

# CHANGING CANCER IN CANADA

**10 YEARS OF COLLABORATION**

Achievement Report 2007-2017



CANADIAN PARTNERSHIP  
AGAINST CANCER



PARTENARIAT CANADIEN  
CONTRE LE CANCER



## 10 YEARS OF COLLABORATION

### Achievement Report 2007–2017

The Canadian Partnership Against Cancer was created by the federal government with funding through Health Canada. Since opening our doors in 2007, our sole mandate has been to move Canada's cancer strategy into action and help it succeed. In this publication, we share achievements of our work from 2007–2017 with partners across the country and across the cancer landscape.

## CONTENTS

- 4 Introduction
- 6 Building on successful cancer prevention strategies
- 8 Improving the quality of cancer screening
- 10 Standardizing data to improve outcomes
- 12 Addressing inequities in cancer care for First Nations, Inuit and Métis
- 14 Accelerating cancer research
- 16 Measuring performance to improve care
- 18 Creating a sustainable cancer system
- 20 Putting the needs of patients and families first
- 22 The next 10 years

## INTRODUCTION

# WE'RE CHANGING HOW CANADIANS EXPERIENCE CANCER. FOR THE BETTER.

Over a decade ago, the Canadian cancer community came together to address the growing number of cancer cases in this country. The result — the *Canadian Strategy for Cancer Control* — set out an ambitious 30-year plan to reduce the burden of cancer in Canada.

To move the plan into action, the federal government created the Canadian Partnership Against Cancer (the Partnership). Our role: to steward and lead the Strategy in partnership with a wide network of provincial, territorial and national partners, cancer experts and people affected by cancer.

The Partnership's collaborative approach has led to shared efforts to improve cancer control across the entire cancer pathway and across the country — from prevention, screening, diagnosis, treatment to survivorship and palliative care. Problems have been identified, solutions found and work undertaken. There have been many successes — and areas where actions have fallen short of what Canadians need.

And we know, all Canadians have not benefitted equally from the cancer system's efforts to date.

The pages that follow highlight the accomplishments of this first decade of the Canadian cancer strategy and point to the work still to be done to achieve our 30-year goals. Moving forward, we will build on these successes, identify gaps and make adjustments to ensure that all Canadians can benefit equally from a pan-Canadian focus on priority areas that address the most urgent cancer control issues, including longer-term efforts such as cancer prevention.

**Together, we're changing cancer in Canada.**

5,600 86

practice changes and over 520 policy changes led by CLASP initiatives that support healthy behaviours and increase access to healthy environments.

recommendations by over 100 participants, including cancer survivors and caregivers, on the principles and types of evidence that should guide decisions about which drugs to fund.

300,000+

3 YEARS

to roll out screening programs for colorectal cancer across 10 provinces. A new record: it took 10 years for breast cancer screening and 50 for cervical cancer.

Canadians across the country have contributed their health and lifestyle information and half have provided blood or biological samples, providing critical research data to the Canadian Partnership for Tomorrow Project.

13,000

cancer survivors from 10 provinces surveyed on their cancer experience and how it could be improved. The first large-scale study of its kind.

THOUSANDS

of data points can now be analyzed by state-of-the-art tool, OncoSim, providing clear answers on the real-world cost of actions related to cancer prevention, screening and treatment.

97+%

of surgical reports are now available in 24 hours when synoptic reporting is in place, compared to 15% previously.

10

initiatives across the country have led to new collaborative relationships between cancer centres and First Nations, Inuit and Métis partners.

\$6 MILLION

in research funding awarded by the Canadian Institutes of Health Research to researchers using the Canadian Partnership for Tomorrow Project data.

25

core cancer system performance indicators collected and reported on in a standardized way by all provinces.



“CLASP projects from Vancouver Island to St. John’s brought together partners from research, practice and policy. The Partnership was instrumental in providing guidance on how to work within these coalitions and helped projects to translate evidence into action to prevent cancer and other diseases.”

**Dr. David Mowat** is a consultant in public health, former senior scientific lead, population health at the Partnership, and former Medical Officer of Health for the Region of Peel.

# BUILDING ON SUCCESSFUL CANCER PREVENTION STRATEGIES

## The challenge

Most people know what they should do to reduce their risk of cancer and other diseases. Eat a healthier diet. Exercise more. Stop smoking. But adopting and maintaining healthy habits isn’t always easy or affordable.

When the Partnership began its work, pilot projects across the country had tried a wide variety of approaches to help people reduce their cancer risk. Many were effective. Yet successful strategies rarely spread from one province or territory to another. And when the pilot projects ended, usually their impact did too.

## The solution

The Partnership launched CLASP (Coalitions Linking Action and Science for Prevention) to capitalize on this growing evidence and experience. A unique funding opportunity, CLASP created 12 partnerships among more than 100 government, health, education, community and business organizations across Canada. The goal was to build on successful prevention strategies that reduce the risk of cancer and other chronic diseases, and do it in a way that would last.

The approach was unusual in many ways. Rather than research new strategies, initiatives were asked to develop and test strategies based on existing knowledge of what worked. To break down geographic barriers, initiatives had to involve at least two provinces or territories. And all project teams would include researchers, policy-makers and people working in the field, so research could guide program and policy decisions, and real-world experience could feed directly back into improving the strategies.

## WHAT WE'VE ACHIEVED



**Cross-country impact.** More than 1,600 locations — municipalities, schools, workplaces, hospitals and community centres — benefitted from new programs, policies or organizational change.



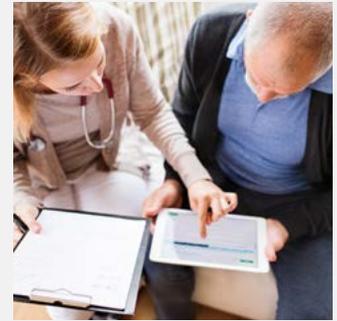
**Cities designed for active living.** Thanks to CLASP, municipalities across the country have integrated health priorities into transportation and land use policies. The result will be cities and communities designed to get people walking, biking and taking public transit.



