

A stylized graphic of a sun with rays and wavy lines below it, rendered in a golden-brown color. The text is centered over the sun's rays.

ONTARIO'S ABORIGINAL HEALTH INFORMATION CHALLENGE

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MAIN MESSAGES

- Ontario's Aboriginal residents, like other citizens, deserve to receive care that is based on the best evidence. Data from the provincial health care system does not include ethnic identifiers, however, so comprehensive analyses of Aboriginal people's utilization of the provincial health care system are unavailable.
- There are a number of data linkage methods which have been used in Canada's other provinces and territories to provide information about their Aboriginal population's health and access to services. These include links to health card identifiers, health premium payments, status verification indexes, membership lists, vital statistics registries and indirect geographical indicators.
- Determining how Aboriginal health information may be gathered, analyzed and used – in Ontario, as well as in the other provinces and territories – requires approaches that are respectful of Aboriginal requirements and cultural understandings; yet, at the same time, take into account the conceptual and operational challenges inherent in health database development.

- Champions are needed to address Ontario’s Aboriginal health information challenge; the individual or individuals who take on this advocacy role must listen to Aboriginal stakeholders, but also have the “ear” of government – and, for that reason, probably be part of the provincial government (e.g. the Minister of Health and Long-Term Care).

EXECUTIVE SUMMARY

Recognizing that the majority of Aboriginal people living in Ontario have less access to quality primary health care than is true for the province's population as a whole, the Ontario Health Quality Council commissioned a study entitled *Assessing the Quality of Primary Care Services Available to Ontario's Aboriginal Residents*. This environmental scan was framed around two broad questions: (a) what is the nature of the services available to Aboriginal people across the province? And (b) what do we (and can we) know about the quality of that care? The answers came from a comprehensive review of published literature, combined with in-depth interviews of individuals responsible for administering and delivering primary care to Aboriginal clients across the province in rural, remote or urban settings.

The results showed that Ontario needs a health information system that would allow Aboriginal people's health status and health services utilization to be completely and accurately documented on a routine basis. Without a means to collect such data, the present gaps in our knowledge about Aboriginal Ontarians' health and well-being will persist, making it impossible to provide fully the culturally appropriate services they are entitled to as citizens. Because it is known that other provinces and territories do better in this regard, the Council commissioned a follow-up study to: (1) review existing data collection systems in other Canadian jurisdictions that have effectively tagged Aboriginal users to the health system; and (2) identify the policy

implications of implementing an all-inclusive health data collection system for Ontario's Aboriginal population. Information was compiled from a review of the policy and technical literature and through interviews with stakeholders in the provinces and territories where data linkage efforts are occurring.

Each province or territory has varying capacity to document Aboriginal peoples' health and their use of health services, depending on their existing health datasets, whether or not Aboriginal identifiers are embedded in their information systems, and their ability to link health data to Aboriginal identifiers outside of the health care system. Some provinces or territories can locate Aboriginal data using health card identifiers, health benefits payment information, or vital statistics identifiers; others rely on linkages using federal or provincial Aboriginal registry and membership lists; all have the capability to conduct geographical analyses to identify health problems and access issues for communities or regions which have significant Aboriginal populations.

Aboriginal health information policies must be shaped by a set of principles that stipulate Aboriginal peoples' collective entitlements with respect to information about their communities. These principles, commonly referred to by the acronym OCAP (Ownership, Control, Access and Possession), have implications regarding the collection, storage, use and interpretation of health information. It is important to recognize and respond to different interpretations of OCAP principles; specifically, on issues of trust, data ownership and research capacity, along with

needs to maintain confidentiality, negotiate appropriate protocols and permissions for data access, and investments to develop Aboriginal health databases. There was one common theme in the advice given – it takes time, as well as financial and human resources to develop and keep comprehensive datasets current.

In order for Ontario to improve its Aboriginal health information system, there are a number of factors to consider. Various strategies are being tried elsewhere in Canada that might be applied in this province, but we need to ensure that data collection is done in ways which respect and respond to the history, cultural understandings, and priorities of our Aboriginal communities and organizations. Procedures must be put in place to make sure that information is of high quality, kept in confidence, and that privacy is maintained. Only through negotiation, whether on a project-by-project basis or under on-going agreements, can a health information system be established that meets the needs of Aboriginal people, decision-makers and care providers.

Champions are needed to address Ontario’s Aboriginal health information challenge. In other words, an individual or individuals who will take on the role of advocating for the establishment and maintenance of mechanisms which permit the appropriate identification and use of data about the health of Aboriginal Ontarians. The champion(s) must listen to Aboriginal stakeholders, but also have the “ear” of government – and, for that reason, probably be part of the provincial government (e.g. the Minister of Health and Long-Term Care).

ONTARIO'S ABORIGINAL HEALTH INFORMATION CHALLENGE

Ontario needs a health information system that allows Aboriginal people's health status and health services utilization to be completely and accurately documented on a routine basis. This was one of the principal messages that came out of the Ontario Health Quality Council's study of primary care services available to the province's Aboriginal residents.¹ Without a means to collect such data, the present gaps in our knowledge about their health and well-being will persist, making it impossible to provide fully the culturally appropriate services they are entitled to as citizens. To date, the province's efforts have been limited to a few short-term projects. Other Canadian jurisdictions do better in this regard, but to varying degrees.

Ontario's shortfall set the objectives for this follow-up to the Council's earlier Aboriginal health study. These were: (1) to review existing data collection systems in other Canadian jurisdictions that have effectively tagged Aboriginal users to the health system; and (2) to identify the policy implications of implementing an all-inclusive data collection system for Ontario's Aboriginal population. Unlike the first study, which involved a wide-ranging environmental scan, the second one focused on a narrow, but highly important topic. The information was compiled from two sources: a review of the literature (which, given the topic,

tends to be quite technical); and interviews with stakeholders in the provinces and territories where data linkage efforts are occurring.

To understand essential aspects of what might be termed *Ontario's Aboriginal health information challenge*, the present report starts by reviewing two topics covered in greater depth by the first study's report: the demographic characteristics and the health status of the province's Aboriginal population. It then discusses the conceptual and operational issues involved in developing Aboriginal database linkages.

ONTARIO'S ABORIGINAL POPULATION: DEMOGRAPHICS

The 2001 Canadian census, the most recent data available,² found that 188,315 Ontario residents identified themselves as being of Aboriginal heritage, whether First Nation, Inuit or Métis.³ This number is an underestimation for several reasons, however. First, seventeen reserves or settlements were not fully enumerated.⁴ In certain cases, communities refused to take part as a matter of principle; they do not believe that the Canadian government has the right to take a census of their people. Second, if patterns from the 1996 census repeated, it is likely that a significant number of people, both on- and off-reserve, who reported that they were of Aboriginal heritage, did not self-identify as Aboriginal.⁵ Smylie notes that some individuals will not reveal their ancestry or claim an Aboriginal identity when dealing with non-Aboriginal census takers, because of "historic, systemic, and attitudinal inequities."⁶ Third, because this

population tends to be very mobile and to be over represented among those who are homeless, an untold number would have been missed in the count. And, fourth, the status of some individuals who rightfully are Aboriginal is not recognized for various anomalous reasons.

