

# Understanding Health Indicators

Report title: Understanding Health Indicators

© Copyright 2007 National Aboriginal Health Organization

ISBN: 978-0-9780785-6-0

Date Published: April 2007

OAAPH [now known as the National Aboriginal Health Organization (NAHO)] receives funding from Health Canada to assist it to undertake knowledge-based activities including education, research and dissemination of information to promote health issues affecting Aboriginal persons. However, the contents and conclusions of this report are solely that of the authors and not attributable in whole or in part to Health Canada.

The National Aboriginal Health Organization, an Aboriginal-designed and -controlled body, will influence and advance the health and well-being of Aboriginal Peoples by carrying out knowledge-based strategies.

This report should be cited as:

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

For queries or copyright requests, please contact:

National Aboriginal Health Organization 220 Laurier Avenue West, Suite 1200 Ottawa, ON K1P 5Z9

Tel: (613) 237-9462

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

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:



## First Nations Centre @ NAHO

220 Laurier Avenue West, Suite 1200 Ottawa, ON K1P 5Z9 Tel: (613) 237-9462 Toll-free: 1-877-602-4445

Fax: (613) 237-1810 E-mail: fnc@naho.ca www.naho.ca

## **Table of Contents**

Introduction	1
What are Health Indicators?	2
Health Indicators and the Real World: A Case Study	2
Where to Get Data	3
How Are Health Indicators Used?	5
What Makes a Good Indicator?	6
Organizing Indicators: Frameworks	7
Health Indicator Development by First Nations	. 11
Glossary	. 15
Endnotes	. 18
Bibliography	. 19
Appendix A: Create Your Own Indicators Worksheet	21

#### Introduction

First Nations often describe health 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." It is fundamentally understood that all things are interconnected. Elder Jim Dumont captures the concept when he speaks of "the total health of the total person in the total environment."

The World Health Organization's constitution defines health holistically as "a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity."

A 1974 landmark Canadian document, the "Lalonde Report", influenced understandings of health internationally. It was one the first government reports to recognize that health involves much more than the health care system. The report said that health was dependent on four related things: biology, environment, lifestyle and access to healthcare services.

According to Lalonde, "Good health is the bedrock on which social progress is built. A nation of healthy people can do those things that make life worthwhile, and as the level of health increases so does the potential for happiness."<sup>5</sup>

This information resource provides information about indicators of health and well-being for First Nations communities. Indicators include things like life expectancy, diabetes rates, surgery wait times, income levels and household crowding. Indicators are important in monitoring population health, factors that influence health and the effectiveness of health services.

This information resource is intended primarily for people working at the community level. It describes and gives examples of indicators. It gives ideas on where to get them, how to use them and how to organize them. It explains what makes a good indicator. First Nations examples and models are highlighted throughout.

A glossary of selected terms related to health indicators and health research is provided.

Finally, a "Create Your Own Indicators" worksheet is provided to help you identify and use indicators of health and wellness issues in your own community.

The First Nations Centre @ NAHO has prepared other information resources including:

- Understanding Research;
- Health Surveillance;
- Privacy;
- Ethics in Health Research;
- Considerations and Templates for Ethical Research Practices;
- OCAP: Ownership, Control, Access, and Possession;
- Assessment and Planning Tool Kit for Suicide Prevention in First Nations Communities;
- Health Careers; and,
- Sacred Ways of Life: Traditional Knowledge.

#### What are Health Indicators?

Health indicators are measurements. They measure different aspects of health within a community or group. Each indicator is like a piece of a puzzle contributing to an overall picture. When indicators are tracked over time, the picture becomes a movie, allowing us to see how the health story is changing. There are two main types of indicators:

**Health status** indicators measure different aspects of the health of a population. Examples include life expectancy, infant mortality, disability or chronic disease rates.

**Health determinant** indicators measure things that influence health. Examples include diet, smoking, water quality, income and access to health services. First Nations also consider language, culture and spirituality to be health determinants.

Indicators help to answer important questions, such as:

- How healthy is our community?
- Is our community in balance?
- What things affect health in our community?
- Are our programs, services or policies working?
- Are we moving towards or away from our vision of health?

Indicators and statistics can be abstract and may seem disconnected from the every day lives of people in our communities. So, before getting into the technical details, let's begin with a little girl's story.

## Health Indicators and the Real World: A Case Study

Consider 3-year-old Raven's experience being hospitalized three hundred kilometres from home\*:

#### WHY WAS RAVEN IN THE HOSPITAL?

Because she was medically evacuated after a severe asthma attack that could not be handled in the community nursing station.

#### BUT, WHY DID SHE HAVE AN ASTHMA ATTACK?

Because her asthma was triggered by mould in her house.

#### **BUT, WHY DOES HER HOUSE HAVE MOULD?**

Because her house has air quality problems.

#### **BUT, WHY IS THE AIR QUALITY POOR?**

Because water leaks into the basement and the ventilation is inadequate.

## BUT, WHY DOES THE HOUSE HAVE THESE PROB-

Because the house was poorly built and the grandfather Raven lives with cannot afford to do the repairs.

## BUT, WHY CAN'T HER GRANDFATHER AFFORD TO DO REPAIRS?

Because he is unemployed and has little income.

#### **BUT, WHY DOES HE HAVE A LOW INCOME?**

Because he didn't graduate high school and is disabled.

BUT WHY ...?

<sup>\*</sup> A fictitious example.

The questions don't stop there. Raven's experience might also trigger questions about the community in general:

- 1) Is childhood asthma common in the community?
- 2) How common are the various factors that led to Raven's hospitalization?
- 3) What can be done?

To answer the first question, we could talk to parents to get a qualitative impression or we could develop a quantitative indicator that measures serious asthma attacks among children.

If it turns out that childhood asthma is a common problem, then we might develop a public health strategy to try and reduce the number of cases. The effectiveness of the strategy could be assessed every year by using the same indicator. But in order to develop an effective strategy, we need to know more about the causes or factors that are contributing to childhood asthma.

