

# ALBERTA BASELINE ASSESSMENT REPORT

Canadian Partnership Against Cancer First Nations, Métis and Inuit Cancer Control Initiative – Increased Access to Culturally- Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote, and Isolated Communities

Cora Voyageur, PhD  
Angeline Letendre, RN PhD  
Bonnie Healy, RN



The Alberta First Nations  
Information Governance Centre

**Edited by:**

Amelia Crowshoe, BCC  
Amy Colquhoun  
Andrew Calliou  
Anita E. Konczi, B.Sc.(Hons), M.A.  
Bethany Kaposhi, B. Sc (Hons), MPH  
Kay Half  
Krista Yao  
Kristin Bernhard, MAIPR  
Lea Bill, RN BScN  
Michelle Voyageur, BSc, MSc IS  
Vivian Collacutt, BCS (Ed), BSW, MSW, RSW

**Design and Artwork by:**

Michal Waissmann - mw creative

**Photography by:**

Lea Bill, RN BScN

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Cora Voyageur, PhD  
Lois Edge, PhD  
First Nations Inuit Health Branch  
Indigenous Physicians of Canada  
Lea Bill, RN BScN  
Maskwacis Health Services  
School of Public Health University of Alberta  
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First Nations Inuit Health Branch-Alberta, Kay Half  
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University of Alberta-Canadian North *Helicobacter pylori* Working Group, Amy Colquhoun  
Dr. Cora Voyageur.



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ALBERTA BASELINE  
ASSESSMENT REPORT:  
CANADIAN PARTNERSHIP  
AGAINST CANCER FIRST  
NATIONS, MÉTIS AND INUIT  
CANCER CONTROL INITIATIVE  
– *INCREASED ACCESS TO  
CULTURALLY SAFE CANCER  
CARE PATHWAYS BY ALBERTA  
FIRST NATIONS IN RURAL,  
REMOTE, AND ISOLATED  
COMMUNITIES*

The 2013 Health Canada: First Nations Health Status Report found that in 2010, First Nations in Alberta experienced cancer incidence at about 200 cases per year, with a reported prevalence rate of 1140 cases.

Current capacities in Alberta cancer control for First Nations is limited by a lack of coordination in care supports, information, and system enablers across the multiple jurisdictions responsible for the cancer care pathways of this population.

Poor projected health outcomes for First Nation cancer patients are not likely to change without purposeful action toward increased partnerships across the multiple health systems, increased information and knowledge gathering activity, and the increased involvement of First Nations communities; organizations and stakeholders in the development of culturally appropriate and safe cancer care pathways and strategies.

# INTRODUCTION

This report, and the information contained herein, is the result of a five-month collaborative Expression of Interest (EOI) between the key stakeholders in Alberta: Confederacy of Treaty Six First Nations; Treaty 7 Management Corporation; Treaty 8 First Nations of Alberta; Alberta Health Services – CancerControl Alberta; The Alberta First Nations Information Governance Centre; Alberta Health Services – Aboriginal Health Program; First Nations and Inuit Health Branch – Alberta Region; Alberta Health Services – Surveillance and Reporting; University of Alberta – School of Public Health; University of Alberta – Faculty of Nursing; The Aboriginal Nurses Association of Canada; and Indigenous Physicians Association of Canada.

The purpose of the EOI was to develop partnerships, and to carry out activities that have supported the development and submission of a 2.5 year project proposal. This project was designed to improve the continuity of care in a culturally responsive and safe way for First Nation cancer patients residing in rural, remote, and isolated communities in Alberta. The underlying aim of this project was to develop a strategy for increased First Nation access to cancer care, which included multi-jurisdictional targeted interventions for an improved cancer care pathway for First Nations people.

## The five proposed areas of focus included:

1. Improved access to cancer care pathways by First Nations: from diagnosis through treatment of care, and until discharge;
2. Completion of a current state and readiness assessment of the cancer care pathway needs of First Nations people in Alberta;
3. Increased knowledge and awareness of the challenges and issues for First Nations cancer patients by the multi-jurisdictional health systems;
4. Engagement of key stakeholders for the purposes of gaining support for the objectives and aims of the EOI; and,
5. Garner support by First Nation communities and organizations in the design, development, and implementation of First Nation patient identification strategies, community needs, and project goals.

This project's purposes and anticipated outcomes align with the Canadian Partnership Against Cancer's (CPAC) 2011 First Nation, Inuit and Métis Action Plan, Health Canada First Nations and Inuit Health Branch 2012 Strategic Plan, and Alberta Government 2013 Report: *Changing Our Future: Alberta's Cancer Plan to 2030*.



The anticipated outcomes represent an important opportunity to build upon research findings that support the engagement of First Nations communities across Alberta.

This report is the result of the current state and readiness assessment of First Nation cancer care pathways in Alberta. There are three parts to this project.

**Part One endeavored to:**

- engage First Nation cancer patients, families, care providers, Elder/knowledge holders and community care professionals.
- better understand the gaps in services.
- determine the availability of culturally appropriate cancer care information and resource tools.
- identify the challenges in accessing diagnoses, treatment, and continued care when facing a cancer illness.

Strategic cancer care planning with First Nation, Inuit, and Métis in Alberta is in its early stages. As a result, there is limited availability of valid information on the First Nations cancer journey within an Alberta context.

**Part Two worked to:**

- investigate current knowledge levels of health systems of the care needs of First Nation cancer patients, families and communities.
- identify existing activities and strategies with the potential to impact the cancer care pathway of First Nation people.
- identify system enablers, including tools, resources and networks that can be engaged and leveraged to improve the First Nation cancer care pathway.

This explains the current state and readiness assessment and includes summary information of what was learned about the cancer care pathway needs of First Nation people in Alberta.

**Part Three:**

- determined the gaps along the cancer pathway with the potential for long-term, sustainable improvements that impact First Nation cancer outcomes.
- determined the barriers along the cancer pathway; with the potential for long-term, sustainable improvements that impact First Nation cancer outcomes.

The work of the EOI was instrumental to the development of true partnerships and trusting relationships with First Nation communities, leadership, and organizations. The anticipated work and desired outcomes of the full 2.5 year proposed project are better positioned to support the collective ownership of cancer control strategies, and the self-determining choices of First Nations to seek out and access cancer care services.

## 2.0 FIRST NATIONS IN ALBERTA

Alberta has one of the fastest growing Aboriginal populations in Canada. Nearly 250,000 First Nations, Inuit and Métis people reside there. This includes 13% of Canada's Registered Status Indians (as defined under the Indian Act) population with approximately 50% of them living on-reserve. Alberta First Nation communities are significantly larger than those in most other regions. For example, the largest First Nation in Canada, the Blood Tribe (Kainai), has a registered population of over 11,500 people.<sup>1</sup>

The following table shows a breakdown of the First Nation population in Alberta as of 2013.

**TABLE 1 – FIRST NATIONS POPULATION IN ALBERTA**

|   |         |
|---|---------|
| First Nations population in Alberta               | 148,251 |
| First Nations registered to Alberta bands in 2013 | 118,164 |
| Treaty area population Treaty 6                   | 44,285  |
| Treaty area population Treaty 7                   | 29,817  |
| Treaty area population Treaty 8                   | 43,178  |

Source: Health Canada. FNIHB – Alberta Region (2014)

Alberta has three main treaty areas: Treaty 6, Treaty 7, Treaty 8. There are 134 reserves with treaty rights to 812,771 hectares of reserve land. The most commonly spoken First Nation languages are: Blackfoot, Cree, Chipewyan, Dene, and Nakoda Sioux.<sup>2</sup>

There are 48 First Nations in Alberta. Per the definitions of Aboriginal Affairs and Northern Development Canada, of the on-reserve First Nation population; 85% reside within

a rural community, 11% reside within a remote community, and the remaining 4% reside within a community that can be considered isolated or without year-round road access.

### 2.1 GOVERNANCE

There are several governance structures in the three treaty regions which include Political Treaty Organizations (PTOs) and Tribal Councils. The Assembly of Treaty Chiefs (AoTC) of Alberta, is comprised of the elected Chiefs of each Alberta First Nation. They gather three times a year to address key political issues. The AoTC elects one of their members to the role of Regional Chief. This elected leader then represents Alberta First Nations at Canada's national First Nations representative organization -- the Assembly of First Nations (AFN). The role of Regional Chief comes with an understanding of strong accountability to the AoTC.

#### 2.1.1 CONFEDERACY OF TREATY SIX FIRST NATIONS

Treaty No. 6 traditional territory stretches from east to the Saskatchewan border, north to the Athabasca River, west to the Canadian Rockies, and south to the Red Deer River. According to AANDC-Health Canada Statistics 2014, the total Registered Indian population of Treaty No. 6 in Alberta is 40,006 (with 27,536 individuals, or approximately 69% living on-reserve).<sup>3</sup> Linguistic groups in the Treaty Six region include: Cree, Dene, Nakota Sioux and Saulteaux.

**The Treaty No. 6 Member Nations are:**

|   |                                   |
|---|-----------------------------------|
| Alexander First Nation                    | Kehewin Cree Nation               |
| Alexis Nakota Sioux Nation                | Louis Bull Tribe                  |
| Beaver Lake Cree Nation                   | Montana First Nation              |
| Cold Lake First Nation                    | O'Chiese First Nation             |
| Enoch Cree Nation                         | Paul First Nation                 |
| Ermieskin First Nation                    | Saddle Lake Cree Nation           |
| Frog Lake First Nation                    | Samson Cree Nation                |
| Whitefish (Goodfish) Lake<br>First Nation | Sunchild First Nation             |
| Heart Lake First Nation                   | Onion Lake Cree Nation<br>(Sask.) |

The office of the Confederacy of Treaty Six First Nations is located in Edmonton. It was created in the spring of 1993 to serve as the united political voice for the protection of both the treaty rights and human rights of First Nations people. The Confederacy is dedicated to ensuring that the terms, spirit, and intent of Treaty No. Six are honoured and respected. This includes: the right to self-determination; the right to choose their own governance and political structures; and the right to determine and direct the social, cultural, spiritual, and economic advancement of Treaty No. 6 First Nations peoples. It is important to note that Treaty No. 6 is the only treaty in Canada that includes the "medicine chest"\* clause. The mandate of the Treaty 6 health program is to develop or improve strategic linkages on behalf of the Confederacy of Treaty Six First Nations; with other First Nations organizations and/or agencies; federal and provincial governments and/or organizations; and international organizations in the area of health.

The program also develops and improves systems in addressing health issues from leadership through to grassroots levels.

**2.1.2****TREATY 7 MANAGEMENT CORPORATION**

Treaty No. 7 was negotiated in 1877. It covers the southern part of present-day Alberta. There are seven member nations from three cultural backgrounds (Blackfoot, Dene and Nakoda) in Treaty No. 7.

**The member nations include:**

|                        |                      |
|------------------------|----------------------|
| Bearspaw Nakoda Nation | Siksika Nation       |
| Blood Tribe (Kainai)   | Tsuu T'ina Nation    |
| Chiniki Nakoda Nation  | Wesley Nakoda Nation |
| Piikani Nation         |                      |

The total population of Treaty No. 7 is 26,751. Although Treaty No. 7 has fewer registered members in comparison to the other treaty areas in Alberta, the proportion of on-reserve residents is the highest at 19,497 or 73%.

Treaty 7 Management Corporation (T7MC) provides "advisory" and "advocacy" services to the seven (7) Nations that compose Treaty No. 7. Unlike other Tribal Councils in Alberta (and across Canada) T7MC does not provide program service delivery. Their mandate is to provide advisory services in areas of common interest to Treaty 7 First Nations.

The Treaty 7 Health Secretariat provides information concerning health, health programming, health funding, and related issues to the Treaty 7 nations. The Health Secretariat acts as a conduit for partnership, advocacy and collective action in the capacity of Health for Treaty No. 7. Most importantly, it provides high-level analysis and interpretive services for Treaty 7 leadership, assisting them in the identification of health issues and trends both regionally and nationally. There are four main program areas: Brighter Futures, Co-Management Liaison, Health Careers, and Indian Residential Schools.

\* "... the medicine chest clause has been regarded as implying the full benefits of medicare." Treaty Research Report - Treaty Six (1876) by John Leonard Taylor, Treaties and Historical Research Centre, Indian and Northern Affairs Canada, 1985 (<https://www.aadnc-aandc.gc.ca/eng/1100100028653/1100100028654>)

**2.1.3****TREATY 8 FIRST NATIONS OF ALBERTA**

Treaty No. 8 was made at Willow Point on Lesser Slave Lake in 1899. The Treaty No. 8 area covers a landmass of 840,000 square kilometres that includes northern Alberta, northwest Saskatchewan, northeast British Columbia, and the southwest portion of the Northwest Territories. Treaty 8 First Nations of Alberta was incorporated in 1997 and is the lead governance body for the First Nations in this region. The purpose of the organization is to protect, promote, bring to life, implement, and sustain the true spirit and intent of Treaty No. 8: "As long as the sun shines, the grass grows, and the rivers flow."

There are 24 First Nations, with 35,934 members (16,192 or approximately 45%) living on-reserve in the Treaty No. 8 region of Alberta:

|                                  |                              |                              |
|----------------------------------|------------------------------|------------------------------|
| Athabasca Chipewyan First Nation | Fort McMurray First Nation   | Sawridge First Nation        |
| Beaver First Nation              | Horse Lake First Nation      | Smith's Landing First Nation |
| Bigstone Cree Nation             | Kapawe'no First Nation       | Sturgeon Lake First Nation   |
| Chipewyan Prairie First Nation   | Little Red River Cree Nation | Sucker Creek First Nation    |
| Dene Tha' First Nation           | Loon River Cree Nation       | Swan River First Nation      |
| Driftpile First Nation           | Lubicon Lake First Nation    | Tallcree Tribal Government   |
| Duncan's First Nation            | Mikisew Cree First Nation    | Whitefish Lake First Nation  |
| Fort McKay First Nation          | Peerless Trout First Nation  | Woodland Cree First Nation   |

Jurisdictional issues can create conflicts between various levels of governments regarding responsibility for the delivery of health services. This often leads to reduced health outcomes and a decrease in quality of life for people living on-reserve. Consequently, Treaty 8 First Nations of Alberta has prioritized the care of people first, over and above complex jurisdictional issues.<sup>4</sup>

The mandate of the Treaty 8 First Nations of Alberta's Health Department is to act as a steward for health and facilitating the ongoing development of a comprehensive health system.

