively participated in this movement. This has meant considering issues such as:

- How research should protect communities against stigmatization and being labeled by stereotyping;

- Community consent to research;

- Community control over the research process;

- Community control over how research results are interpreted; and

- Community control over how research results are used.

Consent and secondary research

"Secondary" research uses existing information that may be part of another organization's records, such as local or provincial records from health facilities. If the project does not require the use of information that can be traced back to an individual, then national codes of ethics allow it to proceed without review by a Research Ethics Board (REB) because these projects pose no threat to individual confidentiality. However, there is still the potential for stigmatization and harm if the project identifies specific communities or First Nations Peoples. Because of this, it is gradually becoming more common for this type of project to proceed only with First Nations consent and involvement. Often the solution is a memorandum of understanding (MOU) between First Nations groups and external researchers. These agreements usually outline how the research information will be used and ensures that First Nations people have a say in interpreting the results.

Research Ethics Boards

Research Ethics Boards (REB) are created by an organization that does research on a regular basis such as a health department, a hospital, or a university. The group reviews research proposals in advance to make sure that they are ethical. Formal ethics approval from the group is required for anyone who works in those organizations, or who is working with them on a research project (for instance, researchers who want to contact the organization's clients). Some of the major funding agencies in Canada require approval from an REB before they will grant funds.

Ethical Review in First Nations Communities

Communities may find it useful to form their own REBs or to develop something similar such as a review committee, a community consultation process, or guidance from Elders. Some First Nations communities have developed their own codes of research ethics that apply to any research done by the community, or by outside organizations working with the community. For instance, the *Kahnawake Schools Diabetes Prevention Project* has developed a code, and the *Mi'kmaw Ethics Watch* sets out protocols and principles for research with Mi'kmaw communities. Some communities have come together to form research committees. The Noojmowin Teg Health Access Centre on Manitoulin Island initiated a community-based process that resulted in the development of *Guidelines for Ethical Aboriginal Research in the Manitoulin Area* (these three documents are available on-line; see Additional Resources, p. 31). Both the James Bay Cree Health and Social Services Commission and the Assembly of Manitoba Chiefs have research committees that review proposals to ensure that they are acceptable to their member communities.

Privacy and Health Information

In general terms, privacy is the freedom from being observed or disturbed by other people. Privacy rights may be defined as the right to control the circulation of personal information about oneself, freedom from unreasonable interference in one's private life and the right to the protection of personal data against misuse or unjustified publication.[28] Concepts of individual privacy are well established in Canada and are defined and protected by legislation.

Personal health information refers to individual medical information that is generated and recorded through the provision of health care. Personal health information is afforded a higher degree of privacy protection than many other kinds of personal information. This is because it is often essential for individuals to disclose sensitive, even potentially embarrassing, information to a health care provider to obtain appropriate care. Individuals with sensitive medical conditions such as substance abuse, mental illness or sexually transmitted diseases may be reluctant to seek treatment if they cannot be assured of the privacy of their personal health information.

However, it is important to remember that there are worthwhile and legitimate purposes for sharing personal health information. These include:

1) Direct patient care: Personal health information sometimes must be shared between health care personnel (e.g. nurse, physician, surgeon) in order to ensure continuous and appropriate patient care;

2) Payment for health services: An insurance company or government department (e.g. N.I.H.B) often requires personal health information in order to pay for medical services or treatment;

3) Administration of health systems: Administrators use health information to determine need for services, evaluate the effectiveness of services and determine funding allocations; and

4) Public (or community) health research and planning: Researchers or health planners need health information in order to identify health patterns and trends (e.g. surveillance, epidemiology) and to plan or evaluate public health interventions.

De-identified health information means personal health information from which names, or any other information that could identify an individual, have been removed. For public health research, administration and planning, de-identified information will often be sufficient for the purpose of the activity. For example, statistics, indicators and surveillance systems are comprised of de-identified health data. Individual consent is usually not required for governments or health authorities to release de-identified health data for appropriate purposes.