This brings us to the second question about factors which played a part in Raven's hospitalization. This question is much more complex, and spins off many other questions such as: How many other children live in houses with mould? How many households have low income? How many people are disabled? We can help to answer these types of questions by developing indicators. Raven's experience suggests several indicator topics:

- Nursing station staffing levels;
- Houses with mould;
- Houses in need of repairs;
- Employment;
- Income (including breakdowns by age, education and disability status);
- Education levels; and,
- Disability and activity limitation.

We may also want to broaden our focus beyond Raven's experience to consider other potential indicators that may be related to the problem. For example, although Raven's grandfather doesn't smoke, it is known that cigarette smoke can also trigger asthma.<sup>6</sup> So, another indicator could be added:

• Exposure to second hand smoke

Some of the indicators are directly associated with asthma while others, like income, are further removed. Some are easier for health workers to tackle while others are more difficult or require help from other sectors. Both types of indicators are important in prioritizing prevention work and health care interventions.

The indicators can be used to assess whether the strategies have an impact. For example, we might ask: "Did anyone have to be medically evacuated due to an asthma attack after a second nurse was hired?", "Did the proportion of houses needing repairs decrease after council allocated new money to tackle the problem?", "Did the proportion of houses with mould decrease?" and "Did the number of serious asthma attacks decrease?"

Of course, we don't develop health strategies or indicators based on a single person's story. Nonetheless the questions that come up when we consider a story like Raven's can help us to understand community health and the use of indicators.

Now that we've identified a set of indicators, the next question is: "Where do we get the information?"

#### Where to Get Data

Data sources are diverse. Sometimes data is available locally. Sometimes it can be found on the Internet or by making a phone call. Sometimes, we might need to develop and implement a new information system. Usually, a number of different sources are required.

Let's return to Raven's hospitalization as an example. Table 1 includes some of the indicators identified in relation to that story and gives examples of where we might get the data. Potential difficulties are also noted.

Table 1: Sample Indicators and Where to Get the Data

Indicator themes	Specific indicators	Where to get the data	Comments on feasibility
Serious asthma attacks among children	Asthma-related hospitalizations among children under ten	Extract cases from provincial hospitalization databases	Data access may be difficult or impossible to negotiate. First Nations status may not be recorded. Asthma related cases might not be identified as such. Knowledge of database required.
Nursing station staffing levels	Number of full time nurses	Ask anyone in the community	Easy
Houses with mould	Proportion of homes with mould, reported by owner	Door-to-door survey (or existing survey data <sup>7</sup> )	Relatively easy. Include all houses or good random sample. Can ask other questions too.
Houses in need of repairs	4. Proportion of homes needing major repairs, minor repairs or regular maintenance	Request or buy existing survey data (or do a new door-to-door survey)	Data may be available through the RHS <sup>8</sup> or Statistics Canada. <sup>9</sup>

The examples in the table include a typical crosssection of the types of data planners normally require:

- Local knowledge;
- Part of a provincial database;
- A new register;
- A new survey; and,
- Existing survey data.

Data sources can be local or "out there", beyond the community:

#### **Some Local Sources**

- Nursing stations (charts, registers and other records, paper or electronic);
- Local stores in isolated communities (sales of fruits, vegetables, alcohol, cigarettes, junk food);
- Local police (statistics);

- Treatment centre (statistics);
- Community meetings, feasts, cultural events, training sessions, health promotion activities, etc. (frequency, number of participants);
- Schools (dropout statistics, absenteeism);
- Hunters (changes in environment, animal patterns); and,
- Elders (spiritual life, adaptation to change).

#### **Some Sources "Out There"**

- The Information Centre on Aboriginal Health (www.icah.ca) is a rapidly growing virtual library for Aboriginal health information of all kinds.
- The First Nations Centre at the National Aboriginal Health Organization has additional information about indicators, data sources and related topics (www.naho.ca/fnc).

- The 2002-03 First Nations Regional Longitudinal Health Survey (RHS), now hosted at the Assembly of First Nations (www.afn.ca), offers unique First Nations data.
- Regional First Nations and Inuit Health Branch (FNIHB) offices manage and analyze First Nations health data (http://www.hc-sc.gc.ca/home-accueil/con tact/branch e.html).
- Indian and Northern Affairs Canada (INAC)
  maintains a large number of Aboriginal data
  bases and produces reports and community
  profiles (http://www.ainc-inac.gc.ca/pr/in
  dex e.html).
- Provincial and territorial health ministries collect and analyse health data for all clients using their services (www.hc-sc.gc.ca/hcssss/delivery-prestation/ptrole/ptmin/index\_ e.html).
- Lots of 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).
- University-based research groups provide support and collaboration. The regional Aboriginal Capacity and Development Re search Environments (ACADRE), in particular, are designed to support Aboriginal communities (www.cihr-irsc. gc.ca/e/9138.html).

#### **Proxy Measures**

Sometimes, it takes too much work or time to gather data needed for an indicator. That indicator can be replaced with another easier-to-obtain one that gets close to what we're interested in. The alternate measure serves as a proxy —a "stand-in".

Example 1: Since lab tests are not always done, FluWatch uses high school absenteeism as a proxy for (possible) influenza outbreaks. (/www.phac-aspc.gc.ca/fluwatch/index.html)

Example 2: Food bank visits are a proxy measure of poverty.

Use a stand-in or proxy when you can't get the real thing.<sup>10</sup>



Now that we have identified some indicators and where to get the data, the next question is: "What do we do with them?"

#### **How Are Health Indicators Used?**

Health indicators are used to measure a population's health, track it over time and compare it with other populations. For example, the health director in Raven's community might measure whether the proportion of houses in her community that need repairs is going up or down and how it compares to the neighbouring non-First Nations community. By providing information on current health concerns, indicators are important tools for evaluating, planning, priority setting and identifying (or validating) health needs. They assist health planners and administrators to make decisions about what types of health services are needed the most, and where funding should be directed.

