Métis Cancer Control in Canada Baseline Report

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

Acknowledgements

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The majority of the information sourced within our series of baseline reports for First Nations, Inuit and Métis Cancer Control, respectively, are sourced from the environmental scans completed in 2012. The environmental scans can be found on cancerview.ca. The environmental scans provided a rich source of information, including detailed descriptions of cancer care pathways experienced by First Nations, Inuit and Métis peoples in Canada and examples of leading practices to advance cancer control for and with First Nations, Inuit and Métis peoples. The purpose of this baseline report is to provide an overview of the state of cancer control for Métis, as of December 2013.

The Partnership gratefully acknowledges the National Aboriginal Organizations Caucus with the Canadian Partnership Against Cancer and the First Nations, Inuit and Métis Advisory Committee on Cancer Control for their guidance.

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1. Introduction – Cancer and First Nations, Inuit and Métis Peoples

While cancer affects everyone, its distribution, impact and outcomes are not shared equally. Rates of common cancers have increased among First Nations, Inuit and Métis people in the past few decades and in some populations are now at or above the incidence rates in the general Canadian populations. Broader determinants of health, including factors such as culture, geography and access to basic health services, contribute to the unique cancer burden faced by First Nations, Inuit and Métis. A few generations ago, cancer was relatively unknown (in part because life spans were shortened by infectious diseases and injuries) but now it is among the top three causes of death.[1]

Advancing cancer control with and for First Nations, Inuit and Métis is a priority of the Canadian Partnership Against Cancer (the Partnership). In 2011, the *First Nations, Inuit and Métis Action Plan on Cancer Control* was released, representing a collaborative effort by many organizations and individuals. Cancer control stakeholders including First Nation, Inuit and Métis people have worked to identify the issues and barriers impacting cancer care delivery to each of the three populations and the findings indicate that many communities are ready, willing and able to undertake the collaborative work required to address and improve the cancer pathways. A number of innovative programs across Canada are already beginning to address these and other issues, and many have had significant regional success. However, with limited communication and sharing of expertise across different jurisdictions, many regional success stories go unheard.

The purpose of this baseline report is to provide an overview of the state of cancer control for Métis, as of December 2013. As such, it provides a baseline against which progress can be measured over the coming years. Information and developments that emerged after December 2013 are included in the epilogue of this report. This is one of three specific reports that will address the distinct cancer pathways specific to First Nations, Inuit and Métis populations. This report will provide a descriptive context of the cancer pathway for Métis and identify existing challenges, as well as successful leading promising practices, across the cancer control continuum.

1.1 Information Sources for This Report

Effective cancer control in any population requires an understanding of the current cancer burden within their communities.[2] There is a need for further information to better understand the unique cancer journey faced by First Nations, Inuit and Métis and to identify the gaps and barriers in cancer care as a priority for addressing cancer and its related health challenges. To address the need for information, the Partnership issued requests for proposals to conduct environmental scans to help gather this information. Contractors were engaged to identify leading and promising practices and models across the cancer control continuum as well as attitudes, values and

behaviours regarding cancer and chronic disease. An environmental scan was also conducted on existing systems of patient ethnocultural identification which offers examples of leading practices for gathering and using health information in culturally appropriate ways.

The information collected from these scans has contributed to the assessment of the current state of cancer control and the identification of leading cancer control practices and models of care in Métis populations. This report will draw on the data and analyses from these scans, as well as other resources including, but not limited to, publications from the Métis Nation British Columbia, Métis Nation of Alberta, Métis Nation – Saskatchewan, Manitoba Métis Federation, Métis Nation of Ontario, Health Council of Canada, provincial cancer agencies, Health Canada and independent published research.

Finally, to address the specific knowledge gap about the cancer journey experienced by Métis, the Partnership, with the Métis National Council, convened a time limited working group comprised of provincial Métis organizations and the Aboriginal cancer care leads in provincial cancer organizations to identify strategies to advance the following common objectives:

- Improve the qualitative information available about the Métis patient cancer journey experience with a focus on the continuity of care.
- Support participating Métis organizations to improve awareness and understanding of continuity of care issues for Métis people during their cancer journey.
- Integrate qualitative information about the Métis cancer journey in this baseline document.

To further this work, funding was made available through a call for proposals, with three jurisdictions submitting a proposal. From October 2013 to January 2014, Métis Cancer Patient Journey projects were undertaken by the Métis Nation of Ontario, Alberta Health Services-Cancer Control with the Alberta Métis Settlements and the Métis Nation British Columbia with the BC Cancer Agency.

Results from each of these three projects are woven throughout this report.

1.2 Data Considerations

Every effort has been made to make this baseline report as comprehensive as possible. There has been considerable progress on health data specific to First Nations, Inuit and Métis peoples. However, data remains far short of the standard of data available for other Canadians. There are a number of gaps and challenges that limit the findings presented in this baseline report, including:[3]

- The majority of the existing sources for cancer information contain gaps. In many cases, ethnicity is not recorded in data sources, which means that information specific to First Nations, Inuit and Métis is lacking.
- First Nations, Inuit and or Métis identification is a challenge, as different jurisdictions use different definitions and criteria.

- National surveys which do not target Aboriginal people specifically do not have a sufficient sample size to be able to determine health trends, including cancer patterns.
- National surveys such as the Canadian Community Health Survey exclude segments of the population and do not contain mechanisms to distinguish between First Nations, Métis and Inuit people.
- Regional surveys and data initiatives have attempted to fill in these gaps, however the collected information is not always comparable across the country.

Due to these data limitations, understanding the burden and impact of cancer for Métis is a complicated task. Without information on Métis cancer statistics, it becomes difficult to determine patterns of cancer, monitor trends over time, and effectively develop initiatives to improve cancer outcomes. It is important to recognize that in many cases, due to these existing information gaps, this report must draw on older data that may not be national in scope. In some situations, available data is more than a decade old, which makes it difficult to understand and analyze current cancer realities for Métis.

2. Cancer Control and Métis – a National Picture

2.1 Who Are the Métis?

The Métis People are one of the three constitutionally recognized Aboriginal groups in Canada. The Métis emerged as a distinct people during the 18th and 19th centuries, as a result of unions between European settlers and First Nations or Inuit women. [4] The Métis National Council adopted the following definition in 2002:

"'Métis' means a person who self-identifies as Métis, is distinct from other Aboriginal people, is of historic Métis Nation Ancestry and who is accepted by the Métis Nation." [5]

Distinct from other First Nations and Inuit, Métis have their own languages, cultures, values and beliefs that vary between communities and geographic regions.[6]

How Many Métis Persons Are There in Canada?

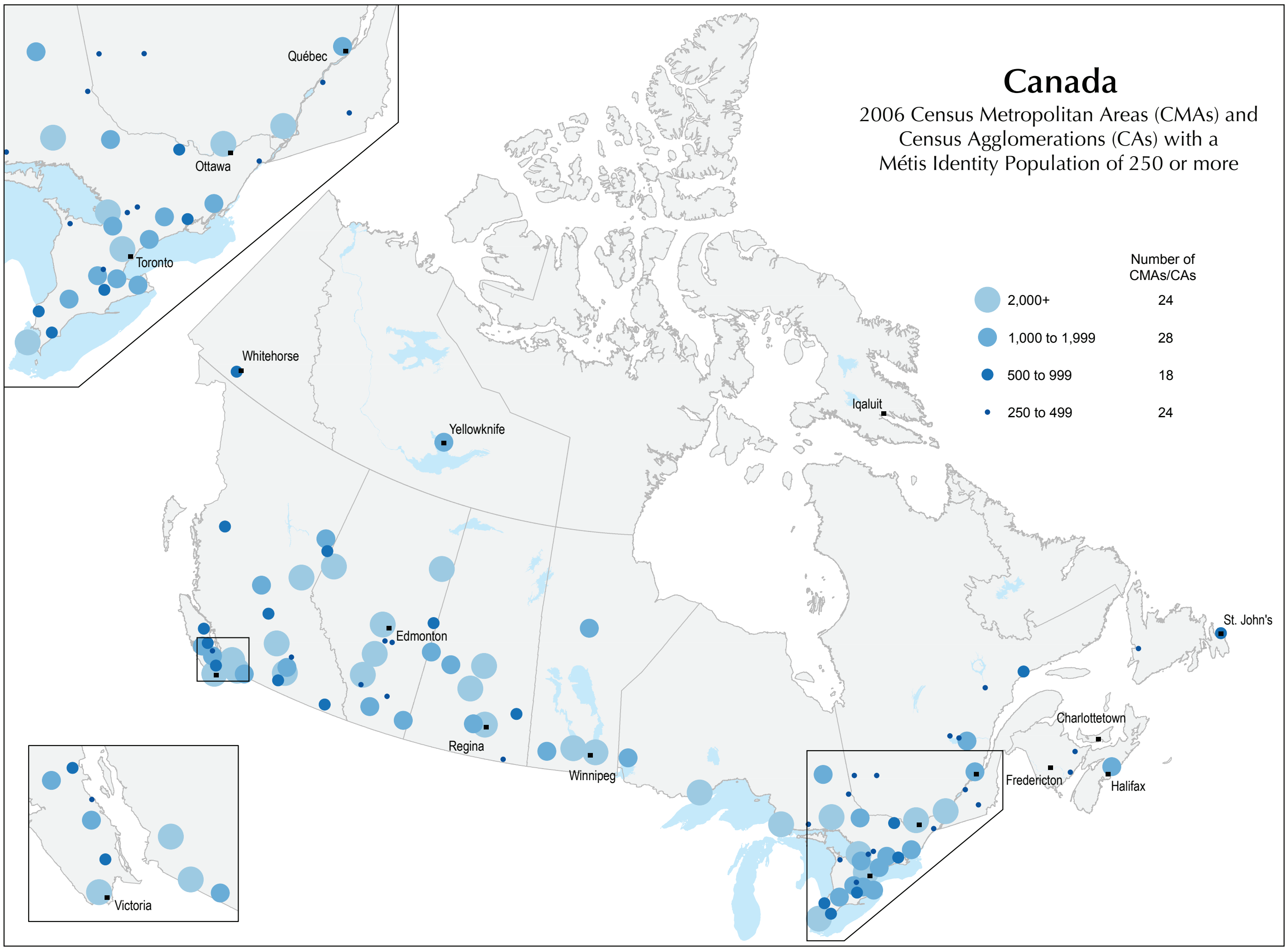
According to the 2006 Census, 389,785 people self-identify as Métis, making up 34 per cent of the 1,172,790 people who identify themselves as an Aboriginal person. The median age of the Métis population in 2006 was 30, 10 years younger than the non-Aboriginal Canadian population.[7]

Where Do Métis Live?

Métis live in all provinces and territories of Canada, but the majority, 87 per cent, live in either Alberta, British Columbia, Saskatchewan, Manitoba or Ontario. In 2006, 69 per cent of Métis lived in urban areas, particularly Winnipeg, Edmonton, Vancouver, Calgary, and Saskatoon, while 29 per cent lived in rural areas and 1 per cent lived on First Nations reserves.[8] Variations in the geographical distribution and size of Métis communities have a direct influence on the health care delivery systems for Métis people that exist in each province and territory.

Figure 1 shows the locations of self-identified Métis populations of 250 and more, by Census Metropolitan Area.

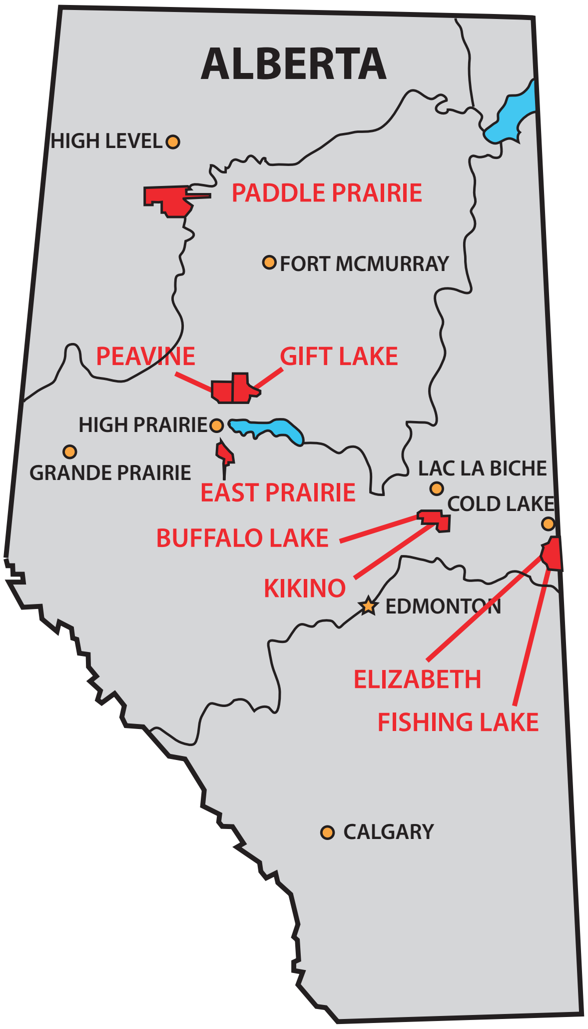
Figure 1: Map of Self-Identified Métis Populations in Canada



Source: Statistics Canada 2006 Census.

Eight Métis Settlements in northern Alberta, shown in Figure 2, comprise the sole Métis land base in Canada. Comprised of 1.25 million acres, the land is collectively owned by the members of the following eight communities: Buffalo Lake, East Prairie, Elizabeth, Fishing Lake, Gift Lake, Kikino, Paddle Prairie and Peavine.[9] The Métis Settlements were established in 1938, and are home to multi-generational families who continue to live on original homestead properties, practicing the traditional lifestyles of their forefathers. The geographic locations of these communities pose a barrier for some Métis when attempting to access healthcare, including cancer control services.

Figure 2: Map of Alberta Métis Settlements



Source: North Eastern Settlements Alliance[10]

How Métis are Represented?

