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or

b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

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Abstract

This study explores how First Nations-run health systems mitigate poor inter-jurisdictional coordination and health service fragmentation, particularly during patient hand-offs or movement. This study used a combination of case studies, qualitative interviews and literature review (especially project evaluations).

This research leads to the following recommended policy options for improving First Nations health care fragmentation: improved information and client registries; standardizing referral, intake and discharge procedures; and, patient navigators.

Keywords: First Nations; Aboriginal; health; jurisdiction; coordination, Canada
For Neil, I am deeply grateful for your encouragement and understanding.
Acknowledgements

I offer my gratitude to Doug McArthur. I was honoured to work with him. Thank you also to John Richards for serving as examiner.

Thanks to both Nancy Olewiler for agreeing to let me join the program part-time while I worked and thanks to Dawn Geil who helped every semester with all the exceptional administrative details of having an unusual, part-time student in the program.

I would also like to acknowledge and give particular thanks to the many participants in this study who shared their insights and experience. It is hoped that in some small way with your help in this research and in the many ways you contribute to the health field, we may continue to work toward improving the health outcomes of First Nations people in Canada.
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<th>Definition</th>
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<tr>
<td>Aboriginal Peoples</td>
<td>Indian, Inuit and Métis peoples of Canada.</td>
</tr>
<tr>
<td>Accountability</td>
<td>Role and responsibility clarity of each organization involved in designing, managing and delivering health services.</td>
</tr>
<tr>
<td>Ambulatory</td>
<td>An ambulatory or “walk-in” visit is any contact with a physician that occurs while the client is not a hospital in-patient.</td>
</tr>
<tr>
<td>Authority</td>
<td>Any authority, other than that of law-making, such as the authority to deliver or administer services or programs.</td>
</tr>
<tr>
<td>Band</td>
<td>See First Nation.</td>
</tr>
<tr>
<td>Body Mass Index</td>
<td>Equal to weight in kilograms divided by height in metres, squared.</td>
</tr>
<tr>
<td>Buy-back</td>
<td>An arrangement between the First Nations Health Authority (FNHA) and Health Canada where the FNHA “buys back” the administration of claims processing and benefits review services from Health Canada.</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>Includes ischemic heart disease (also known as coronary heart disease or coronary artery disease). Fatty deposits accumulate in cells lining the walls of the coronary arteries and the arteries become hard and narrow. This leads to ischemia (a lowering of the supply of oxygenated blood to the heart). Also known as ‘heart disease.’</td>
</tr>
<tr>
<td>Consults</td>
<td>Consult visits occur when a client is referred by one physician to another physician because of the complexity, obscurity, or seriousness of a patient’s illness or because of a request for a second opinion.</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Diabetes mellitus, often simply referred to as diabetes, is a group of metabolic diseases in which a person has high blood sugar, either because the pancreas does not produce enough insulin, or because cells do not respond to the insulin that is produced. This high blood sugar produces the classical symptoms of polyuria (frequent urination), polydipsia (increased thirst) and polyphagia (increased hunger). There are four main types of diabetes covered in this capstone: Type I, Type II, pre-diabetes and gestational diabetes. However, there are other forms of diabetes mellitus including congenital diabetes due to genetic defects of insulin secretion, cystic fibrosis-related diabetes, steroid diabetes induced by high doses of glucocorticoids, and several forms of monogenic diabetes.</td>
</tr>
</tbody>
</table>

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1. As adapted from Wikipedia, Aboriginal Affairs and Northern Development Canada websites and other sources.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
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<tbody>
<tr>
<td>First Nations</td>
<td>The term is used throughout to refer to people who identified as North American Indian. This term is widely used but no legal definition exists. Used to refer to both Status and Non-Status Indians. Some also use the term First Nation to replace the word 'Band' in the name of their community.</td>
</tr>
<tr>
<td>Gestational diabetes</td>
<td>Gestational diabetes occurs when a pregnant woman, who has never had diabetes before, has a high blood glucose level during her pregnancy. It may precede development of Type II diabetes.</td>
</tr>
<tr>
<td>Heart disease</td>
<td>See cardiovascular disease above.</td>
</tr>
<tr>
<td>Hyper-tension</td>
<td>Also known as high blood pressure. If untreated, the condition can lead to heart attack, kidney damage, stroke or enlarged heart.</td>
</tr>
<tr>
<td>Indian Act</td>
<td>Canadian federal legislation, first passed in 1876, that sets out federal government obligations and regulates the management of Indian reserve lands.</td>
</tr>
<tr>
<td>Indian status</td>
<td>An individual's legal status as an Indian, as defined by the Indian Act.</td>
</tr>
<tr>
<td>Inuit</td>
<td>Aboriginal people in northern Canada who traditionally live above the tree line in Nunavut, the Northwest Territories, Northern Québec and Labrador. The singular of Inuit is Inuk.</td>
</tr>
<tr>
<td>Jurisdiction</td>
<td>Law-making authority.</td>
</tr>
<tr>
<td>Lean</td>
<td>Five principles of lean thinking in healthcare are: provide the value patients actually desire; identify the value stream and eliminate waste; line up the remaining steps to create continuous flow (minimize inventory); pull production based on patients’ health care consumption; start over in a pursuit of perfection.</td>
</tr>
<tr>
<td>Life expectancy</td>
<td>Average number of years of life remaining at birth or another age.</td>
</tr>
<tr>
<td>Off-reserve</td>
<td>People, services or objects that are not part of a reserve but that relate to a First Nation.</td>
</tr>
<tr>
<td>Pre-diabetes</td>
<td>Pre-diabetes mellitus is also known as impaired glucose tolerance and occurs when blood glucose is higher than normal but not high enough to qualify as Type II diabetes.</td>
</tr>
<tr>
<td>Regional Health Authority</td>
<td>Recognized jurisdictional health region within a province.</td>
</tr>
<tr>
<td>Registered Indian</td>
<td>See Status Indian.</td>
</tr>
<tr>
<td>Reserve</td>
<td>Land set aside by the federal government for the use and occupancy of an Indian group or Band.</td>
</tr>
<tr>
<td><strong>Self-determination</strong></td>
<td>First Nation has the decision-making power to control planning, management/coordination and delivery of health programs.</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Status Indian</strong></td>
<td>A Status or Registered Indian is a person who is registered under the <em>Indian Act</em>. The act sets out the requirements for determining who is a Status Indian.</td>
</tr>
<tr>
<td><strong>Treaty Indian</strong></td>
<td>A Treaty Indian is a Status or Registered Indian who belongs to a First Nations that signed a treaty with the Crown.</td>
</tr>
<tr>
<td><strong>Tribal Council</strong></td>
<td>Institution established as a grouping of Bands with common interests who choose to work together to provide program and/or advisory services to Bands in their membership.</td>
</tr>
<tr>
<td><strong>Type I diabetes</strong></td>
<td>Results from the pancreas’ failure to produce sufficient insulin, requiring the person to inject insulin. It is also known as insulin-dependent diabetes mellitus (IDDM), or juvenile diabetes.</td>
</tr>
<tr>
<td><strong>Type II diabetes</strong></td>
<td>Type II is a metabolic disorder primarily characterized by insulin deficiency, hyperglycemia (high blood sugar) and insulin resistance and is typically diagnosed in adulthood among the Canadian population (or may be diagnosed among Aboriginal children). Type II results from insulin resistance, a condition in which cells fail to use insulin properly, sometimes combined with an absolute insulin deficiency. This type was formerly referred to as non-insulin-dependent diabetes mellitus (NIDDM), or adult-onset diabetes.</td>
</tr>
</tbody>
</table>
## List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHTF</td>
<td>Aboriginal Health Transition Fund</td>
</tr>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>CLSC</td>
<td>Centre local de services communautaires / Local community service centre (Québec)</td>
</tr>
<tr>
<td>CSSS</td>
<td>Centre de santé et de services sociaux / Health and Social Services Centre (Québec)</td>
</tr>
<tr>
<td>ER</td>
<td>Emergency Room</td>
</tr>
<tr>
<td>FN</td>
<td>First Nation</td>
</tr>
<tr>
<td>FNHA</td>
<td>First Nations Health Authority (BC)</td>
</tr>
<tr>
<td>FNHC</td>
<td>First Nations Health Council (BC)</td>
</tr>
<tr>
<td>FNQLHSSC</td>
<td>First Nations of Québec and Labrador Health and Social Services Commission (QC and Labrador)</td>
</tr>
<tr>
<td>FNHS</td>
<td>First Nations Regional Longitudinal Health Survey</td>
</tr>
<tr>
<td>JBNQA</td>
<td>James Bay and Northern Québec Agreement</td>
</tr>
<tr>
<td>HC</td>
<td>Health Canada</td>
</tr>
<tr>
<td>LPN</td>
<td>Licensed Practical Nurse</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NAHO</td>
<td>National Aboriginal Health Organization</td>
</tr>
<tr>
<td>NIHB</td>
<td>Non-Insured Health Benefits</td>
</tr>
<tr>
<td>NITHA</td>
<td>Northern Inter-Tribal Health Authority (SK)</td>
</tr>
<tr>
<td>NNADAP</td>
<td>National Native Alcohol and Drug Abuse Program</td>
</tr>
<tr>
<td>PHSA</td>
<td>Provincial Health Services Authority (BC)</td>
</tr>
<tr>
<td>RHA</td>
<td>(Provincial) Regional Health Authority</td>
</tr>
</tbody>
</table>
Executive Summary

First Nations patients experience fragmentation and poor coordination in health systems and this is evident in patient handoffs or movement, particularly in cases involving those moving to and from reserves, whether movement results from a patient changing facilities, relocating to a larger city to receive care, or voluntary movement to a new community for other reasons.

Little cross-jurisdictional comparison has occurred on best practices for First Nations-run health systems and their provincial and federal counterparts to mitigate health care fragmentation and poor coordination. This research project examines best practices from Québec, Manitoba, Saskatchewan, the Yukon, British Columbia, Nova Scotia and Newfoundland.

Qualitative research methods were used in this project, including snowball technique to identify 15 interviewees involved in various ways with First Nations health care delivery, programming, policy or evaluation.

Three policy options for improving First Nations health care fragmentation are examined: improved information and client registries; standardized referral, intake and discharge procedures; and, patient navigators. When compared for overall effectiveness, value for money, key player acceptability and administrative simplicity, all three ranked quite high, with patient navigators rated the highest on key player acceptability. While patient navigators is the primary recommendation, the three options are not mutually exclusive. It is therefore, recommended that all three be implemented over time. By creating patient navigator positions first, these individuals could facilitate implementing the other two options (improved information and client registries and standardized procedures).
1. Introduction

When a First Nations person is on-reserve, the health services he or she accesses (e.g., a nursing station) is likely a federally funded health service. However, care from hospitals and private doctors is usually located off-reserve from institutions and care providers under provincial jurisdiction. Uninsured health services such as those located outside of hospitals (mental health, community-based preventative initiatives, dentists, home care, optometrists, etc.) are not generally covered by provinces for First Nations communities and therefore the costs of these uninsured programs are covered by the federal government. The way in which First Nations patients in remote communities access these uninsured health services is by travelling to larger cities themselves or by having the health professionals visit the First Nations community periodically (e.g., a dentist may visit a remote community a few times a year).

In general, First Nations people experience lower health status than the general population regardless of residency (i.e., whether they live on- or off-reserve). While this disparity does not apply across all health conditions in all communities, it is consistently shown by a number of measures, including higher rates and severity of several chronic illnesses, medical complications, and shorter life-spans. For example, the First Nations population experiences significantly higher rates of chronic conditions such as

2 Life expectancy at birth for the First Nations population is estimated at about 7.4 years less for males and 5.2 years less for females when comparing the First Nations population to the Canadian population overall (data from 2000, Health Canada, date unknown).

3 The four leading causes of death for First Nations (in order) are injury and poisoning, circulatory diseases, cancer and respiratory diseases. For Canada overall, the leading causes are cardiovascular, cancer and injuries. For greater detail, please see Richards (2006, pp. 30-54) and Health Canada, (2003a, p. 25).
hypertension, diabetes, and heart problems. Chronic diseases such as these are of particular interest because they “require a complex response over an extended period of time that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment.” (Note, E. & Wa, S., as quoted in Denis et al., 2011, p. 12) A key problem for First Nations in this regard is that the healthcare system is designed around an acute care model and is not designed for response to long-term conditions. Moreover, systems have been designed to respond to single health conditions, not co-morbidities. Exacerbating this problem are three related circumstances specific to First Nations: (1) jurisdictional ambiguity in the Canadian federation; (2) communities’ geographic isolation requiring patients to travel for health services; and, (3) disproportionately high mobility (“hyper-mobility”) of the First Nations population. Each of these factors is explored in this capstone, with particular focus on the lack of jurisdictional clarity in health care.

Jurisdictional ambiguity stems from provinces having primary jurisdiction over health care provision within their borders, while the federal government has primary fiduciary responsibility for ‘Indians’ everywhere in Canada and more specifically, for Indians (First Nations) resident on reserve lands. This means that in many domains, federal jurisdiction ends as soon as one is outside of the geographic boundary of the Indian reserve. This has resulted in piecemeal federal and provincial legislation, and policies that have, in turn, created challenges for effective First Nations health care coordination. As Lavoie et al (2010) point out:

Primary health care for the mainstream population, as well as secondary and tertiary health services are under provincial jurisdiction…. Secondary and tertiary services can be accessed at no cost to the individual. On-reserve services in the form of health centres are supposed to

There are many other measures of relatively poorer health status apparent like higher rates of infant mortality than among the non-First Nations population in Canada. In 1999 the First Nations infant mortality rate was 8 deaths per 1,000 live births, compared to 5.5 for Canada as a whole (Health Canada, 2003a, p. 22); and, higher rates and duration of hospitalization and various chronic conditions.
complement this system, but remain separately funded by the federal government. Physicians paid by the provinces visit the health centres. Patients requiring secondary or tertiary care in between visits or in an emergency situation are transported to the nearest provincial centre. (pp. 11-12)

This overlap leads to uncertainty for patients and health care providers as to who is responsible for healthcare, where and which treatments have been accessed before, and how current treatments will be followed up. This capstone’s policy problem is: **Fragmentation and poor coordination are evident in patient handoffs or movement, particularly in cases involving those moving to and from reserves (whether they occur as a result of changing facilities, relocating to a larger city to receive care, or voluntary movement to a new community for other reasons).**

Recognition by governmental organizations that this is a problem has not necessarily led to improved coordination:

Jurisdictional disputes continue to have significant impacts on the lived experiences of First Nations children particularly those with special needs. Although both the federal and provincial governments embrace the principle that the safety and well being of the child is a paramount consideration, in practice jurisdictional disputes often supersede the interests of children. (Loxley et al., 2005, p. 5)

A poignant example of this is Jordan’s Principle, which came about as a result of jurisdictional disputes in First Nations health care. Jordan’s Principle is named after Jordan River Anderson, a First Nations child from Manitoba who spent his short life in hospital while the Governments of Canada and Manitoba debated who was responsible for funding the child’s care at home. Essentially the Principle states that in the event of a jurisdictional dispute: treat the ailing child first and sort out governmental cost-sharing later if needed. Unfortunately, governments have made little real progress in addressing this issue as the response has not been fully implemented. More detail is available in the section 6 on putting patients before governmental accounting.

While not First Nations-specific, BC’s Public Health Service Agency noted “fragmentation of care is particularly evident in patient handoffs – whether they occur within the walls of the hospital, or during a transfer to another department or facility – making them prone to errors.” In discussing how to improve handoff communications,
the Agency highlights that 35% of errors were caused by communication breakdowns during handoffs. (2010, p. 9)

This capstone explores which policies and implementation approaches promote health care coordination and integration in First Nations-run health systems in Canada and how those organizations learn, build capacity and innovate during that process. This exploration is accomplished through an interdisciplinary literature review, case studies, and interviews. This paper examines best practices for implementing a First Nations health authority or similar health governance structures with the goal of supporting this successful transition toward First Nations-controlled health care delivery. Due to the patchwork of approaches, in part to reflect local circumstances, there are numerous types and degrees of First Nations control over health in Canada. In the search for themes and best practices, this paper also examines various First Nations and Inuit health delivery systems. Through looking at what has worked elsewhere in Canada, it is hoped we may gain insight into what policies and implementation approaches could be adapted to BC’s particular circumstances.

The paper is organized as follows. The background section will provide context, high-level socio-demographics, and social determinants of health and data on hypertension, diabetes and heart problems. This will illustrate the importance of effectively addressing First Nations health issues. It will be followed by brief information regarding governments and organizations with pertinent health delivery mandates related to the cases. The background (section 2) will also provide further detail regarding decentralization of the Canadian health care delivery system as well as touching on increased opportunities for First Nations-specific control of health care by delving into Health Canada’s First Nations health transfer and self-government. The overall purpose of the background section is to provide context for First Nations-specific health delivery. Section 3 will describe in further detail the methodology used (including secondary data sources, literature review), primary sources (interviews), and data limitation. Section 4 will summarize the literature review and key articles. Section 5 will describe cases briefly. Section 6 will set out best practices for effective implementation. Section 7 briefly describes policy options and section 8 will analyse and assess those options and provide recommendations. Finally, based on the foregoing analysis, section 9 concludes with policy recommendations, provide conclusions and suggestions for future research.
Throughout this section, a special focus will be on the effects of patient intake, transfer, tracking and follow-up and how they impact effective coordination of health care for First Nations patients who are moving on- and off-reserve and long-term continuous improvement in First Nations health care organizations.
2. Background

There are five important components to be considered when examining questions about First Nations health, improved inter-jurisdictional coordination and mobility. This background section will explore them in order: the historical, social and geographic determinants of health; health status and general patterns of chronic disease; foundational documents that shape First Nations health jurisdiction; current institutions, policy and program developments in health care delivery; and, finally specific characteristics of Aboriginal mobility.

2.1. Historical, Social and Geographic Determinants of Health

Historical, social and determinants of health impact the extent to which a person has and maintains health and wellbeing. Some socio-economic and geographic determinants of health include: poverty, lower levels of paid employment and income; lower levels of formal education; and – of particular interest in this research – issues of geography and mobility such as geographical remoteness, poorer quality and stability of housing, and higher rates of homelessness. In addition, although not explored below, there is a relationship between First Nations health and the history of colonization, including Indian residential schools.

2.1.1. Poverty and Lower Employment Rates

There is abundant research showing a link between poverty, poor attachment to the labour force, and ill health. For example, First Nations people who have paid employment report better health than those who do not. There are multiple pathways for this relationship. For example, chronic ill health can result in an inability to maintain regular employment, which can inflict an economic burden on poor families by pushing them further into poverty. (Reading, 2009, p. 10) Lower income is also associated with
higher rates of disease and of risky health behaviours correlated with chronic disease (e.g., not eating a balanced and nutritious diet, little or no physical activity or smoking).

### 2.1.2. Risky Health Behaviours

A health pathway model is founded on the idea that exposure to a risk factor increases the likelihood of further exposure and eventually may result in disease. One of the risk factors of developing disease is smoking. Smoking is more prevalent among Aboriginal people than in the Canadian non-Aboriginal population; Aboriginal people start earlier and smoke more frequently. (Assembly of First Nations, 2007a; Reading, 2009)

### 2.1.3. Moving Frequently

Aboriginal people, including First Nations people, change residences more frequently than do non-Aboriginal people in Canada. (Graham & Peters, 2002) Aboriginal people move for numerous reasons and usually cite family, employment and education as reasons. Frequently changing residences can make accessing health services difficult and may exacerbate discontinuity of care and fragmented health service access.

Two of the reasons that migration and service provision matter is that the Corbiere decision (Corbiere v. Canada (Minister of Indian and Northern Affairs) (1999) 2 S.C.R. 203) grants on-reserve voting rights to First Nations members living off-reserve while at the same time First Nations Chiefs claim jurisdiction over their people wherever they live, and seek to provide them services. Another reason, key to this capstone, is that when a First Nations person is on-reserve, she is likely under ‘federal jurisdiction’ for much of her health care whereas as soon as she leaves the reserve for any length of time, she is under provincial jurisdiction.

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5 To a lesser, but still significant, extent they are motivated to move in response to housing and health issues. (Graham & Peters, 2002)
Migration among Aboriginal people from the reserve to urban centres has led to an increase in the number of Aboriginal people now permanently residing in urban areas (Plumb, as referenced in Reading, 2007, p. 18; Graham & Peters, 2002). More than half of the registered Indian population resides off-reserve. The rate of movement into cities from elsewhere, and the frequency of mobility within a city, are both far greater for Aboriginal people than for non-Aboriginal people. (O'Donnell, 2011, pp. 11-14) Once Aboriginal people arrive in a city, they also tend to move within the same community/city more frequently than non-Aboriginal people. This is symptomatic of high levels of residential instability and invisible homelessness. (Distasio et al., 2004, p. 17) Poorer quality and stability of housing and homelessness are associated with poorer health status for a number of reasons. Reading (2007, p. 17), among others, posits that migration patterns have led to both an increase in the number of urban Aboriginal people and also an increased Aboriginal homeless population.\(^6\)

There may not be a clear link between where one lives (on- or off-reserve) and where one accesses health services. For those who are moving on- and off-reserve, the boundary of the reserve is permeable and movement is fluid. For example, anecdotal evidence from friends and colleagues confirmed that patients who use on-reserve health services may actually live near, but not on-reserve, or may wait until they are on-reserve (e.g., while visiting family) to use services. Similarly, residence may not be not static, even though the majority of a person's family doctor visits might occur within a single regional health authority. Notable exceptions are for those in close proximity to large urban centres. Large centres frequently exhibit a ‘pull’ effect for specialist visits as well as general and family practitioners. (Manitoba Centre for Health Policy, 2002, p. 101) While important to administrators, jurisdiction is of decreasing relevance in the lives of First Nations.

\(^6\) Anecdotal and statistical evidence indicates that Aboriginal people are consistently and disproportionately represented among the homeless in most major Canadian cities. (Helin, as referenced in Reading, 2007, p. 16; Privy Council Office, as referenced in Graham & Peters, 2002, pp. 15-16)
In the urban Aboriginal environment, there are multiple points of direct and devolved service delivery; multiple jurisdictions interacting in the field; dozens of federal departments; diverse interests and voices among distinct Aboriginal groups; and, a mobile population. This equates to a challenging policy environment.\(^7\)

**2.1.4. Health Status and Chronic Disease**

This section briefly describes risk factors associated with chronic diseases of particular concern. In general, Aboriginal populations experience poorer levels of health, have more prevalent chronic conditions that are diagnosed at a younger age when compared to the non-Aboriginal population. Moreover, among Canadians (Aboriginal and non-Aboriginal), only 33% have a written plan for the treatment of their chronic condition. This leads to poor follow-up in the health system(s).

