

## **The Canadian Strategy for Cancer Control: A Cancer Plan for Canada**



### **Discussion Paper**

This document has been prepared by the CSCC Governing Council and summarizes the Five-Year Business Plan of the Canadian Strategy for Cancer Control as of April 2006, and the revisions to that plan that have been made as of July 2006.

This document does not necessarily reflect the policies, positions or opinions of the Public Health Agency of Canada or its officials, or the individual members of the CSCC Council, but instead represents the views and opinions of the Council as a whole.

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## The Canadian Strategy for Cancer Control

The Council of the Canadian Strategy for Cancer Control represents a broad, multi-stakeholder group of Canada's leading cancer organizations. The Council has worked with stakeholder groups for seven years to create an innovative strategy and a five-year business plan to address the increasing number of new cancer cases and deaths in Canada due to our aging and growing population and to minimize the social and economic impact of cancer. The goals of the CSCC are:

- To reduce the number of Canadians diagnosed with cancer;
- To enhance the quality of life of those living with cancer; and
- To lessen the likelihood of dying from cancer.

The Canadian Strategy for Cancer Control (CSCC) takes an inclusive, integrated and comprehensive approach to health care management, covering the full cancer control continuum. It harnesses the strengths of Canada's federal system of government and province-based health care by creating pan-Canadian networks of experts to drive action and leverage knowledge and expertise. A knowledge transfer and risk management platform will provide governments, non-governmental organizations and individual Canadians with the information and tools they need to make informed decisions in regard to cancer risk and cancer control. It is estimated that decisive action and better alignment of cancer resources could, over the next 30 years:

- Prevent over 1.24 million Canadians from developing cancer;
- Save the lives of over 423,000 Canadians; and
- Prevent over 7.3 million potential years of Canadian life being lost.<sup>1</sup>

In addition to saving lives and unnecessary suffering, the CSCC will also deliver significant economic benefits. Over the next 30 years, it is estimated that these improved health outcomes will:

- Save over \$39 billion in direct health care costs;
- Prevent the loss of over \$34 billion in total government tax revenues; and
- Prevent the loss of over \$101 billion in wage-based productivity.<sup>2</sup>

Implementing the CSCC will result in a cancer control system that truly benefits all Canadians. This document presents the framework of the CSCC and provides an overview of the Council's initial five-year business plan.

## The Cancer Crisis in Canada

Canada is facing a cancer crisis. Cancer is already the leading cause of premature death in Canada. Cancer is responsible for more Canadian deaths than strokes, COPD (chronic obstructive pulmonary disease) and respiratory disease, pneumonia, diabetes, suicide, unintentional injuries, liver disease and HIV/AIDS combined.<sup>3</sup> On average, two Canadian are diagnosed with cancer every seven minutes. Every seven and a half minutes, one Canadian dies from it. Despite advances in research and health care and a

<sup>1</sup> RiskAnalytica. *Life at Cancer Risk* 2005. Establishing the Strategic Framework for the Canadian Strategy for Cancer Control. April 2005. <http://www.cancercontrol.org>.

<sup>2</sup> RiskAnalytica. *Life at Cancer Risk* 2005. Establishing the Strategic Framework for the Canadian Strategy for Cancer Control. April 2005. <http://www.cancercontrol.org>.

<sup>3</sup> Statistics Canada. *Selected leading causes of death, by sex*. <http://www40.statcan.ca/l01/cst01/health36.htm>.



decreased death rate, these numbers are rising.<sup>4</sup> It is estimated that over the next 30 years:

- Almost six million Canadians will develop cancer;
- Approximately three million will die from the disease; and
- Over 38 million potential life years will be lost due to premature death.<sup>5</sup>

The numbers are rising because our population is aging, placing increasing demands on our health care system. As the baby boom population moves into age groups linked to higher cancer risk, there will be an unprecedented demand for health care services. Cancer patients are also surviving longer and needing longer intervention and care. The burden cancer puts on our health care system is growing. At the same time, cancer will increasingly have a negative impact on tax revenue, corporate profits and wage-based productivity, causing less money to be available to fund our health care system. Over the next 30 years, it is estimated that:

- Cancer will cost the health care system \$177.5 billion in direct health care costs;
- 2.4 million Canadian workers will get cancer;
- 872,000 workers will die from the disease;
- Cancer will reduce taxation revenues by \$250 billion; and
- Cancer will cost the Canadian economy \$543 billion in lost wages.<sup>6</sup>

Unless changes are made, Canada is headed toward a cancer crisis.

## **A National Cancer Control Strategy for Canada**

At present, no single organization in Canada is charged with coordinating the many facets of cancer care. Planning and care are fragmented, leading to an unnecessary duplication of effort and a waste of resources. Opportunities to benefit from economies of scale are being lost. There is no mechanism for coordinating action, sharing learning and distributing best practices to policy-makers, health professionals, patients and the community at large. Over the past 10 years, Australia, New Zealand, Ireland, France and the United Kingdom have all developed and funded comprehensive national cancer control programs. The experiences of these countries show that coordinated and targeted action at the national level delivers results. For example, the “Europe Against Cancer” initiative, begun in the mid-1980s, resulted in an age-adjusted drop in 2000 in expected cancer deaths by 10% in men and 8% in women, or 92,000 lives saved.<sup>7</sup> Canada is falling behind

The CSCC will ensure Canada is prepared to deal with the predicted increases in new cases and deaths. Cancer stakeholders, led by the Canadian Cancer Society, the National Cancer Institute of Canada, the Canadian Association of Provincial Cancer Agencies and Health Canada, first came together in 1999 to develop an integrated, comprehensive and pan-Canadian approach to cancer control. The CSCC is the result of seven years of consultation and collaboration between members of the health and

<sup>4</sup> *Canadian Cancer Statistics* 2006, Tables 10 and 11.

<sup>5</sup> RiskAnalytica. *Life at Cancer Risk* 2005.

<sup>6</sup> RiskAnalytica. *Life at Cancer Risk* 2005.

<sup>7</sup> World Health Organization. *Strategies to Improve and Strengthen Cancer Control Programmes in Europe: Report of a WHO Consultation* 2003.



