

Refreshing Canada's National Cancer Control Strategy



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Foreword

Since its launch in 2006, the *Canadian Strategy for Cancer Control* (the *Strategy*) has guided Canada's progress in cancer control. Today, there is strong evidence that the *Strategy* has resulted in concrete and significant action by partners across the country to improve cancer control. Cancer organizations, health professionals, researchers and countless others are adopting exciting innovations and emerging research to improve cancer prevention, detection and treatment, and cancer patients are helping to shape a more responsive health system that supports their needs.

However, one in two Canadians will develop cancer in their lifetime¹ and the cancer system^a faces new and pressing challenges in delivering cancer services to meet this growing need.

From summer 2018 to spring 2019, the Canadian Partnership Against Cancer (the Partnership) will facilitate a conversation among Canadians to refresh and modernize the *Strategy*. This is at the request of

the federal Minister of Health. These discussions will engage the broader cancer control community and other health sector partners. Patients and families with an experience of cancer, First Nations, Inuit and Métis and the general public will all be consulted.

The discussion paper that follows is intended to support individuals and organizations interested in contributing to the refresh of the *Strategy*. Developed with input from cancer control partners, experts and patients, it provides an overview of the *Strategy* from its development to today, as well as emerging challenges and opportunities. It also includes a series of questions that can be used to provide input. Please see the Partnership website (www.partnershipagainstcancer.ca) for more information on how to get involved.

Thank you to the nearly 200 contributors who provided invaluable insight and time to this paper and the work underway to refresh the *Canadian Strategy for Cancer Control*.

^a In Canada, health care is delivered by 14 different governments (13 provinces and territories and the federal government).

Executive Summary

The *Canadian Strategy for Cancer Control* was launched more than a decade ago to address the growing number of cancer cases and deaths in this country and improve the quality of life for all Canadians living with the disease. The *Strategy* set out three 30-year goals: that fewer Canadians develop cancer, fewer die from cancer and those affected by cancer have a better quality of life.

Since that time, there have been many exciting advances in cancer control in Canada. Girls and boys are now routinely vaccinated against HPV (human papillomavirus) to prevent cervical, throat and other cancers in adulthood.² Advances in targeted cancer genomics and immunotherapy are creating new treatment options that control and cure previously untreatable cancers. Cities and towns across the country have put in place policies to limit Canadians' exposure to the dangers of second-hand smoke.³ And more people with cancer are living longer and living well: survival rates for some cancers in Canada remain among the best in the world and have steadily improved over time.⁴

For more than 10 years, the *Strategy* has added to these achievements as it guides Canada's efforts in cancer control. With funding from the federal government, it has supported collective action by cancer control partners across the country with positive results.

However, the cancer system is facing new pressures and opportunities in its efforts to innovate, provide equitable care for all Canadians and remain sustainable into the future. At the request of the federal Minister of Health, the Canadian Partnership Against Cancer (the Partnership) is facilitating a conversation among Canadians to refresh and modernize the *Strategy*.

Strategy from 2007 to Today

Over the past decade, the *Strategy* has been a powerful tool for change and improvement,⁵ helping cancer organizations, health professionals, researchers and others work together in new ways to improve cancer control across the country. The work is complex and challenging, requiring partners to identify shared priorities and collective solutions to longstanding gaps and issues. High impact accomplishments include:

- Canada is now a world leader in measuring performance of its cancer systems and the experience of cancer patients. This is helping to identify gaps in quality that drive improvements.
- Colorectal cancer screening programs are now in place in most provinces and territories, helping to prevent colorectal cancer or catch it early when it is highly treatable.
- Canadian cancer researchers can lay claim to one of the world's largest population health research databases to help them discover why some people get cancer and others do not.
- Patients representing the diversity of Canada, including First Nations, Inuit and Métis, are participating at many important decision-making tables and changing how care is delivered.

Yet despite progress, the advances made over the last 10 years have not benefitted all Canadians equally. People who are poor or who live in remote areas are still more likely to die of cancer and other chronic diseases than other Canadians.⁶ First Nations, Inuit and Métis continue

to experience poorer outcomes and face inequities and barriers in accessing care.^{7, 8, 9, 10, 11} And some provinces and territories have much higher cancer rates and more deaths from cancer than others.¹²

Addressing New Challenges and Opportunities

Canada's cancer system also faces new challenges. The number of new cancer cases in Canada is expected to increase in the coming decade.¹ The growing numbers reflect our aging population: cancer is more common among people over the age of 50,¹³ and by 2036, seniors will make up an estimated 25 per cent of the population.¹⁴

Costs in cancer care are quickly rising.¹⁵ The most recent estimates of the annual direct costs of cancer to the Canadian health care system range from \$4 billion in 2008¹⁵ to \$7.5 billion in 2012.¹⁶ In the coming decade, advances in medicine and technology will affect every aspect of cancer prevention, early detection, diagnosis and treatment. While these innovations offer new hope to cancer patients, many new treatment options are expensive. Informed choices will be required in the future.

Care today also remains largely hospital-based, a costly model of care that drains limited health care resources.^{17, 18} The long-term sustainability of our system will depend on finding new evidence-based, cost-effective ways to deliver care that are designed with the help of patients. We must make better use of technology, embrace innovation and explore new models of care, including expanded roles and enhanced scopes of practice for nursing and allied health professionals.

At the same time, we need to better understand the experience of patients and address the barriers to care experienced by First Nations, Inuit and Métis, adolescents and young adults with cancer, people who identify as *LGBTQ2*^b, new immigrant populations and poorer Canadians.

Setting Priorities for the Next Decade

To address these and other emerging issues, Canada needs to refresh and modernize its national cancer strategy. The cancer control community will then tackle implementation of the *Strategy* in the years ahead – embracing new priorities and approaches, while letting go of others. Success will depend on the collaboration

of all members of the cancer control community, as well as partners from other parts of the health care system, social services, First Nations, Inuit and Métis leaders, patients and their communities.