In Raven's community for example, the health director might use the houses-in-need-of-repair indicator to support the case for an increased housing budget.

Indicators can help First Nations "...understand their current situation and help them chart a course to make their community a healthy, vital place in which to live for current and future generations."<sup>13</sup> First Nations indicators can:

- Raise awareness of health problems and issues:
- Help in priority-setting, planning and re source allocation;
- Be used to evaluate the performance of a health program, project or intervention;
- Provide evidence to support First Nations concerns, claims or positions;
- Be important tools to influence policy; and,
- Measure cultural or community-specific aspects of health.

Figure 1: The Health Surveillance Cycle

#### **Health Surveillance** Indicators are a basic tool in health surveillance. Though the term may conjure notions of spying or "Big Brother", health surveillance is really just about monitoring health information. It is a core function of public health work. According to the First Nations Centre Toolkit on Surveillance, "Surveillance is the ongoing collection, analysis, interpretation, and dissemination of information (often called "data) about a disease or condition to the people who need to know":11 Surveillance systems usually collect just enough data to detect increases or changes in patterns, such as a spike in cancer rates in a certain area. Figure 1, illustrates how surveillance operates within public health. Figure 1: The Health Surveillance Cycle<sup>12</sup> Collecting data about how many people have a particular condition-Surveillance Giving the information Interpreting the to the people who need results or indicators to know

So far, we have identified some indicators, where to get them and how to use them. Before we go out and actually gather them and report the results, let's see whether the indicators are good ones.

#### What Makes a "Good" Indicator?

Good indicators share the following characteristics: 14,15

#### 1) Validity

An indicator is valid if it actually measures what it is supposed to be measuring. Let's say the health director in Raven's community wants to know the number of children who have asthma. She counts the asthma-related visits on the nursing station data sheet during July and August. There were six. Unfortunately, this does not give her what she is looking for. All six visits may be for the same child. July and August may be unusual. Some children with asthma may go to the city doctor instead of the nursing station or they may not need medical care at all. Although potentially useful to track over time and as a proxy, the visit count does not measure what the health director specifically wants to measure. A more valid count of children with asthma might be obtained through a survey, a review of children's medical charts or a different type of nursing station register.

#### 2) Reliability (Reproducibility)

A measure is reliable if, under the same circumstances, the same result (or nearly) is produced every time. For example, a person's weight should be the same on two different scales. The proportion of homes with mould in Raven's community should be about the same in two separate surveys of randomly selected homes done in the same period.

#### 3) Sensitivity

An indicator is sensitive if it can measure differences (e.g. between groups) or changes over time that are of interest to the user. If childhood asthma rates went from 12% in 2002 down to 10% in 2007, but the margin of error was plus or minus 4% each time, our estimate would not be sensitive enough to know if there was truly a (statistical) change.

#### 4) Acceptability

An indicator that is acceptable will be understandable, credible and useful to its intended users. Sometimes, what may be credible and useful to an academic or government agency may differ from what is acceptable to First Nations. The notion of acceptability may be understood in terms of community and cultural appropriateness.

#### 5) Feasibility

An indicator is feasible if it can reasonably be collected and managed with available human and financial resources. In many First Nations contexts, the capacity for collecting health indicator data is relatively limited. For example, staff in Raven's community might not be able to access and analyze provincial hospitalization records but they could administer a local survey or use nursing station records.

#### 6) Universality

An indicator which is universal can be used in different populations and settings. Although universality is one of the usual standards, it may not always apply. At the community level, it is not uncommon to have highly relevant local indicators that are not applicable elsewhere.

In addition to the conventional standards listed above, one additional characteristic of good indicators applies in the First Nations context:

#### 7) Inclusiveness

An indicator which is developed through an inclusive First Nations process is more likely to be relevant and useful.

Now that we have a good set of indicators, know where to get them and how to use them, we may want to organize them.

#### **Performance Indicators**

Performance indicators are specifically intended to evaluate the performance of a program, service or policy. Quality of service measures are included as well as measures of health status and health outcomes (the goals of improved performance).

In 2000, the Federal and provincial governments agreed to a set of 67 indicators to help assess the health care system. Of those, only 38 could be reported for First Nations due to data limitations. None of the wait time related measures was available for First Nations.

#### **Organizing Indicators: Frameworks**

Sometimes, a handful of indicators is sufficient. We might just want a snapshot of childhood asthma, for example. At other times, we might want a detailed picture of community health overall. On those occasions, an organized set of indicators is useful. There are different ways that indicators can be organized into a framework.

Let's consider two models for organizing indicators and understanding health. The first is Western. The second is grounded in First Nations understandings.

#### Model 1: Population Health Model<sup>17</sup>

According to the Public Health Agency of Canada,

A population health approach recognises that any analysis of the health of the population must extend beyond an assessment of traditional health status indicators like death, disease and disability. A population health approach establishes indicators related to mental and social well-being, quality of life, life satisfaction, income, employment and working conditions, education and other factors known to influence health.<sup>18</sup>

#### **Health Determinants**

Determinants include anything that affects our health— from what we do and eat to our genetics, environment and spirituality.

Determinants combine and work in complicated ways. They don't affect every person the same way. For example, one person who smokes for twenty years might get cancer while another stays healthy.

To understand the impact of determinants we look at groups. We ask if people with certain characteristic are more likely to have a certain result or outcome. The question isn't, for example, whether smokers get cancer but whether smokers are more likely to get cancer.

Determinants are usually not simple "causes". They are things which increase or decrease the likelihood or risk of certain health outcomes.