At the national level, the Métis National Council represents the interests of its Governing Member Organizations, located in Ontario, Manitoba, Saskatchewan, Alberta and British Columbia. Métis who are not linked to the Métis National Council are represented at the national level by the Congress of Aboriginal Peoples, which represents Aboriginal Peoples living off-reserve.[11]

Regionally, Métis are represented by their respective Governing Member Organization.

2.2 Métis Health Care

Health services for Métis living in Canada are provided by provincial and territorial governments. Unlike First Nations and Inuit, Métis people are not eligible for funding from Health Canada's First Nations and Inuit Health Branch. However, Métis are eligible to access health clinics in Aboriginal Friendship Centres, and are generally eligible for a variety of other Aboriginal health services. In Alberta, several of the Métis settlements have health centres funded by Alberta Health Services.

2.3 Chronic Disease and Cancer

In the 2006 Aboriginal Peoples Survey, 58 per cent of Métis adults reported that their health was excellent or very good -- the same percentage as 2001 and slightly below the age-standardized rate for the general Canadian population of 62 per cent.[12]

A national study of mortality among the Métis population from 1991 to 2001 found that, at age 25, the life expectancy for Métis men was about three years less than that of non-Aboriginal men in the study cohort, while Métis women lived, on average, five years less than their non-Aboriginal counterparts. The same study found cancer to be the second leading cause of death among Métis men and the leading cause of death among Métis women. Cancer contributed to shortened life expectancy among Métis women, but not men, when compared to the general population. The study also found that smoking contributed to significantly higher death rates for Métis women, but not men, when compared to the Canadian population.[13]

Researchers in Manitoba compared the health records of registered Métis with non- Métis residents in Manitoba, and found a 21 per cent higher risk of premature death, adjusted for age and sex, among registered Métis residents. The same study found that cancer was the leading cause of death for registered Métis, in comparison with all other Manitobans, for whom the leading cause of death was cardiovascular disease.[14]

Chronic Disease Risk Factors for Métis

The reasons for growing incidence of cancer are varied. Chronic diseases, including cancer, result from both modifiable and non-modifiable risk factors. These risks factors, known as the determinants of health, include social, economic, political and environmental factors and are strongly related to the health status of populations and of individuals.[15]

In many cases, determinants of health for Métis people are holistic, intertwined and fluid, driven by culture and context.[16] Within this framework, determinants such as income, education levels, employment, housing, food security, and health care services combine and work in complicated ways. According to the 2006 Aboriginal Peoples Survey, Métis respondents reported a greater prevalence of negative determinants of health, including lower income, employment and educational levels than the general Canadian population.[17] In a national study of the causes of mortality among Métis, income adequacy, educational attainment and occupational skill level accounted for a large proportion of the differences in death rates for Métis men and women when compared with the general population.[18]

In turn, these determinants influence most modifiable risk factors for chronic disease and cancer including diet, physical activity, alcohol and tobacco use.[19] The probability of developing cancer

Figure 3: Known Modifiable Risk Factors and Their Association with Various Cancers[20]

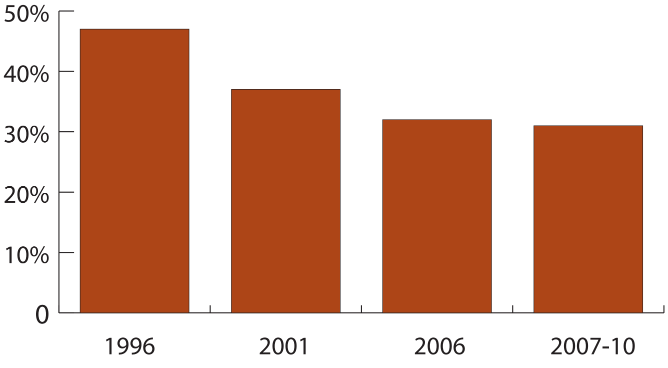
	PREVENTION STRATEGY					
CANCER RISK REDUCTION BENEFIT	Avoid Tobacco	Eat a Healthy Diet	Be Physically Active	Maintain a Healthy Weight	Avoid Alcohol	Avoid Excessive UV Ray Exposure
Bladder	✓	✓				
Breast		✓	✓	✓	✓	
Cervix	✓					
Colorectal	✓	✓	✓	✓	✓	
Kidney	✓			✓		
Larynx	✓	✓			✓	
Lung	✓	✓				
Oesophagus	✓	✓		✓	✓	
Oral	✓	✓			✓	✓
Pancreas	✓	✓				
Prostate		✓	✓			
Skin						✓
Stomach	✓	✓				
Uterus (excuding cervix)				✓		

Source: Adapted from: 1) Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2005, Toronto, Canada, 2005; 2) Institute of Medicine, Curry SJ, Byers T, Hewitt M (eds), Fulfilling the potential of cancer prevention and early detection, Washington, DC: The National Academic Press, 2003; and 3) Cancer Care Ontario, Insight on cancer. News and information on nutrition and cancer prevention. Toronto: Canadian Cancer Society (Ontario Division), 2003.

can be dramatically reduced by adopting healthy living patterns, as shown in the table below.

Half of all cancers have been shown to be preventable, and lifestyle behaviours alone are estimated to be responsible for 30 per cent of cancer deaths.[21] [22] Among Métis, there is a higher prevalence of risk factors for the development of chronic diseases and cancer. For example, premature deaths from smoking-related diseases among Métis were found to be 14 per cent higher for men and 75 per cent higher for women compared with the non-Aboriginal population during the period 1991-2001. [23] Smoking is the primary cause of 30 per cent of all cancer deaths[24] and is linked particularly to deaths from lung and colorectal cancer. Rates of daily smoking among Métis adults have declined significantly during the past two decades[25] as shown in the figure below, to a current prevalence of 31 per cent. However, according to the 2009-2010 Canadian Community Health Survey, the prevalence rates of smoking among Métis adults aged 18 years and older were still double the rates reported among the non-Aboriginal population.

Figure 4: Daily Smoking Trends Among Métis Adults



Source: Canadian Community Health Surveys

Being overweight or obese is also a risk factor for the development of chronic disease and cancer. In 2009 and 2010, the proportion of overweight Métis adults aged 20 years and over, 35 per cent, was similar to that of adults in the general Canadian population, 34 per cent. The proportion of Métis adults who reported being obese was 25 per cent, in comparison to 18 per cent of the general Canadian population. In Ontario, Métis men and women were nearly twice as likely as all Ontario men and women to be classified as obese.[26]

Diet has been linked to the development of many chronic diseases and cancer. Traditionally, many Métis ate a diet that consisted primarily of animals and plants harvested from the local environment. Today, traditional foods are often eaten at special occasions by Métis.[27] A shift away from traditional foods is generally characterized by an increase in absolute energy intake and a decrease in intake of vitamins, nutrients and dietary fibre.[28] In 2009-10, 61 per cent of Métis aged 20 years and older reported eating less than the recommended number of servings of vegetables and fruit per day, comparable to the 56 per cent of non-Aboriginal adults who reported the same.[29]

Regionally, only 21 per cent of Métis in Manitoba aged 12 and over reported consuming at least five servings of fruits and vegetables per day, 32 per cent lower than the general Manitoba population. In response to the question, "Do you feel you eat a healthy balanced diet?" 66 per cent of Métis people in Saskatchewan surveyed answered yes.[30]

In addition to smoking and diet, physical activity and exercise influence the development of chronic disease and cancer. The 2009-10 Canadian Community Health Survey reported that Métis respondents were more likely to have an active lifestyle than non-Aboriginal Canadians;[31] however, physical activity levels vary by region. Fifty-six per cent of respondents to a health survey by Métis Nation-Saskatchewan said they exercised to promote health.[32] In Manitoba, Métis adults' physical activity levels were 28 per cent higher than for Manitobans as a whole.[33] In Saskatchewan, 17.6 per cent of Métis said they did not exercise.[34]

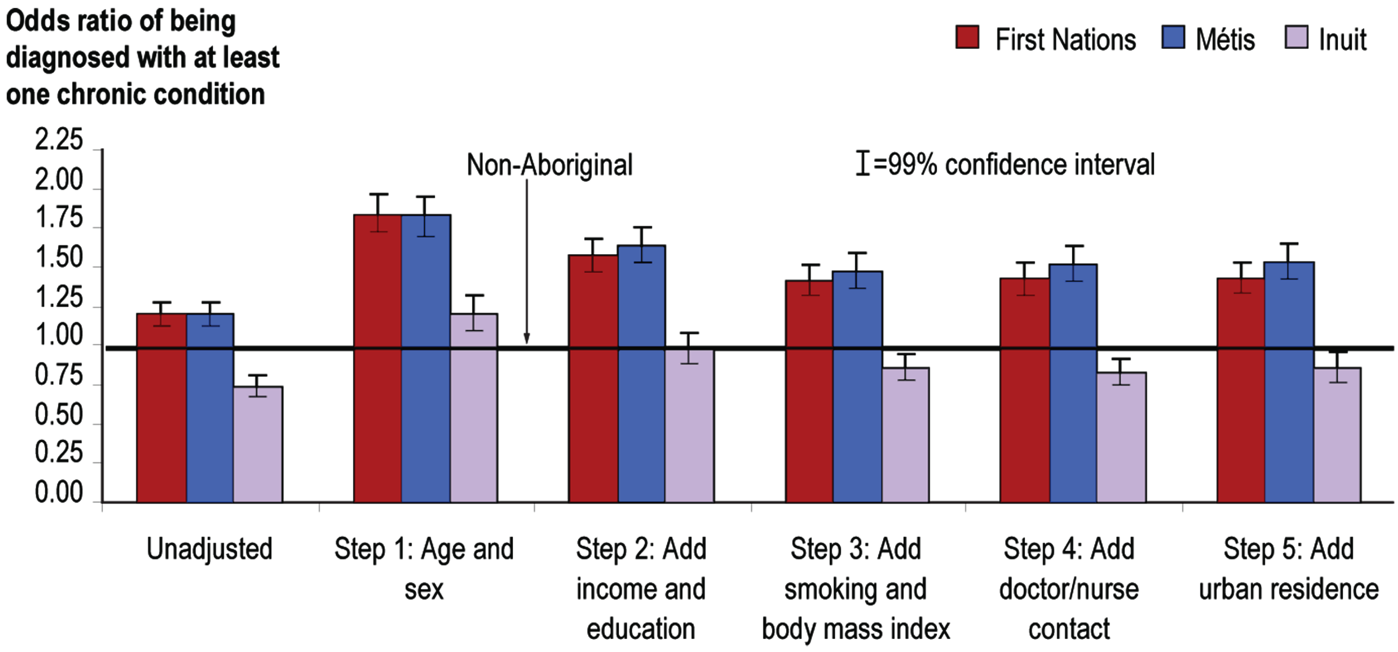
Alcohol consumption is linked to the development of chronic diseases and many types of cancer. National data regarding alcohol consumption among Métis is limited.[35] Regionally, in Manitoba, alcohol consumption was slightly higher among Métis than in the general population[36] and in Saskatchewan, 10 per cent of survey respondents said they were concerned about the amount of alcohol they consumed.[37] In Ontario, Métis men were about 50 per cent more likely to surpass the recommended daily limits of alcohol consumption for cancer prevention, but the difference was no longer statistically significant when socio-demographic differences were taken into account. Among Métis women in Ontario, there was a trend toward increased alcohol consumption in comparison with non-Aboriginal women.[38]

Cumulatively, behavioural risk factors significantly increase the odds of being diagnosed with one or more chronic conditions, as shown in the chart below.

As shown in Figure 4, the risks associated with chronic disease development increase with age, due to the accumulation of risks across the life stages.[39] In 2006, the median age of the Métis population was 30 years — 10 years younger than that of the total population of Canada.[40] In the coming decades, health risks associated with increased age will become increasingly relevant for the expanding Métis population. Cancer is of particular concern because age is one of the largest contributors to cancer risk.[41] The relative risk for a cancer diagnosis rises sharply for a person over 50 years old.

Figure 5: Contributors to Chronic Diseases Among First Nations, Inuit and Métis

Odds ratios showing unadjusted and cumulative effects of socio-economic, lifestyle and health care access factors on being diagnosed with at least one chronic condition, by Aboriginal identity group, off-reserve population aged 20 or older, Canada, 2006-2007



Note: Reference group is non-Aboriginal adults denoted by horizontal line
Source: 2006 Aboriginal Peoples Survey; 2007 Canadian Community Health Survey, cycle 4.1

Current Cancer Patterns

Cancer is a significant cause of mortality in the Métis population. A 2009 study found cancer to be the second leading cause of death among Métis men, responsible for 23 per cent of deaths, and the leading cause of death among Métis women.[42] The increased rate of cancer mortality among Métis women is due to higher mortality rates from cancers of the lung, urinary system, uterus/ ovaries and esophagus/ stomach.[43] According to the 2006 Aboriginal Peoples Survey,[44] two per cent of Métis men reported being told by a health professional that they had cancer. Of those men, 16 per cent indicated they had prostate cancer, eight per cent indicated they had colorectal, colon, or bowel cancer, and six per cent indicated they had skin cancer or melanoma. Five per cent of Métis women reported being told by a health professional that they had cancer. In the Saskatchewan Métis population, four per cent of health survey respondents indicated they had been diagnosed with cancer. [45]

Data on specific types of cancer are available from provincial studies conducted in Ontario and Manitoba, as described below.

A 2012 study linking Métis citizenship records with health records in Ontario was conducted to investigate cancer rates in that province. While the study authors warn that their results may not be representative of the broader Métis population in Ontario because of the small sample sizes and other methodological issues, this preliminary research indicated:[46]

- The most frequently diagnosed cancers among the Métis population in Ontario, in order, are: lung, prostate, colorectal and breast. In the general population prostate, breast, lung and colorectal are the most frequently diagnosed cancers.
- The overall incidence rate of cancer was slightly higher among Métis than the general population for persons over age 65 and markedly higher in Métis over age 75.
- The combined incidence of all cancers, not adjusted for age or sex, is 20 percent lower in the Métis population than in the general Ontario population.

