

# *Partners Taking Action:* A Cancer Control Strategy for Prince Edward Island 2004-2015



Final Report and Recommendations

prepared by the Prince Edward Island  
Cancer Control Strategy Advisory Committee

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September 2004



Canadian Cancer Society  
Société canadienne  
du cancer

*Prince Edward Island Division*



Health and  
Social Services

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*"I have cancer but it doesn't have me."*

Nancy Hamill, during treatment  
December 1995



# ACKNOWLEDGMENTS

The advisory committee would like to acknowledge the enormous assistance it has received in developing this report and strategy. The committee particularly wants to express its appreciation to:

- The past and present board, volunteers and staff of the Canadian Cancer Society, PEI Division, for their efforts in initiating work on a provincial cancer control strategy and their support throughout its development.
- Members of the original cancer control working group, who began the process of developing a provincial strategy for cancer control, and from which members of the advisory committee were drawn.
- Members of the subcommittees, who generously took time from their busy schedules to discuss and make recommendations to improve service within their specific areas of expertise.
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- The government of Prince Edward Island, for its commitment to reducing the burden of cancer in Prince Edward Island, having already made improvements to the Cancer Treatment Centre and initiated comprehensive prevention and palliation strategies, and now the support and development of this strategy.
- The staff of organizations represented by the committee members for their additional work to help to organize, research, edit and otherwise support the development of this strategy.
- Last, but far from least, cancer patients, both those who have survived and those who have not, their family members, healthcare professionals and volunteers for all that we have learned from their experiences.

By continuing to harness the dedication and generosity shown by so many individuals, and as partners taking action, we will work to reduce the burden of cancer in Prince Edward Island.





# ABOUT THIS REPORT

Work began on the PEI Cancer Control Strategy in the spring of 2002 with the formation of a multi-sectorial advisory committee. Unsure of continued staff support or what direction such a strategy would take, the advisory committee determined that their greatest need was for information about community resources available to support cancer patients and their families in Prince Edward Island. An inventory was conducted, and in its preparation, dozens of health professionals and volunteers from across the Island were interviewed. They shared information about their services and observations about the challenges faced by patients and family members in their community. Organizations such as the Cancer Treatment Centre and Canadian Cancer Society, PEI Division immediately benefitted from this information, being able to direct patients to supportive resources. The inventory process also allowed an initial gap analysis on which the strategy would be based.

After a break of several months, in late January 2003, approval was given for a half-time staff person to support the advisory committee's work. With funding confirmed for 15 months, it was decided to attack this project in a more systematic way by establishing the burden cancer represents in PEI, identifying risk factors and their prevalence in PEI, and reviewing PEI's services and programs in light of national research and recommendations. Through this process, it became clear that the provincial strategy could be structured around different aspects of the cancer experience. Subcommittees were created to lend their expertise in specific areas. Prevention, screening and diagnosis, treatment and supportive care, and palliation and end-of-life care were identified as key areas. The Canadian Cancer Society, PEI Division provided funds to support further strategy development.

The primary purpose of this document is to provide background information to support the recommendations made by the PEI Cancer Control Advisory Committee. Its intended audience includes decision-makers, healthcare providers, and interested members of the general public. The report has been structured as follows:

**Section 1** provides background information about the strategy itself, including its purpose, development, and achievements to date.

**Section 2** provides background information about the burden of cancer in PEI to identify the issues being addressed by this strategy.

**Section 3** provides the supporting information and ensuing strategy recommendations structured by the issues encountered throughout the cancer experience, from prevention, to screening and diagnosis, treatment and supportive care, palliation and end-of-life care, and survivorship. Several over-arching recommendations introduce this section. They concern issues that are either beyond the mandate of the advisory committee, or that affect many aspects of cancer care and are referred to throughout the document.

**Section 4** explains how recommendations made by the PEI Cancer Control Strategy will contribute to the sustainability of the healthcare system in Prince Edward Island, the strategy's third goal. This section reflects the advisory committee's effort to provide advice that is both cost-effective and achievable within the confines discussed under the over-arching recommendations.

**Section 5** is the Summary of Recommendations, ordered by the aspect of the cancer experience discussed and whether these recommendations can be targeted in the short-term, mid-term, or are of an ongoing nature. Those to be addressed in the short-term are chosen either because of the urgency of the issue or its achievability. Recommendations to be accomplished in the mid-term are either less urgent or will build upon work to be accomplished earlier. Ongoing recommendations concern issues that will continue to require attention.

**Targets and indicators** have been identified within each of the areas to provide some criteria by which the work undertaken can be assessed. Targets represent the states to which the strategy aspires, and indicators are ways progress can be measured. Knowledge and practices emerging over the next 11 years, to 2015, may completely change our vision of what we currently consider possible. For this reason, targets and indicators are imprecise, and will be updated as work progresses. Indicators in 2004 will be determined either from existing information, such as surveys regarding tobacco use; or the best estimate of those involved, such as the number of complex cases receiving case conferencing. When possible, targets will be based on nationally set guidelines.

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# EXECUTIVE SUMMARY

The Prince Edward Island Cancer Control Strategy has been developed in response to concerns about the increasing incidence of cancer noted in PEI and across Canada. Largely driven by population growth and an aging population (75 per cent of new cancers in males and 63 per cent in females occur after 60 years of age), this trend is expected to continue, with cancer incidence projected to increase by 60 per cent over the next 20 years.

In 2002, the Council for the Canadian Strategy for Cancer Control was formed to prepare for, and where possible, prevent this increase in disease. Each province was encouraged to develop a strategy to be implemented locally. In Prince Edward Island, an advisory committee was drawn from a previous cancer working group and included representatives of the PEI Cancer Treatment Centre; the Canadian Cancer Society, PEI Division; PEI Medical Society; UPEI School of Nursing; Hospice and Palliative Care Association of PEI; Diagnostic Imaging Department, Provincial Health Services Authority; Department of Health and Social Services; and cancer survivors and family members.

Members of the advisory committee shared their expertise and advice to guide development of the PEI Cancer Control Strategy. Subcommittees were created and experts consulted about specific areas of concern, and about the research conducted about cancer related issues and practices across Canada and internationally. As an initial stage of work, an inventory was made of services offering support to cancer patients and their families available across the Island. During this process, dozens of healthcare professionals and volunteers representing many aspects of cancer care were interviewed about their services and the challenges facing cancer patients throughout PEI. The resulting strategy has been informed by this collective body of knowledge and advice.

## What is the burden of cancer in Prince Edward Island?

Many factors are involved in identifying the burden of disease on a community, including incidence, mortality, economic and psychosocial repercussions. This research found that:

- As in Canada overall, the number of cancer cases has increased in PEI: from 455 new diagnoses in 1985 to 696 in 2002. The age-standardized rate, which allows comparisons to be made across regions and over time, is higher in PEI (seven per cent higher for males and five per cent higher for females, averaged over 1996-2000) and in the other Atlantic provinces than the national average. This may be linked to a higher prevalence of lifestyle risk behaviours widely associated with the development of cancer including tobacco use, poor diet, overweight and obesity, and physical inactivity. Socioeconomic

conditions in Atlantic Canada also tend to be lower, a circumstance shown to be inversely related to higher rates of chronic diseases, including cancer.

- As can be expected from higher incidence rates, rates of mortality from cancer are also greater. The ratio of mortality to incidence rates in Prince Edward Island is, however, either the same or slightly lower than the national average, indicating a good basic quality of cancer care in the province. (0.51 per 100,000 for males in both PEI and Canada, 0.44 per 100,000 for females in Canada, 0.43 per 100,000 for females in PEI averaged over 1996-2000).
- Cancer is by far the highest cause of premature death from disease in Prince Edward Island, although it is currently the second most common disease causing death in PEI (after heart disease). Potential years of life lost (PYLL) is a measure of the years of potential life lost to an individual who dies prior to 75 years. **While these numbers can fluctuate widely in a small population such as PEI's, Islanders lost almost 3,300 years of expected life because of cancer in 1997 and about 800 years to heart attack and stroke.** (1999 figure)
- It is estimated that 3,000 Islanders have been diagnosed with cancer during the past fifteen years. As incidence increases and treatments improve, the prevalence of cancer survivors is expected to increase.
- Cancer is currently the twelfth most costly diagnostic category in Canada, estimated to cost approximately \$22,000 per case in direct costs to the healthcare system, including hospitals, hospital-administered drugs, and physician care. Indirect costs of cancer, primarily those associated with loss of productivity due to premature death, are estimated to be five times as high. **In Prince Edward Island, the cumulative total of indirect costs from 2000 to 2015 is estimated to approach \$1.5 billion dollars.**
- Cancer takes an enormous toll on all aspects of health: psychological, emotional, social, spiritual, and physical. Not only patients, but families, colleagues, and communities share in this larger burden.

## Strategy development

The advisory committee agreed upon the following statements to guide the development of this strategy:

### Vision

The PEI Cancer Control Strategy will reduce the burden of cancer in Prince Edward Island.

### Overarching goals

- Reduced cancer incidence, mortality and morbidity.
- Enhanced quality of life for those living with, or recovering from, cancer.
- Improved sustainability of the healthcare system.

### Guiding Principles

The strategy will be:

- evidence-based;
- consumer-focused;
- integrated and efficient;
- sustainable;
- collaborative, building on existing partnerships; and will
- incorporate ongoing monitoring, evaluation and research.

## The strategy

While based on the research and recommendations of the Canadian Strategy for Cancer Control, PEI's strategy was developed to address the province's specific needs and organized around five aspects of the cancer experience: prevention, screening and diagnosis, treatment and supportive care, palliative and end-of-life care, and survivorship. Recommendations related to these areas are summarized in the following pages.

In its review of the provincial situation, the advisory committee noted many positive initiatives which can be built upon and enhanced to meet their concerns. Cancer patients in Prince Edward Island are fortunate to be served in two new facilities by dedicated, well-informed staff and volunteers, and with support from numerous community resources. A newly purchased linear accelerator provides access to radiation treatment close to home. Strategies targeting prevention are already in effect and are making headway quickly, contributing to a reduced use of tobacco, the primary known preventable cause of cancer. The Primary Healthcare Redesign Initiative is investigating different models of improving access to primary healthcare, including family health



centres and expanded roles for nurse practitioners. The Regional Integrated Palliative Care Program has enhanced the capacity to support patients and their families within Island communities during palliative and end-of-life stages.

In similar fashion, the strategy will allow cancer stakeholders throughout PEI to partner to take action on the issues identified within this report, exchanging information and sharing resources when applicable, thereby increasing the overall capacity to meet the needs of cancer patients, their families, healthcare providers and other cancer stakeholders. The strategy builds upon existing strategies, recommending ways to enhance them to meet the particular needs of cancer patients and, in so doing, will benefit those affected by other diseases.

The strategy will encourage Islanders to take an active role to attain their optimal health, from developing healthy lifestyles that may prevent cancer and other chronic diseases to participating in screening programs, learning to recognize early signs or symptoms of cancer and seeking care in a timely manner. Patients must be supported in learning how to navigate the healthcare system, which can seem fragmented and confusing; to participate in making important treatment decisions, many of which have serious side-effects; and to self-advocate to ensure they receive appropriate services in a timely manner. For many patients, their cancer becomes a chronic disease to be managed over time. Such patients and their family members can learn ways to cope and enhance their quality of life through pain and symptom management, nutrition, exercise, stress-relief and emotional support.

The committee identified several major issues which have a great impact on all aspects of cancer care, many stemming from the challenges widely known to be facing our healthcare system. While addressing these issues falls outside of the mandate of the PEI Cancer Control Strategy, they directly affect the delivery of programs and services to cancer patients in Prince Edward Island, including the ability to prevent, diagnose and treat cancers, and to support patients and caregivers during palliation, bereavement or survivorship. Resolution of these issues will support optimal care, not only for cancer patients and their families, but for all Islanders requiring care.

The advisory committee has made the following over-arching recommendations to address these and other issues of overall importance to cancer prevention and care:

- An ongoing financial commitment is necessary to support all aspects of cancer care: prevention, screening, diagnosis, care, palliation, and coordination.
- Aggressive and ongoing recruitment and retention strategies are needed to meet current and future requirements for healthcare professionals and technical staff.

- Access to primary healthcare services is vital to cancer prevention, diagnosis, and patient support. Models of physician care, family health centres, and nurse practitioners must continue to be explored and expanded upon.
- Electronic patient records, with built-in privacy safeguards, will facilitate fast and accurate sharing of pertinent information between hospital departments and physicians.
- Access to medications for cancer treatment and palliation must be improved, including financial assistance for prescribed medications taken outside of the hospital setting and pain management consultations throughout cancer treatment.
- Continued support and expansion of research and evaluation initiatives are needed to provide information on which to base and evaluate prevention programs and health system planning.

Beyond financial and human resources, most of the remaining barriers to providing timely, consistent, integrated and quality care stem from problems in communication and coordination. The Cancer Control Advisory Committee and subcommittee working groups will require ongoing administrative support so they can continue to collaborate to oversee and implement the strategy's recommendations.

## **Major recommendations within five aspects of the cancer experience**

### **1. Prevention**

Research indicates that at least 50 per cent of cancers can be prevented through improved lifestyle behaviours. Similar lifestyle habits are associated with the development of cancer and several other chronic diseases including use of tobacco and exposure to second-hand smoke, low consumption of fruits and vegetables, overweight, and physical inactivity. Several initiatives and strategies have been developed in PEI to address these issues, most notably the PEI Strategy for Healthy Living.

Certain cancers have also been linked to other known carcinogenic agents including alcohol consumption, occupation and environmental exposures, ultraviolet radiation, and infections.

The Prevention Subcommittee will work to reduce cancer incidence, mortality and morbidity in Prince Edward Island. Objectives are to:

- reduce use of tobacco and exposure to second-hand smoke;
- increase consumption of fruits and vegetables;
- achieve healthy body weight;
- increase physical activity to recommended levels;
- reduce alcohol consumption to recommended levels;
- reduce exposure to ultraviolet radiation from sun, sun lamps and sun beds;
- increase knowledge and enhance protection from environmental occupational and domestic carcinogens; and
- promote healthy sexuality, vaccines and screening.

**Action areas:**

- 1: Reduce the incidence of preventable cancers by working with existing strategies to improve lifestyle factors associated with development of cancer and other chronic diseases.
- 2: Reduce exposure to other known carcinogenic agents.

**Major recommendations:**

- Increase public awareness that some cancers can be prevented.
- Identify partners and work to reduce alcohol consumption in PEI to recommended levels.
- Extend the *Occupational Health and Safety Act* to include farmers and farm labourers.
- Monitor national recommendations regarding best practices and policies to reduce exposure to occupational and environmental carcinogens and develop strategies in response.
- Identify partners and work to reduce exposure to ultraviolet radiation.
- Monitor and respond to emerging information about the causes and prevention of cancer.

## **2. Screening and Diagnosis**

Cancers detected at early stages can usually be treated more easily, more cost-effectively, and with more successful outcomes.

The Screening and Diagnosis Subcommittee will work to reduce cancer mortality and morbidity in Prince Edward Island. Objectives are:

- timely presentation of signs and symptoms to a health professional;
- equitable access to primary healthcare;

- effective screening programs for populations at risk of major cancers;
- timely access to diagnostic and staging assessment;
- ongoing monitoring of the diagnostic process; and
- appropriate support for the physical, informational, psychological, social, and practical needs of patients and their families during the peri-diagnostic period.

**Action areas:**

- 1:** Encourage timely presentation of signs and symptoms of cancer to a health professional.
- 2:** Provide effective screening programs targeting populations at risk of specific cancers.
- 3:** Improve timeliness of diagnosis and accuracy of staging assessment.
- 4:** Provide timely, easy access to relevant, understandable information and emotional support for individuals with cancer and their family members during the peri-diagnostic period.

**Major recommendations:**

- Develop procedures to ensure patients without physicians know how to access diagnostic treatment if they have a sign or symptom of cancer and how to follow up on any testing. This would be a temporary measure until equitable access to primary healthcare is provided.
- Develop and implement a strategy to phase in a colorectal screening program in PEI for those aged 50 to 74 years.
- Centralize referrals for diagnostic testing at all hospitals, offering patients access to the earliest available testing.
- Increase awareness among physicians and patients about the need to follow up on diagnostic testing if they have not heard within an identified period.

**3. Treatment and supportive care**

Once a definitive diagnosis has been made, patients may begin a period of treatment to cure their cancer. If cure is not possible, treatment focuses on prolonging life and bringing comfort (palliation). The goals of cure and palliation are carefully balanced throughout treatment, becoming more focused on palliation if the cancer progresses.

Many healthcare professionals may be involved in providing cancer treatment, which can result in care that seems fragmented and lacking in compassion. The average Canadian cancer patient encounters 13 to 97 doctors during the course of their treatment.<sup>1</sup>

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<sup>1</sup>Smith, Nicol, Devereus et al, 1999 cited in Health Canada (2001). “Investigation and Assessment of the Navigator Role in Meeting the Information, Decisional and Educational Needs of Women with Breast Cancer in Canada”. Ottawa: Minister of Public Works and Government Services. p. 5.

The Treatment and Supportive Care Subcommittee will work to reduce cancer mortality and enhance the quality of life of cancer patients and their families. Objectives are:

- timely access to care;
- consistency in standards and guidelines of practice;
- evidence-based, quality treatment and supportive care services;
- seamless, holistic and interdisciplinary management;
- access to clinical trials and new therapies;
- access to supportive and rehabilitative services throughout treatment, including pain and symptom management;
- monitoring of treatment outcomes;
- appropriate care as close to home as possible;
- timely and accurate communication between all care providers; and
- access to ongoing oncology-specific education for all practitioners and volunteers.

**Action areas:**

- 1:** Provide timely access to treatment, supportive care and palliative care.
- 2:** Provide access to consistent and integrated quality care.
- 3:** Increase access to pain control and symptom management throughout the period of cancer treatment.
- 4:** Provide access to supportive, rehabilitative and palliative care throughout treatment.

**Major recommendations:**

- Create the position of patient navigator to coordinate multi-disciplinary cancer care between different care settings, advocate for patients, and to provide support and education to patients and families as they learn to live with cancer.
- Expand the capacity to conduct clinical trials in Prince Edward Island by piloting a one year full-time clinical trials nurse position to inform the sustainability of such a position.
- Explore all avenues to provide catastrophic drug assistance to all Islanders requiring expensive drugs for treatment and palliation of cancer.
- Review all current drug programs to develop a basis on which to establish equitable access to medications.
- Enhance the Integrated Palliative Care Program to include the full scope of outpatient and in-patient pain consults as a provincial service throughout the period of cancer treatment.
- Support and enhance the capacity of existing programs and services so they can provide or direct cancer patients and family members to support for psychosocial needs.
- Develop a program to help cancer patients and family members adjust to living with cancer, access supportive resources, and build skills to manage the disease.

#### **4. Palliative and end-of-life care**

Palliative care is “the combination of active and compassionate therapies intended to comfort and support individuals who are living with, or dying from, a progressive life threatening illness, their families, and the bereaved.”<sup>2</sup>

The Regional Integrated Palliative Care Program was launched provincially in 2003 to develop and train palliative care resource teams within each region to improve access and coordination of palliative services in community settings.

The Palliative and End-of-Life Care Subcommittee will work to enhance the quality of life of cancer patients and their families. Objectives are:

- access to palliative care medications and supplies in all care settings;
- coordination between care settings and care providers;
- consistency of service between care settings; and
- timely access to supportive services, including pain and symptom control, information, psychological, emotional and practical support.

##### **Action areas:**

- 1:** Support and enhance the existing Integrated Palliative Care Strategy in its capacity to provide continuity of palliative care among different care settings.
- 2:** Increase access to palliative care for cancer patients and their families throughout treatment.

##### **Major recommendations:**

- Provide medications and supplies in care settings of choice, particularly for acute palliative patients receiving care in home as a substitute for hospital care.
- Develop strategies to improve access to reasonably priced medications and supplies, particularly in rural communities where they may not be readily available.
- Increase awareness among the public and health providers about the possible role of palliative care throughout cancer treatment.
- Increase access to current information about resources available to support cancer patients and their caregivers to all healthcare professionals, hospice palliative care volunteers, patients and their families.

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<sup>2</sup>PEI Department of Health and Social Services (2003). *PEI Primary Health Care Redesign*. Charlottetown: Department of Health and Social Services. Page 89.

- Provide support and oncology-specific training opportunities to Home Care and Support staff and to other healthcare professionals in supportive roles and hospice palliative care volunteers.
- Encourage increased knowledge and actions to support bereavement for adults and children.
- Expand opportunities to enhance palliative care expertise within various care settings, in addition to that offered by the Regional Palliative Care Resource teams.

## **5. Survivorship**

It is estimated that 3,000 Islanders have been diagnosed with cancer during the past fifteen years. The number of survivors is expected to grow as the incidence of cancer increases and treatments improve. Many survivors and family members may bear ongoing physical, psychological, emotional, and social consequences of cancer.

The Survivorship Subcommittee will work to enhance the quality of life of cancer survivors and their family members. Objectives are:

- to increase general awareness of the ongoing physical, practical, emotional, and psychological needs of cancer survivors and family members; and
- to ensure timely access to necessary supportive resources.

### **Action areas:**

- 1:** Identify and raise awareness about the ongoing needs of cancer survivors and their family members in Prince Edward Island.
- 2:** Develop strategies to respond to the identified needs of cancer survivors and their family members in a timely manner.

### **Major recommendations:**

- Work with members of the existing survivors' support groups to create the Survivors Subcommittee to identify the ongoing concerns of cancer survivors in PEI, and to raise awareness about the needs of cancer patients and their families.
- Develop strategies to respond to the concerns identified by survivors to increase awareness and access to appropriate supports.
- Identify opportunities for volunteer participation in meeting supportive needs of cancer patients and their families, such as developing information kits and methods of dissemination for specific cancers, or adapting information kits and methods from other jurisdictions.

## **A plan for taking action**

The advisory committee will oversee the progress made implementing its recommendations, meeting two or three times a year. Subcommittees already developed to guide recommendations within the first four areas of concern will be formalized and expanded upon to include a wide range of stakeholders. A subcommittee will also be created to address the strategy's fifth area, survivorship. These subcommittees will be responsible for implementing the strategy, including prioritizing recommendations within their section, developing a work plan, and identifying existing indicators and ways to resource their work.

As with the advisory committee, subcommittees will draw their membership from a wide range of stakeholders committed to reducing the burden of cancer in Prince Edward Island. Each will draw upon the resources, expertise, and connections they or their organization can provide to bring these recommendations to fruition.





# 1.0 INTRODUCTION

## 1.1 A strategy to control cancer in Canada

The incidence of cancer has been steadily increasing in Canada, bringing enormous implications to bear on the health of Canadians and the healthcare system. Between 1984 and 1999, the number of cancer cases in Canada increased by 47 per cent, from 88,951 to 130,608 cases<sup>3</sup>. Despite great strides made in treatment, this increase is expected to continue: the Canadian Cancer Society has predicted the number of cancer diagnoses to grow by as much as 60 per cent over the next twenty years.<sup>4</sup> In Canada, almost all the increase in cancer incidence has been driven by two factors: population growth, up 18 per cent during this period, and age, an additional 3.5 per cent of the population were over 65 years, the age after which the majority of cancers are diagnosed.<sup>5</sup>

The Council for the Canadian Strategy for Cancer Control was formed in 2002 by the Canadian Cancer Society, National Cancer Institute of Canada, Health Canada and Canadian Association of Provincial Cancer Agencies to prepare for and, if possible, prevent this increase in disease. The council's mission is to lead development and implementation of a strategy for the control of cancer in Canada. More than 700 Canadians from healthcare and allied professions, academia, the voluntary sector, all levels of government and the cancer patients and survivor community have been involved in the national planning and consultative process, participating in action groups to address core issues spanning the cancer control continuum, from prevention to palliative care.

Their work has resulted in twelve reports containing 94 recommendations, available on the Cancer Control Strategy's Web site, [www.cancercontrol.org](http://www.cancercontrol.org)

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<sup>3</sup>Health Canada (2003). *Cancer Incidence over Time: All Cancer Sites, Both Sexes Combined, All Ages, Canada, 1984-1999*. Cancer Surveillance On-Line. Retrieved April 28, 2003 from [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>4</sup>Canadian Cancer Society(2004). "Cancer is Number One Cause of Early Death in Canada – Number of New Cancer Cases Increasing – National Coordinated Strategy Key to Fighting Canada's Cancer Crisis." Media release, April 14, 2004.