**Policy and practice changes that make a difference.** CLASP initiatives have led to more than 5,600 practice changes and over 520 policy changes that support healthy behaviours and increase access to healthy environments.



**Healthier food environments.** Initiatives worked with schools across the country to make healthy eating the easy choice. Examples include school policies to promote local and fresh produce and school-based gardens in First Nation communities.



## SPREADING A SUCCESSFUL PREVENTION MODEL

Family doctors know the importance of helping patients reduce their risks for cancer, heart disease and diabetes. But doctors juggle many demands, and often don't have time to help patients make the needed changes. A CLASP-funded initiative among primary care teams in Alberta and Ontario tried a different approach.

The BETTER Program trained a nurse practitioner, nurse or dietitian as the team's "prevention practitioner." Patients who could benefit from a more targeted approach were identified and given a one-to-one session to create their own "prevention prescription." The prescription, or wellness plan, identified needed lifestyle changes and screening tests and gave the patients the tools and support to achieve them. For example, they might be referred to a smoking cessation program or a dietitian, sent for mammography or given a home testing kit to screen for colorectal cancer.

The approach worked. Patients in the program were two and a half times more likely to reach their prevention and screening targets than other patients. Based on this success, the Partnership is now working with other provinces to roll out the model.



## How Canadians benefit

CLASP has changed how cancer and chronic disease prevention is carried out in Canada. Collaboration across organizations and jurisdictions is the new standard and has created fresh momentum in cancer prevention. Groups now have structures in place to support joint action, leading to new initiatives and additional funding to sustain their efforts.

For Canadians, changes are happening at the local level. Cities and towns are designing neighbourhoods to encourage physical activity.

And workplaces are creating sun safety programs for their outdoor workers. It all adds up to healthier lifestyles and means fewer Canadians will develop cancer in the future.

## What's next?

The Partnership will focus on areas of cancer prevention where shared action across the country at the local, provincial and territorial level can have the greatest impact. In particular, the Partnership will continue its efforts in tobacco cessation and begin work to address alcohol consumption as a risk factor for cancer. The Partnership will also work with Health Canada and CAREX Canada to reduce Canadians' exposure to radon at home and in the workplace. This naturally occurring gas concentrates in basements and is the second leading cause of lung cancer.

A portrait of Dr. Huiming Yang, an elderly woman with short, curly grey hair, wearing a purple long-sleeved shirt. She is looking slightly to the right of the camera with a gentle smile. The background is a soft-focus outdoor scene with greenery and a light sky.

“The Partnership has been an agent of change and helped to improve collaboration and communication between provinces and territories. The screening networks help us with insight into how effective Alberta’s screening practices are compared to other parts of Canada.”

**Dr. Huiming Yang** is the Medical Director, Screening at Alberta Health Services.

# IMPROVING THE QUALITY OF CANCER SCREENING

## The challenge

Cancer screening is a complex puzzle. Who should be screened, how often and for what cancers? How do we make the experience as convenient and stress-free as possible? How do we balance the benefits of finding cancers early with the risks of unnecessary tests or treatments? Determining the right answers can be a challenging and time-consuming process. And the science is constantly evolving.

For years, each province and territory wrestled with the same questions, spending time and money trying to find the best answers. Meanwhile, there was no way to compare and assess screening programs across the country to identify areas for improvement. Were Canadians being screened for cancer as they should be? No one could say for sure.

## The solution

To address these challenges, the Partnership created national screening networks for cervical, colorectal and lung cancer and took on responsibility for the breast cancer network. Representatives from across the country now meet on a regular basis to discuss what’s working and what’s not and to review new scientific evidence as it emerges. They compare data from their screening programs and problem solve together. And they use OncoSim, the Partnership’s sophisticated microsimulation tool, to project the costs and impact of various policy decisions. (See page 18)

The Partnership and network members also track and evaluate the quality of their screening programs to ensure decisions benefit as many Canadians as possible. The Partnership reports on performance using data collected by the networks and the Public Health Agency of Canada, allowing the provinces and territories to compare their performance against national guidelines and make changes to improve. This focus on guidelines is critical to ensure decisions on screening are based in evidence.

## WHAT WE'VE ACHIEVED



**Better access to screening.** The Partnership's collaborative approach helped network partners roll out screening programs for colorectal cancer across 10 provinces in just three years. That's a new record: it took 10 years for breast cancer and 50 for cervical cancer.



**New evidence adopted faster.** The Partnership worked with partners and experts across the country to review new evidence on the effectiveness of screening people at high risk for lung cancer. Three provinces are now exploring the feasibility of screening programs for this population.



**More Canadians screened.** 1.3 million more Canadians were screened for colorectal cancer in 2014 than in 2008 when the first colorectal cancer screening programs launched.



### How Canadians benefit

Thanks to this new way of working together, provinces and territories benefit from each other's experience in cancer screening and avoid duplicating efforts. Quality is monitored across the system and provinces and territories work to accelerate the uptake of national screening guidelines. The result is fewer unnecessary screening and follow-up tests and significant savings to the health care system.

But individual Canadians stand to gain the most. Evidence-based screening can help prevent some cancers and catch others early when they are highly treatable. That means less aggressive treatments and shorter hospital stays. More importantly, it can lead to better outcomes and a better chance of survival.

### What's next?

While more Canadians now have access to the screening they need, new immigrants, individuals with low incomes, people who live in rural Canada and First Nations, Inuit and Métis do not have the same access as others across Canada. The Partnership is committed to working with the provinces and territories to address this disparity. Quality will remain a focus, with new initiatives to improve the experience for patients and enhance the cost effectiveness and impact of screening programs. Working with the networks, the Partnership will also participate in new initiatives such as the global effort to eliminate cervical cancer.