The original *Strategy* was developed by the cancer community and launched in 2006 with the support of the Prime Minister and the federal Minister of Health. Its long-term goals and Canada-wide focus remain clear and relevant. Going forward, consideration must be given to which elements of the original *Strategy* should remain, and what new elements should be added or given priority.

A refreshed *Strategy* must concentrate on priority areas where a national focus will help Canada address the most urgent cancer control issues, including longer-term efforts such as cancer prevention. It must also take into account the federated nature of Canadian health care. Provincial and territorial governments manage most of cancer control within their own borders and budgets; they face genuine constraints and their priorities must shape the work ahead. A refreshed *Strategy* must continue to support, complement and build on their work.

This discussion paper was developed with input from cancer control partners, experts and the Partnership's patient advisors and is intended to support the Canada-wide consultation process toward a refreshed *Strategy*.

As the cancer community, patients and Canadians begin these conversations, a number of critical questions need to be considered:

- *What are the characteristics of a useful and effective strategy for the future?*
- *Where can a Canada-wide cancer control strategy have the greatest impact in the coming 10 to 20 years?*
- *What will it take to advance the goals of the Strategy within a federated health care system?*
- *How can the cancer control strategy contribute most effectively to the performance and sustainability of the Canadian health care system? How do we identify and tackle the most pressing priorities?*

To inform this work over the coming months, the Partnership will gather input using a mix of in-person and online approaches. The refreshed *Strategy* will be provided to the Minister and her provincial and territorial counterparts in May 2019.

^b LGBTQ2 refers to people who identify as lesbian, gay, bisexual, transgender, queer or two-spirited.

The Canadian Strategy for Cancer Control

Canada was one of the first countries in the world to adopt a comprehensive, national cancer control strategy. The *Canadian Strategy for Cancer Control* was launched more than a decade ago to address the growing number of cancer cases and deaths in this country and improve the quality of life for all Canadians living with the disease.

Research shows that regardless of the financial resources available, countries with a well-managed, evidence-based national cancer control strategy deliver better results and are able to adapt more quickly to changing pressures than those without.^{19, 20}

The World Health Organization (WHO) also recommends a national strategy as an effective way to address the burden of cancer.¹⁹ The approach has many advantages. Canada's strategy serves as an important guide and organizing framework to tackle difficult-to-solve challenges that require new solutions and address the needs and challenges of diverse populations spread across a large country. It also complements and supports cancer priorities of provincial and territorial cancer plans and the work of other organizations that advance cancer care and patient support services across the country, including national charities, patient groups and research organizations.

Of particular importance to a federated country like Canada, the *Strategy* allows individuals and organizations across provinces and territories to contribute their unique skills

and perspectives, and work together to identify and address the most pressing issues affecting cancer care effectively and efficiently.

The Early Days of Canada's Strategy

Canada's original *Strategy* was developed by over 700 Canadians — health professionals, researchers, academics, health system leaders and patient advocates. It was designed to support provincial and territorial health systems struggling to manage a complex disease with more than 200 cancer types, many risk factors and continually advancing diagnostic technologies and treatments.

At the time, provinces and territories were leading effective cancer control efforts, however there was no cross-Canada coordination of planning and care or a system-wide perspective on the many activities and programs across the country. This resulted in duplication of efforts and missed opportunities to benefit from economies of scale. Resources and services varied from place to place, leading to inequities. There was also no ability to measure or compare results across the country, or to learn which approaches worked best and could be scaled up for broader application.

The original *Strategy* set out three shared goals to be accomplished within 30 years: fewer Canadians develop cancer, fewer die from cancer, and those affected by

cancer have a better quality of life. All aspects of cancer control were included: prevention, screening, diagnosis, treatment, survivorship, palliative and end-of-life care, and the use of data and research to drive improvements.

To address identified gaps and opportunities, the *Strategy* called for a coordinated approach to:

- support Canadians' ability to access similar cancer services regardless of where they lived,
- integrate the cancer work of provinces and territories into a cohesive, nation-wide approach, anchored by the principle of collaboration,
- share the latest evidence and best practice among policy-makers and health professionals so the knowledge can be applied to cancer care across the country,
- adopt regular, ongoing measurement of cancer control efforts and outcomes so that problems can be addressed and all Canadians know how well the system is performing, and
- improve cancer prevention, through support for policy changes and programs that promote healthy behaviours and environments and through research to better understand what causes cancer.

Work to develop the *Strategy* began in the late 1990s, and with the support of the Prime Minister and Minister of Health, it was ready for launch in 2006. To move the *Strategy* into action, the federal government provided funding for infrastructure and implementation through the creation of the Canadian Partnership Against Cancer (the Partnership) in 2007.

Right away, the Partnership began working with partners throughout and beyond the cancer system to move the *Strategy* forward and measure its progress. To support these efforts, the Partnership created a governance structure and a network model that established working relationships with the provinces and territories, cancer agencies and programs, non-governmental organizations, researchers, patient groups, health professionals and many others.

While the *Strategy* outlined a comprehensive, Canada-wide approach and five strategic areas for investment, it did not prioritize actions to be taken. The Partnership worked with cancer control organizations to identify these priority areas for action and a wide range of programs were developed and funded.

2006 CANADIAN STRATEGY FOR CANCER CONTROL

The *Strategy* identified five strategic areas for investment:

- Cancer prevention and early detection
- Supporting the cancer patient's journey
- Supporting the cancer workforce
- Encouraging cancer research
- Improving cancer information and access

These were operationalized by the Partnership into the following priorities to guide work with cancer control partners:

- Prevention
- Screening and early detection
- Standards
- Clinical practice guidelines
- Rebalance the focus/cancer journey
- Health human resources
- Research
- Surveillance
- Knowledge management
- Quality initiatives and system performance

While not originally identified as a strategic area for investment, cancer control for First Nations, Inuit and Métis was identified as a priority shortly after the *Strategy* was launched.