Still, although those known are just one per cent of the province's population, it appears that more than one-in-five Aboriginal Canadians are Ontarians. The majority of them live amidst the general population, with only 21.5 per cent residing in some 134 First Nation communities scattered across the province, but concentrated in the north. Of the rest, 61.1 per cent are city dwellers and 17.4 per cent live in rural areas. Compared to the province's population as a whole, because of continuing higher (albeit declining) birthrates, Aboriginal people tend to be younger, with about 46 per cent under 25 years of age.

While it is possible that the results of the 2006 census will be more comprehensive, several of the factors that undermined the accuracy of previous counts have not changed; so a degree of imprecision is likely inevitable. This fact is a significant consideration for those charged with developing population-based health databases, for reasons outlined in later sections of this report.

ONTARIO'S ABORIGINAL POPULATION: HEALTH STATUS

There is no comprehensive epidemiological information for Ontario's Aboriginal population as a whole. Rather there is a mixture of data from various sources, much of it derived

from one-off studies on specific conditions in specific segments of the population. There are Ontario results in the First Nations and Inuit Regional Longitudinal Health Survey, which includes self-selected First Nation communities and is based on self-reported data.⁷ There also have been limited analyses of data from several of Ontario's Aboriginal Health Access Centres.⁸

Although certain groups – including the Cree and Ojibwa of northern Ontario – are subject of numerous studies, comparatively little has been written about First Nations people who live off-reserve in rural areas and urban centres, or the Métis and those who do not have registered status.^{* 9} Some topics, like diabetes, are well researched, but others are largely ignored, including injuries, one of the leading causes of death.¹⁰ In sum, there are significant gaps in what we know about the health status of Aboriginal Ontarians.

Nonetheless, looking at disease after disease, study after study has drawn the same conclusion: Aboriginal people are more at risk of having or developing a serious health problem. For example, comparing results from the First Nations Regional Health Survey with those found in the Ontario part of the National Population Health Survey shows that the prevalence of reported chronic conditions are significantly higher among Aboriginal residents.¹¹ Using diabetes as an example, although treatment has improved for the general population, diabetics living in Aboriginal communities were two times more likely to suffer acute complications.¹²

* The Indian Act identifies a person as having “Status” if they are recorded in the Indian Register. Individuals of Indian ancestry who were not enrolled or removed due to the enfranchisement provisions of the Act are referred to as “Non-Status Indians.”

Cross-group studies show much higher rates of overweight and obese Aboriginals.¹³ They also compare unfavourably when other risk factors linked to cardiovascular disease, like smoking, are considered.¹⁴ Adding to this litany of bad news, hypertension levels are higher overall.¹⁵

The difference in morbidity rates between Aboriginal and non-Aboriginal populations testify to the Aboriginal disadvantage with respect to most determinants of health. For example, raw sewage contaminating the water supplies in many First Nation communities causes the bacterial infection, shigellosis, at almost 20 times the national rate.¹⁶ Over-crowded housing, both on- and off-reserve, is common; this contributes to the spread of infectious diseases, like influenza¹⁷ and tuberculosis.¹⁸ Of course, poverty influences housing choices, particularly for those living off reserve. It also contributes to poor dietary decisions. People opt for the type of high fat, low fibre diets that are cheaper, but lead to diabetes and obesity.¹⁹

Choices in other areas also introduce significant health risks. Consider smoking for example; 79 per cent of males and 72 per cent of females living on-reserve in Ontario report that they smoke, compared to 30 and 27 per cent, respectively, of the general population.²⁰ At the same time, Aboriginal lung cancer rates are rising.²¹ However, cancer rates are still below the national average,²² probably attributable to the youthful demographic profile of Aboriginal communities. But cancer survival rates are poorer, especially for those from remote places, because clients tend to present only after the disease is at a more advanced stage.²³ Cancer is the

third most frequent cause of Aboriginal deaths in the province, after heart disease and violence or accidents.

There is no reason to believe that the individuals in Ontario at highest risk of suffering a deviation in their mental health would differ from those in other jurisdictions — people, who are homeless, incarcerated, who have alcohol and drug problems, or are suffering the aftershock of a catastrophic life event.^{24 25 26} Such marginalized situations are thought to both feed and reflect Aboriginal peoples' mental health status.²⁷ A common root cause of Aboriginal mental health problems, in Ontario and elsewhere in Canada, are the abuses that occurred in residential schools, which not only affect the former students, but also their children and grandchildren.²⁸ Reactions to this social and psychological trauma manifest in the form of “dissociation, mood, personality, or behaviour problems, alcohol or other substance abuse, self harm and suicide.”²⁹ A diminished cultural identity, weakened family and community ties, poverty and economic dependence also contribute to mental health problems, especially among children and youth.³⁰

Results of an analysis of data, from four of Ontario's Aboriginal Health Centres (AHACs) in 2001-02, indicate that chronic health problems persist among the Aboriginal population, with high levels of diabetes and its cardiovascular complications, arthritis, respiratory problems, and mental health disorders. Poor health is prevalent, with one in three clients in the AHAC study being diagnosed with four or more conditions.³¹

These few references do not completely summarize what is known about the health status of Aboriginal Ontarians, but they are sufficient to indicate that disparity, relative to the general population, exists in many situations. And they serve to underscore the need to establish a mechanism through which Aboriginal peoples' health information is available to those who must plan and deliver culturally appropriate health services, regardless of whether their clients reside in First Nation communities, rural areas or urban centres.

ABORIGINAL DATA LINKAGE APPROACHES

Across Canada, the health challenges facing Aboriginal people mirror those found in Ontario. Consequently, concerned Aboriginal leaders, government officials, health service planners, and researchers have been exploring ways to network information in order to make possible a better understanding of this population's health status and use of health services. The attempts, to date, vary from one jurisdiction to another and from one project to another; however, in almost all cases, it is recognized that the coverage achieved is less than complete.

O'Neill outlined the substantial difficulties faced when trying to document Aboriginal peoples' use of provincial or territorial health care services, as well as the strategies being used in parts of Canada to address them.³² Some jurisdictions assign unique health card or health premium identifiers to First Nations individuals with status; others link health datasets, including vital statistics, to Aboriginal membership lists from communities or Aboriginal organizations; and, elsewhere, provincial and territorial data is linked to the federal government's status verification index maintained by Indian and Northern Affairs Canada (INAC). Geographical analyses are widely employed in studies documenting disparities in the health and well-being of Aboriginal populations. In the following section, examples of each of these approaches are summarized.