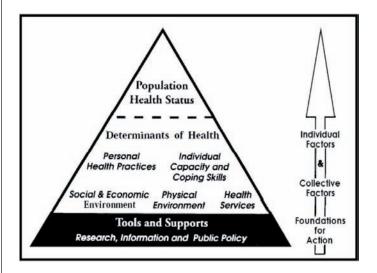
The model in Figure 2 and similar ones are now widely used in Canadian public health. <sup>19,20</sup> The model is illustrated as a pyramid, with "causes" below and "effects" above. In this model, health "determinants" lead more or less directly to health "status" or "outcomes". In the Raven example, asthma would be the main health status issue while housing, income and health services would be among the determinants.

This Western model seeks to improve health at the top by acting on the factors below. The approach emphasizes prevention based on sound research and information.

While the Population Health framework and other Western models tend to highlight cause and effect, First Nations models emphasize the need for balance.

An example of how indicators are organized within a Population Health framework is shown in Table 2.

Figure 2: Population Health Framework



**Table 2: Health Indicators in a Population Health** Framework<sup>21</sup>

THE	ME	SAMPLE INDICATOR TOPICS
	Well-being	Self-rated health status
	CALLED MACHINE CONTRACTOR	Job satisfaction
	Activity	<ul> <li>Disability/activity limitation</li> </ul>
12	limitation	<ul> <li>Conditions causing activity limitation</li> </ul>
at	Injuries	Hospitalization due to trauma
š	12740	<ul> <li>Motor vehicle accidents</li> </ul>
=	Conditions	<ul> <li>Low or high birth weight</li> </ul>
Health Status	and diseases	<ul> <li>Chronic conditions (e.g. diabetes, cancer)</li> </ul>
		<ul> <li>Infectious diseases (e.g. tuberculosis, HIV)</li> </ul>
	Death	Life expectancy at birth
		<ul> <li>Infant mortality</li> </ul>
		Suicide
	Social and	Marital status, family composition
	Economic	<ul> <li>Education, literacy, employment, income</li> </ul>
	Environment	First Nations control of services
	Physical	Crowded homes, mould
	Environment	<ul> <li>Exposure to second-hand smoke</li> </ul>
		<ul> <li>Drinking water quality</li> </ul>
_		Mercury levels in fish
₹	Health	Access to a regular physician
ea	Services	<ul> <li>Availability/use of screening (e.g.</li> </ul>
ב		mammography, PAP smear)
0		<ul> <li>Aboriginal representation in health</li> </ul>
ij		professions
ᅙ		<ul> <li>Difficulties accessing First Nations health</li> </ul>
≣		benefits (NIHB)
e.		<ul> <li>Health expenditures</li> </ul>
Determinants of health	Personal	Social support
	Resources	<ul> <li>Use of and access to home care services</li> </ul>
	Health	<ul> <li>Knowledge of impacts of smoking</li> </ul>
	Knowledge	<ul> <li>Knowledge of healthy eating practices</li> </ul>
	Lifestyle	Smoking, drinking, drug use
	behaviours	Physical activity
		Sexual practices
		Breastfeeding

## Model 2: First Nations Regional Longitudinal Health Survey (RHS) Cultural Framework<sup>22</sup>

A cultural framework was developed to guide the interpretation and presentation of results from the 2002-03 First Nations Regional Longitudinal Health Survey (RHS). Figure 3 shows how the cultural framework was used to organize survey themes. The model is referred to as a "working wheel" or "four directional wheel" \*

The RHS cultural framework places people at the center of the circle. It then organizes health and wellness into four cardinal directions: East (Vision), South (Relationships), West (Reason) and North (Action). The outer circle identifies the themes of indicators gathered through the survey.

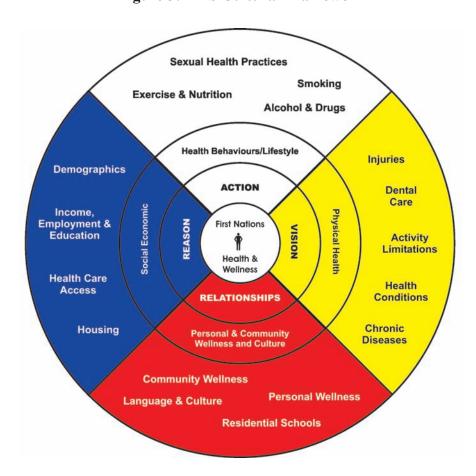


Figure 3: RHS Cultural Framework

<sup>\*</sup> Although similar, a "working wheel" is distinct from a medicine wheel, which is attached to sacred teachings and understandings.

Figure 4, a more complete model of wellness, emphasizes the interconnectedness of all things. It depicts seven connected levels. Each level is a four-directional circle and each circle is just a part of the circle below it. For example humankind (level 4) is a small part of "animals" in level 3.

In this model, health and wellness are about balance. Imagining the levels as wheels spinning on a common axis, it is easy to see how one unbalanced part can affect the whole system.

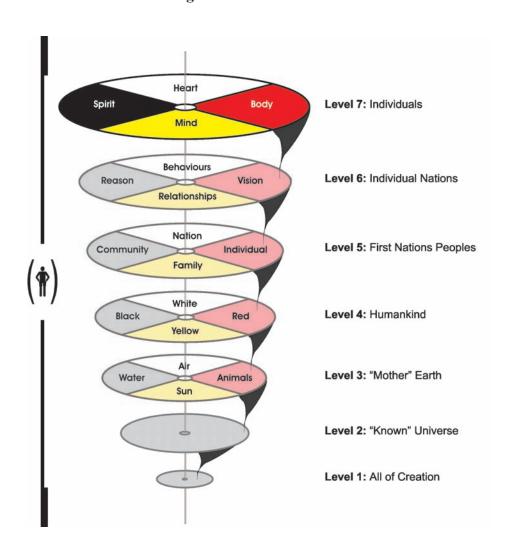


Figure 4: RHS Wellness Model

Starting from a fictitious example, we have walked through the main steps in the development, use and organization of indicators. Now, let's turn to some recent real examples of First Nations indicators development.

