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# Health Policy Research

# Bulletin

## Closing the Gaps in Aboriginal Health

**S**ince the late nineteenth century, the federal government has worked to address the health needs of Aboriginal people. Although much progress has been made, Aboriginal people as a population do not have the same level of health as other Canadians. Among other health disparities, they have disproportionately high rates of injury, suicide and diabetes.

Today, through the First Nations and Inuit Health Branch (FNIHB), Health Canada works with its First Nations and Inuit partners to provide a wide range of health prevention and promotion activities and public health services on First Nations reserves and in identified Inuit communities. In remote and isolated areas, where provincially or territorially insured services are not readily available, on-reserve primary and emergency care services are delivered by the branch. Non-insured health benefits, such as pharmaceutical and dental coverage, are provided to status First Nations and eligible Inuit irrespective of their residence.

Over the last two decades, FNIHB has been working with First Nations and Inuit communities to transfer control of community-based health programs to the communities. This transfer of control occurs at a pace set by individual communities. The Transfer process allows communities to participate in program design, implementation and operational activities that address their specific needs.

In addition to the work of FNIHB, the department's Population and Public Health Branch (PPHB) offers programs that target certain populations, including First Nations living off reserve, Métis and Inuit. PPHB's Aboriginal Head Start in Urban and Northern Communities Program is specifically designed for Aboriginal people, while other programs, such as the Community

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Action Program for Children and the Canada Prenatal Nutrition Program, have large numbers of Aboriginal participants.

Beyond the programs and services offered by Health Canada, the provinces and territories are responsible for providing physician and hospital care to Aboriginal people.

This issue of the *Health Policy Research Bulletin* focuses on collaborative efforts aimed at closing the gaps in health status between Aboriginal people and other Canadians. It examines the importance of culturally relevant health programs and services and the role that Aboriginal women play in the health of their communities. As well, two case studies highlight some of the ways Health Canada works in partnership with Aboriginal people to improve their overall health status. 🌱

## Frequently Used Terms

### Aboriginal People

A collective name for the original peoples of North America and their descendants. The Canadian Constitution recognizes three groups of Aboriginal peoples — Indians (First Nations), Métis and Inuit.

### Indian

A term that collectively describes all the Indigenous people in Canada who are not Inuit or Métis. In Canada, the term Indian has generally been replaced with the term First Nation.

### First Nation

A term that came into common usage in the 1970s to replace the word Indian, which some people found offensive. Although the term First Nation is widely used, no legal definition of it exists.

### Inuit

An Aboriginal people of Arctic Canada who live primarily in Nunavut, the Northwest Territories, and northern parts of Québec and Labrador.

### Métis

An Aboriginal people of mixed First Nations and European ancestry, distinct from First Nations people, Inuit and non-Aboriginal people.

### Status Indians

Aboriginal people who are registered or entitled to be registered as “Indians” with the federal government, as determined by certain criteria in the *Indian Act*. Non-Status Indians are people who consider themselves Indians or members of a First Nation but whom the federal government does not recognize as Status Indians. In 1985, the federal government amended the *Indian Act*. Since then, thousands of people who had previously lost their status have been added to the Indian Register.

### References

*The Indian Register*, Indian and Northern Affairs Canada, November 1997 (available at: [http://www.ainc-inac.gc.ca/pr/info/info111\\_e.html](http://www.ainc-inac.gc.ca/pr/info/info111_e.html)).

*Words First*, Communications Branch, Indian and Northern Affairs Canada, October 2002 (available at: [http://www.ainc-inac.gc.ca/pr/pub/wf/index\\_e.html](http://www.ainc-inac.gc.ca/pr/pub/wf/index_e.html)).

## About the Health Policy Research Bulletin

Health Canada's *Health Policy Research Bulletin* is published three times a year. The Bulletin is part of a larger policy research dissemination program designed to enhance Health Canada's policy-relevant evidence base.

A departmental steering committee guides the development of the Bulletin. The committee is chaired by Cliff Halliwell, Director General of the Applied Research and Analysis Directorate (ARAD) of the Information, Analysis and Connectivity Branch. The Research Management and Dissemination Division (RMDD) within ARAD coordinates the Bulletin's development and production. RMDD would like to thank the steering committee members for their contributions, as well as Nancy Hamilton and Linda Senzilet, Managing Editors, Jaylyn Wong, Assistant Editor, and Raymonde Sharpe, Distribution. Special thanks go to the lead jurisdiction for this issue, the Strategic Policy, Planning and Analysis Directorate, First Nations and Inuit Health Branch.

We welcome your feedback and suggestions. Please forward your comments and any address changes to [bulletininfo@hc-sc.gc.ca](mailto:bulletininfo@hc-sc.gc.ca) or phone (613) 954-8549 or fax (613) 954-0813. Electronic HTML and PDF versions of the Bulletin are available at: <http://www.hc-sc.gc.ca/arad-draa>

## Health Policy Research Bulletin

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Published under the authority of the Minister of Health.

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ISSN 1496-466 X

Editing, design and layout by Allium Consulting Group Inc.

Publications Mail Agreement Number 4006 9608

Return if undeliverable to:  
Health Canada  
2750 Sheppard Road, Bay #1  
Ottawa, ON K1B 3V9



# Working Together to

# Close *the* Gaps

**T**he following article is based on an interview with **Ian Potter**, Assistant Deputy Minister of the First Nations and Inuit Health Branch, Health Canada. The interview was conducted by **Linda Senzilet**, Managing Editor of this issue of the Health Policy Research Bulletin. Special thanks for her assistance to **Franca Santagati**, Assistant Deputy Minister's Office, First Nations and Inuit Health Branch, Health Canada.

**Q** The evidence is fairly overwhelming that the health status of First Nations and Inuit people is not on a par with the rest of Canadians. What are these health disparities and how do you account for them?

It's true that First Nations and Inuit people have historically had a poorer health status than other Canadians. Infectious diseases, injuries, suicide, heart disease and diabetes affect the Aboriginal population at a disproportionate rate (see article on page 6). And, while there have been improvements in the life expectancy and infant mortality of Aboriginal people in recent years, their health status remains far below that of the general population. As a result, it continues to be an important focus for researchers and policy makers.

Although there are no clear answers to these continuing disparities, some factors appear relevant. First, Aboriginal people experience inequities in the conditions that determine health, such as lower quality housing, poorer physical environment, lower educational levels, lower socioeconomic status, fewer employment opportunities and weaker community infrastructure. In order to see sustained health improvements, First Nations and Inuit people need a healthy environment that includes safe housing, clean water and education. Second is geography — many Aboriginal people live in small communities located in rural and remote areas of the country where access to health care services is limited (see Figures 1 and 2).

**Q** How can working together with First Nations and Inuit people address these disparities? Who should be involved?

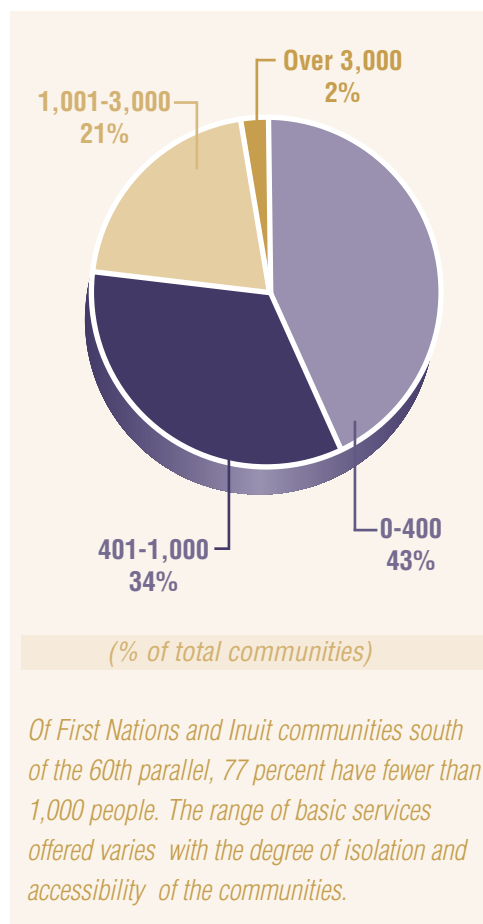
There is great diversity in individual communities and hence in their health service needs. This is one reason why the First Nations and Inuit Health Branch (FNIHB) supports the direct involvement of First Nations and Inuit communities in the design and control of their health programs. Their participation is essential in addressing disparities in health status. The Eskasoni project in Nova Scotia is an excellent example of a successful multisectoral approach to primary health care (see article on page 14).

Our mandate at FNIHB is threefold: to assist First Nations and Inuit people in attaining levels of health comparable to other Canadians; to ensure their access to sustainable health services; and to build a health sector capacity in First Nations and Inuit communities. To accomplish this, the branch works with Aboriginal organizations at the national, provincial, regional and band levels. At the national level, the Assembly ►

of First Nations and the Inuit Tapiriit Kanatami sit on the Branch Executive Committee. Each regional FNIHB office has an extensive system of joint committees with the regional First Nations or Inuit groups that plan and manage the programs. As well, most of our programs have First Nations and Inuit representatives on their steering committees.

Aboriginal organizations also work with other branches in Health Canada. For example, Aboriginal community members are currently participating in an evaluation of the effectiveness of Aboriginal Head Start in Urban and Northern Communities, which is funded by the Population and Public Health Branch (see article on page 17).

Figure 1: **Population Size – First Nations and Inuit Communities<sup>1</sup>**



### **Q** Why is it so important to have culturally appropriate health services available to First Nations and Inuit people?

First Nations and Inuit people view health holistically, as the product of a wide range of interconnected factors, including mental, physical, spiritual and emotional influences, as well as family and community contexts. This perspective on health is not unlike the World Health Organization's definition of health as a "state of complete physical, mental and social well-being."

To be effective in restoring or maintaining health, services need to embrace the culture of the people they serve. Therefore, culturally appropriate program design and delivery must be a focus for health programs in any community, taking into account local customs, priorities, language, foods, resources and sensitivities.

Health Canada's Aboriginal Diabetes Initiative is a good example of a culturally sensitive program. It provides a comprehensive, collaborative and integrated approach to decreasing the incidence of diabetes and its associated conditions among Aboriginal people. (The article on page 20 elaborates on the importance of culturally relevant health care.)

### **Q** In recent years, control over many health programs and services has been transferred from Health Canada to First Nations and Inuit communities. How did this change come about?

The concept of transferring health programs and services has evolved over the past 30 years (see article on page 11). The first step in this evolution followed the release of a 1975 paper entitled *The Canadian Government/The Canadian Indian Relationships*, which set out a policy framework for strengthening Indian control of programs and services. As a result, three quarters of bands assumed responsibility for programs such as the National Native Alcohol and Drug Abuse Program (NNADAP) and the Community Health Representative Program.

Following the 1979 release of the *Indian Health Policy*, which recognized that First Nations and Inuit people could assume responsibility for administering any or all aspects of their community health pro-

grams, Health Canada sponsored a number of demonstration projects in various communities. These experiences became the basis for the subsequent health services Transfer process, which began in 1989. Evaluations of this process — undertaken in the early and mid-nineties — concluded that it was successful in enabling First Nations and Inuit people to design programs and allocate funds according to community priorities. The Transfer process has had other benefits for communities as well, including an increased awareness of health issues, more integration of programs with the communities' social services, education and justice sectors, and more culturally based programs.

As of January 2002, 70 percent of eligible First Nations and Inuit communities had taken on some degree of responsibility for managing their community health programs. Of these, 47 percent, representing some 283 communities, had assumed overall management, while 23 percent had taken on more limited control.

**Q** What types of decisions do policy makers face in providing health services to First Nations and Inuit people? How has past policy research informed these decisions and what type of policy research will be needed to guide future decision making?

Policy makers working in First Nations and Inuit health face the same type of decisions as policy makers working in the general health system. These include: balancing the allocation of resources across the many programs and activities; determining causality of disease and disability; and identifying the most effective interventions for promoting health or treating illness.

