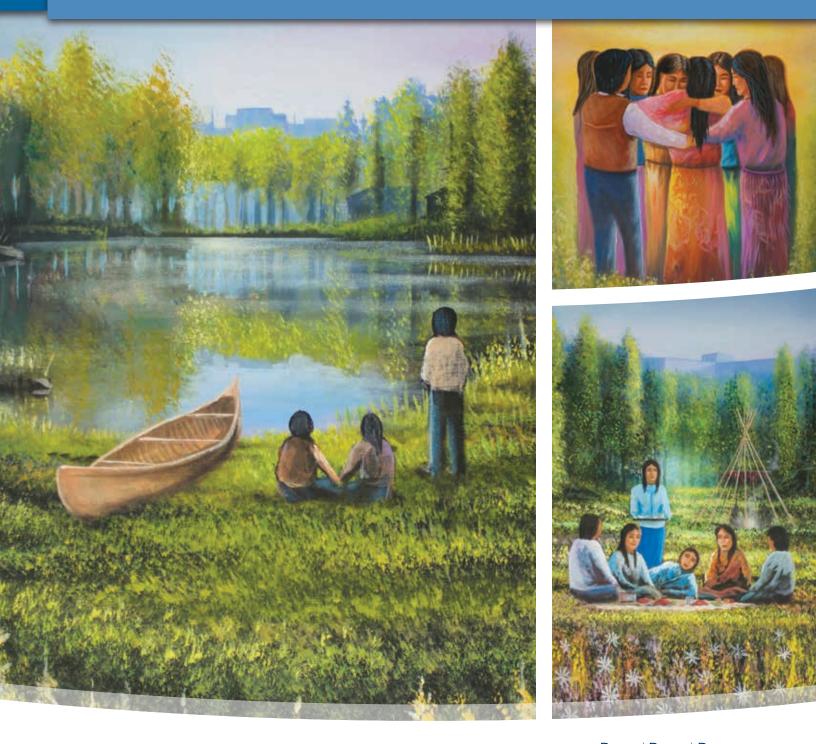
# **Charting Our Course: Northwest Territories Cancer Strategy**

# 2015-2025







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The Department of Health and Social Services would like to thank the numerous organizations and individuals who provided invaluable input and guidance throughout the development of this strategy.

We are particularly indebted to those who so openly and generously shared their experiences with cancer. This strategy could not have been completed without their stories and strength.



Original artwork and descriptions by James Wedzin

"Communities can look to one another for support and knowledge. It is important to share about health systems, medicine, and culture so we can learn. Different communities must work with each other and in the next generation they will learn to share modern and traditional medicine. Uniting together is like a healing journey together—a journey to a better life now and in the future."

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### Message from the Minister of Health and Social Services

Cancer knows no cultural, geographic or demographic boundaries, and it seems each one of us has a cancer story to tell. I am privileged to have been able to visit residents in every community in the Northwest Territories, hear their stories, and share their concerns. *Charting Our Course: Northwest Territories Cancer Strategy* 2015-2025, the first cancer strategy in our territory, represents these stories and concerns well.

We all want better health for our families and communities. Our own behaviour and lifestyle choices are at the core of leading a healthy life. Be it eating good food, being physically active, or living tobacco-free, we each have a role to play in making healthy decisions for ourselves and supporting those around us to take steps toward health and wellness.



In the Northwest Territories we face unique challenges. Cancer care and support services must address the diverse needs of our peoples and communities. As we move forward with health system transformation—the consolidation of health and social services across the territory into one system—it is an opportune time to closely examine how best to standardize and streamline our service delivery to all NWT residents. Implementation of this strategy will greatly contribute to this process, the results of which will include better patient and client care.

Our task does not end here. Let's keep talking about cancer and working together. In this way, we will lessen the burden of cancer on our health system and, most importantly, on our communities, friends, and families.

Glen Abernethy Minister of Health and Social Services

### Message from the Chief Public Health Officer

Over the past few decades, there have been remarkable advances in our knowledge about cancer. In the Northwest Territories, more people are surviving cancer than ever before, which is testament to the quality of our care and treatment. However, the cancer patient experience is impacted not only by the quality of individual clinical care, but also by the coordination and seamlessness of services we provide to support the patient along the whole continuum of care, from prevention and screening to survivorship. We know there are gaps to fill, and *Charting Our Course* is a call to action for all of us.

Preventing cancer before it starts will always be our most cost-effective approach to cancer control. Approximately one third of cancers are related to factors such as eating unhealthy foods, or being overweight and physically inactive. Cigarette smoking is responsible for more than 85% of lung cancers across Canada, and is either the direct cause or a contributing factor in many cancers such as colorectal, cervical, breast, and prostate cancers. This strategy outlines activities to support Northwest Territories residents to lead healthy lifestyles and reduce their risk of cancer. This is called *primary prevention*.

This strategy also examines our next steps in *secondary prevention*, the early detection of cancer through screening, and *tertiary prevention*, support to enhance the quality of life and prevent the emergence of complications for a person living with cancer. Achieving an appropriate combination of primary, secondary, and tertiary prevention activities is the optimal way of making meaningful progress.

The Department of Health and Social Services will not do this work alone. Our diverse partners play a critical role in providing insights into the challenges we face, recommending possible actions and implementing innovative solutions. Their perspective is key to shaping our understanding of the social determinants of health that are at play in health outcome disparities that still prevail among our residents. *Charting Our Course* will guide us as we collaborate to build an accessible, patient-centered cancer system.

Healthy living starts with each of us.

Dr. André Corriveau Chief Public Health Officer

### **Executive Summary**

*Charting Our Course: Northwest Territories Cancer Strategy 2015-2025* outlines the commitment of the Department of Health and Social Services to improve the cancer patient experience in the Northwest Territories (NWT).

Cancer is the leading cause of death in the NWT and in the rest of Canada. Between 2001 and 2010, an average of 111 new cancer cases were diagnosed every year in the NWT and cancer accounted for approximately 25% of all deaths. On average, 45 people died from cancer every year between 2001 and 2010. Understandably, this creates concern in our communities.

Cancer is not just one disease. There are more than 200 different types of cancer, depending on where in the body it starts. Our bodies are made of millions of cells, and when some of these cells become damaged or changed they can begin to grow uncontrollably and invade other parts of the body. The risk of cancer-causing damage to our cells increases as we get older. Particular genetic traits, viruses, and occupational or environmental exposures may also increase our risk. Fortunately, there are other risk factors that we can control, notably tobacco and alcohol use, unhealthy diet, physical inactivity, and unprotected sun exposure.

The NWT cancer pathway, also called the continuum of care, is complex and can be difficult to navigate. Screening, diagnosis, treatment, survivorship, and palliation take cancer patients through a complicated circuit of services provided at primary health care centers in their home communities, Stanton Territorial Hospital in Yellowknife, and the Cross Cancer Institute run by Alberta Health Services in Edmonton.

As the health and social services system moves toward the delivery of health and social services under a single management structure, NWT residents will have increasingly seamless access to care anywhere in the NWT, regardless of their home community. Other initiatives such as the Stanton Territorial Hospital Renewal Project and the implementation of the new Health Information Act will also contribute to building a cancer system that is more flexible to meet the needs of each patient and family.

There are many groups in the NWT—such as residential school survivors, new immigrants, people living in poverty, or people living with mental health and addictions issues—who especially need supportive environments to address key challenges that impact their health, including unemployment, poor housing, and difficulty accessing healthy food. *Charting Our Course* promotes a circle of care model where the patient is at the center of care and a team of health professionals—including physicians, nurses, social workers, counsellors, and dietitians—works collaboratively toward the patient's holistic health and wellness.

*Charting Our Course* has been shaped mostly by our conversations with individuals, communities, and other concerned partners, and will guide us toward addressing our most urgent needs. This strategy is designed to reflect and be consistent with the following guiding principles:

- Patient-and family-centered care;
- · Community ownership;
- An evidence-driven approach;
- Health equity; and
- Cultural capability.

This strategy will not resolve all of our challenges, but will allow us to make significant progress and lay a foundation for continued improvements. The successful implementation of this strategy will lead to the best health and best care of all NWT residents in all communities, charting our course for a better future.

### **Goal One:** Support NWT residents to lead healthy lifestyles that reduce their risk of cancer

Living a healthy lifestyle can prevent at least half of all cancers.<sup>1,2</sup> Health promotion contributes to primary prevention, the most cost-effective long-term strategy for cancer control, by creating a supportive environment in which people assume ownership of their health. Preventing disease before it starts is beneficial to the individual, family, and the community as a whole.

Under this goal, we have three strategic priorities:

- 1. Strengthen initiatives that promote healthy lifestyles and behaviours;
- **2.** Support programs that aim to reduce the consumption of tobacco, alcohol, and other drugs in NWT communities; and
- 3. Support community-driven cancer awareness and prevention initiatives.