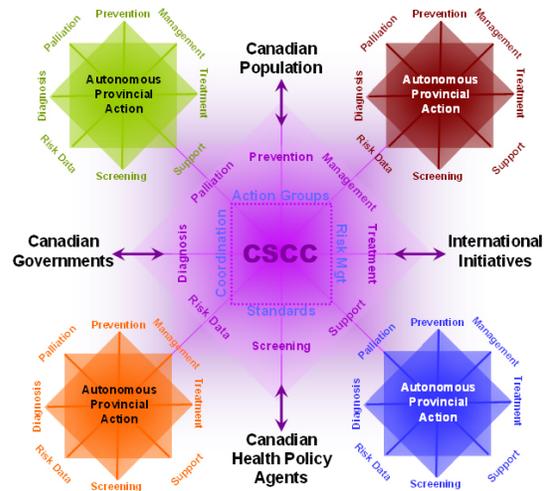
allied professions, academia, the voluntary sector, all levels of government and the cancer patient and survivor community.

### The CSCC: Pan-Canadian Action on Cancer Control

The goal of the CSCC is to reduce the expected number of Canadians being diagnosed with cancer, lessen the severity of the illness, enhance the quality of life of those with cancer and reduce the likelihood of dying from the disease. It is a knowledge-based strategy. It will maximize the development, translation, and transfer of knowledge and expertise across Canada. New research will be developed across the cancer control spectrum. Existing knowledge will be consistently and effectively applied. Cutting-edge, reliable and rigorously derived information will be provided to governments, cancer professionals, cancer support groups, patients, their families and individual Canadians. As a result, fragmentation in the health care system will be reduced, evidence-based best practices will be employed, decision-making will be informed and the health of Canadians will be measurably improved.

The CSCC encourages, supports and facilitates collaborative initiatives within the cancer control community. Through pan-Canadian networks, the CSCC engages experts from the cancer control community, leveraging critical experience and expertise for use by all. It is integrated and inclusive. Members include federal, provincial and territorial representatives, health professionals, key non-governmental organizations and cancer patient and survivor groups. CSCC activities are integrated with other federal, provincial and territorial government investments in cancer control to maximize cancer control effort, including promoting and supporting multidisciplinary action where relevant.

The CSCC supports and respects provincial and territorial jurisdiction over health. It will not impose programs and services. Instead, the CSCC provides evidence-based information and tools to help provinces and territories build cancer management strategies tailored to their own needs and based on a solid foundation of cancer knowledge and comparable national data. These tools include networks of experts, mechanisms for more efficient development and dissemination of best practices, knowledge translation tools for translating research into public policy and clinical practice and a risk management tool to improve performance. The result will be better local management of cancer.



The CSCC approach also permits a national perspective by enabling comparability, transparency, consistency and portability of knowledge across Canada. The CSCC brings together currently disparate agents of the Canadian cancer control system and creates a participative and evidence-based platform for communication and joint action among all stakeholders with the flexibility for multiple partnership arrangements. Sharing knowledge and know-how will enable governments and cancer care organizations across Canada to achieve a more efficient alignment of cancer control resources. This increased efficiency will save lives, reduce suffering and add economic value.



Full implementation of the CSCC will create an inclusive, responsive and evidence-based cancer control system for Canada.

## **Core Components of the CSCC**

The core components of the CSCC include:

- An inclusive Council that serves as the board of directors, setting policy and providing executive direction;
- A broad-based group representing the Patient/Survivor experience;
- Networks of cancer experts, known as Action and Working Groups;
- An enhanced cancer surveillance system; and
- Evidence-based knowledge transfer and performance and risk management system.

### **The Council**

The Council serves as the board of directors for the CSCC, setting policy and providing strategic direction. It operates an inclusive model of decision-making. The Council includes representatives from the federal government, provinces, territories, cancer expert and patient and survivor communities. It is currently made up of 30 members representing Canada's most important cancer organizations, including:

- The Canadian Cancer Society;
- The National Cancer Institute of Canada;
- Provincial Cancer Agency leaders;
- Canadian Association of Provincial Cancer Agencies;
- Canadian Cancer Action Network;
- Canadian Council of Pediatric Hematology/Oncology Directors;
- Public Health Agency of Canada;
- CSCC Action Group Leaders;
- CSCC Working Group Leaders; and
- Selected cancer experts.

This broad-based representation ensures timely decision-making and a transparent process. Overall responsibility for implementation of the five-year business plan will rest with the CSCC Council. This group will advise the federal Minister of Health (through the Public Health Agency of Canada) on progress against plan and cancer management in Canada in general. Further details of the governance model of the CSCC are provided in Appendix I.

The Council is served by an executive management team that provides administrative support to the Council, oversees the development and implementation of the Council's communications and branding and supervises staff supporting the Action and Working Groups. It also tracks and monitors the Action Groups' annual financial requirements.

### **CCAN: The Voice of Patients and Survivors**

No one knows the human suffering inflicted by cancer better than cancer patients, survivors and their families and friends. These individuals offer a unique perspective on cancer and cancer control and the economic and personal disruption associated with surviving a cancer diagnosis.



The Council places a priority on patient/survivor participation in the development and implementation of the CSCC; a balanced approach to cancer control must include the patient perspective and experience. The voice of patients and survivors is brought to the Council table through the Canadian Cancer Action Network (CCAN), a coalition of patient/survivor support groups representing a broad range of cancer types. This arrangement ensures that an organized system is in place to advance the patient/survivor perspective from a variety of groups and to communicate messages and queries from the Council back to the community represented. It also ensures that the issues experienced by survivors of many types of cancer are considered and no single site-specific cancer dominates. Many national cancer site groups are already members of CCAN and ideally every site-specific cancer support group will participate in the future.

The Network is led by a Chair and two Vice-Chairs who are elected by the membership for a fixed term. Leaders of member organizations work together to identify the issues of major concern to their members and to bring these forward for consideration by Council and the Action Groups. Five representatives who are elected by the CCAN membership sit on Council and at least one CCAN representative sits on each Action Group.

### **Network of Experts: Priority Areas for Investment**

Cancer control knowledge and expertise are dispersed throughout Canada's health care system. To make this information and expertise readily accessible to all stakeholders, the Council has established pan-Canadian, collaborative networks of experts in priority areas. These networks of experts, known as Action Groups, have primary responsibility within the CSCC for knowledge formation and direct action. Through data analysis, new research and evaluation, the Action Groups will increase knowledge and understanding about the causes of cancer and the real-world effectiveness of interventions. The Action Groups will reduce the burden of cancer on our health care system by providing an integrated cancer prevention strategy, enabling knowledge transfer, coordinating efforts and making the health system more efficient and effective in diagnosing and treating cancer patients.

Action Groups gather and critically analyze cancer information and knowledge across the cancer control continuum, provide cancer expertise and management advice in specified priority areas, and coordinate and drive action across Canada. They feed information into the Council's risk management and knowledge platform, make recommendations to the Council regarding priority setting, and manage and implement cancer control activities in their areas of expertise, ensuring that action is taken across the continuum of care.