Recent government decisions to support the creation of the National Aboriginal Health Organization (NAHO), as well as the Institute of Aboriginal Peoples Health (IAPH) within the Canadian Institutes of Health Research (CIHR), are positive steps — both for

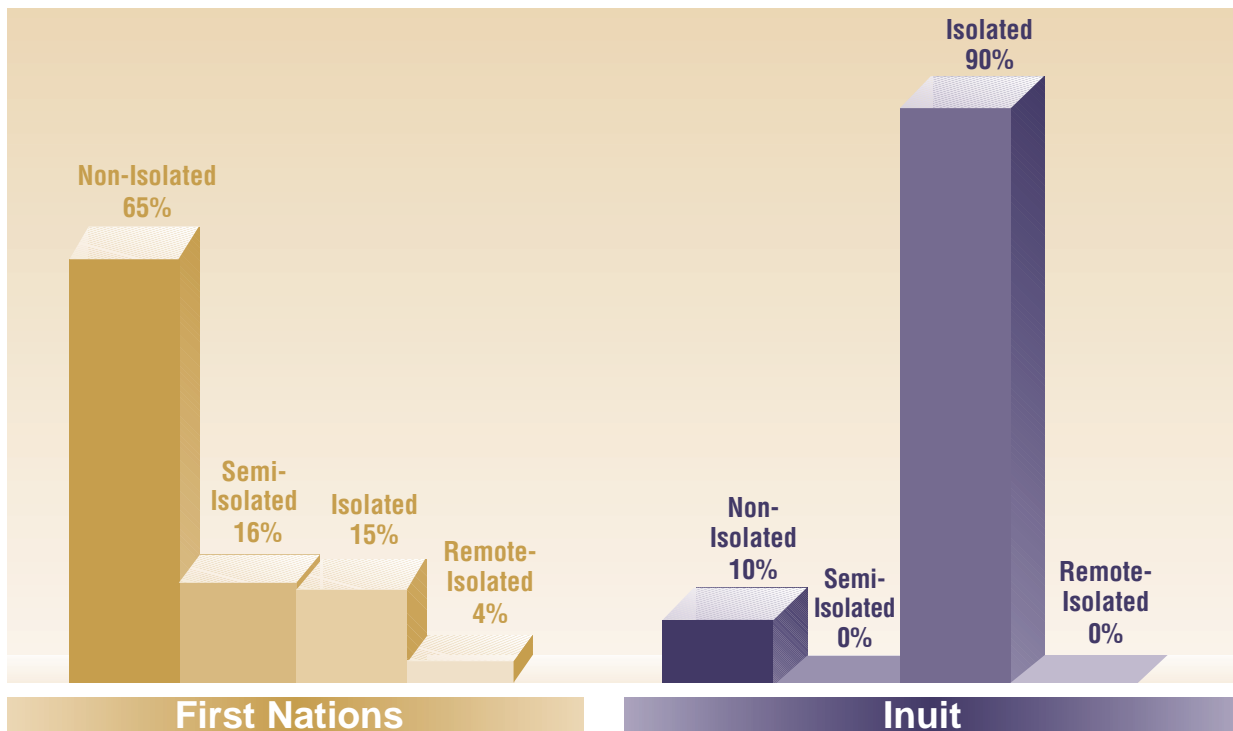
**W**e have opportunities to move forward on existing research gaps related to specific topics, such as chronic diseases and environmental contaminants.

generating new research knowledge and strengthening the links between research and policy. For instance, research on the links between social cohesion and health outcomes has significantly influenced our current policy thinking and has built support for community control of health programs.

Finally, we have opportunities to move forward on existing research gaps related to specific topics, such as chronic diseases and environmental contaminants. We may need to try different ways of conducting research, especially in very small communities where conventional approaches may not be appropriate. In the end, our policy decisions must continue to be based on the evidence provided by our research partners and made with the collaboration and participation of First Nations and Inuit individuals, communities and organizations. 🌐

@ Please note: Full references are available in the electronic version of this issue of the Bulletin: <http://www.hc-sc.gc.ca/arad-draa>

Figure 2: Degree of Isolation of First Nations and Inuit Communities<sup>2</sup>



Four types of communities have been defined to reflect varying degrees of isolation and accessibility:

- **Non-Isolated:** road access less than 90 km to physician services
- **Semi-Isolated:** road access greater than 90 km to physician services
- **Isolated:** scheduled flights, good telephone services, and no year-round road access
- **Remote-Isolated:** no scheduled flights, minimal telephone or radio services, and no road access

Data for Nunavut Territory and the Northwest Territories are not included.

# The Health Status of

# First Nations People in Canada

Adam Probert and Robert Poirier

Strategic Policy, Planning and Analysis Directorate, First Nations and Inuit Health Branch, Health Canada

**F**irst Nations people of all ages have a poorer overall health status than the rest of Canadians. Furthermore, there are major disparities in health status within the First Nations population itself related to gender, age and location of residence. High quality health data is essential to improving the health status of First Nations people.

## How do First Nations People Compare with Canadians as a Whole?

### First Nations People Living On Reserve

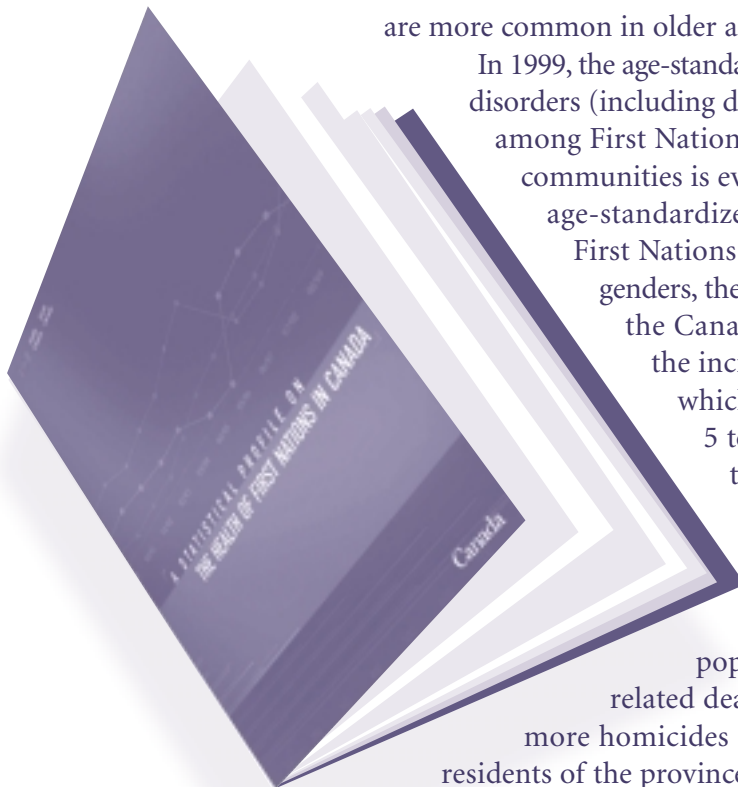
In 2000, life expectancy at birth for First Nations males and females in Canada was 68.9 years and 76.6 years, respectively, compared to 76.3 years for males and 81.8 years for females in the **Canadian population**.<sup>\*</sup> Despite these gaps, First Nations life expectancy has improved considerably since 1980, increasing by 8.0 years for males and 8.6 years for females.<sup>1</sup>

The 1999 **age-standardized** death rates for First Nations people exceeded the 1998 rates for the Canadian population for the following causes of death: endocrine and immune disorders, digestive diseases, and injuries and poisonings. After age standardizing the First Nations death rates to the 1991 Canadian population, circulatory diseases surpassed injuries as the leading cause of death. This is because the Canadian population as a whole is older than the First Nations population and circulatory diseases are more common in older age groups.

In 1999, the age-standardized death rate from endocrine and immune disorders (including deaths related to diabetes) was 1.5 times higher among First Nations. The impact of diabetes in First Nations communities is even more pronounced when considering the age-standardized **prevalence “rate”** for diabetes among First Nations people. In all age categories and for both genders, the rate is three to five times higher than that of the Canadian population.<sup>2</sup> Of particular concern is the increasing **incidence rate** of Type 2 diabetes, which is now occurring in children as young as 5 to 8 years, although it was previously limited to the adult population.<sup>3,4</sup>

The First Nations death rate for injuries and poisonings is 2.9 times higher than the Canadian rate. In British Columbia, between 1991 and 1997, the First Nations population experienced eight times more fire-related deaths, four times more drownings, five times more homicides and three times more fatal falls than all residents of the province combined.<sup>5</sup>

*\*Terms appearing in bold type are defined at the end of the article.*



In 1997, the tuberculosis rate among First Nations was eight times higher than that for the Canadian population. One reason for this is the overcrowded housing conditions in many communities that may increase the risk of exposure to infected individuals (see Figure 1).<sup>6</sup> People living in overcrowded conditions are also more likely to have other risk factors for tuberculosis, such as poverty, living in a remote area, substance abuse and various underlying medical conditions. Communities with overcrowded housing conditions, inadequate sewage disposal and lack of running water are also at increased risk for outbreaks of hepatitis A. Figure 2 shows the rates of selected infectious diseases for the First Nations and Canadian populations.<sup>7</sup> (See also article on shigellosis in *Health Policy Research Bulletin*, Issue 4, page 15.) One statistic that is not shown is the 1999 incidence rate for chlamydia, which was seven times higher in First Nations living on reserve than for all Canadians.

### Aboriginal People Living Off Reserve

The 2000-2001 Canadian Community Health Survey (CCHS), conducted by Statistics Canada, compared the self-reported health status of Aboriginal people living off reserve with that of the non-Aboriginal population living in the same urban, rural and territorial communities.<sup>9</sup> The off-reserve Aboriginal population reported lower levels of education and household income, higher rates of smoking, drinking and obesity, and lower rates of physical activity. Even when controlling for socio-economic status and health behaviours, the off-reserve Aboriginal population reported significantly higher rates for the following measures: self-rated “fair” or

“poor” health; having more than one chronic condition; and having had a major depressive episode in the previous year. The prevalence rate for diabetes in the off-reserve Aboriginal population was twice that of the non-Aboriginal population.

## How Does Health Status Vary Within the First Nations People?

### By Gender

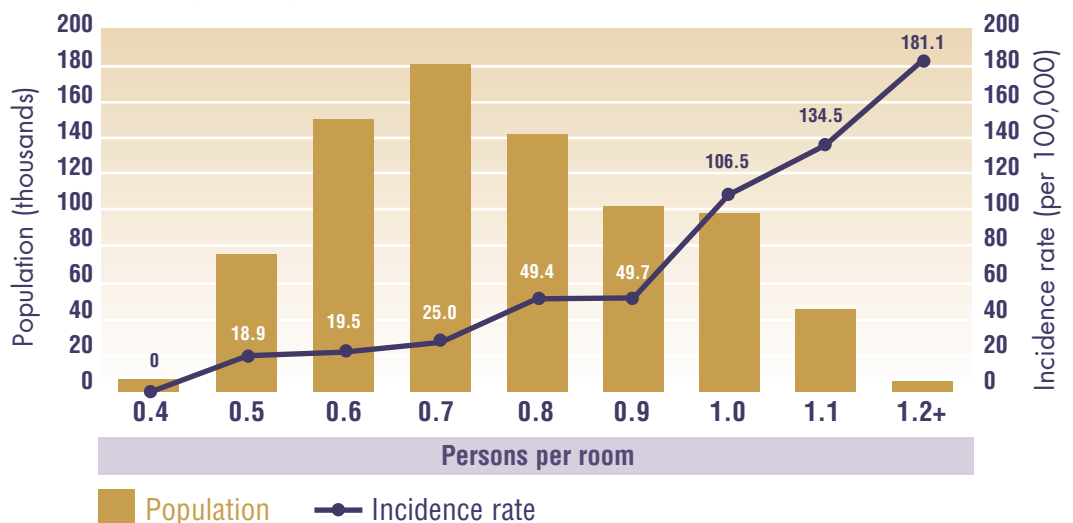
The 1999 **crude death rate** for First Nations males was 30 percent higher than for First Nations females, largely due to higher rates of intentional and unintentional injury. The leading causes of death by injury among males were suicides, motor vehicle accidents, suffocation and drowning, and homicide. Circulatory disease was the second leading cause of death.

Among First Nations females, the leading cause of death was circulatory disease, followed closely by injuries and poisoning. Together, these accounted for almost half of all female deaths. Females were more likely to die from motor vehicle accidents than suicides. As in the Canadian population, the rates of completed suicides were much higher among First Nations males than females, although females *attempted* suicide far more often than males.<sup>10</sup>

#### About the Data

Statistics quoted in this article were collected in 1999 and will soon be published in Health Canada's 2003 report *A Statistical Profile on the Health of First Nations in Canada*,<sup>8</sup> unless otherwise specified. British Columbia and Alberta only report data for Status Indians within the province as a whole (both on and off reserve). Most provinces have some degree of under-reporting for several or all indicators. Unfortunately, very little health information on Inuit is routinely collected and forwarded to Health Canada. Some jurisdictions, including Québec, the Northwest Territories and Nunavut, report health data on all residents combined. As a result, information on Inuit-specific health status is not presented here.

Figure 1: Total Population and Tuberculosis Incidence Rate by Community Housing Density, 1997-1999<sup>6</sup>





The 1999 rate of diabetes-related deaths among First Nations females was 26.8 percent higher than among First Nations males. Approximately two thirds of all First Nations people diagnosed with diabetes were female,<sup>11</sup> unlike the Canadian population, in which males were more likely to be diagnosed with diabetes than females.<sup>12</sup>

### By Age Group

Figure 3 shows the leading causes of death for the Canadian population and among First Nations living on reserve.<sup>13</sup> When the death rates were age standardized, circulatory disease was the leading cause of death, followed by cancer and injury. For all causes of death except cancer and circulatory disease, the First Nations death rate was higher than the national rate, after adjusting for differences in age.