# **Goal Two:** Improve cancer screening rates among eligible NWT residents

Finding cancer early, especially before the appearance of any signs or symptoms, can greatly improve the likelihood of successful treatment and save lives. In the NWT there are screening guidelines and programs for cervical cancer, colorectal cancer, and breast cancer. The Papanicolaou (Pap) test and fecal immunochemical test (FIT) are available in all community health centers. Mammography exams are currently available in Yellowknife, Hay River, and Inuvik only. The Pap test, the FIT, and mammograms are proven to be very beneficial and effective as cancer screening tools.

Under this goal, we have two strategic priorities:

- 1. Improve the accessibility of cancer screening; and
- **2.** Ensure cancer screening programs are coordinated and monitored from a territorial perspective.

1 Colditz G, et al. Harvard report on cancer prevention. Volume 1: Causes of human cancer. *Cancer Causes and Control*. 1996 Nov;7 Suppl 1: S1-55.

2 World Cancer Research Fund/American Institute for Cancer Research. Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective. Washington DC: AICR; 2007.

# **Goal Three:** Improve patient transitions between each stage of the cancer journey

The emotional and physical burdens of cancer can make it difficult for cancer patients to process information. Patients and caregivers who are well informed will be better able to ask questions and seek appropriate support throughout their journey. Strong self-advocacy will allow them to benefit more from available services. Coordination of the cancer journey, including the flow of information to and from the patient, often depends on the efforts of individual patients and their health care providers.

Under this goal, we have two strategic priorities:

- 1. Support health care providers to create an emotionally and culturally safe environment for the delivery of diagnosis; and
- 2. Enhance navigation support services throughout the cancer journey.

# **Goal Four:** Support health professionals to communicate within the circle of cancer care

High quality, patient-centered services depend on the timely flow of information within the circle of cancer care. Access to health records, advance scheduling of appointments and travel, and informed decision making for quality care are all contingent upon clear communication. Defined communication channels between NWT communities, Yellowknife, and Alberta are needed to share patient information efficiently.

Under this goal, we have two strategic priorities:

- Assess information systems and technology for opportunities to improve data flow; and
- **2.** Create information and tools to strengthen cancer prevention and care in primary health care service delivery.

### **Goal Five:**

# Improve the quality of life of cancer patients, their families and caregivers, and cancer survivors

Every patient deserves the highest possible quality of life whether they are healthy or ill. As cancer treatments improve, a greater number of people are surviving cancer or living with cancer long-term. Cancer patients and their families or caregivers should be systematically linked with holistic support in their own communities. In particular, the patient experience after treatment needs to be improved, including survivorship, palliative and end-of-life care services.

Under this goal, we have three strategic priorities:

- 1. Improve the accessibility of holistic support at all stages of the cancer journey;
- 2. Enhance palliative and end-of-life care services for NWT cancer patients; and
- 3. Enhance care and support services for cancer survivors.

### **Measuring progress**

Ongoing monitoring and evaluation will help to identify our strengths as well as opportunities to better serve cancer patients, cancer survivors, and their families and caregivers. In addition to goals and strategic priorities to improve the cancer patient experience over the next ten years, *Charting Our Course* also contains a five-year plan that will be renewed halfway through strategy implementation.

Monitoring and evaluation will include three deliverables:

- 1. Annual progress reports available to the public;
- 2. A process evaluation halfway through strategy implementation; and
- 3. An outcome evaluation at the end of the strategy.

### Let's talk about cancer

Talking about cancer is at the core of this strategy. Open conversation about cancer is needed to ease fear, reduce stigma, learn from one another, and enable healing. Clear communication between health care providers and patients, as well as improved communication pathways between primary and oncology care providers, are equally necessary to improve prevention, early detection, and patient outcomes. Communication within our families, communities, and the health system will be instrumental to our success. The Department of Health and Social Services will develop a social marketing campaign, *Let's Talk About Cancer*, built around this need for open dialogue about cancer.

# **Acronyms and Abbreviations**

AHS	Alberta Health Services
BHBC Action Group	NWT Breast Health/Breast Cancer Action Group
DHSS	Department of Health and Social Services
EMR	Electronic medical record
FIT	Fecal immunochemical test
GNWT	Government of the Northwest Territories
HIA	Health Information Act
HCF	Healthy Choices Framework
NHSN	Northern Health Services Network
NWT	Northwest Territories
Pap test	Papanicolaou test

### Introduction

*Charting Our Course: Northwest Territories Cancer Strategy 2015-2025* outlines the commitment of the Department of Health and Social Services (DHSS) to improve the cancer patient experience in the Northwest Territories (NWT).

Cancer is not just one disease. There are more than 200 different types of cancer, depending on where in the body it starts. Cancer is a group of diseases characterized by unusual cell growth. Our bodies are made of millions of cells, and when some of these cells become damaged or changed they can begin to grow uncontrollably and invade other parts of the body. No two cancers are the same.

The risk of cancer-causing damage to our cells increases as we get older. Particular genetic traits, viruses, and occupational or environmental exposures may also increase our risk. But there are other risk factors that we can control, notably tobacco and alcohol use, unhealthy diet, physical inactivity, and unprotected sun exposure.

Such a complex health problem requires a comprehensive, coordinated response. This strategy will guide the health and social services system and our partners toward the achievement of five goals:

- 1. Support NWT residents to lead healthy lifestyles that reduce their risk of cancer;
- 2. Improve cancer screening rates among eligible NWT residents;
- 3. Improve patient transitions between each stage of the cancer journey;
- **4.** Support health professionals to communicate within the circle of cancer care; and
- **5.** Improve the quality of life of cancer patients, their families and caregivers, and cancer survivors.

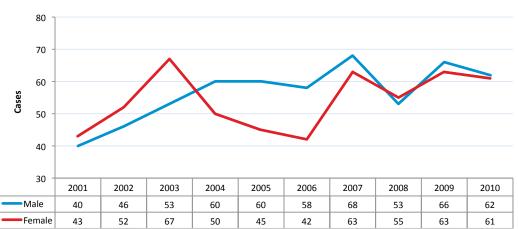
These goals, as well as their respective strategic priorities and activities, emerged from extensive consultation with our partners and stakeholders during the strategy development process. They contain specific activities to address our most urgent needs in the first five years of strategy implementation. As we near 2020, we will develop a second five-year plan to achieve our goals and strategic priorities by 2025.

*Charting Our Course* will not resolve all of our challenges, but will allow us to make significant progress and lay a foundation for continued improvements. The successful implementation of this strategy will lead to the best health and best care of all NWT residents in all communities, charting our course for a better future.

### **Cancer in the Northwest Territories**

Cancer is the leading cause of death in the NWT and in the rest of Canada. Between 2001 and 2010, an average of 111 new cancer cases were diagnosed every year in the NWT and cancer accounted for approximately 25% of all deaths. Understandably, this creates concern in our communities.

*Cancer incidence* refers to the number of people who are diagnosed with cancer every year. When all cancer types are considered together, cancer incidence in the NWT is the same as in the rest of Canada. However, colorectal cancer rates are higher among men and women in the NWT than in the rest of the country. On the other hand, prostate cancer is not as common in the NWT. Breast, colorectal, and lung cancers are the most commonly diagnosed cancers among NWT women. Colorectal, prostate, and lung cancers are most commonly diagnosed among NWT men.



#### Figure 1: New cancer cases by sex in the NWT (2001-2010)

In recent years there has been much debate about whether contaminated land and water have caused more cancer in the NWT. Although research has not shown a link between pollution and cancer in the NWT, we recognize that preserving a pristine environment is crucial for human health.

Regardless, as NWT residents get older and live longer, we can expect to see more cancer. Also, the more people participate in cancer screening, the more cancer we will find. Detecting cancer early greatly improves the likelihood of survival. Since the NWT Cancer Registry was established in 1992, we have seen fewer NWT residents die from cancer every year. On average, 45 people died from cancer every year between 2001 and 2010. Lung, colorectal, breast, and prostate cancer are the most frequent causes of death from cancer among NWT residents. Cancer mortality refers to the number of deaths caused by cancer every year. Compared to other Canadian men, NWT men have significantly lower mortality from all cancers combined. Compared to other Canadian women, NWT women have a very similar overall cancer mortality. However, compared to other Canadian women, more NWT women die from colorectal and lung cancer. As well, a greater number of men die from colorectal cancer in the NWT than in the rest of Canada.