## BRINGING NEW RESEARCH TO SCREENING

Researchers now know that certain types of human papillomavirus (HPV), a sexually transmitted infection, cause cervical cancer.

Fortunately, a reliable test for HPV is now available. Even more significant in the long term, Canadian children from grades four to seven are now immunized against HPV.

These advances have major implications for cervical screening programs. Should HPV testing become the new screening standard? And if young women have been vaccinated, what will that mean for their cancer risk and need for regular screening?

Provinces and territories are looking at these and other questions through the Pan-Canadian Cervical Cancer Screening Network. The answers will shape screening programs over the next decade.

“Synoptic reporting improves cancer care and cancer control by providing clinicians and epidemiologists with complete information. The Partnership’s leadership and funding to implement electronic synoptic reporting in six provinces is improving treatment outcomes for patients in these jurisdictions. We hope to expand to more provinces and territories in the coming years to give more Canadians with cancer the chance to benefit from these practices.”

**Dr. John Srigley** is Expert Advisor, Pathology, Canadian Partnership Against Cancer.



# STANDARDIZING DATA TO IMPROVE OUTCOMES

## The challenge

Good cancer care depends on good information. Details such as the size of a cancer tumour and the stage, or spread of the cancer, are critical to choosing the best treatment options for each patient and predicting the likely course of the disease.

Until recently, this information was not collected and reported in any standardized way. Surgeons and pathologists dictated their reports, which were then transcribed. As a result, the structure of the reports varied, and information was often missing or unclear. Without standardized electronic data there was no way to identify and track differences in care and outcomes between health professionals, hospitals or provinces.

The lack of standardized cancer stage data was a particular problem. Stage data was not gathered and reported consistently across the country; without it, important questions went unanswered. For example, patients with breast cancer were living longer in some provinces than in others. Was it because a different approach to screening meant cancers were found earlier? Or was it because patients with more advanced cancer received a different type of chemotherapy? The answers were waiting in the data.

## The solution

With a major investment in infrastructure by the Partnership, cancer agencies began collecting and reporting stage data in a consistent electronic format for the four most common cancers in Canada — breast, colorectal, lung and prostate cancer. The Partnership also funded and supported the rollout of electronic synoptic reporting for surgery and pathology across the country. Synoptic reporting uses a structured checklist that ensures that information is accurate, complete and consistent with guidelines and best practice.

Trends and patterns can now be identified and monitored, and important questions asked and answered. In particular, the reasons for different patient outcomes across provinces can be analyzed and the information fed back to decision-makers and health professionals to take action.

## WHAT WE'VE ACHIEVED



### **Broad uptake across the country.**

Six provinces have implemented electronic synoptic pathology reporting and approximately two-thirds of Canadian pathologists now submit their reports electronically.



**Faster report turnaround.** Reports are created and sent electronically, so health professionals get faster access to the information they need to guide care. When synoptic reporting is in place, more than 97 per cent of surgical reports are now available in 24 hours, compared to 15 per cent previously.



### **How Canadians benefit**

Standardized data gives health professionals better and faster information to help them provide better care. For system leaders and decision-makers, the data make it possible to monitor and evaluate the quality of cancer care. Better yet, it shines a light on patient outcomes



### **Standardized data to drive action.**

Nine provincial cancer registries are collecting and reporting stage data for over 90 per cent of breast, colorectal, lung and prostate cancer cases compared to only four registries in 2007. By monitoring and comparing data, provinces can see where to focus their quality improvement efforts.



**Reduced variations in practice.** In Ontario, synoptic pathology reporting data highlighted a high rate of positive margins for prostate cancer surgery (indicating that not all of the cancer was removed). The dissemination of this information supported by regional workshops with surgeons and pathologists from across the province led to a reduction in the rate from 34 per cent in 2008 to 21 per cent in 2011.

and allows everyone involved in the cancer system to see where and how improvements can be made. For Canadians, that means better cancer care.

### **What's next?**

Despite progress, Canada has yet to tap the full potential of standardized data collection and reporting to improve quality of care for every patient. To address this gap, the Partnership will focus on helping health professionals, cancer centres and provinces to use synoptic data to improve patient care and outcomes and reduce variations in care.



## IMPROVING CARE WITH BETTER REPORTING

When treating patients with colon cancer, it's important to know whether the cancer has spread to the surrounding lymph nodes. This information tells the oncologist the stage of the cancer and what treatment is needed.

Correctly identifying the cancer stage means patients who need chemotherapy will get it, while those who don't can be spared the treatment and its side effects. It also improves survival rates.

Clinical guidelines recommend that surgeons remove 12 or more lymph nodes during surgery to check whether the cancer has spread and allow pathologists to stage the cancer accurately. The good news is that more and more surgeons are doing just that. A recent Partnership report shows that the per cent of colon cancer surgeries across the country meeting that target increased from 73% in 2009 to 85% in 2011.

Electronic synoptic pathology reporting is part of that success story. Better reporting allowed surgeons and provinces to compare their results, see where improvement was needed and take action.



“Embedding First Nations, Inuit and Métis perspectives in BC’s cancer system was necessary to ensure the province prioritized becoming a leader in culturally safe cancer care. We fostered effective working relationships between Métis Nation British Columbia and BC Cancer and the Partnership provided valuable support in our journey together to improve experiences of Indigenous patients and survivors.”

**Ashley Turner** is Provincial Wellness Coordinator, Métis Nation British Columbia.

# ADDRESSING INEQUITIES IN CANCER CARE FOR FIRST NATIONS, INUIT AND MÉTIS

## The challenge

Cancer rates among First Nations, Inuit and Métis are growing faster than among the general population. Yet a decade ago, the cancer system had done little to identify and address the needs of First Nations, Inuit and Métis in Canada.

