



## Gaining Ground

A Provincial Cancer Control Policy Framework  
for Newfoundland and Labrador

2010



Newfoundland  
Labrador







## Introduction

Cancer touches us all at some point in our lives, if not directly as a patient, then as a relative or friend of someone with cancer. The impacts of this disease are multiple and far reaching, affecting people of all ages. It is a major cause of concern to the public.

Newfoundland and Labrador, along with many other provinces and countries, is seeing an increase in the numbers of people who are developing cancer. There are a range of reasons for this increase such as the aging population, increased life expectancy, high rates of risk factors (e.g. obesity, inactivity, smoking and sun exposure) and some genetic factors.

Many are unaware of how much can be done to prevent, diagnose and treat cancer. One third of cancer can be prevented, and early detection and effective treatment of another third is also possible. Due to advances in cancer care, cancer is increasingly viewed as an illness from which people can survive.

As is stated in the *Canadian Strategy for Cancer Control (2006)*, it is recognized that true cancer control “aspires to prevent cancer, to detect cancer at an early stage, and to treat and hopefully cure the disease in those who are diagnosed, and to increase the survival and the quality of life in those who develop it.”

Great strides have been made in cancer control in Newfoundland and Labrador. However, it is recognized that in order to be more effective, a more concerted and coordinated, forward-looking approach to cancer control is needed in the province.

The development and implementation of a cancer control plan is seen as the most effective means of reducing the incidence and impact of cancer, and improving the quality of life of those living with cancer. Such a plan should focus on the full range of activities that can prevent cancer, detect cancer at an early stage, improve treatment, and support needs of all people affected by cancer.

*Gaining Ground: A Provincial Cancer Control Policy Framework for Newfoundland and Labrador (Framework)* outlines the Provincial Government’s response to the burden of cancer in the province. The goal of the Framework is to provide key policy directions that will be used to guide cancer control efforts in the province in the coming years. This Framework provides a foundation upon which the Provincial Government, the Regional Health Authorities (RHAs) and community-based organizations can build specific action plans that will strategically focus on advancing and improving cancer control in Newfoundland and Labrador.



## **About this Document**

*Gaining Ground: A Provincial Cancer Control Policy Framework for Newfoundland and Labrador* was developed in collaboration with the Canadian Cancer Society and the RHAs. Extensive consultations with more than 100 key stakeholders including cancer experts, cancer care providers, and cancer survivors and their families, helped inform its development. The Framework outlines the evolution of cancer care in the province, recognizing successes and acknowledging that challenges exist. The Framework identifies gaps and opportunities for improvement in current cancer control efforts. It then establishes nine policy directions, together with a series of goals and actions, to address identified needs. Every effort has been made to ensure the goals and proposed actions reflect, and will continue to reflect, current best practices and lessons learned in all aspects of cancer control.

The Framework is supported by government initiatives that focus on improving health and the delivery of health services. Provincially, these initiatives include the Provincial Wellness Plan, the Poverty Reduction Strategy, the Recreation and Sport Strategy and the Healthy Aging Policy Framework (see Appendix A). It also complements the work being done nationally in the areas of cancer prevention and care through the Canadian Strategy for Cancer Control, currently being implemented by the Canadian Partnership Against Cancer. The Framework also supports the efforts of other organizations, health professionals and community-based agencies and their volunteers involved in the many aspects of cancer control. Maintaining links with like-minded partners within, and outside government, will ensure an integrated and collaborative approach to cancer control in the province.

## Key Cancer Care Milestones

- 1971:** *Newfoundland Cancer Treatment and Research Foundation established.*
- 1972:** *Cancer radiation treatment offered in NL.*
- 1980:** *A cancer clinic established in St. John's to provide outpatient chemotherapy.*
- 1985:** *Chemotherapy outpatient services extended to Central NL.*
- 1994:** *Dr. H. Bliss Murphy Cancer Centre was officially opened in St. John's.*
- 1995:** *Medical Oncology Program established in St. John's.*
- 1996:** *Breast Screening Program officially launched in St. John's.*
- 1999:** *NL Alliance for the Control of Tobacco (ACT) was established.*
- 2000:** *Cancer centre in Western NL opened.*
- 2001:** *Stem cell transplants began to be performed in the province.*
- 2003:** *Cervical Screening Initiatives Program launched; NL acquired its first CT scanner for radiation treatment simulation.*
- 2005:** *Cancer Care Program at Eastern Health was established.*
- 2006:** *Teleoncology Program was launched. New cancer centres in Grand Falls-Windsor and Gander.*
- 2007:** *HPV Vaccination Program was launched.*
- 2009:** *Cameron Inquiry report received.*
- 2010:** *Colorectal Cancer Screening Program launched.*

## Evolution of Cancer Care in the Province

In the past, the health care system has been challenged to deliver cancer care services, within contained financial resources, to a population that is widely dispersed across the province. The demand for cancer care services has increased over time reflecting an expanded understanding of cancer prevalence and improvements in early detection. Further, enhanced approaches to treatment have also required a continued growth within health care services.

In response to these challenges, innovative and successful approaches to the organization and delivery of cancer care services in the province have evolved. Historically, cancer care services were available mainly in St. John's. These services were provided by the General Hospital and focused on the diagnosis and treatment of cancer. Over the years, cancer control efforts have expanded to include not only diagnosis and treatment, but prevention, and supportive and palliative care services.