<sup>5</sup>Statistics Canada (2003). *Age Groups and Sex for Population, for Canada, Provinces and Territories, 1921 to 2001 Censuses*. Retrieved April, 24, 2003 from [www.statcan.ca](http://www.statcan.ca)

The national council has identified the following national priorities and goals:

- 1. Clinical Practice Guidelines**  
To establish and sustain a pan-Canadian strategy to facilitate the optimal use of evidence-based guidelines for cancer control.
- 2. Standards**  
To establish an inter-provincial/territorial mechanism to promote and facilitate the development, dissemination, uptake and evaluation of evidence-based national standards in key aspects of cancer control care.
- 3. Primary Prevention**  
To establish a national, provincial/territorial, and municipal primary prevention system to address population-based risk factors for cancer and other chronic diseases, by collaborating with chronic disease constituencies.
- 4. Rebalanced Focus**  
To provide leadership directed toward changing the focus of cancer care so that patients' needs are better served.
- 5. Human Resources**  
To establish a national comprehensive strategy for human resources.
- 6. Research**  
To define national research priorities and create a plan for investment in these priority areas.
- 7. Surveillance**  
To establish and operate a high quality national cancer surveillance system that brings together cancer epidemiological data and cancer care and control information of the provinces and territories to facilitate effective planning, implementation, monitoring and evaluation of Canadian cancer control efforts.

While the council's vision is national in scope, actual implementation of most recommendations will be the responsibility of provincial and community health authorities and organizations. For this reason, each province has been encouraged to develop a strategy to execute the council's recommendations at the provincial level.

Prince Edward Island was the first province to begin working on a provincial strategy in the spring of 2002. Planning is now at various stages in other provinces.

## **1.2 The Prince Edward Island Cancer Control Strategy**

In May of 1998, the Canadian Cancer Society, PEI Division identified a need to bring together stakeholders concerned about cancer control and surveillance in Prince Edward Island. A number of provincial and national events acted as catalysts to stimulate these discussions, including the National Cancer Institute Canada's definition of cancer control, the cancer control report care released by Cancer Care Ontario, and the Schabas Report which provided the framework to look at cancer control in Canada.

With leadership from the Canadian Cancer Society, a number of meetings were held over the next 18 months to determine priority issues in PEI. A stakeholder survey provided a platform for stakeholders to contribute to identifying issues and priorities of concern. This initial stakeholder group from the Canadian Cancer Society, government, and community formed the initial PEI Cancer Control Committee. The purpose was to promote a comprehensive approach to cancer control and assessment of the capacity already available on Prince Edward Island.

After a number of funding proposals were not successful, and aware that a national cancer control strategy was being developed, PEI decided to wait until the national framework was fleshed out so that PEI could be positioned well to move on.

During the ensuing years, the PEI Cancer Control Committee continued to monitor and advocate in PEI to move a PEI control strategy that was in line with the developing national strategy. In early 2001, the national strategy needed commitment from the provinces to move it forward. PEI's background work had positioned it well to be one of the first provinces to have government support to produce a PEI cancer control strategy, which was announced in the speech from the throne in November 2001.

An advisory committee was formed in May of 2002 to provide guidance to develop a provincial cancer control strategy to be integrated with the national work. Membership was drawn from a previous cancer working group and included representation from the PEI Cancer Treatment Centre, the Canadian Cancer Society, cancer survivors, the provincial representative on the national council, PEI Medical Society, UPEI School of Nursing and representatives from the PEI Department of Health and Social Services. Membership has since expanded to include representation from the Hospice and Palliative Care Association of PEI; Diagnostic Imaging Department of the PHSA; the PEI Cancer Registry; and other cancer survivors and family members.

As well as having multi-sectoral guidance, strategy development has been cost-shared by the PEI Department of Health and Social Services and the Canadian Cancer Society, PEI Division.

Advisory committee members have given careful consideration and guidance to all facets of the strategy's development, sharing their expertise and resources. The committee has also drawn upon the input of experts who contributed to this discussion through subcommittees formed to focus discussion on specific topics, or through extensive interviews conducted while preparing an inventory of supportive resources. The resulting strategy reflects their collective knowledge and advice on how to reduce the burden of cancer in Prince Edward Island.

The PEI Cancer Control Strategy has concentrated recommendations on five areas of the cancer experience: prevention, screening and diagnosis, treatment and supportive care, palliation and end-of-life care, and survivorship.

In areas affecting the delivery of medical services, similar issues were continuously encountered, including access to primary care, recruitment of medical and technical staff, commitment of adequate financial resources, coordination of care and access to medications. These issues have an enormous impact on cancer diagnosis and care, although in most cases, solutions are well beyond the mandate of this committee. The committee has made several over-arching recommendations to address these major concerns. These are noted separately.

The process of developing a strategy has already made several contributions to controlling the burden of cancer in PEI, including:

- Creation of a provincial forum through which a wide range of stakeholders can work together to identify and meet the needs of cancer patients, sharing information about cancer from a variety of sectors, disciplines, regions, and perspectives.
- Creation of four subcommittees to identify existing resources, strategies, needs and gaps within specific areas of cancer care: prevention, screening and diagnosis, treatment and supportive care, and palliative and end-of-life care.
- Compilation and dissemination of information to advisory committee members and their organizations concerning the existing cancer burden in PEI: risk factors, major issues, and national and international literature about best practices in cancer prevention, diagnosis, treatment, palliation and survivorship.
- Increased awareness of the different perspectives, programs, and capacities of member organizations. This has facilitated collaboration between member organizations on specific projects to enhance support for cancer patients and their family members in Prince Edward Island, such as the patient and family resource centre at the Cancer Treatment Centre, furnished and stocked by the Canadian Cancer Society, PEI Division.

- Compilation of an inventory of resources that offer support to cancer patients in all areas of the province, including practical, emotional, and palliative care and dissemination to advisory committee members and their organizations.
- Information-sharing and increased understanding among a wide range of professionals and volunteers throughout the province, including assessment of issues faced by cancer patients at local levels and provincial challenges.
- Sharing of background information with other provincial agencies with an interest in cancer issues.



## 2.0 BACKGROUND: THE BURDEN OF CANCER IN PRINCE EDWARD ISLAND

### 2.1 What is cancer?

Cancer is the term given for a variety of diseases, all of which are characterized by the uncontrolled growth and spread of abnormal cells in the body.

Often detected when a lump or tumour becomes apparent to the individual or physician, cancer may also become evident from signs of abnormal bleeding, as in lung or bladder cancer; functional disturbances, as in brain cancer; or pain caused by pressure on nerves.

Cancer develops in several phases, depending on the type of tissue affected. Typically, these phases are dysplasia, a change in the character of the cells; *in situ* carcinoma, non-invasive tumours; localized invasive cancer, invasion and destruction of adjacent tissues; regional lymph node involvement; and distant metastases, spread through the blood or lymphatic system to affect other organs. Metastases is the major cause of death from malignant diseases.<sup>6</sup>

No two individuals will experience cancer in exactly the same way. Treatments will vary for many reasons, including the type of cancer and its stage, the patient's individual physiology, and personal preferences. Patients may also respond to treatments quite differently. For some, their treatment will be relatively non-invasive and they will remain cancer-free, others will undergo ongoing difficulties and distress, sometimes for many years.

In addition to the physical aspect of cancer, it also has emotional, psychological, social, spiritual, financial, and practical repercussions. Receiving diagnosis of a life-threatening illness such as cancer is a traumatic event in the lives of patients and their families regardless of how successfully it is treated. Just as treatments vary, so too will patients' and family members' abilities to cope. Some will be able to draw upon their own support systems to help them through, while others will be completely overwhelmed and experience emotional, marital, or family breakdown.

A variety of interventions are needed to meet the multiple needs of patients and their families in ways that are most appropriate to them.

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<sup>6</sup>World Health Organization (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*; World Health Organization, Geneva, 2002.



## **2.2 Cancer control and the cancer burden**

Cancer control takes a coordinated and strategic approach to reducing the impact of cancer on an individual or a population by preventing cancer, curing cancer, or increasing survival rates and quality of life for those affected by cancer.

Within a population, this impact is referred to as the “cancer burden”, and includes the rates of incidence and mortality, years lost to premature death, prevalence of survivors, and economic cost, and the grief and suffering of patients, families and friends and the demands on healthcare providers.

Possible interventions can be made throughout the cancer continuum. It is estimated that about 50 per cent of cancers can be prevented, by far the preferred option. Certain cancers can be screened for and diagnosed at early stages, when treatments have a greater chance of success and may be less invasive and less costly. Coordinated treatment and supportive care can improve outcomes, enhance the quality of life for cancer patients and their families, and ensure optimal use of supportive resources. Support can also enhance the lives of patients and families throughout palliation, and bereavement or survivorship.

## 2.3 Causes of cancer

Cancer is closely associated with increased age: 66 per cent of males and 59 per cent of females diagnosed with cancer in PEI between 1983 and 1997 were over the age of 65.<sup>7</sup>

Cancer develops through complex interactions of genes and external agents, normally taking many years. It is generally considered that external exposures play a major role in the development of cancer, though genetics and individual sensitivities can cause a great variation in the susceptibility to lifestyle and environmental factors. Current research indicates that at least 50 per cent of cancers can be prevented.<sup>8</sup>

Most experts agree that tobacco exposure is responsible for about 30 per cent of cancers. Other preventable causes include a diet deficient in fruits, vegetables and fibre; obesity; physical inactivity; immoderate use of alcohol; exposure to the sun; occupational and environmental exposure to carcinogens, and infections.<sup>9</sup> Many lifestyle behaviours are further associated with disadvantaged socioeconomic circumstances, including low income, low education, stress, and a lack of choice or control over one's life.<sup>10</sup>

These behaviours and circumstances are also closely associated with development of many other chronic illnesses including heart disease, diabetes, hypertension and mental illness.

Though effectively changing these circumstances presents a daunting challenge, there is also reason for optimism. Some cancers and other chronic diseases are preventable. Concerted efforts to address the fundamental causes of disease provide the greatest opportunity to reduce the burden of cancer on Prince Edward Island.

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<sup>7</sup>Van Til, LD & Dryer, D. (1997). *Cancer Trends in Prince Edward Island 1983-1997*; Epidemiology Unit, Prince Edward Island Department of Health and Social Services, Dec. 1997.

<sup>8</sup>Schabas, Richard (2003). *Primary Prevention of Cancer: Background Paper*, Schabas Associates Inc. retrieved March 27 from [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>9</sup>Ibid.

<sup>10</sup>Hayward K, Colman, R (2003). *The Tides of Change: Addressing Inequity & Chronic Disease in Atlantic Canada: A Discussion Paper*. Prepared for Public Health Branch, Health Canada: Atlantic Office.

## 2.4 The incidence of cancer in Prince Edward Island

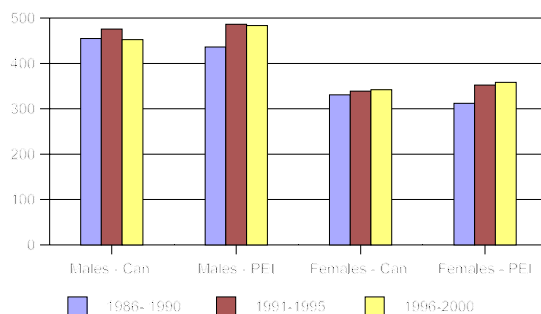
The incidence of cancer has been increasing in Prince Edward Island as it has in Canada overall. In 1985, there were 455 diagnoses of cancer in PEI. By 2002, this number had grown to 696.

Because of PEI's small population, the incidence of specific cancers can fluctuate widely from year to year. Age-standardized rates allow comparisons to be made between regions and beyond the influence of population age and size. Such statistics are calculated per 100,000 population, meaning that information is extrapolated from a very small number of cases in Prince Edward Island, especially concerning rare cancers or rates per age group. The following graph shows age-standardized rates that were averaged and compared over three five-year periods for PEI and Canada. It shows an increase in cancer incidence in PEI beyond that seen nationally.

All Atlantic provinces tend to have higher incidence of cancer and other chronic diseases than do other areas of Canada. The geographic pattern of cancer incidence tends to increase from west to east across Canada, as does the general trend of known major lifestyle risk behaviours: tobacco use, deficient diet, overweight and obesity, and physical inactivity. Socioeconomic conditions, which tend to be lower in Atlantic Canada, have also been shown to be inversely related to higher prevalence of chronic disease, including cancer.<sup>11</sup>

Screening programs introduced during the 1990s in PEI may also cause a temporary increase in cancer incidence by providing a greater window of opportunity in which they can be detected. After programs have become well-established, incidence is expected to return to earlier levels, resulting in screened cancers detected at earlier, and more easily treatable, stages. Incidence may also vary between jurisdictions or over time because of changes in registry standards which may account for the apparently large increase in incidence between the late '80s and early '90s.

**Comparison of Canadian and Prince Edward Island age-standardized rates of cancer incidence averaged over five-year periods, 1986-90, 1991-95 and 1996-2000 (per 100,000 pop.)**



*Data from Cancer Surveillance On-Line*

<sup>11</sup>Hayward K, Colman, R ( 2003).

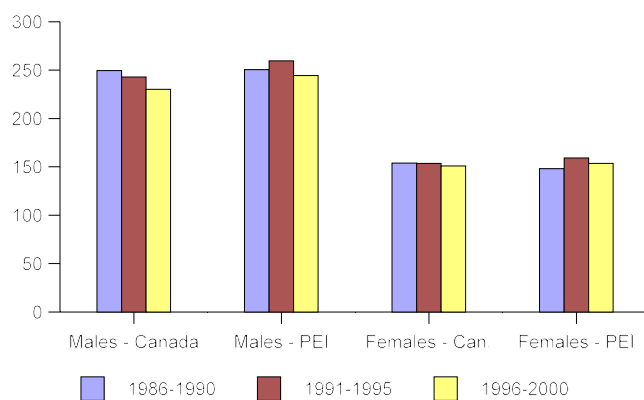
## 2.5 Mortality from cancer in Prince Edward Island

A population's rate of mortality from cancer is influenced by the proportion and prognosis of specific cancers. Lung cancer, for instance, has a much lower five-year survival rate than breast or prostate cancers. In populations with high proportions of lung cancer, such as PEI, mortality will tend to be higher. Mortality rates will also reflect the success of cancer treatments, delays in diagnosis, and early detection through screening and public education programs.

During the period 1984-1999, age-standardized mortality rates have gradually declined in Canada. PEI rates have also started to decline.

As can be expected from higher rates of cancer incidence, rates of mortality from cancer in PEI are also higher than Canadian averages. The ratio of mortality to incidence rates in Prince Edward Island is, however, either the same or slightly lower than the national average, indicating a good basic quality of cancer care in the province: 0.51 per 100,000 for males in both PEI and Canada, 0.44 per 100,000 for females in Canada, 0.43 per 100,000 for females in PEI averaged over 1996-2000.<sup>12</sup> (See Appendix I)

**Comparison of Canadian and Prince Edward Island age-standardized rates of mortality from cancer averaged over five-year periods, 1985-89, 1990-94 and 1995-99 (per 100,000 pop.)**



*Data from Cancer Surveillance-On-Line*

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<sup>12</sup>Cancer Surveillance On-Line (2003). "Cancer Incidence over Time & Cancer Mortality over Time." Retrieved Feb. 17, 2003 from [www.hc-gc.ca](http://www.hc-gc.ca)

## 2.6 Potential years of life lost to cancer in Prince Edward Island

Potential years of life lost (PYLL) refers to the years of potential life lost to an individual who dies prior to 75 years of age. In both Canada and Prince Edward Island, heart disease is the major cause of death, although cancer is by far the leading cause of premature death.<sup>13</sup>

The following table shows the estimated years lost to the major sites of cancer for both men and women in 1999 and from all types in cancer in 1997. For comparison purposes, PYLL is also shown for heart attack and stroke in 1999.

### Potential years of life lost due to selected cancers and heart attack and stroke, age 0 to 74 years, Canada and PEI, 1999, per 100,000 population, by sex

Site of primary cancer	Males		Females	
	Canada	PEI	Canada	PEI
All types of cancer (1997)*	1652	1764	1553	1514
Lung cancer	490.9	694.9	344.3	297.9
Colorectal cancer	158.5	201.9	110.8	193.4
Prostate cancer	55.6	46.6		
Breast cancer			338.5	464.2
Heart attack & stroke	604.9	504.7	264.1	282.4

Prince Edward Island Common Health Indicators Report<sup>14</sup>

\* Statistics Canada<sup>15</sup>

<sup>13</sup>Health Canada (1999). *Toward a Healthy Future: Second Report on the Health of Canadians*. Minister of Public Works and Government Service, Ottawa, Canada.

<sup>14</sup>PEI Department of Health and Social Services, 2002. *Prince Edward Island: Common Health Indicators Report*. Charlottetown, PEI.

<sup>15</sup>Statistics Canada (2003). *Deaths: Potential years of life lost. Health Indicators, vol 2003, no. 2*. Retrieved November 2003 from [www.statcan.gc.ca](http://www.statcan.gc.ca)

## 2.7 Prevalence of cancer in Prince Edward Island

The National Cancer Institute of Canada estimates that 2.1 per cent of Canadian men and 2.4 per cent of women have had a diagnosis of cancer within the past 15 years.<sup>16</sup> While most cancer survivors do not continue to require treatment, a certain number of individuals will continue to need medical, rehabilitation and supportive care. Survivors require careful monitoring because of the risks of recurrence or of developing a second primary cancer. They and their family members may also bear a variety of other physical, emotional, psychological and spiritual effects from their cancer experience.<sup>17</sup> These may not be entirely negative. Many survivors report a heightened appreciation of life and become dedicated volunteers working in a variety of ways to help others.<sup>18</sup>

Similar prevalence rates would indicate that more than 3,000 Islanders are fairly recent survivors of cancer. A 70 per cent increase in incidence would see more than 5,000 recent cancer survivors in PEI in 2015. In future years, prevalence is expected to grow as treatments improve and people live for longer times with cancer. Cancer Care Ontario suggests the increase in prevalence rates may, in fact, be almost twice as high as new incidence, 4.4 per cent annual increase in prevalence as opposed to 2.8 per cent increase in incidence.<sup>19</sup>

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<sup>16</sup>Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada (2003). *Canadian Cancer Statistics 2003*. Available on Internet at [www.cancer.ca](http://www.cancer.ca)

<sup>17</sup>Ibid.

<sup>18</sup>National Institute on Aging and National Cancer Institute (2001). *Exploring the Role of Cancer Centers for Integrating Aging and Cancer Research: Workshop Report*. Retrieved August 18, 2003 from <http://www.nia.nih.gov/health/nianci/reports.asp>

<sup>19</sup>Cancer Quality Council of Ontario (2003). *Strengthening the Quality of Cancer Services in Ontario: Synopsis*. Retrieved from [www.cancercare.on.ca](http://www.cancercare.on.ca)

## 2.8 Economic burden of cancer in Prince Edward Island

Cancer is the twelfth most costly diagnostic category in Canada for direct costs to the healthcare system. Costs include hospitals, drugs, physician care, other institutions and miscellaneous expenditures.

Indirect costs, including the loss of productivity from premature mortality and long-term and short-term disability, place cancer as the second most costly diagnostic category. More than 90 per cent of the indirect costs of cancer, such as costs associated with disability and loss of wages and productivity, result from premature death.<sup>20</sup>

Cancer Care Ontario estimates the current average direct costs for cancer care in 2003, including physicians, hospital care and anti-cancer drugs, to be \$22,000 per individual. Indirect costs are estimated to be about five times as high.<sup>21</sup>

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<sup>20</sup>Health Canada (2002). *Economic Burden of Illness in Canada, 1998*. Policy Research Division, Strategic Policy Directorate, Population and Public Health Branch. Publications, Health Canada. Ottawa. Also available at [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>21</sup>Cancer Care Ontario, Canadian Cancer Society (2003). *Targeting Cancer: An action plan for cancer prevention and detection. Cancer 2020 Background Report*. Retrieved from August 25, 2003 from [www.cancercare.on.ca/pdf/Cancer2020BackgroundReportMay2003.pdf](http://www.cancercare.on.ca/pdf/Cancer2020BackgroundReportMay2003.pdf)

## 2.9 Projected costs of cancer to 2015 in Prince Edward Island

The following estimates are based on direct costs per cancer case of \$22,000 in 2003 dollars.<sup>22</sup> Indirect costs are estimated to be five times as high, indicating the cumulative indirect costs of cancer to 2015 could approach \$1.5 billion dollars.

	Cancer incidence 2000	Est. incidence 2015	Cum. Incidence 2000-2015	Est. direct costs in 2000	Est. direct costs in 2015	Cum. direct costs 2000-2015	Est. indirect costs 2000	Est. indirect costs 2015	Cum. indirect costs 2000-2015
<b>All cancers</b>	672	1050	<b>13300</b>	15M	23 M	<b>293M</b>	75M	115M	<b>1.47 B</b>
<b>Cancers associated with tobacco use (est. 30% of all cancers)</b>	202	320	<b>4000</b>	4M	7M	<b>88 M</b>	22M	35M	<b>440M</b>
<b>Cancers associated with diet/obesity/physical inactivity (possibly linked to 30% of all cancers)</b>	202	320	<b>4000</b>	4M	7 M	<b>88 M</b>	22M	35M	<b>440M</b>
<b>Other preventable cancers associated with exposures to alcohol, occupational &amp; environmental carcinogens, ultraviolet radiation and infections (possibly linked to 20% of all cancers)</b>	135	210	<b>2660</b>	3M	5M	<b>59M</b>	15M	23M	<b>293M</b>
<b>Cancers detectable through screening programs (est. incidence 2003 for breast, cervical &amp; colorectal)<sup>23</sup></b>	210	330	<b>4150</b>	5M	7M	<b>91 M</b>	23M	36M	<b>457M</b>

(Growth in incidence is based on Cancer Care Ontario's estimate of 2.8% per year,<sup>24</sup> similar to the rate of increase in PEI from 1983 to 2001.<sup>25</sup> PEI-specific projections about the effects of the aging population can be expected in 2004. Cost estimates are rounded to the closest million and based on proportion rather than costs of specific associated cancers.)

<sup>22</sup>Cancer Care Ontario (2003).

<sup>23</sup>All estimates of preventable cancers based on World Health Organization (2003) and Miller, Anthony B (2000). "The Brave New World - What Can We Realistically Expect to Achieve Through Cancer Control Early in the New Millennium?", in *Chronic Diseases in Canada*, Volume 20, No. 4, 2000, retrieved from www.hc-sc.gc

<sup>24</sup>Cancer Care Ontario (2003).

<sup>25</sup>PEI Cancer Registry. Also from Van Til, L. and Dryer, D. (1997) *Cancer Trends in Prince Edward Island 1983-1997*; Epidemiology Unit, Prince Edward Island Department of Health and Social Services.



## **2.10 Summary: the cancer burden in Prince Edward Island**

Cancer is known to exact a heavy burden on the population of Prince Edward Island. The incidence, already higher than national average, is growing and expected to continue to do so. While it is the second most common cause of death in Prince Edward Island behind heart disease, it is by far the highest cause of premature death.

National estimates show that cancer ranks twelfth in direct costs to our healthcare system, and second to musculoskeletal disease in indirect costs, or costs associated with disability and loss of wages and productivity because of premature death. There is no measure of personal financial costs, ongoing costs associated with bereavement, or of training staff to replace workers who were in the prime of life.

In a province as small as PEI, people's acquaintanceships reach deeply into the community and it is impossible to read these statistics without seeing names and faces.

Anyone who has experienced cancer, whether their own or a loved one's, knows it takes an enormous toll on all aspects of health: psychological, emotional, social, spiritual, financial, and physical.

Statistics and economic projections can quantify and define only part of cancer's burden on a community.

## 3.0 PEI CANCER CONTROL STRATEGY

The following vision, goals and principles have provided guidance to the development of Prince Edward Island Cancer Control Strategy.

### Vision

**The PEI Cancer Control Strategy will reduce the burden of cancer in Prince Edward Island.**

### Over-arching goals

- Reduced cancer incidence, mortality and morbidity.
- Enhanced quality of life for those living with, or recovering from, cancer.
- Improved sustainability of the healthcare system.

### Objectives

- Equitable access to evidence-based cancer control interventions;
- improved integration of cancer health care, from primary healthcare to palliative care;
- re-balanced investments that sustain effective prevention, psychosocial, supportive and palliative care;
- empowered patients; and
- increased research capacity and knowledge base for cancer control.

### Guiding Principles

The strategy will be:

- evidence-based;
- consumer-focused;
- integrated and efficient;
- sustainable;
- collaborative, building on existing partnerships; and will
- incorporate ongoing monitoring, evaluation and research.

### **3.1 Over-arching recommendations**

#### **Background:**

As most Canadians and Islanders are aware, our national healthcare system is facing several challenges. Studies such as the Kirby and Romanow reports have received a great deal of national and provincial media coverage and raised public awareness about the increased demands on the healthcare system brought about by factors such as the aging population, availability of new technologies, rocketing drug costs, and national – if not global – competition for human resources.

