

Consideration for the Development of Public Health Surveillance in First Nations Communities[©]

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“Considerations for the Development of Public Health Surveillance in First Nations Communities”

Prepared for

Assembly of First Nations
Health Secretariat
First Nations Information Governance Committee

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2. Executive Summary

First Nations believe that true community healing and well-being will be achieved through the path of self-government and self-determination. From a First Nations perspective, health information and public health surveillance is not unlike other forms of data collection and research in terms of the relationship between these activities and First Nations goals of self-determination and self-government. Indeed the very term “surveillance” while on one level only a technical term describing a public health activity, is also fundamentally linked to the capacity of a people to govern itself. Where external agencies and governments carry out “surveillance” activities, however benign, these activities are often seen as oppressive and can have the effect of perpetuating colonial relationships between two populations.¹

First Nations are now advocating ownership, control, access, and possession (OCAP) of information on their communities as part of the development of a First Nations Health Info-structure. This health info-structure has been described to include First Nations control of health information systems, training and capacity development, research and data collection, health surveillance, linkages to other health systems (e.g. provincial), and planning and priority setting. The OCAP movement is resulting in a realignment of responsibilities for health information between FNIHB and communities.

Public health surveillance in Canada is in transition. An important emerging theme is an increasing emphasis on technological solutions to improve the efficiency of data collection, analysis and dissemination. New technology, new sources of health information and new capacity to manipulate large and complex datasets are driving the development of public health surveillance across Canada. This is largely made possible by the rapid development of computer technologies, including the Internet. However, In the First Nations context, technological issues are far less important than the building of institutional and human resource capacity to manage and utilize the health info-structure that is emerging.

Capacity development is more than just computer training and knowledge and use of the Internet; it is building capacity in self-determination and governance in health care that builds upon an individual and community development process. It is developing and applying abilities to govern and manage, solve problems, respond to new situations, make informed, evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to effectively and efficiently manage resources (human and fiscal) and to take responsibility for the success or failure of health interventions. Capacity development also implies the capability of working with internal and external agencies, organizations, institutions, departments and ministries to share knowledge and experiences.

This paper was written at the request of the Assembly of First Nations in order to provide an overview of issues related to the development of a public health surveillance system for First Nations communities. For First Nations, the return to self-government requires a re-thinking of

traditional public health relationships with federal and provincial governments. Together with technological changes and the need for institutional and human resource capacity, self-government creates a unique set of conditions that must be addressed in the development of health info-structure and health surveillance in First Nation communities.

The particular needs and circumstances of First Nations people in relation to public health surveillance are unique. Historical, geographic, cultural, epidemiological and socioeconomic factors together account for both significant differences from the Canadian population generally as well as considerable diversity within the First Nations population. For First Nations, addressing the information needs for public health is a complex task. First, there is the issue of scale. Since each First Nation has its own unique public health situation, it will be important for public health information to be community-specific, to the extent possible. However, achieving this would be an enormous logistic challenge since many of the First Nations may be too small to sustain the human and technical resources required for a fully independent public health information system. Furthermore, the public health information needs of individual First Nations are likely to differ from those of regional or national organizations. Therefore, it will be important to achieve a balance in decision-making and the distribution of resources between national and regional jurisdictions, and individual First Nations. These jurisdictional and scale issues will likely need to be settled early in the process, since the establishment of public health surveillance systems should be preceded by the establishment of surveillance priorities and responsibilities. This Report will address these differences in needs and circumstances from a First Nations perspective.

The Report provides the following recommendations as the basis for the continuing development of a First Nations public health surveillance system:

1. The development of a First Nations Health Info-Structure and the development of public health surveillance systems must be given higher priority by First Nations, federal and provincial leaders. Not only are health surveillance activities a fundamental component of self-government, but the current erosion of a coordinated health surveillance capacity in the context of health transfer is both dangerous from a public health perspective and seriously undermines the health planning process at a time when resources are inadequate to meet health needs.
2. The focus for development should be on the establishment of multiple surveillance systems focusing on specific public health problems rather than a single omnibus national health info-structure or “public health surveillance system” for First Nations.
3. A critical first step will be to establish a process for setting public health surveillance priorities and for planning public health surveillance systems. This process must occur at the regional level to ensure that priority setting reflects community and regional problems and needs. Each region should establish a planning process to be led by regional First Nations authorities and to include regional FNIHB representatives, provincial health

representatives, and where relevant, university-based expertise.

4. Federal and provincial governments should collaborate to establish a dedicated position for a First Nations person to provide oversight of the public health surveillance planning process at the regional level.
5. First Nations need to continue to develop their own capacity to perform the analytical and dissemination functions of a public health surveillance system. Both federal and provincial governments should develop programs and strategies (e.g., internships) to support ongoing capacity development.
6. Consideration should be given to creating a series of regional analytic resources centres that could provide broad technical support to communities and organizations within their region.
7. In the short term at least, First Nations regional analytic centers for health information and public health surveillance will likely involve collaborations and partnerships among First Nations authorities, federal and provincial agencies, and relevant University centers.
8. A national First Nations Health Surveillance Committee should be established to oversee and support health surveillance activities at the regional level, and to ensure that standardization of health information systems across regions is achieved. This Committee should include representation from NAHO, IAPH and other working groups and committees that are involved with the development or integration of health information systems for First Nations communities.
9. The national First Nations Health Surveillance Committee should also take on responsibility for ensuring that OCAP principles are fundamental to further health infrastructure development, and that issues of individual confidentiality and consent to have health data used for research purposes are taken into consideration. In particular, this Committee should establish an appropriate protocol for regions wishing to use federal or First Nations datasets for purposes of identifying First Nations individuals in provincial datasets. These protocols should also address, from a First Nations perspective, ethical issues involved in linking various datasets.
10. Targeted “pilot” health surveillance projects should be established under the direction of both regional and national planning Committees that will provide the opportunity for the various partners to develop the capacity to work together in an environment of mutual trust.

3. Public Health Surveillance – Definitions and Concepts

Public Health and Public Health Information

Any discussion of public health surveillance should begin with a clarification of the concept of public health, since the conduct of public health surveillance is inextricably linked to the practice of public health. Public health has been defined as the “the combination of skills, sciences and activities directed to the maintenance and improvement of the health of all of the people through collective or social actions” (Last, 1988). Defining public health in this way has important implications. To adequately fulfill those prescribed functions, an ideal public health system has the attributes described below.

- **Population Orientation** – Public health is oriented toward the health of the population, rather than the individual. In this respect, public health differs from clinical care that is oriented to providing curative services to individuals. Accordingly, the public health activities and programs are more concerned with the improvement in the basic circumstances and conditions that influence the health of a population. For example, the response of curative services to an infectious disease is concentrated on diagnosis and treatment of those individuals afflicted, whereas the public health imperative is to reduce routes of transmission (e.g. through improving environmental conditions) or reducing the susceptibility of the population to infection (e.g. through vaccination programs). Accordingly, the qualities of public health activities are best measured by assessing the overall health of the population, rather than through determining the efficiency and quality of curative services.
- **Focus on Prevention** – Related to its population orientation, public health is focused on prevention of illness or its consequences, rather than treatment. As a result, public health programs are often directed to those who are not currently affected by illness, with the goal of maintaining health.
- **Strategic Approach** – Effective public health programming is based on a strategic approach. This entails determining which activities are most likely to be effective and which communities or populations are likely to benefit most from those actions. Thus, the planning and implementation of public health programs entails establishing priorities, setting goals and monitoring progress towards the achievement of those goals.
- **Multisectoral and Multidisciplinary** – To achieve the goal of maintaining and improving the health of the population, public health relies on multiple sectors and various disciplines. For example, strategies to reduce youth smoking might involve many sectors beyond Health such as Education, Recreation, and Social Welfare. Similarly, those involved in designing and implementing the program would come from diverse training backgrounds.

The availability of information regarding the health of a population is essential to the practice of

public health. Traditionally epidemiology, which is the quantitative study of the distribution and determinants of health in a population, has provided the main scientific and information underpinning for public health. However, effective public health activity also relies on information from other scientific disciplines including the social sciences, environmental sciences, demography, geography, etc. To optimize their utility, it is useful to integrate and categorize these diverse sources of population health information according to their function in planning, implementing and evaluating public health activities. There are undoubtedly many possible organizing frameworks for articulating the linkage between the various types of health information and the development of public health policies and programs. Indeed, a more holistic approach that is consistent with a First Nations model of the medicine wheel should be an important component of the development of a First Nations Health Info-Structure. Until such a model is fully developed, we offer the following framework that explicitly links the relationship between the public health policy and program development process and the support that these processes should receive from various health information activities.

Public Health Policy/Programs

Identify Health Priorities



Select Opportunities and Imperatives for Intervention (Target Activities)



Design Appropriate Interventions (Program Planning)



Monitor the Impact of Interventions (Evaluation)

Health Information

Measure and Describe the Health Status and Main Health Issues



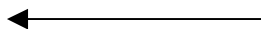
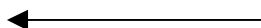
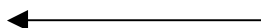
Identify At Risk Populations and Health "Opportunity Gaps"



Identify Factors Leading to Poorer Health Outcomes (Health Determinants)



Continuously Measure Health Status/Outcomes (Surveillance)



This framework proposes that the essential components of public health policy and program development can be categorized into four basic activities. The first step is to identify and articulate strategic public health priorities. This process is not a simple one and will not rely solely on objective data. Rather, it will also reflect the role and mandate of the health organizations, community expectations, and other considerations. However, a key component should also be based on high quality information about the health status of the population and those factors that influence health. For example, information on the leading causes of morbidity, disability and quality of life, premature mortality and health care costs should form an important part of the prioritization process. As an example, ranking major disease areas (e.g. cancer, cardiovascular disease, diabetes, mental health, injuries, communicable diseases, etc.) according to the burden they impose on the population would support the identification of health priorities. However, health priorities need not be focused solely on specific disease entities. Instead, a global assessment of health among certain population groups (e.g. elderly, children, rural populations) could also be used to assist in identifying priority population groups. Methods for obtaining this type of health information include vital statistics data, epidemiologic data based on

disease registries or health care databases, population-based surveys, and qualitative research.

The second step in the framework is to work within a priority area to identify opportunities or imperatives for improving health status and disease outcomes. From a policy or program perspective, this is an important step in determining how to target or concentrate resources. From a population health information perspective, identifying sub-groups where the health status or disease outcomes are sub-optimal could do this. For example, if the focus is diabetes in First Nations communities and the optimization of its outcomes, it would be important to describe regional or demographic variations in the incidence of complications to better target resources and programming.

Once priority health issues have been identified and opportunities for improvement have been defined, appropriate intervention strategies and programs need to be selected and implemented. To do this, an understanding of those factors (“determinants”) that are leading to poorer health status or health outcomes is required. In support of this, information on the distribution of health determinants and risk factors in the population is required. This information must be integrated with evidence from the literature and other sources about those factors that influence health in the focus area.

The final step in the process is to evaluate the impact of interventions. To do this, surveillance and monitoring systems are required to continuously measure population health status and outcomes.

Public Health Surveillance

Surveillance is a fundamental activity in the practice of public health. It has been defined as the “the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice” (Thacker and Berkelman, 1988). A few points in this definition deserve emphasis. First, public health surveillance is a purposeful activity that is explicitly linked to a specific public health agenda, activity or program. In other words, surveillance is not the same as a general health survey that is designed to determine the distribution of health related states or events in a population. Rather, public health surveillance is directed to understanding and monitoring a particular health issue within a population. Thus, public health surveillance systems are designed around specific public health issues, and complement public health programs that are designed to address those health issues. This does not mean that public health surveillance can only be directed to monitoring diseases. For example, a surveillance system could be developed to support a program designed to reduce youth smoking by describing patterns of youth smoking and monitoring trends in the prevalence of smoking among youth in the population over time.

For a specific public health issue, a surveillance system can have several uses. These include:

- Providing quantitative estimates of the magnitude of the health problem – For example, this could include measures of mortality, morbidity or disability rates associated with the health problem.
- Describing health outcomes for a disease – such as the rate of renal failure or other complications in diabetes.
- Detection of epidemics – this could refer to both communicable and non-communicable diseases and other health events (such as suicide attempt).
- Documentation of the distribution of health events/states (time, place, person).
- Evaluation of prevention/control measures.
- Monitoring changes in the frequency and distribution of a health event or state over time.