HEALTH CARD IDENTIFIERS

Saskatchewan, Manitoba and the Northwest Territories have used special identifiers or “flags” on their health cards or within their population health registries to explore Aboriginal people’s utilization of provincial or territorial health services. Each jurisdiction, however, has different methods of assigning identifiers and varying capabilities to link the identifiers to administrative health databases.

Of these jurisdictions, the Northwest Territories has the most comprehensive system in place. Its health card allows individuals to voluntarily self-identify at the time of registration (with supporting documentation) as status First Nations, Métis, Inuvialuit or Indigenous Métis. There also are procedures in place to amend the Aboriginal identity registered, if an individual changes status. Although the information on ethnicity is not routinely validated against the Status Verification Index or other Aboriginal organization membership lists, a diabetes surveillance project which linked health card identifiers to records maintained by the Inuvialuit Regional Corporation (IRC) indicated that the numbers of Inuit identified through health cards were “very close” to the population numbers provided by the IRC.

The Northwest Territories’ health card numbers are alphanumeric, with the initial letter encoding Aboriginal identification. As a result, standard health reports for the territory cover variations by medical condition, community type, gender, age, and ethnicity (Aboriginal Dene, Métis and Inuit groups, or Non-Aboriginal) across the full spectrum of services (hospitals,

physicians, health centres, public health units, medical travel services, and community health services).³³ Data can be analyzed by health region or by community.³⁴ As well, Aboriginal identifiers on the health cards can be linked to the territory's communicable disease, diabetes and cancer registries. Because territorial residents needing specialist care are primarily referred to tertiary treatment centres in Alberta or British Columbia, the Northwest Territory's datasets also can capture information about out-of-territory medical care, through the inter-jurisdictional billing data available.

In contrast, the Saskatchewan and Manitoba cards can only identify First Nations populations with status. Saskatchewan's health cards include an embedded 5-digit residence code that identifies each of the cities, towns, villages, rural municipalities and First Nations in the province, with the codes for First Nations people assigned according to their band of origin, not according to the reserve in which they might be living.³⁵ First Nations residency codes, along with address information in Saskatchewan Health's registry system, permit analysis of health status and service utilization for First Nations. Updated on an annual basis, the system also provides health care planners with relatively accurate estimates of on-reserve and off-reserve First Nations populations.

The Manitoba health insurance registry contains similar coding which can be used to identify many of the province's First Nations people with status. As part of the process of applying for health cards, First Nations people declare status if they present band registration; if

they do so, they are assigned the coding for that band and flagged as First Nations within the health registry.³⁶ Due to historical factors, however, the Manitoba health registry undercounts First Nations people with status who reside in the province; estimates suggest that as many as 30 per cent may not be flagged on their health cards.³⁷ Because of this, most of the recent First Nations health studies in the province combine the registry information with other sources of data, such as INAC's status verification files.³⁸ This information has been linked previously to specialized administrative databases, such as Manitoba's diabetes³⁹ and cancer⁴⁰ registries.

Respondents who discussed health card identifiers noted “there is a lot of political implication in trying to replicate [the methods used] in other jurisdictions.” Where health card identifiers have long been embedded in provincial or territorial administrative datasets and there is a history of successful and collaborative research, the consensus is that the identifiers “worked well” and benefit Aboriginal residents, health care organizations, researchers and government departments planning services. However, establishing the need for Aboriginal-specific health card identifiers may prove politically unpalatable, if a province or territory has not previously made use of ethnic identifiers. One interviewee said of their system of unique identifiers: “That’s what works best for us, but in other jurisdictions, I’m sure there will be a lot of resistance.”

HEALTH BENEFITS IDENTIFIERS

Alberta and British Columbia, where the system of payment for medical care includes health premiums (not a health tax, as in Ontario), the Health Premium database can be used to identify First Nations people with status by flagging individuals whose premiums are paid for by Health Canada under the Non-Insured Health Benefits Program. Information about them as a group can then be found in other administrative databases using their health card numbers.

In Alberta, this approach has been used in numerous epidemiological studies comparing the health of First Nations members to the general population, including examinations of multiple sclerosis,⁴¹ self-inflicted injuries,^{42 43} and critical illness.⁴⁴ Other Alberta projects have used this capability to explore First Nations peoples' utilization of health services.⁴⁵ A particularly comprehensive project, which focused on the calendar year 2000, tapped into a number of databases: the Alberta Health Care Insurance Plan, the Hospital Morbidity Index, the Ambulatory Care Classification System, and the Fee-for-Service Claims Database. Comparisons were made with a sample of non-First Nations individuals, matched in terms of age, sex and geography. Mortality data could not be included in the analysis, however, because Alberta's Vital Statistics registry does not collect information on ethnicity.

Guided by the cultural interpretations of the project's Aboriginal Advisory Group, the analysis examined patterns of service utilization for specific health conditions to determine the source of services used (hospital, emergency rooms, or physician offices), taking into account

gender, age, and geographic variations. The findings were then used to create the baseline for an electronic database that can be continuously updated and made available to First Nations communities, health care administrators, professionals and academic researchers.

STATUS VERIFICATION INDEXES

When there are no Aboriginal identifiers embedded in a given province or territory's health databases, as is the case in Ontario, the common method for exploring health issues involving First Nations peoples is through the INAC Status Verification Index. This was done in Ontario, for example, to study First Nations cancer incidence and mortality for the period from 1968-1991.⁴⁶ Because Ontario's Cancer Registry does not include any ethnic information, the First Nations cancer surveillance project involved a multi-stage process of aggregating information from the INAC status membership lists for the time period, matching it on the basis of identification number, names, date of birth and sex. The resulting cohort of Aboriginal individuals with status was then linked with the provincial mortality and cancer incidence data. The analysis compared rates for the status First Nation cohort with the general population and examined the incidence of specific types of cancer in males and females over three time periods.

The linkage process itself becomes increasing complex, however, when the client identifiers vary in any of the records which must be linked.⁴⁷ For instance, personal identification numbers, such as those contained in the Indian Status Verification Index, may

change over time – when children come of age or women change their name through marriage. The lists may also contain inaccuracies; for example, individuals who have died or left the province may remain on the list, if updating has not been done. The lack of common personal health identifiers across provincial and federal administrative datasets creates similar challenges. Compounding these problems, the technical expertise required to “de-identify” the data is often lacking, except at larger research centres.⁴⁸

MEMBERSHIP LISTS

Although considerable attention has been given provincially and federally to health issues affecting First Nations people who have status, almost nothing is known about the health and service utilization patterns of Métis people. Except for the Northwest Territories, no Canadian jurisdiction has a mechanism in place to identify Métis residents and track their use of the health care system. The only other sources of information are the Aboriginal Peoples Surveys done by Statistics Canada, which includes people who have self-identified in the census as being non-status First Nations, Inuit, Métis or non-specified Aboriginal heritage. Additional information was collected through the 2001 survey, which included a Métis supplement.