Each Action Group is headed by a Chair, who is a subject matter expert and directly accountable to the Council for the actions and activities of the group. Members include health practitioners and administrators, epidemiologists, risk analysts and cancer survivors. The Action Groups work together to share knowledge, eliminate duplication of effort and ensure consistency across activities. The makeup of the Action Groups is flexible and will change as new priorities in cancer control emerge.

Eight of the Action Groups are focused on specific areas of cancer control:

- The Standards Action Group;



- The Clinical Practice Guidelines Action Group;
- The Primary Prevention Action Group;
- The Rebalance Focus Action Group;
- The Human Resources Action Group;
- The Surveillance Action Group;
- The Screening/Early Detection Action Group; and
- The Research Action Group.

The Quality and Performance Assurance Working Group is responsible for target setting and performance evaluation of the CSCC's initiatives. The objectives and five-year business goals of the Action and Working Groups are outlined below.

### **Enhanced Surveillance System**

While Canada has a high-quality surveillance system, many improvements are required to ensure cancer surveillance data collected can contribute to effective planning, implementation, monitoring and evaluation of Canadian cancer control efforts. Problems include:

- Inadequate and unstable financial resources at federal and provincial/territorial levels;
- Variability in cancer surveillance systems (e.g., mandate, data quality and coverage) among provinces/territories;
- A lack of integration of data of different jurisdictions; and
- A lack of centrally coordinated technological infrastructure.

Enhanced surveillance is an integral component of the CSCC. This includes upgrading a mature and reliable but limited cancer surveillance system and developing new approaches and systems (including scenario modeling tools) to deliver evidence and results-based information, education, human resource planning, training and support to decision-makers, health professionals, patients and the community at large.

### **Performance and Risk Management System**

The work of the Council and the implementation of the CSCC are supported by a knowledge platform, information technology and a cancer risk management system. Information and knowledge gathered by the Action Groups and their extended networks of experts is stored in an integrated fashion, ensuring that valuable knowledge and experience is combined, not lost. It enables quick analysis of new breakthroughs in research and cancer control and the systematic review of information and knowledge gaps and overlaps. This facilitates the quick and easy transfer of knowledge to the provinces, territories and individual Canadians, and supports robust target setting, performance management and accountability.

For internal use, the risk management system will enable the Council to make informed decisions about investment and evaluate the impact of its activities on a range of health and economic variables, including cancer incidence and mortality, tax revenues and wage-based productivity. It will also assist in the alignment of resources across the Action Groups – analyzing new breakthroughs in research and cancer control– and with the systematic review of information and knowledge gaps and overlaps.



For external use, the risk management system will be available as an online risk management tool for all levels of government to use. Provinces and territories, for example, will be able to develop cancer profiles over a 30-year period and undertake impact analyses of cancer interventions against demographic, epidemiological and economic factors. This will inform local decision-making.

The performance and risk management system will be implemented and managed by the Knowledge Transfer Platform, Information Technology and Risk Systems Working Group. Its objectives and five-year business goals are outlined below.

## **Strategic Priority Areas for Investment, 2006–2010**

The Council has established a set of strategic investment areas for delivering on the expressed priorities of the Canadian Strategy for Cancer Control. The Strategy is flexible and responsible to ensure that cancer control priorities will be met as they emerge. The initial priority areas are:

- Cancer Prevention and Early Detection;
- Supporting the Cancer Patient's Journey;
- Supporting the Cancer Workforce;
- Encouraging Cancer Research; and
- Improving Cancer Information and Access.

These investments will be coordinated by the Governing Council of the CSCC and Executive Management team and managed by the Action Groups. The business goals for each priority area for 2006 to 2010 are outlined below.

### **Cancer Prevention and Early Detection**

Only a small fraction of resources allocated to cancer control is currently spent on prevention. Governments across Canada require expert help from the cancer community to develop optimal policy solutions. Under the CSCC, the group primarily responsible for this area of investment is the Primary Prevention Action Group. There is also a real need to build cancer screening capacity and capability in Canada, which will be the focus of the Screening and Early Detection Action Group

#### **Primary Prevention Action Group (PP-AG)**

The objective of the PP-AG is the establishment of a pan-Canadian primary prevention system that supports evidence-based practice for policies and programs and addresses the population-based risk factors for cancer. It works closely with the Chronic Disease Prevention Alliance of Canada and other key stakeholders. The PP-AG will provide information and knowledge to the provinces, territories, municipalities, non-governmental organizations and individual Canadians on how to reduce cancer by reducing risk. It will also monitor and oversee the implementation of primary prevention practices across Canada. A current focus of the PP-AG is the development and implementation of effective tools and techniques to ensure the reduction of risk associated with sunlight, nutrition, and environmental and occupational exposure.

#### *Business goals 2006 to 2010*

- Develop national sun safety program;



- Develop national environmental and occupational exposure program;
- Develop nutrition guidelines and tool kits, especially for high-risk groups;
- Pilot and evaluate primary prevention surveillance system;
- Develop primary prevention report card;
- Build primary prevention research, surveillance and training capacity in Canada; and
- Raise awareness of cancer risk behaviours.

### **Screening and Early Detection Action Group (SED-AG)**

Cancer screening, delivered through effective screening programs that are population-based, can contribute significantly to cancer control in Canada. The goal of the Screening/Early Detection Action Group is to maximize the positive impacts of cancer screening in Canada, in terms of reduced mortality, reduced morbidity and improved quality of life (which includes support for informed decision-making about screening). The Screening/Early Detection Action Group will focus on cancer site – specific screening issues, complementing the efforts of the national committees already in existence and on broader issues such as advising on the implementation of organized screening programs in Canada; monitoring new evidence and emerging screening technologies; development and implementation of screening performance indicators; fostering the development and sharing of effective strategies to improve access to and participation in effective cancer screening; establishing effective partnerships with key stakeholders in the health care system to ensure coordination of screening efforts; and active participation in international screening networks.

#### *Business goals 2006-2010:*

- Support the achievement of recruitment targets for breast, cervical and colorectal screening through organized screening programs;
- Identify gaps and key areas for improvement in the delivery of screening programs (existing and new) in Canada and develop strategies to address these gaps;
- Champion the concept of programmatic screening (vs. opportunistic screening) with key partners and stakeholders to promote better understanding of the population health approach and facilitate better integration and linkages with other health care system strategies;
- Develop outcome and process objectives for cancer screening in Canada, including a set of national screening performance indicators and benchmarks, building on previous work and accomplishments of the national breast and cervical screening committees and internationally recognized approaches.