These challenges directly affect the optimal delivery of programs and services to cancer patients in Prince Edward Island, including the ability to prevent, diagnose and treat cancers; and to support patients and caregivers during palliation, bereavement or survivorship. While remedies lie well beyond the mandate of the Cancer Control Advisory Committee, unless the wider issues are addressed, the committee's more easily achievable recommendations can offer only minimal affect on reducing the burden of cancer in Prince Edward Island.

An ongoing commitment of financial resources is essential to support the research and programs to prevent cancer and the specialized equipment, personnel, and facilities to be able to screen, diagnose and treat cancers in a timely manner. Access to medications to treat cancer or offer respite from pain and other associated symptoms is crucial to providing a humane standard of care, as is access to compassionate and practical support throughout the cancer experience.

Human resources will always pose a challenge in a small, rural and fiscally pressed community such as Prince Edward Island. It is, however, impossible to over-state the impact such shortages have on the diagnosis and care of cancer patients. Many Islanders are currently without the primary healthcare providers responsible for coordinating a cancer diagnosis, ensuring the correct tests are analysed in a timely manner, making referrals for treatment, and coordinating follow-up care. While diagnostic testing and analysis is triaged, human resource shortages in these areas can result in lengthy wait periods, during which time a cancer can progress from the early, and more easily treatable stages, to the terminal stage. Human resource shortages bear similar impact within all areas of cancer care and can also be expected to have repercussions on staff recruitment and retention.

While financial and human resource issues are of critical importance, there are other, more positive, circumstances. Cancer patients in Prince Edward Island are fortunate to be served in two new facilities by dedicated, well-informed staff and volunteers, with support from numerous community resources. A newly purchased linear accelerator provides access to radiation treatment close to home. Strategies targeting prevention and palliation are already in effect and quickly making headway, contributing to a reduced use of tobacco, the primary known preventable cause of cancer. Beyond financial and human resources, most of the remaining care issues concern improved communication and coordination.

In its review of the cancer care situation in PEI, the advisory committee has been able to recommend several ways in which they and other stakeholders can work to make the existing system more efficient and improve access to supportive resources for cancer patients and their families. While it is expected these recommendations will help to reduce the burden of cancer in PEI, major issues affecting the health system in PEI and beyond must be addressed to enable optimal care not only for cancer patients and their families, but for all Islanders requiring care.

The following over-arching recommendations address these major issues. Their impact is noted throughout this document and affect many areas of cancer prevention and care.

- **Financial commitment**  
Cancer diagnosis and treatment is expensive. Cancer Care Ontario has estimated average costs per cancer case to be \$22,000 in 2003. An ongoing commitment of financial resources is needed to provide adequate numbers of healthcare professionals and technical staff, specialized equipment, and appropriate facilities to support screening and diagnosis of cancer; access to cancer treatment including prescribed medications; continuity of care between home and hospital or long-term care settings; and support to the ongoing work and strategy development of the cancer control strategy advisory committee and subcommittees.
- **Recruitment and retention of health professionals and technical staff**  
Skilled employees are in short supply throughout the labour market due to the aging demographic. This is of crucial importance in the health sector, since it is both labour intensive and dependent on a specialized workforce. It is even more challenging in a small, rural province such as Prince Edward Island. Inadequate staffing can cause delays in diagnosis and treatment; uncoordinated care; distress for patients, family members and their caregivers; and may negatively affect staff recruitment and retention.

Aggressive and ongoing recruitment strategies are needed to meet current and future needs.

- **Access to primary healthcare services**

Primary healthcare services are those that people access first and most often. Primary healthcare plays an important role in all areas of cancer care: educating patients about prevention and risks; coordinating diagnosis; monitoring and responding to patients' and family members' needs when at home; providing support to patients and families learning to live with cancer and when palliative or bereaved.

The province is exploring different models of providing primary healthcare services including physician care, family health centres and expanded roles of nurse practitioners. These models and other innovations should continue to be explored and expanded upon.

- **Electronic patient records**

Currently, patient records must be transcribed, copied, and physically delivered to different departments within and between hospitals. These procedures can cause delays in communication, loss or misplacement of vital information, and the repetition of expensive testing procedures. Although electronic patient records are expensive to implement, they are the norm in other jurisdictions and would offer unparalleled contributions to the provision of integrated, timely diagnosis and care, the reduction of duplicate or redundant services, and would support continual monitoring and service improvement.

The records would require proper safeguards and levels of confidentiality to protect the privacy of patients. Eventually, access to essential patient records through physicians' offices would also support enhanced care.

- **Improved access to medications for cancer treatment and palliation**

Major issues concerning access to medications include the financial burden experienced by some patients and the lack of access to pain management consultations throughout cancer treatment. Both issues are discussed in greater detail in Section 3.4 Treatment and Supportive Care and Section 3.5 Palliative and End-of-Life Care.

Medication is the fastest growing medical expense in Canada, now accounting for the second largest category of medical expenditures after hospitals.<sup>26</sup> The Canadian healthcare system pays only for medications received in hospital. Meanwhile, hospital care has been drastically reduced during the last decade and new technologies have allowed some drugs which were previously administered in hospital to be taken in home settings. These factors have shifted greater financial responsibility to individual patients.

In Prince Edward Island and the other Atlantic provinces, financial assistance to help purchase prescribed drugs is extremely limited. It is estimated that one in four Islanders have no private drug insurance to help defray these costs, which can create financial hardship for patients and families and in some cases patients may choose not to follow a course of treatment to spare their family from the financial burden. See Appendix II for a breakdown of out-of-pocket prescription drug expenses paid in all Canadian provinces.

Strategies must be developed to improve access to medications needed for treatment or palliation of cancer patients.

- **Evidence on which to base and evaluate programs and practices**  
On-going monitoring and evaluation of programs and practices helps to ensure cost-effectiveness and public accountability. Electronic patient records will significantly assist in this process. Feedback from health professionals and survivors will provide on-going qualitative evaluation.

Epidemiological research into the incidence and trends of cancers is needed to provide information on which to base and evaluate prevention programs and health system planning, while behavioural research about the development of unhealthy lifestyles and best ways to effect changes can provide information on which to base cost-effective and evidence-based interventions. In recent years, PEI has greatly expanded its research capacity, supporting development of some of the most progressive prevention programs and policies in Canada, and as the means to monitor and continually improve them.

The capacity to conduct research must continue to be supported and expanded upon.

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<sup>26</sup>Millar, Wayne, J. (1999). "Disparities in prescription drug insurance coverage". *Statistics Canada: Health Reports, Spring 1999*. Vol. 10, No. 4, p. 13.

- **Continued role of the Cancer Control Advisory Committee**  
Prince Edward Island and New Brunswick are currently the only two provinces without a cancer care agency working to develop and evaluate coordinated policy regarding cancer. Establishment of the Cancer Control Advisory Committee has begun this process in PEI. It has provided a forum for a wide range of stakeholders to share their expertise and perspectives, identifying and developing plans to respond to provincial cancer issues. In its continued role, the committee will oversee and facilitate ongoing collaboration to reduce the provincial burden of cancer and offer a united voice to express the concerns of cancer patients, their families and healthcare providers. Subcommittees, currently operating on an ad-hoc basis, should be formalized and expanded to address concerns within each specific topic.

These committees will require ongoing coordination and project support.

## 3.2 Prevention

**Goal:** To reduce cancer incidence, mortality and morbidity by decreasing the number of preventable cancers.

**Objectives:**

- Reduce use of tobacco and exposure to second-hand smoke.
- Increase consumption of fruits and vegetables.
- Achieve healthy body weight.
- Increase physical activity to recommended levels.
- Reduce alcohol consumption to recommended levels.
- Reduce exposure to ultraviolet radiation from sun, sun lamps and sun beds.
- Increase knowledge and enhance protection from environmental occupational and domestic carcinogens.
- Promote healthy sexuality, vaccines and screening.

**Action area 1:**

Reduce the incidence of preventable cancers by working with existing strategies to improve lifestyle factors associated with development of cancer and other chronic diseases.

**Action area 2:**

Reduce exposure to other known carcinogenic agents.



**Action area 1: Reduce the incidence of preventable cancers by working with existing strategies to improve lifestyle factors associated with development of cancer and other chronic diseases.**

**Rationale:**

Research indicates that at least 50 per cent of cancers can be prevented through improved lifestyle behaviours.<sup>27</sup> Some evidence indicates this figure may be much higher.<sup>28</sup>

**Background:**

Similar lifestyle habits are associated with the development of cancer and several other chronic diseases. These include use of tobacco and exposure to second-hand smoke, low consumption of fruits and vegetables, overweight, and physical inactivity.

Though there are no guarantees for individuals, on a population-wide basis, healthier lifestyles will reduce the incidence of certain preventable cancers.

The latency period of the development of cancers related to lifestyle is unknown, but thought to occur over a long duration. As it is most desirable to establish life-long positive health habits, the primary target audiences are children, youth, young adults and young families. As new information emerges, it may be possible to design prevention programs or information for particular audiences, such as those at genetic risk of specific cancers.

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<sup>27</sup>Schabas, Richard (2003). *Primary Prevention of Cancer: Background Paper*, Schabas Associates Inc. retrieved March 27 from [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca). Page 6.

<sup>28</sup>World Health Organization (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*; World Health Organization, Geneva, 2002. Page 15

## Factors:

- **Tobacco**

The use of tobacco is firmly linked with several cancers. As many as 30 per cent of cancers may be caused by exposure to tobacco.<sup>29</sup> PEI has high rates of smoking and exposure to second hand smoke. Smoking rates have substantially decreased over the last 15 years among men but increased among women.<sup>30</sup> Risks of developing cancer increase with the amount and duration of smoking.<sup>31</sup>

- **Diet**

A plant-based diet is associated with a lower incidence of certain types of cancer. Poor diet, together with physical inactivity and obesity, may be responsible for 30 per cent of cancers.<sup>32</sup> Nutritional surveys show low consumption of fruits and vegetables in PEI.<sup>33</sup> Cancers associated with poor nutrition likely develop as a result of long-term lifestyle habits. It may take 10 years or more for benefits from dietary changes to become apparent.<sup>34</sup> The links between diet and cancer are complex and a topic of much research, particularly as to which cancers can be linked to diet and which nutrients are involved. While poor diet has been associated with many chronic diseases, cancer prevention may have some specific nutritional recommendations such as fibre, folate, etc.<sup>35</sup>

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<sup>29</sup>Miller, Anthony B (2000). "The Brave New World - What Can We Realistically Expect to Achieve Through Cancer Control Early in the New Millennium?", in *Chronic Diseases in Canada*, Volume 20, No. 4, 2000, retrieved from [www.hc-sc.gc](http://www.hc-sc.gc)

<sup>30</sup>"Canadian Tobacco Use Monitoring Survey (2002)." Retrieved from [www.hc-sc.gc.ca/hecs-sesc/tobacco/research/ctums/](http://www.hc-sc.gc.ca/hecs-sesc/tobacco/research/ctums/)

<sup>31</sup>Health Canada (2002). *Sleeping With a Killer: The Effects of Smoking on Human Health*. Retrieved Jan. 27, 2003 from [www.hc-sc.gc.ca/hccs-sesc/tobaco/facts/swak/o8\\_benetis.htm](http://www.hc-sc.gc.ca/hccs-sesc/tobaco/facts/swak/o8_benetis.htm)

<sup>32</sup>Schabas, Richard (2003).

<sup>33</sup>Taylor, Jennifer, Van Til, Linda, MacLellan, Deborah (2002). *Prince Edward Island Nutrition Survey*. PEI Health and Social Services and University of PEI Family and Nutritional Sciences; Document Publishing Centre, Charlottetown, PEI.

<sup>34</sup>Miller, Anthony (2000).

<sup>35</sup>Jenkins, David J.A. (2001). "Diet and Chronic Disease: Potential Impact and Unanswered Questions: A Background Document." Prepared for the Prevention Unit, Division of Preventive Oncology, Cancer Care Ontario. Retrieved from [www.cancercares.on](http://www.cancercares.on)

- Obesity**

Several cancers have been linked to obesity. Body Mass Index (BMI) over 25 (considered overweight) or over 30 (considered obese) are generally associated with poor health.<sup>36</sup> Fifty-seven per cent of Islanders report a BMI over 25.<sup>37</sup> Obesity results from an interaction of genetics, physical activity levels and diet, and is very difficult to change once established.
- Physical inactivity**

Physical inactivity has been linked with several cancers including colon cancer, the second most prevalent cancer in PEI, and possibly breast cancer, the most common cancer among women.<sup>38</sup> More than half of PEI's population is physically inactive.<sup>39</sup>
- Existing prevention strategies**

Strategies developed to address these lifestyle behaviours are at various stages of implementation. Within PEI, the PEI Strategy for Healthy Living takes the principal coordinating role. Targeted strategies have been developed by the PEI Tobacco Reduction Alliance, the Active Living Alliance, and the Healthy Eating Alliance, representing a wide group of stakeholders including community, non-governmental health organizations, health providers, academics, and several provincial government departments. These groups are identifying achievable targets for change, and work cooperatively within their own mandates. Prevention strategies have also been developed at regional and national levels to promote sharing of information and to develop programs and policies aimed at wider populations.

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<sup>36</sup>National Cancer Institute (2001). *Obesity and Cancer in Cancer Facts*. Retrieved May 5, 2003 from <http://cis.nci.nih.gov>

<sup>37</sup>DHSS (2002). *Prince Edward Island Report on Common Health Indicators: September 2002*. Charlottetown.

<sup>38</sup>Marrett Loraine D, Theis Beth, Ashbury Fredrick D, and Expert Panel (2000). "Workshop Report: Physical Activity and Cancer Prevention." *Chronic Diseases in Canada*. Volume 21, no. 4 - 2000. Retrieved April 3, 2003 from [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>39</sup>DHSS (2002).

- **Research**

Epidemiological research into the incidence and trends of cancers provides information on which to base prevention programs and health system planning. This information is currently compiled nationally by Health Canada, National Cancer Institute of Canada and Canadian Cancer Society. Provincial detail and analysis were last provided in 1997 in *Cancer Trends in PEI 1983-1997*. There are plans to update this research in 2004.

Research about the development of unhealthy lifestyle behaviours and best ways to effect changes can provide information on which to base cost-effective and evidence-based interventions. In recent years, PEI has greatly expanded its research capacity, supporting development of some of the most progressive prevention programs and policies in Canada and the means to monitor and continually improve them.

***Recommendation:***

***Formalize and expand the currently ad-hoc prevention sub-committee to include other stakeholders concerned about reducing cancer risks.***

***Increase public awareness that some cancers can be prevented.***

***Provide advice, and support and liaise with the existing national, regional and provincial strategies, programs and services to improve common health indicators, including reduction of tobacco and exposure to second-hand smoke, increased consumption of fruits and vegetables, healthy body weight, and reduced physical inactivity.***

***Identify and respond to gaps in cancer-specific information in existing chronic disease prevention strategies.***

***Monitor and respond to emerging information about lifestyle links to cancer.***

## Measuring Results: Targets and Indicators

**Action area 1:**            **Reduce the incidence of preventable cancers by working with existing strategies to improve lifestyle factors associated with development of cancer and other chronic diseases.**

**Target:**

- By 2015, increase the percentage of Islanders who are smoke-free by \_\_\_ per cent.
- By 2015, increase the percentage of Islanders who consume five or more servings of vegetables and fruits daily by \_\_\_ per cent.
- By 2015, increase the percentage of Islanders who have healthy weights by \_\_\_ per cent.
- By 2015, increase the percentage of Islanders who are physically active by \_\_\_ per cent.

**Indicators:**

- Percentage of Islanders who are smoke-free in 2004; percentage who are smoke-free in 2015.
- Percentage of Islanders who consume five or more servings of vegetables and fruits daily in 2004; percentage who consume five or more servings of vegetables and fruits daily in 2015.
- Percentage of Islanders who have healthy weights in 2004; percentage who have healthy weights in 2015.
- Percentage of Islanders who are physically active in 2004; percentage who are physically active in 2015.

## **Action area 2: Reduce exposure to other known carcinogenic agents.**

### **Rationale:**

Several cancers have been linked to other known carcinogenic agents including alcohol consumption; occupational and environmental exposures; ultraviolet radiation; and infections.

### **Factors:**

- **Alcohol**  
Over-consumption of alcohol has been linked with several cancers, as well as numerous other health conditions and societal problems.<sup>40</sup> Meanwhile, health conditions such as heart disease may benefit from moderate amounts of alcohol. This can result in confusing messages for the consumer. Islanders report high and increasing consumption of alcohol.<sup>41</sup> Existing strategies targeting alcohol consumption focus on substance abuse rather than prevention. Other provincial stakeholders have expressed interest in working together to increase awareness about moderate levels of alcohol consumption, making this a relatively achievable first step.

#### ***Recommendation:***

***Identify and work with other stakeholders to reduce alcohol consumption in PEI to recommended levels.***

- **Occupational or environmental exposures to carcinogens**  
Five to ten per cent of cancers are thought to be associated with occupational or environmental exposure to carcinogens, primarily through occupational exposure.<sup>42,43</sup> Risks are extremely complex and vary according to exposure patterns, chemical nature, individual sensitivities, and compounding effects such

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<sup>40</sup>Jernigan DH, Monteiro M, Room R, Saxena S (2000). "Towards a global alcohol policy: alcohol, public health and the role of WHO." *Bulletin of the World Health Organization*, 2002, 78 (4). Retrieved on March 13, 2003 from [www.who.int](http://www.who.int)

<sup>41</sup>Statistics Canada (2003). *National Population Health Survey, Household Component, 1994-1995; 1996 - 97; 1998-1999*. Retrieved March 13, 2003 from [www.statcan.gc.ca](http://www.statcan.gc.ca)

<sup>42</sup>Canadian Cancer Society (2002). *General information about pesticides*. Retrieved April 14, 2003 from [www.cancer.ca/ccs/](http://www.cancer.ca/ccs/)

<sup>43</sup>World Health Organization (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*; World Health Organization, Geneva, 2002. P. 41.

as smoking or multiple exposures.<sup>44</sup> The latency period in cancer development may be 30 to 40 years, making it extremely difficult to determine origins.<sup>45</sup>

Risks and benefits derived from chemical use are carefully monitored and weighed. For instance, consuming chlorinated water over a long duration is linked to a small increase in the risk of developing some cancers; but risks from not chlorinating drinking water include cholera, typhoid fever and E coli infections, all much more immediate threats to health.

In some occupational settings, workers may unknowingly be exposed to carcinogens. They may be unaware of risks associated with their occupation, their physicians may be unaware of the need for extra vigilance in monitoring these patients' health, and workers may not know to seek compensation should they develop occupationally-related cancer.<sup>46,47</sup> Similar carcinogenic agents may also be used in domestic circumstances without consumer awareness of risks and proper handling.

Within PEI, the Department of the Environment and Energy is responsible for monitoring carcinogens in the environment, and the Workers Compensation Board, through the Occupational Health and Safety Division, monitors worker safety and provides education sessions when requested. Federal departments of health and environment are responsible for the assessment of risks, providing information, and establishing safety thresholds used to limit exposures to cancer causing agents and other controlled products.

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<sup>44</sup>Health Canada and Atomic Energy Control Board (1998). *Assessment and Management of Cancer Risks from Radiological and Chemical Hazards*. Ottawa.

<sup>45</sup>California Occupational Health Branch (1996). *An Introduction to Chemical Hazards in the Workplace*. Retrieved April 10, 2003 from [www.dhs.ca/goc/ohb/HESIS/uts.htm](http://www.dhs.ca/goc/ohb/HESIS/uts.htm)

<sup>46</sup>Teschke K, Barroetavena MC (1993). *Occupational cancer in Canada: what do we know?* National Library of Medicine: PubMed. Retrieved April 10, 2003 from [www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)

<sup>47</sup>Personal communication with George Stewart, Director, Occupational Health & Safety, PEI.

PEI is currently one of the few provinces in which farmers and farm labourers are not covered by the *Occupational Health and Safety Act*, although some pesticides used here have been identified by the International Agency for Research on Cancer (IARC) as possible carcinogens.<sup>48</sup>

A majority of Canadians express concern about health risks associated with environmental agents, though many experts believe the risks are relatively low.<sup>49,50</sup> Canadian law recognizes the precautionary principle, that 100 per cent assurance of harm is not needed before taking action, indicating that emerging information about cancer risks must be monitored and appropriate responses developed.

Determining risks from carcinogens is extremely complex. Nationally, the Environmental and Occupational Exposures Discussion Group, a sub-group of the Cancer Control Prevention Action Group, plans to investigate and make recommendations about best practices in designing policies and programs to reduce exposure to carcinogens in the environment and workplace. Stakeholders in PEI will be interested in the information gathered by this national group of experts.

***Recommendation:***

***Extend the Occupational Health and Safety Act to include farmers and farm labourers, thus providing education, training and work-site monitoring.***

***Monitor national recommendations about best practices and policies to reduce exposures to occupational and environmental carcinogens and develop strategies in response.***

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<sup>48</sup>International Agency for Research in Cancer (IARC). *Overall Evaluations of Chemical Carcinogenicity to Humans*, IARC Monographs, Volumes 1- 82 <http://monographs.iarc.fr/htdig/search.html>

<sup>49</sup>Health Canada (1997). *Health and the Environment: Partners for Life: Executive Summary*. Ottawa, Canada. GoC catalogue no. H49-112/1-1997E Retrieved on April 10, 2003 from [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

<sup>50</sup>World H World Health Organization (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*; World Health Organization, Geneva, 2002. P. 41.



- **Ultraviolet exposure**  
Ultraviolet exposure is the principle cause of melanomas. PEI has a substantially higher incidence rate than the national average.<sup>51</sup> The carcinogenic process is thought to be initiated by intense sun exposure during childhood and promoted through subsequent exposures. Throughout Canada and internationally the incidence of melanomas has increased significantly over the past two decades, possibly due to intense sunlight exposure and improved detection. People with fair complexions are at increased risk. The International Agency for Research on Cancer, an arm of the World Health Organization, has determined that exposure to ultraviolet light from sun lamps and sun beds is a probable carcinogen.<sup>52</sup> The Canadian Cancer Society, PEI Division presents programs to targeted audiences and has developed a strategy to address sun exposure in PEI.

***Recommendation:***

***Identify partners and work to reduce exposure to ultraviolet radiation.***

- **Infections**  
Certain viruses, bacteria and parasites are known or suspected to play a role in the development of certain cancers. Human Papillomaviruses (HPV) has been linked to 90 per cent of cervical cancers, as well as to other cancers of the genitalia. Certain behavioural risk factors are associated with exposure to HPV. The cervical screening program facilitates detection of lesions before they become cancerous, and a vaccine for HPV is in development. A vaccine is currently provided through a school health program to target hepatitis B, another known cause of cancer. Cancer prevention goals include promoting healthy sexuality, vaccines, and cervical screening.

***Recommendation:***

***Monitor and respond to emerging information about viral infections and methods to control them.***

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<sup>51</sup>Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada (2003). *Canadian Cancer Statistics 2003*. Available on Internet at [www.cancer.ca](http://www.cancer.ca)

<sup>52</sup>International Agency for Research in Cancer (2003).

- **Emerging information**  
There is an explosion of research and new information about the causes and prevention of cancer both nationally and internationally.

***Recommendation:***

***Monitor and respond to emerging information about the causes and prevention of cancer.***

## **Measuring Results: Targets and Indicators**

**Action area 2: Reduce exposure to other known carcinogenic agents.**

**Targets:**

- By 2015, decrease the percentage of Islanders consuming immoderate amounts of alcohol by \_\_\_\_ per cent.
- By 2015, increase awareness and protection from occupational and environmental exposures to carcinogens.
- By 2015, decrease the incidence of melanomas by \_\_\_\_ per cent.
- By 2015, decrease the incidence of cervical and liver cancers by \_\_\_\_ per cent.

**Indicators:**

- Percentage of Islanders consuming five or more alcoholic drinks on one occasion 12 or more times a year in 2004; percentage of Islanders consuming 5 or more alcoholic drinks on one occasion 12 or more times a year in 2015.
- Number of initiatives directed at increasing awareness and protection from occupational and environmental exposures to carcinogens in 2004; number of initiatives directed at increasing awareness and protection from occupational and environmental exposures to carcinogens in 2015.
- Number of melanomas in 2004; number of melanomas in 2015.
- Number of cervical and hepatocellular liver cancers in 2004; number of cervical and hepatocellular liver cancers in 2015.