Manitoba, however, did an exploratory study of Métis health in 2002.⁴⁹ Developed at the request of the Manitoba Métis Federation, the project examined the feasibility of linking Métis membership lists with Manitoba Health databases. The pilot study was based on a small

sample, some 2,500 Métis over the age of 15 who lived in a predominantly rural regional health authority. The membership list provided had peoples' names, dates of birth, gender and residential addresses. Using computer record matching software, most of those on the list were linked to Manitoba's provincial health insurance database, which identified personal health information numbers. These could then be employed to locate and analyze information held in hospital and physician billing databases, as well as the province's diabetes and cancer registries. Similar projects are underway in Ontario and Nunavut to examine the feasibility of linking Métis and Inuit membership lists to their respective provincial and territorial health databases.

Although the Manitoba project demonstrates that such linkages can be made, it also shows the problems of using organizational lists as the basis for linkages. Because membership is voluntary in most cases, lists may have different criteria for determining membership from one place to another and, as in the case of the Métis list in the cited study, not represent all age groups. As well, there are often gaps, errors or inconsistencies in the information recorded. The authors of the Manitoba study suggest that additional identifying information on Aboriginal organization's membership lists, such as provincial health insurance numbers, would be required to fully match the lists to provincial databases.

VITAL STATISTICS LINKAGES

Although some provinces and territories allow voluntary reporting of ethnicity on birth or death records, only British Columbia systematically identifies First Nations people with status in its vital statistics databases; birth records rely on information provided by parents, while death registries include the individual's band number. This vital statistics information provides the basis for comprehensive data linkage processes, which can identify most of the provinces' First Nations individuals with status.

Using a multi-stage computerized matching process, British Columbia cross-references this vital statistics information to the INAC Status Verification Files, which list all status Indians resident in the province, and the Status Indian Entitlement files from British Columbia Medical Services, which identifies the health premium payments made for individuals under the federal Non-Insured Health Benefits Program.⁵⁰ Individuals are identified as "Status Indians" if designated as such in any of the above sources, which alleviates the problem of under-counting due to relying on one of the databases alone.⁵¹ To ensure data quality, an audit is done to remove duplicate and non-resident records and review those without valid postal codes; the remaining records are flagged and aggregated, permitting estimates of the status First Nation population for each of the province's Health Service Delivery Areas, which in turn can be linked to the province's administrative health databases. The method has been employed extensively in the province, producing studies of premature mortality,⁵² urban-rural variations in infant

mortality,⁵³ smoking-related mortality,⁵⁴ as well as diabetes-related mortality,⁵⁵ hospitalizations⁵⁶ and prevalence.⁵⁷

With the signing of a memorandum of understanding between the governments of British Columbia, Canada and the province's First Nations (2006), the groundwork has been established for comprehensive data sharing agreements which will permit ongoing utilization of this approach to assess the health of First Nations people with status in the province.⁵⁸ The memorandum also contains provisions for full reports on the health status of this segment of the population every five years, interim reports bi-annually, and the expansion of provincial health surveys to include First Nations communities. Discussion is currently underway between the Métis Nation of British Columbia and the government of British Columbia about framing a similar memorandum regarding Métis people.

GEOGRAPHICAL INDICATORS

When database linkages are not feasible, indirect geographical indicators (postal codes, residence codes, or census subdivision information) have been used Canada-wide to identify patterns of health service utilization in those communities or regions where significant numbers of Aboriginal people are known to reside. Recent studies using spatial or geographical approaches have explored differences in Aboriginal peoples' access to pre-natal care,⁵⁹ hospitalizations for influenza and pneumonia,⁶⁰ and likelihood of kidney transplantation.⁶¹

To highlight an Ontario example, the Institute for Clinical Evaluative Sciences published a report on First Nations people in the *Practice Atlas on Diabetes* for the province in 2003. This analysis used postal codes to locate on-reserve residents and then compared their diabetes-related mortality and morbidity with those found in non-First Nations communities.⁶² The researchers relied on census data to identify communities which had 85 per cent or more of their population residing in recognized First Nations reserves or settlements. With the postal codes for these communities, it was then possible to access data in the Ontario Diabetes Database, the Registered Persons Database, and Canadian Institutes of Health Information (CIHI) data on mortality and hospitalization. The study showed that First Nations people were at greater risk of diabetes and complications and were more likely to be hospitalized for cardiovascular or cerebrovascular diseases; however, they were less likely to have specialized procedures to treat these conditions. Subsequent trend analyses revealed that residents of remote communities with diabetes were more likely to be hospitalized for avoidable complications.⁶³

The study's authors acknowledge, however, that this methodology only works well when Aboriginal populations are concentrated in relatively small geographic areas. Their postal code methodology actually identifies fewer than 7 per cent of the province's Aboriginal residents (including only a portion of those living on reserve); it does not capture care received by First Nations, Métis or Inuit people who live off-reserve, nor does it address the issue of cross-border care, like the numerous individuals from the western most parts of Northwestern Ontario who get treatment in their nearest tertiary care centres, which happen to be in Manitoba.

Geographical analyses, however, are useful in identifying regions within a province or territory in which there are great disparities in access to care. They also provide a means to aggregate data, at the health region level, to get around issues of confidentiality when numbers at the community level are small. In addition, spatial analysis methods can offer insights into the relationships between socioeconomic disadvantages and risk factors which might be addressed through targeted health programming.⁶⁴

TOWARD AN ABORIGINAL HEALTH DATA POLICY FOR ONTARIO

The foregoing illustrates the principle ways Canadian jurisdictions have tried to tag Aboriginal users to the health system. However, several overarching factors influence the policies which determine how health information about Aboriginal Canadians is gathered, analyzed and used. These are seen by Smylie and Anderson as falling into four main categories: coverage and quality, jurisdiction and utility; governance and relevance; infrastructure and capacity.⁶⁵ Taken together with what has been learned through practice, they constitute the essential considerations for Ontario in framing an Aboriginal health data policy.

COVERAGE AND QUALITY

For data to be of the highest quality – the sort required for population-based epidemiological studies – it has to be comprehensive in nature. In other words, it must involve a full count of a condition (e.g. the number of cases of tuberculosis), occurring in a population whose size is known exactly. This implies two things: first that among all of those diagnosed with a condition, Aboriginal patients can be identified as such; second, that census numbers accurately count a given Aboriginal population. To the second point, first; as noted in the preceding section on *Ontario's Aboriginal Population: Demographics*, the Canadian census undercounts the Aboriginal people of the province for known reasons, but to an unknown

extent. This reality has to be taken into account in efforts to improve the quality of Ontario's Aboriginal health data. The ideal – improved census data – will likely continue to elude us because some of the factors impeding complete accuracy will not change in the near term. So the only alternative is to make considered estimations of the undercount and factor these into subsequent calculations and/or interpretations of data.