Increased investment in cancer related services, over \$125 million in the last seven years, has enabled the expansion and enhancement of regional cancer centres and programs across the province and the use of technology such as teleoncology, which has improved access to a number of cancer care services. Increased funding over time has also supported the establishment of a number of prevention programs in the province such as cervical and breast cancer screening programs, and the HPV Vaccination Program. The HPV Vaccination Program, launched in 2007, protects females against HPV, which is known to cause many

types of cervical cancer. Ongoing support for diagnostic equipment and new cancer treatments has helped ensure that those with cancer have access to cutting-edge treatments and technologies. Supportive and palliative care services have evolved over time with varying types of services being provided in each RHA.

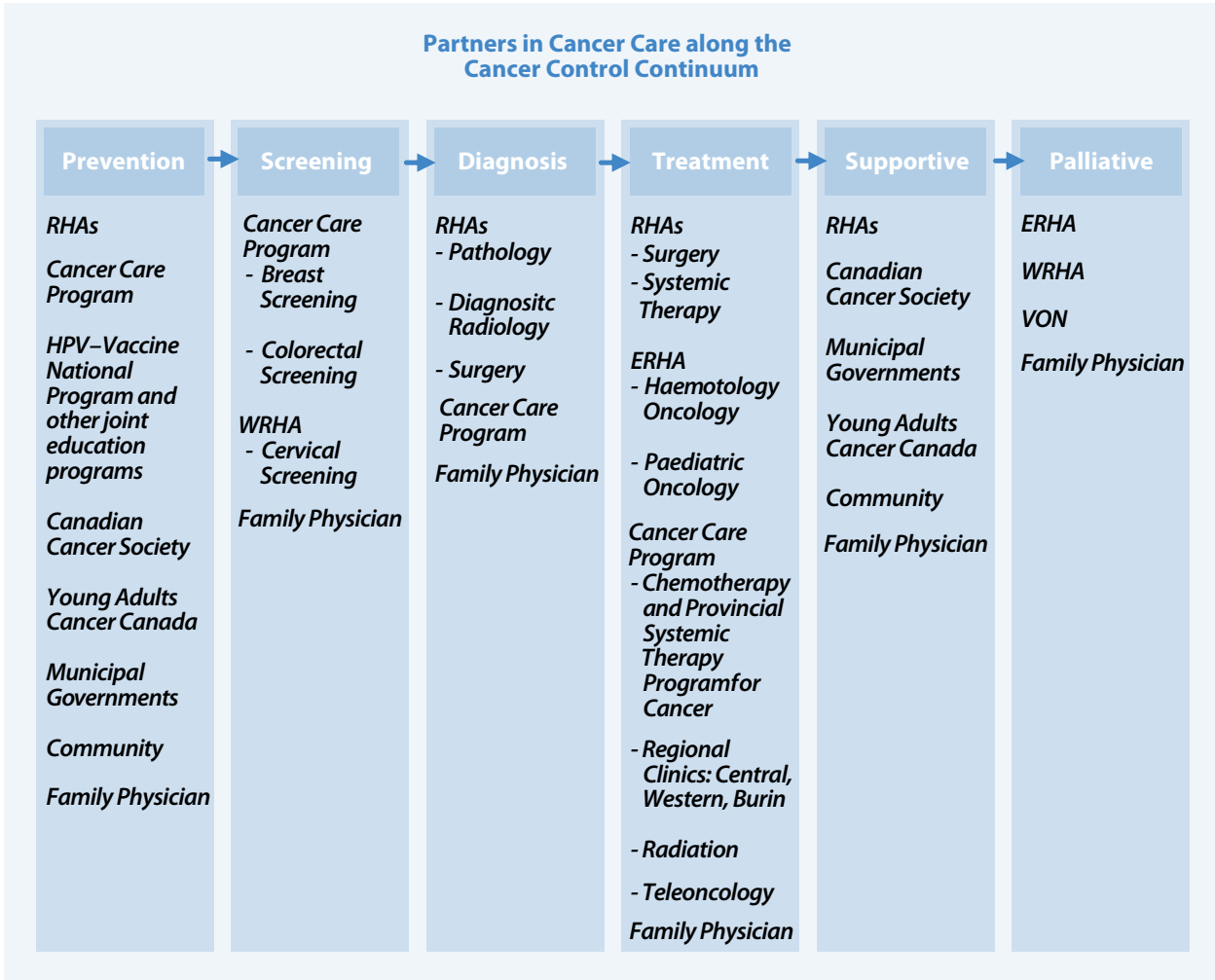
The Commission of Inquiry on Hormone Receptor Testing for breast cancer patients was established in 2007. This was an investigation into the estrogen and progesterone (ER/PR) tests performed in Newfoundland and Labrador from 1997-2005. The report released in 2009 presented a range of recommendations to strengthen the health care system for the people of the province. To date, there has been significant investments in response to the inquiry including enhancements to laboratory services, \$12.6 million for new medical equipment to treat cancer and \$12.7 million for the development of electronic health and patient records.

