



Impact Report 2010
Canadian Partnership Against Cancer

Partnership
makes
the difference

Our vision

The Partnership's work delivers powerful benefits

Working together we will:

- Reduce the number of cancer cases
- Minimize cancer-related deaths
- Improve patient quality of life
- Increase the effectiveness and efficiency of the cancer control domain

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Cancer is the number one disease concern for Canadians and a global health challenge

Who we are. The Canadian Partnership Against Cancer is an independent organization funded by the federal government to accelerate effective action on cancer control across Canada. Bringing together those working to control cancer with patients and families who are affected by cancer, the Partnership shares a commitment and strength in collaboration.

By unifying efforts, the Partnership is driving advances in cancer control that will ultimately:

- Reduce the expected number of cancer cases
- Enhance the quality of life for those affected by cancer
- Lessen the likelihood of Canadians dying from cancer
- Increase the effectiveness and efficiency of the cancer control domain

No single cancer organization carries such a broad mandate for the country.

Collaborating with other organizations in the cancer community, the Partnership identifies and launches successful initiatives fuelled by existing knowledge while encouraging the constant search for new insights – with the ultimate goal of advancing cancer control for all Canadians.

The strategic initiatives are also designed to deliver the greatest impact possible in the five years of the Partnership's initial mandate. By creating and establishing the critical foundations for long-term success, these programs will help to create a powerful, sustainable legacy for the future.

The Partnership's areas of focus align with federal, provincial and territorial priorities to ensure that Canada's cancer strategy is well integrated into broader health considerations. For Canada, where health care is delivered by provinces and territories, the challenge has been to devise a collaborative model that leverages best practices and encourages, supports and facilitates every jurisdiction in customizing resources and applying knowledge to serve its own population. The Partnership has been able to find innovative ways of working with its partners to advance the cancer strategy across this vast country by acting as a catalyst and connecting those working in and affected by cancer across a large and complex health system.

It is this collaborative effort that will drive forward the best of what we know to control cancer, and will find innovative ways of putting this knowledge into consistent practice across Canada.

"In 2002, the World Health Organization urged all countries to develop comprehensive cancer control strategies... In Canada, this challenge has been taken up by the Canadian Partnership Against Cancer, integrating and building with key players across the national cancer system. The overall goal of these collective efforts is to realize the maximum impact as quickly as possible – and ultimately to steer those steadily rising cancer statistics in the opposite direction."

CARY ADAMS // CEO, INTERNATIONAL UNION AGAINST CANCER (UICC)

Partnership makes the difference

Working together to answer Canada's cancer questions

A message from the Chair and CEO. How do we save more lives? How can we prevent cancer and other chronic diseases? Who is making sense of new evidence? How do we measure success? These are just a handful of the critical questions that the Canadian Partnership Against Cancer is tackling together with Canada's cancer community.

The Partnership was established by the federal government with a five-year mandate to shape and implement a national cancer control strategy that will significantly reduce the impact of the disease on all Canadians. The terms of that strategy were defined by the collective vision, expertise and firsthand experience of more than 700 cancer practitioners and survivors from coast to coast. The strategy embraces the full spectrum of cancer control, from prevention to end-of-life care, from research to policy and practice, and from bio-medical to health systems applications. It recognizes that all are essential if incidence, mortality, quality of life, safety and affordability of care are to be controlled.

Understanding that cancer is the leading cause of early death in Canada – and also the number one health concern for Canadians – we took up the cancer control challenge with a sense of urgency. In just three years since we began operations, the Partnership has made significant progress across the entire cancer control continuum. A few key highlights of this work are:

- Catching cancer earlier with the expansion of colorectal cancer screening programs
- Seeking answers to the question of why some people develop cancer with the launch of the largest population health study ever done in Canada
- Teaming up with partners working in heart disease and other chronic diseases to maximize our efforts in cancer and chronic disease prevention
- Creating a cancer control portal to drive information sharing and collaboration across the country

By consciously organizing the Partnership to be a nimble, responsive organization, we are able to leverage existing investments, share knowledge more efficiently and accelerate the adoption of innovative best practices in jurisdictions across the country. By methodically defining, planning, implementing, monitoring and celebrating success, we are able to bring coherence, meaning and credibility to big, complex system changes. This work means Canada's cancer control community can progress faster, with more facts and insights, to marshal our resources intelligently.

All of this is the result of working with a large community of researchers, clinicians, provincial cancer agencies, health ministries, patients, their families and survivors. This large, diverse community is contributing to the successful implementation of Canada's first national cancer control strategy. It is a groundbreaking approach to health-care collaboration in Canada that certainly proves that the whole is bigger than the sum of its parts.

Cancer affects all Canadians, which means we are **all** part of the cancer control community, and all play a role in helping to answer the questions that are central to reducing the impact of cancer on Canadians. While it will take decades to achieve the full scope of our national cancer control strategy, the work underway, and its positive impact – regionally, nationally and worldwide – only three years into the first mandate, are compelling evidence of the extraordinary power of collaboration. And the results will be worth it: fewer people diagnosed with or dying of cancer and improved quality of life for those affected by the disease.



Simon Sutcliffe

Simon Sutcliffe, MD
Chair



Jessica Hill

Jessica Hill
CEO

Having an impact

The big questions

Impact is about making a difference, about having a demonstrable effect. With a large scale population health challenge as complex as controlling cancer, collectively we need to make significant headway on many different fronts to have an impact. We must address needs ranging from catching cancer earlier, improving quality across the cancer system and supporting patients through the cancer journey, to driving innovative research and of course improving disease prevention.

Nearly half of all Canadians will develop cancer in their lifetimes and approximately one in four will die from the disease. To reduce these numbers we must tackle some fundamental cancer control questions:

What are we doing to save more lives today?

How will better information make a difference?

How are we addressing gaps in the human side of cancer?

How can we prevent cancer and other chronic diseases?

What are the benefits of sharing what we know?

Why do some people get cancer and others do not?

Who is making sense of the new evidence?

How do we measure success today and make better choices tomorrow?

In this report, these eight critical cancer questions are each linked to a sampling of the Partnership's work. Together these snapshots create a composite picture of where we have come from, where we are today and what lies ahead. The impact described on these pages is also a sampling of what is possible when the cancer and health communities across Canada come together to achieve something as significant and as critical as controlling cancer.

LEGEND

- ▼ Colorectal Cancer Screening Network (p 10)
- ◆ Canadian Partnership for Tomorrow Project (p 32)
- National Staging Initiative (p 14)
- ★ Report staging data through own provincial registries
- Report staging data through designated provinces
- + System Performance Reports (p 40)

- Coalitions Linking Action and Science for Prevention (CLASP) (p 24)**
- CLASP coalition partners
 - ▲ CLASPs that include collaborations with First Nations and Inuit peoples
- St. Elizabeth @YourSide Colleague® Cancer Course (p 11)**
In partnership with St. Elizabeth Health Care, this initiative includes collaborations with First Nations communities



Yukon



Northwest Territories



British Columbia



Alberta



Nunavut



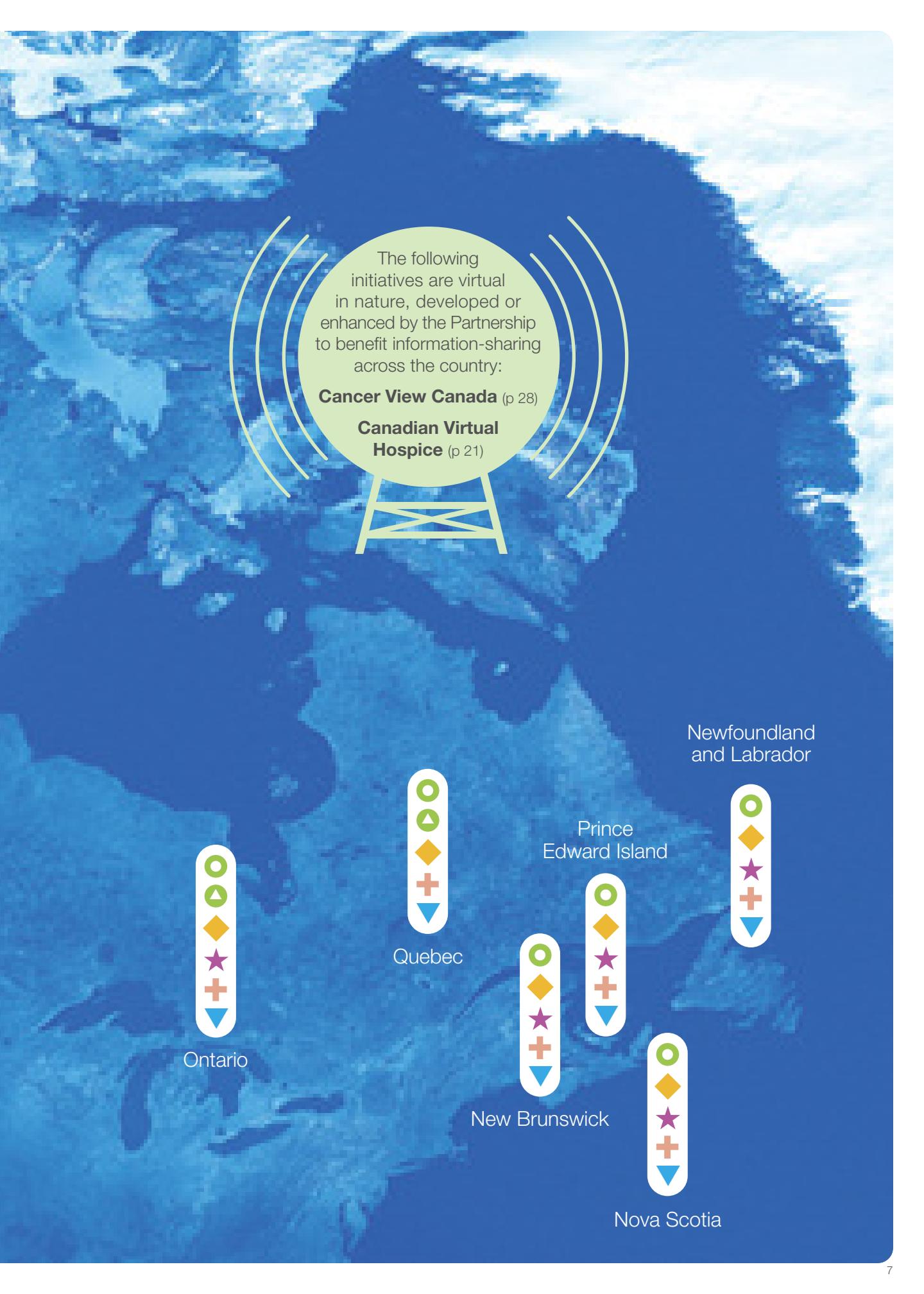
Saskatchewan



Manitoba

The power of partnership

Geographic reach of selected initiatives at April 2010



The following initiatives are virtual in nature, developed or enhanced by the Partnership to benefit information-sharing across the country:

Cancer View Canada (p 28)

Canadian Virtual Hospice (p 21)



Ontario



Quebec



New Brunswick



Newfoundland and Labrador

Prince Edward Island



Nova Scotia

Better. Sooner. Faster. What are we doing to save more lives today?