## Health Indicator Development by First Nations

Despite the potential, it is difficult for First Nations to make the most of health indicators currently available. There are a number of reasons for this:

- Canadian indicators often miss issues that are important in First Nations communities.
   For example, Canadian indicators don't include availability of running water in homes.
- First Nations-specific data is often fragmented or unavailable. This is 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.
- Centrally driven processes and policy em phasize national level accountability rather than First Nations interests or local relevance and utility.
- First Nations, Inuit and Métis data are often combined into pan-Aboriginal statistics that are less useful to all three groups.
- There are significant infrastructure gaps at the community and regional levels.
- Even if the data exists (e.g. in government databases), First Nations may not have access to it.
- Most Canadian indicators currently in use were developed without considering First Nations interests, frameworks or realities.

A recent review of Aboriginal health indicators in Canada further discusses the problems.<sup>23</sup> Despite the challenges, though, there is active First Nations work in the area. Four recent initiatives stand out as innovative:

# 1) The First Nations Regional Longitudinal Health Survey (RHS)

In addition to the cultural framework it developed (see "Organizing Indicators". p 14), the RHS<sup>24</sup> is recognized for its process and values.

The RHS is the only national survey under complete First Nations control. In keeping with the principles of OCAP (Ownership, Control, Access and Possession),<sup>25</sup> the project:

- Enjoys formal First Nations mandates, political support and international recognition;
- Is governed and coordinated by regional First Nations representatives;
- Has invested in First Nations research capacity at the local, regional and national levels;
- Has produced innovations in data sharing, research ethics and computer-assisted interviewing; and,
- Has developed scientifically and culturally validated methods and questions.

An independent review of the second round of the RHS found that "[c]ompared to other national surveys of Indigenous people from around the world, the 2002/2003 RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people and their representatives at each stage of the research process."<sup>26</sup>

An inclusive two-year development phase helped to ensure that RHS data would be useful to First Nations. The RHS reports on health indicators which are uniquely important to First Nations, including residential school experiences, difficulty accessing NIHB services, and perceptions about language, culture and community progress. Regional modules further enhanced the relevance of the data. The longitudinal nature of the survey—it is repeated every few years— makes it an ideal source for tracking changes in First Nations health over time.

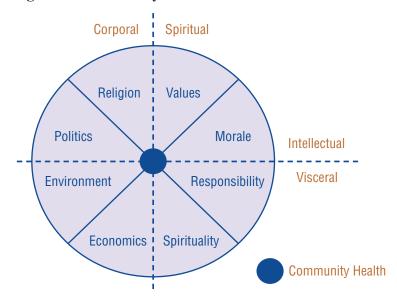
# 2) EAGLE - Effects on Aboriginals from the Great Lakes Environment

The **EAGLE** project was a research and monitoring project examining how environmental contaminants affected the health and well-being of First Nations living in the Great Lakes basin. The project, which ran from 1990 to 2000, was a collaboration between the Assembly of First Nations, the Chiefs of Ontario and Health Canada. Results and other materials from the study continue to be disseminated.<sup>27</sup>

The project sought to blend traditional environmental knowledge and Western science through collaborative processes. The project adopted a broad view of health. It examined the impacts of contaminants on traditional ways of life, health, social and economic well-being. The project developed culturally relevant indicators by combining community disease indicators with indicators of traditional practices such as use of traditional medicines and country food consumption.

Indicators were organized using the wheel reproduced in Figure 5.<sup>29</sup> The indicators were not placed within the "slices" but rather were developed for each facing pair across the circle. The wheel was also used in the Aboriginal Community Health Indicator Project described next.

Figure 5: Community Life Indicators Wheel.



The EAGLE project was a landmark study in terms of its approach to community-based research, First Nations knowledge and concepts of health. The challenges and lessons learned were documented in a process report.<sup>30</sup> Many of the lessons are worth highlighting:<sup>31</sup>

- Outside experts can provide advice but should not have decision-making power;
- Decision-making processes should be formalized and properly documented;
- Financial information should be disclosed to community representatives;
- All aspects of health should be considered;
- Develop partners' roles and responsibilities and the rules of engagement in writing and early on;
- Recognize that relationships take time;

- Community-based research should be initiated, developed, controlled and carried out by the community;
- Develop a protocol to integrate First Nations knowledge at all stages, giving it equal weight to Western scientific knowledge;
- Ensure fully informed participant consent;
- Establish and maintain a majority Aboriginal technical advisory committee;
- Ensure community review, input and validation processes;
- Develop access and dissemination protocols during the planning stage; and,
- Build community capacity during all phases, including analysis and interpretation, and not just data collection.

# 3) Aboriginal Community Health Indicator Project

According to report of the Community Health Indicator Project:

First Nations communities must be understood by the people who live in them... indicators should be culturally sensitive and reflect the interconnectedness of the physical, mental, emotional, and spiritual aspects of life. The approach of developing indicators at the community level calls for a strong respect for the community and its members. It requires seeing the world through the eyes of the people who live in the community and reporting it in their words.<sup>32</sup>

This project, which started in 2000, was 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. The project developed community health indicators based on First Nations community perspectives and starting with the "Life Indicator Wheel" (originally developed as part of the EAGLE project).