While there has been great progress in cancer control in the province, there is still much to be done. Despite ongoing efforts, according to the Canadian Cancer Statistics 2010 report produced by the Canadian Cancer Society, in 2010 an estimated 2,700 new cases of cancer will have been diagnosed in Newfoundland and Labrador, and 1,400 people will have died from cancer. The top three types of cancer for males in the province was expected to be prostate (510 cases), colorectal (300 cases) and lung (180 cases). For females, breast (370 cases), colorectal (210 cases) and lung (160 cases) were expected to be the top three cancers.

Taken together, these four cancer sites represent more than half the total number of cancers diagnosed annually. Also, in 2008, Newfoundland and Labrador reported the highest rates for many risk factors for cancer such as obesity and inactivity.

Newfoundland and Labrador is fortunate to have a rich network of partners who all have an important role to play in improving cancer control efforts. RHAs and professional caregivers are responsible for delivering cancer care services along the entire cancer care continuum, from prevention to end-of-life care. Non-profit organizations, such as the Canadian Cancer Society and Young Adult Cancer Canada focus on advocacy and client support, as well as public education campaigns and research initiatives that provide better information about cancer prevention and treatment.

Municipal governments and communities also play an active role by supporting initiatives that promote wellness and illness prevention. The Provincial Government has a key role to play in funding, facilitating high-quality collaboration and partnership and leading the development of a comprehensive plan. The following diagram shows the numerous partners involved and serving many different but essential functions and contributing a unique set of skills and resources related to cancer control.



\* ERHA – Eastern Regional Health Authority    \*WRHA – Western Regional Health Authority

It is recognized that challenges and gaps exist within the current cancer control system. Stakeholder consultations highlighted key areas to be addressed to ensure effective cancer control in the province. The Cameron Inquiry (2009) further supported these key areas. In particular, it was noted that the provision of cancer care services in the province is somewhat fragmented and access to some cancer care

services, especially for those in rural and remote areas, continue to be a challenge. As well, gaps exist within supportive and palliative care services offered across the province. It is acknowledged that to move forward, our approach to cancer control must be more comprehensive, systematic and integrated.



## ***Moving Forward - The Cancer Control Policy Framework***

The Framework encompasses all aspects of cancer care along the entire cancer care continuum including: prevention, screening, early detection, diagnosis, treatment, rehabilitation, and support and palliative care services. It identifies nine policy directions for more effective cancer control in the province. These directions are well established nationally and internationally and reflect current thinking and best practice in the area of cancer control.

Moving forward, the Framework will guide cancer care planning and investment. Building upon our accomplishments and the strong cancer control network that already exists in the province, it will ensure a more integrated, comprehensive approach to cancer control. It will encourage and support all partners to work closely together to effectively advance cancer control efforts in the province.





## Guiding Principles

The guiding principles of the Framework are consistent with the Canadian Strategy for Cancer Control:

- **Research to Policy to Practice**  
Support research that addresses the needs, gaps, and opportunities in Newfoundland and Labrador, and support the development of evidence to inform policy regarding cancer care.
- **Population Health Based**  
Address both patient-oriented and population components of cancer control.
- **Accessibility**  
Promote reasonable and fair access to appropriate care, regardless of where a person lives.
- **Sustainability**  
Support long-term sustainability of the health care system by dealing effectively with, and reducing the rise in the number of cancer cases.
- **Collaboration**  
Ensure the Framework is collaboratively led bringing together people living with cancer, the public, service providers, community-based organizations and governments.
- **Integration**  
Recognize the common risk factors and opportunities for collaborative, integrative action to reduce the incidence of chronic disease such as cardiovascular disease, diabetes, and respiratory disease, in addition to cancer.
- **Accountability**  
Be accountable to the people living with cancer and their families and the organizations that are involved in cancer control efforts including health professionals, administrators, government, community groups and the public.



## ***Cancer Control Policy Directions and Goals***

The policy directions form the basis of the Framework and the foundation for specific goals that will be advanced, or explored. Under each goal there are a variety of proposed actions that may assist in achieving the goal. These examples of activities were provided to the Provincial Government by stakeholders and experts in cancer control and they, along with a continued review of best practices, will guide the refinement of action plans.

### **Nine Policy Directions**

- 1. Cancer Prevention Through Promoting a Healthy Population***
- 2. Identifying Individuals at Risk***
- 3. Coordinating Care***
- 4. Supportive and Palliative Care***
- 5. Clinical Practice Guidelines***
- 6. Access and Advocacy***
- 7. Surveillance and Information Systems and Technology***
- 8. Education and Training***
- 9. Accountability and Measuring Success***

## ***Policy Direction 1: Cancer Prevention Through Promoting a Healthy Population***

Primary prevention is the most cost-effective form of cancer control and offers the greatest potential for health gains. Research shows that cancer is the leading cause of preventable death in Canada and there is clear evidence that public health action by governments and their partners through the promotion of healthy lifestyles could reduce as many as one third of cancers worldwide.

Factors such as smoking, a diet low in fruits and vegetables, lack of physical activity and obesity are known modifiable risk factors for cancer. More specifically, tobacco use is known to be the single most important cause of cancer. Also, research shows that more than one third of cancers are attributable to diet, obesity and physical inactivity. There is strong evidence that links diet and specific cancers such as colorectal and stomach. Obesity and being overweight are also linked to many types of cancer such as esophageal, colorectal, breast, endometrial and kidney.