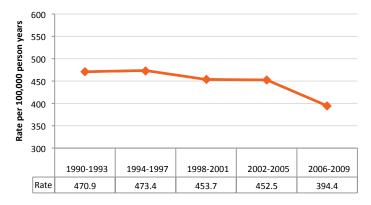


Figure 2: Cancer mortality in the NWT (1990-2009)

For all cancer types combined, there are no significant differences in cancer incidence among Dene, Métis, Inuit, and non-Aboriginal people of the NWT. Looking at specific cancer types, Dene people experience significantly higher rates of colorectal cancer compared with non-Aboriginal people, yet significantly lower rates of prostate cancer. Dene cancer patients also have higher cancer mortality rates than non-Aboriginal patients. Métis and Inuit populations are too small to be included in this analysis.

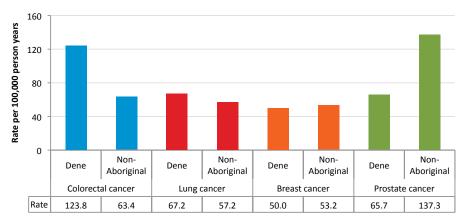


Figure 3: Cancer incidence among Dene and non-Aboriginal peoples in the NWT (2001-2010)

Source: Government of the Northwest Territories. Cancer in the Northwest Territories 2001-2010. Northwest Territories: Department of Health and Social Services; 2014.

### System Transformation

Alongside implementing the territorial cancer strategy, the health and social services system is moving towards delivery of health and social services under a single management structure. The semi-autonomous regional health and social services authorities will be integrated into a single authority that will coordinate services, information flow, travel, and follow-up across the territory. NWT residents will have more seamless access to care anywhere in the NWT, regardless of their home community, and will benefit from services organized to respond more holistically to their health and social needs. Communities, regional wellness councils, and Aboriginal governments will be part of identifying those needs and developing plans to achieve the DHSS vision of *best health, best care, better future.* 

The new territorial management structure will improve the consistent application of cancer care standards and protocols in addition to the implementation of other frameworks and partnerships that aim to promote healthy living, reduce chronic disease, and address the social determinants of health. From October 1, 2015, the DHSS will also be implementing the Health Information Act (HIA) to protect patient privacy while ensuring information is easily shared to provide the best possible care. *Charting Our Course* will contribute to this political framework by providing guidance for cancer prevention and control at the territorial and community levels for the next five years.

Even so, change will not be easy. We will need to develop new territorial processes, structures, and networks for cancer service delivery. Although the hospital renewal project is expected to further improve our capacity to provide better services, we will need to find creative solutions to accessibility challenges and limited space at Stanton Territorial Hospital. Overall, open and inventive collaboration with all our partners will always remain the most critical factor of success.

#### Figure 4: Policy context of the territorial cancer strategy

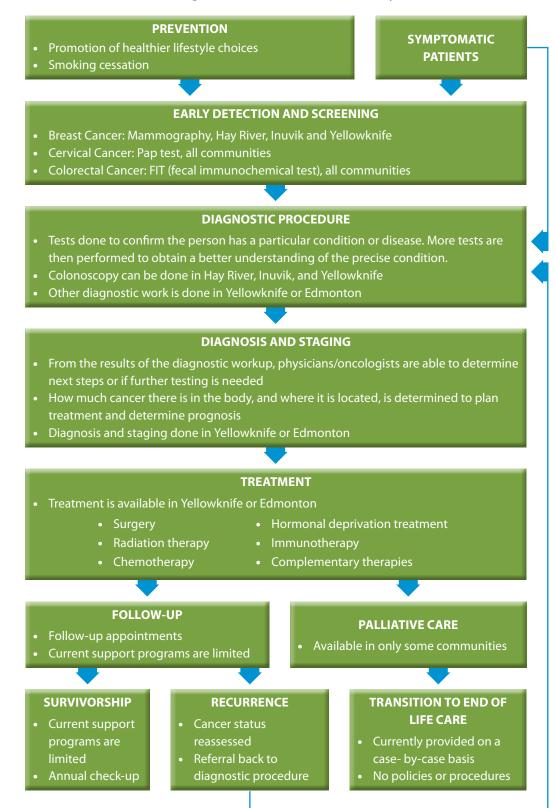


### **The Cancer Pathway**

The NWT cancer pathway, also called the continuum of care, is very complex and can be difficult to navigate. Screening, diagnosis, treatment, survivorship, and palliation take cancer patients through a complicated circuit of services provided at primary health care centers in their home communities, Stanton Territorial Hospital in Yellowknife, and the Cross Cancer Institute run by Alberta Health Services (AHS) in Edmonton.

*Charting Our Course* aims to improve the cancer patient experience throughout the cancer pathway. Currently, the availability of tools and support resources for cancer patients and their families is limited. Ideally, cancer patients, caregivers, and survivors should be linked with formal support at all stages.

#### Figure 5: The NWT Cancer Pathway



### Shared Responsibility, Shared Success

The DHSS will lead strategy implementation in close collaboration with a number of partners whose contributions are crucial to improve the cancer patient experience. We will find ways together to carry out the activities outlined here, and share in the success of this strategy.

### Regional health and social services authorities and Stanton Territorial Health Authority

Despite momentum toward a more unified health structure, at time of writing the health system in the NWT comprises the DHSS as well as six regional health and social services authorities, the Tł<sub>2</sub>cho Community Services Agency, and the Stanton Territorial Health Authority. Responsible for health programs and service delivery in their respective regions, each of these authorities plays an integral role to ensure the success of this strategy across the territory.

#### **Partner governments**

Aboriginal governments, band and Métis councils, community corporations, and municipal governments will provide the perspective and guidance necessary to design and implement people-specific, culturally appropriate, and culturally safe strategic cancer initiatives. They will extend the reach and influence of information disseminated to empower all NWT peoples to take charge of their own health.

#### Elders' Advisory Group

The Elders' Advisory Group, composed of influential elders representing regions across the territory, will guide strategy implementation on matters of culturally appropriate care, traditional ways of healing, and language.

#### **Alberta Health Services**

The DHSS and AHS must examine together the challenges they face with regard to crossjurisdictional communication, data flow, and continuity of care. Cancer Control Alberta and the Northern Health Services Network (NHSN) are among our most prominent partners within the AHS.

#### **Canadian Partnership Against Cancer**

The Canadian Partnership Against Cancer is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. CPAC currently funds DHSS initiatives that aim to improve the quality of the cancer patient journey and increase understanding of the Aboriginal cancer patient experience in the NWT.

#### **Canadian Cancer Society**

The Canadian Cancer Society is a national, community-based organization of volunteers who aim to eradicate cancer and enhance the quality of life of people living with cancer. The Alberta/Northwest Territories chapter will support the implementation of this strategy by sharing research and expertise, particularly in the areas of cancer prevention and social marketing.

#### **NWT Breast Health/Breast Cancer Action Group**

For nearly two decades, the NWT Breast Health/Breast Cancer Action Group (BHBC Action Group) has worked to improve breast health and breast cancer information, services, and support available to NWT women. They provide an invaluable patient perspective that can be applied to many aspects of strategy implementation such as patient self-advocacy and quality of life.

#### **Healthy Choices Framework**

The Healthy Choices Framework (HCF) joins the DHSS with other Government of the Northwest Territories (GNWT) departments to encourage and support healthy choices through programs, services, and healthy public policy. Linkages between the HCF and this strategy will strengthen the primary prevention of cancer while giving NWT residents the tools they need to reduce their cancer risk.

### **Strategy Development**

National and territorial resources, such as *Cancer in the Northwest Territories 2001-2010*,<sup>3</sup> were essential to inform this strategy. However, it has mostly been shaped by our conversations with individuals, communities, and other concerned partners.

In 2012, the DHSS partnered with the Saint Elizabeth First Nations, Inuit, and Métis Program to deliver one cancer sharing circle each in Fort Good Hope and Fort Resolution. The next year, the DHSS and Acho Dene Koe First Nation partnered to hold a cancer sharing circle in Fort Liard for participants from Dehcho communities. A fourth cancer sharing circle was held in partnership with the Inuvialuit Regional Corporation in January 2015 for members of Inuvialuit Settlement Region communities. The sharing circles facilitated meaningful discussion among cancer survivors, health care providers, and other community members that revealed several areas for improvement, notably:

- · Education and awareness of cancer risk factors and screening;
- Support for patients, survivors, and their families;
- Continuity of care; and
- Culturally appropriate information and services.

These sharing circles were decisive events during the strategy development consultation process and were complemented by interviews, meetings, and workshops with key stakeholders. In July 2013, the DHSS convened a cancer advisory group comprised of cancer survivors and caregivers, Aboriginal governments, health care providers, health authority senior managers, community leaders, community health representatives, and DHSS staff. This group met again in October and November 2013 to set the strategy's goals and priorities. Then, in January 2014, 22 focus group participants representing a range of cancer perspectives validated the goals, strategic priorities, and five-year action items that make up the foundation of this document.

In the time that followed, the goals, strategic priorities, and action items were further reviewed, researched, and refined. The Elders' Advisory Group and other contributing partners gave feedback and approval before the finalization of this document.