The project resulted in the creation of unique First Nations indicators. Some of the indicators, <sup>33</sup> organized according to paired aspects of the Community Life Indicators<sup>34</sup> Wheel (Figure 5), include:

#### **Economics-Values**

- Number of hunters in the community
- Catch rate of ungulates (e.g. deer)
- Ungulate population

#### **Environment-Morale**

- Number of community or group celebrations
- Size of forest area
- Extent and types of forest usage

#### Religion-Spirituality

- Number of drums in community
- Number of drumming occasions per year
- Number of religious space (e.g. churches, sweat lodges) in the community

## 4) The First Nations Health Reporting Framework 35,36

The Assembly of First Nations prepared the First Nations Health Reporting Framework (FNHRF) as an alternative to the Federal Aboriginal Health Reporting Framework. The First Nations specific model was designed to "maximize the value of reporting for community health planning, and implement reciprocal accountability between FNIHB and First Nations.<sup>37</sup>

The Framework was developed based on a literature review and a set of guiding principles. Among other things, the framework was designed to:

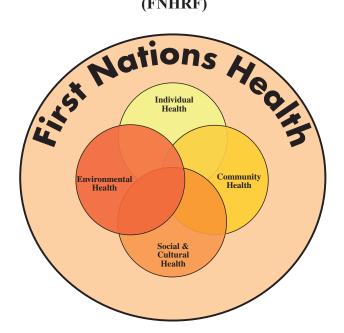
- Support reciprocal accountability;
- Serve both as a planning and reporting tool;
- Allow for comparison with Canadian data;
- Include feasible/existing indicators;
- Exclude traditional indicators that are not measurable; and,
- Respect the principles of OCAP (Ownership, Control, Access and Possession).

The May 2006 FNHRF document organizes health determinants into four overlapping areas as shown in Figure 6.

The indicators in the "social and cultural health" sphere include unique First Nations measures related to:

- Effects of colonization, residential schools;
- Self-determination;
- Language;
- Cultural practices; and,
- Traditional land use.

Figure 6: First Nations Determinants of Health (FNHRF)



#### **Glossary**

**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).

**Data:** Facts, observations or measurements that have been recorded, but not analyzed or interpreted.

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

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

**Health determinants:** Factors and conditions that have an influence on health of individuals or populations. Examples include education, income, smoking or environmental contamination.

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

**Incidence or incidence rate rate:** The number of new cases of a disease among a population during a certain period. Incidence is commonly measured as a rate and may be reported as new cases per 1,000 per year.

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

**Indigenous (traditional) knowledge:** An ancient, communal, holistic and spiritual body of information and understanding that encompasses every aspect of human existence. Knowledge is passed on through teachings, ceremonies, healing practices and everyday living.

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

**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.

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

**Population health framework:** A model (or conceptual framework) for understanding the health of a population.

**Prevalence:** The number or proportion of individuals in a population with a given disease (or condition) at a specified point in time without regard for when they acquired the disease.

**Proxy measures:** Can be used as an alternative when you can't measure the exact thing of interest.

**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. Surveillance supports planning, implementation, and evaluation of health programs and interventions.

**Vital statistics:** Data related to births, deaths, marriages and divorce, usually maintained by governments. May also include health statistics in some jurisdictions.

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

#### **Endnotes**

<sup>1</sup>"Gathering Strength." 1996. Royal Commission on Aboriginal Peoples. Ottawa: Ministry of Supply and Services. 23 April 2004. 10 June 2006. <a href="http://www.ainc-inac.gc.ca/ch/rcap/rpt/gs">http://www.ainc-inac.gc.ca/ch/rcap/rpt/gs</a> e.html>

<sup>2</sup>Dumont, J. Personal communication. March 2005.

<sup>3</sup>World Health Organization. Constitution of the World Health Organization, 1948.

<sup>4</sup>Lalonde, M. *A new perspective on the health of Canadians*. Ottawa: Minister of Supply and Services Canada, 1974. 12 Aug. 2006 <a href="http://www.phac-aspc.gc.ca/ph-sp/phdd/pube/perintrod.htm">http://www.phac-aspc.gc.ca/ph-sp/phdd/pube/perintrod.htm</a>

5Ibid

<sup>6</sup>U.S. Environment Protection Agency. *IAQ Reference Guide, Appendix D- Asthma*. 3 March 2006. 10 June 2006 <a href="http://www.epa.gov/iag/schools/tfs/guided.html">http://www.epa.gov/iag/schools/tfs/guided.html</a>

<sup>7</sup>This question was asked in the 2002-03 First Nations Regional Longitudinal Health Survey. 10 June 2006 <a href="http://www.naho.ca/fnc/rhs">http://www.naho.ca/fnc/rhs</a>. The results may be available for your community.

8Ibid

<sup>9</sup>This question is asked on the Canadian Census. 13 Dec. 2005. 10 June 2006 <a href="http://www.statcan.ca">http://www.statcan.ca</a>

<sup>10</sup>David Eppstein. "Many Elvises." 10 June 2006 <a href="http://www.ics.uci.edu/~eppstein/pix/desrr/Elvis2.html">http://www.ics.uci.edu/~eppstein/pix/desrr/Elvis2.html</a>

<sup>11</sup>National Aboriginal Health Organization Website. "First Nations Centre: Toolkits". 12 June 2006 <a href="http://www.naho.ca/firstnations/english/toolkits.php">http://www.naho.ca/firstnations/english/toolkits.php</a>

<sup>12</sup>Adapted from the First Nations Centre's "Surveillance Toolkit." 10 June 2006 <a href="http://www.naho.ca/firstnations/english/pdf/Surveillance\_Toolkit.pdf">http://www.naho.ca/firstnations/english/pdf/Surveillance\_Toolkit.pdf</a>

<sup>13</sup>University of Ottawa: Institute of the Environment, Mohawk Council of Akwesasne, Little Red River Cree Nation, Miawpukek First Nation Partnership, *Community Health Indicators: First Year of the Project, Final Report*. Ottawa: Health Canada, 2001.

<sup>14</sup>Ware, J., et al. "Choosing Measures of Health Status for Individuals in General Populations." *American Journal of Public Health*, 71.6 (1981): 620-625.

<sup>15</sup>Last, J. A Dictionary of Epidemiology. 4th ed. New York, NY: Oxford University Press, 2001.