THE STRATEGY IN ACTION — 2007 TO TODAY

Over the past decade, the *Strategy* has been a powerful tool for change and improvement.⁵ With the *Strategy* as a guide, cancer organizations, health professionals, researchers and others have been working together in new ways to improve cancer control across the country. The work is complex and challenging, requiring partners to identify shared priorities and collective approaches. Solutions to longstanding gaps and challenges are being implemented and positive results are emerging. High impact accomplishments to date include:

Helping Canadians prevent cancer

Health, education and community organizations across Canada are partnering on projects to help Canadians reduce their risk of cancer and other diseases like heart disease and diabetes through healthier lifestyles. This work is resulting in policies that support healthy living such as those that increase access to healthier food in schools and promote physical activity by making it easier for people to walk, bike or take public transit.

Reducing exposure to cancer-causing substances

CAREX Canada is providing researchers, policy-makers and health professionals with valuable information on how and where Canadians are exposed to cancer-causing substances in their workplace or community. Information is used to support cancer prevention programs and policies to reduce exposure.

Helping cancer patients achieve better health outcomes

Cancer treatments are more effective and survival improves if patients quit smoking.²¹ Seven provinces and two territories have now put in place strategies and supports to help cancer patients reduce or quit smoking, with the remaining provinces and territories on track to do so by 2022. Canada's recently launched Tobacco *Strategy* is also focused on reducing tobacco use and is the result of an effective partnership among cancer networks and federal, provincial and territorial governments.

Saving more lives through better screening and early detection

Colorectal cancer is highly treatable if caught early.²² Today, colorectal cancer screening programs are in place or planned in all 10 provinces and one territory, with national quality indicators to help track, compare and improve screening programs. The quality and effectiveness of breast and cervical cancer screening continues to be monitored and improvements made as needed. And screening for Canadians at high risk of lung cancer is being piloted to assess whether it should be introduced.

Improving cancer diagnosis and treatment

Standard collection of patient stage data^c and reporting in a national database means trends and patterns of care can be studied and used to promote improvements in the quality of cancer care. Nine provinces are now collecting and electronically reporting stage data for over 90 per cent of breast, colorectal, lung and prostate cancer cases (the most common cancers). New standards and guidelines for diagnosing and treating cancer based on the best available evidence are also now available to improve the quality of cancer care across the country.

Implementing person-centred care

Understanding patient symptoms is key to addressing them. Using standardized questionnaires, cancer centres in eight provinces gather information directly from patients about fatigue, pain, anxiety and depression so their care teams can monitor symptoms over time and refer patients to the right supports to help reduce their symptoms. Efforts are also underway to provide cancer patients with better and earlier access to palliative care wherever they may be, including in hospital or at home. In more remote areas, Canadian Virtual Hospice provides online palliative care resources to support patients, families and health care providers.

^c Stage data shows the extent to which cancer has spread at diagnosis.

Measuring and improving the quality of cancer care

Ten years ago, information about the quality of cancer care and outcomes across Canada was largely non-existent. Today, quality indicators and other important measures are available in a much more standardized way across provinces and territories, and organizations are better able to identify and focus on areas that need changes to improve patient care.

Discovering why some people get cancer and others don't

The Canadian Partnership for Tomorrow Project – one of the world's largest population health studies – collects health and lifestyle information from 300,000 Canadians throughout their adult lives. Researchers use the data, along with blood and other biological samples, to explore how genetics, environment and lifestyle interact to better understand cancer and other chronic diseases.

Advancing coordinated cancer research

Many research funding organizations from across Canada support coordination of cancer research at a system level through the Canadian Cancer Research Alliance (CCRA) to provide cancer patients with new options for potentially life-saving treatments. The Canadian Cancer Clinical Trials Network (3CTN) is one result of this coordination and collaboration and has significantly increased the number of investigator-led clinical trials and patients participating in clinical trials in Canadian cancer centres.

Working together to advance First Nations, Inuit and Métis cancer control priorities

The first-ever *First Nations, Inuit and Métis Action Plan on Cancer Control* was developed with the guidance of the Assembly of First Nations, Inuit Tapiriit Kanatami and the Métis National Council. Initiatives across Canada are building new relationships between cancer centres and Indigenous partners to help address ongoing inequities.

Building a world-class, sustainable cancer system

Canada is one of a few countries that can reliably project the impact of decisions in cancer prevention, screening and treatment. OncoSim is a sophisticated microsimulation tool that uses demographic, economic and health data to project how a particular action affects cancer rates, deaths and health care costs.

Progress and Challenges in Cancer Control

Across Canada, there has been significant progress in cancer control. Survival rates for some cancers in Canada remain among the best in the world and have steadily improved over time.⁴ Thanks to investments in areas such as early detection and treatment, the five-year cancer survival rate has increased from approximately 25 per cent in the 1940s to 60 per cent in the last 10 years.¹³

Survival rates for some cancers, such as testicular cancer and a variety of childhood cancers, have improved even more. The five-year survival rate for testicular cancer is now 96 per cent compared to 54 per cent in the 1940s.²³ ²⁴ For many childhood cancers, the rate has increased over the last 40 years from 10 per cent to nearly 90 per cent.²⁵ Cancer incidence has gone down for many cancers because of improved prevention efforts, including tobacco control.¹³

Other developments are equally positive. Emerging research is being integrated into patient care and enhancing our understanding of what causes cancer. Cancer organizations, health professionals, researchers and countless others are also adopting exciting

innovations that improve their ability to prevent, detect and treat cancer. For example, girls and boys are now routinely vaccinated against HPV (human papillomavirus) to prevent cervical, throat and other cancers in adulthood.² Advances in targeted cancer genomics and immunotherapy are creating new treatment options that control and cure previously untreatable cancers.