In the 2006 Aboriginal Peoples Survey, among First Nations women 15 years and over who were living off-reserve, only half reported that their health was either excellent or very good. This is smaller than the percentage of women in the total Canadian population who reported excellent or very good health (62%).

The off-reserve Aboriginal population was less likely (42%) to rate themselves as having very good or excellent health than those asked in the non-Aboriginal population (61%). This holds true for both rural and urban Aboriginal people when compared to rural and urban non-Aboriginal people. Research shows that health inequalities exist even after one takes into account other socio-economic factors. Specifically, when looking across Canada, about 60% of the off-reserve Aboriginal population has at least one chronic condition versus only 50% of the non-Aboriginal population. In terms of female/male differences, in 2006, First Nations women were more likely to have multiple chronic conditions than First Nations men: 61% of First Nations women aged 20 and over living off reserve had been diagnosed by a health professional with one or more chronic conditions, compared to 53% of their male counterparts. (O'Donnell & Wallace, \(^7\) An important point of urban coordination is Friendship Centres, located in larger urban areas.)
More alarming, the Aboriginal population is more likely to have three or more chronic conditions when compared to the general Canadian population. (Statistics Canada, 2007; Wilson et al., 2010, p. 374) For example, among those aged 55 to 64, 7% of the Aboriginal population report three or more chronic conditions compared with only 2% of the non-Aboriginal population. The higher-than-average prevalence continues as people age.⁸ (Wilson et al., p. 369) For both older Aboriginal and non-Aboriginal populations, the percentage reporting no chronic conditions decreased as age increased, while the percentage reporting three or more chronic conditions increased as age increased. (ibid., pp. 369, 374)

Chronic diseases are sometimes left undetected for years and are poorly controlled. Both of these situations can lead to premature mortality and morbidity. (Hwang & Bugeja, p. 161; Reading, 2007, p. 20) The Provincial Health Services Authority in BC projects that chronic conditions are growing at rates of 2% to 5% year-over-year. Moreover, “[I]ndividuals with chronic conditions are frequent users of the healthcare system and are estimated to consume 80% of all health care services.” (British Columbia Ministry of Health, Provincial Health Services Authority, 2010, p. 3) Also, due to the already often above-average usage of services and the growing Aboriginal population, it is anticipated that the costs of government services will continue rise dramatically. This creates a challenge in an environment where governments fiscally constrained.

To illustrate why improving patient coordination for First Nations patients is crucial, First Nations adults have higher rates of hypertension, diabetes and many forms of cardiovascular disease than non-First Nations people in Canada. Further detail on chronic disease patterns is in Appendix A.

⁸ Among those aged 75 and older, 51% of the Aboriginal population report three or more chronic conditions in comparison with only 23% of the non-Aboriginal population.
2.2. Jurisdictional Considerations

This section provides a brief description of foundational documents as they pertain to provincial and federal jurisdiction of First Nations health that play an important part in the current fragmentation of health services.

The 1867 British North America Act, now the Constitution Act 1867, defined health services as residing within provincial jurisdiction but Indian affairs as an area for federal jurisdiction. This has created ambiguity. Health services are within provincial jurisdiction; however, the federal Department of Health Act (S.C. 1996, c. 8) makes provision for health matters of the people of Canada over whom Canada has jurisdiction. The Hospital Insurance Diagnostic Services Act (1957) and Medical Care Act (1968) originally established universal hospital and medical insurance systems. The Canada Health Act (1985) sets out Canadian universal healthcare policy and is supported by analogous legislation in every province. The Act also sets out how provinces qualify for funding with respect to health insurance plans.9

The Constitution Act (1867) defines Indian affairs, including the responsibility for the health of Indians on reserves, as being within federal jurisdiction. Despite this, the federal Indian Act does not define areas of responsibility for health services as they pertain to health care for First Nations generally. Health care, when provided by the federal department of Health Canada, is done strictly as a matter of policy rather than treaty or statutory obligation. For this reason, the federal government’s role in the provision of health services is primarily through the narrowly-defined public health and prevention services offered by the First Nations and Inuit Health Branch (FNIHB) within Health Canada.

9 Of the literature reviewed, Cook (2003) does the best to grapple with the concept of paramountcy: when both federal and provincial statues are valid and yet, inconsistent, the federal one wins out. For example, provincial laws cannot impinge upon treaty.
Many, including international organizations, have pointed to this health jurisdiction disconnect and its symptoms. UNICEF argues that the multiplicity of authorities in the Canadian framework “fails to adequately address the health care needs of... First Nations [individuals]... who are either not registered or not living on reserve/traditional territory.” (Canadian UNICEF Committee, 2009, p. 7) Willingness to find creative solutions and provide resources for those solutions varies from one province/territory to another. UNICEF points out that most provinces are “willing to put aside jurisdictional positions for practical partnerships” and one of UNICEF’s recommendation is to “[r]emove jurisdictional boundaries that block effective health care delivery.” (ibid., p. 8) On the other hand, experts in the area say that, “[i]t is rare that a provincial government will divert resources to Aboriginal-specific programs and much more rare that funding will be provided to Aboriginal groups to develop comprehensive primary care services.” (Lemchuk-Favel & Jock, 2004, p. 37) Exceptions are Ontario, British Columbia and Manitoba, which have all invested to varying degrees in urban Aboriginal health centres, which could be considered one form of provincial support toward improving Aboriginal health outcomes.

The Commission on the Future of Health Care report described a “confusing mix of federal, provincial and territorial programs and services as well as services provided directly by Aboriginal communities.” (Romanow, 2002, p. 212) Other issues raised in the report are: inadequate access to health care and resulting reduced health outcomes; difficult cultural-political influences; the requirement to involve First Nations more in health delivery and design; and, the need to increase autonomy for First Nations in program and services. Key recommendations flowing from the Future of Health Care are that government should: (1) consolidate funding and create an Aboriginal Health Partnership; (2) create a clear structure and mandate for said Partnership; (3) ensure specific health needs are addressed; (4) recruit more Aboriginal health workers; (5) increase access to all levels of health service; and, (5) increase training for non-Aboriginal health workers (presumably cultural sensitivity training).

The 1978/79 New Indian Health Policy was a key turning point for enhanced First Nation control as it recognized First Nations could assume responsibility for administering community health programs. This was also recognized in the 1980 Berger Report and the 1983 Pender Report on self-government. These reports argued for the
federal government to establish a new relationship with First Nations and that an essential element of this new relationship was the recognition of self-government. (ibid.)

Greater community control can be seen in self-government negotiations, notably with: the 1986 Sechelt Indian Band Self-Government Act, which was the first self-government in which a First Nation community assumed control over its health services; the 1988 Health Transfer Policy, which increased First Nation control over health but only applied across the provinces, not to the territories; the 1994 Departmental Executive Committee of Health Canada decision to devolve health resources and transfer knowledge and capacity to First Nations and ultimately, move Health Canada out of health care service delivery; and the Government of Canada’s Approach to Implementation of the Inherent Right and the Negotiation of Aboriginal Self-Government (1995) that recognizes that First Nations have constitutional rights to shape their own government to suit their particular circumstances (and thereby introduced another pathway for increasing their control of health services). The 1996 Royal Commission on Aboriginal Peoples also spoke to this.

Many health professionals and academics recognize that improving relationships among health providers is critical to improving care coordination. For example, Lemchuk-Favel and Jock write,

Good working relationships between Aboriginal and non-Aboriginal systems need not be more than instituting effective referral mechanisms and sharing of patient information as required. The success of instituting collaborative relationships will depend on the attitudes and open-mindedness of all parties who have put aside jurisdictional differences to work on common solutions to health issues. (2004, p. 30)

Setting aside jurisdictional differences will be of increased importance in the future as governments struggle to contain healthcare costs. These same authors point out that,

Partnerships are created among communities where feasible to achieve economies of scale. This may involve community-based services or, in the case of large Tribal Council affiliations, secondary and tertiary services such as dental health, medical officer of health, nursing supervision, and environmental health services. In many cases, this has allowed these latter services to be delivered directly by Aboriginal
Peoples as opposed to federal or provincial offices. Even so, the need for community capacity development and local service delivery must be balanced with the economic considerations of larger affiliations and centralization of services. (ibid.)

Increased community control is necessary but will be insufficient to improve health outcomes in a time of fiscal constraint. “The federal and provincial health care delivery in Canada has been likened to two canoes paddling down the same river. These health agencies both delivery services to communities and its members; they have similar goals but seldom cross paths or share information.” (First Nations Health Managers Association, 2011, p. 7) The result is that with more than 30 federal departments and agencies involved in health and non-health Aboriginal programs, programming for the off-reserve Aboriginal population is largely uncoordinated. In addition, it is challenging to ensure that provincial efforts are aligned with federal efforts.

Primary among the federal departments working on First Nations health is Health Canada and its First Nations and Inuit Health branch. Programs and services are provided as a matter of policy; there is no federal legislation. The provision of health programs and services by Health Canada to First Nations is set out in the Federal Indian Health Policy (1979). Health Canada supports targeted, narrowly-defined health promotion programs for Aboriginal people, regardless of residency (e.g., the Aboriginal diabetes initiative). It also supports programs related to environmental health and communicable disease and non-communicable disease prevention and provision of primary health care services, including nursing stations and community health centres in remote and/or isolated communities.

2.3. Non-Insured Health Benefits

As Health Canada’s website states, “There are a number of health-related goods and services that are not insured by provinces and territories or other private insurance plans. To support First Nations people and Inuit in reaching an overall health status that is comparable with other Canadians, Health Canada’s Non-Insured Health Benefits (NIHB) Program provides coverage for a limited range of these goods and services when they are not insured elsewhere. The Non-Insured Health Benefits Program is
Health Canada’s national, medically necessary health benefit program that provides coverage for benefit claims for a specified range of drugs, dental care, vision care, medical supplies and equipment, short-term crisis intervention mental health counselling and medical transportation for eligible First Nations people and Inuit.”

For those individuals registered under the Indian Act for services not generally insured under provincial health insurance programs, health benefits (NIHB) coverage is provided, regardless of whether one’s residence is on-reserve or off-reserve. This includes prescription drugs, dental care, vision, and importantly for this capstone, medical transportation. Costs for these benefits comprise a very significant portion of the Health Canada’s budget and continue to escalate. According to the 2010/11 NIHB report, total expenditures have grown by approximately 6% year-over-year since 2001/02. (Health Canada, 2011) The First Nations population eligible for NIHB increased almost 10% in just the four years between 1998 to 2002. Although NIHB is a national program with standard guidelines, Cook (2003) shows a large variance in patterns of actual benefit use across provinces. The NIHB program consumes about half of the total federally-funded health budget in most jurisdictions and routinely exceeds the annual 3% budget increase. (Lemchuk-Favel & Jock, 2004, p. 36) While the actual costs associated for the NIHB program may exceed 3% increases year over year as shown above, the maximum increase in funds appropriate from Parliament is 3% over the previous year. This may lead to chronic under-funding over the long-term.

Medical transportation – a key aspect of health delivery for Aboriginal communities that are small and dispersed across the country – is a component of NIHB that may be provided to help access the following types of services: (1) provincial / territorial insured medical services (e.g., doctors’ appointments, hospital care, health programs provided to all provincial residents); (2) eligible benefits that are approved by the NIHB Program; and, (3) alcohol, solvent, drug abuse and detox treatment pre-approved by the NIHB Program.

The table below illustrates the patchwork of federal, provincial/territorial First Nations health programming. As the reader can see, there are distinct programs depending on the regional and residency location (on- or off-reserve). Note the specificity of the programs, except Non-Insured Health Benefits, and their relatively
limited coverage. It appears that on the one hand, much effort has gone into reducing “program stacking” (duplication of programs and ability to access the same service in the same place by the same person). On the other hand, effort has also gone into creating targeted programs designed to address specific needs of the First Nations population (e.g., the Aboriginal Diabetes Initiative).

**Table 2.1. Summary of Health Programs and Services as They Pertain to Case Studies**

<table>
<thead>
<tr>
<th>Population</th>
<th>Federal Jurisdiction</th>
<th>Provincial/Territorial Jurisdiction</th>
<th>Which Case Studies this Applies to</th>
</tr>
</thead>
</table>
| FN people living on-reserve          | • Community health, public health nursing, community health representatives, National Native Alcohol and Drug Abuse Program, Home and Community Care, Aboriginal Diabetes Initiative, dental health, HIV/AIDS, Aboriginal Head Start, TB programs.  
• NIHB.  
• Some hospitals in northern locations, Emergency and non-urgent treatment services in remote and isolated communities in addition to the above. | Provincial services, hospital services as covered under the Canada Health Act. First Nations people can generally access other provincial services in facilities off-reserve | MB, SK, BC, QC except First Nations under the James Bay Northern Québec Agreement (JBNQA), NS. |
| FNs under the JBNQA (Québec)         | • National Native Alcohol and Drug Abuse Program, mental health, Home and Community Care, Canada Prenatal Health Program, Aboriginal Diabetes Initiative.  
• NIHB. | Québec: oversees the JBNQA (funds are funneled from federal government through the province); province provides same scope of health services as for the rest of the population. NIHB was transferred to the Québec government. | Québec only |
| FNs in Yukon                         | • Community health services, Community health reps, Aboriginal Diabetes Initiative, HIV/AIDS, Aboriginal Head Start, TB program.  
• NIHB. | All universally available health services | Yukon only |
| First Nations living off-reserve in provinces | • Aboriginal Head Start, Aboriginal Diabetes Initiative (health promotion), HIV/AIDS.  
• NIHB. | All health services | MB, SK, BC, QC, NS (and all provinces) |

2.4. **Regionalizing Mainstream Provincial Health Services**

Most provinces have opted to transfer the authority over planning, priority setting, and delivery of many services to regional health authorities. (Lavoie, 2011) The goals of transferring authority are to: improve public participation in decisions; set priorities that reflect local requirements; provide greater opportunity for local decision-making; and – importantly, for this capstone – improve coordination. Compared to other health authorities, First Nations-run health authorities “occupy a slightly different position in their provincial health care system.” (ibid.) While nearly all provinces have decentralized their health provision, the systems are virtually devoid of formalized mechanisms to ensure Aboriginal representation or linkages. (ibid.) This raises the important question about how mainstream regional health authorities and First Nations health organizations should work together to improve patient coordination.

2.5. **Approaches for Increasing First Nations’ Control of Programs and Services**

The last 40 years have seen programs to enhance First Nations’ control and delivery of health care in their own communities. One important advantage to a First Nation gaining control of its own programming is, of course, self-determination, indigenization and the ability to design and implement more culturally-appropriate health programs. Another advantage is increased flexibility in funding. The Romanow Commission indicated that the problem is not the quantity of funding but rather, the fragmentation of funding, which in turn leads to poorly co-ordinated programs and services.\(^\text{10}\) (Romanow, 2002, emphasis mine)

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\(^{10}\) Leaving the large issue of underfunding aside, chronic capital under-investment is of particular concern. Capital investment is estimated to comprise less than .5% of overall transfer payments including capital funds flowing from Aboriginal Affairs and Northern Development. (Ashton and Duffie-Ashton, 2008)
With the goals of fostering self-determination, culturally-appropriate programming and flexible funding, the enhancement of First Nations’ involvement in and control over community-based health services occurs or has occurred via numerous vehicles, including: the Health Transfer Policy; treaties; self-government; and, the Aboriginal Health Transition Fund.

2.5.1. Health Transfer Policy

As mentioned above, a key turning point for enhanced control was the 1979 Indian Health Policy that recognized First Nations could assume responsibility for administering community health programs – although only on-reserve. The specific programs that can be controlled by First Nations are purposefully constrained. For example these programs include public health nursing, community health representatives, National Native Alcohol and Drug Abuse Program, Home and Community Care (for a full list, refer to programs identified in the table above listed under ‘Federal Jurisdiction’). Despite the relatively limited on-reserve programming, the subsequent Health Transfer Policy, was an opportunity for communities in the provinces to assume control of resources for community-based programs. The arrangement for greater control was expanded to the territories in 1989. Today, most First Nations design and implement programs related to health in their community and employ a significant portion of their own health services staff. (National Collaborating Centre for Aboriginal Health, 2011)

Although the Health Transfer Policy has promoted greater indigenization and flexible funding, it has not been a panacea. As it has evolved, this policy has given rise to a management framework in which health care is “governed by contracts,” mainly through contribution agreements. (Lavoie as quoted in Ashton & Duffie-Ashton, 2008, p. 4) Ashton and Duffie-Ashton go on to show that the:

11 Almost half of the communities across Canada that were eligible for transfer have signed Health Services Transfer agreements. (Health Canada, 2003, p. 3) Of those, about 60% were multi-community transfers and 40% were single community transfers. By 2003, 176 communities had signed an integrated agreement.
Discordant environment has led to two general types of agreements: maximally three- to five-year contribution agreements to fund ongoing services administration by indigenous people; and special initiatives with fixed timelines for funding distributed to Aboriginal provider groups on a competitive basis. Successful applicant groups may often be those with more advanced administrative capacity and not those with the greatest needs for healthcare improvement. (ibid., p. 56)

There is an ongoing challenge of finding a balance between off-loading and autonomy, control and capacity. With respect to increasing First Nations control through a Health Transfer Agreement, there are mixed results regarding the correlation between a community with a Health Transfer Agreement and access to medical services and its increase or decrease in risky health behaviours. Cook (2003) raises concerns about the program as a way of off-loading programs to First Nations; however, she does not suggest how else to achieve greater First Nation control of health programming and policy. Her concerns regarding a lack of clarity on roles and responsibilities are backed up by evaluations of the program. These evaluations recommend role clarification between First Nations, Health Canada, province(s), regional health authorities, and the residual role of the federal government. Furthermore, the author indicated unresolved jurisdictional issues and the ongoing need to establish protocols for federal/provincial

For example, there is “evidentiary support for better health access among individuals residing in communities with a health transfer agreement.” On the positive side, living in a community that is part of a multi-community transfer and having a job may reduce the odds of some unhealthy behaviours such as smoking during pregnancy. This is important in an environment where the smoking rates among pregnant mothers can be twice as high as the Canadian average and because exposure to smoke in the womb is associated with high risks of chronic disease later on in life. The First Nations and Inuit Regional Health Survey also indicates that “more communities with transfer feel their services are equitable to other Canadians, than do non transferred [sic] communities.” (Lemchuk-Flavel, 1999, p. 25) There is also contrary evidence that shows respondents from First Nations communities that are part of a multi-community transfer are more likely to rate their access to health services as lower than First Nations communities that are not participating in multi-community health administration but rather, administer their health care on their own. In addition, living in a community that is part of a multi-community transfer is also associated with both lower frequency and shorter duration of breastfeeding. (First Nations Centre)
responsibility.  

By contrast, past Auditor General findings have found that the objectives of the transfer program have been realized: notably, there has been increased awareness among community members and health had become a higher priority; however, these findings did not measure health outcomes. Further research will be needed regarding patterns of health behaviours in communities and potential inter-relationships with Health Transfer Agreements and other variables.

**How Health Transfer Agreements Work and Rates of Uptake**

There are three phases as explained by Health Canada in *Ten Years of Health Transfer*: pre-transfer planning, bridging, and transfer implementation. The process is designed to occur within the present funding base of federal programs for First Nations are required to provide certain mandatory programs such as environmental and occupational health and safety and communicable disease control programs. (Health Canada, 1999, p. 6)

“Community-based programs are the first level of transfer. Second and third level services are those services provided at the zone and regional level. Generally, second and third level services are of a coordination, consultative and supervisory capacity. Some community-based programs include resources to carry out second, and third level services. In those few instances where resources for second and third level services were transferred, arrangements were usually made to buy back the services from FNIHB.” (Health Canada, 1999, p. 9) Twenty-two percent of FNs are involved in some form of pre-transfer planning; 15% of FNs that have signed Integrated Community-Based Health Services Contribution Agreements and 41% of FN communities have assumed greater responsibility for their health care resources through Transfer Agreements. In addition to greater control of some primary health services and some health programs on-reserve, as of 1999, FNIHB operates four hospitals: Sioux Lookout

Perhaps symptomatic of this lack of clarity in the program, some of the problems identified by evaluations included provincial diabetes education, homecare, the need to expand the scope of nursing practice in isolated communities, the failure to implement Jordan’s Principle and lack of access to specialists.
Zone Hospital in Ontario; Norway House Hospital in Norway House, Manitoba; Percy E. Moore Hospital in Hodgson, MB and the Blood Indian Hospital in Cardston, AB.

2.5.2. Treaties

Another way to increase First Nations control over health delivery is through effective implementation of health provisions in a historic or modern treaty. However, geographic reality again enters the policy world because geographic boundaries frequently differ (that is, treaty, health authority, provincial, and traditional territory boundaries are usually different), which makes coordination more challenging. Lavoie (2011) calls attention to a lack of clarity regarding health provisions included in historic treaties despite health being discussed during the treaty negotiations. This is a point picked up throughout the literature on this topic (for example, Cook). For this capstone, historic treaty health provisions (or lack thereof) are of interest in the context of the Manitoba and Saskatchewan [case studies] and, to a lesser extent, in North Eastern British Columbia. Section 5 explores further the linkages between treaties and coordinating First Nations health care.

Signing a treaty does not necessarily, in itself, change the funding levels for health services. For example, in case of the Nisga’a First Nation in BC, the real benefit for health delivery did not come from an increase in budgets but in providing administrative flexibility. (Lemchuk-Favel & Jock, 2004, p. 42) However, funding arrangements can be significantly different. An important advantage is that treaties generally provide for improved funding flexibility.

2.5.3. Self-government

Yet another way to increase First Nations control over health delivery is through self-government agreements (as stand-alone arrangements or within the context of
modern comprehensive treaties). Self-government provides Bands more flexibility to establish program priorities in response to tribal needs rather than following federal program objectives. Bands are able to expand, consolidate and create new programs to improve services to their community and to make certain laws. Furthermore, a few provinces and territories have legislation that reflects self-government arrangements and provisions for Aboriginal-specific health arrangements. This is despite First Nations health care becoming more complex as a result of self-government agreements. Self-government can have an important positive impact on health program management. This is particularly true where communities that are self-governing have systematic and predictable financial and other health resources. Interestingly, the only non-comprehensive self-government example included is Sechelt (located in BC). Further discussion of self-government, indigenization, cultural safety and self-determination is below in the Implementing the Policy Options section.