### 3.3 Screening and diagnosis

**Goal:** To reduce cancer mortality and morbidity by improving access to timely and accurate diagnosis of cancer.

**Objectives:**

- Timely presentation of signs and symptoms to health professionals.
- Equitable access to primary health care.
- Effective screening programs for populations at risk of major cancers.
- Timely access to diagnostic and staging assessment.
- Ongoing monitoring of diagnostic process.
- Appropriate support for the physical, informational, psychological, social, and practical needs of patients and their families during the peri-diagnostic period.

**Action area 1:**

Encourage timely presentation of signs and symptoms of cancer to a healthcare professional.

**Action area 2:**

Provide effective screening programs targeting populations at risk of specific cancers.

**Action area 3:**

Improve timeliness of diagnosis and accuracy of staging assessment.

**Action area 4:**

Provide timely, easy access to relevant, understandable information and emotional support for individuals with cancer and their family members during the peri-diagnostic period.

## Background:

- **Screening and Diagnosis**

While the greatest opportunity to reduce future incidence and suffering from cancer in Prince Edward Island may be through cancer prevention, in most cases, improvements will be long-term. In the meantime, demand for diagnosis and treatment of cancer can be expected to grow.

For many cancers, early diagnosis offers the best opportunity to reduce morbidity and mortality, thereby alleviating the suffering and burden of cancer.

The following chart demonstrates the crucial importance of detecting certain cancers at early stages. In many cases, these specific cancers can be effectively detected through screening programs.

### Five-year Relative Survival Rates by Stage at Diagnosis, 1992 - 1999

Site	All Stages	Local Disease (non-invasive or Stages 0 & 1)	Regional Disease (Stages 2 & 3)	Distant Disease (Metastasis or Stage 4)
<b>Cancers recommended for screening programs</b>				
Female Breast	86.6%	97%	78.7%	23.3%
Colorectal	62.3%	90.1%	65.5%	9.2%
Prostate	97.5%	100%	93%*	34%
Uterine cervix	71.3%	92.2%	50.9%	16.5%
<b>Other prevalent cancers</b>				
Lung & bronchus	14.9%	48.7%	16%	2.1%
Melanoma	89.6%	96.7%	47.9%	26.1%
Urinary bladder	81.8%	94.4%	48.2%	5.8%

Source: *Surveillance, Epidemiology, and End Results Program, 1973-2000, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, 2003.*<sup>53</sup>

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<sup>53</sup>American Cancer Society Facts and Figures (2004). Retrieved May 18, 2004 from [www.cancer.org](http://www.cancer.org). Rates are adjusted for normal life expectancy and are based on cases diagnosed from 1992-1999, followed through 2000.

\* 1996 figure

Diagnosis of cancer usually begins with a thorough physical examination and may require any of a number of tests including laboratory, diagnostic imaging or surgical biopsy. This diagnostic process also determines the stage of cancer which, in turn, affects the course of prescribed treatment. Family physicians are normally responsible for coordinating diagnosis, including making appropriate referrals for diagnostic testing or to specialists.

Timeliness of diagnosis is influenced by the patient's awareness and timely response to symptoms suggestive of cancer, access to primary health care and the expertise of specialists, and the needs and complexity of the particular case. Human resource shortages can have a detrimental affect on the timeliness of diagnosis. Prince Edward Island is currently experiencing a shortage of family physicians and at least one diagnostic radiologist. There is also a shortage of primary physicians, with positions sometimes filled by locums. While able to respond to acute care needs, reliance on such short-term placements may not provide the opportunity to develop patient relationships or provide the consistency of care necessary to effectively diagnose some cancers.

The national Diagnosis Working Group identified three targets to work toward to achieve optimal early diagnosis of cancer:

- The time from onset of signs/symptoms suggestive of cancer to presentation to a health care professional should be as short as reasonably achievable (consistent with national guidelines for specific cancers).
- The time from presentation to a health care professional of signs/symptoms that are highly suggestive of cancer to definitive diagnosis should be as short as reasonably achievable, and generally within four weeks.
- There should be an integrated and coordinated cancer system (from community based agencies, through primary care, to specialist care) designed to meet the physical, informational, psychological, spiritual, social and practical needs of patients and their families throughout the peri-diagnostic period.<sup>54</sup>

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<sup>54</sup>Canadian Strategy for Cancer Control: Diagnosis Working Group (2002). "Cancer Diagnosis in Canada; Recommendations". Retrieved June, 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

## **Action area 1: Encourage timely presentation of signs and symptoms of cancer to a healthcare professional.**

### **Rationale:**

Cancers detected at early stages can usually be treated less invasively, more successfully, and more cost-effectively.

### **Background:**

Most cancers are diagnosed when a patient or his/her physician becomes concerned about a symptom of cancer.

Symptoms include:

- a cough which goes on for more than two weeks;
- bleeding from the rectum or blood in the stool;
- any change in bowel habits (constipation or diarrhea) that continues for more than a few days;
- indigestion that continues for more than two weeks;
- unexplained aches and pains that go on for more than two weeks;
- difficulty urinating or blood in the urine
- unexplained bleeding of any sort;
- any lump or mass, especially in the breasts or testicles;
- any sore which does not heal;
- any new growth on your skin;
- patches of skin that bleed, itch or become red; and
- any change in the colour, shape, surface appearance or size of moles or birthmarks.<sup>55</sup>

### **Factors:**

- **Public education**  
Public education about the signs of cancer and importance of early diagnosis can encourage patients to take responsibility for monitoring their own health and to access a physician when signs or symptoms of cancer first appear. Access to consistent care from a healthcare professional allows development of a trusting relationship and supports early presentation.

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<sup>55</sup>Canadian Cancer Society (2003). *Report health changes*. Retrieved Sept. 12, 2003 from [www.cancer.ca](http://www.cancer.ca)

Public and patient education initiatives about cancer care should be coordinated, evidence-based and built around consistent messages; the public should be well informed about the possible signs and symptoms of cancer; patients and families should have easy access to relevant, understandable information.<sup>56</sup>

Currently, public education efforts are either passive, such as through the CCS Web site, or promoted by groups focusing on specific cancers such as colorectal, breast or ovarian.<sup>57</sup>

***Recommendation:***

***Develop strategies to raise public awareness about the signs and symptoms of cancer and importance of early detection, possibly linking with national groups focusing on specific cancers and working with the PEI Medical Society's Health Promotions Committee and regional primary healthcare centres.***

- **Timely access to primary health care professionals and diagnostic testing**  
Timely presentation and monitoring of indefinite signs or symptoms of cancer require access to primary care physicians and timely access to diagnostic testing. PEI has human resource shortages in both areas. Currently, patients without a family physician can visit a walk-in clinic, though there are concerns about follow-up of diagnostic testing in such circumstances. Meanwhile, procedures are needed to ensure these patients are informed about how to access diagnostic testing. For further discussion, see Action area 3 of this section, and over-arching recommendations concerning recruitment and retention of staff and access to primary healthcare services in Section 3.1.

***Recommendation:***

***Develop procedures to ensure that patients without physicians are informed about how to access diagnostic testing if they may have a sign or symptom of cancer, and how to follow up on any testing.***

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<sup>56</sup>Canadian Strategy for Cancer Control: Diagnosis Working Group (2002). "Cancer Diagnosis in Canada; Recommendations". Retrieved June, 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

<sup>57</sup>Personal communication with Neil Berman, Health Canada, Feb. 5, 2004.

## Measuring Results: Targets and Indicators

**Action area 1:** Encourage timely presentation of signs and symptoms of cancer to a healthcare professional.

**Target:**

- By 2015, \_\_\_\_\_ per cent of cancers that can effectively be detected and treated at early stages, will be. Currently, these include breast, colorectal, cervical, and endometrial.

**Indicator:**

- Percentage of specific cancers detected in Stages 1 or 2 in 2004; percentage detected in Stages 1 or 2 in 2015.



## **Action area 2: Provide effective screening programs targeting populations at risk of specific cancers.**

### **Rationale:**

Screening programs can reduce mortality from cancer by detecting certain cancers at asymptomatic stages among a population considered at risk because of such factors as age, gender or lifestyle.

### **Background:**

In Prince Edward Island, there are currently two organized screening programs: breast cancer screening of women aged 50 to 69 years; and cervical cancer screening of women aged 18 to 69 years.

Screening for prostate and colorectal cancers is currently conducted on an individual basis, depending on the judgement of patients and physicians.

Population screening is considered most effective when delivered within an organized screening program. Physicians may also advise screening of individual patients at particular risk of certain cancers. To be effective, screening programs must be “comprehensive, including recruitment, recall, follow-up and timely assessment of people with positive tests”.<sup>58</sup> Essential components include public education, continuous monitoring and evaluation, and adequate resources to support all aspects of screening.

Screening programs are not recommended if diagnostic and treatment support is not available. While there are resource shortages in these areas, PEI should strive to provide Islanders with similar standards of care as those of other Canadians.

Screening programs do have limitations, though. If a cancer is particularly aggressive, even early diagnosis may not prevent death; initial tests may appear normal, even though cancer is present (falsely negative); or appear to be abnormal, even though no cancer is present (falsely positive); serious complications may result from further testing procedures, including death, perforation of the colon, loss of sensitivity of breast tissue.

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<sup>58</sup>Canadian Strategy for Cancer Control: Screening Working Group (2002). “Population Cancer Screening in Canada: Strategic Priorities.” Retrieved June, 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

Participants in screening programs must be well-informed of such risks and programs must be continually monitored to ensure that the benefits outweigh the risks.<sup>59,60</sup>

## Factors:

- **Existing screening programs**

**Cervical cancer screening** is considered the most cost-effective cancer screening program.<sup>61</sup> It is estimated that in Prince Edward Island 10 women will be diagnosed with cervical cancer and five will die. Almost 90 per cent of cervical cancers can be prevented through regular cervical cancer screening.<sup>62</sup> Cervical cancer is the ninth most frequently diagnosed cancer among PEI women<sup>63</sup> and is particularly prevalent among young women.<sup>64</sup>

The Papanicolaou (Pap) smear is able to detect lesions that are pre-cancerous or in early stages of cancer. It is estimated that cervical screening programs save almost 1,000 lives each year in Canada. Sixty per cent of incidences occur in women who have not been screened within the previous three years.<sup>65</sup> Risk factors for cervical cancer include early age at first intercourse, greater number of sexual partners, increasing age, smoking, and low socioeconomic status.<sup>66</sup>

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<sup>59</sup>Health Canada (2003). *Quality Determinants of Organized Breast Cancer Screening Programs in Canada*. Pp. 2 -12.

<sup>60</sup>National Committee on Colorectal Cancer Screening (2003). *Recommendations*.

<sup>61</sup>World Health Organization (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*; World Health Organization, Geneva, 2002.

<sup>62</sup>Cancer Care Ontario, Canadian Cancer Society (2003). *Targeting Cancer: An action plan for cancer prevention and detection. Cancer 2020 Background Report*. Retrieved from August 25, 2003 from [www.cancercare.on.ca/pdf/Cancer2020BackgroundReportMay2003.pdf](http://www.cancercare.on.ca/pdf/Cancer2020BackgroundReportMay2003.pdf)

<sup>63</sup>Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada (2003). *Canadian Cancer Statistics 2003*. Available on Internet at [www.cancer.ca](http://www.cancer.ca)

<sup>64</sup>Health Canada (2002). "Cervical Cancer Screening in Canada: 1998 Surveillance Report". Ottawa: Minister of Public Works and Government Services Canada.

<sup>65</sup>Ibid.

<sup>66</sup>Cancer Surveillance-on-line (2003). *Cancer Incidence over Time*. Retrieved February 17, 2003 from [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

A PAP Screening Program was initiated in Prince Edward Island in 2001. Screening recommendations include PAP screening following initiation of sexual activity or age 18, with screening at least every two years to age 69 after two normal smears. Once an organized screening program is in place, if smears are satisfactory, then re-screening every three years is advised until the age of 69 if there has been no significant abnormality in the past.<sup>67</sup> In the period ending 2001, screening rates in PEI were 42 per cent of women aged 20-69 screened within one year, 58 per cent within two years, and 65 per cent within three years. To improve access to cervical screening, a model Pap screening clinic was launched in September, 2001 in Cornwall, followed by the development of outreach clinics in 2003. The program is working on patient recruitment, establishing provincial screening standards and guidelines for follow-up of abnormal results, and the development of a system for call and re-call. Plans to ensure follow-up of abnormal Pap smears are being developed and implemented.

**Breast cancer** is the most commonly diagnosed cancer among Canadian women. While the prognosis is generally positive, it is also the greatest cause of years of life lost from premature death from disease for Prince Edward Island women.<sup>68</sup> In 2004, it is estimated that 100 Island women will be diagnosed with breast cancer and that 25 will die from it.

Although some lifestyle behaviours have been linked to increased incidence of breast cancer on a population level, there is no known way to prevent breast cancer. Since risks increase with age,<sup>69</sup> incidence can be expected to rise as the population ages. Screening currently offers the best known intervention to save lives.

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<sup>67</sup>Recommendations of the 1989 National Workshop on Screening for Cancer of the Cervix (Miller, 1991) cited by Health Canada (2002). P. 9.

<sup>68</sup>According to Prince Edward Island Health Indicators Report (2002), 464.2 potential years of life were lost to breast cancer in 1999 (death before 75 years of age).Canadian Cancer Society et al's *Canadian Cancer Statistics 2003* reports 30 deaths in PEI to breast cancer in 1999, an average of 15.47 years of potential life lost per individual.

<sup>69</sup>Canadian Cancer Society et al (2003). P. 56.

The breast cancer screening program was introduced in Prince Edward Island in 1998 and offers mammography screening every two years to women ages 50-69. Within seven to 10 years of a screening program reaching 70 per cent of targeted women, it is estimated that one third of breast cancer deaths may be prevented.<sup>70</sup> The PEI program has reached this target and, in 2003, approximately 30 per cent of breast cancers in PEI were detected through the breast screening program. The PEI Cancer Registry has completed cancer staging on all breast cancers diagnosed in 2003. The results are encouraging: approximately 60 per cent were Stage 0 or Stage 1. Such early detection presents good evidence of the effectiveness of the breast screening program. See Appendix V for breast cancer staging synopsis.

Most challenges faced by the breast cancer screening program deal with infrastructure, including the need for improved access to telephone, computer and appropriate software. The program receives ongoing quantitative monitoring but has not yet received a qualitative evaluation or follow-up research about the effects on women who have had false positive findings.

Unlike the cervical screening program, breast screening does not currently have a steering committee or link directly to the Department of Health and Social Services.

Since the targeted population is similar, public education about breast screening could coincide with cervical screening education. Preliminary discussions have taken place regarding this, but no strategy is in place yet.

**Recommendation:**

***Explore avenues to provide public education about the breast screening program in conjunction with the cervical screening program.***

***Provide liaison, advice and support to the existing cancer screening programs.***

***Provide information about the limitations of screening programs to program participants.***

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<sup>70</sup>Canadian Task Force on Preventive Health Care (1994) cited by Cancer Care Ontario (2003).

- **Colorectal cancer screening**

In Canada and in PEI, **colorectal cancer** is the second most prevalent cancer after lung cancer that can occur both in men and women. About 50 men and 50 women will be diagnosed with colorectal cancer in PEI in 2004; almost half will die from the disease.<sup>71</sup> The incidence of colorectal cancer has been steadily increasing and, since it is closely associated with increased age, it can be expected to continue to rise.

Poor diet, obesity and physical inactivity are all closely linked to colorectal cancer, which is thought to develop over long time. Strong evidence indicates screening of those aged 50 to 74 years can reduce mortality from colorectal cancer by 15 to 33 per cent.<sup>72</sup>

Colorectal cancer screening has been nationally recommended as a cost-effective procedure. Implementation has begun in other provinces, including Ontario and Nova Scotia. Initial screening is performed by a faecal occult blood test; diagnosis is currently made using colonoscopy or combination of barium enema and sigmoidoscopy. Development of a colorectal screening program will require strategy development, including costing, and will require healthcare professionals and technical staff, equipment, appropriate facilities, and public and physician communication.

The PEI Cancer Registry has completed cancer staging on all colorectal cancers diagnosed in 2003. The results are very different from that of breast cancer staging: 86 per cent of breast cancers and 63 per cent of colorectal cancers were detected in the earlier stages (Stages 0, 1 or 2). The findings demonstrate the importance of introducing a colorectal screening program in PEI. See Appendix V for definitions and statistics.

***Recommendation:***

***Develop and implement a strategy to phase in a colorectal screening program in PEI for those aged 50 to 74 years.***

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<sup>71</sup>Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada (2004). *Canadian Cancer Statistics 2004*. Available on Internet at [www.cancer.ca](http://www.cancer.ca)

<sup>72</sup>National Committee on Colorectal Cancer Screening (2003). "Reducing Canadian Colorectal Cancer Mortality Through Screening". Retrieved Sept. 4, 2003 from [www.hc-sc.gc.ca/pphb-dgspsp/publicat/ncccs-cndcc/ccsrec\\_e.html](http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/ncccs-cndcc/ccsrec_e.html)

*Recommendations concerning all screening programs:*

*Ensure national quality assurance standards are met for all organized screening programs and programs evaluated every five years, including psychosocial support and tracking of patients having false positive screens.*

*Identify and comply to national screening targets as programs continue to develop.*

- **Other cancer screening**

**Prostate cancer** is the most commonly diagnosed cancer among men both in PEI and in Canada overall. In 2004, it is estimated that 150 Island men will be diagnosed and 25 will die from prostate cancer.<sup>73</sup>

While lifestyle behaviours seem to increase the risk of prostate cancer, it is most closely associated with aging. Ninety per cent of deaths occur after age 65, with prevalence as high as 43 per cent among men aged 80.<sup>74</sup> Incidence can therefore be expected to increase.

Prostate cancer screening is currently performed by digital rectal examination (DRE) and Prostate Specific Antigen (PSA) testing on an individual basis. Though the Canadian Task Force on Preventative Health Care does not recommend a screening program of asymptomatic men,<sup>75</sup> the Canadian Urological Association recommends “men should be made aware of the potential benefits and risks of early detection so that they can make an informed decision as to whether to have this test performed”.<sup>76</sup>

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<sup>73</sup>Canadian Cancer Society et al (2004).

<sup>74</sup>Canadian Task Force on Preventive Health Care (1994) cited by Cancer Care Ontario (2003).

<sup>75</sup>Cancer Care Ontario (2003).

<sup>76</sup>Canadian Urological Association (2004). *Guidelines For Early Detection of Prostate Cancer*. Retrieved February 10, 2004 from [www.cua.org](http://www.cua.org)

Current research indicates that a low percentage of cancers are determined by heredity. Genetic screening is currently available for people with a strong family history of specific cancers occurring at early ages and downward drift in age of onset.<sup>77</sup> Testing must be accompanied by counseling, and referrals are made to Halifax or Ontario. Eventually, it is expected that genetic screening may help to identify individuals at risk for a specific cancer, thus enabling prevention or screening strategies for an individual or family members.<sup>78</sup>

As knowledge and technology improves, it may be possible to detect other cancers through screening programs.

***Recommendations:***

***Provide information to men aged 50 and 70 years about the availability of prostate screening to support informed decision-making about individual participation.***

***Monitor and respond to emerging information and recommendations about cancer screening.***

- **Clinical practice guidelines**

Clinical practice guidelines help to establish a coordinated approach to cancer control based on the best evidence from around the world. A Cancer Control Screening Regional Panel is finalizing screening guidelines for Pap testing and has begun work on guidelines for colorectal screening.

***Recommendation:***

***Review clinical practice guidelines as they are developed to guide diagnostic procedures and adopt and disseminate as considered advisable.***

- **Psychosocial support for screening programs**

Appropriate psychosocial support should be available to patients throughout the screening and diagnostic process, including those with false positive screens. For more information, see Action area 4.

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<sup>77</sup>Dr. Daniel Rayson, Medical Director of the Maritime Hereditary Cancer Centre, presentation at UPEI, May 7, 2003.

<sup>78</sup>World Health Organization (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*; World Health Organization, Geneva, 2002. P. 11.

**Recommendation:**

***Ensure appropriate psychosocial support is provided throughout the screening and diagnostic process, possibly through establishment of a patient navigator and by working with the existing screening programs.***

**Measuring Results: Targets and Indicators**

**Action Area 2: Provide effective screening programs targeting populations at risk of specific cancers.**

**Targets:**

- By 2015, \_\_\_\_ per cent of women within the targeted population will be screened for cervical cancer at recommended intervals.
- By 2015, \_\_\_\_ per cent of women within the targeted population will be screened for breast cancer at recommended intervals.
- By 2015, \_\_\_\_ per cent of Islanders within the targeted population will be screened for colorectal cancer at recommended intervals.
- By 2015, Island men within recommended ages will receive information on which to base decisions about participating in prostate cancer screening.
- By 2015, Islanders will benefit from other cancer screening programs as emerging information indicates the effectiveness.

**Indicators:**

- Percentage of women in target population screened for cervical cancer at recommended intervals in 2004 and 2015.
- Percentage of women in target population screened for breast cancer at recommended intervals in 2004 and 2015.
- Percentage of Islanders in target population screened for colorectal cancer at recommended intervals in 2004 and 2015.
- Number of resources to inform men about prostate cancer screening in 2004 and 2015.
- Percentage of Islanders in target populations screened in other cancer screening programs.



### **Action area 3: Improve timeliness of diagnosis and accurate staging assessment.**

#### **Rationale:**

Timely diagnosis and accurate staging assessment can reduce mortality by facilitating the most appropriate cancer treatment to begin in a timely manner.

#### **Background:**

The cancer diagnostic process can be initiated by the screening program, primary care physician, or a physician in the hospital emergency department. Diagnosis is confirmed by surgical biopsy, diagnostic imaging, or laboratory reports.

Timeliness of diagnosis depends upon timeliness of presentation to the physician; expertise of the physician in ordering appropriate tests; waiting time for testing procedures, which is affected by availability of medical and technical staff, equipment and appropriate facilities; appropriate triage of diagnostic testing; physician advocacy on behalf of the patient; expertise of diagnostic staff; and communication between physicians and diagnostic staff.

#### **Factors:**

- **Coordination of diagnosis**

The primary care physician is responsible for coordinating diagnosis. Patients without a family physician are assigned an “orphan doctor” while in hospital if their disease is advanced enough to be admitted, and they are given priority on a waiting list for available physicians. Currently, there is no coordinated process to ensure patients receive information to ensure follow-up of testing. They should be informed of the need to call the Provincial Patient Registry’s toll-free number and to mention the test so they can be placed on the priority list. Even on the priority list, it may take several months to find an available physician to coordinate care. Both existing screening programs have a process to remind physicians if patients with an abnormal screen have not progressed to diagnosis within a set period of time.

***Recommendations:***

***Investigate the role a patient navigator or case manager can play in providing coordination of diagnoses to patients without physicians.***

- **Access to earliest available diagnostic testing**  
Timeliness of access to certain diagnostic procedures can vary considerably. Wait periods from referral to screening colonoscopy can range from as little as one month to almost two years. The variance is affected by the caseload and waiting times of particular surgeons and services at the two major hospitals and perception of need. Family physicians and patients should be made aware of different options and be offered access to the earliest available diagnostic testing. With the Provincial Health Services Authority (PHSA) responsible for both hospitals, a centralized referral system could help to improve equitable and timely access.

***Recommendation:***

***Centralize referrals for diagnostic testing at all hospitals, offering patients access to the earliest available testing.***

- **Follow-up of diagnostic testing**  
Diagnostic testing procedures have been triaged to cope with personnel shortages. Currently, the Diagnostic Imaging Department of the Provincial Health Services Authority requires another radiologist. While every effort is made to ensure timeliness, personnel shortages can cause critical delays in diagnosis, particularly if the presentation is unusual, the cancer is aggressive, or the level of urgency is misconstrued. Referring health professionals may be unaware of wait periods. They and their patients must be informed of the need to advocate and follow-up on testing. A patient navigator, discussed further under Section 3.4 Treatment and Supportive Care, may also help facilitate this process, particularly for patients without physicians.

Standards for diagnostic testing time periods need to be developed to inform family physicians and patients. An information sheet for patients being investigated for cancer could help to guide patients through the diagnostic process and provide information on how to self-advocate.

In the long-term, aggressive recruitment is needed to ensure the availability of adequate diagnostic health professionals and technical personnel.

***Recommendations:***

***Identify standards for follow-up of diagnostic testing.***

***Increase awareness among physicians about the need to follow up testing requests.***

*Educate patients about the need to follow up on test results if they have not heard within the identified time period.*

*Note: Financial commitment, recruitment and retention of healthcare professionals and technical staff, access to primary healthcare, and electronic patient records are over-arching recommendations essential to timely diagnostic testing for cancer.*

- **Communication between diagnostic specialists**

In some cases, multiple tests are required to confirm a cancer diagnosis. In such instances, direct communication between surgeons, pathologists and radiologists can help to ensure maximum information is obtained from testing procedures.<sup>79</sup> There is no formal tumour board on PEI as there are in bigger cancer centres. Consultations are held on an ad hoc basis if a case is complicated or referred onward.

