CANADIAN PARTNERSHIP AGAINST CANCER

First Nations, Inuit and Métis Action Plan on Cancer Control

Where there's a will, there's a way . . .

Environmental scan and analysis of existing patient identification systems for First Nations, Inuit and Métis peoples

Final Report

March 29, 2012

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APPENDICES

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1.0 EXECUTIVE SUMMARY

Chapter 1.0 summarizes the gap this report attempts to fill, and the key findings, conclusions and recommendations from the environmental scan and analysis of existing patient identification systems for First Nations, Inuit and Métis peoples. This report accompanies the *Inventory of Profiles – Existing Patient Identification Systems with Ethnocultural Identifiers Specific to First Nations, Inuit and Métis Peoples in Canada* (Cats, Withrow & Marrett, 2012) hereafter referred to simply as the *Inventory of Profiles.*

1.1 THE GAP THIS REPORT ATTEMPTS TO FILL

The Canadian Partnership Against Cancer (the Partnership) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership's mission is to bring together cancer experts, charitable organizations, governments, patients and survivors to bring change to the cancer control domain. This includes working with other organizations to (i) reduce gaps in knowledge to enhance cancer control, and (ii) facilitate and accelerate implementation of best available knowledge.

This study, an environmental scan and analysis of existing patient identification systems for First Nations, Inuit and Métis peoples, is one component of the First Nations, Inuit and Métis Action Plan on Cancer Control (2011), an initiative of the Partnership, guided by an Advisory Committee consisting of First Nations, Inuit and Métis peoples and organizations involved in cancer control and chronic disease prevention.

Key gaps in cancer control were identified during the work leading up to The Action Plan. One of these is the lack of cancer control data specific to First Nations, Inuit and Métis peoples. Currently there is no means to identify First Nations, Inuit and/or Métis status among cancer patients because this information is not recorded in cancer registries. Without reliable health data specific to each people, it is difficult to measure the impact of cancer on these populations, to understand the relationship between cancer and other health issues, and to design programs to address gaps in cancer control among FNIM peoples. Also, without acceptable systems to identify patients' ethnicity, many First Nations, Inuit and Métis cancer patients are unable to benefit from culturally responsive services available, such as patient navigation models.

The Partnership recognizes there are barriers, both within and outside the health system, to developing common identifiers/population definitions and standards of data collection, access and analysis. Nonetheless, several jurisdictions have developed ways of identifying First Nations, Inuit and/or Métis individuals through cancer registries or by linking provincial health records with membership lists. Population health data have also been collected using proxies such as postal codes. Also, health systems outside cancer may provide examples of leading practices that can be applied to the cancer system.

The environmental scan has been commissioned in order to contribute to understanding the context where these barriers and opportunities may be addressed and where leading models of patient identification systems for First Nations, Inuit and Métis peoples may be documented and thus shared toward potential system change.

1.2   ACKNOWLEDGEMENTS

1.3   KEY FINDINGS

The environmental scan yielded a number of findings that help set the context for how cancer control data may be enhanced with First Nations, Inuit and Métis identifiers.

1. **All provincial/territorial cancer registries are multi-source databases.** In other words, they depend on their ability to match and link different types of patient records, such as pathology reports, medical records and death certificates. This means that the addition of ethnocultural identifiers to cancer registries requires either their inclusion in an existing data source, or the addition of a new data source.

2. **Not all provincial/territorial cancer registries use the same types of data sources, in the same way.** Each provincial/territorial cancer registry has its own practices for registering and following incident cancer cases and documenting cancer-related mortality. This means that to compare cancer control data with ethnocultural identifiers across jurisdictions, one has to consider feasibility issues associated with different data sources and collection approaches that exist today. Practices that are effective and efficient in one province/territory may not fit equally well elsewhere.

3. **At the national level, the Canadian Cancer Registry (CCR) consolidates provincial/territorial cancer registry data.** This enables estimation of cancer burden nationally as well as comparisons among the provinces/territories. The CCR gets its data from provincial/territorial cancer agencies. The reportable demographic items currently include name, sex, date of birth/death and residency information. For provinces/territories to add ethnocultural information to their reportable data items would require their agreement on the desirability of collecting this information, as well as a data standard. However, the existence of a national data holding offers the option to link at the national level.

4. **There are six potential ethnocultural identifier sources available to provincial/territorial cancer registries.** These are:

   i) Provincial/territorial death certificates from Vital Statistics registries;

   ii) Patient registration records; from: a) cancer centre reports, b) physician reports, or

   iii) Clinician medical records; c) hospital records

   iv) First Nations, Inuit and Métis registers;

   v) Provincial/territorial health insurance registers;

   vi) Census

5. **The same ethnocultural identifier sources (except those held by cancer centres and cancer specialists) are also used to enhance databases in other health domains.** This means that the broader issues and opportunities associated with ethnocultural identification and the use of above identifier sources are not unique to cancer control. Similar information needs exist in e.g., primary care, chronic disease management and mental health. This may have implications for the attractiveness of systematically coordinated versus one-off ethnocultural identification options.

6. **Besides cancer registries, cancer screening registries play an increasingly important role in cancer control and system navigation.** Screening registries support operations and evaluation of organized cancer screening programs. They can help with system navigation, in that they help direct eligible people to early detection services and resources that are available to them. This is particularly important for facilitating screening access to population groups who are under- or never screened. In many Canadian jurisdictions, First Nations, Inuit and Métis people are under-screened for a variety of reasons. The availability of ethnocultural identifiers in screening registries might enable a better understanding of those reasons, as well as the ability to direct specific resources to facilitate improved access to screening and patient navigation.

7. **Some of the potential identifier sources for cancer registries have limited application to the primary uses of screening registries.** Of the six identifier sources listed under point 4, the first three have more limited application to screening registries, which seek to identify people *before* they are diagnosed with cancer. The other three identifier sources can - under defined conditions - be applied to the analysis of aggregate data to support program evaluation and improved system navigation. The two colon cancer screening registries profiled (Ontario, Nova Scotia) source the information to identify eligible participants from provincial health insurance databases. Neither province's health insurance client registry currently contains ethnocultural identifiers. That is why Aboriginal communities and cancer agencies are working towards alternative options.

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In Nova Scotia, screening participants are encouraged to identify themselves as one of seven ethnocultural groups, including First Nations, as part of the screening registration process. In Ontario, an innovative Geospatial Analysis tool applies statistical data to geographically based data to generate maps of screening rates. These maps can help local health care providers pinpoint areas of opportunity, and track progress over time. In the short term, the tool can help local decision makers dimensionalize geographic variations where e.g., Dissemination Area codes fairly closely match First Nations reserves. Over time, as regional partnerships identify more appropriate sources of local data, these data can then be used to help develop culturally appropriate navigation approaches to improve screening for ethnocultural groups while respecting principles of ownership, control, access and protection of the supporting information.

8. **The environmental scan identified fifty ethnocultural identification systems.** Forty-two of these describe health databases with First Nations, Inuit and/or Métis identifiers, and eight describe enabling practices towards such databases. The fifty practices are geographically spread across Canada and across a wide spectrum of health service domains. They demonstrate that different approaches to ethnocultural identification can satisfactorily achieve individual project objectives depending on specific considerations and preferences.

All fifty ethnocultural identification systems are extensively detailed in the *Inventory of profiles of existing patient identification systems for First Nations, Inuit and Métis peoples across Canada* (Cats, Withrow & Marrett, 2012), which accompanies this Analytical Report.

9. **Ethnocultural identification: a means to a - specifically defined - end.** The study's investigators conducted over one hundred key informant interviews. The majority of these informants link ethnocultural identifiers to one or more of the following priorities:

- Closing gaps, equity, diversity, community engagement and outreach;
- Patient navigation and the provision of culturally appropriate care;
- Health service/program planning and priority setting;
- Indicator development and performance management;
- Capacity building, e.g., for the collection, analysis and application of new information;
- A deeper understanding of health issues and the creation of new knowledge (research).

We also observed a subtle, but important difference between informants who were more closely associated with health data in their professional lives (e.g., as designers, collectors, custodians, analysts) versus those who are mostly focused on its application. The former tend to articulate the use and limitations of data in more precise, realistic terms, while the latter tend to articulate these at a more conceptual level. That may not be unexpected, nor is it wrong. However, only when one "drills down" to their specific desired end use is it possible to evaluate the merits of different identifier options in terms of their relative attractiveness. A number of informants referenced extensive dialogue and mutual education between their stakeholders before everyone got on the same page in terms of a) the specific decisions the information needed to enable (the end), and b) different ways to get there (the means).

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This suggests that the fifty practices profiled are best reviewed in the context of their intended utility, which includes inevitable compromises between the ideal, the feasible and the affordable.

1.4   KEY CONCLUSIONS

The findings from the environmental scan provide further insight into the barriers to ethnocultural identification, as well as opportunities to overcome these barriers.

1. **There are barriers to effective patient identification –** the main ones identified by informants are lack of will, lack of supporting relationships, and lack of affordability and time.

   ▪ **Lack of will** does not mean or imply ill will. Rather, informants related "will" to stakeholders (i) not always being *aware* of topics at the intersection of Aboriginal history, culture, health and the complex world of health information, (ii) not *feeling strongly* about the relevance to their work in health care, or (iii) not being in a position or having the *power to act*. In other words, for many people or organizations, ethnocultural identification just has not surfaced as an important priority that is relevant to their busy lives.

   ▪ **Lack of supporting relationships or networks** means that (i) all who can contribute may not be "in the room", (ii) stakeholders may not (yet) understand each others' needs and requirements, or (iii) they may be reluctant to mutually share the investment in, and the value from patient identification projects.

   ▪ **Lack of affordability and timeliness** firstly are a reflection of the complexity of implementing new patient/population data initiatives. Such initiatives typically require investment in strong project management, active project governance, testing, adjusting and quality control, a robust infrastructure for data capture, record linkage, storage, access, reporting, privacy management and - last but not least - a significant effort to build relationships and will with the many participants who need or want to be involved. Informants say that relationship building/communication is often underestimated, and that it frequently takes years to get stakeholders on the same page.

     In addition to significant costs associated with consultation and implementation, additional pitfalls have been (i) insufficient upfront estimation of the true cost of new data projects, (ii) unwillingness to embrace possibly less perfect – but to the health care system more affordable – identifier alternatives, and (iii) missed opportunities to pool resources across organizations and jurisdictional boundaries.

2. **These barriers can be overcome.** Organizations associated with the profiled practices typically employed variations on the following three-pronged strategy:

   ▪ Look for will, i.e., assemble groups with the desire and power to act;

   ▪ Build relationships and networks that respect and actively reflect all participants' needs and priorities;

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- Invest in opportunities based on their potential to be more affordable, timely and sustainable than alternative approaches.

3. **Common methods used to marshal the will to act**

Tripartite and bipartite political processes

Health information policy is set in a wider governance context, which in turn is affected by societal values. Practices like political negotiations and cultural competency training can help shape changes to information policy. The collection and use of ethnocultural identifiers in health data sets serves two purposes: it addresses Aboriginal health-related information needs, and it also addresses commitments made as part of a larger, often political, agenda. This agenda may be about equity, diversity, access to quality care, or capacity building and health human resources. Examples of this approach can be found in B.C., Nova Scotia (Unama'ki), Nunavut (Nutaqqavut) as well as Manitoba and Ontario.

A framework and guidelines for First Nations, Inuit and Métis identification in health data

A data standard is an early "signal" of the intent to promote consistent collection of identifiers. The report profiles five independently developed initiatives that set out to support the collection of good quality, comparable ethnocultural identifiers by providing guidelines for defining standard identifiers, as well as methods for collecting the information. Together, these five practices constitute a de facto, albeit informal and not generally known, standard for First Nations, Inuit and Métis identification. They include the Aboriginal Administrative Data Standard (British Columbia), Aboriginal Identity Indicator in Cancer Patients – Protocol (Ontario), Newfoundland and Labrador Aboriginal Administrative Data Identifier, Electronic Medical Record: Ethnicity Reference Set (CIHI/Infoway; to be used nationally), Mustimuhw Community Electronic Record (Cowichan Tribes; used in B.C., Manitoba, Saskatchewan).

Cultural competency programs

Cultural competency is an important element in preparing frontline staff for, among others, asking patients ethnocultural identification questions in a respectful and safe manner. Cultural competency programs are designed to increase Aboriginal-specific knowledge, enhance individual self-awareness and strengthen skills of non-Aboriginal health care leadership, professionals and service providers. Most provinces/territories have these programs, which have also been used to support the implementation of identification projects. An example is the Indigenous Cultural Competency (ICC) program, which was launched in B.C. as a deliverable of the Transformative Change Accord First Nations Health Plan. ICC training has since been delivered to participants from B.C., Alberta, Manitoba, Ontario, and Québec.

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4. **Common methods and opportunities to build relationships and networks**

    The sponsorship and involvement of First Nation, Inuit and Métis governance and non-Aboriginal governments at the national and especially at the provincial/territorial levels

    Informants emphasize that the sustainable development and use of health databases with Aboriginal identifiers requires the participation and agreement of both Aboriginal and non-Aboriginal governance representatives, especially at the provincial/territorial level, as most health data sets exist at that level. Although resources at First Nations, Inuit and Métis organizations are stretched, many also have health/information specialists who are responsible for health information policy and associated initiatives. Finally, many practices involve the active participation of local community and health service delivery participants, as they are the driving force to apply the "products" of information initiatives to frontline service delivery.

    Leveraging existing nodes of expertise

    In most provinces/territories the experience and expertise for designing and implementing complex Aboriginal health information initiatives is concentrated around a cluster that typically includes First Nations, Inuit and Métis organizations, information custodians, academic researchers and organizations that provincially coordinate disease management (e.g., a cancer agency). Similar clusters exist at the national level. Many of the practices profiled attributed their success to the long term investment, often over decades, in building and sharing the hard and soft resources of these clusters, including expertise in areas ranging from cultural knowledge to database linkage and privacy management.

    Knowledge exchange between stakeholders

    Virtually all practices used knowledge exchange as one component of their stakeholder engagement strategies. However, this was mostly limited to the immediate circle of initiative participants. Most groups felt there is not enough time in the day to stay abreast of potentially useful developments, especially outside their own jurisdiction. There is a keen interest in seeing the results of the Partnership's work in ethnocultural identification. There may also be an opportunity to provide regular updates that highlight new learning and the availability of proven tools that can reduce development effort for other groups.

5. **Common methods and opportunities to save time and money**

    Identification of new approaches to apply existing data to new information needs

    Necessity is the mother of invention. The desire to understand First Nations, Inuit and Métis health opportunities better has inspired innovative approaches to using existing data in new ways. Examples include:

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- Manitoba Metis Population Database – uses Canadian Community Health Survey and family records to build a comprehensive database of the province's Metis Population;

- Canadian Chronic Disease Surveillance System – uses existing provincial/territorial health administrative databases to build a national, standardized database of several chronic diseases, and can be effectively linked to First Nations, Inuit and Métis holdings;

- Canadian Tuberculosis Reporting System – uses records from provincial/territorial tuberculosis registries within a common infrastructure with agreed identifier standards;

- First Nations and Inuit databases that combine with health administrative files, e.g., First Nations Client File (BC), Registered First Nations & Manitoba Health Insurance Registry Linkage, Unama'ki (Nova Scotia) and Nutaqqavut (Nunavut);

- 1991 Canadian Census Cohort: Mortality, Cancer and Residential Mobility Follow-up Study – combines records going back to 1969 (for Canadian Cancer Database) all the way to 2011 and 2012 (for Canadian Mortality Database, Canadian Cancer Database and Tax files) to study health disparities among Métis and Registered Indian adults.

Harmonization of time - and labour-intensive processes

As mentioned under point 1, information/research projects can be complex, with many moving parts to manage. If some of these parts can be standardized or taken away, this can result in significant time and money savings. Examples include:

- Agreement to a data standard – see discussion under point 3;

- Electronic records, if implemented well, can save frontline staff considerable time and improve the quality of documentation. An example is the Mustimuhw cEMR;

- Using provincial/territorial infrastructure for holding, linking and accessing data from different provincial/territorial sources – see discussion under point 4 (nodes of expertise);

- Using national infrastructure to take away the time and administrative resources needed to manage privacy, security and confidentiality requirements associated with linkage projects that could combine existing national, provincial/territorial and regional/local information – without losing ownership or control of one's own data. This is the essential purpose of the Longitudinal Health and Administrative Data Initiative;

- In the future: further standardizing the protocol/administrative requirements for linking to (i) Indian Registry System, (ii) Métis citizenship lists, and (iii) Inuit beneficiary lists.

Phased testing and introduction of new identification approaches

There is a delicate balance between prudent, purposeful testing and interminable "pilots" that never see the light of day. Nevertheless, properly conceived and executed testing and phased roll-out of new ethnocultural identification approaches save money and time in the long run. Practices in one region may have to be tweaked a bit for another. And the distance between "bench and bed" needs to be bridged: researchers and information specialists need the reality check of how things

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work in the lives of e.g., clinicians, other frontline staff and patients. Many profiled practices feature examples of rigorous yet responsive testing, e.g., Interior Health's Aboriginal Self Identification Project, Our Health Counts and Tri-Hospital Health Equity projects in Ontario, First Nations Regional Health Survey and the national surveys at Statistics Canada, among others.

6. **Where there's a will, there's a way.** The eight enabling practices and forty-two database practices in this study demonstrate that, under the right conditions, health data holdings can be augmented with First Nations, Inuit and Métis identifiers. The majority of ethnocultural identification practices described are part of ongoing data collection processes and have been used for a range of analyses, indicating sustained commitment by the parties involved. Broad based interest in ethnocultural identification is also indicated by the breadth of practices across health domains and jurisdictions, and significant associated resource investment.

1.5   RECOMMENDATIONS, IMPLEMENTATION CONSIDERATIONS, AND NEXT STEPS

The following summarizes a number of options for coordinated and collaborative action among decision makers who work at the intersection of First Nations, Inuit and Métis health, cancer control and information management.

Provincial/Territorial Focus

It is to be expected that the opportunities and readiness for adding to existing ethnocultural identification practices will vary across provinces/territories. It is also to be expected that there will continue be variation between provinces/territories in how they combine and utilize ethnocultural identifiers from among the six potential identifier sources.

To support provinces/territories in building on their current identification efforts, *we recommend the Partnership focus on the unique context of each province/territory's cancer agency, ministry of health and First Nation, Inuit or Métis organization to help define the most appropriate option(s) for combining potential data sources into a First Nations, Inuit and/or Métis patient identification system.* Provincial/territorial and national data custodians will also have an important role. Where appropriate, the *Inventory of Profiles* may serve as a starting point to help identify adaptation ideas and key factors for success.

National Focus

Besides provincial/territorial and regional/local Aboriginal health information priorities, a number of informants articulated the need for nationally comparable data. Comparable data enable stakeholders to identify good practices and find efficiencies. Therefore, there is an opportunity to extend the use of national data sets as well as ensure that, wherever possible, information is collected and coded consistently across Canada so that comparisons between provinces, regions and cancer agencies can be made.

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The report identifies a number of national data holdings that consistently collect and code comparable First Nations, Inuit and Métis health data. The Profiles describe how these data sets have been applied towards Aboriginal health information needs (including opportunities for better navigation). Key national holdings include the First Nations Regional Health Survey, Indian Registry System, six databases at the Canadian Institute for Health Information, two at Public Health Agency of Canada, and four at Statistics Canada. *We recommend that the Partnership explore opportunities to extend the use of these national data sets, starting with the Indian Registry System and the Census, both nationally and in combination with provincial/territorial data holdings.* The Longitudinal Health and Administrative Data Initiative provides a mechanism for secure and cost-efficient linkage of national and provincial/territorial databases.

While there will likely be variation in the use of different ethnocultural identifier sources across provinces/territories, this need not be a barrier to inter-jurisdictional comparison. As pointed out earlier, cancer registries also vary in their use of data sources and practices for registering incident cancer cases – yet employ several mechanisms to support national estimates and provincial comparisons. The report profiles five independently developed initiatives that set out to support the collection of good quality, comparable ethnocultural identifiers by providing guidelines for defining standard identifiers, as well as methods for collecting the information. The five initiatives profiled have benefitted from extensive engagement with First Nations, Inuit and Métis communities from across Canada. All apply virtually the same approach to Aboriginal identification. *We recommend that the Partnership work with the developers of the five identification standards and other data standard experts (e.g., CIHI, Statistics Canada) to develop a national framework and guidelines for First Nations, Inuit and Métis identification in health data.*

Focus on addressing barriers to ethnocultural identification in health databases

There are several additional opportunities that leverage the three-pronged strategy used by many of the successful practices profiled in the study.

▪ Look for will, i.e., assemble groups with the desire and power to act.

As described by informants and in the literature (e.g., Kephart, 2007), experience shows that the organizational structures and implementation processes of database/information projects sometimes focus on technical expertise at the expense of "buy-in" from governments, especially provincial/territorial governments and First Nations, Inuit and Métis governance organizations. Both are needed. When governance groups understand better what exactly they are buying into, chances of success may improve.   The alternative is (even) more drawn-out approval processes, contract negotiations and policy reviews. Informants shared numerous painful experiences.

While not an easy task, the success of ethnocultural identification projects is dependent on facilitating and coordinating First Nations, Inuit, Métis, provincial/territorial and federal priority setting. Tripartite and bipartite political processes in B.C., Nutaqqavut 'Our Children" Health Information System

(Nunavut) and Unama'ki Client Registry (Nova Scotia), among others, demonstrate the power of this approach. *We recommend that the Partnership facilitate a recognition among its partners that*

1. *The more technical work associated with ethnocultural identification needs to be grounded in the commitment of First Nations, Inuit and Métis organizations and provincial/territorial ministries of health, and supported by national governments;*

2. *New ethnocultural identification projects will benefit from a specific, coordinated agenda regarding the specific purpose(s) and prioritized use(s) of ethnocultural identifiers, supported by a process that confirms full buy-in from provincial/territorial First Nations, Inuit and/or Métis organizations and ministries of health.*

▪ Build relationships and networks that respect and actively reflect all participants' needs and priorities.

There may be an opportunity to strengthen the link between the estimated 100 - 300 project managers and data custodians across Canada who are actively engaged in First Nations, Inuit and Métis identification initiatives. This virtual community of ethnocultural identifier experts could also participate in the transfer and exchange of new and emerging insights.

Cancer registries and cancer screening registries source their clients' socio-demographic information, including ethnocultural identifiers, from similar source files as many other health domain/disease registries, e.g., hospital records and health insurance client registries. Going forward, primary care and community care may also play a more important role in capturing socio-demographic information on behalf of other parts of the health care system.

Therefore, it may make sense to broaden the user base for identifier initiatives beyond users in cancer control. The Profiles already indicate active interest in ethnocultural identification on the part of data custodians in primary care, home care, First Nations health centres, community care, chronic diseases, infant & maternal health, hospitals and public health.

We recommend the Partnership explore potential interest among First Nations, Inuit and Métis organizations, database custodians and ethnocultural identification experts in supporting mechanism to

1. *Promote knowledge exchange, adaptation of existing practices and collaborative development of improved First Nations, Inuit and Métis identification systems; and*

2. *Strengthen the business case, i.e., feasibility and cost-efficiency, by engaging a broader user base in enhancing (a wider range of) health administrative databases with more uniformly sourced ethnocultural identifiers.*

▪ Invest in opportunities based on their potential to be more affordable, timely and sustainable than alternative approaches.

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Informants identified opportunities related to First Nations, Inuit and Métis registers, the Census, frontline data collection, and health insurance client registries.

First Nations, Inuit and Métis Registers

These registers have been successfully used in, among others, B.C., Manitoba, Ontario, and Nova Scotia to answer important questions regarding Aboriginal cancer control, system access and navigation. They have enabled increasing capacity and ownership among First Nations, Inuit and Métis participants in the areas of data management, policy, research and health service delivery. The Indian Register and the Inuit Beneficiary lists have a high number of records available for matching now, and Manitoba has a potential model for enhancing the number of records in a Métis citizenship list. Data quality has been improving; there is considerable expertise in e.g., privacy management, setting up information sharing agreements and linkage techniques. Investment is limited to linkage costs.

We recommend that the Partnership explore enhancements to the value of First Nations, Inuit and Métis registries to their owners by

1. *Moving from current one-off projects to ongoing data sharing agreements; this would significantly reduce administrative efforts and timelines for First Nations, Inuit and Métis organizations and cancer agencies by creating a common infrastructure for First Nations, Inuit or Métis organizations who wish to pursue linkage projects.*

2. *Expanding linkage of these registries to cancer registries in more provinces/territories, and nationally to the Canadian Cancer Registry (CCR).*

3. *Assessing the feasibility and cost of applying the Manitoba Metis Population Database model to other interested Métis nations; and*

4. *Assessing the potential of the Longitudinal Health and Administrative Data (LHAD) process for harmonizing time- and labour-intensive processes associated with data linkage - so that important First Nations, Inuit and/or Métis cancer control questions may be answered faster and more cost-efficiently than alternative methods that would involve investing in the collection of new information.*

The Census

The Census is a source of First Nations, Inuit and Métis identifiers that can be linked to cancer registries and other databases to measure the impact of cancer, understand the relationship with other health issues, and design programs to address gaps in Aboriginal cancer control. The potential for the Census to be a source of First Nations, Inuit and Métis identifiers for cancer registries and screening registries depends on 1) the specific question that needs to be addressed, and 2) any other data sets a group may wish to bring into the LHAD environment, which already includes a broad range of relevant national databases, e.g., hospital records, CCR, vital statistics.

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We recommend that the Partnership explore the value that can be derived from the Census as a national source of ethnocultural identifiers by

1. *Creating a coordinated research agenda, and inventory of specific research questions that are important to the formulation of cancer control policy and the design of appropriate programs for First Nations, Inuit and Métis peoples;*

2. *Working with Statistics Canada and other research organizations as appropriate to develop methods to address these questions using existing data and linkage mechanisms where feasible;*

3. *Where specific and important research questions cannot be addressed by existing data and linkage mechanisms, define in more detail the data and/or linkage required, so this may inform shared priorities for the development of additional data sources and enabling practices.*

Frontline collection of ethnocultural identifiers

A number of Profiles detail initiatives towards the collection and recording of ethnocultural identifiers by frontline health service staff. Options include clinicians or administrative staff/registration clerks in hospitals, specialized cancer centres, cancer physician offices, primary care physician offices, community care centres and First Nations/Inuit/Métis health centres. Each of these comes with its own pros and cons. A number of evaluations have been documented or will be published in the coming year.

There is evidence that response rate, which is strongly affected by staff compliance in soliciting the information, can be significantly below 100%, with staff comfort and busy workload as key barriers. Improving staff compliance would require ongoing investment in dialogue and training.

What is unknown at this time is the level of investment required to address known issues with frontline compliance. Such investment would primarily depend on the human resources required, e.g., systems development expertise, frontline training and work process integration over a period of time. These investments are rarely trivial.

Therefore, *we recommend that the Partnership help disseminate new learning that is expected to be published in the coming year about a number of important frontline ethnocultural identifier collection initiatives,* including

- Interior Health – Aboriginal Self Identification Project (B.C.);
- Mustimuhw Community Electronic Medical Record (B.C., Manitoba, Saskatchewan);
- Tri-Hospital Health Equity Data Collection Project (Ontario);
- Electronic Medical Record – incorporation of Ethnicity Reference Set into Primary Health Care Voluntary Reporting System (CIHI).