Even if identifiable personal health information is collected for research purposes, it is very rare that any identifiable information will be included in research reports or publications. Usually, results are **aggregated**, meaning that individual records or data are combined to show totals or percentages.

Health researchers may need information about such things as a person's clinical history and use of health care services, as well as about broad determinants of health, such as a person's education, employment, and income level. The Canadian Institutes of Health Research (CIHR) developed the document Best Practices for Protecting Privacy in Health Research (September 2005) as a guide for health researchers and a resource for ethics review boards to use when evaluating health research proposals that intend to collect identifiable personal health information. The following guidelines should be considered if your community is planning to undertake or participate in health research that will collect personal health information: [30]

1) Determine the research objectives and justify the data needed to fulfill them;

2) Limit the collection of personal data;

3) Determine if consent from individuals is required;

4) Manage and document consent;

5) Inform prospective research participants about the research;

6) Recruit prospective research participants;

7) Safeguard personal data;

8) Control access and disclosure of personal data;

9) Set reasonable limits on retention of personal data; and,

10) Ensure accountability and transparency in the management of personal data.

The First Nations Context

In First Nations communities, the individual right to privacy has been extended to include the concept of collective privacy. Collective privacy is unique because it recognizes and expresses the sovereignty of First Nations Peoples. The principles of OCAP (see page 17) express the First Nations concept of collective privacy regarding research information.

At an individual level, First Nations people may be concerned about:

- The confidentiality of personal health information, especially in small communities;

- The accuracy of information that is used to make decisions about health care and entitlements; and,

- The use of information for secondary purposes not related to health care (e.g. market research, insurance premiums).

At the community level, First Nations may be concerned about:

- Protection against negative portrayals, stigmatizations, misinterpretation or misuse of data;

- Confidentiality of traditional cultural practices; and

- Using health data and information for purposes that may not be relevant to communities' priorities and concerns.

For non-transferred communities, federal or provincial/territorial privacy laws apply. So, identifiable personal health information can not normally be released without individual consent. However, community level information "aggregated" from the records – that is, collected but without showing personal identity of individuals – can be accessed if a request is made to the government. This is because the Access to Information Act applies in this case. "Access to Information" means that Canadians have the right to look at information that is within the government's control, if they ask.

Although there is no legislative protection for First Nations community level data, it is becoming an ethical norm that researchers are required to demonstrate First Nations support for a project that involves First Nations data. For example, most research ethics boards (see page 20) would require this before a project would be approved or funded.

For transferred communities, where a community owns the health records, there is no legal protection of these records except for professional regulations and codes of conduct to which nurses, physicians, and other licensed health professionals must comply. Also there are health information acts in Alberta, Manitoba, Ontario and Saskatchewan, and constitutional protection in Québec. Except in Ontario, the provincial laws do not apply to health facilities but they do apply to practices of health professionals licensed in those provinces.

First Nations communities that have assumed control of health services can develop policies regarding the protection and use of personal health information. This is especially important if your community is considering initiating or participating in health research that will involve personal health information.

Additional Resources

This document was designed to provide an overview on health research, information and planning. For more information on specific topics, we encourage you to consult the Internet resources listed below. We have selected information that is understandable and, wherever possible, relevant to First Nations health research and planning.

Developing a Proposal

Guide for Writing a Funding Proposal: www.learnerassociates.net/proposal

Beginner's Guide to the Research Proposal:
www.ucalgary.ca/md/CAH/research/res_prop.htm

Designing Surveys and Questionnaires

Types of Surveys: http://www.socialresearchmethods.net/kb/survtype.php

Quick Tips – Survey Design: http://oir.olin.edu/assessment/docs/qt1.pdf

Survey and Questionnaire Design: http://www.statpac.com/surveys/

Conducting Interviews and Focus Groups

Some Tips for Running a Good Focus Group: http://www-tcall.tamu.edu/orp/orp1.htm

Tips for Designing Data Collection Instruments: http://www.idrc.ca/en/ev-28258-201-1-DO_TOPIC.html

