

*DISCUSSION PAPER No. 18*

***FIRST NATIONS, INUIT AND MÉTIS  
HEALTH INDICATORS IN CANADA***

***A BACKGROUND PAPER FOR THE PROJECT  
'ACTION-ORIENTED INDICATORS OF HEALTH  
AND HEALTH SYSTEMS DEVELOPMENT FOR  
INDIGENOUS PEOPLES IN AUSTRALIA,  
CANADA AND NEW ZEALAND'***

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*Onemda* VicHealth Koori Health Unit

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# Table of Contents

<b>Discussion Paper Series</b>	<b>iii</b>
<b>Acknowledgments</b>	<b>v</b>
<b>Abbreviations</b>	<b>vi</b>
<b>Executive Summary</b>	<b>1</b>
<b>Introduction</b>	<b>2</b>
<b>Methods</b>	<b>3</b>
Data collection	3
Data analysis	4
<b>History of Indigenous Health Systems</b>	<b>5</b>
<b>Current Indigenous Health Indicator Sets</b>	<b>8</b>
National level health indicator sets	8
Statistics Canada	8
Canadian Institute for Health Information	9
Public Health Agency of Canada	10
Health Canada, including the First Nations and Inuit Health Branch	10
Indian and Northern Affairs Canada	11
National Aboriginal Health Organization	12
Inuit Tapiriit Kanatami	12
Assembly of First Nations	12
Provincial/territorial level health indicator sets	13
Regional level health indicator sets	13
Indigenous-operated health authorities	14
<b>Indicators Compendium</b>	<b>15</b>

<b>Indigenous Health Indicators: Barriers to Effective Use</b>	<b>16</b>
Themes	16
Accountability	16
Poor data quality	17
Ethnic identification	17
Jurisdiction	17
Infrastructure	17
Human resources	17
Lack of information to communities	18
Tension between mainstream and Indigenous processes	18
Mistrust	18
Culturally appropriate tools	19
Population health focus	19
Community-initiated processes	19
Discussion	19
<b>Best Practice Examples</b>	<b>21</b>
Inuksiitiin health information framework	21
Development of an evaluative framework for use by First Nations health organisations	21
The West Kitikmeot Slave Study Society community-based monitoring project	22
Community health indicators project	22
Canadian Aboriginal communities: A framework for injury surveillance	23
<b>Concluding Comments</b>	<b>25</b>
<b>References</b>	<b>26</b>
<b>Attachment 1: Compendium of Indigenous Health Indicators in Canada</b>	<b>30</b>

# *Onemda* **VicHealth Koori Health Unit: Discussion Paper Series**

The *Onemda* VicHealth Koori Health Unit (formerly VicHealth Koori Health Research and Community Development Unit), launched in June 1999, has been developed in partnership with Aboriginal communities and organisations, in particular the Victorian Aboriginal Community Controlled Health Organisation. Core funding is provided by the Victorian Health Promotion Foundation, the University of Melbourne through the Centre for Health and Society where the Unit is located, and the Commonwealth Department of Health and Ageing.

At the core of the Unit's work is a commitment to undertaking, collaborating in and supporting research that directly benefits the Koori community. The work of the Unit spans academic and applied research, community development, and medical education. The combination of these activities is a central and innovative aspect of the Unit's function, as is the identification and use of mechanisms to link research with the improvement of health care practices and policy reform. Overall, these tasks are guided by a Strategic Oversight Committee.

In relation to the research program, five key areas govern the inquiry undertaken within the Unit. These comprise: historical research into Koori health policy and practice; historical and contemporary research into health research practice, ethics and capacity building; applied research on the social and cultural experience of Koori health, well-being and health care delivery; health economics research on the factors and processes that impact on the provision and use of Koori health care; and the evaluation of Koori primary health care and related health promotion programs.

The Discussion Paper Series (DPS) is directly linked to this diverse program of research and provides a forum for the Unit's work. The DPS also includes papers by researchers working outside the Unit or in collaboration with Unit staff. Individual papers aim to summarise current work and debate on key issues in Indigenous health, discuss aspects of Indigenous health research practice and process, or review interim findings of larger research projects. It is assumed that the readership for the series is a broad one, and each paper is closely edited for clarity and accessibility. Additionally, draft papers are 'refereed' so as to ensure a high standard of content.

More information on the series, on the preparation of draft papers, and on the work of the Unit can be obtained by directly contacting the Unit. Copies of all discussion papers are available from the Unit, or can be downloaded as pdfs from the *Onemda* website.

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## Discussion Paper Titles

- No. 1: Ian Anderson, Harriet Young, Milica Markovic & Lenore Manderson, *Aboriginal Primary Health Care in Victoria: Issues for Policy and Regional Planning* (December 2000).
- No. 2: Kim Humphery, *Indigenous Health and 'Western Research'* (December 2000).
- No. 3: David Thomas, *The Beginnings of Aboriginal Health Research in Australia* (September 2001).
- No. 4: Michael Otim, *Indigenous Health Economics and Policy Research* (November 2001).
- No. 5: Daniel McAullay, Robert Griew & Ian Anderson, *The Ethics of Aboriginal Health Research: An Annotated Bibliography* (January 2002).
- No. 6: Ian Anderson, *National Strategy in Aboriginal and Torres Strait Islander Health: A Framework for Health Gain?* (March 2002).
- No. 7: Anke van der Sterren & Ian Anderson, *Building Responses to Blood-Borne Virus Infection among Kooris Using Injecting Drugs—Improving the Link between Policy and Service Delivery* (December 2002).
- No. 8: Kim Humphery, *The Development of the National Health and Medical Research Council Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research: A Brief Documentary and Oral History* (December 2002).
- No. 9: Michael Otim, Ian Anderson & Russell Renhard, *Aboriginal and Torres Strait Islander Hospital Accreditation Project: A Literature Review* (November 2002).
- No. 10: Nili Kaplan-Myrth, *Political Visions: Blindness Prevention Policy as a Case Study of Community–Government Relations in Aboriginal Health* (June 2004).
- No. 11: Gregory Phillips & the Project Steering Committee, Committee of Deans of Australian Medical Schools, *CDAMS Indigenous Health Curriculum Development Project: National Audit and Consultations Report* (August 2004).
- No. 12: Ian Anderson, Wendy Brabham, Bill Genat, Helen Keleher, Janice Jessen, Di Fitzgerald & Bernie Marshall, *National Indigenous Public Health Curriculum Audit and Workshop: Project Report* (October 2004).
- No. 13: Katrina Alford, *Comparing Australian with Canadian and New Zealand Primary Care Health Systems in Relation to Indigenous Populations: Literature Review and Analysis* (June 2005).
- No. 14: Terry Dunbar & Margaret Scrimgeour, *Ethical Assessment of Indigenous Health Research: A Review of the Literature* (December 2005).
- No. 15: K. Jane Middleton, *Mothers, Boorais and Special Care: An Exploration of Indigenous Health Care Workers' Perceptions of the Obstetric and Neonatal Needs of Rural Victorian Aboriginal and Torres Strait Islander Families Transferred to the Mercy Hospital for Women* (October 2006).
- No. 16: Marcia Anderson, Ian Anderson, Janet Smylie, Sue Crengle & Mihi Ratima, *Measuring the Health of Aboriginal and Torres Strait Islander Peoples* (December 2006).
- No. 17: Mihi Ratima, Will Edwards, Sue Crengle, Janet Smylie & Ian Anderson, *Māori Health Indicators* (December 2006).
- No. 18: Marcia Anderson, Janet Smylie, Ian Anderson, Raven Sinclair & Sue Crengle, *First Nations, Inuit and Métis Health Indicators in Canada* (December 2006).

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We would like to start by recognising the Askicowahk or Indigenous peoples of the land.

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This paper is a background document for the project 'Action-oriented indicators of health and health systems development for Indigenous peoples in Australia, Canada and New Zealand'. The overall project is led by Dr Janet Smylie (University of Saskatchewan) and Dr Sue Crengle (University of Auckland) and Professor Ian Anderson (The University of Melbourne) are co-principal investigators. The project was funded by a grant from the Canadian Institutes for Health Research (CIHR), Global Health Strategic RFA (Request for Applications). The co-investigators on the original CIHR grant included Janet Hatcher-Roberts (Canadian Society for International Health, University of Ottawa), Dr Bonnie Jeffery (Faculty of Social Work, University of Regina), Dr Peter Tugwell (Department of Medicine/Institute of Population Health, University of Ottawa), Dr Nili Kaplan-Myrth (Anthropology, University of Toronto), Dr Carmel Martin (Department of Family Medicine/Institute of Population Health, University of Ottawa), Dr Caroline Tait (Anthropology/Women's Studies, University of Saskatchewan), Dr Dawn Smith (PhD candidate, Institute of Population Health, University of Ottawa) and Dr Ian Ring (Professorial Fellow, University of Wollongong).

Dr Marcia Anderson (University of Saskatchewan) and Conrad Prince (Institute of Population Health) worked tirelessly as research assistants on this project.