Policy changes are also making a difference. Cities and towns across the country have put in place policies to limit Canadians' exposure to the dangers of second-hand smoke.³ And cancer patients are helping to shape a more responsive health system that supports their needs.

However, other changes within the cancer system are taking longer, and not all Canadians have benefitted equally from Canada's progress. An analysis of global advances in cancer control and the pressures facing health care makes one thing very clear: the cancer system faces many challenges and needs to constantly adapt. The following are some of the most pressing issues that must be addressed in a modernized, Canada-wide strategy.

Addressing Persistent Disparities

First Nations, Inuit and Métis continue to experience poorer cancer outcomes than the general population and to face inequities and barriers in accessing care, especially care that respects and reflects their cultures.⁷⁻¹¹

In recent years, cancer agencies and other service providers have begun to work collaboratively with First Nations, Inuit and Métis partners to address self-determined priorities such as making cancer services more culturally appropriate and culturally safe, and to address other barriers to care, including discrimination and racism. These efforts need to be supported, encouraged and evaluated to determine their impact on health outcomes and on the experiences of First Nations, Inuit and Métis patients with cancer. Those that prove effective should be supported and implemented more broadly.

Other groups of Canadians also face inequities. Poorer Canadians are less likely to be screened for cancer, will wait longer for treatment and are more likely to die of cancer.⁶ Recent immigrants or individuals who have been in Canada fewer than 10 years are less likely to be screened for breast, cervical and colorectal cancer than longer-term immigrants and people born in Canada.^{6,26} People who identify as LGBTQ2 experience marginalization and face barriers accessing the care they need,²⁷ while adolescents and young adults with cancer face their own unique challenges, which are not well tracked or addressed by the cancer system.²⁸ We need better multi-sector approaches to leveraging data so we can improve our understanding of these varied cancer experiences, and we must implement targeted initiatives within and beyond the cancer system to address the gaps.

Often these inequities are made worse by major differences in the broader determinants of health across populations and communities. Factors such as income, education, health practices and social and physical environment can have an impact on a person's health, increasing their risk of disease and earlier death.^{29,30} For example, over 50 per cent of cancers are caused by modifiable behaviours and risk factors (e.g., smoking, physical inactivity, unhealthy eating and exposure to UV radiation), and these risk factors are more common in certain geographic, socio-economic and cultural groups.³¹

Most of these risk factors also play a role in other chronic diseases, such as heart disease and diabetes. When

several of these elements combine (e.g., an individual is poor, culturally marginalized and geographically isolated), the impact is even greater.³²

In Canada, geography also creates disparities. There are significant differences in cancer incidence rates and cancer deaths among provinces (Quebec and the Atlantic provinces often have higher incidence rates than other provinces) and between provinces and the territories (Nunavut has one of the highest incidence rates of lung cancer in the world).³³ People in rural or remote parts of Canada face additional challenges in accessing resources, services and programs.⁶

To add to these challenges, disadvantaged people and people living in rural and remote areas are slower to access screening programs, new treatments or approaches to cancer care, further increasing the disparities that already exist.³⁴

Disparities in health outcomes are not unique to cancer care; they exist across the health care system. However, the *Strategy* and its partnerships are providing a focus and momentum for targeted change that can lead the way in addressing these broader health inequities. It is clear that removing the complex and interrelated barriers to better care and health outcomes will require decision-makers across the health, education, social services, housing and other sectors to work together. Solutions at the policy level will be necessary to help prevent cancer and other illnesses by creating social and physical environments that promote healthier living and to facilitate access to screening and early detection.

Embracing Innovation and Sustainability

We are only beginning to understand the true costs of cancer for our country, our communities and for patients and their families.

One in two Canadians will develop cancer in their lifetime, and one in four will die of cancer.³⁵ The number of new cancer cases in Canada is also expected to increase in the coming decade.¹ Cancer is more common among people over the age of 50,¹³ and by 2036, seniors will make up an estimated 25 per cent of the population.¹⁴ In addition to being at higher risk for cancer, older people are more likely to have multiple health issues and be frail, making cancer care more complex.³⁶ And because cancer survival is improving, many cancer patients (of all ages) will live long enough to experience a second cancer.⁴

Costs in cancer care are quickly rising.¹⁵ The most recent estimates of the annual direct costs of cancer to the Canadian health care system range from \$4 billion in 2008¹⁵ to \$7.5 billion in 2012.¹⁶ New and expensive cancer treatments, such as immunotherapy and targeted cancer therapies, have the potential to drive costs even higher.

In the coming decade, advances in medicine and technology will affect every aspect of cancer prevention, early detection, diagnosis and treatment. While these innovations offer new hope to cancer patients, they are often expensive. Canada is already among the highest spenders on health care per capita in the world. In 2016, Canada ranked seventh among comparable countries, spending 10.6 per cent of our gross domestic product (GDP) on health care.³⁷

Care today also remains largely hospital-based, a costly model of care that drains limited health care resources.^{17, 18} It is clear that the long-term sustainability of our system depends on finding new evidence-based, cost-effective ways to deliver care that are designed with the help of patients. We will need to make better use of technology, embrace innovation and explore less costly models of care that move services out of hospital and into the community, where most patients prefer to receive their care. Proven strategies already exist to deliver cancer care more efficiently: homecare, telehealth, and end-of-life care outside of acute care settings.^{38, 39} These approaches must be shared and implemented more broadly across the country, especially as staff burnout and specialist shortages require new workforce planning efforts.