Community Health Needs Assessment

Community Health Needs Assessment: A Guide for First Nations and Inuit Health Authorities:
http://www.hc-sc.gc.ca/fnih-spni/finance/agree-accord/res-centre/tech/index_e.html

Community Health Needs Assessment Guidelines: http://www.gov.mb.ca/health/rha/chnag.pdf

First Nations Research Ethics

Guidelines for Ethical Aboriginal Research in the Manitoulin Area: http://www.noojmowin-teg.ca/default5.aspx?l=,1,613

Mi'kmaq Ethics Watch: http://mrc.uccb.ns.ca/prinpro.html

Kahnawake Schools Diabetes Prevention Project Code of Research Ethics: http://www.ksdpp.org/code.html

Glossary

Administrative data: Data that has already been recorded through the provision of, or payment for health care.

Aggregate data: Data that is presented or collected in a grouped or a summarized form (e.g. community average income as opposed to each individual's income).

Baseline data: Data that will be used a starting point for future comparison or calculation. Data gathered a community/population health assessment (e.g. rates of diseases) can be used in the future to measure changes.

Chronic disease: A disease that is ongoing (lasts for more than three months) or recurrent, and usually can not be cured. Chronic diseases are not caused by infection, and are not communicable (e.g. asthma, cancer, diabetes).

Communicable disease: A disease which can be transmitted from person-to-person through direct or indirect contact. Communicable diseases are caused by some type of virus or bacteria (e.g. tuberculosis, influenza, hepatitis).

Consent: Agreement. In research, "informed consent" means that a person or group has been provided with enough information to fully understand the project and their participation in it.

Data: Facts, observations or measurements that have been recorded in some way.

De-identified information: Personal health information from which names, or any other information that could identify an individual (e.g. address, social insurance number, etc.), have been removed. Most surveillance systems use only de-identified health information.

Demographics: Numerical or statistical characteristics of a community or population, such as total population, age and gender percentages. Sometimes includes other characteristics like income, education or employment.

Epidemiology: The study of health and factors that affect health in groups or populations.

Ethics: A set of values which define "right" and "wrong". Research ethics is a set of guidelines most commonly applied to research involving human beings.

Evidence Based Decision Making: Decisions based on careful analysis of accurate data and proven research findings.

Health determinants: The range of personal, social, economic and environmental factors that determine or influence the health status of individuals.

Health promotion: Health promotion is the process of enabling people to increase control over, and to improve their health. Health promotion programs and activities aim to foster physical, mental and social well-being and encourage healthy behaviours by supporting, empowering and educating people.

Health protection: Actions that protect against health and safety risks. Research (providing evidence), surveillance (monitoring and forecasting health trends), risk management (assessing and responding to health risks) and program development (taking action) form the basis of health protection activities.

Health status: Measurements and/or descriptions of different aspects of health for a community or group, such as infant mortality, disability or chronic disease rates.

Hypothesis: As assumption that is made as a basis for further investigation or research. It is similar to a research question, but it is expressed as a statement to be proved (or disproved), rather than a question to be answered.

Indicators: Measurements, signs or gauges. Health indicators measure different aspects of health within a population.

Information: Data that have been recorded, classified, organized, related or interpreted within a framework so that meaning emerges.

Life expectancy: The average number of years a person would live if mortality rates did not change.

Longitudinal research: Research about an individual or group that gathers data at multiple intervals over a long period of time, in order to measure changes in one or more aspects of health.

Mortality (or death) rate: The proportion of a population that dies in a specified period. It is calculated by dividing the number of deaths by the total population and commonly expressed as deaths per 100,000 persons per year. Cause-specific mortality rates (e.g. suicide rate) and age-specific rates are also used.

Notifiable disease: Diseases that health care workers are legally obligated to report to public health authorities. Notifiable diseases are usually communicable diseases that pose a public health risk.