3 Report available online at http://www.hss.gov.nt.ca/sites/default/files/cancer-in-the-nwt.pdf.

### Figure 6: Stakeholder consultation timeline

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2 0 1 2	June Cancer sharing circle in Fort Good Hope (with cancer survivors, residents and health care providers) Challenges and opportunities in cancer pathway identified.	August Cancer sharing circle in Fort Resolution (with cancer survivors, residents and health care providers) Challenges and opportunities in cancer pathway identified.
2 0 1 3	March Elders' Advisory Group in Yellowknife (with Elders' Advisory Group) Elders committed to advise in strategy development process.	July Strategy design meeting in Yellowknife (with cancer advisory group) Cancer advisory group formed.
	September Cancer sharing circle in Fort Liard (with cancer survivors, residents and health care providers from Dehcho communities) Challenges and opportunities in cancer pathway identified. November Strategy design meeting in Yellowknife (with cancer advisory group) Broad actions identified.	<ul> <li>October</li> <li>Strategy design meeting in Yellowknife (with cancer advisory group)</li> <li>Priorities identified.</li> <li>November to January</li> <li>Key informant interviews in Yellowknife and by email or phone (with DHSS staff, health care providers, AHS staff and non-profit organizations)</li> <li>Goals, strategic priorities, and actions refined.</li> </ul>
2 0 1 4	January Strategy development focus group discussion in Yellowknife (with cancer advisory group) Goals, strategic priorities, and actions refined and validated.	April Elders' Advisory Group in Yellowknife (with Elders' Advisory Group) Goals and strategic priorities approved by Elders.
2 0 1 5	January     Cancer sharing circle in Inuvik     (with cancer survivors, residents and health care     providers from Inuvialuit Settlement Region)     Challenges and opportunities in cancer pathway     identified.	May Partner review (including Elders' Advisory Group, Canadian Cancer Society, BHBC Action Group) Final feedback from partners incorporated.

"In this painting, a nurse comes from the hospital with Western medicine for a patient. The patient is enjoying traditional food with her family and friends. Our cultures have always been here in this land, and the hospital does a better job when it understands people's lifestyles. Working together, the hospital and culture can keep patients healthy and happy."

### **Conceptual Framework**

Early in the consultation process, members of the cancer advisory group agreed that all activities implemented under the territorial cancer strategy should promote cooperation among partners to build a health system that is more flexible to meet the needs of each patient and family. In other words, we must promote a circle of care model where the patient is at the center of care and a team of health professionals—including physicians, nurses, social workers, counsellors, and dietitians—works collaboratively toward the patient's holistic health and wellness.

Too often, medical care deals with physical health issues without addressing the patient in a holistic way. Understanding the whole person requires close examination of the social determinants of health in the NWT.

The NWT is home to diverse peoples with unique cultures, languages, and perspectives. Different groups understand cancer and cancer care in different ways and may face specific barriers to accessing health services, meaning they may not experience the same health benefits as others.

Although Aboriginal peoples comprise more than half of our population, NWT health and social services do not always meet their needs. Historical trauma stemming from events such as colonization and residential schooling, combined with geographic, cultural, and linguistic barriers to accessing health services, influence an individual's health. There are many other groups in the NWT—such as new immigrants, people living in poverty, or people living with mental health and addictions issues—who also need more supportive environments to address key challenges that impact their health, including unemployment, poor housing, and difficulty accessing healthy food.

Anyone in a cancer patient's circle of care must be aware of the social determinants of health at every stage in the cancer journey, regardless of the patient's background. *Charting Our Course* is designed to reflect and be consistent with the following guiding principles:

- Patient- and family-centered care;
- Community ownership;
- An evidence-driven approach;
- Health equity; and
- Cultural capability.

Careful implementation of this strategy should contribute to building a health system that is more responsive to patient, family, and community needs and that is, therefore, better equipped to reduce health inequities in the NWT.

#### What is cultural capability?

Cultural capabilities refer to an organization or system's ability to provide services that are equitable and respectful of other cultures and practices. Cultural capability:

- Recognizes, respects, and honours the beliefs and values of the patient;
- Can be learned and achieved through openness, asking questions, and cultural orientation;
- Is a necessary component of high quality care.

"Living on the land is both active and part of my culture. Being active is healthy. If you are diagnosed with cancer, being active will keep you stronger through the illness. Whether you're old or not, your choices at any stage of life are important for your current and future health."

Tames We

ACAUSE IN

### **Goal One:** Support NWT residents to lead healthy lifestyles that reduce their risk of cancer

Living a healthy lifestyle can prevent at least half of all cancers.<sup>4,5</sup> Health promotion contributes to primary prevention, the most cost-effective long-term strategy for cancer control, by creating a supportive environment in which people assume ownership of their health. Preventing disease before it starts is beneficial to the individual, family, and the community as a whole.

The DHSS coordinates with NWT communities to develop and implement tailor-made wellness plans that identify what communities need to address their own priorities. As well, the GNWT Healthy Choices Framework (HCF) coordinates intersectoral health promotion programming throughout the territory with a focus on healthy behaviours that include eating traditional foods, tobacco-free living, and getting active.

Under this goal, we have three strategic priorities:

- 1. Strengthen initiatives that promote healthy lifestyles and behaviours;
- Support programs that aim to reduce the consumption of tobacco, alcohol, and other drugs in NWT communities; and
- **3.** Support community-driven cancer awareness and prevention initiatives.

<sup>4</sup> Colditz G, et al. Harvard report on cancer prevention. Volume 1: Causes of human cancer. *Cancer Causes and Control*. 1996 Nov;7 Suppl 1: S1-55.

<sup>5</sup> World Cancer Research Fund/American Institute for Cancer Research. Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective. Washington DC: AICR; 2007.

# **Strategic Priority One:** Strengthen initiatives that promote healthy lifestyles and behaviours

Successful health promotion must take a holistic approach to health, focusing on all aspects of our lives. Instead of operating separately, health and social services programs and community groups need to work collaboratively to support healthy lifestyles. Furthermore, NWT residents should be able to access all the health information they need in a single location.

The DHSS brings cancer prevention and control programming together with initiatives in anti-poverty, early childhood development, Aboriginal health, community wellness, mental health and addictions, and health and wellness promotion. We aim to implement integrated, community-driven programming, but more can be done to harmonize activities with other NWT actors and ensure health promotion is tailored to the needs of our peoples.

Many Aboriginal residents are still managing the trauma related to events such as colonization, the shift away from a primarily land-based economy, and residential schools. Many others may also face geographic, cultural, and linguistic barriers to accessing Western-style health care, and are impacted by social determinants of health including education, employment, and housing. This complex situation has led to a higher prevalence among Aboriginal residents of cancer risk factors such as poor nutrition and physical inactivity.<sup>6</sup>

6 Government of the Northwest Territories. 2012 NWT Report on Substance Use and Addiction. Northwest Territories: Department of Health and Social Services; 2015.

Traditional lifestyles and food help to protect from cancer by promoting nutritional, cultural, spiritual, and community health. In a non-traditional diet, eating fruit and vegetables is very important. The percentage of Aboriginal residents in the NWT aged 15 or older who eat at least five servings of fruits and vegetables is 31.3% compared to 44.5% of non-Aboriginal residents aged 15 and older.<sup>7</sup> Unfortunately, in many grocery stores in remote communities, the availability of affordable, healthy foods is quite limited. To ease this situation, GNWT departments such as Industry, Tourism and Investment and Environment and Natural Resources implement programs to support community gardens and traditional hunting and trapping.

Physical activity and maintaining a healthy weight reduces cancer risk. The promotion of activities such as organized sport, hunting, trapping, fishing, berry-picking, and traditional games and dance is important as sedentary lifestyles become more common.

Our five-year plan:

- Investigate social determinants of health in the NWT and their influence on healthy living;
- Create an online source of accurate and current information to support healthy living;
- Explore solutions to food security challenges in the NWT;
- Identify foods and nutrition data gaps that impede population-based policy and interventions for cancer and other chronic disease; and
- Work in collaboration with HCF partners to support opportunities for youth to be physically active.

7 NWT Bureau of Statistics. Food and Nutrition Indicators. Retrieved September 2014 from www.statsnwt.ca.

### **Strategic Priority Two:** Support programs that aim to reduce the consumption of tobacco and alcohol in NWT communities

Smoke from cigarettes, marijuana, or other drugs is a primary cause of cancer. Cigarette smoking alone is responsible for more than 85% of lung cancers across Canada and is either the direct cause or a contributing factor in many cancers such as colorectal, cervical, breast, and prostate cancers.<sup>8</sup> In our small communities, 53% of residents smoke whereas 29% in regional centers and 23% in Yellowknife are smokers. Smoking rates in Aboriginal populations are alarmingly high: 51% of Aboriginal people smoke whereas only 18% of non-Aboriginal people report being smokers.