### **Supporting the Cancer Patient's Journey**

Cancer patients and their family members report that cancer care in Canada is not operating as an integrated whole or in a patient-focused manner. Many feel isolated. Others sense their care is fragmented and are uncertain where to turn for help. Access to information, support and services often depends upon where one lives. Under the CSCC, four Action Groups have primary responsibility for investment in this area: Screening/Early Detection, Standards, Clinical Practice Guidelines, and Rebalance the Focus.



## **Standards Action Group (S-AG)**

The Council has identified a lack of standards as a significant impediment to the provision of high-quality cancer care across Canada. Without standards, it is impossible to share information, compare practices or evaluate outcomes. Canadians are unable to determine whether the health care system is delivering equitable, effective and efficient care. The objectives of the S-AG are to develop pan-Canadian best-practice standards for cancer diagnosis, treatment and care and to establish performance indicators to evaluate service delivery and foster improved access and quality. The S-AG also assists in the development of key measures used by other AGs.

### *Business goals 2006-2010*

- Establish an inter-provincial mechanism to promote and facilitate the development, dissemination, uptake and evaluation of evidence-based, pan-Canadian standards and performance indicators for cancer diagnosis, treatment and care;
- Develop common data and technology system for storing and accessing performance indicators and best-practice standards information; and
- Improve access to standards and performance indicator information by professionals, patients and the community at large.

## **Clinical Practice Guidelines Action Group (CPG-AG)**

Evidence-based clinical practice guidelines are used to guide clinical practice and policy decisions. They promote appropriate practice, help inform investment in new technologies, and contribute to quality improvement programs. Through its three interconnected strategic directions (CPG Tools, CPG Cancer Knowledge Resource and Partners), the CPG-AG will facilitate co-operation among provincial cancer guideline programs, establish common principles and develop communication infrastructure and training opportunities. The CPG-AG champions the optimal use of evidence through clinical practice guidelines, promoting a consistent approach to cancer control. An important part of the CPG-AG's function is to communicate cancer control knowledge to other Action Groups, cancer control practitioner groups and other stakeholders. The CPG-AG will enhance the ability of provinces, territories, municipalities, NGOs and individual Canadians to access, evaluate, use and share knowledge about the best cancer control practices.

### *Business goals 2006-2010*

- Champion through national collaboration a pan-Canadian strategy to facilitate the optimal use of evidence through clinical practice guidelines for cancer control;
- Champion, through the provision of a quality Canadian-based online resource, the optimal use of evidence in cancer control. This comprehensive resource will include high quality Canadian and international evidence-based products that address the spectrum of cancer control.
- Provide resources and tools to help provinces develop, adapt, appraise, disseminate, implement, evaluate and maintain high quality evidence-based clinical practice guidelines; and
- Develop innovative partnership models for collaborative learning and sharing of knowledge to minimize duplication in effort and transfer skills effectively across Canada.



## **Rebalance Focus Action Group (RB-AG)**

When someone is diagnosed with cancer, there are emotional, social, spiritual and practical consequences for both the individual and family members. Support, access to information, and effective communication with health care providers are critically important, yet patients report difficulty accessing information and services in a timely manner. The objective of the RB-AG is to ensure that cancer patients' needs are better served by the health care system. The RB-AG will develop and promote strategies, tools and targets to address the urgent need for resources, including programs and staff, and ensure that health care professionals receive education in psychosocial, supportive and end-of-life care. It will also work to improve coordination and continuity of cancer care through a formal partnership between Canadian accreditation stakeholders. The RB-AG is most responsible for representing cancer patients with the other Action Groups.

Business goals 2006-2010:

- Establish pan-Canadian cancer supportive and palliative care network;
- Establish resource centre of best-practice standards and performance indicators in the areas of psychosocial, supportive and palliative care;
- Increase patient access to knowledge about supportive and palliative care (e.g., develop online patient navigation tools, use of telehealth systems, and services for First Nation and Inuit communities); and
- Build supportive and palliative care research, training and accreditation capacity in Canada.

## **Supporting the Cancer Workforce**

The CSCC Council has identified a lack of human resources as a potential threat to cancer control efforts in Canada. Shortages in the cancer workforce have limited the health care system's ability to care for patients and threatened its sustainability. In coming years, the increasing number of cancer patients will put an even greater strain on Canada's ability to provide timely and effective cancer care. Under the CSCC, the group primarily responsible for addressing this issue is the Human Resources Action Group.

## **Human Resources Action Group (HR-AG)**

The objective of the HR-AG is to coordinate the development of a pan-Canadian workforce strategy and to help rectify deficiencies in the cancer workforce across the country by providing provinces, territories and cancer control organizations with reliable tools and information. The HR-AG examines the nature and extent of the human resource crisis, addresses issues of recruitment, retention and training, and tracks and predicts workforce supply in light of changing models of delivery. It will also establish an effective human resources planning information system (HR-PIS) that will serve as a prototype for use in other health sectors. The HR-PIS will provide an objective standards-based tool to inform planning, policy and decision-making regarding human resources and capital equipment expenditures. Initial phases of the HR-PIS have been completed and pilot testing is under way in Nova Scotia and New Brunswick.



### *Business goals 2006-2010*

- Develop a coordinated pan-Canadian cancer workforce strategy addressing issues of repatriation, recruitment, retention and training;
- Build (from current prototype) effective pan-Canadian HR-PIS to provide standards-based tools to help provinces plan for cancer human resources and capital equipment demands;
- Perform a privacy impact assessment; and
- Complete a health sector study.

### **Encouraging Cancer Research**

Over the past decades, billions of dollars worldwide have been invested in cancer research. Outstanding progress has been made in the treatment and cure of childhood cancer and certain adult cancers. The challenge lies in applying what we know. Under the CSCC, the group primarily responsible for this function is the Research Action Group.

### **Research Action Group (R-AG)**

To capitalize on Canadian research strengths and focus them on the challenges in cancer control, the R-AG has established the Canadian Cancer Research Alliance (CCRA). The CCRA brings together all the major organizations and agencies funding cancer research in Canada to coordinate a united research response for cancer control. The objective of the CCRA is to provide a pan-Canadian voice on key research issues, promote the integration of research with all aspects of cancer control and champion biotechnology and translational research. The CCRA will promote the translation of science into easily accessible knowledge products. It will also organize a major investment in understanding cancer risk factors in the context of other chronic diseases. The CCRA will provide oversight for the development, implementation and evaluation of major research initiatives linked to the CSCC.