According to the latest statistics from Statistics Canada, Newfoundland and Labrador has the highest prevalence of overweight and obesity for adults and children among the provinces in Canada, and one of the highest rates of inactivity. In addition, about 20.2 per cent of the population report being current smokers. Addressing these risk factors will not only impact the incidence of cancer, but a number of other chronic diseases that share common risk factors.

A number of environmental factors have also been linked with an increased risk of cancer. Research shows that approximately 65 to 90 per cent of skin cancers are caused by exposure to ultraviolet radiation. In 2006, the Newfoundland and Labrador Cancer Registry recorded 65 cases of melanoma in the province, the most serious form of skin cancer. According to the 2010 Canadian Cancer Statistics report, it is estimated that in 2010 the number of cases of melanoma will likely increase.

The presence of some infectious diseases has been associated with the development of certain cancers, most notably, stomach cancer, liver cancer and cervical cancer. For example, it is known that the HPV is a contributing factor in the development of certain types of cervical and head and neck cancers, particularly HPV induced tonsillar carcinoma which is rising at an alarming rate throughout the world.

Various environmental and occupational hazards have also been linked with an increased risk of cancer. However the linkages are not as clear as with other risk factors and therefore require additional research and surveillance to inform actions in this area. CAREX Canada, a multi-disciplinary team of researchers, is currently undertaking a number of projects to develop estimates of the number of Canadians exposed to cancer-causing agents in their workplace and community environments. Such information will be useful for primary prevention, exposure and disease surveillance, and further research.

Effective cancer prevention efforts will require a greater understanding of the various risk factors for cancer and how they contribute or lead to cancer. Research to increase knowledge

in this area is ongoing through the Canadian Partnership for Tomorrow Project currently being conducted by the Canadian Partnership Against Cancer. This large pan-Canadian study will explore the complex association of factors – genetic, lifestyle, and environmental that lead to cancer and how Canadians are affected by prevention and public health programs in different parts of the country. Information generated will inform the development of more effective prevention and public health initiatives.

#### Six priority areas for cancer prevention:

- Tobacco use
- Nutrition
- Physical activity
- Ultraviolet radiation
- Infectious diseases
- Environmental and occupational exposures

Promoting a healthy population and preventing cancer in the province will require a targeted approach, focusing on the six priority areas of tobacco use, nutrition, physical activity, ultraviolet radiation, infectious diseases, and environmental and occupational exposures. It will require raising awareness and educating people to adopt healthy lifestyles. Because people's exposure to risk factors for cancer is generally the result of a complex range of behavioural, social, economic, environmental and cultural factors that are not easy to

change, efforts to reduce the incidence of lifestyle-related cancers require a multi-faceted, comprehensive approach.

Comprehensive public health policies and interventions that support healthy social environments and support people to make healthy lifestyle choices are essential.

Several initiatives and strategies have been developed in Newfoundland and Labrador to promote a healthy population including the Provincial Wellness Plan, the Poverty Reduction Strategy, the Recreation and Sport Strategy and the Healthy Aging Policy Framework. Effective cancer prevention efforts will require building upon these and other initiatives, demonstrating an integrated, collaborative approach to cancer prevention.

*Goal: Implement a comprehensive cancer prevention plan that is developed in collaboration with key stakeholders.*

#### What Kind of Actions Can Achieve This Goal: What We Heard

- Support the development and implementation of existing and future prevention strategies targeting the six areas previously noted for cancer prevention.
- Strengthen links with stakeholders who can facilitate actions to target the six priority areas identified in the prevention of cancers.
- Ensure key messages regarding the links between unhealthy lifestyle choices and cancer are incorporated into relevant strategies/initiatives.

- Work with partners to ensure consistent messaging and to develop appropriate messaging for target groups (e.g. Aboriginal peoples, teens, seniors, persons with disabilities).
- Achieve healthy settings, organizations and products through the establishment of policies and practices that promote sun protection.
- Strengthen community capacity for action on skin cancer prevention.
- Improve links among groups that promote sun safe activities (e.g. RHAs, municipalities, schools, Canadian Cancer Society).
- Increase awareness of relationship between infectious diseases and cancer.
- Review and improve plans to reduce the transmission of HPV.
- Increase participation in the HPV Vaccination Program.
- Research literature/information regarding environmental factors that are believed to be risk factors for cancer to inform the development of an action plan to address the issue.

## ***Policy Direction 2: Identifying Individuals at Risk***

### ***General Population***

It is a well-known fact that cancer screening is effective in detecting some types of cancer early. Detecting cancer early, before it has a chance to spread, remains the best strategy for reducing cancer-related deaths. The aim of cancer screening is to improve survival, decrease morbidity and increase the quality of life of those living with cancer. The World Health Organization (WHO) has recommended population-based screening for breast, cervical and colorectal cancer.

There are currently screening programs in place in the province for cervical and breast cancer. The Cervical Screening Program is provincial in scope; however, Newfoundland and Labrador still has the highest incidence rates and the lowest screening rates of cervical cancer in the country. The Breast Screening Program offers services in three centres located across the island portion of the province. The average participation rate for the province is presently about 64 per cent for women aged 50 to 69 years. A colorectal cancer screening program was announced for the province in 2010. The program will be implemented using a phased-in approach with province-wide coverage anticipated within three years.