**24** First Nations

**35,934** Members

FIGURE 1

Treaty 8

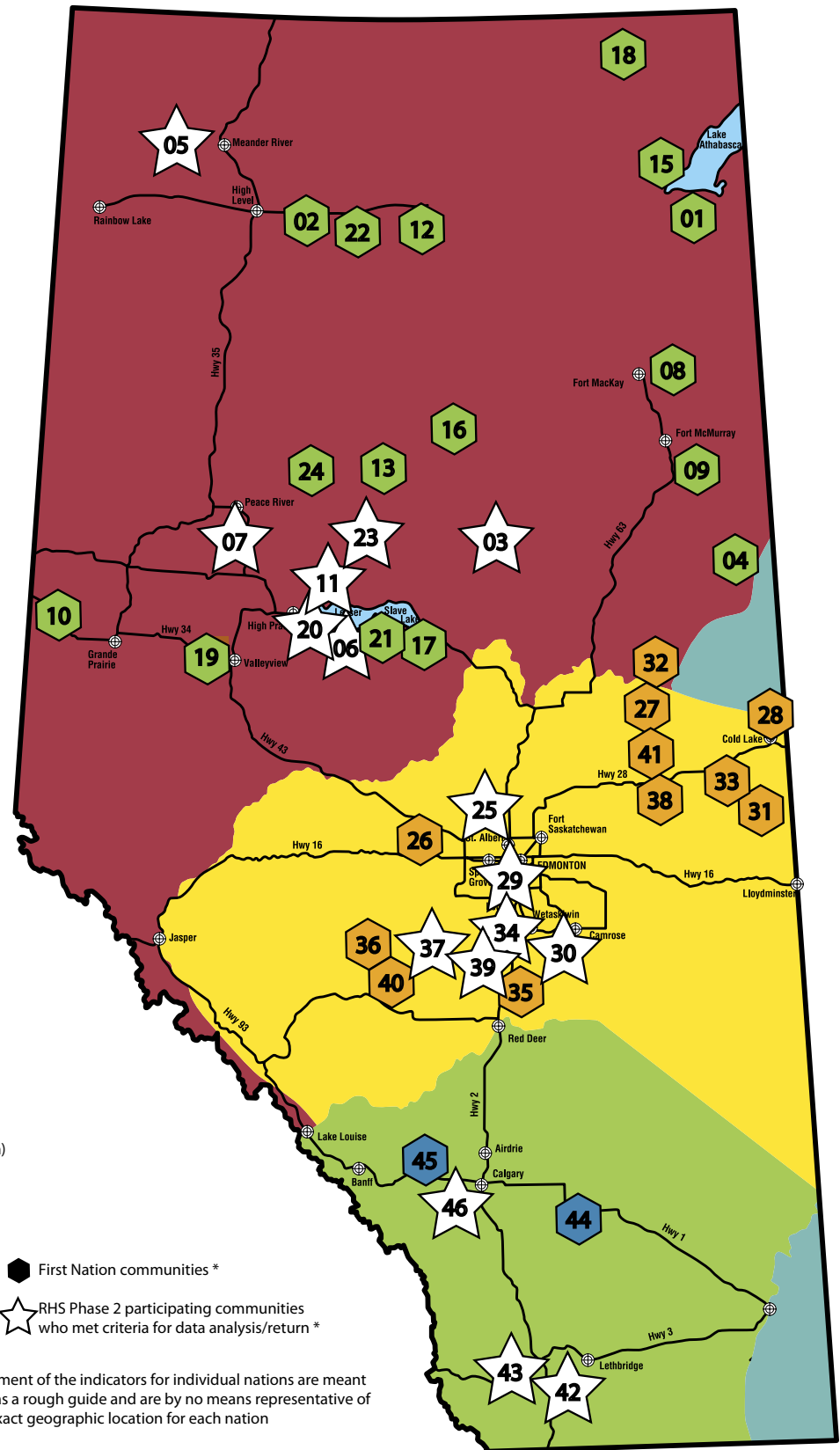
- 01 Athabasca Chipewyan First Nation
- 02 Beaver First Nation
- 03 Bigstone Cree Nation
- 04 Chipewyan Prairie First Nation
- 05 Dene Tha' First Nation
- 06 Driftpile First Nation
- 07 Duncan's First Nation
- 08 Fort McKay First Nation
- 09 Fort McMurray First Nation
- 10 Horse Lake First Nation
- 11 Kapawe'no First Nation
- 12 Little Red River Cree Nation
- 13 Loon River First Nation
- 14 Lubicon Lake Nation (No Reserve)
- 15 Mikisew Cree First Nation
- 16 Peerless Trout First Nation
- 17 Sawridge First Nation
- 18 Smith's Landing First Nation
- 19 Sturgeon Lake First Nation
- 20 Sucker Creek First Nation
- 21 Swan River First Nation
- 22 Tallcree First Nation
- 23 Whitefish Lake First Nation (Atikameg)
- 24 Woodland Cree First Nation

Treaty 6

- 25 Alexander First Nation
- 26 Alexis Nakota Sioux Nation
- 27 Beaver Lake Cree Nation
- 28 Cold Lake First Nation
- 29 Enoch Cree Nation
- 30 Ermineskin Cree Nation
- 31 Frog Lake First Nation
- 32 Heart Lake First Nation
- 33 Kehewin Cree Nation
- 34 Louis Bull Tribe
- 35 Montana First Nation
- 36 O'Chiese First Nation
- 37 Paul First Nation
- 38 Saddle Lake Cree Nation
- 39 Samson Cree Nation
- 40 Sunchild First Nation
- 41 Whitefish Lake First Nation #128 (Goodfish)

Treaty 7

- 42 Blood Tribe
- 43 Piikani Nation
- 44 Siksika Nation
- 45 Nakoda Nations (Stoney)
  - Bearspaw Nakoda Nation
  - Chiniki Nakoda Nation
  - Wesley Nakoda Nation
- 46 Tsuu T'ina Nation



First Nation communities \*  
 RHS Phase 2 participating communities who met criteria for data analysis/return \*

\* placement of the indicators for individual nations are meant only as a rough guide and are by no means representative of the exact geographic location for each nation

Map adapted from the First Nations of Alberta Report, 2013, pg 3  
 Aboriginal Affairs and Northern Development  
[http://www.aadnc-aandc.gc.ca/DAM/DAM-INTER-AB/STAGING/texte-text/fnamarch11\\_1315587933961\\_eng.pdf](http://www.aadnc-aandc.gc.ca/DAM/DAM-INTER-AB/STAGING/texte-text/fnamarch11_1315587933961_eng.pdf)

Source: The Alberta First Nations Information Governance Centre (2012) First Nations Regional Health Survey (RHS) 2008/10. Prepared by D. Pace and A.E. Konczi. p. 39

## 2.2 ROLES AND RESPONSIBILITIES FOR THE PROTECTION OF FIRST NATIONS RIGHTS THROUGH THE PRINCIPLES OF OCAP™

OCAP™, which stands for Ownership, Control, Access, and Possession, provides an ethical framework for information and knowledge-sharing and guides a community in decision-making regarding why, how, and by whom information is collected, used, or shared.

OCAP™ reflects First Nation commitments to use and share information in a way that brings benefit to the community while minimizing harm. It expresses First Nation jurisdiction over information about the First Nation – a key aspect in self-determination for First Nation people in Canada. OCAP™ is an opportunity for First Nation people to express their unique worldview and protocols related to ideas of community privacy and information governance currently not protected by Canadian privacy laws, while concentrating on all aspects of information governance including creation and management. The principles of OCAP™ have altered the way First Nation research and information governance is undertaken, and has broad applications over research, monitoring, surveillance, surveys, statistics and cultural knowledge.

Research and related activities that are OCAP™ compliant ensure that First Nation communities are participatory in all related processes and that First Nations' interests related to research and data are protected. OCAP™ principles have evolved to be inclusive of community-level data, which may emerge from any research or data-related activity. This includes jurisdiction over information that may result from First Nation identification within health surveillance systems.

Provincial, territorial and federal (P/T/F) legislation protects personal information (PI) and personal health information (PHI), including First Nation PI and PHI. In addition to these protections, OCAP™ is a vision and protocol for principled research that protects First Nation people and information from harmful, insensitive and exclusive research relationships. OCAP™ principles also extend to data that is communal in nature as P/T/F registries and databases may allow for the identification of First Nation data sets. Applying OCAP™ principles to these data collections ensures that First Nations are protected from undue analyses or misinterpretation of First Nations information. First Nation control of data reduces the risk of information being used or published in a way that is perceived as harmful to communities and/or their collective privacy. First Nation communities benefit from these principles of information governance to better protect individual and community privacy; while also creating cultural safety within an ethical space of mutual understanding.

## 3.0

# ALBERTA FIRST NATIONS AND CANCER

The age of a population is a key factor in the prevalence of cancer. In Canada, 69 percent of new cases and 62 percent of cancer deaths occur among those between the ages of 50 and 79. A larger proportion of the First Nations population living in Alberta is becoming part of this age cohort, making this pattern of cancer prevalence particularly significant. From 2001 to 2011, for instance, the First Nations population aged 65 and over (living on-reserve or on Crown land in Alberta) experienced the highest rate of population growth at 56 percent. This changing population demographic is sure to require health programming to meet the needs of a rapidly increasing senior cohort.<sup>5</sup>



### 3.1 ALBERTA FIRST NATIONS CANCER STATISTICS SUMMARY

The number of new cancer cases in Alberta First Nations (excluding non-melanoma skin cancer) between 1997 and 2010 was 2,726. Prostate cancer was the most common diagnosis for males; while breast cancer was the most common for females.<sup>2</sup>

The types of newly diagnosed cancers differ between First Nations and non-First Nations populations in Alberta. Breast, lung, colorectal, and prostate cancers were the most frequently diagnosed among both populations (Figure 2). Breast cancer was the most commonly diagnosed cancer in First Nations while it ranked second in non-First Nations. Prostate cancer was the most commonly diagnosed in non-First Nations while it was ranked fourth in First Nations.

These top four cancers account for more than half of the total incidences of cancer for both populations (51% in First Nations and 53% in non-First Nations). Other relatively common cancer types among First Nations people include leukemia (4%), non-Hodgkin's lymphoma (4%), and cancers of the kidney (5%), cervix (5%), stomach (3%) and pancreas (2%) (Figure 2).

Lung cancer was the leading cause of the reported 1,082 cancer deaths among Alberta First Nations. It is the leading cause of cancer deaths for both First Nations and non-First Nations males and females.

The cancer stage (extent or severity of cancer) at diagnosis impacts survival. Most cancer types diagnosed at earlier stages (I & II) have better survival rates than those diagnosed at later stages (III & IV). First Nations tend to be diagnosed at later stages of cancer than non-First Nations.

Kidney, cervical, and stomach cancers each comprise a higher percentage of the total number of cancer cases diagnosed compared to those cancer sites in non-FNs.<sup>6</sup> The incidence of lung cancer did not differ between First Nations and non-First Nations in Alberta. First Nations were more likely to experience a delay in diagnosis (at 87%) than non-First Nations (at 79%); though both populations tend to be diagnosed in the later stages of disease. In addition to this, the number of deaths in First Nations was higher than would be expected based on non-First Nations mortality rates.

The incidence of breast cancer is generally no different between First Nations and non-First Nations women. Breast cancer mortality rates also show no difference between the two populations. A higher proportion of First Nations women were diagnosed with breast cancer in Stages III & IV than in the non-First Nations population, who were generally diagnosed in Stages I and II.

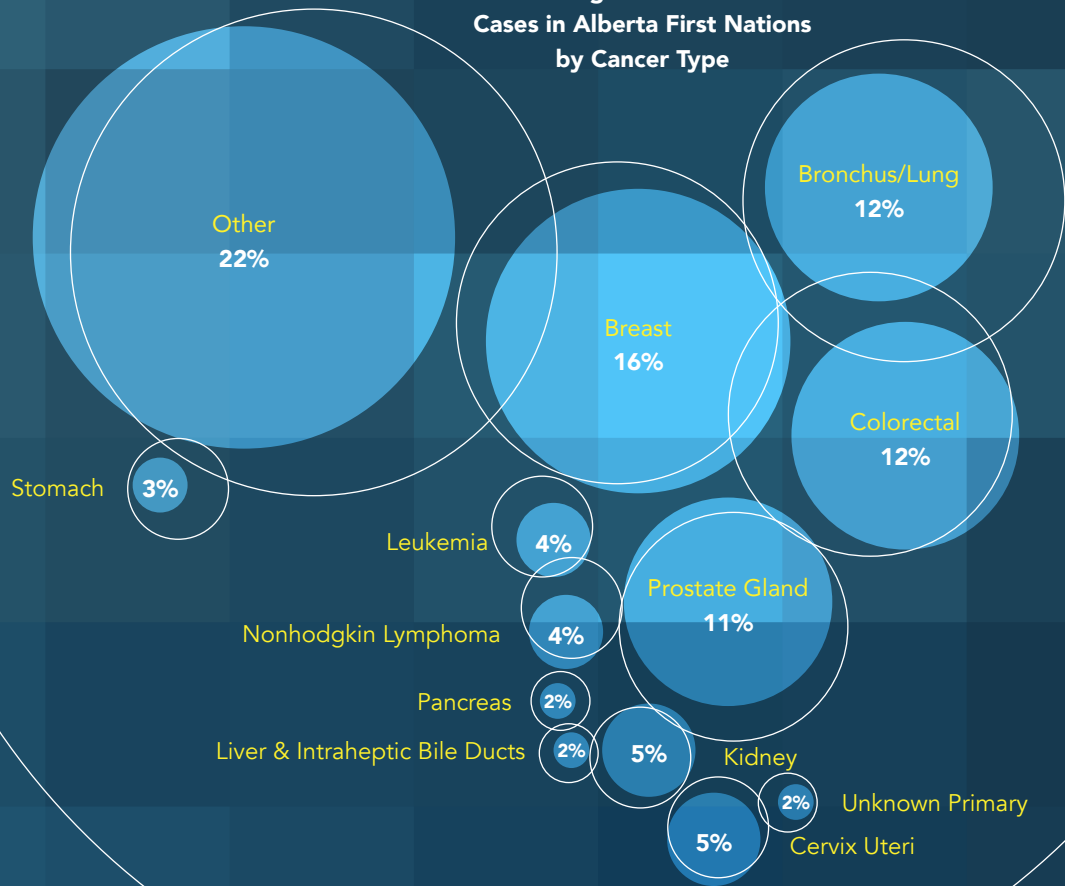
As with the previous two types of cancer, the incidence of colorectal cancer was not different between First Nations and non-First Nations. The number of deaths due to colorectal cancer in First Nations was higher than expected. Once again, First Nations populations were more likely to be diagnosed at later stages of disease than non-First Nations.<sup>6</sup>

The number of prostate cancer cases diagnosed in First Nations people was lower than would be expected based on non-First Nation rates. The number of deaths from prostate cancer, however, was higher than would be expected. The stage at diagnosis of prostate cancer was similar between First Nations and non-First Nations.