Individuals in remote communities face long travel times to access cancer services, close to 30 hours for those living in northern communities. Far from their families, patients often receive care that does not reflect their culture, values and traditional practices. At a system level, there are major gaps in data because some provinces and territories do not record whether a patient is First Nations, Inuit or Métis, and many patients are reluctant to self-identify due to racism and negative experiences in the past.

## The solution

To find a way forward, the Partnership began a comprehensive process to consult and work with First Nations, Inuit and Métis to determine how to address cancer care priorities. The work was guided by the Partnership’s National Indigenous Organization Caucus, which included representatives from the Assembly of First Nations, Inuit Tapiriit Kanatami and the Métis National Council. The result was the first-ever *Action Plan on First Nations, Inuit and Métis Cancer Control*.

The Partnership also began to fill the data gap with baseline reports that described the cancer journey of First Nations, Inuit and Métis, shining a light on inequities and identifying opportunities for action. Across the country, Partnership-funded initiatives began to build new relationships between cancer agencies and First Nations, Inuit and Métis partners as they worked together to make cancer services more culturally appropriate and accessible. Through national gatherings, learnings from these and other efforts were shared among partners, patients, communities and organizations working to improve the cancer experience of First Nations, Inuit and Métis.

## WHAT WE'VE ACHIEVED



**A roadmap for change.** An action plan of shared priorities was created with First Nations, Inuit and Métis stakeholders, including patients, community leaders and governments and organizations involved in health and cancer control.



**Identification of gaps and barriers.** Three baseline reports were developed, creating the first comprehensive picture of cancer care among First Nations, Inuit and Métis and revealing inequities in areas such as accessing care and financial burden.



**Strengthened relationships.** Through 10 funded initiatives across the country, new collaborative relationships were initiated between cancer agencies and First Nations, Inuit and Métis partners. New resources were also created to improve the patient journey for First Nations, Inuit and Métis living in rural, remote and isolated communities.



### IMPROVING CANCER CARE FOR FIRST NATIONS AND INUIT

Conversations. Listening. That's how the Northwest Territories (NWT) began its work to improve the experience of First Nations and Inuit cancer patients.

The Partnership-funded initiative focused on building relationships between First Nations and Inuit communities and health care providers, and on providing better support for patients and families throughout the cancer journey. Sharing circles provided the starting point.

Held across the NWT, these discussions brought together cancer survivors, community members and health care providers. For many of the participants, talking about cancer was difficult. The sharing circles provided them with a safe space to speak about their fears and about their need for care that recognizes and respects their culture. Participants raised other concerns too, including lack of access to cancer services and the challenges patients face when they return to their communities after treatment.

The conversations have already led to action. The Northwest Territories now has its first comprehensive cancer strategy — a strategy that reflects the priorities and concerns of all NWT residents.



### What it means for Canadians

A critical foundation is now in place to improve the cancer journey for First Nations, Inuit and Métis. The first action plan and the initiatives that grew from it were important steps in meaningful engagement with First Nations, Inuit and Métis organizations and communities. However, much work remains to address the inequities within the cancer system.

### What's next?

Over the past decade, there have been many improvements in cancer control. But First Nations, Inuit and Métis have not benefitted from these advances as much as others across the country. The Partnership will continue to focus on solutions that reflect distinct and self-determined First Nations, Inuit and Métis needs and priorities and will work with provinces and territories to support the creation of regional cancer control strategies with First Nations, Inuit and Métis. The Partnership's relationships with First Nations, Inuit and Métis also continue to evolve through efforts to establish strong bi-lateral relationships to facilitate future work.



“The data we received from CPTP has helped answer research questions we could not have in the past. Cancer and other disease researchers around the world will be able to use these data sets to gather important pieces to these puzzles, which may lead to significant advances in disease prevention.”

**Dr. Aaron Drucker**, Scientist, Women’s College Research Institute; Dermatologist, Women’s College Hospital; Assistant Professor, Division of Dermatology, Department of Medicine, University of Toronto.

# ACCELERATING CANCER RESEARCH

## The challenge

Why do Canadians in some parts of the country have higher rates of cancer than others? What role do genetics, environment and lifestyle habits play? To answer these and other questions, researchers need data from a wide range of Canadians. But recruiting research participants is an expensive and time-consuming process.

To address the problem, several provinces had started their own research cohorts, collecting health and lifestyle information from volunteer participants. But each province gathered different information, so researchers couldn’t combine or compare data across provinces. And without data from Canadians across the country, the potential for significant discoveries was limited.

## The solution

A coordinated, national approach was needed. To achieve it, the Partnership connected scientific leaders from across the country to create the Canadian Partnership for Tomorrow Project (CPTP).

CPTP established new population cohorts in British Columbia (BC Generations Project) and the Atlantic provinces (Atlantic PATH) and linked them with the three existing cohorts (Alberta’s Tomorrow Project, the Ontario Health Study and Quebec’s CARTaGENE). It was an immense undertaking that required the sites to recruit thousands of participants and determine how to collect information in a standardized way across the country so it could be combined and analyzed.

The result is a powerful research tool that is now one of the largest population health research platforms in the world. The database includes information from 300,000 Canadians aged 30–74 about their health, lifestyle and behaviour. Over half of the participants have also provided blood or biological samples. Using this comprehensive information, researchers can explore links between cancer or other chronic diseases and factors like genetic makeup, lifestyle and exposure to environmental toxins. Because participant data can be linked to administrative health records, researchers can also determine whether changes to policies and practices can help prevent or better manage disease.

## WHAT WE'VE ACHIEVED



### A place on the world stage.

CPTP is one of the world's largest population health research platforms and a valuable resource for researchers around the globe.



### Comprehensive, Canadian data.

More than 300,000 Canadians across the country have contributed their health and lifestyle information. Half of participants provided blood or biological samples and the DNA of almost 5,000 blood samples has been genotyped.