Living smoke-free is a crucial part of cancer prevention. However, more Yellowknife residents are able to successfully quit smoking in their lifetime (44%) than those living in smaller communities (27%).<sup>9</sup> Clearly, there is more we can do to support smokers to quit, and to deter others from starting to smoke in the first place. When combined with other preventive measures, high tobacco prices can be influential: a 10% increase in tobacco price is estimated to result in a 4% to 6% decrease in sales.<sup>10,11</sup> The World Health Organization recommends that cigarette taxes represent at least 70% of retail value.<sup>12</sup>



The NWT Quitline is a tollfree, confidential telephone helpline for people who want to quit smoking. In 2014, only 24 new individuals enrolled for counselling services and only 27 follow-up calls were made by Quitline counsellors to their clients. In the same year, Quitline counsellors made 132 calls that were not answered by their clients. The DHSS and Quitline counsellors are working to improve awareness and accessibility of this service, including through the implementation of a new patient referral form that health care providers complete with their patients.

Source: Sykes Assistance Services Corporation. NWT Quitline Monthly Reports; 2014.

- 8 Canadian Cancer Society. Risk Factors for Lung Cancer. Retrieved January 2014 from http://www.cancer.ca/en/ cancer-information/cancer-type/lung/risks/?region=ab.
- 9 Government of the Northwest Territories. 2012 NWT Report on Substance Use and Addiction. Northwest Territories: Department of Health and Social Services; 2015.
- 10 Centers for Disease Control and Prevention. Response to increases in cigarette prices by race/ethnicity, income, and age groups, United States, 1976-1993. *Morbidity and Mortality Weekly Report*. 1998 47(29): 605-609.
- 11 Chaloupka FJ, et al. The Taxation of tobacco products. Tobacco control in developing countries. New York: Oxford University Press; 2000.
- 12 World Health Organization. WHO Technical Manual on Tobacco Tax Administration. Geneva, Switzerland: WHO; 2011.

Alcohol is another substance linked with cancer, including breast and colorectal cancers.<sup>13</sup> Yellowknife residents drink more frequently than in other communities. However, the proportion of drinkers who drink heavily<sup>14</sup> at least once a month, for the past 12 months is greater in small communities than in Yellowknife (55% versus 35%). Also, heavy drinking at least once a week is more common in regional centers than in Yellowknife (21% versus 12%).<sup>15</sup>

Our five-year plan:

- Establish a mechanism to obtain feedback and guidance from target populations regarding activities to reduce the consumption of tobacco, alcohol, and other substances associated with cancer;
- Increase awareness and availability of smoking cessation services;
- Investigate opportunities to support mental wellness and addictions initiatives at the community level;
- Expand On the Land programming to include tobacco-free activities and awareness; and
- Continue to research the potential for increasing taxes on tobacco products.

<sup>13</sup> Canadian Cancer Society. Alcohol. Retrieved January 2014 from http://www.cancer.ca/en/cancer-information/ cancer-101/what-is-a-risk-factor/alcohol/?region=ab.

<sup>14</sup> Heavy drinking is defined as the consumption of five or more drinks in a single sitting at least once a month for the past 12 months.

<sup>15</sup> Government of the Northwest Territories. 2012 NWT Report on Substance Use and Addiction. Northwest Territories: Department of Health and Social Services; 2015.

# **Strategic Priority Three:** Support community-driven cancer awareness and prevention initiatives

NWT communities know what they need. A project that is designed, implemented, and evaluated by community members will be meaningful and sustainable. Active collaboration among system staff, elders, communities, and cancer survivors, as well as recognition of traditional knowledge, can empower local groups to make changes they want to see.

The DHSS has established links with Aboriginal governments, prominent NWT elders, and community leaders, and allocates funding to support regional priorities and community-driven initiatives.

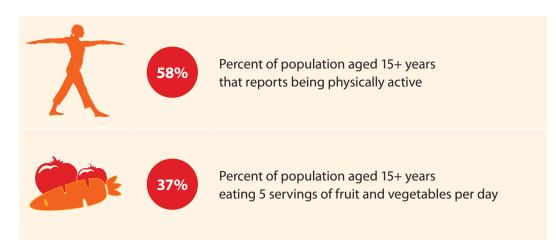
### What is traditional knowledge?

Traditional knowledge refers to knowledge of indigenous populations that is gained through spiritual practice and close connection with the land. This knowledge is usually passed orally from generation to generation.

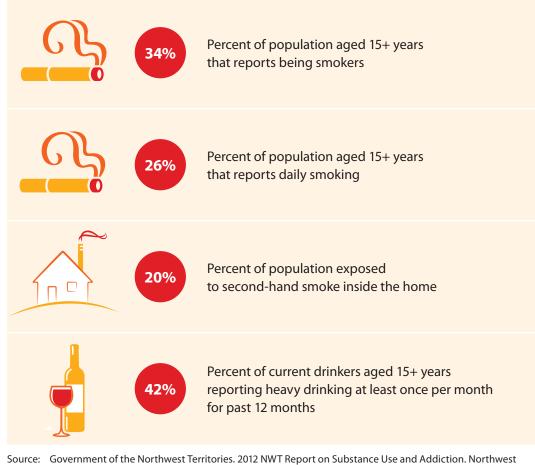
Our five-year plan:

- Facilitate cancer sharing circles each year, ensuring coverage of all regions;
- Integrate cancer prevention and tobacco cessation into community wellness plans; and
- Provide community groups with financial and material resources to implement tobacco prevention programs for children and youth.

#### Figure 7: Healthy Lifestyle Indicators in the NWT



Source: NWT Bureau of Statistics. Health Lifestyle Behaviour. Retrieved September 2014 from www.statsnwt.ca.



Territories: Department of Health and Social Services; 2015.

"It is important to get regular check-ups to detect cancer or other disease at an early stage. Be sure to get your check-ups. Patients feel more comfortable with health care professionals who are open to their culture."

## **Goal Two:** Improve cancer screening rates among eligible NWT residents

It is important for individuals and health care providers to be able to recognize possible warning signs of cancer and take prompt action. Finding cancer early, especially before the appearance of any signs or symptoms, can greatly improve the likelihood of successful treatment and can save your life. Early signs of cancer include lumps, sores that do not heal, unusual bleeding, and persistent indigestion.

Organized screening programs promote cancer screening tests among people who do not have

You could be eligible for a different screening test, or screening at an earlier age.

If you have family cancer history, personal cancer history, or are experiencing any unusual signs or symptoms, see your health care provider.

any signs or symptoms of cancer. In the NWT there are screening guidelines and programs for cervical cancer, colorectal cancer, and breast cancer (Figure 7). The Papanicolaou (Pap) test and fecal immunochemical test (FIT) are available in all community health centers. Mammography exams are currently available in Yellowknife, Hay River, and Inuvik only. The Pap test, the FIT, and mammograms are proven to be very beneficial and effective as cancer screening tools.

Which cancer?	Breast Cancer	Cervical Cancer	Colorectal Cancer
Who?	Most women aged 50-74	Most women aged 21-69*	Most men and women aged 50-74
What test?	Mammogram	Pap test	Fecal immunochemical test
When?	Every 2 years	Every 2 years**	Every 1-2 years
Where?	Yellowknife Hay River Inuvik	Community health centers	Community health centers

\* Or 3 years after becoming sexually active

\*\* After 3 consecutive annual normal Pap tests

Under this goal, we have two strategic priorities:

- 1. Improve the accessibility of cancer screening; and
- **2.** Ensure cancer screening programs are coordinated and monitored from a territorial perspective.

### **Strategic Priority One:** Improve the accessibility of cancer screening

Cancer screening is for healthy people who do not have any symptoms of illness. Simple screening tests are able to find early signs of cancer. However, NWT residents have low participation rates in routine cancer screening programs. In 2011 and 2012:

- 55% of eligible women had a mammogram;
- 53% of eligible women had a Pap test; and
- Only 20% of eligible men and women had a screening test for colorectal cancer.<sup>16</sup>

The early detection of cancer begins with educating NWT residents to recognize the warning signs and seek early detection services, including routine cancer screening. Health care providers should be knowledgeable about current screening guidelines and have all the information they need to initiate conversations about cancer screening services. As a whole, the health system must ensure these services are easily accessible.

Our five-year plan:

- Investigate barriers that may prevent NWT residents from accessing screening services, and identify possible solutions;
- Provide ongoing education based on current screening guidelines for health care workers and community health representatives; and
- Set standards for mammography sites to allow drop-in appointments for breast cancer screening to accommodate last-minute travellers.

16 Government of the Northwest Territories. Cancer in the Northwest Territories 2001-2010. Northwest Territories: Department of Health and Social Services; 2014.