In order to increase the effectiveness of early detection in the province, the public must be educated about the benefits and availability of screening programs. Equally important is ensuring that screening services in the province are reasonably accessible. Health professionals, especially primary care providers, also need to

be knowledgeable about the latest screening recommendations ensuring patients are provided with accurate up-to-date information.

Enhancements to current cancer screening programs are also needed to ensure that programs are as integrated and comprehensive as possible. Processes need to be developed to increase participation rates through population-based recruitment and the establishment of recall protocols. Equally important is the establishment of processes to facilitate follow-up of abnormal results to help ensure prompt diagnosis and treatment.

***Goal: Early detection screening programs for appropriate cancer sites.***

**What Kind of Actions Can Achieve This Goal:  
What We Heard**

- Establish a provincial approach to oversee population-based screening programs and ongoing evaluation.
- Ensure all screening programs contain the core components of organized cancer screening including recruitment and retention, quality control and assurance, education and training, program evaluation and information systems.
- Collaborate with health partners to identify ways to evaluate performance and quality assurance.
- Provide increased education for primary health care providers about the importance of screening as well as information about referral networks and other resources.

- Establish a collaborative approach between health partners and community groups on the development of a provincial campaign to educate the public on the importance of screening in the prevention of cervical, breast and colorectal cancer.
- Support efforts of screening programs to increase participation rates through the establishment of a recall and follow-up protocol.
- Review alternate models of service delivery that would improve access to screening for underserved areas.
- Continue to support the current efforts underway by the Cervical Screening Program, including the adoption of a continuous quality improvement process and electronic transfer of data.
- Maintain linkages with the National Cancer Screening Network to help inform the implementation of the Colorectal Cancer Screening Program.

***Families at Increased Risk***

Certain individuals in a population may be at a higher risk of developing cancer and therefore require more targeted cancer screening. This includes individuals in families with hereditary cancer syndromes. These families typically have several family members with the same or related cancers, multiple cancers in one individual, and cancers diagnosed at a young age. It is believed that up to 10 per cent of all cases of cancer in the population are a result of hereditary cancer syndrome.

The Provincial Medical Genetics Program currently offers a variety of services for families with hereditary cancer syndromes. Genetic screening and counseling programs are available to those at increased risk. As part of the new community genetics program, a clinic for colorectal cancer screening has been established in Grand Falls-Windsor and other community genetics screening clinics are being planned. The genetics screening program is an important element of the new colorectal cancer screening program in the province. Establishing screening guidelines and a targeted, organized screening program for this sub-group of the population is an important step in ensuring early detection and treatment and ultimately increased survival rates.

*Goal: Hereditary Screening for appropriate cancers and populations at risk.*

**What Kind of Actions Can Achieve This Goal:  
What We Heard**

- Build upon current activity to develop a hereditary cancer screening program ensuring best practice and necessary support, infrastructure (e.g. genetic counseling) and resources.
- Ensure appropriate and timely clinical screening is accessible to members of families with hereditary cancer syndrome.
- Further explore the area of genetic testing and build upon current policies regarding testing.

**Policy Direction 3:  
Coordinating Care**

Cancer is a multi-faceted disease and its treatment is a complex process. The provision of care usually involves a number of health care providers throughout the health system. Limited coordination amongst health care providers often poses unnecessary challenges for patients and health care providers alike. For those living with cancer, the experience is often very difficult and overwhelming. Care may seem fragmented with gaps in communication and access to services. The experience is perhaps most challenging for those who are not financially self-sufficient or lack the skills and stamina required to navigate the system.

Supports are required to enhance continuity of care for individuals with cancer; to help ensure that care is delivered in a logical, connected and timely manner so that the medical and personal needs of the patient are met. The Cameron Inquiry highlighted the importance of communication and coordination of care throughout the cancer journey, recommending patient navigators to assist patients.

This approach to coordination of care has been shown to result in greater patient satisfaction, decreased stress, improved access to services, improved communication among care providers and better patient outcomes. The exploration and implementation of best practices with respect to coordination of cancer care, including the utilization of patient navigators, is required to enhance coordination of cancer across the province.

*Goal: Improve coordination of services along the cancer control continuum.*

**What Kind of Actions Can Achieve This Goal:  
What We Heard**

- The promotion of comprehensive care networks built on primary health care organizations throughout the province.
- Review patient navigator programs across the country to inform decisions regarding the use of patient navigators in the province.
- Support the implementation of patient navigators in all four RHAs.
- Research and explore best practice with respect to coordination of cancer care.

**Policy Direction 4:  
Supportive and Palliative Care**

The diagnosis of cancer impacts the whole person. The depth and breadth of cancer challenges the physical, psychological, social, spiritual, intellectual and emotional dimensions of the patient and family members. Individuals with cancer and their families have significant supportive care needs from the time cancer is suspected through all stages of treatment to recovery, or in some cases, to death and bereavement. A variety of interventions are needed to meet the multiple needs of patients and their families in ways that are most appropriate to them.