FIGURE 2

Percentage of New Cancer Cases in Alberta First Nations by Cancer Type



Source: Alberta Health Services, Surveillance & Reporting, 2012

2,726

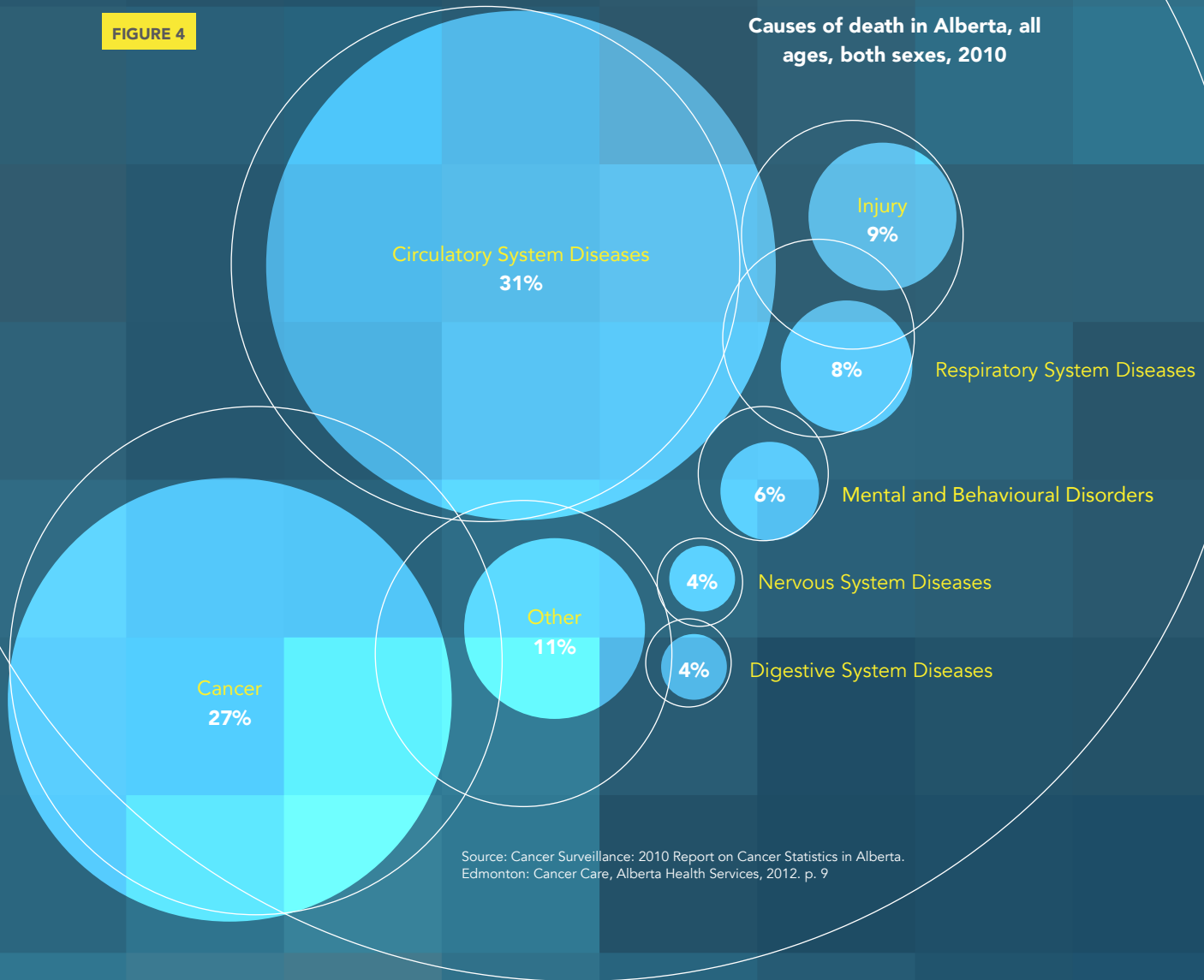
Number of new cancer cases between 1997 and 2010

1,082

Cancer deaths among Alberta First Nations

FIGURE 4

## Causes of death in Alberta, all ages, both sexes, 2010



Source: Cancer Surveillance: 2010 Report on Cancer Statistics in Alberta. Edmonton: Cancer Care, Alberta Health Services, 2012. p. 9

### 3.2 TRENDS IN ALBERTA FIRST NATIONS CANCER STATISTICS

Nearly 1 in 2 people will develop cancer in their lifetime, and 1 in 4 people will die from cancer. From 2009 to 2011, circulatory disease and cancer were the top two causes of death in Alberta.<sup>7</sup> In 2010, about 15,250 Albertans were diagnosed with cancer (not including non-melanoma skin cancer) and about 5,550 people died from the disease. Cancer accounts for over a quarter of deaths in the province.<sup>8</sup>

As age increases, the rate of cancer diagnosis also increases. Around the age of 40, cancer rates increase quickly among First Nations. Screening and cancer education in the middle-aged population are particularly important. Around 68% of all cases occur between the ages of 45 and 74.

The survival rate of First Nations with cancer five years after diagnosis is 53 percent. First Nations in Alberta have significantly lower survival rates than non-First Nations. Cancer mortality may be reduced, and survival rates increased when cancers are detected and treated in the early stages.

The standardized mortality rate for all cancers among First Nation males was nearly 56 percent higher than that of First Nation females. The number of cases of cervical cancer in First Nations women in Alberta was significantly higher than expected based on rates among non-First Nations women.

### 3.3 SURVEILLANCE AND REPORTING CHALLENGES

Current capacities in cancer control for Alberta First Nations are limited in a number of areas. This includes the lack of coordination in care supports, limited availability of Alberta First Nation-specific cancer information, and the need for system enablers across the multiple jurisdictions responsible for the cancer care pathway.

Alberta Health Services Surveillance & Reporting uses data from the Alberta Cancer Registry. This registry has information (name, date of birth, type of cancer, etc.) about anyone who has been diagnosed with cancer, or who has died from cancer in Alberta. Surveillance & Reporting looks to address questions about cancer occurrence by providing information on request from individual communities based on their geographical boundaries.<sup>10</sup>

There are two main challenges in collecting First Nations cancer data and information:

1. The identification of First Nations people. The Alberta Cancer Registry does not house information about ethnicity and therefore Alberta Health Services cannot identify First Nations people in the Alberta Cancer Registry directly; and
2. Alberta Health Services does not have permission to access First Nation population identification information; it is therefore difficult to address First Nation community concerns or answer questions which require comparisons between First Nations and non-First Nations communities.

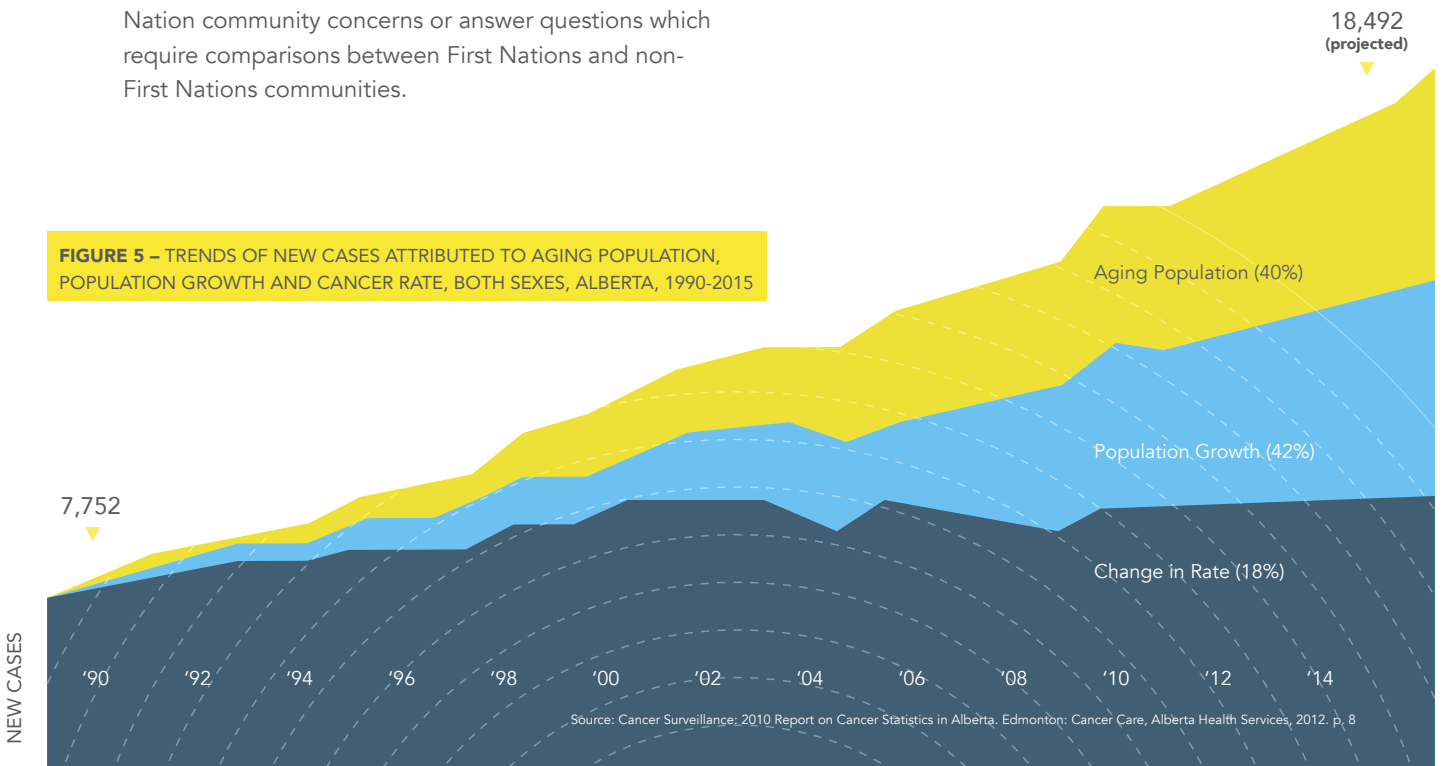
The Alberta Health Care Insurance Premiums Act enabled the identification of First Nations individuals in Alberta until 2009. This allowed for the compilation of First Nations-specific health data and information. Discontinued health premiums in Alberta have resulted in the loss of First Nations-specific cancer data and information. This lack of First Nations-specific data makes it difficult to support First Nations communities and their requests for cancer information.

Alberta Health Services is currently unable to provide the following potentially useful First Nations-specific information:

- Comparative data between First Nations and non-First Nations.
- First Nations cancer-specific data that can assist in prioritization of cancer services.
- First Nations data that tracks changes over time.
- First Nations cancer morbidity/mortality data, and information.
- First Nations-specific cancer-related information and statistics.

High quality and complete data on a population is necessary to effectively support the planning, implementation, and evaluation of health services and policies. Without this data, it is difficult for public health agencies to provide First Nations communities with a comprehensive picture of their health, including current status and risks.

**FIGURE 5 – TRENDS OF NEW CASES ATTRIBUTED TO AGING POPULATION, POPULATION GROWTH AND CANCER RATE, BOTH SEXES, ALBERTA, 1990-2015**



# 4.0 READINESS AND CURRENT STATE ASSESSMENT PART ONE: COMMUNITY ENGAGEMENT

This project explores ideas, gathers data, and interprets the findings. The purpose is to establish a baseline regarding the readiness and current state of health systems for meeting the cancer care needs of First Nations. Including the perspectives of First Nations people and communities is essential to identifying existing gaps along the care pathway for First Nations cancer patients. A comprehensive understanding of where to focus our efforts would not be possible without this component.

Trusting relationships are a key factor in working with First Nations communities. Community engagement, through collaboration and partnership building, is identified as a foundational strategy for addressing the social and cultural barriers that impact the health of vulnerable populations. Collective decision-making with community stakeholders ensures 'inclusiveness, fairness and equity'.<sup>11</sup> Three large community health organizations, each with varied perspectives, were invited to participate in this project. These are: Maskwacis Health Services (Treaty 6), Siksika Health Services (Treaty 7), and Bigstone Health Commission (Treaty 8). A summary of each health organization follows.