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We also recommend that the Partnership explore how it can work with stakeholders to better quantify and assess the investment required to collect ethnocultural identifiers via a frontline collection strategy versus doing so via the alternative approaches available. In particular the investment required to address frontline staff compliance and the underlying factors (staff comfort and workload) need to be understood and quantified better.

Provincial/Territorial health insurance client registries

For cancer registries and screening registries it would be advantageous to source First Nations, Inuit and Métis identifiers from provincial health care client registries. These registries cover a very high percent of the provincial population. And health insurance identifiers/health card numbers are critical to linking a broad range of provincial/territorial health databases. Good practices are found in Nunavut and the Northwest Territories, and under development in B.C. and Newfoundland and Labrador. Key informants have pointed to four factors that need to be in place for such a project to happen: 1) a reason, 2) champion(s) and supporters, 3) a standard, and 4) an implementation plan.

We recommend that the Partnership explore options to

1. *Initiate and coordinate the development of a national framework and guidelines for the identification of First Nations, Inuit and Métis peoples in health administrative data sets;*

2. *Facilitate the exchange of knowledge and learning from jurisdictions who are planning, implementing or using First Nations, Inuit and Métis identifiers in their health insurance client registries; and*

3. *Work with individual provincial cancer agencies, First Nations, Inuit and Métis organizations and ministries of health to develop a shared agenda and plan that lays out the options and conditions for implementing a First Nations, Inuit and Métis identifier standard in their provincial health insurance client registry.*

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2.0   INTRODUCTION

Chapter 2.0 describes how the project fits with the First Nations, Inuit and Métis Action Plan on Cancer Control and why ethnocultural patient identification of First Nations, Inuit and Metis cancer patients is important to achieving cancer control objectives for and with First Nations, Inuit and Métis peoples.

2.1   THE CANADIAN PARTNERSHIP AGAINST CANCER

The Canadian Partnership Against Cancer (the Partnership) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership's mission is to bring together cancer experts, charitable organizations, governments, patients and survivors to bring change to the cancer control domain. With other organizations, the Partnership works to stimulate generation of new knowledge and accelerate the implementation of existing knowledge about cancer control across Canada. The Partnership's vision is to achieve improvements in cancer control in Canada by being a catalyst for a coordinated approach that will reduce the expected number of cancer cases, enhance the quality of life of those affected by cancer, lessen the likelihood of Canadians dying from cancer, and increase the efficiency of the cancer control domain, with the following strategic objectives:

- Reduce gaps in knowledge to enhance cancer control

- Facilitate and accelerate implementation of best available knowledge

- Optimize quality and access

- Improve the cancer experience for Canadians

The Advisory Committee on First Nations, Inuit and Métis Cancer Control consists of appointed members from the following organizations and groups:

- Assembly of First Nations

- Inuit Tapiriit Kanatami

- Métis National Council

- First Nations, Inuit and Métis elders

- First Nations, Inuit and Métis cancer patients

- Public Health Agency of Canada

- First Nations and Inuit Health Branch, Health Canada

- Canadian Association of Provincial Cancer Agencies

- Canadian Cancer Society

- Heart and Stroke Foundation of Canada

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2.2   KEY GAPS IN FIRST NATIONS, INUIT AND MÉTIS CANCER CONTROL

As a foundation for planning, key gaps in First Nations, Inuit and Métis cancer control were identified and prioritized between 2007 and 2009. The process of identifying the gaps was as follows:

- In 2007, funding was provided by the Public Health Agency of Canada to five national Aboriginal organizations for the development of cancer control strategies and discussion documents. These were produced in 2007-2008, including submissions from a number of Assembly of First Nations' regions.

- Key gaps in cancer control were identified at the Partnership-hosted National Forum on First Nations, Inuit and Métis Cancer Control (March 2009).

The table below presents the key gaps identified by the National Forum on First Nations, Inuit and Métis Cancer Control:

Key gaps in cancer control
System Integration An overarching concern is the need for a system of cancer control that integrates all components of the health-care system and implements services in a way that is responsive to the practical and cultural needs of First Nations, Inuit and Métis populations.
Primary Prevention In general, there appears to be a lack of awareness about cancer and cancer risk factors within First Nations, Inuit and Métis communities. As well, a precursor to better cancer control and modification of associated behavioural risk factors (i.e., smoking, alcohol use, healthy eating and physical activity) is to address the socio-economic determinants of health (poverty, educational attainment, food insecurity, housing, environmental contamination, etc.).
Screening There is a need for organized cancer screening programs that are adapted to be relevant to cultural worldview, safety and practical needs of First Nations, Inuit and Métis populations, and that are systematically implemented.
Cancer Journey Culturally appropriate and community-relevant care is needed that integrates traditional practices and provides patient support.
Health Human Resources Workers are required across all aspects of cancer control continuum, and dedicated resources for cancer control are needed in the communities.
Research and Surveillance There is a lack of cancer control data specific to First Nations, Inuit and Métis populations.

2.3   FIRST NATIONS, INUIT AND MÉTIS ACTION PLAN ON CANCER CONTROL

The identified gaps were then viewed through the mandate of the Partnership and where it was best positioned to take action, and turned into the Action Plan in 2009/2010. The process of defining the strategic areas of focus was as follows:

- Reviews of published documents and ongoing work were developed and shared by the Partnership for planning purposes (April 2010);

- Working from the list of key gaps identified at the forum and informed by the reviews conducted by the Partnership, the Advisory Committee on First Nations, Inuit and Métis Cancer Control developed a list of 22 possible actions (May 2010);

- The list of possible actions was further narrowed based on the priorities of partner organizations and the ability of the Partnership, given its mandate, to best advance the work (July-August 2010);

- The resulting list of 11 possible actions was validated by partner organizations (September - October 2010), from which emerged four areas of strategic focus; and

- Based on the four areas of strategic focus, a proposed list of seven actions was approved by the Partnership's advisory committee, First Nations, Inuit and Métis national Aboriginal organizations' caucus, and board (December 2010 - January 2011).

It should be noted that while this Action Plan was borne from cancer control, its focus goes beyond a cancer-specific approach. In the prevention domain in particular, the priorities for action cut across cancer and chronic diseases such as diabetes, heart and lung disease because of the many interrelated risk factors. As an independent pan-Canadian organization, the Partnership has been funded to work across federal, provincial and territorial jurisdictions to increase collaboration and reduce duplication, and therefore a significant portion of this Action Plan is dedicated to collaboratively working across diseases where appropriate.

The diagram below captures the four areas of focus and their interdependencies. The scheme also envisions the path of progress in each area. The 2011-12 period will concentrate on building a base of knowledge and evidence which will be foundational for future work in these areas. The focus of the following five years will be on putting the new evidence into action and disseminating and facilitating the adaptation of leading/promising practices to address identified priorities.

The Environmental Scan and Analysis of Existing Patient Identification Systems for First Nations, Inuit and Métis peoples is one component of the First Nations, Inuit and Métis Action Plan on Cancer Control.

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First Nations, Inuit and Métis Cancer Control Actions

Community-based health human resource skills and capacity and community awareness

2011/12

2012-17

Community awareness surveys

Identify/facilitate development of educational programs

Community awareness campaigns

1. Assess educational needs of front-line health workers

2. Scan & analyze community cancer prevention and screening awareness surveys

3. Scan leading practices (including navigation and traditional models) across cancer control spectrum.

Share leading practices across all regions and populations

Share leading practices across all regions and populations

Share/develop new models of care across cancer control spectrum

5. Scan and analyze patient identification systems

4. Scan and analyze leading models of care

First Nations, Inuit and Métis patient identification

Access to care in remote and rural communities

Culturally-responsive resources and services

Leadership:
6. Facilitating Cross-sectoral collaboration on social determinants of health
7. Raising the profile of cancer control with First Nations, Inuit and Métis leaders

2

3.0 OBJECTIVE OF THE PROJECT

Chapter 3.0 describes the purpose and scope of the project, as well as the desired impact on cancer control for First Nations, Inuit and Métis peoples.

3.1 PROJECT OBJECTIVE AND 2011/2012 ACTIONS

The objective of The Environmental Scan and Analysis of Existing Patient Identification Systems for First Nations, Inuit and Métis peoples is to identify good and emerging practices for ethnocultural identification that can be shared across Canada, and to determine gaps in identifying the ethnocultural identity of cancer patients among First Nations, Inuit and Métis peoples. The specific goal and actions to be taken in 2011/2012, as laid out in the Action Plan are:

Goal:

- Identify existing systems of patient identification specific to First Nations, Inuit and Métis ethnicity;
- Analyze the barriers to developing common standards for data collection, access and reporting (as a means to improve patient navigation).

Actions for 2011/2012:

- Document existing systems of ethnocultural patient identification for First Nations, Inuit and Métis populations;
- Analyze and identify leading practices.

The project's scope focuses on existing systems of patient ethnocultural identification for First Nations, Inuit and Métis peoples that are related but not limited to cancer care. Minimum scope requirements include (I) cancer treatment & other health systems, (II) regional, provincial/territorial, federal and First Nations, Inuit and Métis geographies/jurisdictions (ideally, separate for each population), and (III) analysis, including framework development, recommendations, implementation considerations and next steps.

The Action Plan describes the relationship between *The Environmental Scan and Analysis*, its immediate impact and the longer term impact as follows (*Action Plan*, page 22):

5. Document existing systems of ethno-cultural patient identification for First Nations, Inuit and Métis populations. Analyze and identify leading practices.	
Scope of activity	Includes cancer registries and other areas of the health system where First Nations, Inuit, Métis and/or other ethnicity is recorded. Documentation of leading practices includes an analysis of barriers to developing acceptable systems of ethno-cultural identification, and of standards for data collection, access and analysis.
Immediate impact	Environmental scan and analysis of existing patient identification systems for First Nations, Inuit and Métis will help to inform the development of common identifier standards/population definitions.
Implementation	Request for Proposal issued February 22, 2011. Completion by March 2012.
2012-2017 strategic focus	Share gaps in cancer control-related data with relevant organizations (i.e., Public Health Agency of Canada and Statistics Canada) that may help facilitate solutions. Share leading practices across all regions to promote the use of common identifier standards/population definitions, which will further enable patients to benefit from culturally-responsive services available such as patient navigation models.
Longer-term impact	Improved ability to collect baseline data (i.e., incidence, care patterns and outcomes) and thus target services to areas of most need, leading to improved integrative and supportive care. Provides leaders with evidence to advocate for improvements in cancer control.

The project was implemented between May 2011 and January 2012. Data collection and verification took place between June 2011 and November 2011.

4.0 METHODOLOGY AND ANALYTICAL FRAMEWORK

Chapter 4.0 describes the methods and framework that were developed to collect and analyze systems of patient ethnocultural identification, the rationale for their development, and how they were used in this study. The methodology includes the approach taken to search for patient ethnocultural identification systems across a range of parameters, e.g., types of systems, geographies/jurisdictions; primary and secondary research methods.

4.1 METHODOLOGY

We estimate that there are well over ten thousand health information holdings currently in use across Canada. These holdings contain structured health and health-related data (e.g., insurance, demographics) in an electronic format. They are used every day by clinicians, administrators, researchers and policy makers to make decisions that affect patients as well as healthy people.

The project methodology is the approach taken to go from this starting point, thousands of health databases, to the desired end point, i.e., an inventory of Canadian health databases with ethnocultural identifiers and leading practices that support these health databases. There are three steps (WHAT) in this approach:

   I.   Identify First Nations, Inuit and Métis patient identification systems;

  II.   Create Profiles of these patient identification systems to describe and categorize them; and

 III.   Analyze the profiled patient identification systems.

The method (HOW) for conducting these three steps are to:

1. Apply a Search Method and Screener to identify relevant databases among the thousands of data bases that exist today;

2. Design a Data Collection Tool that can capture the salient features of selected databases for reference and analysis; and

3. Develop the Analytical Method that may help highlight leading practices, and enablers/barriers to acting on these leading practices.

METHODOLOGY
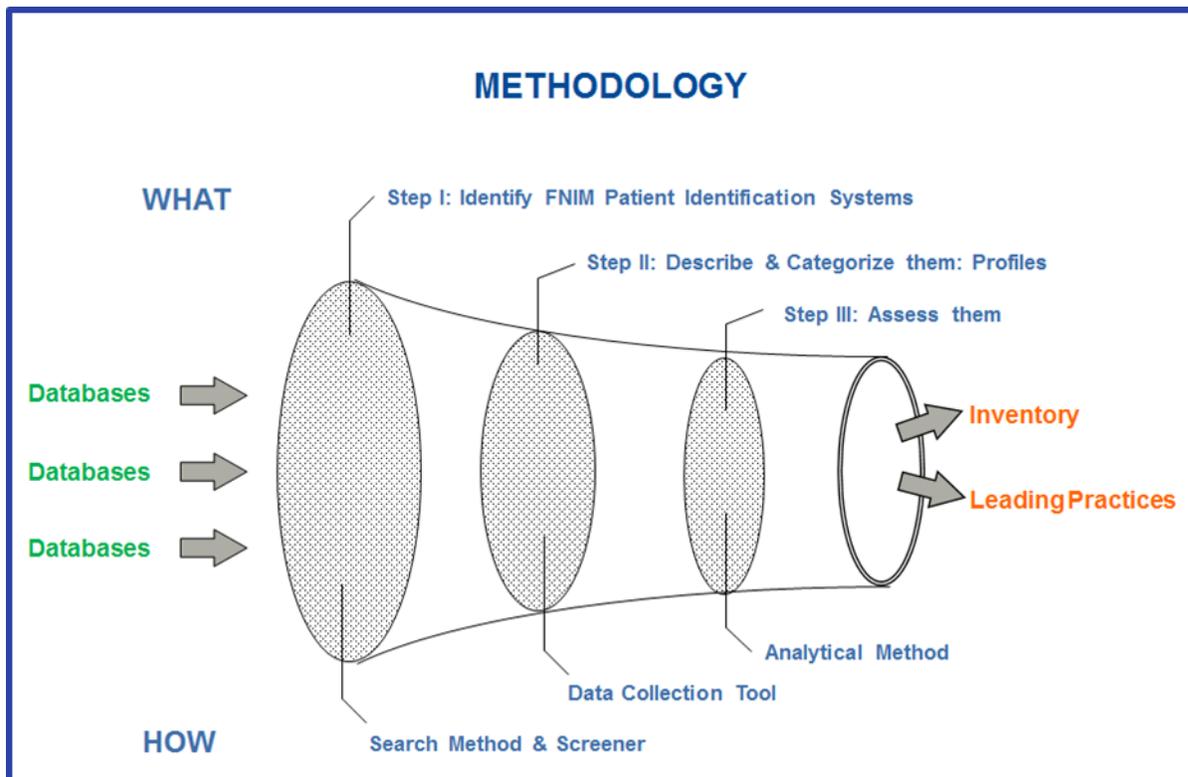
The Search Method and Screener, the Data Collection Tool and the Analytical Method function as screens in a funnel. They gradually narrow down the search to identify databases that meet the objective of the study. Steps I through III then form the basis for a discussion and formulation of initial recommendations relating to:

a) The enablers and barriers to developing valid and useable systems of ethnocultural identification for First Nations, Inuit and Métis peoples; and

b) Potential standards for data collection, access and reporting.

4.2   IDENTIFYING FIRST NATIONS, INUIT AND MÉTIS PATIENT IDENTIFICATION SYSTEMS

This section describes the methods used to identify First Nations, Inuit and Métis identification systems. This involved the development and application of a search method and screener to identify the most relevant databases and practices.

4.2.1   Search Method

The approach used to identify First Nations, Inuit and Métis identification systems was an iterative one. This sub-section describes how the search was approached and evolved. Briefly, a review of the peer-reviewed and grey literature revealed that ethnocultural identification occurred at a multitude of encounters throughout the life course, and that the published literature had insufficient breadth, depth and timeliness for the purposes of this report. Accordingly, we shifted our focus to identify and classify encounters where people may self-identify as First Nations, Inuit and Métis and used these encounters as a starting point to identify source forms and databases.

Step 1: Literature Search

Keywords for the literature search fell into one of two themes; the first theme captured Aboriginality and included the keywords "First Nations", "North American Indian", "Inuit", "Métis", "Aboriginal" and "Indigenous". The second theme related to administrative data and included keywords and MeSH medical subject headings such as "Patient Identification Systems", "Medical Records", "Databases", and "Vital Statistics". Using these terms, English publications from 1990 onwards were searched in the following databases: Medline, Cumulative Index to Nursing and Health Literature (CINAHL), Native Health Database, Ovid HealthStar, EMBASE and Scopus. This search yielded 2,744 citations. After screening titles and abstracts for relevance, 394 relevant articles remained.

A grey literature search was also conducted on the internet using popular search engines (e.g., Google) and searching websites of relevant organizations and institutions (e.g., websites of First Nations, Inuit and Métis organizations, federal, provincial, territorial, regional and local governments, cancer agencies, university research centres, hospitals and health- or Aboriginal-related foundations). Seventy-four additional documents were identified through this grey literature search.

In the next step, retrieved articles were assessed and information was abstracted from each study relating to its purpose, the source of the ethnocultural identifier, the population and geographic regions included and study results. During the data abstraction phase, we concluded that while it served as a valuable starting point, the content of the literature made a limited contribution to our search as a result of insufficient breadth, depth and timeliness.

First, it was apparent that only a subset of health databases with identifiers were being used for research purposes, and that only a subset of these would be included in the peer-reviewed literature.

Second, when health information holdings were used for research and present in the peer-reviewed literature, the data source was typically only described superficially, if at all, with insufficient detail to inform our report. Finally, patient identification systems are rapidly evolving and many initiatives to include ethnocultural identifiers in pre-existing and newly developed health (and other) databases have begun only recently. Given the amount of time required to collect sufficient data in a new database, to familiarize oneself with the database and recognize potential for research, and to conduct and publish research, the peer-reviewed literature did not adequately capture the current landscape of ethnocultural identification.

Step 2: Focus on People and When They May Self-Identify

Using the results of the literature search as a starting point, we identified six types of health-related encounters where Canadians may be asked to self-identify. Self-identification can include the sharing of personal or demographic information such as name, address, date of birth, and gender. This information is typically obtained when Canadians 1) register a birth, marriage or death, 2) register for a health program or service (e.g., at a hospital), 3) provide information during an intake or assessment interview with a health care professional, 4) register as a Status First Nation, Inuit Beneficiary, or Métis citizen, 5) respond to a survey or the Census, and 6) register for publicly funded health insurance.

FOCUS ON PEOPLE, AND WHEN THEY MAY SELF-IDENTIFY
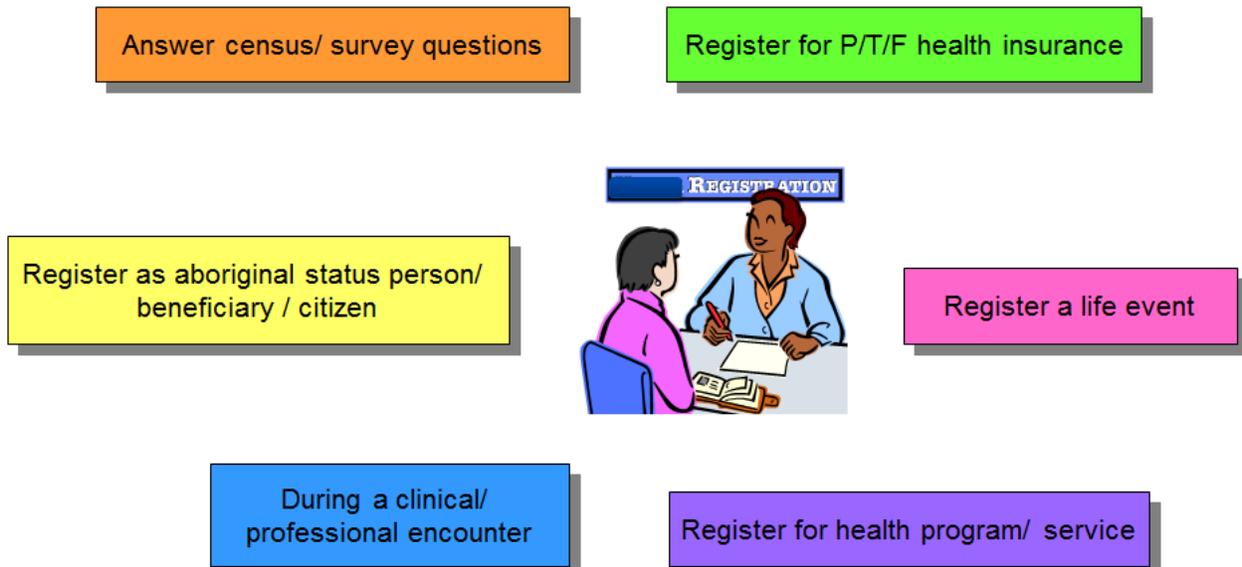
Vital events (birth, marriage, death) and health insurance registrations are provincial/territorial responsibilities. Additionally, the federal government registers eligible Aboriginal peoples for the Non-Insured Health Benefits (NIHB) program. Registration as Status First Nation, Inuit Beneficiary or Métis citizen takes place through registration processes under the responsibility of the Indian Registrar, Registrars of the four Inuit Beneficiary lists and Registrars for Métis citizenship registers. We therefore collected, where available, the blank application forms for these registration processes for all provinces and territories, and at the national level where applicable. Appropriate surveys were identified through the literature review, key informants at provincial research institutes and Statistics Canada, as well as a grey literature search that included the keywords "First Nations", "Inuit", "Métis", "Aboriginal" and "Indigenous" plus terms such as "survey" and "questionnaire".

Step 3: Create and Apply a Taxonomy of Health Entitlements

Following Step 2, we still needed to structure our search for forms used to register patients and document personal demographic information obtained during clinical intake and assessment interviews. For this we developed a taxonomy or classification for the types of health programs and services that are available to Canadians who are enrolled in publicly funded health insurance plans.

TAXONOMY OF HEALTH ENTITLEMENTS

Health Plan Enrollees				
Client Registry & Identification Management				
Public Health	**Primary Care**	**Home & Community Care**	**Institutional Care**	**Clinics, et al.**
PH units (communicable)	FPs, nurses & teams	Home care	Hospitals (inpatient, ambulatory)	Clinics (e.g. allied health)
FN health centres	Nursing stations	Community health centres		Screening programs
	Eye, ear, dental	FN health centres		
Schools (immunization)	professionals, midwives	Community agencies	Long term care	Pharmacies
		Community mental health		Labs
Specializations: babies & moms, the aged, chronic diseases, mental health & addictions				

The above taxonomy then guided a systematic search of organizations associated with the administration and delivery of these types of health services and/or who might have an interest in the data collected in the course of program administration.

In summary, the Environmental scan started with the academic/peer-reviewed literature related to the topic of First Nations, Inuit and Métis ethnocultural identification, and evolved to focus on 1) data collection forms, 2) descriptions of the databases associated with these forms, 3) additional documents, reports and websites that provide information on these databases, and 4) key informant interviews.

4.2.2 Screener

To decide which of the practices found through the search method would be included in the inventory of good practices, we used the following screening process.

For each potential practice, we first checked for the presence of *ethnocultural* identifiers, i.e., indicators of ethnic, racial or ethnocultural groups, and then for the presence of *First Nations*, *Inuit* and/or *Métis* identifiers. If the practice involved ethnocultural identification, we collected the source form for the associated question, e.g., a health insurance application, a registration form or a clinical assessment form. Of note, we were only interested in blank forms – not actual data.

Next, we established whether information describing the practice in more detail could be obtained and verified. Descriptive information was considered usable and reliable if it was (i) in the public domain, and (ii) sourced from a reliable documentation source, and/or (iii) reviewed by the custodian of the database/practice. Reliable documentation sources, for the purpose of this study, include key informants who represent the custodian, documents published by the custodian, as well as related studies, analyses and peer-reviewed articles by other parties familiar with the data practice.

The final step aimed to ensure that the inventory of ethnocultural practices profiled illustrates the breadth of practices that can be found across Canada without creating duplication of broadly similar practices that add relatively little value to the purpose of the study. Therefore, we made a judgement as to whether (i) a particular database was a unique or instructive example of similar databases with ethnocultural identifiers, or (ii) a practice was a helpful illustration of a practice that supports the creation and use of a health database with ethnocultural identifiers. In the latter case, we focused on selecting practices that fit in one of the following two categories: (i) practices that exemplify either a standard or a protocol, or create harmonization between databases, and (ii) practices that aim to improve awareness of the importance and use of ethnocultural identifiers, or offer relevant training.

The Screening Tool to Select Relevant Practices for Inclusion in the *Inventory of Profiles* is summarized in the next diagram.

Potential practice identified

Does practice involve ethnocultural identifier(s)? FNIM identifiers?

NO → **Practice not profiled**

YES

Source form is collected

YES

Is there a source form for the identity question?

NO → **Practice not profiled**

YES

Can the information be verified?

NO → **Practice not profiled**

YES

Is the practice a helpful example of similar DBs?

NO → **Is the practice a helpful example of a DB enabler?**

YES

NO

YES

Practice included in the Inventory of Profiles

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4.3   DESCRIBING AND CATEGORIZING ETHNOCULTURAL IDENTIFICATION SYSTEMS: ANALYTICAL FRAMEWORK

To describe and analyze a health database with ethnocultural identifiers, we need a framework to guide our thinking on what aspects of the database merit description and further investigation. Such a framework can be the process that is commonly used for developing new data sets. The next figure shows this process.
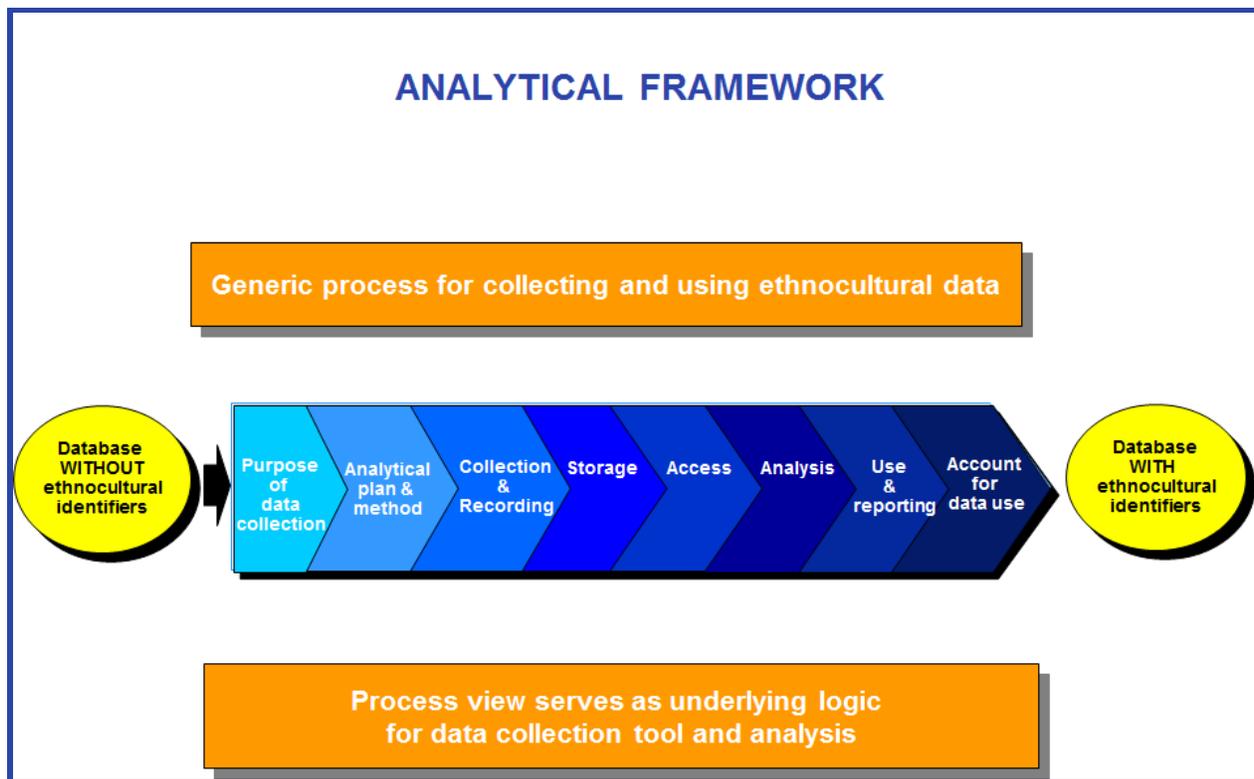
The process has a starting point and an end point. It begins with a database without First Nation, Inuit and Métis identifiers, and it ends with a database that includes ethnocultural identifiers. The intervening process describes the key steps involved in collecting, accessing and using the required information.