### 2.5.4. Aboriginal Health Transition Fund

The Primary Health Care Transition Fund had an Aboriginal-specific envelope for projects: the Aboriginal Health Transition Fund (AHTF) that ran from 2004/05 to 2010/11.

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14 The Government of Canada’s Approach to Implementation of the Inherent Right and the Negotiation of Aboriginal Self-Government (1995) recognizes that First Nations have constitutional rights to shape their own forms of government to suit their unique contexts.

15 Health legislation in the Yukon, Québec and Newfoundland and Labrador contain provisions related to existing self-government agreements. (Lavoie, 2011)

16 Given the otherwise thoroughness of Lavoie’s 2011 piece, it is surprising that the author did not also include the Westbank First Nation (also located in BC). Its self-government agreement, signed in 2003, states that the “Westbank First Nation may enter into agreements with any level of government, including any government agency or entity or any other national, regional or local entity, group or organization, concerning delivery of health services or the application of provincial or other health standards.” (Westbank First Nation Self-Government Act, 2004, S.C. c. 17) Perhaps Westbank was not included in the author’s analysis because no particular health domains or activities are defined within the agreement except jurisdiction over traditional Okanagan medicine. On the other hand, this appears to be generally consistent with the scope of numerous other health provisions found in self-government agreements across Canada and included in the author’s inventory. Since signing nearly 10 years ago, Westbank has chosen to not draw down any further health jurisdiction and looks unlikely to do so in the future, although in April 2012 it publicly announced plans to build an entirely private 100-bed medical facility on its lands.
Set up initially as a five-year initiative, it was renewed for one year only. The fund was not designed to provide monies for new programs and services, nor assume any ongoing financial costs. The AHTF was used for seven projects across Canada and was funded by the federal, provincial and territorial governments. Goals of the projects that were funded included: increased participation of the Aboriginal peoples in the conception, implementation and evaluation of health programs and services; the adaptation and integration of provincial programs to the needs of First Nations, particularly those individuals living off-reserve; fostering increased collaboration and strengthening partnerships; improved coordination of health services and referrals (protocols for patient referrals); and, ultimately, “enhancing service delivery coordination between federal and provincial/territorial governments and Aboriginal communities.” (Health Canada, 2007, p. 8)

Evaluations of these projects described the following as key “ingredients for success”: clear, shared understanding among participants of objectives, roles and direction; trust between parties; recognition of the values each party brings to the table; readiness for change; open minds, willingness to engage in dialogue and explore innovative options; commitment to on-going collaboration – adequate human resources, time, senior level support; political will at all levels; community involvement; flexibility in approach, given the different levels of readiness and priorities among parties; realistic timelines; and, achievable outcomes. (Health Canada, 2010, p. 2) Challenges identified included: multiple parties, specialties and structures; poor understanding of partnerships

Projects were: (1) the Vancouver Island Chronic Illness Care Project, which explored an integrated approach to the management of chronic illness care for First Nations individuals in BC; (2) a cross-sectoral approach to diabetes management in Alberta; (3) Norway House’s Health Care Integration Planning Project, which create an independent health board and plan for an integrated health care delivery structure for First Nations residents and those of the neighbouring community in Manitoba; (4) a plan for holistic primary health care to integrate all services under a First Nations governance in Sioux Lookout, Ontario; (5) nursing colleges in Nova Scotia and New Brunswick; (6) integrated primary health care with Elsipogtog First Nation in New Brunswick that aimed to improve collaboration with Regional Health Authorities; and, (7) a project to create a First Nations health authority under provincial legislation located in James Bay, Québec. Some of the projects funded under a separate enveloped for "Adaptation" were also related to improving cross-jurisdictional harmonization.
in each system; multiple organizational cultures and processes; limited resources (human and financial); and, the significant time required to build relationships. (ibid.) The overall results of the seven projects included an “enhanced awareness among the partners and interveners regarding the catalysts of adaptation and integration and the existing obstacles… The pilot communities demonstrated that many of the identified service barriers can be fully or partially overcome through integration and coordination of services.” (ibid., p. 4)
3. **Methodology**

The methodology included an interdisciplinary literature review, case comparisons and interviews. The literature review used on-line, public and unpublished sources that included academic, government and material produced by health organizations themselves. See section 4 for detail on the types and themes from the literature.

3.1. **Primary Data: Case Comparisons and Interviews**

Much of the data for cases came from literature review, supplemented, where possible, by primary data gathered via interviews. The rationale for using a combination of interviews and literature review is that each approach complements the other. The analysis of key variables relies on the 15 interviews conducted. Interviewees were recruited using personal and professional networks. Interviews were semi-structured to allow for flexibility in the discussions (see list of sample questions in Appendix E). Five were face-to-face; 10 were over the telephone.

In summary, two interviewees worked in direct health delivery (e.g., health directors, nurses); two were provincial health or community policy analysts/directors;

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18 These networks provided opportunities for reaching other federal employees but posed challenges when approaching First Nations organizations. It is possible, that First Nations representatives felt uncomfortable speaking candidly about controversial issues with someone who worked for the Government of Canada. Partly to overcome this potential discomfort, the snowball technique was used in the hopes that an introduction from a known person might increase the chances of getting an interview.
seven were current or retired federal employees working on First Nations health\textsuperscript{19}; three worked for First Nations organizations in the area of health policy or program administration (not direct service delivery); and, two interviewees worked for Inuit organizations. The remaining interviewee is an academic who writes, teaches and consults in this topic area.\textsuperscript{20} In terms of regional representation, interviewees were located or could speak from experience about the following regions: seven in British Columbia; one each in Manitoba, Saskatchewan, the Northwest Territories and Newfoundland; two in the Yukon; and, two at the national level. All interviewees except three were comfortable with being cited if given a chance to review quotes before publishing (see consent form in Appendix D).\textsuperscript{21} Interviews primarily took place between February 15 and April 25, 2012 with two last key interviews taking place, after multiple contact attempts, in June and August of 2012. Data received from the interviews are reflected throughout the capstone but are particularly evident by using quotes in the cases (section 5), best practices for implementation (6), policy options (7) and assessing those policy options (8).

All cases were located in Canada, have existed for an extended period of time, and drew on several years of experience. Case studies and interviewees were initially chosen because the health organizations were First Nations-specific: were health delivery systems run by and for First Nations and served a sizable First Nations population. Due to the fact that delivery systems are different in different jurisdictions, there was no ‘typical’ case. Lack of compatible data and non-standardized approaches made it difficult to compare successes directly. However, the variation proved to be useful because, where best practices emerged in multiple jurisdictions, their validity was

\textsuperscript{19} Several of these individuals had crossed jurisdictional boundaries in their careers and had alternated working with the Government of Canada and First Nations organizations. I have categorized individuals by the organization they were working with at the time of the interview.

\textsuperscript{20} Numbers do not add up as some interviewees fell into more than one category.

\textsuperscript{21} Where I have indicated my source is an interviewee but have not provided a name, this has been an interviewee that has requested their name not be used or their quote was sensitive enough to remove the ability to attribute the comment to that particular individual.
strengthened by seeing initiatives work in multiple locations. Owing to the lack of uniform sampling, the use of the field notes and transcripts were analyzed using the ‘constant comparison method.’ This involved multiple readings and listenings of the interviews along with comparisons to each set of notes and recordings of previous interviews. Repeated themes were sought on the basis of questions in the interview guide or independent themes emerged as a result of being repeatedly mentioned. Findings were also reviewed with two participants for validity and further feedback.

As this paper deals with a socially constructed problem, the analysis is not a neutral endeavor but embedded in my own socially-constructed values. The reader is encouraged to question whether I, as a non-First Nations researcher, have the appropriate knowledge to make statements about First Nations health. I also come with biases from working for the federal government, as well as having an academic and professional background in sustainable community development. While I am in no way an expert in the area of First Nations health, it is hoped that this capstone provides food for thought, if not definitive answers, to health delivery challenges.
4. Literature Review

This research is about unique jurisdictional challenges in Canada; therefore, the literature review focussed on Canadian sources, where possible. Also, wherever possible, information that was First Nations-specific was sought. Two main types of documentation were reviewed: academic and non-academic (‘grey’) literature. As this is not a well-studied area academically, there was greater emphasis on grey literature than academic literature. When it became clear that practitioners (e.g., nurses) at the local level were too busy for interviews, the document review of First Nations-Provincial Ministries of Health-Health Canada coordination issues was broadened to include more than those in the four provinces originally selected for case studies. Given the practical search for viable best practices, reliance on practical, operationally-focused literature was deemed appropriate. Whether for academic or non-academic literature, a wide interdisciplinary net was cast in an effort to seek out and synthesize varied perspectives. With a view to gain practitioner’s operational perspectives and because as my research progressed, insight was gained about the pivotal role nurses play in coordination, much of the literature from the health field was from a nursing perspective. Additionally, several key scholarly documents used were graduate students theses. Other authors researching in this area, such as Cook (2003) and Browne (2003), have noted that few academics other than graduate students are publishing about First Nations health coordination.

22 This led to adding a project at Eskasoni, Nova Scotia, and an organization in Labrador.
4.1. Interdisciplinary Literature and Critiques

For the academic literature, the main areas of reading were epidemiology, health policy, and performance measurement theory. Each of these areas are briefly described below. The academic health literature can be grouped by epidemiological studies and articles about health policy, health systems and First Nations critiques of those policies and systems. Articles describing health status typically compared Aboriginal to non-Aboriginal health status and situations, often grouping First Nations, Metis and Inuit Peoples (“Aboriginal”) together when comparing to non-Aboriginal Peoples. Where data is aggregated for First Nations, Métis, Inuit and any respondent self-identifying as Aboriginal, it remains a useful reflection of the relatively poorer health situation of First Nations people in Canada. Where it is possible to disaggregate data for First Nations population specifically, I have done so.

Both academic and government literature shows that First Nations and Aboriginal Peoples’ health status is generally lower on most measures than that of non-First Nations/non-Aboriginal populations. (Reading, 2009; Assembly of First Nations, 2007; Royal Commission on Aboriginal Peoples, 1996; Romanow Commission, 2002; Aboriginal Peoples Survey, 2006; Young, 2006; Health Canada, 2003a)

Epidemiological rates of disease and morbidity often include, at minimum, a nod toward holistic concepts of First Nations (Aboriginal) health and healing. Commonly, poor health status is linked to social and historical determinants of health. Articles highlighted poverty, low levels of education, unstable and unfit housing and residential schools attendance. A great deal of the latest information on health status of First Nations in Canada is based on surveys. These are self-assessments of one’s own health status and are considered by academia to be roughly consistent with physician assessments and robust enough to form an accurate picture of true rates of disease.

Strategic plans typically agree that chronic medical conditions pose a growing challenge for health systems and that improved communications and coordination are critical to meeting that challenge. BC’s Provincial Health Services Authority indicates that, as the number of individuals with multiple chronic conditions grows, care
coordination will become more complex and programs and services will need to evolve. I argue that this evolution should include better inter-jurisdictional integration.

As we are examining a hyper-mobile population and the policies to improve health programming for this population, it is interesting to note that when describing the health status of on- or off-reserve First Nations people, the literature commonly takes location of residency as a static fact. This may be because longitudinal data is relatively scarce so description and analysis is often based on a snapshot at one point in time.

Importantly, analysis regarding residency’s impact on health status compared populations of on-reserve to off-reserve First Nations people or urban to rural populations. Findings of this comparison were that, generally, First Nations have poorer health status regardless of residency. As Wilson et al (2010) point out:

The effect of place of residence on health status was the opposite in both populations. Older Aboriginal people living in a rural area were 1.15 times more likely to report fair / poor health than their counterparts living in an urban area, while non-Aboriginal people living in a rural area were less likely to report fair/poor health than those living in urban areas. (p. 375)

Regarding accessibility and availability, Aboriginal people generally rate their health care services worse on these two measures. There is one exception: in rural areas, non-Aboriginal people also report health service accessibility challenges. (Tjepkema, 2002) Regarding migration and rural/urban residency, there has been a dramatic increase in the number of Aboriginal people in urban centres and there is also a disproportionate representation of Aboriginal people among those who are homeless in Canada. In terms of rural/urban residential differences, regardless of ethnicity, rural residence is associated with poorer nutrition, inactivity and higher smoking rates. When coupled with lower socio-economic status, there may be reduced access to health care. On the other hand, rural living is also associated with some health benefits for Aboriginal people, especially in Northern Canada. For example, there are some lower incidences of chronic disease among rural Aboriginal people living in the North. Similar to findings in Health of the Off-reserve Aboriginal Population, Crisis of Chronic Disease Among Aboriginal Peoples also speculates that avoiding a Western lifestyle has led to positive health outcomes among Aboriginal people in the North. Contrasting with this is that living
in isolated communities in the North or elsewhere creates health challenges related to fewer physicians, lowered accessibility to medical specialists and long distances to health facilities.

Several authors (for example, Reading) speculate about acculturation as a determinant of health (e.g., groups that start to eat a more westernized diet with higher fat or adopt a more sedentary lifestyle would have lower health status), although this theory has not yet been borne out in the evidence. In the northern territories, reported health status is more similar between Aboriginal and non-Aboriginal populations and the authors speculate that this could be because lifestyles have not been ‘Westernized’ to the same extent as elsewhere. That is, lifestyles are not as sedentary and eating habits have not shifted to diets with higher calories but lower nutritive value. The lack of traditional foods adds to problems with insufficient diets, where fish and wild game have become tainted or difficult to catch. Poor diets are linked to diabetes, obesity and other problems. Although diet and nutrition are important factors for overall wellbeing and can benefit from coordinated health education, due to space constraints they are not explored in detail in this capstone. The Crisis of Chronic Disease Among Aboriginal Peoples showed similarly low levels of physical activity in leisure time when comparing Aboriginal and non-Aboriginal populations. That is, there is little difference between physical activity levels of off-reserve (Aboriginal) and non-Aboriginal people. In Northern Canada, the patterns are a slightly different: Aboriginal people are slightly less likely to be active. This contradicts the theory that there are generalizable statements about ‘Western’ and ‘Aboriginal’ levels of physical activity. Moreover, Manitoba’s First Nations report that in Tribal Council areas in Northern Manitoba, First Nations people live longer than those living in southern Manitoba. (Manitoba Centre for Health Policy, 2002, p. 49) This appears to contradict the theory that the sedentary component of a so-called Westernized lifestyle has been uniformly adopted or rejected by Aboriginal groups. Further research is warranted and currently underway by a number of researchers.

Related to these acculturation theories and determinants of health is a broad discussion of correlations between risky behaviours such as smoking, weight and co-morbidity. Aboriginal people are more likely to have multiple chronic conditions than non-Aboriginal Canadians. This is partly due to higher rates and greater frequency of smoking, which is strongly correlated with diabetes, hypertension and heart disease.
Aboriginal people are more likely to smoke and more likely to smoke frequently than non-Aboriginal Canadians. For all age groups and genders, the smoking rate is approximately twice that found in the Canadian population. (Assembly of First Nations, 2007, p. vii) Regarding weight, the off-reserve Aboriginal population in Canada is just as likely to be considered overweight as non-Aboriginal people. However, off-reserve Aboriginal people are more likely to be considered obese than non-Aboriginal people.

Table 4.1. **Comparison of Off-reserve Aboriginal and Non-Aboriginal Weight (Body Mass Index)**

<table>
<thead>
<tr>
<th>Body Mass Index (BMI)</th>
<th>Off-reserve Aboriginal People (%)</th>
<th>Non-Aboriginal Canadians (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low or Acceptable (BMI less than 25)</td>
<td>45.2</td>
<td>54.2</td>
</tr>
<tr>
<td>Overweight (BMI between 25 and 30)</td>
<td>32.0</td>
<td>31.8</td>
</tr>
<tr>
<td>Obese (BMI greater than 30)</td>
<td>22.8</td>
<td>14.1</td>
</tr>
</tbody>
</table>

Note: Adapted from Richards (2006, p. 35) as based on Tjepkema (2002).

With respect to the hypothesis that increased distance to the nearest (Westernized) health facility results in lower health status, a “simple causal relationship between immediate access to acute care and health status does not exist.” (Health Services Utilization and Research Commission as cited in Lemchuk-Favel & Jock, 2004, p. 34) Therefore, this relationship is not established.

Health policy articles surveyed included academic commentary on mainstream and First Nations health policy reform and First Nations systems analysis. Critiques of Aboriginal or First Nations health systems in Canada are often, but not always, written by academics who are themselves Aboriginal (e.g., Reading). This documentation usually points to both social and historical determinants of health and key foundational documents (e.g., the Constitution, the *Indian Act*) to explain jurisdictional challenges and relatively poorer health status when compared to the Canadian population overall. For example, the starting point for much of the non-scientific, non-federal/provincial writing is the impact of federal assimilation policies and the terrible history of colonization that directly resulted in health care systems that lack cultural sensitivity. With this context, fiscal pressures is often a key driver in promoting and maintaining jurisdictional ambiguity in health care. Some authors, such as Cook, postulate that both provincial and
federal levels of government have gained financially by sustaining jurisdictional ambiguity. Regarding First Nations Health Systems, Lavoie’s *Looking for Aboriginal Health Legislation and Policies* points to failings of the health care system as a result of jurisdictional ambiguity (e.g., how the “framework fails to adequately address the health care needs of… First Nations… people who are not living on-reserve/traditional territory.”) (UNICEF as quoted in Lavoie, 2011) Academic commentary on First Nations health systems frequently includes calls for greater coordination and cohesive approaches to health legislation. These calls are interpreted here to typically mean overcoming jurisdictional fragmentation although this is rarely identified and explored as a ‘jurisdictional’ problem.

Regarding evaluation and performance measurement theory, particularly in the health field, academic approaches are typically technical and positivist. As this did not seem to be a good fit for First Nations’ holistic, integrated concepts of wellbeing and the need to take into account complex socio-economic relationships, capacity-building and indigenizing, other theory-based evaluation models were sought. This led me to a particularly promising and relatively new evaluation model called developmental evaluation. (Patton, 1993 and 2011) The applicability of this approach to First Nations health systems is analysed further in the Section entitled, “Best Practices for Implementation.”

**4.1.1. Holism, Life-Course and Mind-Body Approaches**

There is a need to seek a balance between patients’ use of the Western biomedical system in tandem with traditional Aboriginal health practices. One such approach, the “life-course epidemiological approach” studies long-term effects of physical or social exposures during various stages of one’s life on one’s developmental health and risk for disease. (Reading, 2009, pp. 5-9) Life-course epidemiology integrates scientific, sociological and cultural data holistically. This way of thinking about health is closer to the Aboriginal perspectives on health. A sign of cultural appropriateness is that holism is “integrated into community program design, from the level of patient care to administrative integration of health and social services and integrated planning with housing, training, justice and corrections, schools and other community-based services.” (Lemchuk-Favel & Jock, 2004, p. 29) This matters because if health is defined narrowly,
one coordinates only with a small number of actors. By contrast, if one defines health and wellbeing holistically, one realizes the importance of coordinating with a wider range of actors. Moreover, a holistic, mind-body link is important in Aboriginal concepts of health as is a sense of self-empowerment. There is a relatively higher prevalence of chronic mental illness among Aboriginal people in Canada, yet, considerable variation in rates and types of mental illness exist among First Nations. For the purposes of this capstone, it is worth highlighting an important and complex inter-relationship between poor mental health and chronic physical disease. This may manifest as, among other things: a delay in seeking help; acute mental trauma following a diagnosis of disease; and, a breakdown of key relationships in the patient’s personal and professional life. Depression can be a strong predictor for disease outcomes. These mind-body inter-relationships further emphasize the need for a holistic approach to health coordination.

In particular, this capstone argues that persons with chronic illnesses, who require ongoing contact with health services for monitoring and treatment, can benefit from a holistic, interdisciplinary approach. As is discussed further later in this capstone, clinical integration can be enhanced through the use of clinical protocols, pathways, guidelines, care plans, case management, outcome measures developed by clinical experts around standard treatments, and care processes based on clinical evidence. (Health Canada, 2002, p. 6) The literature, however, does not discuss stretching this concept further to include health care providers from multiple jurisdictions, as proposed in this capstone.

4.2. Reports, Statements, Agreements and Evaluations

The main types of non-academic literature reviewed were policy statements, strategic plans, memoranda of understanding and program evaluations. Sources included documents, websites and books published by governments (federal, provincial

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23 To illustrate, diabetics who suffer from depression are at an increased risk for cardiovascular disease.
and documentation by health agencies. An example is Health Canada’s 2005 *Blueprint on Aboriginal Health*, a self-described plan for improving access and quality of health services through comprehensive, holistic and coordinated service provision.

Regarding program evaluations, there is a plethora of First Nations health system models. However, these tend to be relatively new so there is little trends analysis. Description of pilot projects does not tend to include components that fell away, were abandoned, mistakes made or innovative adaptations. Conversely, there exists a long list of factors of success in the grey literature that is similar to those found in academic First Nations systems critiques. High-level recommendations include: a vision; patient-centred care; commitment to a model of care embedded in social determinants constructs; evidence-based decision-making; stronger patient tracking systems and information systems overall; coordinated entry, case management and discharge, particularly between primary care and secondary/tertiary care (e.g., a health care ‘navigator’ or patient coordinator function) and through interdisciplinary teams.

4.2.1. Fragmentation vs. Continuity and Coordination

Continuity of care is important. The literature and practitioners identify at least three types of continuity: informational, relational and management. (UBC Centre for Health Services and Policy Research, n.d.) Further, the relationship between health facilities (types of integration) is sometimes referred to as "longitudinality, relational, or personal continuity, and it fosters improved communication, trust, and a sustained sense of responsibility." (Reid, 2003) The literature has typically focussed on particular domains: nursing; mental health; primary care; and, disease management. Although patients' individual experiences can be aggregated to the group level—such as doctors' practices or healthcare organisations—the unit of measurement of continuity is fundamentally the individual. Continuity is not an attribute of providers or organisations. Continuity is how individual patients experience integration of services and coordination and continuity as represented by a coordination of care among several different providers may have a significant potential impact on health outcomes. (Reid et al., 2003, p. 9)
4.2.2. Partnerships and Place-Based Policy

The literature varies a great deal when it comes to key components of successful partnerships. One list that fit well for this capstone was the following: (1) a trigger that makes working together worthwhile; (2) favourable political and social climate; (3) clear purpose; (4) clear principles (particularly trust and commitment); (5) structures and processes; (6) capacity; and, (7) evaluation, assessment, and, performance measurement. (Adapted from Apolonio, 2008, pp. 13-18)

In addition to literature regarding partnerships, the concept of place-based policy was explored. Place-based policy is directed at particular locales. An OECD review concluded that Canada’s “disjointed approach” has resulted in “a failure to draw up an integrated urban policy.” (OECD, 2002, p. 159) A key message is multi-level governance and policy require careful management of cross-jurisdictional pressures. Place-based policy often involves multiple agencies and jurisdictions that are not effectively coordinated. To illustrate, one interviewee indicated that national programs aimed at reducing Aboriginal chronic disease both on- and off-reserve had non-integrated components, even when administrators were within Health Canada’s portfolio. The on-reserve component was managed through a branch within Health Canada and the off-reserve component done via the Public Health Agency (a related but separate agency of Health Canada). These components were at times coordinated, and at other times fragmented.