Finding ways to identify Aboriginal people within general population health surveys or surveillance data in a reliable and consistent way is equally challenging.⁶⁶ Canada's national population-based health surveys do not cover all Aboriginal groups or all Aboriginal communities, even within a given province or territory.⁶⁷ The Canadian Community Health Survey, which is conducted on a biennial basis, allows individuals the option of identifying as Aboriginal, First Nations, Métis or Inuit; however, the survey is not delivered to on-reserve communities, so First Nations people may be under-represented.⁶⁸ The Aboriginal Peoples Surveys, directed towards people who have self-identified as Aboriginal in the census, obviously does not include Aboriginal individuals or First Nations communities who declined to participate in the census.⁶⁹ And the First Nations Regional Longitudinal Health Surveys, developed and administered in partnership with provincial First Nations organizations, also are limited in coverage. They include the on-reserve communities that choose to participate; in the last survey just 40 of Ontario's 134 First Nations took part.⁷⁰ As for surveillance data, only basic demographic information is usually collected; clients' ethnicity is not generally captured for reasons of privacy and human rights protection. Lack of opportunities for Aboriginal peoples

to self-identify within the health care system is a further barrier to collecting accurate data on their needs.⁷¹

JURISDICTION AND UTILITY

The collection of information, like many aspects of Aboriginal health, is affected significantly by issues of jurisdiction and entitlement. Aboriginal people in Canada receive health care from a complicated system of services provided through the federal and provincial or territorial governments, as well as by Aboriginal organizations (sometimes in partnership with one or other level of government). Although the federal government is often thought of as having primary responsibility for Aboriginal health, in fact the majority of services are provided by either the provincial or territorial governments.

Still, Health Canada does fund and in many cases delivers services to people who have status and live on-reserve. In addition, “non-insured” benefits (so-called because they are not covered by provincial health plans) like prescription medicines, dental and eye care are covered for people with status, or Inuit, regardless of where they live. The federal government also provides services normally covered by a province, such as physician care, in remote communities where they would not otherwise be available. Métis and other Aboriginals who lack a status card have limited access to federally supported programs, except for some health prevention and promotion efforts.

Of course, the federal government contributes substantially to supporting services offered by the provinces and territories. The Canada Health Transfer provides both cash and tax transfers to ensure predictable and sustainable funding is available so that all Canadians have access to health care as mandated by provisions of the *Canada Health Act*. For their part, the provinces and territories have constitutional and legislative obligations to provide health care for all residents. Some provinces, like Ontario, support Aboriginal-specific facilities, such as Aboriginal Health Access Centres and Aboriginal Community Health Centres. But most services Aboriginal people access, like other citizens, are those funded by provinces or territories, such as hospital, physician or nurse practitioner services, home care, assistive devices and ambulances.

Despite the overlapping involvement of various levels of government in service delivery and the fact that First Nation clients cross jurisdictional boundaries as they move from primary care on-reserve to provincially provided tertiary care off-reserve, data documenting Aboriginal health and well-being gets caught on the invisible barbed-wire that seems to surround jurisdictional perimeters. Differing mandates, incompatible data, turf protection, lack of will – all are reasons suggested for the failure to generate useful information that transcends divisions based on status, location, or jurisdictional responsibility. Smylie and Anderson write that “[a]ppropriate public-health planning and response requires health-assessment information that accurately reflects Aboriginal ethnicity and geographic location while effectively negotiating jurisdiction complexities.”⁷²

GOVERNANCE AND RELEVANCE

Over the past twenty years there have been significant public policy shifts as both the federal and provincial governments have come to recognize the right of Aboriginal peoples to determine for themselves how fundamental aspects of their lives are organized.⁷³ In the health domain, these changes are manifest in agreements with Health Canada that transfer responsibility for planning and delivering services to local control; these transfers have occurred in about three-quarters of the 599 First Nation and Inuit communities across the country where current policies permit some form of self-determination.⁷⁴ In Ontario, the shift is also reflected in the diverse group of programs now offered under the Aboriginal Healing and Wellness Strategy, which is jointly managed by Aboriginal organizations and provincial decision-makers.

Accompanying these changes was a realization on the part of Aboriginal people that they had a “right to self-governance of population-based information, including health information.”⁷⁵ In the mid-1990s, the Royal Commission on Aboriginal People noted the political nature of collecting information; historically, Indigenous Canadians were not party to deciding what was gathered, how it was used, or by whom. As a result, data collection by outsiders, government representatives and researchers alike, was “met with resistance in many quarters.”⁷⁶ People simply grew tired of answering questions about themselves when their communities never seemed to benefit as a result – they were tired, in their words, of being “researched to death.”⁷⁷ This was the mood of the times when plans were being made for the

First Nations and Inuit Regional Longitudinal Health Survey, a major federally funded, but Aboriginal led initiative. In 1998, those overseeing the survey's development articulated a set of guiding principles – principles which are now widely seen as touchstones for all research and data collection involving First Nations, Métis and Inuit people in this country.⁷⁸

OCAP PRINCIPLES

These principles are commonly referred to by the acronym OCAP, comprised of the first letter of four words (Ownership, Control, Access and Possession) which encapsulate the relationship that people are collectively entitled to with respect to information about their group or community. The aural similarity of the first three letters to the name “Oka” – site of the 1990 crisis – can not be missed, nor should it be.⁷⁹ It underscores the profound confrontation (in the best sense of the word) occurring over the collection and use of information about Aboriginal peoples.⁸⁰

Because of their fundamental and far-reaching implications, the OCAP principles need to be considered at length. The First Nations Centre at the National Aboriginal Health Organization succinctly summarizes them as follows:

Ownership – First Nations communities have a right to own their cultural knowledge and all information that is produced from this knowledge, the same way that individuals own their personal information.

Control – First Nations, their communities and leaders have the right to control every stage of a research project, from start to finish. This includes the resources involved, the

review process, creating the research design, handling the information, and developing new policy based on the research results.

Access – First Nations must have access to information about themselves and their communities without facing any barriers, regardless of where it is held. They must also be able to make decisions concerning who has access to their information and how this access is given.

Possession – While ownership describes the relationship between a people and its information in terms of a right, possession is the physical control over the information. Possession is a way for First Nations to assert their ownership and protect their information. If information is owned by someone but possessed by someone else, there is a risk that the information can be leaked or misused.⁸¹

These ideas, taken together, alter the way data is compiled and the use to which it is put. They also, arguably, make the information more meaningful and relevant because, from collection through interpretation, it is continually processed through Aboriginal sensibilities.