<sup>16</sup>Canadian Institute for Health Information. *Comparable health and health system performance indicators for Canada, the provinces and territories*. Sept. 2002. 10 June 2006 <a href="http://secure.cihi.ca/cihiweb/dispPage.jsp?cw">http://secure.cihi.ca/cihiweb/dispPage.jsp?cw</a> page=pirc e>

<sup>17</sup>Federal, Provincial, and Territorial Advisory Committee on Population Health. *Strategies for Population Health: Investing in the Health of Canadians*. Ottawa: Minister of Supply and Services Canada, 1994. 12 Oct. 2006. <a href="http://www.phac-aspc.gc.ca/ph-sp/phdd/pdf/e">http://www.phac-aspc.gc.ca/ph-sp/phdd/pdf/e</a> strateg.pdf >

<sup>18</sup>Public Health Agency of Canada. "What Determines Health?" June 16 2003. 12 Aug. 2006 <a href="https://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html">www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html</a>

<sup>19</sup> Public Health Agency of Canada, Atlantic Region. *Population Health Concepts for Considering Impacts on Youth*. Feb. 14 2006. 12 Aug. 2006.

<a href="http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Chasing">http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Chasing</a> the wave/1 e.html>

<sup>20</sup>Public Health Agency of Canada. *Towards a Common Understanding: Clarifying the Core Concepts of Population Health, Appendix B: Population Health Framework.* 29 Nov. 2002. 12 Aug. 2006

<a href="http://www.phac-aspc.gc.ca/ph-sp/phdd/docs/common/appendix">http://www.phac-aspc.gc.ca/ph-sp/phdd/docs/common/appendix</a> b.html>

- <sup>21</sup>Adapted from: Federal, Provincial and Territorial Advisory Committee on Population Health. *Statistical Report on the Health of Canadians*. Ottawa: Health Canada, 1999. 29 Nov. 2002. Aug. 2006
- <a href="http://www.phac-aspc.gc.ca/ph-sp/phdd/report/stat/report.html">http://www.phac-aspc.gc.ca/ph-sp/phdd/report/stat/report.html</a>
- <sup>22</sup>First Nations Regional Longitudinal Health Survey. *Results for Adults, Youth and Children Living in First Nations Communities*. Aug. 2006.
- <a href="http://www.naho.ca/firstnations/english/documents/RHS2002-03TechnicalReport">http://www.naho.ca/firstnations/english/documents/RHS2002-03TechnicalReport</a> 001.pdf
- <sup>23</sup>Anderson M, Smylie J, Anderson I, et al. First Nations, Métis, and Inuit Health Indicators in Canada. A background paper for the project "Action oriented indicators of health and health systems development for Indigenous peoples in Canada, Australia, and New Zealand." Saskatoon: Indigenous Peoples' Health Research Centre; 2006. 10 August 2006: www.iphrc.ca/text/canadian. pdf
- <sup>24</sup>National Aboriginal Health Organization website. "Regional Health Survey Homepage". Aug. 2006. <a href="https://www.naho.ca/fnc/rhs">www.naho.ca/fnc/rhs</a>
- <sup>25</sup>First Nations Centre, Ownership, Control, Access and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities, first prepared for the First Nations Information Governance Committee, Assembly of First Nations (Ottawa: National Aboriginal Health Organization).
- <sup>26</sup>Harvard Project on American Indian Economic Development. *Review of the First Nations Regional Longitudinal Health Survey* (RHS) 2002/2003. April 2006
- <sup>27</sup>Assembly of First Nations, Chiefs of Ontario, Health Canada. *E.A.G.L.E. Project:Socio-cultural Pilot Project Technical Report.* May 2001. Aug. 2006.
- <a href="http://www.chiefs-of-ontario.org/environment/docs/socio-c.pdf">http://www.chiefs-of-ontario.org/environment/docs/socio-c.pdf</a>
- <sup>28</sup>Assembly of First Nations, Chiefs of Ontario, Health Canada. *E.A.G.L.E. Project: A Review of the EAGLE Project's Approach to Community-Based Reseach* [sic]. May 2001. Aug. 2006.
- <a href="http://www.chiefs-of-ontario.org/environment/docs/Particip.pdf">http://www.chiefs-of-ontario.org/environment/docs/Particip.pdf</a>
- <sup>29</sup>Leech, D., Lickers, F. H. and Haas, G. Innovating a New Way of Measuring the Health of Aboriginal Communities. Aug. 2006. <a href="https://www.innovation.cc/news/innovation-conference/leech.pdf">www.innovation.cc/news/innovation-conference/leech.pdf</a>
- <sup>30</sup>Assembly of First Nations, Chiefs of Ontario, Health Canada. E.A.G.L.E. Project: A Review of the EAGLE Project's Approach to Community-Based Reseach [sic]. May 2001. Aug. 2006.
- <a href="http://www.chiefs-of-ontario.org/environment/docs/Particip.pdf">http://www.chiefs-of-ontario.org/environment/docs/Particip.pdf</a>
- <sup>31</sup>Lessons are synthesized and adapted from the original.
- <sup>32</sup>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.
- <sup>33</sup>Leech, D., Lickers, F. H. and Haas, G. Innovating a New Way of Measuring the Health of Aboriginal Communities. Aug. 2006. <a href="https://www.innovation.cc/news/innovation-conference/leech.pdf">www.innovation.cc/news/innovation-conference/leech.pdf</a>
- <sup>34</sup>Assembly of First Nations. *Draft First Nations Health Reporting Framework*. 2005.
- <sup>35</sup>Assembly of First Nations. The Development of A First Nations Health Reporting Framework. May 2006.
- <sup>36</sup>National First Nations Health Technicians Network, *Recommendations to the Chiefs Committee on Health*. January 2005.