4.2.3. Key Finding from Literature: Fragmentation in Patient Data

The extent of non-comparability and poor quality of health systems data is surprising. Better quality information is required to “inform policy directions and to provide evidence to support choices on how to bring about substantial and lasting change to… health care.” (Health Canada, 2005, p. 24) For example, Aboriginal Health

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24 Established in 2004, partly in response to a SARS outbreak, Canada’s Public Health Agency is one of the agencies that makes up the Government of Canada’s health portfolio. The Agency is managed by Canada’s Chief Public Health Officer.
Transfer Initiatives, such as the evaluation for the Kanesetake Health Center, showed that fragmentation of information led to additional time, effort and cost. Evaluators stated that not knowing about the significant research and previous projects that had been completed meant that many of the steps in their own evaluation could have been skipped. (Kanesetake Health Center, 2011) Further Health Canada admits that,

the multi-jurisdictional complexity of health services delivery to First Nations… challenges the ability to gather comprehensive health information. In many provincial jurisdictions, no mechanism exists to flag data on First Nations… Since it is possible for First Nations… to access physician services in a number of locations (e.g., different communities, cities, or provinces) data are fragmented and not amenable to comprehensive reporting. (2003, p. 9)

I was also surprised by the extent to which policy development has not been cohesive. Policy in this area is often being developed, as I would describe it, “by stealth” – that is, through seemingly endless sample service models/pilots. Ideas are tried and tested, often without documentation or information sharing with other service providers that these pilots are occurring, resulting in massive fragmentation of information and inconsistency of approaches. This feeds further fragmentation of information and inconsistency of approaches. One former senior official from Health Canada (not an interviewee) spoke at a meeting about his time working with the Aboriginal Health Transfer pilots and how the learning from each pilot was designed to occur by “viral contamination.” While this may have been effective on some level, the transfer of knowledge and impact seems to have been quite fragmented leading to my questioning whether the sector is benefitting fully from a pilot-based approach. Some interviewees agreed and some did not with this assessment. For example, in BC, when questioned about a potentially excessive reliance on pilots, James Rankin from the FNHA (2012) responded,

The Prototype Initiative model... it does involve pilots but it’s more than that. It’s looking for successful programs that have been around and identifying if they need pieces that are missing. Like an evaluation piece or more communication or presentation of a successful model to other regions of the province that could use it.... [We can then] identify the successful and not-so-successful models.
It is noted that the health system is fragmented and further, that approaches to improving the fragmentation are in themselves fragmented. The solution is not, of course, one large institution or a massive policy response. The true challenge lay in finding the balance between reflecting unique local circumstances and broad standardization to achieve an integrated system.
5. Cases

The following cases are included in this capstone’s analysis: the James Bay and Northern Québec Agreement; Kanesatake; the Intergovernmental Committee on First Nations Health; the Northern Intertribal Health Authority; File Hills Qu’Appelle – First Nations Health Services; the Athabasca Health Authority; Kwanlin Dun First Nation; the First Nations Health Authority; Eskasoni; and, Nunatsiavut. More detailed summaries of each case are located in Appendix B.

Two cases were explored in Québec: the James Bay and Northern Québec Agreement and Kanesatake. The James Bay and Northern Québec Agreement was a treaty signed in 1975 by the Government of Canada, the Province of Québec and the Cree and Inuit of northern Québec. This treaty includes health provisions that shape the way health is delivered across the territory. Second, Kanesatake is a quasi-urban Mohawk community of about 1,700 people located near Montreal that has second- and third-level health administration.

One case came from Manitoba: the Intergovernmental Committee on First Nations Health. This Committee comprises three levels: Ministerial and Grand Chief; Senior Officials; and, a technical working group. All of these levels have representatives from federal, provincial, and First Nations governments.

Three cases were examined in Saskatchewan: an intertribal health authority, a partnership in File Hills Qu’Appelle, and another health authority located in Athabasca. The Northern Intertribal Health Authority, is a third-level First Nations partnership.

It was later joined by the Naskapi First Nations.
organization comprised of four health organizations flowing from a Tribal Council\(^{26}\), two First Nations and a Grand Council. File Hills Qu’Appelle’s First Nations Health Services is a well-established partnership that includes the All Nations’ Healing Hospital along with a multi-jurisdictional health pilot project. The Athabasca Health Authority, also in Northern Saskatchewan, receives integrated acute care funding from the province and funding from Health Canada. The acute care facility is located on-reserve and has a board that is comprised of First Nations and non-First Nations.

One case was studied from the Yukon. Kwanlin Dun, a self-governing First Nation in Yukon Territory, administers three main health areas: home and community care; clinic nursing services, child health services, and the healthy Aboriginal program; and, clinical counselling.

The case from British Columbia was the First Nations Health Authority. The transfer of health governance to British Columbia (BC) FNs is grounded in numerous agreements, including the Tripartite Framework Agreement on First Nation Health Governance signed by Canada, BC and the First Nations Health Society. Flowing from these past agreements is the creation of a First Nations Health Authority (FNHA), designed to run parallel to, but not duplicate, mainstream health authorities. The FNHA is scheduled to take over the Non-Insured Health Benefits Program in BC in 2013. The governance structure has four components: a First Nations Health Council, the FN Health Directors Association, the First Nations Health Authority and a Tripartite Committee on First Nations Health.

One pilot project was used as a case study from Cape Breton, Nova Scotia. The Eskasoni health integration pilot project involved the First Nation, federal and provincial governments and Dalhousie University. These partners designed, implemented, and evaluated a holistic model of health service delivery in Eskasoni to improve integration and accessibility of health systems.

\(^{26}\) Meadow Lake Tribal Council signed on to an Agreement-in-Principle in 2001 that draws down jurisdiction of health services.
Lastly, one case was chosen from Labrador: the Labrador Inuit (Nunatsiavut). They have a regional office in Happy Valley-Goose Bay and seven community offices that are located in Nain, Makkovik, North West River, Happy Valley-Goose Bay, Rigolet, Hopedale and Postville. Teams work closely with Labrador-Grenfell Health to deliver health services.

To summarize, a comparison of location (e.g., province or territory), and whether the organization is First Nations and/or Inuit, is below.

<table>
<thead>
<tr>
<th>Health Organization/Community Name</th>
<th>Location (Province / Territory)</th>
<th>First Nations (FN) and/or Inuit</th>
</tr>
</thead>
<tbody>
<tr>
<td>James Bay and Northern Québec Agreement</td>
<td>QC</td>
<td>FN and Inuit</td>
</tr>
<tr>
<td>Kanesatake</td>
<td>QC</td>
<td>FN</td>
</tr>
<tr>
<td>Intergovernmental Committee on First Nations Health</td>
<td>MB</td>
<td>FN</td>
</tr>
<tr>
<td>Northern Intertribal Health Authority</td>
<td>SK</td>
<td>FN</td>
</tr>
<tr>
<td>File Hills Qu’Appelle</td>
<td>SK</td>
<td>FN</td>
</tr>
<tr>
<td>Athabasca Health Authority</td>
<td>SK</td>
<td>FN</td>
</tr>
<tr>
<td>Kwanlin Dun</td>
<td>Yukon Territory</td>
<td>FN</td>
</tr>
<tr>
<td>First Nations Health Authority</td>
<td>BC</td>
<td>FN</td>
</tr>
<tr>
<td>Eskasoni</td>
<td>NS</td>
<td>FN</td>
</tr>
<tr>
<td>Nunatsiavut</td>
<td>NFLD/ Labrador</td>
<td>Inuit</td>
</tr>
</tbody>
</table>

5.1. Summary and Analysis of Case Studies

The cases point to several broad conclusions. Better data and health information are required on many fronts. Second, we should strive for a better balance between patient flexibility and responsiveness to unique circumstances on the one hand and a more standardized approach to patient transfers on the other. Standardizing the processes associated with patient intake, transfer and discharge will go a long way toward improving patient follow-up and aftercare as well as provide valuable data and information for the first point above. Thirdly it was found that there is a shortage of resources. Finally, it was found that having a nexus or person helping navigate the
patient transfers is likely the least expensive, most acceptable and effective intervention for reducing system fragmentation.

First, lack of coordination across levels of government is a key concern. It was found that the problem statement created for this capstone is valid: fragmentation is particularly evident in First Nation patient handoffs or movement between health care facilities in different jurisdictions (especially where the patient is moving to and from reserves). Further, there is a distinct lack of integration across the health system. While integrating that system meaningfully does not mean we need one single institution, a complete lack of consistency across provincial/territorial systems means there is significant difficulty in comparing approaches, and ultimately, improving policies. The apparent scarcity of coordinated knowledge sharing poses problems for developing recommendations for best practices. From the concerns about poor linkages at Kanesatake (Québec) to the uncertainty about retaining knowledgeable federal staff in British Columbia, the use of differing standards and practices at key points along the patient pathway was described as a challenge across a number of cases. Related to system fragmentation, a lack of appropriate data is exacerbated by data systems that cannot exchange patient information and therefore cannot coordinate with each other. Nevertheless, the cases do point to broad areas of concern, namely: that better data and improved health information is required.

Second, the cases demonstrate that--balancing the need for improved system integration--is the need to be mindful of striking the right balance between First Nations' unique histories and current circumstances on the one hand and yet achieving some measure of standardization or comparability between First Nations and provincial/territorial health systems. While improving system integration one must be mindful of striking the right balance between First Nations' unique histories and current circumstances on the one hand and achieving some measure of standardization or comparability between First Nations and provincial/territorial health systems on the other hand. Some measure of standardized intake, referral and discharge procedures at the point of hand-offs could go a long way to improving consistency, if not absolute conformity, across health care facilities. However, standardization should not go so far as to ignore the specific needs of at-risk populations. At the organizational level,
processes can be standardized, but care needs to be taken that clients can feel comfortable accessing health care.

Third, another area of commonality, also found in the literature and in interviews, is the concern is the lack of human and financial resources. This is a widespread concern and one that is not limited to First Nations health.

Fourth, an overarching theme is that self-determination and accountability promote better coordination and ultimately, one hopes, better health outcomes. This suggests that, broadly, health authorities across the country are on the right track as they all search for ways to devolve more health responsibility to the local level and that continued efforts to transfer responsibility for health care to First Nations will facilitate improved patient care.

Finally, facilitating client navigation of the health care system appears to produce results and the ‘patient navigator’ as a relatively new role appears to work in various places.

As a result of the themes identified above, policy options proposed in this capstone will be evaluated in terms of their effectiveness, value for money, and administrative simplicity. As well, they will be evaluated in terms of their acceptability to key players in the field of health care coordination; the most economically efficient system will be of little use if it is not acceptable to those who have to use it. Further, based on the cases, interviews and the literature, the key cross-system factors that undermine coordination are: lack of information and poor or no ability to track a client’s use of the health care system, lack of standardized approaches to the critical points along the health care continuum where a patient is moving from one form of health service to another (intake, referral and discharge); and, challenges for patients and their caretakers in navigating between the various health services and facilities.
6. **Best Practices for Implementation**

Best practices in implementation require prioritizing the needs of the patient over intergovernmental needs; self-determination; accountability; considering only substantive formal agreements and second-level organizations; encouraging continuous learning through meaningful evaluations; and, interdisciplinarity. These were developed through repeated readings of the literature from multiple sectors and domains (health, First Nations, community development, private sector management, public administration). Through multiple readings, themes for effective implementation emerged. Those best practices that were reinforced through repeated themes in my interviews with participants, discussions with colleagues and follow-up conversations with research participants, and my own work experience in the area of Aboriginal policy are included below. While they are not policy options, *per se*, they are important best practices and approaches to improving health care coordination for First Nations patients.

6.1. **Patients First**

Successful implementation of policy options to improve coordination must keep the patient as the primary driver for system decisions. The patient’s health outcomes supersede financial or other administrative difficulties between governments. For example, Jordan’s Principle comes from this approach. Jordan’s Principle is named after Jordan River Anderson, a First Nations child from Manitoba who spent his short life in hospital while the Governments of Canada and Manitoba debated who was responsible for funding the child’s care at home. The proposed solution was Private Members Bill 296 that states, "[t]he obligation to meet the needs of the child first always supersedes government interests to establish jurisdictional dispute processes." This essentially means that in the event of a jurisdictional dispute over funding for a First Nation child, the government of first contact will pay for services and seek cost-sharing later. Despite reaching consensus on Jordan’s Principle in the House of Commons and its
endorsement by several provinces, “little progress has been made on implementing it.” (National Collaborating Centre for Aboriginal Health, 2011) For example, in Manitoba, where Jordan Anderson lived, a bill for the implementation of Jordan’s Principle never made it through the provincial Legislature, which chose to only partially implement the Principle on a case-by-case basis for a relatively small number of children experiencing complex medical conditions. (UNICEF, 2009, p. 50) The lack of a systematic approach in inter-jurisdictional cost-sharing is perceived by some as falling short of expectations. Research published in 2005 by the First Nations Child and Family Caring Society of Canada indicates there are not just isolated instances but that bureaucratic conflicts are common: 393 cases in 12 sample First Nations. As the mother of a First Nations child with complex needs says, "There’s a complete lack of access across the country to Jordan’s Principle… This is a gatekeeper practice. The feds can say there are no jurisdictional issues and therefore the need for [Jordan’s Principle] doesn’t exist." (Pictou as quoted in Peters, 2011) The Assembly of First Nations and the First Nations Child and Family Caring Society of Canada filed a complaint in 2007 with the Canadian Human Rights Commission alleging that Canada was discriminating against First Nations children through its “ongoing jurisdictional wrangling.” (UNICEF, 2009, p. 49)

Not specific to Manitoba and heard about and seen in multiple provinces and territories, there continues to be suspicion between federal and provincial levels of government with respect to funding. Jordan’s Principle is just one manifestation of this problem. One of the interviewees described new, direct First Nations-Provincial health care relationships as difficult to establish because of the potential for political and financial challenges. There are often fears that if the FN start working directly with the province, the federal funding and other support will disappear. This was eloquently described by one interview as a fear that the “feds would slip out the back door.” Therefore, it is of utmost importance that health care for the patient be prioritized above financial or other governmental wrangling.

6.2. Self-determination

Self-determination can mean many things to different people including: self-government; cultural adaptation and appropriateness; and/or, decision-making power to
control planning, management/coordination and delivery of health programs. While this capstone emphasizes the operational aspects of decision-making, each of these three inter-related definitions are explored briefly.

First, one definition of self-determination is First Nations’ self-government (and the inherent right to self-government). The “inherent right to self-government” is related to the Aboriginal and treaty rights in s. 35 of Canada’s Constitution Act, 1982; that is, the right of First Nations to self-govern is inherent and existed long before the Indian Act. Moreover, in international law, which Canada respects, all peoples have a right of self-determination. This includes self-determination in governance, which is interpreted to mean that First Nations are entitled to choose their own forms of governance within existing states. Self-government involves moving from the dependency model of the Indian Act, to modern governance arrangements that, if they include health services delivery, can promote stability and transparency, ensure jurisdictional clarity and clarify roles and responsibilities for health programs. Theoretically it also promotes new relationships and inter-jurisdictional arrangements that support Aboriginal socio-economic development and Aboriginal integration into broader Canadian health delivery systems, where appropriate. Effective Aboriginal governance structures tailored to community circumstances establish a better foundation to achieve self-reliance by being able to shift resources to priorities, maximize positive health outcomes, and better manage relationships with other governments.

Second, another element that is related to self-determination is cultural appropriateness, adaptation and safety. Although this form of self-determination is not a primary focus in this capstone, it is important for effective health policy. A good summary of factors that support First Nations culture can be found in Lemchuk-Favel & Jock (2004, p. 29) and include: working toward Aboriginal title to traditional lands; self-government; a cultural facility; and, importantly for the health sector, that “health services are divided between funding for permanent health care providers in their community and those that relied on temporary clinics, fly-in providers or out-of-community health services.” Repeatedly, findings show that “success of the services was not determined by the service model itself, but rather by how well the model fit with the needs of the community, the degree to which it had the support of the leadership and the dedication of appropriate human resources to the services.” (Health Canada, 2001, p. 3) This
demonstrates two things: first, that culture is a key component of health and wellbeing, and second, there is no single gold standard, making it challenging to find (let alone compare) standardized approaches to health administration.

Finally, while the higher-level inherent right to self-government and the need to ensure cultural appropriateness is acknowledged, for the purposes of this research, self-determination is defined more narrowly and pragmatically here: i.e., that the FN has the decision-making power to control planning, management / coordination, and the delivery of health programs. Much of the literature assumes (implicitly or explicitly) that First Nations’ self-determination or ‘indigenizing’ of health systems will improve health status. A great deal of the literature and health policy approaches call for, at least in theory, integration of cultural values of family and community into health programs and services. To illustrate, the First Nations Health Reporting Framework, flowing from the Health Blueprint, “draws a distinct relationship between self-determination and improved health status.” (Ashton & Duffie-Ashton, 2008) Furthermore, Aboriginal groups have long asserted that they seek “control over, not involvement in” health care. (Maar, 2004, p. 55; FNQLHSSC, 2007, p. 4, emphasis mine)

It is important that First Nations have the ability to control health planning, coordination and delivery. The Royal Commission on Aboriginal Peoples, developed recommendations for the health sector that included increasing Aboriginal Peoples’ control over their health system. The value of self-determination is reaffirmed successful indigenous health programs in Canada and other countries where there is indigenous authority over those programs. For example, “[a] decade of Harvard Project research has been unable to uncover a single case of sustained development that did not involve the recognition and effective exercise of tribal sovereignty.” (Cornell & Kalt, 1998, p. 210) Exercising and expressing self-determination involves, among other things, internal accountabilities, choice and the ability to act on opportunities to improve

27 The Harvard Project on American Indian Economic Development is a research project operated under the auspices of the Kennedy School of Government at the Harvard University and the Udall Center for Studies in Public Policy at the University of Arizona.
health program delivery. Theoretically at least, the greater First Nations’ self-determination and autonomy over their own health programming and health delivery, the better the health outcomes, all other things being equal.

As described in the literature review, policy and program discussions on First Nations health endeavor to address systemic power imbalances sourced in various social determinants such as poverty and discrimination. Proponents of this view are implicitly or explicitly embedding the goal of self-determination. One of this capstone’s purposes is to suggest options that promote First Nations capacity and self-determination. While this concept is an easy one to agree with on paper, it is oftentimes difficult for governments at all levels (including First Nations governments) to bring to fruition. One interviewee, speaking from a federal standpoint, said, “This is a hard concept for governments to understand, I think. When you transfer control that means you are no longer in control. And that you have essentially empowered another organization to govern and make those decisions.” Given the programs and services focus of this capstone, self-determination is defined as FN collaboration in or control over the design and delivery of health processes. This may manifest as a process that explicitly, formally and regularly involves shared decision-making regarding the design of programs and strategic policies that directly and positively improve patient movement and coordination.

6.3. Accountability

Accountability is related to self-determination. For the purposes of this capstone, accountability is defined as the obligation to take – and demonstrate – responsibility for performance based on agreed expectations and within the limits of budgets and existing authorities. In an operational sense then, accountability in the context of this research means clarity in the roles and responsibilities of each organization involved in designing, managing and delivering health services. Effective management and delivery of health programming includes the ability of the health organization to operate within their allocated budget. As program delivery moves from federal direct delivery through contribution, integrated, transfer and self-government agreements, other perspectives on accountability will become increasingly important: the accountability of the Chief and
Council to community members and the accountability of Chief and Council to the Minister of Health as well as the accountability of the Minister of Health to First Nations. (Health Canada, 1999, p. 19) Accountability only works if there is a common and shared understanding of what is legitimate, what is required and who should be accountable to whom. The appropriate balance between supporting and funding health organizations and allowing them do their own learning (that is, make mistakes) is a challenging balance to achieve. As one interviewee said about funding another level government to do health service delivery, “Well, I think you have to take a good hard look at what the agreement says. People put a lot of judgments into things without looking at what we agreed to do …I think people have to be very careful, what is it we made agreement to do in those documents and not take it beyond that.”

Given the complexity of the health sector and of accountability measures that contribute to improvement and success, it is difficult to achieve cooperation and partnerships on the basis of edicts. The day is long past, if ever that day existed, when health programming can operate under a command and control system. This applies as much to accountability and accountability reporting as to anything else. Effective compliance can only be realized if responsible parties see, understand and share the commitment. Two-way accountability is key and the day is also long past when any one party can usefully prioritize its accountability needs over those of other parties. Accountability provisions, although necessary, and particularly as funding governments have to demonstrative results to a wider Canadian population, can be seen as onerous. Several interviewees expressed frustration at the reporting burden for Aboriginal health delivery organizations. For example, one said,

Nobody has argued against the need for accountability. They just don’t like the way that it’s being done. It’s too onerous. Let’s rethink it. …Really ask the question, ‘Why do we need this?’ You know, we went through this exercise …once, we spent, oh, a-year-and-a-half. And, what we found was that even though people couldn’t justify certain information being collected, and couldn’t show how it was being used, they insisted on it being collected.

That [is the] kind of mentality you’ve got to deal with…. We’ve got how many [Auditor General] reports now saying we’ve got to do this? And it really hasn’t happened yet, although Health
Canada is at the forefront. ... Aboriginal Affairs [AANDC] is the big partner in all this and they haven’t done a whole lot.

...Government looks at this from the perspective of their own needs, not from the perspective of the clients’ needs.

However, the use of contribution agreements as funding mechanisms presents a challenging balancing act, because government then has only limited control over the FN provider while retaining ultimate responsibility for public expenditures. Implementation of any new approaches to health care programming must facilitate two-way, meaningful accountability without making reporting more time-consuming.