The increase in cancer cases and the need to deliver better care to hard-to-reach populations is also increasing the demand for trained health professionals. We will not be able to fill this need through traditional health human resource approaches. New models of care must include expanded roles and enhanced scopes of practice for nursing and allied health professionals.^{40, 41} This will increase our ability to fill service gaps in remote and other underserved communities and allow medical and surgical specialists to be used more effectively.

To ensure sustainability, difficult decisions must be made about where limited budgets will be spent. As new diagnostic technologies, drugs and models of care become available, we must think about discontinuing others that no longer provide good value for money. Priorities and potential trade-offs need to be clearly

identified, and decisions must consider the values of the Canadian public.⁴²

Canada's federated health care model can lead to duplication of efforts as each province and territory addresses common problems. Significant gaps also can emerge when provinces and territories have neither the population nor the resources to undertake important initiatives. However, with the *Strategy* providing a framework for working together, innovations and efficiencies are being identified and shared across the country. This will help to bring about positive change that is sustainable for future generations.

Meeting the Needs of Patients

Patients, survivors and family members commonly experience emotional and psychological stress throughout their cancer journey. Younger people who experience cancer, in particular, have complex and lifelong needs that continue beyond treatment.²⁸

In 2018, the Partnership released a report reflecting the voices of over 30,000 Canadians with cancer. It is the country's largest accumulation of patient data on the experiences of people living with, and beyond, a cancer diagnosis. The report revealed that many cancer patients experience significant and debilitating physical and emotional side effects and that these are not always addressed. For example, one in four reported they were not satisfied with the emotional support they received during outpatient cancer care. Patients also continue to face challenges after treatment ends: eight in 10 patients reported physical challenges, seven in 10 reported emotional challenges, such as depression, and four in 10 reported practical challenges, including returning to work or school.⁴³

To address these issues, we must continue our efforts to create a person-centred cancer system, where the needs of the person with cancer come first and patients have a say in planning and directing their own care. We must provide support for the physical, emotional and mental symptoms of cancer, including access to traditional and cultural supports, as well as culturally safe care for First Nations, Inuit and Métis patients and families.

We need to address the unique challenges faced by children, adolescents and young people with cancer, and the family members that support them through their cancer experiences and beyond. More consistent and earlier access to palliative care is also needed to provide

patients with better pain and symptom management, as well end-of-life care when needed.

It is essential that we improve coordination among cancer centres, primary care providers and community care so that patients are supported while navigating the cancer system and experience smooth transitions from diagnosis through treatment and follow-up care. This is especially important for First Nations, Inuit and Métis patients and families, many of whom face compounding issues such as a lack of culturally safe care in locations far away from family and community.

We must also pay particular attention to the stress for families caused by the financial burden of lost work hours, uninsured drugs, transportation and other associated costs. This is particularly relevant to Canadians in rural and remote locations, where home care services are not available and care is provided by family and volunteers. In many instances, First Nations, Inuit and Métis patients face additional financial and geographic barriers, including limited access to health services, follow-up treatment, home care and reliable technology to support health services, as well as issues relating to food security – all of which affect recovery and long-term health.

Above all, patients, families and caregivers expect to be partners with health providers and others in the system. Developing solutions together is key to improving patients' experiences.

Advancing a High-Quality Cancer System

A high-quality cancer system ensures all Canadians have access to care that reflects not only the latest global evidence and best practices, but also their own needs and preferences. It provides the best outcomes for people with cancer given the resources that are available, and it achieves the right balance between:

- Well-established guidelines *and* new and emerging evidence
- Identifying new knowledge *and* ensuring uptake of what we already know
- Scientific data *and* what is important to patients and families
- Extending someone's life *and* ensuring they have good quality of life
- Doing everything possible for the individual patient *and* using resources equitably so that everyone has access to the care they need.

Improving quality at a system level requires decisions and actions at the local level that promote quality. Policy-makers must pass legislation and provide funding to create incentives for high quality cancer care delivery. Health professionals must provide care that is supported by evidence. And health administrators must manage competing demands for human and financial resources in order to provide equitable and appropriate care for all, while measuring quality and making the necessary changes to improve it.

Measuring and identifying gaps in quality is critical. This requires gathering comparable data on performance across provinces and territories that will allow health professionals, organizations, provinces and territories to compare their performance against targets and benchmarks and to develop strategies to close the gap.

We must also ensure we measure against evidence-based standards, that decision-makers are aware of those standards and that they have the tools and support to take action when improvement is needed.

Optimizing Data

Data are critical to our ability to identify and solve problems and improve the quality of cancer care. Canada is a leader in gathering and reporting standardized data to measure the performance of the cancer system. But some challenges remain.

We have yet to use the data we already have to its full potential. Data can be difficult to access and we need better analytical tools and skills to use it well. There are also critical data gaps, particularly when it comes to parts of the cancer journey that take place before diagnosis and after treatment – areas such as primary care, diagnostic labs and community care. Children with cancer are often treated in different parts of the system than adults, so special attention needs to be given to linking data so we understand their experience of care. We need to link cancer data to other health system and socio-demographic databases so we can look at all factors that lead to variations in cancer care. In addition, we need to address barriers to accessing data caused by overly restrictive interpretation of privacy requirements, while building tools and skills in data analysis across the country.^{12, 44,45}

There are many other information sources available to guide improvements in cancer care. We must enhance the use of electronic health and medical records to share information and coordinate patient care across the health

system. And we need to expand the use of standardized questionnaires and other tools that provide important information about patients' symptoms and experience.⁴⁶

Finally, it is critical that we address our lack of data on cancer incidence,^d survival, and use of health services among First Nations, Inuit and Métis. A challenge is the lack of reliable identifiers of First Nations, Inuit and Métis in existing data sets.⁴⁷ Without data, we will be unable to measure whether efforts to reduce the impact of cancer are making a difference.