Public health surveillance results from a series of connected activities. These include a system of data collection, a system of data organization and analysis, and a system of response (or information dissemination). Ideally, the planning of each of these systems should be done in a coordinated fashion. For example, the system of data collection should be appropriate to the resources and plans for data analysis. Similarly, the system for data analysis needs to be congruent with the response or data dissemination plans.

Public health surveillance systems are generally not used for analytic research or for managing individual clinical cases. The attributes of a good public health surveillance system are:

- Feasibility
- Acceptability
- Accuracy
- Flexibility
- Timeliness
- Cost-effectiveness

To achieve these attributes, it is important that surveillance systems have clear and limited objectives.

4. Public Health Surveillance in Canada

The system of public health surveillance in Canada has many components. The most well developed and widely distributed system of surveillance is focused on communicable diseases. Many communicable (infectious) diseases are notifiable to local and provincial public health authorities under public health legislation at the provincial level. Decisions regarding which diseases are notifiable are taken at the provincial level, but these decisions are influenced to a large degree by national consensus through scientific bodies. There is substantial variability between provincial jurisdictions in the mechanisms for data collection, analysis and reporting. For example, some provinces such as Manitoba have a system whereby laboratories routinely, and often electronically, submit reports of positive tests for notifiable diseases. Recently, British Columbia has implemented a new, efficient public health information system (PHIS) for collecting and reporting information on notifiable diseases. Health Canada maintains national databases for many of the notifiable diseases, relying primarily on reports from the provinces as the source of data.

Historically, surveillance in First Nation communities has posed logistic difficulties, which are compounded by jurisdictional uncertainties. Most notifiable disease systems are funded and maintained by provincial governments. Thus, notifiable diseases that occur in First Nation communities are generally documented and analyzed by provincial health authorities. However, responsibility for data collection and public health interventions has generally been the responsibility of the federal government and more recently the First Nations themselves. This situation can lead to a disconnect between surveillance and public health practice, and quality control in surveillance systems can be compromised. The transfer of health services to the control of First Nations could further complicate these relationships unless concerted efforts are made to promote collaboration between provincial public health agencies and First Nations.

Public health surveillance in Canada is in transition. An important emerging theme is an increasing emphasis on technological solutions to improve the efficiency of data collection, analysis and dissemination. This is largely driven by a rapid expansion in the availability of computer technologies, including the Internet. Thus, more than ever before, surveillance initiatives at the federal, provincial and territorial levels are being led by those offering health information technology solutions. Examples of these new systems include but are not limited to:

The Canadian Integrated Public Health System (CIPHS) will link, in a standard manner, data from health laboratories, public health units and other potentially valuable information sources to provide timely information to manage risks to health.

The Global Public Health Intelligence Network (GPHIN) is an early warning, real-time, Internet-based system that continuously monitors international sources of information to detect outbreaks of infectious disease of international public health importance. The World Health

Organization is a partner for verification of the information, while Canadian federal institutions and the public health community use the information to monitor the potential risk of these outbreaks to the health of all Canadians.

The Local Public Health Infrastructure Development (LoPHID) pilot focuses on developing the skills of public health workers at the regional level and strategies and processes for managing local public health information.

The Spatial Public Health Information eXchange (SPHINX) is an interface for presenting information from existing databases and analyzing and displaying this information in a variety of formats, including mapping, to enhance local, provincial/territorial and national public health surveillance.

However, as yet the results and public health benefits of these initiatives have been slow to materialize. There are several reasons for this. Most of these examples are still in the pilot phase or have been developed in only one or two jurisdictions. Although new systems for data capture are being developed, most new technologies still depend largely on existing data collection mechanisms. Thus, unless there is commensurate investment in data collection (including the development of new standards), expansion of health information technologies will offer little in the way of new health information. Commitment for these new data collection resources has not matched the enthusiasm for new health information technologies. This disconnect between systems for data collection and systems for data organization, analysis and dissemination is exacerbated by the reality that data collection usually occurs at a local or regional level, whereas most major new health information technology developments are provincial or federal initiatives. A further difficulty with a technological approach to the development of new surveillance systems is that the specific public health rationale is often underdeveloped. Health agencies, especially local ones, are reluctant to put resources into enabling new health information systems when the benefits to them are not clear.

Recently, Health Canada has initiated a process to attempt to organize and promote the various health surveillance initiatives. The concept is to establish a national surveillance network that would link initiatives, support the development of infrastructures and disseminate innovations. To that end, a Federal/Provincial/Territorial Working Group has been struck to develop a strategic plan for the surveillance network.

Another important new theme in public health surveillance in Canada is a much greater emphasis on non-infectious diseases. Within the past decade, a number of new national surveillance initiatives have emerged, largely through the support of Health Canada. These include the Canadian Perinatal Surveillance System, the National Diabetes Surveillance System and an emerging system for surveillance of cardiovascular disease. Conducting surveillance on these health issues has motivated new mechanisms for collecting surveillance data. The model for national health surveillance for infectious diseases and cancer was based on individual or aggregate case reports from provincial or local jurisdictions. This model is impractical and

inappropriate for non-communicable diseases. One reason is the sheer numbers of cases. For example, for a disease like diabetes, there are approximately 1.5 million persons with the disease and more than 100,000 persons diagnosed each year. Furthermore, since these are chronic conditions, maintaining and updating information on outcomes in these conditions would be a formidable task for a system that relied on case reporting. Therefore, for these non-infectious diseases, existing provincial health information systems are being used. The best-developed example of this approach is the National Diabetes Surveillance System (NDSS). The NDSS is guided by a Steering Committee that is comprised of representatives from federal, provincial and territorial governments, academic institutions, NGOs and national Aboriginal organizations. For data collection and collation, the NDSS has funded provinces and territories directly to extract the data from their administrative health information systems in a standardized fashion, and to send aggregated data to a central repository for national analyses. The appeal of this approach is its relative efficiency, since it relies primarily on existing databases. Another unique aspect of the NDSS approach is the intention to establish a distinct Aboriginal component. Although the Aboriginal component is still taking shape, the goal is to ensure that comparable diabetes surveillance data on Aboriginal populations will be available and managed by an Aboriginal technical group. This surveillance model of collective planning, common methodology and distributed responsibility is one that is now being contemplated for the establishment of additional national surveillance systems.

5. First Nations Context for Public Health Surveillance¹

It is easy to forget, with so many First Nations people marginalized in Canadian society that in the first waves of European invasion to the shores of what is now known as Canada, Europeans interacted with First Nations people on a nation-to-nation basis. Indeed, the first agreement between these two groups spoke of peaceful co-existence – of two nations co-existing along parallel paths that would never cross. The Two Row Wampum, the physical existence of this contract, was recorded in the 1600's and stands to this day as a recognition of the nationhood of the people of the Five Nation confederacy, who negotiated this treaty with Britain.

The *Royal Proclamation of 1763* explicitly confirmed this nation-to-nation status. It also went ahead to describe British colonial policy that ultimately contributed to the near destruction of Indian nations. It did however, specify that Indian people possessed land, and furthermore, that the advancing settlements under the direction of the British Crown, could not encroach on this

¹ Much of the material in this section draws from a previous two volume Report on Aboriginal Health Info-Structure, commissioned by the Assembly of First Nations for the Ministerial Advisory Committee on the Health Information Highway. Dr. O'Neil was a primary consultant on that Report, but significant contributions were also provided by Gail MacDonald, Health Consultant to the Assembly of First Nations, Ms. Laurel Lemchuk-Faval of FAVCOM Consultants, Mr. Carman Maracle of Strategic Design and Production, Tyendinaga First Nation, and Mr. Yvon Allard, Ph. D. Candidate, Community Health Sciences, University of Manitoba.

land without negotiation. The *Proclamation* marked a turning point in treaty negotiations. Prior to the *Proclamation*, mainly peace and friendship treaties were negotiated which were intended to secure the assistance or at least the neutrality of Indian nations, in exchange for a commitment that Indians would not be impeded in their lives and livelihood. The *Proclamation* laid the framework for treaties whose sole purpose was to clear lands of Indian title. However, the spirit of the *Proclamation's* declaration to Indian nations has been entrenched in Section 25 and 35 of the *Constitution Act, 1982*, and it forms one of the main European historical records supporting contemporary definitions of Aboriginal and treaty rights.

Jurisdictional Barriers

It is in the creation of the nation of Canada through the *British North America Act, 1867* that the cause can be found of much of the jurisdictional wrangling between federal and provincial governments over who has the responsibility for provision of health care to First Nations people today. The *BNA Act* gave legislative authority over Indians and Indian Bands to the federal government, as the new Canadian government now assumed responsibility (including the provision of health services) for First Nations people for the British Crown. The *Indian Act, 1876* which followed, addressed these federal responsibilities to Indians and forced an arbitrary class structure on Indians: those who had 'status' and therefore were entitled to special rights and considerations from the new nation of Canada; and those who missed being included in this legal definition, through reasons as diverse as marriage or military enlistment.²

The *BNA Act* also stipulated provincial roles, and in section 92, laid out provincial responsibilities for establishing and delivering health services. Perhaps unwittingly the groundwork had been laid for the federal and provincial governments to disclaim responsibility for health services provided to First Nations people. The provinces interpret the *BNA Act* as a clear statement that the federal government should be responsible for delivering First Nations and Inuit health services (and indeed in some cases, even all First Nations health programs), outside of those prescribed in the *Canada Health Act*. Although the *Canada Health Act* ensures accessible hospital and physician services to all Canadians, and all First Nations people are included in the financing formula to provinces and territories (through both the Canada Health and Social Transfer, and its predecessor, the Established Programs Financing Act), provincial governments with few exceptions (such as the James Bay and Northern Quebec Agreement between the Cree and Inuit and the government of Quebec), have never ventured into directly providing service in First Nations and Inuit communities.

Federal Policy

The federal government does not acknowledge any legal or legislative responsibility for the provision of health services to First Nations people,³ and has stated that it does provide these to First Nations and Inuit only as a matter of policy.

The federal role for health services extends to public health and nursing services in most First Nations and Inuit communities, and medical and hospital services to those which are remote (provincial reimbursement is obtained for the latter.) Since the 1979 Indian Health Policy of the federal government, a program has been in place for the provision of some federal benefits to all First Nations persons, whether resident on or off reserve. The non-insured health benefits (NIHB) program is a payer of last resort for health services (meaning those services not provided by provincial resources or paid by third party insurers), and an eligible list of benefits are determined through medical or dental necessity. Even with this program, there have been many areas where First Nations and Inuit needs have slipped between federal and provincial jurisdictions, including home care and mental health services. The federal government's view of what constitutes a 'health service' is narrowly defined to include primarily clinical medical services. This has created further fragmentation in the provision of health services and presents a barrier to an integrated holistic approach to health.

Treaty Rights

An historical record exists to prove treaty entitlements, although again the extent of this entitlement has never been decided through a court decision. At issue is the broadness of the terminology "pestilence" and "medical care" in a contemporary context. There is no dispute that a promise to provide relief for pestilence was made in certain treaties, and history has recorded Lieutenant-Governor Alexander Morris, who negotiated treaties on behalf of the Crown, as promising the Crees that it was the Queen's way to provide relief in the case of national famine and medical care in the case of national pestilence. Furthermore, Governor Morris assured the Crees that writing appropriate provisions in the treaty would not affect these policies.⁴ Modern courts have upheld the validity of oral records. In particular, the Supreme Court has put forward a broad common-sense approach in defining a treaty to include "agreements in which the word of the white man is given and by which the latter makes certain of the Indians' cooperation."⁵

Treaty #6 negotiated with the Cree Chiefs for the area which extends across central Saskatchewan and Alberta, was the only treaty which went beyond a pestilence clause to provide a written record of a promise of health care:

"That a medicine chest shall be kept at the house of the Indian Agent for the use and benefit of the Indians at the direction of such agent."

Historical reviews have recorded verbal promises of medical care by Governor Morris, specifically at the Treaty #7 and # 8 signings.⁶ First Nations people argue forcefully that a contemporary, broad definition of what is meant by medicine chest and pestilence should be used, as at the time of the treaty process, this terminology was sufficient to describe the health concerns of First Nations people.