Canadians are seeing some early benefits from their national cancer strategy in the form of innovative approaches to information sharing that will increase the number of Canadians being screened for cancer and improve prevention efforts.

The Partnership established the National Colorectal Cancer Screening Network three years ago to help increase the number of Canadians being screened for colorectal cancer. Colorectal cancer is the second leading cause of cancer deaths in Canada. International research shows that screening can reduce mortality.

Dr. Heather Bryant, the Partnership's Vice president, Cancer Control, describes the accelerated impact in colorectal cancer screening: "Representing all provinces and territories, members of this Network are able to build and expand on each others' experience with colorectal cancer screening. This is helping to get screening programs in place faster than if provinces and territories were working in isolation. More screening programs in place means more Canadians are getting screened for colorectal cancer."

Dan Coulombe, Director of Operations, New Brunswick Cancer Network, notes, "Being part of the National Colorectal Cancer Screening Network has given us the opportunity to work with provinces experienced in setting up a colorectal cancer screening program and to learn from their best practices. This will help us plan and design a program that works with the particular way we deliver care in New Brunswick, rather than starting from scratch. We look forward to implementing our recently announced program to increase screening and ultimately, save lives."

Another collaboration making important progress is with First Nations, Inuit and Métis communities. One such project is with Saint Elizabeth Health Care, which is providing a unique online cancer course for health care providers working in remote First Nations communities. More than 200 First Nations communities and organizations in Manitoba, Saskatchewan and British Columbia are using the course, which includes important information about screening and prevention, as well as other important information about cancer control.

"I learned a lot about the importance of screening and early detection. I shared this information with my community and, as a result, several people were tested and had their cancer detected early and are going through treatments and are doing well," says Patty Wilson, Community Health Representative, Kwakiutl District Council Health Services. "The course material on the importance of screening may well have saved many lives."

Finally, the Partnership is expanding work into cervical cancer screening. Over the past few years, cervical screening programs began examining their practices as new tests for screening became available. And now, as more young women are being vaccinated against human papillomavirus (HPV) – the virus that causes cervical cancer – there are questions as to whether the common types of testing should change. Vaccinated women may need different screening than non vaccinated women. The Partnership is working with partners to coordinate integration of screening with HPV vaccination to maximize future impact and efficiencies, with the potential to almost eliminate cervical cancer within a generation.



“As a colorectal cancer patient who was diagnosed at Stage 3, so a more advanced cancer, I underwent invasive surgery and intensive chemotherapy. I can tell you I encourage anyone over 50 to get screened for colorectal cancer – when you have a chance to catch it earlier, when it is usually easier to treat. This national screening initiative is having a real and immediate impact!”

ARCHIE McCULLOCH // MEMBER, CANADIAN CANCER ACTION NETWORK

Colorectal Cancer Screening

Reflects progress
at April 2010

Decrease in the number of Canadians who develop or die from colorectal cancer

Targeted increase in number of Canadians being screened from 20% to 30% in the next two years

We are here

- National public awareness program "Colonversation" launches (2010)
- Screening programs or pilots announced by all provinces
- National survey shows 56% of Canadians aged 50 to 74 not up to date with screening tests and unaware that screening happens before signs and symptoms (2010)
- Network's first "Colorectal Cancer Screening Indicator Report" in development
- *Quality Determinants in Colorectal Cancer Screening in Canada* published (2009)

National Colorectal Cancer Screening Network hosts quality determinants workshop to discuss development of screening database and key variable collection (2008)

Colorectal cancer screening programs initiated in Alberta, Manitoba, Ontario and Nova Scotia (2007–2008)

Partnership brings together National Colorectal Cancer Screening Network (2007)

Only 9.5–16.5% of eligible Canadians are screened for colorectal cancer (2005)



Nearly 22,000 Canadians are diagnosed each year with colorectal cancer. If detected early, when the disease is easier to treat, survival rates can be up to one-third higher. Most Canadians who should be getting screened regularly for colorectal cancer – those aged 50 to 74 – are not up to date on the screening tests.

To help improve screening rates and to develop a shared approach to colorectal cancer screening programs across Canada, the Partnership established the National Colorectal Cancer Screening Network three years ago. Network membership includes provincial screening program staff, provincial and territorial government representatives, and representatives from the Canadian Cancer Society, Public Health Agency of Canada, Canadian Cancer Action Network, Canadian Medical Association, Colorectal Cancer Association of Canada and Canadian Association of Gastroenterology.

Results of this innovative approach to information sharing are promising: every province has now announced a colorectal cancer screening program, with eight of the 10 already underway. Data also indicate that the number of Canadians being screened is slowly rising.

To further support public education and awareness about the importance of screening, the Partnership, with members of the Network, launched a campaign to help encourage Canadians 50+ years of age to get screened. Research done before the campaign was developed indicated that conversation was the primary driver to someone getting screened, so the campaign – called "Colonversation" – was developed with that in mind.

The main hub of the campaign is www.colonversation.ca. Housed on the Partnership's portal, www.cancerview.ca, the Colonversation site offers useful features to support ongoing education efforts in Canada, including clear guidelines about who should get screened and when; information on where and how to get screened in each jurisdiction; instructional videos on doing a stool test at home and on how colonoscopy works; and information and statistics supporting screening recommendations.

Partners

- Provinces and territories: All 10 provinces have announced comprehensive colorectal cancer screening programs

Benefits

- *Health system impact:* Less treatment demand; learnings will be applied to other cancer screening programs as well as to other chronic diseases
- *Human impact:* Colorectal cancers will be diagnosed at an earlier stage, reducing incidence and lowering mortality rates



Coordinating Efforts on Cervical Cancer Control

The Canadian Cancer Society estimates that last year 1,300 Canadian women were diagnosed with cervical cancer and 380 died from it.

Cervical cancer is caused by changes in cervical cells, which may occur after infection of the cervix with HPV. While the introduction of the HPV vaccine offers women increased protection against cervical cancer, it does not offer complete protection. Given this fact, it is important that all women, whether they have been vaccinated or not, continue to be screened for cervical cancer.

The Partnership is therefore expanding work into the area of cervical cancer screening. Over the past few years, cervical screening programs had already been examining their practices as new tests for screening became available. And now, as more young women are being vaccinated against HPV, there are questions as to whether the common types of testing should change, and whether vaccinated women will need different screening than non-vaccinated women. The Partnership is working with partners to coordinate the integration of screening with HPV vaccination to maximize the impact on reduced incidence and mortality as quickly and efficiently as possible.

To support this work, two initiatives are currently underway:

1. HPV/Cervical Screening Senior Partnership Group: The Partnership is allied with the Public Health Agency of Canada and the International Centre for Infectious Diseases to allow synergy among the groups' respective areas of work in cervical cancer control and screening, HPV immunization, testing and surveillance.

2. Pan-Canadian Cervical Screening Initiative: Bringing together stakeholders from government, health-care professions and other groups dedicated to population-based screening for cervical cancer, this initiative leads to knowledge exchange about screening programs and the creation of national guidelines, and maps the steps required to integrate screening with HPV testing and vaccination.

Through this work, the Partnership will, with its partners, maximize the impact on reducing incidence and mortality as quickly and efficiently as possible. With the HPV vaccination and an effective screening program, we have the opportunity to almost eliminate cervical cancer within a generation.

Working Together for First Nations, Inuit and Métis Cancer Control

Cancer rates in First Nations, Inuit and Métis communities are increasing faster than in the overall Canadian population, the disease tends to be found at more advanced stages and deaths from preventable cancers are higher.

As part of its mandate to advance Canada's cancer control strategy, the Partnership is responding to these challenges. Guided by the Advisory Committee on First Nations, Inuit and Métis Cancer Control, the Partnership is building on innovative work of the First Nations, Inuit, Métis and cancer control communities, as well as federal agencies, to create meaningful change.

Several collaborations are making important strides.

They include:

- Work with Cancer Care Ontario to enhance cancer data on Aboriginal peoples in Ontario
- The upcoming launch of a new online site about First Nations, Inuit and Métis cancer control as part of the Partnership's portal Cancer View Canada
- Collaboration with Saint Elizabeth Health Care on an online cancer course for health-care providers working in remote First Nations communities

The online cancer course, part of Saint Elizabeth Health Care's @YourSide Colleague® educational series, is now being used by more than 630 community-based health-care providers. The course reaches more than 200 First Nations communities and organizations in Manitoba, Saskatchewan and British Columbia. The course is being credited with helping community health workers identify people at risk. Further expansion of the course offerings to other provinces is being considered.



"I was diagnosed with Stage 2 breast cancer, and it was an aggressive type of cancer as well. Because my health-care team was able to accurately diagnose and stage the cancer, they helped me to understand which treatment options would be most effective."

KAREN // CANCER SURVIVOR

Sharpening the picture

How will better information make a difference?

A procedural checklist in the cockpit is standard in the airline industry, to which health policy experts have long pointed as the benchmark in engineering systems for safety. Now, a similar innovation in the health care sector is making its way into operating rooms and pathology laboratories across the country: structured checklists for surgeons and pathologists to use when they are writing case reports.

The Partnership is supporting two parallel but distinct projects geared towards achieving national consensus on standards and content for structured checklist reports in surgery and pathology. The implications of this work are a win win win situation for patients, physicians and researchers – with cost savings to the system as well.

“The synoptic surgery reporting project will enable surgeons to enter their reports electronically at the point of care – a giant leap forward in knowledge transfer,” says Dr. Kelley Temple, Chief of the Division of Surgical Oncology at Calgary’s Tom Baker Cancer Centre. “The adoption of electronic synoptic reporting by surgeons represents a whole new culture, allowing for the generation of real time records and outcomes that will significantly improve our patients’ lives. This pan Canadian first is also leading the way internationally.”

“An accurate and complete pathology report is essential in correctly diagnosing a patient’s cancer,” says Dr. John Srivley, Head of the Pathology and Laboratory Medicine Program at Cancer Care Ontario, and a professor at McMaster University’s Faculty of Health Sciences. “A structured checklist brings order to a complex report. It’s easy for

pathologists to fill out and easy for clinicians to understand – reducing the need for interpretation and helping them decide on the appropriate treatment for their patients.”

“The information in a patient’s surgery and pathology reports is used to assess the stage of a cancer – in other words, how advanced it is,” says Dr. James Brierley, Chair of the Partnership’s National Cancer Staging Advisory Committee and a radiation oncologist at Princess Margaret Hospital in Toronto. “For an individual patient, correctly staging a cancer helps his or her health care team to identify the best treatment options. At a systems level, collecting stage data for a given population can enable much more accurate cancer control activities.”

The Partnership is also supporting the work of Canada’s provincial and territorial cancer registries to electronically receive relevant data from cancer centres, and then capture it using common cancer stage categories. The cancer registries and their rich data holdings are the key providers of data that are used regionally and in some cases nationally to study patterns of care and trends in cancer incidence, risk, mortality and survival.

With registries staging cancer cases in a standard way, experts will be able to monitor patterns and trends at a broader population level. Eventually, this will enable health professionals to evaluate such questions as whether screening programs are doing what they were designed to do: diagnose cancers earlier and save lives.