The assumption is that a good approach yields a good result. In other words, a good process starts with a clearly articulated purpose, and then follows through with an appropriate analytical plan and data collection method, applies that plan to how data are collected, recorded, stored, made accessible and analyzed, and how the results are then reported and accounted for to those who have a rightful stake in the information. All the steps have implications for principles of data ownership, control, access and possession. And all the practice steps lend themselves in principle to description and analysis.

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The analytical framework served as the underlying logic for this study's data collection tool. This tool aimed to collect more detailed information about each of the following process steps:

Process Step	Scope
Starting point	A health data set without ethnocultural identifiers.
Purpose of data collection	Answers what decisions need to be taken by whom, why current data don't suffice, and how new data will be used to take decisions/action.
Analytical plan & method for data collection	Create the design for the entire process, including data collection, target population, budget, timing, testing plans and a project plan that respects all the requirements, e.g., data sharing protocols.
Data collection & recording	Collect and record the data elements.
Data storage	Process, categorize, present and securely store the data in a usable format.
Data access	Facilitate access to data, including secondary use, while protecting individual privacy, confidentiality and any applicable peoples rights.
Data analysis	Analyze data to answer questions posed at beginning of project, and develop new insight.
Data use & reporting	Turn insightful analysis into informed decisions regarding policy, practice, education or research. This includes documenting the method & analysis, and knowledge exchange to ensure policy makers and practitioners understand the evidence for (new) decisions.
Accountability for data use	Close the loop with the original purpose: communicate to all stakeholders why data was collected/analyzed, how that was done, what was found, and what was done with that.
End point	A health data set with ethnocultural identifiers and, ideally, evidence informed decisions which the data enabled.

4.3.1 Data Collection Tool

The data collection tool went through several iterations to ensure the questions could be understood in the context of a key informant interview and as a stand-alone questionnaire. This included a number of trials and revisions by members of the research team using databases they were familiar with.

The tool includes a brief introduction, and a four-page electronic questionnaire. To facilitate relatively fast completion use was made of check boxes and drop down menus where appropriate. Free form text entry spaces encourage key informants' additional perspectives. The questionnaire - and the resulting Practice Profile - includes four separate sections:

1.   The database, including a general description of the holding, and ethnocultural identifiers available;

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2. Data design, collection, recording and storage practices, including, the exact ethnocultural identity question used in the source database;

3. Data access practices, including privacy constraints and First Nations, Inuit and Métis engagement processes; and

4. Data use and reporting practices, including thoughts on the potential application to other jurisdictions.

Two slightly different versions were created for single-source and multi-source databases. The former is included in Appendix A.

4.4   ASSESSING ETHNOCULTURAL IDENTIFICATION SYSTEMS

The methodology steps in Sections 4.2 and 4.3 detail 1) the search method and screener used to identify First Nations, Inuit and Métis identification systems, and 2) the data collection tool used to collect information about these identification systems and describe them. At this stage, the methodology steps should produce a list of ethnocultural identification practices that have been found - systematically organized into an Inventory of Profiles. This then satisfies the first goal of the study, i.e., to identify existing systems of patient identification systems specific to First Nations, Inuit and Métis ethnicity. And it supports the commitment to document existing systems of ethnocultural patient identification for First Nations, Inuit and Métis populations in 2011/2012.

What is left is to analyze and identify good practices, and analyze the barriers to developing common standards for data collection, access and reporting. The approach used for this task is described next.

4.4.1 Analytical Method

The starting point for our approach to identifying good practices is the Partnership's internal definition: "a leading practice refers to a practice that has been shown to be at the forefront of change and that addresses important barriers or gaps. Evidence indicating leadership may include formal evaluation and peer-reviewed publication; however a lack of formal evaluation will not exclude a practice from being considered as leading". The important point here is the inclusive approach to identifying and analyzing existing practices. There is a recognition that practices - like those used for ethnocultural identification - operate in their own complex and evolving contexts. What constitutes a good practice is often specific to that context. As a result, there may need to be some tolerance for a number of different approaches, each of which can be relevant and produce the results for which it is designed.

Rather than getting unnecessarily restrictive in our analysis of good practices, we decided to focus on identifying patterns or themes that were common across different practices. These themes relate to common barriers to the implementation of ethnocultural identifiers, and how these have been addressed. The output for this step is the identification of empirically observed enablers to developing and using ethnocultural identifiers.

The second step in the analysis was to bring out the unique features of cancer databases to assess how the potential application of existing practices fits with the way cancer databases integrate data from different sources. The output for this step is the identification of options for augmenting cancer databases with First Nations, Inuit and/or Métis identifiers.

5.0 INVENTORY OF PROFILES OF EXISTING PATIENT IDENTIFICATION SYSTEMS FOR FIRST NATION, INUIT AND MÉTIS PEOPLES ACROSS CANADA

Chapter 5.0 describes the results of applying the methodology and framework to the Canadian health care system to create an inventory of patient identification systems currently in existence. Implications and recommended next steps are discussed for the purpose of identifying leading practices that can be shared across Canada and determining gaps in identifying (the ethnocultural identity of cancer patients among) First Nations, Inuit and Métis peoples.

5.1 RESULTS - OVERVIEW

The search process yielded fifty ethnocultural identification systems. Forty-two of these describe health databases with First Nations, Inuit and/or Métis identifiers, and eight describe enabling practices towards such databases. Fourteen profiles (28%) describe relatively recent (2010/2011) initiatives and some are still under review or at the early stages of implementation. The database and enabling practices are geographically spread across Canada and across health service domains. For details, see Cross Reference Chart I in Appendix B.

The fifty ethnocultural identification systems show a significant number and diverse range of approaches to identify First Nations, Inuit and Métis people. In fact, First Nations, Inuit and Métis peoples were found to be the first and foremost focus of the majority of health databases with ethnocultural identifiers. While some databases include identification of other ethnocultural groups, this is far less common – and we found no ethnocultural identification practices without Aboriginal identifiers.

Thirty-one databases profiled are single source databases (74%), where the data elements, including ethnocultural identifiers are collected from one source. Eleven databases are multi-source databases (26%), which achieve their purpose by linking two or more databases, at least one of which contains ethnocultural identifiers. The forty-two profiled databases demonstrate a range of sources* for First Nations, Inuit and/or Métis identifiers, as follows:

Self-Identification occurs at the time of *				
Census/Survey	P/T Insurance Enrolment	Status/Beneficiary/ Citizen Enrolment	Point of Service or Care	
			Registration	Clinical/Professional Encounter
9 profiles	6 profiles	16 profiles	4 profiles	12 profiles

* Identifier sources in the table above add up to more than forty-two, as some databases use more than one source for First Nations, Inuit and/or Métis identifiers.

For details, see Cross Reference Chart II in Appendix C. The frequency distribution should not be interpreted as an indication of the relative feasibility of different approaches to ethnocultural identification, but rather as a demonstration that a range of approaches can achieve the objective – depending on specific considerations and preferences.

The forty-two profiled databases also demonstrate a wide range of health domains that include databases with ethnocultural identifiers. Ethnocultural identification practices were found, among others, in public health, home & community care, hospital and long term care, and specialized programs for babies and young mothers, chronic diseases, cancer, and mental health.

5.2   RESULTS - DETAILED PROFILES

All fifty ethnocultural identification systems are extensively detailed in *Inventory of profiles of existing patient identification systems for First Nations, Inuit and Métis peoples across Canada* (Cats, Withrow & Marrett, 2012), which accompanies this Analytical Report. The balance of Chapter 5.0 presents summaries of the profiles to help set the stage for our subsequent discussion of their potential application to cancer registries in Chapter 6.0.

In Section 5.3, we first present eight enabling practices that support ethnocultural database development and use. In Sections 5.4 to 5.9, the balance forty-two database profiles are summarized. They have been grouped according to their source of self-identification. Sections 5.10 and 5.11 discuss implications and suggested next steps, which will be further refined in Chapter 6.0 in the context of the potential application of existing practices to Canadian cancer databases.

5.3   ENABLING PRACTICES THAT SUPPORT ETHNOCULTURAL DATABASE DEVELOPMENT AND USE

Practice Type	Practices Profiled
Identification standards	Aboriginal Administrative Data Standard (British Columbia)
	Aboriginal Identity Indicator in Cancer Patients - Protocol
	Newfoundland and Labrador Aboriginal Administrative Data Identifier
	Electronic Medical Record: Ethnicity Reference Set
	Mustimuhw Community Electronic Record
Process harmonization	Longitudinal Health and Administrative Data Initiative
Awareness creation	Tripartite and Bipartite Political Processes
	Indigenous Cultural Competency Training Program

The **Aboriginal Administrative Data Standard (AADS)** aims to enable consistency in the way the B.C. government promotes identification of Aboriginal citizens. It is a guide to British Columbia ministries and affiliated agencies to support the collection of self-reported data on Aboriginal identity by applying a standardized set of questions and data elements to their information management systems. The Data Standard came into effect in 2007 and applies to all nine ministries and agencies responsible for the delivery of services and programs designed to improve the social and economic opportunities and outcomes for Aboriginal persons. It represents the first time a Canadian jurisdiction has set a cross-governmental standard for First Nations, Inuit and Métis identification. The data elements are

- Aboriginal Identity Indicator: Aboriginal identity, i.e., First Nations, Métis or Inuit
- Aboriginal Identity Group :   First Nations, Métis or Inuit identity
- First Nations Status Indicator: Registered under Indian Act of Canada, i.e., Status Indian
- First Nations On-Reserve Indicator: Living on a reserve

If the Aboriginal Identity Indicator question is answered "yes", then the Aboriginal Identity Group question is asked to elicit the specific Aboriginal group with which an individual identifies. If the response to the Aboriginal Identity Indicator question is "no" or "unknown/not provided", no more ethnocultural questions are asked. The first two data elements are required to be asked, the second two data elements are optional. In accordance with the Canadian Charter of Rights and Freedoms, when asking individuals for personal information, such as their Aboriginal identity, the province must be clear that disclosure is optional and for what purposes the information is being collected. It is also not permissible to refuse service(s) on the basis of a person refusing to answer a request for personal information.

The **Aboriginal Identity Indicator in Cancer Patients Protocol** is a protocol developed in 2011 by Cancer Care Ontario (CCO) for collecting Aboriginal identity indicators in cancer patients attending a specialized cancer centre. The protocol is based on a 2009 pilot project CCO undertook with the Ontario Ministry of Health and Long Term Care to test the feasibility of collecting Aboriginal ethnicity data in cancer centres. The project included development of a data collection tool and procedures which were then piloted in two cancer centres, one in the urban south and one in the more rural north. The pilot was evaluated by CCO (Lidstone-Jones & Stewart, 2009) as well as external reviewers (Cats, MacAdam & Johnston, 2010). While there is a relatively small database associated with the pilot, the long term value of this project is in the extensive documentation of the processes used, the evaluation, and the resulting protocol.

The recommended questions and associated data elements, which are very similar to the B.C. Aboriginal Administrative Data Standard, are:

a. **Are you an Aboriginal person, that is, First Nation (North American Indian), Métis or Inuk?**

IF YES, Please select all that apply

○ Yes, First Nation (North American Indian) ⟶ ○ Status

○ Yes, Métis   ○ Non-Status

○ Yes, Inuk   ○ Other - please specify: _____

○ Yes, Other - please specify: _____

○ No, not an Aboriginal person ⟶ END

○ Don't know   ⟶   END

○ Prefer not to answer   ⟶   END

b. **Is your _permanent_ address on a First Nations territory or reserve?**

○   Yes

○   No

○   Prefer not to answer

In regions where greater numbers of Inuit or Métis reside, other questions could replace or augment question b., as recommended in the Statistics Canada's 2008 Report[6]:

○ If Inuk: are you a beneficiary of a Northern / Inuit land claim agreement – if so, which one?

○ If Métis: Do you have membership in a Métis settlement or in a Métis organization?

In addition to west coast and central Canada development work towards an Aboriginal identifier standard, one is being developed on the east coast, as described below.

The **Newfoundland and Labrador Aboriginal Administrative Data Identifier** is a provincial project initiated by the Department of Health and Community Services, who established a provincial working group in January 2010 to work towards a provincial data standard for Aboriginal identification within key health information systems, as well as a plan for implementation. The provincial project followed the successful conclusion of the regional Labrador Aboriginal Identifier Project, whose participants concluded that identifying Aboriginal people in (mostly provincial) health data sets requires a provincial scope. As of November 2011, the proposed standard is being submitted to the Department of Health and Community Services, Government of Newfoundland and Labrador for approval, which will involve cross-ministerial review. The development of the proposed standard involved all the province's Aboriginal peoples.

The specific identifiers being recommended incorporate, and go beyond, the differentiation between First Nation, Inuit and Métis, to reflect the priorities of the Newfoundland and Labrador Aboriginal communities. Therefore, the recommended taxonomy also defines values for each of the six communities, as well as "Aboriginal, but not a member/beneficiary associated with one of the specified communities". Specifically, residents can identify as members/beneficiaries of:

- Labrador Inuit Land Claim (Nunatsiavut)
- Miawpukek First Nation
- Mushuau Innu First Nation
- NunatuKavut (formerly Labrador Métis Nation)

- Qalipu Mi'kmaq First Nation
- Sheshatshiu Innu First Nation
- None of the above

While the above data elements support specific identifiers that are important in the local context, the recommended taxonomy can still be mapped to more general data elements (e.g., First Nations, Inuit, Status/Registered) for cross-jurisdictional consistency. If the recommendations are accepted through the government review process, the identifiers could be linked to key health data holdings in Newfoundland and Labrador, including the Medical Care Plan (MCP) Beneficiary Registration Database, Vital Event databases, the Clinical Database Management System (hospital inpatient and day surgery data) and disease-specific data holdings such as the Cancer Registry. At this point, three options for implementation are being considered:

1. Embed identifiers in all health data collection processes;

2. Collect identifiers once, and electronically link them - where feasible - to other data sets; and

3. Collect identifiers where feasible, and share them electronically where not feasible.

An example of the second option is to collect the identifiers at the point of registration, or 5-yearly re-registration, for the provincial health insurance plan (MCP) - with a 2-digit code being embedded into the MCP card. This would give residents the opportunity to self-identify at five-yearly intervals. Regional Health Authorities would be able to input the information into their local information systems. Through cross linkage of the MCP file with records in other provincial health databases, the identifier could be embedded within other systems.

The Electronic Medical Record: Ethnicity Reference Set is a value set that supports the pan-Canadian Primary Health Care Content Standard (PHC CS) to enable consistency in the way ethnicity is captured in Canadian electronic medical records. This ethnicity reference set is at the draft stage as of November 2011. The goal is to complete development by February 2012. The development of an Ethnicity Reference Set has been led by the Standards Collaborative Working Group for Public Health and Primary Care (SCWG 1) at Canada Health Infoway in collaboration with the Canadian Institute for Health Information (CIHI). This is the first time a pan-Canadian value set for First Nations, Inuit and Métis identification has been set.

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The entire Ethnicity Reference Set comprises several hundred ethnicities, as it is based on an international system for medical terminology, SNOMED CT, whose values are used in many countries worldwide. The SCWG, whose recommendations are also reviewed by clinicians, decided to use the ethnicity hierarchy in SNOMED CT - complemented by key terms used by Statistics Canada in its surveys, specifically the addition of "First Nations", "Inuit" and "Métis".

These additional identifiers would be "Canadian extensions" to the existing Reference Set, and first have to pass a Canadian review process to be included in the Canadian value set. There is no limit on the number of terms that can be included in a Reference Set. Through a "Request for Change" process, it is possible to generate identifiers that are not in SNOMED CT, but can be shown to be important to support the ultimate objective of standards: better patient care. Also, it is possible to request the addition of "Local extensions". This is generally not promoted, as it impedes the interoperability of electronic medical records.

Mustimuhw is a client information management system, designed specifically for First Nation Health Centres. This **community Electronic Medical Record (cEMR),** a not-for-profit product owned by Cowichan Tribes, is currently deployed in over 50 First Nations/sites in three provinces: British Columbia, Manitoba and Saskatchewan. Mustimuhw has been developed specifically to meet the needs of First Nation health care organizations and communities, honoring and recognizing the principles of Ownership, Control, Access, and Possession (OCAP). Each community using the Mustimuhw cEMR owns and maintains its own data within the Mustimuhw system.

Ethnocultural identifiers are not routinely collected at primary and community care centres. One of a number of barriers to collecting this information is the still limited use of EMRs in primary & community care. By putting a community EMR system at the centre of their community health service delivery approach, First Nations who have adopted Mustimuhw are able to connect ethnocultural identifiers to a range of health assessments, outcomes and metrics. The current system provides for the collection of First Nations identifiers, including Status – Non-status, On-reserve – Off-reserve, and Band ID. In future, possible identifiers will also include Inuit, Métis and Other.

Mustimuhw is also designed with the ability to collect comparable data across sites or interface with larger systems such as the Integrated Public Health Information System or Panorama. It is designed to be interoperable more generally, with federal and provincial health information systems. This expands the range of opportunities for ethnocultural specific research and patient navigation, without compromising individual communities' ownership, control, access and possession of their information.

The **Longitudinal Health and Administrative Data (LHAD) Initiative** is a partnership that allows for linking provincial/territorial health administrative databases to existing Statistics Canada data to effectively answer important health policy questions in a cost-efficient manner. LHAD is not a database. Rather, it is a process or mechanism to enable high quality, timely and cost-efficient linkage of existing databases and the associated data elements, such as ethnocultural identifiers, for the purpose of statistical research. This could include identifiers on the Census, or identifiers present in

jurisdictional data sets. For example, the Census includes large samples of First Nations, Inuit and Métis people across Canada, including some typically under-represented groups. The participating databases remain with their own custodians. The LHAD initiative allows linkage through the creation of a key registry.

The LHAD Initiative is a partnership between Provincial/Territorial Ministries of Health, Statistics Canada, Canadian Institute for Health Information, Canadian Council of Cancer Registries and Vital Statistics Council for Canada to complement important record linkage research already being done within individual provinces and territories, learn from comparisons among jurisdictions, and facilitate larger scale studies for less common types of events and conditions. This means that LHAD is an open data model that combines a common infrastructure of record linkage and privacy management with high flexibility of source files that can be linked for highly customized research.

The **Tripartite and Bipartite Political Processes** profile describes the history of First Nations tripartite and Métis bipartite political processes in British Columbia between 2005 and 2011. Tripartite and bipartite political processes, such as the ones that have evolved in B.C., are negotiations that commit the parties to establishing a new relationship based on mutual respect and recognition, reconciling Aboriginal title and rights with those of the Crown, and closing the socio-economic gap between Aboriginal peoples and other Canadians. In B.C., framework accords have led to joint health planning, which in turn has led to data quality and data sharing agreements. B.C. data sharing agreements have led to information policy initiatives towards the adoption of data with Aboriginal identifiers. Thus, in B.C., these political processes have been foundational towards the establishment of the Aboriginal Administrative Data Standard (described above), and the development and use of the First Nation Client File, which is based on information contained in the Indian Registry, the Ministry of Health's Medical Services Plan and administrative health data, and the Vital Statistics databases.

Similarly, Métis Nation British Columbia (MNBC) signed the Métis Public Health Surveillance Program Information Sharing Agreement with the B.C. government in September 2011, to match consenting members in the MNBC's Citizenship Central Registry with key Ministry of Health databases. This enables, for the first time, creation of health-related statistics on the Métis citizens of B.C. The Central Registry can act as a cohort for linkage studies. For example, the Chronic Disease Surveillance Program (CDSP) is a three-way partnership between the MNBC, Public Health Agency of Canada and the B.C. Provincial Ministry of Health Services to establish data linkages between the MNBC Citizenship registry and administrative data held by the provincial government, specifically the Ministry of Health Services and Vital Statistics. The analysis of this data will provide a valuable resource to Métis communities by making available a valid and reliable measure of Métis health status.

Indigenous Cultural Competency Training Program is a training program designed to increase Aboriginal-specific knowledge, enhance individual self-awareness and strengthen skills for non-Aboriginal health care leadership, professionals and service providers. ICC was launched in B.C. in January 2010 in response to the Transformative Change Accord First Nations Health Plan requirement to provide mandated training to increase cultural competency among employees of the Provincial Health Services Authority, Ministry of Health and the five regional health authorities. ICC

training has since been delivered to participants from B.C., Alberta, Manitoba, Ontario, and Québec. Cultural competency is an important element in preparing frontline staff for asking patients ethnocultural identification questions in a respectful and safe manner. The Ontario cancer care Aboriginal Identity Indicator in Cancer Patients Protocol recommends cultural competency training. ICC and similar programs have been used across Canada to support the implementation of identification projects.

In Sections 5.4 to 5.9, the other forty two database profiles are summarized. They have been grouped according to their source of self-identification.

42 DATABASE PROFILES GROUPED ACCORDING TO WHEN PEOPLE MAY SELF-IDENTIFY

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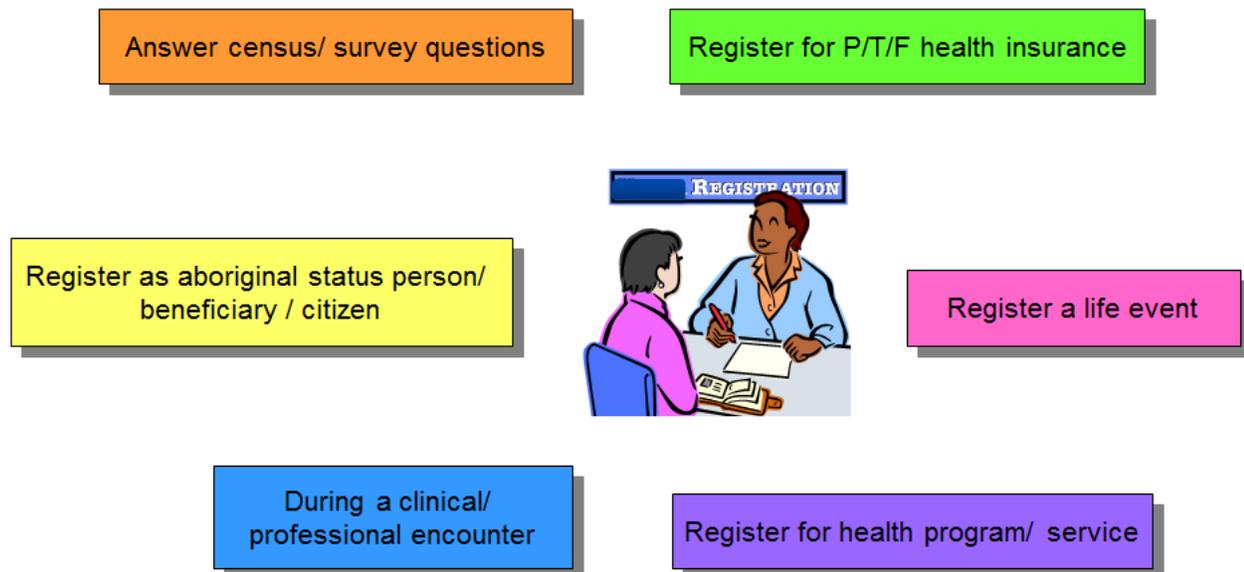
5.4   VITAL STATISTICS: BIRTH AND DEATH REGISTRATION PRACTICES

Database Segment	Databases Profiled
Vital Statistics databases	Northwest Territories Vital Statistics Registry

The **Northwest Territories Vital Statistics Registry** holds the records for all live births, stillbirths, marriages, and deaths in the territory, which are compulsory through the Northwest Territories Vital Statistics Act.   The registration of vital events process allows Northwest Territories residents to self-identify at the time of registration. The ethnic group choices are: *Inuit, Métis, Treaty Indian, and other (specify).* By linking to other data sets, such as the provincial health insurance database and the cancer registry, the vital statistics registry can help assess the burden of disease among First Nations, Inuit and Métis.

5.5   HEALTH PROGRAM / SERVICE REGISTRATION PRACTICES

Database Segment	Databases Profiled
Hospital/Health Centre databases	Interior Health – Aboriginal Self Identification Project
	Tri-Hospital Health Equity Data Collection Project
Screening registries	Nova Scotia – Colon Cancer Screening Registry
	Ontario – Colorectal Cancer Screening Registry

The Aboriginal Self Identification (ASI) Project is an initiative to collect data on the Aboriginal identity of Interior Health (IH) clients, patients and employees that will assist in efforts to design and deliver more culturally sensitive programs. The ASI project is made up of two components: the employee self-identification program, which started June 2011 and a four-phase patient/client identification program. Phase 1, a pilot project with 9 acute care hospitals and 6 health centres in East Kootenay and Kootenay Boundary and in close collaboration with Ktunaxa First Nation (KFN) and Métis Nation of British Columbia (MNBC), started July 2011. The employee ASI will help IH deliver culturally appropriate care by implementing health human resource strategies aimed at encouraging Aboriginal people to consider careers in health care. For the patient ASI, trained registration staff will ask all patients during the registration process to self-identify as Aboriginal or Non-Aboriginal. If patients self-identify as Aboriginal, they will be asked a few more questions including whether or not they want to receive Aboriginal Patient Navigator services. All patients are being given the opportunity to self-identify as Aboriginal or non-Aboriginal; no assumptions are being made as to who is Aboriginal and who is not as outlined in the B.C. Aboriginal Administrative Data Standard. Patients will only be asked once and their answers will become part of their electronic patient record. Registration staff enter registration information directly into the electronic patient record. Patients can change their ASI response at any later time.