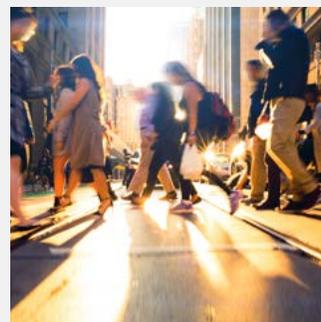
### Support to accelerate research.

Recruiting participants for a research study can take up to a decade. Access to ready-to-use data from over 300,000 individuals saves researchers time and money, allowing them to advance their research more quickly.



### Valuable research grants.

In 2015/16, researchers using CPTP were awarded two significant Canadian Institutes of Health Research (CIHR) grants for a total of more than \$6 million in research funding. Two recent CIHR grant competitions were specifically for researchers using CPTP or other existing databases.



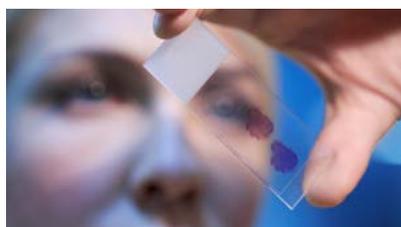
## UNCOVERING THE RELATIONSHIP BETWEEN DISEASE AND THE ENVIRONMENT

A group of scientists is using data from the CPTP database to discover how air pollution, a person's surroundings and their genes combine to affect their health.

The research is focused on metabolic syndrome (MetS), a group of conditions — obesity, hypertension, high cholesterol, high blood sugar and insulin resistance — that are common among older adults. Because people with MetS are more likely to develop diabetes and cardiovascular disease, its impact on health and health care costs is significant.

Genes, lifestyle and the environment all contribute to MetS, but their exact role remains a mystery. CPTP offers researchers a unique opportunity to find answers by providing access to blood samples that have been analyzed for various markers.

Using this information, researchers will try to discover how air pollution and surroundings contribute to metabolic syndrome, and whether these factors influence the role genetic factors play.



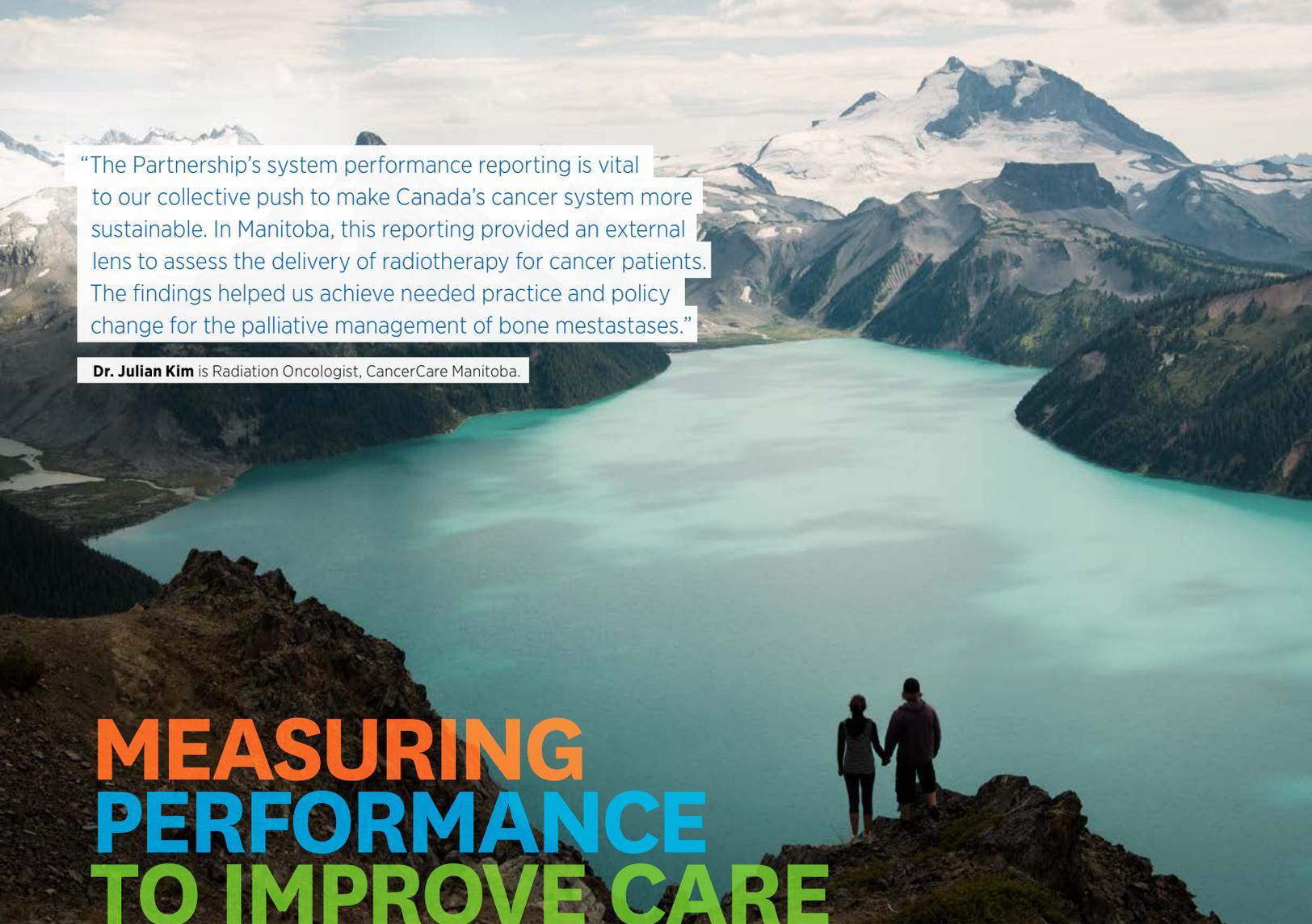
### How Canadians benefit

The creation of such a significant population cohort makes groundbreaking, made-in-Canada discoveries possible.