National Staging Initiative

Reflects progress
at April 2010

Earlier stage diagnosis of cancer, better and more informed treatment decisions, better patient outcomes, increased patient survival, more informed policy decisions by system leaders

Better data to enable improved patient outcomes and to plan, monitor and evaluate cancer control efforts

Provinces and territories collecting relevant data to stage new cases (for the top four cancer sites) diagnosed on or after January 1, 2010

We are here

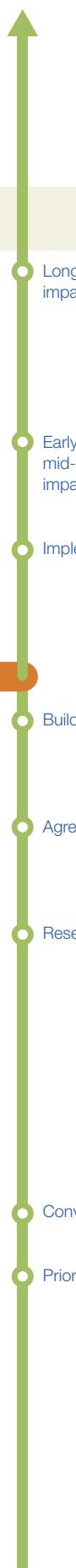
Provinces and territories developing infrastructure for data collection (April 2009–March 2012)

Finalize funding agreements with provinces and territories for work on data collection (April 2009–January 2010)

- Provincial/Territorial Cancer Registry Staging Audit Report: Document reports on audit conducted on accuracy of staged cases (April 2009–April 2010)
- Provincial/Territorial Cancer Registry Staging Baseline Report: Snapshot of provinces and territories currently staging which types of cancer (April 2009–early 2010)

Kick off of National Staging Initiative (fall 2008)

Collection and completeness of staging data vary across the country



Long-term impact

Early and mid-term impact

Implement

Build

Agree

Research

Convene

Prior state

The National Staging Initiative supports the collection of national, population-based, standardized stage data for the four most commonly diagnosed cancers in Canada – colorectal, lung, breast and prostate – for new cases diagnosed on or after January 1, 2010. By capturing the stage of a patient's cancer at diagnosis in a standardized format, provinces and territories are better equipped to observe and monitor trends and patterns over time, and in turn to identify gaps and improvements.

Partners

- **National:** Canadian Association of Provincial Cancer Agencies, Canadian Council of Cancer Registries, Public Health Agency of Canada, Statistics Canada
- **Provinces and territories:** Nine provinces and three territories

Benefits

- **Health system impact:** Better patient outcomes; evaluation of the effectiveness of treatment and screening programs
- **Pan-Canadian impact:** Consistency of information
- **Human impact:** More Canadians surviving cancer and achieving a better quality of life



Synoptic Reporting (Surgery)



The synoptic surgery reporting pilot project is improving the collection and application of surgical information through standardized electronic operative reports, which several centres will use. The project builds on work that started in Alberta with funding from Canada Health Infoway, and it has the potential to revolutionize the way surgeons capture information.

Coupled with advances in information technology that allow the capture of standardized responses at the point of care through the web, operative reports can be submitted within minutes of surgery and instantly transmitted to health-care personnel. The most valuable aspect of this approach is that it enables practitioners to analyze outcomes and feedback. By tracking their own practices and the practices of their community, clinicians can gauge their adherence to clinical evidence and safety procedures that are embedded in the reporting templates. This information can lead to practice improvements.

CAREX



Research has uncovered many substances in our environments that may cause cancer, leading to efforts to limit exposure. However, few of these substances can be completely eliminated, and so it is natural that many Canadians have questions about whether cancer-causing substances are present in their community and work environments.

CAREX Canada, a Partnership-funded initiative based at the University of British Columbia, is the first project of its kind to map probable patterns of exposure to cancer-causing agents in the workplace – as well as in air, water and soil – on a pan-Canadian basis. This information will allow researchers, health and safety professionals, policy-makers and partners to address important questions about occupational and environmental exposure, and potentially to prioritize and develop strategies to enable Canadians to reduce their risk of carcinogenic exposure.

Synoptic Reporting (Pathology)



Surveillance and Epidemiology Networks

This initiative seeks to deliver information products that clinicians, researchers and policy-makers need to inform and monitor their efforts in cancer control. Information delivery will be achieved by building analytic capacity through training workshops and by working with key stakeholders to create informative surveillance products.

Currently, four pan-Canadian teams, or networks, have been funded to lead the charge, each on a specific priority topic: cancer survival and prevalence; colorectal cancer; palliative and end-of-life care; and future projections to predict the burden of cancer. To ensure that the work addresses needs and concerns from a broad range of perspectives, each network is composed of a cross-section of experts, including clinical scientists, biostatisticians, epidemiologists and knowledge translation specialists.

Each network will develop and deliver materials beyond the scope of information that is currently available in such formats as reports, fact sheets and journal articles to various end users. The new materials will have national, provincial and territorial perspectives. Networks will also conduct knowledge translation workshops to share what they have learned with the broader cancer control community.



Through the cancer maze and beyond

How are we addressing gaps in the human side of cancer?

For many people affected by cancer, having meaningful and informed participation in their cancer care and ongoing health can help them make sense of the journey. Equally important is access to information and resources that can help address non medical challenges, such as the complex physical, social, emotional, psychological, spiritual, financial and other practical needs that accompany cancer.

By improving how the cancer system addresses these human needs and by enabling people to play a more active role in their care, the Partnership is helping to make the journey better for all patients – whether they are entering, navigating or moving beyond the cancer system.

One example is the Partnership's pioneering work in screening cancer patients for distress. Using simple methods such as checklists, health care professionals are able to identify patients who might benefit from professional counselling, homecare, peer support groups or pain control. Accreditation Canada now recognizes distress as the sixth vital sign, and the Partnership's working group of experts is helping British Columbia, Ontario, Quebec and Nova Scotia implement screening in their cancer centres.

The Partnership is also exploring how tools such as care plans can help patients make the often difficult transition from active treatment at a cancer centre back to their primary health care provider. This is a time when many patients report feeling isolated and overwhelmed. Care plans – short, plain language documents that bring a patient's health information together in a single place – help patients keep track of their own health information.

"While care plans serve an important practical purpose in ensuring that health care providers interacting with a patient have all the needed information at hand, they are also about empowerment of the individual. Feeling in control is incredibly important in promoting well being and informed follow up," says Elisabeth Ross, CEO of Ovarian Cancer Canada and Co chair of the Partnership's Survivorship Working Group.

The Partnership's work is grounded in a philosophy of comprehensive, patient centred care and enhanced self management. "Every person's experience with cancer is unique – but there are common threads that guide our work to improve the cancer journey for all," says Dr. Margaret Fitch, Head of Oncology Nursing and Co lead of the Patient and Family Support Program at the Odette Cancer Centre, Sunnybrook Health Sciences Centre, and Chair of the Partnership's Cancer Journey Advisory Group. "From offering patients support and guidance, to putting practical tools in place that will help people to advocate for their care even after treatment ends, the range of work underway is powerful and promising. I believe we are helping make sense of the cancer maze."

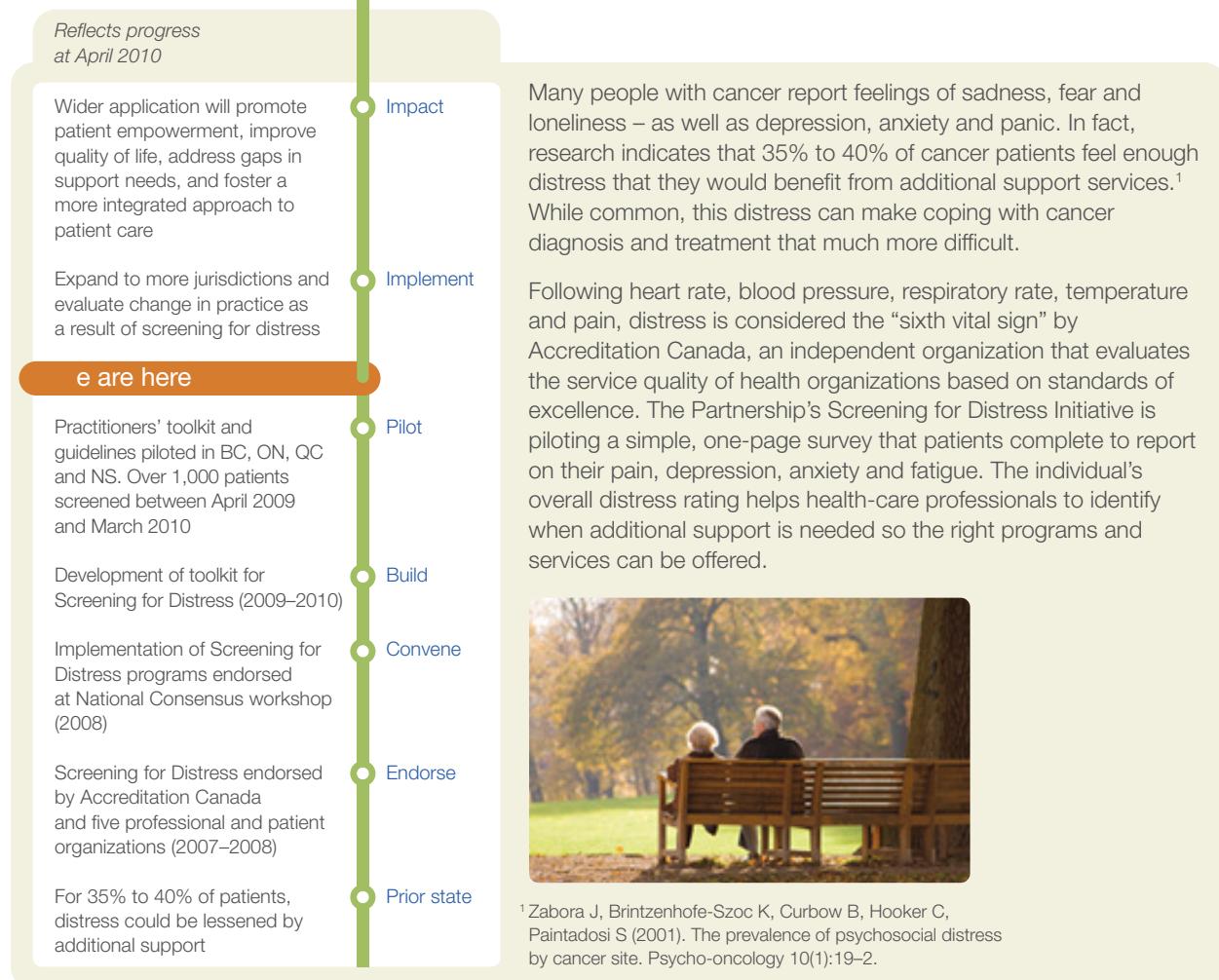
"This work is having an impact on how we, as professionals, deliver care. It promotes awareness of people's needs beyond their cancer treatment," says Dr. Lise Fillion, Professor in Nursing Sciences at Université Laval. "The system is changing to ensure that we consider the whole person. More and more, patients are being viewed as people, not cases."



"Having been through the cancer system twice, I'm well aware of how the experience can have a de-personalizing effect, where a patient becomes a number in a system that seems heavily concentrated on tumour treatment. What excites me about the Partnership's work is the emphasis on the patient as an active agent in his or her own wellness and decisions. Cancer care is at its best where it achieves that fine balance of personal empowerment and support."

BETH // CANCER SURVIVOR

Screening for Distress



Survivorship

Nearly one million Canadians count themselves among a growing population of cancer survivors. While their lives have been altered – often profoundly – many have gone from active treatment to survivorship with very little information and few tools to prepare them for the complexities of this transition out of the cancer system. Now, a survivorship initiative, led by the Partnership’s Cancer Journey Advisory Group through its National Survivorship Working Group, is addressing the needs of people living beyond cancer treatment. Based on recommendations from a national meeting it convened on the needs of survivors, the Partnership is funding four care plan demonstration projects aimed at the post-treatment challenges people face. At a time when many survivors feel tremendous uncertainty, these programs address critical information and care gaps.