Personal information: Information about an individual(s) that directly identifies the individual(s), or contains personal details that indirectly reveal their identity.

Primary research: The collection of new data or information.

Population health: An approach to health that aims to improve the health of an entire population. Population health goes beyond the individual focus of clinical care by addressing a broad range of factors that impact health on a population level, such as environment, social structure, income, education, governance, etc.

Privacy: In general terms, privacy is the freedom from being observed or disturbed by other people. Privacy includes the right to control the circulation of personal information about oneself.

Public health: The science and practice of protecting and improving the health of communities or groups (as opposed to individual patients). Public health practice consists of policies, programs and other public activities that support health promotion, protection and education.

Research: An organized and systematic way of finding answers to questions.

Risk factor: A factor that is associated with increased risk of disease or ill health. It is important to note that a risk factor is not the same as a cause. For example, obesity is a risk factor for diabetes, but not all obese people will become diabetic. Risk factors are identified through epidemiological research which shows that certain factors are significantly more prevalent among people with certain health conditions.

Sample: A small part or quantity which represents the whole. In health research and statistics, a study sample refers to a group of people selected from a larger population/community (randomly, or by specific criteria) who participate in a research project. The conclusions drawn about the sample group can be generalized to the population/community at large, without having to actually study the entire population/or community.

Secondary research: The analysis of existing information or previously conducted research about a particular topic.

Statistics: Numerical data that describes or measures specific aspects of a population or issue. Statistics usually represent a proportion of a whole.

Qualitative research: Research that uses descriptive information to examine and interpret an issue, in order to discover underlying meanings and patterns.

Quantitative research: Research that uses numerical information to quantify an issue, in order to describe its nature and magnitude.

Surveillance (of health): The systematic collection, analysis, interpretation, and dissemination of health data in order to monitor important health issues in populations.

Wait times: The time between the decision to provide medical treatment, such as a surgical procedure, and when the treatment is received.

Endnotes

[1] Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples, v.3, Gathering Strength* (Ottawa: Ministry of Supply and Services, 1996). Retrieved from http://www.ainc-inac.gc.ca/ch/rcap/rpt/gs_e.html>

[2] Dumont, J. Personal communication. March 2005.

[3] Statistics Canada, *Data, Information and Statistics: Definitions* (2006). Retrieved from http://www.statcan.ca/english/edu/power/ch1/definitions/def.htm

[4] Adapted from Public Health Data Standards Consortium, *Public Health Data Standards Tutorial: Glossary of Terms* (2006). Retrieved from www.phdatastandards.info/knowresources/tutorials/glossary.htm

[5] Assembly of First Nations, *First Nations Public Health: A Framework for Improving the Health of Our People and Our Communities* (Ottawa: Author, 2006), p. v.

[6] Warren, Reg and Gordon Mutter."Marketing Health Research Information." Unpublished article (1991).

[7] Montour, Louis Tekaronhiake and Ann Celia Macaulay. Editorial: Diabetes mellitus and atherosclerosis: returning research results to the Mohawk community. *Canadian Medical Association Journal*, 139:1 (1988), pp. 201-202.

[8] Canadian Institute of Health Research, *Proceedings of the "Think Tank on the Future of Public Health in Canada"* (Calgary, June 2003). Cited in Assembly of First Nations, First Nations Public Health: A Framework for Improving the Health of Our People and Our Communities (Ottawa: Author, 2006), p. 9.

[9] Health Canada, *Healthy Canadians: A Federal Report on Comparable Health Indicators 2002*. Retrieved from http://www.hc-sc.gc.ca/hcs-sss/pubs/care-soins/2002-fed-comp-indicat/2002-health-sante7_e.html

[10] Public Health Agency of Canada, *Towards a Common Understanding: Clarifying the Core Concepts of Population Health, Appendix B: Population Health Framework*. Retrieved Aug. 12, 2006 from http://www.phac-aspc.g.c.ca/ph-sp/phdd/docs/common/appendix_b.html

[11] Assembly of First Nations, *The Development of a First Nations Health Reporting Framework* (Ottawa: 2006), p. 6.