On the other hand, as some arrangements move from contribution agreements to complex financial, oftentimes very large, financial transfers, the First Nations health organization may have challenges maintaining accountability and remaining within their allocated budgets. It is not easy in a non-Aboriginal health administration to maintain accountability, even when the beneficiaries pay taxes (and therefore, indirectly fund their own health services).28 It is much harder in the context of FN patients when the funder is even less direct and in a sense, a third party: the federal government. This latter issue is of particular concern with the First Nations Health Authority’s taking on the BC Non-Insured Health Benefits program (worth over $200M annually). Difficult trade-offs will need to be made to remain within budget, rather than appealing to the federal government for further funding.

Whether First Nations or not, there is potential for weak accountability when people who are receiving health services are not those who have paid for the services (via taxes or fees, for example). In addition, it is possible there will be lower satisfaction levels with health programs and services. This is because federal or provincial funding is removed from the recipient and therefore, severing the normal local, political mechanisms for accountability FN members may request more services than they would

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28 For a good discussion of the pitfalls for relying on fiscal transfers from the federal government without individual beneficiaries’ paying taxes or fees for health services, see Graham and Bruhn (2008) especially pp. 20-21.
be willing to pay for, because they do not fund the health services themselves. Within the federal government, there will be a relatively high incentive to underfund the services it support. Again, these issues may arise in either a First Nations or non-First Nations context. As such, until there are direct financial links and local feedback mechanisms between health service beneficiaries and services delivered, it will be especially important for those administering health services (including managing a system like the First Nations Health Authority in BC) to have: clear roles, responsibilities and performance expectations; balance between service expectations and institutional capacities; transparent reporting that accounts for expenditures and results; and, opportunities for adjustments to the way health services are funded and delivered.

6.4. Formal Agreements and Second-level Administration

Formal agreements between First Nations and provinces are so common in various domains, not just health, that they were originally included as potential policy options. Formal agreements can come in a variety of forms such as high-level, often politically endorsed memoranda of understanding; letters of agreement or publicly announced health delivery frameworks; or, formalized dialogue/process arrangements. However, while formal agreements have the potential to be useful in providing a predictable forum for working together, through my research I discovered that they are rarely a necessity. While formal agreements may facilitate policy initiatives, they may also impede progress as described below. Related to this, many second-level administrative bodies were examined. These come in many shapes and sizes. Typical forms in the First Nations health sector are Tribal Councils and other First Nation aggregations that come together to administer health programs and services. Second-level administration appears to be more useful than formal agreements as discussed further below.

More money across the board is not necessarily the solution. There appears to be no correlation between community size and the assumption of responsibilities. Better-resourced communities were less likely to have assumed responsibility for second-level services than communities who were funded at lower levels. (Lavoie et al.,
Interviewees indicated that some of the most successful projects (primary care health transition fund, health integration initiative, the Aboriginal Health Transition Fund, and now the health services integration fund) created a more strategic and coordinated funding relationship. Where projects required the province (RHA or provincial health ministry) to officially sign-on for funding in order for the First Nation to then secure federal funding, interviewees mentioned greatly improved project outcomes. While one interviewee admitted it was “sort of a ‘forced’ relationship” and that it seemed “demanding” interviewees also readily agreed that this formal funding relationship had a positive influence in “getting organizations together.” Moreover, this structured financial relationship promoted greater coordination outside of the financial realm. One interviewee said that, “once they start working together on a project they see the value in doing more of this stuff. So [the inter-jurisdictional funding has] been a factor in really increasing wide-spread interaction between FNs and RHAs.” This also reinforces the requirement to try and make funding as close as possible to the beneficiary/location of the health services as discussed in the Accountability section above.

Although formal agreements are potentially useful tools, they are not always appropriate. Through my research, I found passionate people at the working level ‘just getting on with the job’ despite many coordination obstacles. One such example was discussed with an interviewee, Gail Turner (2012): the Inuit in Labrador have been working through several Memoranda of Understanding. These MOUs provide a structure for collaborative working arrangements while practitioners are effectively dealing with day-to-day problems at the working level.

On the downside, once formal agreements lose touch with their primary purpose, they cease to be helpful. Furthermore, formal agreements can be problematic in situations where it is politically unpopular to collaborate formally with other levels of government. An interviewee observed,

For example, an assessment of major organizational change in the National Health Service concluded that cooperative inter-organization networks worked best if they were informal and purposeful.
The First Nations [health organization] and RHAs have seen some value in working together, coordinating their services in advance of the political acceptance. So while you saw the province and the First Nations publicly saying, ‘First Nations have only a direct relationship with the federal crown’; in the meantime you saw the actual health services on the ground working together [with the provincial RHA].

In Saskatchewan, First Nations are often organized into groupings that provide versions of second-level administration. These were described as tending “to be the larger, multi-community Bands or Tribal Council, you know, health services that have the capacity to go through annual program planning and procedures to examine programs or assess programs, reallocate money and that kind of stuff.” (Interviewee, 2012) Plus, these second-level administrative bodies, including Grand Councils such as the Prince Albert Grand Council… “explicitly acknowledge challenges created by jurisdiction.” (Prince Albert Grand Council, n.d.)

Formal agreements and second-level administrative bodies can foster longer-term relationships while informal relationships and collaborative arrangements can effective but can be too dependent on individual relationships in delivering programs and overcoming service fragmentation and suffer from staff turnover… “If you don’t have the structured relationship, you might lose the relationship essentially. One of the things we’re pursuing is more of those formalized structures and arrangements between FN-Provincial [organizations]… to avoid a significant loss of the built-up collaboration, their knowledge and shared experience.” (Dean Norton, 2012)

Collaborative arrangements with provincial systems are a significant capacity feature for FNs: they need to be connected with systems that can assist them, give them professional advice, and provide service arrangements and career laddering. However, without preparation when partners in the arrangement leave, “there can be a big gap, with practitioners starting all over again in terms of some of the conversations their predecessors have been having for years.” Interviewees suggested that the last number of years have been a particular challenge in the federal system. To illustrate, Dean Norton (2012) says,
Say over 10 or 15 years, you’ve had a series of conversations with different people every year and a half to two years, you essentially get to a point where you reach an understanding or a common knowledge base. And then the person goes, [and you] start all over again. And that’s because there is quite a high level of turnover in the federal system at the national level. You end up rolling your eyes, and saying, ‘Okay, I have to spend the next 10 months explaining, hopefully they’ll stick around long enough to actually get some stuff done.

The experience of the Northern Intertribal Health Authority (NITHA) in Saskatchewan is telling with respect to the politics of having formal arrangements and second-level administration. The province likely found that NITHA – a single forum – meant it was easier to coordinate with many First Nations. That is, NITHA provided one point of contact for half the First Nations population in Saskatchewan. By virtue of these things, the simple existence of NITHA, a second-level, formalized body, brought the ability to interact in a more coordinated way.

In Québec at Kanesetake, the First Nations health centre itself recommended formalized liaison with the province so health workers would know “who to speak to at the hospital or community health centre” and to ensure that “clients’ needs are better met and resources are used more efficiently.” (Kanesatake Health Center, 2011, p. 21) In their case they set up a multi-agency steering committee with joint working groups. Evaluators indicated that formal “collaboration agreements” should be a fundamental condition of project implementation.” (Aboriginal Psychosocial Interventions Research Group, 2011, p. 38) Moreover, a sign of moving from mere coordination to collaboration is that the Board of Directors of the Kanesatake Health Center was described as participating in the strategic planning session of the local health centre. This is evidence of joint, shared decision-making at an early enough stage to effect change in provincial health programming and bodes well for future work. Generally, people were supportive of a formal agreement between the local community health care system and the local, provincial community health services system (Lac-des-deux-montagnes). Interestingly, this was not always the case. As can be expected, sometimes such arrangements were viewed negatively. For example, the multiple levels of decision-making “weighed down” the reporting and approval processes and were subsequently perceived as being
responsible for implementation delays. (ibid., pp. 39-47) In BC, collaboration was described by one interviewee (2012):

It’s on the ground. In my experience, there’s a lot going on in the regional health authorities... but a lot of it is established through relationship. It may not be formally captured anywhere. There’s a lot of work that takes place that is beneath the radar, that you don’t see in a formal way but it’s there. That’s being cultivated or more enhanced through this initiative.

Provinces have developed second level administrative systems such as health services boards and social service organizations. There are many advantages of organizations that can supply vital expertise and develop a means of efficient and effective coordination and delivery of services. Although provinces and municipalities usually have such bodies (e.g., regional health authorities), there are few analogous organizations within First Nations. This is because the Government of Canada established each First Nation as an autonomous entity and provides separate program funding to each, and there are a multitude of cultural, linguistic and historic heterogeneities among First Nations. Many health services benefit from scale economies because those services cannot be efficiently supplied under the direction of a small First Nation. Many of these First Nations are hindered for reasons discussed previously (small population, geographically remote, and/or a lack of expertise to meet the administrative requirements for delivering key programs and functions such as patient tracking, case management and follow-up). Programs and policies that are designed or delivered in isolation from one another may have difficulty attaining their full potential. In evaluating the Kanesatake health arrangements in Québec, the First Nations health centre found that health services should be “offered through one structure.” (Kanesatake Health Center, 2011) The situation in Saskatchewan was described by Dean Norton (2012) as:

Smaller First Nations, or stand-alone health services – [it’s] harder for them to do everything. I mean, you’ve got a health director who supervises staff, who needs to be a planner, who needs to be an intergovernmental person, who needs to relate to Chief and Council, who needs to relate to the board... who needs to be all of those things, [who has all] those kinds of capacities, and not often do you find that.
In these cases, where there are significant challenges to First Nations capacity, a Tribal Council, or less formal aggregation of communities could be helpful.

On September 4, 2012, the Government of Canada announced significant funding changes to many second-level First Nations administrative bodies, including Aboriginal Representative Organizations (that sometimes also deliver programs and services), and Tribal Councils. AANDC began funding Tribal Councils in the mid-1980s to provide for aggregated delivery of programs and services to affiliated Bands. While, the reduction in overall funding will perhaps not be appreciated by Tribal Councils, the attempt to create incentives for First Nations to aggregate program delivery (the greater the aggregation, the higher the funding provided) could be a positive step forward for coordinated health delivery.

As mentioned above, accountability is a key factor for success and cannot be an afterthought. Formal agreements are not likely to make a significant impact if those agreements do not also have measures of success and accountability built into them. Although exceptionally passionate practitioners at the working level are able to find ways of coordinating patient transfers with or without formal agreements, second-level administrative bodies appear to be effective at fostering consistent, coordinated patient intake, hand-offs and transfers. Formal agreements can set the tone that fosters greater First Nations cultural input and control. Both formal agreements and second-level administrative bodies are possible options for facilitating accountability among organizations. However, formal agreements without sufficient operational substance are not to be relied upon. Formal agreements for the sake of political optics are frequently not useful over the long-term. The value for money is low for formal agreements if they are not concrete and pragmatic. Based on the literature review and interviews, it appears that it is quite rare to have concrete, pragmatic formal Memoranda of Understanding (or whatever form the agreement takes).

As discussed above, there are both advantages and pitfalls involved in formal agreements and second-level administrative organizations. Advantages include providing a structured forum for discussion and decision-making, fostering First Nation capacity, overcoming staff-turnover challenges and ideally, to improving coordination as well. However, disadvantages include scenarios where arrangements are not pragmatic
but symbolic only, that require too much reporting, or where it is politically unpopular to be seen to be formally collaborating.

6.5. Evaluations for Continuous Improvement

More useful and strategic, cross-jurisdictional reporting is important. The Auditor General has repeatedly called for First Nations to meet the requirements for health transfer evaluations and community health plans. For example, when the Auditor General reviewed transfer arrangements (1997), agreements were not based on updated community health plans but on plans developed at the beginning of the transfer process, more than five years earlier. This means that no one was looking to the results in either evaluations or community health plans. Health Canada has worked to improve this. The Auditor General has also pointed to reports that included lists of activities but not performance information. Over and above meeting basic requirements, there is a need for a higher-level, less atomistic approach to evaluations to show that together, the policies and programs are indeed achieving overall strategic objectives. Despite progress, there remains room for further improvement.

In performing the Aboriginal Health Transfer Fund evaluation at Kanesatake, the evaluation team indicated that the most positive outcome of the process was improved communication and awareness: “Awareness was created on both sides, and for Kanesetake in particular, this awareness involved discovering its place within the region and in relation to what the community has and doesn’t have regarding services.” (Kanesatake Health Center, 2011, p. 28)

There is a need for longer health policy, program and evaluation time-horizons. One of the challenges with collaborative evaluations is that it takes longer than the prescribed, non-collaborative evaluation. (Marr, 2004, p. 57) Clear evaluation frameworks need to be built into the collaborations from the outset. This may mean benchmarking success as something that gets tracked for one or two decades, not one or two years. (Canadian Policy Research Networks, 2005) Successful cross-jurisdictional collaborations take time as they ask governments, departments, and societal organizations to define shared goals and work together, often for the first time. Trust relations must develop and new capacities for collective action must be built.
rapid health policy and program shifts can hinder the ability to assess health outcomes. As Marr explains, “Continuous changes in health systems do not allow for an adequate maturation and evaluation phase for newly developed community-based health services.” (2004, p. 58) Further, as one interviewee commented, “Too much of what happens in First Nations, I find, is quick and dirty.” By contrast, another interviewee, in discussing a project in BC (“Ahp-cii-uk”), Al Garman, suggested that, “[t]he fact that we are there for the long-haul is one of the key positives.” (2012)

Research has shown that celebrating adaptation matters. For example, in the National Health Service, one of the key factors for organizational change was shifting how success is defined. In this capstone I postulate that one way to facilitate this change is to move away from traditional evaluation approaches to a developmental evaluation approach (particularly for new health initiatives) that celebrates adaptation. Traditional evaluation approaches usually focus on pre-determined program outcomes. Adaptations are seen as irregularities that need to be sifted out to assess the program logic. As a result, key local adaptations are not measured. As one interviewee described it:

[t]he ability to take risks and do things differently is the primary beginning of where change occurs. You’ll never have different outcomes if you keep doing things the same way. Whether it’s a scaled version in a contribution agreement... or if it’s on a full-scale, giant project like the tripartite health plan.... That, I think is very important for people to understand.

A good example of where developmental evaluation would have been helpful is the Aboriginal Health Transition Fund for the Diabetes Community/Home Support Services for First Nations/Inuit in which, “[s]everal variables had influenced progress in each of the communities: the short project time lines and the extensive requirements; the complexity of diabetes; the varied learning needs of both health staff and community members and the length of time needed for change to happen.” (p. 10) Although these same pilots continued to develop and be modified through the project in response to client feedback, etc., there was insufficient tracking of the process or outcomes of modification to show learning, decision-making or identify opportunities for policy.

First Nations capacity to do evaluations that are meaningful for themselves, community-based and that foster further capacity-building is key for improving health
coordination and outcomes. Evaluations are accountability instruments as well as for policy learning and design. Reporting need not be an imposed process for First Nations. FNs are developing their own assessments and creating their own evaluation tools. A key aspect of building health capacity is self-assessment and actively working with partners to do so. Unfortunately, longer-term outcomes and so-called ‘soft’ outputs like capacity building are often left out of evaluations. Finding evaluation approaches that enable on-the-ground collaboration to overcome jurisdictional silos is an important step in achieving policy objectives at the community level as well as the individual patient level. Some project evaluations show a virtuous cycle in which greater coordination among health care staff leads to improvements in patient self-care and empowerment. For example, one Health Canada report stated, “the coordination of follow-up services has improved. As a result, clients are better able to self-manage.” (Health Canada, 2001, p. 15) That is, greater control over services can lead to improved coordination. And improved coordination can lead to improved self-determination and control. It bodes well that the people working toward implementing the First Nations Health Authority are actively engaged in and creating spaces for self-assessment of collaboration:

That experience was good because it allowed participants to work, even collaboratively together in a pair, to look at... collaboration and say ‘here is how we think we are doing.’ Pairs would report back to the group and... we’d have an opportunity... to think about how we are doing.... So that was a good process to go through; one that was planned to be repeated in a year’s time. (James Rankin, 2012)

6.6. Interdisciplinarity

We see from the literature that there are numerous benefits, challenges and recommendations regarding how to improve coordination through interdisciplinary (or “inter-professional”) teams. Recommendations lean toward clinical integration as a means of improving coordination. This capstone proposes to take this one step further and recommend that, where relevant, there is also inter-jurisdictional representation for First Nations patients.

As Health Canada writes in one of its Primary Health Care reports (2005, p. 5), there is a “growing consensus that multi-disciplinary teams will result in better health,
enhanced access to services, improved use of resources and greater satisfaction for both patients and providers.” Interdisciplinary teams are effective and promote improved, holistic health care. Among the cases studied, one excellent example of this was found at the Kanesatake Health Centre. The centre is actively working to support a “professional, holistic, multidisciplinary team approach to client care.” This included, rather unusually, both internal Health Center employees as well as external representatives and departments from outside of the First Nation. (Kanesatake Health Center, 2010, p. 11)

A key challenge to inter-disciplinary teams, and a greater reliance on nurses or other allied health professionals, is scope of practice. This can be politically unpopular with physicians. The challenges associated with blurring roles and responsibilities and creeping scope of practice cannot be under-estimated. Some nurses express the view that “professional boundaries among the various health professionals and between the health professionals and community members [are] uncertain and hence a barrier to improving Aboriginal health.” (Lloyd et al., 2009, p. 8) On the other hand, as Gail Turner (2012), an interviewee, pointed out:

Now is a really good time to look at... if you are delivering... creating your own health system, what would it look like? We’ve often said that we’ve inherited a very cumbersome system in the North and if we were to redesign it, we’d be less reliant on doctors and nurses... and we would build up the capacity of the non-professional at the community level.

As the interviewee alludes to above, there are more nurses than doctors in smaller communities and they play an important role (often with significant decision-

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30 There are many examples of successful integrated health teams because, “team work amongst all health service staff both within and outside the community was found to be crucial” (Health Canada, 2001, p. 4, italics mine). One illustration is the Katzie First Nation Health Promotion team working with First Nations clients with support from governmental and non-governmental agencies, including the local provincial health authority. “Data on accessibility and continuity of care suggest that local health networks have improved the follow-up for patients with chronic diseases and increased the reliance on primary care for patients usually seen by specialists.”
making power) in patient coordination and follow-up as they frequently administer patient referral, tracking, monitoring and discharge.

6.7. Summary of Best Practices

In summary, when implementing any of the three policy options identified below, (information/client registries; standard intake/referral/discharge; and, patient navigators), one must consider how to put the patient first, foster self-determination and accountability; consider whether formal agreements and second-level organizations are a good fit for the particular circumstance; encourage continuous learning through meaningful evaluations; and, finally, promote interdisciplinarity.
7. Policy Options

The policy problem explored in this capstone is that fragmentation and poor coordination in First Nation patient handoffs between health care facilities or programs in different jurisdictions (whether they occur as a result of changing facilities within the same community, relocating to a larger city to receive care or voluntary movement to a new community for other reasons). This is especially so in cases where the patient is moving to and from reserves. There is a multitude of possible policy options initially identified in a scan of academic and non-academic literature, discussions with colleagues, interviews and case studies. Several initially promising options were subsequently discarded because they appeared to be less effective or less acceptable by health care providers. This capstone’s policy options are intended to address some of the challenges and concerns and build on successful projects and approaches raised by the interviewees and literature regarding poorly coordinated First Nations patient transfers. Through gathering best practices and preliminary screening that eliminated less effective or acceptable options, three policy options are recommended. These three outlined below had the highest level of effectiveness (ceteris parabis) compared to other preliminary options. Given that this capstone is looking at improvements to the status quo, the status quo is not included. Each section below contains considerations, examples from various locations and then outlines the recommendation.

7.1. Information and First Nations Client Registries

The first proposed option is improving information and patient databases. This is put forward as a separate option but because it underpins all other proposed options it is presented first. There are numerous barriers that must be overcome. These incomplete administrative data in databases; partial patient documentation located in multiple sites; privacy concerns. First, better quality information and data is required throughout both
First Nations and non-First Nations-run health care systems. The Canadian Institute for Health Information’s research on the mainstream health system reveals a “deeply flawed and fractured systems of provincial/federal health data keeping.” (Mable & Marriot, 2002, p. 37) When looking at First Nations health particularly, one interviewee said, “It is not so much that the province and federal systems are tracking different things, it’s that they are totally different paradigms.” An analogy used by this same participant was that, “one organization prefers to use a lawn mower and the other organization has decided that we’re not going to record the grass – we’ll just let it grow.” In attempting to measure continuity of primary care with (non-First Nations- specific) administrative data, there are several good tools including the Hospital Discharge Abstract Database (reported nationally by the Canadian Institute for Health Information). Although First Nations are included in administrative records, such as these types of hospitalization intake and separation databases, it is usually difficult to identify these patients as First Nations.  

(Health Canada, 2003a, p. 9) The option suggested in this capstone assumes that, while eventually adding First Nations to provincial databases as desirable, it is currently not desired by provinces on a large-scale. The proposal in this capstone is much more modest and would work on a small-scale to show that it can be done on a larger scale.

Second, documentation for First Nations patients is often located in many places: labs, community nursing stations, physicians’ offices, hospitals, chronic care clinics, etc., or not recorded at all, when the patient enters the mainstream provincial health care system.