Care plans summarize personal information, treatment and follow-up protocols, as well as available resources, so individuals feel more empowered to manage their own care.

The demonstration projects will reach diverse audiences through different delivery methods:

- A web-based tool, developed in Newfoundland, for young adults between 15 and 39 years of age
- A peer-delivered program for a community-based organization in Ontario designed for patients who are within six months of ending treatment
- A Manitoba plan developed specifically for rectal cancer patients
- An Alberta-based project for survivors of breast and head and neck cancer, delivered by nurses in cancer centres and rural areas

Navigation

Connecting patients and their families with specially trained professionals or volunteers who offer proactive, practical help to negotiate the maze of treatments, services and challenges on their cancer journey is known as patient navigation. While patients and their families often feel overwhelmed by the complexity of cancer treatment and care, patient navigation is not yet delivered in any standardized form across Canada.

Joining forces with the Public Health Agency of Canada, the Partnership convened three National Cancer Patient Navigation workshops to explore with stakeholders how additional navigational programs could provide more effective support to patients, survivors and caregivers. The Partnership's working group has developed a manual that defines roles and responsibilities for three different models of patient navigation:

- Peer or lay navigation, with trained survivors as navigators
- Professional navigation, with nurses as navigators
- Virtual navigation, an online form of navigation

The Partnership's initiative facilitates more integrated care by enhancing the range and quality of navigation assistance available to patients and families, improving access to counselling and support and helping to ease transitions throughout the cancer journey, including to survivorship or palliative and end-of-life care. The models will serve as a base for the customized development of local, provincial and territorial navigator programs.

Reflects progress
at April 2010



Palliative and End-of-Life Care

About 75,000 Canadians die every year from cancer. Palliative and end-of-life care are not systematically integrated into cancer care across the country, which can cause unnecessary distress at a difficult time. The Partnership's work in this area examines ways of integrating palliative and end-of-life care into the cancer care continuum. Developing education and competency-based training for oncology professionals is just one example. The Partnership is also working with Canadian Virtual Hospice (www.virtualhospice.ca) to expand awareness of this web-based resource, which provides information and support in palliative and end-of-life care, as well as loss and grief support for patients, families and professionals. This online tool is

particularly meaningful to geographically remote and hard-to-reach communities.

Additionally, palliative and end-of-life care are the focus of one of four pan-Canadian networks selected by the Partnership to create information products that clinicians, researchers and policy-makers can use to assess whether terminally ill patients and family members receive appropriate care and support. This network, comprising a cross-section of experts, will develop and deliver materials beyond the scope of information currently available and will conduct knowledge translation workshops to share learnings with the broader cancer control community.

Shoulder to shoulder How can we prevent cancer and other chronic diseases?

Chronic diseases – for example, heart disease, diabetes and cancer – account for two thirds of all deaths in the country.¹ While much still needs to be researched and understood about why some people develop chronic diseases and others do not, a great deal is known: for example, it is widely recognized that obesity, smoking, lack of physical activity and poor eating habits play a role in the development of chronic disease.

Across the country, organizations and agencies are implementing programs to promote healthier living and create healthier communities. Recognizing these common goals, the Partnership is bringing many disease specific groups together in a new approach to prevention. The acceleration of change – and learning from its efforts for constant improvement – is key to the Partnership's philosophy.

Called Coalitions Linking Action and Science for Prevention, or CLASP, the initiative will broaden and deepen the impact of existing disease prevention efforts by harnessing their collective efforts across the country. Uniting more than 30 organizations and agencies from every province and territory as partners in seven disease prevention coalitions, CLASP cuts across more than geographic lines: each coalition brings together leaders in research, policy and health promotion practice, with the aim of putting scientific evidence for prevention initiatives into action.

"CLASP shares knowledge across research, practice and policy specialties, disease groups, and jurisdictions, adding value so the whole is greater than the sum of its parts," says Dr. Jon Kerner, the Partnership's Senior Scientific Advisor and Chair of the Primary Prevention Advisory Group. "These collaborations will lead to tangible, meaningful

outcomes – for example, culturally appropriate disease prevention programs and a better understanding of the relationship between our health and our physical living and working environments – that in turn translate into program and policy change."

"We are leading a coalition that brings together organizations in three provinces and one territory to reduce childhood obesity," says Craig Larsen, Executive Director of the Chronic Disease Prevention Alliance of Canada. "As part of this coalition, we and our partners will be able to move farther and faster than we would have acting individually."

While the coalitions will incorporate scientific, practice and policy expertise and evidence into their planning, they will also collect important information about the effectiveness of the innovations in real Canadian contexts, and across different jurisdictions. As they implement state of the art health promotion concepts, they will add to the knowledge base for future work.

"The seven coalitions brought together and funded through CLASP have the potential to significantly improve the health and wellness of Canadians," says Sally Brown, CEO of the Heart and Stroke Foundation which, in addition to co funding two of the seven coalitions, is also a member of a separate coalition supported by CLASP. "We are proud to be part of a new and integrated approach that recognizes and celebrates that we can achieve more for chronic diseases that affect millions of Canadians by working together."

¹ Chronic Disease Prevention Alliance of Canada website, http://www.cdpac.ca/content.php?doc_1, accessed April 1, 2010



"Healthy eating and lifestyle options need to be easy for people to fit into their daily routines so they can live long and healthy lives. That's what I want for my four daughters."

SANDRA // CANCER SURVIVOR

Coalitions Linking Action and Science for Prevention

Reflects progress
at April 2010

Well-coordinated, more efficient approaches to cancer and chronic disease prevention that complement federal, provincial and territorial healthy living strategies. These lead to fewer cancers and significantly reduce burden from cancer and other chronic diseases (beyond 2012)

Increases in adoption of evidence-based public health and clinical prevention practices and policies (2011–2012)

CLASP-initiated coalitions help consolidate new and existing knowledge into more effective ways of implementing chronic disease prevention programs (2010–2012)

CLASP projects benefit from innovative Partnership-funded evaluation platform entitled CAPTURE (2010–2012)

Funded CLASPs share lessons and evaluate work through regular knowledge exchange opportunities (2009–2012)

We are here

- All CLASPs in early stages of implementation
 - Following adjudication, the Partnership and its partners fund seven initiatives
- CLASP brings together almost 300 researchers, practitioners and policy experts from across Canada to identify strategic partnership opportunities. More than 40 proposals accepted for peer review (2009)
- Disease-specific efforts lack synergies and shared learnings



Healthy living and healthful environments reduce the risk not only of cancers but of other chronic illnesses such as diabetes, lung disease and heart disease. Working shoulder to shoulder with other disease-specific groups, the Partnership's Coalitions Linking Action and Science for Prevention (CLASP) initiative is developing new ways to integrate prevention strategies targeting factors that affect the overall health of Canadians, including body weight, tobacco use and environmental exposure to toxic substances. Preventing chronic diseases, including cancer, benefits everyone – especially vulnerable populations that are hardest hit by these health challenges.

Together with its funding partners, the Public Health Agency of Canada and the Heart and Stroke Foundation, the Partnership is funding seven CLASP projects as well as providing ongoing ways to share knowledge, promote best practices and advance more effective prevention coalitions. Of the \$15.5 million invested in CLASP, the Partnership is funding \$12.5 million.

Partners

- **National:** Chronic Disease Prevention Alliance of Canada, Federation of Saskatchewan Indian Nations, Green Communities Canada, Heart and Stroke Foundation, Ontario Healthy Communities Coalition, Propel Centre for Population Health Impact, University of Toronto Department of Family Medicine
- **Provinces and territories:** The seven funded CLASP organizations and agency partners include representatives from every province and territory

Benefits

- **Health system impact:** Integrated approaches to prevention and screening can reduce the incidence of cancers and other diseases. Boosting early detection helps identify diseases when they can be more easily cured
- **Impact for all chronic diseases:** Learnings are shared across cancer and other chronic diseases, notably heart disease and stroke, diabetes and lung disease
- **Human impact:** Positive changes in risk-associated behaviours, such as reducing tobacco use, improving nutrition, increasing physical activity and improving sun safety; reductions in environmental exposure; improvements in built environments



Funded CLASPs

The BETTER Project

Goals: Increase prevention and screening for heart disease, diabetes and cancer in primary-care physicians' offices in Alberta and Ontario. Electronic medical records will help doctors identify patients who could benefit from screening, prescribe lifestyle changes, track results and follow up regularly.

Cancer and Chronic Disease Curriculum for Saskatchewan and Manitoba First Nations Communities

Goals: Enhance health programming to improve cancer and chronic disease prevention; monitor and reduce the growing burden of these diseases in First Nations populations.

Children's Mobility, Health and Happiness: A Canadian School Travel Planning Model

Goals: Promote healthy lifestyles by targeting the use of active transportation to get to and from school; encourage supporting policies and practices. Projects are underway in Ontario, British Columbia, Alberta, Nova Scotia, Manitoba, Saskatchewan and Yukon and will be disseminated to all provinces and territories.

Collaborative Action on Childhood Obesity

Goals: Reverse the escalating trend in childhood obesity by decreasing unhealthy food choices in schools and improving availability of healthy alternatives. This project is focused on Northern and remote regions with initiatives in British Columbia, Northwest Territories, Ontario, Quebec and First Nations communities.

Healthy Communities, Healthy Nation

Goals: Expand and evaluate the effectiveness of the Healthy Community approach in British Columbia, Ontario, Quebec and New Brunswick. The Healthy Community movement, a dynamic force in many places across Canada, brings together groups from diverse sectors to plan and implement strategies that enhance community well-being and address complex community issues.

Promoting Health and Chronic Disease Prevention by Changing the Built Environment

Goals: Examine the impact of neighbourhood design and community planning on health and chronic disease, working with planners, public health officials, developers, policy-makers and the public through partnerships in British Columbia, Alberta, Manitoba, New Brunswick, Newfoundland and Labrador, and Prince Edward Island.

Youth Excel

Goals: To improve the health of Canada's youth by building knowledge exchange capacity within provinces and territories and creating collaboration opportunities among researchers, policy-makers, practitioners and communities so they can assess and guide policies and programs focused on physical activity, tobacco use and healthy eating. Partner organizations from British Columbia, Alberta, Manitoba, Ontario, New Brunswick, Newfoundland and Labrador, and Prince Edward Island are participating.

Casting a wider knowledge net

What are the benefits of sharing what we know?

Every day, researchers, clinicians, policy makers and others generate new information and knowledge that is vital to improving cancer control across Canada. Ensuring that this information reaches the right people in a useful and timely way, in a country as vast and diverse as Canada, is central to the Partnership's knowledge management mandate.

Several Partnership initiatives are helping to widen the knowledge net so that professionals working in Canada's federated health care system can make the best and most timely use of current and emerging information in order to improve cancer outcomes. These initiatives include the creation of a national searchable repository of cancer trials currently recruiting Canadian participants; helping broaden awareness of palliative and end of life care resources; and building publicly available databases of prevention policies and evidence based guidelines.