Statistics showing potential years of life lost (PYLL) are often used to illustrate the causes of premature death. (Please refer to *Health Policy Research Bulletin*, Issue 3, page 32, for a detailed description of PYLL.)<sup>14</sup>

**F**rom ages 1 to 44, the most common causes of death among First Nations were injury and poisoning. Motor vehicle accidents were a leading cause of death in all age categories except seniors. Even a partial reduction in the injury death rates among First Nations would have a profound effect on premature death rate and on the health of that population in general.

For example, if a 20-year-old dies accidentally, she/he has lost 55 potential years of life (using a life expectancy at birth of 75 years). Injuries have a major effect on PYLL compared with other causes of death, as they occur in all age groups, while many other causes of death are associated with aging (see Figure 4).<sup>15</sup>

From ages 1 to 44, the most common causes of death among First Nations were injury and poisoning. For children, these deaths are non-intentional. However, *intentional* injury and poisoning accounted for 38 percent of deaths among youth (10 to 19 years) and 23 percent of deaths for early adults (20 to 44 years). Motor vehicle accidents were a leading cause of death in all age categories except seniors. Even a partial reduction in the injury death rates among First Nations would have a profound effect on premature death rates and on the health of that population in general.

### By Geographic Location

In a Manitoba study, the prevalence of diabetes varied among First Nations people living in different provincial regions,<sup>16</sup> with rates as high as 25 percent in some northern Tribal Councils and as low as 15 percent in the southern Tribal Councils. (A Tribal Council is a regional group of First Nations members that delivers common services to its members.) For the province as a whole, the on-reserve prevalence rate was 20.3 percent, while the off-reserve rate was 17 percent. The hospitalization rate for injury in the northern Tribal Councils was nearly twice the rate in the south,

Figure 2: Selected Infectious Diseases in the First Nations On Reserve and Canadian Populations, 1999<sup>7</sup>

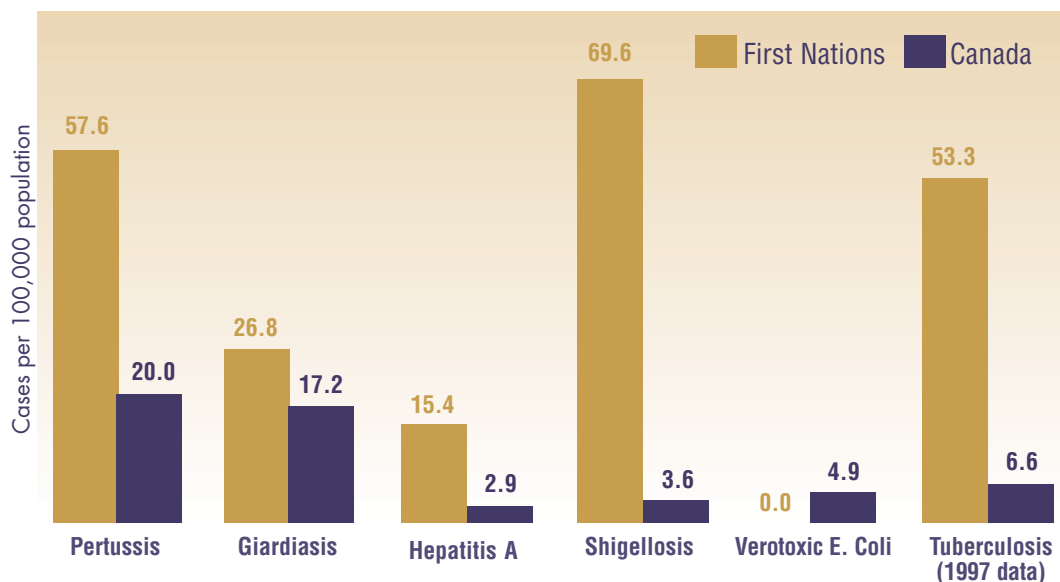
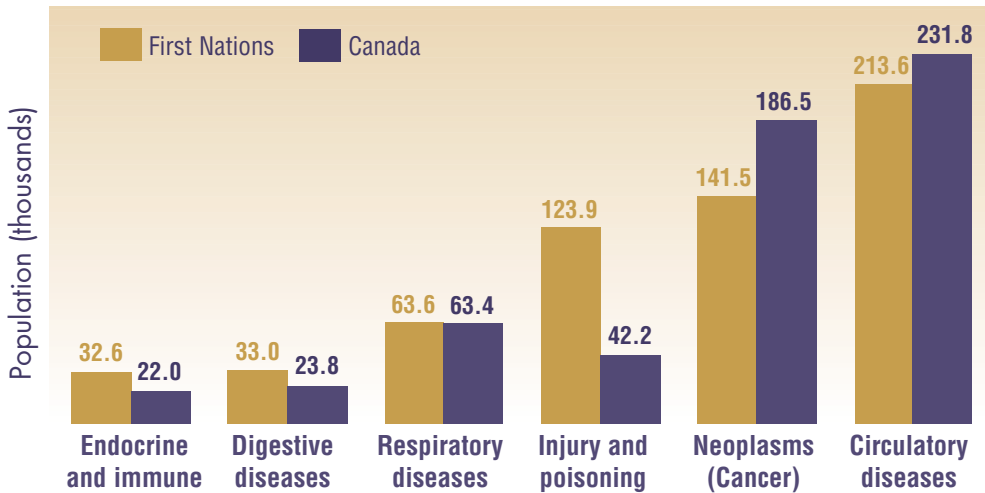


Figure 3: **Age-Standardized Leading Causes of Death in First Nations, 1999, and in Canada, 1998<sup>13</sup>**



Ranking based on mortality (deaths per 100,000 population) for First Nations in 1999.

and almost 23 percent higher for people living on reserve compared with those living off reserve. However, premature death rates and PYLL were higher and life expectancy was lower in the south, despite generally greater access to health services. This Manitoba study reinforces the importance of considering other factors, in addition to access to health services, when describing the health and well-being of First Nations people.

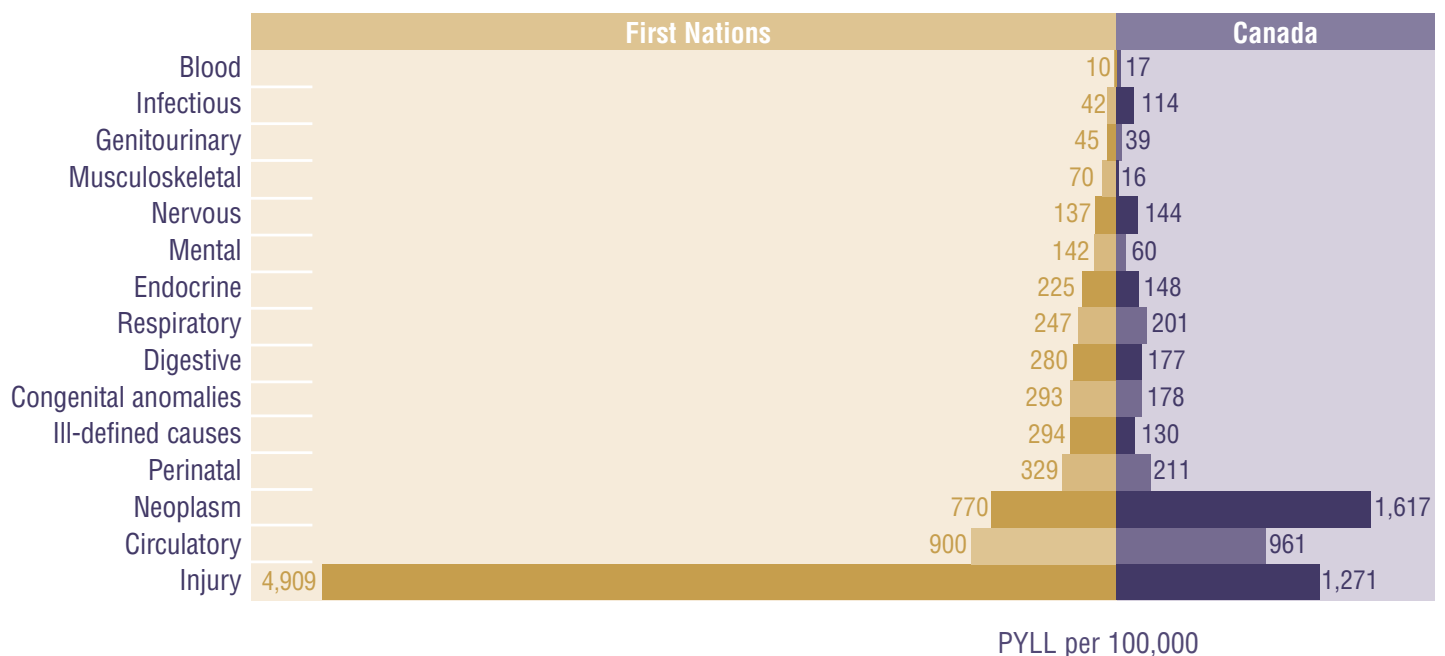
### Why Are Good Data Important?

The First Nations and Inuit Health Branch (FNIHB) of Health Canada administers one of the largest public health and primary care programs in Canada, delivering services to approximately 400,000 First Nations people in 640 communities and providing non-insured health benefits to an additional 300,000 First Nations living off reserve and Inuit. While there are significant gaps in First Nations and Inuit health data that need to be addressed, the existing

information on the health status of First Nations helps FNIHB carry out its mandate.

There are many difficulties in collecting health information specific to First Nations people. Some of these difficulties are discussed in more detail in the article entitled “Linking Health Records” (see page 30). However, it is clear that accurate and timely health-related data are essential to understanding the health status of First Nations. Health Canada uses the data

Figure 4: **Potential Years of Life Lost (PYLL) by Cause, First Nations and Canada, 1999<sup>15</sup>**



it collects to assess current national and regional health information needs regarding First Nations living on reserve. The department also obtains appropriate data from existing **surveillance** systems across Canada to compare health outcomes among selected populations and to identify emerging priorities. These types of information are also useful to health professionals, researchers, community leaders and policy makers for community and regional health systems planning.

*The authors gratefully acknowledge the assistance of the following members of the regional FNIHB offices, particularly in the collection and analysis of health data used in this article: John David Martin (Pacific Region), Marion Perrin (Alberta Region), Lynda Kushnir-Pekrul (Saskatchewan Region), Suzanne Martel (Manitoba Region), Nicolette Kaszor (Ontario Region), Marino Argentin (Québec Region) and Susan Ross (Atlantic Region).*

## Glossary

### Age Standardization

A statistical procedure for adjusting rates (e.g., death rates) that is designed to minimize the effects of differences in age composition when comparing rates for different populations.<sup>17</sup> For example, the First Nations population is a much younger population than the population of Canada as a whole. For this article, the 1991 Canadian population was used to standardize the ages of the two populations.

### Canadian Population

The total population of Canada (or the specific age/sex group referred to), including the First Nations component of that population.

### Crude Death Rate

An estimate of the portion of a population that dies during a specified period. The numerator is the number of persons dying during the

**A**ccurate and timely health-related data are essential to understanding the health status of First Nations. Health Canada uses the data it collects to assess current national and regional health information needs regarding First Nations living on reserve. The department also obtains appropriate data from existing surveillance systems across Canada to compare health outcomes among selected populations and to identify emerging priorities.



period, while the denominator is the size of the population, usually estimated as the mid-year population.<sup>17</sup> It is not age-standardized and is often expressed as a rate per 100,000 persons per year.

### Incidence Rate

The rate at which *new* events (e.g., diagnoses of a disease, suicides) occur in a population during a defined period.<sup>17</sup> It is often expressed as a rate per 100,000 persons per year. For example, 61.5 persons per 100,000 First Nations persons were diagnosed with tuberculosis during 1999.

### Prevalence “Rate”

The proportion of a population at risk of having a disease or attribute at a particular time (or during a particular period) that actually has the disease or attribute at that time (or mid-way through the period).<sup>17</sup> It is often expressed as a rate per 100,000 persons. For example, a cross-sectional health survey can determine the number of people per 100,000 persons who currently have diabetes. (See also *Health Policy Research Bulletin*, Issue 1, page 18.)

### Surveillance

Surveillance includes the ongoing collection of data, and the review, analysis and dissemination of

findings on disease incidence and prevalence, hospitalizations and deaths. Surveillance can also collect information concerning the knowledge, attitudes and behaviours of the public with respect to practices that prevent cancer, facilitate screening, extend survival and improve quality of life. (See also *Health Policy Research Bulletin*, Issue 4, page 25.)

@ Please note: Full references are available in the electronic version of this issue of the Bulletin: <http://www.hc-sc.gc.ca/arad-draa>

# *Evolving Control of*

## **Community Health Programs**

**Mark Wigmore**, *Intergovernmental Affairs Directorate, Health Policy and Communications Branch, Health Canada, formerly with Strategic Policy, Planning and Analysis Directorate, First Nations and Inuit Health Branch, Health Canada, and Keith Conn*, *Community Programs Directorate, First Nations and Inuit Health Branch, Health Canada*

**O**ver the past 10 years, Health Canada, through its First Nations and Inuit Health Branch (FNIHB), has forged new relationships with First Nations and Inuit communities. Aimed at improving their health status, many of these agreements have encouraged communities to take control of their health programs in order to better address local needs.