## **Abbreviations**

APS	Aboriginal Peoples Survey
ASPHFNC	A Statistical Profile on the Health of First Nations in Canada
CAHR	Center for Aboriginal Health Research
CCHS	Canadian Community Health Survey
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes for Health Research
CMHC	Canadian Mortgage and Housing Corporation
CPSS	Canadian Perinatal Surveillance System
FN	First Nations
FNHIS	First Nations Health Information System
FNIHB	First Nations and Inuit Health Branch
FNIRHS	First Nations and Inuit Regional Health Survey
FNRHS	First Nations Regional Health Survey
FRCHI	Federal Report on Comparable Health Indicators
INAC	Indian and Northern Affairs Canada
i-PHIS	Integrated Public Health Information System
KHAS	Keewatin Health Assessment Study
ITK	Inuit Tapiriit Kanatami
NAHO	National Aboriginal Health Organization
NDSS	National Diabetes Surveillance System
NIHB	Non-Insured Health Benefits
OCAP	The right of Indigenous people to Own, Control, Access and Possess Indigenous health information
PHAC	Public Health Agency of Canada
RHS	Regional Health Survey
StatCan	Statistics Canada

# Executive Summary

Multiple indicators of Indigenous health exist in Canada, but the use of these indicators has not effectively contributed to improved health of First Nations, Inuit or Métis peoples. The ineffectiveness of these indicators in health-care monitoring, evaluation and surveillance systems is not clearly understood by health researchers. This paper is a background document for the project entitled 'Action-oriented indicators of health and health systems development for Indigenous peoples in Australia, Canada and New Zealand'. The goal of the study is to conceptualise and pilot a health indicator development cycle that will contribute to effective health information, surveillance and monitoring systems, and translate into action to improve the health of Indigenous peoples in Australia, Canada and New Zealand. This paper reports on our stocktake and assessment of Indigenous health measurement systems in Canada. We base our findings on our review of the published and unpublished literature, expert consultation and key informant interview data.

We identified challenges in Canadian Indigenous health measurement systems at the national, provincial/territorial, regional and community levels. At the national level, the continued inability to identify all three of Canada's Aboriginal peoples in health care databases leads to very poor coverage of Canada's Indigenous population, with a specific paucity of health information for non-registered First Nations, Inuit and Métis peoples. Provincial and territorial systems generally do not collect ethnic-specific utilisation data, and their ethnic flags for vital statistics are inconsistent or absent.

Despite growing acceptance of the notion that the effectiveness of primary health services is generally hinged on the ability to respond to locally identified health priorities and service infrastructure (Dept of Health, UK 2004), we found the most marked gaps in infrastructure development at the community and regional levels. Currently collected health information sets are of limited utility to community or regional service delivery and planning. These limitations appear to be linked to centrally driven development processes that have inadequate regional and community level Indigenous consultation, inadequate national level sampling, and inadequate community/regional level reporting of data. Current policy pertaining to Indigenous data appears to prioritise national level accountability goals at the expense of local relevance and utility. We did identify several best practice examples in which Indigenous organisations and communities have responded to the gap in local Indigenous health information system development by initiating their own health measurement models.

First Nations, Inuit and Métis health monitoring frameworks that allow for respectful ethnic self-identification and draw on culturally and locally relevant understandings of health will be necessary if there is to be a comprehensive and empirical base for the planning and delivery of First Nations, Inuit and Métis health services. Such frameworks will need to draw on accurate and relevant universal public health measures as well as First Nations-, Inuit- and Métis-specific indicators. This will only be possible with strong First Nations, Inuit and Métis leadership and participation in development and implementation.

# Introduction

The Indigenous peoples of Canada include those of First Nations, Inuit and Métis descent. These three groups are recognised in the *Constitution Act 1982*. According to the 2001 national census, just over 1.3 million people in Canada report Aboriginal ancestry (Statistics Canada 2003). This represents 4.4 per cent of the total Canadian population. Of the total participating population identified as Aboriginal, approximately 62 per cent identified themselves as 'North American Indian',<sup>1</sup> 30 per cent as Métis; 5 per cent as Inuit; and the remaining 3 per cent identified themselves with more than one Aboriginal group and/or were 'registered Indians'<sup>2</sup> or members of First Nations bands that did not identify as Aboriginal (Statistics Canada 2003). These numbers underestimate the actual Aboriginal population, as there was significant non-participation in the census by a number of First Nations on-reserve communities, and it is likely that a significant number of individuals chose not to self-identify Aboriginal ancestry to government workers. These and other limitations with respect to this census data are discussed in the section 'National level health indicator sets'.

The Aboriginal population of Canada is growing at a much faster rate than the rest of the Canadian population. For example, the Métis population of Canada grew by 43 per cent between the 1996 and 2001 censuses. First Nations, Inuit and Métis communities are also much younger than others in Canada. Together, the mean age of Aboriginal peoples in Canada was 24.7 years, compared to 37.7 years for the non-Aboriginal population. In Nunavut, one of Canada's four northern Inuit territories, the mean age of Aboriginal residents was 19.1 years. Finally, it is important to note that approximately half of Canada's Aboriginal population now lives in urban areas (Statistics Canada 2003). A more detailed explanation of the diverse histories, cultures and socio-demographics of Canada's First Nations, Inuit and Métis peoples is beyond the scope of this paper and can be found elsewhere (Dickinson 1997).

Striking and persistent disparities in health status between First Nations, Inuit and Métis populations and the rest of the Canadian population have been documented for decades (Health Council of Canada 2005; First Nations and Inuit Regional Health Survey National Steering Committee 1999; First Nations Centre 2005; Macmillan *et al.* 1996), despite the challenges and gaps with respect to accurate and comprehensive health information, which are the subject of this text. It is our hope that the new information we have uncovered in this study will contribute to the development of Indigenous health information systems that can contribute to rectifying Indigenous health disadvantage in our homelands.

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1 This is the census term used to identify persons of First Nations ancestry. It is in quotations marks because the word 'Indian' is recognised as a misnomer for Aboriginal people of First Nations ancestry.

2 This term indicates that an individual of First Nations ancestry is federally recognised by the Indian Act.

# Methods

Information was gathered on the history of Indigenous health systems, current health indicator systems in use, the relationship of such systems to Indigenous peoples with respect to their development and ongoing use, and previous methods for community-based indicator development. Information was collected through a review of published and unpublished literature, key informant interviews and consultations with leaders in the field.

## Data collection

Published references were identified by searching Medline, Embase, Cumulative Index to Nursing and Allied Health Literature, Allied and Complementary Medicine, the Cochrane Database and social science databases. The following MeSH (Medical Subject Headings) descriptors were used: 'health surveys' or 'health indicator' and 'community health services' or 'community-based' and 'American Native Continental Ancestry Group' or 'health services, Indigenous' or 'Aboriginal or Indigenous or Inuit or Eskimo or first nations' and 'Canada'. Ancillary and unpublished references were identified through review of article references, website reviews of health agencies and the recommendation of experts identified by the team of Canadian investigators.

Key informants were deliberately sampled to represent First Nations, Inuit, Métis and non-Aboriginal government and non-governmental organisations at national, provincial and regional levels. The interviews were performed either face-to-face or via telephone, and were recorded and transcribed. Interviews were semi-structured and investigated the following research questions:

1. What community health system performance measurement systems do you currently use/are developing?
2. What individual and community health status measurement systems do you currently use/are developing?
3. What about measures of wellness or wellbeing?
4. What about broader determinants of health? (e.g., housing, education)

## **Data analysis**

Identified references were reviewed and included as best practice examples if they demonstrated community-level relevance, involved partnerships between academics/public health practitioners and community representatives, and involved the development of health measurement systems.

Transcripts of the key informant interviews were reviewed and content extracted pertaining to currently available health indicator sets, their underlying goals, involvement of Indigenous people in their development, and their relationship to Indigenous peoples specifically with regards to utility for health planning. Thematic analysis of the transcripts was performed by three reviewers and, once consensus was achieved on possible themes, the transcripts were reviewed in depth by the lead author to ensure the themes were supported by the text. This information was used to support the sections on current health indicator sets in use, and informed the discussion on Indigenous health indicator issues.

# History of Indigenous Health Systems

Prior to contact with European settlers, First Nations peoples had health systems founded on holistic and ecologic understandings of health and wellness that strove for balance in the physical, mental, emotional and spiritual aspects of life. This balance was carried out within oneself, and also within the context of family, community, and natural and Creator's laws (First Nations Centre 2004). For Inuit people this holistic understanding is called *Inuuqatigiittiarniq* and includes balance and harmony of social, economic, cultural, environmental and biological factors (Boyd & Associates 2002). Medical practices were diverse and included the use of plant and animal products as medicines and for ceremonies and other activities as guided by recognised healers and midwives.

It is difficult to articulate in an academic text how communities and individuals would historically have measured their health, as the public health concept of health measurement does not translate easily into Indigenous languages. This has been echoed in a community-based indicator development project that examined local Indigenous understandings of the terms health, indicator, measure and monitor (Parlee & Marlow 2001).

With European contact came many changes, including a different understanding of health, disease and the practice of medicine. Medical aid was offered at various times by physicians with the Hudson's Bay Company, missionaries, fur traders, whalers, and Royal Canadian Mounted Police and military personnel (Parlee & Marlow 2001). Organised government health care services were not developed until significantly after the formation of Canada in 1867, although the British North America Act assigned responsibility for 'Indians' to the newly formed federal government. It was considered within the right of the government to outlaw Indigenous cultural and healing practices over this period of time, including ceremonies, dances, potlaches and, in residential schools, even the speaking of one's own language. This practice—superimposed on new diseases such as smallpox and alcoholism, and socio-economic conditions that promoted epidemics of tuberculosis and influenza—led to reliance on Western/European medical systems.

The Department of Indian Affairs was established in 1880, but did not include any medical services or personnel. Medical care may have been provided by non-medically trained Indian agents with some supplies from a medicine chest, as alluded to in Treaty 6, or through the hiring of private physicians. The first federal official responsible for Indian health was appointed in 1904, although it took this official many years to influence the delivery of health care to First Nations people. Under his influence, mobile nurse-visitors began in 1922 and the first nursing station was opened in Manitoba in 1930. These nursing stations are still the cornerstone of health care in many First Nations and Inuit communities (Waldram *et al.* 1995).

The health system performance of this time period does not seem to have been formally measured. There were reports published about the health status of Indigenous people, for example, in residential schools or in specific communities, although it is less clear that these reports of deplorable conditions had any influence on policy. Arguably, from examining statements made by government officials and physicians of the era, one can appreciate how poorly these services responded to Indigenous health needs. As an example, a physician in Norway House, Manitoba, wrote, 'I do not believe an Indian can be treated for any sickness unless he is hospitalized, as he can not be trusted to take medicine intelligently' (Corrigan 1946).