The data available through CPTP will also shape future priorities for the cancer system. Information about why Canadians develop cancer can be used to develop new strategies to prevent cancer or to detect it early, and options to improve cancer treatment can be explored.

### What's next?

CPTP needs strong leadership and infrastructure to expand and sustain robust scientific activity into the future. To ensure CPTP's value continues to grow, the Partnership is transferring responsibility for CPTP to a new scientific home — the University of Toronto's Dalla Lana School of Public Health. This change will ensure a strong scientific vision for CPTP. The Partnership will continue to provide the leadership needed to ensure a smooth transition and ongoing impact. During this period of transition, CPTP is already expanding to include a population cohort from Manitoba — another important step in creating a truly national research resource.



“The Partnership’s system performance reporting is vital to our collective push to make Canada’s cancer system more sustainable. In Manitoba, this reporting provided an external lens to assess the delivery of radiotherapy for cancer patients. The findings helped us achieve needed practice and policy change for the palliative management of bone metastases.”

**Dr. Julian Kim** is Radiation Oncologist, CancerCare Manitoba.

# MEASURING PERFORMANCE TO IMPROVE CARE

## The challenge

It’s hard to improve if you don’t know where the problems are.

Ten years ago, information on the quality of cancer care across Canada was largely non-existent. Data were scarce and efforts to measure quality were few and far between. As a result, there was no way to compare cancer services from one province to another. No way to know if some provinces were better at diagnosing and treating certain cancers and if so, why. And no way for Canadians to know if their cancer system was working or not.

Canada lacked a comprehensive approach to look at quality across the entire cancer journey, from screening, diagnosis and treatment — to survivorship and palliative care.

## The solution

The Partnership began by working with national partners and provincial cancer agencies to identify what data existed and could be measured. In 2009, the first system performance report was published, reporting on 14 performance indicators.

The gaps in data were enormous. But with the Partnership’s support, those gaps are being filled. Data collection has been standardized across the provinces and expertise in measurement and analysis continues to grow. Data are collected on more indicators and the reports are increasingly user-friendly, clearly showing where improvement is needed, what should be done and who should do it. Special topic reports provide deeper analysis in areas of concern, uncovering unexpected quality issues and valuable success stories.

The result? Measuring and reporting on the cancer system’s performance is driving improvement. Key to all of this work is the close involvement of leaders in provincial cancer centres, epidemiologists and cancer experts. Together, they ensure that the data is relevant, collected consistently and interpreted correctly.

## WHAT WE'VE ACHIEVED



**World leadership in performance reporting.** No other country reports and compares national performance in cancer control with the same depth and breadth.



### Improved alignment with guidelines.

Regular reporting can reveal where gaps exist between guidelines and practice. For example, a 2012 report showed that across Canada, only 55-60 per cent of older patients (aged 70-79) diagnosed with Stage III colon cancer in 2007-2009 received chemotherapy after surgery as recommended in the clinical guideline. The most recent data is beginning to show an increase in the proportion of patients treated according to guidelines.



**Reduced wait times.** Reporting wait times and sharing strategies to reduce them is making a difference. Women who have an abnormal mammogram but don't need a biopsy now get their results much faster. In just over a decade, the wait time for results in the jurisdiction with the longest waits dropped from 27 to 11 weeks for 90 per cent of women.



### How Canadians benefit

When all provinces and territories collect the same data in the same way, everyone can see how well the cancer system is working. When problems are identified, changes can be made.

Just as important, successful strategies for high quality care are now highlighted and shared across the country, promising better cancer care for all Canadians.

### What's next?

Building on this strong foundation, the Partnership will work with the provinces and territories to identify and address areas where additional data is needed to measure and assess quality and to bring about change. Data partnerships with Statistics Canada and the Canadian Institute for Health Information will enhance reporting even further, allowing the Partnership to look at factors such as geography, income and education and their impact on care. The Partnership will continue to support First Nations, Inuit and Métis partners to work alongside other leaders in data collection to better capture and use data to improve outcomes and the quality of cancer care. Above, all, the focus remains on helping the cancer community use the results of performance measurement to take action to improve the quality of cancer care.



## REDUCING UNNECESSARY RADIATION TREATMENTS

When cancer spreads to the bone, radiation can play an important role in palliative care by reducing pain. Research has shown that for patients with uncomplicated cases, receiving radiation once is just as effective as receiving it multiple times, a finding reflected in current clinical guidelines.

A 2016 Partnership report found that many patients in Manitoba and Saskatchewan were receiving unnecessary radiation. Not only did the extra radiation provide no additional benefit, it was an unneeded expense to the system.

To address the problem, the Partnership turned to partners like the Canadian Association of Radiation Oncologists, the Canadian Partnership for Quality Radiotherapy and physician champions in both provinces and extensive outreach to drive a change in practice took place. Presentations at grand rounds in the cancer centres were followed by province-wide meetings, and 85 per cent of radiation oncologists attended at least one session.

In a follow-up survey six months later, 90 per cent of the specialists who participated in the meetings said they had changed their practice.



“From a health economics perspective, the Partnership’s OncoSim model has the potential to inform all kinds of cancer-related questions and help decision-makers project impacts at the system-level. In fact, OncoSim proved invaluable in helping assess whether implementing lung cancer screening in Saskatchewan would be cost-effective for the province’s health system.”

**Dr. Erika Penz** is Respiriologist, University of Saskatchewan.

# CREATING A SUSTAINABLE CANCER SYSTEM

## The challenge

Cancer care can be expensive. And decision-makers across the country have to make tough choices about how to spend limited health care budgets. In the past, lack of information made those choices even harder. Cost projections are complex and often data didn’t exist. As a result, important decisions — whether to pay for a new cancer drug, for example — were made without knowing the long-term costs or how many lives might be saved.