In the past decade, the role of FNIHB has evolved from service delivery to providing funding, health expertise, policy and program frameworks and other support to assist communities as they take over increasing responsibility for health care delivery with the aim of achieving better health outcomes.

### **How Did the Transfer of Services Come About?**

Until the 1970s, federal employees delivered public health and prevention services to all First Nations and Inuit communities, as well as front-line primary care services to remote and isolated communities.

The trend towards increased involvement of First Nations and Inuit communities in the delivery of health services began with the 1979 *Federal Indian Health Policy*. Aimed at helping Indian communities generate and maintain improvements in their health status, the policy was based on three pillars:

- community socioeconomic, cultural and spiritual development
- the traditional relationship of the Indian people to the federal government (a relationship to be strengthened by encouraging greater involvement in the planning, budgeting and delivery of health services)
- the Canadian health system (which consists of many inter-related elements that are the responsibility of the federal, provincial or municipal governments, Indian bands or the private sector)

Approximately 10 years after the *Indian Health Policy*, the federal government approved a health Transfer policy framework giving control of resources for community-based health programs to communities south of the 60th parallel wishing to assume this responsibility. At the same time, work continued to help the

territorial governments north of the 60th parallel to assume responsibility for health care delivery.

The decision to transfer these responsibilities to First Nations and Inuit communities was the culmination of many years of discussions between the federal government and the communities, discussions that are ongoing today. Currently, more than 80 percent of the funds for federal community health programs are channeled through agreements with First Nations and Inuit organizations. Direct management of these programs and services by the federal government is becoming increasingly rare. First Nations communities now employ the majority of their community health nurses, as well as most of their addiction counselors and community health workers. Furthermore, community-based

**“N**otwithstanding that medical services are now delivered to Aboriginal people even in the remotest parts of the country . . . the gap in the health and well-being between Aboriginal and non-Aboriginal people remains stubbornly wide.”

*Royal Commission on Aboriginal Peoples  
Final Report, 1996, Vol. 3*

health directors manage health programs in the majority of First Nations communities. (In addition, the federal government continues to be responsible for the Non-Insured Health Benefits program, while the provinces and territories continue to provide hospital and physician care.)

### How Has Health Status Been Affected?

Part of the rationale for increasing community responsibility for health delivery is that First Nations and Inuit organizations are the best placed to understand their communities’ needs and to manage and deliver health services. The empirical evidence to date on the impact of local control on health status is encouraging. A long-term evaluation conducted by Health Canada in June 1994

## A Historical Perspective: Transfer of Control Over Community Health Programs

1969	1970	1975	1979	1983-1986	1988
<i>Federal White Paper on Indian Policy</i> calls for an end to federal responsibility for First Nations and the termination of their special status	<i>First Nations Red Paper</i> (First Nations response to White Paper) calls for keeping their special status but with more community control of programs and services	<i>The Canadian Government/The Canadian Indian Relationships Paper</i> (policy framework for strengthening Indian control)	<i>Federal Indian Health Policy</i> (aimed at helping Indian communities generate and maintain improvements in their health status) recognizes that Indian people may assume responsibility for administering any or all aspects of their community health programs	Health Canada sponsors a number of community health demonstration projects to provide both federal and First Nations authorities with substantive information with respect to First Nation control of health services	Final Transfer Agreement devolves responsibility for Universal Health Programs to the Government of the Northwest Territories (NWT), while assuring that First Nations and Inuit in the NWT would continue to have access to any new federal programs for First Nations and Inuit

found that transferring management control had resulted in an increased awareness of health issues among community members and more culturally sensitive health care delivery. As well, health care had become a higher priority for the communities.<sup>1</sup>

A British Columbia study provided further evidence of a positive impact.<sup>2</sup> Communities in British Columbia that were self-governing and/or had control over their health, education and other services, experienced a much lower incidence of suicide than did other communities without such control.

While more policy research on the impact of local control of health services on health status is needed, it is important to recognize that many of the factors associated with poor health status lie outside of health service

**“The government will take further action to close the gap in health status between Aboriginal and non-Aboriginal Canadians by putting in place a First Nations Health Promotion and Disease Prevention strategy with a targeted immunization program, and by working with its partners to improve health care delivery on-reserve.”**

*Speech from the Throne, September 30, 2002*

delivery. Both the health determinants (population health) views expressed by governments and the holistic view of health held by many First Nations and Inuit recognize that improvements in areas such as water quality and quantity, education, employment and housing will also contribute to better health. It is certain that the engagement of First Nations and Inuit people in developing their own solutions — whether in health care or in other determinants of health — will continue to be an integral part of the strategy identified by the Royal Commission on Aboriginal Peoples and committed to by the federal government. 🌐

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## to First Nations and Inuit Communities

**1988-1989**

Cabinet and Treasury Board approve health Transfer south of the 60th parallel (the policy framework, financial authorities and resources for transferring control of community-based health programs south of the 60th parallel to Indian communities)

**July 1989**

First Tribal Council signs a health services Transfer Agreement

**1994**

Treasury Board approves the financial authorities and resources to support the Integrated Community-Based Health Services approach (an alternative for bands that are not ready for or interested in Transfer)

**1995**

*Inherent Right to Self-Government Policy* recognizes that the inherent right to self-government is an existing Aboriginal right under section 35 of the Constitution

**1997**

Yukon Territory resumes administration and delivery of Universal Health Programs in Yukon Territory, with assurance that Yukon First Nations would continue to have access to any new federal programs for First Nations and Inuit

**April 1999**

Nunavut Territory is created with the conditions of the 1988 Northwest Territories Final Transfer Agreement applying to the Government of Nunavut

# The Eskasoni Primary Care Project

Nicki Sims-Jones

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**T**he Eskasoni Primary Care Project embraced a multisectoral, multi-disciplinary model of primary health care in a First Nations community, which includes salaried family physicians and nursing, health education, nutrition and pharmacy services. This case study is based largely on an evaluation report authored by Mary-Jane Hampton for Health Canada in 2001.<sup>1</sup>

## An Opportunity for Change

It has been suggested that if improvements are to be made in primary health care, they are unlikely to be as a result of a “big bang” reform effort. Rather, they will come about as policy makers identify “opportunities for progressive incremental change.”<sup>2</sup> One such opportunity for change occurred in Eskasoni, where a Primary Care Project (PCP) was implemented in 1999 as a result of multisectoral collaboration.

Eskasoni, a First Nations community of 3,200 people, is located in Cape Breton, Nova Scotia. Eskasoni has a young population with few elderly people; in fact, nearly half (48 percent) of its residents are under 20 years of age. Children are encouraged to speak Mi’kmaq and are taught about their culture at home and in school.

The community has been challenged by particularly high rates of death and illness associated with substance abuse and chronic diseases such as diabetes, heart disease and respiratory illnesses. There is a high rate of addiction, mostly to prescription drugs. Sixty percent of adults report smoking, almost twice the rate for the province as a whole (33 percent). Forty percent of Eskasoni residents have diabetes.<sup>1</sup>

## History of Health Services

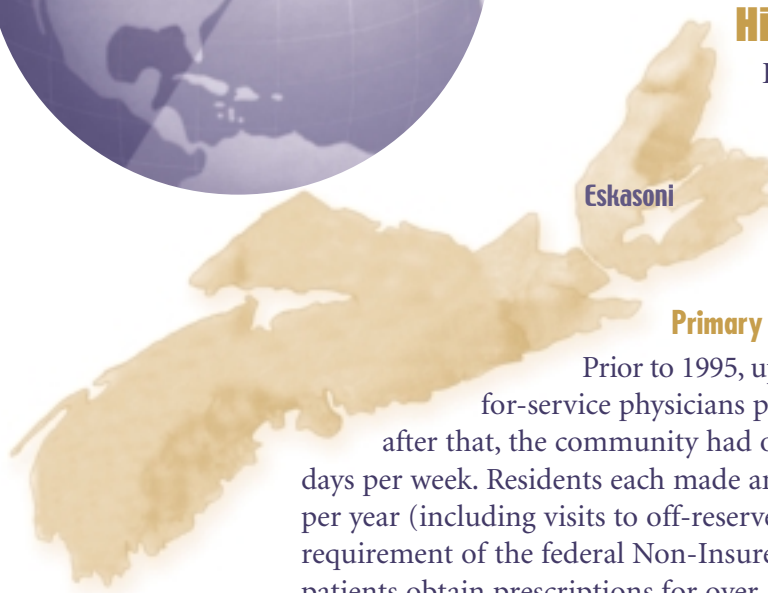
Eskasoni has managed its own community-based health services since 1997. The main referral centre for the community is in Sydney, approximately 40 minutes away.

## Primary Care

Prior to 1995, up to four provincially-funded, fee-for-service physicians provided primary care in Eskasoni; after that, the community had only one physician working three days per week. Residents each made an average of 11 physician visits per year (including visits to off-reserve physicians), in part because of a requirement of the federal Non-Insured Health Benefits program that patients obtain prescriptions for over-the-counter medications.



Eskasoni



Indications are that pregnant women received little or no prenatal care until the time of their delivery.

### Community Health Programs and Services

Before the PCP was implemented, Health Canada's Community Health Programs provided Eskasoni residents with a range of community-based services, including community health nursing, nutrition education during pregnancy, communicable disease control and an immunization program. Housed in the band office, these programs operated independently, with no coordination either among themselves or with community physicians. Although Community Health Representatives were hired to act as a liaison between community members and health care providers, there was little communication between the two groups.

### The Change Agents

Two key factors prompted the changes in Eskasoni's primary health care system. One was the collaborative effort among three levels of government and Dalhousie University to improve the community's health services. On the government side, Health Canada's First Nations and Inuit Health Branch (FNIHB) provided technical support and financial resources for the project, while Nova Scotia's Department of Health contracted physi-

cian services for the community. The Eskasoni Band Council — which was developing its administrative capacity as a result of the management Transfer program begun in 1997 — supported the new model of primary care, and was involved in planning and managing the project. The Dalhousie University Department of Family Medicine recruited salaried physicians to replace the retiring fee-for-service physician and established Eskasoni as a teaching practice site and as the only community-based telemedicine site in the province.

The other factor that made the project possible was the funding received through Health Canada's Health Transition Fund (HTF). Established in 1997 to support innovation and improvement in crucial areas of the health system, the HTF supported transitional costs for the project and acted as a catalyst to bring the partners together.<sup>3</sup>

### Preliminary Impacts

An evaluation of the PCP was conducted 18 months after the project began. Although the results are very preliminary and the timing did not permit an evaluation of changes in health outcomes, there were some encouraging immediate and intermediate outcomes, including: ▶

## The Eskasoni Model

The Eskasoni model of primary care includes the following four key elements:

- The process of transferring responsibility for the administration of community-based health care to the Eskasoni Band Council continued over the life of the project (and continues today). Efforts were made to integrate key elements of services provided by the primary care team and community health practitioners including, for example, patient records.
- The model for physician services was changed from “fee-for-service” to a multidisciplinary team approach in which team members, including physicians, were paid a salary. Salaried physicians are particularly important for effective primary care in a community with a high prevalence of

chronic disease, since they are able to spend more time focusing on preventive care, patient assessment, and interdisciplinary case management of clients with complex medical needs.<sup>2</sup>

- A new health care complex was constructed using federal and provincial funding. Since both levels of government wished to ensure that their respective shares of the construction costs provided facilities for their staff and programs, two separate buildings were constructed side by side with a connecting door.
- In order to facilitate referrals to physician and other services (diagnostic, etc.) outside the community, partnerships were established with regional health centres.



- **More appropriate use of physician services and hospital-based services.** For example, the average number of physician visits per resident decreased from 11 to 4 a year, while the number of visits to the regional hospital's emergency department declined by 40 percent. In part, these declines were a result of the community's increased access to a multidisciplinary health care team (i.e., five days a week rather than three).
- **High level of community satisfaction.** Eighty-nine percent of residents thought that the quality of health services in Eskasoni had improved compared to five years previously.
- **Increased interdisciplinary referrals and a greater range of primary care services.** For example, there were eight times as many referrals from local family doctors to the nutritionist/health educator for diabetes management. Access to specialist medical care also increased, through visiting physicians and by accessing telemedicine.
- **Changes in prescribing patterns.** There were fewer prescriptions for antibiotics, antihistamines and cough preparations, resulting in lower prescription costs overall to the community and to the Non-Insured Health Benefits program.
- **Improved prenatal care.** Almost all (96 percent) of expectant women received appropriate care from physicians and other members of the multidisciplinary team throughout their pregnancy and delivery, and into the postpartum period.
- **Integration between primary care and community health staff.** Early indications were that federally- and provincially-funded staff continued to work in isolation, although steps had been taken to consolidate each patient's records. However, more recent information indicates that staff are now working together more closely.<sup>4</sup> For example, women are now regularly referred to the federally-funded community-based services for prenatal information. As a result of this and the improved prenatal care described above, hospitals now consider most of the community's pregnant women to be at low risk because they are adequately prepared for labour and delivery.