The department responsible for the health care of Canada's Indigenous peoples has evolved from the first Medical Branch in the Department of Indian Affairs in 1927 to the Indian and Northern Health Service branch of National Health and Welfare in the 1940s, to the Medical Services Branch in the 1960s, and to the First Nations and Inuit Health Branch (FNIHB) of Health Canada in 2000. The federal government, through FNIHB, accepts responsibility for the health care of registered First Nations and Inuit people only. Non-status First Nations people and Métis people (who represent close to 40 per cent of Canada's Indigenous population) do not have access to the services provided through FNIHB or the Non-Insured Health Benefits (NIHB) program, which includes drug coverage, allied health care services, dental services, medical equipment and transportation for medical services. Furthermore, many of the services and programs provided through FNIHB are only available to First Nations persons living on-reserve and/or to Inuit living in the north. These populations represent only one-third of Canada's total Indigenous population.

The performance of these health systems is difficult to measure because of the multiple jurisdictions involved in the delivery of health care. Non-status First Nations people and Métis people access care through provincial health systems, most of which do not offer an opportunity to self-identify; thus, there is extremely limited data on how adequately this health system addresses the needs of these peoples. An exception would be a pilot study done in Manitoba that linked Manitoba Health and CancerCare Manitoba databases with a sample of the membership list from the Manitoba Métis Federation (Kliwer *et al.* 2002). This report provided some indicators such as physician utilisation and hospitalisation rates, but is incapable of addressing topics such as unmet health care needs or barriers to accessing appropriate health care.

The complexity of care can be illustrated if one considers that primary care—including, for example, immunisations, disease screening and medication refills—can be done in community health centres for First Nations and Inuit people who live in their own communities. These services would be federally funded. However, to access many diagnostic services, specialist services or hospital-based care, many people need to leave their communities and access these services through provincially operated systems. Also, although First Nations children might live on-reserve, they may go to school off-reserve—and may receive their immunisations at school and thus be entered without an ethnic identifier into the provincial database. If there is inappropriate communication between federal and provincial jurisdictions, an underestimate of immunisation coverage could result.

The barriers and gaps between federal and provincial jurisdiction become more pressing when one takes into account the increasing urbanisation of Canada's Indigenous population. For the greater than 50 per cent of Indigenous people living in urban areas, the majority of the health programs and services they access will fall under provincial jurisdiction. For those who have access through their treaty rights to federal services such as NIHB, this access is often restricted because of the limited knowledge of urban service providers regarding these federal programs. Further, the lack of accurate ethnic identification by the provinces means that they are mainly invisible with respect to provincial vital statistics, surveillance and utilisation databases.

Understanding the interaction of registered First Nations people with the provincial health care system to obtain health systems performance measures relies on using processes that link information from the Indian Register, maintained by Indian and Northern Affairs Canada (INAC), with health-care records. Aside from the technical challenges of performing these linkages, the ethics of this practice without appropriate consent from Indigenous governing bodies has been challenged. Consequently, use of the information in the Indian Register now requires negotiation on a project-by-project basis. Finally, even if these challenges are overcome, the coverage is only 60 per cent, as these types of linkages do not allow for identification of non-status First Nations, Inuit or Métis.

# Current Indigenous Health Indicator Sets

In Canada there are data sets that exist at national, provincial and regional levels. It is important to be aware of which Indigenous peoples are represented in the data. As discussed earlier, Canada uses the constitutionally defined term 'Aboriginal' as an umbrella term for registered and non-registered First Nations, Inuit and Métis people. As there is no opportunity to self-identify when encountering the health care system, there is no continuous collection of health information for any Aboriginal group. Technically, the most feasible way of obtaining Indigenous-specific data, therefore, is by linking the Indian Register with health care databases. It is important to note that such databases generate data that is reflective of federal priorities, categorised by externally imposed political definitions of who 'Aboriginal' people are, and allows for a coverage of less than 60 per cent.

## National level health indicator sets

National agencies that have Indigenous health data include government agencies such as Statistics Canada, Canadian Institute for Health Information (CIHI), Public Health Agency of Canada (PHAC), Health Canada, FNIHB, INAC, and non-government organisations such as the National Aboriginal Health Organization (NAHO). Although none of the national Aboriginal organisations currently collect health status indicators, some developments are being made, such as the health information frameworks developed by the Inuit Tapiriit Kanatami (ITK) and the Assembly of First Nations.

### *Statistics Canada*

Statistics Canada has multiple data sets beginning with the Canadian census (Statistics Canada 2001a). The census includes the opportunity to self-identify Aboriginal origins, Aboriginal identity or both, and further classifies 'Aboriginal' as status or non-status North American Indian, Inuit, Métis or multiple. The ethnic identification questions are included on only 20 per cent of census forms. The census contains demographic data on population, language, education, income, employment, family characteristics, housing and religion. An important limitation of the census is the number of reserves that choose not to participate or are incompletely enumerated. In addition, it is likely that a significant number of Aboriginal people may choose not to self-identify to a government worker. Finally, the over-representation of Aboriginal people among homeless populations means that there is another Aboriginal group that will be under-represented. These problems with the census in turn affect other Statistics Canada data sets, such as the Aboriginal Peoples Survey (APS), as they draw the sample from the census Aboriginal identity population that is only available for a 20 per cent sub-set of census participants.

The APS was done in 1991 and 2001, and generally included non-reserve Aboriginal peoples, although all reserves in the Northwest Territories and certain reserves or other band-affiliated communities from Quebec, Saskatchewan, Alberta and the Yukon were also included (Statistics Canada 2001b). The APS was done in partnership with the Congress of Aboriginal Peoples, ITK, Métis National Council, National Association of Friendship Centres and Native Women's Association of Canada. The Assembly of First Nations participated in the development of the questionnaire. The 2001 APS included an Arctic and Métis supplement, which was administered to these northern Inuit and Métis populations.

The APS contains information on health status, language, employment, income, schooling, housing and mobility. It incorporates in its design an Indigenous understanding of health, and so attempts to explore the physical, mental/intellectual, emotional and spiritual facets of wellbeing. As such, it contains some standard items such as self-reported health status, but also explores further the holistic concepts of what makes Aboriginal peoples well by asking questions about healthy connections, as an example. The survey asks about the ability to speak an Aboriginal language, and also who taught the person to speak the language, and requests that the respondent rate the importance of being able to speak an Aboriginal language. Within the section on schooling, the survey seeks information on residential school attendance, highest educational attainment and reasons for not completing secondary or post-secondary school. In this way, it adds significant Indigenous-specific and Indigenous-centred information to the demographic information collected by the census. There are tentative plans for a third APS, which are contingent on funding support by the federal government.

The Canadian Community Health Survey is performed on a two-year cycle, but excludes sampling from reserves (Statistics Canada 2001c). It uses the same ethnic identity questions as the census, and seeks information on health determinants such as smoking and body mass index, health status, and primary health care services such as screening and immunisation. The Aboriginal population sample is too small to allow reporting below a provincial/territory level or to allow for the reporting of First Nations-, Inuit- or Métis-specific information. The purpose of this survey is to provide health information at a regional health authority level for policy and program planning, which was an identified gap in data availability when the shift from provincially operated to more regional health authority-operated systems occurred. In this regard, this survey fails to meet its purpose in relation to Aboriginal people.

### *Canadian Institute for Health Information*

The Canadian Institute for Health Information collects and publishes data on comparable health indicators, which include health status, non-medical determinants of health, health system performance measures, and community and health system characteristics (CIHI 2005a). CIHI also maintains multiple health service databases, including the Canadian Joint Replacement Register, Organ Replacement Register, Discharge Abstract Database and the Hospital Morbidity Database. A complete list is available on the CIHI website (CIHI 2005b). This data is arranged by geographic region and, in some areas, such as Nunavut or Northern Saskatchewan, where there is a high proportion of Indigenous peoples in identified geographical locales, geography could be used as a proxy measure of Indigenous identity.

### *Public Health Agency of Canada*

The Public Health Agency of Canada contains surveillance systems, such as the National Diabetes Surveillance System (NDSS) (PHAC 2002). In the NDSS the proposed method of collecting Indigenous-specific data is to link provincial or territorial data with Indigenous group membership information in that region, putting a temporary identifier to selected records to collect that data, which would then undergo routine NDSS calculations and aggregation to be reported at a national level. The limitation of this is that it will only provide information on registered First Nations people. While the PHAC contains many other surveillance programs, only the notifiable diseases reports contain Indigenous-specific data.

### *Health Canada, including the First Nations and Inuit Health Branch*

Most Indigenous health data in Health Canada is retained by FNIHB. An exception is Health Canada's report *Healthy Canadians a Federal Report on Comparable Health Indicators* (2002), which contains health status indicators ranging from life expectancy to mortality rates from various common malignancies. It only includes data for registered First Nations people on-reserve—with the exception of British Columbia and Alberta, where both on- and off-reserve populations were included—and cites its data source as FNIHB in-house statistics for most of the indicators. It is not clear how this data is generated within FNIHB, specifically with respect to cancer mortality rates, because the Canadian Cancer Registry does not contain an ethnic identifier. FNIHB has published this data on its website in a report entitled *First Nations Comparable Health Indicators*, which contains similar indicators referenced to in-house statistics with no description of how the data was generated (FNIHB 2005a).

FNIHB collects information from First Nations communities on immunisation programs and communicable diseases. It publishes an annual report of the NIHB program, which includes information on the total resources available to First Nations and Inuit communities, expenditures by benefit, per capita expenditures, dental and pharmacy utilisation rates and medical transport expenditures (FNIHB 2005a). In 2004, FNIHB published *A Statistical Profile on the Health of First Nations in Canada*, which contains information under the headings demographics, health status and non-medical determinants of health (FNIHB 2004b). It combines multiple data sources including Statistics Canada, INAC and FNIHB in-house statistics, and provincial/territorial databases, and information on registered First Nations people, generally on-reserve. It includes three pages detailing the limitations of the data in the report, which are extensive and include variable coverage of off-reserve populations, incomplete reporting for several or all indicators in most regions, and the lack of available Inuit-specific data.