### *Business goals 2006-2010*

- Establish pan-Canadian cancer research network promoting integration of research across Canada;
- Coordinate funding for a major project on cancer translational clinical research to foster the transfer of new knowledge between the scientific community, health professionals, policy-makers and the community at large; and
- Coordinate funding for a risk factor cohort study to better understand cancer and other chronic disease factors and design effective intervention strategies.

### **Improving Cancer Information and Access**

Accurate, integrated and accessible information is required to facilitate effective planning, implementation, monitoring and evaluation of cancer control. Canada is recognized as a world leader in the production of high-quality surveillance data. However, resources are limited, vary in quality between jurisdictions, and lack integration and a centrally coordinated technological infrastructure. Under the CSCC, the groups primarily responsible for addressing these issues are the Surveillance Action Group, the Knowledge Translation Working Group and the Quality and Performance Assurance Working Group.



### **Surveillance Action Group (SUR-AG)**

The objective of the SUR-AG is to establish and operate a high-quality, pan-Canadian cancer surveillance system that brings together cancer epidemiological data and cancer control information from the provinces and territories for use in planning, implementing and evaluating Canadian cancer control efforts. The SUR-AG will monitor and evaluate the Canadian cancer control system, identify opportunities to link together information silos across Canada, build upon the successes of the previous Canadian surveillance coalition (Canadian Council of Cancer Registries, Canadian Institute for Health Information, National Cancer Institute of Canada, Canadian Oncology Society, etc.) and facilitate the expansion of the current cancer control surveillance system, now limited to incidence and mortality data, to acquire and utilize data about cancer staging.

#### *Business goals 2006-2010*

- Expand and standardize core set of epidemiological data collected by cancer registries;
- Implement pan-Canadian strategy for collection and storage of cancer staging data;
- Extend pilot program for linking treatment variables to cancer registries (radiation oncology data); and
- Improve record link between existing databases.

### **Knowledge Translation Working Group (KTR-WG)**

The core operating goals of the CSCC are to form, transfer and apply knowledge about cancer and cancer control. The objective of the KTR-WG is to promote and facilitate coordinated cancer management throughout the Canadian health system and provide timely access to evidence-based information to decision-makers, health professionals, patients and the community at large through its knowledge and risk management platform. It will give health care professionals online access to cancer risk information across Canada. It will also provide policy-makers in each province with the information needed to make informed decisions about cancer control.

#### *Business goals 2006-2010*

- Build a knowledge transfer platform and risk management system connecting provinces to the Council's online resource centres and real-time demographic and cancer risk economic and health state model.

### **Quality and Performance Assurance Working Group (QPA-WG)**

Independent evaluation is critical to objective and realistic target setting and real world achievement. The objective of the QPA-WG is to provide the Council with cancer control targets and timely, evidence-based analysis of the results of CSCC activities. The QPA-WG monitors the impact of cancer control initiatives on a gender, age, provincial and site-by-site basis and relates them to trends in cancer incidence and mortality. The QPA-WG also determines priorities for future action across the cancer control spectrum.

#### *Business goals 2006-2010*



- Establish achievable targets for the Council across cancer control continuum; and
- Develop performance monitoring and accountability system for measuring long-term trends and expected outcomes.

## Financial Plan of the CSCC, 2006-2010

The Council's five-year financial plan outlines the financial requirements of implementing the CSCC by strategic investment area. All figures, unless otherwise stated, are in Canadian dollars. These budgets take into account the anticipated expansion of Council activities as the Council gathers momentum and expands its scope. Total expected expenditures over the five-year period from 2006 to 2010 are \$260 million, with an even allocation of \$52 million per year.

### CSCC Proposed 5 Year Budget Allocation

CSCC Financial Plan Summary	1st Year		2nd year		3rd Year		4th year		5th Year		Total	
Establishment of Governance Structure	\$ 725,000	1.4%	\$ 108,750	0.2%	\$ -	0.0%	\$ -	0.0%	\$ -	0.0%	\$ 833,750	0.3%
<b>Pan-Canadian Co-ordination</b>												
Operations of the Executive Management Team, New Initiatives Programs, Governance Reporting and Administration	\$ 2,084,568	4.0%	\$ 2,576,350	5.0%	\$ 3,131,093	6.0%	\$ 3,954,404	7.6%	\$ 5,192,170	10.0%	\$ 16,938,586	6.5%
Board level policy research, provincial development grants, capacity building, alliance creation program support.	\$ 2,519,357	4.8%	\$ 2,446,700	4.7%	\$ 2,430,268	4.7%	\$ 1,555,929	3.0%	\$ 538,031	1.0%	\$ 9,490,285	3.7%
Knowledge Platform, Information Technology and Risk Systems	\$ 1,729,246	3.3%	\$ 2,289,420	4.4%	\$ 2,942,337	5.7%	\$ 1,833,761	3.5%	\$ 1,833,641	3.5%	\$ 10,628,404	4.1%
Community Linkage	\$ 395,000	0.8%	\$ 410,800	0.8%	\$ 427,232	0.8%	\$ 444,321	0.9%	\$ 462,094	0.9%	\$ 2,139,447	0.8%
<b>Cancer Prevention and Early Detection</b>												
Primary Prevention	\$ 6,827,398	13.1%	\$ 8,260,320	15.9%	\$ 8,269,250	15.9%	\$ 8,547,054	16.4%	\$ 9,163,013	17.6%	\$ 41,067,035	15.8%
Cancer Screening	\$ 2,853,775	5.5%	\$ 2,354,361	4.5%	\$ 1,908,991	3.7%	\$ 1,652,920	3.2%	\$ 1,514,247	2.9%	\$ 10,284,293	4.0%
<b>Cancer Patient's Journey</b>												
Standards	\$ 3,231,897	6.2%	\$ 3,798,372	7.3%	\$ 3,708,299	7.1%	\$ 3,636,851	7.0%	\$ 3,580,570	6.9%	\$ 17,955,990	6.9%
Clinical Practice Guidelines	\$ 2,945,566	5.7%	\$ 2,361,736	4.5%	\$ 1,879,722	3.6%	\$ 1,613,296	3.1%	\$ 1,475,764	2.8%	\$ 10,276,084	4.0%
Rebalance Focus	\$ 2,824,632	5.4%	\$ 3,087,449	5.9%	\$ 3,121,999	6.0%	\$ 3,178,298	6.1%	\$ 3,254,384	6.3%	\$ 15,466,761	5.9%
<b>Cancer Control Workforce</b>												
Human Resources	\$ 2,502,033	4.8%	\$ 2,420,992	4.7%	\$ 2,367,231	4.6%	\$ 2,339,838	4.5%	\$ 2,334,511	4.5%	\$ 11,964,605	4.6%
<b>Cancer Research</b>												
Strategic Research	\$ 11,151,185	21.4%	\$ 10,869,584	20.9%	\$ 8,743,810	16.8%	\$ 9,537,994	18.3%	\$ 10,451,197	20.1%	\$ 50,753,770	19.5%
<b>Cancer Information and Access</b>												
Surveillance	\$ 3,089,677	5.9%	\$ 3,358,296	6.5%	\$ 3,362,984	6.5%	\$ 3,378,675	6.5%	\$ 3,404,264	6.5%	\$ 16,593,897	6.4%
Surveillance - Canadian National Cancer Staging	\$ 6,955,322	13.4%	\$ 5,243,649	10.1%	\$ 7,292,812	14.0%	\$ 7,866,248	15.1%	\$ 6,260,782	12.0%	\$ 33,618,813	12.9%
<b>Performance Management and Accountability</b>												
Quality and Performance Assurance	\$ 2,165,344	4.2%	\$ 2,413,221	4.6%	\$ 2,413,971	4.6%	\$ 2,460,412	4.7%	\$ 2,535,333	4.9%	\$ 11,988,281	4.6%
<b>TOTAL ANNUAL EXPENDITURES</b>	<b>\$ 52,000,000</b>	<b>100.0%</b>	<b>\$ 260,000,000</b>	<b>100.0%</b>								