**The Eskasoni project is an excellent example of the kind of incremental change that has been proposed to reform the primary health care system.**

## What Have We Learned?

The Eskasoni experience has provided numerous opportunities for learning about how to enhance the effectiveness of health care services in First Nations communities.

### Primary Health Care Team

Fewer physician visits, an increase in nutritionist referrals and improvements in prenatal care are early indications of the benefits of a multidisciplinary primary health care team.

### Provincial Health Care Savings

Provincial costs decreased significantly when physician and emergency room costs were reduced. However, budgeting practices precluded these savings from being used to support non-physician members of the multidisciplinary team. Restrictions on transferring funds from the fee-for-service system to support alternate primary care models may hinder the widespread adoption of such models in the future.

### Multisectoral Collaboration

One of the themes of federal health policy that has received increasing attention over the past 25 years is "*the call for cross-sector collaboration* in developing policy that affects health."<sup>5</sup> The willingness of the three levels of government and Eskasoni residents to work together was essential to the project's success. As a result of Dalhousie University's involvement, the project was able to recruit physicians who were open to alternate methods of payment.

## A Model for the Future?

Although the Primary Care Project no longer receives HTF funding, it is being sustained through funding by the provinces and Health Canada's Community Programs.

The Eskasoni project is an excellent example of the kind of incremental change that has been proposed to reform the primary health care system.<sup>2</sup> If the Eskasoni project is any indication, it may be that significant health care reform in Canada will be achieved community by community, as opportunities for progressive change present themselves. 🌐

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# Participatory Evaluation of Aboriginal Head Start

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**A** boriginal Head Start (AHS) in Urban and Northern Communities is a collaborative effort of the Population and Public Health Branch of Health Canada and community-based Aboriginal groups in urban and northern communities. The primary goal of the program is to demonstrate that locally controlled and designed early intervention strategies can provide Aboriginal children with a positive sense of themselves, a desire for lifelong learning and opportunities to develop fully as successful young people.<sup>1</sup> Through this program, Health Canada also seeks to improve health status by enhancing access to education and other community resources. Participatory evaluations at the national level are essential to achieving all of these goals.

## Background

AHS is an early childhood development program for First Nations, Inuit and Métis children aged 6 and under and their families living off reserve. Since the AHS program began in 1996, the number of project sites has grown to 114, with more than 3,500 children enrolled at urban and northern sites in eight provinces and three territories. AHS urban and northern sites accept all First Nations, Inuit and Métis children and their families they are able to accommodate.

## Program Components

The program typically provides half-day preschool experiences that prepare young Aboriginal children for their school years by supporting their spiritual, intellectual, physical and emotional growth. Each project reflects the local culture and language while focusing on six program components: health promotion; nutrition; education and school readiness; culture and language; parental involvement; and social support. These components have the potential for benefitting Aboriginal children in a number of ways, including socially and educationally. In addition, because of the role that factors such as nutrition and educational attainment play as determinants of health, it is hoped that health status will also be improved. (See box outlining the determinants of health on page 21.)

There is strong evidence that the development of healthy behaviours in early childhood has a positive impact on health outcomes that extends into later stages of life.<sup>2</sup> These healthy behaviours may help prevent the onset of diseases such as Type 2, or adult-onset, diabetes. In recent years, the incidence of Type 2 diabetes has been increasing even among Aboriginal children, with cases diagnosed in children as young as 5 to 8 years of age (see article on page 6). Primary prevention efforts for the disease focus on improving diet and physical activity levels, both of which are components of the AHS program. ►



As a community-based program, AHS is respectful and inclusive of the different needs of individual communities. In fact, since one of the program's goals is to demonstrate the effectiveness of locally controlled and designed early intervention strategies, each AHS project is run by local Aboriginal non-profit organizations. Although project programming must incorporate the six component areas, specific content is determined by the sponsoring organizations. Parents and guardians are also encouraged to play a key role in developing the program.

## Participatory Evaluation

National evaluations are an important way to demonstrate the effectiveness of AHS programs and improve their implementation. For programs such as AHS, in which each community controls program development, the participation of sponsoring communities in all stages of the evaluation process is vital to improving program effectiveness. This in turn will lead to better outcomes, including improved health status.

The AHS program is undergoing two types of evaluation. The National Process and Administrative Surveys collect information on activities and participation in the program, while the National Impact Evaluation focuses on how AHS has affected children, their parents and communities. Health Canada provides training to local sites to participate in these evaluations and collaborates with the sponsoring communities throughout the evaluation process.

While the results from the initial administrative surveys have been published on an ongoing basis,<sup>3-5</sup> evaluation work continues. The first National Impact Evaluation began in the winter of 2002 with a pilot test of evaluation tools at a number of sites across Canada. All of the groups with an interest in the program — including parents, sponsors and site teams — are helping to design evaluation tools and indicators, as well as a process for the response phase of the evaluation. Because the program is relatively new and requires a longer timeline to accurately

measure its impacts, a full assessment must be staged over a number of years.

While the long-term benefits of early childhood education can be understood on theoretical and intuitive levels, evaluating the impact of programs like AHS is sometimes challenging. Unlike programs such as prenatal nutrition, which can be evaluated using standard indicators of child health such as birthweight, programs such as AHS require more elaborate and culturally sensitive tools and methods of measuring program effectiveness. Furthermore, evaluation tools must accommodate the diversity among AHS communities and in the goals they set for their programs.

Despite these challenges, the findings from the 1999 and 2000 Process and Administrative Evaluations suggest that program activities in such areas as health promotion and nutrition are having positive benefits (see box on page 19).

### The Benefits of Participatory Evaluation

Community participation has been a strong focus during all stages of the AHS program, including the national evaluations. Community involvement has resulted in scientifically sound and culturally appropriate evaluations that take into account all aspects of the program and incorporate a holistic view of child development. Training for AHS staff and participating families has enhanced the quality of these evaluations and, as a result, will improve both programs and health outcomes for AHS communities. At the same time, communities will benefit from greater capacity in these skill areas.<sup>6</sup>

Another benefit of the participatory approach to evaluating AHS programs has been the development of a mechanism for ensuring that measurements and indicators are inclusive and respectful of diverse community needs. Participants have suggested culturally based indicators such as: “parents taking a strong stand for Aboriginal language retention” and “supportive and cohesive communities.”<sup>7</sup> Now the challenge is to measure such concepts with precision in order to provide relevant information to the communities.



## Findings from the Process and Administrative Evaluations

“Changes in attitude, behaviour and physical appearance are documented in the child’s or family’s files or daily journals . . . children integrate the routine of washing hands and brushing teeth without prompting, their physical activity increases, they make better food choices and avoid using other children’s hats and clothing.”<sup>8</sup>

“Staff note that parents appear more knowledgeable about what constitutes a healthy diet and that participation in the collective kitchen program has increased. . . . The children also volunteer information about what they are eating at home

**T**he overwhelming majority of sites (90 percent) reported using an Aboriginal language in class on a daily basis.<sup>11</sup>

or speak positively about the new foods that they are enjoying.”<sup>9</sup>

“Twenty-three sites reported that they now engage in menu planning or have made significant improvements in their menus. A further 11 sites reported the addition of potluck dinners and collective kitchens, while some managed to offer workshops or increase parental involvement in [the nutritional] component. Two sites reported changes via increased partnerships, increased resources/staff, and changes to curriculum to include nutrition. One site reported adding a food bingo.”<sup>10</sup>

AHS has also contributed to community capacity in the area of cross-sectoral integration. As part of a federal initiative operating under provincial and territorial jurisdictions of health and education, AHS projects collaborate with other programs and services in the community. This has helped to ensure that participants are aware of the range of services available to them — for instance, a small number of AHS sites are co-located with licensed daycare facilities. This range of services also works to meet the AHS objective to provide a base of social support, which is an important determinant of health.

### Conclusion

Overall, the evaluation process has received enthusiastic support from participating sites, staff and community members. For example, in the fall of 2002 there were more sites wishing to participate in the pilot evaluations than could be accommodated. Furthermore, as a result of the success of AHS and the enthusiasm it has generated, a similar initiative is now offered to First Nations children aged 6 and under living on reserve. Created in 1998, the AHS On Reserve Initiative is administered by the First Nations and Inuit Health Branch of Health Canada and encourages the development of locally controlled projects in First Nations

communities. This initiative has approximately 305 projects designed and controlled by First Nations communities which serve about 7,700 First Nations children.<sup>12</sup> Early indications suggest that community participation is also essential for AHS On Reserve and that the initiative has resulted in more comprehensive and integrated programming for the children it serves.

Evaluators of AHS in Urban and Northern Communities are calling for the broader development of this type of participatory evaluation, which has demonstrated that it can meet the needs of participants, federal funders, academics and researchers, as well as accommodate Aboriginal ways of life.<sup>6</sup> While the long-term health benefits of the AHS program have not yet been demonstrated, findings like those outlined in the box above are early indications of intermediate benefits for Aboriginal children. It is anticipated that the intermediate improvements in health and nutrition behaviours will result in better long-term health outcomes. In the meantime, community members clearly have an important role to play in determining their needs, assessing the program’s effectiveness in meeting those needs and making appropriate adjustments. 🌟

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# The Importance of Culture

## to Aboriginal Health and Health Care

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**M**any First Nations people share a holistic view of health that, in some communities, is embodied in the concept of the medicine wheel. The foundation for the medicine wheel is the belief that good health is a balance between body, mind, emotions and spirit. All of these components are intertwined — an imbalance or problem with one component can affect the others. The Inuit philosophy of health is also based on the balance between mind, body and spirit. When one component is affected, the approach suggests that interventions should be directed to that particular component.<sup>1</sup> There is mounting evidence that culturally relevant health care programming can have a positive effect on the health of Aboriginal people.

### Culture as a Determinant of Health

The 1974 Lalonde Report<sup>2</sup> provided the first formal recognition that the health of Canadians is not determined solely by the health services they receive, but that genetic, environmental and non-biological factors also contribute to health. In response to mounting evidence supporting the importance of factors traditionally seen as outside the health agenda, Health Canada adopted a new population health model in the mid-1990s. This model is based on 12 determinants of health, including culture, which research has shown to influence health status. (See box on page 21 for a list of the determinants of health.)

The concept of population health proposes that the 12 individual determinants of health do not act only in isolation. Rather, the complex interaction among the determinants also affects health. As one of the determinants of health, culture is particularly important in shaping the way people interact with the health care system, including their participation in prevention and health promotion programs, access to health information, health-related lifestyle choices, understanding of health and illness, and priorities in the areas of health and fitness.<sup>3</sup>

### How Important is Culture?

Over the last 20 years, a number of studies have demonstrated the importance of culture to the health and health care of Aboriginal people. Morse et al.<sup>4</sup> concluded that Aboriginal people in Canada are frequently dissatisfied with the contemporary biomedical system, given its superficial acknowledgement of holism and the expectation that individuals will play a



passive rather than participatory role in their own health care.

The limited understanding of Aboriginal cultures by some biomedical health care professionals can result in health conditions going unrecognized, or errors occurring in diagnosis and treatment.<sup>6</sup> One study noted that psychiatrists often describe Aboriginal children as “passive, difficult to assess and not forthcoming.” The study suggested that psychiatrists may sometimes diagnose a psychopathology rather than considering the behaviour as a possible reflection of an Aboriginal culture.<sup>7</sup>

Another study, based on a comparative analysis of Aboriginal and non-Aboriginal hospital psychiatric admissions in northwestern Ontario, suggested that some Aboriginal people admitted for substance abuse may also have undiagnosed depression.<sup>8</sup>

Traditional Aboriginal medicine has been shown to be effective in treating many mental and physical health conditions. For example, the use of traditional medicine in substance abuse programs has been shown to increase levels of sobriety, employment, education and income levels.<sup>9</sup> Likewise, traditional sweat lodges have “achieved remarkable results” in treating depression and preventing suicide.<sup>10</sup> A study conducted at the University of Alberta demonstrated that traditional Aboriginal methods were just as effective in treating psoriasis as biomedical methods, if not more effective.<sup>11</sup>

## Aboriginal People Speak Out

As the following examples illustrate, culturally appropriate health services are strongly supported by Aboriginal communities and organizations:

- In the First Nations and Inuit 1997 Regional Survey, two thirds of respondents believed that First Nations and Inuit spirituality, ceremonies and traditional health practices were gaining importance in their communities.<sup>12</sup>
- At the 1996 Royal Commission on Aboriginal Peoples (RCAP), witnesses called for the “protection and extension of the role of traditional healing,

## What Determines Health?<sup>5</sup>

- income and social status
- social support networks
- education
- employment/working conditions
- social environments
- physical environments
- personal health practices and coping skills
- healthy child development
- biology and genetic endowment
- health services
- gender
- culture

traditional values and traditional practices in contemporary health and social services,” and stated that “the integration of traditional healing practices and spirituality into medical and social services is the missing ingredient needed to make those services work for Aboriginal people.”<sup>13</sup>

- The 2002 Aboriginal Forum, co-hosted by the Romanow Commission and the National Aboriginal Health Organization, recommended that the design of health policies

be specific to each cultural group and encouraged increased recognition and use of traditional practices.<sup>14</sup>

## Integrating Traditional and Biomedical Approaches

According to RCAP, Aboriginal healers view themselves as specialists in the health care field who work in collaboration with the biomedical system by making referrals and cooperating in client treatment. The literature supports this model as the most likely to produce a successful health system.<sup>15-17</sup>

To date, integration of traditional and biomedical approaches to delivering health programs and services has occurred in a few areas within the federal, provincial and territorial health care systems. Health Canada’s Non-Insured Health Benefits program provides transportation, meals and accommodation to eligible clients while in transit to a traditional healer. Furthermore, its Aboriginal Diabetes Initiative supports communities in incorporating traditional beliefs and practices into the delivery of programs and services, and ensures that Aboriginal people are involved at all stages of program development, implementation and delivery.