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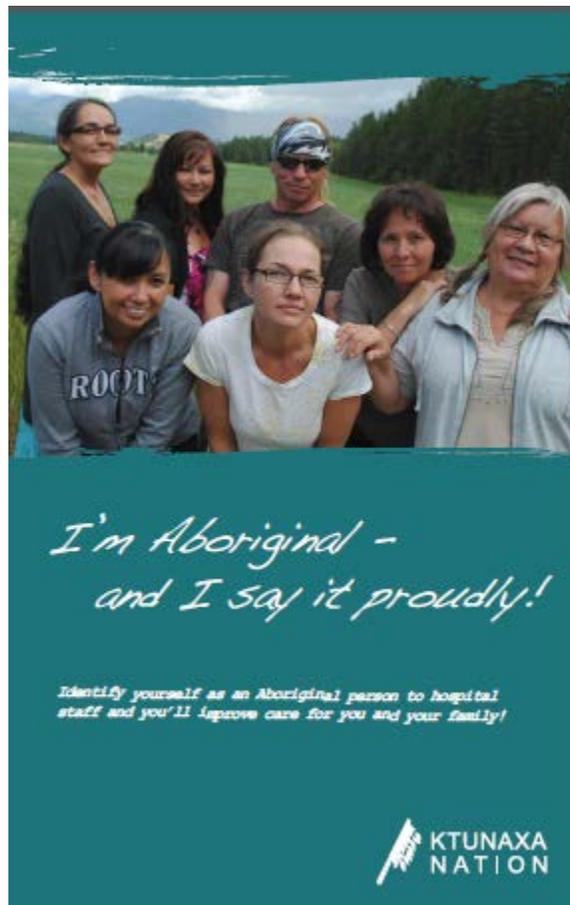
Tri-Hospital Health Equity Data Collection Project - Three Toronto hospitals (Mount Sinai Hospital, St. Michael's Hospital, and the Centre for Addiction and Mental Health) as well as Toronto Public Health are piloting a sociodemographic data collection tool in order to link sociodemographic identifiers to patient-level health outcomes and reduce health disparities where these exist. The preparation for this pilot took place during 2010 and 2011. The pilot will start by January 2012 and is expected to run for six months. Key learning objectives at the pilot stage are to determine: 1) which sociodemographic data to collect; 2) what questions to ask and how to ask them; 3) the most effective ways to gather sensitive personal information; and 4) IT solutions that will integrate the collection of socio-demographic patient data into hospital systems.

The data collection tool has evolved considerably in the course of about 50 iterations over two years. It currently contains 15 questions on demographic topics that research has shown may be associated with lack of equity in access to service, care delivery and outcomes. Topics include: race, language, disability, sexual orientation, gender, place of birth, income and age. Aboriginal identification/affiliation may occur under four of these topics: 1) Race, which includes the option to describe one's race as First Nation, Inuit, Non-Status Indian, Métis, Aboriginal person from outside Canada, alongside with other choices, such as Asian, Black, Middle Eastern, etc.; 2) Language (includes Ojibway and Oji-Cree); 3) Sexual orientation (includes "two-spirit"); and 4) Religion (includes "native spirituality").

The pilot is also expected to provide learning on the medium for asking the questions, which includes the ability for the patient to provide the information via an electronic interface (tablet) - which might save staff time - and administration by clinicians, clerical staff or at the bedside with a research assistant. A full description of the data collection tool, together with pilot learning of its use, is expected to be published by the end of 2012.

Nova Scotia's Colon Cancer Screening Registry is a registry of all eligible Nova Scotians who are participating in the organized, population based colon cancer screening program that Cancer Care Nova Scotia is rolling out across the province. Participants in the colorectal screening program are encouraged to identify themselves as one of seven ethnocultural groups: Acadian, African Canadian, Asian, First Nations, Immigrant - Other, Middle Eastern, and White. The ethnocultural identity question is embedded into a two page participant form. This form provides instructions on how to participate in the Colon Cancer Prevention Program, who to contact for questions, requests personal information (name, health card number, date of birth, address info) as well as name and address of medical care provider (family doctor, nurse practitioner), and opt-in and opt-out information.

This approach is noteworthy in a number of regards: 1) it uses a Direct Mail approach using the provincial health insurance database (which itself contains no ethnocultural identifiers); 2) it asks people to self-identify at a point in time when they are - for the most part - still unaffected by cancer, i.e., at the prevention/screening stage, and 3) it asks people to identify along seven selected dimensions of ethnocultural communities that are relevant to Nova Scotia. This approach fits with Cancer Care Nova Scotia's strategies to invest in outreach to diverse communities, patient navigation, and to apply a cultural competency lens to e.g., practice guidelines. As of October 2011, very early in the provincial roll-out, 32% of the target audience has successfully completed a colorectal cancer

screening test. No analysis has been done yet on the response rate to the ethnocultural identity question or the completeness of the ethnocultural data, as the priority is the roll-out of the program, and overall participation in the screening test.

Ontario's Colorectal Cancer Screening Registry supports ColonCancerCheck, the population-based provincial colorectal cancer screening program that was launched in 2008. The registry does not include ethnocultural identifiers, as none of its provincial source files include these. However, a funded initiative for cancer screening partnerships with First Nations, Inuit and/or Métis health care and governance groups is exploring data pooling options that respect Aboriginal principles of ownership, control, access and protection as well as provincial legislative and regulatory requirements for individual information privacy, security and confidentiality. A number of First Nations, Inuit and Métis groups have expressed a need for better information on how cancer affects their communities, and how initiatives like screening can reduce the burden of cancer. In response to this, regional cancer centres are currently working with their regional Aboriginal partners to improve screening and find ways to source local data.

In the meantime, Cancer Care Ontario - in collaboration with the Institute for Clinical and Evaluative Studies - has developed a Geospatial Analysis Tool to apply statistical data to geographically based data to generate, regional maps of screening rates (example in Profile 4.4.3). In the short term, this tool, which will have a web interface, can help local decision makers dimensionalize geographic variations where Dissemination Area codes fairly closely match First Nations reserves. Over time, as regional partnerships identify more appropriate sources of local data, these can then be used within the registry's database to develop culturally appropriate navigation approaches to improve screening for ethnocultural groups.

5.6   CLINICAL / PROFESSIONAL ENCOUNTER PRACTICES

Database Segment	Databases Profiled
Hospital/Health Centre databases	Tri-Hospital Health Equity Data Collection Project (described under Health Program Registration above)

Database Segment	Databases Profiled
Provincial /territorial/ national registries that are specific to a health domain	Northwest Territories Cancer Registry
	Nunavut Cancer Registry
	Better Outcomes Registry & Network (BORN)
	Nutaqqavut 'Our Children' Health Information System
	Canadian Chronic Disease Surveillance System
	Canadian Tuberculosis Reporting System
	Canadian Organ Replacement Register
	Continuing Care Reporting System
	Home Care Reporting System
	National Rehabilitation Reporting System
	Ontario Mental Health Reporting System
	Primary Health Care Voluntary Reporting System

The **Northwest Territories Cancer Registry** is a registry that records all newly diagnosed cases of cancer among NWT residents under authority of the NWT Public Health Act and the Disease Surveillance Regulations, regardless of whether they obtain cancer services in- or outside the territory. Mandatory reporting of cancer in the NWT began in 1990. The NWT Cancer Registration Form - which is completed for most cancer cases - includes the NWT Health Card Number, including a Letter Prefix whereby N=Non-Aboriginal, M=Métis, D=Dene, and I=Inuit.

The **Nunavut Cancer Registry** is a registry that records all newly diagnosed cases of cancer among Nunavut residents under authority of the Nunavut Disease Registries Act. Nunavut came into being in 1999, consisting of the Baffin, Kivalliq and Kitikmeot regions of the former Northwest Territories. The NCR retrieved cases whose residence was in what is now within the boundaries of Nunavut from the NWT Cancer Registry retroactively to 1992. NCR distinguishes Inuit (~85% of the population) and all others in terms of ethnic status. This is done on the basis of the 9-digit code that is assigned to every Nunavut person registered with the territorial health care insurance plan. The first 8 digits are a unique life-time identifier. The 9th digit is an ethnic identifier, as follows: Dene (3), Métis (4), Inuit (5), Non-Registered Métis (6), Non-Aboriginal (7), and Out-of-territory (8).

BORN Ontario is a registry operating under Public Health Information Protection Act (PHIPA) in Ontario and is the repository for the province's maternal child information. Data held by BORN is collected from multiple health information sources including laboratories providing prenatal and newborn screening, midwifery practices and hospitals for prenatal, labour, birth and early newborn information. BORN is adding other data sources as they become available. BORN recognizes the importance of Aboriginal identifiers, however the Registry is currently in transition, and BORN is still establishing stakeholder partnerships and is seeking appropriate approvals for the collection of Aboriginal identifiers at this time. When the new BORN system goes live in January 2012, Aboriginal

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identity questions will not be collected as part of the BORN system. Once agreements have been reached with the appropriate stakeholders, however, BORN is constructed so that this field can easily be added to the existing system.

In the previous version of the BORN system, the Aboriginal identity variable came from the Niday Perinatal database. Maternal Aboriginal identity was recorded by the health care provider by means of an electronic form containing multiple patient and care-related factors. Potential response categories to the question "Aboriginal?" were: (1) Unknown (2) Not applicable (3) First Nations (4) Métis (5) Inuit. When the new system goes live, the following variable is present, but hidden until stakeholder engagement is complete (and is subject to change, depending on feedback).

Is the mother of this child an Aboriginal person, that is, First Nations, Inuit or Métis? (Mark all that apply).

a) No

b) Yes, First Nations person registered under the Indian Act of Canada living on-reserve

c) Yes, First Nations person registered under the Indian Act of Canada living off-reserve

d) Yes, First Nations/Indian person not registered under the Indian Act of Canada

e) Yes, Inuit

f) Yes, Métis

In addition to routinely collecting information on maternal Aboriginal self-identification in the future, the current BORN system will collect information pertaining to the care provided to maternal/child pairs. Additional information added to the new database (while not a direct identifier) may be useful. For birth location, one of the new choices added is "Aboriginal birthing centre". As well, BORN will document the care provider attending the birth and one of the response options is "Aboriginal midwife".

Nutaqqavut 'Our Children' Health Information System (NHIS) is a standardized way to document health information about pregnant women, new mothers and young children throughout Nunavut. The data for the Nutaqqavut Health Information System is already being collected by health care providers. The Nutaqqavut Health Information System simply collects all this information in one database. Data collection begins at the first prenatal visit and continues through to preschool. It compiles data from a number of existing sources (sources of identifiers are underlined):

1. Nunavut Prenatal Records 1, 2, 3 - identify mother and father as Inuk, Dene, Other First Nation, Métis, or Non-Aboriginal;

2. Nunavut Labour & Delivery Records 1, 2;

3. Nunavut Newborn Record;

4. Hospital Discharge Summary;

5. Well Child Forms: 2, 6 & 12 months, 2-3 years & 4-5 years;

6. <u>Birth Defect Reporting Form</u> - identifies infant as Inuk, Dene, First Nation, Métis, Other, or Unknown;

7. <u>Nunavut Health Care Plan</u> - The last digit of the Nunavut Health Card number indicates the health benefit entitlement of its holder as follows: 5 = Recognized Inuit, 3 = Status First Nation, 7 = all others except Métis, 4 = Métis.

The **Canadian Chronic Disease Surveillance System (CCDSS)** is a collaborative network of provincial and territorial chronic disease surveillance systems, supported by the Public Health Agency of Canada. It provides a national, standardized database of Canadian data on chronic disease including diabetes, hypertension, chronic respiratory disease (Asthma, COPD), mental Illnesses and other diseases (as feasibility is confirmed) and their complications. The CCDSS uses data from various population-based sources in order to estimate the prevalence, incidence, mortality, and the utilization of health care services related to chronic diseases. In each province and territory, the health insurance registry database is linked to the physician billing and hospitalization databases. If there is sufficient evidence of use due to a selected chronic disease it is assumed that a person has diagnosed with the selected chronic disease. For example, for diabetes, the minimum requirement is at least one hospitalization or two physician claims, with a diabetes specific code(s), over a two year period.

CCDSS contains an "Aboriginal Component" intended to address some of the unique information concerns of these populations. A goal of the CCDSS has been to encourage and facilitate the collaboration between the Aboriginal peoples and the provinces and territories so that, together, we can better understand and track the severity of diabetes in these communities. In British Columbia there has been a successful example of this approach. A partnership was formed between the Ministry of Health, Indian and Northern Affairs Canada, Health Canada and the First Nations Leadership Council. As a result, data representing about 168,000 First Nations people who lived in British Columbia and were included in either the Status Verification File (SVF) or the British Columbia Medical Services Plan Entitlement File were analysed. The results were presented in the *Provincial Health Officer's Annual Report 2007* (Provincial Health Officer, 2009).

The **Canadian Tuberculosis Reporting System (CTBRS)** is derived from records of provincial/territorial tuberculosis registries which capture information on all new active and re-treatment cases of tuberculosis (TB) and the treatment outcomes for these cases. All provinces/territories voluntarily submit their case and outcome data to CTBRS. National definitions are based on Statistics Canada Census definitions. The standard for the national Case Report Form (Long & Ellis, 2007) is set by the provinces/territories, and defines the data elements that get submitted to CTBRS by the

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provinces/territories, who in turn work with local/regional public health units on specific jurisdictional requirements.

While the rates of TB have been declining and the overall numbers are proportionately low (1,623 cases per year over the past seven years up to 2009), TB is increasingly a disease of high-risk populations such as Aboriginal Canadians. It is therefore important to have a process and infrastructure that allows communities - both Aboriginal and non-Aboriginal - to assess the burden of TB and the outcomes of the TB control program. During the prolonged period of treatment, treating physicians and public health staff educate patients and their family or household members about TB treatment and help reduce barriers to healing by navigating to appropriate socio-cultural supports.

The next six data holdings are held at the Canadian Institute for Health Information (CIHI). They all include Aboriginal identifiers. This data element was aligned with a Health Canada definition in 2002 in collaboration with interRAI. Also, different identity questions in CIHI databases were adopted at different times, and are, in a number of cases, the Canadianized version of international standards set by InterRAI, who develops and owns assessment instruments. Starting in 2012, CIHI is moving towards a harmonization of these questions to reflect a more systematic approach and growing interest across the country in First Nations, Inuit and Métis identifiers. CIHI has dedicated resources for the coordination of the organization's First Nations, Inuit and Métis information strategy.

The **Canadian Organ Replacement Register (CORR)** records, analyzes and reports on the level of activity and outcomes of vital organ transplantation and renal dialysis activities in Canada. CORR collects data from Hospital Dialysis Programs, Regional Transplant Programs, Organ Procurement Organizations and independent Kidney Dialysis Service Facilities via standardized paper forms or spreadsheets. Aboriginal (North American Indian, Métis, Inuit) identity is captured as part of an ethnocultural identity question that has ten options for "race". CORR has captured a race field since inception.

CORR has extensive data quality processes in place, including checks on agreement rates for patient race. Ethnocultural data have resulted in a wide range of analyses, reports and publications, which in turn have pointed to policy implications. For example, research has been conducted that looks at distance and access to treatment based on ethnocultural identifiers; this research demonstrates how distance from a dialysis centre can improve outcomes.

The **Continuing Care Reporting System (CCRS)** contains demographic, clinical, functional and resource utilization information on individuals receiving continuing care services in almost 1,100 hospitals or long-term care homes in seven jurisdictions across Canada. Participating organizations also provide information on facility characteristics to support comparative reporting and benchmarking. The interRAI Resident Assessment Instrument Minimum Data Set (RAI-MDS 2.0) © is used to identify the preferences, needs and strengths of continuing care hospital patients or long-term care home residents and provides a snapshot of their services. The information, gathered electronically at the point of care, provides real-time decision support for front-line care planning and monitoring.

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Aboriginal status is collected as part of RAI-CCRS assessment, and can be used for aggregate analysis of health status, access and outcomes. As of 2012-2013, the RAI-CCRS clinical assessment will require that the clinician ask the client or family whether the client identifies him or herself as a member of an Aboriginal community (Inuit, Métis, or First Nations).

The **Home Care Reporting System (HCRS)** contains demographic, clinical, functional and resource utilization information on clients served by publicly funded home care programs in Canada, from jurisdictions participating in the HCRS. The HCRS captures standardized client-specific clinical, demographic, administrative and resource utilization information within a single reporting framework. Demographic information may be collected as part of a RAI-HC assessment or through other processes, such as referral and admission. The Home Care Reporting System currently captures Aboriginal identity and is planning to move to separate identification for First Nation, Inuit and Métis in 2013.

Together with six First Nations communities in Alberta and the First Nations and Inuit Health Branch at Health Canada, CIHI is engaged in a national pilot to test the implementation of HCRS in First Nations communities. As part of this, all data elements in the assessment instrument were reviewed and accepted as an appropriate standard.

The **National Rehabilitation Reporting System (NRS)** records, analyzes, and reports on the level of activity and outcomes of hospital inpatient rehabilitation from approximately 101 participating facilities in nine provinces in Canada. NRS data include demographic, administrative and clinical client information. Ontario has mandated NRS data for all designated rehab beds since Oct 2002; participation in all other Provinces is voluntary. The Aboriginal status question is a mandatory data element that must be asked upon admission. Aboriginal status was included in 2009-2010 to allow clients entering adult inpatient rehabilitation to self-identify as First Nations, Inuit or Métis.

The **Ontario Mental Health Reporting System (OMHRS)** contains demographic, administrative and clinical information collected on clients admitted to adult mental health beds at 74 participating hospitals in Ontario since October 1, 2005. The data is collected at admission, discharge and every three months for patients with extended stays. OMHRS data is sourced from the Resident Assessment Instrument–Mental Health (RAI-MH) ©, a standardized data collection system for mental health. The RAI-MH© clinical assessment requires that the clinician ask the client or family whether the client identifies him or herself as a member of an Aboriginal community (Inuit, Métis, or North American Indian).

The **Primary Health Care Voluntary Reporting System (PHC VRS)** contains a subset of the data from EMR applications that support Primary Health Care (PHC) delivery, and use the Content Standard (CS) that has been developed by the Canadian Institute for Health Information in collaboration with Canada Health Infoway and jurisdictions. The PHC EMR CS was released in early 2011 as a pan-Canadian standard. Full implementation of the PHC EMR CS is expected to occur over the next two to three years. Once the EMR CS is implemented, CIHI is collaborating with clinicians and

jurisdictions on a subset of that data flow to the PHC Voluntary Reporting System (PHC VRS) to support health system analysis and reporting. Though data is currently collected in the PHC VRS from Ontario, Manitoba and British Columbia, Aboriginal status is not currently available.

To enable the consistent capture of ethnocultural data in Canadian electronic medical records, the Electronic Medical Record - Ethnicity Reference Set (see Section 5.3) has been developed as a value set for the PHC CS, with completion expected by February 2012.

The collection of ethnicity data in PHC EMRs, therefore, requires the implementation of the PHC EMR CS and subsequently, clinician use of the data fields to capture the information. The PHC VRS is being designed as a receiver data holding where the PHC EMR CS is implemented in vendor products and will capture the ethnicity data elements where it is recorded in the PHC EMR. Within the PHC VRS, these would then be included with other information, such as: health concerns, diagnostic imaging, labs, medications, social behaviour (risk factors), referral and intervention, and date of birth. All of these can help identify vulnerable populations and support quality improvement.

5.7   FIRST NATIONS, INUIT AND MÉTIS REGISTRATION PRACTICES
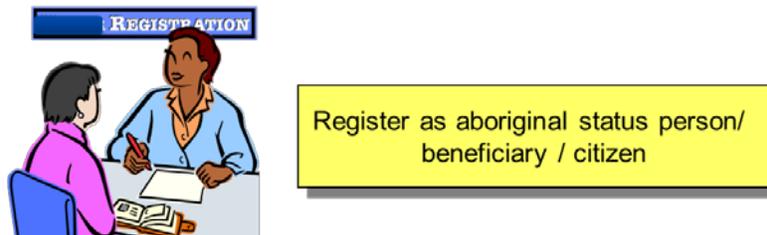
Database Segment	Databases Profiled
First Nations registers	Indian Registry System
	Status Verification System
	Register of Cree, Inuit and Naskapis
Inuit registers	Inuvialuit Regional Corporation Enrolment Registry
	Nunavut Inuit Enrolment List
	Nunavik Inuit Beneficiaries List
	Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement
Métis registers	Métis Nation British Columbia Central Registry
	Métis Nation Saskatchewan Citizenship Registry
	Manitoba Metis Federation Membership Registry

Database Segment	Databases Profiled
Associated linked databases	Métis Nation of Ontario Citizenship Registry
	Ontario Cancer Registry /Indian Register Linkage (1968-2001)
	Registered First Nations & Manitoba Health Insurance Registry Linkage
	Unama'ki Client Registry & Data Linkage Model
	Manitoba Métis Population Database

The following table summarizes the approximate number of First Nations, Inuit and Métis people who are registered on First Nations, Inuit and Métis registers. The Métis registers enumerated are for the five Métis Nation governments from Ontario westward who are represented by the Métis National Council.

Number of people in First Nations, Inuit and Métis Registers [1]	First Nations	Inuit	Métis
Indian Registry System (IRS)	860,000		
Status Verification System [2]	In IRS & Inuit lists		
Register of Cree, Inuit and Naskapis	11,000	In NIBL	
Inuvialuit Regional Corporation Enrolment Registry		3,904	
Nunavut Inuit Enrolment List		23,000	
Nunavik Inuit Beneficiaries List (NIBL)		9,045	
Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement		7,089	
Métis Nation British Columbia Central Registry			5,920
Métis Nation of Alberta Membership Registry [3]			35,000
Métis Nation Saskatchewan Citizenship Registry			1,400
Manitoba Metis Population Database [4]			90,915
Métis Nation Ontario			15,000
Total	860,000	43,038	148,235

Notes:

[1] Numbers represent most recent numbers available as of December 2011 and vary in exact date of measurement; some numbers are approximations provided by registry informants.

[2] Numbers included in Indian Registry System and applicable Inuit Beneficiary Lists.

[3] According to a statement on its website (www.albertametis.com; accessed January 27, 2012), the Métis Nation of Alberta has a membership that exceeds 35,000 people spread across the province.

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⁴ The Manitoba Metis Federation Membership Registry has 42,500 registered members, and is the foundation for the Manitoba Metis Population Database; the latter includes 90,915 individuals identified as Métis from a variety of sources and approximates the entire Métis population as reported based on the 2006 Census.

The **Indian Registry System** is the official record identifying all Registered Indians in Canada. Registered Indians are people who are registered with the federal government as Indians, according to the terms of the Indian Act. Registered Indians are also known as Status Indians. The Register holds around 850,000 active registered Indians as of October 2011, will hold an estimated 860,000 active records by end November 2011, and resides at Aboriginal Affairs and Northern Development Canada (AANDC).

The Indian Register supports the following business functions: 1) Register eligible First Nations individuals as Registered Indians under the Indian Act in the Indian Register; 2) Record life events (e.g., birth, death, marriage, adoption, transfer of band membership, etc.) in the Indian Register; 3) Issue Certificates of Indian Status (Status Cards) to identify persons as eligible for services and benefits that are specifically designed for Registered Indians; and 4) Renew or replace Certificates of Indian Status. The Indian Register has been used for record linkage purposes, several examples of which are discussed at the end of this section.

Besides the name of all Status Indians, the Indian Register also has information such as dates of birth, death, marriage and divorce, as well as records of persons transferring from one band (or First Nation community) to another. This includes Status Indians on reserve and off reserve, in and outside of Canada. The registration of life events and the update of identity information are enabled through authorized secure on-line access to the Indian Registry System by government departments and Indian Registration Administrators (IRAs) in First Nation membership offices. The Indian Register captures 100% of active registered Indians. In addition, it contains records on people who are ancestors of registered Indians, who may be deceased and/or non-Indian. This is because the Indian Registry is an ancestry-based database; historical records may be used by First Nations people to build family trees.

The most significant initiative that is expected to improve the quality and timeliness of the information in the Indian Registry is the roll-out of new secure Indian Status cards over the next five years. This is expected to improve information categories like residency, and major life events, as the card will be renewed every five years. Currently, the Registry contains records that have not been updated since they were first entered, which in some cases may be > 30 years ago. That means that e.g., residency information will often be out of date, due to migration. Other initiatives that can have a positive effect on quality are related to removing barriers to complete and timely information about births. For example, new approaches enabled by the B.C. Tripartite agreement, that involve waiving the cost of birth certificates for First Nations people, and sharing the data directly from source between the B.C. Vital Statistics Agency and the Indian Registry, can result in better, more timely data. It is currently not uncommon that new births take at least one to two years to be registered.

Of note, "Band Membership" and "Indian Status" are two different concepts. Indian Status is determined by a process overseen by the Office of the Indian Registrar. Band Membership is determined by a process overseen by an individual Band or First Nation. For example, a person can be a Status Indian without being a member of a band.

The **Status Verification System (SVS)** is a national database that is used to store, process, track and maintain a record of every person who is eligible to receive Non-Insured Health Benefits (NIHB), a federal insurance program administered by the First Nations and Inuit Health Branch (FNIHB) at Health Canada. The SVS is used within the NIHB Program to confirm eligibility. SVS contains a complete list of registered First Nations and Inuit beneficiaries. The sources of information for the SVS are:

1. Indian Register, AANDC – for the list of registered Indians; this data is provided by AANDC to Health Canada FNIHB through an MOU for use by NIHB.

2. Government of the Northwest Territories - for the land claims beneficiary list from Inuvialuit Regional Corporation;

3. Government of Nunavut - for the land claims beneficiary list from Nunavut Tunngavik Incorporated;

4. Regional FNIHB office in Quebec - for the land claims beneficiary list from Makivik Corporation.

The SVS has a specific purpose in supporting the administration of the NIHB program, and is not used for record linkage or other secondary purposes. This is because the information is collected and already stored by AANDC and the Inuit Land Claims Corporations. It is being included in the inventory because the Status Verification System is frequently confused with the Indian Register.

The **Register of Cree, Inuit and Naskapis** supports the implementation of the James Bay and Northern Québec Agreement (JBNQA). This land claim settlement was approved in 1975 by the Cree and Inuit of northern Québec, and later slightly modified in 1978 by the North-eastern Québec Agreement, through which Québec's Naskapi First Nations joined the treaty. The agreement covered economic development and property issues in northern Québec, as well as establishing a number of cultural, social and governmental institutions for First Nations and Inuit who are members of the communities involved in the treaties. The Register has three components:

1. The Cree Registry: it has personal information about ~10,000 Cree beneficiaries. The data are held by the Ministère de la Santé et des Services Sociaux (MSSS);

2. The Naskapis Registry: it has personal information about ~1,000 Naskapis beneficiaries. The data are held by the Ministère de la Santé et des Services Sociaux (MSSS); and

3. The Nunavik Inuit Beneficiaries Register: it has personal information about ~10,000 Inuit beneficiaries. This register has been officially transferred from MSSS to the Nunavik Enrolment Office, and is described separately later in this section.

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The **Inuvialuit Regional Corporation Enrolment Registry** supports the implementation of the Inuvialuit Final Agreement (IFA), signed in 1984 by the Inuvialuit - Inuit of Canada's Western Arctic and the Government of Canada.   The goals of the IFA are to:

- Preserve Inuvialuit cultural identity and values within a changing northern society;

- Enable Inuvialuit to be equal and meaningful participants in the northern and national economy and society;

- Protect and preserve the Arctic wildlife, environment and biological productivity.

In 2010, there were 3,904 Inuvialuit beneficiaries, around 60% of whom live in the Inuvialuit Settlement Region or Inuvik, and 40% live elsewhere.   The registry is held at Inuvialuit Regional Corporation.

The **Nunavut Inuit Enrolment List** supports the implementation of the Nunavut Land Claims Agreement (NLCA), ratified in 1993 by Tunngavik Federation of Nunavut and the federal government. Nunavut Tunngavik Incorporated (NTI) is responsible for enrolling individuals as beneficiaries of the NLCA. Today, there are approximately 23,000 Inuit beneficiaries in the Nunavut Settlement Area (NSA). The NLCA involves the largest number of beneficiaries and the largest geographic area of any land claim agreement in Canadian history.

