

First Nations, Métis, and Inuit Health Indicators in Canada

A Background Paper for the project
“Action Oriented Indicators of Health and Health
Systems Development for Indigenous Peoples in
Australia, Canada, and New Zealand”

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We would like to start by recognizing the askicowahk or Indigenous peoples of the land.

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1.0 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, Métis, or Inuit 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 conceptualize 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 Canada, Australia and New Zealand. This paper reports on our stock-take 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 We base our findings on our review of the published and unpublished literature, expert consultation, and key informant interview data.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 healthcare databases leads to very poor coverage of Canada’s Indigenous population, with a specific paucity of health information for non-registered First Nations, Métis, and Inuit Peoples. Provincial and territorial systems generally do not collect ethnic specific utilization 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 infrastructure¹, 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 prioritize national level accountability goals at the expense of local relevance and utility. We did identify several best practice examples in which Indigenous organizations and communities have responded to the gap in local Indigenous health information system development by initiating their own health measurement models.

First Nations, Métis, and Inuit 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, Métis, and Inuit health services. Such frameworks will need to draw on accurate and relevant universal public health measures as well as First Nations, Métis, and Inuit specific indicators. This will only be possible with strong First Nations, Métis, and Inuit leadership and participation in development and implementation.

2.0 Introduction

The Indigenous peoples of Canada include people of First Nations, Inuit and Métis descent. These three groups are recognized in the Constitution Act, 1982. According to the 2001 national census, just over 1.3 million persons in Canada report Aboriginal ancestry.² This represents 4.4% of the total Canadian population. Of the total participating population that identified as Aboriginal, approximately 62% identified as ‘North American Indian’ⁱ, 30% identified as Métis, 5% identified as Inuit, and the remaining 3% identified with more than one Aboriginal group and/or were ‘registered Indians’ⁱⁱ or members of First Nations bands who didn’t identify as Aboriginal.² 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

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

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

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 section 5.1.1.

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% between the 1996 and 2001 Census. First Nations, Métis, and Inuit communities are also much younger than the rest of Canadians. 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.² A more detailed explanation of the diverse histories, cultures, and socio-demographics of Canada's First Nations, Métis, and Inuit peoples is beyond the scope of this paper and can be found elsewhere.³

Striking and persistent disparities in health status between First Nations, Métis, and Inuit populations and the rest of the Canadian population have been documented for decades,⁴⁵⁶⁷ 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 the rectification of Indigenous health disadvantage in our homelands.

3.0 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.

3.1 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 headings 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 by recommendation of experts identified by the team of Canadian investigators (JS, PT, CM, JHR, DS, NKM, CT).

Key informants were deliberately sampled to represent First Nations, Métis, Inuit, and non-Aboriginal government and non-governmental organizations 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 well-being?
4. What about broader determinants of health? (i.e. Housing, education)

3.2 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 (MA, JS, RS) and once consensus was achieved on possible themes, the transcripts were reviewed in depth by the lead author (MA) 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.

4.0 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, natural and Creator's laws.⁸ For Inuit people this holistic understanding is called *Inuuqatigiittiarniq*, and includes balance and harmony of social, economic, cultural, environmental and biological factors.⁹ Medical practices were diverse and included the use of plant and animal products as medicines, ceremonies, and other activities as guided by recognized 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.¹⁰

With contact came many changes, including a different understanding of health, disease, and the practice of medicine. Medical aid was offered by physicians with the Hudson's Bay Company, missionaries, fur traders, whalers and RCMP and military personnel at various times.¹⁰ Organized 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, potlatches, and in residential schools even the speaking of one’s own language. This practice, superimposed on new diseases like small pox and alcoholism, and socioeconomic conditions that promoted epidemics of tuberculosis and influenza, led to reliance on western/European medical systems.

The Department of Indian Affairs was first established in 1880, but didn’t 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.¹¹

The health system performance of this time period doesn’t 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’s 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.”¹²

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, 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% 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.¹³ This report provided some indicators such as physician utilization and hospitalization 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, immunizations, disease screening, and medication refills, can be done in community health centers for First Nations and Inuit people who live in their 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 a First Nations child may live on reserve, they may go to school off reserve,

receive their immunizations at school and thus be entered without an ethnic identifier into the provincial database. If there is not appropriate communication between federal and provincial jurisdictions, an underestimate of immunization coverage could result.

The barriers and gaps between federal and provincial jurisdiction become more pressing when one takes into account the increasing urbanization of Canada's Indigenous population. For the greater than 50% 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 utilization 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 were overcome, the coverage is only 60%, as these types of linkages do not allow for identification of non-status First Nations, Métis, or Inuit.

5.0 Current Indigenous Health Indicator Sets

In Canada there are data sets that exist at national, provincial, and regional levels. It's 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, Métis, and Inuit 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, categorized by externally imposed political definitions of who “Aboriginal” people are, and allows for a coverage of less than 60%.