#### **Strategic Priority Two:**

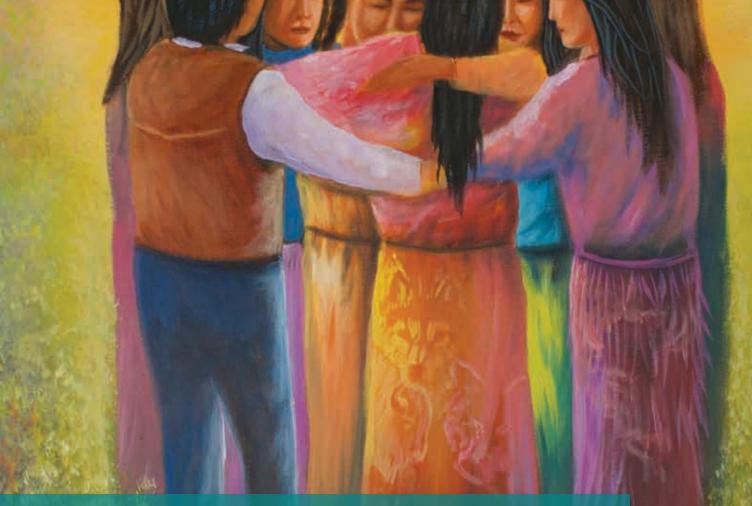
# Ensure cancer screening programs are coordinated and monitored from a territorial perspective

In the face of many geographic, transportation, and human resource challenges, cancer screening services in the NWT need to be well organized. Because screening programs currently operate at a regional level rather than a territorial level, service coordination and monitoring can be difficult.

A territorial cancer screening committee would fill this need, taking the lead to disseminate information and education materials, consistently enforce screening standards across the NWT, and regularly update NWT clinical practice guidelines according to the latest evidence and technology.

Our five-year plan:

- Establish a territorial collaborative cancer screening committee to oversee standardized screening;
- Develop a framework to implement organized screening programs to coordinate promotion, enrolment, reminders, and quality assurance; and
- Standardize territorial screening data collection and management.



"In this painting, a family member has just learned that she has cancer. Her mother, father, sisters, brothers, and grandparents are around her, showing their emotion and their support. It is better to have a circle of loved ones around you than to be left alone."

## **Goal Three:** Improve patient transitions between each stage of the cancer journey

The emotional and physical burdens of cancer can make it difficult for cancer patients to process information. Patients and caregivers who are well informed will be better able to ask questions and seek appropriate support throughout their journey. Strong self-advocacy will allow them to benefit more from available services.

Coordination of the cancer journey, including the flow of information to and from the patient, often depends on the efforts of individual patients and their health care providers. At present, patients and caregivers do not receive information in a systematic way, nor are they immediately linked with emotional support at the time of diagnosis. Emotional support programs for cancer patients and survivors are limited throughout the NWT.

Under this goal, we have two strategic priorities:

- 1. Support health care providers to create an emotionally and culturally safe environment for the delivery of diagnosis; and
- **2.** Enhance navigation support services throughout the cancer journey.

#### **Strategic Priority One:**

#### Support health care providers to create an emotionally safe environment as part of culturally capable delivery of diagnosis

The patient enters the continuum of cancer care upon receiving his or her diagnosis. The manner in which the diagnosis is delivered can set the tone for the remainder of the cancer journey. Any health service that is not emotionally or culturally capable may detract from the patient's ability to navigate the continuum of care and advocate for his or her own needs.

Currently there is no standard procedure to ensure emotionally and culturally capable delivery of a cancer diagnosis, or to link patients and their families with information or support. Diagnostic services are available in Inuvik, Hay River, Yellowknife, and Edmonton only, meaning that many patients receive their cancer diagnosis alone, far from their support networks. Many patients report difficulty understanding the information delivered during diagnosis—this is even more difficult for patients who are uncomfortable speaking English.

Our five-year plan:

- Define best practices and standards for the delivery of a cancer diagnosis and develop systems to ensure compliance;
- Explore options for health care providers to deliver a cancer diagnosis in the patient's home community;
- Develop a cancer resource package for patients and caregivers that is approved by the Elders' Advisory Group and other partners; and
- Develop cancer terminology in Aboriginal languages.

## **Strategic Priority Two:** Enhance navigation support services throughout the cancer journey

Cancer patients face a complex journey. Navigation support at every step would increase patient and caregiver understanding and ease in the cancer journey. However, cancer patient navigation support at Stanton Territorial Hospital is limited, and many other support resources, such as services provided by the Northern Health Services Network based in Edmonton, are not well known.

The DHSS is currently reviewing the GNWT Medical Travel Policy in light of extraordinary challenges posed by the need to travel to southern medical appointments. For example, there are inconsistencies with regard to the approval of some non-medical escorts. Also, cancer patients with weak immune systems, who should avoid shared accommodation, do not have many options for housing while in Edmonton. The Larga boarding home provides a valuable service, but has a limited number of private rooms.

Our five-year plan:

- Create a cancer pathway template, modifiable for individual patient needs, to guide patient navigation;
- Ensure that the cancer patient perspective is represented during review of policies and procedures related to medical escorts;

#### The Northern Health Services Network is an

AHS program that helps NWT residents to coordinate their care and support while in Edmonton. NHSN has significant experience coordinating treatment and discharge care as well as access to equipment and supplies for cancer patients, and liaises with the Cross Cancer Institute, Stanton Territorial Hospital, and the patient's community health center. All NHSN staff members have nursing experience in Canada's north and can advocate on behalf of northern clients to meet their linguistic, cultural, and spiritual needs.

### For more information, call 780-735-5761.

- Formalize and streamline collaboration with Alberta-based support services and treatment centers;
- Ensure that the cancer patient perspective is considered during review and renewal of boarding home contracts;
- Strengthen cancer navigation services to support and track patients as they navigate their cancer journey; and
- Compare the feasibility and benefits of a drop-in cancer support center in Yellowknife versus a territorial peer support network.

"When a group of people come together around the patient, she has more options for care and support. Doctors and traditional healers can work together. When you put a team together, it's like a family for the patient and she will feel more comfortable."

## **Goal Four:** Support health professionals to communicate within the circle of cancer care

High quality, patient-centered services depend on the timely flow of information within the circle of cancer care. Access to health records, advance scheduling of appointments and travel, and informed decision making for quality care are all contingent upon clear communication. Defined communication channels between NWT communities, Yellowknife, and Alberta are needed to share patient information efficiently.

This goal addresses information flow between all health professionals in the circle of cancer care, as well as the need for tools and training so that care providers can put the information they receive to good use. The HIA supports the circle of care, ensuring that all members have the information they need to provide timely and appropriate care.

Under this goal, we have two strategic priorities:

- Assess information systems and technology for opportunities to improve data flow; and
- **2.** Create information and tools to strengthen cancer prevention and care in primary health care service delivery.

#### **Strategic Priority One:**

# Assess information systems and technology for opportunities to improve data flow

Health information systems—the people and computers that manage and interpret health data—are essential to ensure health professionals have access to the right data at the right time. The HIA also supports data sharing, including between NWT and Alberta, and can be applied to improve information flow as necessary to provide the best possible care to cancer patients.

However, we are challenged to ensure timely information flow within the circle of cancer care, particularly between specialists at the Cross Cancer Institute and primary care providers in the NWT.<sup>17</sup> For one, the NWT Cancer Registry cannot easily access the cancer registry in Alberta to collect information about NWT residents who receive a cancer diagnosis or treatment in Alberta. Electronic access would allow for a more complete, up to date database in the NWT.

The GNWT continues its move toward a paperless patient record system as part of the Territorial Electronic Medical Record (EMR) project. Authorized health care providers will have instant, secure access to their patients' medical information, enhancing continuity of care. We have an opportunity now, before the EMR is rolled out in all regions, to incorporate variables and functions in support of cancer prevention, care, and support.

Remote communication technologies such as telehealth systems have the potential to allow patients in small communities to communicate in real-time with a physician. They can also be used to facilitate communication between members of

#### **Cancer Data Collection**

The NWT Cancer Registry collects data from the following sources:

- Health care providers;
- Laboratory results;
- The Canadian Cancer Registry;
- The Alberta Cancer Registry; and
- Death certificates.

a patient's care team—removing the burden of travel on the patient, family, or physician. Although every NWT community has a telehealth unit, some are located in schools rather than health centers, making scheduling for medical appointments more difficult.

Our five-year plan:

- Develop a data flow diagram to describe how patient data can be shared within the circle of cancer care;
- Introduce checklists to remind health care professionals who else within the circle of cancer care should receive patient data;
- Establish software linkages and systematic information sharing between CancerControl Alberta and the NWT Cancer Registry;
- Develop protocols to collect cancer treatment information using the territorial EMR system;
- Identify options to use the EMR system to identify and proactively offer assistance to patients who are smokers and may need support quitting; and
- Assess opportunities to use remote communication technologies for health care provider conferences and patient consultation.