## 4.1 PARTICIPATING COMMUNITY ORGANIZATIONS

# MASKWACIS HEALTH SERVICES (TREATY 6)

### Health Services information:

The Maskwacis Health Board, established in 1983, provides health facilities and services to 15,000+ registered Maskwacis Cree band members belonging to Samson, Ermineskin, Louis Bull and Montana First Nations. Maskwacis health programming and services aim to address the needs of these growing populations through the use of both traditional and contemporary healing practices while maintaining respect for cultural and spiritual beliefs.

### Health Services Mandate:

Maskwacis Health Board leadership serves to protect, secure and advance the collective rights of Treaty 6 and the medicine chest clause. The Maskwacis Health Board is committed to ensure that planning and the provision of high quality health care services to nation members occurs in a respectful, honest, fair, trusting, open and transparent manner for the benefit of all clients.

### Location:

Ponoka County in Central Alberta, approximately 85 kilometres south of Edmonton.

### Composition:

#### Four First Nations:

- Ermineskin Cree Nation
- Louis Bull Tribe
- Montana First Nation
- Samson First Nation

### Land Mass Covered:

32,116.2 hectares.

### Treaty Area Info:

Treaty No. 6 traditional territory stretches east to the Saskatchewan border, north to the Athabasca River, west to the Canadian Rockies and south to the Red Deer River.

### Number of Nations in Treaty Area:

There are 16 First Nations in the Treaty No. 6 region.

### Population:

According to AANDC-Health Canada statistics as of February 2014 the registered population of Treaty No. 6 in Alberta is 40,006 people (with 27, 536 living on reserve).

### Service Area Population:

#### As of February 2014, the number of registered individuals:

- Ermineskin Cree Nation 4381 registered; 2978 living on-reserve
- Louis Bull Tribe 2168 registered; 1490 living on-reserve
- Montana First Nation 978 registered; 674 living on-reserve
- Samson Cree Nation 7968 registered; 5698 living on-reserve



# SIKSIKA HEALTH SERVICES (TREATY 7)

## Health Services information:

Services include public health, home care, NNADAP, Fire/EMS, Dental, Optometrist, Pharmacist, Nutritionist (Dietician), Lab/Diagnostics, Occupational Therapist, Health Assistance, Medical Transportation, Mental Health Services, Head Start, Brighter Futures, Health Promotions, FASD programs, Family Violence programs, Crisis Response services, Disaster services, and within the past two years, Tele-Health services.

There are specialist services offered at the Siksika Health and Wellness Centre; saving a client time and costs for travel to external health facilities. The organization has undertaken initiatives to overcome some of the challenges related to cancer care through research, programs and services designed to assist Siksika members with cancer. These programs and services focus on physical, psychological and emotional well-being.

## Health Services Mandate:

Siksika Health Services, a nationally accredited service and authorized health organization for Siksika First Nation has moved forward in obtaining good quality health programs and services. The service is currently a model of 'best practices' for other First Nations within Canada.

Siksika Health Services has a mission to improve and promote Siksika quality of life through safe, accountable and efficient health service delivery, based on the needs of Siksika Nation members. As a First Nation, Siksika values opportunities for sharing their knowledge to benefit the people that they serve. Therefore, throughout the years they have formed partnerships to develop the much needed research and gathering of information that can lead to programs, services and other goals, including the fulfillment of the Siksika Health Services mission to the members of Siksika Nation.

## Location:

Rural southern Alberta approximately 80 kilometres east of Calgary.

## Composition:

Siksika First Nation.

## Land Mass Covered:

71,087.5 hectares.

## Treaty Area Info:

Treaty No. 7 traditional territory covers the southern part of Alberta.

## Number of Nations:

There are 7 First Nations in the Treaty 7 region.

## Population:

According to AANDC-Health Canada statistics as of February 2014 the registered population of Treaty 7 in Alberta is 26,751 people (with 19,497 living on reserve). The proportion of on-reserve residents in Treaty 7 is the highest of all three treaty areas, at 73%.

## Service Area Population:

As of February 2014, there were 6988 individuals registered as members of Siksika Nation; 3826 of them living on-reserve.

# BIGSTONE HEALTH COMMISSION (TREATY 8)



## Health Services information:

Bigstone Health Commission (BHC) has administered the Non-Insured Health Benefits Program for Bigstone Cree Nation members since 2004.

## Health Services Mandate:

The goal of the Bigstone Health Commission is to promote a healthy and successful community in which all community members have the means to live safely, work, learn and play.

The vision of the Bigstone Health Commission is to revive, strengthen and protect community members' treaty rights to health.

The Mission of Bigstone Health Commission is to develop full capacity within the community to effectively and efficiently develop, administer and control programs and services which will achieve this vision.

### Objectives include:

- Develop human resource capacity to fulfill its mandate
- Develop the necessary physical facilities
- Utilize the latest information and other technology
- Ensure effective and open communication within the Bigstone Health Commission, the Bigstone Health Commission, Chief and Council and the community
- Deliver appropriate health services to meet the needs of the community
- Accept the authority to manage and control health services of the community
- Promote a healthy lifestyle within the community
- Keep informed of changing needs and opportunities in the field of health services
- Create and encourage self-sufficiency of community members<sup>12</sup>

## Location:

Northern boreal forest of Alberta, adjacent to four lakes: North and South Wabasca Lakes, Calling Lake, and Sandy Lake. It is 320 km north of Edmonton.

## Composition:

There are 7 reserves in total: Desmarais, John Baptiste Gambler 183, Wabasca 166, Wabasca 166A, Wabasca 166B, Wabasca 166C and Wabasca 166D.

## Land Mass Covered:

21,066.6 hectares.

## Treaty Area Info:

Treaty No. 8 traditional territory covers northern Alberta, northwest Saskatchewan, north-east British Columbia and the southwest portion of the Northwest Territories.

## Number of Nations:

There are 24 First Nations in the Treaty No. 8 region of Alberta.

## Population:

According to AANDC-Health Canada statistics as of February 2014 the registered population of Treaty No. 8 in Alberta is 35,934 people (with 16,192 living on reserve).

## Service Area Population:

As of February 2014, there were 7455 individuals registered as members of Bigstone Cree Nation; 2816 of them living on-reserve.

## 4.2 COMMUNITY ENGAGEMENT

Members of the Project Team travelled to each community to engage Health Directors and Chief Executive Officers. These meetings focused on the following three goals:

1. To discuss challenges, issues and concerns with regards to First Nations cancer experiences;
2. To begin a dialogue about the challenges, issues, ongoing work, processes and models for collecting First Nations data and information; and,
3. To explore possibilities for each community's involvement in the larger 2.5 year project.

While each community's priorities may be unique, cancer was viewed as a growing area of concern by all. Each organization shared information about their cancer-related challenges and issues. The following sections summarize this information.

### 4.2.1 MASKWACIS HEALTH SERVICES

The project team met with staff of Maskwacis Health Services including Chief Executive Officer, Randy Littlechild; Nurse Director, Bonnie Graham; and Treaty 6 Non-Insured Health Benefits Navigator, Alison Tremblay.

A recent informal survey was carried out with the staff at Maskwacis Health Services regarding the cancer-related challenges and issues that may exist within communities. The following summarizes the information that was gathered:

- Delays in diagnosis and treatment are related to fears associated with cancer.
- Community members face difficulties in accessing physician services.
- Community members lack sufficient, reliable and culturally relevant information about cancer.
- There is a need for increased screening and health centre staff trained to conduct screening on-reserve.
- Transportation to appointments is cited as a primary challenge for cancer patients.
- The lack of coordinated discharge planning to their home community is a major concern.

- Many community members are unaware of home care services that may be available.
- On-reserve physicians are viewed as critical to supporting First Nations in managing their health.
- Access for early diagnosis and referral to off-reserve health care programs and services are needed.
- Support through liaisons able to speak the languages of community members, particularly for Elders at hospitals sites is needed.
- First Nations identifiers are required for those who may have cancer.
- Statistical data and information is critical for successful cancer program planning and service delivery.
- A data sharing agreement that incorporates OCAP™ principles is a requirement for Maskwacis Health Services to participate in this project.

### 4.2.2 SIKSIKA HEALTH SERVICES

The project team met with the staff of Siksika Health Services including Chief Executive Officer, Tyler White; Quality Assurance Officer, Kory Duck Chief; and Accreditation Coordinator, Janis Many Heads.

There have been challenges in the community with cancer care related to the fear that 'cancer' evokes. Apparent in the 1960s within the Siksika Nation; cancers were poorly understood and led to the mention of the word 'cancer' being associated with fear and leading to inevitable death for the person. This contributed to negative health effects that are not only physical, but also psychological and emotional, which often necessitated other forms of care that were not yet available in these areas.

Since then challenges and barriers regarding cancer care include:

- Delayed funding for medication by the federal Non-Insured Health Benefits program.
- Limited availability and cost of transportation (travelling for testing and screening).
- Difficulties with open communication (language or a misunderstanding of medical terminology).
- A lack of knowledge and clearly understood information of required tests or treatments (e.g. the appropriateness of colon screening/testing).



The organization has undertaken initiatives to overcome some of the challenges related to cancer care through research, programs and services designed to assist Siksika members with cancer. These programs and services focus on physical, psychological and emotional well-being.

#### 4.2.3 **BIGSTONE HEALTH COMMISSION**

The project team met with the staff of Bigstone Health Commission, including Chief Executive Officer, Barry Phillips; Health Centre Director, Gloria Fraser; and Operations Manager, Lorraine Muskwa.

The Bigstone Medical Clinic started using an Electronic Medical Records (EMR) system in October 2012, which provides health care professionals with a more complete picture of patient health. Client medical and clinical information such as medication profiles, lab results history, test results and hospital discharge summaries can now quickly and easily be accessed through the EMR system by the doctors working at the Bigstone Medical Clinic only. A discussion between Bigstone Health Commission, Alberta Health Services – CancerControl Alberta and local doctors found there is a disconnect between community cancer patients and health care providers. This is because cancer patients may access both the Bigstone Medical Clinic and the Municipal District of Opportunity Medical Clinic. This disconnect is further complicated by minimal-to-no communication between the two jurisdictions involved in the care of individual cancer patients.

The scope of collecting First Nations data is an important element to this project. Bigstone Health Commission will share lessons learned on data collection and will work toward partnering and sharing best practices.



## 5.0

# READINESS & CURRENT STATE ASSESSMENT PART TWO: HEALTH SYSTEM KNOWLEDGE AND ACTIVITY

Health services are made available to First Nations through multiple care providers which include Federal, Provincial, and Community stakeholders. Challenges to care are often related to jurisdictional boundaries. An improved cancer pathway for First Nations will not only require gaps in care to be identified, but points of intersection across the multiple jurisdictions of care should also be examined. Integrating services across jurisdictions is the ultimate goal.

In order to determine the readiness of stakeholders to work together to meet the goals and desired outcomes of the full 2.5-year project, a baseline of minimum information was gathered. The focus for collecting a baseline on the available knowledge, resources and current activities for First Nation cancer control in Alberta provided important information. This included an indication of the current capacities of health systems (AHS/FNIHB/First Nation) to work toward improved access to culturally appropriate cancer care for rural, remote, and isolated communities. Additionally, activities and strategies, as well as system enablers were identified that may provide important opportunities for leverage within, between, and amongst services and services providers. Work within Alberta Health Services, in particular, has largely focused on activities aimed at increased prevention and screening. Work in First Nations organizations, namely The Alberta First Nations Information Governance Centre (AFNIGC), has a number of ongoing partner initiatives focused on cancer data and information needs.

The 'Baseline Data' indicates that there are minimal to no services, activities, or resources specifically designed to improve the First Nation cancer pathway at points of diagnosis, through treatment of care, and upon discharge. What this information does indicate, however, is current services provided across the multiple jurisdictions of care may provide important points for the leveraging of resources, enhanced coordination of services, and improved standards of care.

## 5.1 ALBERTA HEALTH SERVICES

Canada's first province-wide, fully integrated health system, Alberta Health Services (AHS), is comprised of:

- 100 acute care hospitals;
- 5 stand-alone psychiatric facilities;
- 8,230 acute care beds;
- 22,533 continuing care beds and spaces;
- 202 community palliative and hospice beds;
- 2,327 addiction and mental health beds; plus
- equity partnership in 41 primary care networks.

Programs and services are offered at over 450 facilities throughout the province, including hospitals, continuing care facilities, mental health facilities, and community health sites. The province also has an extensive network of community-based services designed to assist Albertans in maintaining good health and achieving an improved health status.

The mission of AHS is to provide a patient-focused, quality healthcare system that is accessible and sustainable for all of Alberta. AHS has seven leading values that provide for a foundation that continually strives to provide quality patient care. These include: respect, accountability, transparency, engagement, safety, learning, and performance.

Released on May 29, 2013, the AHS 2013-2016 Health Plan and Business Plan – “Better Quality, Better Outcomes, Better Value” – guides the organization through operational goals, which have been set for the next three years. Three strategic directions support these goals:

1. Bringing Appropriate Care to Community;
2. Partnering for Better Health Outcomes; and,
3. Achieving Health System Sustainability.

## 5.1.1 CANCERCONTROL ALBERTA

CancerControl Alberta reduces the impact of cancer on all Albertans and provides expert care and support for patients from their first symptom to survivorship. The goal of the program is to be a leader in cancer prevention, diagnosis, treatment, survivorship and palliative care, all on a foundation of world-class research.

Services are provided at tertiary facilities: the Cross Cancer Institute (Edmonton) and Tom Baker Cancer Centre (Calgary), 4 associate cancer centres (Grande Prairie, Red Deer, Medicine Hat, and Lethbridge), and 11 community cancer centres across Alberta. Located in many regions or zones across Alberta, cancer care utilizes ‘community-driven’ models of care that are uniquely designed to meet the needs of the surrounding communities and populations. This structure supports an increased ability for community outreach and approaches or models of care that offer appropriate and safe service delivery to all Albertans.