The cancer system also couldn’t answer the big question: What is the burden of cancer in Canada? Experts had calculated some costs in areas such as hospital care, but little data existed on the expenses paid by patients and families, the economic costs of lost work time or the impact of cancer on people’s mental and emotional well being.

## The solution

To begin to address these gaps, the Partnership leveraged expertise at Statistics Canada and developed OncoSim, a sophisticated microsimulation tool. Using demographic, economic and health data, OncoSim can project the impact of a particular action or decision on outcomes such as cancer rates, deaths and health care costs. The tool is available for colorectal, lung, breast and cervical cancer, and the Partnership is working on an option that will project how reducing risk factors (obesity and alcohol consumption, for example) will affect cancer rates and treatment costs for all cancers.

For provinces facing tight health care budgets, OncoSim provides valuable information to help make decisions. For example, the tool can project what it would cost to increase the number of Canadians screened for colorectal cancer and how many lives it would save. Or how much survival rates for lung cancer would improve if a province invested in a screening program.

## WHAT WE'VE ACHIEVED



### **World-class model for cancer care decisions.**

Canada is now one of a few countries that can reliably project the impact of decisions in cancer prevention, screening and treatment. A state-of-the-art tool, OncoSim crunches thousands of data points to provide clear answers on the expected cost of any action.



### **More efficient and effective policy-making.**

The Partnership provides the OncoSim tool and analytical support to cancer agencies and governments at no cost to help them make informed and timely decisions about cancer care.



### **Increased analytical capacity across the country.**

The Partnership is training researchers and policy analysts across the country to use OncoSim. The tool is designed to be fully transparent so users can replicate and share projections.



## TAKING THE GUESSWORK OUT OF DECISION-MAKING

New Canadian guidelines released in 2016 recommended that adults at high risk for lung cancer be screened using low-dose CT scans. But when Nova Scotia began to consider a provincial screening program, there were many questions. Screening is costly and policy-makers needed more information to make a decision.

The province turned to the OncoSim tool. With training from the Partnership, analysts used the tool to do a comprehensive analysis. For example, they projected how many people would be eligible, how many CT scans would be required each year and what it would cost. They also looked at related issues, such as how many people would need additional testing after the initial CT scan and how often those tests would show nothing was wrong (false positives).

With the help of OncoSim, the province was able to accelerate its planning efforts and develop a comprehensive business case for a lung cancer screening program.