The age at which cancer is diagnosed may also dictate the type of supportive services required. It is recognized that children diagnosed with cancer have different supportive care needs than adults diagnosed with cancer. As well, the needs of youth/young adults and older adults differ. The literature supports that many children with cancer struggle with transitioning to adulthood, requiring unique supportive care needs. Young adults and youth with cancer struggle with feelings of isolation and lack of customized care to meet their cancer care needs. It is acknowledged that more needs to be done to understand and meet the needs of children, youth, and their families who are experiencing cancer.

Research findings reinforce the importance of providing all recently-diagnosed patients with information and quality psychological supports. In those with advanced cancer or those requiring palliative care, patients and families identify needs for information, emotional/psychological support, pain and symptom management, as well as assistance with day-to-day living.





Currently, dedicated oncology supportive care services are primarily available through the Cancer Care Program; children with cancer are supported through the Pediatric Oncology Program at the Janeway. Other supportive services are available through the RHAs and community organizations such as the Canadian Cancer Society and Young Adult Cancer Canada. The current approach to the provision of supportive care services has resulted in inconsistencies in care across the province. The standards and types of supportive care services offered vary both within and across the regions, with more rural areas experiencing the greatest need. While certain rehabilitative support services such as lymphedema service and speech therapy for laryngectomy patients are offered in larger centres in the province, the current system does not offer a comprehensive rehabilitation program needed to support those with cancer in returning to their highest level of functioning and independence possible.

Similar issues exist with respect to palliative care services. For example, while palliative care programs have been established in St. John's and Corner Brook, these services are extremely limited in more rural and remote areas due to obstacles like travel and equipment costs. As well, there is no designated leader for supportive care within the provincial Cancer Care Program. The various disciplines that do exist are not coordinated under one umbrella, and there is limited awareness among professionals and the public of the importance and contribution of supportive care.

Efforts are required to raise the profile of supportive, rehabilitative, and end-of-life care in the province, and to address gaps within these service areas. A needs assessment of palliative care in Newfoundland and Labrador, undertaken by Fiona O'Shea in 2008, identified

a number of issues with palliative care in the province that need to be addressed to ensure comprehensive end-of-life care. Her work highlighted the need for dedicated leadership and provincial coordination of supportive and palliative care services throughout the province to help ensure consistent standards and quality of care. Many of the recommendations arising from the needs assessment are reflected in the suggested examples below.

*Goal: Social policies and initiatives which increase access to supportive care and palliative and bereavement services.*

#### **What Kind of Actions Can Achieve This Goal: What We Heard**

- Conduct an audit of supportive care resources.
- Support research on the unique needs of children, youth and young adults with cancer and best practice with respect to meeting identified needs.
- Identify human and financial resources required to address gaps in supportive and palliative care services.
- Improve access to supportive care services.
- Build upon current rehabilitative services to meet the unique needs of cancer survivors, children and adults.
- Identify supportive care providers and establish a formalized network to facilitate provincial coordination of services within the RHAs.
- Establish supportive care standards for quality improvement for volunteers and professionals.

- Ensure palliative and end-of-life care is recognized and designated as core interdisciplinary service within RHAs.
- Establish dedicated palliative and end-of-life care interdisciplinary consultative teams within RHAs to work with primary health care teams on service delivery.
- Explore the development and implementation of a provincial palliative and end-of-life care program.
- Conduct a retrospective audit to determine potential service use.
- Develop a framework for patient referral, including eligibility criteria and clinical practice guidelines that ensure timely and regional access to palliative and end-of-life care.
- Collaborate with professional schools to ensure integration of palliative and end-of-life care education as part of core curriculum across all disciplines and sectors.
- Ensure continuing education and standardized training in palliative and end-of-life care for all health care providers, volunteer support care providers, patients, families, and the general public.
- Ensure the electronic health record includes communication of palliative care planning and needs.
- Implement standards of palliative care, including clinical practice guidelines, policies, procedures, patient education materials, and assessment and documentation tools.
- Coordinate bereavement support services.

### ***Policy Direction 5: Clinical Practice Guidelines***

Clinical Practice Guidelines (guidelines), based upon best practice from around the world, help health care professionals and patients make decisions about prevention, screening, early detection, and/or treatment of a specific health condition. Guidelines have been developed for a number of cancers.

The application of guidelines across the cancer control continuum promotes a coordinated approach to cancer control, ensures consistency in standards of care, and helps to ensure accountability and transparency regarding cancer care. While guidelines exist for a number of cancers, anecdotal information suggests they are not applied consistently across the province, resulting in different standards of cancer care. This may be related to a lack of awareness regarding the latest guidelines, or lack of resources suggested in the guidelines.

It is important that all health care providers involved in cancer care are supported in adopting and adhering to established guidelines for the prevention, detection, diagnosis and treatment of cancer. Provincial cancer care guidelines, based upon national guidelines, need to be adopted and implemented. Consideration must also be given to how to disseminate these guidelines, ensuring appropriate care providers are aware of existing guidelines. Strategies will also need to be developed to ensure maximum uptake of, and compliance with, established guidelines.