**Recommendation:**

*Continue to encourage and facilitate case-conferencing among specialists involved in making diagnoses.*

- **Cancer staging**

Once a cancer diagnosis has been made, cancer staging is established and noted on the patient's chart. Such information can help to “monitor clinical practice guidelines, treatment regimens, and the impact of screening programs; to estimate local resource utilization and needs; to allow for standardized comparisons between institutions and regions; to plan rehabilitation, palliation and support; and to educate and inform.”<sup>80</sup> The national goal is for provincial and territorial cancer registries to capture this information for all cancers.

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<sup>79</sup>Canadian Strategy for Cancer Control: Diagnosis Working Group (2002). “Cancer Diagnosis in Canada; Recommendations”. Retrieved June, 2002 from [www.cancercontrol.org](http://www.cancercontrol.org) P.. 28.

<sup>80</sup>Ibid. p. 13.

Staging is currently performed by oncologists, or partially by pathologists or staff of the PEI Cancer Registry. Some patients with cancer will never see an oncologist. In these cases, the cancer registry conducts research and analysis to establish diagnosis and staging. Currently, fewer than half of all cancers diagnosed in PEI are staged. Additional staff and allocation of resources to upgrade software will be required to bring the capacity to stage cancers in PEI to national standards.

***Recommendations:***

***Ensure staging assessment continues to be recorded.***

***Improve the capacity to stage cancers in compliance with national recommendations, including additional staffing and software upgrades.***

- **Monitoring the diagnostic process**

The diagnostic process varies from cancer to cancer and is generally not monitored. An organized program such as the breast screening program is able to track the period from abnormal mammograms to diagnosis. It is therefore difficult to set and evaluate timeliness standards, assess issues, or plan resource needs. Electronic patient records would facilitate such monitoring (see over-arching recommendations). Lacking such records, an external analysis of the current diagnostic processes should be conducted and recommendations made to staff about ways to overcome any identified issues.

***Recommendation:***

***Conduct an external review to analyze the diagnostic process and work with staff to develop strategies to ensure optimal timeliness and accuracy of diagnoses.***

## Measuring Results: Targets and Indicators

### **Action area 3: Improve the timeliness of diagnosis and accurate staging assessment.**

#### **Targets:**

- By 2015, \_\_\_\_ per cent of diagnostic testing will be monitored and occur within nationally recommended timelines.
- By 2015, \_\_\_\_ per cent of cancers will receive accurate staging assessment.
- By 2015, \_\_\_\_ per cent of patients being investigated for cancer will be offered access to the earliest available diagnostic service.
- By 2015, \_\_\_\_ per cent of patients will be given information empowering them to follow-up diagnostic testing and self-advocate.
- By 2015, \_\_\_\_ per cent of complex cancers will receive case conferencing.

#### **Indicators:**

- Percentage of cancers diagnosed within nationally recommended time lines in 2004; percentage of cancers diagnosed within nationally recommended time lines in 2015.
- Percentage of cancers receive accurate staging assessment in 2004; percentage of cancers receive accurate staging assessment in 2015.
- Percentage of patients being investigated for cancer offered access to earliest available diagnostic service in 2004; percentage of patients being investigated for cancer offered access to earliest available diagnostic service in 2015.
- Percentage of patients given information to empower them to follow up diagnostic testing and self-advocate in 2004; percentage of patients given information to empower them to follow up diagnostic testing and self-advocate in 2015.
- Percentage of complex cancers estimated to receive case conferencing in 2004; percentage of complex cancers receiving case conferencing in 2015.

**Action area 4: Provide timely, easy access to relevant, understandable information and emotional support for individuals with cancer and their family members during the peri-diagnostic period.<sup>81</sup>**

**Rationale:**

Research indicates that supportive care offered throughout the peri-diagnostic period can impact psychological and clinical outcomes and is a priority for patients and their families.<sup>82</sup>

**Background:**

Psychosocial supports include services meeting the physical, informational, psychological, social, spiritual and practical needs of patients and families. Primary concerns of patients and families during the peri-diagnostic period are for emotional support and relevant information, particularly about the diagnostic process, diagnostic tests, and interpretation of tests.<sup>83</sup>

**Factors:**

- **Access to reliable sources of information**  
Several reliable sources of information and support exist, although patients tend to be unaware of them at the earliest stages of the cancer experience, finding them only by chance. These sources include the Canadian Cancer Society's Cancer Information Service, the PEI government's Health Information Resource Centre, and the Canadian Cancer Society's Web site. Programs also exist to provide information to women with breast cancer at the time of diagnosis through the PEI Breast Cancer Information Partnership's *Sunflower Seeds of Knowledge* information kits, and immediately after surgery through the Canadian Cancer Society's Reach to Recovery visitation program.

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<sup>81</sup>Canadian Strategy for Cancer Control: Diagnosis Working Group (2002). "Cancer Diagnosis in Canada; Recommendations". Retrieved June, 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

<sup>82</sup>Ibid.

<sup>83</sup>Ibid. P. 17 Citing Sainsbury R, Johnston C, Haward B. "Effect on survival of delays in referral of patients with breast-cancer symptoms: a systematic review." *Lancet* 1999; 353 (9159): 11 12-3 and Krupat E, Irish JT, Kasten LE, Freund KM, Burns RD, Moskowitz MA, et al. Patient assertiveness and physician decision-making among older breast cancer patients. *Soc Sci Med* 1999;49 (4):449-57.

An increasing number of patients seek information from internet sites. These vary in both quality and appropriateness to the Canadian healthcare system. Unreliable information can upset patients, frustrate physicians, and require interpretation by a healthcare professional offered in a patient and caring manner. Physicians may lack the time and communication training to satisfy these needs. Currently, most services offering emotional support become available after a diagnosis is made.

The Cancer Information Service (CIS) offers high quality information, and callers speak to trained professionals, many of whom are oncology nurses. They are able to explain the tests, suggest questions the patient may want to ask their physicians, and to allay fears during investigational testing. Patients and their healthcare providers may be unaware that the CIS can help in this way, as it is not promoted until a diagnosis is confirmed. Such a promotion would require sensitivity as patients may be unprepared to seek information from a cancer service at this early stage.

***Recommendations:***

***Provide information to health professionals dealing with patients being investigated for cancer regarding how patients can access reliable information about the diagnostic process and available support resources.***

***Promote the services and contact information for the Health Information Resource Centre and Cancer Information Service through social marketing campaigns and system communication.***

- **Psychosocial support throughout the diagnostic period**

The Canadian Strategy for Cancer Control's Diagnosis Working Group suggests that appropriate support during the diagnostic period enhances the patients' and families' quality of life: "A prospective Swedish study found that the most significant factor in the long-term psychosocial adjustment of women with breast cancer was the patient's perception of the way the diagnosis was first communicated".<sup>84</sup>

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<sup>84</sup>Canadian Strategy for Cancer Control: Diagnosis Working Group (2002). p. 19

Patient navigators and case managers in several jurisdictions have been evaluated highly. They provide assistance and support for patients and family members at the time of diagnosis, helping patients to understand their treatment options and coordinating care. A patient navigator or case manager can play an important role in educating and empowering patients. See further discussion under Section 3.4 Treatment and Supportive Care.

***Recommendation:***

***Ensure appropriate psychosocial support is provided throughout the screening and diagnostic process, possibly through a patient navigator.***

## **Measuring Results: Targets and Indicators**

**Action area 4:** Provide timely, easy access to relevant, understandable information and emotional support for individuals with cancer and their family members during the peri-diagnostic period.

**Targets:**

- By 2015, \_\_\_ per cent patients and families will be able to access reliable sources of information during the peri-diagnostic period.
- By 2015, \_\_\_ per cent of cancer patients will be able to access psychosocial support during the peri-diagnostic period.

**Indicators:**

- Number of resources available to patients and families during the peri-diagnostic period in 2004; number of resources available in 2015.
- Percentage of cancer patients or family members accessing psychosocial support during the peri-diagnostic period in 2004; percentage of cancer patients accessing psychosocial support during the peri-diagnostic period in 2015.



### 3.4 Treatment and supportive care

**Goal:** To reduce cancer mortality and enhance the quality of life of cancer patients and their families.

**Objectives:**

- Timely access to care.
- Consistency and standards and guidelines of practice.
- Evidence-based, quality treatment and supportive care services.
- Seamless, holistic and interdisciplinary management.
- Access to clinical trials and new therapies.
- Access to supportive and rehabilitative services throughout treatment, including pain and symptom management.
- Monitoring of treatment outcomes.
- Appropriate care as close to home as possible.
- Timely and accurate communication between all care providers.
- Access to ongoing oncology-specific education for all practitioners and volunteers.

**Action area 1:**

Provide timely access to treatment, supportive and palliative care.

**Action area 2:**

Provide access to consistent and integrated quality care.

**Action area 3:**

Increase access to pain control and symptom management throughout the period of cancer treatment.

**Action area 4:**

Provide access to supportive, rehabilitative and palliative care throughout treatment.

## Background:

- **Treatment and supportive care**

Cancer treatment varies according to the site and stage of cancer and patients' individual physiology. Many cancers, especially those diagnosed when non-invasive, can be treated successfully by one or a combination of surgery, chemotherapy (drug therapy) or radiation. Improved treatments have caused many cancers to become a chronic disease managed over time, increasing the emphasis on management of associated pain and symptoms throughout care. The course of cancer care may include many periods of active treatment interspersed with periods of relative stability.<sup>85,86</sup>

Once a definitive diagnosis has been made, patients may begin a period of treatment to cure their cancer. If cure is not possible, treatment focuses on prolonging life and bringing comfort (palliation). Usually, there is no definite demarcation between the two. The goals of cure and palliation are carefully balanced throughout treatment, becoming more focused on palliation if the cancer progresses.

**Surgery** is used in several ways in cancer treatment, most commonly for surgical removal of a malignant tumour. In some cases, surgery is followed by a course of chemotherapy, radiation, or a combination of the two. Surgery can also play a role in cancer prevention, diagnosis and palliation.<sup>87</sup>

**Radiation** can be used either externally or internally, and is most often used in conjunction with surgery, chemotherapy, or a combination of the two.<sup>88</sup>

**Chemotherapy** uses drugs to kill cancer cells that are circulating in the body or that are difficult to reach by other methods. Chemotherapy is administered either orally by pill or intravenously and may be used by itself or with surgery, radiation, or a combination, to shrink the tumour prior to other treatment or afterward to eradicate remaining cancer cells.

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<sup>85</sup>Cancer Quality Council of Ontario (2003). "Strengthening the Quality of Cancer Services in Ontario:Synopsis". Retrieved November 17, 2003 from [www.cancercare.on.ca/pdf/Synopsis\\_CQCO\\_Report.pdf](http://www.cancercare.on.ca/pdf/Synopsis_CQCO_Report.pdf)

<sup>86</sup>Denicoff, Andrea M. reported by Hightower, Dorie & Vaughn, Peggy (2003). "Survivorship and the Changing Role of Palliative Care". National Cancer Institute. [www.nci.org](http://www.nci.org)

<sup>87</sup>Gale Group of Medicine (2003). "Cancer". Retrieved November 26, 2003 from [www.gov.pe.ca/hirc](http://www.gov.pe.ca/hirc)

<sup>88</sup>Ibid.

Usually, many physicians are involved in cancer treatment. One Canadian study found the average cancer patient encounters 13 to 97 doctors during the course of their treatment, with a median of 32.<sup>89</sup> Although presumably this number would be lower for most PEI cancer patients, it illustrates some of the issues involved in coordinating care. While undergoing treatment, the oncologist generally acts as the primary physician and is responsible for coordinating care.

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<sup>89</sup>Smith, Nicol, Devereus et al, 1999 cited in Health Canada (2001). “Investigation and Assessment of the Navigator Role in Meeting the Information, Decisional and Educational Needs of Women with Breast Cancer in Canada”. Ottawa: Minister of Public Works and Government Services. p. 5.

## **Action area 1: Provide timely access to treatment, supportive and palliative care.**

### **Rationale:**

Timely access to care can reduce cancer mortality and improve psychosocial outcomes.

### **Background:**

Timely access to care relies on timely diagnosis and accurate assessment of staging; accurate assessment of prescribed treatment; appropriate prioritizing and communication of needs; and system capacity including specialists, equipment, medications, supportive and palliative resources.

### **Factors:**

- **Access to care for patients without primary care physicians**  
If a patient without a primary care physician is diagnosed with cancer, a referral will be made by the attending physician to the Cancer Treatment Centre or a surgeon, who will become responsible for the patient's treatment. Some confusion remains about who will oversee supportive care and care after treatment, which is normally the responsibility of the primary care physician. In the absence of adequate primary healthcare services, procedures must be developed to ensure healthcare providers and patients are informed about how patients can access care post-treatment. A patient navigator may be able to help in this role. See further discussion under Action area 3 of this section.

#### ***Recommendation:***

***Develop clear procedures to ensure patients without primary care physicians can access supportive and post-treatment care and inform health providers and patients.***

- **Appropriate referrals**  
When a diagnosis has been confirmed, the attending physician may make a referral to a specialist. In some cases, a surgeon is able to both diagnose and treat the cancer. Recent advancements in cancer care, including multi-disciplinary treatment, have changed treatment protocols, which may cause referrals to be made to the wrong service (medical or radiation oncology), thus delaying treatment. Centralized referrals made to the Cancer Treatment Centre would allow the oncologists to triage the referrals appropriately among services. Oncologists triage their own cases and treatments begin immediately if warranted.

**Recommendation:**

***Develop a system for centralized referral to the Cancer Treatment Centre, enabling team assessment of patients' needs and primary referrals to the most appropriate oncological service.***

- **Communication among healthcare providers**

Several departments may be involved in treating cancer. Surgery may be performed at either the QEH or PCH; chemotherapy is administered at the Cancer Treatment Centre in the QEH or its satellite clinic at the PCH; and radiation is performed at the QEH. Currently, patient charts must be physically shared between these sites, including departments within the hospitals. This can cause delays in communication and impedes multi-disciplinary care.

Clear and timely communication is essential to multi-disciplinary care. In addition to diagnostic and treatment specialists, others involved in cancer care may include primary health care providers, regional hospital staff, Home Care and Support staff, and a wide range of support professionals and volunteers. Miscommunication can affect the quality of care, cause duplication of resources, and is a source of frustration for patients, family, and staff alike. Ultimately, a patient navigator and electronic patient records would alleviate these issues. For more information, see Action area 3 of this section. Meanwhile, strategies need to be developed to improve communication, particularly between the oncology clinics and regional staff and hospitals.

**Recommendation:**

***Analyze communication pathways among multi-disciplinary and regional physicians and staff to develop strategies to improve communication.***

- **Access to treatment equipment and facilities**

The Cancer Treatment Centre in the QEH has been newly renovated and now includes a linear accelerator, providing local access to most Island patients requiring radiation treatment. Radiation treatment is usually administered over several weeks. Previously, patients had to leave their homes and support systems during this immensely difficult time. As a result, it was not uncommon for patients to choose to forego treatment. Access to this service within the province is a great improvement in cancer care. Cancer centres normally have two linear accelerators to provide back-up in case of equipment failure; PEI is the only centre in Canada with only one. To ensure treatments are not interrupted, it may be possible to reach an agreement with another province to access their linear accelerator during off-hours with staff supplied by PEI.

An equipment breakdown would interrupt treatment for indefinite time periods. As incidence increases and more cancers are treated by radiation or multi-disciplinary approaches, demand is likely to grow. The combination of demand and obsolescence will likely see the need for another linear accelerator within five years.

Long-term fundraising plans are needed to support the purchase of equipment and to meet emerging needs as equipment becomes obsolete and new technologies are introduced.

***Recommendations:***

***Identify priority fund-raising needs to inform fund-raising partners to support emerging oncology equipment needs.***

***Investigate the possibility of making backup arrangements with New Brunswick or Nova Scotia to provide access to radiation services for patients undergoing treatment in case of equipment failure.***

- **Oncology specialists**

Timeliness relies on access to appropriate resources, including facilities, equipment, health professionals and technical staff. The Cancer Treatment Centre is currently staffed by two medical oncologists and one radiation oncologist. Funding has been approved for another full-time medical oncologist for some time, although recruitment efforts have not been successful to date.

***Recommendation:***

***Create an ad hoc recruitment committee including staff of the Provincial Health Services Authority and Department of Health and Social Services to develop a recruitment and retention strategy for oncology personnel.***

## Measuring Results: Targets and Indicators

### **Action area 1: Timely access to treatment, supportive and palliative care.**

#### **Target:**

- By 2015, time from a definitive diagnosis of cancer to treatment referral will be within \_\_\_ days or weeks.
- By 2015, \_\_\_ per cent of initial referrals will be to the most appropriate care professional.
- By 2015, \_\_\_ per cent of health providers will have access to clear and timely communication about patients' care.
- By 2015, adequate resources, including health professionals and technical staff, equipment and physical facilities will be available to provide cancer treatment.

#### **Indicators:**

- Number of days from cancer diagnosis to referral in 2004; number of days from cancer diagnosis to referral in 2015.
- Number of initial referrals made to most appropriate care professional in 2004; number of initial referrals made to most appropriate care professional in 2015.
- Number of hours to communicate information among health providers in 2004; number of hours to communicate information among health providers in 2015.
- Number of vacancies and gaps in health professionals and technical staff, equipment and physical facilities available to provide cancer treatment in 2004; number of vacancies and gaps in health professionals and technical staff, equipment and physical facilities available to provide cancer treatment in 2015.

## **Action area 2: Provide access to consistent and integrated quality care.**

### **Rationale:**

Consistent and integrated quality care can reduce mortality by ensuring treatment is based on best practice and improve psychosocial outcomes for patients and family members.

### **Background:**

As well as ensuring timeliness of treatment and access to pain and symptom management, both discussed separately, quality care offers patients access to therapies based on the most current and best evidence; coordinated access to care among all involved health professionals and services; and supportive care including reliable information about cancer, treatments and possible side-effects; community resources; and emotional and practical support.

### **Factors:**

- **Coordination of care**

PEI's cancer patients are served by two new facilities, dedicated and well-informed staff, and numerous support resources. Aside from resource shortages, many of the barriers to providing consistent, integrated and quality care result from coordination issues.

Treatment for cancer can be extremely complex and may rely on a number of specialized health providers, which increases the challenge to ensure that care is coordinated. The medical oncologist normally coordinates the specialists involved in active treatment, while diagnosis and follow-up care are coordinated by family physicians. Professionals involved in supportive care could also involve social workers, psychologists, physiotherapists, occupational therapists, regional hospital staff, palliative care specialists, Home Care and Support staff, dieticians, pharmacists, hospice palliative care volunteers and community support staff. In some cases, patients do not have a family physician to coordinate and oversee care and advocate on their behalf.



Patients and families may be unsure about who is responsible for the care, and frustrated by communication problems with – and among – their healthcare providers. Care can seem fragmented, gaps may occur in communication and access to services, patients and caregivers may feel unsupported.<sup>90</sup>

Although the Cancer Treatment Centre has recently added two new positions to support patients, a social worker and part-time spiritual advisor, not all cancer patients are treated at the centre. Their cancer may be appropriately treated by another specialist, such as a surgeon or urologist, they may choose alternative therapies or forego treatment altogether. As a result, such patients do not access the supports made available through the centre and may not be informed about supportive programs and services available within the community.

Nationally, and as treatment protocols evolve, interdisciplinary rounds and case management are becoming the standard of care. Although difficult to achieve when medical staff are in short supply, the small size of the Island community fortunately facilitates communication on an informal basis.

Similar issues are of concern in most jurisdictions and patient navigator programs have been developed in response. In Nova Scotia, a pilot program introduced in three health districts was quickly expanded to two more districts as the benefits played by this role became apparent. A patient navigator offers a single point of entry to the cancer care system, helps to coordinate care, informs and educates patients and their families, supports the health care team in providing continuity of care and access to standards of care, and builds community capacity to support cancer patients and their families by identifying gaps in services and resources.<sup>91</sup> For more information, see Access to reliable information under Action area 4 of this section.

Limited human resources and the lack of electronic patient records can present particular challenges to care coordination in PEI. Recruitment and retention of sufficient health professionals and technical staff are always likely to pose problems in small and financially constrained communities, and may become more so as the cancer case load grows and care continues to become more complex. Coordinated care can help to ensure the best use of limited resources.

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<sup>90</sup>Canadian Cancer Society, Ontario Division (2003). *Breaking down the Barriers: Study of Cancer Patient and Caregiver Needs in Ontario*. Retrieved Feb. 12, 2004 from [www.cancer.on.ca](http://www.cancer.on.ca)

<sup>91</sup>Personal communication with Sandra Cook, Patient Navigator Coordinator, Cancer Care Nova Scotia, April 1, 2004.

Patients and families faced with life-threatening illness are often stressed and may not be able to navigate a complex system themselves, sometimes missing out on valuable sources of support. Those without family physicians have to navigate their own care and support.

This strategy recommends three approaches to improve care coordination, depending on patients' and families' preferences and needs. These include a "paper navigator" – an easily accessible written guide to community programs and supports; a self-management program to help patients learn the skills needed to live with an ongoing chronic disease; and a patient navigator to help those without physicians or with complex needs. See Action area 4 of this section for further discussion of the first two options.

***Recommendation:***

***Create a Patient Navigator position to coordinate multi-disciplinary care between different care settings, advocate for patients, and provide support and education to patients and families as they learn to live with cancer.***

- **Clinical Practice Guidelines**

Clinical practice guidelines (CPGs) provide information about treatment options and side-effects. They are available in both physician and patient formats and can "improve patient outcomes by reducing inappropriate variation in oncology care, promote the uptake of innovation in cancer management, and assist patients in making informed choices from best practice options".<sup>92</sup> Based on current and best-evidence, CPGs can help to ensure a consistent standard of care.

CPGs have been developed in some provinces and are available on the Canadian Medical Association Web site. A national action group is developing clinical practice guidelines which can be adapted as required to fit the circumstances of each province.

***Recommendation:***

***Monitor work being accomplished by the National Clinical Practice Guidelines Action Group and identify stakeholders, including the PEI Medical Society, surgeons and oncologists, to adapt them for at least the four most common cancers. A communication plan to reach physicians and the public will also be required.***

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<sup>92</sup>Cancer Control Strategy Treatment Topic Working Group (2001). "Clinical Practice Guidelines Subgroup Report."

- **Access to clinical trials**

Clinical trials help provide evidence on which to base changes in treatment and offer patients access to new treatments. To participate in a clinical trial, the treating physician and/or the patient must be aware of the trial and fit the eligibility criteria; there must be adequate numbers of patients available to take part in the trial, trained personnel, and satisfaction of ethical and regulatory issues. Such factors may limit a small community's capacity to become involved in clinical trials. There may be insufficient patients with specific cancers or profiles; a lengthy legal process must be undergone to gain approval even though participation is minimal; and there may be insufficient staff. In PEI, clinical trials are staffed by a .5 full-time equivalent clinical trials nurse, which limits the capacity to become involved in more trials.

Greater participation in clinical trials is cited as one of the factors involved in improving cancer survival among children compared to the rates for adults (the ratio of deaths to new cases is estimated to be .47 per 100,000 for adults in Canada in 2004, and .18 per 100,000 for children).<sup>93</sup>

The national research action group has recommended that a cohort study be conducted across Canada, and participation in clinical trials be increased through establishment of a national Cancer Clinical Trials Bureau to promote access to clinical trials and “expedite trials development, approval and activation process, and knowledge generation and application.”<sup>94</sup> A national group would help to reduce duplication of efforts and facilitate greater participation in clinical trials in small communities such as PEI, if primarily to support human resource needs: “Participation in clinical trials is considered highly desirable for physicians and other health care professionals and is strongly related to recruitment and retention of those professionals.”<sup>95</sup>

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<sup>93</sup>Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada (2004). *Canadian Cancer Statistics 2004*. Available on Internet at [www.cancer.ca](http://www.cancer.ca)

<sup>94</sup>*Cancer Control Strategy Treatment Working Group - Clinical Trials/Research Subgroup*. (2001) “Appendix B: Clinical Trials/Research Subgroup Report.”

<sup>95</sup>*Treatment Working Group - Systemic Therapy Subgroup* (2001). “Appendix G: Systemic Therapy Subgroup Report.” P. 26.