Implementation of the First Nations and Inuit Regional Longitudinal Health Survey has shown that actualizing the OCAP principles can achieve the intended goals without impeding the quality of data or its appropriate use. In Manitoba, for example, the mechanics for doing the survey “established the social and cultural structures necessary to develop First Nations’ and universities’ capacity to work collaboratively in the area of First Nations population health research.”⁸² The operative word here is capacity; functional capacity on the part of the Aboriginal people and organizations undertaking a complex new activity, and conceptual capacity on the part of the non-Aboriginal researchers and institutions involved because they have had to rethink their accustomed approaches.

Since responsibility for health care on-reserve (and off-reserve in some cases) has been taken over by Aboriginal people to a large extent, those charged with the task of planning and delivering services require reliable data on communities' health status and program needs. And because situations change continually, the information must be kept current (the First Nations and Inuit Regional Longitudinal Health Survey is now being done for the third time). The survey provides accurate, relevant and timely evidence on which to base decisions. It also forms a sound foundation on which caregivers can advocate for their clients and the Aboriginal leadership can negotiate the interests of their people with various levels of government.⁸³

The federal and provincial governments generate and hold a great deal of the health data potentially relevant for First Nations, Métis or Inuit communities; however, by its very nature, it is well outside the fundamental principles of OCAP. This state of affairs is no longer tenable. O'Neil writes: "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 Nation authorities."⁸⁴ The expectation is that the required protocols will be established and respected as a matter of course.⁸⁵

INFRASTRUCTURE AND CAPACITY

Several co-existing pressures will transform our health information system: the need of Aboriginal controlled services for current data understood from a cultural perspective; the need

for seamless data sets that transcend jurisdictional and entitlement divisions; and the need to adhere to the principles of Aboriginal ownership, control, access and possession of their own data. Accompanying these changes is the need to establish the infrastructure required for Aboriginal organizations to collect, store and manage data on a large scale, while ensuring that the groups' collective rights and individual privacy are protected.

Doing this requires a substantial number of people with diverse backgrounds (e.g. public health, statistics, and computer technology). Because, as yet, those of Aboriginal heritage with advanced level training in such areas are few and in very high demand, a significant investment in resources – technological and human – must be made to achieve optimal, or even functional capacity.

EXPERIENCE AND PRACTICE

For years, the fact that there are information gaps has been thrown up as a barrier to improving the health of Aboriginal Canadians. Indeed, there have been discussions about resolving the problems – and attempts made to do so – since the early 1990s. “But we are still doing studies to see if it’s possible,” an interviewee said, with a note of exasperation. She felt that successes, like those in Manitoba, show it is possible if there is goodwill and governments are willing to fund and champion the effort on an on-going basis. Nonetheless, there are two sets of issues, conceptual and operational, that require careful consideration. The first involves ways of thinking about health information and its proper use. The second includes the technical fundamentals.

CONCEPTUAL ISSUES

In discussing conceptual challenges, informants emphasized the need to achieve consensus on the interpretation of the OCAP principles. There is a tendency to see OCAP as impeding effective collaboration around database development. When Aboriginal organizations and communities interpret and apply the principles differently, for example, there can be confusion and uncertainty over the way that research must be conducted. There also can be differences of opinion about responsibilities for data ownership and control between federal and

provincial or territorial governments. As a researcher noted, “*everybody* has OCAP concerns ... indigenous communities have their databases, the province has their databases and the federal government has their databases.” While such differences are not insurmountable, they do add “additional layers” to the process of developing mutually acceptable protocols for accessing information. As a researcher said, “what people need to be cognizant of, is [that] it just takes a long time to negotiate.”

Addressing Trust Issues

Public confidence is a fundamental element underlying the collection, storage and retrieval of any set of health data. But an added degree of trust must be established when it comes to Aboriginal health data – between people and their leaders, between their leaders and those representing the organizations, institutions and governments involved. The first step toward achieving trust, according to one researcher, is creating a dialogue with Aboriginal stakeholders to address their concerns about ownership and control of data. This person’s experience was that there was “a lot of questions and, maybe, a lot of misunderstanding on both sides.”

The best approach is to ensure that Aboriginal organizations are fully engaged in the research process, right from the start. Several interviewees were members of indigenous research networks, which facilitate collaborative research between Aboriginal organizations,

government representatives and academic institutions. They advise “face-to-face” meetings so community members can “feel free to discuss what their issues are, how they can be addressed and what are their research priorities.” Community discussions also are more likely to achieve the desired results, rather than researchers just presenting “reams and reams of paper” for community leaders to consider, because this might slow down or entirely stop the engagement process. As an epidemiologist said, “it makes a difference [to visit] the community or the organization, as opposed to just maintaining a long distance relationship.” On their part, government representatives and academic institutions have to recognize that Aboriginal leaders “are involved in so many things, it’s hard to get full engagement” concerning a research project. “Patience” is highly recommended.

Ensuring Aboriginal Access to Data

The OCAP principles of access and possession are intertwined and raise a number of issues. Concerns over data possession may not be a problem when the Aboriginal organizations involved are functioning within national or provincial-territorial mandates; it is more likely to be a worry when the organizations operate at a regional or local level and consequently have less information management capacity. Effective possession requires accessible, but secure storage facilities, as well as people trained in correct procedures for data management.

If data is of such complexity that it has to be analysed at a specialized research facility, arrangements for “data warehousing” must be negotiated with the relevant groups. However, the preference is to build the “capacity within Aboriginal organizations.” Several of our interviewees mentioned recent agreements between certain universities and Aboriginal health centres to establish database management operations in partnership with First Nations, Métis and Inuit organizations; in each case, these will involve the training of Aboriginal people in data handling and analysis.

Aboriginal organizations also want access to aggregate information about their communities held at the federal, provincial or regional health authority levels and, collectively, for “bands [to] have ownership of the aggregate data.” Moreover, they want assurances that any “database will only be used with and for the Aboriginal people and their programs, as opposed to a decision-making mechanism to reduce funding.” Essentially they want to know that such information will not be used to “marginalize” their communities by impeding access to services or funding. However, protocols have yet to be put in place to ensure aggregated data is “accessible both for the communities that generate it and for programming or policy development.”

Bridging Challenges

Although discussions between government representatives and First Nations, Métis and Inuit organizations have occurred across the western provinces and territories, except in British Columbia, no formal agreements are in place to guide development of data collection and reporting. It is generally recognized that negotiating OCAP appropriate agreements will be a lengthy process because the number of Aboriginal communities and organizations involved in each province or territory. However, the time required is a given and should not, in any way, be viewed as an excuse for further delaying development of Aboriginal health databases. In the opinion of a research administrator, the challenges often are: “Overblown ... I think we are putting too much emphasis on [the] challenges,” rather than recognizing that OCAP is simply a framework guiding a process. “It is just a matter of how [the principles] are bridged.”