- After adjusting for age and sex, the incidence rates of most cancers remain lower in the Métis population, with the exception of lung cancer.

A similar data linkage study, conducted in 2011 in Manitoba[47] found that:

- Rates of all invasive cancers, defined as forms of cancer that have spread beyond the immediate site of origin to surrounding tissue, are the same in the Metis and general populations of Manitoba.
- Cancer is the leading cause of death for Metis men and women, responsible for 30.6 per cent of all deaths between 2002 and 2006.
- Cancer rates tended to be higher in males than females in both populations.
- Metis and all other Manitobans had the same distribution of cancer stage at diagnosis, and the types of treatment received did not differ significantly.

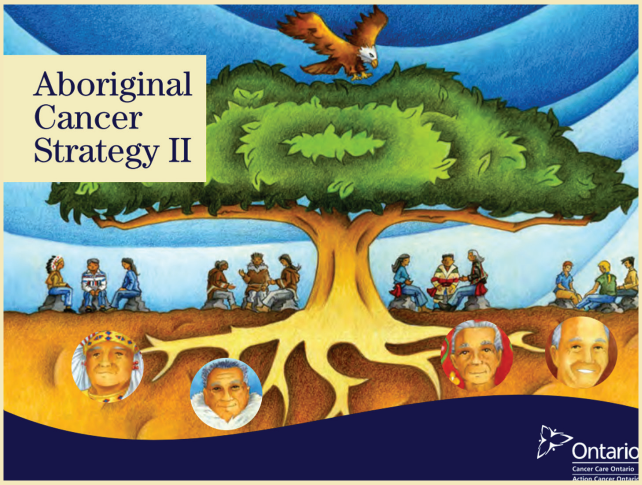
2.4 Métis Cancer Care

Cancer care is provided to Métis by a provincial cancer agency, hospital or cancer centre. Some provincial cancer agencies are responsible for service provision, while others manage provincial cancer services, but are not direct service providers. Cancer centres are able to provide a wide range of specialized cancer care services that may be critical for the health of many Métis, including screening, diagnostic tests, and treatments such as radiation and chemotherapy.

Health indicators and health system performance measures do not currently include dimensions

Aboriginal Cancer Strategy, Cancer Care Ontario

The Aboriginal Cancer Strategy II (ACSII) was released by Cancer Care Ontario (CCO) in June 2012. This report builds on learnings from the first Aboriginal Cancer Strategy (2004-2009) and was created in close collaboration with Ontario's Aboriginal leaders.



The ACSII sets out a clear plan for reducing risk and preventing cancer from 2012 to 2015. It recognizes the challenges faced by Aboriginal Ontarians, and provides both the tools and the control to create change. It seeks to improve the performance of the cancer system with and for First Nations, Inuit and Métis in Ontario in a way that honours the Aboriginal Path of Well-being.

This document sets out six strategic priorities specific to First Nations, Inuit and Métis cancer control that support the overarching Ontario Cancer Plan III:

- Build productive relationships
- Research and surveillance
- Prevention
- Screening blitz
- Supportive care
- Education

Its success depends on maintaining open and respectful two-way relationships with First Nations, Inuit and Métis

of well-being from a Métis perspective. For many Métis, like the determinants of health, well-being is a holistic, intertwined and fluid concept, driven by culture and context. With cancer control emerging as an important priority, many Métis people and organizations have stepped forward to advocate their perspective on well-being in relation to cancer control.

Cancer Pathways

The cancer journey of each Métis person is unique; every community, family, and individual experiences cancer in a way that reflects their distinct local realities, past experiences, and personal beliefs. However, many of the challenges and barriers to cancer control for Métis are common across the country.

The following sections present some of the challenges that many Métis experience throughout the cancer journey, and highlight opportunities to address these challenges.

Métis Patient Cancer Journey
Métis Cancer Journey Canoe Activity

In direct response to the Partnership's First Nations, Inuit and Métis Action Plan on Cancer Control strategic priority, "culturally responsive resources and services" the Métis Nation British Columbia and the BC Cancer Agency used a canoe to represent the story of the Métis cancer journey. The canoe activity was part of a focus group that included Métis cancer patients, survivors and their caregivers.

Using colored paper, participants were asked to provide their input on the following themes, in relation to their cancer journey:

- Pink, to represent the individual's relationships and how cancer impacted them;
- Green, representing what participants wished they had packed for the journey;
- Orange, symbolizing the concept of safety and culturally relevant information and support;
- Yellow, for any other important information they wished to share about their journey.

Participants were asked to place their comments on a large picture of a canoe, according to the point in their journey the comment referred to. The stern of the canoe symbolized the beginning of the cancer journey, diagnosis for some participants; the middle of the canoe represented treatment; and the bow symbolized the end of the journey, including survivorship, palliative or end-of-life care.

Participants reported on the importance of having an extensive support network, particularly in the early stages of the cancer journey. There was a common desire for more culturally appropriate treatment options and assistance with the cost of travel to and from treatment centres. Significant emphasis was also placed on the importance of having some form of spirituality during treatment and concern for the stress levels of caregivers.

In the bow of the canoe, there was continued emphasis on the need for financial assistance for either the patient or the caregiver, for example, compassionate leave to assist a family member with treatment.

Participants expressed concerns related to their physical appearance, sharing that they often felt excluded or overlooked by Aboriginal programs and services. Participants hesitated in their support of self-identification, arguing that it was unclear how self-identification might affect the quality of care they received. They suggested that when medical staff engage with a patient and their support network about their Métis heritage, it must be done in a safe way to assure patients it is a means of attempting to provide the best care possible for their specific needs. Finally, the participants suggested that part of achieving quality engagement for health care providers working with Métis is about letting the patient and their families know who you are, not just your position, to establish a connection and increase a patient's comfort level.[48]

3. Barriers to Health Service Delivery

Barriers to health service delivery prevent Métis from accessing high quality care across the cancer control continuum. From prevention, to screening, treatment, palliative care and survivorship, many interrelated factors stand in the way of the patient receiving optimum care. By understanding the nature of the obstacles and their importance, resources can be marshaled to change those factors that will have the greatest impact on improving cancer control for Métis.

Métis Patient Cancer Journey
In their Voices, Focus-Group Dialogue Session

To gain an increased understanding of the barriers and supports that determine access to cancer control services, Métis Nation of Ontario hosted a focus group with Métis cancer survivors. Participants reported experiencing barriers at various levels, as noted below:

At the Cancer Care level participants perceived or noted that:

- They were on the receiving end of discriminatory behaviours, which they attributed to a lack of cultural competency by some health care providers;
- nurse navigators and other similar supports lacked information and knowledge about Métis-specific resources;
- significant wait times resulted in heighten anxiety;
- some cancer care centres do not permit certain cultural practices;
- the spoken and written language used in health care settings can be difficult to understand;
- there was variation in the amount of information patients received;
- a lack of insurance coverage for prescription drugs; and,
- those with private health insurance fared significantly better than those without.

At the community level participants perceived or noted that:

- Smaller hospitals often found in rural areas, tend to have less expertise and capacity, limiting their ability to provide up-to-date treatments and technologies;
- patients from smaller communities seem to experience longer wait times;
- accessing specialist care and cancer treatment within and beyond local communities is difficult, resulting in frequent travel, created logistical and financial challenges for patients and their families;
- available home care is inadequate, and family members may be dealing with their own significant health concerns, limiting their ability to care for a cancer patient.

Participants reported on various supports, as noted below:

- Strong and healthy relationships with family, friends, community, including the Métis community;
- awareness campaigns that help with early detection;
- spirituality and doing things that make you feel better such as music, spending time with people you love, journaling and activities that release endorphin;

- ownership of personal health, and a strong mind/body connection;
- access to Elders and cultural activities;
- physicians that take patient concerns seriously, offer options and clear explanations of what is going on;
- insurance for prescription drugs and other supports not covered in the provincial health system;
- support from the Métis Nation of Ontario (e.g., both directly, by providing transportation to and from treatments, and also support with personal transportation costs);
- not-for-profit organizations (such as the one that offers cottage vacations to cancer patients at no cost);
- quick turnaround time for treatment when necessary;
- online resources;
- alternative therapies such as naturopathy, reflexology and massage;
- accessing second opinions.

Overall, the participants perceived cancer care to be a somewhat discriminatory system, with insurance, geography and ethnicity determining the level and type of care received. Several participants mentioned feeling pushed into having surgery, without an explanation or the option of other forms of treatment. Others mentioned feelings of confusion, of being overwhelmed with treatment options they did not understand. Finally, many participants noted that there was a lack of cultural supports present during their cancer journey, including Elders and culturally competent care providers. However, barriers encountered by participants were often overcome with the support of family, friends, caring health professionals and community or provincial organizations and programs.[49]

3.1 Access to Care in Rural and Remote Communities

Across the country, most Métis reside in semi-rural or urban areas proximal to primary care services, including screening and diagnostic testing. Access to secondary and tertiary-level care can be limited for Métis, especially those living in rural, remote or isolated areas. Distances from facilities dissuade many Métis from accessing cancer control services, regardless of the type of community in which they live. This is due to a number of factors, including the time-consuming nature of travel, the priority of day-to-day responsibilities in the community, and significant travel related costs.[50 51 52]

For Métis living in the Northwest Territories, medical travel is sponsored by the Government of the Northwest Territories, and covers travel to the nearest health clinic or hospital to receive health services not available in the home community.[53] A similar program, funded and operated by the Government of Nunavut, covers medical travel for Métis living in Nunavut.[54] The Government of Yukon also provides funding for medically necessary travel.[55] Most provinces provide some form of funding for medically necessary travel in addition to funding available through private insurance plans and not-for-profit organizations. Making services available closer to home through community-based programming, and making transportation more affordable can help to improve health care access for Métis living in rural and remote communities.

As illustrated in this report, many provinces and jurisdictions have developed or are in the process of developing initiatives to improve health care access for geographically dispersed populations, including Métis. For example, in Saskatchewan a medical bus pass is available for individuals travelling

PROMISING PRACTICE PROFILE: TELEHEALTH

Telehealth is the use of communications and information technology to deliver health care services and information over large and small distances; this may include the use of interactive video-conferencing for patient examinations and the use of telephones for patient consultations. Telehealth reduces the need for travel by patients, families, and health care providers, which can help to improve care coordination, timeliness of care, and equitable access to specialized services.[56]

By providing opportunities to overcome barriers to access and jurisdictional collaboration, and by working to improve educational and professional development, telehealth initiatives cut across the cancer care continuum and offer solutions to a number of health challenges faced by Métis. Telehealth has been shown to be most effective when used as a complement to in-person medical visits and is not recommended as the sole source of service provision, even in remote communities.[57]

between two locations to access health care. The Saskatchewan Transportation Company Medical Pass has the potential to improve the ability of rural Métis to access health services.[58]

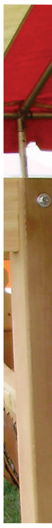
Health Human Resources

Health care professionals play a critical role in the delivery of cancer services and are able to contribute to more positive experiences along the cancer care continuum. Patient-centred care, combined with an understanding of cultural needs and local realities, can help improve a patient's cancer journey. However, access to physicians is a problem across Canada,[59] and may be especially acute among Métis. Of Métis aged 15 and over, 77 per cent of males and 84 per cent of females reported having a regular doctor in the 2006 Aboriginal Peoples Survey; this is lower than was observed for the non-Aboriginal population in which 80 per cent of males and 89 per cent of females had a regular doctor.[60] In the same survey, one in nine, or 11 per cent of Métis respondents said that in the last year there was a time when they needed health care but did not receive it.[61] Only 19 per cent reported that the availability of doctors in their community was excellent. There were no differences in the responses of urban and rural participants, suggesting that while part of this gap is due to isolation of communities, other reasons may be cultural.

Various forms of incentives are offered by the federal, provincial, and territorial governments to encourage health care workers to locate in rural and northern communities. In addition to these incentives, many regions have identified the need to create supportive environments for health human resources working with Métis by providing opportunities to enhance the cultural competency of front line health workers.

3.2 Coordination of Care

The cancer pathway for Métis involves interactions with multiple health organizations; however ensuring that appropriate care is coordinated between these different service providers is often a challenge. It has been well documented that the lack of two-way communication between health care providers in primary (community) and tertiary (hospital/cancer centre) care systems complicates the continuity of care for Métis patients.[62] Many existing information systems do not support adequate documentation or case management to enable the communication of patient information between service providers.[63]



Provincial Cancer Agencies

Cancer care in most provinces involves programs and initiatives from provincial cancer agencies. Cancer agencies support the reduction of the burden of cancer on Canadians by facilitating effective leadership, collaboration, communication, and advocacy for cancer care and control. Some provincial cancer agencies are responsible for service provision, while others manage provincial cancer services, but are not direct service providers. Most cancer agencies work across the cancer service spectrum, with efforts in prevention, early detection, diagnosis, treatment and care and palliation or end of physical life care. As a result, they touch the lives of individuals on many different levels, and at different stages of their cancer journeys.

Métis organizations have development relationships with cancer agencies through cancer awareness, education, and screening programs. Initiatives of cancer agencies to provide services closer to home, through mobile screening and telehealth, have the potential to ease the burden of accessibility of health services for Métis in rural and remote areas. In addition, some cancer agencies, including Cancer Care Ontario[64] and CancerCare Manitoba[65] have developed population specific programs and strategies for Aboriginal citizens in their respective provinces.

Despite evidence of some positive connections between provincial cancer agencies and some Métis organizations, Métis have identified the need for improved strategic alliances in order to facilitate better communication and collaboration with provincial cancer agencies. Some Métis have expressed that existing links with external agencies, including cancer agencies, have not been developed to a point to support extensive resource or program development that is culturally appropriate. In some regions, Métis have identified that the role of cancer agencies in the provision of health services is unclear.