All of these important information sources and resources are housed together in the online cancer control hub – www.cancerview.ca. The Partnership developed this portal to make it easier for Canadians working in cancer control, and for those affected by cancer, to access the best information, services and resources.

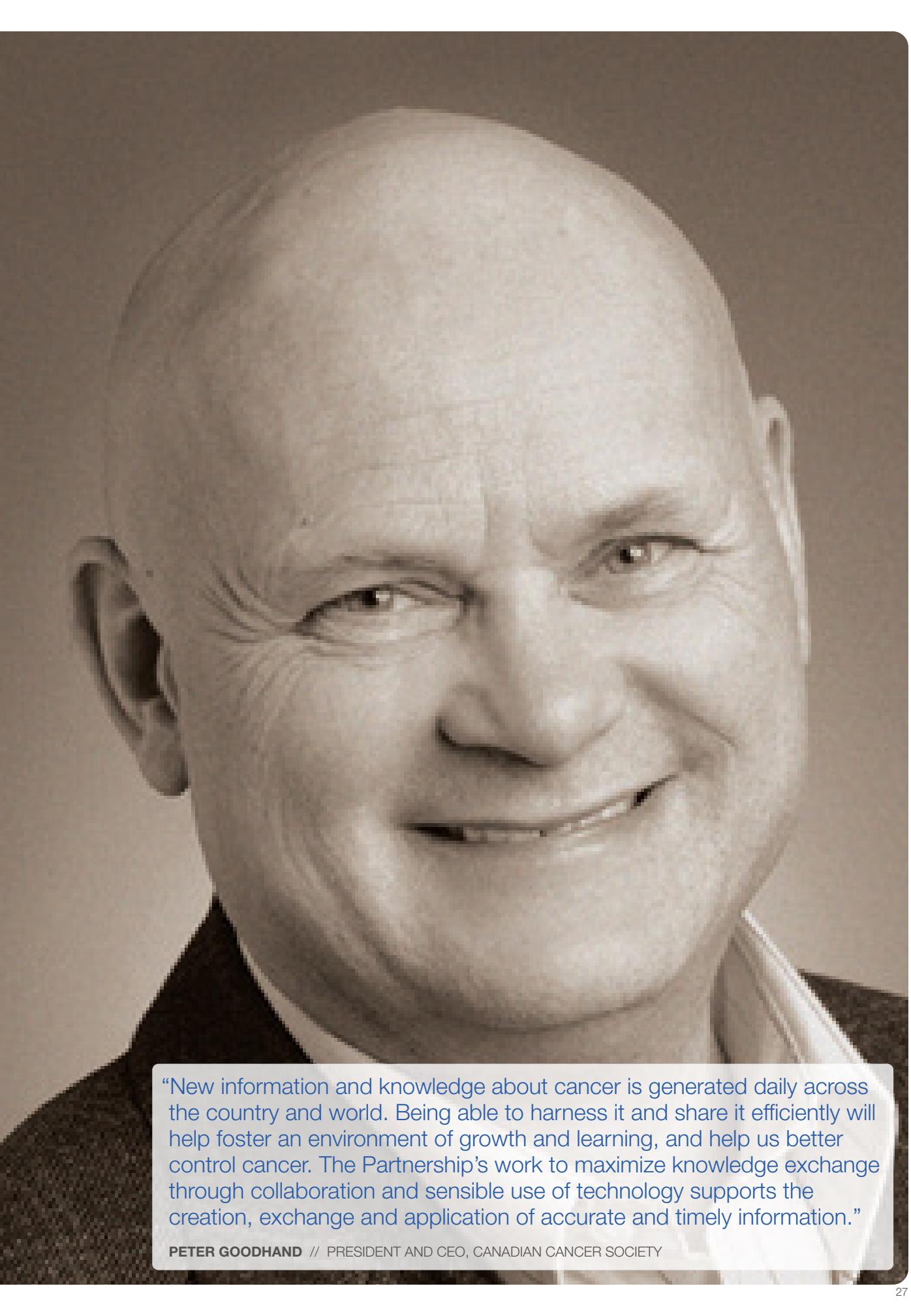
"In a country as diverse as Canada, working together and having equal access across the country to the newest information about the best options for cancer treatment is challenging but necessary," says Dr. George Browman, Chair of the Partnership's Cancer Guidelines Advisory Group. "For example, by creating a searchable online repository of cancer guidelines on www.cancerview.ca, the Partnership is supporting doctors, nurses and other health professionals,

cancer patients, researchers and policy makers to access, reference and use the best available knowledge for their day to day decisions. This will contribute to the best possible outcomes for Canadians, regardless of where they live."

A pillar of the Partnership's mandate is identifying the gems from one part of the country and being a catalyst to disseminate innovations nationally. One such example is Canadian Virtual Hospice (www.virtualhospice.ca), which is funded in part by the Canadian Partnership Against Cancer and is a featured service of www.cancerview.ca.

"The Canadian Virtual Hospice is grateful for the continuing support of the Canadian Partnership Against Cancer," says Dr. Harvey Max Chochinov, Chair, Canadian Virtual Hospice and Canada Research Chair in Palliative Care. "Their contribution allows us to provide personalized, evidence based information and support to Canadians about palliative and end of life care, loss and grief."

In addition to linking Canadians working in or affected by cancer with valuable services and resources such as the Virtual Hospice, the Cancer View Canada online community serves as a collaborative hub. In a country the size of Canada with a relatively small population that is widely dispersed, opportunities for online collaboration and information exchange are central to the ongoing development and nurturing of new knowledge.



“New information and knowledge about cancer is generated daily across the country and world. Being able to harness it and share it efficiently will help foster an environment of growth and learning, and help us better control cancer. The Partnership’s work to maximize knowledge exchange through collaboration and sensible use of technology supports the creation, exchange and application of accurate and timely information.”

PETER GOODHAND // PRESIDENT AND CEO, CANADIAN CANCER SOCIETY

Cancer View Canada

Reflects progress
at April 2010

- Reducing duplication of effort across jurisdictions by sharing innovation and best practice solutions to advance cancer control
- Greater collaboration will accelerate use of existing cancer control knowledge, supporting a more efficient and equitable system across the country
- Improved access to information to support decision-making, planning and quality improvement

Expand content and populate with knowledge as it emerges

We are here

Launch of www.cancerview.ca, Partnership's web portal, linking users to cancer services, information and resources across Canada (2009)

Creation of common knowledge management infrastructure for cancer control in Canada (2008–2009)

Partnership brings together key organizations, individuals and technologies to maximize value of constantly evolving information, through establishment of collaboration networks

Vital knowledge about cancer control generated daily throughout Canada. No central repository where "best available knowledge" can be vetted and shared



Within its knowledge management strategy, the Partnership provides access to new and existing information resources, translates research insights into practical solutions and develops versatile decision-support tools. It also helps foster the knowledge-sharing culture required to support all of these activities going forward. A key focus for the Partnership's efforts has been the creation of a unique online portal, Cancer View Canada (www.cancerview.ca).

Launched in July 2009, Cancer View Canada is a hub of valuable information and services dedicated to cancer control. Designed for professionals working in the health system and for those who treat and support people with cancer, the site also provides resources to individuals and families affected by the disease. Online content, including that developed by the Partnership's partner organizations, covers all areas within the Partnership's cancer control mandate, from prevention to surveillance to survivorship.

Showcasing content from more than 20 partners and featuring eight searchable knowledge databases, Cancer View Canada offers high-quality Canadian cancer control information in a single online destination – bringing sense and order to the vast amount of information available. To date, 60 stakeholder groups have started developing password-protected virtual communities on topics ranging from prevention to end-of-life care, and from basic science to service delivery. This online collaboration will help to promote the timely exchange of information among professionals in different parts of the country.



In addition to these important collaborative spaces, other services and resources available on Cancer View Canada include the following:

- Canadian Cancer Trials is a searchable directory where patients and health-care professionals can find out about trials currently recruiting patients across Canada.
- Standards and Guidelines Evidence (SAGE), a searchable repository with over 550 clinical practice guidelines, helps guide the delivery of high-quality patient care by bringing current evidence to the point of care, where it counts the most.
- Health Human Resources Service Delivery Model Database, a searchable database of approximately 100 innovative and leading Canadian and international models of service delivery, supports sharing the knowledge and experience of health-care professionals in the structure, function and inter-relationships of providing cancer care for patients.
- Canadian Virtual Hospice, an online resource that connects the public and health-care providers to a team of palliative care and end-of-life experts, offers over 150 end-of-life care clinical tools plus evidence-based information.
- Cancer Control P.L.A.N.E.T. Canada provides data and resources for cancer control planning and research.
- The Prevention Policies Directory is a searchable inventory of cancer and chronic disease prevention policies and legislation.
- “Colonversation” is the first pan-Canadian site dedicated to colorectal cancer screening information and a gallery of international public service campaigns.
- The Community Services Locator, in collaboration with the Canadian Cancer Society, connects Canadians with important services offered in the community.

In addition, the Pan-Canadian Oncology Drug Review (pCODR) collaboration will use the Cancer View Canada platform to create a public website to post information about the review of cancer drugs and a collaborative space for clinicians and experts to share evidence and conduct pharmacoeconomic reviews more efficiently.

Cancer View Canada will continue to grow to offer an ever-expanding view of cancer control in Canada.

Partners

Provincial and territorial cancer agencies and ministries

- Alberta Health Services
- BC Cancer Agency
- Cancer Care: A Program of Eastern Health
- CancerCare Manitoba
- Cancer Care Nova Scotia
- Cancer Care Ontario
- New Brunswick Department of Health
- Prince Edward Island Cancer Treatment Centre
- Quebec Ministry of Health and Social Services
- Saskatchewan Cancer Agency

Federal and national health and cancer control organizations

- Canada Health Infoway
- Canadian Agency for Drugs and Technologies in Health
- Canadian Association of Provincial Cancer Agencies
- Canadian Cancer Society
- Canadian Institutes of Health Research
- Canadian Virtual Hospice
- Health Canada
- Public Health Agency of Canada
- Statistics Canada
- Kidney Cancer Canada
- Canadian Bladder Cancer Network
- Thyroid Cancer Canada
- Canadian Liver Foundation
- Lymphoma Foundation Canada
- Lung Cancer Canada

International partners

- International Union Against Cancer (UICC)
- Cure4Kids

Thinking big: Citizen #1

Why do some people get cancer while others do not?

Why do some people get cancer while others do not? Why do some develop heart disease or diabetes at early ages? To help answer these complicated questions, the Canadian Partnership for Tomorrow Project – the largest study of its kind ever undertaken in Canada – is enrolling 300,000 Canadians, who agree to be tracked during their adult lives. Researchers will use the data collected from this broad range of Canadians to help explore how genetics, environment, lifestyle and behaviour interact and contribute to the development of cancer and other chronic diseases.

“Cancer is really as many as 200 different diseases, so understanding how our environment, genetics and behaviour make us prone to – or protect us from – cancer is tricky. With 300,000 participants, the Canadian Partnership for Tomorrow Project will be big enough to help us tease out many elements of both cancer risk and protection,” says Dr. John Potter, Chair of the Governance Committee for the Canadian Partnership for Tomorrow Project and Senior Advisor at Fred Hutchinson Cancer Research Center in Seattle, Washington; Nelson, New Zealand.