31 Hospitalization separation statistics specific to First Nations were only available for BC, Saskatchewan and Manitoba. See Health Canada’s “Statistical Profile on the Health of First Nations in Canada” especially pp. 45-51 and pp. 9-10 for detail on current data limitations for First Nations vital statistics, immunization, reportable diseases, hospital separations and other data sources. First Nations identifiers in provincial databases is a key challenge in Saskatchewan currently being worked on, according to Dean Norton, Senior Advisor to the Regional Director General, in Health Canada’s Prairie Region, who says, “Families with little children might move into the city. They access or don’t access public health services in the city. Not having the identifier into the electronic system for the child means you don’t know if that child has been immunized – they don’t pop up. In the provincial system they tend to generate their data, their numbers about FNs in different ways, sometimes it’s self-identification… but if they don’t self-identify you don’t know. Numbers can be suspect.”
Third, one legal issue being successfully overcome by some systems across Canada is privacy concerns about the storing/management/sharing of patients' personal information.³²

Notwithstanding the difficulties, there have been notable achievements. A Québec partnership among the Institut national de santé publique, Cree Board of Health and Social Services of James Bay has led to an agreement for a one-time merging of two client databases that provides the Québec Diabetes Surveillance System with enhanced data on hospitalizations and medical service by Cree of Eeyou Istchee. Manitoba is developing a Status Verification System for better tracking of patients. Also in Québec, there is a partnership between the First Nations of Québec and Labrador Health and Social Services Commission, Aboriginal Affairs and Northern Development Canada and the provincial health ministry (ministère de la Santé et des Services sociaux du Québec) for sharing data, called “I-CLSC.”³³

In Saskatchewan, data sharing agreements in place between First Nations and local health delivery agents were described as a “developing picture” but “we’re not quite there yet.” Although nascent, it is promising that there is a working group established to look into the situation. For example, work continues between the Northern Intertribal

³² Although not First Nations-specific, BC’s Electronic Medical Summary initiative showed it is possible to encrypt and transfer patient information electronically among various health care providers (Health Canada, 2007, p. 11) and maintain the integrity of that data. Regarding First Nations-specific management of patient information, the good news is that the Assembly of First Nation’s general assembly recently agreed to the interdependence of health information between First Nations and provincial/territorial systems. This acknowledged that the “current availability and access to health information for First Nations depends in part on an infrastructure with existing provincial/territorial systems.” (Assembly of First Nations, 2009, Resolution no. 03/2009) In one province, when questioned about the ability to share patient information between systems, one respondent indicated the “damn privacy and confidentiality legislation” seemed to be “choking [the former] kind of collaborative, integrative service” and went on to explain that the new rules around [Provincial] privacy restrictions are negatively impacting efforts at collaborative practice between First Nations and mainstream health organizations.

³³ The objective is to “equip First Nations of Quebec with a client information management system that is comparable to the one found in the provincial health and social services sector, in order to address the clinical and administrative needs.” (Kanesatake Health Centre Inc., 2012, p. 6)
Health Authority and the Province of Saskatchewan about “arrangements that have to be in place so that a FN health authority can be recognized under the health privacy legislation, [like an] entrusted holder of information – they have to be recognized, the province will recognize you as an entity… that holds this information and it’s private.”

Another positive initiative is called CommunityNet where they have achieved interoperability of data with the province through network standardization. Another example of good work in Saskatchewan’s File Hills Qu’Appelle’s First Nations Health Services (File Hills Qu’Appelle Tribal Council), the Health Quality Council of Saskatchewan and the Saskatchewan Ministry of Health, where organizations worked to develop an electronic database to track all on-reserve clients with diabetes within 11 FN communities.

In the Yukon, an interviewee for Kwanlin Dun’s health services described funding received from Health Canada that has allowed for training in electronic medical records. However, these records are mainly for the physician’s patients and would not yet be available for clients using other programs (but not the physician’s services.)

In BC, to improve patient data management, an information management system called “Inter-RAI” is one of the Ministry of Health tools being used for patient and medical information. Apparently, stakeholders are encouraging the federal government to participate. Currently, FNIHB’s data systems and general approaches to information are not compatible. One interesting pilot is a partnership between the Cowichan Tribes and the Vancouver Island Health Authority around the exchange of electronic records (the project is called “Mustimuhw”). The project does not quite reach inter-operability but Cowichan and VIHA will be able to exchange information.

In Nova Scotia’s Eskasoni Aboriginal Health Transition Fund project, there was a partnership between Eskasoni and Dalhousie University. Part of this project was the development of a FN client registry of community members that allows the First Nations community to extract data from the Province of Nova Scotia’s existing databases. However, it was discovered that more capacity for data sharing at the First Nation’s community level was required for the initiative to be fully effective.
7.1.1. Recommendation

The recommendation is as follows. First, the patient that moves between facilities needs one location for their patient data. For the patient normally resident on-reserve, the nexus would usually be the family doctor or the nursing station on-reserve. The family doctor/nursing station becomes the keeper of the patient record. Second, other facilities that the patient is attending for care need to be able to access that patient’s centralized information. This can be done through a simple patient consent form (signed by the patient) to allow the other facility (e.g., a cardiac specialist) to be able to access appropriate information on the patient record. Third, the other facility, say it is this specialist, needs to acknowledge that the primary keeper of information remains with the family doctor to ensure that the specialist’s information is also reflected in the patient’s primary file. The scenario up until now deals with pre-arranged visits where the patient is likely referred to a specialist by the primary family doctor or nurse.

Information and patient data needs to also occur where a patient accesses allied health facilities without family doctor referral or the patient has an emergency off-reserve. The fourth recommendation deals with these types of scenarios: the health facilities/providers off-reserve that are commonly accessed by First Nations people normally resident on-reserve (e.g., a hospital or clinic within driving distance of a reserve) need to agree to specifically track First Nations patients at intake and discharge. Further they need to agree, and know who to contact on-reserve to alert the on-reserve health professionals that there has been an intake/discharge of one of their First Nations members, this ensures that this is reflected on the primary patient file. Fifth, to facilitate this, the patient should have, if they agree, a sticker on their (provincial) health card that indicates the patient is a First Nations patient and who the health care contact is in the patient’s home community. This sticker does two things: it helps the non-reserve or non-federal health facility collect better data about First Nations patients accessing services off-reserve to improve services and it also alerts the off-reserve staff that they need to call the patient’s family doctor/nursing station on-reserve to reflect the off-reserve (e.g., hospital) visit on the patient’s file. Sixth and importantly, while this could be done in a paper-based environment, ideally this is done in a web-based, electronic format to reduce administrative burden, particularly for the on-reserve nursing staff. A web-based set-up is initially more expensive but allows data input and access from
multiple sources. For the purposes of this capstone’s analysis, a paper-based system is assumed.

7.2. Standard Referral, Intake and Discharge

As a result of fragmentation of care, numerous experts recommend standardized referral, intake and discharge information for patients. Underpinning this option is, of course, standardized patient data and information (see above). Regarding the mainstream health system, “Clarifying procedures and processes is particularly important when patients cross service delivery sites or institutional boundaries to receive different types of care.” (Health Canada, 2002, p. 6) Informal discussions with tele-health experts in BC as well as Health Directors in other jurisdictions confirmed that standard referral, intake and discharge procedures are critical to improved patient tracking and continuity of care. Moreover, processes for patient hand-off are of limited use if those systems are not integrated. On the other hand, when done well, protocols that are standardized across multiple agencies can lead to improved patient tracking and monitoring in the short-term and improved treatment, especially post-discharge.

Regarding First Nations patients specifically, it was found that there can be large differences in post-discharge care both between First Nations and non-First Nations patients and among First Nations. Health Canada (2001, pp. 19, 21) is aware of these challenges. It suggests establishing or enhancing linkages to by implementing systems and processes such as clinical practice guidelines and standardized expectations for care, improving case management and timely follow-up. For example, Blackmer and Marshall’s study comparing First Nations versus non-First Nations patients’ post-discharge care for head-injured patients in Saskatchewan showed that there was less
post-discharge planning for First Nations patients than non-First Nations patients. Interviews also showed poor planning and standardization for post-discharge care. As an illustration, one interviewee indicated:

When the province was undertaking provincial health reforms, the province closed small community hospitals. One of the policies that was implemented was an early discharge. While financially and administratively it may have made sense to avoid using an acute care bed for a recovery when the bed is needed by someone more acutely ill, problems can arise. For example, recovering patients are released and sent to a smaller regional facility or sent back into the community. However, [the province] didn’t do this in a planned way with Health Canada or the First Nations. So they implemented the policy and suddenly First Nations find that people are coming home earlier and they have greater care needs. There was no corresponding increase on the [federally-funded] side or capacity to handle [incoming patients recovering from acute health issues]. So it was an inter-jurisdictional lack of coordination. We need a greater emphasis on getting home-care services out to patients who are living back in the First Nations community.

The value of standardized processes is also borne out by the First Nations and Inuit and Community Care Program in Québec, set up to complement Aboriginal Affairs and Northern Development Canada’s Assisted Living Program, which determined that the essential element is “case management, referrals/referral protocols and service linkages for both on- and off-reserve.” (First Nations of Québec and Labrador HSSC, 2006, p. 18) In Saskatchewan, Prairie North Region’s Aboriginal Health Transition Fund project called for integrated intake between Aboriginal communities and the health

34 Factors influencing different post-discharge plans may have included relative distance from a major city and that First Nations patients were more likely to rely on their family and community rather than employing outside help. The study concluded, “[t]here is little doubt... that more emphasis needs to be placed on pre-discharge planning for native North American patients in the form of better family and patient communication as well as on increased post-discharge support for the patients and their families.” (1999, p. 633) Moreover, among Aboriginal Health Transition pilot projects related to First Nations diabetes, a common theme was the absence of coordination of care and follow-up – partially due to lack of standardization.
region. The Eagle Moon Health Office (in the Regina Qu’Appelle Health Region) has a system-wide admission and discharge system although the extent of this system is unknown. In Kwanlin Dun in the Yukon, an interviewee indicated that the Yukon Government has a more formal paper process because they do [occupational therapy], physio[therapy], social work, personal hygiene but not adult care. Kwanlin Dun now does the home assistance. What works particularly well is “very much dependent on whether there is a First Nations discharge planner and they understand what it involves.” (Maureen Crill, 2012) In Québec, at Kanesatake, evaluators recommended and then the health centre created a model for pre-hospital, in-hospital and post-hospital care. The model is based on the role of the Kanesatake Health Centre in the continuum of care before, during and following a stay at St-Eustache hospital. (Kanesatake Health Center, 2010, p. 10)

7.2.1. Recommendation

It is recommended that any First Nations health system identify key points of transitions; and, for those points with the highest patient volume to assess potentially problematic transfer points and develop clinical practice guidelines specific to the highest risk transfer points. The paperwork and administrative steps at those high-traffic patient hand-off points should be re-examined to ensure it is consistent and sets out clinical protocols for coordinated referral, intake and discharge and post-discharge follow-up. This can be done in the form of a binder including appropriate forms and instructions.

7.3. Patient Navigators

In the mainstream health system, various organizations including the Canadian Policy Research Networks (2005) recommend ‘institutional intermediaries’ to help make connections between agencies. One example of this in the health domain is the patient navigator. Patient navigators have numerous titles and functions. These include patient or hospital liaison, community health aide, and, patient advocate. Plus, Community Health Representatives, a position funded by Health Canada, often performs patient navigation-type duties. The navigator helps guide the patient through the complex treatment "maze," facilitates access to local resources (including culturally-appropriate
supports), assists in arranging transportation to medical appointments and may provide advice to the patient and health care professionals about improving communication. The following core characteristics of the navigation function are: time-limited interactions with the patient (targeted around high-risk hand-off/transition phases on the patient pathway – e.g., post-operative discharge) to address service delivery gaps. (Adapted from Pfizer, 2008; British Columbia Ministry of Health’s BC Cancer Agency, 2005)

For First Nations patients, navigators are considered an important tool in helping to manage patients and family members as well. They can remind health care professionals and other service providers to ensure patients are receiving appropriate and timely care (Lloyd et al., 2009, p. 9) and in Aboriginal contexts, provide an important cultural and language translation function. Navigators are typically located in provincial hospitals or larger health clinics where there is a significant First Nations population.

Examples of patient navigators were found in nearly all jurisdictions examined. In Québec, Kanesatake health programming includes hospital liaison staff for the local hospital to improve coordination of care. In British Columbia, “Aboriginal patient navigator projects… led to improvements in access. For instance, the Vancouver Coastal Health Authority reports an increase in referrals from the community – as opposed to hospital referrals.” (Health Canada, 2010, p. 5) Also in BC, a "second First Nations Patient Advocate has been added to BC Children’s Hospital and Sunny Hill Centre for Children and BC Women’s Hospital.” (British Columbia Ministry of Health, Provincial Health Services Authority, 2010, p. 11) In Newfoundland, for another example, a ‘Community Health Aide’ and they work closely with nurses. They were described as having a respected holistic perspective because they “know everything in the community” and are “absolutely invaluable.” Newfoundland also has liaisons in the hospital in Goosebay and in the tertiary hospital at St. John’s. Saskatchewan’s Northern Intertribal Health Authority identified a need and arranged for hospital liaisons. Dean Norton (2012) described them this way:

They tend to be more in-house, cultural appropriateness-focussed.... In the General Hospital in Regina... like a Native Services area where First Nations can go and have ceremonies... talk to somebody. ...I think the roles have been more related to feeling comfortable in the acute care facility, making available interpretive services.
The roles described do not so much involve case management, or intake/discharge coordination but rather translation and access to culturally appropriate healing practices (e.g., facilitating burning sage inside a hospital). In some locations, similar positions have been filled for many years. For example, in Saskatchewan’s Athabasca Health Authority, patient navigators have been in place for over ten years. Yet, simply having a job filled for an extended period of time does not necessarily maximize its usefulness. Hamilton and Dunn-Pierce (2001) critique whether having someone who only makes connections is as useful as someone who acts in a case management capacity. Moving into expectations of case management implies higher skills and training requirements.\(^{35}\)

At Kwanlin Dun in the Yukon, patient navigators were called First Nations liaison workers. “In our hospital we have a First Nations health program which is run with First Nations liaison workers and they do discharge planning so they frequently call us to discuss and refer patients… we’ll talk about meals-on-wheels and other services.” (Maureen Crill, 2012) While useful and positive, the patient navigator function can have difficulties associated with it:

\begin{quote}
It has its ups and downs. It’s a very demanding job for those liaison workers. There’s a fairly constant [staff] change – I think it’s actually been quite stable for a while now. But it went through a time of a lot of staff changes/turnover. And then we found there was quite a bit of breakdown within communications especially around discharge planning. It’s going very well. The liaison worker would go in to see the client, and discuss what they think the patient will need. The liaison worker will also get told by the nurse on the unit, ‘This person is getting discharged tomorrow and will need dressing changes or meals-on-wheels.’ If it’s a service offered by Kwanlin Dun, the First Nations client is offered this service.
\end{quote}

\(^{35}\) Hamilton & Dunn-Pierce (2001, p. 6) also point out that navigators can create greater demand for health services because “as you allow more time to build the trust you open the door to more diverse and complex issues being discovered.”
In summary, patient navigators can be a challenging job to fill, yet are recognized as an effective bridge between health systems or facilities and subsequent follow-up.

### 7.3.1. Recommendation

It is recommended that patient navigators become part of an interdisciplinary team that undertakes formal, regular case review processes. In addition to facilitating cultural appropriateness and basic coordination, this navigator should have the skills and training and be given the responsibility and authority for patient case management.
8. Assessing Policy Options

This section outlines the criteria and measures used to assess the policy options and each option is evaluated for each of the criteria and measures. Using the literature review, cases and interview data analysis above, this section establishes criteria against which policy options’ feasibility are measured. Each criterion is discussed along an explanation of how it is measured. The goal is to assess and compare each of the options to make clearer the trade-offs inherent in health policies while aiming for options that promote health care coordination for patients moving between systems operating under different jurisdictions.

The section starts with a table to show the sub-components and weighting for each criteria, goes on to define each of the criteria and measures separately. At the end of the section, the reader will find a table that condenses and summarizes each option’s scoring against the criteria (a summary of the results). The end goal is to show, in a truncated but easily comprehensible way, the relative strength for each option. It is worth noting, none of these options works in isolation from other policy options.

For example, data and patient registries can be an important foundation for other options. High scores received three points, medium scores received 2 points, and low scores received 0 points. There was weighting used in the analysis, where double points were allotted for effectiveness given it is the primary goal of patient coordination in the policy problem.

8.1. Criteria and Measures

The criteria are: (1) effectiveness; (2) value for money; (3) key player acceptability; and, (4) administrative simplicity. Further information on each of these is below. Ultimately, it is hoped that the analysis, scoring and relative comparisons of options will provide fodder for further discussion and refinement of options in the future.
### Table 8.1. Criteria and Measures Matrix

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Measure</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effectiveness (Total weight: 6)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inter-jurisdiction coordination</td>
<td>The extent to which the option improves patient intake, tracking and follow-up between facilities under different jurisdictions. For the capstone, the emphasis is on- and off-reserve transfers.</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low</td>
</tr>
<tr>
<td><strong>Value for Money (Total weight: 3)</strong>(^1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compared to status quo</td>
<td>Set-up and implementation costs over medium-term</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low</td>
</tr>
<tr>
<td>Compared to other options</td>
<td>Set-up and implementation costs over medium-term</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low</td>
</tr>
<tr>
<td><strong>Acceptability (Total weight: 3)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First Nations coordinators</td>
<td>Degree to which there is potentially strong support for the option from the key coordinators of the option based on interviewees’ expressed views, current literature, and priorities in First Nations policy networks.</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low</td>
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<tr>
<td>Provincial health system</td>
<td></td>
<td></td>
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<tr>
<td>Federal health system</td>
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<tr>
<td><strong>Administrative Simplicity (Total weight: 3)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minimizing resource diversion</td>
<td>Minimizing the extent to which already fully-subscribed human and other (e.g., infrastructure, capital, technology) resources are diverted to the option</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medium</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low</td>
</tr>
</tbody>
</table>

Note: This is a relative measure: there is a high degree of variability within and across options and jurisdictions. However, for exploratory purposes, the reader is referred to Appendix C for further costing scenarios.

### 8.1.1. Effectiveness

This criterion estimates the extent to which each option addresses poorly coordinated First Nations patient intake, transfer, tracking and follow-up, particularly between medical facilities under different jurisdictions (e.g., when the patient is moving on- and off-reserve). A high score of effectiveness signifies an option that very significantly addresses poor patient coordination when a patient is moving between
jurisdictions. A medium score maintains the status quo or somewhat improves on the current state of coordination. A low score does not improve on coordination in any substantive fashion.

8.1.2. Medium-term Value for Money

This criterion relates to estimated set-up and implementation costs (in financial terms) over the medium-term, defined as the next five or six years. This relatively short time-frame is chosen to align with the current funding periods for Health Canada contribution agreements (typically about five years in length). An option that ranks high on value for money means it was estimated to have more savings to the health system in the medium-term than the existing or initial circumstances and compared to the other options presented. By comparison, a medium value for money ranking means roughly equal or marginally more costs compared to savings in the medium-term. A low value for money score signifies significantly more costs to the system over the medium-term than in savings. Please see costing details in Appendix C.

8.1.3. First Nation, Federal and Provincial Health Provider Acceptability

The criterion of acceptability assesses acceptability of an option to key players involved in First Nations health care coordination. Depending on the location, key players may include for example, individual First Nations Chief and Council, especially

36 There are many economic feasibility criteria that attempt to quantify various costs associated with a policy option and the overall economic impact it has on funders. Some researchers have attempted to quantify alternate patient care pathways. For example, using one facility for care that could be provided through a less expensive facility. A specific illustration of this is a patient visiting their family doctor’s office is less expensive than visiting an emergency department. In fact, more and more research is being published that attempts to assess the health care costs of (over)use of emergency departments. Although it would paint a fuller picture, I do not attempt to value the costs and savings resulting from a patient’s improved continuity of care over their individual life. As Marr notes, there is an “expectation to connect specific health outcomes to a particular funding stream without taking into account the bigger picture such as the existence or absence of complementary programs and support systems at the community level. (Marr, 2004, p. 58) For this reason, the reader is encouraged to recall that policy option assessments would need to be further analyzed within a particular context for appropriateness.
the Health Director; second-level First Nations administrative bodies including Tribal Councils; provincial regional health authorities; representatives from the First Nations and Inuit Health Branch within Health Canada, staff at the First Nation’s nursing station, local specialists, interdisciplinary clinicians, local hospital staff, provincial and territorial Ministries of Health, national or regional bodies of the Assembly of First Nations and so forth. Patients and their families are not included in this list of key players although it is hoped that at a future date, capacity and technology will allow for improved direct patient engagement. A policy option assessed as high acceptability means there is a potentially strong support for the option based on interviewees’ expressed views, current literature and priorities in First Nations policy networks. Medium acceptability among key players reflects mixed, shifting or completely unclear levels of support; for example, where players representing the same agency have expressed multiple, contradictory views or where priorities have shifted recently. An option with low acceptability signifies opposition among the majority of key players (especially those who are instrumental in implementation). Opposition may manifest as lacking commitment required to create and implement the option, inability or unwillingness to build and maintain the required processes or infrastructures or significant substantive concerns such as privacy issues.

8.1.4. Administrative Simplicity

The criterion of administrative simplicity is assessed based on existing knowledge, resources, and infrastructure available to implement the policy option. Given that the health system is ‘at capacity’ already, all scenarios include situations where existing resources would likely need to be reprofiled away from current activities to the new policy option. A policy option characterized as high on the scale of administrative simplicity means that human resources with appropriate skills, background and experience and infrastructure (e.g., bricks and mortar/buildings/capital investment, technology) already exist. An option with low administration simplicity means there are significant gaps in human resources, infrastructure or technology would need to be closed in order to implement.
8.2. Discussion of Policy Options and Criteria and Measures

The following assessments of each of the three policy options are based on discussions with interviewees, follow-up conversations with experts and interviewees, researching the literature and developing case studies.

8.2.1. Information and First Nations Client Registries

Effectiveness

Recalling that effectiveness is measured by a standardized, comprehensive and consistent approach to patient intake, transfer, hand-off and tracking, it is hard to imagine any of the options listed below occurring without the underlying information and patient registries required. This option is assigned a high level of effectiveness for a score of 6. However, it is worth noting that data collection alone is not enough to guarantee an adequate flow of information that can improve the effectiveness of health systems.

Value for Money

While initial outlays could be significant, even for a primarily paper-based initiative, the overall positive spin-off effects for all other policy options is extremely high. A primarily paper-based information gathering and tracking system would be less expensive than a fully digital version. A system that initially relies primarily on paper-based records is suggested. See Appendix C for further detail.

As other options’ success is based on having quality information systems, the value for money of implementing this option is higher than that of implementing those alone. This option ranks high with a score of 3.

First Nation, Federal and Provincial Health Provider Acceptability

There are major obstacles to the acceptability of this option including the long-term commitment required to develop and implement anything other than the most basic paper-based approach. Considerable forward planning would be required for keeping even a paper-based approach for collecting, consolidating data and generally running
smoothly. Governments are currently loath to commit to funding projects for longer than the medium-term (e.g., longer than the duration of one funding agreement). If one contemplates at any time to migrate to electronic health records, digital information infrastructure will require more commitment among numerous health providers. Additionally, providers will need to overcome privacy issues, which are of concern to First Nations and others. Assuming all of those issues remain, even for a mostly non-computerized set-up, this option receives a low for acceptability with a score of 1.

**Administrative Simplicity**

Echoing some of the challenges identified above, long-term administration for set-up, implementation and ongoing maintenance will be required. Setting up and maintaining lines of communication between health providers and patients requires ongoing administrative time and resources. While a paper-based approach involving few organizations is the simplest, even then accurate collection and documentation of patient data will not be without its challenges. As such, this option is given a low score for administrative simplicity with a score of 1.