In 2005, FNIHB released the *FNIHB Fact Sheet* (FNIHB 2005b), which stated the 'First Nations infant mortality rate in 2004 was 6.4 per 1000 live births'. When this figure was presented to the foetal and infant health study group and the steering committee of the Canadian Perinatal Surveillance System (CPSS) in April 2005, its validity was challenged by multiple members of these committees (CPSS Steering Committee & Fetal and Infant Health Study Group Minutes 2005). The CPSS steering committee wrote a letter to FNIHB expressing concerns that this figure was derived from inconsistent data sources, was in disagreement with regional rates that had been recently published in peer-reviewed journals, and was likely an underestimate.

A recurrent theme voiced by key informants is that the health information collected by FNIHB is largely project- or program-specific, and driven primarily by fiduciary accountability purposes. Thus, there is inadequate public health expertise surrounding the definition and collection of health indicator data. This makes the available information difficult to use for public health monitoring or programming, which is seen as more of a secondary purpose of the data collection. Another concern raised by regional level users of Indigenous health information is the delayed turnaround time they experience after reporting information to FNIHB. This was attributed to inadequate funding and infrastructure at the national level to input, process and analyse the information. This will be discussed more in a later section.

There is a First Nations Health Information System (FNHIS), which contains thirteen modules, although most key informants who were familiar with the system suggested that communities only used the immunisation module, and occasionally the tuberculosis module. The original goal of FNHIS was for communities in Ontario to improve the quality of clinical care and service in their own communities. Hence, it was primarily a service delivery and case management tool, as opposed to a public health surveillance tool.

According to key informants, FNHIS will not be used much longer. There are attempts to switch over to the Integrated Public Health Information System (i-PHIS), but challenges include a hesitancy to abandon a system that was designed in partnership with First Nations communities in favour of a system that has been developed completely externally to First Nations communities. I-PHIS is a tool that the Public Health Agency of Canada will allow public health jurisdictions to use without a licensing fee, and FNIHB is piloting its use in some communities. Included in i-PHIS are immunisation tracking, communicable disease case management and surveillance components. It is designed to be used centrally and, thus, it is unclear how it will be used by reserve communities. A potential advantage is that it allows multiple public health care providers access to an electronic patient record, which may improve cross-jurisdictional communication in areas of high mobility on- and off-reserve. The difficulty lies in understanding where the monitoring takes place. If monitoring takes place at a regional level will the responsibility for this monitoring be held by the provincial medical health officer, the FNIHB regional office or the tribal councils?

### *Indian and Northern Affairs Canada*

Indian and Northern Affairs Canada collects indicators on registered First Nations and Inuit people, although there is little Inuit-specific health data. Available health status indicators include life expectancy, birth and infant mortality rates, disability, suicide, addiction and solvent-abuse rates (INAC 2004a). INAC also maintains demographic data including housing, education, and the number of children in the custody of child and family services agencies. INAC has performed surveys of First Nations people on-reserve examining issues such as health, education, employment, television programming, Internet access and environmental concerns (INAC 2002, 2004b).

Again, the primary purpose of this data collection is fiduciary accountability. Concerns about its quality lead to policy makers relying on other sources of data, such as the census.

### *National Aboriginal Health Organization*

The National Aboriginal Health Organization, an Aboriginal-designed and controlled body, contains First Nations, Métis and Ajunnginiq (Inuit health) centres. The First Nations Centre hosted the First Nations Regional Health Survey (FNRHS), which was released in November 2005 and contains information in more than thirty areas, including demographics, language, housing, health status, culture and community development (First Nations Centre 2005). The 1997 First Nations and Inuit Regional Health Survey included eleven Labrador Inuit communities, but only includes registered First Nations people living on-reserve (First Nations and Inuit Regional Health Survey National Steering Committee 1999; First Nations Centre 2002).

The purpose of the FNRHS is to obtain longitudinal, comparable data that is centred around First Nations conceptualisations of health, is First Nations-controlled, reflects the priorities of First Nations communities, and respects the principles of OCAP (the right of Indigenous people to own, control, access and possess Indigenous health information). The FNRHS survey fills a gap left by large national population-based surveys that exclude sampling from reserves and do not provide respondents with an opportunity to self-identify, thereby failing to generate any Indigenous-specific health information.

The information collected through the FNRHS is available for reporting at a national or regional level, with the appropriate consent procedures. Community-level information is generally not available because of budget constraints, which required sampling to be from a sub-regional level, such as a tribal council, thereby making community-level data generally unreliable.

NAHO has also performed separate public opinion polls in 2002 that sampled registered First Nations and Métis peoples (First Nations Centre 2003; Métis Centre 2002). The public opinion polls asked about self-reported health and health services, including access to health care providers, procedures such as mammograms and dental examinations, and the need for home maintenance services for those with a physical, mental or other health condition. Aside from this poll, the Métis Centre relies on census data and the APS for Métis-specific health information. Inuit-specific health data is limited.

### *Inuit Tapiriit Kanatami*

In recognition of the lack of Inuit-specific data, the ITK is working on an Inuit Health Information Initiative, which will provide longitudinal data that is separated from First Nations or provincial/territorial data and will allow for reporting at a national, regional and local level (ITK 2005).

### *Assembly of First Nations*

In response to the federal/provincial/territorial initiative to develop an Aboriginal Health Reporting Framework, the primary motivation of which is accountability of the provincial premiers to the federal government, the Assembly of First Nations has developed a First Nations Health Reporting Framework. This framework uses the medicine wheel as its graphic conceptualisation, with the four sectors being individual health, health services,

community health and health determinants. According to a key informant, the purpose of this is to enable First Nations communities to measure their health and then use the information for community planning and to identify funding and program requirements.

### **Provincial/territorial level health indicator sets**

Since health care is, in most cases, a provincial- or territorial-operated system, all provinces maintain health information databases including vital statistics, physician billing systems, hospital administrative databases, notifiable diseases, chronic diseases, cancer registries and public health surveillance. Generally speaking, the provincial systems do not collect ethnic identifiers, thus Indigenous-specific data is not readily available in these data systems. In British Columbia, Alberta, Saskatchewan and Manitoba, the provinces do have ways of linking provincial health data with a subset of the resident First Nations populations; such links are through health card flags for First Nations persons who are registered with bands or INAC as treaty status and/or by performing linkages with INAC or other databases that identify First Nations persons with treaty status. These systems vary in quality, and again exclude non-status First Nations, Inuit and Métis populations. In addition, there are published reports that use data linkage processes to link this data with band membership lists, the Indian Register or Métis membership lists to generate Aboriginal-specific data. Examples include, *The Health and Health Care Use of Registered First Nations People Living in Manitoba: A Population-Based Study* (Martens *et al.* 2002), *The Health and Well-Being of Aboriginal People in British Columbia* (British Columbia Provincial Health Officer 2002) and *The Health of Manitoba's Métis Population and their Utilization of Medical Services: A Pilot Study* (Kliwer *et al.* 2002).

The purpose of these types of reports is variable. One key informant described a report coming about as a result of a consensual decision between the provincial health department and a university-based health policy research unit that Indigenous health was a priority to address. Using these types of databases, it is not possible to incorporate Indigenous understandings of health into the indicator framework or definitions because these rely on pre-existing universal frameworks. The reports can be useful as academic or policy reference documents, but it is less clear how individual communities could use this type of information.

### **Regional level health indicator sets**

Regional health authorities will have data similar to the data collected by the provinces disaggregated to the provincial health regions level, and generally do not have Aboriginal-specific data available. Another challenge here is that the provincial health regions usually do not correspond geographically to First Nations regional health authorities or tribal councils.

The *Northern Saskatchewan Health Indicators Report 2004* contains information on community characteristics including language and mobility status, non-medical determinants of health including income, education and environment, and health status (Irvine *et al.* 2004). The report includes information grouped by health region: Athabasca Health Authority, Keewatin Yatthe

Health Region and the Mamawetan Churchill River Health Region. Although no Aboriginal-specific data is presented as such, these regions contain self-identified Aboriginal populations of 93.4 per cent, 94.5 per cent and 76.6 per cent respectively. This serves as an example of how geography can serve as a proxy measure for ethnic identity in some situations.

### **Indigenous-operated health authorities**

Indigenous-operated health authorities may publish and maintain health indicator reports such as the *Prince Albert Grand Council Health Indicators Report 2004*, which is currently in draft form (Prince Albert Grand Council 2005). The information is grouped into sections on population and demographics, non-medical determinants of health, infectious diseases, health status and interaction of health determinants. The purpose of synthesising the information into this report was for community education and planning, with the goal of improving health status.

Ongoing surveillance at this level is generally limited to immunisation programs and notifiable diseases as required by FNIHB. There may be further indicators available scattered among other departments related to housing, education, and water quality or other environmental concerns, but this would be variable in availability, consistency and quality. Other health programs will depend on specific health authorities, the stage of transfer they are in, and the resources available for health information systems.

# Indicators Compendium

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A Compendium of Indigenous Health Indicators, which contains health indicators from both government sources and published literature, can be found in Attachment 1. The compendium uses the typology presented in the American Public Health Association's publication *Information Systems in Primary Health Care* (American Public Health Association 1983). Following this typology, the indicators are classified into the following sections: demographic, health status, resources (inputs), health services and activities (outputs) and community health. In recognition of the effects and differing stages of health transfer to First Nations communities, a sixth category on health transfer evaluation is also included. Since not all indicators will have specific data for each of Canada's Indigenous peoples, a column is included that identifies for which population's information is available.