## Moving Forward: Cancer Control Vision for Canada

Canada is facing a cancer crisis. However, we are well positioned to implement a comprehensive cancer control strategy. Many of the foundations of that strategy are already in place, requiring only enhancement or further development. We have world-class researchers and cancer control professionals. Without coordinated action to address gaps and fragmentation in the system and ensure evidence-based knowledge and informed decision-making drive public policy and clinical practice, these opportunities and strengths will be lost.

Non-governmental organizations and patient and survivor groups are demanding action. Governments across the country recognize the unsustainable pressure growing numbers of cancer cases and deaths are placing on our health care system. We need an inclusive, integrated and comprehensive strategy to meet this crisis. By implementing the Canadian Strategy for Cancer Control, Canada can rise to the challenge.



## Appendix I: Governance Model

The Council has undertaken a thorough examination of different governance options for the CSCC, as the model of governance and management will ultimately determine the effectiveness and success of the CSCC. In the view of the cancer community, the type of vehicle established to move the CSCC forward should embrace the following principles:

- The CSCC must be efficient. Decisions should be made faster and take into account the needs of patients and stakeholders; knowledge must be transferred across the country efficiently and effectively; and duplication of effort in cancer control must be minimized.
- The CSCC must be transparent. Decisions and rationale should be communicated and discussed publicly; any one should have the ability to review investment against targets, goals and outcomes; the CSCC must support the achievement of real and measurable results.
- The CSCC must be accountable. The CSCC should be accountable for decisions and actions to both its own governing body and to external organizations that have a substantive interest in one or more of the programs, including governments (federal and provincial), cancer agencies, non governmental organizations and industry.
- The CSCC must be inclusive. Canada will be one of the first jurisdictions worldwide to give cancer patients/survivors and stakeholders an active role in both decision-making and policy setting. Establishing Priorities for action should be done by all stakeholders, based on the needs of patients and the knowledge of experts in cancer from across the country.
- The CSCC must be flexible. It should enhance our ability to adapt more quickly to evidence and knowledge as it becomes available. The CSCC must allow all stakeholders, including governments, cancer agencies, medical professionals and patients to access and use our best evidence and knowledge to better manage and control cancer in Canada.

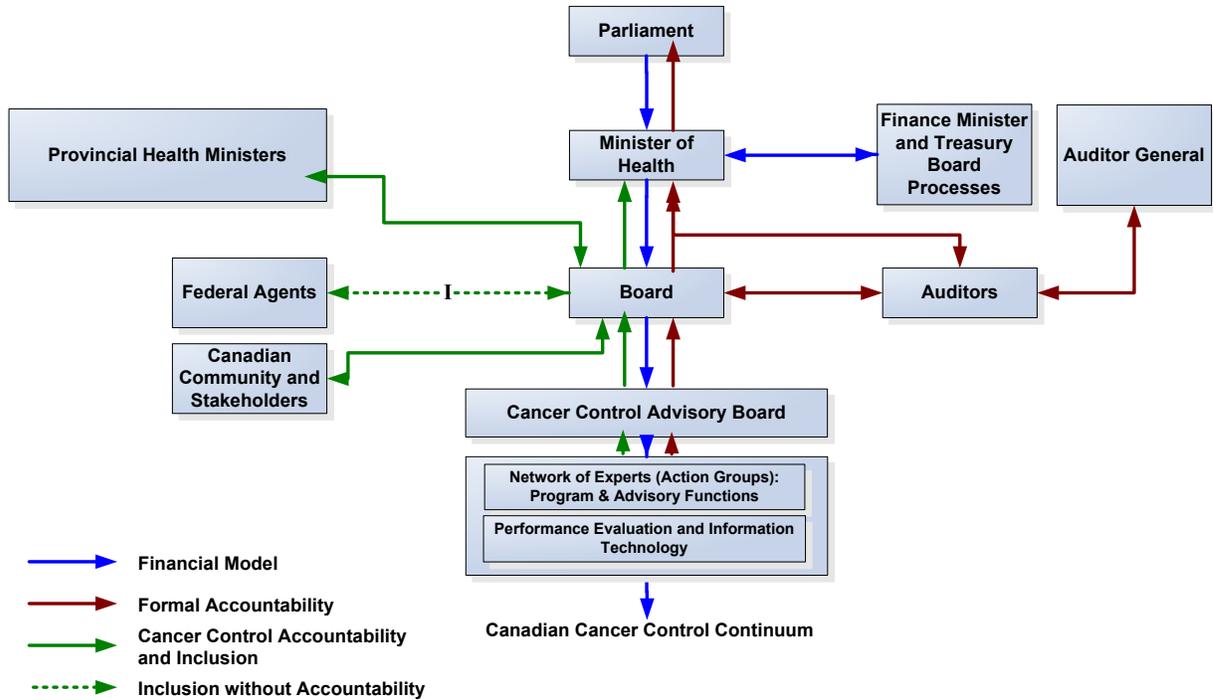
After a detailed examination of the merits and weaknesses of different governance options, it is the strongly held belief of the Council that these principles can be best represented in an independent stand-alone model of governance, which is the structure recommended in the Council's Business Plan.