In 1991, the Ontario Ministry of Health approved policy guidelines addressing cultural diversity in health programs and services.<sup>18</sup> Ontario Aboriginal healers and midwives practising on reserve are exempt from the regulations for health professions. Similarly, the Yukon Transfer Agreement provides for the delivery of a traditional medicine and diet program at the Whitehorse General Hospital. ►

In addition to such government policies supporting integration, communities have also taken steps to integrate traditional and biomedical approaches. Two excellent examples of successful collaborative approaches to integration are the Inuit Midwifery program in Puvirnituk and the Kahnawake Schools Diabetes Prevention Project.

### Inuit Midwifery Program

In the 1970s, federal government practice was that all pregnant First Nations and Inuit women gave birth in hospitals. This left few opportunities for traditional Inuit midwives to practice and teach their skills, and resulted in pregnant women spending long periods of time away from home. Responding to these issues, the Inuit women of Puvirnituk in Northern Québec collaborated with health care providers to open the Inuulitsivik Maternity Centre in 1986. The Maternity Centre serves as an excellent example of how traditional Inuit approaches to health can be successfully integrated into the mainstream medical system.

As a result of the success of this project, other Inuit communities have opened their own birthing centres or are in the planning stages.

### Kahnawake Schools Diabetes Prevention Project

In 1994, concerns about increases in children's obesity, combined with the Mohawk tradition of caring for future generations, prompted government sponsors, researchers and the Kahnawake community to collaborate on the development of a Type 2 diabetes prevention program. The project, which is aimed at increasing physical activity and encouraging healthy eating habits, successfully integrates a culturally appropriate learning style with a health promotion planning model.<sup>19</sup>

The preliminary phase of the program, which was funded by Health Canada's former National Health Research and Development Program (NHRDP), was not long enough to yield evidence of a decrease in the incidence of Type 2 diabetes. Health Canada's Aboriginal Diabetes Initiative is currently working with a number of private foundations to provide funding support for the initiative and to conduct a longer term evaluation of the program and its health outcomes.

## Meeting the Challenges


One reason that many traditional healers are opposed to formal regulation of their healing practices and services<sup>13</sup> is that they believe it would reduce the legitimacy of both their system and the traditional practitioner's role as a healer. Moreover, the implication is that the medical value of a traditional system can somehow be separated from its cultural value.

Some researchers have advocated that traditional healers should validate the efficacy of their interventions against biomedical standards.<sup>20</sup> This view is not shared by some traditional practitioners, whose evidence of efficacy derives from hundreds or even thousands of years of experience that has been passed down through the generations.

## What is Health Canada Doing?

One of the department's activities focuses on natural health products. In April 2002, the Natural Health Products Directorate (NHPD) sponsored an

Aboriginal Roundtable to discuss the regulation of natural health products, including traditional Aboriginal medicines. In line with one of the recommendations of the Parliamentary Standing Committee on Health,<sup>21</sup> health care practitioners (for example, Aboriginal healers, pharmacists, traditional Chinese medicine practitioners, etc.) who compound products at the request of a patient are excluded from the proposed Regulations as they do not meet the NHPD definition of "manufacturer." The Directorate is also developing guidelines on standards of evidence for safety and efficacy that are more specific to natural health products.

The level of required data will vary depending on the type of health claim and other factors, but will include traditional references and history of use, expert committees and opinions, and randomized controlled trials, where appropriate.<sup>22</sup> 

**“In the beginning, our women used to ask their questions to the qalunaats (white people), not to us. Now women ask us the questions, and they trust us. It means our self-esteem, not only personal, but as a community, is coming back. We are trusting our own people again. We are providing great care to our women and their families, in our own cultural way, and within a provincial health care system . . . ”**

*Inuit midwives*



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# Aboriginal Women and Healthy Communities

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**A** boriginal women play a myriad of roles in their communities — from mothers and caregivers to health care professionals and health researchers. Through participation in, and collaboration with, various sectors, they are having an influence in the delivery of health services and the setting of priorities for research, policies and programs. While the assessment of the longer term health outcomes of many of these initiatives is years away, it is clear that the contribution of Aboriginal women to the health of their communities is increasingly being acknowledged as vital.

## A Diversity of Roles

Through their work in health care delivery and administration, health promotion and health education, Aboriginal women play many diverse and vital roles in their communities. They work as nurses, traditional healers, midwives, nutritionists, physicians, counselors and practitioners of alternative therapies — roles that are particularly important, given the critical shortage of health care providers in most Aboriginal communities.<sup>1</sup> For instance, First Nations and Inuit women comprise 95 percent of the approximately 1,600 Community Health Representatives (CHRs) in Canada.<sup>2</sup>

As well, Aboriginal women influence the health of their communities as mothers, community Elders and in other social roles. They provide food and clothing for children and other community members — often with very limited options — and must cope with the high rates of injury, chronic diseases and addictions that exist in many communities. These caregiving roles may extend over much of a woman's lifetime, since Aboriginal mothers tend to be young, have birth rates twice that of non-Aboriginal mothers and have a longer life expectancy than Aboriginal men.<sup>3,4</sup>

## Healthy Women, Healthy Families, Healthy Communities

While Aboriginal women play an essential role in community health, often under difficult social and economic conditions, their own health status is poorer than that of women in the general Canadian population<sup>5,6</sup> (see article on page 6). Furthermore, at least three quarters of Aboriginal women in Canada have been victims of family violence, the physical and emotional impacts of which are severe for both the women and their children.<sup>7,8</sup>

Struggling to address these realities, Aboriginal women have led the way in articulating a holistic approach to health. They view their own health as integrally linked to that of their families and communities, and identify strong families, supportive structures, safe homes and communities, and healthy child development as determinants of better health.<sup>9</sup> ►





## Catalysts for Change

Since the 1970s, organizations such as the Native Women's Association of Canada, Aboriginal Nurses Association of Canada, Pauktuutit Inuit Women's Organization, Quebec Native Women and others have been important catalysts for change. Despite limited resources and frequent exclusion from the decision-making process at all levels, these organizations have conducted or contributed to research on the health-related needs of Aboriginal women and children, identified gaps in policies, programs and services, and developed strategies and models to address these gaps.<sup>10</sup>

These strategies are based on traditional knowledge and healing practices that conceptualize good health as a balance of physical, emotional, spiritual and

mental elements. They emphasize respect for self and others, the interconnectedness of the individual and the environment, and the need for community involvement and control. As well, they recognize that women and men may bring different needs and approaches to healing and well-being.<sup>11,12</sup> These approaches are being applied to a wide range of health issues, including diabetes treatment and prevention, maternal and child health, addictions, and HIV/AIDS.<sup>13,14</sup>

In advancing their work, Aboriginal women have engaged in dialogue and new forms of collaboration with many sectors, including government, professional associations, service agencies, academic researchers and various non-governmental organizations. Some of these partnerships are described next.

## Sheway — Outreach to High-Risk Pregnant Women and Mothers

Sheway is an agency that provides women and their families with prenatal and postnatal medical care and nursing services, nutritional support, counseling on substance abuse, crisis intervention and advocacy on child custody and other issues (see Figure 1) in a way that respects Aboriginal culture, history and tradition. Located in downtown eastside Vancouver, one of Canada's poorest neighbourhoods with a high crime rate and an active drug and sex trade, the agency is managed by a council of representatives of Aboriginal and other agencies and multiple levels of government.

An evaluation of Sheway health outcomes based on a three-year period was conducted by the British Columbia Centre for Excellence for Women's Health, with funding provided by the Women's Health Bureau, Health Canada.<sup>15</sup> Among the findings:



- Thirty percent of women had no medical/prenatal care when they entered the program; by the time they gave birth, 91 percent of women had a physician or midwife to support their deliveries.
- When they entered the program, 79 percent of women had various nutritional concerns;<sup>16</sup> only 4 percent had such concerns six months after giving birth.
- The majority of women (86 percent) who gave birth while accessing Sheway services had babies with a birthweight over 2,500 grams; this compared favourably with birthweights in other areas of the city with less poverty.

It is still too early to evaluate the project's long-term impact on reducing women's substance use. However, Sheway has been successful in providing comprehensive care and working from a service philosophy that is culturally sensitive, women-centred and empowering.

**Collaboration for Training and Best Practices**

- The Aboriginal Nurses Association of Canada (ANAC) has collaborated with the First Nations and Inuit Health Branch, Health Canada and with First Nations authorities to address current and future nursing shortages in First Nations and Inuit communities. In a Health Canada-funded study conducted in 2000, ANAC surveyed nurses working in remote First Nations communities† and provided

†Nursing services in northern, remote and isolated First Nations and Inuit communities are provided by nurses employed by either the First Nations and Inuit Health Branch, Health Canada or First Nations authorities. Nurses are the largest group of professional health care providers in First Nations and Inuit communities. Non-Aboriginal nurses make up the majority of nurses working in these communities.

valuable information on the importance of nurse-community relationships as a critical indicator of nurse retention.<sup>17</sup> This research laid the groundwork for initiatives such as the development of strategies to increase Aboriginal student enrolment in nursing programs, and the investigation of best practice community models for recruitment and retention of nurses in First Nations and Inuit communities.

- Aboriginal women physicians, nurses, midwives and other care providers played a key role in the development of practice guidelines for health professionals working with Aboriginal peoples.<sup>18</sup> Aboriginal women are also working with professional associations and governments to increase opportunities for maternity services, including

**Figure 1: Sheway – Approach and Services**

Sheway’s approach and services are based on the recognition that the health of women and their children is linked to the conditions of their lives and their ability to influence these conditions.



Used with permission of Sheway, Vancouver, British Columbia, 2000.

midwifery training. The initiative is designed to redress the long-standing practice of removing First Nations and Inuit women from remote communities to major urban centres for birthing.<sup>19,20</sup> International research and community experience in Canada, such as the Inuulitsivik Maternity Centre, have demonstrated that health and social initiatives based on the involvement of local Aboriginal women result in improved participation in health programs, better health outcomes for mothers and infants, and enhanced sustainability of services.<sup>21-24</sup>

### Collaboration in Aboriginal Women's Health Research

Aboriginal women are increasingly involved in community/academic research partnerships that focus attention on the need for cultural sensitivity in the research process and for accountability to Aboriginal communities. This was highlighted in a synthesis of over 30 research initiatives on Aboriginal women's health issues and health policy, all of which were supported by Health Canada's Women's Health Bureau through the Centres of Excellence for Women's Health.<sup>25</sup> The review underscored the need for new research sensitive to the diversity within and between First Nations, Métis and Inuit women in order to develop accurate indicators of Aboriginal women's health and to serve as the basis for setting priorities for future health research, policies and programs. As well, the review identified an important shift in research towards documenting and understanding health-seeking behaviours, many of which have significant gender differences.<sup>26</sup>



**A** boriginal women

have identified positive action, pragmatism and resilience as the key strengths of community health initiatives. Increasingly, others are recognizing the scope and depth of Aboriginal women's contributions to the health of their communities.

### Nurturing Healthier Communities

Since many of these collaborative initiatives are relatively recent, the long-term health outcomes cannot yet be assessed. However, Aboriginal women are helping to build the capacity for healthier communities. As clients, community board members, volunteers and health providers, they are designing culturally-appropriate health care settings and developing and delivering health policies, programs and other services carefully attuned to local needs. They are nurturing new skills in leadership, community development and research.

Aboriginal women have identified positive action, pragmatism and resilience as the key strengths of community health initiatives. Increasingly, others are recognizing the scope and depth of Aboriginal women's contributions to the health of their communities. Future challenges to improving the health of all Aboriginal people cannot be met without such recognition or broad-based support for the contributions of Aboriginal women. 🌟

*\*Preparation of this article was coordinated by Sari Tudiver with help from Virginia Adamson and Cathy Winters, Women's Health Bureau, Health Policy and Communications Branch, Health Canada. Special thanks to Madeleine Dion Stout, Researcher and Consultant, for many thoughtful contributions to the development of this article.*

*Thanks also to the following for sharing information and expertise: Kerry Bebee and Carole Couchie, Aboriginal Midwives of Canada; Judi Jacobs, National Indian and Inuit Community Health Representatives Organization; Monica Stokl, Program Manager, Sheway; Nancy Poole; Dawn Smith; Marsha Forrest; and Kathleen MacMillan, Sharon Stanton and Ray Amiro, First Nations and Inuit Health Branch, Health Canada.*

@ Please note: Full references are available in the electronic version of this issue of the Bulletin: <http://www.hc-sc.gc.ca/arad-draa>



# Who's Doing What?

**W**ho's Doing What? is a regular column of the Health Policy Research Bulletin that looks at key players involved in generating policy research within a specific theme area. This issue's column profiles a sample of initiatives being undertaken by various organizations and governments to improve the health status of Aboriginal people.