Clinical trials are funded either by the National Cancer Institute of Canada Clinical Trials Group (NCIC CTG) or pharmaceutical companies. NCIC CTG is a non-profit group. Their funding is intended to recover patient costs and does not cover clinical trials staffing, whereas cost recovery may be greater from participating pharmaceutical companies.

***Recommendations:***

***Monitor national efforts to improve access to clinical trials.***

***Expand the capacity to conduct clinical trials in Prince Edward Island by piloting a one year full-time clinical trials nurse position to inform the sustainability of such a position.***

- **Access to medications for the treatment of cancer**

At one time, systemic oncology (chemotherapy or drug treatment) was used with largely modest effect in the treatment of advanced cancers. More recently, advances in drug effectiveness and tolerance have increased survival rates for patients with several common cancers (breast, prostate, colon, ovary) and been effective in improving survival and enhancing quality of life for patients with several advanced cancers (lung, colon, breast, ovary, lymphoma).<sup>96</sup> Treatments may continue for longer periods of time, causing an increase in case loads. A study conducted in British Columbia showed the case load to have increased by six to 10 per cent annually, whereas incidence of new cancer cases increased by approximately three per cent per year, mainly associated with the aging population. Meanwhile, the cost of drugs increased at rates of 20-30 per cent per year.<sup>97</sup> This growth creates continuing pressure on both human and financial resources.

Access to medications is critical to cancer treatment, because of the reliance on new and sometimes costly medications, some of which may be taken in home settings and consequently, are not paid for by the healthcare system.

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<sup>96</sup>Ibid.

<sup>97</sup>*Treatment Working Group - Systemic Therapy Subgroup* (2001). “Appendix G: Systemic Therapy Subgroup Report.”

The Canadian health system provides coverage only for drugs taken in hospital, although each province provides drug assistance for specific groups of people. In PEI, these include seniors, those receiving social assistance or with only slightly higher incomes, low-income families with children under 18 years, and those qualifying under an assortment of disease-specific plans. None of the disease-specific plans include cancer or palliative drugs. As a cost-controlling measure, each of these groups has a formulary – a list of drugs eligible for reimbursement. The cancer drugs on these formularies are limited. Other Islanders may have private drug insurance plans, though 27 per cent<sup>98</sup> are thought not to have private insurance. The co-payments of private drug insurance plans are often about 20 per cent, an amount which can quickly add up when cancer treatment drugs may cost several thousands of dollars. Costs for drugs can be unsustainable within small group plans where costs are defrayed amongst plan members. As a result, some people are unable to afford their prescribed drug treatment when taken outside of hospital.

Access to cancer treatment medications is a major concern for cancer patients, particularly in the Atlantic provinces. Other provinces offer a variety of plans to assist with catastrophic drug costs. See Appendix II for a breakdown of out-of-pocket drug expenses for patients across Canada.

There are many complex issues involved in the escalating cost and use of medications and, in response, the viability of a national catastrophic drug plan is being explored. This issue affects not only cancer but all chronic diseases and palliative care and threatens the sustainability of Canada's healthcare system.

Strategies must be developed to address this issue either nationally, or possibly through creation of a broad-based, user-pay drug insurance program accessible to all Islanders.

**Recommendations:**

***Explore avenues to provide catastrophic drug assistance to all Islanders, particularly for cancer treatment.***

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<sup>98</sup>The Standing Senate Committee on Social Affairs, Science and Technology (2002). *The Health of Canadians - The Federal Role. Volume Six: Recommendations for Reform*. P. 135. Citing Fraser Group/Tristat Resources. "Drug Expense Coverage in the Canadian Population: Protection From Severe Drug Expenses". August 2002, pp. 48-49.

*Review all current drug programs to develop a basis on which to establish equitable access to medications.*

## **Measuring Results: Targets and Indicators**

**Action area 2: Provide access to consistent and integrated quality of care.**

**Target:**

- By 2015, \_\_\_ per cent cancer patients will have access to centralized care coordination.
- By 2015, \_\_\_ number of clinical practice guidelines will be available to physicians and patients to ensure a consistent standard of care.
- By 2015, \_\_\_ per cent cancer patients will be able to participate in clinical trials if considered appropriate and desired.
- By 2015, \_\_\_ per cent of cancer patients will be able have equitable access to medications for treatment and palliation.

**Indicators:**

- Percentage of cancer patients receiving centralized care coordination in 2004; percentage of cancer patients receiving centralized care coordination in 2015.
- Number of clinical practice guidelines available to physicians and patients in 2004; number of clinical practice guidelines available to physicians and patients in 2015.
- Percentage of cancer patients participating in clinical trials in 2004; percentage of cancer patients participating in clinical trials in 2015.
- Percentage of cancer patients receiving equitable access to medications for treatment and palliation in 2004; percentage of cancer patients receiving equitable access to medications for treatment and palliation in 2015.

### **Action area 3: Increase access to pain control and symptom management for cancer patients throughout the period of cancer treatment.**

#### **Rationale:**

Timely treatment of pain and other symptoms associated with cancer can reduce suffering, enhance the quality of life of cancer patients and their families, and prevent some acute care costs.

#### **Background:**

Great strides were made in cancer prognosis during the latter part of the 20<sup>th</sup> century, largely due to earlier diagnoses and improved treatments. While most cancers once progressed fairly quickly to a palliative or end-of-life phase, many are now managed as a chronic disease over an extended period of time.

It is estimated that approximately 40 per cent of cancer patients in active treatment and 80 per cent of patients with advanced disease suffer from pain, with more than half under-treated for a variety of reasons.<sup>99</sup> Left untreated, pain can cause changes to the central nervous system, increasing the severity of pain and compromising the ability to effectively treat it.<sup>100</sup> Forty percent of patients also report symptoms such as nausea, anorexia, and dyspnea.<sup>101</sup>

#### **Factors:**

- **Pain consults for ambulatory and hospital patients**  
Existing provincial policies separate access to active therapy and palliative therapy even though there is no definitive line between curative and palliative care. The goals of cure and palliation are carefully balanced throughout treatment, becoming more focused on palliation if the cancer progresses. Access is currently denied to consults with the provincial palliative medicine consultant or to stabilization at the provincial Palliative Care Unit if patients are still receiving chemotherapy or radiation, even through such treatments may be palliative. The Integrated Palliative Care Program is working to increase the capacity to treat pain and symptoms within the regions and outpatients may access this program;

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<sup>99</sup>Personal communication with Dr. Joan MacIsaac, Provincial Palliative Medicine Consultant, May 19, 2004.

<sup>100</sup>Ferris, FD (1998). "Hospice Palliative Care in Prince Edward Island - A Consultation Report to PEI Department of Health & Social Services".

<sup>101</sup>Ibid.

but access may depend on awareness of the program and self-advocacy. As well, pain associated with cancer can be complex and may require a specialist's expertise. Patients and families are often reluctant to access palliative care at earlier stages of cancer because of its association with dying, and they may needlessly experience unrelieved pain and distress. In fact, patients may live with advanced cancer for several years and a palliative program would be inappropriate.

Models delivering simultaneous palliative and active cancer treatments indicate improved quality of life for patients, greater adherence to chemotherapy protocols, increased referrals to hospice care, and reduced distress on behalf of primary caregivers both during the illness and during bereavement.<sup>102</sup>

Provision of pain and symptom management throughout the period of treatment is a national standard for cancer care accreditation. Section 7.4 of the Accreditation Guidelines states: "the (cancer care) team knows how to assess and manage pain; all clients receive a pain assessment; and the team identifies and consults with experts in pain." Services at the Cancer Treatment Centre do not currently reach this standard.

A proposal has been developed to increase access to pain and symptom control for cancer patients receiving treatment at regular ambulatory clinics to be held at the Cancer Treatment Centre and for those admitted to the QEH. The annual cost is estimated to be \$127,000, at least some of which may be recouped through reduced admissions to acute care or emergency visits.

***Recommendation:***

***Enhance the Integrated Palliative Care program to include the full scope of outpatient and in-patient pain consults as a provincial service.***

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<sup>102</sup>Foley KM, Gelband, H. Editors (2003). *Improving Palliative Care for Cancer: Summary and Recommendations*. National Academy of Sciences. Retrieved Feb. 24, 2004 from [www.nap.edu](http://www.nap.edu) p.11



## Measuring Results: Targets and Guidelines

**Action area 3:**            **Increase access to pain control and symptom management for cancer patients throughout the period of cancer treatment.**

**Target:**

- By 2015, \_\_\_ per cent of cancer patients will be able to access pain and symptom consults throughout their treatment for cancer.

**Indicator:**

- Percentage of cancer patients receiving pain and symptom consults throughout their treatment for cancer in 2004; percentage of cancer patients receiving pain and symptom consults throughout their treatment for cancer in 2015.

## **Action area 4: Provide access to supportive, rehabilitative, and palliative care throughout treatment.**

### **Rationale:**

Provision of supportive and rehabilitative care throughout treatment can improve cancer patients' and family members' ability to cope, likeliness to comply with treatment and may help avoid other acute care needs.<sup>103</sup>

### **Background:**

Cancer is a life-threatening illness that often causes great emotional, psychological, financial, social, and spiritual stress for the patient and family members. Holistic care, termed "re-balanced focus" by the National Cancer Control Council, recognizes the role stresses play on successful treatment and helps patients and families find ways to manage their situation.

Supportive care can include a wide range of services offered both inside and outside the health system. Existing supportive care services offered by the PEI Cancer Treatment Centre include a social worker and half-time spiritual advisor and dietician. When home, patients can access Home Care and Support services if required. Pain and symptom consults are currently available to patients primarily during end-of-life care. For more information, see Action area 3. If needed, patients can also access physiotherapy, occupational therapy or mental health services within the health system.

Supportive care available outside the health system includes income support such as Employment Insurance and Canada Pension Plan; emergency financial assistance from the Canadian Cancer Society, PEI Division for patients with low incomes; emotional support and information from CCS's Cancer Information Service or DHSS's Health Information Resource Centre; and home-based services such as equipment loan, Meals-on-Wheels, and hospice palliative care volunteers. Patients may also access private practitioners such as physiotherapists or psychologists. A growing number of patients seek alternative therapies.<sup>104</sup>

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<sup>103</sup>Canadian Strategy for Cancer Control Supportive Care/Cancer Rehabilitation Workgroup (2002). "Final Report." Retrieved June 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

<sup>104</sup>Treatment Working Group, Canadian Cancer Control Strategy (2002). "Appendix C". Retrieved June 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

Informal support can also play an important role, and includes the care of family, neighbours and friends; pastoral care; and community fundraising. The extent of this type of support depends on the patient's personal circumstances and community.

**Factors:**

- **Accommodations during treatment**

The recent closure of the Queen Elizabeth Lodge left a gap in accommodations available for patients receiving radiation treatment, visiting family or as a respite for caregivers. With enhanced radiation services now offered within the province, some patients must travel long distances for their treatment without benefit of appropriate accommodations, whereas these are provided to those travelling out of province for their treatment. Radiation treatment is administered five days per week, usually for several weeks at a time, and patients may be very ill. The QEH Auxiliary is investigating this issue, including the possibility of building a lodge on land adjacent to the hospital, or negotiating prices at local hotels.

***Recommendations:***

***Investigate ways to provide accommodations to patients and family members during treatment.***

***Support the efforts of the QEH Auxiliary to provide accommodations to patients and family members during cancer treatment.***

- **Increased awareness of psychosocial needs**

Timeliness of psychosocial interventions can be facilitated by assessing patients' and families' needs at each professional encounter. The Cancer Treatment Centre has a full-time social worker and part-time spiritual advisor, both of whom are available to support patients and family members. These are new positions and require the ongoing support of up-to-date information about community resources, as do other people working in supportive roles.

A variety of services also exist within the community to provide emotional support to cancer patients and family members. These include the Cancer Society's CancerConnection, Cancer Information Service, Reach to Recovery, and Living with Cancer emotional support groups; and the breast cancer and prostate cancer support groups.

***Recommendations:***

***Provide continuing education opportunities to health professionals and volunteers to raise awareness about the psychosocial needs of cancer patients and their families, and of supportive resources.***

***Support and enhance the capacity of existing programs and services so they can provide or direct cancer patients and family members to support for psychosocial needs.***

***Develop procedures to ensure patients' and families' psychosocial needs are assessed at each professional encounter and appropriate referrals made. Conduct a social marketing campaign to inform patients, families, and health professionals of the resources available to meet psychosocial needs.***

- **Easy access to reliable information about cancer and supportive community resources.**

A variety of supportive resources are available from community organizations, government departments and private practitioners, although access tends to be ad hoc. A coordinated effort is needed to ensure all patients and their health providers can easily access such information. During the development of the PEI Cancer Control Strategy, an inventory of supportive resources available throughout the province was prepared. This information needs to be widely disseminated among all support professionals and volunteers throughout the province.

The increased access to information and proximity to the United States can create further demands on physicians. For example, in the US, “guidelines can be less well defined and [there is great] public expectation, in the private sector of health care, for immediate access to the newest drug,”<sup>105</sup> even though the effectiveness of the drug over time may be unproven.

Patients and families may be confused by the plethora of information available and need reliable assistance in navigating and assessing it. The Cancer Society’s Cancer Information Service is an excellent source of information for patients and caregivers. Callers speak to trained personnel, many of whom are oncology nurses. Other ways of providing information include paper navigators and the internet. Wide dissemination of information to all health professionals and

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<sup>105</sup>Treatment Working Group, Canadian Cancer Control Strategy (2002). “Appendix C”. Retrieved June 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

volunteers working with cancer patients will also help to improve access to information about cancer and community support resources.

***Recommendations:***

***Promote the Canadian Cancer Society's Cancer Information Services as a key information service about cancer, and promote key community resources to patients, families and health providers.***

***Regularly update information about supportive care resources.***

***Provide information about supportive care resources to patients and their families in a variety of ways that are clear and easy to access, as well as to all health professionals and volunteers working with patients.***

***Provide patients with appropriate information packages about cancer, treatment options, and resources at the time of diagnosis.***

- **Patient skills education**

Patients' and families' support needs will differ according to their personal circumstances, the nature of the cancer, treatment needs, etc. A cancer diagnosis is often life-threatening, and they may have to quickly learn a large number of new skills. While under stress, information retention is often minimal. For an ever increasing number of patients, cancer will become a chronic disease to be managed over many years. Efforts to help patients and families self-manage their cancer need to be made available consistently, through a variety of means, and for a variety of educational levels and learning styles.

Programs designed to help people coping with other diseases could provide a model for a similar program to support cancer patients and families. For instance, the Arthritis Society offers a volunteer-led Arthritis Self-Management Program covering such topics as exercise, managing pain, healthy eating, preventing fatigue, taking medications, dealing with stress and depression, working with the doctor and healthcare team, evaluating alternative treatments, and problem solving.<sup>106</sup> These topics are of similar concern to many cancer patients. Information sessions may also facilitate development of informal peer support.

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<sup>106</sup>The Arthritis Society (2002). "Arthritis Self-Management Program". Retrieved February 16, 2004 from [www.arthritis.ca](http://www.arthritis.ca)

Not all patients or family members would be interested or able to participate in sessions. Some will be able to draw upon their own resources for support while others, particularly those with complex needs, may require the more individualized attention of a patient navigator discussed under Action area 2 of this section.

***Recommendation:***

***As a collaborative project of the Canadian Cancer Society, PEI Division and the Cancer Treatment Centre, develop a program to help cancer patients and family members adjust to living with cancer and build skills to manage their disease.***

- **Complementary and Alternative Medicine**

Most complementary and alternative medicine (CAM) therapies treat cancer holistically, using approaches that combine physical, mental and spiritual healing. It is estimated that close to half of cancer patients in Canada use some form of CAM therapy, usually at the same time as using conventional therapies. Many do not tell their physician,<sup>107</sup> although negative interactions may result from concurrent use of CAM and conventional therapies.

There is wide diversity in the types of CAM therapies available. Information is often difficult to assess and frequently inconsistent and contradictory. Some pharmacists have a particular interest in CAM therapies and may be able to assist patients in making an assessment. There is a general lack of communication between practitioners of conventional and CAM therapies, though some CAM therapies may offer cost-savings to the healthcare system since they use low technologies and are often preventative in nature.

Studies have shown that stress-relieving CAM therapies can improve compliance with conventional treatment and help to improve appetite and alleviate depression. Therapies include “massage, yoga, training in relaxation and stress reduction techniques, meditation, imagery, walks in nature, journal and dream work, reflection, and other forms of artistic expression and personal exploration”.<sup>108</sup> These techniques can largely be recommended without fear of

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<sup>107</sup> *Treatment Working Group*, Canadian Cancer Control Strategy (2002). “Appendix C”. Retrieved June 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

<sup>108</sup> U.S. Congress, Office of Technological Assessment, 1990. *Unconventional Cancer Treatments*. OTA-H-405. U.S. Government Printing Office, Washington D.C. Retrieved July 16, 2002 from [www.wws.princeton.edu/~ota/ns20/alpha\\_f.html](http://www.wws.princeton.edu/~ota/ns20/alpha_f.html) p. 31

negative interaction with conventional therapy, although massage, since it physically manipulates the body, should be performed by an experienced practitioner knowledgeable about massage of cancer patients and with the knowledge of the physician.

**Recommendation:**

***Educate patients about the importance of discussing any alternative and complementary therapies they may consider using with their physician.***

## Measuring Results: Targets and Indicators

### **Action area 4: Provide access to supportive, rehabilitative, and palliative care throughout treatment.**

#### **Targets:**

- By 2015, \_\_\_ per cent of patients and family members requiring accommodations will be able to access them at reasonable cost.
- By 2015, \_\_\_ per cent of professional encounters with a cancer patient and family will incorporate a psychosocial assessment.
- By 2015, \_\_\_ per cent of cancer patients and their families will have easy access to reliable, up-to-date information about their cancer and community supports.
- By 2015, \_\_\_ per cent of cancer patients and their families will be offered support to develop skills to help them self-manage their cancer.
- By 2015, \_\_\_ per cent of cancer patients using CAM therapies will discuss their use with their physicians.

#### **Indicators:**

- Number of reasonably priced accommodations available to cancer patients and their families in 2004; number of reasonably priced accommodations available to cancer patients and their families in 2015.
- Percentage of professional encounters incorporating a psychosocial assessment of the patient and family in 2004; percentage of professional encounters incorporating a psychosocial assessment of the patient and family in 2015.
- Number of cancer patients and their families accessing reliable information and community supports in 2004; number of cancer patients and their families accessing reliable information and community supports in 2015.
- Percentage of cancer patients and their families receiving support to develop skills to help them self-manage their cancer in 2004; percentage of cancer patients and their families receiving support to develop skills to help them self-manage their cancer in 2015.
- Percentage of cancer patients and their families using CAM therapies who discuss them with their physician in 2004; percentage of cancer patients and their families using CAM therapies who discuss them with their physician in 2015.



### 3.5 Palliative and end-of-life care

**Goal:** To enhance the quality of life of cancer patients and their families.

**Objectives:**

- Access to palliative care medications and supplies in all care settings.
- Coordination between care settings and care providers.
- Consistency of service between care settings.
- Timely access to supportive services, including pain and symptom control, information, psychological, emotional and practical support.

**Action area 1:**

Support and enhance the existing Integrated Palliative Care Strategy in its capacity to provide continuity of palliative care among different care settings.

**Action area 2:**

Increase access to palliative care for cancer patients and their families throughout treatment.

## Background:

- **Palliative and end-of-life care**

Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals who are living with, or dying from, a progressive life threatening illness, their families, and the bereaved.<sup>109</sup>

Elements of palliative care include:

- relief from pain and other distressing symptoms;
- dying seen as a normal process;
- integrating the psychological and spiritual aspects of care;
- offering a support system to allow the patient to live as normally as possible, for as long as possible;
- a system to support the family cope during the illness, and in bereavement;
- a team approach to addressing the needs of patients and their families;
- availability early in the course of illness and including investigations to better understand and manage clinical complications.<sup>110</sup>

In Prince Edward Island, palliative care is provided through acute and long term care services, the Palliative Care Unit, the PEI Cancer Treatment Centre, the Hospice Palliative Care Association of PEI, Southern Kings Hospice, and Home Care and Support staff. The Regional Integrated Palliative Care Program, launched provincially in 2003, has developed and trained interdisciplinary palliative care clinical resource teams within each region to improve access and coordination of palliative services in the most appropriate care settings. The program has improved the system's capacity to provide care and home support particularly during end-of-life stages. It has provided palliative care resource teams to support staff and physicians as well as case management to improve coordination between care settings.

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<sup>109</sup>Department of Health and Social Services (2003). *PEI Primary Health Care Redesign*. DHSS: Charlottetown.. Page 89.

<sup>110</sup>World Health Organization (2002). *Palliative care*. Retrieved Feb. 24, 2004 from [www.who.int/cancer/palliative/en](http://www.who.int/cancer/palliative/en)

Patients can be referred to the palliative care resource teams by anyone. Each referred patient has an assessment done by a member of the resource team. Patients are assigned a case manager as central coordinator of care during this stage. When the patient enters the program, a case conference is called with all involved professionals and others at the patient's request. Access to the Prince Edward Home and consults with the provincial palliative medicine consultant are available to patients after active treatment has ceased.

A provincial consultation about palliative care needs was conducted in 1997/1998 by Dr. Frank Ferris and an interprovincial rural palliative home care project was conducted in Southern Kings and East Prince Health Regions and Nova Scotia's Northern Health Region in 1998-2001. These projects informed development of the current Integrated Palliative Care Program. The program has been designed to target many of the recommendations made by Dr. Ferris. Remaining gaps include access to adequate in-patient acute, respite, long term and end-of-life care; funding for medications, equipment, supplies and services in all care settings; a central system to broker medications, equipment, supplies, and services; and provincewide plans to market hospice palliative care.<sup>111</sup>

In 2000, 339 deaths on PEI listed cancer as the cause of death (30 per cent of total deaths). Of these, 65.5 per cent occurred in acute care facilities; 13 per cent occurred in the palliative care unit; 14.5 per cent occurred in other long term care facilities; and 7 per cent occurred at home. Surveys indicate that the majority of Islanders would prefer to receive end-of-life care in their own homes.<sup>112</sup> Early reports indicate that, while patients may still need to be hospitalized during final days, the Regional Integrated Palliative Care Program has helped them remain at home for longer periods.

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<sup>111</sup>Ferris, FD (1998). "Hospice Palliative Care in Prince Edward Island - A Consultation Report to PEI Department of Health & Social Services".

<sup>112</sup>Department of Health and Social Services (2001). "Strategy for PalliativeCare in PEI".

**Action area 1: Support and enhance the existing Integrated Palliative Care Strategy in its capacity to provide continuity of palliative care among different care settings.**

**Rationale:**

Seamless palliative care can enhance the quality of life for cancer patients and families, reduce duplication of services and reduce the likelihood of gaps in service.

**Factors:**

- **The Integrated Palliative Care Strategy**  
The existing Integrated Palliative Care Strategy will address many issues facing cancer patients during palliative and end-of-life care.

***Recommendations:***

***Provide advice, support and liaise with the existing provincial strategy to improve access to palliative and end-of-life care to cancer patients and their families in all regions of the province.***

***Identify and respond to gaps in the existing palliative care strategy as to needs specific to cancer patients and their families.***

- **Access to medications and supplies during palliative and end-of-life care in all care settings**  
Care delivered in home settings is often preferable to patients and their families and reduces pressure on acute and long-term care resources. However, this care also shifts some of the associated financial responsibility to patients. Costs can present a financial hardship, particularly to those without personal resources, private drug insurance or who do not qualify for provincial drug programs.

While patients' needs vary, some examples of monthly costs during palliation and end-of-life care include approximately \$500 for basic nutrition used with feeding tubes; \$190 for oxygen (now included in provincial government coverage for patients with some lung diseases, but not cancer); \$260 for basic pain relief (higher during late stages of cancer) and other assorted costs including ostomy supplies (\$125); relief of other symptoms associated with cancer and palliative care (possibly \$100); feeding tubes, dressings and equipment rental or purchase. Some palliative patients may also incur costs associated with travel.

During these times, families may also lose their source of income, possibly that of the dying patient, the caregiver, or both.