Under this proposed model, the CSCC would be guided by an independent legal entity with the dedicated mandate of improving cancer control in Canada. Its Board would hold the discretion to invest funds according to its mandate. However, the CSCC would have both performance-based and financial accountability to the federal Minister of Health. The Auditor General would also be consulted to ensure this model is acceptable and an independent auditor would be used who would report to the CSCC Board, the federal Minister of Health and the Auditor General.

The CSCC will also have performance-based accountability to provincial and territorial Ministers of Health and to cancer community stakeholders through the use of advisory and performance evaluation committees and risk-based performance evaluation information platforms. Federal, provincial and territorial cancer control initiatives will be included through the use of these advisory and performance evaluation committees and standards and practice information platforms.



It is also important to note that the governance principles used to determine the CSCC's preferred governance structure are an amalgamation of the CSCC Council Operating Principles, the Treasury Board Secretariat Management Accountability Framework, and the Treasury Board Secretariat Integrated Risk Management Framework. The resultant governance structure recommendations for funding, accountability and inclusion considerations are illustrated below.



### Role of the Board

The Board would be responsible for administering the CSCC, establishing the priorities and outcome-based goals of the CSCC and ensuring that the CSCC is implemented in accordance with the views of all stakeholders. In the Council's view, that Board would include provincial/territorial representatives, as well as federal health representatives and representatives with cancer control or patient/survivor experience. Such a "stand-alone" Board could engage with existing entities to enact elements of the CSCC within one all-encompassing, comprehensive framework.

The CSCC entity and the Board will have both performance-based and financial accountability to the Federal Minister of Health and the Auditor General. The CSCC will also have performance-based accountability to provincial and territorial Ministers of Health and to cancer control stakeholders, while also being responsible for including the views of these stakeholders in the planning and guidance of the CSCC.



The key tasks of the Board include:

- Establishing the priorities and outcome-based goals of the CSCC, based on the CSCC Strategic Framework and the CSCC Business Plan 2006–2010;
- Ensuring that the CSCC addresses the full range of cancer control from prevention through diagnosis and treatment to supportive and palliative care;
- Ensuring that the CSCC addresses key infrastructure concerns that will contribute to successful cancer outcomes;
- Allocating the financial resources of the CSCC;
- Monitoring the performance of the CSCC against the established priorities;
- Reporting to the Minister and the Canadian public on the performance of CSCC against established priorities;
- Ensuring financial, legal and auditing reporting requirements are met according to federal government guidelines;
- Providing strategic advice to the Council of Federal, Provincial and Territorial Health Ministers on matters pertaining to cancer control;
- Responding to requests for advice on specific cancer control issues from federal, provincial and territorial governments; and
- Establishing a robust advisory function that fosters collaboration and cooperation among bodies delivering cancer control across Canada.

### **Role of the Cancer Control Advisory Council**

The Advisory Council will be comprised of cancer control experts, cancer stakeholders and cancer survivors, as well as the Chairs of the Action Groups and Working Groups.

The Advisory Council will:

- Be inclusive and will create robust links to the cancer control community, nationally and in the provinces and territories, including providers, patients, survivors and non-governmental organizations (NGOs);
- Advise the Board on national targets for cancer control;
- Advise the Board on strategic directions, goals and priorities related to achievement of the national targets;
- Establish and maintain the pan-Canadian networks of cancer experts and stakeholders (currently represented by the CSCC Action Groups) that will drive elements of the CSCC forward, including disbanding current networks and establishing new networks as new priorities emerge;
- Identify and prioritize for the Board's consideration additional evidence-based objectives that have the potential to improve the control of cancer in Canada; and
- Advise the Board on technology and other solutions to maximize translation, transfer and dissemination of knowledge about best practice in cancer prevention and control across Canada's cancer systems.



## **Appendix II: CSCC Council Members**

Dr. Simon Sutcliffe – Chair, CSCC  
CEO, BC Cancer Agency

Mr. Bob Allen – Chair, Surveillance Action Group  
CEO, Saskatchewan Cancer Agency

Dr. Philip Branton – Chair, Research Action Group  
Director, Institute for Cancer Research  
Canadian Institutes of Health Research

Dr. George Browman – Chair, Clinical Practice Guidelines Action Group  
Director, Tom Baker Cancer Centre; Vice President, Alberta Cancer Board

Dr. Dhali H. S. Dhaliwal  
President and CEO, CancerCare Manitoba

Dr. Bill Evans  
President, Juravinski Cancer Institute, Cancer Care Ontario

Dr. Margaret Fitch – Chair, Rebalance the Focus Action Group  
Head, Oncology Nursing and Supportive Care, Cancer Care Ontario, Toronto-Sunnybrook Regional Cancer Centre

Dr. Paul Grundy  
Council of Canadian Pediatric Hematology/Oncology Directors

Dr. Gerald Johnston  
Associate Dean, Research, Faculty of Medicine, Dalhousie University  
National Cancer Institute of Canada

Ms. Barbara Kaminsky – Chair, Primary Prevention Action Group  
CEO, Canadian Cancer Society, British Columbia and Yukon Division

Dr. Eshwar Kumar  
New Brunswick Department of Health and Wellness  
Head, Department of Oncology, Atlantic Health Sciences Corporation

Dr. Antoine Loutfi  
Directeur, Direction de la lutte contre le cancer,  
Ministère de la Santé et des Services Sociaux

Dr. Verna Mai – Screening Action Group  
Director, Screening Programs, Cancer Care Ontario

Dr. Anthony Miller – Chair, Quality and Performance Assurance Action Group  
Professor Emeritus, Department of Public Health Services, University of Toronto

Dr. Andrew Padmos – Chair, Human Resources  
Commissioner, Cancer Care Nova Scotia



Patricia Pilgrim  
Chief Operating Officer, Cancer Care, Children's and Women's Health,  
Eastern Health, Nfld.