<sup>17</sup> Lutra Associates. NWT Breast Cancer Journeys Final Report. Yellowknife, NT: NWT Breast Health/Breast Cancer Action Group; 2014.

#### **Strategic Priority Two:**

#### Create information and tools to strengthen cancer prevention and care in primary health care service delivery

Primary care providers are the patient's first point of contact within the health care system. They guide and inform cancer patients before, during, and after treatment. Even so, current standards, protocols, and guidelines for primary care providers do not contain dedicated sections on cancer. All health care providers should have sufficient guidance and education to deliver cancer prevention and care services.

It is well known that quitting smoking is the single best action to prevent cancer, but less well known that quitting smoking also benefits people living with cancer. Cancer patients and survivors who continue smoking are more likely to die from their first cancer, a second cancer, or other illness. Smoking may even interfere with cancer treatment.<sup>18</sup> Services such as the NWT Quitline must be fully integrated into the NWT health system. For this to happen, health care providers need training and tools to deliver smoking cessation services, including counselling.

### The 5 Rs of Smoking Cessation

- RELEVANCE: Think
   about why smoking is
   personally relevant and
   important
- **RISK:** Identify the risks of smoking
- **REWARD:** Think about the benefits of quitting
- ROADBLOCKS: Identify barriers to quitting and options to address these barriers
- **REPETITION:** Discuss these issues frequently

Our five-year plan:

- Update cancer standards, protocols, and guidelines for primary health care providers;
- Develop tools to assist communication between patients and health care providers; and
- Develop tools and training modules for primary health care providers to integrate smoking cessation into service delivery.

<sup>18</sup> US Department of Health and Human Services. The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2014.

"The patient is at the center and is together with her loved ones. Even though she has cancer, she can still live her traditional lifestyle: living on the land, doing crafts and other activities with her family, and just being open about her cancer. It's okay to be out there even if you have cancer. Quality time with family is important. Have a lot of time with your family."

## **Goal Five:** Improve the quality of life of cancer patients, their families and caregivers, and cancer survivors

Every patient deserves the highest possible quality of life whether they are healthy or ill. As cancer treatments improve, a greater number of people are surviving cancer or living with cancer long-term. Furthermore, research shows that a patient who is satisfied with his or her quality of life is more likely to live longer and survive cancer.<sup>19,20,21</sup> This underscores the need to examine how support services can be improved.

Cancer patients and their families or caregivers should be systematically linked with holistic support in their own communities. In particular, the patient experience after treatment needs to be improved, including survivorship, palliative, and end-of-life care services.

Under this goal, we have three strategic priorities:

- 1. Improve the accessibility of holistic support at all stages of the cancer journey;
- 2. Enhance palliative and end-of-life care services for NWT cancer patients; and
- 3. Enhance care and support services for cancer survivors.

#### **Strategic Priority One:** Improve the accessibility of holistic support at all stages of the cancer journey

Dealing with cancer, whether personally or through a loved one, can be a difficult and frightening experience. Holistic care requires looking at the whole person: emotional, spiritual, and financial needs are no less important than a person's physical needs, and there may also be pressing health needs other than cancer treatment.

<sup>19</sup> De Aguiar SS, Bergmann A, Mattos IE. Quality of life as a predictor of overall survival after breast cancer treatment. *Quality of Life Research*. 2014 23:629-639.

<sup>20</sup> Braun DP, Digant G, Staren ED. Quality of life assessment as a predictor of survival in non-small cell lung cancer. BMC Cancer. 2011 11:353.

<sup>21</sup> Montazeri, A. Quality of life data as prognostic indicators of survival in cancer patients: an overview of the literature from 1982 to 2008. *Health and Quality of Life Outcomes*. 2009 7:102.

Cancer patients, survivors, and their families or caregivers must often weave together whatever support they can find from an array of different groups and organizations. Patients do not have options within the health system to use traditional medicine alongside their cancer treatment, even if they consider it an important part of their holistic care. By providing tools to be healthy in all domains of life throughout the cancer journey, we can positively impact their quality of life.

Our five-year plan:

- Increase the knowledge of health professionals and community health representatives about cancer and how to connect cancer patients with other support;
- Develop and disseminate a directory of emotional support available to NWT cancer patients, families, caregivers, and cancer survivors;
- Connect with health navigators in the NWT health system to exchange information about non-insured health benefit coverage for First Nations and Inuit cancer patients;
- Create accountability mechanisms to encourage health care providers to screen cancer patients for tobacco use, offer intervention, and support users to quit; and
- Acknowledge the benefits of other non-insured forms of healing, such as traditional medicine and naturopathic medicine, within the cancer care system.

#### **Strategic Priority Two:**

# Enhance palliative and end-of-life care services for NWT cancer patients

Palliative care focuses on relieving the symptoms, pain, and stress of illness. As an individual approaches the end of life, palliative and end-of-life services offer comfort and dignity. Cancer patients need not wait until the end of life to receive palliative care—it can be started immediately to treat problems proactively and preventatively.<sup>22,23</sup> Studies in other Canadian regions show that as many as 90% of patients accessing palliative care are cancer patients.<sup>24,25</sup>

- 23 Zimmerman C, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet*. 2014 383(9930):1721-1730.
- 24 Cancer Care Ontario. Improving the quality of palliative care services for cancer patients in Ontario. Ontario: Cancer Care Ontario; 2006.
- 25 Cancer Care Nova Scotia. Supportive Care. Retrieved May 2015 from http://www.cancercare.ns.ca/en/home/ nscancerservices/palliativeandsupportivecare.aspx.

<sup>22</sup> Bakitas M, et al. Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer: The Project ENABLE II Randomized Controlled Trial. *Journal of American Medical Association*. 2009 302(7):741-749.

The palliative approach to care is a best practice. However, palliative and end-of-life care is limited in the NWT, particularly in small communities where family members or other informal caregivers with little training have often provided these services. The new NWT Continuing Care Standards include a standard for palliative care services, and the DHSS is examining next steps under three major priorities for action: education and awareness for professional and informal caregivers; expert support and consultation for health care providers; and ensuring the quality and consistency of care. The palliative approach to care and *Charting Our Course* are mutually supportive.

Our five-year plan:

- Ensure a cancer perspective in the implementation of the palliative approach to care;
- Train primary care providers, home support workers, and social workers in palliative and end-of-life care for cancer patients; and
- Improve the accessibility of information, respite services, and training opportunities for family members and other informal caregivers.

### **Strategic Priority Three:** Enhance care and support services for cancer survivors

Cancer care does not end with treatment. Patients may need help managing a range of physical and emotional issues. They may also have an increased risk for a recurrence or spreading of cancer, and so should continue to participate in screening. However, it is not uncommon that NWT cancer survivors initiate requests for screening themselves because it is not systematically offered to them.<sup>26</sup>

Whatever their condition, follow-up or survivorship services are important to monitor the individual's health. Different health care providers, community health representatives, and social workers may have different ideas about the needs of patients who have completed cancer treatment. Patient discharge can be poorly documented, and there is room for improvement in the collaboration between oncology and primary care teams to implement survivorship care plans. The BHBC Action Group, with DHSS support, has taken the lead developing survivorship care planning tools that will be tested early in the life of this strategy.

Our five-year plan:

- Define survivorship care goals and services for the NWT; and
- Collaborate with the BHBC Action Group to test survivorship care tools.

26 NWT Breast Health/Breast Cancer Action Group. Personal communication; May 2015.

"A community that goes through a patient's healing journey will learn together about cancer and traditional ways. A community that comes together gives hope to the patient with cancer now, but also hope for those who have cancer in the future. Even if there is cancer, it's a brighter future for everyone. In the future, no patient is left alone."

## **Measuring Progress**

*Charting Our Course* outlines goals and strategic priorities to improve the cancer patient experience in the NWT over the next ten years. Halfway through strategy implementation we will develop new five-year plan activities to build on progress made by that time. The monitoring and evaluation plan that has been developed to supplement this strategy is framed over ten years.



#### Figure 9: Monitoring and evaluation framework

Monitoring and evaluation of this strategy will take place in a consistent, efficient, and effective manner. We will monitor trends that influence the burden of cancer in the NWT while generating data for analysis within the wider DHSS performance management framework. Indicator measurement will generate data for improved accountability and informed decision-making.

The monitoring and evaluation plan contains three deliverables:

- 1. **Annual Progress Reports:** On an annual basis we will transform our data into information that is accessible to all NWT residents. This information will be presented as a yearly report card on the quality of cancer prevention and control in the NWT, comparing our progress with previous years and identifying priorities for subsequent years. The report card will also summarize improvements for which there may be no numerical data, such as health promotion activities and community-driven initiatives.
- 2. **Process Evaluation:** The process evaluation will take place halfway through strategy implementation. It will focus on performance assessment, identifying changes to improve performance, and generating lessons learned to apply to future territorial strategies.
- 3. **Outcome Evaluation:** An outcome evaluation will take place at the end of this strategy. It will determine the extent to which we have contributed to achieving our goals and strategic priorities.