Cancer agencies are accountable for, or play a significant role in, province-wide cancer planning and policy development. Partnerships between cancer agencies and Métis organizations could help to address some of the challenges currently experienced by Métis in coordinating care across the cancer control spectrum, by ensuring that specific strategies designed with and for Métis are included in the provincial cancer control program. These strategies could help to develop culturally appropriate resources, expand the outreach of screening programs, ensure timely referrals for diagnosis and treatment, and provide cancer and palliative care education to community members and health care workers.[66]

Hospitals

The reliance of Métis on hospital health services varies between and within provinces, according to accessibility, availability of services and the roles of other health service providers. In many areas, the networks linking service providing agencies to Métis individuals and organizations are weak, which results in a lack of information about how the cancer care system works and the various options and locations for care that are available. Significant overlap between provincial cancer agencies and hospitals often causes confusion and delays, as Métis are unsure of where to turn to access the information and services they need.[67] [68]

Métis' utilization of hospital cancer services depends on many factors, including their geographic location, cultural preferences, and the state of primary care in their community. As a result, Métis individuals may access hospital services at different stages throughout their cancer journey. Hospitals across Canada also have varying capabilities when it comes to accommodating and supporting the unique needs of Métis patients, which may influence a Métis person's decision to go to a hospital.

Levels of Government

Provincial, territorial, and sometimes regional governments each play a role in the delivery of health services to Métis. While the coordination of cancer care for Métis patients is complicated less by jurisdictional boundaries than it is for First Nations and Inuit patients, it is essential that jurisdictions work in concert to improve cancer pathways for Métis patients.

3.3 Patient Identification

Métis-specific health data are critical in order to survey the impact of cancer, to design programs to address gaps in cancer control and coordinate efforts across jurisdictions. At present, the ethnocultural identity of cancer patients is not collected by most health care systems in Canada. The ability to identify Métis cancer patients can help jurisdictions to improve the value of programs they believe are having positive impacts.[69]

By linking provincial health records with various databases, Manitoba and Ontario have been able to measure the impact of cancer on Métis. These measures are invaluable for understanding the needs of Métis, for identifying new research directions and for prioritizing actions for improvement at the level of the system and the community.

Throughout the development of the *First Nations, Inuit and Métis Action Plan on Cancer Control*, participants have expressed a need for people-specific surveillance data. Currently there are few instances where Métis have an opportunity to self-identify within the cancer control system, and consequently, Métis patients may not receive culturally appropriate care or be able to access culturally relevant materials to support them along their cancer journey.

> ***"Like a lot of us, my daughter doesn't 'look' Aboriginal – or at least what the general public thinks an Aboriginal person looks like. So she wouldn't have been told about the services that are already available simply because of her appearance."*** [70]

Developing Métis patient identifiers and data standards requires overcoming barriers including a lack of awareness and/or will, few supporting relationships or networks, expertise in the design of complex health information systems and significant cost outlays. Designing a patient identification process should include an understanding of the importance of involving Metis leadership to ensure Métis values are integral to the design, implementation and management of patient identification systems.

As of November 2011, there were 50 known ethnocultural identification databases in existence or in the process of development in Canada; these systems were spread geographically across the country and across a wide spectrum of health service domains.[71] Some include identifiers for 'Aboriginal' Canadians while others were specific to each First Nations, Métis and Inuit. Each database represents opportunities to consider more widespread and culturally competent systems of patient ethnocultural identification.

Métis Patient Cancer Journey
Métis Settlements, Focus-Group Dialogue Sessions, Alberta Health Services

From November to December 2013, a series of focus group dialogue sessions were hosted by Alberta Health Services, with participants from seven of the eight Alberta Métis Settlement communities.

The Focus-Group Dialogue Sessions were conducted according to the principles of respectful engagement, which include equity, fairness, relevance, reciprocity, and responsibility. These principles are considered elements of "ethics of practice" for culturally safe and appropriate engagement with First Nations, Inuit and Métis people. In this work, the application of respectful engagement principles included dedicating time and energy to following community practices and protocols and the use of talking circles or focus group dialogue sessions to speak with participants in their respective communities.

In total, 25 individuals from seven of eight Métis Settlement communities participated in the group dialogue sessions. Participants included cancer survivors, primary caregivers, and individuals who were both survivors and caregivers.

The dialogue sessions began once all questions were addressed and a short summary of the aims and potential outcomes of the project were presented. After the first session, participants at subsequent gatherings were provided with emerging themes from previous discussions and asked to comment and/or validate these findings. Additional time was spent meeting with the Métis Settlements Health Board to provide a thematic summary of the focus group session dialogues.

Several themes reoccurred throughout the focus groups, including:

- Geographic isolation of the communities in relation to cancer centres, and the resulting costs, both
- financial and time spent away from home and community activities;
- the financial burden of covering treatment-related costs not covered by private or public insurance;
- a lack of trust and confidence in the cancer care/health care system;
- the need for emotional support for both the patient and family;
- the need for preventative health and cancer awareness education at the community level;
- the role of family and community support in healing;
- the importance of positive patient-provider relationships; and,
- the value of culturally-specific support services.[72]

Included in these 50 known systems are eight enabling practices that support their development and use by creating awareness, identification standards, and process harmonization.

Need for Information

Métis organizations have acknowledged that current processes for identifying Métis cancer patients are insufficient and have recognized the need to address this gap through collaborative action. Identifying Métis at the health system level can enable data collection on cancer incidence and mortality rates, as well as relationships between cancer and other health issues. Cancer care organizations and governments across the country have recognized the barriers to creating a system of patient ethnocultural identification. The wide range of practices across Canada indicates that many in the system are working to address these gaps. Examples are listed below:

- The Métis Nation of Alberta's (MNA) Health and Wellness department operates the Public Health Surveillance Program -- a unique, long-term partnership agreement between the Métis Nation of Alberta, Alberta Health Services, the Public Health Agency of Canada and the University of Alberta, School of Public Health. Through this partnership, the MNA is pursuing Métis health data collection to form baseline Métis health information with a particular focus on the prevalence of chronic disease. This information will be used to guide health policy, health service delivery, and health programs for Métis in Alberta.[73]

- With funding from the Public Health Agency of Canada, the Manitoba Metis Federation partnered with CancerCare Manitoba to link data from the Manitoba Métis Population database to provincial cancer registry data for the 2011 report, Cancer and Related Health Care Utilization in the Manitoba Metis Population.[74]

- In 2010 the Metis Nation of Ontario, in collaboration with the Institute for Clinical Evaluative Sciences with funding from the Public Health Agency of Canada linked the MNO registry and provincial disease databases to produce a report on cancer that was released in 2012.[75]

- Although not Métis specific, the Aboriginal Self Identification (ASI) Project is an initiative to collect data on the Aboriginal identity of patients accessing services from British Columbia's Interior Health Authority that will assist in efforts to design and deliver more culturally sensitive programs. The project, which started July 2011, includes the Métis Nation British Columbia and the database is being built based on individual consent. Patients who self-identify as Aboriginal are offered the assistance of an Aboriginal Patient Navigator.

- Our Health Counts - Baseline Population Health Database for Urban Aboriginal People in Ontario, is a forthcoming report on urban Métis living in Ottawa.[76] The report is part of a wider project to measure health indicators in the Ontario Métis population.

Supporting a patient's journey through the cancer system requires an effective flow of information between a patient, their family, and community-based health care providers. The creation of acceptable systems and approaches for identifying patients' ethnicity will improve the flow of information and reduce barriers to accessing culturally appropriate cancer care.

Data Sources

Every province and territory has a cancer registry which collects information on residents with a diagnosis of cancer. These registries are multi-source databases, meaning that they depend on their ability to match and link different types of patient records. However not all provincial/territorial cancer registries use the same types of data sources in the sameway, which complicates the feasibility of comparing cancer control data across jurisdictions.

There are six potential sources available to cancer registries for identifying Métis patients, which are used to varying degrees by the provinces and territories. These sources include: mortality databases from Vital Statistics registries, patient registration records and clinical medical records from cancer centre, hospital or physician reports, Métis registers, provincial/territorial health insurance registers and the Census. Each of these sources may be more or less useful to identifying Métis in cancer registries. The information pathways that inform cancer registries are not always direct and may link with systems which do not contain Métis identifiers. The transfer of patient information between multiple records systems may therefore contribute to gaps in the identification of Métis throughout their cancer journeys.

Cultural Competence and Cultural Safety in Nursing Education

The Canadian Association of Schools of Nursing (CASN) and the Aboriginal Nurses Association of Canada (A.N.A.C.) both recognized the need to improve the health delivery and outcomes for First Nations, Inuit and Métis peoples in Canada. A particular area of concern was the need for all registered nurses, who graduate from nursing programs in Canada, to understand the unique context of delivering care to First Nations, Inuit and Métis peoples. Incorporating competency training into nursing curricula was identified as a way to improve the cultural safety of interactions between Aboriginal patients and nurses. A framework for core nursing education competencies was developed with six main focuses - post-colonial understanding, communication, inclusivity, respect, indigenous knowledge and mentoring and supporting students for success. The framework has implications for nursing employers, ongoing education for nurses, and relationships between nurses and patients. Nursing school across Canada to utilize this framework in their programs. In addition, A.N.A.C. worked with the Canadian Healthcare Association to develop, implement and evaluate a continuing education course in cultural competence and cultural safety.

Health Care Professionals

The collection of ethnocultural identifiers during a patient's cancer journey involves healthcare professionals responsible for asking identification questions or inputting identifier data into records systems. However in many jurisdictions, there is a lack of awareness of health databases, the type of information they hold and how Métis identifiers could be used to enhance cancer care. Expertise in the design and implementation of complex ethnocultural health information initiatives is usually concentrated around clusters of experienced individuals and organizations. As a result, many health care professionals that could benefit from improved Métis patient identification processes are not in a position to act.

Consistent collection and recording of Métis identifiers by frontline health staff has been identified as a barrier for implementing more widespread systems. Frontline staff includes clinicians and administrative staff in hospitals, cancer centres, primary care physician offices, and community care centres. Time constraints, language barriers and issues of cultural competency between staff and Métis patients restrict the ability of these care providers to identify Métis as they access health services.[77] Education and training are required to prepare frontline staff to ask patients ethnocultural identification questions in a respectful and safe manner. Cultural competency programs, such as one developed by the Aboriginal Nurses Association of Canada work to increase the number of health care professionals trained to understand the cultural context of working with Métis.

PROMISING PRACTICE PROFILE: HEALTH INSURANCE CLIENT REGISTRIES

Provincial and territorial health insurance client registries typically cover a very high percent of the provincial or territorial population.[78] Currently, two territories include a Métis identity question during health insurance application processes, as well as Métis identifiers in provincial health card numbers. Identifying Métis through these registries creates the potential to link this information with other data sources that incorporate provincial health card numbers in their records.

The Northwest Territories and Nunavut demonstrate leading practices in collecting Métis identifiers and integrating this information with its cancer registry. In both these territories, health care plan client registries capture Aboriginal people specific status by including an alpha or numeric character that denotes ethnicity in all personal health card numbers. This character is used by a wide variety of health service providers, as well as policy makers and researchers, as a starting point to help clients navigate to the most appropriate services for their needs, as well as monitor population health status and outcomes. For example, the Stanton Hospital in the Northwest Territories uses health care identifiers as a trigger to ask patients admitted to the hospital about their preferences for a range of culturally relevant supports.[79]

Health card numbers are used within these territories to record linkage across different health databases, within strict parameters for data security and privacy. For example, the North West Territories and Nunavut cancer registry are able to determine the ethnic status of patients by including health card numbers, with Aboriginal identifiers, on all cancer registration forms.
By using health care plan client registries as sources of ethnocultural identifiers, these cancer registries are able to better assess the burden of cancer among Métis.[80]

3.4 Community Awareness and Cancer Education

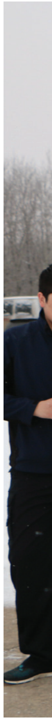
Cancer affects all Canadians, either through personal experience with the disease or indirectly through family and social connections.[81] However, a history of poor cancer outcomes and personal beliefs about cancer may pose barriers to open discussion about the disease. While most Métis are aware cancer is a problem, there is a lack of culturally relevant information about Métis further increasing the barriers to discussion.

Views of Cancer

Cancer is a single word, but it represents more than 200 different diseases. The complexity of these diseases and of health systems in general, makes tackling cancer a difficult task for most Canadians. For Métis, distinct historical and cultural contexts contribute to unique views of cancer, which may impact the delivery of effective cancer care.

> ***"Historically, they didn't identify it (cancer) as a disease. They called it 'muchomunso' – which means, like a bug or worm eating you up."*** [82]

Although few studies are available on Métis attitudes and beliefs about cancer, the research literature from Indigenous communities around the world reveals a generally pessimistic attitude toward cancer, with most people viewing cancer as a frightening disease associated with death. Métis cultural conceptions of cancer may help to



explain lower rates of participation in prevention, early diagnosis, and treatment programs. Cancer information resources generally do not address Métis culture, therefore Métis may experience difficulty in accessing relevant resources to inform themselves. Education is needed not only to inform people about the facts of cancer, but also to help overcome deeply held beliefs about cancer that may contribute to later stage diagnosis. Métis have identified that adequate information can help to enhance their sense of control throughout the cancer journey, as well as diminish their fears.

Many health care professionals are unaware of the historical cultural factors that contribute to Métis views of cancer, and views of general health care. Cultural differences create barriers to effective cancer care, as caregivers generally do not understand and are unable to address Métis perceptions of cancer.[83] Many health care providers have expressed a desire to have more information about the culture of their clients, to help them improve their cultural sensitivity and provide more effective cancer education.[84]

Prevention Through Education

Cancer can, to a large extent, be prevented; in fact, it is estimated that about half of cancers can be prevented by adopting healthy eating, physical activity, and maintaining a healthy weight.[85] Although not all cancers have known causes, and some people may develop cancer without having any of the known risk factors, studies have shown that healthy living can help to reduce cancer risk.[86] However many Métis are unaware of the association between cancer and prevention due to gaps that exist in basic cancer education. Cancer is generally not perceived as having any link to prevention, and common risk factors linked to chronic disease are often not recognized as also being relevant to cancer.