A broad approach to treaty interpretation has been supported in the courts. In particular, the British Columbia Court of Appeal *Claxton v. Saanichton Marina Ltd (1984)* concluded regarding the interpretation of treaties that it should be fair, large and liberal in favour of the Indians, that the treaty be construed in terms which would be naturally understood by the Indians, that the Crown should avoid sharp dealings and that interpretations of ambiguous wordings should not prejudice the Indians if another construction is possible.⁷

The current government has made a commitment to “seek the advice of treaty First Nations on how to achieve a mutually acceptable process to interpret the Treaties in contemporary terms giving full recognition to their spirit or intent.”⁸ Unfortunately, to date, most if not all issue resolution between governments and First Nations people have occurred through the court process. This government has also indicated a willingness to address the poor health of First Nations through an approach that has emphasized partnerships and true control by First Nations.

As will be discussed below, this has been implemented through a health transfer process where First Nations and Inuit communities assume responsibility for the provision of health services. In the complex area of Aboriginal and treaty rights, some First Nations are unwilling to proceed with transfer, as they fear it will diminish their treaty rights. The federal government has not allayed this concern, as it in the past has stated that it regards a transfer of responsibility between the federal government and a First Nation to trigger a corresponding reduction in any fiduciary responsibility of the federal government.⁹

Overview of Health Services

The European invasion had immediate detrimental effects on First Nations people, as the explorers and settlers brought a multitude of infectious diseases, including small pox, influenza, measles, polio, diphtheria and tuberculosis, all to which First Nations peoples had no immune resistance. Compounding this was the disruption of traditional lifestyle and diet, enforced residence of First Nations people on reserve lands, an incompatibility of existing sanitation customs (based on a nomadic way of life) with permanent residence in one area, and the long-reaching grasp of Christianity which devalued traditional practices, including those of medicine men.

Tuberculosis was a scourge in First Nations communities, sometimes killing whole families, and was equally deadly in the residential schools that served to educate and assimilate First Nations children. If children survived tuberculosis, they became victims of mental, physical and sexual abuse in residential schools - an experience that resulted in the breakdown of traditions, social cohesion and family bonding in First Nations life.

It is not surprising then, that the first medical services provided to First Nations people were for public health and humanitarian reasons as the settlers feared the spread of disease. RCMP and missionaries, as well as the Hudson’s Bay Company were the source of these medical services; the latter as it had a vested interest in the health of First Nations hunters and trappers. Indeed, the

introduction of public health surveillance to First Nations communities occurred in the context of protecting the general community from infectious diseases.

The Office of General Medical Superintendent was established in the Department of Indian Affairs in 1904. This began the history of organized federal health services to federally established reserves, which marked the beginning of health services segregated to specific groups of First Nations people, and the historical inequities with respect to the federal and provincial adherence to the *Indian Act* definition of eligible recipients. Between 1905 - 1927, hospitals were constructed and communities were visited by traveling field nurses. The extent of health services should be placed in the context of all Canadian health services. Even in the pre-Medicare era, First Nations health services government expenditures in 1930 were less than one third of those for the rest of Canadians.¹⁰

The period of 1930 - 1950 was marked by the establishment of nursing stations and other health facilities, the creation of public health regulations, and management of outbreaks of infectious disease, including tuberculosis. Today's health services are not remarkably different from the mold cast in the early part of the century. Core health services for a community of 1500 - 2000 persons typically involve one or two nurses assisted by two community health representatives, and the sporadic services of a physician, dentist, ophthalmologist, and environmental health officer. A committee of the Band Council may interact with the nurse on public health matters. For isolated communities where there is no year round road access, a nursing station is equipped with basic diagnostic equipment and a few beds and primary care services include urgent care, short-term in-patient care and community health. Secondary and tertiary care is provided by the provincial health system.

First Nations health services were eventually separated from the Department of Indian Affairs in the 1940s when they were moved to the federal department of Health and Welfare. The federal responsibility for health still resides there today in First Nations and Inuit Health Branch (formerly Medical Services Branch - MSB). A progressively greater role of First Nations in the management of their own health services has occurred over the last 20 years. The federal government committed to greater participation by First Nations and Inuit people in health service planning and delivery in 1979. Initially, this was merely a transfer of administrative responsibility for a few defined programs. As a result of a demonstration program in 1982, the policy of Health Transfer was developed, which provided a process for communities to develop health plans and assume a greater role in the control and management of health services. Although this agreement mechanism has been roundly criticized as just a more sophisticated version of a federal delegation of administrative responsibility to communities, or a "dump and run" approach of the federal government in removing itself from an area where it has had limited success,¹¹ the challenge has been taken up by 281 First Nations and Inuit communities to date, who represent 153 Transfer agreements¹². Major areas of concern for First Nations and Inuit have been the exclusion of off-reserve community members from services, the lack of program enrichment in the funding arrangements, and the effect these agreements may have on existing treaty rights and fiduciary responsibility of government. Recent pilot projects to transfer the

NIHB program have generated their own set of concerns related to the disconnect between resource projections and demographic and morbidity trends. More profound perhaps is the impact in some communities of lack of capacity in communities to meaningfully exploit the potential of the transfer mechanism. Inadequate transitional management strategies, the demands of meeting needs immediately, and the segregation of health and social budgets may present barriers to a community 'pushing the envelope' and developing innovative strategies to better manage resources and meet health needs.

However, the transfer initiative has also had beneficial effects and some communities have been very successful in developing new and innovative approaches to health systems. The Royal Commission on Aboriginal Peoples has summarized these gains as flexibility in the use of program funds, more freedom to adapt services to local needs and priorities, reduced reporting paperwork, and increased community sense of ownership of health services.¹³

Self Government

First Nations people believe that true community healing and well being can only be found through the path of self-government and self-determination which gives full control over services provided to their communities, not merely the administration of separate federal programs through a single funding envelope such as Health Transfer. The federal government has recently affirmed a major recommendation of the Royal Commission on Aboriginal Peoples when it recognized the inherent right to self-government for Aboriginal people as an existing Aboriginal right within section 35 of the *Constitution Act, 1982*¹⁴.

The first self-government agreement, which was negotiated among the James Bay Cree, the Inuit of Nunavik, the federal government and the government of Quebec, was the James Bay and Northern Quebec Agreement in 1975. It provided for the establishment of the first independent First Nations health and social services board. Although there are mixed opinions as to JBNQA's success as a self-government model, undoubtedly more community control was obtained and some positive examples of First Nations health services delivery have resulted.

Self-government negotiations are taking many forms in Canada. Although most Canadians would equate self-government with high profile agreements such as the Nisga'a Treaty in British Columbia or the creation of the new territorial government of Nunavut in April 1999, much more modest initiatives are being negotiated at both an organizational and community level. The federal government has also indicated a commitment to work with First Nations that have existing treaties, to achieve self-government in the context of this treaty relationship. As of 1997, approximately 80 self-government negotiation arrangements were established with First Nations and Inuit communities, the federal government, provinces and territories.

Health Status of First Nations

First Nations people bear a disproportionate burden of illness in Canada. Several recent reports demonstrate that, compared with the general population, many First Nations people are at increased risk for a range of health problems, including infectious diseases, chronic diseases such as diabetes and cardiovascular diseases, cervical and lung cancer, suicide, injuries and substance abuse.¹⁵ Other particular problems of concern include mental illness, alcoholism and fetal alcohol syndrome, suicide, family violence, injuries, tuberculosis, HIV infection and AIDS. Incidence rates for these health problems among First Nations groups are often several times higher than those in the general population.

Some health status problems have been highlighted in the 1996 Royal Commission on Aboriginal Peoples Report:

- Life expectancy at birth is about seven to eight years less for registered First Nations than for Canadians generally.
- Part of this difference in life expectancy is explained by high rates of infant mortality among registered First Nations peoples. For infants, the death rate is about twice as high as the national average. There are also high rates of injury and accidental death among First Nations children and adolescents. Mortality in all age groups is higher for registered First Nations than for Canadians generally.
- Infectious diseases of all kinds are more common among First Nations people than others.
- The incidence of life-threatening degenerative conditions such as cancer, heart, liver and lung disease – previously uncommon in the First Nations population – is rising.
- Overall rates of injury, violence and self-destructive behaviour are disturbingly high.
- Rates of overcrowding, educational failure, unemployment, welfare dependency, conflict with the law and incarceration all point to major imbalances in the social conditions that shape the well-being of First Nations people.

Mortality rates

Data from regional offices of Medical Services Branch indicate that from 1995 to 1997 the First Nations infant mortality rate was up to 3.5 times higher than the 1996 national rate.¹⁶ Most of the difference in the infant mortality rate on First Nations reserves is due to postneonatal causes of death, including infectious diseases, respiratory illness, sudden infant death syndrome (SIDS) and injuries. First Nations children have much higher rates of death from injuries than all children in Canada. A comparison of First Nations children with the total Canadian population of children shows that, for infants, the rate of deaths from injuries is almost four times greater among First Nations children (63 versus 17 per 100000 population; among preschoolers, the rate is more than

five times greater (83 versus 15 per 100,000); and among teenagers 15 to 19 years of age, the rate is more than three times greater (176 versus 48 per 100,000). In these data there is no distinction between intentional and unintentional injuries.

Although the mortality rate among First Nations people declined during the 1980s, it remains higher than the rate for Canada as a whole. In 1996-97, First Nations and Inuit people from Eastern Canada, the Prairies and Western provinces had mortality rates that were almost 1.5 times higher than the 1996 national rate.¹⁷ In 1993, the age standardized mortality rate of First Nations compared to the 1991 national population was 10.8 deaths per 1000 population (1.6 times the Canadian rate).¹⁸ There was an increased risk of death from alcoholism, homicide, suicide, injury, poisoning and pneumonia among First Nations persons.

Morbidity due to infectious and chronic disease

Over the past several decades First Nations people in Canada have undergone a health transition marked by a decline of infectious diseases and an increasing burden of chronic diseases and injuries in the First Nations population.

Infectious Diseases

Despite significant reductions in rates of tuberculosis (TB) among Inuit people during the past 30 years, most aboriginal Canadians continue to be at high risk of TB. Between 1984 and 1989, the estimated incidence rates among registered First Nations persons (73 cases per 100,000 population) and Inuit (63 and 77 cases per 100,000) were approximately nine times the Canadian average. Canada's First Nations peoples, in general or particular subgroups, have been reported to be at an increased risk of other infectious diseases, including hepatitis A and B, gastroenteritis, meningitis, and sexually transmitted diseases (STDs). HIV infection and AIDS are of major concern to First Nations peoples, especially in Northern and remote communities where HIV testing and AIDS treatment is limited or unavailable. There is some evidence that First Nations children are at an increased risk of infectious diseases, compared with non-aboriginal children. First Nations children in Canada have higher rates of lower respiratory tract infections (bronchitis, pneumonia, croup and asthma). Both children and adults in the First Nations population suffer an increased frequency of acute respiratory infections compared with that among non-aboriginal people. Severe otitis media (chronic middle ear infection) appears to be more frequent among First Nations children than among non-aboriginal children. Haemophilus influenzae type b infections are significantly more common among Inuit infants than among other Canadian infants. Although the reasons why First Nations people are at an increased risk of some infectious diseases are unknown, suggested risk factors include nutritional problems, genetic factors, poverty and crowding, and environmental pollutants such as tobacco smoke and wood smoke.

Control of TB is an urgent priority in infectious disease control among First Nations peoples in Canada. However, it is only one of many contagious and infectious diseases to occur often in First Nations than non-Aboriginal communities. In almost all categories of infectious disease identified by the international classification of diseases, First Nations peoples run a greater risk of illness than other Canadians. In some cases, the ratio of First Nations to total Canadian disadvantage is four to one. There is a special concern that HIV/AIDS poses a growing threat to First Nations peoples.

Chronic diseases

Although still serious, rates of infectious disease have declined among First Nations peoples since the turn of the century. Cardiovascular disease, cancer, metabolic disorders (particularly diabetes), respiratory and digestive disorders are significant factors in First Nations illness and death.

Chronic conditions are sometimes called the diseases of modernization, or western diseases, because they attend the lifestyles typical of western industrial nations: reduced physical exercise; diets overloaded with fat and sugar; high levels of stress; and increased exposure to a wide range of pollutants in the air, water and food supply. As well, there is excess use of caffeine, alcohol, non-traditional use of tobacco and recreational drug usage.