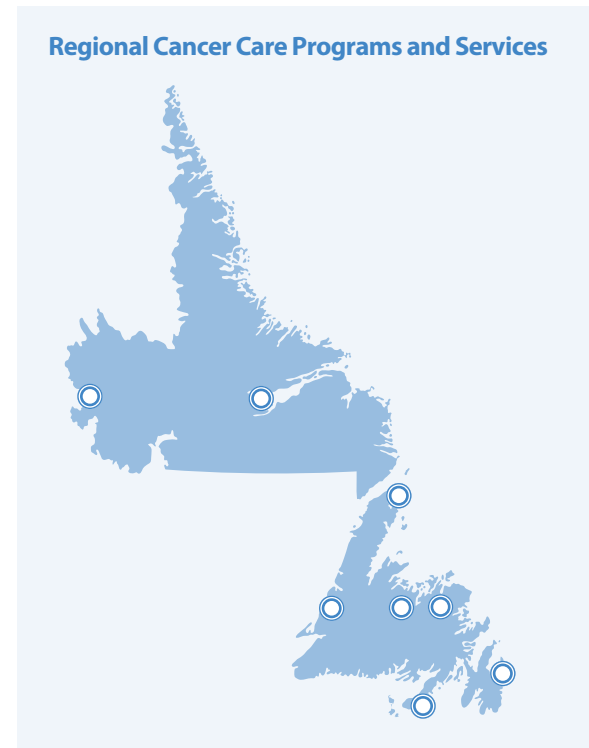
*Goal: National and international clinical standards and guidelines for cancer care along the cancer control continuum in use as applicable in Newfoundland and Labrador.*

**What Kind of Actions Can Achieve This Goal:  
What We Heard**

- Support clinicians' involvement in clinical research regarding cancer care and engagement in continuing professional development through participation in research projects.
- Collaborate with relevant stakeholders and expand upon existing processes in the development of provincial clinical practice guidelines for cancer diagnosis, treatment and patient education, based upon national and international guidelines, refined and tailored to reflect available resources.
- Develop an organized structure for the dissemination of guidelines.
- Ensure appropriate clinicians are educated regarding existing guidelines to ensure accurate up-to-date information is communicated to patients and families.
- Establish a system to evaluate and monitor the uptake of, and compliance with clinical practice guidelines.

**Policy Direction 6:  
Access and Advocacy**

The ability to access needed services along the cancer control continuum is essential for those living with cancer. Providing equitable access to cancer services in the province is challenging due to the geography of the province and the specialty nature of many cancer treatments.



The establishment of regional cancer centres and the use of technology, such as teleoncology, have improved access to a number of cancer care services; however, many individuals still have to travel away from their home for different aspects of treatment. This is especially true for radiation treatment, which

is only available at the Dr. H. Bliss Murphy Cancer Centre in St. John's. As previously noted, discrepancies exist in the availability of supportive and palliative services between urban and rural areas, requiring individuals to travel to urban areas to access these services.

Those living with cancer often face financial challenges, or barriers, to accessing services. The financial costs associated with travel and medication costs, may prevent some individuals from accessing optimal treatment. The financial impact of cancer will vary greatly from one individual to another depending on the type of cancer, geographic location, personal wealth and health insurance.

There are currently provincial supports in place to help minimize the costs associated with accessing needed services such as the Medical Transportation Assistance Program and the Newfoundland and Labrador Prescription Drug Program. However, during consultations, persons living with cancer and care providers voiced concerns regarding inadequate financial support. The need for regular review of relevant policies to identify and address inadequacies was noted. Also highlighted was the important role of patient advocates in supporting and representing cancer patients and ensuring supports are in place to adequately deal with both the medical and financial aspects of cancer. To help ensure reasonable access to cancer care services, innovative approaches to addressing barriers to access in all areas of the cancer continuum need to be actively explored and encouraged. The role of patient advocates, representing cancer patients, also needs to be acknowledged and supported. It is important that social policies and initiatives promote reasonable access for those living with cancer.

*Goal: Social policies and initiatives which increase the ability for cancer patients to access services along the cancer control continuum.*

#### **What Kind of Actions Can Achieve This Goal: What We Heard**

- Make decisions regarding the location of cancer care services based on need.
- Review existing social policies and initiatives to increase access to services along the cancer control continuum.
- Review the financial and treatment aspects of services accessibility and apply best practice to policies as resources permit.
- Investigate formulary and supportive drug issues in the provincial and Canadian context.
- Explore research and advocacy capacity as they pertain to service accessibility.



## ***Policy Direction 7: Surveillance and Information Systems and Technology***

Information regarding the effectiveness of cancer control efforts, including preventative, diagnostic and treatment programs and services is essential to the ongoing development of appropriate cancer control policies, program planning and evaluation. Currently, the technology and expertise that exist for surveillance and informatics differs across the province. Various agencies are involved in the collection of data regarding cancer risk and care; however, the data is not standardized and is not being utilized to its fullest potential. Cancer surveillance activities focus primarily on incidence, survival and mortality.

Data collection efforts need to be supported and expanded to ensure that data in the province is valid, reliable, timely, and population based. A comprehensive cancer surveillance and information program, supported by a dedicated provincial research agenda, is necessary to inform decisions regarding cancer care services along the cancer control continuum.