Information about cancer prevention, early detection and treatment can help to enhance patients' sense of empowerment throughout the cancer journey, as well as diminish their fears.[87] A 2010 health survey conducted by the Métis Nation-Saskatchewan[88] revealed that levels of awareness and personal responsibility about healthy living were quite high in that region. Many respondents reported that exercise and other forms of physical activity, fresh air, healthy eating, spirituality and not smoking all contributed to good health. Many gave credited their good health to the relationships in their lives and social activities. When asked what they did to help themselves stay healthy, 58 per cent indicated they ate a healthy diet, and 47 per cent indicated that they exercised at least twice a week. Information and education were identified as an important contributor to health and well-being. When asked about community-based programs, many talked about a desire for more information, awareness, workshops, education and programs that would support health and well-being.

Participants at the Métis Settlements Focus-Group Dialogue Session, hosted by Alberta Health Services in November-December 2013, consistently expressed a desire to have more information made available within their communities about cancer prevention and emphasized the need and importance for materials that contain culturally-appropriate messaging. Participants viewed the need for information to be made available to all generations as important, and included in-classroom education to school-aged children.

Other Métis organizations across Canada have recognized the need for greater awareness about cancer and chronic diseases and have taken steps to understand the gaps, to inform their constituents and to implement health promotion programs. For example:

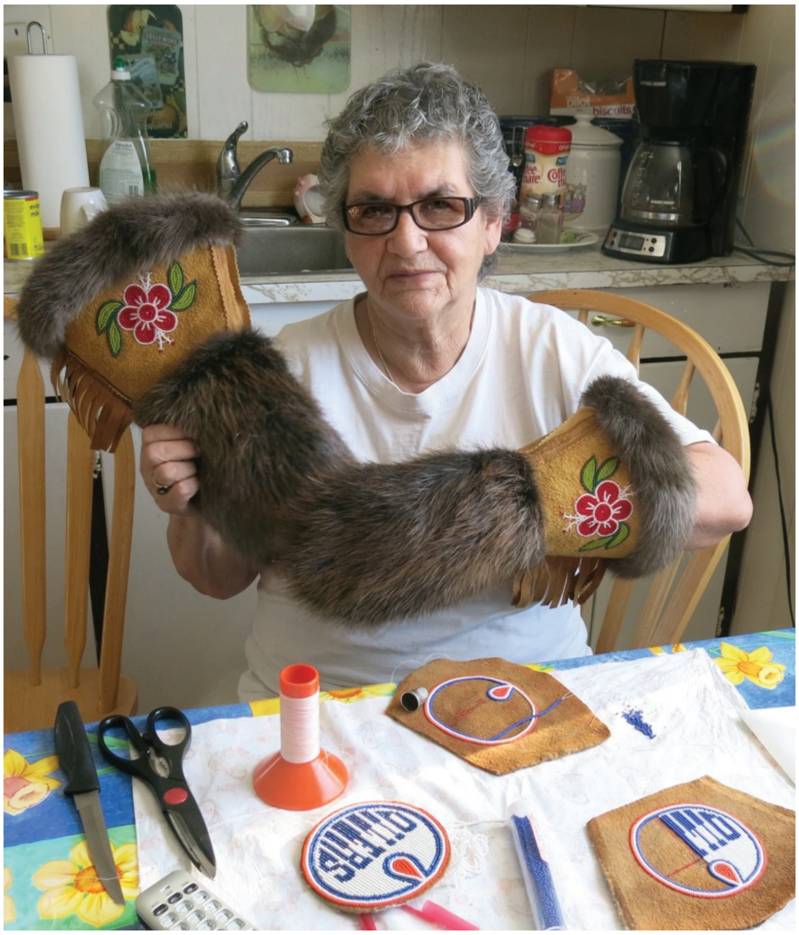
- Métis Nation British Columbia conducted a provincial survey of its members in 2006 including areas such as health, culture, education, housing, employment to better understand their concerns;
- Métis Nation British Columbia utilized ActNow BC funding to support community health promotion projects in 33 out 36 Chartered Métis Communities;
- Métis Nation - Saskatchewan implemented a Green Light program to celebrate smoke-free homes and reduce the impact of second-hand smoke on individuals and families.
- In Manitoba, the 'Community-Driven Cancer Prevention Initiatives' program was created to help CancerCare Manitoba staff and community members work cooperatively to create meaningful prevention and awareness materials and events. Each initiative is community-motivated, promoting ownership at the local level.
- The Public Health Agency of Canada's Cancer Program, in its 2011 solicitation of proposals, focused on 'Removing barriers, raising awareness and/or promoting participation in cancer screening and early detection among underserved populations', including Métis. The types of projects that were funded included: tools, resources, models, demonstration or pilot projects, knowledge transfer, best and promising practices, qualitative research and evaluation studies, and training modules. As these initiatives are completed, it is expected that more tools, resources and programs will become available to Métis.

4. Patient Experience

"Sometimes all you need is to hear from someone who's been there, to reassure you that you're okay, while you're going through it." [89]

4.1 Beginning the Cancer Journey: Screening and Diagnosis

Controlling cancer amongst Métis goes beyond caring for those who have already been diagnosed with cancer to include all members of the population, even those who are well. For some cancers, there is no known cause; for others, there may be no signs or symptoms until the cancer is at a later stage.[90 91] Early detection of cancer through screening of healthy populations has proven effective in reducing mortality and morbidity from some cancers.[92]



Most provinces and territories now offer organized screening programs for breast, cervical and colorectal cancers. Although organized screening programs are not in place for prostate and other cancers, doctors may offer tests for patients who may be at higher risk as part of their routine preventive care.

Addressing barriers to accessing cancer screening and improving the timelines of cancer diagnoses are critical elements of controlling cancer in the Métis population.

Early Detection

Early detection means finding a cancer at an early stage; when cancer is found early enough, it is often easier to treat.[93] The goal of screening programs across Canada is to detect as many cancers as possible, as early as possible.[94] At present, information on the current status of cancer screening among Métis is lacking, primarily because most health surveillance systems in Canada do not capture information on ethnicity. Cancer screening is a provincial responsibility; cancer agencies and ministries of health provide, organize and coordinate screening programs for their populations. Where no organized program exists, opportunistic screening takes place in doctors' offices or in specialized clinics.

"If my uncle would have gone to see the doctor sooner, maybe he would have survived. It wasn't until he moved to the city that he started seeing a doctor and found out he had cancer. He had symptoms for three years." [95]

The following section describes Métis participation in screening programs for breast, cervical, and prostate, colorectal health.

Breast Screening

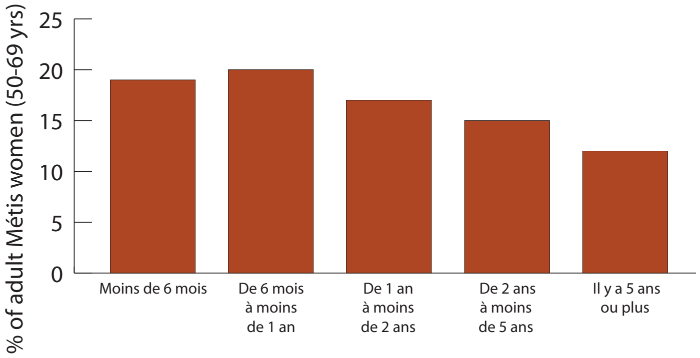
Breast cancer screening programs, including regular mammograms, clinical examinations and breast self-examination, are in place in most provinces and territories, and are coordinated to meet national standards. The Canadian Task Force on Preventative Health Care recommends that women between the ages of 50 to 69 and 70 to 74 should have a mammogram once every 2 to 3 years. Routine mammography is not recommended for women between the ages of 40 to 49 but women at high risk should consult with their physician.[96] Mammography screening, offered in an ongoing and timely basis through organized programs, could potentially reduce mortality due to breast cancer by as much as 20 per cent.[97]

The 2006 Aboriginal Peoples Survey found that about 57 per cent of Métis females aged 50 to 69 had had a mammogram within the past two years, compared to 73 per cent of non-Aboriginal females in 2008. About 39 per cent of Métis females in that age group had never had a mammogram or had had one more than two years prior to the 2006 survey. Métis and non-Aboriginal women with a regular doctor were more likely to have had a mammogram within the two years prior to the survey. Métis women with a regular doctor were twice as likely to have had a mammogram within the previous two years compared to those without a regular doctor.[98] Mammography participation patterns differ regionally. For example, a 2010 study in Manitoba reported mammography rates for Métis women at 60 per cent, compared with 62 per cent for all other Manitoban females.[99] In Ontario, rates of mammography among Métis women aged 50 to 69 were about 90 per cent, the same rate of all other Ontario females. However, only 60 per cent reported having had a mammogram within the recommended interval of two years, compared with 73 per cent of women in the general population.[100]

Cervical Screening

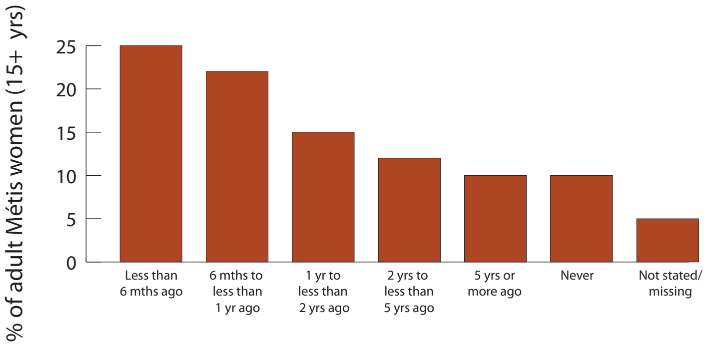
Cervical cancer is one of the most preventable cancers; the Papanicolaou (Pap) test has been used to screen women for the past 50 years and is estimated to reduce death from cervical cancer by 99 percent.[101] Women who are sexually active are recommended to have a Pap test every one to three years, depending on previous test results.[102] Access to cervical screening depends on the availability of local health care providers, including nurses or nurse practitioners trained to perform Pap tests.[103]

Figure 6: Last Mammogram as Reported by Métis Women



Source: Statistics Canada, Aboriginal Peoples Survey, 2006

Figure 7: Last Pap Smear Test as reported by Métis Women



Source: Statistics Canada, Aboriginal Peoples Survey, 2006

The 2006 Aboriginal Peoples Survey found that 67 per cent of Métis females aged 18 to 69, had a Pap test within the two years prior to the survey while 28 per cent reported that they never had a Pap test or had one two or more years earlier. Of Métis women who reported having a regular doctor, 72 per cent had had a timely Pap test, in comparison with the 51 per cent of Métis women who reported not having a regular doctor.[104]

Regionally, cervical cancer screening rates vary. In a 2010 Saskatchewan health survey, 91 per cent of Métis women indicated that they had ever had a Pap test, and 78 per cent had had one within the last two years.[105] Manitoba Métis women have a cervical screening rate of 69 per cent, higher than the 67 per cent of all other Manitoban women. In Ontario, the proportion of Métis women aged 18 and over who had been screened within the last five years was not significantly different than the general population.[106]

Several provinces and territories are implementing initiatives to improve the rate of cervical cancer screening in underserved populations, including Aboriginal communities. For example, in Ontario the 'Underscreened/Never Screened Project' is focused on engaging groups with low participation rates, including Aboriginal populations.[107] Alberta Health Services cancer screening programs have developed cancer screening information materials for Aboriginal populations and, in 2007-2008, provided grants to Métis communities to promote screening.[108]

Colorectal Screening

Colorectal cancer is 90 percent preventable if detected early.[109] The entry-level screening tests for colorectal cancer include the fecal occult blood test (FOBT), guaic-based fecal occult blood test (gFOBT) or fecal immunochemical test (FIT). The Canadian Task Force on Preventive Health Care recommends that men and women over the age of 50 have an FOBT every one or two years; however these guidelines are currently under revision.

Organized screening programs for colorectal cancer are relatively new in Canada. As of early 2012, organized screening programs were established across the country with ten provinces and one territory having announced or currently running organized colorectal cancer screening programs or pilot programs.[110]

Currently, 50 per cent of Canadians in this age group report having had a screening test.[111] There is no information available on Métis participation rates for colorectal screening.

Other Screening

Most cancers do not have organized screening programs and some cancers, including lung cancer and ovarian cancer, do not yet have a reliable test for early detection.[112] Routine screening of some cancers, including prostate cancer, is not recommended due to the potential risks associated with screening. However, those with a family history of prostate or other cancers, or with concerns about screening guidelines, should consult with a health care professional. For prostate cancer, screening is usually a digital rectal exam or a prostate specific antigen (PSA) test. [113]

The 2006 Aboriginal Peoples survey found that 27 per cent of Métis men aged 40 to 49 had had a PSA test within the five years before the survey, while 65 per cent had never had a PSA test or had had one five or more years previously. Métis men aged 40 to 49 who reported having a regular doctor were over three times more likely to have had a PSA test within the five years prior to the survey compared to those without a regular doctor.[114]

Person-centred Perspective

My daughter Melinda

By Fred Shore, Metis, Caregiver

What happened really came as a big surprise. Basically our oldest daughter was not feeling well in the summertime, July and August, and just flu-ish type symptoms and things. And she was getting really tired.

She was also in a position where she was just about to become an assistant manager at a big store here in the city. And she thought that it was the stress of that and everything else. So anyway, she started at the new place.

But then she found herself going to work and sitting in the office unable to get up and do anything, just no more energy left, really not feeling well. So her mother and I both started getting a little pushy about going to see a doctor about it. So eventually she did.

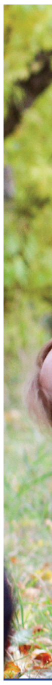
The surgeon put her in the hospital that same day and not only put her in the hospital, but had her on morphine before the hour was out.