Since palliative care provided in homes is a replacement for care in hospitals, patients should be able to obtain necessary drugs and supplies from their local hospital or purchase them at reduced cost. A precedent has been set by New Brunswick, which has operated the Extra-Mural Program or ‘hospital without walls’ since 1981. Through this program, acute palliative care patients who are being cared for at home as a substitute for hospital care are provided with most supplies, including drugs if the patient does not have private drug insurance coverage.<sup>113</sup>

***Recommendations:***

***Investigate different models of improving drug coverage, providing medications and supplies in care settings of choice, particularly for acute palliative patients receiving care in home as a substitute for hospital care.***

***Develop strategies to improve access to reasonably-priced medications, nutrition for those using feeding tubes, and supplies needed for patients cared for in home settings.***

***Investigate the possibility of dispensing drugs and supplies in PEI in a similar way to New Brunswick’s Extra-Mural Program.***

- **Access to medications and supplies in rural communities where they may not be readily available**

Access to medications and supplies may be difficult in rural communities where there is isolated lower need, and therefore lower supply. Costs also vary; in some cases, local stores pay higher wholesale costs than the retail costs in larger centres. The patient or family is not only at a disadvantage because of cost or inconvenience, but may have to use precious respite time driving to buy supplies. Compensatory behaviours may include re-using feeding tubes, changing dressings less frequently, or using fewer drugs, all of which could entail further risks to health.

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<sup>113</sup>Personal communication with Roberte Vautier, Health Care Consultant, Extra-Mural Program, NB Department of Health and Wellness.

Equipment needed for palliative care can be either borrowed or rented at minimal cost in some Island communities. In some regions of PEI, pain pumps – one of the most effective ways to treat pain – have been purchased with donations. The lack of access to such equipment may cause some patients to seek hospital care earlier than they otherwise might were such equipment available.

Being able to obtain necessary drugs and supplies from local hospitals, or to purchase them at reduced cost, would also improve access to these supplies in rural communities.

***Recommendation:***

***Develop strategies to improve access to reasonably-priced medications and supplies, particularly in rural communities, where they may not be readily available.***

- **Psychosocial care for cancer patients and their families**

Dying, or providing care for a loved one who is dying, are among life's most difficult circumstances. Patients and their caregivers may be physically exhausted and experience spiritual or psychological distress, including depression and anticipatory grief. Anxiety can be exacerbated by care delivery that is fragmented or physical needs that are unmet, particularly uncontrolled pain and other symptoms.<sup>114</sup>

When bereaved, family members are better able to cope if the patient has died peacefully. Those who experience traumatic death of a loved one may encounter their own health problems. "If (dying) is managed poorly, patients may suffer unnecessarily, life closure may not be completed, and families may experience considerable distress both during and after the patient's death."<sup>115</sup>

Recommendations concerning coordinated care, access to pain and symptom management, and some financial relief can make important contributions to improving patients' and families' psychosocial care.

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<sup>114</sup>Canadian Cancer Society, Ontario Division (2003). *Breaking down the Barriers: Study of Cancer Patient and Caregiver Needs in Ontario*. Retrieved Feb. 12, 2004 from [www.cancer.on.ca](http://www.cancer.on.ca)

<sup>115</sup>Ferris, FD (1998). "Hospice Palliative Care in Prince Edward Island - A Consultation Report to PEI Department of Health & Social Services".

Several initiatives have recently been introduced to improve psychosocial support for patients and caregivers during palliative and end-of-life care, including the Regional Integrated Palliative Care Program's case-management approach and interdisciplinary clinical resource team. The Cancer Treatment Centre has also been enhanced to include a full-time social worker and part-time spiritual advisor. For more information, see **Emotional support for paid and unpaid caregivers** below.

Patients and families frequently do not access the Palliative Care program in time to truly benefit from these supports. They may resist the program, feeling that to access it is tantamount to giving up. Greater general awareness is needed about the nature of palliative care and the benefits it can provide to patients and their caregivers.

***Recommendation:***

***Increase awareness among the public and health providers about the importance of palliative care throughout cancer treatment.***

- **Emotional support for paid and unpaid caregivers**

Home-based care relies on paid and unpaid caregivers. Paid caregivers may include Home Care and Support staff or private nursing and housekeeping staff. Unpaid caregivers may include family, friends and hospice or other volunteers. Caregiving can be emotionally draining for both groups: paid caregivers and volunteers may care for a number of patients and their families, and experience stress when dealing with heart-wrenching circumstances or in small communities where the lines between personal and professional life may be blurred. Their parent organizations are responsible for providing de-briefing and support.

Family caregivers may find every aspect of their own lives affected. Concerns range from financial and practical issues to need for psychological, emotional, and spiritual support. Deaths from cancer are often lengthy processes with periods of decline and re-stabilization. The patient may experience long-term pain and suffering from a variety of symptoms and possibly lose control over either physical or mental faculties, or both.

An assortment of programs offer support to unpaid caregivers although access varies, usually due to lack of information. Programs include the newly launched Employment Insurance Compassionate Care Program; peer emotional support and informational support available through the Cancer Society's CancerConnection program and Cancer Information Service; Bereavement support groups; and respite care available at long-term care facilities, depending on the availability of beds.

The Cancer Treatment Centre has recently added two positions to provide emotional and spiritual support to patients and their families, a full-time social worker and part-time spiritual advisor. Home Care and Support staff and hospice palliative care volunteers also provide respite and emotional support to caregivers.

***Recommendations:***

***Increase awareness among healthcare professionals about the emotional needs of paid and unpaid caregivers, particularly those dealing with palliative care.***

***Provide support and oncology-specific training opportunities to Home Care and Support staff and other healthcare professionals in supportive roles, and to hospice palliative care volunteers.***

- **Enhance support from volunteers**

The Island is fortunate to have hospice palliative care volunteers active in all communities, offering care and support to dying patients and their families and advocating to enhance the care, benefits and protection of the terminally ill and their families. Volunteers are often known to the family because of community connections, and can be a good source of information. Knowledge retention when undergoing the stress of dying and bereavement is low and needs to be continually reinforced in a variety of ways, including personal contact. There is potential to increase the role of hospice palliative care volunteers to provide current information about available resources.



Including key volunteers in training opportunities would help to recognize volunteer contributions and increase the capabilities of this sector. Since seniors are among the greatest community volunteers,<sup>116</sup> it is possible that one benefit of the aging population may be an increased number of people willing to work in meaningful volunteer roles. There may be opportunities to encourage their participation and expertise at relatively small expense.

***Recommendation:***

***Provide current information about resources available to support cancer patients and their caregivers to all healthcare professionals, hospice palliative care volunteers, patients and their families.***

- **Palliative care within hospitals**

Patients and their caregivers need different care options during the end-of-life period. Designated palliative care beds are available in most hospitals and eight beds are available in the provincial Palliative Care Unit located at the Prince Edward Home for this purpose. These beds are intended for temporary use until the patient's condition is stabilized and the patient returns home or to a long-term care facility. In reality, patients may not be able to return to their home and may require extended periods of care. Since palliation requires specialized knowledge and more intensive care, it is important to maintain and enhance the skills of staff with palliation expertise within hospitals.

Pain consults can be provided by the palliative care resource team consultant physicians, who have received training in pain and symptom management and expressed interest in palliative care; or after admission to the Prince Edward Home, with the Provincial Palliative Medicine Consultant. Death is impossible to time, so patients are admitted to the Prince Edward Home at different stages of the disease. A patient's stay can vary from a few days to nine or more months. As a result, some patients do not receive optimal comfort until late stages, or may not be able to access it at all due to lack of beds. Access can be improved through enhancement of the Integrated Palliative Care Program to provide pain consults to hospital in-patients. For more information, see Action area 2 of this section.

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<sup>116</sup>Selbee L. Kevin, Reed Paul B. (2001). "Patterns of volunteering over the life cycle." *Canadian Social Trends*, Summer 2001. Statistics Canada - Catalogue No. 11-008.

**Recommendations:**

***Expand opportunities to enhance palliative care expertise within various care settings in addition to those offered by the regional palliative care resource teams.***

***Increase access to palliative care expertise needed to support respite and end-of-life care within acute and long-term care facilities.***

- **Bereavement care**

There is growing recognition of the extraordinary stresses placed on families as they prepare for the death of a loved one and during bereavement. The palliative care resource teams have identified a gap in services to support bereavement. A provincial bereavement care policy is being developed in response. A gap is particularly evident in specialized care for children, who may feel lost in the stressful situation both before and after the death of a loved one.

Bereavement, like dying, is subjective and can be traumatic, complex and long-lasting. Suffering can affect a person's ability to cope with daily life and can have physical, psychological and financial repercussions.

Several groups and individuals offer bereavement support throughout the province. As well, volunteers with the Hospice Palliative Care Association of PEI have broadened their scope of care to include support to bereaved families. In East Prince, volunteers phone bereaved families at regular periods for about two years after their loved one's death.

**Recommendation:**

***Encourage increased knowledge and actions to support bereavement for adults and children.***

## Measuring Results: Targets and Indicators

**Action area 1:**            **Support and enhance the existing Integrated Palliative Care Strategy in its capability to provide continuity of palliative care among different care settings.**

**Target:**

- By 2015, drugs and supplies will be available to cancer patients receiving palliative care in their home settings at reasonable cost.
- By 2015, drugs and supplies will be easily accessible to cancer patients receiving palliative care in their home settings, particularly in rural communities.
- By 2015, more patients and families will benefit from palliative care services for longer periods of time.
- By 2015, paid and unpaid caregivers of palliative patients will be offered easy access to support resources and education.
- By 2015, palliative care expertise will be accessible in all care settings.
- By 2015, emotional support will be available to bereaved family, including children.
- By 2015, the capacity of hospice palliative care volunteers to support patients and their families will be enhanced.

**Indicators:**

- Percentage of cancer patients receiving palliative care within their home settings receiving assistance to purchase necessary medical supplies, including drugs, oxygen, supplies, feeding tubes and nutritional supplements in 2004; percentage of cancer patients receiving palliative care within their home settings receiving assistance to purchase necessary medical supplies, including drugs, oxygen, supplies, feeding tubes and nutritional supplements in 2015.
- Percentage of cancer patients receiving easy access to drugs and supplies, particularly in rural communities in 2004; percentage of cancer patients receiving easy access to drugs and supplies, particularly in rural communities in 2015.
- Number of patients enrolled in the Integrated Palliative Care Program and for number of days in 2004; number of patients enrolled in the Integrated Palliative Care Program and for number of days in 2015.
- Number of resources available to support and educate paid and unpaid caregivers in 2004; number of resources available to support and educate paid and unpaid caregivers in 2015.
- Percentage of patients and families able to access palliative care expertise in their preferred care setting in 2004; percentage of patients and families able to access palliative care expertise in their preferred care setting in 2015.
- Percentage of bereaved family offered emotional support in 2004; percentage of bereaved family offered emotional support in 2015.
- Percentage of hospice palliative care volunteers offered oncology-specific training and informational support in 2004; percentage of hospice palliative care volunteers offered oncology-specific training and informational support in 2015.

## **Action area 2: Increase access to palliative care for cancer patients and their families throughout treatment.**

### **Rationale:**

Palliative care offers many benefits to cancer patients and their families, though many do not access this care in time to receive optimal comfort.

- **Pain and symptom control**

Cancer and its treatment may involve a range of side-effects. Pain and symptom management offered throughout treatment can offer increased comfort for the patient and family, contributing to the success of treatment and reducing the likelihood of complications<sup>117</sup>. The Regional Integrated Palliative Care Program trains physicians within each region to act as pain consultants. As their expertise grows, they will become increasingly able to provide palliative care to patients at all stages of treatment.

The Cancer Treatment Centre has also been seeking funding to hold pain and symptom management clinics with the provincial palliative medicine consultant on a regular basis for both outpatients and in-patients. This is a national accreditation standard for both cancer care and hospice palliative care. For further discussion, see Section 3.4 Treatment and Supportive Care, Action area 3. Comprehensive assessment and management of pain and symptoms is Accreditation Standard 7.5 of the national Hospice Palliative and End-of-Life Care Standards, currently being developed. Current provincial policies deny access to consultations while patients are receiving chemotherapy or radiation treatment, even though the treatments may be palliative in intent. The “separation of palliative and hospice care from potentially life-prolonging treatment within the health system” is considered one of the major barriers in delivering effective palliative care.<sup>118</sup>

In some cases, physicians are limited in their capacity to provide pain relief due to regulatory issues. Methadone is an effective pain medication but, since doctors must receive training and licensing in order to prescribe, its use has been limited. A training session arranged locally would improve access to these medications.

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<sup>117</sup>Cancer Control Strategy Palliation Subcommittee (2002). “Final report.” Retrieved June 2002 from [www.cancercontrol.org](http://www.cancercontrol.org)

<sup>118</sup>Foley Kathleen M., Gelban, Hellen, Eds. (2003). *Improving Palliative Care for Cancer: Summary and Recommendations*. National Academy of Science Press. Retrieved from [www.nap.edu](http://www.nap.edu)

**Recommendations:**

*Enhance the Integrated Palliative Care Program to include the full scope of outpatient and in-patient pain consults as a provincial service.*

*Provide local training opportunities to certain physicians to increase access to methadone.*

**Measuring Results: Targets and Indicators**

**Action area 2:            Increase access to palliative care for cancer patients and their families throughout treatment.**

**Target:**

- By 2015, cancer patients will be able to access pain consults throughout their treatment of cancer, both as outpatients and in-patients.

**Indicator:**

- Percentage of patients receiving pain consults as outpatients or in-patients in 2004; percentage of patients receiving pain consults as outpatients or in-patients in 2015.

### **3.6 Survivorship**

**Goal:** To enhance the quality of life of cancer survivors and their family members.

**Objectives:**

- Increased awareness of the ongoing physical, practical, emotional, and psychological needs of cancer survivors and family members.
- Timely access to necessary supportive resources.

**Action area 1:**

Identify and develop strategies to meet the ongoing needs of cancer survivors and their family members in Prince Edward Island.

**Action area 1: Identify and develop strategies to meet the ongoing needs of cancer survivors and their family members in Prince Edward Island.**

**Rationale:**

Increased awareness of the ongoing needs of cancer survivors and their family members can inform development of strategies to provide timely access to preventative care.

**Background:**

As cancer incidence grows and treatments improve, the prevalence of cancer survivors within the community has increased. Many survivors and family members may bear ongoing physical, psychological, emotional, or social consequences of their cancer. As well, increased knowledge about the genetic links to cancer may also impact family members. Support services provided by the healthcare system and by non-government organizations must be prepared to meet these increased demands..

The National Cancer Institute of Canada estimates that 2.1 per cent of Canadian men and 2.4 per cent of women have had a diagnosis of cancer within the past 15 years.<sup>119</sup> Similar prevalence rates would indicate that more than 3,000 Islanders are fairly recent survivors of cancer. Cancer Care Ontario suggests the increase in prevalence rates may, in fact, be almost twice as high as new incidence (4.4 per cent annual increase as opposed to 2.8 per cent incidence). Prevalence is expected to continue to grow as incidence grows, treatments improve and people live for longer times with cancer.<sup>120</sup>

- **Ongoing needs of cancer survivors and their families**

While most cancer survivors don't require active treatment, a certain number of individuals will continue to need medical, rehabilitation and supportive care. All survivors are monitored carefully because of the risks of recurrence or developing a second primary cancer.

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<sup>119</sup>Canadian Cancer Society, National Cancer Institute of Canada, Statistics Canada, Provincial/Territorial Cancer Registries, Health Canada (2003). *Canadian Cancer Statistics 2003*. Available on Internet at [www.cancer.ca](http://www.cancer.ca)

<sup>120</sup>Cancer Quality Council of Ontario (2003). *Strengthening the Quality of Cancer Services in Ontario: Synopsis*. Retrieved from [www.cancercare.on.ca](http://www.cancercare.on.ca)

Late physical and medical effects of cancers range from learning to live with body changes including scars, disfigurement, or amputation; to cardiorespiratory symptoms; cognitive dysfunction; fatigue or decreased energy; immune dysfunction; infertility; lymphedema; ongoing pain; sexual dysfunction; depression or feelings of sadness and vulnerability. The cancer experience can bear long lasting financial impact and cause changes in social and family relationships, including emotional and mental breakdowns and marriage failures. Some cancer survivors report a new appreciation of life, changed values and goals, and a sense of purpose.<sup>121,122</sup>

Bereaved family members may experience ongoing distress about their loved one's cancer experience, particularly if the experience has been traumatic.<sup>123</sup> They may also feel anxious about their own health and benefit from genetic counselling.

Leaders of emotional support groups find that, in many cases, simple acknowledgement of these issues and awareness that they are normal can have a great impact on patients' well-being. Inviting cancer patients to provide feed-back about their cancer experience may help give some closure to a traumatic experience.

Cancer patients and their families can provide a good source of qualitative evaluation about provincial programs and treatment for cancer, helping to identify gaps in service, prioritize essential services, and determine which services work well, and which need improvement.

As an example of how this can work, members of the PEI Breast Cancer Support Group became concerned about lymphedema, a swelling of the limb experienced by some women who had had lymph node dissection. Lymphedema can be prevented and successfully treated at early stages. Without treatment, it can cause a great deal of pain, disfigurement and distress to the individual and can require acute and ongoing care. This concern was raised to members of the PEI Breast

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<sup>121</sup>Dr. Patricia A. Ganz, cited by National Institute on Aging and National Cancer Institute (2001). *Exploring the Role of Cancer Centers for Integrating Aging and Cancer Research: Workshop Report*. Retrieved August 18, 2003 from <http://www.nia.nih.gov/health/nianci/reports>

<sup>122</sup>Canadian Cancer Society, Ontario Division (2003). *Breaking down the Barriers: Study of Cancer Patient and Caregiver Needs in Ontario*. Retrieved Feb. 12, 2004 from [www.cancer.on.ca/Breaking down the Barriers](http://www.cancer.on.ca/Breaking%20down%20the%20Barriers).

<sup>123</sup>Ferris, FD (1998). "Hospice Palliative Care in Prince Edward Island - A Consultation Report to PEI Department of Health & Social Services".



Cancer Information Partnership, a provincewide organization of breast cancer stakeholders who were able to raise awareness and garner support from a variety of funding organizations to train a physiotherapist from PEI in lymphedema prevention and treatment. As well as affecting 28 per cent of breast cancer survivors, lymphedema can occur whenever there has been a lymph node dissection, including melanoma, prostate and cervical cancers or as a result of radiation or coronary bypass.<sup>124</sup>

This is an excellent example of how partnerships can build the capacity of the health system and community to respond to the ongoing needs of patients and their families.

***Recommendations:***

***Work with members of the existing survivors' support groups to create a survivors subcommittee to identify the ongoing concerns of cancer survivors in PEI, and to provide feedback about the needs of cancer patients and their families.***

***Develop strategies to respond to the information identified by survivors to increase awareness and access to appropriate supports.***

- **Provide opportunities for volunteer participation**

Many volunteers working with the Cancer Society and provincial hospice palliative care programs have themselves been touched or bereaved by cancer, demonstrating the power such personal experiences have to motivate people to want to make a difference for others. Activities volunteers participate in include fundraising to support research and purchase specialized equipment; emotional support through programs such as CancerConnection, Reach to Recovery, Living with Cancer groups; and providing respite to families and care to patients through the hospice palliative care programs. Their organizations work to identify needs, advocate on behalf of patients and their families, and provide educational opportunities and information to patients, family members, healthcare professionals, volunteers and members of the general public.

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<sup>124</sup>Tilley Andrea (2004). From presentation at Rehabilitation after Cancer Conference. Saint John, N.B. May 8, 2004. Statistics: Petrak 2000, Logan 1995.

Opportunities to benefit from the experience, skills, and motivation of volunteers should be sought and encouraged . One of the identified needs of cancer patients has been to have information provided at the time of diagnosis. For more information, see Section 3.3 Screening and Diagnosis. An information kit has been provided to women at the time of a breast cancer diagnosis for several years as part of the work of the PEI Breast Cancer Information Partnership. This kit was evaluated in 2000. Responding women, family members and physicians all rated it highly for its contributions to coping, accessing community resources and participating in meaningful discussions with health providers.

A survivor group may be willing to take on a similar task in preparing information kits for those diagnosed with other cancers, in consultation with healthcare professionals.

***Recommendations:***

***Identify opportunities for volunteer participation to meet supportive needs of cancer patients and their families.***

***Identify teams to work together to develop information kits for specific cancers, or to adapt kits from other jurisdictions, and to develop methods of dissemination.***

**Measuring Results: Targets and Indicators**

**Action area 1: Identify and develop strategies to meet the ongoing needs of cancer survivors and their family members in Prince Edward Island.**

**Target:**

- By 2015, a mechanism will be in place to enable identification of the ongoing needs of cancer survivors and family members in Prince Edward Island.
- By 2015, strategies will be developed to meet the identified ongoing needs of cancer survivors and family members in Prince Edward Island.

**Indicator:**

- Number of mechanisms available to allow cancer survivors and family members to identify their ongoing needs in 2004; number of mechanisms available to allow cancer survivors and family members to identify their ongoing needs in 2015.
- Number of initiatives aimed at supporting the ongoing needs of cancer survivors and family members in 2004; number of initiatives aimed at supporting the ongoing needs of cancer survivors and family members in 2015.

## 4.0 CONCLUSION: CONTRIBUTING TO THE SUSTAINABILITY OF THE HEALTHCARE SYSTEM

The primary goals of the Cancer Control Strategy are to prevent cancer and enhance the quality of lives of those living with cancer and their families. Recognizing that higher demands brought about by increased disease incidence and associated costs will create an enormous burden on the already over-burdened healthcare system, the strategy has been developed to be fiscally responsible, thus achieving its third goal, to contribute to the sustainability of the healthcare system. Recommendations which will ensure efficient use of resources include:

- **A coordinated approach**

All members of the Cancer Control Strategy Advisory Committee work within their organizations towards one or both of the strategy's main goals. Working together will allow the committee and subcommittee members to share information, identify common issues and gaps in service, reduce duplication of services, and build capacity through collaboration. Taking a coordinated approach to cancer control will not only improve the quality of service, but result in cost savings.

Coordination of programs and services will also be improved, reducing duplication of expensive testing procedures and inappropriate referrals to an already limited number of specialists, both of which can cause further delays in the system and gaps in referrals. Uncoordinated care seems confusing and uncaring to patients and their families. As well as having direct cost repercussions, coordinated care will improve the psychosocial health of patients and their families.

The committee's primary recommendations to improve care coordination include continued collaboration of the committee and creation of a patient navigator position. A patient navigator can provide optimal utilization of limited resources, educate and inform patients, and facilitate timely access to existing resources.

- **Emphasis on cancer prevention**

The best way to reduce the burden of cancer is to prevent it from developing. It is also cost-effective: fewer cancers will reduce direct and indirect costs as well as any ongoing physical or psychosocial repercussions. For example, an estimated \$4 million dollars is spent each year in PEI on direct healthcare costs associated with tobacco-related cancers. Meanwhile, costs of various programs aimed at reducing tobacco use are estimated to be about \$200,000 per year. These programs appear to be effective: 23 per cent of people aged 15 years or older in PEI smoked in 2002, down from 27 per cent in 1999.

- **Evidence-based programs and services**  
Ongoing monitoring and evaluation of programs and services is essential to be able to identify and conform to standards, ensure quality and cost-effectiveness, and provide public accountability. Support for behavioural and epidemiological research, electronic patient records, and qualitative feedback from stakeholders are recommendations that will provide ongoing evaluation about the cancer care program in PEI, facilitating timely and coordinated response to identified issues, and ensuring best use of limited resources.

The PEI Strategy will also connect to the work being performed by the Council of the Canadian Strategy for Cancer Control and through this structure, to initiatives being undertaken throughout Canada. This network will allow PEI stakeholders to benefit from a broad-base of knowledge and experience, adapting best practices from other regions that are suited to our own requirements.

- **Improved access to primary healthcare services**  
Primary healthcare professionals can work with patients to prevent illness and detect cancers at early stages. If a patient has cancer and requires treatment, professionals can advocate for patients, support them if they become palliative, or help them learn to live with their cancer. All of these functions help to ensure patients receive appropriate services in a timely manner and, in many cases, can reduce acute care needs. The Primary Health Care Redesign Initiative is exploring different models of providing care, including physician care, family health centres and an expanded role for nurse practitioners. These models offer cost savings by ensuring patients are seen by the most appropriate healthcare professional in a timely manner and referred to existing resources within the community.
- **Cancers detected in early stages**  
In many cases, cancers detected at early stages will have lower direct and indirect costs, have better outcomes and require less intensive treatment. These cancers may also be less devastating to the psychosocial health of patients and their families and require fewer supportive interventions.

The Cancer Control Strategy has made several recommendations to improve timeliness of cancer detection, including centralized referrals to provide earlier and more equitable access to diagnostic testing and implementation of screening programs nationally recommended as being cost-effective.

The breast cancer screening program provides a good example of the cost savings possible through early detection, with about 60 per cent of breast cancers in PEI detected in Stages 0 or I in 2003. Many of these cancers will be treatable through surgery alone, without requiring expensive chemotherapy or radiation treatments. Literature indicates that 97 per cent of these women will survive for five or more years, reducing the potential years of life lost to breast cancer and associated indirect costs.