# Indigenous Health Indicators: Barriers to Effective Use

In order to generate more useful Indigenous-specific health information, it is necessary first to understand why the currently available data has not been effectively used to inform health service planning.

## Themes

The following themes were identified through analysis of the key informant interviews:

- currently collected data is driven by accountability requirements;
- the quality of existing data is poor;
- data availability is limited by lack of appropriate ethnic identification;
- data quality is affected by jurisdictional issues;
- there is a lack of infrastructure at all levels;
- human resources are inadequate;
- little information is returned to the communities;
- tension exists between agencies that collect universal indicators and Indigenous-owned processes;
- there is mistrust of externally imposed processes;
- there is a need for culturally appropriate tools;
- there is a desire for a population health focus; and
- community-initiated processes that include capacity building are needed.

## *Accountability*

Many key informants note that much of the continuous, or annually collected, health indicators are primarily used to satisfy fiduciary accountability requirements.<sup>3</sup>

There's a lot of demand on First Nations communities to comply with information requirements, the same with data. They always have the data to justify why to give them the money but there's no real plan in place to actually use the data for anything real, other than to justify the expenditure.

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<sup>3</sup> The following quotes from key informants are confidential and, thus, anonymous.

### *Poor data quality*

The utility of currently available Indigenous-specific health data is limited by its poor quality.

There is very little data now—objective, valid, complete data—on, in terms of health assessment of, the First Nations in Canada... We have very little data, basic data, vital statistics, denominators, birth, death. We have very, very little data and it's probably not usable.

### *Ethnic identification*

The availability of non-registered First Nations-, Inuit- and Métis-specific data is limited by the lack of opportunity to self-identify when encountering the health care system.

They said it's too difficult; it takes too long to [go] through the process, to negotiate the data linking between the Status Verification System and the health data system within Manitoba Health. But you could actually change that all with, including, some ethnicity identifiers within all databases in all of Canada... The current data systems that exist are using First Nations as surrogate measures for Indigenous people in all of Canada. And I don't think there's any evidence to show that's actually a good valid measure of all Indigenous populations.

### *Jurisdiction*

The multi-jurisdictional nature of health care for Indigenous peoples impacts the quality of the available data. A main gap identified is the lack of communication between jurisdictions.

We don't have links to vital statistics, to the provincial systems and that's a very ... big problem for us.

Gaps and barriers. Well, for Métis, of course, there's jurisdictional ... barriers, being primary. The second one would be, as I mentioned, infrastructure resources and funding.

### *Infrastructure*

There is a lack of infrastructure at all levels to support the collection of relevant Indigenous-specific health indicators.

The accountability is based on a lot of process measures that don't really guarantee that we're going to obtain the objective of reducing mortality of incidence rates from injuries. And in the middle, all the epidemiological data and the data systems that have to be in place, and the collection systems, that is very underdeveloped and usually unfunded.

### *Human resources*

Inadequate human resources, including the capacity of front-line service providers who act as data collectors, limit the ability to collect, analyse and, therefore, respond to Indigenous-specific health indicators.

My experience is, you know, you have a three-nurse station and you're happy to have two... You know, all the time you hear of public health? Well, that takes second fiddle to the urgent needs of primary care.

For years we've been filling out these day-book reports, and every service that is provided at the clinic, there's a code... All of that used to go to FNIHB and they were supposed to give us back the information in a timely fashion. But over the last two years they don't—they say they don't have enough staff to input the data so it just kind of sits in boxes.

### *Lack of information to communities*

Despite submitting much-required data, there is a lack of meaningful and useful information being fed back into communities to inform public health planning or service delivery.

The reports are to reflect the needs of the organization, period... Now the data, any health-related data, doesn't go to the communities. Communities have no access to data.

We've always had difficulty trying to get information from FNIHB.

### *Tension between mainstream and Indigenous processes*

There is tension between agencies that collect universal, comparable health indicators and agencies that promote the development and collection of Indigenous-centred and owned health information.

We say we provide the data and remain as objective as possible... The Stats Act [states that] the data collected is the property of the Crown, and that's, yes, it is a subject of controversy between Aboriginal people and Stats Canada.

More and more Aboriginal and Indigenous researchers become recognized as scholars and participatory to mainstream research processes. One other gap and barrier that I'm going to identify... [is] the limitations and constraints placed by mainstream research institutions on—or in that Aboriginal organizations and/or researchers have, continue to have, difficulty in—accessing research funding dollars... Thereby non-Aboriginal scholars are better positioned in terms of their relationships with established scholars to access those dollars.

### *Mistrust*

Given prior negative experiences with academic researchers or government organisations, there is a lack of trust for processes that are derived external to the communities, and concern around how data will be used if the principles of OCAP are not respected.

And to me, there's a problem of trust... There's a problem of trust between governments and First Nations.

With increased trust in the national process after the first round, which, like I said, was very regional, it's possible to do bigger national components.

### *Culturally appropriate tools*

There is a need for culturally appropriate health measurement tools that are not pan-Indigenous and that incorporate a wellness perspective, are based on traditional health frameworks including midwifery, and incorporate Indigenous ways of knowing.

If we want to reflect something that's Indigenous, than we need to look at, well, what are Indigenous ways of living, and [to try] to capture that so that we actually can see that... And currently that doesn't exist. Everything is a reflection of the colonial system.

[The First Nations Health Reporting Framework has] a graphic conceptualization of it in terms of the medicine wheel. So, in the medicine wheel there are four areas: individual health, health services, community health and health determinants... And then we have community health. We have community control of health services, involvement of youth and Elders in decision-making, language knowledge in youths, traditional use of land and participation in traditional spiritual ceremonies or rituals. And then within health services there are two sections, one for traditional services... and [one for] Western-based services.

### *Population health focus*

There is a desire to use a population health approach, with a community level focus as opposed to individual level health status.

We attempt as best we can to adopt both a holistic approach and a population health approach within the work that we do... [but] most of the data is, you know, is I would say, the data is more indicative of individual health than it is of population.

### *Community-initiated processes*

There is a preference for community-initiated and driven processes that adequately address the need for building the capacity to define, collect, analyse and respond to health information.

We developed it as a community template that communities can use and our regions can use to report on their health, and then hopefully they can negotiate with the provinces and with FNIHB.

The process of developing the national questionnaires took two years, like it was a huge process. It involved input from hundreds of people, community-level people...

## **Discussion**

The identified themes inform our understanding as to why the use of current Indigenous health indicators has not effectively translated into programming and policies that are able to contribute to the improved health of Indigenous peoples. The currently available data highlights the disease status and health disparities between registered First Nations people and the non-Indigenous population. It has limited utility at a community level as the data

is more reflective of national priorities, fails to incorporate Indigenous conceptualisations of health, and has been selected largely to satisfy fiduciary accountability requirements, with little public health expertise in its design.

Serious concerns were raised about the quality of the existing data. The calculation of indicators such as birth and death rates necessitates accurate population estimates in order to have appropriate denominators. However, there are differing population estimates for registered First Nations people depending on whether the Indian Register, the census or band lists are used. Census counts have differed because of the phenomenon of ethnic mobility in inter-censal periods, and whether one considers the 'Aboriginal origin' or 'Aboriginal identity' population. With each census, there are more communities that choose not to participate or are incompletely enumerated, which compounds the difficulty with obtaining accurate population estimates, and limits the comparability of such rates over time.

Despite concerns regarding the quality of the data available for registered First Nations people, existing data continues to be used as a marker of 'Aboriginal' health in Canada. The absence of appropriate ethnic identification on health records, which is maintained by the lack of opportunity to self-identify, contributes to the ongoing oversight of non-registered First Nations, Métis and many Inuit people, particularly in urban communities. This allows for a tacit acceptance of the disparity in health status, since it cannot be accurately quantified, and is, therefore, not addressed with programs, policies and appropriate funding for each population. As a result of this lack of self-identification, the only source of Indigenous-specific health information is periodic surveys, which rely on self-reported health status, only occur every few years and have insufficient sampling to provide data below the provincial/territorial level. These factors contribute to the inadequacy of the surveys in serving as the bases for regional or community-level planning and surveillance.

One of the arguments against voluntary self-identification as First Nations, Inuit or Métis when accessing the health care system is concern over who will own and control the Indigenous-specific data generated. Many key informants mentioned this concern. There is ongoing controversy between Aboriginal groups and Statistics Canada over data ownership. The Statistics Act states that any data collected by Statistics Canada is owned by the Crown, but the Chiefs Committee on Health of the Assembly of First Nations has raised concern over the fact that permission has never been granted to Statistics Canada to collect and use First Nations-specific data. These concerns need to be balanced with the current capability of Indigenous organisations to define, collect, analyse and respond to Indigenous health information.

## Best Practice Examples

The following examples of community-based collaborative health indicator or health measurement systems were identified through an extensive literature review, as detailed in the Introduction.

### **Inuksiutiin health information framework**

In 2002 the ITK published a report entitled *Inuksiutiin Health Information Framework* (Boyd & Associates 2002). This was commissioned as part of a process to enable the Inuit people to secure strategic Inuit-specific data based on the Inuit understanding of health, which would help them to become participants and leaders in their health planning. The report articulates some key principles around the need for, and development of, Indigenous-specific information. This includes the need to understand the Indigenous-specific values for attaining health, the multiple jurisdictions providing health care, the diversity and complexity of health information systems and telecommunications technology, and the need to build the required capacity.

The report does not include a detailed methodology, but the process included eighteen months of extensive consultation and the drafting of background documents. The intent of the process was to maximise discussion and achieve consensus.

The components of the framework deemed necessary in securing Inuit-specific health data include a vision; key milestones and outcomes; affirmation of national relevant Inuit-specific health indicators; process(es) for identification of common data elements, implementation of a data integrity model and assessment of technological compatibility to support data sharing; OCAP requirements, including research parameters; operating requirements; recommendations that support the circumpolar (or relevant local) perspective; requirements for evaluation of progress; and assurance of privacy. Although this framework is specific to Inuit health measurement, the list of components provides a reasonable and relevant checklist for the development of other Indigenous-specific health measurement systems.