Diabetes mellitus is a major health and wellness issue among First Nations peoples in Canada. In 1991, 6% of Canadian First Nations people 15 years of age and older reported that they had diabetes mellitus, whereas 2% of the Canadian population reported having the disease. The First Nations and Inuit Health Survey reported a prevalence rate of 10.9 % for diabetes in 1997; almost a twofold increase over six years. Diabetes mellitus was considered rare among First Nations people until the 1940s, but since then the prevalence of non-insulin-dependent diabetes mellitus (NIDDM) has increased greatly in many First Nations peoples. However, even among closely related indigenous populations, age-standardized prevalence rates vary widely, indicating that NIDDM is not strictly a genetic inherited disease. Data from the FNIRHS for Manitoba indicate a prevalence rate of 18% for First Nations people living on-reserve in Manitoba. First Nations people living in urban areas, women and particularly First Nations people living in southern Canada had an increased risk. The variation in NIDDM prevalence among different subgroups of Canada's First Nations population underscores the need to assess health problems by region, especially northern and southern Canada.

First Nations people suffer more end-stage renal disease (ESRD) than other Canadians; the age-standardized incidence rate of newly registered chronic renal failure among First Nations people is 2.5 to 4.0 times higher than the national rate; the total (crude) rate for all Canadians is 5.66 cases per 100,000 population each year. The First Nations population has at least a twofold higher risk of ESRD due to diabetes mellitus, glomerulonephritis and pyelonephritis than the total Canadian population.

Cardiovascular disease is a leading cause of illness and death in the Canadian population as a whole, and recent studies in Canada and the United States have shown that cardiovascular is a new an increasing health problem in First Nations peoples in North America. Specific prevalence data about risk factors for cardiovascular disease, except for smoking, in the Canadian First Nations population are sparse. Hypertension is of particular concern to First Nations peoples in Canada. An important recent revelation is that adult-onset diabetes (NIDDM) is a major risk factor for subsequent cardiovascular disease, especially in First Nations women.

Lung cancer is an emerging health concern of First Nations people, due to the non-traditional usage of tobacco products. FNIRHS data indicate that 65% of First Nations people in Canada report smoking regularly. Smoking cessation programs need to be made culturally based for use in First Nations communities.

Social and Emotional Health

Health and wellness involves much more than physical health, i.e. the absence of infectious and chronic disease. Good health is a state of balance and harmony involving body, mind, emotions and spirit. It links each person to family, community and the earth in an interconnected and interrelated circle of life described by some in the language of the Medicine Wheel. Many of the mental health issues reported as problems by First Nations people are closely linked with social conditions.

Suicide rates among First Nations Canadians are two to three times higher than those among non-aboriginal Canadians. Between 1984 and 1988, the 5-year mean annual rate of suicide among registered First Nation people in Canada was 36.1 per 100,000 population; suicide rates were highest in Alberta (among women) and the Yukon (among men). From 1986 to 1990, the mean annual suicide rate among Canadian First Nation youth was 37 per 100,00, five times greater than the rate in the total Canadian youth population. Substance abuse, including drug and alcohol abuse, is a common problem and a major issue of concern to Canada's First Nations people. Studies have shown that improvement in socioeconomic conditions reduced alcohol consumption. A major concern in First Nations communities is Fetal Alcohol Syndrome (FAS), since children with FAS have major learning and socializing problems. Some First Nations groups have identified use of inhaled intoxicants as a major health problem. Solvent use, involving the inhalation of volatile substances such as gasoline, glue and cleaning products, has been increasingly reported in isolated First Nations communities and in urban low-income areas. Family violence is a major concern in First Nations communities.

6. First Nations Developments in Public Health Surveillance

First Nations people are involved in or affected by a range of strategic initiatives that influence the effort of communities to achieve self-determination and control of health programs. These ongoing initiatives contribute to the body of First Nations health data that First Nations communities need to exercise control and undertake informed health management and planning.

First Nations and Inuit Health Information System

The First Nations Health Information System (HIS) is a community-based computerized system, which was adopted by the First Nations and Inuit Health Branch (FNIHB) as its standard health information and surveillance system. The HIS currently consists of 13 subsystems: Client Information, Immunization, Reportable Diseases, Maternal Health, Environmental Health, Abuse Profile, Test/Exam, Medication, Medication Allergy/Adverse Reactions, Public Health Education and Client Mortality Information. Data for all subsystems are collected according to standard clinical and public health practice. The HIS software is the joint property of Ontario First Nations and FNIHB.

The HIS was created in response to a 1988 assessment of health-related data for the First Nations population in Ontario Region, which revealed many inconsistencies in data collection practices. This assessment highlighted the need to develop a comprehensive Health Information System that would standardize data collection practices and improve the reliability of the data available for case management, program planning and evaluation and surveillance.

Currently 349 First Nations health facilities serving 427 First Nations communities (approximately 60%) are enabled to use the HIS. Implementation in remaining communities is continuing.

In order to fully realize the potential of the HIS to support case management, surveillance and long term health planning, community users need to be trained in the principles and practices of information management as well as have the prerequisite computer skills. Access to the FNHIS through a series of regional networks requires that communities have a communications infrastructure that can reliably access and support the high-speed transfer of data. Capacity building, in terms of human resource and infrastructure development and the principle of First Nations control over First Nations data developed in consultation with First Nations, must be an integral component of the HIS national roll-out.

Health Transfer

The Government of Canada, in support of its stated intent to advance First Nations toward self-government, undertook the 1983 Penner Report on Indian Self-Government. This report identified three streams of activity to strengthen self-government. These are Constitutional Entrenchment, Legislative Enactment and Administrative Reform. Health Canada and Indian and Northern Affairs Canada created processes to transfer federal programs to First Nations in response to the Administrative Reform strategy. The Health Transfer initiative enables First Nations to design and manage community-based health programs, previously controlled by FNIHB, by entering into agreements that allow the transfer of existing federal resources to First Nations communities.

The transfer process has been designed to respond to the individual circumstances of each community in terms of its capacity to assume control of health programs. Communities choosing to maintain some or all existing FNIHB programs are assured there will be no loss in service compared to communities that choose to operate their own health programs.

The Transfer initiative is intended to enable First Nations to design Health Programs, establish services and allocate funds according to community health priorities, while strengthening the accountability of health programs to community members. Transfer agreements also ensure public health and safety is maintained through adherence to mandatory programs.

Health Transfer Agreements allow improved planning for the community through multi-year agreements that can be a minimum of 3 years or a maximum of 5 years. Recent changes to the format of transfer agreements allow more flexibility in program administration. Funds can be transferred between programs and communities keep program surpluses from year to year. They are also responsible for deficits. The Minister remains accountable to Parliament for resources expenditures for First Nations health.

Currently there are 153 transfer agreements covering 281 (out of a total of 599 eligible for transfer) First Nations.¹⁹ This includes 7 Inuit communities. In addition, partial transfer of services (through Integrated Transfer Agreements) has occurred with 138 communities and there are 71 First Nation communities that are involved in pre-transfer activities.

Transfer of responsibility for a health service has important implications for public health surveillance. In the pre-transfer environment, FNIHB (or MSB) maintained responsibility for the regional and national monitoring of health conditions in communities. In the context of transfer, these responsibilities (and to some extent the resources required to meet them) have been allocated to either individual communities or regional First Nations organizations. In the process of dividing resources for public health surveillance activities, the capacity to produce a comprehensive analysis of changing health conditions has been weakened. Efforts to renew this capacity under First Nations control and with the addition of new surveillance technologies such

as HIS and the Longitudinal Health Survey are important priorities.

Non-Insured Health Benefits (NIHB)

NIHB is one of several federal programs for First Nations people that flow from constitutional and statutory provisions, treaties and customary practices. Registered Indians, recognized Inuit, and Innu regardless of income and place of residence in Canada are entitled to receive NIHB.

NIHB has provided prescription drugs; dental care; eye care including eyeglasses, eye exams and repairs to frames; medical supplies such as wheelchairs, crutches, hearing aids and orthotic services; medical transportation to health facilities outside the community including meals and accommodations; mental health counselling and health insurance premiums for First Nations people in B.C. and Alberta; and allied health which included podiatry, chiropractic and physiotherapy. These are services that are not covered by provincial or territorial health insurance programs or other forms of third party coverage.

In April 1998 Medical Transportation and Allied Health was moved from NIHB and became a community-based health program. The remaining services, Drugs, Dental Services, Vision Care, Mental Health and Medical Supplies and Equipment were made available for transfer to communities. Administrative frameworks were prepared to support transfer and facilitate community management of medical transportation. In June 1996 transfer of NIHB was initiated with three pilot projects; three more were added in 1997 and ten more were initiated in 1998.

The NIHB Directorate at FNIHB maintains an extensive database on services provided primarily for administrative purposes. In particular, the Directorate is able to track pharmaceutical and dental services provided in considerable detail. Although this data could potentially be an important component of a First Nations public health surveillance system, issues of privacy and confidentiality need to be addressed prior to further utilization of the database for general surveillance purposes.

Aboriginal Peoples Survey - 2

The 1991 Aboriginal Peoples Survey (APS) was conducted by Statistics Canada and was intended to provide information to support the planning and development of programs and services for First Nations People. It was also intended to provide a demographic profile of all First Nations groups and gathered data on a wide variety of characteristics.

In order to establish the population to be surveyed, the APS was conducted following completion of the 1991 Census. Information gathered from responses to two census questions, pertaining to original and registered Indian/Band membership were used to identify the First Nations population. As a result, a sample of approximately 92,000 persons living in First Nations communities and 44,000 living in other areas participated in the 1991 APS. The sample included

people from all Aboriginal groups; Metis, Inuit and First Nations, both on and off reserve, children and adults. Data was collected on income, housing, employment, education, mobility, disability, lifestyle and social issues, health and language. However, a significant proportion of First Nations communities and territories decided not to participate in either the Census or the APS, which has seriously undermined the accuracy of the ensuing database and analyses.

In its response to the RCAP final report, the federal government through its Aboriginal Action Plan “Gathering Strength” mandated Statistics Canada to carry out a second APS (APS-2) following the 2001 Census. For APS-2 to be successful, Statistics Canada must work in cooperation with First Nations authorities and approach APS-2 with flexibility and innovation. In the absence of strengthened partnerships with all the stakeholders involved, community participation will likely be similar or poorer than it was in 1991.

Statistics Canada has undertaken a process of consultation with First Nations organizations and various stakeholders including other federal and provincial governmental departments on their information needs and the management process for the APS-2. Interested Federal Departments established their own internal consultation and management processes to ensure their data needs are addressed in APS-2. First Nations represented by their national organizations, conducted internal consultations and provided input to Statistics Canada on how they wished to approach the development of APS-2.

Unfortunately, these consultations have not resulted in management agreements considered satisfactory by all parties. At issue are the extent of First Nations ownership and access to databases, and the relationship of APS-2 to the First Nations and Inuit Regional Longitudinal Health Survey (see below). Statistics Canada is of the view that is bound by statutory regulations that govern access to raw data by external agencies, and the resulting limited access and ownership of data is not acceptable to First Nations authorities. Although DIAND have supported the position of Statistics Canada, Health Canada has been more supportive of the First Nations perspective on data access and ownership.

First Nation and Inuit Regional and Longitudinal Health Survey

First Nations people living on reserve are excluded from three national longitudinal population surveys – Survey of Labour and Income Dynamics, the National Longitudinal Study on Children and Youth and in particular the National Population Health Survey. In recognition of this serious gap in health information on First Nations health and social conditions a national consultation process and a feasibility study was undertaken by three federal departments (Health Canada, Department of Indian and Northern Affairs Canada and Human Resource Development Canada).

The First Nation and Inuit Regional Longitudinal Health Survey eventually was funded only by Health Canada under the Tobacco Demand Reduction Strategy in 1996. This Survey was the first initiative in which a national research project was conducted under the total control and authority

of First Nations and Inuit. The Survey was conducted in 183 First Nations and 5 Inuit of Labrador communities with a sample of 9,870 adults and 4,138 children.

The First Nation and Inuit Regional Longitudinal Health Survey Project involved nine participating regions, which each developed and conducted their own survey process within the framework of the national survey. Each regional survey incorporated a set of national core questions developed and approved by the mandated First Nation and Inuit National Steering Committee established to oversee the process

This initiative was undertaken to facilitate a First Nations and Inuit owned and controlled process of community, participatory research and health surveillance on the health status health determinants, health behavior and health care in First Nations communities. The Survey will also provide data at the regional and community level that will be very useful in developing programs and services that have a direct impact on community health.