- **Empowered patients**

Empowered patients can make lifestyle changes to prevent the onset of cancer or other chronic disease, access diagnostic testing at the first sign or symptom of cancer, work with their doctor to make complex decisions about treatments which may bear life-long consequences, self-advocate to ensure they receive the appropriate services and care in a timely manner, and learn to manage their disease in order to enhance their and their families' quality of life. Treatment and psychosocial outcomes are improved when patients are able to exercise maximum control over their health and circumstances.

System cost savings are offered through improved utilization of resources, use of relatively inexpensive self-management techniques such as diet, exercise and stress-relief, and lower direct and indirect costs provided by improved outcomes.

Recommendations to help empower patients include a patient navigator, improved access to reliable sources of information, and programs to help patients and family learn how to self-manage their disease.

- **Improved access to medications for cancer treatment and palliation**

Issues impacting on access to medications include individual financial responsibility, access to expert pain consults throughout the course of treatment, and access to medications and supplies during palliation, particularly in rural communities.

A number of studies suggest that patients' health may be compromised without access to drug therapy, causing the disease to progress to a more acute level requiring more intensive care. These strategies were conservatively estimated to have cost \$7 billion to \$9 billion per year in Canada in 1998.<sup>125</sup> Proportionately, costs would have been \$30 million to \$45 million in PEI.

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<sup>125</sup>The Standing Committee on Social Affairs, Science and Technology (2002). "The Health of Canadians-The Federal Role. Volume Two: Current Trends and Future Challenges. The Senate: Ottawa. Chapter Two", p. 19. Retrieved November 5, 2003 from [www.parl.gc.ca/37/1/parlbus/commbus/senate/comm-e/SOCI-E/rep-e/repjan01vol2-3.pdf](http://www.parl.gc.ca/37/1/parlbus/commbus/senate/comm-e/SOCI-E/rep-e/repjan01vol2-3.pdf)

As interventions become increasingly reliant on medications taken outside of the hospital system and therefore the responsibility of patients, a certain number of individuals will either not be able to access their prescribed treatment or will face financial hardship. It is estimated that 27 per cent of Islanders do not have private drug insurance.<sup>126</sup>

In the long-term, our healthcare system will not be sustainable without addressing equitable access to prescribed treatment, either through a national plan for catastrophic drugs, or through development of a broad-based user-pay catastrophic drug plan accessible to all Islanders.

Access to expert pain consults throughout cancer care can improve treatment and psychosocial outcomes for patients and families alike and is a national standard for cancer care. While the annual cost of consults is estimated to be \$127,000, much of this may be recouped through reduced admissions to acute care or emergency visits. Access will contribute to the sustainability of our healthcare system by ensuring a humane standard of care, its ultimate goal.

The Canadian healthcare system has saved money on acute care and chronic care facilities through enhancements to care offered in home settings. While this care is shown to be preferable to many patients and their families, it also places an enormous burden on them, one that is increased by shifting responsibility for finding and purchasing essential care needs. Being able to obtain necessary drugs and supplies from local hospitals or to purchase them at reduced cost would improve access to these supplies, particularly in rural communities, and enhance the Regional Integrated Palliative Care Program in its capacity to provide access to consistent and coordinated care in a variety of care settings at a reduced cost to the healthcare system.

- **Improve access to existing supportive programs and services**

Numerous programs exist to support cancer patients and their families, from practical resources like the Canada Pension Plan long-term disability pensions and medical tax credits to informational and emotional support groups and care provided by hospice palliative care volunteers (see Appendix III). Patients and families, overwhelmed by their diagnosis and treatment, may not find these programs and services early enough to benefit.

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<sup>126</sup>The Standing Committee on Social Affairs, Science and Technology (2002). “The Health of Canadians-The Federal Role. Final Report on the state of the health care system in Canada.” (2002). Ottawa: The Senate. P. 131.

Improving access will decrease some of the stresses facing cancer patients and their families, and help to improve their ability to cope. This, in turn, may reduce their need for acute care interventions.

Through these approaches and recommendations, the PEI Cancer Control Strategy will contribute to the long-term sustainability of our healthcare system.





## 5.0 SUMMARY OF RECOMMENDATIONS

### Over-arching recommendations

- **Financial commitment:** An ongoing financial commitment is necessary to support all aspects of cancer care - prevention, screening, diagnosis, treatment and supportive care, palliation, communication and coordination.
- **Recruitment and retention of health professionals and technical staff:** Aggressive and ongoing recruitment strategies are needed to meet current and future needs.
- **Access to primary health care services:** Access to primary healthcare services is vital to cancer prevention, diagnosis, and patient support. Models such as physician care, family health centres and expanded roles of nurse practitioners should continue to be explored and expanded upon.
- **Electronic patient records:** Electronic patient records with appropriate privacy safeguards will facilitate fast and accurate sharing of pertinent information between hospital departments and among physicians.
- **Improved access to medications for cancer treatment and palliation:** Access must be improved, including financial assistance for prescribed medications taken outside of the hospital setting, and pain management consultations throughout cancer treatment. Avenues should be explored to provide catastrophic drug assistance to all Islanders, particularly for cancer treatment, and all current drug programs should be reviewed to develop a basis on which to establish equitable access to medications.
- **Continued support and enhancement of behavioural and epidemiological research in Prince Edward Island:** Continued support and expansion of research and evaluation initiatives is needed to provide information on which to base and evaluate prevention programs and to inform health system planning.
- **Continued role of the Cancer Control Advisory Committee:** The Cancer Control Advisory Committee and Subcommittees will require ongoing coordination and project support to facilitate continuing collaboration and to oversee and implement the strategy's recommendations.

*The following recommendations within specific areas of cancer prevention and care are arranged as short-term, mid-term, and ongoing recommendations. Time lines are generally based on the issue's urgency and the ease with which it can be addressed.*

## **Recommendations Concerning Cancer Prevention**

### **Short-term**

- Formalize and expand the currently ad-hoc prevention subcommittee to include other stakeholders concerned about reducing cancer risks.
- Identify and work with other stakeholders to reduce alcohol consumption in PEI to recommended levels.

### **Mid-term**

- Increase awareness that some cancers can be prevented.
- Identify partners and work to reduce exposure to ultraviolet radiation.
- Extend the *Occupational Health and Safety Act* to include farmers and farm labourers, thus providing education, training and work site monitoring.

### **Ongoing**

- Provide advice and support, and liaise with the existing national, regional and provincial strategies, programs and services to improve common health indicators, including reduction of tobacco and exposure to second-hand smoke, increased consumption of fruits and vegetables, healthy body weight, and increased physical activity.
- Identify and respond to gaps in cancer-specific information in existing chronic disease prevention strategies.
- Monitor and respond to emerging information about lifestyle links to cancer.
- Monitor national recommendations about best practices and policies to reduce exposures to occupational and environmental carcinogens, and develop strategies in response.
- Monitor and respond to emerging information about viral infections and methods to control them.
- Monitor and respond to emerging information about the causes and prevention of cancer.

## **Recommendations Concerning Cancer Screening and Detection**

### **Short-term**

- Formalize and expand the currently ad-hoc screening and diagnostic sub-committee to include other stakeholders concerned about screening and early detection.

### **Diagnosis of patients without physicians**

- Investigate the role a patient navigator or case manager can play by providing coordination of diagnosis to patients without physicians.
- Develop procedures to ensure patients without physicians are informed about how to access diagnostic testing if they may have a sign or symptom of cancer, and how to follow up on any testing.

### **Screening programs**

- Develop a strategy to phase in a colorectal screening program in PEI for those aged 50 to 74 years.
- Ensure appropriate psychosocial support is provided throughout the screening and diagnostic process, possibly through a patient navigator, and by working with the existing screening programs.
- Explore avenues to provide public education about the breast screening program in conjunction with the cervical screening program.
- Provide information about the limitations of screening programs to program participants.

### **Psychosocial support during the peri-diagnostic period**

- Provide information to health professionals who are dealing with patients being investigated for cancer regarding how patients can access reliable information about the diagnostic process and available support resources.
- Promote the services and contact information for the Health Information Resource Centre and Cancer Information Service through social marketing campaigns and system communication.

### **Centralized referrals**

- Centralize referrals for diagnostic testing at all hospitals, offering patients access to the earliest available testing.

### **Testing follow-up**

- Identify standards for follow-up of diagnostic testing.
- Increase awareness among physicians about the need to follow up testing requests.
- Educate patients about the need to follow up on test results if they have not heard within the identified time period.

### **Mid-term**

#### **Public education**

- Develop strategies to raise public awareness about the signs and symptoms of cancer and importance of early detection, possibly linking with national groups focusing on specific cancers and working with the PEI Medical Society's Health Promotions Committee and regional primary healthcare centres.
- Provide information to men aged 50 and 70 years about the availability of prostate screening to support informed decision-making about individual participation.
- Explore avenues to provide public education about the breast screening program in conjunction with the cervical screening program.

#### **Diagnostic procedures**

- Conduct an external review to analyze the diagnostic process and work with staff to develop strategies to ensure optimal timeliness and accuracy of diagnoses.

#### **Screening**

- Implement the strategy to phase in colorectal screening.

#### **Staging**

- Improve the capacity to stage cancers in compliance with national recommendations, including additional staff and upgraded software.

### **Ongoing**

#### **Screening programs**

- Provide liaison, advice and support to the existing cancer screening programs.
- Ensure national quality assurance standards are met for all organized screening programs and programs evaluated every five years, including psychosocial support and tracking of patients with false positive screens.

- Identify and comply to national screening targets as programs continue to develop.
- Monitor and respond to emerging information and recommendations about cancer screening.

### **Diagnostic procedures**

- Continue to encourage and facilitate case-conferencing among specialists involved in making diagnoses.
- Ensure staging assessment continues to be recorded.

### **Clinical practice guidelines**

- Review clinical practice guidelines as they are developed to guide diagnostic procedures, and adopt and disseminate as considered advisable.

## **Recommendations Concerning Treatment and Supportive Care**

### **Short-term**

- Formalize and expand the currently ad-hoc sub-committee to include other stakeholders concerned about cancer treatment and supportive care.

### **Patients without primary care physicians**

- Develop clear procedures to ensure patients without primary care physicians can access supportive and post-treatment care and inform health providers and patients.

### **Centralized referral**

- Develop a system for centralized referral to the Cancer Treatment Centre, enabling team assessment of patients' needs and primary referrals to the most appropriate oncological services.

### **Care coordination**

- Create a position of patient navigator to coordinate multi-disciplinary care between different care settings, advocate for patients, and provide support and education to patients and families as they learn to live with cancer.
- Provide current, accurate information about supportive care resources in ways that are clear and easy to access to all health professionals and volunteers working with patients.

### **Patient education and psychosocial support**

- As a collaborative project of the Canadian Cancer Society, PEI Division and the Cancer Treatment Centre, develop a program to help cancer patients and families adjust to living with cancer and build skills to self-manage the disease,.

### **Recruitment and retention of oncology personnel**

- With the Provincial Health Services Authority, create an ad hoc recruitment committee to develop a recruitment and retention strategy for oncology personnel.

### **Clinical trials**

- Expand the capacity to conduct clinical trials in Prince Edward Island by piloting a one year full-time clinical trials nurse position to inform the sustainability of such a position.

### **Access to pain consults**

- Enhance the Integrated Palliative Care Program to include the full scope of outpatient and in-patient pain consults as a provincial service.

### **Accommodations**

- Investigate ways to provide accommodations to patients and family members during treatment.
- Support the efforts of the QEH Auxiliary to provide accommodations to patients and family members during cancer treatment.

## **Mid-term**

### **Coordination**

- Analyze communication pathways among multi-disciplinary and regional physicians and staff to develop strategies to improve communication.

### **Patient education and psychosocial support**

- Provide patients with appropriate information packages about cancer, treatment, and resources at the time of diagnosis.
- Educate patients about the importance of discussing with their physician any alternative and complementary therapies they may consider using.
- Develop procedures to ensure patients' and families' psychosocial needs are assessed at each professional encounter and appropriate referrals made.

- Conduct a social marketing campaign to inform patients, families, and health professionals of the resources available to meet psychosocial needs.

### **Clinical Practice Guidelines**

- Monitor the work of the National Clinical Practice Guidelines Subgroup and identify stakeholders – including the PEI Medical Society, surgeons and oncologists – to adapt the guidelines for at least the four most common cancers. A communication plan to reach physicians and the public will also be required.

### **Ongoing**

#### **Oncology equipment needs**

- Identify priority fund-raising needs to inform fund-raising partners to support emerging oncology equipment needs.

#### **Clinical trials**

- Monitor national efforts to improve access to clinical trials.

#### **Information**

- Regularly update information about supportive care resources.

#### **Accommodations**

- Support the efforts of the QEH Auxiliary to provide accommodations to patients and family members during cancer treatment.

#### **Patient education and psychosocial support**

- Provide continuing education opportunities to health professionals and volunteers to raise awareness about the psychosocial needs of cancer patients and their families, and supportive resources.
- Support and enhance the capacity of existing resources to provide or direct to support for psychosocial needs of cancer patients and family members.
- Promote the Canadian Cancer Society's Cancer Information Services as a key information service about cancer and key community resources to patients, families and health providers.
- Regularly update information about supportive care resources.
- Provide clear, easy to access information about supportive care resources to patients, their families, all health professionals, and volunteers in a variety of ways.



## **Recommendations Concerning Palliative and End-of-life Care**

### **Short-term**

- Formalize and expand the currently ad-hoc subcommittee to include other stakeholders concerned about palliative and end-of-life care.

### **Access to services**

- Enhance the Integrated Palliative Care Program to include the full scope of outpatient and in-patient pain consults as a provincial service.
- Provide local training opportunities to certain physicians to increase access to methadone.

### **Access to medications and supplies**

- Investigate different models of improving drug coverage to provide medications and supplies in care settings of choice, particularly for acute palliative patients receiving care in home as a substitute for hospital care.
- Develop strategies to improve access to reasonably-priced medications, nutrition for those using feeding tubes, and supplies needed for patients being cared for in home settings.
- Investigate the possibility of dispensing drugs and supplies in PEI in a similar way to New Brunswick's Extra-Mural Program.
- Develop strategies to improve access to reasonably priced medications and supplies, particularly in rural communities, where they may not be readily available.

### **Information**

- Provide current information about resources available to support cancer patients and their caregivers to all healthcare professionals, hospice palliative care volunteers, patients and their families.

### **Mid-term**

#### **Caregiver support**

- Increase awareness among healthcare professionals about the emotional needs of paid and unpaid caregivers, particularly those dealing with palliative care.

### **Continuing education**

- Encourage increased knowledge and actions to support bereavement for adults and children.
- Expand opportunities to enhance palliative care expertise within various care settings, in addition to that offered by the regional palliative care resource teams.

### **Access to services**

- Increase access to palliative care expertise needed to support respite and end-of-life care within acute and long-term care facilities.

### **Ongoing**

- Provide advice and support, and liaise with the existing provincial strategies to improve access to palliative and end-of-life care to cancer patients and their families in all regions of the province.
- Identify and respond to gaps in the existing palliative care strategy as to needs specific to cancer patients and their families.
- Provide support and oncology-specific training opportunities to Home Care and Support staff and other healthcare professionals in supportive roles, and to hospice palliative care volunteers.
- Increase awareness among the public and health providers about the possible role of palliative care throughout cancer treatment.

### **Recommendations Concerning Survivorship**

- Work with members of the existing survivors' support groups to create a survivors subcommittee to identify the ongoing concerns of cancer survivors in PEI, and to provide feedback about the needs of cancer patients and their families.
- Develop strategies to respond to the information identified by survivors to increase awareness and access to appropriate supports.
- Identify opportunities for volunteer participation to meet the supportive needs of cancer patients and their families.
- Identify teams to work together to develop information kits for specific cancers, or to adapt kits from other jurisdictions, and to develop methods of dissemination.



## **APPENDICES**

- Appendix I: Age-standardized rates of cancer incidence and mortality, PEI and Canada, 1985-1999 (per 100,000 population)
- Appendix II: Out-of pocket costs for prescription drug expenses throughout Canada
- Appendix III: Members of Subcommittees and key informants
- Appendix IV: Staging
- Appendix V: Breast Cancer and Colorectal Cancer Staging Synopses, 2003



**Appendix I: Age-standardized rates of cancer incidence and mortality, PEI and Canada, 1985-1999 (per 100,000 population)**

	1986	1987	1988	1989	1990	1986-90 average	1991	1992	1993	1994	1995	1991-95 average	1996	1997	1998	1999	2000	1996-2000 average	
<b>Males, PEI</b>																			
incidence	348.73	466.48	416.50	483.06	466.79	436.31	415.12	495.84	532.74	532.94	455.73	486.47	457.96	500.64	482.31	512.49	464.52	483.58	
mortality	243.08	259.33	243.23	238.00	267.35	250.57	262.08	277.97	227.58	265.32	264.88	259.57	277.57	237.33	232.02	234.52	240.32	244.35	
mortality in ratio to incidence	0.7	0.56	0.58	0.49	0.57	0.57	0.63	0.56	0.43	0.50	0.58	0.53	0.61	0.47	0.48	0.46	0.52	0.51	
<b>Males, Canada</b>																			
incidence	451.90	456.27	458.44	451.48	457.61	455.14	469.00	480.05	494.15	479.74	455.73	475.73	446.98	449.60	448.15	459.30	458.59	452.52	
mortality	248.98	248.20	254.71	249.51	246.44	249.57	247.17	244.64	242.64	241.62	238.68	242.95	236.21	231.77	229.99	228.65	224.78	230.28	
mortality in ratio to incidence	0.55	0.54	0.56	0.55	0.54	0.55	0.53	0.51	0.49	0.50	0.52	0.51	0.53	0.52	0.51	0.50	0.49	0.51	
<b>Females, PEI</b>																			
incidence	245.03	294.00	319.39	334.56	367.57	312.11	352.59	367.55	313.28	382.71	344.87	352.2	350.01	348.90	417.78	340.31	334.05	358.21	
mortality	173.92	135.50	118.63	144.16	168.47	148.14	167.32	154.28	148.37	169.86	156.86	159.34	157.91	125.98	163.81	169.09	151.89	153.74	
mortality in ratio to incidence	0.71	0.46	0.37	0.43	0.46	0.47	0.47	0.42	0.47	0.44	0.45	0.45	0.45	0.36	0.39	0.50	0.45	0.43	
<b>Females, Canada</b>																			
Incidence	324.89	330.68	336.02	329.96	333.18	330.95	337.06	340.91	340.91	339.04	337.47	339.08	335.45	338.40	345.84	346.57	345.06	342.26	
Mortality	154.35	153.97	155.32	153.05	153.03	153.94	153.53	153.05	154.78	155.02	151.84	153.64	155.05	150.15	151.02	149.35	149.30	150.97	
mortality in ratio to incidence	0.48	0.47	0.46	0.46	0.46	0.47	0.46	0.45	0.45	0.46	0.45	0.45	0.46	0.44	0.44	0.43	0.43	0.44	

Data from Cancer Surveillance On-Line, [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

## Appendix II: Out-of pocket costs for prescription drug expenses throughout Canada

Out-of-pocket costs for prescription drug expenses of \$5,000  
(percentage of population)

	Up to \$750	\$751 - \$2,000	Over \$2,000	No coverage	Total
BC	70%	30%	0%	0%	100%
ALTA	43%	57%	0%	0%	100%
SASK	68%	24%	8%	0%	100%
MAN	84%	13%	3%	0%	100%
ONT	70%	25%	5%	0%	100%
QC	100%	0%	0%	0%	100%
NB	45%	28%	0%	27%	100%
NS	47%	29%	0%	24%	100%
<b>PEI</b>	<b>48%</b>	<b>25%</b>	<b>0%</b>	<b>27%</b>	<b>100%</b>
NFLD	48%	24%	0%	28%	100%
Canada	73%	23%	2%	2%	100%

Out-of-pocket costs for prescription drug expenses of \$20,000  
(percentage of population)

	Up to \$750	\$751 - \$2,000	Over \$2,000	No coverage	Total
BC	70%	30%	0%	0%	100%
ALTA	43%	0%	57%	0%	100%
SASK	67%	25%	8%	0%	100%
MAN	84%	13%	3%	0%	100%
ONT	70%	12%	18%	0%	100%
QC	100%	0%	0%	0%	100%
NB	45%	0%	28%	27%	100%
NS	47%	0%	29%	24%	100%
<b>PEI</b>	<b>48%</b>	<b>0%</b>	<b>25%</b>	<b>27%</b>	<b>100%</b>
NFLD	48%	0%	24%	28%	100%
Canada	73%	20%	5%	2%	100%

Source: Fraser Group/Tristat Resources, Drug Expense Coverage in the Canadian Population: Protection From Severe Drug Expenses, August 2002. Cited by Standing Senate Committee on Social Affairs, Science and Technology (2002). The Health of Canadians - The Federal Role: Final Report on the state of the health care system in Canada. Volume Six: Recommendations for Reform. Ottawa: The Senate. pp. 135.

## **Appendix III: Members of ad-hoc subcommittees**

### **Subcommittee members:**

#### **Prevention Subcommittee:**

Dawn Binns, Primary Prevention Coordinator, Canadian Cancer Society, PEI Division  
Deborah Bradley, Manager, Health Promotion/Disease Prevention, DHSS  
Donna Murnaghan, Director, PEI Health Research Institute  
Laraine Poole, Healthy Living Coordinator, DHSS  
Maureen Paquet, Wellness Coordinator, East Prince Health

#### **Screening and Diagnostic Subcommittee:**

Liz Dobbin, Manager, Cancer Treatment Centre  
Dr. Dagny Dryer, Medical Oncologist  
Dr. Rosemary Henderson, Manager, Pathology  
Calvin Joudrie, Provincial Manager, Diagnostic Imaging  
Dr. Anne MacDonald, physician, PEI Medical Society  
Norah Smith, Coordinator, PEI Breast Screening Program  
Heather MacMillan, Coordinator, PEI Cervical Screening Program  
Kim Vriends, Manager, PEI Cancer Registry

#### **Treatment and Supportive Care Subcommittee:**

Cathie Bernard, Oncology Nurse, Cancer Treatment Centre  
Liz Dobbin, Manager, Cancer Treatment Centre  
Thelma Fraser, Chair, Patient Services, Canadian Cancer Society, PEI Division  
Kim Vriends, Manager, PEI Cancer Registry

#### **Palliative and End-of-Life Care Subcommittee**

Liz Dobbin, Manager, Cancer Treatment Centre  
Thelma Fraser, Chair, Patient Services, Canadian Cancer Society, PEI Division  
Angela Webb, Home Care Nurse, West Prince Health  
Marie Salamoun-Dunne, President, Hospice Palliative Care Association of Prince Edward Island  
Margaret Kennedy, Acting Palliative Care Coordinator



## Appendix IV: Staging

Cancer staging is the grouping of cases into broad categories based on the extent of disease. The AJCC or TNM staging system is based on an assessment of:

T - extent of primary tumour- i.e. size and invasiveness

N - absence or presence and extent of regional lymph node involvement

M - absence or presence of tumour at a distance from the primary site

The following are general guidelines to describe cancer stages using the AJCC or TMN staging system:

Stage O: cancer is confined to tissue of origin and is usually non-invasive

Stage I: cancer limited to tissue or organ of origin but is invasive

Stage II: limited, local +/- regional spread of cancer

Stage III: extensive local and regional spread of cancer

Stage IV: metastases (spreading of cancer) to any distant part of the body.<sup>127</sup>

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<sup>127</sup>Clinical Reference Systems (2002). Classification of Cancer (Adult Health Advisor 2002.1). Retrieved June 29, 2004 from [www.gov.pe.ca/hirc](http://www.gov.pe.ca/hirc)

## **Appendix V: Breast Cancer and Colorectal Cancer Staging Synopses, 2003**

### 2003 Breast Cancer Staging Synopsis

STAGE GROUP	# by stage group*	% by stage group
Stage 0=	10	8.06 %
Stage 1=	63	50.8 %
Stage 2=	33	26.6 %
Stage 3=	10	8.06 %
Stage 4=	3	2.41 %
Unstageable=	5	4.03 %
<b>TOTAL=</b>	<b>124</b>	

### 2003 Colorectal Cancer Staging Synopsis

STAGE GROUP	# by stage group*	% by stage group
Stage 0=	6	6.06 %
Stage 1=	23	23.23 %
Stage 2=	33	33.33 %
Stage 3=	21	21.21 %
Stage 4=	9	9.09 %
Unstageable=	7	7.07 %
<b>TOTAL=</b>	<b>99</b>	

\*The numbers diagnosed include only those colorectal histologies that are stageable using the AJCC Cancer Staging Manual 6<sup>th</sup> Edition.