### **Development of an evaluative framework for use by First Nations health organisations**

Doctors Sylvia Abonyi and Bonnie Jeffery of the Saskatchewan Population Health and Environmental Research Unit have developed a community health and wellness framework, which includes the following domains: economic viability, environment, identity and culture, healthy lifestyle, food security, and services and infrastructure (Abonyi *et al.* 2005). The purpose of this research project was to develop a framework and set of indicators that

would help First Nations and Aboriginal communities in Northern Saskatchewan to plan, track and evaluate community-based health and human service programs.

The methodology used to develop the framework began with a literature review used to draft community health frameworks and indicators. Logic models describing each health program in the six participating First Nations communities were developed in order to identify potential baseline indicators. Interviews and focus groups were then held with community collaborators to revise and refine a final framework and set of indicators. The resulting toolkit was piloted in one community. In evaluation, the health directors saw the value of the toolkit in its proposed objectives of planning, tracking and evaluation of programs.

### **The West Kitikmeot Slave Study Society community-based monitoring project**

Between 1996 and 2001, the Lutsel K'e Dene First Nation undertook a community-based monitoring project with the aim of meaningfully involving community members in understanding and documenting changes in the health of their community as a result of mineral resource development (Waldram *et al.* 1995). The project contained three phases: gathering ideas and Chipewyan terminology for concepts such as monitoring, indicators and community health; developing themes and indicators of community health through open-ended home visits with 100 households in the community; and a four-step process for monitoring the defined indicators. The methodology included facilitated involvement of the community in three main areas: training and employment of community members; strong communication and working relationships with the band membership and leadership; and participation and communication with the broader band membership.

A formal evaluation of the processes used to develop the community-based indicators was not done, but the indicators were used by the local band council, health and social services board, justice committee and wildlife committee in setting community goals, community planning and assessment of resource development, and in designing and evaluating community projects.

### **Community health indicators project**

The Mohawk Council of Akwesasne and the Institute of the Environment at the University of Ottawa worked together on a project entitled 'Community Health Indicators', with the objective of developing community health indicators based on the knowledge and valid requirements of Aboriginal communities for use by them (Grafton 2001). There was an identified need for a system of indicators that recognises the principles of self-determination, inherent in which is empowering the communities themselves to understand and rectify deficiencies in health. Key underlying principles of the project included involving community members in the process of community health as a way to help the community create new visions of their future, develop new relationships, and define assets, problems and opportunities in new ways.

There were two processes for indicator development described in the project. The first process entailed an interaction between the Western knowledge constituency and the traditional knowledge constituency. After a literature review identified possible health indicators, both constituencies reviewed the indicators. The objective of the Western knowledge constituency was to determine if the indicators were valid. The traditional knowledge constituency could add new indicators or veto indicators if they were deemed unacceptable. The reviewed lists were compared and the overlap considered consensually agreed upon indicators. This revised list was then assessed to determine the quality of the relationship between the condition indicator and the aspect of health it measures, or between the stress indicator and the condition indicator it impacts, and to assess the quality and availability of data for the indicator. The final step was to ensure that each aspect of the 'life indicators wheel' was represented.

The life indicators wheel was the agreed upon indicator framework in this project. A wheel was felt to be appropriate as it reflects the circle of life, the prayer wheel and the medicine wheel. The wheel is divided into a corporal and a spiritual section. The corporal section includes the concrete and practical sections of the health paradigm. The aspects of life included in this section are environment, religion, politics and economics. The spiritual section includes the intangible aspects of community health: values, morale, responsibility and spirituality (being connected to the 'Good Mind' and through this mind to the universe, performing our responsibilities not to religious institutions but to the Creator and to the world).

The second process of indicator selection was carried out in Conne River First Nation. One-on-one open-ended interviews were conducted with Elders in the community who were asked these questions: 'What is a healthy Conne River community? How would you describe a really healthy community here in Conne? How would you know when Conne River was not healthy?' Elders were prompted, if necessary, to ensure the areas of religion and spirituality, politics and responsibility, environment and morale, and economics and values were addressed.

A report was written based on the results of the interviews, and then a survey drafted with all the identified indicators. The survey was done door-to-door, and all adults in the household asked if they felt each indicator was 'good', 'not good' or 'no opinion'. The revised list was then assessed by the Conne River Health and Social Services Department for relevancy, reasonability and acceptability.

In the available reports there is no mention of how or if these processes were evaluated.

### **Canadian Aboriginal communities: A framework for injury surveillance**

Auer and Andersson published an article entitled 'Canadian Aboriginal Communities: A framework for injury surveillance', in which they describe a methodology for the development of a community-based surveillance system (Auer & Andersson 2001a). It was recognised that the surveillance system would need to be culturally relevant, acceptable, owned by the target population (a reserve), and meet the specific requirement for injury data and data collection methods of the community.

The process began with understanding the medical service patterns for the management of injured patients (Auer & Andersson 2001b). National focus groups were held to establish consensus on a conceptual framework to guide the development of the injury surveillance system. Community focus groups established safeguards to protect confidentiality, developed protocols for data handling and storage, determined training requirements, piloted the data collection instrument and the overall system, and developed recommendations for standardised community reports. The community focus groups were used to ensure that the injury surveillance system was developed and tested in the context of its intended environment by its intended target group.

## Concluding Comments

The delivery of health care to Indigenous people in Canada is complex and multi-jurisdictional, and differs among registered First Nations people on-reserve, registered First Nations people off-reserve, non-registered First Nations people, Inuit and Métis. Understanding how the health care system performs in relation to each of these groups is similarly difficult; especially with the ongoing lack of appropriate Indigenous-specific data to populate currently used health system performance frameworks such as that used by CIHI.

Currently collected health information has limited utility at a community or regional service delivery and planning level. Identified reasons for the limited utility include the poor quality of the data; the lack of reporting of data below a provincial/territorial level; the predominant use of centrally defined or universal indicators that are not reflective of Indigenous understandings of health or local priorities; the requirement of submission of health information for accountability purposes as opposed to health surveillance or planning; and the lack of infrastructure, including human resources, at all levels to support the appropriate definition, collection, analysis and response to health information.

While there are good examples of community-based and regional health measurement projects, it is important to realise that these are not given the same sustained funding as government data collectors such as Statistics Canada, and as a result they function within the confines of project-based funding.

The desire exists to have Indigenous-specific and Indigenous-centred health information that is based on culturally relevant conceptualisations of Indigenous health, captures notions of collectivity as opposed to solely measuring individual health status and incorporates a wellness perspective. The processes used to develop such systems need both to be community driven and to address adequately the need to build the capacity of communities to define, collect, analyse and respond to health information. This information will be an important complement, not replacement, to universal comparable health indicators, which have an ongoing role in highlighting health disparities between Indigenous and non-Indigenous people in Canada. Both of these systems are necessary: the community-based system to allow for effective health service planning and surveillance, and the universal system for measuring the progress towards the elimination of existing health disparities.

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# Attachment 1: Compendium of Indigenous Health Indicators in Canada

Category	Indicator	Source	Available for	Notes
Demographic	Population	Band list, census data StatCan, INAC Indian Register (Status Verification System)	Status and non-status FN people on and off reserve, Inuit urban and remote, and Métis	In 2001, 30 reserves were incompletely enumerated or did not participate in the census, since APS samples from census would not be included in that survey either
	Population growth rate	StatCan	Note INAC has basic departmental data for population changes in registered Indians only; Northern Indicators Report does not have Aboriginal specific data	Although no Aboriginal-specific data, geography can act as ethnic proxy in regions with a high proportion of Aboriginal people, e.g. Northern Sask, Nunavut
	Population density per square kilometre	Census	By geographic region	
	Number of FN Communities by degree of isolation	FNIHB in-house data	Registered FN	
	Age distribution	Census	Status and non-status FN on and off reserve, Inuit and Métis urban and rural	
	Percentage of population under 20 years of age	StatCan	As above	
	Common-law/ Marital Status	Census	As above	
	Language use: English, French, or other	Census	As above	
	Language use: Aboriginal language	Aboriginal Peoples Survey	APS: Status and non-status, Inuit, Métis	2 <sup>nd</sup> survey (RHS) expanded questionnaire, included registered FN only
	FNIRHS	FNIRHS: FN on reserve and some Labrador Inuit communities		

Category	Indicator	Source	Available for	Notes	
Demographic	Mobility status: place of residence 1 and 5 years ago	Census	FN on and off reserve		
	In past 2 years, no. of times lived outside of FN community	Fall 2002 FN Survey	Inuit, Métis FN on reserve		
	Aboriginal self-identity	Census	As above		
	Life expectancy		A Statistical Profile on the Health of First Nations in Canada—INAC basic departmental data	INAC: Registered FN on/off reserve Inuit living in some northern regions	Both sources identify INAC basic departmental data as primary source
			Health Canada: A Federal Report on Comparable Health Indicators	Registered FN: note that some data based on certain provinces only, not national results	
	Disability-free life expectancy	Health Canada FRCHI	FNIHB in-house data		
	Dependency ratio: population age <15 divided by population age 15–64 multiplied by 100	ASPFNC	Registered FN	This document contains a lot of footnotes to explain where data comes from and why it is incomplete, e.g. misses certain provinces	
	Birth rate	ASPFNC—FNIHB in-house data	Registered FN		
INAC					
Demographic: Education	Total population 15+ attending school full-time; also divided age 15–19, 20–24	Census	Status and non-status FN, Inuit, Métis		
	Total population 15 and over attending school part time; also divided age 15–19, 20–24	Census	As above		
	Highest level of schooling	Census, APS; INAC data for people who receive funding for post-secondary; FNIRHS	As above		