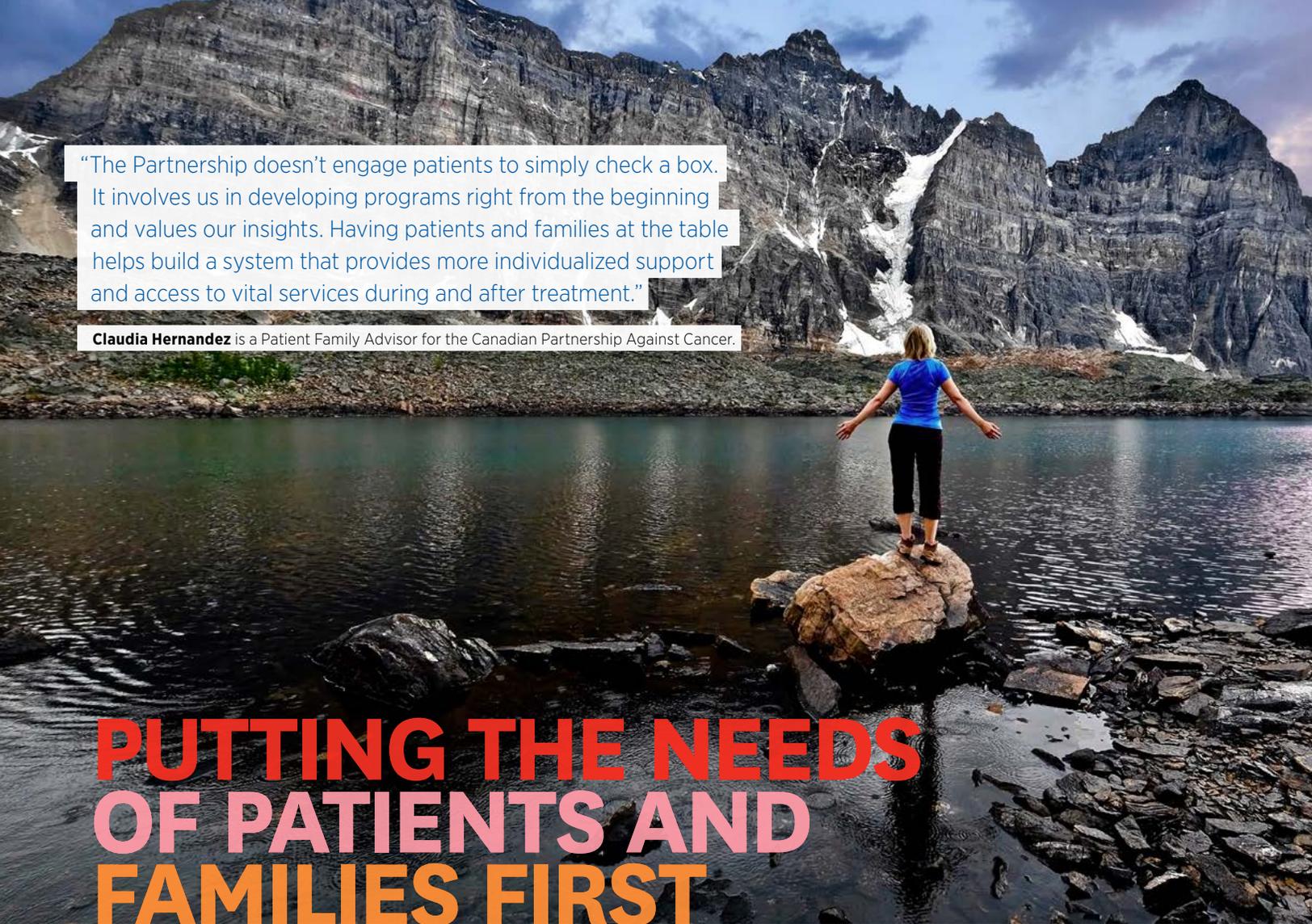


### **What's next?**

With OncoSim now in place, the Partnership is working with partners across the country to help them use the tool by providing training and support where it is needed. Over the next five years, the Partnership will also take on the challenge of calculating the full burden of cancer in Canada, including the indirect burden (such as the impact of a diagnosis on a person's earnings) and psycho-social burden (including pain and anxiety). All of this work reflects the Partnership's increased use of a health economics approach to assess the value and benefits of efforts to improve cancer care.

### **How Canadians benefit**

The chance of developing cancer increases with age. As the number of older Canadians grows, so will pressure on the health care system. Tools like OncoSim will help decision-makers achieve the best value for available health care dollars, and ensure the decisions they make on behalf of Canadians are the right ones.



“The Partnership doesn’t engage patients to simply check a box. It involves us in developing programs right from the beginning and values our insights. Having patients and families at the table helps build a system that provides more individualized support and access to vital services during and after treatment.”

**Claudia Hernandez** is a Patient Family Advisor for the Canadian Partnership Against Cancer.

# PUTTING THE NEEDS OF PATIENTS AND FAMILIES FIRST

## The challenge

The definition of good cancer care has changed dramatically over the last decade. Health professionals have learned — with the help of their patients — that good care is about more than diagnosing and treating the disease. Cancer can be overwhelming, and patients need support to find their way through the many emotional, psychological and practical issues they face.

It isn't easy to create a cancer system where the needs of people with cancer come first. But the first step is understanding those needs. And that means listening to patients and families.

## The solution

At the patient care level, medical appointments provide a critical opportunity for health professionals to hear and address a patient's needs. With that in mind, the Partnership supported the implementation of Patient-Reported Outcomes (PROs) in cancer centres across eight provinces. PROs are collected through standardized questionnaires given to

patients when they arrive for their medical appointment to gather information on symptoms like fatigue, pain, anxiety and depression. Members of the team can then address any of those concerns during the visit and put in place the care and support the patient needs.

The Partnership also began reporting on how well the cancer system is working from the patient's perspective. One report looked at the experience of adolescents and young adults with cancer. Another addressed the needs of patients who require palliative care. A third report presented data on patient experience drawn from a variety of sources, including the first large-scale study of cancer survivors across the country. More than 13,000 survivors participated in a Partnership survey on their cancer experience, their needs and how well those needs were met.

Patients are also working with the Partnership to bring the patient perspective to all aspects of the cancer system. More than 40 patient and family advisors are actively involved in Partnership initiatives, helping to drive change across the country.

## WHAT WE'VE ACHIEVED



### Better support for patients.

Sixty per cent of cancer patients across six provinces completed questionnaires on symptoms like pain and fatigue so their health care team could provide them with better care and support.



**Giving patients a voice.** In the first large-scale study of its kind, more than 13,000 cancer survivors from 10 provinces provided the Partnership with insights on their cancer experience and how it could be improved.



### Highlighting unmet needs.

A Partnership report on how patients experience cancer care revealed that many have significant physical and emotional side effects that aren't being addressed.



### A role in shaping the future.

Every year, more than 40 patient and family advisors guide the Partnership's initiatives, bringing the patient's perspective to every decision.



### How Canadians will benefit

Patients and their families must have a strong voice in designing the cancer care system they need and want for the future. By measuring and reporting how patients experience the cancer system, the Partnership brings those voices to the forefront. Guided by those voices, the cancer community can make changes to improve cancer care for all Canadians.

### What's next?

The Partnership will continue to respond to patient needs in areas such as increasing access to palliative care and improving transitions from cancer treatment to follow-up care. Work will also continue with partners across the country to expand the use of electronic PRO questionnaires so that health professionals can provide patients with better symptom management and other supports they need. And the Partnership will maintain its commitment to listening to patients and families, using activities like citizens panels (see sidebar) to give a wider range of Canadians a say in the future of cancer control in Canada.



## INVOLVING CANADIANS IN DECISIONS ABOUT DRUG FUNDING

Provincial spending on cancer drugs has risen dramatically in recent years. New cancer drugs have high price tags and the number of Canadians affected by cancer continues to rise. That means tough decisions in the future, as policy-makers have to choose which drugs to fund.

In 2016, the Partnership held six citizen panels across the country to give Canadians a say in how these complex decisions should be made. More than 100 people with different life experiences and backgrounds were recruited to participate, including cancer survivors and caregivers.

Together, they developed 86 recommendations. Some recommendations focused on the principles and types of evidence that should guide decisions about which drugs to fund. Others emphasized the importance of a transparent decision-making process. All participants were concerned that Canadians have equitable access to cancer drugs no matter where they live.

The recommendations will be shared with organizations involved in decisions about cancer drug funding, including ministries of health across Canada.

# THE NEXT 10 YEARS

Canada will continue to face new challenges and pressures in cancer control over the next decade. Innovative cancer treatments are improving care, but raising questions about what our public health system can afford and how those decisions will be made. The demand for cancer services is growing as our population ages. And there is an urgent need to improve cancer care and outcomes for Indigenous peoples and other vulnerable groups.

A refreshed *Canadian Strategy for Cancer Control* is needed. Over the coming year, the Partnership will work with the cancer community, people affected by cancer and the public to determine priorities for the future and ensure Canada can respond to emerging priorities as they arise. With their help, we will continue to build and strengthen cancer care in Canada.