Good, Inuit-specific information that can substantiate the positions of NTI and advocate for funds is a priority for the organization. The Inuit Health Survey (see Section 5.8), for example, was an important project that resulted in Inuit-specific community data, and also demonstrated the growing capabilities of NTI in the area of research. As part of the Inuit Health Survey, community members helped to identify Inuit participants for both survey participation and for coming on the research ship to participate in clinical assessments. Over the past five years, it has been a priority to collect more Inuit-specific community data and build research capacity. The beneficiaries list is an important resource for this.

The **Nunavik Inuit Beneficiaries List** supports the implementation of the James Bay and Northern Quebec Agreement (cf. Register of Cree, Inuit and Naskapis). The Nunavik Inuit Beneficiaries Register is composed of the two following lists, maintained and updated in accordance with the decisions of the Community Enrolment Committees and of the Nunavik Enrolment Review Committee:

1. Nunavik Inuit Beneficiaries List; and

2. List of Nunavik Inuit Beneficiaries Living Outside the Territory for Ten (10) or More Continuous Years.

Approximately 10,000 people live in Nunavik, 9,045 of whom are Inuit beneficiaries of the JBNQA.

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The **Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement** supports the implementation of the Labrador Inuit Land Claims Agreement (2005) which established Nunatsiavut as the first of the Inuit regions in Canada to have achieved self-government. Although Nunatsiavut remains part of Newfoundland and Labrador, the government has authority over many central governance areas including health, education, culture and language, justice and community matters. Since 2007, the Nunatsiavut Government prepares and maintains a register that contains the name of each individual who is determined to be a beneficiary of the Agreement. Prior to the LILCA, The Labrador Inuit Association administered applications for the Labrador Inuit. As a result, the Registry includes data going back 26 years, to 1985. As of October 2011, there were 7,089 beneficiaries. 2,568 of these live in the Labrador Lands Claim Area, the balance live in other parts of Labrador and across Canada.

In R. v. Powley (2003), the Supreme Court of Canada provided guidance on the interpretation of Section 35 of the Constitution Act, 1982, in a case where Steve and Roddy Powley, two Métis men from Sault Ste. Marie, argued the right of Métis to hunt for food. Section 35 recognizes and affirms the existing Aboriginal and treaty rights of the Indian, Inuit and Métis peoples of Canada. The court had already established the test for Aboriginal rights in earlier decisions (1990, 1996) but it was not until 2003 that the test for rights was adjusted to fit the distinct origins of Métis people. The criteria used to determine eligibility for inclusion in the provincial Métis registries are based on the four factors determined by the Supreme Court in R. v. Powley:

1. Self-identification

2. Ancestral connection to the historic Métis community

3. Contemporary Métis community acceptance

4. Distinct from other Aboriginal peoples

Below are summaries of four of the five Métis Nation's governments from Ontario westward that are represented by the Métis National Council.

The **Métis Nation British Columbia (MNBC) Central Registry** was introduced in October 2004 and fully implemented in 2005 to compile and maintain a database of Métis citizens in British Columbia. The registry holds 5,920 records, around 10% of self-identifying Metis in B.C. In the fall of 2006, MNBC used the register to conduct their first provincial survey. The survey was distributed to households of existing MNBC members and covered a variety of topics, including demographics, education, health, socio-economic indicators, cultural awareness, Métis governance and veterans' issues. The findings of that survey were presented in the Provincial Health Officer's Report, Pathways to Health and Healing (Provincial Health Officer, 2009). MNBC is currently in the process of collecting consent for the Chronic Disease Surveillance Project, which is expected to yield more analyses and inspire further research and policy initiatives.

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The **Métis Nation - Saskatchewan (MN-S) Citizenship Registry** registers eligible Métis citizens in Saskatchewan. 1,400 MN-S citizens have received citizenship cards since the introduction of the current registry in 2009, and 4,600 applications are currently being processed. 8,600 records have been archived from a previous iteration of the citizenship registry. The Métis Nation - Saskatchewan Citizenship Registry can potentially act as a cohort for linkage studies.

The **Manitoba Metis Federation (MMF) Membership Registry** is a database of Metis citizens in Manitoba. It holds about 42,500 Manitoba Metis who qualified before and after 2008, which is approximately 60% of the size of the self-identifying population as measured by the 2006 Census. The MMF Membership list has served as the foundation for the creation of a full provincial Metis database, the Manitoba Metis Population Database. This database, produced December 31, 2006, includes 90,915 individuals identified as Métis from a variety of sources and approximates the entire Métis population as reported based on the 2006 Census. The Manitoba Métis Population Database is discussed in more detail later in this section, and has been extensively used for collaboration between the MMF-Health and Wellness Department and external researchers.

The **Métis Nation of Ontario (MNO) Citizenship Registry** is the provincial Registry for Métis in Ontario. The database has around 15,000 records going back to 1994. This is about 20% of the self-identifying population in the 2006 Census. Recently, the registry has also served as a basis for collaboration between the MNO and external researchers.   The MNO has collaborated with provincial research institutions and health agencies such as the Institute for Clinical Evaluative Sciences and Cancer Care Ontario to produce chronic disease reports based on linkages between the registry and administrative health databases.

The **Ontario Cancer Registry/Indian Register Linkage (1968-2001)** involved creating a cohort of 141,920 Ontario Registered First Nations from registration files maintained by Aboriginal Affairs and Northern Development Canada. Cancers and deaths were ascertained by linkage to the provincial cancer registry (1968-2001) and mortality file (1968-2005), which also provided general population comparison data. This linkage yielded the first large study of cancer incidence, mortality and survival in First Nations in Canada and overcame many limitations of earlier, smaller studies. Advantages of this study over others include: a relatively large number of cancers in First Nations; a long follow-up time; a large and representative population of First Nations (both on and off reserve) from which both those with cancer were identified and person-years at risk were calculated. Because of these strengths, the authors were able to estimate stable estimates of cancer incidence, mortality and survival rates by site and time for Ontario First Nations and the Ontario general population.

Since this linkage was conducted, similar methodology has been used in other jurisdictions, including Manitoba (see next summary). There are plans to repeat this linkage in Ontario via a partnership between the Chiefs of Ontario, the Institute for Clinical and Evaluative Sciences, Cancer Care Ontario and First Nations Inuit Health (Ontario).

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The **Registered First Nations & Manitoba Health Insurance Registry Linkage** is a linkage between the Indian Register and the Manitoba Health Insurance Registry (MHIR) that created the Manitoba Registered First Nations Database in 1999. This linked file helped overcome problems with large undercounting of the Registered First Nations in the MHIR: prior to linkage, 65,526 individuals were identified Registered First Nations based on the MHIR, while 92,869 Registered First Nations were linked to MHIR in 1999. The 1999 linkage is estimated to have reduced the undercount of Registered Manitoba First Nations individuals from 35% to 5%.

The database was part of a research initiative between the Manitoba Centre for Health Policy (MCHP) and the Assembly of Manitoba Chiefs (AMC) to produce a Manitoba First Nations atlas of health and health services usage. The linkage also involved Aboriginal Affairs and Northern Development Canada, First Nations and Inuit Health Branch and Manitoba Health. The atlas was used to inform health policy, such as health system integration. This linkage project was OCAP compliant. Although the data are housed at MCHP, the AMC and AANDC are the data owners and gave permission for its use.

The linkage enabled First Nations identifiers in the MHIR to be applied to the collection of data holdings at the MCHP collectively known as the "Population Health Research Data Repository", which is a large collection of databases including vital statistics, hospital records, medical claims, home care data and surveys. Individual-level data can be analyzed over time and anonymously across databases without requiring names, addresses or other identifying information through the use of unique encrypted Personal Health Identification Numbers.

The **Unama'ki Client Registry (UCR)** is an anonymous electronic registry of community members from the five Unama'ki (Cape Breton) First Nations, who are responsible for delivering a wide range of community-based health services. Members were identified using Indian Registry System data from AANDC's Indian Registry System and demographic data from EMRs used at the five First Nations' health centres. A provincially recognized identifier, the Nova Scotia Health Card number, was added to the UCR to allow linkage with provincial health data sources. The data linkage model enables First Nations' health information to be pulled from administrative data and clinical registries for the purposes of generating health status reports for the five First Nations. The database has records on 9,888 First Nations community members.

The Unama'ki Client Registry is the first of its kind in Canada. It is a unique registry combining First Nations, federal and provincial government data to allow extraction of administrative data from provincial systems for use by First Nations in their own health planning. This is another practice that is OCAP compliant. Establishing the UCR required partners to work through a myriad of complex inter-jurisdictional privacy, governance and technical issues. The UCR is an important innovation in that it arose from an unprecedented data sharing agreement that involved the five First Nations' Tui'kn Partnership, the provincial and federal government. The Unama'ki Client Registry Data Sharing Agreement confirmed Nova Scotia's unique relationship with the province's First Nations in recognizing First Nations' rights to share information at the level of government-to-government communications, with the associated information privacy rights.

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Capacity building is central to the overall strategy to improve the quality of health planning, management and evaluation, so local staff have been trained in various aspects of data collection, interpretation and reporting. Related to this, research partnerships to help plan the future health care of the Mi'kmaq in Cape Breton are producing reports with, among others, Dalhousie Faculty of Medicine, Dalhousie's Population Health Research Unit and Cancer Care Nova Scotia.

The **Manitoba Métis Population Data-Base (MPDB)** was developed to identify the Métis population in Manitoba with the intention of linking it to administrative health data for the purposes of population studies. The database, produced December 31, 2006, includes individuals identified as Métis from a variety of sources and approximates the Métis population size as reported based on the 2006 Census. The Manitoba Centre for Health Policy houses the MPDB under a data sharing agreement with the Manitoba Metis Federation, thus ensuring that the database remains under full MMF authority i.e., Métis Ownership, Control, Access, and Stewardship (MOCAS).

Métis registries in Canada include fewer individuals than self-identify as Métis on the Census. The MPDB is a unique linkage of multiple data sources that expands upon the registry in order to approximate the size of the self-identifying population. The inclusion of self-identifying Métis from surveys, and parents and offspring of registered and self-identifying Métis is an innovative way to increase the number of identified Métis in a cohort and potentially, to have a sample that is more similar to the entire self-identifying Métis population of a province. An updated database will be created after the 2011 Census.

The creation of the MPDB has led to a number of related initiatives, which include (i) the production of the first comprehensive Metis health report; currently the MPDB is being used primarily by the MMF-Health & Wellness Department to produce reports for its Public Health Agency of Canada-funded chronic diseases surveillance program (2010-2015); (ii) the application of these studies to inform policy and programming within Manitoba's Regional Health Authorities through MMF Knowledge Networks; and (iii) further building of indigenous capacity to meet health needs and combat health disparities.

5.8   SURVEY / CENSUS PRACTICES
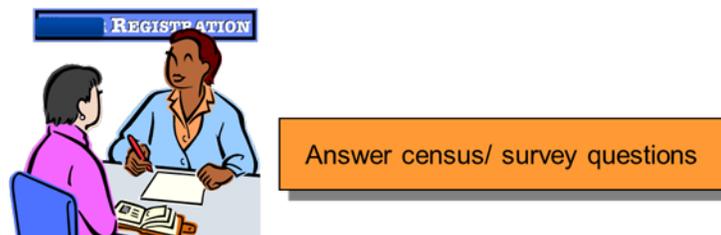
Database Segment	Databases Profiled
Surveys specific to First	Aboriginal Peoples Survey (APS)

Database Segment	Databases Profiled
Nations, Inuit and Métis peoples	First Nations Regional Health Survey (RHS)
	Inuit Health in Transition Survey
	Our Health Counts – Baseline Population Health Database for Urban Aboriginal People in Ontario
	Urban Aboriginal Peoples Study (UAPS)
Surveys that include First Nations, Inuit and Métis	Canadian Community Health Survey (CCHS)
	Census – Long Form
Associated linked databases	1991 Canadian Census Cohort: Mortality, Cancer and Residential Mobility Follow-up Study

The **Aboriginal Peoples Survey (APS)** is a cross-sectional post-censal survey that has been carried out three times, following the collection of the 1991, 2001 and 2006 Census of Population. Over 45,000 First Nation, Inuit and Métis people participated in the 2006 survey. It describes the socio-economic and health status of Aboriginal people who live, as of the 2006 APS, mostly outside First Nations communities. The use of the Census as a sampling frame enables the inclusion of some typically under-represented Aboriginal groups, such as urban Aboriginal people, Non-Status First Nations, off-reserve First Nations, and Métis.

The target population for the 2006 APS is composed of the Aboriginal population in Canada living in private dwellings, six years of age and older as of October 31, 2006. In the provinces, people living in Indian Settlements or on reserve were excluded from the APS however, in the territories, all Aboriginal people were included. The survey yields information that cannot be found anywhere else and can be used to answer a wide range of questions related to, among others, community planning, program development and health care priorities. People who report Aboriginal ancestry and/or identity on the long form Census are eligible to participate. The next APS will be conducted in 2012 with a sample size of 50,000 people.

The **First Nations Regional Health Survey (RHS)** is the only First Nations governed national health survey in Canada. It is longitudinal in nature and collects information for and with the First Nation on-reserve and northern First Nations communities based on both Western and traditional understandings of health and wellbeing. Information covers > 30 topic areas including demographics, language, housing, health status, culture, and community development. The RHS Phase 2 was initiated in 2008 and completed in the fall of 2010. In RHS Phase 2, 21,757 surveys were collected in 216 First Nations communities.

The RHS National Team at the First Nations Information Governance Centre in Ottawa is mandated to report on national level statistics; it cannot provide or report on regional level statistics. Each of the ten RHS Regional Partners is completely independent and responsible for its own database and regional

coordination and reporting. The National Team and Regional Partners collaborate on collective issues as well as share ideas and knowledge. Besides comprehensive community engagement, RHS is about capacity building for First Nations people and communities through their active involvement in the design, administration, analysis and use of the survey.

An independent evaluation was completed by Harvard University's Project on American Indian Economic Development in 2006. The Harvard review team found that the RHS Phase 1 (2002/03) iteration of the survey was technically rigorous, included numerous improvements over the RHS 1997 pilot survey and had many advantages relative to other surveys internationally. The report found that, "Compared to … surveys of Indigenous people from around the world, … RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people … at each stage of the research process" (Harvard Project on American Indian Economic Development, 2006).

The **Inuit Health in Transition Survey (IHTS)**, also referred to as the Inuit Health Survey, refers to a collection of international health surveys of Inuit residing in arctic regions. In Canada, the study includes Inuit residing in Nunavik, Nunavut, the Northwest Territories and Labrador. Investigators aim to repeat the study in future to be able to track changes in the health over time. The IHTS includes Qanuippitaa? which was conducted in Nunavik in 2004 and Qanuqitpit? Qanuippitali? Kanuivit? (How about us? How are we?), conducted in 2007/2008 in the Inuvialuit Settlement Region, Nunavut and Nunatsiavut. The latter is profiled in this study.

Qanuippitali? is a collaboration that includes the Centre for Indigenous Peoples' Nutrition and Environment at McGill University, the Inuvialuit Regional Corporation, the Nunatsiavut government, the Government of Nunavut and Nunavut Tunngavik Incorporated. Participants came from 24 coastal communities in Nunavut, four in the Inuvialuit Settlement Region and five in Nunatsiavut. Households in each community were randomly selected to participate in the Inuit Health Survey. An adult survey was administered to men and women aged 18 and older and a child survey was offered for children aged three to five. Participants in the "Qanuqitpit? Qanuippitali? Kanuivit?" study belong to an international cohort designed to have comparable health data for 12,000 arctic residents.

Our Health Counts - Baseline Population Health Database for Urban Aboriginal People in Ontario holds the data generated from a health assessment survey that was developed and administered to urban Aboriginal people in Hamilton (790 First Nations respondents) and Ottawa (Inuit and Métis) starting in 2009. The First Nations report was released in December 2011. The Inuit and Métis reports have yet to be released.

Study participants were identified through respondent driven sampling, a technique that has been used in other settings to capture members of communities that might be otherwise hard to reach (e.g., the homeless). Following participation in the survey, respondents were asked whether they would provide their Ontario Health Insurance Plan (OHIP) number in order to link their survey responses to health care system usage information available through the Institute for Clinical Evaluative Sciences (ICES).

The opportunity to work with ICES enabled the Our Health Counts research team to produce, for the first time, urban Aboriginal population-based rates of emergency room use, hospital admission and participation in preventative screening programs, including breast, cervical and colorectal cancer screening.

This First Nations Urban Health Database has also resulted in the development of an infrastructure of partnerships, data governance and management of protocols/agreements between four core urban Aboriginal provincial organizations (Ontario Federation of Indian Friendship Centres, the Métis Nation of Ontario, Tungasuvvingat Inuit and Ontario Native Women's Association), with two research institutes and the provincial ministry of health.

The **Urban Aboriginal Peoples Study (UAPS)** is a large, national study of First Nations, Métis and Inuit living in eleven urban centres across Canada that seeks to better understand and document the experiences, aspirations, values and identities of Aboriginal people living in Canadian cities. It is accompanied by a survey of the general public's attitudes toward Aboriginal peoples and issues. The study was conducted in 2009 with the aim not to replicate past survey work, but rather explore new areas of inquiry concerning the factors currently leading Aboriginal peoples toward success, autonomy, cultural confidence and spiritual meaning.

UAPS is unique in having developed and implemented a methodology to finding and interviewing a large, representative sample of 2,614 urban First Nations, Inuit and Métis people in 11 cities across the country and reporting on these interviews. Some of the distinguishing features are:

- To overcome a lack of sampling frame for the urban Aboriginal population, investigators used 'snowball' or 'network-based' sampling, a technique typically used to capture hard to reach populations. Quotas were established for age, gender, education and identity groups in each city, based on estimated distribution in the city, and filled using this response-driven sampling methodology;

- Training >100 interviewers, mostly Aboriginal, to capture responses via one to two hour in-person interviews; an Aboriginal-owned and operated firm oversaw the coding process;

- The development of city-specific reports and a video archive, in addition to the data tables;

- The engagement of Aboriginal guides and experts at every stage, including an Advisory Circle; and

- The ability to compare and contrast some of the findings with findings from the survey of the general public.

The resulting cohort has also been used to better understand the factors associated with health among Aboriginal people living in urban settings. Previous research focuses largely on "risk factors" among individuals, families and environment, while the UAPS data permit investigation of "protective factors" at the individual and environment levels (e.g., self-esteem, sense of identity, sense of community). A multivariate regression ("driver") analysis was conducted to determine the relative importance of

these protective factors to urban Aboriginal peoples' self-perceived health. The model was revisited by identity group, age and gender to determine if the same factors are equally at play for these population segments (Roberton, 2011).

The findings suggest that policies designed to improve the health of urban Aboriginal peoples need to consider a broader group of factors. Much of the previously existing research has focused on determinants at the individual level, including socioeconomic status and health behaviours (e.g., smoking, physical exercise, access to health care), and has found that they explain some but not all of the inequality in Aboriginal peoples' health status. Both the UAPS and other research suggests that both community factors (e.g., social networks, close relationships, experience with the health care system, and security) and broader societal factors (e.g., social inclusion or acceptance) play a role in determining Aboriginal peoples' health.

One of the most intriguing and promising findings of the available research is the importance of Aboriginal identity and cultural continuity to Aboriginal health. While the evidence is not yet sufficiently conclusive for formulating health policy and programs, it helps reveal some of the more complex, layered factors that determine urban Aboriginal peoples' health and the limitations of an exclusive focus on traditional risk factors. As such they may inform deeper investigation - reflecting First Nations, Métis and Inuit perspectives - of concepts of Aboriginal identity and cultural continuity, how their development may be supported, and how this informs policy and programs.

The **Canadian Community Health Survey (CCHS)** is a cross-sectional survey that collects information related to health status, health care utilization and health determinants for the Canadian population . Prior to 2007, data collection occurred every two years on an annual period. Data collection now occurs every year. CCHS relies upon a very large sample of 65,000 respondents across Canada, including 3,200 respondents with Aboriginal identity, and is designed to provide reliable estimates for the general population at the national, provincial and intra-provincial levels. The target population of the CCHS is all Canadians aged 12 and over. Excluded from the sampling frame are individuals living on Indian Reserves and on Crown Lands, institutional residents, full-time members of the Canadian Forces, and residents of certain remote regions. The database includes information on First Nations, Inuit and Métis people on the basis of ancestry as well as self-identification. Unlike Aboriginal-specific surveys, it allows for uniform collection of data across Aboriginal and non-Aboriginal populations and accordingly, provides a metric by which Aboriginal groups can consider their own health status. Furthermore, the population-wide nature of this survey results in the inclusion of some typically under-represented groups, such as urban Aboriginals, off-reserve First Nations, and Métis. The repetition of the survey enables the examination of trends over time. The survey is one component of the Longitudinal Health Administrative Data Initiative. It has also been used in the Manitoba Metis Population Database to help identify more Metis people.

The **Census - Long Form (2006)** is a key source of detailed data for ethnocultural groups. Prior to 2011, the ethnocultural and Aboriginal identity questions appeared on the long form of the Census. In general, 20% of households were asked to complete the Census long form and 80% of households were to complete the Census short form. In the Yukon, the Northwest Territories (with the exception of

Whitehorse and Yellowknife), Nunavut, and Indian reserves, Indian settlements, Indian government districts and 'terres réservées', however, the Census long form was administered to every household. The short form Census contained eight questions on basic topics such as relationship to other household members, age, sex, marital status, and mother tongue. The long form Census contained the eight questions from the short form plus 53 additional questions on topics such as Aboriginal identification, education, ethnicity, mobility, income, employment and dwelling characteristics. In 2011, the long form Census was replaced by the voluntary National Household Survey (NHS).

An ethnic origin question has been asked in the Census since 1871. However, the question has undergone several changes over the years. The areas that underwent changes involved the criteria used to determine ethnic origin or ancestry, the terminology used to designate Aboriginal peoples, as well as changes to the question itself, and to the way the data have been collected. Prior to 1951, Aboriginal people in Canada were defined by their tribal descent or their matrilineal descent (from the mother's side). This changed between 1951 and 1971 when Aboriginal people were defined by their patrilineal descent (from the father's side). From 1981 to the present, Aboriginal ancestry has been defined by descent from both the mother's and the father's side. In addition, since then, the ethnic origin question has allowed for the reporting of single and multiple responses. Prior to 1981, only single responses were permitted. Also, starting in 1996, questions on Aboriginal identity, Registered or Treaty Indian status, and Membership in an Indian Band or First Nation have been used to derive the concept of Aboriginal Identity, which is used in most Census products.

Because of its long history of use, testing and extensive First Nations, Inuit and Métis engagement across Canada, the Census Aboriginal identification questions have been the subject of intensive study and review. While the questions have evolved over time, at any point they are a compromise between a number of sometimes competing considerations. Examples are comparability over time and capturing a tremendous amount of diversity in how the people captured under a particular definition may view themselves to be different from others in the same group. Nevertheless, the Census represents the largest statistical holding of Canadians who have chosen to identify as First Nations, Inuit and/or Métis, including indicators such as ancestry, status, residency and geographic information, as well as First Nation affiliation. It also represents 140 years of experience with key factors that affect response rate and the production of valid and usable information. These include question design, data collection modes (e.g., by mail, personal interview or online) and factors that affect interviewer and respondent behaviour (e.g., the use of interpreters, form translation into 18 Aboriginal languages).

For this reason, the Census approach to and taxonomy for Aboriginal identification, which itself attempts to be a reflection of Aboriginal and Canadian views on ethnocultural identity, has influenced the development and design of all subsequent identification projects in some way. The personal data in the Census is protected by the Privacy Act and by the Statistics Act, and therefore cannot be linked to health records. However, the Census is one of the data holdings in the Longitudinal Health Administrative Data Initiative, and therefore can be linked to provincial/territorial health administrative databases and cancer registries for the purpose health policy research. An example of a linkage with national data sets is provided in the Census cohort described below.

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The **1991 Canadian Census Cohort: Mortality, Cancer and Residential Mobility Follow-up Study** involves a recently updated linkage of four national databases. The source files include the 1991 Census of the Population (long form), Canadian Mortality Database (CMDB), the Canadian Cancer Database (CCDB) and annual tax summary files (TSF) (non-financial data). The varying methods used to identify First Nations, Inuit and Métis within Canada have typically limited research to provincial/territorial or regional boundaries and have made it challenging to distinguish real differences across the country from those that may have arisen as a result of different methods employed. These regional analyses are often limited by a lack of sufficient power to identify important temporal and site-specific patterns of disease.

This linkage provides an opportunity to consider the health of First Nations, Inuit and Métis across the country, with the same methodology used to identify individuals and health outcomes as in the general population. This database also benefits from the use of the Census as its source file for First Nations and Métis identifiers, which is not limited to Status, on-reserve or registered individuals. The database holds records on 2.7 million Canadians, incl. 11,800 Métis and 56,700 Registered Indians. By using a large, validated sample with long term consistent data collection (Census) and linking it to the Canadian Cancer Database and the Canadian Mortality Database, it is possible to cost-effectively assess the patterns in mortality and cancer on ethnocultural populations that are not otherwise captured in these databases.

5.9   HEALTH INSURANCE REGISTRATION PRACTICES

Register for P/T/F health insurance

Database Segment	Databases Profiled
Health Insurance Plans – Client Registries	Northwest Territories Health Care Plan Client Registry
	Nunavut Health Care Plan Client Registry

The **Northwest Territories Health Care Plan Client Registry** holds records on all eligible Northwest Territories (NWT) residents who register for access to medically necessary hospital and physician services. The NWT also provides a supplementary health benefits program specifically for indigenous Métis residents. Each NWT resident enrolled with the NWT Health Care Plan is given a Health Care Card with a personal health number. This number remains the same, regardless of any changes to

personal status. The HCN starts with an alpha character whereby N=Non-Aboriginal, M=Métis, D=Dene, and T=Inuit.

The alpha character is used by a wide variety of health service providers (clinicians and administrators), as well as policy makers and researchers as a starting point to help clients navigate to the most appropriate services for their needs, as well as monitor population health status and outcomes. Health card numbers are also used within the territory as a key to record linkage across different data sets - within strict parameters for data security, confidentiality and privacy. This ensures that NWT is a jurisdiction that is, and can be, very responsive to the unique needs of First Nations, Inuit and Métis peoples.

The **Nunavut Health Care Plan Client Registry** holds records on all Nunavut Health Care Plan (NHCP) enrollees. Every person enrolled in the NHCP is given a Health Care Card (HCC) with their own unique nine digit number. The last digit of the Nunavut Health Card number indicates the health benefit entitlement of its holder as follows: 5 = Recognized Inuit, 3 = Status First Nation, 7 = all others except Métis, 4 = Métis, and 6 = Non-registered Métis. Unlike the NWT, there is no Métis health benefits program in Nunavut, nor a Métis organization to administer it. The 4-digit, however, does allow Métis people who provide a Métis registration card, or write in their self-identified status to be recognized as such. The last digit on Nunavut's HCC is used for the same purposes as the alpha character in the NWT. Record linkage examples are the Nunavut Cancer Registry and Nutaqqavut 'Our Children' Health Information System.