5.1 National Level Health Indicator Sets

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

5.1.1 Statistics Canada

Statistics Canada has multiple data sets beginning with the Canadian Census.¹⁴ 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, Métis, Inuit, or multiple. This ethnic identification is done on 20% 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 amongst homeless populations means that there is another Aboriginal group who will be under-represented. These problems with the Census in turn affect

other Statistics Canada data sets such as the Aboriginal Peoples Survey, since they draw the sample from the Census Aboriginal Identity population.

The Aboriginal Peoples Survey (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.¹⁵ The APS was done in partnership with the Congress of Aboriginal Peoples, Inuit Tapiriit Kanatami (ITK), Métis National Council (MNC), National Association of Friendship Centres, and Native Women's Association of Canada. The Assembly of First Nations (AFN) 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 respectively.

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 well-being. 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 around healthy connections, as an example. It questions the ability to speak an Aboriginal language, but also who taught the person to speak the language, and to rate the importance of being able to speak an Aboriginal language. Within the section on schooling there is 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-centered 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 (CCHS) is performed on a 2 year cycle, but excludes sampling from reserves.¹⁶ It uses the same ethnic identity questions as the

census, and provides information on health determinants such as smoking and body mass index, health status, and primary health care services such as screening and immunization. The Aboriginal population sample is too small to allow reporting below a provincial/ territory level or to allow for the reporting of First Nations, Métis, or Inuit specific information. The purpose of the CCHS was to provide health information at a regional health authority level for policy and program planning, as this 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 as it relates to Aboriginal people.

5.1.2 Canadian Institute for Health Information

The Canadian Institute for Health Information (CIHI) collects and publishes data on comparable health indicators, which includes health status, non-medical determinants of health, health system performance measures, and community and health system characteristics.¹⁷ 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.¹⁸ This data is arranged by geographic region, and in some areas such as Nunavut or Northern Saskatchewan where there is a very high proportion of Indigenous Peoples in identified geographical locales, geography could be used as a proxy measure of Indigenous identity.

5.1.3 Public Health Agency of Canada

The Public Health Agency of Canada (PHAC) contains surveillance systems such as the National Diabetes Surveillance System (NDSS).¹⁹ 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.

5.1.4. Health Canada, including the First Nations and Inuit Health Branch

Most Indigenous health data in Health Canada is retained by First Nations and Inuit Health Branch (FNIHB). An exception would be Health Canada's report, "Healthy Canadians a Federal Report on Comparable Health Indicators," published in 2002.²⁰ This report contained health status indicators ranging from life expectancy to mortality rates from various common malignancies. It only included data for Registered First Nations people on reserve, with the exception of B.C. 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 their 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.²¹

FNIHB collects information from First Nations communities on immunization programs and communicable diseases. They publish an annual report of the NIHB program which includes information on the total resources to First Nations and Inuit communities, expenditures by benefit, per capita expenditures, dental and pharmacy utilization rates, and medical transport expenditures.²² 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.²³ It combined multiple data sources including Statistics Canada, INAC and FNIHB in-house statistics, and provincial/ territorial databases, and includes 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”.²⁴ In this document it stated the “First Nations infant mortality rate in 2004 was 6.4 per 1,000 live births”. When this figure was presented to the fetal and infant health study group and the steering committee of the Canadian Perinatal Surveillance System in April 2005, its validity was challenged by multiple members of these committees.^{25 26} The CPSS steering committee wrote a letter to FNIHB expressing concerns that this figure was derived from inconsistent data sources; was 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 was 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 turn around time they experience after reporting information to FNIHB. This was attributed to inadequate funding and infrastructure at the national level to input, process, and analyze the information. This will be discussed more in a later section.

There is a First Nations Health Information System (FNHIS) that contains 13 modules, although most key informants who were familiar with the system suggested that communities only used the immunization module, and occasionally used 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 used primarily as a service delivery and case management tool as opposed to a public health surveillance tool.

FNHIS will not be used much longer, according to key informants. There are attempts to switch over to the Integrated Public Health Information System (i-PHIS), but challenges with this 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 immunization tracking, communicable disease case management, and surveillance components. It is designed to be used centrally and thus, it is unclear how it would 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?

5.1.5 Indian and Northern Affairs Canada

INAC 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.²⁷ INAC also maintains demographic data including housing, education, and the number of children in 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.^{28, 29} 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.