Interdepartmental Committee on Aboriginal Information Management

The Interdepartmental Committee on Aboriginal Information Management is comprised of a membership of 12 federal departments and three Aboriginal organizations and is committed to the exchange and sharing of Aboriginal information, which exists in government and in Aboriginal Organizations.

Within the federal government, there are numerous services provided to Aboriginal peoples, primarily First Nations communities. Despite a common mandate among many of the federal departments, there has been no clear communication links among these various Aboriginal services and no shared knowledge of associated data holdings that are compartmentalized in programs or departments.

The Committee acts as a forum for discussion of activities related to information management issues affecting Aboriginal Peoples. Through quarterly meetings, members have shared information on best practices, have disseminated knowledge about existing databases and have taken a lead role in addressing the issue of territoriality and data ownership – the two barriers that have prevented the easy flow of information.

The Interdepartmental Committee on Aboriginal Information Management is one of the first coordinated endeavors to examine Aboriginal information issues, many of which are salient to the development, management and control of Aboriginal health data. However, the potential for the cross jurisdictional free flow of First Nations health data is a particular concern for First Nations groups. First Nations require protocols that ensure the integration and utilization of this data will not be undertaken without First Nations authorization and participation in the process.

FNIHB – Health Canada Health Research and Information Initiatives

One of the FNIHB's most important activities is gathering information on First Nations and Inuit health trends for use by Aboriginal organizations, field workers, policy-makers and program funders. The work involves surveillance, research and mapping of Aboriginal health trends, as well as providing expert advisory support to Pharmacy, Nursing and Dental programs. In 1998/99, the FNIHP Directorate embarked on a Knowledge Management program to ensure that the rapidly expanding information and knowledge base that FNIHB operates remains both accessible and manageable within the Branch, and in its work with its Aboriginal organizations, communities and other partners.

In addition to some of the initiatives discussed above, FNIHB is also involved in several health information initiatives that are relevant to a First Nations Public Health Surveillance system:

A. Maternal Mortality and Fetal/Infant Mortality Studies

At present, FNIHB collects basic information on infant mortality that involves linking the national Maternal mortality database and the Infant Birth-Death database to the Indian Register Population. The aim of the study is to provide accurate information about the occurrence of maternal and infant mortality in the First Nations population and to determine the magnitude of difference on these indicators with the general population. It is noteworthy that the August 2000 Annual Review of FNIHB Programs states that although the data linkage is complete, the study is on hold due to a staff shortage.

B. Injury Surveillance

FNIHB has identified injuries as a significant health hazard facing First Nations and Inuit people. In fact, injury is one of the greatest causes of morbidity and mortality among First Nations populations across North America. In Canada, injuries are the second leading cause of death overall for First Nations and Inuit people, and the leading cause of death among those between 0-44 years of age. Injuries represent between 28% and 35% of all deaths among registered Indians and Inuit, compared to just 8% of deaths in the Canadian population as a whole. The excess risk of death from injury for First Nations people compared to all Canadians ranges from two-to-five-fold, depending on the region.

To begin to address the injury problem, FNIHB commissioned in 1998/99 an environmental scan with the goal of "gaining insight into the current reality of injuries and injury-related activities among Canada's First Nations and Inuit population." The project focused on developing a current "injury snapshot" in order to assess the amount of work being undertaken in the area from both the regional and national perspective.

As a follow-up, a National Working Group on First Nations and Inuit Injury Prevention was established to work with the Health Technical Data Working Group (HTWG) to develop a Knowledge Map of injury surveillance and prevention.

C. Addictions

To better coordinate its activities in the area of Alcohol and Drug Abuse, and Solvent Abuse prevention and treatment, the FNIHP Directorate placed its work in these related fields under the umbrella of the Addictions program in 1998/99. It also initiated a number of projects designed to improve the administration and support the work of both the National Native Alcohol and Drug Abuse Program (NNADAP) and Youth Solvent Abuse Prevention Program (YSAP). Among these was an updated treatment activity reporting system, known as the Substance Abuse Information System (SAIS), from which it collects and analyses the gathered data annually. A new initiative to compile a comprehensive database on Fetal Alcohol Syndrome is also underway.

D. Diabetes

In 1998, the Directorate participated in a series of working groups with its First Nations and Inuit partners, and other Aboriginal and non-Aboriginal representatives, to develop the five-year Aboriginal Diabetes Initiative (ADI). The initial consultations were completed in 1999/2000 under the direction of the National Aboriginal Diabetes Initiative Steering Committee, which includes representatives from the Assembly of First Nations, Inuit Tapirisat of Canada, Métis National Council, Congress of Aboriginal Peoples, Native Women's Association, the National Aboriginal Diabetes Association (NADA) and FNIHB Regions and Headquarters.

In November 1999, the Minister announced \$58 million in funding for the Aboriginal Diabetes Initiative over the five-year period from 1999 to 2004. The ADI objectives include:

1. Improving care and treatment for First Nation on-reserve and Inuit communities
2. Improving prevention and promotion programs for all Aboriginal peoples
3. Offering lifestyle support services in communities
4. Building capacity to manage sustainable diabetes programs addressing surveillance needs through the National Diabetes Surveillance System

In 1999/2000, the Directorate also completed the Manitoba Diabetes Study and incorporated the Aboriginal diabetes requirements into the National Diabetes Surveillance System. FNIHB also continues to participate in the development and implementation of the overall Canadian Diabetes Strategy.

E. HIV

Unlike the AIDS epidemic in the Canadian population as a whole, where the cumulative number of AIDS cases has stabilized, the AIDS cases among Aboriginal peoples have

increased steadily over the past decade. Aboriginal people now represent 10% of all AIDS cases in Canada compared to 1.5% before 1989.

Aboriginal people with HIV/AIDS also tend to be younger than their non-Aboriginal counterparts (31% are diagnosed before age 30, as compared to 19% of non-Aboriginal people). The increase can be attributed in part to the fact that Aboriginal people are over represented in high-risk groups such as intravenous drug users and prison inmates. Because of the high mobility of many Aboriginal people, the HIV risk found in the inner city can be readily transferred to remote Aboriginal communities.

FNIHB provides HIV/AIDS education and prevention programming and related health care services to First Nations and Inuit communities. AIDS funding targeted at First Nations and Inuit communities began with \$300,000 in 1988-89. In Phase I of the National AIDS Strategy (1989-93) \$5.3 million was provided to Aboriginal communities and organizations. For Phase II (1993-97) that amount was increased to \$12 million.

Although various initiatives focused on prevention and education have been undertaken, HIV surveillance in the First Nations context is as yet undeveloped. The Centre for Infectious Disease Prevention and Control publishes regular estimates of HIV incidence and prevalence but concludes that their data are under-estimated because of incomplete ethnic information in HIV and AIDS case reports and because most studies have been done among high risk populations and may not reflect the general First Nation population.

F. Tuberculosis

While the incidence of tuberculosis has been decreasing steadily over the past several decades, First Nations and Inuit people still have a rate almost seven times higher than the Canada-wide rate. A commitment to dramatically reduce tuberculosis rates through aggressive monitoring and control measures led to the establishment of the Tuberculosis Elimination Plan in 1995, which seeks to reduce the tuberculosis rates in Aboriginal communities from 58.1 cases per 100,000 people in 1991 to less than 1 case per 100,000 by the year 2010. The program has a \$3.6 million annual budget, most of which the First Nations and Inuit Health Programs (FNIHP) Directorate allocates to the Regions for case identification and treatment and prevention activities.

G. Drug Utilization

The pharmacy section manages a wide range of drug information and drug utilization requests. Although the majority of this information is for the internal use of FNIHB, a growing number of requests, particularly related to drug utilization, are from external clients. In 1999/2000, pharmacists provided drug utilization information related to a variety of diseases including diabetes, tuberculosis, asthma and AIDS.

In 2000/2001, utilization trends will be provided in support of the ABX Project (a joint initiative of Saskatchewan Health, the Saskatchewan Pharmaceutical Association and the Health Services Utilization and Research Commission), which is seeking solutions for optimal antibiotic use, antibiotic utilization trends.

Ongoing support is also provided to the Drug Utilization Review Advisory Committee, which has the mandate to review utilization trends in order to identify areas of concern and to recommend interventions to optimize drug therapy.

An important part of FNIHB's activity is providing the data for research, surveillance and mapping trends in First Nations and Inuit health to allow policy-makers, FNIHB Regions and First Nations communities and organizations to design and evaluate health programs. To help make the information more useable, and to allow users to more easily link information from different sources, the Directorate has combined its Annual Health Data and Vital Statistics into the Health Information and Capacity Development program. Consolidating information sources will contribute to the ongoing policy of transferring control of health information, as well as programs, to First Nations organizations and communities. As part of its data reorganization, the Directorate is also re-assessing the quality of information gathered from all sources.

In 1999/2000, the Directorate worked to establish the Health Technical Data Working Group (HTDWG), which includes representatives from the FNIHP Directorate and the Regions, national Aboriginal organizations and other government departments. The HTDWG's mandate is to identify the health indicators for future data collection and the necessary population denominators, as well as to review data quality. A priority was to develop a shortlist of essential indicators for immediate use. Work was also begun on diabetes surveillance in developing record linkages with provincial medical records.

The Directorate also participated in the interdepartmental Aboriginal Information Management Committee, which includes representatives from a number of federal ministries as well as the national Aboriginal organizations.

Although all of these FNIHB activities are important initiatives in order to maintain and develop a modern public health surveillance system on behalf of First Nations, they are nonetheless largely undertaken with relatively minimal First Nations input. Indeed the general FNIHB philosophy has been that health info-structure and health surveillance should be the residual functions of the federal government (in a post-transfer environment) that should be undertaken in partnership with the provinces with First Nations participating as either clients or advisors. This philosophy is clearly directly opposed to the First Nations perspective that surveillance and self-government are inseparable.

7. Integration and Management of Health Information Across Jurisdictional Boundaries

Currently, federal First Nations health data is generally maintained by Health Canada (First Nations and Inuit Health Branch). At the provincial/territorial level, health data (based on physician claims for services provided) and health services utilization data (physician claims and hospitalization data) is maintained within the various provincial/territorial health ministries; often with no clear indication of the First Nations status of the user of the services. When First Nations communities and organizations need to gather information and data relevant to their citizens or communities, they must rely on information and data that is made available from the federal and provincial/territorial departments and ministries who hold the information about their communities.

Since government controls much of the data, the analysis of both federal and provincial health data is conducted by non-Aboriginal organizations and agencies on behalf of the respective levels of government. Increasingly, provincial governments and regional health authorities are interested in comparative or cost analysis of, for example, First Nations health utilization patterns. Sometimes these analyses are conducted by specialized Units set up within provincial health departments. In other instances, university-based research units are contracted to examine First Nations health issues using provincial administrative data. Since most provincial governments have only recently begun to recognize the need to work collaboratively with First Nations governments, this information is generally not available for First Nations organizations or communities to utilize in health planning.

Five provinces identify First Nations clients in their databases through unique health card numbers or First Nations health premium lists (New Brunswick, British Columbia, Alberta, Saskatchewan, and Manitoba). No province claims to have an exhaustive coverage of all First Nations. In Manitoba for example, the Health Department estimates that their data undercounts First Nations persons by as much as 30%, since First Nations persons and their descendants registered under Bill C-31 are not identified as First Nations on their health cards.

In Ontario, a residence code analysis has been done by the provincial government to extract hospital utilization information for First Nations clients living on reserve. In this case, identification is through postal code correspondence to reserve location, not health card number.

The western regions also have linkages with provincial vital statistics departments, either directly (Pacific, Alberta, Saskatchewan) or indirectly through DIAND (Manitoba) in order to obtain birth information for registered Indians. Both on and off reserve populations are included.

- Pacific is the only region where the Status Verification System (SVS) file is shared with

the provincial vital statistics department under a memorandum of understanding (MOU), allowing all verification of status births to be done by the province.

- In both Saskatchewan and Alberta, the FNIHB regional office conducts a record matching exercise on provincial births using the SVS file to extract First Nations births. Saskatchewan goes one step further, and requests that Community Health Nurses (CHNs) verify information and secondly, determine on or off reserve residency.
- In Manitoba, the birth database is sent by the province to the DIAND regional office, which verifies status entitlement and forwards this information to Manitoba Region FNIHB.

