



Partnerships in Action

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“Collecting this data helps to provide a snapshot of how well a province’s cancer system is performing. This information also helps us to understand interprovincial variation and provides a strong incentive for provinces to assess how they can capture and share information to improve Canada’s cancer system as a whole.”

– Sharon Smith
Director, Cancer Care Program,
Eastern Health

Measuring progress to help drive improvements in cancer control

New *2010 System Performance Report* highlights ongoing collaboration to address gaps in cancer control

Optimizing the cancer control system for Canadians is at the heart of the Partnership’s work. But unless it is clear how well the cancer control system is performing, it is difficult for cancer agencies or other partners to know where to focus any improvement efforts. In response to this challenge, the Partnership developed the System Performance Initiative, a pan-Canadian approach to reporting on performance across the cancer control continuum.

The System Performance Initiative is a collaboration among the Partnership and the provincial cancer agencies.

The initiative collects data from many sources, including the provincial registries, the provincial cancer partners, and Statistics Canada. It brings together existing cancer-related data from across the country and makes this information available as a baseline for measuring progress. Overall, it will help to shape the planning and delivery of the entire cancer control system, from prevention, screening and diagnosis to treatment, supportive care and survivorship.

Results are shared with provincial cancer agencies and health ministries as the Report is developed, and their feedback shapes the report’s final presentation.

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MEASURING PROGRESS...Cont'd from first page



“Having good data and using it effectively are critical to improving quality in the cancer system,” says Dr. Carol Sawka, VP of Clinical Programs and Quality Initiatives, Cancer Care Ontario. “Thanks to the collective work of the provinces, we now have the first set of pan-Canadian indicators to drive performance from coast to coast. Led by the Partnership, this work will help guide better decision-making.”

While there are many ways in which the performance of the cancer system can be assessed, consultation at a pan-Canadian level resulted in the identification of an initial set of 17 indicators for the first-ever report on the performance of Canada’s cancer control system. Entitled *The System Performance Initiative – A First Year Report*, it was published in October 2009 and included background on the initiative’s first year and how the indicators were developed.

Building on the inaugural report, *The 2010 System Performance Report* will shortly be released. The 2010 report expands on existing indicators and includes new ones that focus on diagnosis and treatment, areas the cancer control community identified as gaps in indicator reporting.

The report presents inter-provincial data, time trends and data on demographic and socio-economic determinants of health across Canada. It also includes two special sections: one on colorectal cancer, which evaluates system performance for this cancer site along the continuum of care and outcomes; and one on radiation therapy, which reports on measures of capacity, utilization, wait times and guideline concordance.



“The System Performance Initiative is based on the knowledge that systematically measuring and reporting on cancer control and health-care delivery is crucial to improving the system,” says Dr. Heather Bryant, the Partnership’s VP of Cancer Control. “While *The 2010 System Performance Report* does not intend to deliver definitive conclusions on the performance of the system, it promotes discussion on indicator results and helps to identify priorities for action at the provincial and national levels.”

Going forward, the System Performance Initiative will continue to collaborate with the provinces and leverage expertise from the pan-Canadian System Performance Working Group and stakeholders across the country to deepen findings from the 2010 report.



“Data helps us to see how well the cancer control system is working and identify what areas to focus on,” says Mary Spayne, the Partnership’s Director of System Performance. “Through an ongoing collaborative process with partners across the provinces and territories to measure performance and identify gaps, we are working together to provide critical baseline information, which will drive quality improvements throughout cancer control.” ■



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Video interviews with cancer patients like Lindsay give health-care professionals a unique inside view of what it's like to be a cancer patient.

Online video series provides insights into cancer experience

New resource on Cancer View Canada offers a range of insights to benefit cancer patients and health-care providers

The cancer journey is not an easy one—just ask anyone who has experienced it. But understanding the challenges that come with a cancer diagnosis can help patients to cope and health professionals to provide better care.

A new online video series aims to do just that. Available on the Cancer View Canada portal (www.cancerview.ca), *The Truth of It* is one of many Partnership initiatives with the goal of improving people's cancer experience and strengthening the cancer system's ability to address human needs. It is the first pan-Canadian online video series to document a range of powerful stories from cancer patients sharing their experiences in their own words.

Every person's cancer journey is unique but common themes present valuable opportunities to offer support, according to Dr. Michael Evans, who collaborated with the Partnership on the series. He is a family physician and Director of the Health Design Lab at the Li Ka Shing Knowledge Institute at St. Michael's Hospital in Toronto.



"In marrying technology with stories, *The Truth of It* enables people to engage with other Canadians whose experiences resonate with their own," says Dr. Evans.

"As a result, people may feel less alone at a difficult time."

At the same time, *The Truth of It* is designed to meet the information needs of professionals, researchers and policy-makers. "These interviews highlight emotional health and well-being and quality of life as important aspects of cancer care," says Dr. Margaret Fitch, a psychosocial expert who chairs the Partnership's Cancer Journey Advisory Group and is co-lead of the Patient and Family Support Program at Sunnybrook's Odette Cancer Centre. "These videos give health-care professionals a unique inside view of what it's like to be a cancer patient."