Category	Indicator	Source	Available for	Notes
Demographic: Education	Percentage with selected reasons for not completing elementary, secondary or post-secondary school	APS	Status and non-status FN, Inuit and Métis	
	Percentage of people 15+ who attended residential school	APS, FNIRHS	Status and non-status FN, Inuit, Métis	
Demographic: Income	No. of persons with earnings	Census	As above	
	Average earnings—all persons with earnings	Census	As above	
	Persons 15+ with income	Census	As above	
	Median total income of persons 15+, and composition (earnings, government transfer, other)	Census	As above	
Demographic: Employment	No. who worked full year, full-time	Census	As above	
	Mode of transportation to work	Census	As above	
	Persons reporting hours of unpaid work, and type (e.g. housework, childcare, assistance to seniors)	Census	As above	
	Labor force participation rate	Census	As above	
	Employment and unemployment rate	Census	As above	
	No. of people involved in selected workforce areas (e.g. health, agriculture, education)	Census	As above	
Demographic: Family characteristics	Total number of families	Census	As above	
	Number of female lone-parent families	Census	Status and non-status FN, Inuit, Métis	
	Number of male lone-parent families	Census	As above	

Category	Indicator	Source	Available for	Notes
Demographic: Housing	Total number of households	Census	As above	
	Median household income	Census	As above	
	Percentage of people living in crowded conditions (1 or more people per room)	APS, INAC, Keewatin Health Assessment Study, Canadian Mortgage and Housing Corporation	INAC registered FN on reserve and Inuit in northern communities only  APS status and non-status FN, Inuit, Métis	CMHC has data that is derived from census
	Percentage of houses needing regular maintenance, minor or major repairs, replacement	INAC	Registered FN on reserve, Inuit in Northern communities	
CMHC		On and off reserve status and non-status FN, Inuit, Métis		
Demographic: Religion	No. Catholic, Protestant, etc.	Census	Status and non-status FN, Inuit, Métis	
Health status: Perinatal	Infant mortality rate and cause	ASPENC: FNIHB in-house data	Registered FN	FNIHB no data from 1994–98
		INAC		Full reference at end of document
		Luo <i>et al.</i> 'Infant Mortality in BC'		
	Birth weight, prevalence of low and high birth weight	ASPENC: FNIHB in-house stats,	Registered FN	
		FNIRHS	Registered FN on reserve and Labrador Inuit	
	Rate of breast-feeding: had the child been breast fed, analysed by age group	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Breast feeding initiation rates	Health and Health Care Use of Manitoba's First Nations	Registered FN on and off reserve	
	Knowledge of important things pregnant women can do to increase likelihood of having a healthy baby	Fall 2002 FN Survey	Registered FN on reserve	
Respondent-reported health of child	FNIRHS	Registered FN on reserve and Labrador Inuit		

Category	Indicator	Source	Available for	Notes
Health status: Child	Respondent-reported specific health problems in child, e.g. ear problems, asthma, bronchitis	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Lifetime prevalence of specific injuries, e.g. broken bones, serious burn	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Percentage who report child getting along with family	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Percentage who rate child's knowledge of Native culture 'very satisfied', etc.	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Percentage of children routinely immunised by age group	FNIHB in-house stats	Registered FN on reserve only	
	Age-specific rates of communicable diseases like pertussis	FNIHB in-house stats, Canada Communicable Disease Report	Registered FN on reserve only	
	Percentage of children with no decayed, missing/extracted or filled teeth	In ASPFNC	Ref. oral health study	
Health status: Overall	Crude mortality rate	FNIHB in-house stats	Registered FN	
	Premature mortality rate	Health and Health Care Use of Manitoba's First Nations: linkage from administrative databases and SVS	Registered FN on and off reserve	
	Age-specific death and mortality rates by gender	FNIHB in-house stats	Registered FN	
	Leading causes of death by age group; also available age-standardised	FNIHB in-house stats	Registered FN	
	Potential years of life lost by cause of death		FNIHB in-house stats	Registered FN on and off reserve
Health Canada: FRCHI				

Category	Indicator	Source	Available for	Notes
Health status: Overall	Incidence rates of 11 notifiable diseases including STIs, TB, enteric and waterborne diseases	FNIHB in-house stats	Registered FN on reserve	
		Canada Communicable Disease Report	Communicable disease surveillance collects ethnicity data for some diseases, e.g. TB	
		Health Canada: FRCHI	Registered FN on and off reserve	
	Self-reported influenza immunisation	CCHS	Off reserve status and non-status FN, Inuit and Métis	
	Hospital separations for all causes; also available for unintentional and intentional injuries; cancers; diabetes; IHD; cerebrovascular disease	In ASPFNC, source MB Health and SK Health, BC Ministry of Health Planning, CIHI Hospital Morbidity Database	Registered FN on and off reserve	CIHI uses postal codes, so could use location as ethnic proxy for Inuit in Nunavut
	Rates of smoking	FNIRHS	Registered FN on reserve and Labrador Inuit	
		Health Canada: FRCHI	Registered FN on and off reserve	
		Keewatin Health Assessment Study	Inuit in Keewatin region	
	Rates of smoking and smoking initiation age	CCHS	Off reserve status and non-status FN, Inuit and Métis	
	Non-smokers with reported exposure to second hand smoke	CCHS	Off reserve status and non-status FN, Inuit and Métis	
Self-reported amount and frequency of alcohol intake	CCHS	Off reserve status and non-status FN, Inuit and Métis		
Number of in-patient admissions to NNADAP treatment facilities	FNIHB in-house stats	Registered FN		
Self-reported functional health status	CCHS	Off reserve status and non-status FN, Inuit, Métis	StatCan, personal communication 'The reason we don't collect data on reserve is they don't allow us to'	

Category	Indicator	Source	Available for	Notes
Health status: Overall	Self-rated health status	APS, FNIRHS KHAS CCHS	Status and non-status FN on and off reserve, Inuit, Métis	
	Self-reported prevalence of chronic diseases, e.g. diabetes, arthritis, heart disease, hypertension, asthma, stomach problems	APS, FNIRHS KHAS CCHS	As above	
	Incidence of self-reported injuries in past 12 months	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Mortality rates for malignancies, acute MI, stroke	Health Canada: FRCHI	Registered FN on and off reserve	Cites FNIHB in-house stats, qualifies that the BC and Alberta data is on and off reserve
	Incidence rates for lung, prostate, breast, and colorectal cancer	Health Canada: FRCHI, Health of Manitoba's Métis People	Registered FN on and off reserve	
	Prevalence of diabetes	Health Canada: FRCHI  Health of Manitoba's Métis People	Registered FN on and off reserve  Métis	
	Number of lower limb amputation secondary to diabetes per 1000 people age 20–79	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Physical activity	Health Canada: FRCHI  CCHS.	Registered FN on and off reserve  Off reserve status and non-status FN, Inuit, Métis	
	Body weight	Health Canada: FRCHI  KHAS	Registered FN on and off reserve  Inuit in Keewatin Region	
	BMI	CCHS	Off reserve status and non-status FN, Inuit, Métis	

Category	Indicator	Source	Available for	Notes
Health status: Overall	Self-reported eating habits healthy, mainly healthy, not healthy, have they improved in past few years	Fall 2002 FN Survey  KHAS	Registered FN on reserve  Inuit Keewatin region	
	Self-reported consumption of fruits and vegetables	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Self-reported level of physical activity, reasons for inactivity	Fall 2002 FN Survey	Registered FN on reserve	
	Percentage classified as overweight or obese	FNIRHS  KHAS	Registered FN on reserve and Labrador Inuit  Inuit Keewatin region	
	Percentage with pain that limits activity, degree of pain	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Percentage with two-week disability days	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Disability rates secondary to hearing, sight, speech, mobility	StatCan	Status and non-status on and off reserve, Inuit, Métis	
	Percentage experience activity limitation (no specified cause)	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Self-reported risk of depression	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Self-reported level of life stress	CCHS	Off reserve status and non-status FN, Inuit, Métis	
Resources (inputs)	Percentage of communities involved in health transfer agreements	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Total resources to FN and Inuit health programs; broken down to health services, hospital services, NIHB	FNIHB–NIHB Annual Report	Registered FN and Inuit	

Category	Indicator	Source	Available for	Notes
Resources (inputs)	NIHB expenditures by benefit (transportation, pharmacy, dental, other health care, premiums, vision care)	FNIHB–NIHB Annual Report	Registered FN and Inuit	
	NIHB per capita expenditures	FNIHB–NIHB Annual Report	Registered FN and Inuit	
	Dental and pharmacy utilisation rates by region	FNIHB–NIHB Annual Report	Registered FN and Inuit	
	National top 10 drug products by expenditure or claims incidence	FNIHB–NIHB Annual Report	Registered FN and Inuit	
	National top 10 medical supplies and equipment by claims incidence or expenditures	FNIHB–NIHB Annual Report	Registered FN and Inuit	
	NIHB Expenditures on medical transportation by type and region	FNIHB–NIHB Annual Report	Registered FN and Inuit	
	Perceived danger to health of illegal drugs, drinking alcohol, smoking cigarettes, smoking marijuana	INAC Fall 2003 Survey of FN People Living on reserve	Registered FN on reserve	
	Rate of repeated marijuana use, and frequency of use	INAC Fall 2003 Survey	Registered FN on reserve	
Health Services and Activities (Outputs)	Number and purpose of health center visit	Nurses Daybook, sent to FNIHB	Registered FN on reserve and Inuit in Northern communities	No funds/staff to process these once sent to FNIHB
	Childhood immunisation rates	ASPFNC–FNIHB in-house	Registered FN on reserve	
	Rates of screening like pap smears or mammography	May be available provincially, but not uniformly and require data linkage, e.g. Health and Health Care Use of Manitoba’s First Nations  CCHS	Registered FN  Off reserve status and non-status FN, Inuit, Métis	CCHS has mammography rates for women aged 50–69, and Paps for women 18–69 within 1 year, within 3 years, more than 3 years or never