Dr. Brent Schacter – Chair, Standards  
CEO, Canadian Association of Provincial Cancer Agencies

Ms. Theresa Marie Underhill  
COO, Cancer Care Nova Scotia

Dr. Barbara Whyllie  
CEO, Canadian Cancer Society

### **Canadian Cancer Advocacy Network**

Ms. Pam Del Maestro  
Brain Tumour Foundation of Canada

Mr. Steve Phillipow  
Canadian Prostate Cancer Network

Ms. Elisabeth Ross  
Executive Director, National Ovarian Cancer Association

Mr. Jack Shapiro  
Co-Chair, Canadian Cancer Advocacy Network

Ms. Liz Whamond  
Co-Chair, Canadian Cancer Advocacy Network

### **Public Health Agency of Canada**

Dr. Gregory Taylor  
Director General  
Centre for Chronic Disease Prevention and Control



## Appendix III: CSCC Stakeholders

### Charitable/Voluntary/Advocacy/Survivor/Support Organizations

- Anemia Institute Leucan
- Assembly of First Nations
- Breast Cancer Action Nova Scotia
- Breast Cancer Action Saskatchewan
- Canada's Association for the Fifty-Plus
- Canadian Breast Cancer Foundation
- Canadian Breast Cancer Network
- Canadian Cancer Advocacy Network (CCAN)
- Canadian Cancer Society
- Canadian Centre on Minority Affairs
- Canadian Council of Pediatric Hematology/Oncology Directors
- Canadian Palliative Care Association
- Canadian Prostate Cancer Network
- Canadian Public Health Association
- Canadian Thyroid Cancer Support Group
- Canadian Virtual Hospice
- The Canadian Women's Health Network
- Cancer Advocacy Coalition of Canada
- Candlelighters Canada
- CanSurmount Victoria
- Colorectal Cancer Association of Canada
- Congress of Aboriginal Peoples
- Consumers Association of Canada
- Elizabeth Lu Group/Foundation
- First Nations Breast Cancer Society
- Fondation quebecoise du cancer
- Heart and Stroke Foundation of Canada
- Hereditary Breast and Ovarian Cancer Society of Alberta
- Leukemia Research Foundation
- Lymphoma Foundation Canada
- Nancy's Chair in Women's Studies
- National Cancer Institute of Canada
- National Ovarian Cancer Association
- Neutropenia Support Association Inc.
- New Brunswick Breast Cancer Information Partnership
- New Brunswick Breast Cancer Network
- Nova Scotia Hospice Palliative Care Association
- Ovarian Cancer Canada
- ProCURE Alliance
- Prostate Cancer Alliance of Canada
- Prostate Cancer Research Foundation of Canada
- Vancouver Prostate Support and Awareness Group
- Wellspring London and Region
- Wellwood Resource Centre
- Windsor Cancer Prevention Coalition



- Women Alike Breast Cancer Group
- The Working Group on Women and Health Protection
- WRHA Comprehensive Breast Health Program Advocate Advisory Committee

### **Cancer Agencies/Centres/Institutes**

- Alberta Cancer Board
- BC Cancer Agency
- Canadian Association of Provincial Cancer Agencies
- Canadian Breast Cancer Initiative
- Cancer Care Nova Scotia
- Cancer Care Ontario
- CancerCare Manitoba
- Chronic Disease Prevention Alliance of Canada (CDPAC)
- Ontario Cancer Institute
- Ottawa Regional Cancer Centre
- Prince Edward Island Cancer Treatment Centre
- Saskatchewan Cancer Agency
- Toronto-Sunnybrook Regional Cancer Centre

### **Provincial/Regional Departments of Health**

- Alberta Health and Wellness
- British Columbia Ministry of Health and Ministry Responsible for Seniors
- Department of Health and Community Services
- Department of Health and Wellness
- Direction de la santé publique de Montréal-Centre
- Health and Community Services
- Manitoba Department of Health
- Ministère de la santé et des services sociaux
- Ministry of Health and Long-Term Care
- Newfoundland Cancer Treatment and Research Foundation
- Régie régionale de la santé et des services sociaux de l'Outaouais
- Saskatchewan Health
- Vancouver/Richmond Health Board

### **Research Organizations**

- Alberta Heritage Foundation for Medical Research
- Canadian Institute for Health Information
- Canadian Institutes of Health Research (CIHR) – Institute of Cancer Research
- Canadian Institutes of Health Research (CIHR) – Institute of Population and Public Health
- Centre for Behavioural Research and Program Evaluation
- Centre for Bioethics – Clinical Research Institute of Montreal
- Institut National de Santé Publique du Québec
- Institute for Clinical Evaluative Sciences
- LOEB Research Institute
- Manitoba Institute of Cell Biology
- NCIC National Cancer Institute of Canada Clinical Trials Group



- Ontario Cancer Research Network

### **Professional Associations and Societies**

- L'Association des Hopitaux du Quebec
- Association of Canadian Medical Colleges
- Association Quebecoise des Infirmières en oncology
- Canadian Association of Medical Oncology
- Canadian Association of Medical Radiation Technologists
- Canadian Association of Nurses in Oncology
- Canadian Association of Occupational Therapists
- Canadian Association of Pathologists
- Canadian Association of Pharmacy in Oncology
- Canadian Association of Psychosocial Oncology
- Canadian Association of Radiation Oncologists
- Canadian Association of Radiologists
- Canadian Association of Social Workers
- Canadian College of Physicists in Medicine
- Canadian Healthcare Association
- The Canadian Nurses Association
- Canadian Oncology Society
- Canadian Public Health Association
- Canadian Society of Nuclear Medicine
- Canadian Society of Palliative Care Physicians
- Canadian Society of Surgical Oncology
- College of Family Physicians of Canada
- Colorectal Cancer Association of Canada
- Consumer's Association of Canada
- Dietitians of Canada
- The Lung Association
- Pediatric Oncology Group of Ontario
- ProCURE Alliance
- Royal College of Physicians and Surgeons of Canada
- Society of Obstetricians and Gynecologists of Canada
- Society of Rural Physicians of Canada

### **Health Canada**

- Cancer Bureau
- Office of the Information Highway
- Tobacco Control Programme

### **Initiatives**

- Canadian Breast Cancer Research Initiative
- Canadian Coalition on Cancer Surveillance
- Canadian Prostate Cancer Research Initiative
- Coalition Priorité Cancer au Québec



### **Universities/Institutes**

- Centre Universitaire de santé McGill
- Dalhousie University, School of Nursing
- Faculté des sciences infirmières
- Faculty of Health Sciences
- Jewish General Hospital
- Mount Sinai Hospital
- Princess Margaret Hospital
- Queen Elizabeth II Health Sciences Centre
- Sunnybrook and Women's College Health Science Centre
- University of Calgary
- University of New Brunswick
- Faculty of Medicine, University of Newfoundland, Faculty of Medicine
- University of Ottawa Institute of Palliative Care
- University of Prince Edward Island
- Wilfred Laurier University

### **Annual Fund-Raising Events**

- Dive For A Cure
- Ride To Survive
- Run For The Cure