5.10 DISCUSSION OF DATABASE AND ENABLING PRACTICES THAT SUPPORT ETHNOCULTURAL DATABASE DEVELOPMENT AND USE

The eight enabling practices and forty two database practices in this study demonstrate that, under the right conditions, health data holdings can be augmented with First Nations, Inuit and Métis identifiers. The majority of ethnocultural identification practices described are part of ongoing data collection processes and have been used for a range of analyses, indicating sustained commitment by the parties involved. Broad-based interest in ethnocultural identification is also indicated by the breadth of practices across health domains and jurisdictions, and significant associated resource investment.

Practices involve strong subject matter expertise in areas ranging from community engagement and cultural safety to response management and database linkage. First Nations, Inuit and Métis people have been extensively involved in the majority of practices. They have shaped the purpose and approach to collecting and using identifiers, as well as taken on roles in the areas of data collection, custody and access, analysis and use for policy and program changes.

As a result, there is considerable capacity at the local, provincial/territorial and national level to manage ethnocultural identification projects. Examples include staff at the provincial Métis nations, Inuit land claims organizations, provincial/territorial First Nations organizations, Aboriginal cancer programs within cancer agencies, First Nations Information Governance Centre, First Nations Statistical Institute, Inuit Qaujisarvingat, Ts'ewulhtun Health and Tui'kn Partnership, among others.

In addition, expert, and often dedicated, resources for collecting, storing and analyzing identifier-enhanced data exists, among others, at provincial/territorial health information centres with large data repositories, population registries and their research programs, First Nations Inuit Health Branch and its regional offices, Public Health Agency of Canada, Aboriginal Affairs and Northern Development Canada, Canada Health Infoway, Canadian Institute for Health Information and Statistics Canada.

So while it is common for individual organizations to be concerned about their resource base for projects involving ethnocultural identifiers, there is considerable collective capacity, in terms of experience and expertise. The collective experience with so many projects also offers insight into common barriers to enhancing data sets with First Nations, Inuit and Métis identifiers, and hence what some of the "right conditions" or enablers are.

5.10.1   Barriers to Developing and Using Ethnocultural Identifiers

The number one barrier is the significant time and investment it takes to bring ethnocultural identification projects to a successful conclusion. However, even before time and money become a potential issue, will and relationships can be key stumbling blocks.

Will is defined here as the resolve to overcome a status quo, e.g., a lack of ethnocultural identifiers in health databases. "Will" assumes three conditions: awareness, acuity, and action-ability (see also Charney, 2009).

1. **Awareness** – In order to productively engage in identifier projects, people have to be aware of health databases, the type of information they hold, and how such information can be used to support better health; they also need to be aware that First Nations, Inuit and Métis peoples may face unique health challenges, and that ethnocultural identifiers could help formulate better responses to these challenges. Not all people who are needed to successfully implement ethnocultural identification projects are necessarily familiar with these things. For example,

   − The Newfoundland and Labrador Aboriginal Administrative Data Identifier project found that "the health database world is not familiar to the majority of participants. Our experience suggests that upfront time invested in creating a baseline understanding re what health databases exist, where they reside, what they contain, who uses the data for what purpose, etc., is time well spent." "Beyond the immediate goal of creating a consensus around a new data standard, the work in and around the Work Group is raising awareness of the potential of the data and its uses."

   − The Better Outcomes Registry & Network suggested that "it would be helpful if your group could work with us and others to help hospitals and health care providers understand that it is not discriminatory to ask about a person's Aboriginal background."

Beyond barriers in awareness of health databases and the potential of data and its uses, our interviews indicate that awareness of other ethnocultural identification projects was typically limited to projects within one province/territory or within a particular health domain. As a result, we found only a few examples where project leaders had accelerated the implementation of their initiative by tapping into resources and learning outside their jurisdiction or domain. Common barriers to tapping into other experiences are 1) lack of time, e.g., to search for other experiences, 2) lack of trusted information relationships, e.g., to understand the complete picture including problems encountered during a project, and 3) doubt whether or how experience in a different context translates to one's own situation.   Similarly, national database custodians often lack time to stay abreast of provincial/territorial developments.

2. **Acuity** – another word for this is intensity, i.e., people may have some awareness of an issue, but they may not feel very strongly about it. Population health researchers, administrators and policy makers understand complex relationships between ethnocultural identity and health access/outcomes, as they devote part of their working life to the study and management of these issues. But the same may not be true for many of the other two million people employed in health care or the general patient population.   For example,

   – The Tri-Hospital Health Equity Data Collection project views "negative association/misunderstanding among patients and service providers about the need to collect demographic data" as a key challenge.

   – The Urban Aboriginal Peoples Study has identified "a basic tension in the minds of Non-Aboriginal urban Canadians about where Aboriginal people fit into the Canadian mosaic. They clearly feel Aboriginal people possess unique cultural identities that other Canadians can learn and benefit from. But [they] are divided over whether Aboriginal people should hold unique rights and privileges or whether they should be seen as no different than other cultural or ethnic groups in Canadian society."

   – Nutaqqavut 'Our Children' Health Information System made "a clear description of the real health gap in early child health outcomes a key focus for building broad support among public health medical officers, local clinicians, nurses, midwives, community health representatives as well as lay Inuit stakeholders."   This in turn was critical to project participation as well as multi-level funding.

3. **Action-ability** – even if people are aware of an issue and feel strongly about it, they may not be in a position or have the power to take action. For example,

   – The Newfoundland and Labrador Aboriginal Administrative Data Identifier project recognizes that "adding Aboriginal identifiers to key data holdings requires a provincial initiative, not just a regional approach."

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– The Aboriginal Identity Indicator in Cancer Patients Protocol notes "the overarching importance of a strong project governance and accountability structure" as a key condition for action.

– The Unama'ki Client Registry & Data Linkage Model experience shows that "having champions with the right connections is key …. Political will is essential."

Relationships can be a barrier - if they are lacking - or an enabler if they help groups understand participants' true needs and priorities, what value the project represents to them, and what different participants can contribute. For example,

▪ Ktunaxa Nation Council and Interior Health senior executives have invested time in deeply understanding each other's health plans and long terms strategies to support the mutual commitments to the Aboriginal Self Identification Project.

▪ Canadian Chronic Disease Surveillance System experience indicates that "relationship building, role definition, setting common priorities, and capacity building go hand in hand in re-applying the approach to other First Nations, Inuit and Métis communities. This, in turn, requires close work between community representatives, provincial and national governance and health care contributors."

▪ The Newfoundland and Labrador Aboriginal Administrative Data Identifier project notes key success factors such as "creating the right process and structure for provincial participation and collaboration … getting many key participants around the table … previous working relationships … Aboriginal community participation … and government support."

Affordability and time are affected by the investment it takes to build relationships and will. Affordability also reflects the extent to which participants perceive the value of a project, the availability of less perfect – but more affordable – alternatives, and database sustainability. For example,

▪ Primary Health Care Voluntary Reporting System expects the need for "a fair bit of education/clinician training to improve data capture of priority elements."

▪ Statistics Canada regards the relatively larger burden on interviewers and respondents associated with the five questions used to identify First Nation, Inuit and Métis people on the Census and APS as a barrier to reapplication to other data sets versus choosing potentially simpler questions.

▪ Unama'ki Client Registry notes the importance of "access to skills and infrastructure support for the project, including transfer of skills to First Nations members" and advises others to "map out a realistic time … then double it."

▪ All provincial Métis organizations commented on the time consuming nature of the citizen application process, both for the applicant and the registry office, as a barrier to applying for citizenship, as well as processing application backlogs.

▪ Mustimuhw cEMR recognizes that upfront resource investments in hardware, IT support and training must be justified by longer term efficiencies.

- Tri-Hospital Health Equity Data Collection Project is concerned about "the lack of IT interoperability of patient records, resulting in potential duplication of effort in terms of collecting and recording socio-demographic data."

- Manitoba Métis Population Database created significant "cost efficiencies through the amalgamation of several pre-existing data sources since ethno-cultural identifiers have already been assigned to individuals and no new data regarding Métis identification was required." Still, the custodian expressed concern about "lack of sufficient financial resources to update and maintain the list."

Several informants commented on how they manage cost and time pressures:

- Interior Health's Aboriginal Self Identification Project "builds in time, resources and tools for communication, outreach and training."

- Registered First Nations & Manitoba Health Insurance Registry Linkage notes that "the use of pre-existing data greatly reduces the human and financial resources associated with implementing a new ethnocultural identification system."

- Unama'ki Client Registry deals with a desire to overcome the limitations of small data sets and understand broader determinants of health by considering "the potential to link the UCR with other non-health administrative databases in order to get a more complete picture of population health."

- Newfoundland and Labrador Aboriginal Administrative Data Standard points out that "there is no need to reinvent the wheel: taking someone else's work, e.g., the questions used in Statistics Canada surveys, and the Aboriginal Administrative Data Standard developed in B.C., were obvious starting points." The project team is also planning for the potential of comparing to other provinces' data and notes that "most of the NL Aboriginal groups will easily map to a national First Nations, Inuit and Métis taxonomy."

- Nutaqqavut 'Our Children' Health Information System optimized scarce resources by "adopting standards validated elsewhere (Canada and international, leveraging established best practices, and allowing for cross-jurisdictional comparisons) where it can, yet has been sensitive to adapt to local information needs where necessary."

5.10.2 Options to Enhance Databases with Ethnocultural Identifiers

If the foregoing describes key barriers to augmenting health databases with ethnocultural identifiers, then the right conditions - or enablers – for overcoming these barriers are to 1) look for will, i.e., groups with the desire and power to act, 2) build relationships and networks around participants' needs and priorities, and 3) invest in project opportunities based on their potential to be more affordable, timely and sustainable than alternative approaches.

The following are some enablers that have proven their value in one or more of the profiled practices, and therefore may offer a starting point for reapplication elsewhere.

1. **Options to build on the existing desire and power to move towards ethnocultural identifiers in health data sets**

Knowledge Exchange

Informants commented on the need for outreach, awareness creation, dialogue, assistance with project management and standard development, and proven tools for frontline education and communication. Some groups had done research into practices elsewhere, but most felt there is not enough time in the day to stay abreast of potentially useful developments, especially outside of their own province/territory.

There is a keen interest in seeing the results of the Partnership's work in this area. Given the amount of development and testing that is currently underway, there may also be an opportunity to provide regular updates that highlight new learning and the availability of proven tools that can reduce development effort for other groups. For example, Intercultural Competency Training modules developed for B.C. have already been adapted to a number of other jurisdictions.

Tripartite and Bipartite Political Processes

The collection and use of ethnocultural identifiers in health data sets serves two purposes: it addresses Aboriginal health-related information needs, and it also addresses commitments made as part of a larger, often political, agenda. This agenda may be about equity, diversity, access to quality care, or capacity building and health human resources.

Health information policy, while it involves health information specialists and researchers, is set in a wider governance context which in turn affects and is affected by societal values and priorities. Practices like political negotiations and cultural competency training can help shape changes to non-Aboriginal perceptions about Aboriginal history, culture and rights in order to change future roles and relationships in areas such as information policy and information management. It is not obvious that the development and use of health databases with Aboriginal identifiers can be sustained long term without the participation and agreement of both Aboriginal and non-Aboriginal governance representatives, especially at the provincial/territorial level, as most health data sets exist at that level.

Therefore, the tripartite and bipartite political processes that have evolved in B.C. offer learning to other jurisdictions who perceive an opportunity for developing better Aboriginal health information on a platform of political will. That does not mean that every ethnocultural identifier project has to follow the specific path being followed in B.C. However, each jurisdiction has to plan how First Nations, Inuit, and Métis governance and provincial governments can enable these projects. The Unama'ki Client Registry showed another successful approach that brought the Mi'kmaq Chiefs from Cape Breton together with the Ministers of Health from Nova Scotia and the Federal Government on a common agenda that involves sharing of health information.

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2. **Options to help develop productive relationships and networks**

Building a community of ethnocultural identification experts & broadening the user base

Canada has significant breadth and depth of experience and expertise in ethnocultural identification, which in this country is virtually synonymous with First Nations, Inuit and Métis identification. However, pockets of excellence are often focused on provincial/territorial priorities or specific disease/health sector domains. And national and provincial/territorial project streams do not always connect. Also, the potential scope of system changes and associated investments may go beyond cancer control. There may therefore be an opportunity to create a forum for people/organizations to pursue common objectives. The people and organizations who informed this environmental scan may be a starting point. Besides participants from cancer control, they include primary care, home & community care, chronic disease, infant & maternal health, hospitals and public health as well as national resources at CIHI, Health Canada and Statistics Canada.

3. **Options to improve the affordability and timeliness of identifier-enhanced databases**

Creation of a national framework and guidelines for First Nations, Inuit and Métis identification in health data

The five initiatives grouped together under "identification standards" in section 5.3 all aim to support collection of good quality, comparable Aboriginal identifiers by providing guidelines for defining standard identifiers, as well as how to go about collecting the information.

The authors of the profiled identifier standards all reference the extensive development, consultation and testing by Statistics Canada for the Census and Aboriginal Peoples Survey to optimize the quality of First Nations, Inuit and Métis identification. As one author points out, "one must recognize that there is no set of Aboriginal identity questions that is supported by all leaders in the Aboriginal communities, and that some indigenous people feel that the term "*Aboriginal*" is a government artifact and not meaningful." (Marrett, 2011) Nonetheless, Statistics Canada's explorations of concepts of ancestry and identity, and methods for asking ethnocultural questions have been de facto benchmarks.

The five initiatives profiled have benefitted from extensive engagement with First Nations, Inuit and Métis communities from across Canada and all apply virtually the same approach to Aboriginal identification. They allow respondents to first differentiate between First Nations, Inuit and Métis identity, and then provide for the recognition of those who are registered/status/beneficiaries of treaties and those who are not, as well as of First Nation individuals whose permanent address is on a reserve and those who live off-reserve. The Newfoundland and Labrador and Mustimuhw standards also specify a person's affiliation with a specific community and, in the case of First Nations, band ID.

The five identification standards are not theoretical but have been validated in practice. Almost all databases profiled in this report, including those governed by First Nations, Inuit or Métis data owners, use the same identifiers and taxonomy. Only one data custodian collects "Aboriginal" as its only

identifier, and this custodian is already working with stakeholders to transition to separate "First Nation", "Inuit" and "Métis" identifiers.

All profiled practices recognize that self-identification is the only acceptable method for supporting individuals in their expression of ethnocultural affiliation, and that self-identification always has to be voluntary. We have not come across any federal or provincial/territorial legislation that discourages organizations with a legitimate purpose from collecting the information. For example, the Ontario Human Rights Commissioner has publicly stated that collecting human rights-based data is good for health care organizations, the patients they work for and the communities they serve – and that it is supported by Canada's human rights legislative framework. The Human Rights Commissioner concludes "yes, it is okay to collect this kind of data" (Hall, 2011).

We therefore conclude that Canada has a de facto, albeit informal, standard for First Nation, Inuit and Métis identification data elements and the associated questions. This de facto standard could be at the core of a national guideline for First Nations, Inuit and Métis identification in health data sets. A national framework for Aboriginal identification in health data sets does not exist today, and could be of considerable value according to key informants. Benefits would include saving development time and providing guidance on how to create locally meaningful identifiers that can also be linked to provincial and national data holdings.

Many informants who contributed to the fifty practice profiles, including the creators of the five identification standards, would have the expertise and experience to help the Partnership create a first version of a national framework and guidelines.

Specification of a First Nations, Inuit and Métis identifier standard for EMR/EHR use

The Electronic Medical Record (EMR) systems at the Unama'ki Client Registry and fifty First Nations/sites in British Columbia, Manitoba and Saskatchewan are examples of local information holdings that can serve highly customized community needs while honouring the principles of OCAP and similar Inuit and Métis data ownership protocols. To ensure that local EMR systems can also interface with larger systems, such as provincial data holdings, both the local and provincial systems must be compatible (interoperable) in how they collect and record ethnocultural identifiers.

This is why Canada Health Infoway and the Canadian Institute for Health Information have specified a Primary Health Care Content Standard including an Ethnicity Reference Set for EMRs. These are minimum specifications. In fact, the Unama'ki and Mustimuhw systems already have the capability for more detailed identifier collection and recording.

A national framework and guidelines for First Nations, Inuit and Métis identification in health data could help ensure that vendors of EMR/EHR systems also incorporate design standards and specifications that can meet communities' needs for local as well as provincial/national data.

5.11   RECOMMENDATIONS AND NEXT STEPS

We recommend that the Partnership focus its efforts on setting the right conditions for overcoming potential barriers regarding will, relationships and affordability by building on the full spectrum of ethnocultural identification practices that have been developed and successfully used to-date. Specifically, the Partnership could work towards

1. **Systematic knowledge exchange** of the insights, tools and resources developed by the participants in the forty two database practices and eight enabling practices profiled. This can be a starting point for ongoing updates and the identification and dissemination of other practices that support ethnocultural identification.

2. A recognition that the more technical work associated with ethnocultural identification (e.g., a national framework and data standard) needs to be grounded in the **commitment of national, and especially provincial/territorial governance organizations** – First Nations, Inuit, Métis and P/T governments. To get awareness, understanding and commitment, the Partnership needs to get the topic of more and better Aboriginal health information on the agenda of these governance groups. The adoption of a cross-jurisdictional framework and standard for Aboriginal identification can then be positioned as a practical and necessary first step.

3. A **community of ethnocultural identification experts** who already support provincial/territorial and national projects and can help the Partnership more quickly transfer new and emerging insights and tools across jurisdictions.   **Broadening the user base** would support gaining commitment of governments as well as ensure that a national framework is relevant to a broader range of data custodians and users. This would also spread the resources required across a broader range of funding opportunities.

4. A **national framework and guidelines** for First Nations, Inuit and Métis identification in health databases that can also be specified for the opportunity presented by increasing EMR/EHR adoption.

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6.0 CANADIAN CANCER DATABASES

In Chapter 6.0 we summarize how provincial/territorial cancer registries collect data, referencing the recent work of the Colorectal Cancer Network (CRCNet). We then analyze the implications of using the six types of registration/response practices described in Chapter 5.0 as sources of ethnocultural identifiers for cancer registries.

Cancer registries are the main source of information to assess and manage the burden of cancer in a defined population, and the main focus of this chapter. However, cancer screening registries play an increasingly important role in cancer control in a number of jurisdictions, and will also be referenced.

6.1 CANADIAN CANCER REGISTRIES AND THEIR DATA SOURCES FOR REGISTERING NEW CANCER CASES

In order to review how the ethnocultural identification practices identified in the previous section might apply to cancer registries, we first need to confirm how Canadian cancer registries collect data. For this, the following section is much indebted to the work of the Colorectal Cancer Network (CRCNet), one of the registry-based, multi-provincial networks the Canadian Partnership Against Cancer established as part of its Surveillance and Epidemiology Networks initiative. In 2009/2010, CRCNet conducted a comprehensive assessment of provincial cancer registry comparability, i.e., the extent to which registry practices such as coding and classification, data sources, and registration criteria adhere to agreed-upon guidelines (CRCNet, 2010).

For the purposes of our study, two attributes of Canadian cancer registries are important, and have implications for the opportunities and limitations for applying practices for ethnocultural identification that have proven their value in other contexts:

1. All Canadian cancer registries are multi-source databases; and

2. Not all Canadian cancer registries use the same types of sources, in the same way.

This is because the registration of new cancer cases falls under provincial jurisdiction in Canada, and each provincial cancer registry has its own practices for registering and following incident cancer cases and documenting cancer-related mortality.

The implication of the first attribute is that the addition of ethnocultural identifiers to Canada's provincial/territorial cancer registries requires either their inclusion in an existing data source, or the addition of a new data source. The implication of the second attribute is that an objective of cross-jurisdictional comparability of ethnocultural identifiers has to take into account feasibility issues that are associated with different data sources and collection approaches that exist today.

Canadian Cancer Registry

A mechanism exists at the national level to retrieve and organize provincial/territorial cancer data: The Canadian Cancer Registry (CCR), which receives data from provincial/territorial administrative files in a standard format. The function of the Canadian Cancer Registry is to enable estimation of cancer burden (e.g., incidence, survival, etc.) nationally and to permit comparisons among the provinces/territories. The CCR is a patient-based system that records the kind and number (incidence) of primary cancers diagnosed for each person. Each year, approximately 145,000 new cancer cases are added to the Canadian Cancer Registry (CCR) database which is housed and maintained at Statistics Canada. The CCR employs specialized record linkage software to detect duplicate records (e.g., when the same cancer diagnosis is recorded in more than one P/T registry) and to identify deaths among those with cancer. The reportable demographic data items currently include name, sex, date of birth/death and residency information. Ultimate authority and responsibility for the degree of coverage and the quality of data reside with the provinces and territories. Asking the provinces/territories to add ethnocultural information to their reportable data items would require their agreement on the desirability of collecting this information as well as a data standard. At the same time, the existence of a national data holding at Statistics Canada offers the opportunity to link data at the national level, as has been done in the 1991 Canadian Census Cohort: Mortality, Cancer and Residential Mobility Follow-up Study (Profile 5.7.3).

Provincial/Territorial Data Sources for Cancer Registries

Provincial and territorial cancer registries record cases of cancer in their respective populations by combining information from some or all of the following types of sources:

1. Pathology and cytology reports, including other laboratory/autopsy reports;

2. Cancer centre reports, i.e., reports from specialized cancer treatment centres;

3. Physician reports;

4. Hospital records, i.e., records from in-patient hospitals and out-patient clinics;

5. Death certificates/listings, i.e., reports on cancer deaths from Vital Statistics registrars;

6. Reciprocal notifications, i.e., case information exchanged between provinces/territories via Statistics Canada;

7. National death clearance, i.e., a process to furnish the official date and cause of death by linking patient records to death registrations at the national (Canadian Cancer Registry) level; and

8. Linkage, i.e., ongoing linkage with ethnocultural identifier files, e.g., in a provincial health insurance client registry with ethnocultural identifiers.

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Reciprocal notifications and national death clearance are not viable options for the collection of ethnocultural identifiers, because the information can only be exchanged at the national level if it exists in a complete and shareable form at the provincial/territorial level. The breadth of the remaining data sources for provincial/territorial cancer agencies, as well as the cross-jurisdictional variation in these sources is illustrated in the following table.

Data Sources for Registering New Cancer Cases by Province / Territory

Province/ Territory	Path./ Cytology Reports	Cancer Centre Reports	Physician Reports	Hospital Records	Death Certificates / Listings	Ongoing Linkage
BC	●	●			●	
AB	●		●		●	
SK	●		●		●	
MB	●		●	●	●	
ON	●	●		●	●	
QC				●	●	
NB	●	●		●	●	
NS	●	●	●		●	
PE	●	●		●	●	
NL	●	●			●	
NT	●		●	●	●	●
NU	●		●			●

Sources: For the ten provinces, the Registry Comparability Report (CRCNet, 2010).
For Northwest Territories and Nunavut, cancer registry profiles in *Inventory of Profiles*.
Data for Yukon not available at time of publication.

Pathology/cytology reports are not a primary source of demographic information, which typically comes from the requesting physician or hospital charts; hence they also are not a viable option. The following are therefore potential sources of ethnocultural identifiers in cancer registries:

1.   Provincial/territorial death certificates from Vital Statistics registries;

2.   Cancer centre reports;   For cancer centre reports & hospital records:

3.   Physician reports;   a. from hospital patient registration records; or

4.   Hospital records   b. from clinician medical records;

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5.   Linkage with non-cancer files

   ▪   First Nations, Inuit and Métis registers;

   ▪   Provincial/territorial health insurance registers;

   ▪   Census database linkage.

6.2   CANCER SCREENING REGISTRIES AND THEIR DATA SOURCES FOR REGISTERING ELIGIBLE RESIDENTS

Cancer screening registries support operations and evaluation of organized cancer screening programs. Their size, i.e., the number of people eligible to be screened, is much larger than the size of cancer registries. Their functionality may include identifying people who are eligible for screening, sending screening information and invitations, notifying participants when results are available and facilitating reports to health service providers.

Two screening registries are described in the Inventory of Profiles: the Ontario Colorectal Screening Registry (Profile 4.4.3) and the Nova Scotia Colon Cancer Screening Registry (Profile 4.6.1). Both source the information to identify persons who are eligible for screening from provincial health insurance databases, e.g., the Registered Persons Database (RPDB) in Ontario. The RPDB contains client information such as name, gender, date of birth, address, citizenship, OHIP/ODB eligibility and Health Card. Nova Scotia, which is in the early stages of rolling out organized, population based colon cancer screening, is using a similar approach. Neither province's health insurance database currently contains ethnocultural identifiers. Aboriginal communities and cancer agencies are working on strategies to collect better information on how screening can reduce the burden of cancer. In Nova Scotia, screening participants are encouraged to identify themselves as one of seven ethnocultural groups, including First Nations, as part of their screening registration process.

Screening registries can play an important role in system navigation, in that they help direct eligible people to early detection services and resources that are available to them. This is particularly important for facilitating access to screening for groups who are under- or never screened. In many Canadian jurisdictions, First Nations, Inuit and Métis people are under-screened for a variety of reasons. The availability of ethnocultural identifiers in screening registries might enable a better understanding of those reasons, as well as the ability to direct specific resources to facilitate improved access to screening and patient navigation.

The remainder of this chapter describes the potential for vital statistics registries, different types of hospital/physician reports, and linkage with non-cancer files to act as sources of identifiers for cancer registries.

6.3 POTENTIAL FOR VITAL STATISTICS REGISTRIES TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

Currently, Yukon, Northwest Territories, Nunavut, British Columbia, Saskatchewan, Manitoba and New Brunswick include a question on Aboriginal identity on birth and/or death registration forms. In the Northwest Territories, First Nations, Inuit and Métis identifiers are linked to other health data sets, e.g., the provincial health insurance database and cancer registry. This is an important aid in assessing the burden of disease among these population groups in NWT (cf. *Inventory of Profiles 4.8.4*).

Mortality databases are important data sources for cancer registries as they often provide additional information about patients and their cancers, and are the primary source of death information. Mortality databases are not an ideal source of ethnocultural information, however. If mortality databases were the sole source of ethnocultural identifiers, this information would only be added to a record when an individual died, leaving a significant gap in coverage for living patients. Furthermore, it would take a significant amount of time from the initiation of this strategy to have sufficient numbers of identified individuals to make any conclusions about their cancer experience.

Beyond cancer, mortality databases are used in a variety of population health domains. For example, comparable, high quality ethnocultural birth and death data are critical for the calculation of the infant mortality rate (IMR), which is viewed as a universal indicator of population health status. Because of concerns with the quality and comparability of Aboriginal IMR data, existing practices of Aboriginal identification in Vital Statistics registries have been the subject of a number of related studies and discussions in recent years. The evolution of these discussions may offer insight into some of the practical considerations that could arise in potential discussions about Aboriginal identification in cancer registries. For this reason, we have summarised some highlights of these discussions, and added our interpretation regarding potential implications for future discussions around ethnocultural identification in cancer registries.

Aboriginal Infant Mortality Rates & Vital Statistics Registries – 2007-2010 Reviews

In 2007, Health Canada commissioned a jurisdictional review of methodologies for reporting IMRs for Aboriginal populations (Green, 2007). The review looked at Vital Statistics as well as other approaches, such as file linkage to the Status Verification File at First Nations and Inuit Health Branch and community-based reports. It concluded that there are significant regional variations in the way both birth and death data are collected for Aboriginal populations, and that it is not currently possible to provide reliable IMRs for any of the three Aboriginal groups at the national level. The review recommended that governments work with Aboriginal stakeholders to develop new policies and procedures to ensure accurate data be available in the future.