Alberta's Cancer Plan to 2030<sup>13</sup> was developed to address the cancer needs of Albertans and improve projected cancer outcomes by creating a vision for the future: Alberta will be a place where most cancers are prevented, more cases of cancer are cured, and the suffering of people affected by cancer is dramatically reduced. The Plan will bring together and advance the initiatives, resources, and transformations necessary to realize this vision through the following:

- Making Alberta a leading international destination for cancer researchers and cancer care providers.
- Improving prevention strategies, screening, diagnosis, treatment and care.
- Supporting Albertans in becoming active participants in their own well-being.
- Further reducing the use of and exposure to tobacco and tobacco smoke which accounts for one-third of all cancer cases.

### 5.1.2 CANCER SURVEILLANCE

Public health surveillance is the on-going and systematic analysis, interpretation, and dissemination of health data and information for the purpose of public health action. Surveillance activities are distinct from research activities in that they are on-going processes that support policy and evidence-based decision-making rather than a one-time project aimed at creating new scientific knowledge.

To be effective, public health surveillance activities require access to data for the timely assessment of health, health risks, and potential actions to be taken to mitigate risk and promote health. The data are used regularly to conduct public health surveillance activities such as the detection of new or existing public health problems. The data is also useful to support the planning, implementation and evaluation of health services and policies, as well as to inform populations about their health status and risks.

The Surveillance & Reporting department collects, integrates, analyzes, interprets, and disseminates cancer information concerning occurrence, deaths, treatment, and risk factors in Alberta. The department ensures that timely, accurate, and relevant information is distributed to support effective planning, monitoring, and evaluation of cancer control programs in prevention, early detection, patient treatment and care, as well as research.

The Surveillance & Reporting department is composed of team members with various backgrounds who integrate, analyze, and interpret cancer occurrence and risk factor information. This information is compiled using data from the Alberta Cancer Registry and other data sources. This data is analyzed using quantitative and qualitative methods. Relevant cancer statistics information is then disseminated to a variety of stakeholders.<sup>14</sup>

### 5.1.3 ALBERTA CANCER CARE INITIATIVES

In 2012, CancerControl Alberta began to explore the needs of First Nation, Inuit, and Metis (FNIM) populations regarding cancers. Initial work was aimed at the development of a base of information and knowledge from which to better understand the priorities for cancer care from FNIM perspectives. Dedicating a 1.0 FTE to these endeavors resulted in the development of a work plan, an informal needs assessment with cancer care professionals across the province, and two strategy documents for moving forward. The underlying goals within the strategy documents are stated as:

1. Increased FNIM access to cancer care; and,
2. Building trusting relationships with FNIM people.

Several projects have been/are being carried out with First Nation, Inuit and Métis (FNIM) people in Alberta since that time. They are:

1. Alberta Cancer Foundation – Exploring a Community of Practice with First Nations;
2. Alberta Cancer Foundation – Aboriginal Access Resource Tool Project;
3. CPAC – First Nations Project (Current focus of this document);
4. CPAC – FNIM Primary Care Project (Inter-Provincial Partnered Initiative with NWT, BC, MN & AB); and,
5. CPAC – Métis Cancer Journey Project.

Key points of all cancer control activity and planning in a context of Alberta's Aboriginal people, including First Nations include:

- Engage FNIM key stakeholders to develop a framework of support for community partnered responsibility.
- Design and implement a CancerControl Alberta FNIM strategic framework of activity.
- Conduct activities of information gathering with FNIM communities.
- Explore the feasibility for the design of a FNIM public health surveillance database.
- Establish a baseline of knowledge and information for provincial FNIM cancer control.

#### 5.1.4

### AHS-ABORIGINAL HEALTH PROGRAM

Alberta Health Services has a dedicated Aboriginal Health Program. Priorities of the Program include:

- Engagement and relationship building with respect to Aboriginal Involvement in the planning, implementation and evaluation of health services delivery.
- Improving access to health services across the continuum of care regardless of geographic location.
- Enhancing cultural competencies of Alberta Health Services staff and physicians.
- Enhancing the prevention and management of chronic diseases and disability (including mental health and addictions) across the lifespan.
- Exploring ways to prevent injuries.<sup>15</sup>

Alberta Health Services has adapted its strategic plan to focus on chronic disease as a broad category. This is in alignment with Federal planning in which Health Canada-First Nations Inuit Health Branch (Alberta Region) is expanding work in the area of chronic disease. Engagement between these two service providers has been ongoing to ensure consistency and continuity in planning. The Aboriginal Health Program has also adopted this broader focus of chronic disease management in support of a provincial and federal health focus on chronic disease.

Prior and ongoing work supported through the Alberta Cancer Prevention Legacy Fund includes initial needs assessments/talking circles to determine the best chronic disease programs and organizational program structure for these populations. This project, led by the Aboriginal Health Program is expected to provide key information for future programming and services to these populations including First Nations and Inuit Health services and programming, as well as FNIM-specific screening kits for breast, cervical, and colorectal screening. Additional work by AHS includes cervical screening training, and initiatives for First Nation communities in Alberta such as First Nations belonging to the Western Cree Tribal Council.

FNIM-specific cancer resources focus on prevention and screening as well and include The Alberta Cervical Cancer Screening Program's "Aboriginal Cervical Cancer Education Toolkit". The toolkit contains a PowerPoint presentation and CD; flip chart cards and pamphlets on four topics related to cervical cancer; personal stories from Aboriginal women; a cervical model and medical Pap test supplies; a video on colposcopy examinations; and other information resources.<sup>16</sup>

Cancer-related services for FNIM cancer patients include a full-time Aboriginal Health Navigation position, which provides support to cancer patients and families who access services at the Cross Cancer Institute in Edmonton. Similar services may be available across the province at urban hospital sites through Aboriginal Care Coordinators including the Alberta Hospital, Glenrose, Grey Nuns, Misericordia, Royal Alexandra, Stollery, Sturgeon, University of Alberta Hospitals, and WestView Health Centre. Cancer patients and families can request support services through doctors and nurses at these sites.

A Community Mental Health and Community Care Coordinator is also available to support FNIM patients and their families. Spiritual supports for patients and families are currently available at some hospital sites such as the University of Alberta Hospitals through Cultural Helpers or Advisors.

All other examples of cancer-related services or programming that were identified during this project were found to focus on screening and prevention. For instance, the Primary Care Network Nurse Practitioner and the Screening for Life Program – Alberta Health Services' mobile mammogram trailer visit several First Nations communities and surrounding sites in Alberta. Participating First Nations communities include Brocket, Cold Lake First Nations, Fort McKay, Frog Lake, Goodfish Lake, Maskwacis, John D'Or Prairie, Morley, Saddle Lake, Siksika, Standoff, Sturgeon Lake, Sucker Creek, and Wabasca.

## 5.2 FIRST NATIONS AND INUIT HEALTH BRANCH

The intra-jurisdictional contexts for First Nations health care are based upon a mandate most recently derived from the 1979 Indian Health Policy, which is currently under review.<sup>17</sup> Provincial governments deliver hospital, physician and public health programs to all Canadians, including First Nation, but generally do not operate direct health services on-reserve.<sup>18</sup>

Non-Insured Health Benefits provide a range of medically necessary goods and services to First Nations people and Inuit regardless of where they live. This supplements benefits provided by private or provincial/territorial programs.<sup>19</sup> FNIHB also undertakes health surveillance, information, and analysis, including data development, data analysis, research evidence and evaluation advice to support policy development, program priority-setting and decision-making on health-related investment.

First Nations health system challenges include increasing costs, health human resource shortages, quickly growing populations with a higher rate of disease burden, and populations living largely in remote and rural areas of the country.<sup>20</sup>

Current cancer-related work at FNIHB in Alberta includes the following:

- Analysis of cancer trends, incidence and prevalence among First Nations in Alberta by FNIHB Health Assessment and Surveillance and Alberta Health Services Surveillance.
- Development of a FNIHB Framework for Chronic Disease Management (inclusive of cancer) by Health Promotion and Disease Prevention.
- Ongoing provincial cancer screening activities in First Nation communities.

## 5.2.1 FIRST NATIONS AND INUIT HEALTH - ALBERTA REGION

FNIHB Alberta Region provides funding to support on-reserve local health programs and services; or in some cases, provides health care resources and services.

In most First Nations communities, community health programs are delivered by a local health centre or nursing station. These facilities are managed by the local First Nation to serve the health needs of their communities with staffing levels based on the size of the First Nation community in which it is located. Staff can include public health nurses, home care nurses, community health representatives, and other non-regulated healthcare providers who support health programs and community health initiatives. Physicians are not stationed at nursing stations. They visit the communities on a rotational basis. Nursing stations are located in communities defined as remote or isolated. These facilities offer community health programs as well as primary care. Primary Care is available 24 hours a day, seven days a week with after-hours emergency and on-call service.

## 5.2.2 NON-INSURED HEALTH BENEFITS DIRECTORATE

FNIHB provides eligible First Nations and Inuit individuals with a specified range of medically necessary health-related goods and services when they are not covered through private insurance plans or provincial/territorial health and social programs.<sup>21</sup> Health Canada indicates that the Non-Insured Health Benefits (NIHB) program provides benefit coverage for registered First Nations on a limited range of medically necessary health-related goods and services.

The Assembly of First Nations (AFN) is currently seeking to increase political pressure to achieve real change in the NIHB program through engagement, dialogue, and solution-focused action from First Nations at the community, regional, and national levels. A National First Nations NIHB Strategy Forum to inform a National Action Plan on NIHB was tabled for discussion at the 2014 AFN Annual General Assembly.

### 5.2.3 NURSING DIRECTORATE

For many communities, nurses are often the main point of contact within the health care system. They routinely provide primary health care in remote and culturally diverse areas and operate in homes, schools, health centres and nursing stations. Their work requires advanced knowledge, skill and clinical judgment and they use a holistic approach to care in routine, acute, and emergency situations.

### 5.2.4 ALBERTA FIRST NATION HOME CARE PROGRAM

In Alberta, Home and Community Care (HCC) provides funding for communities in order to assist people in need of home care, allowing them to stay in their homes for as long as possible. Funding is provided for essential service elements.

### 5.2.5 COMMUNITY HEALTH REPRESENTATIVES

Community Health Representatives (CHRs) are community members trained to assist in the delivery of health care programs. The role of CHRs in community health evolved from that of a translator/liaison to that of community and public health. In communities, the CHR position is a key position on the health team for the delivery of public health programs and services to all First Nations communities. Their key focus today is on health education.

### 5.2.6 E-HEALTH INFOSTRUCTURE

“The First Nations and Inuit Health Branch (FNIHB) has sponsored the development of a First Nations Health Infostructure. All participants are committed to effectively linking a range of First Nations telecommunication activities, such as telehealth, broadband deployment and Public Health Surveillance System (Panorama), to a First Nations Infostructure. This infostructure will support First Nations health services and health care delivery. It will ultimately link supporting systems with provincial and territorial infostructures through joint Infoway initiatives.”<sup>22</sup>

### 5.2.7 TELEHEALTH

Telehealth videoconferencing can be used to access clinical services from a variety of medical and mental health professionals. This technology can also be used to facilitate meetings and to access educational opportunities. All First Nations Health Centres and nursing stations are equipped with videoconferencing capabilities that are networked through the provincial SuperNet. FNIHB provides videoconference bridging services for First Nations across Alberta.

## 6.0 FIRST NATIONS CANCER CONTROL IN ALBERTA INITIATIVE

### 6.1 INTRODUCTION TO “INCREASED ACCESS TO CULTURALLY SAFE CANCER CARE PATHWAYS BY ALBERTA FIRST NATIONS IN RURAL, REMOTE, AND ISOLATED COMMUNITIES”

The report *Summarizing Aboriginal Cancer Strategy Documents & Information in an Alberta Context: A Community Oncology Aboriginal Cancer Planning Initiative* identifies leading cancer care strategies and practices to encompass the following:

1. First Nations, Inuit, and Métis cancer control leadership;
2. Improved jurisdictional responsiveness;
3. Community engagement and collaborative partnership development;
4. Data collection;
5. Cultural competency and safety training;
6. Navigation to improve patient and family experiences throughout the cancer journey; and,
7. Use of virtual technology.

In 2013, Alberta Health Services-CancerControl Alberta, in collaboration with the Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta, the Alberta First Nations Information Governance Centre, Dr. Cora Voyageur and other partners submitted a 2.5 year project proposal to CPAC: “*Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote, and Isolated Communities.*”

The purpose of the project is to **a)** develop and implement a strategy for increased access to cancer care by First Nations in rural, remote, and isolated communities, and **b)** initiate and implement strategies for First Nations community and stakeholder engagement that support targeted interventions for improving the First Nations cancer care pathway.



### 6.1.1 STRATEGIES

A coordinated, holistic, and comprehensive approach will contribute to gathering information and increased understanding of the elements required for long-term impact on both the cancer care journey and improved experiences for First Nations cancer patients. These strategies include:

1. Development of a two-part project to build upon established relationships and partnered activities;
2. Creation of a framework for culturally competent investigation of needs specific to First Nations cancer pathways including the acceptance of traditional supports;
3. Carrying out consultative processes with First Nations communities, organizations and stakeholders necessary for the development of methodologies to gather First Nations cancer data that complies with First Nations' OCAP™ principles - Ownership, Control, Access and Possession; and,
4. Development of culturally appropriate processes, resources and tools to increase support for First Nation cancer patients and their families from diagnosis, through treatment of care, and upon discharge to various primary care and community services.