Ongoing monitoring and evaluation will help to identify our strengths as well as opportunities to better serve cancer patients, cancer survivors, and their families and caregivers.

"It is important to be open about cancer so that others—even little ones and elders—can learn about it. This prepares others if cancer comes in their own future, and also helps the patient feel supported and strong. It's okay to be afraid sometimes, but talking about it helps people learn not to be afraid. It is better not to bottle things up, but be yourself and go on living."

## **Let's Talk About Cancer**

Talking about cancer is at the core of this strategy. Open conversation about cancer is needed to ease fear, reduce stigma, learn from one another, and enable healing. Clear communication between health care providers and patients, as well as improved communication pathways between primary and oncology care providers, are equally necessary to improve prevention, early detection, and patient outcomes. Communication within our families, communities, and the health system will be instrumental to our success.

The DHSS will develop a social marketing campaign built around this need for open dialogue about cancer. The campaign, *Let's Talk About Cancer*, will support the GNWT HCF and carry the Choose NWT brand. By encouraging learning and discussion about cancer prevention, early detection, and supporting one another, campaign activities will contribute to individual- and community-level change for healthier living.

*Let's Talk About Cancer* will help the DHSS to communicate strategically with NWT residents, targeting groups who are the most in need of information and support to lead healthy lifestyles. Furthermore, the campaign will support the development and distribution of culturally appropriate messages and materials.

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## Glossary

Caregiver	In this document, a caregiver is defined as a spouse, adult child, other family member or friend who provides unpaid care to someone living with cancer, allowing them to remain in their home and community.
Cancer journey	The cancer journey is the full experience of cancer in all its stages, either first-hand or through a loved one.
Circle of care	The circle of care is a model where the patient is at the center of care and a team of health professionals works collaboratively toward the patient's holistic health and wellness.
Commercial tobacco use	Commercial tobacco use is the use of tobacco as a drug that causes damage to your health over time, including smoking cigarettes or using chew.
Community health representative	A community health representative is a community member who links the community with the formal health system through the delivery of health promotion, treatment, and surveillance programs.
Continuum of care	The continuum of care is a concept to describe the delivery of health services throughout all stages of an illness from diagnosis to the end of life.
Cultural competence	Cultural competence is the individual ability to interact and communicate with people of other cultures and backgrounds in a way that is effective and respectful.
Cultural capabilities	Cultural capabilities refer to an organization or system's ability to provide services that are equitable and respectful of other cultures and practices.
Cultural safety	Cultural safety is a concept to describe when a health care provider combines cultural competence with inquiry about an individual patient's preferences, resulting in an atmosphere where the patient feels no fear or judgment.
Culturally appropriate	A culturally appropriate care or service aligns with the characteristics, preferences, and values of a particular cultural group.
Emotional safety	Emotional safety is a concept to describe when an individual feels that his or her thoughts and feelings will be respected for what they are.

End-of-life care	End-of-life care is care for patients with advanced and incurable disease.
Fecal immunochemical test	The fecal immunochemical test (FIT) is a simple stool test that is used as the primary colorectal cancer screening test in the NWT for individuals aged 50-74 years who are at average risk of the disease. The test is available in all health centers, can be done at home, and does not have any dietary restrictions.
Food security	Food security is the state of having reliable access to a sufficient quantity of affordable, nutritious food.
Health inequities	Health inequities are differences in health, between groups or individuals, that follow unfair patterns created by the social determinants of health.
Health promotion	The Ottawa Charter for Health Promotion defines health promotion as the process of enabling people to increase control over, and to improve, their health.
Heavy drinking	Heavy drinking is defined as the consumption of five or more drinks in a single sitting.
Historical trauma	Historical trauma refers to the unresolved emotional and psychological effects of colonization that are experienced by many generations of Indigenous populations across Canada.
Holistic care	Holistic care focuses on all aspects of an individual's life, including his or her physical, emotional, spiritual, and social needs. Healing the person as a whole is the goal of holistic care.
Home support workers	Home support workers are community-based workers who provide support services to patients in their homes and collaborate with community health representatives.
Incidence	Cancer incidence refers to the number of new cancers that occur in a specific population in one year. Cancer incidence is usually expressed as the number of cancers per 100,000 individuals at risk in the population.
Information system	An information system is made up of people and computers that manage and interpret data.

Mammogram	A mammogram is a specialized x-ray of the breast that is used as the primary breast cancer screening test in the NWT for women aged 50-74 years who are at average risk of the disease. Mammograms are available in Yellowknife, Hay River, and Inuvik.
Mortality rate	A cancer mortality rate is the number of deaths due to cancer that occurs in a specific population in one year. Cancer mortality is usually expressed as the number of deaths due to cancer per 100,000 individuals in the population.
NWT Cancer Registry	The NWT Cancer Registry is the collection of data on tumours and cancer screening tests among NWT residents. It is an important tool for evidence-based, data-driven decision making.
Oncology	Oncology is the field of study and medicine devoted to cancer.
Palliative care	The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering and pain, and other physical, psychosocial, and spiritual challenges. Palliative care includes, but is not limited to, end-of-life care.
Papanicolaou test	A Papanicolaou (Pap) test is used as the primary cervical cancer screening test in the NWT. Women should have an annual Pap test starting at age 21 years or three years after becoming sexually active, whichever comes earlier. Following three consecutive tests with normal results, the Pap test can be taken every two years.
Primary prevention	Primary prevention of disease includes actions to reduce or avoid disease before it occurs. Examples of primary prevention include maintaining a healthy diet, exercise, and not smoking.
Risk factor	A risk factor is any behaviour or thing that increases the likelihood of developing a disease. Risk factors that we can control, such as smoking and exercise, are referred to as modifiable risk factors.
Screening	Cancer screening involves simple tests that are used to find early signs of cancer. Screening is for healthy people who do not have any symptoms of illness.

Secondary prevention	Secondary prevention of disease includes actions to detect and treat a disease early, prior to the appearance of symptoms. Cancer screening is an example of secondary prevention.
Self-advocacy	Self-advocacy is a term to describe the actions of individuals or groups to represent their own needs or interests.
Social determinants of health	The social determinants of health are the economic and social conditions that influence the health of individuals or groups.
Social marketing	Social marketing is an approach to develop activities that aim to change or maintain certain behaviours for improved health of individuals and communities.
Survivorship care	Survivorship care involves regular medical check-ups to identify and monitor changes in a person's physical and psychosocial health after completing cancer treatment. Survivorship care may also be called follow-up care, after care, or discharge care.
Telehealth	Telehealth is the use of communications technology to connect remote patients with health care, removing the need for travel.
Tertiary prevention	Tertiary prevention of disease includes actions to reduce the damage of disease through rehabilitation and treatment. Surgery and palliative care are examples of tertiary prevention.
Traditional knowledge	Traditional knowledge refers to knowledge of Indigenous populations that is gained through spiritual practice and close connection with the land. This knowledge is usually passed orally from generation to generation.
Traditional medicine	The World Health Organization defines traditional medicine as the sum of knowledge, skills, and practices based on the theories, beliefs, and experiences of Indigenous cultures that are used to maintain health and treat illness.
Traditional tobacco use	Traditional tobacco use is the use of tobacco as part of ceremony or other sacred, healing practices part of certain Indigenous cultures. When tobacco is used in this way, people are exposed to very little smoke.



#### Kīspin ki nitawihtīn ā nīhīyawihk ōma ācimōwin, tipwēsinēn. Cree ?erihtl'ís dëne súliné yati t'a huts'elkër xa beyéyati the?a ?at'e, nuwe ts'ën yólti. Chipewyan If you would like this information in another official language, call us. English Si vous voulez ces renseignements en français, contactez-nous. Français Jii gwandak izhii ginjìk vat'atr'ijahch'uu zhìt yinohthan jì', diits'àt ginohknìi. Gwich'in Hapkua titiqqat pijumagupkit Inuinnaqtun, uvaptinnut hivajarlutit. Inuinnaqtun Inuktitut UVANITTUAQ ILITCHURISUKUPKU INUVIALUKTUN, QUQUAQLUTA. Inuvialuktun K'éhshó got'ine xədə k'é hederi vedihtl'é yeriniwe nídé dúle. North Slavey Edi gondı dehgéh got'je zhatié k'éé edatl'éh enahddhe nide. South Slavey Thícho yati k'ệệ dè wegodiì wek'èhoizo neewo dè, gots'ò goahde. Tłįcho

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