**Tiffany Thornton**, Applied Research and Analysis Directorate, Information, Analysis and Connectivity Branch, Health Canada, formerly with Strategic Policy, Planning and Analysis Directorate, First Nations and Inuit Health Branch, Health Canada

## Aboriginal Healing Foundation (AHF)

The AHF sponsors strategic research that contributes to the design, implementation or evaluation of community-level healing projects.

Completed in 2001, the Foundation's first interim evaluation report is based on a survey of 344 projects funded in 1999, as well as an in-depth review of 36 sample project files. The report shows that 59,224 participants engaged in healing activities and that 1,686 communities were served by AHF-funded projects. The results of the second interim report, completed in 2002, suggest that AHF projects are enjoying reasonable success.

However, there is still a need for additional family services and new strategies for healing men and youth. A final impact evaluation report will be available in 2005 (see: <http://www.ahf.ca>).

## The Future of Children and Youth of the Arctic (FCYA)

By increasing knowledge and understanding of sustainable development, this initiative by the Arctic Council aims to improve the health and well-being of Arctic children and youth, and to contribute to sound decision making. Current activities focus on the three

components of FCYA — health, internship and networking — and include collecting and analyzing data on 16 key indicators from eight circumpolar countries, as well as identifying best practice models in the areas of maternal and infant health, psycho-social health and suicide, respiratory and other communicable diseases, and alcohol and substance abuse prevention (see: <http://www.arctic-council.org/> or E-mail [judith\\_stanway@hc-sc.gc.ca](mailto:judith_stanway@hc-sc.gc.ca)).

## CPHI-Sponsored Dialogue

Aboriginal peoples' health is a priority for the Canadian Population Health Initiative (CPHI). From November 2002 through 2003, the organization will bring together leaders in population health issues from

First Nations, Métis and Inuit communities in a series of brainstorming sessions to explore social determinants of health, especially at the community level, and to identify policy approaches for reducing health inequalities. CPHI's goal is to encourage dialogue and promote an iterative approach to identifying future areas for research and policy making (see: <http://www.cihi.ca>).



## First Nations and Inuit Telehealth

Telehealth involves the use of information and communications technology to improve access, offer support and enhance the efficiency and effectiveness of health care, health education and health information. In First Nations and Inuit communities, telehealth increases access to expert medical advice, links health care professionals and encourages sharing of health information. Results from a recently completed National First Nations Telehealth Research Project (2001) will be used to identify success factors for the implementation of future initiatives in First Nations and Inuit communities (see: <http://www.hc-sc.gc.ca/fnihb/phcph/telehealth>). ▶

## Inuit Early Childhood Development (IECD)

In 2001, Inuit Tapiriit Kanatami (ITK) began collaborating with an IECD working group to assess IECD programs and issues. The resulting report, *Inuit Early Childhood Development Issues: A Discussion Paper*, uses data collected from teachers, parents and community social workers from six northern Inuit regions to identify the benefits of IECD programs, such as daycare and Aboriginal Head Start, and to highlight the importance of early childhood development issues among the Inuit (available at: <http://www.itk.ca>).

## Planning Nursing Services

In 2002, the Office of Nursing Services (ONS) at Health Canada commissioned a national survey of all registered nurses working for Health Canada's First Nations and Inuit Health Branch. The survey results will assist ONS in addressing human resources requirements across Canada over the next five years, with specific emphasis on: national and regional baseline data on the current nursing work force, including demographics and employment and educational characteristics; projected changes in the work force over the next five years; and employee satisfaction with work environments and work-life balance. More information is available at: <http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/ons.htm> or E-mail [Sharon\\_Stanton@hc-sc.gc.ca](mailto:Sharon_Stanton@hc-sc.gc.ca)

## INAC Studies Population and Service Trends

Indian and Northern Affairs Canada (INAC) is completing a study of population projections and trends in program service utilization and cost patterns, entitled "Implications of First Nations Demography II." The study will also present expenditure models for dental care, non-insured health benefits, education, housing, employment and corrections (see: <http://www.ainc-inac.gc.ca/pr/ra> or E-mail [beavond@inac.gc.ca](mailto:beavond@inac.gc.ca)).

## Research on Sexual and Reproductive Health

Since 1998, Health Canada's Enhanced Surveillance of Canadian Street Youth has collected disease prevalence and risk behaviour data on street youth in various Canadian cities (approximately 30 percent of street youth self-identified as Aboriginal in 1999). The department also collects data on the incidence of sexually transmitted infections in a number of Aboriginal

communities. Complementary data from these projects will be used to help plan and implement new programs, justify resource needs, and enhance and support community-based sexual and reproductive health initiatives. For more information, please contact Susanne Shields (Enhanced Surveillance) at (613) 946-8637 and Maureen Perrin (STI Surveillance) at (613) 946-4827.



## Social Cohesion Project

Researchers from the University of Western Ontario recently joined forces with Indian and Northern Affairs Canada on a five-year project to address social cohesion in First

Nations communities. Funded by the Social Sciences and Humanities Research Council of Canada, the project will investigate social capital, social cohesion and population outcomes in First Nations communities. It will also establish a high quality research information base on First Nations communities and train a new generation of First Nations and non-Aboriginal researchers (see: <http://www.ssc.uwo.ca/sociology/firstnations/research.html>).

## Statistics on First Nations Health

The First Nations and Inuit Health Branch of Health Canada will soon be releasing a *Statistical Profile on the Health of First Nations in Canada*. This report will present an overview of the health status and conditions affecting the health of First Nations living on reserve in Canada. Information on immunization, perinatal health, mortality and communicable diseases was gathered for 1999 and compared with similar





**U**sing Canada's Health Data is a regular column of the Health Policy Research Bulletin highlighting some of the methodologies commonly used in analyzing health data. In this issue, we examine the technique of record linkage.

## Linking Health Records

**Adam Probert**, Strategic Policy, Planning and Analysis Directorate, First Nations and Inuit Health Branch, Health Canada

Every province and territory has a number of administrative databases containing information on births, deaths and hospitalizations. Generally used for disease surveillance, risk assessment and health services planning and priority setting, these databases can also be linked to population health survey data, allowing researchers to paint a longitudinal portrait of health status. This is especially useful in the case of First Nations people living on reserve, as comprehensive data on their health are often difficult to obtain.

### Health Information Challenges for First Nations

For a number of reasons, it is far more challenging to obtain health data for First Nations people than for other Canadians:

- Most health care records do not identify people by ethnic ancestry; First Nations people may be included in aggregate data, but it is difficult to separate their records.
- Health care services and data for First Nations people are divided among the federal government (First Nations and Inuit Health Branch (FNIHB), Health Canada), provincial/territorial governments, and communities to whom responsibility for health programs and services has been transferred from the federal government.
- Each jurisdiction uses different methods to identify First Nations, even when it is possible to make this identification. This makes comparisons among the provinces and territories difficult.

- Even in databases that identify ethnicity, self-reported ethnic status is often under-reported. For example, ethnicity is recorded in only 84 percent of AIDS case reports and in 25 percent of HIV test records.<sup>1</sup>

### How Does Record Linkage Work?

A method known as **record linkage** allows researchers to overcome these challenges. In this process, two or more records from different databases or files are combined to yield one new record. This is accomplished by matching personal information such as name, birth date and/or social insurance number. The process of computer matching compares files containing information for thousands or even millions of people. The result is a list of “exact matches,” in which all variables are the same, and “probable matches,” in which the likelihood of the match is less certain.

In the following example (see Figure 1), File A represents the Indian Register, which is maintained by Indian and Northern Affairs Canada for Status Indians who are eligible to receive certain benefits. File B represents the Canadian Mortality Database, a listing of all deaths in Canada since 1950. Each file contains more variables than are shown; however, only a few variables common to both, such as name, date of birth (DOB) and sex, are required to link the files.

In Figure 1, fictional names and personal information are used to illustrate how record linkage is carried out. For instance, the most likely match for “Raymond Whiteduck” in File A appears to be “R. Whiteduck” in File B. Other potential matches have different DOBs and/or spelling. Although other methods can be used to take into account such differences, “Raymond White Duck” in File B is approximately 50 years younger than “Raymond Whiteduck” in File A and is most likely not a match.

There are no matches in File B for the second example, “John Fox.” Even though a male with the same DOB has been located, the name is

**A** method known as record linkage allows researchers to overcome these challenges. In this process, two or more records from different databases or files are combined to yield one new record.

completely different. In the third example, “William Bearhead” is most likely a match for “Bill Bearhead,” ‘Bill’ being a nickname for William. The mismatch in DOB can likely be explained by a transcription error that has reversed the month and day fields in one or the other database.

### Record Linkage in Practice

In Manitoba, a record linkage study was recently conducted by a multisectoral committee to examine health status and the use of preventive care, hospitalization and physician services.<sup>2</sup> The project linked the Status Verification System (a FNIHB file generated from the Indian Register) to the Manitoba Hospital Morbidity, Mortality and Surgical Procedures files, among others. Using the process of record linkage, researchers were able to obtain the same health status and health care utilization data for First Nations as were available for other residents of the province. Researchers and policy makers are hopeful that more information of this kind

can be generated in the future, and that this model of record linkage can be extended to other provinces and even to a national level. There are currently no comprehensive lists available for the Métis or Inuit populations. However, if these lists are generated, similar methods can then be used to link their health records as well.

### What Are the Concerns?

Due to the level of detail needed to perform record linkage, issues related to protection of privacy and confidentiality of personal information are important concerns. Other issues that need to be addressed involve access to and ownership, control and possession of data; obtaining consent to link files; and ensuring the security of the linked data. The linkage in Manitoba was successful, in part, because the Assembly of Manitoba Chiefs were integral members of the investigation team. Respondents to both the National Population Health Survey and the Canadian Community Health Survey

*Continued on page 35* ►

Figure 1: **Simplified Example of Record Linkage**

File A <i>Indian Register</i>			File B <i>Canadian Mortality Database</i>		
Name*	DOB*	Sex*	Name*	DOB*	Sex*
Raymond Whiteduck	09/15/42	M	R. Whiteduck	09/15/42	M
			Ray Whiteduck	12/03/71	M
			Raymond White Duck	03/14/92	M
John Fox	05/28/68	M	Bob Okimaw	05/28/68	M
			Jennifer Fox	11/11/24	F
Bill Bearhead	02/06/54	M	Peter Bearhead	10/05/62	M
			William Bearhead	06/02/54	M

\*Note: All names and personal information are fictional.





**D**id You Know? is a regular column of the Health Policy Research Bulletin examining aspects of health research and data that may be subject to misconceptions. In this issue, we examine the ways in which bias can affect research findings.

## How and Why Do We Identify Bias in Research?

**Bernard Choi, PhD**, Centre for Chronic Disease Prevention and Control, Population and Public Health Branch, Health Canada; Associate Professor, Public Health Sciences, University of Toronto; Adjunct Professor, Epidemiology and Community Medicine, University of Ottawa

Bias in epidemiology is defined as the deviation of results from the truth.<sup>1</sup> For example, if there are 30 people at a meeting, but you keep counting only 20 participants, then there must be something wrong with your counting. Your bias (deviation) is 20 minus 30 which is minus 10. In practice, bias in health policy research can affect the validity of the evidence base used for developing policies.

### Random Versus Systematic Error

**Random error** (or “noise”) is not considered to be bias. In the above example, if you count 20 people the first time, 40 the second time, 35 the third time, and 25 the fourth time, then this is random error. When you average the four results, you get 30 participants, which is accurate. Bias, on the other hand, is **systematic error**. If you consistently under- or overestimate the true number (for example, if you keep counting 20, 19, 21 or 20 participants), then your results are biased. Increasing sample size reduces random error, but has no effect on bias. So, even if you count 100 times, you will still get a biased estimate if there are systematic errors. There are many possible

**I**f you count 20 people the first time, 40 the second time, 35 the third time, and 25 the fourth time, then this is random error. When you average the four results, you get 30 participants, which is accurate. Bias, on the other hand, is systematic error. If you consistently under- or overestimate the true number (for example, if you keep counting 20, 19, 21 or 20 participants), then your results are biased.

sources of bias, including selection bias, information bias and confounding.<sup>2</sup> Each of these is described briefly below.

### Selection Bias

Selection bias occurs in the **design stage** of a study, for example, when subjects who should be included in the study are not.<sup>2</sup> In the example above, consistent under-counting of participants may be due to the fact that 10 people are sitting in a corner of the room where they cannot be seen.