Category	Indicator	Source	Available for	Notes
Health Services and Activities (Outputs)	Patient satisfaction with overall health care services received	Health Canada: FRCHI	Registered FN on and off reserve	CCHS also breaks down to hospital care, community based health care, family doctor, telephone health line service
		NAHO Public Opinion Poll	Registered FN on or near reserve	
		KHAS	Inuit Keewatin region	
		CCHS	Off reserve status and non-status FN, Inuit and Métis	
	Percentage having a regular family doctor	Health Canada: FRCHI	Registered FN on and off reserve	
		NAHO Public Opinion Poll on Health Care		
	Utilisation of home care services	Health Canada: FRCHI	Registered FN on and off reserve	FNIHB spreadsheet
	Hospitalisation rates for ambulatory care sensitive conditions	Health Canada: FRCHI.	Registered FN on and off reserve	
		Shah, 'Markers of Access to Primary Care for Aboriginal People in Ontario Canada' <i>AmJ Public Health</i>	Registered FN	
	Self-reported ease of access to various health care providers	NAHO Public Opinion Poll on Health Care 2002	Registered FN on or near a reserve	
	Self-reported inability to access needed health care in the past year	NAHO Public Opinion Poll on Health Care	Registered FN on or near a reserve	
	Percentage accessing the use of a traditional healer or medicines in past year	NAHO Public Opinion Poll on Health Care	Registered FN on or near a reserve	
	Percentage reporting contact with alternative health care provider	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Percentage reporting contact with mental health professional in past 12 months	CCHS	Off reserve status and non-status FN, Inuit, Métis	
Contact with following health care professional: family doctor or GP, dentist or orthodontist, eye doctor, other medical doctor, nurse, traditional healer	APS	Status and non-status, Inuit, Métis	CCHS reports contact with medical doctor, dental professional in past 12 months	
	CCHS	Off reserve status and non-status FN, Inuit, Métis		

Category	Indicator	Source	Available for	Notes
Health Services and Activities (Outputs)	Contact with telephone health line in past 12 months	CCHS	Off reserve status and non-status FN, Inuit, Métis	
	Average annual number of physician visits for Métis people by age, gender, diagnosis	The Health of Manitoba's Métis People and their Utilization of Health Services	Métis	
	Hospitalisation rates for Métis people by age, gender, diagnosis, procedure	As above	Métis	
	Percentage of people believing health service is equal with the rest of Canada	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Ambulatory visit rate	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Ambulatory consult rate	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Ambulatory specialist contact rate	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Ambulatory visit providers: per cent GP vs specialist	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Location of ambulatory visit to GP and specialists, of hospitalisation	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Total days of hospital care per person	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Cardiac catheterisation, CABG, and angioplasty rate per 1000 people	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Caesarean section rate per 1000 women giving birth	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Hysterectomy rate per 1000 women age 25 years or over	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	

Category	Indicator	Source	Available for	Notes
Health Services and Activities (Outputs)	Tonsillectomy, adenoidectomy rate per 1000 children age 0–14	Health and Health Care: Manitoba's First Nations	Registered FN on and off reserve	
	Percentage of people surveyed believing need for improvement in various services (e.g. mental health services, dialysis)	FNIRHS	Registered FN on reserve and Labrador Inuit	
Community Health	Percentage of on reserve houses having an adequate water supply (piped, wells, trucked or other)	ASPHFNC–INAC data	Registered FN on reserve	
	Percentage of on reserve houses having an adequate sewage system (piped, septic field or tank, septic truck, other)	ASPHFNC–INAC	Registered FN on reserve	
	Food Basket Costs (designed for particular study, to feed family of four)	Northern Sask Population Health Unit: The Cost of Healthy Store-Bought Foods in Northern Saskatchewan	Not Aboriginal specific, based on region of residence	
		Pauktuutit: Inuit Women's Health: Overview and Policy Issues. 2000	Inuit	
	Percentage of people reporting unsafe drinking water at some point in past year, non-reserve	APS	Status and non-status FN, Inuit, Métis	
	Number of First Nations Communities under boil water advisories by duration of advisory	ASPHFNC–FNIHB in-house data	Registered FN on reserve	
	Percentage of people surveyed reporting exposure to environmental tobacco smoke	FNIRHS	Registered FN on reserve and Labrador Inuit	

Category	Indicator	Source	Available for	Notes
Community Health	Percentage of people with ability to speak an Aboriginal language, non-reserve areas	APS	Status and non-status FN, Inuit, Métis	
	Percentage taught Aboriginal language by parents, grandparents, aunts and uncles, other relatives, school teachers	APS	As above	
	Percentage of people rating learning, relearning or keeping an Aboriginal language as important or somewhat important, non-reserve	APS	As above	
	Percentage with Aboriginal language as first language	Census	Status and non-status FN on and off reserve, Inuit, Métis	
	Percentage able to converse in Aboriginal language	Census	As above	
	Percentage of people surveyed believing progress made in various areas of community wellness	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Percentage of respondent communities involved in health transfer	FNIRHS	Registered FN on reserve and Labrador Inuit	
	Percentage of people aged 15 or over with healthy connections: someone to call for help, involved in some form of physical activity and social support, participate in traditional Aboriginal activities	APS	Status and non-status FN, Inuit, Métis	

Category	Indicator	Source	Available for	Notes
Community Health	Percentage of children in custody of CFS agencies	INAC basic departmental data	Registered FN on and off reserve	
	Percentage of people surveyed who believe that the following are a problem in their community: family violence, rape, sexual abuse	APS	Status and non-status FN, Inuit, Métis	
	Percentage of incarcerated people reporting Aboriginal ancestry	Adult Correctional Services Survey, conducted annually	Status and Non-status FN, Inuit, Métis	
	Number of Aboriginal youth in custody	A One-Day Snapshot of Aboriginal Youth in Custody 2000 and 2003	Status and non-Status FN, Inuit, Métis	
	Percentage with sense of belonging to family, FN, Canada, province	Fall 2002 FN Survey	FN on reserve	
	Percentage of people concerned about climate change	Fall 2002 FN Survey	FN on reserve	
	Health Transfer Evaluation	Percentage of people surveyed who agree that health transfer or integration model improves service delivery, provides flexibility, or increases control over programs and service delivery	CAHR 'The Evaluation of the First Nations and Inuit Health Transfer Policy', Lavoie <i>et al.</i> March 2005	Registered FN and Inuit on reserve
Percentage of people surveyed who report being able to allocate funding to local needs		As above	As above	
Percentage of people surveyed who stated they were able to develop administrative, management, service delivery and programming skills		CAHR 'The Evaluation of the First Nations and Inuit Health Transfer Policy'	Registered FN and Inuit on reserve	

Category	Indicator	Source	Available for	Notes
Health Transfer Evaluation	Percentage reporting increase in employment opportunities in community as result of transfer	As above	As above	
	Percentage reporting increased stability of workforce	As above	As above	
	Percentage reporting difficulty recruiting/ retaining nursing and other professional staff	As above	As above	
	Percentage reporting system in place to meet needs of community accountability	As above	As above	
	Percentage reporting ability to meet day-to-day public health and safety requirements of mandatory programs	As above	As above	
	Percentage reporting linkages with provincial public health systems	As above	As above	
	Percentage reporting unresolved jurisdiction issues causing difficulty accessing care	As above	As above	
	Percentage reporting increased health of community after transfer	As above	As above	
	Percentage reporting administrative concerns because funding does not match needs, does not provide for population growth, does not include non-status or off reserve people	As above	As above	

**Notes:**

1. Aboriginal Peoples Survey: 2001 last survey; sampled from people who self-identified on Census as North American Indian, Inuit or Métis. Interestingly (and frustratingly), although the report is called 'Aboriginal Peoples Survey 2001: Well-being of the Non-Reserve Aboriginal Population', when I reviewed the sampling details there were on-reserve people surveyed. I do not know if this means that data isn't presented, but it would be available—somewhere.
2. First Nations and Inuit Regional Health Survey: 1997 surveyed only Registered FN on reserve and some Labrador Inuit communities; latest survey (release pending Fall 2005) sampled only FN on reserve.
3. FNIHB and INAC both contain little Inuit-specific data.
4. A Statistical Profile on the Health of First Nations in Canada 1999: Registered FN only.
5. The Health and Health Care use of Registered First Nations People Living in Manitoba: A Population-Based Study was a one-time study using administrative databases and status verification system for linkage, Registered FN only.
6. Federal Report on Comparable Health Indicators: relies on administrative databases and data linkage, Registered FN only.
7. Fall 2002 and 2003 Survey of First Nations People Living On-Reserve: on INAC website under Aboriginal Peoples Survey, but content different from APS and only includes Registered FN living on reserve.
8. The Health of Manitoba's Métis Population and their Utilization of Medical Services: A Pilot Study linked administrative databases with a sample of the Manitoba Métis Federation's Membership List.
9. Keewatin Health Assessment Study carried out once in 1991 in eight predominantly Inuit communities in NWT.
10. Lavoie *et al.* 2005, *The Evaluation of the First Nations and Inuit Health Transfer Policy, Vol. 1, Executive Summary*, Center for Aboriginal Health Research, March.
11. Canadian Mortgage and Housing Corporation 2001, *Census Housing Series, Issue 6: Aboriginal Households*, August 2004.
12. Canadian Community Health Survey. Two-year cycle, does not include reserve populations, gives opportunity to self-identify.
13. Z. C. Luo *et al.* 2004, 'Infant Mortality among First Nations Versus non-First Nations in British Columbia: Temporal trends in rural versus urban areas 1981–2000', *International Journal of Epidemiology*, vol. 33(6), pp. 1252–9.