In 2009/2010, a systematic review of Canadian IMR calculations by the Joint Working Group on First Nations, Indian, Inuit, and Métis Infant Mortality of the Canadian Perinatal Surveillance System came to a similar conclusion. The Working Group included, among others, representatives of First Nations, Inuit

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and Métis groups, the Public Health Agency of Canada, the First Nations and Inuit Health Branch at Health Canada and researchers. It called for a more standardized approach to the collection of birth and death data in the provinces and territories, particularly for non-status Indians and Métis (Smylie, 2010).

The Joint Working Group on Aboriginal Birth Outcomes subsequently brought forward a proposed standard question for consideration at the Vital Statistics Council of Canada. The Council's Data Quality and Standards Committee undertook a survey among the provincial/territorial vital statistics registrars, who identified the following main barriers to implementation:

- **Standardization**: How do you determine common definitions; if national data are required, a standard question is necessary.

- **Cost**: Adding a question to the birth registration form incurs costs to change policies and procedures, redesign the form, the data capture, and data reporting. Also, many jurisdictions noted that consultation with provincial stakeholders is essential prior to incorporating a question on the birth registration form. However, this is proving to be a very time consuming process taking several years, and getting the wide range of stakeholders to agree on how the question should be asked is proving to be challenging.

- **Privacy**: Some jurisdictions raised concerns about collecting the information as its purpose and use were not clear.

- **Quality Control**: The data quality management aspect of this information is unclear; how does one verify the information provided?

The Committee concluded that there are several barriers to a standard question being adopted by all jurisdictions, some of which may be overcome, while others would require a considerable amount of resources. Therefore, the Committee suggested that other sources for this information be investigated, such as surveys, which could then be linked to the Canadian Vital Statistics Birth Database (CSV:B). Suggested linkage options were a cohort of new mothers or the Census. The latter was felt to be a better alternative because of a separate, equally important issue: a problem in all jurisdictions in getting Aboriginal mothers to register their babies at birth. Under-registration results in Aboriginal infants being under-represented in the CSV:B.

6.3.1 Discussion

The Aboriginal Infant Mortality Rate reviews illustrate the complexities surrounding implementation of ethnocultural identification projects. The issues on both sides of the discussion are real ones: Aboriginal IMR calculations suffer from weak data, and there are significant barriers to implementing Aboriginal identification standards across provincial/territorial vital statistics registries. Every project unfolds under its own unique circumstances. However, it is not unreasonable to assume that similar barriers to the ones raised by the Vital Statistics Council will come up in discussions about ethnocultural

identifiers in cancer registries. If they do, thought needs to be given to new approaches to overcome existing barriers.

Of all the barriers encountered in the IMR project "cost", i.e., the investment of time and resources to implement with quality, may top the list. Cost also consistently came up as the number one barrier during key informant interviews for this study.

In regard to augmenting cancer registries with ethnocultural identifiers, the Partnership may want to consider new ways to reduce the costs associated with such projects. In addition, there may be options to share the benefits of ethnocultural identifier projects and use these options to justify cost-sharing. Some of the strategies for cost reduction and cost-sharing are to

1. Identify new ways to apply existing data to new information needs;

2. Harmonize time- and labour-intensive processes;

3. Broaden the user base for new First Nations, Inuit and Métis identifiers;

4. Test and invest incrementally, i.e., systematically test new options in a phased and coordinated approach with interested and invested jurisdictions; only invest more resources when a qualifying test meets the criteria that have been set in advance by participating decision makers.

The potential next steps for the Partnership to pursue these strategies are explored in Sections 5.10, 5.11 and the balance of this chapter.

6.4   POTENTIAL FOR CANCER CENTRE REPORTS TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

The following three sections look at the suitability of cancer centre, physician or hospital reports to act as the source for First Nations, Inuit and Métis identifiers. All three of these sources depend on the ability of frontline resources to collect the identifiers, i.e., collection happens at the interface between cancer care service providers and patients.

The most recent, formally evaluated experience with adding ethnocultural identifiers to cancer centre reports is the Aboriginal Data Indicators Pilot conducted in two specialized cancer centres in Ontario in 2009. The evaluation confirmed the feasibility of generating First Nations, Inuit and Métis identity data as well as the importance of several supporting processes. These include strong project governance, a survey methods framework, cultural sensitivity, awareness and engagement, and a communications plan. The learning from the pilot (Stewart et al., 2010), as well as internal (Lidstone-Jones & Stewart, 2009) and external (Cats, MacAdam & Johnston, 2010) evaluations has been reflected in a protocol (Marrett, Kewayosh & Stewart, 2011) for collecting identifiers in cancer centres.

For other, well-documented practices for ethnocultural identification in specialized care settings, those used in infant health in Nunavut (Nutaqqavut 'Our Children' Health Information System) and Ontario (Niday Perinatal Database), and in dialysis/organ replacement, continuing care, home care, rehabilitation and mental health stand out. The Canadian Institute for Health Information is the database custodian for the latter five specialized care reporting systems, many of which are used across Canada.

Of all the factors potentially affecting the suitability of cancer centres to be the source for First Nations, Inuit and Métis identifiers, three considerations are reviewed:

- Cancer centres' coverage of provincial/territorial cancer patients;

- The degree of alignment in patient assessments between cancer centres, across provinces or even within a single province; and

- Evidence regarding the level of accuracy and completeness of ethnocultural identifiers in cancer centres and other specialized care settings.

Cancer Centres' Coverage of Provincial / Territorial Cancer Patients

Specialized cancer centres are key participants in cancer control programs and services, but not a primary data source for registering new cancer cases in some jurisdictions (cf. table on page 72). In addition, the percentage of patients seen at a specialized cancer centre can vary considerably according to type of cancer. For example, in Ontario nearly 100% of breast cancer patients are treated at Regional Cancer Centres, while very few melanoma patients are treated there. For these two reasons, the participation of cancer centres, while important, would not ever capture all Aboriginal cancer patients. However, given the importance of the cancer centres, any frontline data collection process would have to include them. And if the objective is to have identifiers assist in delivering appropriate care or outreach within cancer centres, the fact that not everyone is seen in a cancer centre does not limit identifier use within the cancer centre.

The Degree of Alignment in Patient Assessments between Cancer Centres

Nutaqqavut, Niday and the six reporting systems held at CIHI have all implemented standardized forms, or even standard assessment tools for collecting patient information. For example, interRAI assessment systems include standard forms and user manuals to ensure compliance with data collection standards. There is more diversity in the standards and forms used for collecting patient information between Canadian cancer centres. This does not mean a standard Aboriginal identifier cannot be implemented. However, collecting a standard identifier might require more development and implementation effort to meet the unique requirements of each cancer centre. Similarly, the absence of standard assessment forms and supporting systems is a complicating factor in collecting comparable data from physician and hospital records, which would considerably affect implementation time and effort required.

Evidence Regarding the Completeness of Ethnocultural Identifiers in Cancer Centres and Other Specialized Care Settings

One part of data quality is ensuring the data are complete. A metric for this is response rate. Ideally, one would want 100% compliance (i.e., no unknowns), in terms of both asking the identification question(s) of all newly admitted patients as well as ensuring that all patients answer the question(s). Several quality assurance studies have looked at this, including the Aboriginal Data Indicators Pilot, the Niday Perinatal Database and the Canadian Organ Replacement Registry (CORR). One common area for improvement that emerges across these studies is staff compliance in asking the question(s) of all newly admitted patients. The following findings illustrate this.

The three-month survey completion rate for the two cancer centres participating in the Aboriginal Data Indicators Pilot was 56% and 34% (Lidstone-Jones & Stewart, 2009). The completion rate was affected by staff comfort levels, workload and forgetting.

The Aboriginal identifier data element has historically not been well completed in the Ontario Perinatal Surveillance System. Of the demographics reported, this variable had the highest rate of non-completion with 56% of records missing data, compared to, for example, 11% missing smoking status, or 15% missing pre-existing maternal health issues (Bottomley et al., 2008). Helping hospitals and health care providers understand that it is not discriminatory to ask about a person's Aboriginal background is viewed as one of the conditions for improving completion.

The 2009 CORR Data Quality Study found that three of four demographic data elements that are frequently used in CORR analysis (health card number, date of birth, sex) were very reliable, with agreement rates exceeding 97%. Lower agreement was observed for patient's race (58%); but agreement rate was highest for Aboriginal (87.3%). Discrepancies typically traced to Unknown codes reported: 10.3% for Aboriginal versus 45.4% for Caucasian/white. The major barrier is consistent collection and recording of ethnocultural identifiers by busy frontline staff. The study found that frontline staff in dialysis units completing CORR forms utilized multiple methods for determining race: medical chart extraction (49%), asking patients (68%), inference from appearance (42%), language (22%), name (18%), and deducing race from physical description recorded by nephrologist (32%) (Canadian Institute for Health Information, 2009). More specific guidelines in the CORR Instruction Manual are expected to improve the recording of this information.

6.4.1 Discussion

Collecting identifiers in specialized cancer centres would not cover the entire universe of provincial cancer patients, but could be an important component of a frontline identifier collection strategy. There is good evidence that Aboriginal identifiers can be collected in specialized health care centres across Canada, including cancer centres. A protocol and tools have been developed for collecting Aboriginal identifiers in specialized cancer centres. It includes a standard Aboriginal indicator question as well as suggested key processes and activities.

There is also evidence that response rate, which is strongly affected by staff compliance in soliciting the information, can be significantly below 100%, with staff comfort and busy workload as key barriers. Improving staff compliance would require ongoing investment in dialogue and training.

What is unknown at this time is the level of investment required to address known issues with frontline compliance and patient assessment process variation between cancer centres. Such investment would primarily depend on the human resources required, e.g., systems development expertise, frontline training and work process integration over a period of time.

6.4.2 Recommendations and Next Steps

Provincial cancer agencies will want to assess the investment required to collect ethnocultural identifiers via a frontline collection strategy versus doing so via the alternative approaches laid out in this report. A frontline collection strategy would include further experience with collection standards and methods in specialized cancer centres, physicians and hospitals.

While we know that all three potential frontline identifier sources (specialized cancer centre reports, physician reports and hospital reports) are used for registering new cancer cases across the provinces/territories, the CRCNet study does not quantify what percentage of cancer patients are seen by cancer centres versus hospitals versus physicians. Knowing the relative importance of the three identifier sources – by province/territory, as well as at the national level - would assist each provincial cancer agency in prioritizing investment towards further developing an identifier collection process for its most important source(s) of new cancer registrations. In other words, it would help provinces/territories apply the 80/20 rule, and avoid excessive investment for marginal returns. It will also help the Partnership assess the opportunity for reducing duplication of development effort if provincial cancer agencies are willing to take on development and test roles for one of the three potential identifier sources on behalf of the balance of the country. The first step, then, would be to calculate the percent of cancer patients seen by cancer centres, hospitals or individual physicians for each province/territory.

For each of the potential frontline data sources, cancer agencies could work with the cancer centres, hospitals, and physicians involved to establish 1) the key barriers to implementing collection of ethnocultural identifiers, and 2) what evidence would be required to overcome these barriers.

Recommendation: for the Partnership to work with provincial cancer agencies to:

1. Establish which provincial cancer agencies are willing and able to work on a Feasibility and Cost Assessment for collecting First Nations, Inuit and Métis identifiers through frontline collection (cancer centre reports, hospital records, and physician records);

2. Look for opportunities to partner and coordinate resource investment with other relevant initiatives, e.g., Interior Health – Aboriginal Self Identification Project, Tri-Hospital Health Equity Data Collection Project, Electronic Medical Record – Ethnicity Reference Set;

3. Confirm, or replace, the barriers (frontline staff comfort and workload) identified in this report;

4. Create a test plan to establish the conditions and cost associated with addressing these barrier(s); and

5. Use the results to help provincial cancer agencies assess the relative attractiveness, i.e., feasibility and cost, of frontline data collection versus alternative sources of ethnocultural identifiers.

6.5 POTENTIAL FOR PHYSICIAN REPORTS TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

Physician reports represent an important, and in some provinces (Alberta, Saskatchewan) only frontline data source for registering new cancer patients in provincial cancer registries. Where physicians do this work separately from hospitals and cancer centres, the suitability of their reports to be a source of ethnocultural identifiers becomes subject to their interest in collecting this data.

Given the busy workload on physicians, it is reasonable to assume that they could be subject to the same pressures that affect identification response rates in cancer centres and other specialized health care settings. Further specification of the investments required to help address these pressures could follow the same approach recommended for cancer centres above.

Two additional practices to those identified in Section 6.4 may provide learning for ethnocultural identification by physicians: the Canadian Tuberculosis Reporting System (CTBRS) and the Electronic Medical Record – Ethnicity Reference Set (EMR-ERS).

CTBRS, which is estimated to capture close to 100% of all incident tuberculosis cases in Canada, collaborates with provincial/territorial public health agencies and tuberculosis registries on the standard for the national Case Report Form. The National Case Form, which is available in paper and electronic format, includes specific instructions for collecting, among others, First Nations, Inuit and Métis identifiers. With tuberculosis increasingly a disease of high-risk populations such as Aboriginal Canadians, treating physicians are invested in a process that supports tuberculosis control. During the prolonged period of treatment, treating physicians and public health staff educate patients and help reduce barriers to healing, e.g., by navigating to appropriate socio-cultural supports.

The EMR Ethnicity Reference Set, which includes First Nations, Inuit and Métis identifiers, aims to support better patient care by helping primary care physicians using electronic medical records capture ethnicity easily and consistently. Similar to the National Case Form, this Reference Set provides a practice standard for potential application to how physicians might collect and report ethnocultural identifiers of newly diagnosed cancer patients.

6.5.1 Discussion

As with cancer centres, collecting identifiers in physician reports could be an important component of a cross-provincial frontline identifier collection strategy. Besides the standards and practices identified for cancer centres, the National Case Form used for the CTBRS and the newly developed EMR Ethnicity Reference Set provide good practices for potential adaptation.

Similar to the discussion of collecting ethnocultural identifiers in cancer centres, physician support will require dialogue and training, and a realistic assessment of the investment required for implementation.

6.6 POTENTIAL FOR HOSPITAL RECORDS TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

Hospital records represent the third important, and in Québec only frontline data source for registering new cancer patients in provincial cancer registries. There are different options for collecting this information in hospitals. The key ones are 1) during the patient registration process, or 2) during the clinical assessment process.

An added complication to transferring patient information from hospital records to cancer registries is that in some provinces the information path is directly into cancer registries, while in other provinces this is handled via linkage with in-patient discharge and/or ambulatory care record linkage to the Discharge Abstract Database (DAD) and National Ambulatory Care Reporting System (NACRS). Neither DAD nor NACRS currently have an ethnocultural identifier data element, which would have to be added as an optional data element.

Therefore, the investigation of the optimal approach to collecting identifiers via hospital records would need to take into account the two collection and recording options, as well as the interface with a provincial cancer registry. Two important initiatives are underway to help provide answers to these questions: firstly, the Aboriginal Self Identification (ASI) Project in the Interior Health region of B.C., and secondly, the Tri-Hospital Health Equity Data Collection Project (THEDCP) in Toronto.

The two projects are in very different jurisdictions with unique population health challenges. Nonetheless, as the next table illustrates, their objective and approach to qualifying hospital records as a source of First Nations, Inuit and Métis identifiers are compatible. Both approaches would yield similar Aboriginal Identity Group data elements: First Nations, Inuit, Métis, null/other, as well as the ability for Non-Status Indians to self-identify. And both projects will yield important insight into different information collection options with initial results becoming available in 2012.

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Hospital Tests	Aboriginal Self Identification Project	Tri-Hospital Health Equity Data Collection Project
Health region	Interior Health – B.C.	Toronto Central LHIN - ON
Participants	9 acute care hospitals in Phase I	3 tertiary care hospitals & Public Health
Policy foundation	Transformative Change Accord & Métis Nation Relationship Accord	Excellent Care for All Act, TC-LHIN Health Equity Framework, Hospitals' Health Equity Programs
Purpose	Close quality of life gap between Aboriginal peoples and other British Columbians	Address gaps in equitable health care for all of Ontario's/Toronto's diverse populations
Intended data users	IH clinicians/service providers; Ktunaxa Nation Council & MNBC staff (aggregate data)	Individual hospital's clinicians/program administrators; external users (aggregate data)
Identifier standard used	Aboriginal Administrative Data Standard	None yet; topic areas and questions to be validated by test
Test objective	Confirm appropriateness of all processes supporting implementation to allow modification before implementing next phase in 4-phase roll-out plan	Confirm 1) which socio-demographic data to collect, 2) what questions to ask & how, 3) most sensitive way to collect information, 4) IT solutions to integrate into hospital systems
Identifier collection point(s)	Patient registration	Patient registration, assessment or at bedside
Collection method	Registration staff ask patients face to face; answers entered directly into electronic patient record	4 test methods: adm by clinician, clerk, at bedside with research assistant, or via patient electronic interface (tablet)
Sociodemographic identifiers collected	All patients are given opportunity to self-identify as Aboriginal or non-Aboriginal	15 topics associated with lack of equity, incl. race, language, disability, sexual orientation, gender, place of birth, income, age
Aboriginal identifiers collected	Aboriginal indicator Aboriginal identity group First Nations status Reserve indicator	Aboriginal identity group: First Nation, Inuit, Non-Status Indian, Métis, Aboriginal person from outside Canada
Related information collected	INAC registration number Métis citizenship number Referral to Aboriginal Patient Navigator	Language incl. Ojibway, Oji-Cree Sexual orientation incl. two-spirit Religion incl. native spirituality
Staff support	Training & materials to support culturally competent patient interactions and registration practices	Training and communication materials for care providers and patients

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6.6.1 Discussion

The Aboriginal Self Identification (ASI) Project in the Interior Health region of B.C., the Tri-Hospital Health Equity Data Collection Project (THEDCP) in Toronto and the Protocol for Collecting Aboriginal Identity Indicators in Cancer Patients Attending a Specialized Cancer Centre in Ontario all describe compatible practices. They indicate that collecting ethnocultural identifiers in health data sets may occur under either an Aboriginal equity policy agenda or a broader equity agenda for diverse populations. A broader equity agenda may also strengthen the political will and funding options for data collection in jurisdictions where population health disparities are affected by access issues for a broader group of socio-demographic populations. Under either scenario, the collection of better information is seen to enable population-specific, culturally appropriate policy, programs and services.

The ASI and THEDCP projects will continue to benefit from testing and fine-tuning over the next few years. Therefore, there may be an opportunity to link and coordinate cross-jurisdictional efforts to assist hospitals with effective and efficient options to augment their data sets with ethnocultural identifiers.

In addition, there may be an opportunity to link and coordinate efforts with the Canadian Institute for Health Information (CIHI), as CIHI is mandated to work with stakeholders to create and maintain a broad range of health databases and standards including the DAD and NACRS hospital databases. In the area of ethnocultural identification, CIHI brings expertise and experience with six reporting systems, as well as plans to harmonize Aboriginal identifier data elements across its holdings.

6.7   POTENTIAL FOR FIRST NATIONS, INUIT AND MÉTIS REGISTRIES TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

There is a difference in the process for registering as a Status Indian, Inuit Beneficiary or Métis Citizen versus self-identifying as a First Nations, Inuit or Métis person via the Census. Nevertheless, it would appear that a large number of Canadians who self-identify as First Nations or Inuit are also registered on the Indian Register and Inuit Beneficiary Lists. Métis registries include fewer individuals than self-identify as Métis on the Census. However, Métis registers are growing. In Manitoba, an innovative practice to create a more comprehensive list of self-identifying Metis has been developed. The Manitoba Metis Population Database includes individuals identified as Métis from a variety of sources and approximates the entire Métis population size as reported based on the 2006 Census.

	Number of People in First Nations, Inuit and Métis Registers [1]	Statistics Canada Aboriginal Identity Population Projections [2]	
		2006 Census Observed	2011 Projection Range
First Nations	860,000	785,000	850,000 – 880,000
Inuit	43,038	57,000	57,000
Métis [3]	148,235	404,000	428,000 – 502,000

[1]   Numbers represent most recent numbers available as of December 2011 and vary in exact date of measurement; some numbers are based on approximations provided by registry informants.

[2]   Population Projections by Aboriginal Identity in Canada, 2006-2031 (Statistics Canada, 2011).

[3]   Métis registers in B.C., Alberta, Ontario and the Manitoba Metis Population Database.

The Indian Register represents a source of information that - within the strict legislative requirements for individual privacy, confidentiality and security, and at the discretion of the Indian Registrar - may be used for the public good to improve information that supports better knowledge and decisions regarding health status among the First Nation peoples. The Indian Register has been used extensively and successfully for that purpose. Examples include the Unama'ki Client Registry and Data Linkage Model, the Ontario Cancer Registry and Indian Register Linkage, the Manitoba Registered First Nations and Health Insurance Registry Linkage, and the B.C. First Nations Client File.

Similarly, the Inuit Beneficiary Lists allow for the use of personal information for research and health benefit administration purposes deemed to be in the best interest of beneficiaries. To-date, information on these lists has been used mainly by land claims organizations and the Governments of the Northwest Territories and Nunavut for the administration of territorial health insurance plans as well as the federal Non-Insured Health Benefit plan. They have also been used as a data source for the Inuit Health in Transition Study.

Métis Registries are also being used as cohorts for linkage studies and chronic disease surveillance. The Ontario Métis Registry has been linked to administrative health databases to produce chronic disease and cancer reports. The Manitoba Metis Registry has enabled building a full provincial Manitoba Metis Population Database, which in turn has been linked to administrative data for a number of Metis health initiatives. The B.C. Registry will be linked to administrative data held by the B.C. Ministry of Health Services and Vital Statistics to produce valid and reliable measures of Métis health status. To this end, MNBC signed the Métis Public Health Surveillance Program Information Sharing Agreement with the B.C. government in the fall of 2011, and has launched the Métis Nation British Columbia's Chronic Disease Surveillance Program.

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6.7.1 Discussion

The custodians of First Nations, Inuit and Métis Registries and associated databases have identified four factors that drive the potential for linking First Nations, Inuit and Métis Registries to provincial/territorial cancer registries:

1. The high and growing number of records available for matching now;

2. Continuously improving quality assessments and quality initiatives; for example, the Indian Registry will roll-out new secure Indian Status cards over the next 5 years. This is expected to improve the quality of information categories like residency, and major life events, as the card will be renewed every 5 years;

3. Cost effectiveness: investment is limited to linkage expenses as no new identifier data needs to be collected.; and

4. The experience and expertise developed in the course of previous linkage projects, i.e., how to work through complex inter-jurisdictional issues regarding privacy and de-identifying data, governance and information sharing, linkage/matching techniques.

All the above databases and associated projects have succeeded in building capacity and ownership among First Nations, Inuit and Métis participants in the areas of data management, policy, research and health service delivery. The successful experience with using the Indian Register, Inuit Beneficiary lists, and Métis Citizenship registers are therefore a promising starting point for further initiatives to enhance the value of these registers in the service of First Nations, Inuit and Métis health information needs.

6.7.2 Recommendations and Next Steps

A logical next step could be to build on the success and learning from previous projects, and invite governance representatives and health information stakeholders for each of the First Nations, Inuit, Métis and cancer registries to build the value of these registries to support common health information goals. Options could include:

- Moving from one-off projects to ongoing data sharing agreements, such as the ones negotiated for the Unama'ki Client Registry, the B.C. First Nations Client File and the Métis Public Health Surveillance Program Information Sharing Agreement;

- Expanding linkage of First Nations, Inuit and Métis registers to cancer registries in more provinces/territories, or linking nationally to the Canadian Cancer Register;

- Assessing the feasibility and cost of applying the Manitoba Metis Population Database model to other interested Métis nations; and

▪ Assessing the potential to answer important First Nations, Inuit and/or Métis health questions faster and more cost-efficiently by utilizing the Longitudinal Health and Administrative Data process.

Recommendation: for the Partnership, including national and provincial/territorial First Nations, Inuit and Métis governance organizations, AANDC, provincial/territorial health ministries and cancer agencies to develop a shared agenda and plan that lays out the options and conditions for sustained linkage of status/beneficiary/citizenship registers to more cancer registries including the Canadian Cancer Register.

6.8 POTENTIAL FOR HEALTH INSURANCE CLIENT REGISTRIES TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

Some provinces (e.g., B.C., Alberta, Saskatchewan, Manitoba, Ontario) include a First Nation and/or Inuit status verification question on their (supplemental) health insurance application form or process. While in some provinces this information has been used in the past to link to health administrative data, the quality and completeness of the information has been problematic.

For the purpose of this study, the most complete identification of First Nations, Inuit and Métis people occurs in the Territories. Profiles of the health care plan client registries in the Northwest Territories and Nunavut show these jurisdictions' leading practices, not only for collecting the identifiers, but also for integrating the resulting information with cancer registries, vital statistics registries and infant health information. As a result, these Territories can be very responsive to the unique needs of different ethnocultural groups at the population health planning level as well as for individual navigation. For example, Stanton Hospital uses health card identifiers as a trigger at admission to ask patients about their preferences for a range of culturally relevant supports.

British Columbia and Newfoundland and Labrador are leading important new Aboriginal administrative data standard initiatives, and the associated identifiers reflect the input of First Nations, Inuit and Métis groups in these jurisdictions. Both provinces are actively evaluating the options and requirements for implementing the identifier standard into their provincial health insurance application process. This may require a significant investment in changes to forms, processes and systems.

Paying for surveys and access to special data sets is expensive. Migration to an Aboriginal administrative data standard will entail costs (financial and human resources) but, once established, will provide an inexpensive source of data that can be used for the above stated purposes.

6.8.1 Discussion

For cancer registries and screening registries it would be very beneficial to source First Nations, Inuit and Métis identifiers from provincial health care client registries. These registries cover a very high percent of the provincial population. And health insurance identifiers/health card numbers are critical to linking a broad range of provincial/territorial health databases. Key informants have pointed to four

factors that need to be in place for such a project to happen: 1) a reason, 2) champion(s) and supporters, 3) a standard, and 4) an implementation plan.

1. A reason: the two territories and two provinces who are using or working towards Aboriginal identifiers in their health insurance client registries all put a high value on improving government administrative data in order to 1) develop culturally appropriate, effective policy, programs and services, 2) manage and measure performance, and 3) for chronic and communicable disease surveillance, health service utilization management, and socio-economic research and reporting.

2. Champions and supporters: The four profiled practices benefitted from the support of a broad range of experts and stakeholders. Central in these are champions from Aboriginal organizations, the Ministry of Health, sometimes the Ministry of Aboriginal relations, and support from a research/information centre that deeply understands health administrative data bases and related processes.

3. A data standard: All four practices either started from an established data standard, or made developing one their first priority.

4. An implementation plan: This is where a strong reason, committed champions, knowledgeable supporters and relations developed in the course of planning the standard and project pay off in a well-considered and well-funded implementation plan that recognizes that "paying for surveys and access to special data sets is expensive. Migration to [the identifier standard] will entail costs, but once established will provide an inexpensive source of data that can be used for the above stated purposes." (cf. Profile 4.7.2. Newfoundland and Labrador Aboriginal Administrative Data Identifier)

6.8.2 Recommendations and Next Steps

Recommendation: for the Partnership to

1. Initiate and coordinate the development of a national framework and guidelines for the identification of First Nations, Inuit and Métis peoples in health administrative data sets;

2. Facilitate the exchange of knowledge and learnings from jurisdictions who are planning, implementing or using First Nations, Inuit and Métis identifiers in their health data sets.