**Berkson’s bias**, or **hospital admission bias**, affects epidemiological studies in which subjects are all hospitalized patients. For example, it may not be appropriate to generalize the results from hospitalized diabetes patients to all persons with diabetes, because hospitalized patients likely have more severe diabetes than non-hospitalized persons with the disease. **Neyman’s bias**, or **selective survival bias**, is caused by excluding those who have died before the study starts, because the exposure being studied increases the risk of

death. Using different mailing strategies in a questionnaire survey may result in **response rate bias**. For instance, using large commemorative paper stamps instead of business reply stamps was shown to increase response rates among nurses.<sup>3</sup>

Health status itself can cause a selection bias, as in the **healthy worker effect**.<sup>4-6</sup> Because people in the labour force have better health than the general population (which also consists of the sick, disabled and elderly), they frequently have lower disease and death rates. When the health of an occupational group is compared with that of the general population, this bias affects the ability of the study to detect small occupational health hazards.

**Diagnostic work-up bias** occurs when the positive results of a diagnostic or screening test prompt a health care provider to order the

“gold standard” diagnostic test, while patients with negative screening test results are not referred for the same procedure.<sup>7</sup> Therefore, diseased persons with negative screening results are systematically less likely than diseased persons with positive screening results to be identified, for example, by a surveillance system that is using mass screening to track new cases of the disease. Information collected by the surveillance system would then be biased.

**Gender bias** can affect clinical research as well as program and public policy development. One type of gender bias, overgeneralization, can occur when the perspective of one sex is applied to both sexes.<sup>8</sup> For instance, clinical trials of new drugs historically tended to be conducted only on men, in order to avoid risks to women’s reproductive functioning. However, this form of selection bias ultimately put women at risk, as the findings were then generalized to women, sometimes quite inappropriately.<sup>9</sup>

### Information Bias

This type of bias occurs during the **data collection stage**, for example, when the results are distorted either by measurement errors or by misclassifying the subject for exposure (e.g., smoker or non-smoker) and/or outcome variables (e.g., presence or absence of cancer).<sup>2</sup>

**Interviewer bias** is caused by an interviewer’s subconscious or even conscious gathering of selective data. For example, questions about specific exposures may be asked several times of cases (study subjects with the disease), but only once of those subjects in the control group. **Questionnaire bias** refers to leading questions and wording problems that may lead the subject to a particular response. **Cultural bias** can, for example, affect IQ tests by erecting systematic barriers to performance for immigrant children and children from low-income families. **Recall bias** refers to the defective recall of events by interview or questionnaire respondents. Dietary questionnaires are often affected by recall bias because people may not accurately remember what they have eaten days, weeks or months earlier. **Social desirability bias** can occur when respondents who are self-reporting on topics such as smoking, exercise, weight or income

give what they believe are the socially desirable answers to questions rather than revealing their activities, behaviours or exposures.

### Confounding Bias

This type of bias occurs when techniques for controlling confounding (i.e., when a particular factor is associated with *both* the exposure of interest and the outcome of interest) are not used in the **data analysis stage**. For example, in a study of the association between drinking alcohol and lung disease, smoking must be treated as a potential confounder because smoking and drinking alcohol are often associated, and smoking is known to cause lung disease. A spurious, or artifactual, association between the exposure of interest (alcohol) and the outcome of interest (lung disease) may result if the researchers do not control for smoking.

Stratification, for example, by using age-standardized rates (see page 10), is a traditional method of controlling for confounding.<sup>10</sup> In our example, the counting of participants may be confounded if there are two different meetings being held simultaneously in the same room. One of the meetings represents the exposure of interest, while the other meeting represents the confounder. To stratify, you would simply ask participants attending one meeting to move to one end of the room, and those attending the other meeting to move to the other end. Covariate adjustment, such as multiple logistic regression, is a newer method and uses mathematical modelling to control for confounding.<sup>11</sup> Using our example, you would not have to group the participants physically, but just ask them to wear different coloured hats, for example, black to indicate one meeting and white for the other. However, covariate adjustment is complex and caution must be used to correctly formulate the variables in the models and interpret the results. Model building is a complex process that may itself lead to other biases.<sup>12</sup>

### Conclusion

Awareness of potential biases is not only the responsibility of those who design, carry out and analyze research, but also of those who read the research reports and make policy and other decisions based on the results. 🌀



**You would not have to group the participants physically, but just ask them to wear different coloured hats, for example, black to indicate one meeting and white for the other.**



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**N**ew and Noteworthy is a regular column of the Health Policy Research Bulletin highlighting “up and coming” policy research in the health field.

## International Comparisons of Chronic Disease Policy

The Centre for Chronic Disease Prevention and Control is a World Health Organization (WHO) Collaborating Centre on Non-Communicable Disease Policy. The Centre has prepared a comparative analysis of chronic disease policy development and implementation in 30 countries that participate in the WHO program entitled “Countrywide Integrated Non-Communicable Disease Intervention.” For information or for copies of the report, E-mail Deborah\_Baldwin@hc-sc.gc.ca

## Surveillance of Cervical Cancer Screening

The *Cervical Cancer Screening Surveillance in Canada: 1998 Surveillance Report* presents baseline information from provincial health departments and established cancer screening programs. Among the key findings are:

- Most women who develop cervical cancer have not had Pap smears prior to diagnosis.
- Identifying and addressing the barriers to screening is a prerequisite for reducing the number of new cervical cancer cases and deaths.
- Surveillance of women who have Pap smears and those who do not has helped to identify particular groups of women who would benefit from educational campaigns promoting regular screening.
- One of the goals is to adopt a standard system of classifying and reporting on the results of Pap smear screening in all provinces.

(Available at: <http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/ccsic-dccuac/index.html>).

## A Diagnostic of Ontario’s Children

This report combines research evidence and statistical trends to present an overview of the current and future health status of children, youth and families living in Ontario. It was developed using a population health approach — specifically, by assessing the effects of the

broad determinants of health on the health of children and families. Each chapter addresses one determinant of health, describing statistical trends and their potential impact on the health and well-being of children and families, as well as the implications of these trends on future research, programming and policy development.

## End-to-End Health Surveillance Architecture



A collaborative initiative of Health Canada’s Centre for Surveillance Coordination and several provincial governments, the “End-to-End Health Surveillance Architecture Project”

identifies the types of data, functions, business processes and networks needed to get the maximum possible benefit from the disease surveillance process. The project includes research on the current status of public health information systems and an analysis of additional information required by public health physicians and nurses to better protect the health of Canadians. It describes an optimum public health surveillance information system, in which surveillance data is a natural by-product of the information and communication technologies that health professionals use in their daily work. The project also identifies the resources needed to: further develop and implement practical tools; use information standards and definitions currently being developed; and ensure that Canada’s health surveillance community has access to Canadians’ electronic health records (see: <http://www.hc-sc.gc.ca/pphb-dgspsp/csc-ccs/>).

## Women’s Health and Homelessness

A recent study used a community-based, participatory action approach to capture the experiences of 126 women who are, or have been, part of Toronto’s homeless population and to determine the impact on their emotional, mental, spiritual and physical health. The study, which is entitled *Common Occurrence:*

*The Impact of Homelessness on Women's Health* (June 2002), concludes that the full extent of women's homelessness and particularly hidden homelessness in Toronto — is both underestimated and misunderstood. Using a determinants of health lens, the study identifies poverty as a key contributing factor and makes 12 recommendations linking over 100 action strategies. The report was sponsored by Sistering: A Women's Place, in partnership with the Toronto Community Care Access Centre. It was jointly funded by Ontario/Nunavut Region's Population Health Fund and Status of Women Canada. For more information about the report, see <http://www.Sistering.org>. A video featuring the women who were interviewed has also been produced for use as an educational and training tool for service providers and policy makers.

## Statistics Canada Reports on Health

Statistics Canada has published a number of major reports on the health of Canadians, including:

- *National Population Health Survey 2000 Overview* (September 2002)
- *Participation and Activity Limitation Survey (PALS) 2001 Report* (December 2002)



- *Aboriginal People's Survey (APS) 2001 Report* (March 2003)
- *The Health of the Off-reserve Aboriginal Population* (This report compares the off-reserve Aboriginal population with the rest of the Canadian population in terms of health status, health behaviours and health care utilization. It is included in the third *Report on the Health of Canadians*, which was released in December 2002 under the title *How Healthy are Canadians? Annual Report 2002*.)

Information on these and other Statistics Canada releases is available on the department's website at <http://www.statcan.ca/>

## Health Expenditures Information from CIHI

The Canadian Institute for Health Information (CIHI) has just released the *National Health Expenditure (NHEX) Trends Report*. CIHI's mandate is to provide the kind of accurate and timely information that is needed to establish sound health policy, manage the Canadian health system effectively and create public awareness of the factors affecting good health. More information about this and other CIHI releases is available at: <http://www.cihi.ca/> 🌐

## Linking Health Records, *continued from page 31* ▶

are given the opportunity to indicate consent to future linkages of their files by Statistics Canada. Interestingly, consent rates are, in fact, very high.

There are also concerns about using data for purposes other than which they were intended. For example, researchers may wish to link income tax records to a hospital discharge database to determine if socio-economic status is a determinant of health status. In cases such as these, concerns about conducting record linkages must be balanced against the public benefits to be derived from generating new knowledge.

In Canada, most record linkages using national databases are performed by Statistics Canada. All record linkage proposals (including detailed information on the databases to be linked, the type of information to be generated and the organizations that endorse the

project) are approved by a linkage review board. If the results of the linkage are likely to result in harm to a person or group, the linkage will not be approved.<sup>3</sup>

## Record Linkage and Longitudinal Data

The health impacts of exposures or interventions may take many years to manifest themselves. This often requires data that are collected by tracking individuals over time — i.e., longitudinal data. Record linkage is one of the most practical methods for obtaining longitudinal as well as cross-sectional health information. This methodology is particularly useful when records are held in a number of locations, as is the case with First Nations people. 🌐

@ Please note: Full references are available in the electronic version of this issue of the Bulletin: <http://www.hc-sc.gc.ca/arad-draa>

# Mark Your Calendar



What	When	Theme
21st Annual “Protecting Our Children” National American Indian Conference on Child Abuse and Neglect	April 13-16, 2003 Portland, Oregon <a href="http://www.nicwa.org/services/conferences/protecting/index.asp">http://www.nicwa.org/services/conferences/protecting/index.asp</a>	Reclaiming our Native youth: Examining the core issues that Native youth face today and highlighting successful programs that demonstrate community resolve to reclaim our youth
Safety in Numbers: Working Together from Research into Practice	April 28-29, 2003 Atlanta, Georgia <a href="http://www.cdc.gov/ncipc/conference">http://www.cdc.gov/ncipc/conference</a>	Effective practices to prevent and control injury and reduce disability; the latest advances in injury research; programmatic and research skills, abilities and effectiveness; partnerships
Canadian Public Health Association 94th Annual Conference: A View to the Future	May 10-13, 2003 Calgary, Alberta <a href="http://www.cpha.ca/english/conf/94thAnl/94conf.htm">http://www.cpha.ca/english/conf/94thAnl/94conf.htm</a>	Emerging opportunities, challenges and strategies for public health in health care reform; partnerships in public health; technology: the portal to the future
Child Health 2003 — 3rd World Congress and Exposition	May 12-16, 2003 Vancouver, British Columbia <a href="http://www.venuewest.com/childhealth2003/welcome.htm">http://www.venuewest.com/childhealth2003/welcome.htm</a>	Deliberation of key issues and introduction of preventative measures and innovative approaches to reduce illness and death rates and boost the level of wellness of children
E-Health 2003 International Conference: A Catalyst for Change	May 24-27, 2003 Toronto, Ontario <a href="http://www.e-healthconference.com">http://www.e-healthconference.com</a>	Electronic health records, health information protection, best practices in information management, telehealth, patient safety, emerging trends and catalysts for change
4th Nordic Health Promotion Research Conference	June 10-13, 2003 Vasteras, Sweden <a href="http://www.mdh.se/ivf/nhprc2003/">http://www.mdh.se/ivf/nhprc2003/</a>	The paradigm shift in health promotion research: Practical implementations based on the shift in research design philosophy and methodology
14th International Congress on Women’s Health Issues	June 15-18, 2003 Victoria, British Columbia <a href="http://www.uvcs.uvic.ca/conf/ICOWHI/welcome.cfm">http://www.uvcs.uvic.ca/conf/ICOWHI/welcome.cfm</a>	Building alliances for living, working, research and practice: Women’s health in the postcolonial context
iHEA 2003 4th World Conference	June 15-18, 2003 San Francisco, California <a href="http://www.healthconomics.org">http://www.healthconomics.org</a>	Global health economics: Bridging research and reforms
Conference on Health and Economic Policy	June 27-28, 2003 Munich, Germany <a href="http://www.cesifo.de/">http://www.cesifo.de/</a>	Various themes, including: the effect of public policy on health, forecasting supply and demand for health, and aging
The Health Work Force: Managing the Crisis	June 25-27, 2003 Caltanissetta (Sicily), Italy <a href="http://www.ehma.org/conf2003/index.html">http://www.ehma.org/conf2003/index.html</a>	Adapting the health work force to changes in health systems

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