***Goal: A comprehensive cancer surveillance and information program supported by a dedicated research agenda.***

### **What Kind of Actions Can Achieve This Goal: What We Heard**

- Work with the Canadian Partnership Against Cancer, the Public Health Agency of Canada and other national agencies to enhance both provincial and national surveillance.
  - Ensure the Provincial Cancer Registry is based on the total population and all cases of cancer.
  - Explore the development of provincial legislation that addresses mandatory cancer reporting and data sharing/ownership.
  - Expand and implement data sharing frameworks that respect the privacy of individuals.
  - Develop and implement data collection strategies to address gaps in existing data along the cancer control continuum.
  - Continue to develop electronic systems that are interoperable.
  - Ensure cancer is a priority in the ongoing development of the Electronic Health Record (EHR).
- Create an agenda for cancer surveillance and research.
  - Improve provincial capacity for collecting, analyzing and disseminating evidence by enhancing human, technological and data resources.

## ***Policy Direction 8: Education and Training***

Education regarding cancer prevention, diagnosis and treatment is a key component of all cancer control efforts. The education and training of the general public, individuals and families living with cancer, and health professionals is important to reduce the incidence and impact of cancer in our province. Educating the public regarding the importance of recognizing the signs and symptoms of cancer, early presentation with any suspicious symptoms, and the importance of healthy behaviours and self-management will contribute to the prevention and early detection and treatment of cancer.

It is important to educate those living with cancer regarding the various components of cancer care and what to expect along their cancer journey. Increased knowledge and information has been shown to contribute to a sense of empowerment at a time when patients often feel they have little control. Research supports that empowerment leads to greater patient involvement in care, reduced fear regarding the diagnosis, and more informed decision making regarding all aspects of their care.

Ongoing education and training for health care providers is also essential to cancer control efforts. There is evidence to indicate that people in this province present at a later stage of cancer at the time of diagnosis and have higher rates of mortality from cancer. Continuing education requirements and opportunities for health professionals, focusing on improving and maintaining professional skills in the area of cancer care is critical.

*Goal: Awareness programs for the public and continuing education and awareness programs for health professionals within the cancer control continuum.*

### **What Kind of Actions Can Achieve This Goal: What We Heard**

- Develop a social marketing strategy based on best practices to address major cancer issues in the province.
- Collaborate with other provincial strategies to build and deliver a public awareness campaign on risk reduction and recognition of common signs and symptoms of cancer.
- Develop a province-wide continuing education program for health care providers based upon identified need.
- Collaborate with professional associations (national and provincial), unions, regulatory bodies and advocacy groups to prioritize/support continuing education for professionals and volunteers.
- Seek opportunities to network with other organizations on education and training.
- Ensure continuing education programs are a priority for the Department of Health and Community Services and RHAs.
- Ensure continuing education programs include a community health component.

### ***Policy Direction 9: Accountability and Measuring Success***

The Framework is the first step in the development and implementation of a comprehensive and coordinated cancer control program for Newfoundland and Labrador. The next phase will involve identifying priority areas for action, planning implementation, and monitoring success.

A Provincial Cancer Control Advisory Committee will be established to advise the Minister of Health and Community Services on: i) priorities for action; ii) monitoring progress; and, iii) the development and implementation of an evaluation plan for the Framework.

In addition, the Advisory Committee may be asked to liaise with the cancer control community, nationally and provincially including patients, survivors, advocates and community organizations, and identify for the Minister's consideration, additional evidence-based objectives or priority directions that have the potential to improve the control of cancer in Newfoundland and Labrador.

The implementation of an action plan will be the responsibility of a great number of stakeholders. The Department of Health and Community Services and the RHAs will take a lead role in reporting on success. Those involved with the implementation of the Framework will be accountable to the Minister of Health and Community Services, the public, cancer patients, cancer survivors and cancer advocates.





## Conclusion

It is possible to improve upon the predicted cancer trends with the implementation of a comprehensive Provincial Cancer Control Policy Framework.

*Gaining Ground: A Provincial Cancer Control Policy Framework for Newfoundland and Labrador* builds on existing strengths and partnerships to reduce the impact and incidence of cancer in the province. It focuses on prevention efforts, earlier detection and access to coordinated, consistent and effective care. It provides a comprehensive, integrated approach to cancer control and a solid foundation to reduce the effects of cancer in the province in the years ahead.

To achieve the desired outcome, the Framework will require the Provincial Government to work with all partners – the health care sector, community groups, communities, families and individuals. It will require targeted efforts along the entire cancer control continuum, exchanging knowledge and the sharing of resources where applicable, thereby increasing overall capacity to prevent cancer and meet the needs of cancer patients in the province. Working together we can make a difference.





## *Appendix A*

Initiatives and Strategies which have been developed in Newfoundland and Labrador to promote a healthy population:

Provincial Wellness Plan: Go Healthy  
<http://www.health.gov.nl.ca/health/wellnesshealthyliving/index.html>

Poverty Reduction Strategy: An Action Plan for Newfoundland and Labrador  
<http://www.hrle.gov.nl.ca/hrle/poverty/consultations/2008/poverty-reduction-strategy.pdf>

Recreation and Sport Strategy: Active, Healthy Newfoundland and Labrador  
[http://www.tcr.gov.nl.ca/tcr/publications/2007/active\\_healthyNL.pdf](http://www.tcr.gov.nl.ca/tcr/publications/2007/active_healthyNL.pdf)

Provincial Healthy Aging Policy Framework  
[http://www.health.gov.nl.ca/health/publications/ha\\_policy\\_framework.pdf](http://www.health.gov.nl.ca/health/publications/ha_policy_framework.pdf)





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