As we work to improve data collection, information systems and data sharing with First Nations, Inuit and Métis, it is essential that we abide by relevant First Nations, Inuit and/or Métis principles of information governance. These include the First Nations' principles of Ownership, Control, Access and Possession (OCAP[®]), Inuit research principles, Métis research protocols and other data/research information relevant to First Nations, Inuit and Métis.

Supporting Coordinated Research

Cancer research includes a broad range of activities: basic science research to understand the biology of cancer; population studies to help us understand the causes of cancer and how cancer can best be prevented; trials of new ways to diagnose and treat cancer; studies that test new approaches to delivering health care and supporting cancer survivors; and research that supports policy development and helps us understand how to implement new discoveries and innovations.

New and promising approaches to diagnose, treat and manage cancer are usually tested in randomized controlled trials that assess their effectiveness. It is important that clinical trials recruit patients who represent the full range of cultural and demographic diversity that exists in Canada. Groups often under-represented in trials include adolescents and young adults, patients 80 years of age and older, First Nations, Inuit and Métis and people with certain gender identities and sexual orientations. These gaps need to be addressed if the research results are to reflect and be applicable to the entire population.⁴⁸

Research is also critical to understand what causes cancer in the first place. The Canadian Partnership for Tomorrow Project (CPTP) is one of the largest studies of its kind

in the world. It was created to provide world-class opportunities for research on genetic and other causes of cancer and chronic diseases. Working together, researchers across the country created this large collection of information from more than 300,000 Canadians, and it will continue to grow over time and increase in value to researchers. Over the next 10 years, we must help researchers use the full potential of this resource to create knowledge with value for Canadians.

Evidence can be drawn from formal studies and clinical trials, and it can also be experiential and contextual. For First Nations, Inuit and Métis, for example, critical insights can be found in community experience, lived experience and the knowledge and stories of Elders.^{49, 50}

Researchers can be more effective if they coordinate their efforts and work together, particularly given Canada's large geography and relatively small population compared to places like the United States and Europe. CPTP is one such example. Collaboration by regional teams across Canada resulted in standardized data collection, which provides researchers with comparable data from across the country.

Other examples of effective collaboration are the Canadian Cancer Clinical Trials Network (3CTN) and the Canadian Cancer Research Alliance (CCRA). 3CTN provides supports for staff and systems conducting academic clinical trials in regions and centres across the country that would not normally be able to support this level of research. The CCRA is a forum of organizations that fund most of the cancer research in Canada. Its goal is that research activity across Canada is guided by a common vision and set of priorities.

These examples demonstrate a collaborative and Canada-wide approach to coordinating research at the system level. We must continue to build on this model and on the benefits of these and other Canada-wide research collaboratives to ensure a strong future for cancer research in Canada.

^d Cancer incidence is the number of new cancers of a specific type that occur in a specific group of people during a year.

Setting Priorities for the Next Decade

It is now nearly 20 years since the early work in the late 1990s to develop the *Canadian Strategy for Cancer Control*. Much has changed since then. Our population is aging, medical advances and innovations have changed how we treat many cancers and new models of care are emerging. In an exciting and fast-paced era of scientific discovery and advances in care, Canada must be both able and equipped to remain a leader.

As we refresh the *Strategy*, there are many factors to consider. A refreshed, modernized *Strategy* must concentrate on priority areas where a national focus will help Canada address the most urgent cancer control issues, including longer-term efforts such as cancer prevention. Consideration must be given to which elements of the original *Strategy* should remain and new elements that need to be added and given priority.

Current Canada-wide health care priorities that provincial, territorial and federal governments are addressing include the impact of the growing opioid crisis; dialogue regarding national strategies on pharmacare, palliative care, dementia and seniors; the new national tobacco strategy; the recent national report on health equity; and the overarching need for a modernized health system and efficient workforce.

Any effort to update and refresh the *Strategy* must account for the federated nature of Canadian health care. Provincial and territorial governments manage most of cancer control within their own borders and budgets. They face genuine constraints and their priorities must shape the work ahead.

A refreshed *Strategy* must also be informed by provincial and territorial cancer priorities and reflect input from members of the cancer community, First Nations, Inuit, Métis leaders, patients and families and the public.

Learnings can also be drawn from the national cancer control strategies and programs of other countries.

Success to date is the result of shared ownership and a commitment to the *Strategy's* goals. Reaffirming that commitment and ensuring clear accountabilities will be a critical aspect of refreshing the *Strategy*.

Confirming Cancer Control Themes

A refreshed national strategy must reflect current and future areas of focus of Canada's provincial, territorial and federal governments and cancer agencies. In a scan of provincial, territorial and federal cancer plans the following themes emerged:

- **Equitable care for all people in Canada:** to minimize disparities and improve care for disadvantaged populations, including the poor, immigrants, people of various gender identities, adolescents and young adults with cancer, people living in rural or remote areas, First Nations, Inuit and Métis.
- **System sustainability:** to address rising costs, assess value for money and prioritize investments in the cancer control system.
- **Person-centred care:** to ensure care that focuses on the whole person is the standard for design and delivery of all cancer services – including prevention programs – in hospital, community or at home.
- **Population-based approaches to prevent cancer:** to reflect evidence that the greatest impact on cancer outcomes – particularly on the number of people who get cancer – is made through policies that support a healthy population, reduce risk of cancer in communities and are part of a broader population health strategy that includes legislation, public education and screening programs.

- **Evidence-based and leading practices:** to ensure the most effective evidence-based and promising approaches are used in policy, program development and clinical practice and that efforts are constantly made to improve quality across the system.
- **Better use of cancer and other health system data:** to help health care administrators, policy-makers and front-line health professionals make faster, more evidence-based decisions and build better programs.