She was diagnosed with Stage 4 colon cancer. There were three major tumours and all of them had really metastasized everywhere...it was in her liver and everything so... that was September 25th and she died on November 12th.

It was tough. As a parent watching a child dying is not fun. There was nothing we could do. The only thing we could do was make her as comfortable as possible and, you know, by and large just have to tough it out.

We had a lot of friends that were there...and they stayed as long as they could. And they were actually present when Melinda passed.

We didn't have time to get angry, it just happened so fast. And the reality of the matter was, one day she was dead and that was it. She died on November 12th. November 11th is my wife's birthday. We always said she waited until after, you know, midnight. Knowing Melinda she probably did.[116]



According to a 2010 health survey conducted in Saskatchewan, 48 per cent of Métis males indicated they have had a prostate exam, while 56 per cent of those respondents indicated that they had one regularly.[115]

Screening Challenges

Overall, it appears that Métis are participating in cancer screening at similar rates to the general population. However, these rates are generally below the national targets for organized screening programs and vary significantly by region.

There are many reasons why Métis do not participate in screening programs. Although these may vary across the country, some general themes have emerged. Barriers to accessing cancer screening services include personal fears and beliefs, geographic isolation, economic factors, and health system capacities.[117] [118]

Personal Fears and Beliefs

Past experiences with the health system have a lasting effect on the decision to participate in screening programs. Poor experiences with cancer for many Métis may manifest as a belief that a cancer diagnosis represents a death sentence. For some, rather than motivating them to seek help earlier, this fear of cancer acts as a deterrent to pursuing preventative procedures, such as screening.[119]

Many Métis in their 50s and 60s who are within the age range for screening are living with past childhood experiences of sexual, physical and psychological abuse that may have led to distrust of health care professionals performing screening exams. In particular, residential school experiences make older people reluctant to undergo screening procedures and interact with care providers that they do not know and trust.[120]

Trusting relationships and culturally safe environments can work to encourage Métis people to participate in screening programs and contribute to more positive experiences.

> ***"The healthcare professionals are great, but they're so used to dealing with cancer every day. They need to slow down when dealing with you as a patient because it's overwhelming and scary."*** [121]

Many health care organizations have identified the need to create supportive environments for health care professionals working with First Nations, Inuit and Métis through cultural competency training and the provision of culturally appropriate resources. For example, the Society of Obstetricians and Gynaecologists of Canada produced guidelines for working with Aboriginal people in 2001,[122] and in 2009, the Indigenous Physicians Association of Canada and the Association of Faculties of Medicine of Canada collaborated to develop two First Nations, Inuit and Métis health curriculum frameworks for continuing and postgraduate medical education.[123] To address the needs of health care professionals based in communities, the @YourSide Colleague courses[124] offered by Saint Elizabeth, a health care organization, are designed to help provide professional development for nurses and health care professionals working with First Nations, Inuit and Métis patients, communities and organizations.

Economic and Social Factors

For some Métis, access to cancer screening is limited by economic factors, particularly in relation to transportation costs. According to the 2006 Census, the average income in 2005 for Métis aged 15 and above was about 80 per cent of the average income for the total population of Canada. Twenty-one per cent of all Métis were living below the low-income cut-off level calculated by Statistics Canada, compared with 15 per cent of the total population of Canada.[125] Employee assistance plans, public health insurance or not-for-profit organizations generally have limited funding for prevention-related travel, placing the financial burden of screening-related travel on individuals.[126] In addition to costs, the time consuming nature of travel may act as a barrier for some Métis. Their desire to access screening may be overshadowed by community responsibilities, such as primary childcare or an inability to get time off work. Day-to-day priorities may take precedence over the pursuit of prevention services, including screening, especially for those that have to travel long distances.

> ***"Having to pay for parking was too expensive and felt like a slap in the face given the ordeal we were going through."*** [127]

PROMISING PRACTICE PROFILE: MOBILE BREAST SCREENING

Outreach strategies are currently in place across the country to improve the participation of remote and rural populations, including Métis, in screening programs. Regional and mobile screening facilities are now in place in most provinces and territories to help overcome issues of access, especially for remote populations.

Mobile breast screening, in particular, is an outreach program that has demonstrated positive effects.[128] Most provinces and territories have mobile breast screening clinics that travel to remote communities on a regular basis, from twice a year to once every two years.[129] Quebec, in addition, has a plane that carries mammography equipment and technicians to fly-in communities in the province's northern regions. Women in the Yukon can be screened in Whitehorse or at a mobile unit provided by the BC Cancer Agency. In the Northwest Territories, mobile units are not used, however screening facilities are available regionally. Nunavut does not have any mammography facilities, and women must usually travel out of the territory to be screened.[130]

The Northwestern Ontario Breast Screening Mobile Program, an initiative of Cancer Care Ontario, is dedicated to providing high quality breast screening services for eligible women aged 50 to 74 living in rural and remote communities. The mobile unit travels to over 55 locations, visits more than 30 communities, and is available in the evenings and on weekends to accommodate schedules and further increase accessibility.[131]

CancerCare Manitoba's (CCMB) BreastCheck program operates mobile breast screening sites across Manitoba in over 90 locations, to help increase screening participation rates across the province.[132] From 1991 and 1999, mammography participation by women living in rural areas of Manitoba increased from about 13 per cent to almost 53 per cent.[133]

Health System Capacities

Shortages of health care providers and high staff turnover rates across Canada create challenges for Métis as they attempt to access cancer screening. In provinces where doctors are the gate-keepers to screening services for certain cancers, including prostate and colorectal, staff shortages are even more problematic. Doctors may be overwhelmed with the immediate needs of clients and have little time to promote or perform cancer screening.[134] Nurses are increasingly being trained to deliver some screening services, such as Pap tests.

Diagnosing Cancer

Most cancer registries do not identify the ethnicity of patients, therefore information about cancer diagnoses for Métis is lacking. Some jurisdictions have worked to fill in this information gap through regional studies. For example, In Manitoba, a data linkage study showed no differences in the stage of cancer at diagnosis between Métis and other Manitobans.[135]

Cultural sensitivity is an important factor in delivering a cancer diagnosis, as Métis may have distinct beliefs in relation to talking about disease and illness. For some, direct references to cancer are thought to bring death closer and promote fear and pain; therefore more indirect communication processes are preferred. In addition, health for most Métis is focused on achieving balance and wellness within all domains of human life.[136] However, many health professionals tend to focus on physical diagnosis and treatment and often overlook the emotional aspects of cancer.

Health system challenges also have implications for cancer diagnoses. For those individuals that are able to access a screening program, and whose test results show abnormal results, referrals are made through their health services provider to a specialist for further diagnostic tests. Coordination and communication between patients, family doctors and specialists can be problematic for persons without a regular health service provider or for those who have accessed screening services directly without involving their regular provider. Health system shortages mean that frontline staff are typically focused on acute care needs, and for those unable to access screening, certain symptoms may go untreated for extended periods of time, which may delay a diagnosis. Improving the cultural competency of health care providers can help to ensure that cancer diagnoses are culturally sensitive to Métis beliefs.

> ***"There were many periods of waiting; it weighs on your mind and makes you anxious."*** [137]

Participants in the Focus-Group Dialogue Session hosted by Métis Nation British Columbia and the BC Cancer Agency suggested that no one should ever receive their diagnosis alone.[138]

4.2 Living with Cancer: Treatment

Cancer treatment options are diverse, based on the type and stage of cancer, as well as personal factors unique to each patient, such as their health status prior to diagnosis and their family health history. Treatment to help overcome cancer, extend life, or improve the quality of life may include surgery, cancer drugs, chemotherapy, and/or radiation therapy. Treatment goals may be to eliminate the cancer, extend life, or improve the quality of life.

The complexity of the cancer care system and treatment options may create challenges for some Canadians living with cancer. For Métis, numerous factors including geographic isolation, communication barriers, and a limited availability of culturally appropriate care, contribute to frustrations throughout their cancer treatment.[139]

Receiving a cancer diagnosis can be scary and the treatment process may be confusing, if the relevant

Receiving a Diagnosis

Excerpt from a conversation with Dr. Esther Tailfeathers

I think it's really important that when you speak with a patient, they bring a family member in with them. I've learned to ask the patient to invite as many family members that are a part of the care team into the examination room and we review and talk about the whole process - this is what he or she has, this is going to be the next step, this is what you're going to need to expect for the next two or three months.

I think those kind of discussions are really important with the family group. Not just with the patient because often the patient will leave the examination room if they're in there by themselves and forget most of the stuff that you've told them. Because they're in shock and they're hearing two or three words and everything else they don't hear because they're scared.

Having the family come in is really helpful to the patient because they feel the support of the family with them. It's also really helpful to the family because they need to know what to expect. So that is an important part of cancer care with Aboriginal patients and I think most patients in the rural areas.[140]

and appropriate information is not available for patients. Providing emotional and informational support for Métis throughout their cancer journey can help to improve patient experiences as they interact with the cancer care system.

Treatment Information

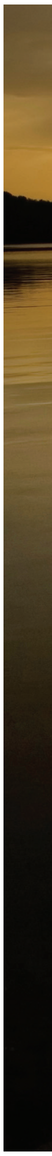
> ***"Three women I know were diagnosed with cancer refused to take the medication afterward because they didn't understand. They took the prescription from the doctor, but never got it filled."*** [141]

Effective doctor-patient communication is particularly crucial in cancer care, where miscommunication can lead to feelings of anxiety and confusion, and procedures may be carried out without fully informed consent.[142] Trust also plays an important role in influencing communication between physicians and Métis during cancer treatment. Qualitative feedback suggests that some Métis do not feel comfortable asking questions about their treatment options, due to a lack of trust in their relationships with care providers. Past negative experiences with the health system, a general distrust of Western medicine and issues of cultural competency may prevent Métis from interacting effectively with their care providers.

Resources designed to improve the effectiveness of communication during treatment consultations are being developed across Canada. (See the epilogue for an example of these resources).

Traditional Healing and Culturally Appropriate Care

While the western medical model tends to focus on the absence of disease, for many Métis an understanding of health and wellness considers the holistic balance of mind, body and spirit and involves the dimensions of the individual, family and community, and the stages of one's lifecycle.[143]



“Spirituality is vital at this time... Medicine people or healers should be made available to provide a sense of cultural safety.” [144]

According to the 2006 Aboriginal Peoples Survey, 32 per cent of Métis adults reported that there were traditional medicines, healing or wellness practices available in the city, town or community where they were currently living. Métis living in urban areas were more likely than those in rural areas to say that traditional medicines, healing or wellness practices were available where they lived. The survey did not report on what percentage of Métis used traditional healing.[145]

A Métis Nation British Columbia survey reported that the need for traditional healing alternatives was among the primary health concerns of its population.[146] In a study of the urban Métis population in Ottawa, 56 per cent of respondents reported having used traditional medicine.[147] And a recent health survey conducted by the Métis Nation-Saskatchewan[148] showed that one in five respondents, or 19.2 per cent, accessed traditional healing services.

PROMISING PRACTICE PROFILE: MÉTIS NATION-SASKATCHEWAN HEALTH AND WELL-BEING STRATEGY

In the summer of 2012, the Métis Nation-Saskatchewan Health Department rolled out their new Health and Well-Being Strategy. Central to the strategy is the Michif phrase, miyo âyâwin, which captures the holistic Métis concept of living well or being in good health.

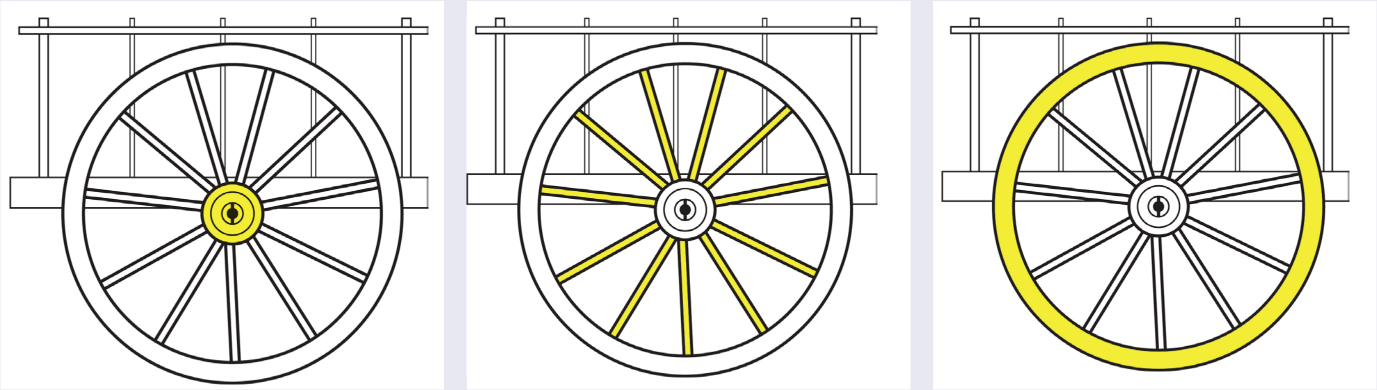
Miyo âyâwin:

> *"When we think about health from this perspective, we are encouraged to consider factors such as worldview, culture, language, identity, history, and experience. … Métis traditional knowledge, health knowledge, and healing practices are integral to our well-being and are intrinsically linked, through language and traditional practices, to our relationship with the land. Métis traditional knowledge is embedded in the Michif language, in our cultural teachings, and in the stories and histories of our communities."*

Among the culturally appropriate tools and resources developed by the Health Department of Métis Nation-Saskatchewan is the Red River Cart Model for Métis health and wellness.

The Red River Cart: A Model for Métis Health and Wellness

The Red River Cart is a culturally recognizable symbol for Métis.[149] Métis Nation-Saskatchewan uses the Red River Cart to model to model Métis health and wellness, and inspire community engagement, dialogue and vision.