#### **Bibliography**

Anderson M, Smylie J, Anderson I, et al (2006). First Nations, Métis, and Inuit Health Indicators in Canada. A background paper for the project "Action oriented indicators of health and health systems development for Indigenous peoples in Canada, Australia, and New Zealand." Saskatoon: Indigenous Peoples' Health Research Centre; 2006. Retrieved August 10 2006 from www.iphrc.ca/text/canadian.pdf

Assembly of First Nations, Chiefs of Ontario, Health Canada (2001). *E.A.G.L.E. Project Socio-cultural Pilot Project Technical Report*. Retrieved August 10 2006 from www.chiefs-of-ontario.org/environment/docs/socio-c.pdf

Assembly of First Nations, Chiefs of Ontario, Health Canada (2001). *E.A.G.L.E. Project: A Review of the EAGLE Project's Approach to Community-Based Reseach* [sic]. Retrieved August 10 2006 from www.chiefs-of-ontario.org/environment/docs/Particip.pdf

Assembly of First Nations (2005). Draft First Nations Health Reporting Framework. Ottawa: Author.

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

Canadian Institute for Health Information (2002). *Comparable health and health system performance indicators for Canada, the provinces and territories*. Retrieved June 10 2006 from http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\_page=pirc\_e

Federal, Provincial, and Territorial Advisory Committee on Population Health (1994). *Strategies for Population Health: Investing in the Health of Canadians*. Ottawa: Minister of Supply and Services Canada. Retrieved October 12 2006 from www.phac-aspc.gc.ca/ph-sp/phdd/pdf/e strateg.pdf

Federal, Provincial and Territorial Advisory Committee on Population Health (1999). *Statistical Report on the Health of Canadians*. Ottawa: Health Canada. Retrieved August 10 2006 from www.phac-aspc.gc.ca/ph-sp/phdd/report/stat/report.html

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

First Nations Centre (2003) *Surveillance Toolkit*. Ottawa: National Aboriginal Health Organization. Retrieved June 10 2006 from www.naho.ca/firstnations/english/pdf/Surveillance\_Toolkit.pdf

First Nations Regional Longitudinal Health Survey, First Nations Centre (2005). *First Nations Regional Longitudinal Health Survey. Results for Adults, Youth and Children Living in First Nations Communities.* Ottawa: National Aboriginal Health Organization. Retrieved August 10 2006 from www.naho.ca/firstnations/english/documents/RHS2002-03TechnicalReport 001.pdf

First Nations Information Governance Committee (January, 2005). *First Nations Regional Longitudinal Health Survey, Code of Research Ethics – Revised draft*. Ottawa: Assembly of First Nations.

Harvard Project on American Indian Economic Development (2006). *Review of the First Nations Regional Longitudinal Health Survey (RHS) 2002/2003*. Cambridge, MA: Author.

Lalonde, M (1974). *A new perspective on the health of Canadians*. Ottawa: Minister of Supply and Services Canada. Retrieved August 12 2006 www.phac-aspc.gc.ca/ph-sp/phdd/pube/perintrod.htmLast, J. (2001). *A Dictionary of Epidemiology*. 4th ed. New York, NY: Oxford University Press.

Leech, D., Lickers, F. H. and Haas, G. (2002). *Innovating a New Way of Measuring the Health of Aboriginal Communities*. Aug. 2006. Retrieved August 10 2006 from www.innovation.cc/news/innovation-conference/leech.pdf

Public Health Agency of Canada (2003). *What Determines Health?* Retrieved August 12 2006 from www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html

Public Health Agency of Canada, Atlantic Region (2006). Population Health Concepts for Considering Impacts on Youth Retrieved August 12 2006 from www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Chasing the wave/1 e.html

Public Health Agency of Canada (2002). *Towards a Common Understanding: Clarifying the Core Concepts of Population Health, Appendix B: Population Health Framework.* Retrieved August 12 2006 from www.phac-aspc.gc.ca/ph-sp/phdd/docs/common/appendix\_b.html

Royal Commission on Aboriginal Peoples (1996). *Gathering Strength*. Ottawa: Ministry of Supply and Services. Retrieved June 10 2006 from www.ainc-inac.gc.ca/ch/rcap/rpt/gs\_e.html Royal Commission on Aboriginal Peoples. Report of the Royal Commission on Aboriginal Peoples, Volume:

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

U.S. Environment Protection Agency (2006). *IAQ Reference Guide, Appendix D- Asthma*. Retrieved June 10 2006 from www.epa.gov/iaq/schools/tfs/guided.html

Ware, J., et al. (1981) "Choosing Measures of Health Status for Individuals in General Populations." *American Journal of Public Health* 71.6: 620-625.

World Health Organization (1948). *Constitution of the World Health Organization*. Geneva: World Health Organization.

## Appendix A - Create Your Own Indicators Worksheet

Fill-in the blanks below to develop a sample set of health indicators. You may want to copy or adapt this page or use extra pages.

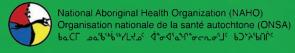
st tilligs t	nat are related of com	tribute to the problem/issue	e and/or its solutions	·············	
				that	lead to the problem lessen the problem, or result from the problem
		ms listed in the nine boxes	above. Identify who	ere you might	get the data
	comments:				1
ify things u want to ire, relat-	Indicator  1.	Data source	Comments		
ify things u want to ire, relationer issue blem and er factors	Indicator	Data source	Comments		
ify things u want to ire, relationer issue blem and er factors	Indicator  1.	Data source	Comments		
ify things u want to are, relatthe issue blem and er factors	Indicator  1.  2.	Data source	Comments		
ify things u want to are, relatthe issue blem and er factors	Indicator  1.  2.  3.	Data source	Comments		
ify things u want to ure, relatthe issue blem and er factors	Indicator  1.  2.  3.  4.	Data source	Comments		
d add any  tify things u want to urre, relat- the issue blem and er factors ed above	Indicator  1.  2.  3.  4.  5.	Data source	Comments		Identify whe to get the di

This page can be photocopied to be shared or re-used as necessary.

data sources



## First Nations Centre @ NAHO Le Centre des Premières Nations de l'ONSA



220 Laurier Ave W, 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