Many of these priorities were identified in the original *Strategy* launched in 2006. However, over the last 10 years, the importance of ensuring equitable care for Canadians and system sustainability have come into sharper focus.

Learning from International Cancer Control Partners

WHO has long called for countries to develop national cancer control programs or strategies to improve cancer care and outcomes efficiently and effectively. In 2006, 13 countries — including Australia and France — had national cancer plans in place. Since then, Canada and many more countries have followed their lead. Today there are more than 80 national plans in place.⁵¹

High quality and effective cancer plans address key domains defined by WHO: prevention; screening and early detection; diagnosis and treatment; physical, psychosocial and palliative support; and research. WHO places a strong emphasis on achieving change through creating partnerships, engaging stakeholders, ensuring a patient-centred approach across all aspects of cancer control, establishing high quality cancer data and using data, research and knowledge to drive improvements.¹⁹

The International Cancer Control Partnership's guidance on national cancer control planning also outlines common elements of successful cancer plans.^{52, 53} These include ensuring a clear understanding of how a country's context determines planning and implementation; ensuring the strategy framework and associated programs are evidence-based; recognizing the importance of a broad range of stakeholder relationships; and adopting a practical approach to sustainability and measurement.

Canada's current *Strategy* has many of these critical elements, as well as key enablers such as: an effective system for gathering, monitoring and reporting cancer data; a focus on actively sharing and moving research and knowledge into action across the country; and committed funding from the Canadian government. Canada is one of the few countries worldwide in which a government created an independent organization (the Partnership) to guide the implementation of a national cancer strategy and funded the development of infrastructure.²⁰ Given Canada's federated health system and the complexity of cancer control, the *Strategy* and the government's support for infrastructure have provided an important backbone for cancer control efforts across the country.⁵

However, the experience of international partners suggests that the scope and impact of Canada's cancer strategy would be further strengthened by increased emphasis on:

- Reflecting the current Canadian context by addressing persistent disparities in cancer care and outcomes across Canada's diverse population, wide geography and range of provincial and territorial health systems
- Modernizing the *Strategy's* content to reflect emerging priorities and challenges, while increasing uptake of proven approaches to improving outcomes and the quality of patient care and cancer prevention efforts
- Building on the network model to broaden relationships that leverage expertise and know-how found inside and outside the cancer system, and that include representation from all provinces and territories
- Increasing sustainability by maximizing partnerships and collaboration, and focusing on achieving the greatest value and impact for investments in cancer control through innovation and improved efficiency

We can also learn from the experience of countries that are considered international leaders in specific domains of cancer control. This includes experience in integrating palliative care and primary care into cancer care (Australia), tobacco control (New Zealand), early diagnosis and integrating research into practice (United Kingdom) and colorectal cancer screening (the Netherlands).

Broadening the Partners Engaged in the Strategy

In the *Strategy's* first decade, the Partnership worked with provinces and territories, cancer organizations and institutions to ensure the *Strategy* was embedded across the cancer system. Moving forward, a greater diversity of partners is needed to mobilize the scope and type of change that is needed. This needs to include:

- Cancer care delivery organizations (cancer agencies and programs and the private sector)
 - National and pan-Canadian health organizations
 - Canada-wide social sector organizations
 - A broad range of health professionals across all areas, including primary care and community health
 - First Nations, Inuit and Métis organizations and leaders
 - Canadians and communities affected by cancer, including high risk populations
 - Non-profit and charitable organizations with a focus on cancer, and social enterprises
- The cancer and non-cancer research community
 - National and provincial health and medical associations, professional associations and medical regulatory authorities
 - Federal, provincial and territorial governments and agencies across a variety of sectors, including social services
 - Universities and colleges

There is potential for greater involvement and synergies with national and pan-Canadian organizations working in areas related to health. These organizations provide critical leadership and coordination of national health priorities such as linking health and population data, ensuring consistent measurement and comparison of results across Canada, supporting health research and innovation and assessing the value of new medicines and health technologies.

Moving Forward Together

For more than a decade, the *Canadian Strategy for Cancer Control* has guided Canada's tremendous progress in cancer control. As the cancer system faces new pressures and new opportunities that need to be addressed, we need to build a sustainable cancer system and ensure vulnerable Canadians have equitable support and access to the cancer care they need.

Canada's cancer community has worked together to move the *Strategy* into action. We need to build on our shared successes, while expanding the circle of partners to move cancer control forward. We also need to allow ourselves to think big and be creative as we plan for the future.

We need to consider the factors that drive change in a world of technology, including the promise offered by artificial intelligence (AI). We must also tackle the difficult task of identifying priorities together. This is particularly important given the 13 different health systems within Canada's federated health model.

The long-term goals and Canada-wide focus of the original *Strategy* remain clear and relevant. However, as we work together to refresh and modernize the *Strategy*, a number of critical questions need to be addressed:

- *What are the characteristics of a useful and effective strategy for the future?*
- *Where can a Canada-wide cancer control strategy have the greatest impact in the coming 10 to 20 years?*
- *What will it take to advance the goals of the Strategy within a federated health care system?*
- *How can the cancer control strategy contribute most effectively to the performance and sustainability of the Canadian health care system? How do we identify and tackle the most pressing priorities?*

A refreshed *Strategy* should support the vision of a high quality, accessible cancer control system for all Canadians. It must serve as a catalyst for everyone who is able to effect change — not just those within the cancer control system. Ultimately it must help reach our shared goal of a future in which fewer Canadians develop cancer, fewer die from cancer and those affected by cancer have a better quality of life.

At the request of the federal Minister of Health, the Partnership is facilitating a conversation among Canadians to inform a refreshed Canadian *Strategy* that will be provided to the Minister and her provincial and territorial counterparts in May 2019. Following approval of the *Strategy*, an implementation plan will be developed.