The wheel, with its centre hub, spokes, and rim, demonstrates the interconnectedness of Métis understandings of health and well-being. In this model, Métis culture, language, values, and traditional knowledge are held within the wheel hub, which provides strength and anchors the wheel.

The spokes radiate from the centre and are of equal length, demonstrating balance and equality in priority areas for health action. When communities are under stress or facing challenges, spokes get broken and must be repaired. It is up to the community to identify what is broken, as well as the solutions and actions required to repair the spokes, returning balance to the cart wheel and the community.

The felloes, or rim of the wheel, holds the spokes in place and provides strength and support to the wheel. In this model, the felloes are the individuals, communities, partners, and stakeholders working together towards common goals and objectives of improving Métis health.[150]

Navigating the System

Timely access to informational and emotional support during treatment is crucial in helping patients navigate the cancer care system.[151] However, qualitative feedback suggests that Métis do not always have access to culturally relevant support, which may create challenges on their care journey.[152]

For many Métis patients, healing and treatment involve interconnectedness with their family and community. Therefore for those living in rural and remote communities, who must travel significant distances to access cancer care, it is very difficult to leave the support network of the family and community to face cancer alone.[153] Fears of leaving the community, lengthy stays in unfamiliar cities during treatment, and feelings of isolation while in hospital or cancer centres may complicate the ability of some Métis to navigate the cancer care system.

"We need an Aboriginal person from our community, who knows us and who knows the system to help us through the system." [154]

In some regions, hospitals and cancer centres have hired Aboriginal patient navigators to support patients and their families on their journey through the cancer care system, with a goal of enabling them to receive quality culturally appropriate care.

The examples below speak about 'Aboriginal' or 'First Nations, Inuit and Métis' patient navigation. In practice, there are not yet Métis-specific patient navigators, although in some cases Métis have been involved in the creation of these roles. The concept of patient navigators who serve Aboriginal populations is new and studies on their effectiveness have not yet been published. Qualitative feedback from First Nations and Inuit patients indicates that patient navigators play a vital and appreciated role, especially for patients from remote and isolated communities.[155] [156] Similar information is not yet available on the experience of Métis patients, however this approach may represent an opportunity to enhance wellness for Métis.

Several programs in the Regina Qu'Appelle Health Region of Saskatchewan are tailored to the needs of First Nations and Métis people. These include: the Eagle Moon Health Office, Native Counseling Services, Al Ritchie Health Action Centre and the Four Directions community Health Centre.[157] In Saskatoon, the First Nation and Métis health service provides clinical and cultural health staff, clients and families according to the guidance of the First Nations and Métis Health Council.[158]

Alberta Health Services has a dedicated Aboriginal Health Program, which works throughout the province in partnership with Aboriginal people and organizations to provide high-quality, accessible, culturally appropriate health service. The program includes Aboriginal Hospital Liaisons, Care Coordinators and cultural helpers who help Aboriginal families and families throughout their hospital stay and connect them to the health services and programs in their home communities.[159]

Participants in the Métis Settlements Focus-Group Dialogue Sessions reported the need for patient support during the cancer journey from a navigator or liaison familiar with Métis communities and culture. The participants emphasized the value of existing relationships between Settlement communities and staff from the Alberta Health Services Aboriginal Health Program.[160]

In interviews with key informants, conducted during the Métis Nation of Ontario's, In their Voices project, it was identified that the Aboriginal Patient Coordinator helped Métis patients and families to:

- Fill out cancer symptom assessments;
- access psychosocial support programs;
- access prescription drugs or other non-insured health benefits not covered by the province or hospital;
- appeal for access to health services and benefits;
- facilitate the patient's return home, by ensuring supports are in place;
- guide patients from referral to discharged as needed;
- locate psychosocial, hospital and library services;
- voice their needs and concerns;
- access spiritual guidance when requested; and
- increase awareness of available cancer care for Métis patients and their families.[161]

Cancer Care Ontario has hired Aboriginal Patient Navigators and Regional Aboriginal Cancer Leads in regions of the province that are home to significant First Nations, Inuit and Métis populations. By 2015, the number of navigators will increase from five to nine in the 14 cancer regions in the province.[162]

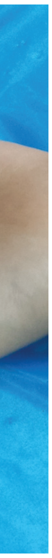
PROMISING PRACTICE PROFILE: ABORIGINAL PATIENT NAVIGATION

Aboriginal patient navigators touch the human side of cancer directly, reaching out to vulnerable patients and families to assist and advocate on their behalf in a complex and confusing health care system.[163] Navigators help to bridge the divide between Western and traditional care by working as liaisons between the cancer care system and Aboriginal communities. Patient navigators also work to promote patient access to community services that enhance continuity of care and efficient use of resources.

Aboriginal patient navigation is a promising practice for enhancing Métis access to culturally responsive care, and improving the coordination of treatment. Aboriginal patient navigation projects in various provinces across Canada are currently working to improve Métis experiences in the cancer care system.

In Ontario, the Aboriginal Patient Navigator at the Juravinski Cancer Centre has been recognized as a leading best practice.[164] The Juravinski Cancer Centre serves over 1.4 million people living in Hamilton, Niagara and the surrounding areas, including almost 40,000 Aboriginal people. The Aboriginal Patient Navigator role became a permanent full-time position at Juravinski in 2009, with funding from the Hamilton Niagara Haldimand Brant Local Health Integration Networks.[165] The Aboriginal Patient Navigator assists patients throughout the cancer journey, including providing support and referrals for mental, physical, emotional and spiritual healing.[166]

The Navigator is a staff member in the Supportive and Palliative Care Program at Juravinski Cancer Centre. Navigation services may be accessed by patients and families self-identifying as having Aboriginal ancestry, or who are part of an Aboriginal family, or who have Aboriginal cultural needs. The Navigator program has been successful in helping patients and their families understand what to expect during various aspects of the cancer journey



4.3 Home and Community Care

Home and community care refers to health related services that enable people with disabilities, chronic or acute illness, and the elderly, to receive the care they need in their home communities. For cancer patients, having access to this type of care can help with the transition of returning home from a cancer care facility after receiving treatment.

Typically, a case manager meets with the patient and the patient's primary caregiver while in the hospital to identify the level of home care needed and to develop a follow-up plan. Due to shortages of health care services in rural and remote communities, however, discharge plans may not be implemented as intended.

Challenges include communication and coordination between community-based care providers and cancer care facilities.[167] Especially in rural and remote communities, patients' care needs may not be communicated to local health staff, and cancer specialists and hospital staff may be unaware of these gaps.

Where health care provider shortages exist, patients might not have answers to their questions about follow-up care or the side effects of cancer treatment, and communication barriers may make it difficult to consult with cancer specialists.

Both Métis and cancer care providers have identified the need to support cancer patients when they return home following cancer treatment.

> ***"When you are first diagnosed, everybody comes to see you. Then when you're going through treatment, they're not there anymore. Once treatment is done, the journey is still going, but often you go home to nothing, no support."*** [168]

Palliative Care

Palliative care is a special type of health care provided to patients with life-threatening cancer; it focuses on pain and symptom management and provides other non-medical services to support the emotional, spiritual and cultural needs of the patient and their family.[171]

Qualitative feedback suggests that most Métis would prefer to pass away at home, surrounded by family and friends.[172] However, in smaller communities there may not be formal palliative care programming to support these individuals.[173] As a result, patients must turn to formal palliative programs located at care facilities in large urban centres, or at smaller local hospitals in the nearby area. This can be an isolating and lonely experience for patients and their families.[174] Significant travel distance may prevent some family members and friends from making the trip out to the care facility and as a result, the patient may not be able to receive the emotional support they need in their final days.

When receiving care at a hospital, Métis people usually have access to the same palliative services as other Canadians; however these services are not typically designed to accommodate cultural differences or create an atmosphere of cultural safety.[175] Métis who have specific palliative care needs related to their traditions around death and dying may not be able to realize their wishes.

PROMISING PRACTICE PROFILE: HOSPITAL DISCHARGE PLANNING

Discharge planning is a process used to decide what a patient needs for a smooth transition from one level of care to another. This discussion often includes the physical condition of the patient, details of the types of care required, information on medications and diet, and possible referrals to other services. Effective discharge planning has the potential to decrease the likelihood of readmission to the hospital, assist in recovery, and adequately prepare family members and local care givers to support a patient in the next stage of their cancer journey.[169]

Hospitals across Canada have hired discharge planners to support patients in their transition out of the hospital's care. In Nova Scotia, the Cape Breton Home-Care Discharge Planning program has been identified as a promising practice in providing support for discharged First Nations patients who are returning to their reserve communities.[170] The Discharge Planning program began in 2002 as a pilot project in the Cape Breton Health District and has since become normal practice. The potential has also been identified to expand the program to the entire province.

A clearly defined model such as this may benefit Métis living in rural and northern communities where access to care is more difficult.

Research in First Nations communities has shown that hospital policies sometimes pose as barriers to traditional practices and care providers are not always able to accommodate the needs of Aboriginal patients.[176] Busy workloads, a lack of cultural sensitivity training, and communication barriers contribute to the absence of culturally appropriate palliative care in some hospitals and care facilities. Although health staff in some regions are showing a willingness to learn and understand other cultures, and some are even engaging in cultural sensitivity training, there is inconsistency in the respect shown for Aboriginal customs.[177]

In some regions, Métis may be able to receive palliative care closer to home, if services are available at a hospital or care centre located in a closer proximity to their community. However these services are not always able to fully meet the needs of Métis patients. For example at some local centres, health service providers have expressed there is a lack of funding for 24-hour palliative care.[178] In most cases, their schedule is nine to five, which is inadequate for providing palliative care. In addition, with the constant turnover of care providers and staff shortages in some areas, ensuring that palliative care is seamless and culturally appropriate may be a challenge.

Due to the existing gaps in Métis palliative care, family members and Métis communities have often stepped in to provide care for their loved ones. Some Métis patients have chosen to forgo the services of formal palliation programs at hospitals or care centers and instead remain in the comfort of their home. During focus groups held in British Columbia, Alberta and Ontario, the role of family in the cancer journey of Métis patients was frequently mentioned as essential, central to feelings of safety, wellness and strength.[179] [180] [181]

Rural Palliative Care Model in Western Australia

In the past, palliative care in Western Australia had been developed in an ad hoc way, leading to inconsistencies in coordination across the rural health region. The Rural Palliative Care Model (RPCM) was developed in 2008 as a quality improvement framework to help ensure that sustainable regional palliative care services are designed to meet standardized criteria. By improving local care coordination and access to medical care and establishing formal links with urban palliation specialists, the RPCM is helping to improve palliative care for rural residents. The RPCM also has a special focus on Indigenous Australians located in the region. According to the model, all health regions in Western Australia will have a Steering Committee comprised of stakeholders such as residential care providers, Aboriginal Medical Services, public hospitals, community services and Home and Community Care. Regional and local coordinators work to maintain consistent standards of care and ensure that all patients have comprehensive care plans. Indigenous organizations consulted on community palliative needs and health care providers who work with Indigenous Australians were interviewed to inform the development of strategies to promote holistic and culturally appropriate care for Indigenous people. Although this model has not yet been evaluated, and it is too early to discern the long term health benefits, the model has clearly addressed identified gaps in Indigenous palliative care.

However, without formal training, sufficient resources, and standards for Métis palliative care, providing this kind of support may place a burden on the patient, their family and the community. The required time commitment is often overwhelming, and some families may feel unprepared to provide appropriate care and often fear making mistakes.[182] The lack of available supports and resources may limit the ability of some families to support their loved one's desire to pass at home.

"When I looked after my mom, her friends dropped her. She would wonder why they never came. People shouldn't drop you if you have cancer. They don't know what to say, so they just stay away."[183]

4.4 Surviving Cancer

"I had no idea that I went through so much, at the time you just get through each day."[184]

Many people who have been treated for cancer now live for many years after their cancer diagnosis.[185] However, physical, emotional, and financial challenges often persist after cancer diagnosis and treatment; these challenges are wide ranging and may include practical issues related to personal finances, psychological struggles, and the fear of reoccurrence.[186] Throughout Canada, there is a growing requirement to address the needs of patients and their families in the years after their treatment in the cancer system ends.

Survivor support groups and networks have arisen in regions across Canada; some have been formal programs developed by cancer organizations, and others have been grassroots movements initiated by community members. However Métis across Canada have expressed that many of these programs are not accessible in their communities or relevant to the unique experiences of Métis cancer survivors. Improving the availability of culturally appropriate informal and emotional support can help Métis cancer survivors to adjust to life after cancer.

Supporting Survivors

Adapting to life as a cancer survivor is not always an easy transition and dealing with the aftermath and side effects of cancer treatment can often be a challenging experiences. Cultural, socioeconomic and environmental factors contribute to the fact that Métis cancer survivors may have different experiences of survivorship than other Canadians.[187] As a result, formal survivorship programs may not be relevant for some Métis, as they may experience difficulty relating to non-Métis cancer survivors.[188]

Many Métis have established beliefs about healing and overcoming illness, which corresponds with a need for different resources and types of support for cancer survivors. Consulting traditional healers and re-establishing balance and wholeness in the spiritual environment may be important to some Métis, and this need cannot always be accommodated by support services. Establishing an environment for cancer survivors that is culturally based can help to ensure that the spiritual component of healing is adequately addressed.

During the focus group hosted by the Métis Nation British Columbia and the BC Cancer Agency participating cancer survivors and caregivers discussed what defines a survivor and what survivorship means to them.