5.1.6 National Aboriginal Health Organization

NAHO, an Aboriginal designed and controlled body, contains a First Nations Centre, Métis Centre, and Ajunnginiq Centre (Inuit health). The First Nations Centre is housing the performance of the First Nations Regional Health Survey (FNRHS), which was released in Fall 2005 and contains information in over 30 areas, including demographics, language, housing, health status, culture, and community development.⁶ The 1997 First Nations and Inuit Regional Health Survey included 11 Labrador Inuit communities, but this survey only includes registered First Nations people living on reserve.^{5 30}

The purpose of the FNRHS is to obtain longitudinal, comparable data that is centered around First Nations conceptualizations 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 which exclude sampling from reserves and do not provide respondents 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 which sampled Registered First Nations and Métis peoples.^{31, 32} The Public Opinion Polls asked about self-reported health and health services including access to health care providers, tests such as mammograms and dental exams, 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 Aboriginal Peoples Survey for Métis-specific health information. Inuit-specific health data is limited.

5.1.7 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.³³

5.1.8 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 (AFN) has developed a First Nations Health Reporting Framework. This framework uses the medicine wheel as its graphic conceptualization, 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 identifying funding and program requirements.

5.2 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 BC, Alberta, Saskatchewan, and Manitoba, the provinces do have ways of linking provincial health data with a subset of the resident First Nations populations through health card flags for First Nations person 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, Métis, and Inuit populations. In addition there are published reports which 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,”³⁴ “The Health and Well-Being of Aboriginal People in British Columbia,”³⁵ and “The Health of Manitoba’s Métis Population and their Utilization of Medical Services: A Pilot Study.”¹³

The purpose of these types of reports is variable. One key informant described the 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.

5.3 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.³⁶ 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%, 94.5% and 76.6% respectively. This serves as an example of how geography can serve as a proxy measure for ethnic identity in some situations.

5.4 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.³⁷ 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 synthesizing 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 immunization programs and notifiable diseases as required by FNIHB. There may be further indicators available scattered amongst 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.

6.0 Indicators Compendium

A compendium of Indigenous Health Indicators is attached which contains health indicators from both government sources and published literature. The compendium uses the typology presented in the American Public Health Association's publication, "Information Systems in Primary Health Care."³⁸ 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 populations information is available.

7.0 Indigenous Health Indicators: Barriers to Effective Use

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

7.1 Themes

The following themes were identified through analysis of the key informant interviews as outlined in Section 2.0:

- 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 which 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
- community initiated processes that include capacity building are needed.

7.1.1 Accountability

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

“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.”

7.1.2 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.”

7.1.3 Ethnic Identification

The availability of non-registered First Nations, Métis, and Inuit 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 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.”

7.1.4 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, that's a very big problem for us.”

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

7.1.5 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.”

7.1.6 Human Resources

Inadequate human resources, including the capacity of front line service providers who act as data collectors, limit the ability to collect, analyze, 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.”

7.1.7 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.”

7.1.8 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-centered 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.”

7.1.9 Mistrust

Given prior negative experiences with academic researchers or government organizations 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.”

7.1.10 Culturally Appropriate Tools

There is a need for culturally appropriate health measurement tools that are not pan-Indigenous, 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 trying 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”.

7.1.11 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.”

7.1.12 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, analyze 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...”

7.2 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 which 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 conceptualizations 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 intercensal periods, and whether one considers the “Aboriginal origin” or

“Aboriginal identity” population. With each Census, there are more communities who 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 their inadequacy 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 organizations to define, collect, analyze, and respond to Indigenous health information.

8.0 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 Section 2.0.

8.1 Inuksiutiin Health information Framework

In 2002 the ITK published a report entitled “Inuksiutiin Health Information Framework.”⁹ 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, including 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 18 months of extensive consultation and the drafting of background documents. The intent of the process was to maximize 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.

8.2 Development of an Evaluative Framework for use by First Nations Health Organizations

Drs. 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 domains: economic viability, environment, identity and culture, healthy lifestyle, food security, and services and infrastructure.³⁹ 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 tool kit 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.

8.3 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.¹⁰ The project contained three phases: gathering ideas and Chipewyan terminology for concepts like monitoring, indicators and community health; developing themes and indicators of community health through open-ended home visits

with one hundred 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 and community planning, assessment of resource development, and in designing and evaluating community projects.

8.4 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 communities.⁴⁰ There was an identified need for a system of indicators that recognizes 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 be 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.

8.5 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.⁴¹ It was recognized 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.⁴² 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 standardized community reports. The community focus groups were used to ensure that the injury surveillance systems was developed and tested in the context of its intended environment by its intended target group.

9.0 Concluding Comments

The delivery of health care to Indigenous people in Canada is complex and multi-jurisdictional, and differs amongst registered First Nations people on reserve, registered First Nations people off reserve, non-registered First Nations people, Métis, and Inuit. 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 realize that these are not given the same sustained funding as government data collectors such as Statistics Canada, and thus function within the confines of project-based funding.

The desire exists to have health information that is Indigenous-specific and Indigenous-centered, which is based on culturally relevant conceptualizations 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 to be community driven, and adequately address the need to build the capacity of communities to define, collect, analyze 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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