Study data will provide both short-term and long-term benefits. “In the short term, researchers will be able to gather insight into how Canadians are responding to public health and prevention programs, and in the longer term, look for patterns

among people who develop cancer or other diseases, and test theories about the risk of cancer and other chronic diseases,” says Dr. Elizabeth Eisenhauer, Chair of the Partnership’s Research Advisory Group and Co-chair of the Canadian Cancer Research Alliance, a group of 23 of Canada’s major national cancer research funders that helped to identify the need for such a large-scale study.

“The Canadian Partnership for Tomorrow Project is the gold standard for studying cancer in the Canadian population. By using modern data collection and exposure measurements – and focusing on environmental, lifestyle and genetic risk factors – this study will make a major contribution to what we know about cancer and other chronic diseases, and will provide information about how to prevent these diseases,” says Dr. Robert Phillips, Interim Executive Director of the Canadian Partnership for Tomorrow Project and recently retired Deputy Director, Ontario Institute for Cancer Research. “This is an incredibly exciting and important contribution to Canadian and global cancer research.”



"I believe that one person's contribution matters, and 300,000 of us can make a powerful difference. That's why I was one of the first people to sign on to the Partnership for Tomorrow study in Alberta. I believe this kind of research – made in Canada for Canadians – is the best way to do something meaningful for future generations."

MARY O'NEILL // STUDY PARTICIPANT

Canadian Partnership for Tomorrow Project

Reflects progress
at April 2010

Capacity to identify patterns among people who develop cancer and other chronic disease and to test theories about risk

Insight into how Canadians are responding to public health and prevention programs

- Recruitment set to complete in 2012, with ongoing data gathering for study duration
- Currently recruiting 1,000 Canadians per week; many more needed

We are here

Construct regional databases and launch in three new regions

Harmonization of common research elements, such as protocols, sample collection methods, consent forms, in five regions

Teams and infrastructure built within regional cohorts

Cohort team recruits renowned world leader Dr. John Potter to convene Principal Investigator group and advise on study design

Canadian Partnership for Tomorrow Project builds on regional projects in Alberta and Quebec

Alliance of 23 major funders of cancer research in Canada brought together to identify a legacy project that would benefit all Canadians and would be possible only through collaboration



Long-term impact

By following 300,000 Canadians for their adult lives, the Canadian Partnership for Tomorrow Project hopes to answer some of cancer's most challenging questions.

At enrolment, study participants provide information about their health, lifestyle and environment; biological samples such as urine and blood; and physical measurements such as weight and height. Participants are then followed for decades, building layers of information that will create a rich database. This is much more than a single study: it is the construction of a "population laboratory" that will yield results for decades to come.

The benefits of this massive study are far reaching. Population health research is often difficult because collection of the masses of needed data is complex, expensive and time-consuming – more time than many students are able to devote to graduate training, or young faculty members to launching their careers. With this "laboratory," researchers will have access to data and can propose analyses that will identify patterns and information that will potentially explain some of the causes of cancer and other chronic diseases such as diabetes and heart and lung disease.

Because the study occurs across many communities in Canada, researchers can also study the "natural experiments" that occur when some jurisdictions enact health policies that others do not immediately adopt. By comparing the behaviour of people across the country, researchers can study the impact of these natural experiments, and public health practitioners and decision-makers will be able to use these results to help inform prevention strategies.

This living population laboratory is being built on the foundation of two existing studies – the Tomorrow Project with Alberta Health Services and Université de Montréal's CARTaGENE. In addition to these two organizations, the pan-Canadian effort is being driven forward by the BC Cancer Agency, Cancer Care Ontario with the Ontario Institute for Cancer Research, and Cancer Care Nova Scotia with Dalhousie University collaborating on work in the Atlantic Provinces.



Recruitment is now underway, with approximately 1,000 people signing up per week. Many more are needed.

How many...

- *Provinces and territories:* British Columbia, Alberta, Ontario, Quebec and the Atlantic provinces are currently participating
- *Participants:* The largest study of its kind ever undertaken in Canada, and one of the most far-reaching population studies in the world to date
- *Investment:* \$42 million by the Partnership, additional \$57.1 million by other partners to leverage other investment

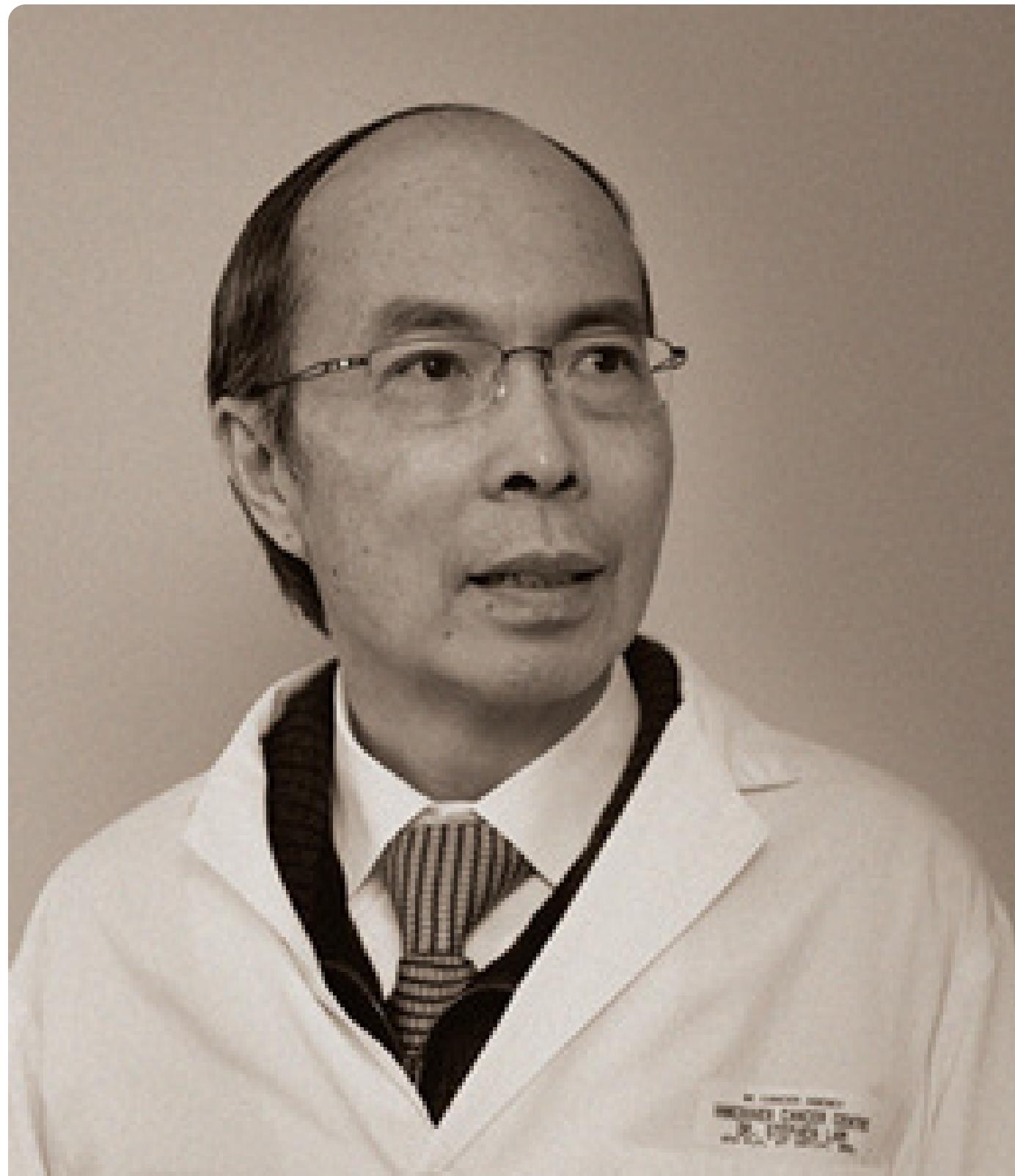
Benefits

- *Impact for researchers:* A rich, ever-expanding database provides an unprecedented platform to look for patterns in cancer, diabetes, heart disease, lung disease and other chronic illnesses, and then launch further investigations
- *Policy impact:* The study will produce an unprecedented comprehensive Canadian database that will provide policy-makers with information on how to target prevention efforts for cancer and other chronic diseases
- *Human impact:* Will help answer fundamental questions about the causes of cancer and chronic disease for future generations

Canadian Cancer Research Alliance

The Canadian Cancer Research Alliance (CCRA), which also functions as the Partnership's Research Advisory Group, brings together most of Canada's major national cancer research funders. At this time, 23 major organizations are collaborating to coordinate their efforts on large research initiatives or other collaborative activities. Two large-scale initiatives have already begun – the Canadian Partnership for Tomorrow Project, a long-term population study (see page 32), and the Pan-Canadian Biomarker Research Initiative (see page 35).

In addition, the CCRA conducts a major annual survey of cancer research across Canada and publishes a report on it. The survey collects data not available from other sources and analyzes funding provided by governments and volunteer groups for cancer research in Canada to help identify gaps. The CCRA is also leading a Pan-Canadian Cancer Research Strategy, which provides a framework to guide cancer research investment in Canada, highlight gaps and opportunities for new collaborations, and provide a vision for Canadian cancer research achievements over the next five years. Cancer agencies are already reporting that the research strategy is helping to build their own priorities.



"The Early Detection Study in lung cancer is a practical approach that in the long term could make a real difference in how we screen for lung cancer. In the short term, we are finding lung cancers that may have remained undiagnosed until later, and getting those people into treatment."

DR. STEPHEN LAM // CO-LEAD INVESTIGATOR, EARLY LUNG CANCER DETECTION STUDY,
TERRY FOX RESEARCH INSTITUTE // PROFESSOR OF MEDICINE, UNIVERSITY OF BRITISH COLUMBIA //
CHAIR, PROVINCIAL LUNG TUMOUR GROUP, BC CANCER AGENCY

Translating and applying new information Who's making sense of new evidence?

Every day, we learn more about cancer. Newspaper headlines and websites regularly carry stories about cancer studies and new discoveries. What is happening to this information? How are new discoveries contributing to what we know? How does new information get incorporated into practice?

The Partnership is helping to make sense of emerging evidence in a number of different ways. One such approach is by helping translate research findings into practical applications through collaborating with Terry Fox Research Institute on their Pan Canadian Cancer Biomarker Initiative.

This initiative includes several projects to advance research in cancer screening and treatment methods using biomarkers – biochemical features, typically measured in the blood, that indicate the progress of disease or effects of therapy. The first of these projects is a national study investigating how emerging technologies can improve early detection of lung cancer.

The study builds on current large international trials investigating whether spiral computed tomography (CT) scanning offers the most effective means of screening individuals who are at high risk for lung cancer. This Canadian study also screens high risk individuals using other methods, including a breathing test, questionnaires and a blood biomarker test. The research aims to identify who could most benefit from spiral CT screening and to examine how the combination of tests could maximize the impact of lung cancer screening as quickly as possible in Canada.

"In addition to this unique integrated screening approach, the study offers further beneficial and practical outcomes. If large international CT

scanning trials show screening can reduce lung cancer mortality, our Canadian study would result in both a system and health professionals in place across Canada to implement lung cancer screening," says Co lead Investigator Dr. Stephen Lam.