Below are paraphrased participant responses to the definition of survivor often used by the medical community, which states that a survivor is someone who has been cancer-free for five years:

> *There should be no time limit...you are a survivor every morning you get up and continue to live through the diagnosis.*
>
> *A survivor is an individual who carries on despite turmoil or trauma, so [in the Métis worldview] this definition extends to the caregivers and support system.*
>
> *The word survivor has quite an emotional attachment; you can survive a lot of things.*
>
> *Regardless of the time frame, survivorship is a state of well-being that cannot be measured; establishing a new concept of normal is vital in surviving and survivorship for the patient and their support system; it is being present and having a positive outlook.*[189]

During this discussion, participants explained their view of the medical system as a one way process, similar to a tunnel, with diagnosis at one end, survivorship at the other. Participants explained how this conflicted with their own circular view of diagnosis and survivorship, stating that for many Métis, you are a survivor when you decide you are going to survive, a decision that can come at any point in the cancer journey, supported by positivity and spirituality.[190]

Focus group discussions in Alberta revealed that historically, regardless of their geographic location, Métis communities have joined together, shared resources and formed social and cultural networks. During the dialogue sessions, it was evident that this sense of community continues to be an important part of the everyday lived experience for Métis living in Settlement communities.[191]

Practical challenges of survivorship, such as finances and employment, also need to be considered. After their treatment, some cancer patients may not be able to take time off of work to heal and regain their strength. In addition, the financial burden of cancer treatment and associated costs may be challenging for some Métis cancer survivors.[192]

For Métis living in rural and remote communities, accessing community-based support organizations may be difficult.[193] Telehealth, presented as a promising practice below, may facilitate these connections. In Washington and Alaska, a telehealth initiative has experienced success in bringing together cancer survivors from these two states that live in rural communities.

Case Management

Even though they are well, most survivors remain on their cancer journey, as they must continue going to follow-up appointments. The general challenges related to accessing health services tend to persist

Telehealth for Cancer Support Groups in Rural American Indian/Alaska Native Communities

In recent years, American Indian and Alaska Native communities throughout the USA have expressed that cancer support groups were often not available in rural areas. Connecting with other cancer survivors was identified as very important to Indian and Native patients, especially those in an isolated rural community, where survivors are typically fewer in number. Telehealth was identified as an opportunity for addressing follow-up care and quality-of-life needs for rural cancer survivors. The Telehealth for Cancer Support Groups program arose as a way to facilitate support group meetings, bridge geographic distance and increase access to care in rural settings. A total of 25 rural tribal sites in Washington and Alaska participated in the program, and 12 support group meetings were conducted from February 2008 to September 2009. The meetings were led by an urban based facilitator, and each site had a local meeting coordinator, such as a nurse, social worker or a cancer survivor from the community. Videoconferencing was usually set up in a rural tribal health clinic for the monthly meetings. Meeting content varied, but included group counselling, education programs, presentations by experts and information on topics chosen by meeting participants. Over the course of several months, participants in the program were able to develop a level of comfort and trust; participants also indicated that they benefited from learning that they were not alone. Geographical barriers and low population density meant that in most sites, before the videoconferencing, support groups were completely unavailable for cancer survivors. The Telehealth for Cancer Support Groups has been successful in filling this gap and participants have expressed satisfaction with the program.

Person-centred Perspective

Living with cancer

By Fred Shore, Metis, Caregiver

It's now a part of our daily life, you know, we just accept that it's there. I don't want it to do any more damage to us, I really don't. But it's always in the back of the head that it could, you know?

I refuse I guess to spend all my time worrying about that factor. If it's going to, it's going to and then we'll deal with it.

The last thing I want to see happen is one of my grandchildren, suddenly get something serious. And it can happen, there are all different kinds of childhood cancers that could come up and that I think would be horrible. But again — what are you going to do about it? Spend all your life worrying about it?

Or deal with it when you can? Take those steps you can, to avoid having to suffer through it. So colonoscopies and rectal exams and mammograms...do what you can, but at the same time... life goes on.[194]

for many survivors. In addition, due to the lack of cancer resources in some communities, Métis may be unaware of the need to continue with the follow-up care, as well as strategies for reducing the risk of cancer recurrence.

Life After Cancer

The days, months and even years following a final cancer treatment can be very exciting, but also an uncertain time for survivors and their loved ones. For most, the journey towards surviving cancer is not easy, and many factors can contribute to challenges along the way. For Métis, unique health concerns and barriers to health service delivery, add to the number of obstacles that patients must overcome to beat cancer. Surviving cancer can have a powerful influence on an individual's attitudes, experiences and approaches to life. Integrating these new outlooks with the local realities of their community can help survivors to adjust to life after cancer.

5. Conclusion

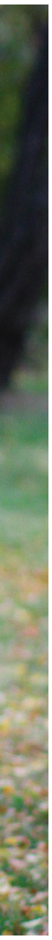
This report provides an overview of the landscape of Métis cancer care and control as we currently know it. Addressing the gaps identified in this report will have positive effect on the patient experience and outcomes.

The promising practices profiled in this report provide examples of efforts to address the gaps in the existing cancer care system and can be leveraged and adapted by others to meet the needs of Métis patients and to improve the patient journey.

There exists a need for updated national information on cancer incidence, mortality and patient experience. Aboriginal-specific cancer research has been identified in this report as a key gap and existing efforts to improve the identification of Métis cancer patients will be highlighted as potential opportunities to address this gap.

Developing culturally responsive methods to identify Métis cancer patients can contribute to a better understanding of cancer in this population and lead to more effective cancer control efforts.

5.1 Epilogue



Advancements in Métis cancer care continue to be made since the release of the Action Plan. The Partnership has partnered to support the expansion of the Saint Elizabeth @YourSide Colleague® Cancer Care Course and provincial agencies and Métis organizations continue to address these gaps with initiatives like the Aboriginal Cancer Strategy II from Cancer Care Ontario, and the recently released Manitoba's Cancer Strategy (2012-2017) from the government of Manitoba.

Cultural Safety For Métis

In January 2013, the National Collaborating Centre for Aboriginal Health (NCCAH) released a publication from the Métis Centre of the National Aboriginal Health Organization: "Towards Cultural Safety for Métis: An Introduction for Health Care Providers".

SETTING THE CONTEXT

TOWARDS CULTURAL SAFETY FOR MÉTIS: AN INTRODUCTION FOR HEALTH CARE PROVIDERS

Prepared by the Métis Centre of the National Aboriginal Health Organization

BACKGROUND

The concept of cultural safety was first introduced in New Zealand in response to ongoing concern over the effects of colonialism and the perpetuation of inequities from neo-colonial processes that "disregarded" the beliefs of the Maori and "instead privileged those of the dominant 'Euro-white' culture" (University of Victoria, n.d. – a). As a result, New Zealand implemented changes to health care practices that included cultural safety training in nursing programs and in health care settings. Similarly, in Canada the health care system is based on mainstream Euro-Canadian culture that may not meet the specific needs of Métis patients and health care workers. Cultural safety is an on-going and evolving process that will require health care providers to revisit and adjust modes of services in order to meet the needs of Métis. Culturally safe health care systems and environments are established by a continuum of building blocks – cultural awareness, cultural sensitivity, and cultural competency – as outlined in Figure 1 below.

This fact sheet aims to demonstrate how health care providers can provide a culturally safe health care environment when caring for Métis patients. To do this, each of these building blocks – cultural awareness, sensitivity, competency, and safety – will first be defined. This will be followed by the presentation of various health care scenarios that highlight differences in the provision of health care services to Métis patients when that building block is lacking and when it is being actively practiced. At the end of each scenario are tips on how to be culturally aware, culturally sensitive, culturally competent, and culturally safe.

Figure 1 - Goal: Cultural Safety

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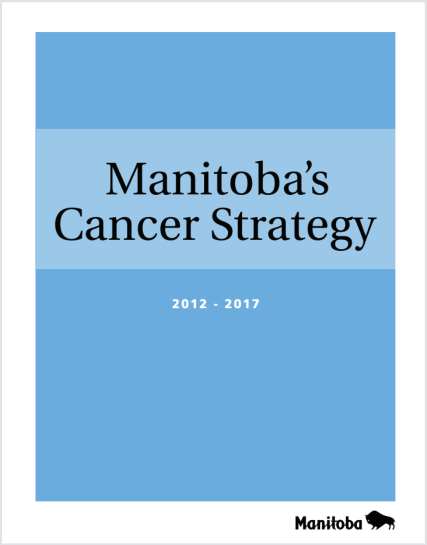
[1] 'Aboriginal' throughout this fact sheet refers collectively to the Indigenous inhabitants of Canada, including First Nations, Inuit and Métis peoples (as stated in Section 35(2) of the *Constitution Act*, 1982).

NATIONAL COLLABORATING CENTRE FOR ABORIGINAL HEALTH
CENTRE DE COLLABORATION NATIONALE DE LA SANTÉ AUTOCHTONE

sharing knowledge · making a difference
partager les connaissances · faire une différence

Manitoba's Cancer Strategy 2012-2017

Built on the first five year plan released in June 2007, Manitoba's Cancer Strategy 2012-2017 focuses on measuring need and addressing inequalities in cancer care. Engaging patients in the journey and decision-making is a priority of the new strategy. As part of this approach, the Province of Manitoba is establishing a 'Vulnerable Populations Program' at CancerCare Manitoba, the goal of which is to improve access to cancer services for First Nations, Inuit and Métis populations, among others.



Manitoba's
Cancer Strategy

2012 - 2017

Manitoba

Alberta's Cancer Plan to 2030

Changing Our
FUTURE:
ALBERTA'S CANCER
PLAN TO 2030

Alberta
Government

© 2013 Government of Alberta

Ten strategies for change are set out in Changing Our Future: Alberta's Cancer Plan to 2030 to create a comprehensive and effective system of cancer control in the province. Parts of the plan relevant to the priorities identified by Métis include:

- Support, engage and integrate primary health care providers in the delivery of cancer services in the home or community and to underserved populations
- Increase the participation of Aboriginal and ethnocultural communities in cancer screening
- Implement a provincial Advance Care Planning process to provide patients and families with the opportunity to define goals for their care.
- Provide cancer patients, survivors, their families and caregivers with the best possible psychosocial, physical and supportive care throughout their cancer journey. Introduce palliative care early in the course of cancer treatment, where appropriate.

Saint Elizabeth @Yourside Colleague® Cancer Care Course

The Cancer Care course was developed by Saint Elizabeth in 2009 as part of their @Yourside Colleague® platform through partnership with the Canadian Partnership Against Cancer. Originally launched in British Columbia, Manitoba and Saskatchewan, the course was extended to Alberta and Ontario in the first phase of expansion and to Quebec and the Atlantic provinces in the next phase. The Cancer Care course is now available in all provinces and work is underway to bring this course to the Northwest Territories. The Cancer Care course has reached more than 1,300 health workers from almost 360 First Nation communities and organizations across the provinces. A Métis module is in development.

Cancer Care

Saint Elizabeth
Well beyond health care

First Nations Cancer Care

I was a participant in the first study group for aYSC Cancer Care. Through participating, I learned a lot about the importance of screening and early detection. I was able to share this information with my community and as a result several people were tested and had their cancer detected early and are going through treatments and doing well. Cancer is a brutal, vicious disease. Your course material on the importance of screening may well have saved many lives.

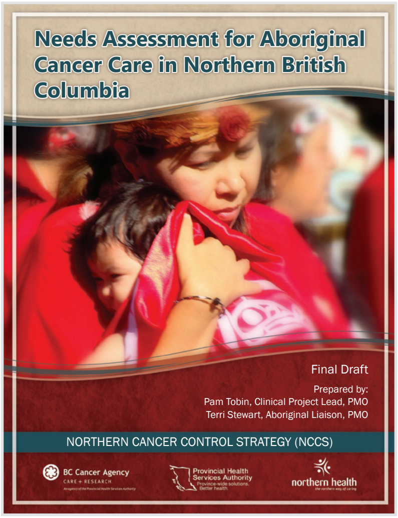
~ **Patricia Wilson**
Community Health Representative
Kwakiutl District Council, Cape Mudge Village, British Columbia

The Vision
The Saint Elizabeth First Nations, Inuit and Métis Program has partnered with providers working in First Nation communities to provide evidence-based, culturally sensitive professional development opportunities in cancer control for community based health care workers.

The @YourSide Colleague® First Nations Cancer Care Course
The @YourSide Colleague® First Nations Cancer Care Course is a joint initiative of Saint Elizabeth Health Care and the Canadian Partnership Against Cancer. The @YourSide Colleague® First Nations Cancer Care Course is one of 12 web-based professional development courses that the Saint Elizabeth First Nations, Inuit and Metis Program provides at no charge to First Nation communities.

Key Features
- Comprehensive evidence-based information
- Developed with and for health care providers working in First Nation communities
- Dynamic and interactive
- Library of cancer care education materials
- Tools and templates to support client education and care
- Virtual discussion boards that connect health care providers with their colleagues and cancer experts
- Online resources to supplement learning
- Practice quizzes and final knowledge test to assess learning and progress
- Available anytime and anywhere
- Learn at your own pace at your own time and join scheduled e-learning events to support your learning

The Aboriginal Cancer Care Strategy (ACCS)
Northern Cancer Control Strategy (NCCS)
British Columbia



Needs Assessment for Aboriginal Cancer Care in Northern British Columbia

Final Draft

Prepared by:
Pam Tobin, Clinical Project Lead, PMO
Terri Stewart, Aboriginal Liaison, PMO

NORTHERN CANCER CONTROL STRATEGY (NCCS)

BC Cancer Agency CARE + RESEARCH
Provincial Health Services Authority
northern health

The ACCS was developed in response to feedback from the NCCS Aboriginal Needs Assessment which was undertaken in 2010. Concerns had been expressed that, without a formal process in place, Aboriginal cancer care needs may not be fulfilled. By developing a strategy specific to the Aboriginal population in Northern B.C. and involving interested individuals, Aboriginal cancer care needs will be addressed. The strategy helps to give ownership to communities across the North with respect to project development and implementation, and ensures that Aboriginal voices are heard in the planning of cancer care services. Through the NCCS, the BC Cancer Agency, Northern Health, and the Provincial Health Services Authority are working together to improve cancer care in northern B.C.

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1 University Avenue, 3rd Floor
Toronto, Ontario, Canada, M5J 2P1
tel: 416.915.9222, toll-free: 1.877.360.1665
www.partnershipagainstcancer.ca