Appendix A includes sample discussion questions that will help to guide input. The questions are focused on the following areas:

- Benefits, attributes and goals of a national cancer strategy
- Priority areas for Canada's cancer strategy moving forward
- System sustainability
- Public values, patient and public involvement
- Integration across the broader health system

Input will be gathered in a variety of ways, including a mix of in-person and online approaches, such as interviews, group discussions, a request for submissions in response to the discussion paper and surveys. More information is available on the Partnership's website at www.partnershipagainstcancer.ca.

Thank you to everyone for your interest, participation and contributions.

Appendices

APPENDIX A: SAMPLE DISCUSSION QUESTIONS

Consultation will take place with cancer control partners, cancer stakeholders, the public, cancer patients and survivors. These questions will be refined and expanded as the consultation process unfolds.

Benefits, attributes and goals of a national cancer strategy

1. What are the benefits for Canadians of a national cancer control strategy?
2. What are the core principles of a national cancer control strategy?
3. Thinking of the *Canadian Strategy for Cancer Control's* 30-year goals (reducing new cases and deaths from cancer, and improving the quality of life for those affected by cancer) what does success look like in 2037?
4. What are the key elements of a national cancer control strategy for the future?

Priority areas for Canada's cancer strategy moving forward

5. Where could a national cancer control strategy make the biggest impact in the coming 10 to 20 years?
6. The *Strategy* spans prevention, screening, diagnosis, treatment, survivorship, system surveillance, palliative and end-of-life care. Is this still a useful way of thinking and are these still the appropriate areas of focus?
7. What will it take to continue to advance the goals of the *Strategy* within a federated health care system?

8. Are the thematic areas of focus listed on page 13 (equitable care for all people in Canada, system sustainability, person-centred care, population-based approaches to prevent cancer, evidence-based and leading practices, and better use of cancer and other health system data) the cornerstones for the refreshed *Strategy*? Should some be prioritized or are there others that should be considered or dropped?
9. How can a national strategy assist Canada in planning for new technology and disruptive trends, as well as advances in care and treatments?
10. What conditions supported successes of the *Strategy* to date? Which require ongoing support and which are outdated? Are these conditions the same today and are there new ones to consider?
11. What lessons can we apply from other health strategies or other countries to prepare for future challenges? What else is needed to achieve more progress sooner?
12. In general, are there other advances in cancer control that have been made since the *Strategy* was introduced that were not outlined in this paper?

System sustainability

13. How can an effective cancer control strategy contribute to the performance and sustainability of the Canadian health care system?
14. How do we identify priorities with potential for the best and highest yield to support system sustainability?
15. How do we measure progress towards system sustainability?
16. Understanding that the health care system has finite resources, how can we shift investment from less impactful practices to those that would have greatest value?

Public values, patient and public involvement

17. What are the best ways to engage and involve underserved populations in addressing cancer care and control priorities?
18. How can a national cancer control strategy address social determinants of health, including conditions or environments that promote risk factors for cancer or poor cancer outcomes?
19. How do we meaningfully engage Canadians so the national cancer control strategy reflects our common values, to best guide cancer care decision-making and achieve the best value for money?
20. What are the best ways to engage and involve First Nations, Inuit and Métis in addressing First Nations, Inuit and Métis cancer care and control priorities?
21. How can we ensure that the needs and priorities of First Nations, Inuit and Métis are represented in a culturally appropriate and culturally safe way?
22. What successful initiatives or partnerships already exist, which focus on cancer prevention, cancer care or outcomes of different population groups, that can be leveraged for cancer control?
23. What successful initiatives or partnerships already exist in other chronic diseases can be leveraged for cancer control?

Integration across the broader health system

24. How can we ensure successful implementation of the *Strategy*? How do we create and sustain a strong sense of collective ownership?
25. Does the *Strategy* need an organization to steward its implementation and monitor progress?
26. As patients with cancer live longer and want care at home, what are the roles of primary and community care in the *Strategy*?
27. What are successful approaches to engaging primary care and public health?
28. How will we incorporate accountability into the implementation of the *Strategy*?

APPENDIX B: ADDITIONAL RESOURCES

For further information about the Canadian Strategy for Cancer Control and its implementation since 2007:

- The *Canadian Strategy for Cancer Control: A Cancer Plan for Canada* (2006)
<https://www.partnershipagainstcancer.ca/wp-content/uploads/2017/09/canadian-strategy-for-cancer-control-a-cancer-plan-for-canada.pdf>
- We See Progress: Canadian Partnership Against Cancer 2017-2022 Strategic Plan
<https://www.partnershipagainstcancer.ca/wp-content/uploads/2017/08/canadian-strategy-cancer-control-2017-2022-en.pdf>
- Evaluation of the Canadian Partnership Against Cancer Activities 2012–2013 to 2015–2016
www.canada.ca/en/public-health/corporate/transparency/corporate-management-reporting/evaluation/2012-2013-2015-2016-canadian-partnership-against-cancer-activities.html

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ABOUT THE CANADIAN PARTNERSHIP AGAINST CANCER

The Canadian Partnership Against Cancer was created by the federal government in 2006 with funding from Health Canada to work with Canada's cancer community to reduce the incidence of cancer, lessen the likelihood of Canadians dying from cancer, and enhance the quality of life of those affected by cancer. This work is guided by the *Canadian Strategy for Cancer Control*, which was developed by hundreds of healthcare and cancer leaders, patients and advocates. Today there is strong evidence that the *Strategy* is resulting in concrete and significant action by partners across the country to improve cancer control. Working together over the last decade, Canada has improved cancer screening programs, adopted exciting innovations and emerging research, standardized the collection of patient data and created one of the world's largest population health databases among many other advances. For more information visit www.partnershipagainstcancer.ca.

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 **Canadian Strategy
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