In the eastern part of Canada, no formal linkages exist with provincial vital statistics registries and birth information is obtained for the on reserve population only. FNIHB birth information is obtained directly from the communities, most often through reports provided by the Community Health Nurses (CHNs) to the regional office. The estimated coverage of communities varies, from 90% in the Atlantic Region, to fewer than 50% in Quebec. Ontario Region is unable to provide an estimate of their coverage of birth information as the mechanism of data capture is the First Nations Health Information System (FNHIS), which is not being used by some First Nations.²

In summary then there are three main methods used to identify First Nations persons in provincial health databases:

- *Identification of those health card numbers* that belong to First Nations. From that, a search can be made of all health records belonging to the First Nations health card numbers. Most provinces do not have ethnic identifiers on health card numbers. This includes Nova Scotia, Newfoundland, Prince Edward Island, British Columbia, Alberta, Ontario and Quebec. Although New Brunswick and Manitoba discontinued the use of ethnic identifiers some years ago, existing numbers were not changed meaning that there can be a partial identification of the First Nations population in these provincial health card number databases. In Alberta and British Columbia the health insurance premium database for First Nations people has been linked to health card numbers. This has allowed a First Nations utilization and expenditure analysis to occur in these provinces.
- *Utilization of a geographic indicator*, such as postal codes or residency codes that belong to First Nations communities. In this case, all records of residents in the selected areas will be extracted, not just First Nations. Also, the postal code may extend past the reserve boundaries and include other provincial residents.

² Ontario Region did not submit either birth or mortality information to the MSB Second Diagnostic published in 1999.

Currently, Ontario uses a version of a geographic identifier to provide information on First Nations. Pacific Region in association with the vital statistics department is currently developing a methodology based on postal codes to separate on and off reserve in their already identified First Nations population.

- *Sharing the DIAND Status Verification System database* with provincial health departments. This database contains the names, sex, birth dates, and band membership information of all registered First Nations persons living on or off reserve who are eligible for federal benefits through DIAND or FNIHB. Sharing of SVS information with provincial departments or agencies should require the permission of the First Nations in the province, generally through provincial First Nations bodies. In recent projects that have investigated provincial health care utilization and expenditures to First Nations, FNIHB has established a policy that sharing of SVS data with the province would require First Nations approval and participation.

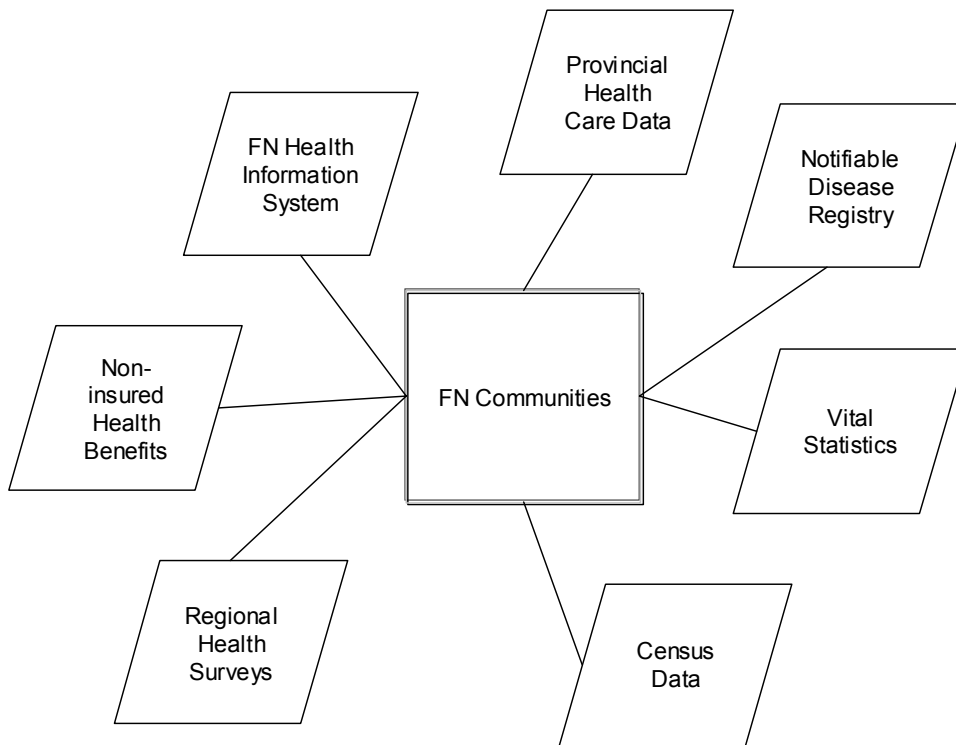
None of these methods for identifying the First Nations population in provincial health databases are perfect however. In addition to the problems in coverage identified above, identification of First Nations persons through probabilistic linkage methodology (identifying persons based on matches across two databases on variables such as name, age and sex) is inherently problematic for obvious reasons related to similarity of names in many First Nations communities.

Analysis using the health premium database may predispose the First Nations population to a slightly poorer socio-economic profile than would be the case if the SVS were used to identify First Nations. This is because some employers provide premium coverage as a benefit, and therefore some working First Nations people would be excluded from the premium list shared with the province. There are also concerns in Alberta, that as health card numbers encompass dependents, some dependents may not actually be First Nations under the *Indian Act* (re: Bill C-31 inheritance rules). When subsequent analyses are undertaken, they may reach conclusions that are not accurate representations of the entire First Nations population.

Of the five provinces with a capacity to identify First Nations in the provincial health databases, three (Manitoba, Saskatchewan and British Columbia) currently share hospital separation data on a regular basis with FNIHB regional offices, whereas Alberta and Ontario do not.

Data quality is difficult to address as a stand alone issue, but rather should be an integral component or a philosophy in activities involving information management, from data collection to dissemination. The reliability and soundness of information becomes more important as information is disseminated and a climate of evidence-based decision-making is created. Communities will likely perceive data quality as a higher priority if they routinely receive data reports with intra-regional comparisons and trend analyses from the FNIHB regional office, and use this information in program planning and evaluation activities. At the moment, this kind of feedback rarely occurs.

These are some of the important technological issues in the establishment of a system for First Nations health information and public health surveillance. These issues relate to the likelihood that diverse data sources will be required to create a comprehensive system. Data from collection systems with First Nation communities will likely have to be combined with collection systems outside of those communities. These external data sources could include provincial health databases, vital statistics databases, Statistics Canada data, health surveys, etc. The following figure illustrates some of the complexity in the data sources.



Combining these data will present unique technical and policy challenges. From a technical perspective, there will be challenges in identifying First Nations persons, linking data sources and reconciling differences in population counts and distributions. The policy challenges will include issues of data privacy and data ownership. Any process of data linkage will have to respect the various privacy laws across Canada. First Nations interest in promoting OCAP principles for data ownership will need to be reconciled with both privacy laws and federal and provincial policies related to data stewardship.

Clearly any proposal to develop a system where all First Nations persons are routinely identified in all provincial health databases will not only require careful consideration by Privacy Commissioners and Human Rights Tribunals, but First Nations authorities are unlikely to support such a proposal until formal agreements have been reached between federal, provincial and First Nations authorities that assure First Nations that these data will not be used without their consent and participation. Until OCAP principles are enshrined in

legal agreements among the various stakeholders, a discussion of the routine inclusion of First Nation identifiers in provincial health data will only generate resistance from First Nations authorities.

8. Capacity-Building Issues for a First Nations Public Health Surveillance System

Capacity development is more than just computer training and knowledge and use of the Internet; it is building capacity in self-determination and governance in health care that builds upon an individual and community development process. It is developing and applying abilities to govern and manage, solve problems, respond to new situations, make informed, evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to effectively and efficiently manage resources (human and fiscal) and to take responsibility for the success or failure of health interventions. Capacity development also implies the capability of working with internal and external agencies, organizations, institutions, departments and ministries to share knowledge and experiences.

Generally, when First Nations and First Nations communities and organizations need to gather information and data relevant to their citizens or communities, they must rely on information and data that is made available from the federal and provincial/territorial departments and ministries who hold the information about their communities. Developing the capacity to manage, analyze, and implement a health surveillance system requires investment in two areas of human resource development. First, academic training of First Nations people in the area of health research and information sciences is urgently needed. Several Universities, such as Manitoba and Alberta, currently provide specialized access and support programs to encourage First Nations students to pursue careers in medicine and allied health fields. Although some Aboriginal physicians pursue additional training in epidemiology and health services evaluation, particularly at the University of Manitoba, more career development in this area is required. Aboriginal students need to have the same support options available to them for graduate studies in the population health field, as they currently do in medicine, nursing, dentistry, etc. Continued career development of Aboriginal health research professionals at the post-doctoral and academic levels must also be supported.

A second stream for developing First Nations capacity in health surveillance can be achieved through continuing education opportunities. Most First Nations organizations and communities employ Health Technicians who are generally responsible for health policy development, program planning, and evaluation. Acquiring specialized skills in the effective use of health information must be a priority for this cadre of health professionals. One example of the kind of continuing education opportunities that need to be provided is the “Summer Institute in First Nations Applied Population Health Research”, offered at the University of Manitoba. This Institute, developed in partnership with the Assembly of Manitoba Chiefs, and partially funded by NHRDP, is offered on an annual basis to approximately 25 Aboriginal Health Technicians. The weeklong accredited course provides opportunities for participants to become familiar with various relevant health information

datasets derived from surveys, and provincial and federal administrative data. One day is spent examining the First Nations Health Information System and its potential for meeting the health information needs of First Nations communities. Participants work collectively to formulate policy and develop programs supported by evidence they assembled from data analysis.

However, these capacity-building initiatives must also support the development of Aboriginal post-secondary institutional development. Universities and community colleges offering or developing programs of study relevant to the interests outlined above, must undertake these initiatives in partnership with existing and planned First Nations institutions and organizations.

At the national level, several very important institutional capacity development initiatives have occurred that will strengthen First Nations capacity to take a leadership role in the shaping of a health info-structure. These new organizations are still young but with experience and maturity will be significant components in public health surveillance.

National Aboriginal Health Organization

The concept for an Aboriginal Health Institute was introduced within the Liberal Government's Red Book II – Securing Our Future Together commitment that stated that it would work with Aboriginal Groups to establish an Aboriginal Health Institute as recommended by the National Forum on Health. This institute would provide a vehicle for the development of capacities and expertise in the field of Aboriginal Health. The objectives of such an Institute would be to:

- Conduct health research on the needs of Aboriginal peoples
- Gather and disseminate information on the practice and efficacy of culturally appropriate medicines and treatments.
- Support basic and advanced training of Aboriginal health workers
- Serve as a support system for health workers in Aboriginal communities and
- Build on existing capacity.

The Federal Government committed \$20 million dollars over four (4) years to establish an Aboriginal Health Institute. In September, 1998, Health Canada provided funding to each of the five (5) national Aboriginal organizations to begin consulting with their constituencies: the Assembly of First Nations, Inuit Tapirisat of Canada, Metis National Council, Native Women's Association of Canada and the Congress of Aboriginal People.

Consultations led to the creation of the Organization for the Advancement of Aboriginal People's Health in 1999, which recently changed its name to the National Aboriginal Health Organization (NAHO). NAHO is governed by a Board with accountability to the five

Aboriginal organizations and is the process of developing three Research Centres for the First Nations, Metis, and Inuit communities.

The National Aboriginal Health Organization and its constituent Research Centres will be a critical element in the development of an Aboriginal Health Info-Structure as it could serve as a single window of available, validated Aboriginal health information and data to aid in research, community program planning and evaluation, sharing of knowledge, training and education. Negotiations are nearly complete to transfer resources from Health Canada to NAHO to fund the long-term implementation of the First Nation and Inuit Longitudinal and Regional Health Survey.

Institute for Aboriginal People's Health – Canadian Institutes for Health Research

The Institute for Aboriginal Health (IAPH) is one of the thirteen founding and equal institutes of the Canadian Institutes of Health Research (CIHR). The goal of the IAPH is to lead a national advanced research agenda in the area of Aboriginal health, and to promote innovative research in this field. The IAPH strives to “excel, according to international standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system.” The IAPH promotes holistic and cross-disciplinary health research, which addresses the four pillars, or dimension of research, namely; the biomedical, clinical, health services and systems, health, and the environment, society culture and population.