**8.2.2. Standard Referral, Intake and Discharge**

**Effectiveness**

This option targets the point a lack of patient coordination is most likely (e.g., of patient hand-off, intake and release). It allows the health provider to improve coordination by examining and changing what is not currently standardized and may not be working. It encourages multiple health providers who typically transfer or receive patients from one another (e.g., a family doctor on-reserve to a local heart specialist) to communicate regarding processes and protocols for coordinated patient transfers. Because this option targets the most uncoordinated parts of the patient pathway, it appears to have one of the highest possibility of addressing fragmentation. Consequently, this option receives a high rating with a score of 6.

**Value for Money**

A relatively small investment in standardizing key patient hand-offs could greatly improve effective coordination over the medium-term. As the network of facilities grows, the benefits of this option grow in a greater than linear fashion as the facilities interact.
This option does not require as intensive a level of investment as implementing a new information system or training patient navigators. It has a high rating with a score of 3.

First Nation, Federal and Provincial Health Provider Acceptability

The acceptability of this option to key administrators is variable. This will require some experimentation and will likely require considerable time and effort in the early stages. The acceptability of this option could be medium to high if second-level organizations are able to set up the approach. However, it could be low to medium if individual, relatively low capacity or under-resourced organizations are left to attempt standardization. Given this variability, this option is assigned a medium rating with a score of 2.

Administrative Simplicity

This primarily depends on the complexity of the patient pathway being standardized. The greater the number of options/locations/types of treatment/frequency of decision-points, the more complex the pathway and, consequently, the complexity of implementing this option. As with the criterion of acceptability, there are a range of possibilities across health care jurisdictions and facilities, so this option is assigned a medium rating with a score of 2.

8.2.3. Patient Navigators

Effectiveness

Navigators who provide comprehensive coordination services to the patient can be an effective tool. Comprehensive coordination in this case means having the skills and knowledge to effectively refer and follow up patients. This option is assigned a high rating with a score of 6.

Value for Money

Although initial and ongoing training would be required, the potential for greatly improved coordination for the patient based on even one patient navigation function is high compared to both the status quo and the other options. Even when a patient navigator is not on duty, there is a positive impact on effective follow-up. This option is assigned a high rating with a score of 3.
First Nation, Federal and Provincial Health Provider Acceptability

Navigators have proven successful in numerous jurisdictions. This empirical data suggests that it is more likely that decision-makers would be more inclined to implement it than other options. This option is ranked **high** with a score of 3.

**Administrative Simplicity**

At a small scale, this option is potentially fairly simple to implement. Depending on how complex the responsibilities of the navigators are (and higher-functioning navigators are recommended), running a program and staffing several patient navigators could be complex. Positively, there are many pilot projects and successful initiatives from which organizations can learn. As the capstone focuses on the use of higher-functioning facilitators, this option is ranked **low** with a score of 1.

### 8.3. Summary and Recommendations

Although other options were considered, my analysis shows that three policy options are feasible for improving inter-jurisdictional coordination and overcoming fragmentation when First Nations patients move between health facilities. Note that the three options are not mutually exclusive. The three options are identical in terms of effectiveness and medium-term value for money (medium value for money for the options discussed were compared but not ranked as this was a qualitative, not quantitative, analysis). The criterion that varies the most between the three options is acceptability – highest for patient navigators, medium for the standardized intake and discharge and lowest for information and client registries. Therefore, to overcome fragmentation and poor coordination, particularly around patient handoffs or movement, patient navigators should be considered first. These individuals could also then help facilitate standard referral, intake and discharge protocols. While the option for information and client registries is a critical underpinning to improving coordination overall, given some of the administrative and other challenges, it is not recommended as the initial (or easiest) option. Below is a table summarizing the options against the criteria and measures. Recall that as effectiveness was the most important criterion, it is given double the weight as the other criteria.
<table>
<thead>
<tr>
<th>Criteria</th>
<th>A Information and Client Registry</th>
<th>B Standard Referral, Intake and Discharge</th>
<th>C Patient Navigators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness</td>
<td>High (6)</td>
<td>High (6)</td>
<td>High (6)</td>
</tr>
<tr>
<td>Value for money</td>
<td>High (3)</td>
<td>High (3)</td>
<td>High (3)</td>
</tr>
<tr>
<td>Acceptability</td>
<td>Low (1)</td>
<td>Medium (2)</td>
<td>High (3)</td>
</tr>
<tr>
<td>Administrative Simplicity</td>
<td>Low (1)</td>
<td>Medium (2)</td>
<td>Low (1)</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>13</td>
<td>13</td>
</tr>
</tbody>
</table>
9. Conclusion

Some of the areas that were discovered but not explored here and that could benefit from further research include the following. First, theories of acculturation, sedentary and Westernized lifestyles and the link to urban versus rural First Nations health outcomes as compared to non-First Nations people. Second, patterns of health behaviours in communities and potential inter-relationships with Health Transfer Agreements and other variables (for example, do Health Transfer Agreements really correlate with improved health behaviours such as reduced smoking?). Third, while this research used a small and highly select sample of health professionals, future studies would benefit from hearing other voices in the communities. Finally, further exploration and assessment of medical officers of health that are funded federally but permitted to exercise provincial authority would be useful to building knowledge around how to better coordinate First Nations health care and close inter-jurisdictional gaps. Fundamentally, researchers and practitioners need to address the root causes of health inequalities. Understanding the complexities of this patchwork of health care practices requires understanding the historical development of health delivery mandates in Canada. Inequalities were demonstrated through a discussion of high-level socio-demographics, social determinants of health and data on chronic diseases such as hypertension, diabetes and heart problems. This illustrated the importance of effectively addressing First Nations health issues.

This capstone set out to examine best practices for overcoming fragmentation and poor coordination for First Nations patient handoffs or movement, as they move between not only different facilities and care providers but also federal and provincial health jurisdictions. One of the ways to overcome fragmentation and lack of coordination is for First Nations to design and run their own programming. As we saw in the background section, these have evolved to a point where there are now increased opportunities for First Nations-specific control of health care. However, due to the patchwork of approaches and in part to reflect local circumstances, there are numerous
types and degrees of First Nations control over health in Canada. To develop themes and best practices this paper examined various First Nations and Inuit health delivery systems, pilots and projects across the country in an attempt to gain insight into what policies and implementation approaches could be adapted to BC’s particular circumstances.

In terms of these conclusions, this paper analyzed three options (information and client registries, standardized intake, referral and discharge and patient navigators) on the basis of four criteria: (1) effectiveness; (2) value for money; (3) key player acceptability; and, (4) administrative simplicity. All three options demonstrate effectiveness to a similar—but not identical—degree.

Improving information and client registries can be a fundamental step toward improving coordination for patient hand-offs and transfers. The other two options will benefit from it. However, patient navigators look to be the most promising initiative for quickly improving coordination. They would directly and fairly rapidly improve health service coordination. The advantage of creating patient navigators as a first step is that they could also then help facilitate standard referral protocols based, in part, on their hands-on experiences coordinating patient transfers. The locus of control should be particularly focused on the First Nation, as self-determination is a strong factor in improving health outcomes. Improved coordination and self-determination include strong accountability and evaluation measures that facilitate continuous improvement, and interdisciplinary collaboration. Future researchers will also benefit from greater evaluation measures and information sharing in this field. These need to be in place to improve the health care coordination for patients, and ultimately help address health inequalities we see in First Nation populations.
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Appendices
Appendix A.

Chronic Disease Patterns

First Nations experience higher rates of many chronic diseases than non-First Nations people. Details on hypertension, diabetes and cardiovascular disease are provided for illustrative purposes.

Hypertension

First Nations adults have a higher rate of hypertension than the Aboriginal population or Canadian adults generally. Results of the First Nations Regional Longitudinal Health Survey showed that hypertension affected 20.4% of the First Nations respondents (versus 16.4% in the Canadian population). The differences become more striking when one looks at gender: nearly one-quarter (23.4%) of First Nations women have hypertension compared to 17.4% of other women. (Assembly of First Nations, 2007a, p. 16)

About 15% in the Aboriginal population versus 13% non-Aboriginal population report being diagnosed with hypertension. Compared to rates included in the First Nations Regional Longitudinal Health Survey, this shows that hypertension may at times be even higher in the First Nations population than in other Aboriginal (Métis and Inuit) populations. Also interestingly, the off-reserve rates of hypertension are lower than the on-reserve rates. (Tjepkema, 2002, p. 13)

Diabetes

Diabetes mellitus, often simply referred to as diabetes, is a group of metabolic diseases in which a person has high blood sugar, either because the body does not produce enough insulin, or because cells do not respond to the insulin that is produced. This high blood sugar produces the classical symptoms of polyuria (frequent urination), polydipsia (increased thirst) and polyphagia (increased hunger). Complications include loss of
feeling in hands and feet, depressed kidney function and infections. There are several types of diabetes.  

Social determinants of health play a role. In particular, low education and income are strong predictors of this condition. These determinants are over-represented in Aboriginal communities, part of the reason why diabetes prevalence in many First Nations is disproportionately high. Frequently, the rates are two to three times higher than in non-First Nations communities. There are multi-directional contributing factors and pathways between diabetes, high blood pressure, heart disease and other complications. Diabetes comes with a long list of potential complications that generally appear more often in the First Nations population than the non-First Nations population. For example, First Nations diabetics are 20 times more likely than other British Columbians to have eye damage resulting from diabetes. (Daily News, September 23, 2011) As with hypertension, rates for diabetes are higher for women than men.

Moreover, usually Type II diabetes is diagnosed after age 30 among non-Aboriginal diabetics, but there is an alarming trend with First Nations children being diagnosed with Type II at an earlier age: on average at only 11 years old. (Assembly of First Nations, 2007a, p. vii) Another example is with First Nations women living off reserve (age-standardized) across Canada: 21.9% (18.9% for Canadian women generally).

There appear to be links between diabetes and real or perceived denial of medical services through the federal Non-Insured Health Benefits program. When First Nations respondents of the First Nations Regional Longitudinal Health Survey were asked whether they were denied access to Non-Insured Health Benefits, those with diabetes reported denial of benefits more frequently than First Nations people without diabetes. Despite this, it would appear that overall there is generally decent access to treatment. The majority of First Nations adults diagnosed with diabetes are undergoing treatment. (89.8% of respondents reported receiving care for their diabetes). (Assembly of First Nations, 2007a, p. vii) For those who reported not receiving adequate care (in this

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Type I results from the body's failure to produce insulin, and presently requires the person to inject insulin. It is also known as insulin-dependent diabetes mellitus (IDDM) or juvenile diabetes. Type II is a metabolic disorder primarily characterized by insulin deficiency, hyperglycemia (high blood sugar) and insulin resistance and is typically this is diagnosed in adulthood among the Canadian population (or may be diagnosed among Aboriginal children). Type II results from insulin resistance, a condition in which cells fail to use insulin properly, sometimes combined with an absolute insulin deficiency. This type was formerly referred to as non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset diabetes. Gestational diabetes occurs when a pregnant woman, who has never had diabetes before, has a high blood glucose level during her pregnancy. It may precede development of Type II diabetes. Pre-diabetes mellitus is also known as impaired glucose tolerance and occurs when blood glucose is higher than normal but not high enough to qualify as Type II diabetes. Finally, other forms of diabetes mellitus include congenital diabetes due to genetic defects of insulin secretion, cystic fibrosis-related diabetes, steroid diabetes induced by high doses of glucocorticoids, and several forms of monogenic diabetes (definitions adapted from Wikipedia and other sources).
situation, not attending a diabetes clinic), reasons for not attending a clinic included cost, insufficient information and cultural inappropriateness. (ibid., p.21)

**Cardiovascular Disease**

Cardiovascular disease is comprised of many things. One is ischemic heart disease (also known as coronary heart disease or coronary artery disease). Fatty deposits accumulate in cells lining the walls of the coronary arteries, build up, and the arteries become hard and narrow. This leads to ischemia (a lowering of the supply of oxygenated blood to the heart.

Cardiovascular disease survey results display a pattern we see in other literature: that First Nations have higher rates of heart disease than the overall Canadian population and heart attack rates among First Nations is about 20% higher than the Canadian rate. Heart disease can be up to three times higher than the general population and hypertension is about two-and-a-half times higher than the general population. (Assembly of First Nations, 2007a, p. 16; O’Donnell & Wallace, 2011, p. 46; Reading, 2009, p. 89)
Appendix B.

Case Study Descriptions

Québec

A key organization for both the James Bay and Northern Québec Agreement (JBNQA) area in the North and the Kanesatake in the South is the First Nations Québec and Labrador Health and Social Services Commission (FNQLHSSC). This commission, according to its self-stated goal, seeks to develop a “respectful partnership between governments, First Nations authorities and organisations and service providers.” (FNQLHSSC, 2007, p. 3) To support this goal, the Commission releases regular master plans in which the Québec and Labrador First Nations aim to address disparities and improve health. This document is consistent, in many ways, with the Health Blueprint. The Commission works closely with both the regional office of Health Canada as well as the provincial health ministry (ministère de la Santé et des Services sociaux du Québec) at a broad level.

However, at the local community level, individual provincially-run health centres (Centres de santé et de services sociaux or CSSSs or Centres local de services communautaires or CLSCs) do not normally have exceptional clarity on roles and responsibilities as it pertains to their neighbouring First Nations. As in most provinces, there are often significant organizational constraints (both human and financial). (Aboriginal Psychosocial Interventions Research Group, 2011, p. 36) There appears to be no standard referral, intake or tracking mechanisms. This lack of clarity and sometimes low levels of resources, extends across the care continuum to include gaps in federal-only programming as well. For example, despite Aboriginal Affairs’ federal Assisted Living Program and Health Canada’s First Nation and Inuit Home and Community Care program, “significant gaps remain in the service continuum, particularly with regards to higher levels of care provided in the facilities located in the communities.” (FNQLHSSC, 2006, p. 49)

James Bay and Northern Québec Agreement

The James Bay and Northern Québec Agreement was a land claim settlement (treaty) signed in 1975 by the Government of Canada, the Province of Québec and the Cree and Inuit of northern Québec. It was later joined by the Naskapi First Nations. Driven in large part by economic development (a large hydro project), it also contained health provisions. It was a pioneering agreement in that it was the first modern-day treaty. As a result of the treaty, responsibility for health and social services in Cree communities is the responsibility of the Cree Board of Health and Social Services of James Bay. Although eight of the nine Cree communities are accessible by road, transportation is typically by air due to long distances. Population of each of the communities ranges between approximately 624 and 4,000 (Cree Board of Health and Social Services James Bay).
There is a regional hospital in Chisasibi. The Coastal CLSC includes a clinic in Whapmagoostui (Poste-de-la-Baleine, Great Whale River), Wemindji (Paint Hills, Nouveau-Comptoir), Eastmain, and Waskaganish (Fort Rupert, Rupert's House); these communities are located on the eastern coast of James Bay and Hudson’s Bay. The Inland CLSC includes a clinic in Mistissini (Baie-du-Poste), Waswanipi, Ouje-Bougoumou and Nemaska (Nemiscau).

The Cree Board of Health And Social Services of James Bay (CBHSSJB) offers services in general medicine, public health, home care, dentistry, and also social services in each community. In each community nurses provide primary care with the help of a physician (on site or over the telephone) and manage various prevention and health education programs. The CBHSSJB also manages social services in the territory. This facilitates interactions between the personnel of both health and social services. Some First Nations have achieved a “considerable level of community control over health and social services” through the James Bay and Northern Québec Agreement (1975). Services that were previously fragmented are “now integrated under the Weeneebayko Area Health Authority to better meet the needs and priorities of James Bay Coastal First Nations.” (Health Canada, 2010, p. 4) In terms of financial investments, in 2005/06 Health Canada invested some $13.7 million in a range of health programs for Cree, Inuit and Naskapi communities. It is also worth noting that in 2008 the Government of Canada paid an additional $1.4 billion for resolution of litigation over past JBNQA implementation issues as well as other things. While this was not health-specific, it does point to room for improvement in the (federal) government to (First Nations) government relationship in Québec.

**Kanesatake**

Kanesatake is a quasi-urban Mohawk community located in southern Québec, near Montreal. The population is approximately 1,700. They have second- and third-level health administration. As mentioned above, evaluators for Kanesatake health programming indicating that limited funding was a challenge and made it difficult to “build bridges” across organizations and governments. For example, evaluators cited challenges to “increasing linkages with the local provincial partners when the resources at the local [provincially-run community health centre] are already very limited.” (Kanesatake Health Center, 2011, p. 29)

**Manitoba: Intergovernmental Committee on First Nations Health**

Patterns of health care use by First Nations shows differentials between areas of the province as well as differences when compared to non-First Nations Manitobans. There is a history of the Province of Manitoba and the federal government working on health issues in a structured, formal way. Perhaps as a reflection of this work, there are second- and third-level services transfer in Manitoba such as the Anishinaabe Mino-Ayaawain Inc. with the Interlake Reserves Tribal Council.

However, there is some scepticism about true motivations for those formal federal/provincial arrangements. As evidence, the 1964 Memorandum of Understanding (MOU) between the Province of Manitoba and the Government of Canada setting out how to deliver services in northern Manitoba is described as how “governments, when convenient, will swap responsibility for service delivery to First Nations people.” (Cook,
2003) The MOU is based on the proportion of population within Northern Manitoba communities that are treaty First Nations. Communities with a majority treaty population became federal jurisdiction for clinical and community health services while communities with a majority of non-treaty people saw the province take over management of health services. One might argue that federal-provincial coordination of programming such as this is a positive, pragmatic approach.

One unique pilot project discovered was that each (federal) First Nations and Inuit Health regional office has a public health specialist (a medical doctor). In Manitoba the regional medical officer has been designated under provincial legislation. This is significant because there is no comparable federal legislation for public health officers on-reserve. Therefore, designation under provincial legislation provides the individual the full legal authority that provincial public health officers have off-reserve, while they are on-reserve (based on a conversation with Al Garman and another interviewee, 2012). This approach was not seen frequently elsewhere so is not explored in detail within this capstone. However, it is a worthy example of coordination that warrants further evaluation.

**Saskatchewan:**
**Northern Intertribal Health Authority, File Hills Qu’Appelle and Athabasca**

The Northern Intertribal Health Authority (NITHA) is a third-level First Nations partnership organization comprised of four health organizations (flowing from a Tribal Council, two First Nations and a Grand Council). They are located in Northern Saskatchewan. Smith and Lavoie (2008) indicate, "A great deal of invaluable knowledge transfer has occurred between the partners…. The four NITHA First Nation partners have developed strengths through delivery of their individual second-level programs and through their collaborative governance of NITHA’s third-level services.”

**File Hills Qu’Appelle - First Nations Health Services**

This is a well-established partnership that includes the All Nations’ Healing Hospital along with a multi-jurisdictional health pilot project. Two of the goals of the pilot were to define the First Nations health model and foster participation with other national organizations for information sharing and evaluation. The Health Services organization “[w]orked with First Nations partners and the Province of Saskatchewan to expand access to prenatal and women’s health services at the All Nations Healing Hospital. Expectant mothers can now access provincially funded midwifery, ultrasound and nurse practitioner services closer to home.” (Health Canada, 2010, p. 5)

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38 Also found in Alberta later in the research.
39 Meadow Lake Tribal Council signed on to an Agreement-in-Principle in 2001 that draws down jurisdiction of health services.
**Athabasca Health Authority**

This health authority receives integrated acute care funding from the province and funding from Health Canada. The acute care facility is located on-reserve and has a board that is comprised of First Nations and non-First Nations indicating a fairly high level of cross-jurisdictional communication.

**Yukon: Kwanlin Dun First Nation**

Yukon Territory assumed the administration and delivery of universal health programs. The Council of Yukon First Nations is a party to the agreement. Kwanlin Dun is a self-governing First Nation that is fairly urban. The three main health areas administered by Kwanlin Dun are: (1) home and community care; (2) wellbeing - clinic nursing services, child health services, healthy Aboriginal program; and, (3) clinical counselling. All are co-located in one building to facilitate coordination. Referrals of patients into and out of programs was portrayed as “very much a two-way thing.” In addition, Maureen Crill, who was A/Director for the health services at the time she was interviewed (2012), said:

We work very, very closely with all the health and social services government departments here... The doctor has nurse back-up. It’s a nurse who runs the clinic (and LPN)... so not just secretary back-up. We do the blood-work here, we make sure the specimens get down to the hospital. [For the] home and community care program – we have chronic conditions management side of things. We are part of the [Yukon Government] Health and Social Services. ...Mainly the physicians in town, Kwanlin Dun, and pharmacists. We meet maybe once every four months... and the person in the Department of Health and Social Services who pulls off goals/stats [of the electronic tracking system, tells us] how close we are [to reaching our goals]... The government provided a lot of resources (computers, financial administrative support to the doctors). The program now includes diabetes, hypertension, coronary heart disease, asthma/COPD and is beginning to look at depression.

This shows quite a high level of coordination including nursing back-up and coordination, coordination for medical tests, and tracking joint goals electronically as well as financial support. The fact that they are considering expanding to new health conditions is a further sign that this system is working well.
British Columbia: First Nations Health Authority

The provincial health system is divided into six regional health authorities. Five deliver services regionally and the sixth, the Provincial Health Services Authority (PHSA), is responsible for among other things, coordination of services across the province.\(^{40}\) For this reason the PHSA will play an important role in working with the new First Nations Health Authority (FNHA) (more on the FNHA below). Coordination will be key as the mainstream approach to primary care has not embraced group practices.

There are 206 FN communities in British Columbia eligible for some sort of health programming transfer from Health Canada. As of about 2003, there were 114 Health Services Transfer Agreements covering about half of the communities in the province. (Health Canada, 2003, p. 17)

There is significant aggregation in terms of health delivery administration in British Columbia. Continuity of care between an individual community and secondary or tertiary health systems is an issue with all First Nations health systems, but is compounded in a remote environment. Provicially, British Columbia set standards on how far patients must travel to receive medical care. In BC, 98% of patients in any health area will be guaranteed 24-hour emergency services within one hour’s travel time or 50 km from their home, and acute care services within two-hours’ travel time. (Craig McInnes as cited in Lemchuk-Favel & Jock, 2004, p. 34) However, it is estimated that 6% of the First Nations population is in communities that are “too distant from other communities to facilitate intercommunity approaches to health services.” (First Nations Summit as cited in Lemchuk-Favel & Jock, 2004, p. 33) Despite significant aggregation already, it is as of yet unknown how many (remote and non-remote) communities will sign on to having their health services delivered through the First Nations Health Authority.