3. Work with individual provincial cancer agencies, First Nations, Inuit and Métis organizations and ministries of health to develop a shared agenda and plan that lays out the options and conditions for implementing a First Nations, Inuit and Métis identifier standard in their provincial health insurance client registry.

6.9   POTENTIAL FOR NATIONAL SURVEYS TO BE A SOURCE OF FIRST NATIONS, INUIT, AND MÉTIS IDENTIFIERS

There are limitations to the use of surveys as a source of ethnocultural identifiers in cancer registries, as some surveys, especially local and provincial ones, are relatively small in size, and the national Statistics Canada surveys can only be used for research purposes as defined by the Statistics Act.

Nevertheless, surveys with First Nations, Inuit and Métis identifiers have been successfully used, often in combination with other databases, to address important questions that influence Aboriginal health policy, programs and services. For example,

- The Our Health Counts survey database (790 respondents in Hamilton) has been successfully linked to Ontario administrative health data to produce, for the first time, urban Aboriginal population-based rates of emergency room use, hospital admission and participation in preventative screening programs, including breast, cervical and colorectal cancer screening.
- The Canadian Community Health Survey has been used to help augment the number of Métis people in the Manitoba Metis Population Database.

A number of key informants commented on the considerable logistical and organizational barriers to combining federal and provincial databases and expertise, and the associated negative impact on cost and timing. The diversity of approvals required for information projects, both within as well as between provinces, and the lack of procedures and policies to facilitate data sharing between jurisdictions have been the subject of several studies (Kephart, 2002; Centre for Health Services and Policy Research, 2005).

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Some recent initiatives now offer a relatively time- and cost-efficient opportunity to link cancer registries to the national Census database. This opportunity is available through

- The 1991 Canadian Census Cohort: Mortality, Cancer and Residential Mobility Follow-up Study, which includes the Canadian Cancer Database (CCDB). This database uses the Census as its source file for First Nations and Métis identifiers, is not limited to status, on-reserve or registered individuals and provides the opportunity to consider the health of First Nations, Inuit and Métis across the country. The cohort has limitations, in that it only contains persons aged 25 – 64 years who have filed taxes. Nonetheless, by using a large, validated sample with long term consistent data collection and linking it to the CCDB and the Canadian Mortality Database, it is possible to cost-effectively assess the patterns in mortality and cancer on ethnocultural populations that are not otherwise captured in these databases.

- The Longitudinal Health and Administrative Data (LHAD) Initiative takes this analytical power one step further by cost-effectively enabling linkage of provincial/territorial databases to existing national data including the Census, Canadian Cancer Registry and CIHI databases. First Nations, Inuit and Métis identifiers can be sourced from the Census or other jurisdictional data sets. The participating databases remain with their own custodians. LHAD is an open data model that combines a common infrastructure of record linkage and privacy management with high flexibility of source files that can be linked for highly customized research. For example, it has been used to link hospitalization data with Census data to explore health care utilization patterns among the Aboriginal population. For the first time in Canada, researchers can analyse in a methodologically consistent and cross-jurisdictionally comparable way, variations in hospital usage for specific sub-populations. At the same time, they can incorporate a wide range of socio-economic variables (e.g., income, education, employment, housing etc.) for additional contextual information.

6.9.1 Discussion

The potential for national surveys to be a source of First Nations, Inuit and Métis identifiers for cancer registries and screening registries depends on 1) the specific question that needs to be addressed, and 2) any other data sets a group may wish to bring into the LHAD environment. National surveys can have limitations due to sampling. Other data limitations relate to the relative rarity of cancer, especially in younger populations, and the need for long follow-up to accrue person-years at risk. However, of all the identifier sources reviewed, the Census is the most time- and cost-efficient source of First Nations, Inuit and Métis identifiers in cancer registries.

6.9.2 Recommendations and Next Steps

Part of the problem statement the Partnership formulated for this study is that "Without reliable health data specific to each people, it is difficult to measure the impact of cancer on these populations, to understand the relationship between cancer and other health issues, and to design programs to address gaps in cancer control among First Nations, Inuit and Métis peoples."

The Census is a source of First Nations, Inuit and Métis identifiers that can be linked to cancer registries and other databases to measure the impact of cancer, understand the relationship with other health issues, and design program to address gaps in Aboriginal cancer control.

Recommendation: for the Partnership to bring First Nations, Inuit and Métis health policy stakeholders and provincial/territorial cancer agencies together to

1. Develop an inventory of specific research questions that are important to the formulation of cancer control policy and the design of appropriate programs for First Nations, Inuit and Métis peoples;

2. Work with Statistics Canada and other research organizations as appropriate to develop a joint research agenda to address these questions with existing data and linkage mechanisms where feasible;

3. Where specific and important research questions cannot be addressed by existing data and linkage mechanisms, define in more detail the data and/or linkage mechanism required, so this may inform shared priorities for the development of additional data sources and enabling practices.

7.0 REFERENCES

Note: references to publications associated with specific database practices or enabling practices are included in individual profiles in the *Inventory of Profiles.*

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APPENDIX A
DATA COLLECTION FORM "S"

CANADIAN PARTNERSHIP AGAINST CANCER

Enviro scan and analysis of existing patient identification systems for First Nations, Inuit, and Métis peoples

DATA COLLECTION FORM

VERSION 2.0-S

SEPTEMBER 1, 2011

The Bridge Consulting Group

The Canadian Partnership Against Cancer has asked The Bridge Consulting Group to conduct an Environmental Scan and Analysis of Existing Patient Identification Systems for First Nations, Inuit and Métis peoples. This project is part of the Partnership's First Nations, Inuit, and Métis Action Plan on Cancer Control (June 2011).

The goal of the project is to identify existing systems of patient identification specific to First Nations, Inuit and Métis ethnicity, and to analyze barriers to developing common standards for data collection, access and reporting (as a means to improve patient navigation). The Partnership's 2011/12 action plan includes a commitment to document existing systems of ethnocultural patient identification for First Nations, Inuit, and Métis populations, and to analyze and identify leading practices.

The attached Data Collection Form has been designed to capture information about electronic health databases that include ethnocultural identifiers for First Nations, Inuit, and/or Métis populations. This information will assist us in i) developing profiles of selected databases, and ii) analyzing barriers to developing acceptable systems of ethnocultural identification, and of standards for data collection, access and analysis.

The longer term impact the Partnership pursues is to improve the ability to collect baseline information (i.e., incidence, care patterns and outcomes), and thus target services to areas of most need, leading to improved cancer care for and with First Nations, Inuit and Métis peoples.

For questions or information about this form or the project, please contact
     Drs. Henneke Cats, Engagement Lead
     The Bridge Consulting Group
     Telephone: 416-226-2251   E-mail: Henneke@yourbridge.com

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Definitions of key terminology:

Demographic data:	**e.g., name, address, date of birth, gender**
Ethnocultural data:	**e.g., Aboriginal, First Nations, Inuit, and/or Métis identifiers**
Enrolment:	**e.g., enrolment in health insurance, or in health care program**
Membership:	**e.g., band membership/First Nation affiliation, Métis group membership**
OCAP:	**First Nations principles for Ownership, Control, Access, and Possession of health data**
Support Organization:	**typically, the database custodian provides support for questions regarding the database**

Before entering data into the Data Collection Form, please do a Save As and rename the document by including the date of completion, your first initial and last name, i.e., DCFv2.0-M_DB_2011-07-16_JSmith.doc.
There are three options for entering data in the Data Collection Form:
- **Use the TAB key to tab through each section to enter the information, or**
- **Use the up/down arrows on the keyboard to move to each section to enter the information, or**
- **Select each field using the mouse cursor to enter the information.**

Name of interviewee/key informant:	
Title:	
Organization:	
Phone number:	
E-mail:	
Title/citation for key information document(s):	
Interviewer:	
Date of interview, or completion of data form:	

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I.	DATABASE – Actual name given by Custodian
Geography	☐ **Canada** ☐ **BC** ☐ **AB** ☐ **SK** ☐ **MB** ☐ **ON** ☐ **QC** ☐ **NB** ☐ **NS** ☐ **PE** ☐ **NL** ☐ **YT** ☐ **NT** ☐ **NU** ☐ **Other** **Specify**
Description	**Summary of description of the database**
Custodian	**Name of organization that holds database**
	Mandate of Custodian: Please specify
Purpose	**Principal decision(s) or activities that the information is intended for (in your words)**

	☐ **Public Health & Surveillance**	☐ **Operating a Health Organization or System**	☐ **Research**	☐ **Service Delivery**
	☐ screening ☐ immunization ☐ communicable disease ☐ other **Specify**	☐ funding & reimbursement ☐ transactions, e.g., drug dispensing ☐ capacity & utilization planning ☐ performance mgmt. & accountability	☐ population ☐ clinical ☐ program/service ☐ public policy	☐ enrolment/membership ☐ evaluation ☐ equity ☐ patient navigation

Demographics	☐ **Database includes demographic data**	☐ **Database includes Aboriginal, First Nations, Inuit and/or Métis ethnocultural identifiers**		
	☐ **First Nation/North American Indian**	☐ **Inuit/Inuk**	☐ **Métis**	☐ **Aboriginal**
	☐ **Status (registered, treaty)** ☐ **Non-status** ☐ **On-reserve** ☐ **Off-reserve** ☐ **Band name or number**	☐ **Inuvialuit** ☐ **Nunavut** ☐ **Nunavik** ☐ **Nunatsiavut**	☐ **On Métis register** ☐ **Other Specify**	☐ **Other Specify**
	Comments (Optional)			

Status & Update	Database status **Select One**	Database update frequency **Select One** **Frequency of Updates:**

Availability	**Month/year of earliest available ethnocultural identifiers (e.g., FEB-98):** **Month/year of latest available ethnocultural identifiers:**

Level of Detail	1. **Select One**
	     2. If **Individual Record** was selected: **Select One**
	           3. If **Not identifiable** was selected: **Select One**

Geographic Codes	**Geographic level to which ethnocultural FNIM identifiers can be obtained:** ☐ **National** ☐ **Province/Territory** ☐ **Regional (e.g., RHA/LHIN)** ☐ **Local (e.g., facility)** ☐ **Other Specify** **Select One**

Service Domain	☐ **Acute Care** ☐ **Emergency Care** ☐ **Complex Continuing Care** ☐ **Rehabilitation** ☐ **Mental Health/Addictions** ☐ **Palliative Care** ☐ **Long Term Care** ☐ **Home & Community Care** ☐ **Primary Care** ☐ **Drugs** ☐ **Cancer** ☐ **Diabetes** ☐ **Renal Dialysis** ☐ **Immunization** ☐ **Communicable Disease**

Users	**Primary users of this database - A short list of key users** **Select One**

Populations	**Population groups included in this database – A short list of key populations**

I.	DATABASE – Actual name given by Custodian

	Population Coverage - % of population targeted by the database that has been captured: **Example: this provincial cancer registry captures around x% of all incident cancer cases**
	Alternatively, sample with weights? **Select One .** **If yes, sample size % of population**
Records	**Total # of records in database:** **Annual number of records collected/updated:**
Contact/ Questions	**Support Organization Title of person in support role:** **Name: Phone: E-mail:**
Web site	**URL for further information**

II.	DATA DESIGN, COLLECTION, RECORDING & STORAGE

Ethnocultural Identity Question	**Verbatim reproduction of the ethnocultural identity question(s):** **Please, attach a <u>blank</u> electronic or hard copy of the questionnaire/data entry form that includes this question** ☐ **copy attached**
Question Design	**Reason why the above question and/or identifier was chosen: Please describe**
	Ethnocultural identity question(s) has been tested Select One **Test report re question design is available Select One** **Name/citation for test report:**
Method	**This method for collecting, accessing and/or reporting ethnocultural identifiers addresses important barriers or gaps in First Nations, Inuit and/or Métis patient identification Select One , If yes, barriers/gaps that have been addressed: Please describe**
	This method for collecting ethnocultural identifiers has been tested, validated, and/or formally evaluated Select One **Test /pilot/ evaluation report is available Select One** **Title/ citation for report:**
Data Linkage	**Potential, i.e., "technical feasibility", for data linkage (check highest level possible, with 1 being highest): Select One** 1. **Person-specific, longitudinal linkage to other databases is possible** 2. **Aggregate level linkage (e.g., using three digit postal code) to other databases possible** 3. **Record linkage within the database is possible** 4. **No record linkage is possible, either within the database or to other databases**
Data Quality	**Documented Guidelines for asking and recording ethnocultural identity are available** **Select One**
	Staff Training Program for these guidelines is in place (e.g., to ensure questions are asked consistently and in a culturally appropriate way) **Select One**
	Awareness/education materials for patients/clients are available (e.g., to explain why patients/clients are asked to self-identify) **Select One**
	A systematic approach to evaluating the quality of ethnocultural identification data is in place **Select One**
	Data quality indicators that are used: Please specify

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II.	DATA DESIGN, COLLECTION, RECORDING & STORAGE	
	Formal evaluation of the validity, usability and completeness of the ethnocultural identity data has been done	Select One
	Title/citation for test/pilot/quality evaluation report:	
	Comments on quality (optional)	
Data Cost	This approach replaces a more costly way to collect ethnocultural identifiers	Select One
	Comments on cost (optional)	
Capacity	The custodian plans to keep collecting the ethnocultural identifiers	Select One
	Barriers - if any – to ongoing collection of ethnocultural identifiers:	

III.	DATA ACCESS	
Privacy Constraints	**Privacy constraints (e.g., legislation, protocols, agreements) that govern access to this database**	
	A Privacy Impact Assessment has been done for this database	Select One
	Information has been used for secondary purposes	Select One
	If yes, examples of secondary data use:	
First Nations, Inuit, and/or Métis Engagement	First Nations, Inuit and/or Métis groups were consulted on the purpose and/or design of the database	Select One
	An MOU or formal agreement governing development and/or use of the database is in place	Select One
	First Nation, Inuit and/or Métis people have taken on role(s) in this ethnocultural identification project as	
	☐ Designer (e.g., of question) ☐ Collector of data ☐ Custodian ☐ Analyst ☐ User for decisions	
	Comments on the nature and/or outcome of engagement (optional)	
OCAP	The Custodian has done an OCAP review of database to ensure its development and use meet the principles and requirements of First Nation, Inuit and/or Métis peoples as follows:	
	First Nations OCAP principles Inuit Land Claims research protocols Métis requirements Select One	
	Select One Select One	

IV.	DATA USE & REPORTING	
Data Products	Analyses, reports, publications have been done using ethnocultural identifiers in the database	Select One
	Examples of analyses, reports, publications:	
	1.	
	2.	
Evidence-informed Decisions	The ethnocultural identifiers have informed practice, policy and/or research decisions	Select One
	Examples of evidence-informed decisions:	
	1.	
	2.	
Reporting	Information/analysis has been shared with ethnocultural groups who have an interest in its collection and use	Select One

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IV. DATA USE & REPORTING	
	Comments on communication approach used and response (optional)
Application of First Nations, Inuit and/or Métis Identification Approach to Other Jurisdictions	**Other jurisdictions plan to adapt or adopt this approach to ethnocultural identification** **Select One**
	Comments (optional)
	Thoughts/advice on factors that would **Support the re-application of this ethnocultural identification approach to other jurisdictions: Please comment** **Limit the re-application of this ethnocultural identification approach to other jurisdictions: Please comment**
Additional Comments	**Please provide any additional information or advice that would be useful to health care planners, policy makers, researchers or administrators regarding the approach used for collecting, accessing and reporting health care information with ethnoculturalidentifiers**

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APPENDIX B
CROSS-REFERENCE CHART I

CROSS REFERENCE CHART I

Cross Reference Chart I	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Information Holding Name																																							
PROVINCIAL / TERRITORIAL, REGIONAL / LOCAL																																							
British Columbia																																							
Aboriginal Administrative Data Standard	31	•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•												
Indigenous Cultural Competency [1]	38										•	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•		•	•	•							
Interior Health – Aboriginal Self Identification Project [2]	40	•	•	•	•	•		•	•		•	•															•												
Métis Nation British Columbia Central Registry	46								•																		•												
Mustimuhw cEMR	53	•	•	•	•	•	•								•			•	•			•		•	•		•		•	•									
Tripartite & Bipartite Political Processes	62																										•												
Saskatchewan																																							
Métis Nation Saskatchewan Citizenship Registry	69								•																				•										
Manitoba																																							
Manitoba Métis Federation Membership Registry	76								•																					•									
Manitoba Métis Population Database	83								•		•				•			•	•	•	•	•	•		•					•									

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Cross Reference Chart I

Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Registered First Nations & Manitoba Health Insurance Registry Linkage	89	•	•		•	•	•				•	•	•	•	•	•	•	•	•	•	•	•	•	•	•					•									
Ontario																																							
Aboriginal Identity Indicator in Cancer Patients - Protocol	98	•	•	•	•	•		•	•	•											•										•								
Better Outcomes Registry & Network (BORN)	104	•	•	•	•	•		•	•	•	•								•												•								
Colorectal Cancer Screening Registry	109																				•										•								
Métis Nation Ontario Citizenship Registry	116								•																						•								
Ontario Cancer Registry/Indian Register Linkage (1968-2001)	124	•	•																		•										•								
Our Health Counts – Baseline Population Health Database for Urban Aboriginal People in Ontario	128	•	•	•	•	•					•	•			•				•	•	•	•	•	•	•						•								
Tri-Hospital Health Equity Data Collection Project	134	•		•				•	•	•	•				•				•						•						•								
Quebec																																							
Nunavik Inuit Beneficiaries List	140							•																								•							
Register of Cree, Inuit and Naskapis	148	•	•					•																								•							

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Cross Reference Chart I

Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Nova Scotia																																							
Colon Cancer Screening Registry	154	•																			•													•					
Unama'ki Client Registry & Data Linkage Model	160	•	•	•	•	•	•				•	•			•				•	•	•	•												•					
Newfoundland and Labrador																																							
Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement	167							•																												•			
Newfoundland and Labrador Aboriginal Administrative Data Identifier	173	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•											•			
Northwest Territories																																							
Inuvialuit Regional Corporation Enrolment Registry	180							•																														•	
Northwest Territories Cancer Registry	189	•	•					•	•												•																	•	
Northwest Territories Health Care Plan Client Registry	194	•	•					•	•	•	•	•			•	•	•	•	•	•	•	•	•	•	•													•	
Northwest Territories Vital Statistics Registry	201	•	•					•	•																													•	
Nunavut																																							
Nunavut Cancer Registry	206	•						•	•												•																		•

Cross Reference Chart I

Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Nunavut Health Care Plan Client Registry	210	•	•					•	•		•	•		•	•	•	•	•	•	•	•	•	•	•	•														•
Nunavut Inuit Enrolment List	215							•																															•
Nutaqqavut 'Our Children' Health Information System	220	•						•	•		•								•																				•
NATIONAL																																							
National First Nations, Inuit and Métis Databases																																							
First Nations Regional Health Survey	228	•	•		•		•								•	•		•	•		•	•				•	•	•	•	•	•	•	•	•	•	•	•	•	
Inuit Health in Transition Study	235							•							•							•														•		•	•
Urban Aboriginal Peoples Study	240	•	•	•		•		•	•																		•	•	•	•	•	•		•					
Aboriginal Affairs and North Development Canada																																							
Indian Registry System	240	•	•		•	•	•																			•													
Canada Health Infoway																																							
Electronic Medical Record: Ethnicity Reference Set	250	•						•	•										•							•													
Canadian Institute for Health Information																																							
Canadian Organ Replacement	265									•													•			•													

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Cross Reference Chart I

Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
Register																																							
▪ Continuing Care Reporting System [3]	271	○						●	○	○			●				●										●		●	●	●			●			●	●	
▪ Home Care Reporting System	277									●								●									●	●	●	●	●			●				●	
▪ National Rehabilitation Reporting System	281									●				●													●	●	●	●	●		●	●	●	●			
▪ Ontario Mental Health Reporting System	285									●					●															●								
▪ Primary Health Care Voluntary Reporting System	292	●						●	●										●								●			●	●						●		
Health Canada – First Nations and Inuit Health Branch																																							
▪ Status Verification System	300	●	●					●	●									●								●													
Health Canada – Public Health Agency of Canada																																							
▪ Canadian Chronic Disease Surveillance System [4]	305	●	●								●								●			●				●	●												
▪ Canadian Tuberculosis Reporting System	310	●	●	●	●	●		●	●	●															●	●													
Statistics Canada																																							
▪ Aboriginal Peoples Survey [5]	316	●	●	●		●	●	●	●																	●													
▪ Canadian Community Health Survey	323	●						●	●	●	●	●			●			●	●	●	●	●		●	●	●													

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Cross Reference Chart I

Information Holding Name	Page	First Nations	FN Status	FN Non-Status	FN On-Reserve	FN Off-Reserve	FN Band	Inuit	Métis	Aboriginal	Acute Care	Emergency Care	Complex Continuing Care	Rehabilitation	Mental Health/Addictions	Palliative Care	Long-term Care	Home & Community Care	Primary Care	Drugs	Cancer	Diabetes	Renal Dialysis	Immunization	Communicable Disease	Canada	British Columbia	Alberta	Saskatchewan	Manitoba	Ontario	Quebec	New Brunswick	Nova Scotia	Prince Edward Island	Newfoundland and Labrador	Yukon	Northwest Territories	Nunavut
1991 Canadian Census Cohort: Mortality, Cancer & Residential Mobility Follow-up Study	329	•	•	•	•	•	•		•												•					•													
Census – Long Form	333	•	•	•	•	•	•	•	•	•																•													
Longitudinal Health and Administrative Initiative [6]	341	•	•	•	•	•		•	•		•	•			•						•	•				•				•	•								

Notes

1) To-date, the Indigenous Cultural Competency program has been delivered to participants from B.C., Alberta, Manitoba, Ontario, and Québec.
2) Longer term roll-out target would expand Aboriginal self-identification to all Interior Health clients across all service domains.
3) The question underlying this information is expected to be changed in 2012-2013 to: "Client identifies self as First Nations (ye, no), Métis (yes, no), Inuit (yes, no).
4) Aboriginal component to CCDSS is exemplified in British Columbia and Newfoundland & Labrador data sets.
5) The 2006 Aboriginal Peoples Survey asks about membership in Indian Band or First Nation.
6) As of September 8, 2011, Ontario and Manitoba have signed partnerships in the Longitudinal Health and Administrative Initiative.

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APPENDIX C
CROSS-REFERENCE CHART II

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CROSS REFERENCE CHART II

Cross Reference Chart II: Source File for FNIM Identifier		Self-Identification occurs at the time of					Comments
Information Holding Name	Page	Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
PROVINCIAL / TERRITORIAL, REGIONAL / LOCAL							
British Columbia							
▪ Interior Health – Aboriginal Self Identification Project	40				●		Initiative also includes employee self-identification.
▪ Métis Nation British Columbia Central Registry	46			●			
▪ Mustimuhw cEMR	53					●	
Saskatchewan							
▪ Métis Nation Saskatchewan Citizenship Registry	69			●			
Manitoba							
▪ Manitoba Métis Federation Membership Registry	76			●			
▪ Manitoba Métis Population Database	83	●		●			
▪ Registered First Nations & Manitoba Health Insurance Registry Linkage	89			●			

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Cross Reference Chart II: Source File for FNIM Identifier		Self-Identification occurs at the time of					Comments
					Point of Service or Care		
Information Holding Name	Page	Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Registration	Clinical/ Professional Encounter	
Ontario							
▪ Aboriginal Identity Indicator in Cancer Patients - Protocol	98					●	
▪ Better Outcomes Registry & Network (BORN)	104					●	Maternal Aboriginal identity field developed, but hidden pending successful completion of stakeholder engagement.
▪ Colorectal Cancer Screening Registry	109						Screening maps use Geospatial Analysis tool (cf Profile).
▪ Métis Nation Ontario Citizenship Registry	116			●			
▪ Ontario Cancer Registry/Indian Register Linkage (1968-2001)	124			●			
▪ Our Health Counts – Baseline Population Health Database for Urban Aboriginal People in Ontario	128	●					
▪ Tri-Hospital Health Equity Data Collection Project	134				●	●	Also being tested via patient electronic interface, and at bedside.
Quebec							
▪ Nunavik Inuit Beneficiaries List	140			●			
▪ Register of Cree, Inuit and Naskapis	148			●			
Nova Scotia							
▪ Nova Scotia - Colon Cancer Screening Registry	154				●		Participant form is mailed to eligible Nova Scotia residents.

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Cross Reference Chart II: Source File for FNIM Identifier		Self-Identification occurs at the time of					Comments
Information Holding Name	Page	Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
▪ Unama'ki Client Registry & Data Linkage Model	160			●			
Newfoundland and Labrador							
▪ Enrolment Register of Beneficiaries to the Labrador Land Claims Agreement	167			●			
▪ Newfoundland and Labrador Aboriginal Administrative Data Identifier	173						Best option to be determined.
Northwest Territories							
▪ Inuvialuit Regional Corporation Enrolment Registry	180			●			
▪ Northwest Territories Cancer Registry	189		●				
▪ Northwest Territories Health Care Plan Client Registry	194		●				
▪ Northwest Territories Vital Statistics Registry	201				●		
Nunavut							
▪ Nunavut Cancer Registry	206		●				
▪ Nunavut Health Care Plan Client Registry	210		●				
▪ Nunavut Inuit Enrolment List	215			●			
▪ Nutaqqavut 'Our Children' Health Information System	220		●			●	

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Cross Reference Chart II: Source File for FNIM Identifier		Self-Identification occurs at the time of					Comments
Information Holding Name	Page	Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
NATIONAL							
National First Nations, Inuit and Métis Databases							
▪ First Nations Regional Health Survey	228	●					
▪ Inuit Health in Transition Study	235	●					No specific screening question was used to identify Inuit community members. A list of Inuit residents in each community was generated based on community informants.
▪ Urban Aboriginal Peoples Study	240	●					
Aboriginal Affairs and North Development Canada							
▪ Indian Registry System	249			●			
Canada Health Infoway							
▪ Electronic Medical Record: Ethnicity Reference Set	259					●	
Canadian Institute for Health Information							
▪ Canadian Organ Replacement Register	265					●	
▪ Continuing Care Reporting System	271					●	
▪ Home Care Reporting System	276					●	
▪ National Rehabilitation Reporting System	281					●	
▪ Ontario Mental Health Reporting System	285					●	

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Cross Reference Chart II: Source File for FNIM Identifier		Self-Identification occurs at the time of					Comments
Information Holding Name	Page	Census/ Survey	P/T Insurance Enrolment	Status/ Beneficiary/ Citizen Enrolment	Point of Service or Care		
					Registration	Clinical/ Professional Encounter	
▪ **Primary Health Care Voluntary Reporting System**	292					●	
Health Canada – First Nations and Inuit Health Branch							
▪ **Status Verification System**	300			●			
Health Canada – Public Health Agency of Canada							
▪ **Canadian Chronic Disease Surveillance System**	305		●	●			
▪ **Canadian Tuberculosis Reporting System**	310					●	
Statistics Canada							
▪ **Aboriginal Peoples Survey**	316	●					
▪ **Canadian Community Health Survey**	323	●					
▪ **1991 Canadian Census Cohort: Mortality, Cancer & Residential Mobility Follow-up Study**	329	●					
▪ **Census – Long Form**	333	●					
▪ **Longitudinal Health and Administrative Initiative**	341	●					Data custodians can also bring their own data into the LHAD environment.

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