The IAPH is currently in its first year of operation and is developing a strategic plan that will identify research, capacity-building and partnership priorities for the coming years. In order to support the development of Aboriginal health research capacity, the IAPH recently funded a network of Training Centres (ACADRE Centres) in Ottawa, Manitoba, Saskatchewan and Edmonton. Additional Centres will likely be funded through future competitions. The IAPH also funded the creation of an Aboriginal Health Survey Support Centre at the University of Manitoba that will be work with NAHO to implement the FNILRHS. The IAPH will play an important role in the development of a First Nations public health surveillance system through partnerships with federal and provincial government departments and other Aboriginal agencies.

9. Political, Ethical, and Cultural issues for a First Nations Public Health Surveillance System

From a First Nations perspective, public health surveillance is not unlike other forms of data collection and research in terms of the relationship between these activities and First Nations goals of self-determination and self-government. Indeed the very term “surveillance” while on one level only a technical term describing a public health activity, is also fundamentally linked to the capacity of a people to govern itself. Where external agencies and governments

carry out “surveillance” activities, however benign, these activities are often seen as oppressive and can have the effect of perpetuating colonial relationships between two populations. The sections below present perspectives of the past and present, and show two polarities of data collection; that which was initially “on and about” First Nations peoples; and that which is “for and by” First Nations peoples and which is strongly tied to the First Nations self-determination and self-government movement.

The Past: Data Collection on First Nations People

First Nations and Inuit people, particularly since the reserve system was created and federal health services established in these reserve communities, have been literally captive specimens for all manner of researchers, investigators, government officials, consultants, academics, and the like. This has happened for many reasons, which encompass the spectrum from altruistic to selfish. Certainly documentation has been and is needed to determine required levels of health and other services, whether programs are effective in accomplishing their goals, to assist communities in accessing resources available in government programs, and for planning purposes. However, the feeling among many First Nations people has been that data collection has been one-sided; that investigators enter communities for motives of personal career enhancement, academic publishing, and/or financial incentives, in addition to the more laudable goals of improving health and well being. This is essentially the situation that has characterized data collection and research in First Nations communities until the late 1990’s.

Perhaps the suspicion and distrust of data collection conducted by non-Aboriginal outsiders might have been less severe, had First Nations communities in the past participated in the process and received concrete, positive benefits. Research ethics for past data collection activities in First Nations communities can be characterized as a colonizing process that has negatively contributed to First Nations’ oppression, First Nations’ science, and First Nations development. Research in the past could be described:

- The research is short term in nature
- The researcher enters into a community
- The researcher extracts information and/or biological samples
- The researcher leaves the community (without clearing the results)
- The researcher later publishes his/her own conclusions without the community’s consent, knowledge or any verification.

Research activities in this model had many limitations, most if not all which were negative to communities. There was no cultural context on which to base conclusions and researchers likely did not use culturally sensitive methods to collect data or recognized the importance of oral traditions. They may have indiscriminately published information with no regard to the effects on the community it came from, and left the community without helping to develop capacity in communities through training community members in data collection protocols or analysis. The resulting reports may have published erroneous conclusions that did not have the benefit of a community’s analysis or input. Just as important, there was no consultation with the community before the research process was initiated to determine if the research

addressed a health priority, an activity that by itself could generate important present and future partnerships between the community and the investigator.

Due to the realities of the situation facing First Nations communities, the vast majority of publicly disseminated research has projected a negative image of First Nations people in the media, as unhealthy mentally and physically, unemployed, poorly educated, marginalized and vulnerable. The magnitude of the harm that this has done to the esteem and pride of a people is significant for both the community and individuals.

Epidemiological research on First Nations health can function as a powerful social instrument for the construction of First Nations identity²⁰. International research has shown that public health surveillance systems perform disciplinary and regulatory functions in society independent of their overt purpose of tracking health conditions.²¹ This analysis points out the ways in which knowledge is constructed about sectors of society that reinforces unequal power relationships; in other words an image of sick disorganized communities can be used to justify paternalism and dependency.

External analysis of epidemiological data often constructs an image of First Nations communities as desperate, disorganized and depressed. This image is usually created with the intent to provide evidence for greater need for health care resources in the First Nations community. However, this image is often reflected through the Canadian media to the general public with quite different results. This image can re-enforce racist and other stereotypic images held by Canadians generally of First Nations people. This image is also sometimes internalized by First Nations communities and individuals, reinforcing dependency relationships. But this image is radically different from the reality in many First Nations communities where strong cultural traditions and social relationships continue to produce vital and resilient people.

The Present: Knowledge is Power

Resistance to the oppressive effects of external research is emerging in First Nations communities who are increasingly asking that health research be under First Nations control. Several recent examples of First Nations ownership of health research are discussed earlier in this Report. In general, First Nations communities require data collection activities to be vetted through appropriate First Nations authorities, and that all health research provide significant opportunities for research capacity-building. First Nations involvement in directing all phases of the data collection including design, implementation, analysis and interpretation is becoming routine. The formality of these requirements ranges considerably and several examples are provided.

Indeed, one of the areas where First Nations people are now enjoying their greatest success in the path to self determination is in the area of relevant and appropriate, community controlled research. First Nations people no longer tolerate externally driven research agendas, the lack of community needs and perspective, and research protocols that are alien to traditional methods of knowledge acquisition. As more First Nations people have become health

professionals or entered the professions of epidemiology, policy development, public health and the world of academia, a culturally sensitive perspective is appearing in research results. Research protocols are assuming a holistic perspective, as the physical, emotional, mental and spiritual domains are incorporated into their design. Importantly, data and other results of research remain firmly in the hands of the First Nations communities from where they originated. These developments in the area of academic research must be extended to include all forms of data collection including public health surveillance.

First Nations control of data collection has a number of benefits:

- There is an expanded interest in health as opposed to simple descriptions of illness;
- A strict control over its dissemination and use ensures that rather than a piecemeal approach to analysis and usage, a holistic community perspective is retained;
- It is a positive contribution to the broad self-determination and healing activities of communities, and may be a catalyst to community empowerment;
- It allows a participatory approach to research, which means that people are involved in research, not just as subjects but as collaborative partners throughout the entire research process;
- The research has a higher probability of being useful for community policy making as it has been developed and driven by community priorities;
- Data collection is likely to be more accurate as communities and organizations perceive that the time invested is worthwhile in terms of benefits to their planning and program activities;
- It allows training and development of First Nations people and contributes to economic development in a global sense; and
- It ensures that the analysis is not biased by non-Aboriginal values and beliefs, which may be unconsciously held by external researchers.

Codes of ethics are now being developed in First Nations research activities to guide the process, analysis, use and dissemination of information. The largest Canadian data gathering exercise in First Nations issues was the Royal Commission on Aboriginal Peoples, which overcame serious barriers and mistrust by First Nations peoples in its five year history. It did so, in part, through an integrated research plan which clearly spelled out the ethical guidelines for all sponsored research. More recently, the First Nations and Inuit Regional Health Survey has provided a successful example of a national-level First Nations designed and led survey of health status, practices and perceptions of health.

A current example of the significance of First Nations ownership for the development of a First Nations health information system can be found in the difficulties that have surrounded the implementation of the second wave of the First Nations and Inuit Regional Longitudinal Health Survey (see Survey description on Page 25).

Although designed as a Longitudinal Survey to be fielded every three or four years, the implementation of the second wave of the Survey has been hampered by the situation described above with the Aboriginal Peoples Survey II. The First Nations perspective was to find a way to coordinate and fund both surveys that would be consistent with the OCAP principles of ownership, control, access and possession that are fundamental to First Nations

interests in data collection and research. Further development of the FNIRLHS is under negotiation with Health Canada and Statistics Canada.

The First Nation and Inuit Regional Longitudinal Health Survey Project represents a continued opportunity for First Nation and Inuit peoples to own, control, manage, validate and determine a national research process which will provide important health and social data and community information which will aid in the identification of health and social priorities, evaluate programs and effectiveness of program interventions, provide information for political advocacy and allow the regions and communities themselves to analyze and interpret their own data and validate its findings.

10. Summary of Critical Issues in Health Information and Surveillance in First Nations Communities

Governance, Surveillance and Ownership of Health Information

First Nations people believe that true community healing and well-being can only be found through the path of self-government and self-determination, which gives full control over services provided to their communities. From a First Nations perspective, health information and public health surveillance is not unlike other forms of data collection and research in terms of the relationship between these activities and First Nations goals of self-determination and self-government. Indeed the very term “surveillance” while on one level only a technical term describing a public health activity, is also fundamentally linked to the capacity of a people to govern itself. Where external agencies and governments carry out “surveillance” activities, however benign, these activities are often seen as oppressive and can have the effect of perpetuating colonial relationships between two populations.

Historically, health surveillance in First Nation communities has posed logistic difficulties, which are compounded by jurisdictional uncertainties. Most notifiable disease systems are funded and maintained by provincial governments. Thus, notifiable diseases that occur in First Nation communities are generally documented and analyzed by provincial health authorities. However, data collection and public health interventions have generally been the responsibility of the federal government and more recently of First Nations themselves. This situation can lead to a disconnect between surveillance and public health practice, and quality control in surveillance systems can be compromised. The transfer of health services to the control of First Nations could further complicate these relationships unless concerted efforts are made to promote collaboration between federal and provincial public health agencies and First Nations.

Transfer of responsibility for a health service has important implications for public health surveillance. In the pre-transfer environment, FNIHB (or MSB) maintained responsibility for the regional and national monitoring of health conditions in communities. In the context of transfer, these responsibilities (and to some extent the resources required to meet them) have

been allocated to either individual communities or regional First Nations organizations. In the process of dividing resources for public health surveillance activities, the capacity to produce a comprehensive analysis of changing health conditions has been weakened. Efforts to renew this capacity under First Nations control and with the addition of new surveillance technologies such as HIS and the Longitudinal Health Survey are important priorities.

First Nations are now advocating ownership, control, access, and possession (OCAP) of health information on their communities as part of the development of a First Nations health info-structure. This health info-structure has been described to include First Nations control of health information systems, training and capacity development, research and data collection, health surveillance, linkages to other health systems (e.g. provincial), and planning and priority setting. The OCAP movement is resulting in a realignment of responsibilities for health information between FNIHB and communities. For example, the FNHIS implementation process involves the creation of MOUs between FNIHB and First Nations that specify, among other items, control and ownership of health information and access to the electronic database by First Nations and FNIHB.

Integration and Management of Health Information Across Jurisdictional Boundaries

Currently, federal First Nations health data is generally maintained by Health Canada (First Nations and Inuit Health Branch). At the provincial/territorial level, health data (based on physician claims for services provided) and health services utilization data (physician claims and hospitalization data) is maintained within the various provincial/territorial health ministries; often with no clear indication of the First Nations status of the user of the services. When First Nations communities and organizations need to gather information and data relevant to their citizens or communities, they must rely on information and data that is made available from the federal and provincial/territorial departments and ministries who hold the information about their communities.

Since government controls much of the data, the analysis of both federal and provincial health data is conducted by non-Aboriginal organizations and agencies on behalf of the respective levels of government. Increasingly, provincial governments and regional health authorities are interested in comparative or cost analysis of, for example, First Nations health utilization patterns. Sometimes these analyses are conducted by specialized Units set up within provincial health departments. In other instances, university-based research units are contracted to examine First Nations health issues using provincial administrative data. Since most provincial governments have only recently begun to recognize the need to work collaboratively with First Nations governments, this information is generally not available for First Nations organizations or communities to utilize in health planning.

Data quality is difficult to address as a stand alone issue, but rather should be an integral component or a philosophy in activities involving information management, from data collection to dissemination. The reliability and soundness of information becomes more important as information is disseminated and a climate of evidence-based decision-making is created. Communities will likely perceive data quality as a higher priority if they routinely

receive data reports with intra-regional comparisons and trend analyses from the FNIHB regional office, and use this information in program planning and evaluation activities

Combining these data will present unique technical and policy challenges. From a technical perspective, there will be challenges in identifying First Nations persons, linking data sources and reconciling differences in population counts and distributions. The policy challenges will include issues of data privacy and data ownership. Any process of data linkage will have to respect the various privacy laws across Canada. First Nations interest in promoting OCAP principles for data ownership will need to be reconciled with both privacy laws and federal and provincial policies related to data stewardship.