OPERATIONAL ISSUES

There are a number of operational issues which affect our ability to examine Aboriginal peoples’ health status and use of health services. The principal one, noted by Anderson and associates in their recent review of First Nations, Métis and Inuit Health indicators, is the lack of reliable and consistent ethnic identifiers in federal and provincial health databases.⁸⁶ But there are other concerns, too, such as the challenges of maintaining confidentiality, negotiating permissions and protocols, creating multiple database linkages, expanding and updating existing

databases, developing pan-Aboriginal databases and making investments in Aboriginal health research capacity. Each of these is summarized in the following sections.

Addressing Absence of Aboriginal Identifiers

There is little Aboriginal-specific information in federally maintained health databases because very few of them include ethnic identifiers of any type. The only exceptions are the strategic administrative data about the health of status First Nation people compiled either by Indian and Northern Affairs Canada or Health Canada's First Nations and Inuit Health Branch, and the information for non-reserve populations collected in the Aboriginal Peoples Surveys and the Canadian Community Health Surveys. But even where ethnic identification is possible, there are limitations inherent in the sources.

Much of the federal data is aggregated for program management purposes, and, as such, cannot be readily used for health surveillance. Procedures used by Health Canada to capture vital statistics, immunization and reportable diseases data for First Nations – and the exact information gathered – varies from one region to another, and from one indicator to another.⁸⁷ Under-reporting is common; in some regions, only 50 per cent of communities may submit data in a given year. Similar concerns arise with respect to health data aggregated by Indian and Northern Affairs Canada, from departmental surveys and direct reporting from First Nations communities.⁸⁸ Census-based surveys, like the Aboriginal Peoples Surveys or Canadian

Community Health Survey produce samples which are too small to allow analysis of Aboriginal health information at anything below the provincial or territorial level.

Deficits are found in provincial and territorial data, too. Except for mandatory reporting of some infectious diseases, most of the data on Aboriginal clients remains with clinicians. Although Ontario's Aboriginal Healing and Wellness Strategy collects performance data from its Aboriginal Health Access Centres (AHACs), there is no central database that links the AWHs client information to the provincial health care system. However, secondary analyses of non-identifying client data from four of the AHACs in 2001-02 show its potential for further applications.⁸⁹

Although only the Northwest Territories allows self-identification of Aboriginal status on its health cards, researchers from other jurisdictions noted that self-reported ethnicity can be a valuable component of database development, if the information is collected in a consistent and rigorous manner. The key to collecting self-reported data on ethnicity, is to do it "right at the beginning" when people first register for a health card, or, in the case of data collected for specific projects, at first point of contact. Opportunities to self-identify often are lost, however, because staff in busy clinical settings simply do not remember "to ask the question." If the enrolment or registration process is "poorly done," the numbers may be insufficient to permit meaningful analysis when linked to other datasets, or they will be unrepresentative of the Aboriginal client population as a whole.

Negotiating Permissions and Protocols

Researchers must go through “appropriate channels” to obtain permission to access Aboriginal health databases. This process varies, of course, depending on whether data is held by an Aboriginal organization, a government department, or an academic institution. It also depends on the policies that determine who can use the information and for what purposes. In some cases, consent is required from provincial/territorial organizations, in other cases, from tribal councils and community leaders; the level involved is dictated by the scope of the enquiry and the data sources to be used. Often permission must be sought from several parties. For example, to examine utilization data for a First Nation community in northern Ontario in which the federal government is still responsible for service delivery, permission would be required from the community as well as from Health Canada, and possibly from a local Aboriginal health authority, too. As one informant noted, at all levels, “legislation for privacy prevails.”

Those interviewed agreed that the process of going “through several layers” of permission should not be viewed as an insurmountable obstacle. Rather it is a predictable process that simply takes time. But they also noted various factors that expedite things, all of which are as would be expected. The keys to success cited are: following established protocols, proceeding in a “responsive and respectful” manner, and recognizing and addressing Aboriginal concerns that the information might be used to “prejudice their care.” Negotiating access is a smoother process if “strong working relationships” exist between the parties. It is relatively

easy for organizations “to come together to talk about what can be done” if they have a history of working together and their past relationships have been good.

Even in situations where there are “trusting relationships,” obtaining the required permissions is “very time consuming.” A Manitoba interviewee, despite having gone through the process in a very supportive environment, said: “you have to plan for two years, because the whole protocol of gaining access and getting permissions is a long one ... if you are going to do it you have to be in for the long haul and you have to have the money to do it ... that’s expected.”

Creating Multiple Database Linkages

Attempting to identifying information for two or more Aboriginal client groups at the same time, increases the complexity of the task exponentially, not just arithmetically, and requires a high degree of technical expertise, as well as time and financial resources. Interviewees who were familiar with database matching processes pointed out some of the challenges that are encountered. Individuals may be affiliated with more than one group, or be misclassified as members of one group when they actually belong to another. So, for example, a person might be “non-status but claim Métis status . . . have Métis status and be registered First Nations people or . . . have status but their families may not be registered First Nations.” The more steps that are required in the matching process, the greater the likelihood that errors will

occur. Consequently, some Aboriginal groups will be over- or under-counted. Regardless of the efforts made to ensure that registry or membership lists are complete, “it’s not an easy thing to do to identify Aboriginal people through administrative databases ... you still end up missing people.”

Each health database tends to record information in a unique way, so information cannot readily be transferred from one database to another. As a result, time-consuming cross-checking of records and manual entry of information is the only way that the data can be combined. As a medical researcher commented: “a lot of our data comes in formats that we cannot convert, so we do a lot of duplicate entry ... we are patching things up all the time.” Unfortunately, some registries or membership lists often do not contain sufficient detail “to compare and cross-reference the groups to make sure they aren’t in both registries.”

Expanding and Updating Existing Databases

To date, most linkages are done on a “one-time project” basis; these take a snapshot or, at most, a retrospective look at a situation. But databases must be updated regularly if they are to be effective tools for health planning. Kept current, they can be used to track trends, identify emerging issues, and document on-going systemic problems. Speaking about the benefits of updating existing data, a health services researcher said: “There needs to be work done ... [to

find] what's happening in the system that's preventing access ... what are the barriers beyond the individual ... the barriers the system is creating.”

Recognizing the various challenges of creating new databases from scratch, some of the individuals interviewed recommended that Ontario invest in replication studies – applying the same methods used previously to expand and update the information already available. Marrett and Chaudry's⁹⁰ investigation of Aboriginal cancer trends over an extended period is an example of the type of study that might usefully be repeated.