Another Partnership program helping to make sense of emerging evidence uses expert panels, which gather together to sift through information and help to increase shared understanding at a pan Canadian level.

"The Partnership has adopted a 'think tank' approach to emerging evidence that leverages the collective wisdom of experts across the country. This helps to synthesize issues and evaluate new information on outcomes of major screening trials," says Dr. Verna Mai, Chair of the Partnership's Screening Advisory Group and Provincial Lead, Public Health, Cancer Care Ontario. "The aim is to provide timely, synthesized information to cancer agencies and provincial screening program planners at or shortly after published results, to support their need to develop a response to the new findings."

Dr. Tom Pickles, Chair of the Partnership's first expert panel and radiation oncologist with the BC Cancer Agency, comments, "Prior to this coordinated approach, a lot of energy was expended duplicating effort, with substantial variability in how health care professionals and others were adopting new evidence and innovation. These ad hoc expert panels mobilize and produce useful briefing documents on key aspects of the evidence, facilitating increased understanding of screening evidence across Canada. It is efficient and effective."

Early Lung Cancer Detection Study

Reflects progress
at April 2010

- Improved lung cancer detection and survival rates
- Study will act as basis for accessible early detection program – best hope for improving survival rates
- Study participants with lung cancer being identified and moved into treatment
- Drive recruitment efforts
- Direct, indirect cost of diagnosing and treating lung cancer being recorded prospectively for health economics analysis

We are here

- 1,936 enrolled, with 26 lung cancers identified and 150 suspicious nodules being tracked (February 2010)
- Early Lung Cancer Detection Study launched in seven cities (2008)

Identified potential tumour sites for targeted research

Partnership joins forces with Terry Fox Research Institute to co-fund translational cancer biomarker research projects

- Long-term impact
- Mid-term impact
- Early impact
- Build
- Implement
- Strategize
- Convene

Lung cancer is Canada's leading cause of cancer death, with over 20,000 deaths every year. It is responsible for 1.2 million deaths annually worldwide. That is more than colorectal, breast and prostate cancers combined. Unfortunately, it has proven difficult to treat and still has a five-year survival rate of only 16% in Canada.

The Early Lung Cancer Detection Study is evaluating the effectiveness of identifying high-risk individuals using questionnaires, a spirometry breathing test and a blood biomarker test. By using these tests to triage high-risk individuals, the hope is to help identify those who would be recommended for an in-depth examination using the more sensitive, and costly, spiral CT, if current international studies show it to be effective in reducing mortality. Spiral CT rotates continuously around the body to capture cross-sectional three-dimensional pictures and is able to detect small abnormalities better than a conventional CT scan. The Canadian study is also examining whether the addition of fluorescent bronchoscopy to spiral CT tests will add to the utility of CT scans in screening.

Currently into the second year of recruitment, seven centres across Canada are actively recruiting participants, with a recruitment goal of 2,500. As of February 2010, 1,936 people have been identified as eligible and 1,455 have completed their baseline visit. At this time, the study has detected 26 cancers and 150 participants showed suspicious nodules in the baseline CT scan.

This important made-in-Canada lung cancer screening study builds on large international trials that are currently investigating whether spiral CT scanning offers an effective means of screening individuals who are at high risk for lung cancer. If those studies show spiral CT to be valuable in reducing mortality, the Canadian study will provide evidence to help Canada decide how to proceed with an early detection and treatment program for lung cancer as quickly as possible.

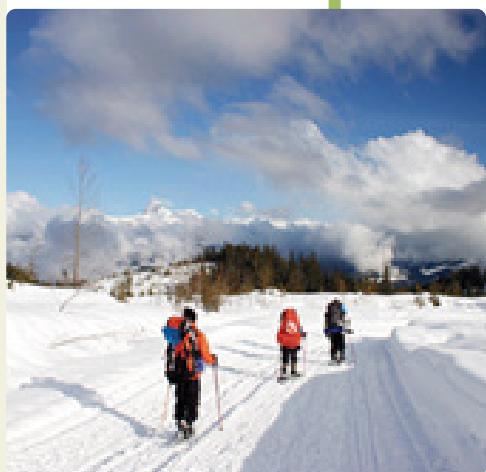
Co-funded with the Terry Fox Research Institute, the Early Lung Cancer Detection Study is the first of a series of translational research projects. Translational research is defined as research that puts discoveries into action, and this study is well designed to realize this goal.

How many...

- Participants: 2,500 current and former smokers
- Cities: Study sites include Vancouver, Calgary, Toronto, Hamilton, Ottawa, Quebec City and Halifax
- Investment: \$4 million over five years

Benefits

- *Health system impact:* Findings will support the development of a Canadian lung cancer detection program and infrastructure
- *Human impact:* Finding lung cancer earlier should improve survival rates from current 16%



Anticipatory Science

Regular screening for cancer can help to detect it at the earliest stage and in some cases can even prevent it. When new evidence or information becomes available about the effectiveness of screening, it is met with immediate interest from specialty groups, health ministries and media. To complicate matters, emerging evidence can conflict with existing evidence.

This creates an urgent need, in all provinces and territories, for review of new evidence to respond in a timely, credible way to media and briefing requests from ministries of health.

To promote a timely, streamlined, pan-Canadian synopsis and distribution of new information on specific screening tests, the Canadian Partnership Against Cancer gathers together pan-Canadian expert panels. These ad hoc groups review existing trial-related publications and then develop a common understanding of key aspects of the potential screening benefits and harms based on the new available data. This reduces duplication of effort and also supports consistency of approach across the country.

The first such “think tank” panel was convened to discuss prostate-specific antigen (PSA) testing for prostate cancer. Panel members provided a synthesis of the main issues, incorporating responses to the results of ongoing European and North American screening trials. They concluded that the evidence indicated that expansion of PSA screening practices beyond the current ad hoc situation was not justified in light of the available evidence. This summary was provided to provincial and territorial cancer agencies and ministries of health in advance of publication, supporting consistency in information across the country.

A second panel convened 11 colorectal and screening experts from across the country to gain a shared understanding of the literature on the use of flexible sigmoidoscopy as an initial screening test for colorectal cancer. A separate expert panel is gathering to address use of the CA-125 blood test and trans-vaginal ultrasound to screen for ovarian cancer.



Impact that matters

How do we measure success today and make better choices tomorrow?

Canada has a strong cancer registry system that collects information about cancer incidence, stage and location at diagnosis, and about treatment – as well as risk factor data. However, until now there was no comprehensive, pan Canadian approach to reporting on needs and performance across the system, nor a way of capturing existing information from different sources to model the future impact of investments made today.

In response to this challenge, the Partnership is undertaking two substantial health care decision making initiatives that tackle far reaching questions: How do we know that we're improving care for cancer patients and making the system better? How do we invest our health care dollars to realize the best value in the environment of an aging population and other increasing demands on the health care system?

The first of the Partnership led initiatives is the System Performance Initiative, developed to facilitate the exchange of information through reporting on cancer control indicators in Canada across provincial jurisdictions and throughout the cancer control continuum. The second is known as the Cancer Risk Management Platform. Drawing on a broad range of the latest evidence, ranging from cancer incidence and death rates to the impact of risk factors and effectiveness of prevention and screening programs, this computer based model projects the impact of targeted interventions.

"System improvement is a complex and long term undertaking, but in order for it to be successful, strong data collection and reporting are fundamental. Canada is fortunate to have a clear

vision of desired results, where partner organizations – including provinces and territories – can learn from each other to improve cancer care across the board. Canada has a more complicated health care delivery system than many countries, and it is setting a good example that it can be done through collaborative effort," says Dr. David Currow, CEO of Cancer Australia.

Building on the fundamentals of good data and registries and building consensus on the benchmarks through which system evaluation happens have been key areas of focus for the Partnership, working with provinces and territories.

"The Cancer Risk Management Platform gives provincial and territorial decision makers the ability to model the impact of different cancer control interventions and plan accordingly," says Arlene Ilgosh, President and CEO of the Winnipeg Regional Health Authority, and formerly Deputy Minister of Health and Healthy Living for Manitoba and a member of the Partnership's Board of Directors. "As a result, funders of the cancer system have more information to do their jobs."

Both the System Performance Initiative and the Cancer Risk Management Platform are good examples of the unique role of the Partnership: activating knowledge to make system wide improvements; accelerating the uptake of good, effective ideas; and empowering provinces and territories to make the best decisions possible for their citizens.



"Improving quality in the cancer system requires us to have good data and to be able to use the information more effectively. Thanks to the collective work of the provinces, we now have the first set of pan-Canadian indicators to drive performance from coast to coast. Additionally, we now have access to a modelling tool to evaluate the impact of interventions at the national level. Led by the Partnership, this work will help guide decision-making."

DR. CAROL SAWKA // VICE-PRESIDENT, CLINICAL PROGRAMS AND
QUALITY INITIATIVES, CANCER CARE ONTARIO

System Performance Initiative

Reflects progress
at April 2010

Ongoing review of cancer performance system; reduction in burden of cancer; outcomes improvement

Provincial agencies, cancer control partners can use pan-Canadian indicators to address system gaps

We are here

- Conduct first group review of new indicator data, prior to publication (March–May 2010)
- Refine existing indicators and develop new ones, especially in treatment (October 2009–March 2010)
- Issue call for data for new indicators (January–March 2010)
- First pan-Canadian system performance report published (October 2009)
- Gather and develop data
- Feedback from provinces and territories on reporting style, content
- Present indicators at series of regional workshops
- Craft final indicator reporting based on workshop feedback
- Identify additional indicators for following year's reporting (summer 2009)

Steering committee identifies 17 high-level, pan-Canadian indicators of status of cancer control in Canada (November 2008)

National conference identifies large group of indicators for consideration (2008)

Commission review of cancer system performance indicators (2004, with an update in 2007)

- No organized pan-Canadian approach to reporting on needs and performance across cancer control system (2002)
- Cancer Care Ontario begins publishing province-specific annual Cancer System Quality Index (2005)

Mid-term and long-term impact

Early impact

Adapt

Implement

Share

Build

Convene

Research

Prior state

Improving the cancer system for Canadians is at the heart of the Canadian Partnership Against Cancer's work. But unless it's clear how the cancer control system is working, it's difficult to know where to start or what to focus on.

The System Performance Initiative is a collaboration among provincial and territorial partners. It brings together existing cancer-related data from across the country, provided by a number of partners, and makes this data available to all cancer agencies and health ministries as a baseline for measuring progress. This information will help to shape the planning and delivery of the entire cancer control system, including prevention, screening, diagnosis, treatment, supportive care and survivorship.

While there are many ways in which the performance of the cancer system can be assessed, consultation at a pan-Canadian level identified an initial 17 indicators for the first-year report. These indicators cover the entire cancer control continuum from prevention and screening to survivorship and supportive care. As part of the Partnership's series of workshops reporting on the first-year data, consensus was reached on new indicators for collection and reporting in the 2010/11 fiscal year.