[12] Assembly of First Nations, *First Nations Holistic Policy and Planning Model*: A Health Determinants Perspective (Ottawa: 2005), pp. 3-4.

[13] Ibid.

[14] Ibid., p. 2.

[15] University of Ottawa: Institute of the Environment, Mohawk Council of Akwesasne, Little Red River Cree Nation, and Miawpukek First Nation Partnership, *Community Health Indicators: First Year of the Project, Final Report* (Ottawa: Health Canada, 2001).

[16] Assembly of First Nations, *First Nations Public Health: A Framework for Improving the Health of Our People and Our Communities* (Ottawa: 2006), p. 50.

[17] Ibid., p. 47.

[18] Ibid.

[19] Royal Commission on Aboriginal Peoples, p.4.

[20] Cathryn George of the Association of Iroquois and Allied Indians is credited with the original acronym "OCA". The "P" (Possession) was added to establish that RHS First Nations data should remain in the hands of First Nation authorities in order to respect First Nations' principles and protect their collective information.

[21] First Nations Information Governance Committee (FNIGC) is the new committee name given to the previous First Nation and Inuit Regional Health Survey National Steering Committee. The name change reflects the broadened mandate and range of issues that years of work on the RHS had brought into focus. The FNIGC address issues such as university research, government data collection processes, health information systems and initiatives, research ethics, development of First Nations research infrastructure, etc…

[22] The initial RHS included the Inuit of Labrador and was titled the First Nations and Inuit Regional Longitudinal Health Survey. The 2002/03 RHS survey included First Nations on-reserve/communities only and is called the First Nations Regional Longitudinal Health Survey. The Inuit have opted for Inuit specific research initiatives.

[23] Ibid. p.12.

[24] First Nations Centre, *Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Aboriginal Research Practice and Some Options for Aboriginal Communities* (Ottawa: National Aboriginal Health Organizations, 2005), pp. 1-2.

[25] O'Neil, 4.

[26] Castellano, Marlene Brant, "Ethics of Aboriginal Research". *Journal of Aboriginal Health* 1:1 (Ottawa: National Aboriginal Health Organization, 2004), p.109.

[27] Assembly of First Nations, *First Nations Health Research and Information Acton Plan* (Ottawa: Author, 2005), pp. 2-3.

[28] Partnership for Health Informatics/Telematics. *Working Group 3: privacy, confidentiality, data integrity, and security. Background document (revised)*. Ottawa: Canadian Institute for Health Information, 1997.

[29] Cancer Care Ontario, *Principles and Policies for the Protection of Personal Health Information at Cancer Care Ontario* (Toronto: Author, 2005), p. 3.

[30] Canadian Institutes of Health Research, *CIHR Best Practices for Protecting Privacy in Health Research* (2005). Retrieved from http://www.cihr-irsc.gc.ca/e/29072.html#Values

[31] Assembly of First Nations, *First Nations Public Health: A Framework for Improving the Health of Our People and Our Communities*, p. 157.

[32] Ibid.

Bibliography

Assembly of First Nations (2005). F*irst Nations Health Research and Information Acton Plan*. Ottawa, ON: Author.

Assembly of First Nations (2005). *First Nations Holistic Policy and Planning Model: A Health Determinants Perspective*. Ottawa, ON: Author.

Assembly of First Nations (2006). *First Nations Public Health: A Framework for Improving the Health of Our People and Our Communities*. Ottawa, ON: Author.

Assembly of First Nations (2006). *The Development of a First Nations Health Reporting Framework*. Ottawa, ON: Author.

Canadian Institutes of Health Research (2005). *CIHR Best Practices for Protecting Privacy in Health Research*. Ottawa, ON: Public Works and Government Services Canada.