### 6.2 BASELINE ASSESSMENT STRATEGIES AND INDICATORS

Key to the success of a 2.5 year project is the 'readiness' of multi-jurisdictional stakeholders to plan, carry out, and meet the goals for the proposed areas of focus listed in the previous section. The stakeholders include service and delivery organizations (Alberta First Nations, First Nations and Inuit Health Branch, Alberta Health Services-CancerControl), project co-lead partners (Provincial Tribal Organizations - Confederacy of Treaty Six First Nations, Treaty Seven Management Corporation, Treaty 8 First Nations of Alberta, Alberta First Nations Information Governance Centre, Dr. Cora Voyageur, Alberta Health Services-Aboriginal Health), and various project collaborators (Aboriginal Nurses Association of Canada, Indigenous Physicians Association of Canada, Canadian *North Helicobacter pylori Working Group* at University of Alberta). Each of these stakeholders can be shown to have vested interests in improved cancer care for First Nations cancer patients, their families, and caregivers.

Four strategies were utilized to gather information regarding the 'readiness' of these stakeholders. The following sections outline the minimum requirements for the baseline assessment (carried out as part of this report), which includes key considerations, definitions, proposed metrics, and outcomes.

**Strategy 1:**

# FIRST NATIONS CANCER DATA COLLECTION, MANAGEMENT AND STEWARDSHIP

The Alberta First Nations Information Governance Centre, a project co-lead, currently collects and manages the Regional Health Survey (RHS) First Nations health data as well as the First Nations Regional Early Childhood, Education, and Employment Survey (FNREEES) data.

The quantitative cancer incidence data for First Nations that is currently available to inform care is for the period between 1997 and 2010. These data are available from Alberta Health Services, Surveillance & Reporting.

Population-based First Nations-specific cancer data are reliant upon information from the Alberta Cancer Registry (ACR) and on the identification of First Nations people within the ACR. With the discontinuation of Alberta Health Care Insurance Plan (AHCIP) premium payments in 2009, the ability to identify First Nations and to compile First Nations-specific cancer information is eroding.

A collaborative undertaking between the Government of Alberta-Alberta Health Services (AHS), The Alberta First Nations Information Governance Centre (AFNIGC), Alberta Treaty representatives, and First Nations and Inuit Health Branch (FNIHB)-Alberta Region to access the Indian Registry System (IRS) held by Aboriginal Affairs and Northern Development Canada (AANDC) is in progress.

There is currently no baseline available to advance the uptake of First Nations identification for the improvement of patient navigation, the provision of access to culturally responsive services, or the creation of appropriate programs. Process and protocol guidelines for information access and use must be developed.

The project partnership between the Alberta First Nations Information Governance Centre (AFNIGC), Dr. Cora

Voyageur, and Alberta Health Services (AHS)-CancerControl Alberta was supported through the development of a service agreement that upholds the privacy and protection of First Nations rights through compliance with the First Nations principles of OCAP™. This achievement becomes a stepping-stone for the respectful engagement of First Nation organizations, communities, and people. Consideration for the inclusion of information in the readiness assessment included:

- Quantitative data.
- First Nations population demographics.
- Geography.
- First Nations cancer incidence data.

Information was gathered from the following sources:

- Alberta First Nations Information Governance Centre data.
- Alberta First Nations Map.
- Health Co-Management more than numbers: caring for First Nations and Inuit in Alberta – on-reserve health programs and services.
- Health Determinants for First Nations in Alberta.
- Alberta Health Services (2013) Cancer Surveillance in Alberta. Surveillance & Reporting Unit, Cancer Measurement Outcomes Research and Evaluation.
- Aboriginal Health Program data.
- Access to Indian Registry System and First Nations Information Working Group Terms of Reference.
- Bigstone Health Commission Report, 2014.

### Key anticipated outcomes of Strategy 1:

- Baseline data of First Nations cancer incidence and information.
- Development of the protocol for a First Nations cancer patient identification system.

**Strategy 2:**

# COMMUNITY ENGAGEMENT AND COLLABORATIVE PARTNERSHIP DEVELOPMENT

Several jurisdictions participated in the Baseline Assessment activity for this report:

- Federal - Health Canada, First Nations and Inuit Health Branch Alberta Region.
- The Alberta First Nations Information Governance Centre.
- Provincial - Alberta Health Services, CancerControl Alberta, Aboriginal Health Program, Surveillance & Reporting.
- Treaty areas of Alberta - Confederacy of Treaty Six First Nations, Treaty 7 Management Corporation, Treaty 8 First Nations of Alberta.
- First Nation community health organizations - Siksika Health Services, Maskwacis Health Services, and Bigstone Health Commission.

None of these jurisdictions currently have a First Nations cancer control strategy and there is no baseline cancer data available. All of the participants have worked together as either partners or collaborators.

A Service Agreement between Alberta Health Services and The Alberta First Nations Information Governance Centre was negotiated and signed off. This agreement complies with First Nations principles of OCAP™. A leadership and stakeholder engagement event took place on February 21, 2014 to address decision-making. Both leadership and stakeholders agree that there is a need for improved cancer care pathways.

The main goal of this work is to ensure that the findings of this project (including all of the information gathered and knowledge gleaned) will be used for action to improve the cancer care pathway and experiences of Alberta First Nations cancer patients, their families, and caregivers.

Consideration for the inclusion of information in the readiness assessment included:

- Number of jurisdictions participating in the initiative.
- Number of jurisdictions with cancer control strategies.
- Impact captured through standard knowledge transfer and exchange measures.
- Accountability, decision-making, and dispute protocols.
- Organizations/partner initiative sustainability.
- Examples of successful change of practice pattern, change theory, and processes.

Information was gathered from the following sources:

- Treaty No. 6, Treaty No. 7, and Treaty No. 8 background and description .
- Treaty 6, Treaty 7, and Treaty 8 Community Engagement Session summaries 2014.
- Aboriginal Health Program staff Learning Survey Outcomes 2014.
- Screening and prevention projects through the Aboriginal Cancer Prevention Legacy Fund and FNIHB.
- Training for nurses to do screening in First Nations communities is available through AHS
- FNIHB Chronic Disease Framework and a Cancer Tool Kit. AHS CancerControl and Aboriginal Health Program projects.

### Key anticipated outcomes of Strategy 2:

- Increase in number jurisdictions with specific actions to address cancer control for First Nations people.
- Framework for First Nations and community stakeholder engagement.
- First Nations collective ownership of a cancer control strategy.
- Improved access to resources and acceleration of progress as a results pan-Canadian collaborative approach, common tools, resources, and networks.
- Measuring Current State Readiness.
- Description of a Provincial Control Strategy/Action Plan for First Nations, Inuit and Métis.

**Strategy 3:**

# FIRST NATIONS CANCER NAVIGATION CULTURAL COMPETENCY FRAMEWORK

First Nations and Inuit Health Branch (Alberta Region) currently provides a nursing orientation in cultural safety and misconception training. Alberta Health Services is developing a cultural safety framework for AHS employees. Both of these factors support the statement: There is no cultural competency training available for cancer care professionals.

During 2014, three First Nation community engagement sessions were conducted at Bigstone, Maskwacis, and Siksika. An important finding from these sessions identified discharge planning as a core issue. Protocols and processes for culturally and emotionally safe diagnosis delivery methods, and increased patient or caregiver understanding of diagnoses, are required for decision-making. There are currently no strategies, such as the use of telehealth as a strategy for increased communication and planning, in place to improve the situation regarding Alberta First Nations cancer patients or care.

This readiness assessment also found that there is no baseline available concerning discharge (both ambulatory and in-patient). Effective and efficient processes are required to ensure patients are appropriately supported along the continuum of cancer care. This support has been found to reduce the cancer patient's post-treatment hospital stays, re-admissions, and complications when returning to their home community.<sup>23</sup>

Consideration for the inclusion of information in the readiness assessment included:

- Understanding and acting on diagnosis.
- Discharge: rural hospital site data, e. g. chart audit and self-identifiers.
- Culturally appropriate supports and resources.
- Existing formal referral and/or collaborative protocols to effect traditional health support.
- Cultural competency requirements of participating organizations and access to training.

Information was gathered from the following sources:

- The Alberta First Nations Information Governance Centre – RHS data.
- AHS Health Program Staff.
- FNIHB Staff.
- University of Calgary, Faculty of Medicine.
- (2012) First Nations eHealth Evaluation Alberta Region. Interim Report. August 2012.
- Treaty region specific projects to address traditional health support.
- Alberta Health Services Aboriginal Health Program Cultural Liaison position at Cross Cancer Institute.
- Treaty 6, 7 and 8 Community Engagement Sessions.
- Alberta First Nations Home Care.
- Alberta Cancer Board, First Nations and Inuit Health Branch and Portage College, Community Health Representative (CHR) Skill Enhancement Course: Cancer – The Challenge for Aboriginal Communities. June 11-15, 2001 (Final Report, Agenda, Elder Notes, Sharing Circle Notes and Participant Evaluation).
- Contact List for Rural Family Physicians Working with Cancer Patients (Bigstone Cree Nation Region).
- Alberta Health Services Aboriginal Health Program traditional support provided by Elders.
- AHS access resource/FNIHB list, including cancer toolkit.

### Key Anticipated Outcomes of Strategy 3:

- Evidence-based practice strategy in First Nations cancer care.
- Cancer diagnosis is delivered in a culturally and emotionally safe way.
- First Nations patients have appropriate supports at diagnosis appointment, traditional supports are considered, and relevant resources made available.
- Increased use of telehealth to support First Nations cancer care at time of diagnosis.
- First Nations are referred to culturally relevant and safe cancer care navigation and traditional supports.

**Strategy 4:**

# FIRST NATIONS CANCER CARE JOURNEY AND CONTINUUM OF CARE

Two important sessions were held in support of the future project and planning in February 2014. This included a Leadership/Stakeholder Engagement Event that brought leaders, service providers, and key people from First Nations, AHS-CancerControl, and First Nations Inuit Health Branch together. The goals of the event were:

1. To establish a foundation for relationship building.
2. To present pertinent information about the initiative.
3. To facilitate discussion for a shared understanding.
4. To gain a shared commitment to implement initiative recommendations.

A First Nations Cancer Patient Navigation Dialogue Meeting invited CancerControl navigators, Alberta Treaty area Non-Insured Health Benefit Navigators, First Nation community partners, and stakeholders to initiate relationships for the 2.5- year project. This meeting was facilitated by project team members to meet the following goals:

1. Working session focused on how to remove roadblocks and resolve issues related to cancer patient navigation.
2. Panel discussion, question and answer session, and break out groups to discuss challenges and priorities.
3. Agree on priorities which, when addressed, will improve cancer patient navigation.

Information learned from these two events confirmed that there are currently no strategies or accompanying information for the following:

- First Nation patient satisfaction with cancer care.
- Patient diagnosis or discharge planning for First Nations.
- Protocols used to support First Nation patients returning to communities.
- Existing organizational protocols and procedures within jurisdictions related to initiative outcomes.

Consideration for the inclusion of information in the readiness assessment included:

- Qualitative data.
- Literature scan of existing reports and resources.
- Description of cancer journey for First Nations in rural, remote, and isolated communities.

Information was gathered from the following sources:

- Alberta Health Services- Community Oncology, Aboriginal Patient Needs and Centres Questionnaire and Response Summary Table.
- Treaty 6, 7, and 8 Community Engagement Sessions.
- Contact List for Rural Family Physicians Working with Cancer Patients (Bigstone Cree Nation Region).
- Aboriginal Health Program Resource Guide.
- The Alberta First Nations Information Governance Centre.

### Key anticipated outcomes of Strategy 4

- Improved transfer of care for First Nations patients who return to home communities from secondary/tertiary care centres over the course of cancer care.
- Improved knowledge of First Nations patients' experience through their cancer journey.
- Information and knowledge base of First Nations cancer care experiences.

### 6.3

## BASELINE READINESS ASSESSMENT CONCLUSIONS AND FORWARD PLANNING

Potential or emerging challenges and issues have been identified through the work to carry out the Baseline Readiness Assessment for this report. This report determines that there are:

1. time requirements needed to build trust and sustain trusting relationships with First Nation cancer patients, families, and communities;
2. limited available resources to support and carry out information-gathering activities within communities;
3. huge gaps of knowledge and information on the cancer experiences of First Nations in an Alberta context; and,
4. competing interests and complex health issues facing many First Nations communities.

The overall goal of the readiness assessment was met. Success of the 2.5-year project, and its desired outcomes for improved health outcomes in relation to cancers, requires an agreement that sanctions stakeholder commitment to enact system change for an improved First Nations cancer pathway. Attention is now to be focused on building partnerships capable of supporting activities designed for the development of a knowledge-based inclusion of the voices and perspectives of First Nations people who are in need of these services. To this end, and as part of the work to meet the goals of the short-term project, this baseline report signifies the importance of the pending 2.5-year initiative and the emergent need for this work to continue in partnership with Alberta First Nations.

The four strategic areas utilized to gather information for this report have provided a robust rationalization for further concentrated work in the areas of; First Nations cancer data collection, management and stewardship, Community engagement and collaborative partnership development, a First Nation cancer navigation cultural competency framework and issues surrounding a First Nation cancer care journey and continuum of care.

It is apparent the current status of First Nations cancer data is limited for application towards developing an evidenced based First Nations Cancer Strategy and further for program planning and development. Further work in this area requires First Nations participation in developing data management agreements, protocols, along with a First Nations identifications system to capture accurate data to support future recommended cancer care strategies.

Meaningful partnerships and collaborative partnership development are key components to building sustainable programing reflective of the overarching goal of “ Increased Access to Culturally Safe Cancer Care Pathways by Alberta First Nations in Rural, Remote and isolated Communities”. Providing an opportunity for First Nations to contribute in a meaningful way will ensure that appropriate systems and processes are created to meet needs currently not being met.

A cultural framework for cancer care navigation is a critical aspect to ensuring cultural emotional safe care throughout the continuum of care, whether tele-health or other systems of care access are developed to meet First Nations of Alberta cancer access gaps in the future. First Nations of Alberta Cancer Care journey and continuum of care requires more work in the four areas identified with this work; patient satisfaction with cancer care, patient diagnosis and discharge planning, along with the need for appropriate protocols to support First Nation patients returning to communities, including an evaluation of existing organizational protocols and procedures within the different jurisdictions related to initiative outcomes.