Partners

- *National:* Public Health Agency of Canada, Statistics Canada
- *Provinces and territories:* Cancer agencies or equivalents, provincial and territorial departments of health. Where possible, data from all 10 provinces and three territories are presented as part of this pan-Canadian initiative

Benefits

- *Provincial and territorial impact:* A springboard for meaningful, evidence-based actionable information to drive system change and priority-setting
- *Health system impact:* Performance indicators will inform where to focus cancer system change by identifying potential gaps, with the goal of reducing the burden of cancer and improving outcomes



Cancer Risk Management

Every day, health planners across the country face difficult decisions about how to invest scarce health-care dollars for cancer care and cancer prevention. The goal is always to ensure that each investment made – whether it is a prevention program, a certain type of screening test or a new treatment – delivers maximum benefit for Canadians by reducing the number of Canadians developing cancer, increasing survival rates and improving the patient experience.

For decision-makers, weighing the options can be very challenging. Investments in new cancer initiatives can take years to show results, so modelling and comparing impact over the long term helps to support decision-making.

The Partnership's Cancer Risk Management Platform, an innovative online tool, enables the exploration and assessment of the projected long-term benefits and impact of cancer investments. The sophisticated tools help planners compare, for example, whether a screening program would have greater long-term impact from an economic perspective than a prevention initiative.

One of the strengths of the platform is its flexibility; health system leaders and policy-makers can make adjustments to data assumptions to reflect considerations in their own jurisdictions, while benefiting from a consistent approach that will help inform decisions about cancer control investments.

Partners

- *Organizations and experts involved:* Canadian Institute for Health Information; Statistics Canada; cancer agencies; senior government policy decision-makers; senior leaders in cancer control, including health economists, statisticians and epidemiologists; international involvement from leading authorities
- *Provinces and territories:* The advisory and technical committees contributing to its development included representation from organizations in British Columbia, Alberta, Manitoba, Ontario and Quebec; future collaborations with provincial representatives will address policy-specific questions

Benefits

- *Provincial and territorial impact:* Health planners in each province and territory may use the tool to project the long-term benefits of allocating scarce health-care dollars in different ways within their jurisdiction
- *Health system impact:* Enables policy-makers to make informed decisions about their investments in cancer control
- *Cancer strategy impact:* The Partnership will use it as a strategic tool to prioritize initiatives and to measure the impact of internal investment at the Partnership level and in the country as a whole



Canada's team cancer

Working together with the hundreds of dedicated professionals working in cancer control and people affected by cancer, the Partnership is having an impact. As part of Canada's "team cancer," the Partnership carries out work guided by many collaborators:

Board of Directors

The Partnership's Board of Directors represents diverse perspectives from key stakeholder groups. Members (see facing page) include federal and provincial official appointees, regional appointees, policy experts and leaders in cancer control, as well as representatives from the Canadian Cancer Society, Aboriginal communities and cancer patients. Their insight, energy and leadership ensure that all Partnership initiatives deliver meaningful outcomes for all Canadians.

Advice and engagement

Because cancer control knowledge and expertise are widely dispersed across Canada's health-care system, the Partnership relies on input and advice from various individuals and organizations to ensure that its work builds on other initiatives across the country and addresses new breakthroughs and emerging issues. The Partnership taps into the knowledge within provincial cancer agencies and ministries of health, federal agencies, patient groups and national organizations in a range of ways.

For the first two years of the Partnership's mandate, an Advisory Council on Cancer Control acted as a resource to the organization as initiatives got underway. As work advanced and evolved, more than 40 groups, committees and networks guide and support the Partnership's priority areas through both formal networks that implement the work, and through additional expertise.

Each of the Partnership's strategic initiatives is driven by a leader in the cancer community, such as a clinician or researcher, generally employed by one of the Partnership's partner organizations. The Partnership's Advisory Groups, formerly called Action Groups, are aligned with priority areas of the national cancer strategy: prevention, screening, research, surveillance, the cancer journey, quality and standards, and cancer guidelines. Chaired by

recognized subject experts, the Advisory Groups typically include health practitioners and administrators, epidemiologists, researchers, patients and families. The strategy has become a reality thanks to the active participation of all these individuals across the country – nearly 400 people in total, representing more than 150 organizations.

Various working groups, advisory groups and steering committees, chaired by recognized cancer leaders, also provide guidance for specific Partnership initiatives. These groups include the Cancer Risk Management Advisory Committee, the National Colorectal Cancer Screening Network, the Quality Programs for Cancer Control Advisory Committee, the National Cancer Staging Advisory Committee and the Advisory Committee on First Nations, Inuit and Métis Cancer Control. The Partnership also convenes ad hoc groups to share insights on emerging evidence and to build consensus.

Canada's Aboriginal peoples

The Partnership devotes special attention to cancer control among Canada's Aboriginal Peoples. Working with national Aboriginal organizations and the relevant branches of cancer and public health agencies, the Partnership ensures that its program planning and delivery take into account the unique cultural perspectives and social challenges of First Nations, Inuit and Métis communities. The Partnership collaborates closely with stakeholders from these communities to create initiatives such as the unique Aboriginal section of the Cancer View Canada web portal.

The patient voice

Ensuring that patients, survivors and families have a voice in Canada's national cancer strategy is a core operating principle. Members of the Canadian Cancer Action Network are engaged in initiatives such as establishing research priorities and informing the work of the Partnership's National Survivorship Working Group. The Partnership continues to work closely with patient-related organizations through its Advisory Groups and by sharing the latest developments in cancer control through numerous channels.

Board of Directors

at April 2010

Simon Sutcliffe, MD

Chair, Canadian Partnership Against Cancer

René Gallant

Vice-chair, Canadian Partnership Against Cancer;
Past National President, Canadian Cancer Society

Mel Cappe

President and Chief Executive Officer,
Institute for Research on Public Policy

Chris Clark

Chief Executive Officer and Canadian Senior Partner,
PricewaterhouseCoopers LLP

Catherine L. Cook, MD

Executive Director, Aboriginal Health Programs,
Winnipeg Regional Health Authority

Bruce Cooper

Assistant Deputy Minister, Policy and Planning,
Newfoundland and Labrador Department of Health
and Community Services

Peter Crossgrove

Past Chair, Canadian Association of Provincial
Cancer Agencies

Louis Dionne, MD

Cancer surgeon; palliative care pioneer;
Founder, Maison Michel-Sarrazin

Peter Goodhand

President and Chief Executive Officer,
Canadian Cancer Society

Christine Power

President and Chief Executive Officer,
Capital District Health Authority, Nova Scotia

Jay Ramotar

Deputy Minister, Alberta Health and Wellness

Gary Semenchuk

Past Chair, Saskatchewan Cancer Agency

Marla Shapiro, MD

Medical contributor, CTV's Canada AM;
medical consultant, CTV News

Terry Sullivan, PhD

President and Chief Executive Officer,
Cancer Care Ontario

Milton Sussman

Deputy Minister, Manitoba Ministry of Health
and Healthy Living

Laura M. Talbot

President and Senior Partner, TalbotAllan Consulting

Sally Thorne, PhD

Professor and Director, University of British Columbia
School of Nursing

Elisabeth Wagner

Executive Director, Corporate Policy and Research,
B.C. Ministry of Health Services

Elizabeth Whamond

Vice-chair, Canadian Cancer Action Network;
Chair, Cochrane Collaboration Consumer Network

Antoine Loutfi, MD (Observer)

Director of Cancer Control, Quebec Ministry of
Health and Social Services

*Directors who stepped down in the
2009/10 fiscal year:*

Jeffrey C. Lozon

Inaugural Chair,
Canadian Partnership Against Cancer;
President and Chief Executive Officer,
St. Michael's Hospital

Joy Maddigan

Assistant Deputy Minister, Newfoundland
and Labrador Department of Health and
Community Services

Paddy Meade

Executive Operating Officer, Continuum of
Care Division, Alberta Health Services

Linda Miller

Deputy Minister, Alberta Health and Wellness

Barbara Whylie, MB, BCh, BAO

President and Chief Executive Officer,
Canadian Cancer Society

Arlene Wilgosh

Deputy Minister, Manitoba Ministry of Health
and Healthy Living

Initiatives

Organizations worldwide share cancer control priorities: enhancing prevention, screening and early detection, person-centred care, development of cancer guidelines and standards, research, gathering and analyzing data related to cancer, and enabling quality across the cancer control system.

The Partnership has identified areas of focus across these priorities – these are areas where the Partnership knows it can work with partners to have an impact on the cancer control landscape. Some priorities address very specific areas of cancer control, such as population-based screening, while others target the broader cancer control domain. The following is a list of initiatives grouped by priority area as outlined in the cancer control strategy.

More information about these initiatives can be found at www.partnershipagainstcancer.ca.

Knowledge Management

- Cancer Risk Management
- Cancer View Canada, including
 - SAGE
 - Section for First Nations, Inuit and Métis communities
 - Canadian Cancer Trials

Primary Prevention

- Coalitions Linking Action & Science for Prevention (CLASP)
- Canadian Platform to Increase Usage of Real-World Evidence (CAPTURE)
- CAREX Canada
- Healthy Public Policy Knowledge Exchange

Research

- Canadian Partnership for Tomorrow Project
- Translational Cancer Research
- Pan-Canadian Cancer Research Strategy

Screening

- Colorectal Cancer Screening
- Cervical Cancer Control
- Anticipatory Science

Cancer Guidelines

- Synoptic Surgery Reporting
- CAN-ADAPTE (guideline adaptation)
- Capacity Enhancement Program

Surveillance

- National Staging Initiative
- Surveillance and Epidemiology Networks
- Cancer Control P.L.A.N.E.T. Canada

Health Human Resources

- HHR Service Delivery Models

Cancer Journey

- Survivorship
- Integrated Person-Centred Care

Standards and Quality Initiatives

System Performance Initiative



“Working together with the hundreds of dedicated professionals in cancer control and patients and survivors, we are making a difference. Canada’s national cancer strategy will take decades to fully achieve its goals. Having just completed three years of the initial mandate, the Partnership is demonstrating that by working together we can have an impact.”

DR. BRENT SCHACTER // PROFESSOR, DEPARTMENT OF INTERNAL MEDICINE, UNIVERSITY OF MANITOBA
DEPARTMENT OF MEDICAL ONCOLOGY AND HEMATOLOGY, CANCERCARE MANITOBA

“As the population ages, the number of Canadians with cancer is on the rise and more Canadians are surviving. To meet the increasing demands on the health system for treatment and supportive care, we need to identify and develop innovative ways to work efficiently and effectively. The work of the Partnership – from prevention to research to palliative care – is providing much-needed support to achieve this goal.”

DR. ANDREW PADMOS // CEO, ROYAL COLLEGE OF PHYSICIANS AND SURGEONS OF CANADA
CHAIR, HEALTH HUMAN RESOURCES ADVISORY GROUP, CANADIAN PARTNERSHIP AGAINST CANCER

“Drawing on the strengths and capabilities of a wide range of partners, the Partnership is facilitating collaborative, pan-Canadian initiatives that are supporting improvements in quality across the cancer system, as well as helping to inform cancer control strategies worldwide.”

DR. ANTHONY MILLER // ASSOCIATE DIRECTOR, RESEARCH, DALLA LANA SCHOOL OF PUBLIC HEALTH
CO CHAIR, CANCER RISK MANAGEMENT ADVISORY COMMITTEE

Working together
to answer Canada's
cancer questions



www.partnershipagainstcancer.ca