Cancer Care Ontario (2005). *Principles and Policies for the Protection of Personal Health Information at Cancer Care Ontario*. Toronto: Author.

Brant Castellano, M. (2004). Ethics of Aboriginal Research. *Journal of Aboriginal Health* 1:1. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2007). *Considerations and Templates for Ethical Research Practices*. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2007). *OCAP: Ownership, Control, Access and Possession*. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2007). *Understanding Health Indicators*. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2005). *Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Aboriginal Research Practice and Some Options for Aboriginal Communities*. Adapted from a paper prepared for the First Nations Information Governance Committee, Assembly of First Nations. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2005). *Privacy Tool Kit: The Nuts and Bolts of Privacy*. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2003). *Ethics Tool Kit: Ethics in Health Research*. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2003). *Research Tool Kit: Understanding Research*. Ottawa, ON: National Aboriginal Health Organization.

First Nations Centre (2003). *Surveillance Tool Kit: Health Surveillance – The Basics*. Ottawa, ON: National Aboriginal Health Organization.

Health Canada (2006). *Healthy Canadians: A Federal Report on Comparable Health Indicators 2002*. Ottawa, ON: Minister of Health.

Kahnawake Schools Diabetes Prevention Project (2007). *KSDPP Code of Research Ethics*. Kahnawá:ke, QC: Author. Retrieved from http://www.ksdpp.org/code.html

Mi'kmaw Ethics Watch (2000). *Research Principles and Protocols*. Sydney, NS: Mi'kmaq College Institute, University of Cape Breton. Retrieved from http://mrc.uccb.ns.ca/prinpro.html

Montour, L. T., and Macaulay, A. C. (1988). Editorial: Diabetes mellitus and atherosclerosis: returning research results to the Mohawk community. *Canadian Medical Association Journal,* 139:1.

Njoh, A. J. (2002). Barriers to community participation in development planning: lessons from the Mutengene (Cameroon) self-help water project. *Community Development Journal,* 37, 233-248.

Partnership for Health Informatics/Telematics (1997). *Working Group 3: Privacy, confidentiality, data integrity, and security. Background document (revised)*. Ottawa, ON: Canadian Institute for Health Information.

Public Health Agency of Canada (1996). *Towards a Common Understanding: Clarifying the Core Concepts of Population Health* – A Discussion Paper. Retrieved from http://www.phac-aspc.g.c.ca/ph-sp/phdd/docs/common

Public Health Data Standards Consortium (2006). *Public Health Data Standards Tutorial: Glossary of Terms*. Retrieved from www.phdatastandards.info/knowresources/tutorials/glossary.htm

Research Review Working Committee (2003). *Guidelines for Ethical Aboriginal Research in the Manitoulin Area*. Little Current, ON: Noojmowin Teg Health Centre. Retrieved from http://www.noojmowin-teg.ca/default5. aspx?l=,1,613

Royal Commission on Aboriginal Peoples (1996). *Report of the Royal Commission on Aboriginal Peoples,* v.3 - Gathering Strength. Ottawa, ON: Ministry of Supply and Services.

Statistics Canada (2006). *Data, Information and Statistics:* Definitions. Retrieved from http://www.statcan.ca/ english/edu/power/ch1/definitions/def.htm

University of Ottawa: Institute of the Environment, Mohawk Council of Akwesasne, Little Red River Cree Nation, and Miawpukek First Nation (2001). *Community Health Indicators:* First Year of the Project, Final Report. Ottawa, ON: Health Canada.

Notes

First Nations Centre, National Aboriginal Health Organization

Le Centre des Premières Nations, Organisation nationale de la santé autochtone

National Aboriginal Health Organization (NAHO)
Organisation nationale de la santé autochtone (ONSA)
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220 Laurier Ave West, Suite 1200
Ottawa, Ontario K1P 5Z9

Tel: (613) 237-9462
Toll-free: 1-877-602-4445
Fax: (613) 237-1810
E-mail: fnc@naho.ca
www.naho.ca/fnc

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