## APPENDIX A:

LIST OF FIGURES  
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## APPENDIX B:

FIRST NATIONS  
POPULATION IN ALBERTA

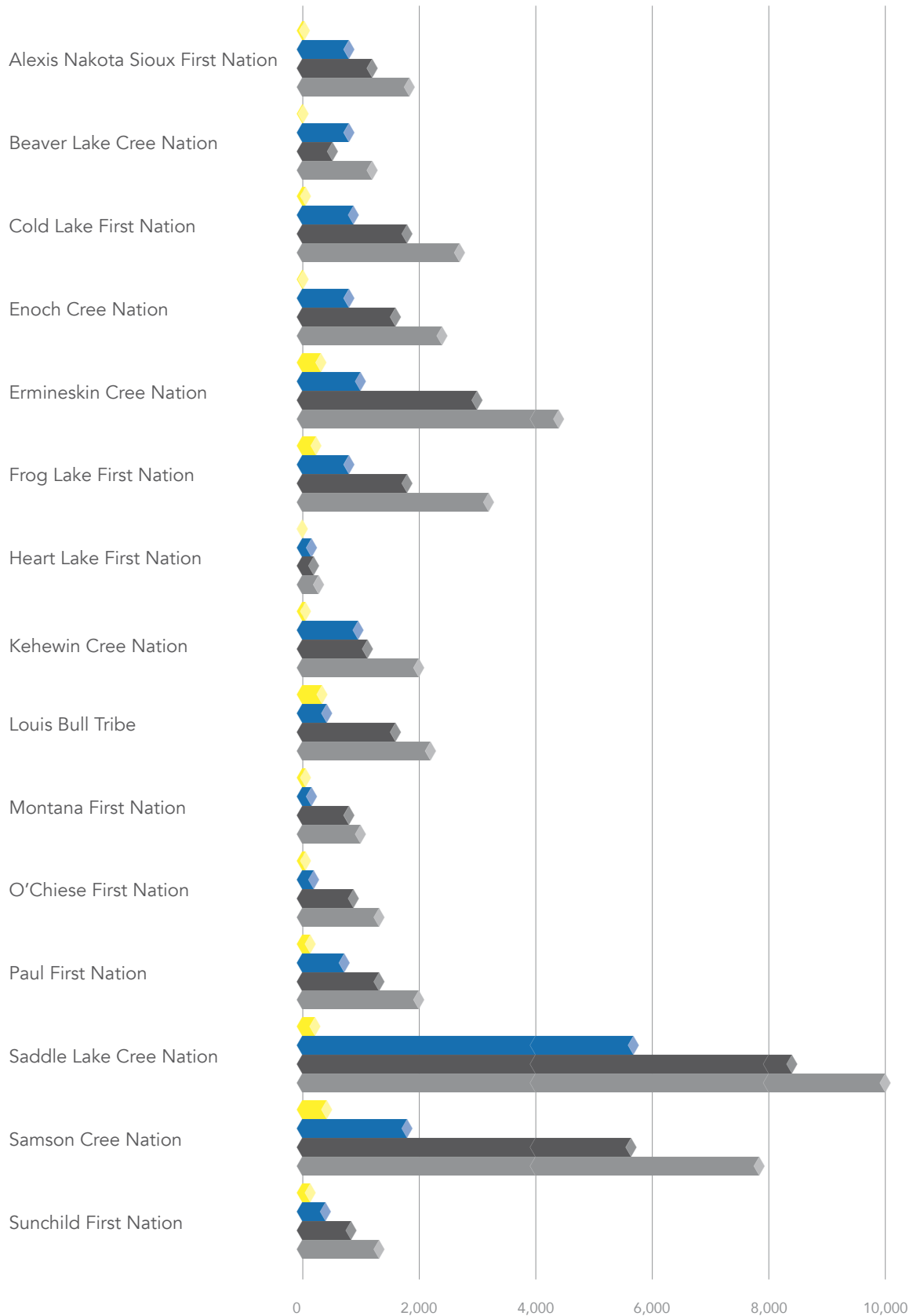
TABLE 1A – TREATY 6 FIRST NATIONS IN ALBERTA – PER AANDC FIRST NATION PROFILES FEB. 2014

| Nation                           | Total Registered | On-Res | Off-Res | Other |
|----------------------------------|------------------|--------|---------|-------|
| Alexander First Nation           | N/A              | N/A    | N/A     | N/A   |
| Alexis Nakota Sioux First Nation | 1,862            | 1,076  | 720     | 66    |
| Beaver Lake Cree Nation          | 1,092            | 363    | 694     | 35    |
| Cold Lake First Nation           | 2,730            | 1,286  | 1,387   | 57    |
| Enoch Cree Nation                | 2,442            | 1,598  | 805     | 39    |
| Ermineskin Cree Nation           | 4,381            | 2,978  | 988     | 15    |
| Frog Lake First Nation           | 3,059            | 1,694  | 1,101   | 64    |
| Goodfish Lake First Nation       | N/A              | N/A    | N/A     | N/A   |
| Heart Lake First Nation          | 332              | 189    | 124     | 9     |
| Kehewin Cree Nation              | 2,007            | 1,080  | 836     | 1     |
| Louis Bull Tribe                 | 2,168            | 1,490  | 429     | 249   |
| Montana First Nation             | 978              | 674    | 225     | 9     |
| O'Chiese First Nation            | 1,264            | 836    | 373     | 5     |
| Paul First Nation                | 2,005            | 1,237  | 650     | 18    |
| Saddle Lake Cree Nation          | 10,034           | 6,144  | 3,698   | 192   |
| Samson Cree Nation               | 7,968            | 5,698  | 1,786   | 84    |
| Sunchild First Nation            | 1,301            | 779    | 426     | 96    |



**CHART 1A – TREATY 6 FIRST NATIONS IN ALBERTA**

Other Off-res On-res Total registered

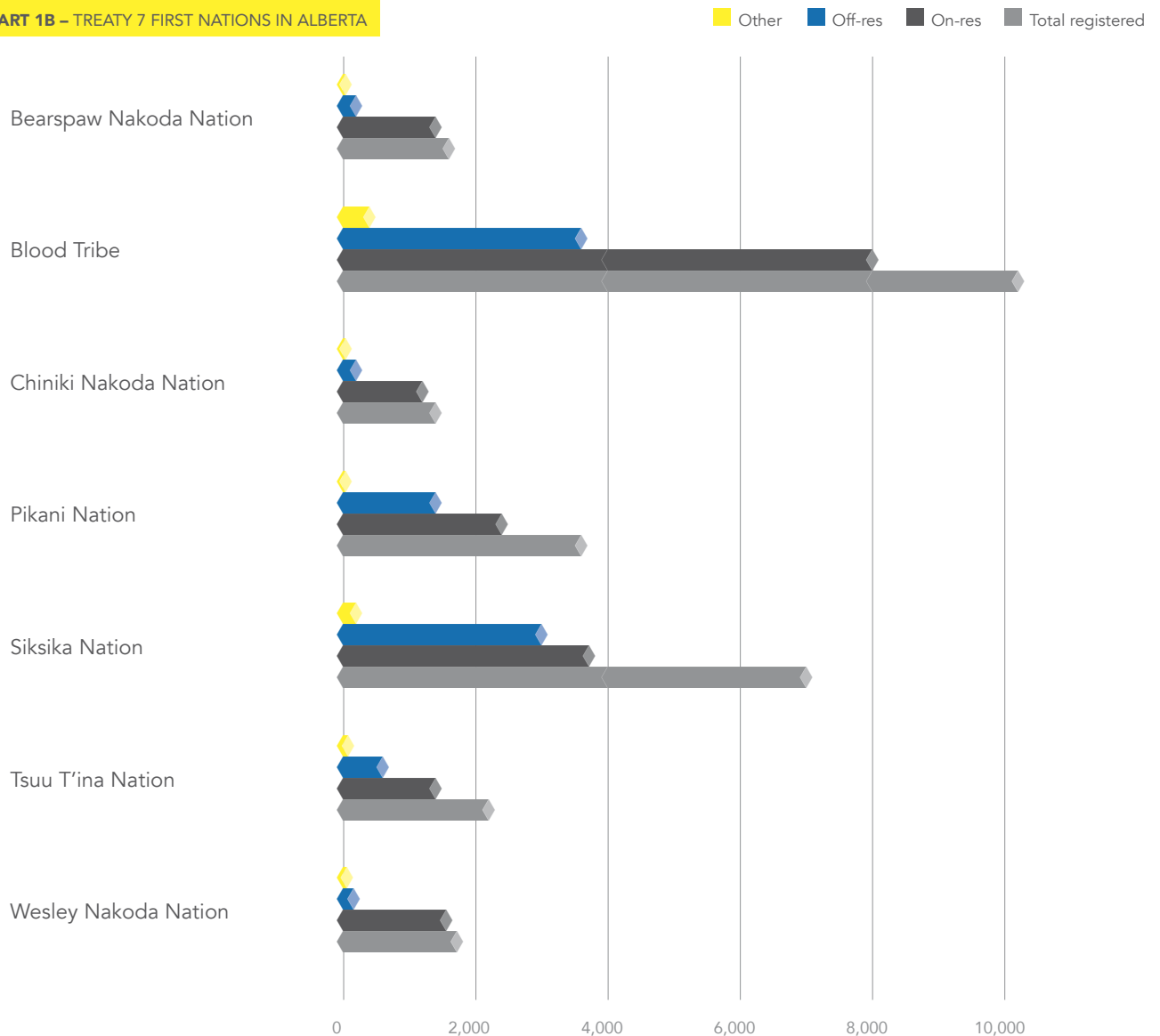


\* Population values for Alexander First Nation and Goodfish Lake First Nation are not available

**TABLE 1B – TREATY 7 FIRST NATIONS IN ALBERTA – PER AANDC FIRST NATION PROFILES FEB. 2014**

| Nation                  | Total Registered | On-Res | Off-Res | Other |
|-------------------------|------------------|--------|---------|-------|
| Bears paw Nakoda Nation | 1,857            | 1,665  | 140     | 52    |
| Blood Tribe             | 11,820           | 8,015  | 3,605   | 200   |
| Chiniki Nakoda Nation   | 1,720            | 1,518  | 149     | 53    |
| Piikani Nation          | 3,638            | 2,358  | 1,245   | 35    |
| Siksika Nation          | 6,988            | 3,826  | 2,957   | 205   |
| Tsuu T’ina Nation       | 2,132            | 1,522  | 498     | 112   |
| Wesley Nakoda Nation    | 1,775            | 1,532  | 174     | 69    |