Clearly any proposal to develop a system where all First Nations persons are routinely identified in all provincial health databases will not only require careful consideration by Privacy Commissioners and Human Rights Tribunals, but First Nations authorities are unlikely to support such a proposal until formal agreements have been reached between federal, provincial and First Nations authorities that assure First Nations that these data will not be used without their consent and participation. Until OCAP principles are enshrined in legal agreements among the various stakeholders, a discussion of the routine inclusion of First Nation identifiers in provincial health data will only generate resistance from First Nations authorities.

Ethical Issues in Data Collection and Management

From a First Nations perspective, public health surveillance is not unlike other forms of data collection and research in terms of the relationship between these activities and First Nations goals of self-determination and self-government. Although the term “surveillance” may be at one level a technical term describing a public health activity, it is also fundamentally linked to the capacity of a people to govern itself. Where external agencies and governments carry out “surveillance” activities, however benign, these activities are often seen as oppressive and can have the effect of perpetuating colonial relationships between two populations.

First Nations and Inuit people, particularly since the reserve system was created and federal health services established in these reserve communities, have been literally captive specimens for all manner of researchers, investigators, government officials, consultants, academics, and the like. This has happened for many reasons, which encompass the spectrum from altruistic to selfish. Certainly documentation has been and is needed to determine required levels of health and other services, whether programs are effective in accomplishing their goals, to assist communities in accessing resources available in government programs, and for planning purposes. However, the feeling among many First Nations people has been that data collection has been one-sided; that investigators enter communities for motives of personal career enhancement, academic publishing, and/or financial incentives, in addition to the more laudable goals of improving health and well being.

External analysis of health information often constructs an image of First Nations

communities as desperate, disorganized and depressed. This image is usually created with the intent to provide evidence for greater need for health care resources in the First Nations community. However, this image is often reflected through the Canadian media to the general public with quite different results. This image can re-enforce racist and other stereotypic images held by Canadians generally of First Nations people. This image is also sometimes internalized by First Nations communities and individuals, reinforcing dependency relationships.

Resistance to the oppressive effects of data collection driven by external agendas is emerging in First Nations communities who are increasingly demanding that data collection be under First Nations control. Several recent examples of First Nations ownership of health information are discussed elsewhere in this Report. In general, First Nations communities require data collection activities to be vetted through appropriate First Nations authorities, and that all health information activities to provide significant opportunities for First Nations capacity-building. First Nations involvement in directing all phases of the data collection including design, implementation, analysis and interpretation is becoming routine. The formality of these requirements ranges considerably. First Nations communities have clearly recognized ownership of health information as a component of self-determination in health care.

The First Nation and Inuit Regional Longitudinal Health Survey Project represents a continued opportunity for First Nation and Inuit peoples to own, control, manage, validate and determine a national research process which will provide important health and social data and community information which will aid in the identification of health and social priorities, evaluate programs and effectiveness of program interventions, provide information for political advocacy and allow the regions and communities themselves to analyze and interpret their own data and validate it's findings. The importance of this survey data for the development of a comprehensive First Nations Health Info-Structure is consistent the extent to which federal and provincial agencies are relying on the longitudinal data from the National Population Health Survey and the National Longitudinal Survey of Children and Youth for determining health policy and planning health programs.

Human Resource and Institutional Development

Capacity development is more than just computer training and knowledge and use of the Internet; it is building capacity in self-determination and governance in health care that builds upon an individual and community development process. It is developing and applying abilities to govern and manage, solve problems, respond to new situations, make informed, evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to effectively and efficiently manage resources (human and fiscal) and to take responsibility for the success or failure of health interventions. Capacity development also implies the capability of working with internal and external agencies, organizations, institutions, departments and ministries to share knowledge and experiences.

Public health surveillance in Canada is in transition. An important emerging theme is an

increasing emphasis on technological solutions to improve the efficiency of data collection, analysis and dissemination. This is largely driven by a rapid expansion in the availability of computer technologies, including the Internet. Thus, more than ever before, surveillance initiatives at the federal, provincial and territorial levels are being led by those offering health information technology solutions.

However, as yet the results and public health benefits of these initiatives have been slow to materialize. There are several reasons for this. Although new systems for data capture and management are being developed, most new technologies still depend largely on existing data collection and analysis mechanisms. Thus, unless there is commensurate investment in human resources for data collection, analysis and dissemination, expansion of health information technologies will offer little in the way of new health information. Commitment for these new human resources has not matched the enthusiasm for new health information technologies. This disconnect between human resources for data collection and analysis, and technological systems for data organization and management is exacerbated by the reality that data collection usually occurs at a local or regional level, whereas most major new health information technology developments are provincial or federal initiatives. A further difficulty with a technological approach to the development of new health information systems is that the specific public health rationale is often underdeveloped. Health agencies, especially local ones, are reluctant to put resources into enabling new health information systems when the benefits to them are not clear.

11. Proposal for a First Nations Strategic Plan for Public Health Surveillance

The nature of public health surveillance in First Nations communities may preclude the establishment of a single, omnibus health info-structure or indeed, “public health surveillance system” for First Nations. Rather it may be more productive to promote the establishment of multiple individual surveillance systems. As discussed previously, the multiple jurisdictional levels in the management of First Nation health issues will entail variability in the roles in and expectations from surveillance. In general, local communities including individual First Nations will carry the primary load for new data collection, but may have few resources to use the surveillance data. Other jurisdictions will likely have more technical resources for data analysis, but will be dependent on more local jurisdictions for data collection, and will likely feel pressure to serve the analytic needs of individual communities. Furthermore, different jurisdictions may have different health information priorities and require different types of information, thus complicating the planning of surveillance systems. Thus, some durable process is required to plan surveillance systems and to set surveillance priorities.

Since many individual First Nations may not have the technical capacity within their community to analyze, interpret and report data from the surveillance systems, it will be important for First Nations to establish some more centralized capacity to perform this function. To do this, a determination will have to be made as to where those responsibilities lie, and how those technical capacities will be developed. One approach would be to create a

fairly centralized national analytic resource that would provide this service for more local jurisdictions. However, such a resource might not be close enough to the field to provide the kind of service required by communities and regional organizations. Another alternative would be to create a series of regional analytic resources centres. Each could provide broad technical support to communities within their region, while functioning as a national centre of excellence for one or more specific health information areas. The advantage of establishing regional analytic resource centres is that they could provide services that extend beyond surveillance per se and might include more general expertise and infrastructure in population research.

Optimally, these regional analytic resource centers should be under the control of First Nations authorities and should be staffed by First Nations technicians. In reality, few regions have the capacity to realize this goal, even in the long term. Indeed, most provincial health departments and regional FNIHB offices struggle to find competent people to fulfill these functions. Developing, managing and utilizing complex health databases is a demanding task which requires highly qualified individuals who are in high demand from both the public and private sector. University Units involved in health information system development also struggle to retain competent staff and are constantly looking for resources to expand training programs.

Just as First Nations authorities are reluctant to relinquish possession of health information that has been collected under their jurisdiction, so are provincial and federal departments reluctant to relinquish databases that have been aggregated through their service activities. In addition to the sense of “ownership” that data stewardship implies, provincial and federal agencies must be concerned about their legal responsibilities related to both the legislation through which data has been collected, and to the privacy and ethical requirements that are increasingly applied to the use and potential abuse of confidential information about individuals.

In the short term at least, First Nations regional analytic centers for health information and public health surveillance will likely involve collaborations and partnerships among First Nations authorities, federal and provincial agencies, and relevant University centers. These collaborations are necessary in order to maximize existing human resources, to resolve many of the technical problems related to linking and developing databases, and particularly in order to build trust among the various partners that the principles of OCAP can be respected and implemented.

The data in these systems will come for the most part from community and provincial service and data collection activities. Although the FNIRLHS survey data is important, it is only one piece of a system that must rely on other data in order to be effective. Data collection at the First Nations community level (i.e., through HIS) will always be difficult if the service providers who generate the data are not properly trained and resourced, and do not see the value in ensuring that data collection is consistently of high quality. Current efforts within the FNHIS environment to promote training and First Nations management of the process are extremely important and must continue to be supported. Data quality will be a more easily achieved goal if the results of data analysis are relevant to community needs and can be easily

disseminated and utilized in community health planning. Regional centers are more likely to be able to provide the logistic support for training and data utilization.

Setting priorities for public health surveillance must also be closely linked to public health activities. In the context of transfer, First Nations are relying increasingly on the resources of provincial health departments and regional health authorities. Dealing with health threats such as HIV/AIDS or water quality, or providing regionally distributed services for diabetes care, requires extensive interaction with provincial services and integrated health information systems must reflect this focus. In this context, provincial health authorities rely heavily on university-based research units for technical and analytical expertise, and these resources must learn to be responsive to First Nations concerns, such as OCAP.

A First Nations public health surveillance system based on regional partnerships and targeted public health priorities must shift the focus away from the current emphasis on bilateral federal/First Nations discussions of an omnibus national health info-structure/public health surveillance system. Regional tables (or Steering Committees) need to be established that bring together representatives from First Nations, FNIHB, provincial health authorities and Universities. National First Nations and federal representatives must participate in these discussions in order to ensure standardization and universality across regions necessary for the national roll-up and analysis of health information.

Targeted regional health surveillance projects should be established under the direction of these Steering Committees to provide the “experimental context” where these new partnerships can work out the political and policy issues related to data sharing and utilization, and where institutional and human resource capacity can be developed in a context that is accessible to communities and organizations.

An important barrier to the achievement of an effective and efficient First Nations health info-structure and health surveillance system is a perception within FNIHB that many of these health surveillance activities should be the residual functions of the federal government (in a post-transfer environment) and that they should be undertaken in partnership with the provinces with First Nations participating as either clients or advisors. This philosophy is clearly directly opposed to the First Nations perspective that surveillance and self-government are inseparable. Multisectoral partnerships guided by the OCAP principles are the only solution to advancing this critically important agenda.

Summary of Strategic Recommendations:

- 1) The development of a First Nations Health Info-Structure and the development of public health surveillance systems must be given higher priority by First Nations, federal and provincial leaders. Not only are health surveillance activities a fundamental component of self-government, but the current erosion of a coordinated health surveillance capacity in the context of health transfer is both dangerous from a public health perspective and seriously undermines the health planning process at a time when resources are inadequate to meet health needs.

- 2) The focus for development should be on the establishment of multiple surveillance systems focusing on specific public health problems rather than a single omnibus national health info-structure or “public health surveillance system” for First Nations.
- 3) A critical first step will be to establish a process for setting public health surveillance priorities and for planning public health surveillance systems. This process must occur at the regional level to ensure that priority setting reflects community and regional problems and needs. Each region should establish a planning process to be led by regional First Nations authorities and to include regional FNIHB representatives, provincial health representatives, and where relevant, university-based expertise.
- 4) Federal and provincial governments should collaborate to establish a dedicated position for a First Nations person to provide oversight of the public health surveillance planning process at the regional level.
- 5) First Nations need to continue to develop their own capacity to perform the analytical and dissemination functions of a public health surveillance system. Both federal and provincial governments should develop programs and strategies (e.g., internships) to support ongoing capacity development.
- 6) Consideration should be given to creating a series of regional analytic resources centres that could provide broad technical support to communities and organizations within their region.
- 7) In the short term at least, First Nations regional analytic centers for health information and public health surveillance will likely involve collaborations and partnerships among First Nations authorities, federal and provincial agencies, and relevant University centers.
- 8) A national First Nations Health Surveillance Committee should be established to oversee and support health surveillance activities at the regional level, and to ensure that standardization of health information systems across regions is achieved. This Committee should include representation from NAHO, IAPH and other working groups and committees that are involved with the development or integration of health information systems for First Nations communities.
- 9) The national First Nations Health Surveillance Committee should also take on responsibility for ensuring that OCAP principles are fundamental to further health info-structure development, and that issues of individual confidentiality and consent to have health data used for research purposes are taken into consideration. In particular, this Committee should establish an appropriate protocol for regions wishing to use federal or First Nations datasets for purposes of identifying First Nations individuals in provincial datasets. These protocols should also address, from a First Nations perspective, ethical issues involved in linking various datasets.

10) Targeted “pilot” health surveillance projects should be established under the direction of both regional and national planning Committees that will provide the opportunity for the various partners to develop the capacity to work together in an environment of mutual trust.

12. ENDNOTES

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