Ensuring Community-Sensitive Data Interpretation

Community-level information is vital to “target services and programs more specifically.” Because of the great diversity among Aboriginal communities, north to south and rural to urban, however, “a blanket program or solution for the entire province isn't going to work.” For example, one researcher reports that the communities she works with have different patterns of disease complications; for some, “diabetes-related foot problems are one of their major problems, but for other groups, kidney disease is huge.” As a consequence, interviewees point out that administrative database analyses must be supplemented from other sources, using qualitative methods, to ensure full understanding of “the strengths or assets of the community ... and focusing on that which the community needs to address.” An epidemiologist from one of

the western provinces said: “Communities know themselves best” and can provide the “strong evidence” needed for effective Aboriginal health planning and program development.

Developing Pan-Aboriginal Databases

While there may be some appeal, from an administrative point of view, to developing “pan-Aboriginal” databases “down the road” that include all categories of Aboriginal people, respondents argue that it is more feasible “to work with groups separately” at first. One of our informants, who had experience with a previous attempt to construct a comprehensive database, observed that creating “a big consortium actually slowed the process down and [eventually] brought it to a standstill” when one community decided to “opt out” of the endeavour. She thought that “one of the things that might work is doing it piece by piece,” creating a flexible Aboriginal health database system, which could be expanded to accommodate additional Aboriginal organizations, if and when they desire to participate.

It is equally important to recognize that First Nations, Métis and Inuit peoples have vigorously challenged the pan-Aboriginal health strategies through which certain provinces and territories have tried to meet their obligation to treat equally “all people” within their jurisdiction. The reason for their resistance is acknowledged in Ontario’s *Blueprint on Aboriginal Health* (2005): “no single approach to health will address or resolve the needs of all Aboriginal communities” because of profound differences in traditions, identity and residency.⁹¹

Summarizing his thoughts about developing an all-inclusive Aboriginal health database in his province, an interviewee said: “You’re not going to go very far without a lot of work between the [provincial] Chiefs’ office, the provincial government and others . . . up until now [Aboriginal organizations] have been pretty slow to want to do anything like that.”

Making Investments in Aboriginal Health Research Capacity

Our respondents underline the fact that “it takes a lot of work to set up databases” and once set up, that significant human resources are required to maintain and make maximum use of them. In other words, we need to invest in people, but we do not do so. The absence of dedicated funding for health information positions within Aboriginal organizations at the local or tribal council level is an impediment to building capacity. As an interviewee said, “There are people at the local level that would be more than interested to take on research or health information functions, but there are not sufficient funds . . . to pay people to input the data; until the federal or provincial government puts up the money, it will never happen.” Moreover, the money needs to be used to hire people locally “to collect the information . . . in a respectful and responsive way that ensures you are getting good data, as opposed to data that has haphazardly been put into a data system.”

At present, neither physical nor human resource capacities exist in most of the Aboriginal organizations which – for understandable reasons – want to develop, maintain and

analyse databases of their own. “They will have to be engaged in a way that allows them to own it, maintain it, manage it ... the capacity isn’t there [yet], but that is the only way those databases will be created and maintained.” Summarizing the investments required, a researcher said, “If you don’t put in the dollars, if you don’t have the personnel, if you don’t continually train the personnel ... you won’t have it.” But, she added, encouragingly: “with time and money and people in place, it will happen.”

There is a need to get beyond the conceptual and operational challenges outlined. If, “the desired end is a database that allows us to make better decisions ... the potential is there and the interest is there.” Decision-makers in both Aboriginal and non-Aboriginal organizations just need to focus on what can be done. The spokesperson for an Aboriginal research centre said of the opportunity before her group: “You need to look at how databases have been used in a general population and then let your imagination run as to how you can use it for an Aboriginal population, whether it’s specific to the population or a comparison of one population to another ... it’s as far as your imagination can go.”

ADVICE TO THE OHQC

A number of words beginning with the letter “C” set the parameters of the challenge before Ontario’s Health Quality Council. In order to create an Aboriginal Health Information system that is *comprehensive, current* and *culturally* appropriate, the province must *commit* to effective *collaboration* and respectful *communication* with all Aboriginal stakeholders. It must also put *cash* on the table to ensure that necessary resources are in place. But it is clear that none of this will likely happen, unless there is a *champion* for the cause – someone or perhaps a government body that understands the issue and its importance, and is prepared to act as an advocate.

In our view, the Ontario Health Quality Council should take a lead in identifying a potential champion (whether individual or group) and urge the Minister of Health and Long-Term Care to create a formal mandate for them. As to who might take on the role, we considered and set aside a few possibilities. However, two received particular attention. On one hand, Ontario’s new Minister of Aboriginal Affairs seems a likely candidate, especially in light of the consultative model which he and his ministry mean to apply to their work. However, considering the range and nature of the matters with which they are dealing, our concern is that a highly specialized health issue (something outside the ministry’s main mandate) will be lost amidst other, more immediately pressing matters, such as particular land claim files.

On the other hand, the issue clearly fits under the ambit of the Minister of Health and Long-Term Care (MOHLTC), and thus is not subject to the concern just raised. Although progress has been made on inter-ministerial approaches, government functions are still sometimes constrained by a “silo-effect” – in other words, a health issue will receive more immediate attention within the ministry most directly responsible for health than it might in another ministry. Moreover, there are well established avenues for exchange between the provincial and federal governments within the health domain. The issue of Aboriginal health information clearly crosses this jurisdictional divide, and requires the attention of both levels of government. For these reasons, we recommend that the OHQC look within the MOHLTC for a champion – and, ideally, to the Minister himself.

SUMMARY

How then, do we address Ontario's Aboriginal health information challenges? The information reviewed for this report suggests that a number of different approaches could be used to more accurately assess the health status and health service needs of Ontario's Aboriginal residents on a continuing basis. Certainly, some of the strategies used elsewhere in Canada, might be applied in this province: opportunities to voluntarily self-identify on health cards, linkages with Aboriginal community or organization membership lists, or, in the case of First Nations individuals with status, linkages with INAC's verification system. Although not as exact, geographical analyses also can produce meaningful information for health regions in which the majority of residents are of Aboriginal heritage.

At the same time, both published reports and our key informants emphasize the need to ensure that the collection, linkage and analysis of Aboriginal health information is done in ways which respect the history, cultural understandings, and priorities of Aboriginal communities and organizations. On this subject, there was clear agreement: Aboriginal stakeholders must be fully engaged throughout the process. Procedures also must be put in place to ensure that the information is of high quality, kept in strictest confidence, and maintains the privacy of individuals. Negotiation, on a project-by-project basis or in ongoing agreements, will ensure that

the information meets the needs of Aboriginal communities, health care planners and providers, all of whom share the common goal of improving the health of Aboriginal Ontarians.

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