**CHART 1B – TREATY 7 FIRST NATIONS IN ALBERTA**

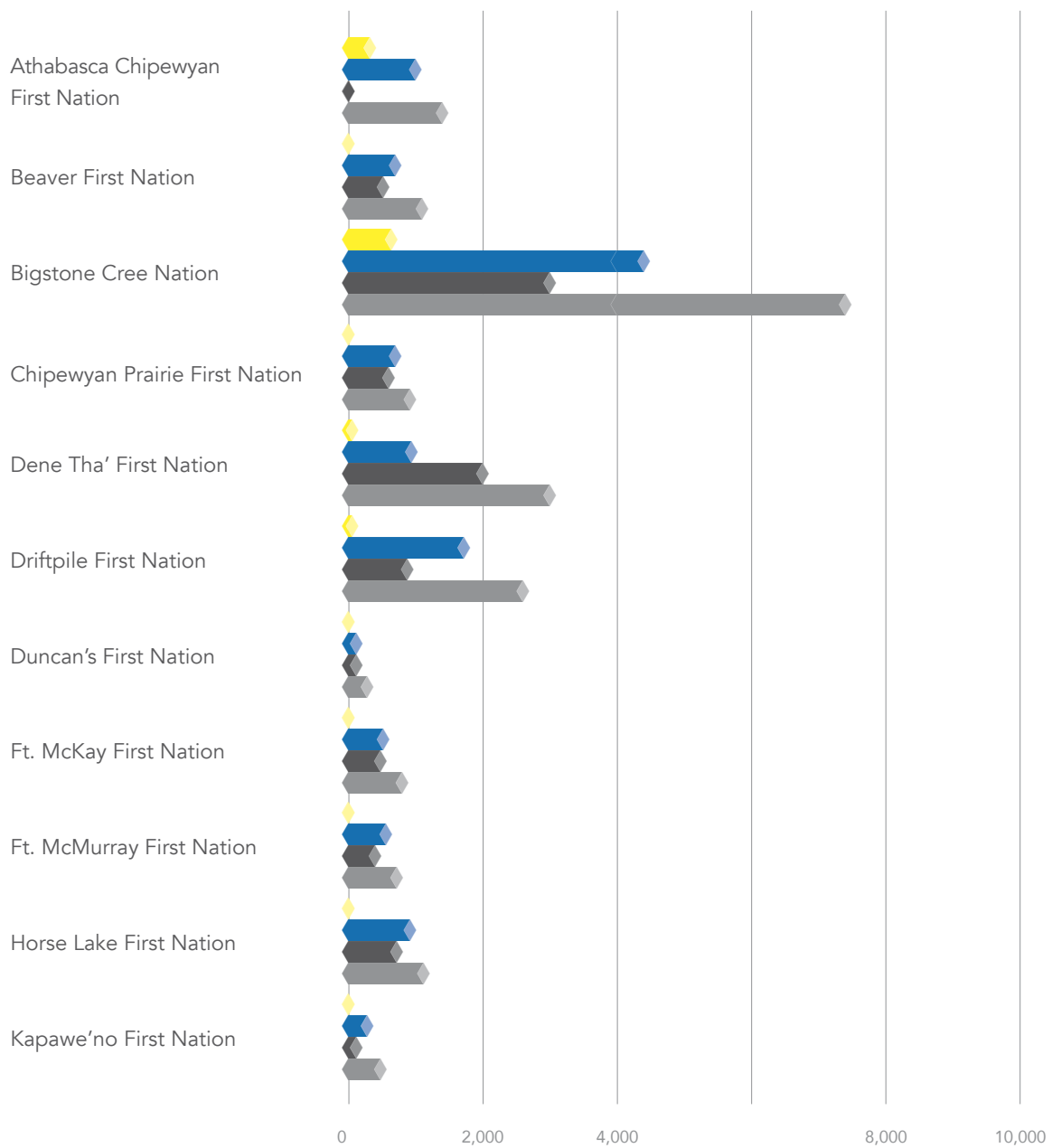


**TABLE 1C – TREATY 8 FIRST NATIONS IN ALBERTA – PER AANDC FIRST NATION PROFILES FEB. 2014**

| <b>Nation</b>                    | <b>Total Registered</b> | <b>On-Res</b> | <b>Off-Res</b> | <b>Other</b> |
|----------------------------------|-------------------------|---------------|----------------|--------------|
| Athabasca Chipewyan First Nation | 1,109                   | 25            | 863            | 221          |
| Beaver First Nation              | 1,022                   | 416           | 569            | 37           |
| Bigstone Cree Nation             | 7,455                   | 2,816         | 4,275          | 364          |
| Chipewyan Prairie First Nation   | 851                     | 365           | 476            | 10           |
| Dene Tha' First Nation           | 2,902                   | 1,970         | 875            | 57           |
| Driftpile First Nation           | 2,596                   | 880           | 1,667          | 49           |
| Duncan's First Nation            | 284                     | 141           | 141            | 2            |
| Ft. McKay First Nation           | 815                     | 393           | 406            | 16           |
| Ft. McMurray First Nation        | 706                     | 265           | 429            | 12           |
| Horse Lake First Nation          | 1,083                   | 461           | 609            | 13           |
| Kapawe'no First Nation           | 364                     | 124           | 233            | 7            |
| Little Red River Cree Nation     | 5,144                   | 3,945         | 636            | 563          |
| Loon River Cree Nation           | 568                     | 445           | 108            | 15           |
| Lubicon Lake First Nation        | N/A                     | N/A           | N/A            | N/A          |
| Mikisew Cree First Nation        | 2,939                   | 151           | 2,151          | 637          |
| Peerless Trout First Nation      | 860                     | 40            | 102            | 718          |
| Sawridge First Nation            | N/A                     | N/A           | N/A            | N/A          |
| Sturgeon Lake First Nation       | 3,127                   | 1,431         | 1,658          | 38           |
| Sucker Creek First Nation        | 2,712                   | 721           | 1,941          | 50           |
| Swan River First Nation          | 1,264                   | 389           | 868            | 17           |
| Tallcree Tribal Government       | 1,266                   | 479           | 721            | 66           |
| Whitefish Lake First Nation      | 2,578                   | 1,169         | 1,054          | 355          |
| Woodland Cree First Nation       | ???                     | ???           | ???            | ???          |

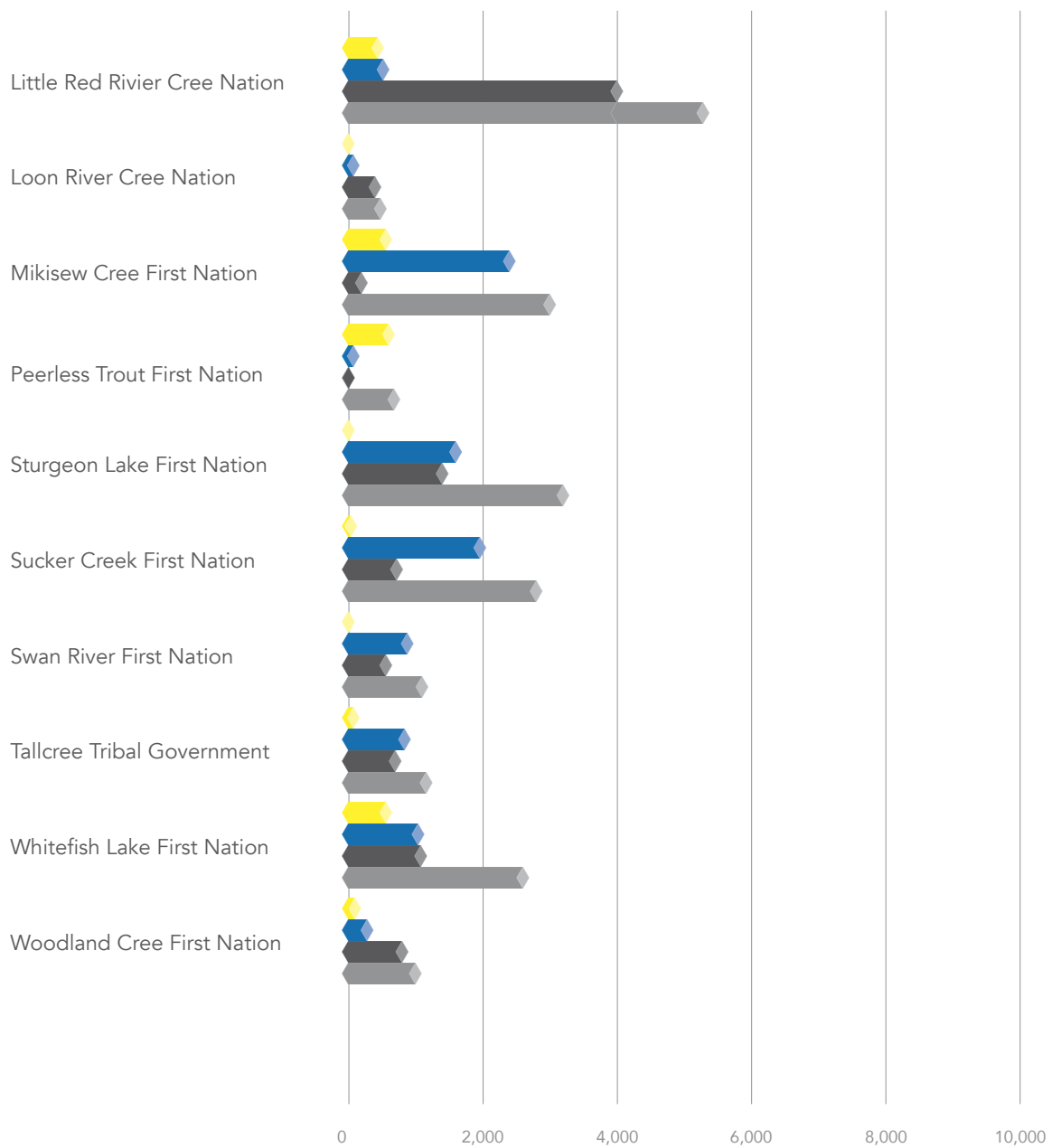
**CHART 1C – TREATY 8 FIRST NATIONS IN ALBERTA**

Other Off-res On-res Total registered



**CHART 1C – TREATY 8 FIRST NATIONS IN ALBERTA (CONTINUED)**

Other Off-res On-res Total registered



\* Population values for Lubicon Lake First Nation and Sawbridge First Nation are not available

## APPENDIX C:

# LEADERSHIP/STAKEHOLDER ENGAGEMENT EVENT SUMMARY

Building on the findings of the Baseline Assessment and the outcomes of the Leadership/Stakeholder Engagement Event, the project team will move forward to meet the following goals as outlined in the proposal:

### PART A

Trusted working relationships amongst the Project Team, FN communities and Cancer Care systems.

Improved cancer care systems and stakeholder awareness; further understanding and knowledge of the needs and cultural perspectives of FN cancer patients, families and their caregivers.

Increased understanding of FN challenges for access to cancer care;

Increased understanding of the points across cancer care and primary care to focus improvements for sustainable impact on the FN cancer journey (e.g. diagnosis, treatment of care and homecare); and,

Increased health systems' knowledge and awareness of the challenges and issues for FN cancer patients, families and care providers along the cancer care pathway.

Increased awareness and knowledge by FN people of cancers and cancer care services.

Increased awareness and understanding of FN cancer care needs across jurisdictions is identified;

Increased evidence-based knowledge of the cancer care experiences of Alberta FN cancer patients, families and care-givers; and,

Identification and improved understanding of the gaps across multi-jurisdictional services of care that are shown to have specific impacts for Alberta FN cancer outcomes.

Enhanced coordination of services across multiple jurisdictions of care, with a focus on points of access for diagnosis, through treatment of care and upon discharge to a variety of primary and community care services.

Increased role clarity; improvements in communication between participants – at different systems and levels of care.

Stakeholder/leadership engagement will lead to the selection of partners who then take actions identified through the project findings.

Improved FN cancer experiences and needs are identified and modifications are made to existing and developed processes, protocols and resources.

Earlier diagnosis, improved treatment of care experiences and improved discharge and follow up by FN patients and care givers as a result of increased access to cancer care.

Established relationships/roles of advisory and stakeholder groups at 3 levels of impact: individual pursuit of care; service and delivery; policy and decision-makers.

## PART B

Processes, protocols and partners have been determined for working together in order to create a framework for the development, use and tracking of FN data and information.

Data sharing needs have been determined and stakeholders/leadership are engaged to support the required agreements and processes, including the development and use of FN identifiers for cancer care. FN leadership, organizations and communities are engaged in the design, development and implementation of FN patient identification strategies.

## ACTIVITIES

The project intends to conduct a systemic review of Standards of Care in Rural, Remote and Isolated clinics and Hospitals. Outcomes may include an evaluation that identifies delays in diagnosis at the time of first presenting with symptomatic complaints.

NIHB Approval processes will be assessed for communication gaps related to the denial of authorized treatment. Examples include a policies review regarding access to care, including the following kinds of questions:

Does Medical Transport availability contribute to a delay in treatment?

Is Cultural Sensitivity at time of diagnosis practiced at the larger institutions?

Does service delivery incorporate Traditional Healing/ Ceremony into Treatment planning?

What support systems are available at home to the patient and family?

Are counseling or financial advisors available?

Is information available related to establishing a will and testament?

Do FN have access to palliative care at home?

What is the level of care that can be received by home care in the community?

What are the distances and availability of palliative care services and facilities for FN?

In particular, Part A needs assessments will identify areas of most concern for FN cancer patients and families. The project team, including ANAC/IPAC and university collaborative partners, will work together to develop culturally appropriate protocols, resources, communication mechanisms etc... to support improved cancer care provided to FN patients and families.

The project team will work with multiple jurisdictions of service and delivery, including AHS, FNIHB and FN, to identify points of intersect where the most impact can be anticipated through the use of the developed resources and tools.

Leadership and advisory members are expected to provide guidance for the results and outcomes of the initiative to produce actionable system change.

Part B will produce data sharing agreements, terms of references, relationship protocols as needed to utilize FN identifiers for the purposes of providing FN-specific resources and the future collection of FN data and information. We anticipate new knowledge to be developed in relation to the application of OCAP principles in a context of cancer care that may act as a model for work in other areas of healthcare.

To date, there is no reliable and valid information of the cancer experience of First Nations from diagnosis, through treatment of care and upon discharge in an Alberta context. Although the focus of this work is not research, investigation to ensure the actions proposed/undertaken are well-suited and appropriate to the needs and concerns of FN cancer patients in an Alberta context is required. As well, leadership and program delivery require evidence to support policy change by decision-makers. Part A of this project has been designed to provide this important information for several specific reasons. First, improved understanding of the special needs of these populations with regards to cancer diagnosis, treatment of care and discharge can only have validity if this information is sought directly from those affected by a cancer.

Second, increased awareness of both the cancer care system and First Nations is anticipated to increase to an exponential degree with the support of cross jurisdictional leadership, care professionals and cancer patients and community members to engage in shared learning processes to better understand the challenges and issues specific to the experiences of FN impacted by cancer.

Third, shared resources directly with the Treaty organizations to carry out this work demonstrates the commitment of the project, the project team, leadership and CPAC to engage FN in a meaningful way toward a 'shared ownership' of cancer strategy and planning, and reflects the current shift of developing new knowledge and information on FN by FN people themselves.

Fourth, the potential for increased capacity by FN to carry out this important work in accordance with self-determined priorities becomes a reality through the use of this framework and with the support of the expertise of members on the project team.

Fifth, meaningful engagement of traditional knowledge holders, healers and medicine people can only be considered culturally appropriate if the work is carried out

by FN people themselves. In other words, engagement of these individuals would likely be superficial if it is not led and carried out by FN people themselves.

In addition to these important outcomes, particular resource development at important points of impact across jurisdictions and within cancer care, which has been determined through this work and which will be further supported through the engagement of the ANAC and IPAC, will be informed by the FN people it is designed to provide improved cancer care to. For example, collaborative partnerships with researchers at the University of Alberta will provide in-kind support for the knowledge translation of findings directly to communities through the increased capacity of community members. Community Champions will be trained to share important information about cancers at the concerned points of access to the cancer care system and upon discharge. This is one creative and meaningful way in which the findings of the project work are expected to benefit communities, care professionals and stakeholders.

Sound methodology that is ethical in its practice and respectful of First Nations OCAP™ principles needs to be incorporated at the onset of planning and cannot be debated at the end of this work, including methodology of survey designs; data utilization and access during the evaluation process; and, demonstrated free, prior informed consent.

Part B explores the feasibility of collecting FN data and information in accordance with the FN principles of OCAP™ and will develop a framework of possibilities for moving forward to use FN identifiers for the purposes of providing FN-specific resources and tools to these cancer patients and families. As well, feasibility will be determined for the development of a baseline of cancer data and information in an Alberta FN context. All of these activities will provide the evidence for the development of new resources, tools, processes and mechanisms that improve the FN cancer journey.



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