In February 2007, the First Nations Health Council (FNHC) was created. Soon thereafter, the federal government, provincial government and the FNHC signed the Tripartite First Nations Health Plan, whose goal is to close the gap in health outcomes between First Nations and non-First Nations people through increased collaboration and joint decision-making. The transfer health governance to BC FNs is grounded in the BC’s Tripartite Framework Agreement on First Nation Health Governance (from 2011). The signatories to this Framework Agreement were Canada, BC and the First Nations Health Society.\(^{41}\) The First Nations Health Authority (FNHA) is scheduled to become a (provincial) Medical Services Plan group administrator in July 2013\(^{42}\) and completely take over the (federal) Non-Insured Health Benefits Program in British Columbia in October 2013. Over the coming near-term, this will necessitate the FNHA making some

\(^{40}\) Additionally, only a minority of primary physicians are in group practices in British Columbia. (Reid et al., 2003, p. 8)

\(^{41}\) The goal was to have the Health Authority implemented by July 2, 2013 (although complexities caused delays).

\(^{42}\) MSP premiums are currently paid by Health Canada to BC on behalf of all FN residents in BC. On July 2, 2013, the FNHA will assume responsibility for these payments and will become an MSP group administrator for eligible First Nations residing in BC.
very tough decisions about how best to expend the budget associated with the benefits program.

As of 2013, federal staff were still pondering how best to align work and strategies. For example, they were still sorting out by what means AANDC and the FNHA would analyse and determine gaps and intersections between respective programs and services. There continues to be work required on clarifying roles and responsibilities, particularly as a means to improve on-the-ground delivery of programs and services.

There is concern that changes to the First Nations Health delivery structure could replicate the existing weaknesses of the current mainstream health care system in British Columbia, rather than First Nations’ objectives and goals. Positively, since interviews were done, in December 2012 a Health Partnership Accord was signed between the Ministry of Health in BC, the Federal Minister of Health and the First Nations Health Authority. This Accord builds on important components of the Transformative Change Accord and reaffirms commitments and sets out in greater detail, the plan for achieving improved outcomes.

The further concretization of plans somewhat reduces the risk that the FNHA representatives will continue to be seen as simply an extension of the federal health care system. To illustrate, Smith and Lavoie write about an experience in another jurisdiction: “[A]s liaison with the federal government, another First Nations Health Network informant reported a sense of inadvertently inheriting the mistrust and blame normally directed by First Nations at the federal government, to the point where the Health Network’s representatives were equated with the notorious ‘Indian agents’ by their own stakeholders.” (2008) On the other hand, an incremental transitional approach to changing from a top-down federal structure can be prudent, acknowledging that it is not possible to change all structures and practices at once. With reference to this transition period, one federal employee I interviewed (2012) indicated that:

Initially, what’s been publicly articulated is that [the First Nations Health Authority] are going to honour the agreements that we have in place. You can’t do too much change, all at once. I mean, what’s realistic? We do have funding agreements in place. We’ve been working in this stuff for decades. So I think that the transfer will occur, the agreements will continue to be honoured... so that the organizations know that the programs and services, the plans they have in place, things will be carrying on. We have to be realistic too – there’s an opportunity for things to change. ...How they will choose to make investments in areas of priority and maintain relationships.

The new governance structure has four components, which will work together: the FNHC, the FN Health Directors Association, a new FNHA and the Tripartite Committee on First Nations Health. This latter committee includes the CEOs of the provincial health authorities, the deputy minister of health, senior federal representatives and representatives from the FN organizations mentioned. In terms of organizing key actions, an 18-month “Improvement Charter” has been created. According to James Rankin, Regional Health Liaison for the Vancouver Coastal Region with the FNHA, this action plan is:
based around our tripartite structure. There’s a strategy council that involves high-up decision-makers, leaders from FNIHB, from the Ministry and Health Actions… and that Council is responsible to oversee the work of four planning committees: (1) communicable disease; (2) physicians, nurses and allied professionals; (3) healthy lifestyles and health promotion; and, (4) injury prevention and first responders.

“Not every intervention has to be a huge collaboration every time. Sure, for some of the problems, it needs long-term collaboration. Sometimes there just needs to be a simple fix and no one knew that this was possible. There was just a little switch that had to be turned on. Oh, that’s all we had to do for that? Why haven’t we been doing that?” (James Rankin, 2012). For example, James Rankin went on to explain,

With home and community care, our planning committee, Physicians, Nurses and Allied Health Professionals, that community involves, AANDC home and community care, members from FNIHB nursing. That’s a pretty concrete example of where one program, the Ministry’s program has components of end-of-life care Patients/clients who live on-reserve [but] do not receive palliative care. And sometimes they have to be moved off-reserve to be put into a palliative care centre. It’s disruptive. Those concrete problems are addressed at committees by trying to outline, in this case, all the components of one program in the Ministries, all the components in the federal program and identifying where the gaps are and then trying to get decisions made around how to adjust – how to close -- lose – those gaps. And that’s where we’re stuck – is getting decisions... and sometimes it can be as basic a problem as you needed the right person at the meeting that day.

It is interesting to note that Health Canada anticipates no staff located in BC left from the current FNIH branch. This is notwithstanding past experiences with transferring control of health programs that showed the department may have underestimated the ongoing work required to support First Nations as they take on transfer agreements (Auditor General of Canada, 2000, item 15.51); Health Canada is once again considering removing all local support staff (as they will all be considered for transfer to the First Nations Health Authority). On this topic, one federal employee said, “…I think there will be a number of areas of residual role, a number of them will likely be maintained by our headquarters. [For example, how we interface] with emergency response. Some of these [areas] are not even too high on the radar screen yet… but somebody’s got to be monitoring the agreement. There’s got to be accountability.”

**Nova Scotia: Eskasoni**

Eskasoni First Nation’s oft-cited pilot project located in Cape Breton, Nova Scotia involves the First Nation, federal and provincial governments and Dalhousie University.
These partners designed, implemented, and evaluated a holistic model of health service delivery in Eskasoni to improve integration and accessibility of health systems. The project’s elements were: the continuing transfer of health care administration from the federal government to the local Band; a change of physicians’ services from a solo, fee-for-service model to a multi-doctor, multi-disciplinary clinic; the construction of a health complex, housing services from both within and outside the community; the better utilization of physicians, hospitals, and prescription drugs; the integration of doctor-based services with community-based programs; and, the establishment of links with the regional health centre. Key characteristics promoting integration and accessibility of health system were: moving to salaries for physicians, significant provincial funding, funding for human resources (nurses, evaluation consultants, etc.) and co-location of complementary services (e.g., pharmacy). During the first year, visits to the emergency department declined by 40%, visits to family doctors declined from a high of 11 per year to four per year between 1997 and 2000; and the cost of prescribed medicines decreased 7% despite a 10% increase in population. (Mable & Marriot, 2002, p. 35) While viewed as a success, this project was not without challenges, including gaining community acceptance and involvement of multiple jurisdictions.

**Labrador: Nunatsiavut**

Regarding the Labrador Inuit, they have a regional office in Happy Valley-Goose Bay and seven community offices that are located in Nain, Makkovik, North West River, Happy Valley-Goose Bay, Rigolet and Postville. According to the Nunatsiavut website, at the level of the community, teams work closely with Labrador-Grenfell Health to deliver health services. Health teams consist of a community health nurse and community health aids. There are also community health workers who work in the community teams but are not as directly involved in client care or working with the Labrador-Grenfell Regional Health Authority in delivering care.
Appendix C.

Costing Analysis

Costing estimates are explained below for each of the three policy options below. Analysis sets out costing assumptions to consider when designing and implementing recommended policy approaches.

A. Information and First Nations Client Registries

<table>
<thead>
<tr>
<th>Key Components/Assumptions</th>
<th>Initial set-up</th>
<th>Labour/Human Resources</th>
<th>Ongoing Costs</th>
<th>Totals for 1st Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smaller-scale, multi-location (5 sites), mostly paper-based file management</td>
<td>Training / training materials required for intake/discharge staff</td>
<td>Training intake/discharge staff (users) of the system $50/hour X 3 hours per site = $2,250</td>
<td>Working together to trouble-shoot/improve paper-based system (one to three conferences per year) plus one in-person meeting = $6,000</td>
<td>$2,250 $4,000 $6,000 $9,000</td>
</tr>
<tr>
<td>Hardware – not needed – paper-based</td>
<td>Assumes that individuals sites have own filing/office supplies</td>
<td>$0</td>
<td>No server upgrade required</td>
<td>$0</td>
</tr>
<tr>
<td>FN status stickers on health care cards</td>
<td>Equipment for sticker application &amp; maintenance</td>
<td>$800</td>
<td>Maintenance, cleaning, etc. (not included)</td>
<td>$800</td>
</tr>
<tr>
<td></td>
<td>Training for intake staff, communications materials</td>
<td>1 hour per site (5) of training, travel plus development of communications materials ($25/hour) (e.g., who to call/how to get onto site) = 80 hours @ $25/hour = $1,000 twice a year = $2,000</td>
<td>Also, requires ongoing check-ins, trouble-shooting with individual intake sites (not included)</td>
<td>$2,000</td>
</tr>
<tr>
<td>Estimated Total for Start-up and Some Ongoing Costs</td>
<td></td>
<td></td>
<td></td>
<td>$24,050</td>
</tr>
</tbody>
</table>
### B. Standard Referral, Intake and Discharge

<table>
<thead>
<tr>
<th>Key Components/Assumptions</th>
<th>Initial set-up</th>
<th>Labour/Human Resources</th>
<th>Ongoing Costs</th>
<th>Totals for 1st Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smaller-scale, multi-location (5 sites), mostly paper-based process management</td>
<td>Training / training materials required for intake/discharge staff</td>
<td>Time to develop forms, and data collection tools. Assumes a health worker involved in development and working closely with primary intake / discharge nurses = $5,000</td>
<td>Working together to trouble-shoot/improve system (one to three conferences per year) plus one in-person meeting = $6,000</td>
<td>$5,000 $2,250 $4,000 $6,000</td>
</tr>
<tr>
<td>Assumes current staff, with help of a consultant or health care worker, will take on initial development of standardized processes and protocols</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hardware – not needed – paper-based</td>
<td>Assumes that individuals sites have own filing/office supplies</td>
<td>$0</td>
<td>No server upgrade required</td>
<td>$0</td>
</tr>
<tr>
<td>Estimated Total for Start-up and Some Ongoing Costs</td>
<td></td>
<td></td>
<td></td>
<td>$17,250</td>
</tr>
</tbody>
</table>
## C. Patient Navigators

<table>
<thead>
<tr>
<th>Key Components/ Assumptions</th>
<th>Initial set-up</th>
<th>Labour/Human Resources</th>
<th>Ongoing Costs</th>
<th>Totals for 1st Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 patient navigators reporting to a nurse coordinator, assumes navigators already have high level of functioning and health care knowledge, but do need to be trained for current context (e.g., local health facilities, services available, etc.) Assumes office space already available, incremental office supplies required</td>
<td>Training / training materials required for navigators One desk with office and appropriate supplies $3,000</td>
<td>Training navigators and nurse coordinator staff $50/hour X 12 hours per 3 people = $1,800 Writing and upkeep of user manuals/reference material = $4,000 Incremental salaries 1 navigator at $55,000 / per annum plus benefits = $65,000 per person (based on average entry-level wages for social workers in Canada)</td>
<td>Working together to trouble-shoot/improve processes (one to three conferences per year) plus one in-person meeting = $5,000</td>
<td>$3,000 $1,800 $4,000 $65,000 $5,000</td>
</tr>
<tr>
<td>Estimated Total for Start-up and Some Ongoing Costs</td>
<td></td>
<td></td>
<td></td>
<td>$78,800</td>
</tr>
</tbody>
</table>
Appendix D.

Consent Form

Although verbal consent was one option available, all consent received from participants was done in writing using a form similar to the one copied below. This document was provided to interviewees by e-mail or in person. Interviewees who agreed to participate signed the form and returned it to me (the interviewer) prior to the interview. I accepted scanned/digitized versions of signatures (e.g., forms that were signed and faxed or e-mailed back to me were deemed reliable). Where being shared by regular mail, e-mail or in person, a copy of the consent was left with the potential interviewee for their reference.

Lisa (Marie) Nixon
Master of Public Policy

Consent Statement Form

Research Study:
Coordinating First Nations Health Care: Policy and Implementation Challenges and Opportunities

By signing this form, I agree to be interviewed for a research project about First Nations health care in Canada. I understand that:

• The research is about health care. The study looks at ways organizations and people work together to improve coordination for First Nations patients.

• The researcher is a Master candidate at the School of Public Policy at Simon Fraser University in Vancouver, British Columbia.

• I am being asked for this interview because I can offer important information and experiences to help understand what works or doesn’t work related to improving First Nations health care in Canada.

• The information from my interview will be used in the researcher’s Master thesis.

• The interview will be recorded in written notes and/or on a digital recorder.

• All the information provided in the interview may be confidential if I so choose based on the level of confidentiality I prefer below. I may choose:
  a) To allow direct quotes to be attributed to me (express permission will be sought by the researcher before finalizing the thesis) and to be listed as a participant in the study; or,
  b) To have my name listed as an interviewee but no direct quotes attributed to me and no identifying details included; or,
  c) I may choose to have all the information I share become confidential and completely anonymous. In this case, my name will be changed in any documents related to this study.

• I may change my mind about the level of confidentiality I am seeking at any point during the interview.
• Participation in this study is completely voluntary. That means that I do not have to participate. I may also stop the interview at any time if I am uncomfortable and do not wish to continue and all records of the interview will be destroyed. Refusing to participate will have no adverse effects on my employment, my employer or any project or initiative in my community.
• I also understand that the interviewer might not have obtained permission from my organization, employer or community and that I have been contacted personally.
• In addition, I also understand that the interviewer may not have agreements with First Nations communities for approval of the data to be acquired, or use of that data.
• There are no risks or benefits associated with the study other than those encountered in the aspects of my daily life.
• This research is being done according to research ethics policies at the researchers' university, Simon Fraser, in Vancouver, British Columbia.
• I do not need to answer any question or give any information that I feel could harm my reputation or role in my organization or community.
• If I have any concerns or questions about this study or my interview, I can contact:

Principal ethics supervisor:
Dr. Hal Weinberg
Director, Office of Research Ethics, Simon Fraser University
e-mail: hal_weinberg@sfu.ca
phone: (1) 778-782-6593
8888 University Drive, Multi-Tenant Facility, Burnaby, British Columbia, Canada
V5A 1S6

Supervisor:
Professor Doug McArthur
School of Public Policy, Simon Fraser University
e-mail: doug.mcarthur@sfu.ca
phone: (1) 778-782-5208
3rd Floor, 515 West Hastings Harbour Centre Vancouver, British Columbia, Canada
V6B 5K3

If I would like to receive the results of the research, I can contact:
Doug McArthur or Dawn Geil
3rd Floor, 515 West Hastings Harbour Centre
Vancouver, British Columbia, Canada
V6B 5K3
Consent

Name of interviewee: ________________________________________________________________

Community or institution: __________________________________________________________

Level of confidentiality from least to most:

I consent to the researcher using direct quotes attributed to me by name. I will receive a copy of quotes as they will be included in the thesis before the thesis is finalized. I may request that the quote not be included at all or be edited for accuracy. I understand that the researcher will obtain express written or electronic e-mail permission on the actual quote(s) before finalizing the thesis. I also consent to being listed as a participant in the study. (Please check one)

Yes _______ No _______

Signature ___________________________ Date ___________________________

I do not consent to being directly quoted. I do consent to having my name listed as an interviewee in the study. I understand that no identifying details or quotes will be attributed to me (Please check one)

Yes _______ No _______

Signature ___________________________ Date ___________________________

I agree to this interview only if all the information I share becomes confidential and completely anonymous. In this case, I understand that my name will be changed in any documents related to this study.

Yes _______ No _______

Signature ___________________________ Date ___________________________
Appendix E.

Sample Interview Questions

Baseline data, Ways of Working Together, Innovation

**Baseline Data**

Today’s date:
Name:
Location/Employer:
Position:
(main duties if unclear):
How long you have been doing this position? _______
How long have you been with this organization? __________________

**Other contextual information as needed:**

Type and complexity of services provided by organization (for health care providers):
Can you talk a bit about the kinds of health services your organization provides to First Nations patients?
Could you describe the geographic spread of patients and your health service delivery sites?
Are any of your health clinics/sites co-located with other related offices / services?
Approximate number of patients; types of patients (e.g., mostly adult/children, etc.);
common health conditions; approximate % of patient load with 1, 2 or more chronic conditions (may do this qualitatively)
Does your organization do patient intake?
Patient assessment?
Referrals to specialists?
On-site tests?
Patient transfer/transportation?
Patient follow-up or monitoring? (what kinds?) (by phone, in-person, scheduling appointments, liaison with local health care providers, etc.)
What other types of patient follow-up/monitoring does your organization provide?
What takes the most of your time?
What is the most challenging?

**Governance / Administration, Intra-Organizational Relationships and Management: What Works/Doesn’t Work**

Can you think of recent events/meetings where staff were involved in thinking about ways to improve coordination of patient care? Or patient follow-up (circle one)

Describe the meeting. What did you think of that meeting/event? Comments?

Can you think of any recent events or meetings/activities related to aligning activities across more than one organization? (e.g., with the Province, with Health Canada, with the local Health Authority, with bands, etc.)

Who initiated that event?

Do you see regular evidence, or know of regular shared decision-making between organizations? (not just implementation)

Nature of the collaboration between key players

In your work, do you see interdependency in designing your organization’s work? Could you give me an example?

Do you see regular evidence, or know of regular shared decision-making between organizations? Which organizations?

Are there primary care teams at the service delivery level that comprise both mainstream and (insert case name) workers?

Do you see differences in organizational attitudes (e.g., with First Nations organizations, with Provincial organizations, with federal organizations, etc.)?

Could you talk about one that gets in the way of working together? One difference that helps working together?

Would you describe most of the communication at work as top to bottom or bottom to top?

**Discussion of “Cooperation versus coordination versus collaboration”**

Is there someone in your organization who you see as a champion or a leader who promotes a culture of teamwork between organizations? (If yes, perhaps interview them)

Do you think I might be able to interview them too?

Thinking back to situations where organizations or people weren’t working so well together, have you seen or heard about turf wars?

If you’re comfortable, could you provide a bit more detail about this?

(Other than getting more money) What would be your ideal solution if there were no other impediments?

When coordinating programming with other organizations, what might be a typical financial challenge? (e.g., not paying on time, reporting burden, no care provided until financial cost-sharing arranged, etc.)
How predictable is your funding?

Patient Movement/Follow-up and Coordination – What Works / Doesn’t Work
Do you have patients that moving on- and off-reserve? If so, what’s the biggest challenge/most promising practice in tracking patients and effective patient follow-up/care?

Access to Non-Insured Health Benefits?
When it comes to patients that are being transferred or moving on their own, what do you see as your top barrier(s) to effective coordination/follow-up?

Further detail – based on this example or another - can you think of any potential or existing policies, regulations, structures or attitudes that create a barrier to improving patient transfer/follow-up?

What is one of the best ways your organization manages to overcome long distances/geographic isolation in First Nations communities?

Can you think of any potential or existing policies, regulations, structures or attitudes that facilitate that kind of patient transfer/follow-up?

Who is this challenge mainly with? (e.g., The Provincial Health Authority? With Health Canada? Internal? With First Nations? The patient themselves? Someone/another institution?

Regarding Non-Insured Health Benefits, do you notice any differences in patterns for denying patients’ requests for transportation? If yes, how so/why.

Are any services or programs being tailored for patients that are transferred or are moving residences?

How do you facilitate access to specialists? Other than cost, what are some challenges associated with this and how have you overcome (or not) these challenges? What successes have you had in improving access to specialists?

Do you think better coordination might improve access? If yes, why. If no, why.

Evidence-based Organizational Learning / Policy Development
Does your organization have priority areas for improvement with specific targets and timelines?

How do you think your organization learns from mistakes, or keeps improving? (on patient coordination?)

Is there someone in your organization who is a champion for continuous improvement?

How do you evaluate {insert case name/program name}?

Who does the evaluation? Are any of them joint evaluations (done with another organization)? Or prescribed by another organization?

Do the evaluations cover the types of issues we’ve discussed so far? Other coordination issues?
If yes, which ones:
Who are these evaluations shared with? (internally, funders, your partners, the public?)
Do you think I might be able to see these evaluations?
System in place to monitor compliance? Feed information back into the system?
Measure uptake of recommendations/changes?
How easy is it to adapt practice guidelines / approaches to care?
Is there a plan in place for regular engagement with/feedback from First Nations patients? How does this information get reflected in program evaluations?
Does your organization have a ‘champion’ for patient engagement?

Planning, Training and Health Human Resources
What kind of planning processes do you use / anticipate generally?
(regular meetings? Sending out documentation for written commentary? strategic plan?)
More specifically, what kind of planning do you use / anticipate for improving patient transfer and follow-up, if any?
Of the types of planning you’ve mentioned, what do you think has the greatest positive impact on patient follow-up/care?
What’s your biggest challenge with staff turn-over?
What steps are being taken to recruit primary health care delivery professionals (nurses?) (or follow-up question to biggest challenge identified above)
Retention strategies? What about nurses in remote communities?

Innovation
System in place for intentional spreading of best practices (multi-level spread and cross-organizational/horizontal spread)
Testing / piloting of innovations
When you’re trying something new, is it supported by a budget of sorts/internal resourcing?
What does ‘First Nations control’ of health service delivery mean to you?
How has it impacted coordination of services?
Do you have a patient follow-up practice that really shines/works for you? For a patient moving from one facility to another, or being discharged altogether, can you give me an example of an approach that has promoted effective integration of care that promotes seamless care transitions? (probe re: what types of transfers).
• location
• number of patients
• how long innovation in place
• challenges in start-up and how they were overcome
• potential for scalability up and down
• Number of stakeholders involved
• regulatory frameworks involved
• distance between health care delivery sites
• available technology
• other

One or two elements of the [your organization] that shine when compared to other FN-run health structures in Canada.

If you could share one practice or suggestion that you think people working with the First Nations Health Authority in BC might be interested in, what would it be? Why do you think it might be of interest?

Can you think of anyone else who might be able to share insights about First Nations design and management of health care?

What other key issues have I missed that you’d like to talk about?