In addition to full-length interviews, viewers may choose to watch compilations of interview clips, organized by theme, that offer varying perspectives on common challenges faced by cancer patients and their families. These videos cover a wide range of issues that arise at various stages of the cancer journey – from receiving the diagnosis, telling friends and family, talking to kids and being your own advocate, to issues of body image, coping and practical advice.

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In this video interview, Doug opens up about his experience with cancer.

ONLINE VIDEO SERIES...Cont'd from page 3

One of the patients featured in the video series is Lindsay, who was training to be a nurse when she was diagnosed with acute lymphoblastic leukemia in 2006 at age 29. Her treatment to date has included chemotherapy, a stem-cell transplant, full-body radiation and spinal-tap radiation.

In her video, Lindsay speaks candidly about reactions to her diagnosis. "Although there is no one common experience in coping with a cancer diagnosis, the video series helps people to learn from others who have been there too," she says. She now works for the Leukemia Lymphoma society with outreach programs and support services.

Others may relate to Doug, who was diagnosed with prostate cancer in 2001 at age 49. He is now dealing with a recurrence with metastases that surfaced five years after his initial diagnosis, and he hopes *The Truth of It* will help others to cope. "I have benefitted greatly from reading about the experiences of others on their cancer journeys," says Doug. "The use of video to share these stories adds a much more intimate dimension that I can relate better to, and that others may find useful as well."

The Truth of It aims to meet Canadians' information needs by sharing the experiences of people with a range of attitudes, backgrounds and experiences – diversity that reflects the vastly differing realities of the thousands of Canadians affected by cancer.

The men and women featured in the videos range in age from 20 to 73 and are affected by different types of cancer, including breast, colorectal, lung, testicular and ovarian. Videos are available in both English and French and are accompanied by complete transcripts. Currently, the series has 42 videos, including interviews with six patients from First Nations communities and two interviews with patients from Inuit communities. ■

To view *The Truth of It* videos, visit www.cancerview.ca/thetruthofit.



www.cancerview.ca/thetruthofit



National Staging Initiative a win for cancer control system and Canadians

Standardized stage data will help with cancer control planning and save lives

How do we know if cancer screening programs are finding the disease earlier? How do we know which treatments are helping people live longer?

These are some of the questions that the National Staging Initiative will help to answer. A milestone 20 years in the making, it will result in the standardized collection of cancer stage information across the country for the four most commonly diagnosed cancers: prostate, lung, breast and colorectal, which will account for 94,600 new cancer cases in 2010 alone.¹

Through participation from provinces, territories and national partners, the National Staging Initiative represents a \$20 million infrastructure and technology investment by the Partnership.

Cancer stage is an assessment of the extent to which cancer has spread to other parts of the body at the time of diagnosis. There are four possible stages for any type of cancer. Doctors use stage information to assess the probable course of a patient's disease and plan treatment. When stage data is standardized and gathered for an entire population, as it will be through the National Staging Initiative, health-care planners and policy-makers can use the information to gain deeper insight into trends such as incidence, mortality and survival, which can help to evaluate and improve the cancer control system.

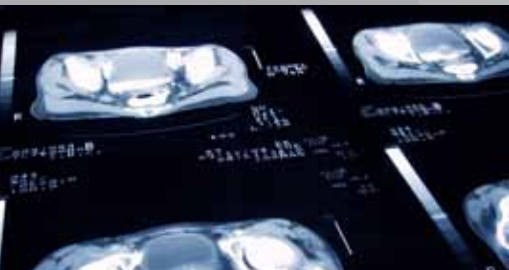
While provincial cancer registries have been collecting cancer data for years, the National Staging Initiative provides a way to share common language for reporting stage data. As a result, data can be shared across jurisdictions and used to enable a deeper understanding of cancer

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“With investment and support by the federal government and collaboration among provinces and territories and non-governmental organizations, the National Staging Initiative will generate better data and better evidence – which will improve the cancer system and ultimately save lives.”

– the Honourable Leona Aglukkaq, federal Minister of Health



How do we know if cancer screening programs are finding the disease earlier? How do we know which treatments are helping people live longer?

NATIONAL STAGING INITIATIVE...Cont'd from page 5

in Canada, while also enabling provinces and territories to use the information for their own planning purposes.



For patients, the initiative translates into improved outcomes. "This type of information can be put to practical use for Canadians by driving changes that will result in more effective detection, diagnosis and treatment," says Archie McCulloch. A Stage 3 colorectal cancer survivor, he is a member of the Canadian Cancer Action Network, a volunteer-driven organization dedicated to ensuring patient interests remain a key priority on the national cancer agenda.



"The strength of the National Staging Initiative is that it builds on what currently exists in the provinces," says Heather Logan, Executive Director of the Canadian Association of Provincial Cancer Agencies. "This major step forward in cancer control is the result of many years of hard work by Canada's cancer control community. There has always been the will for a standardized collection system for cancer stage data, and now we have the right combination of partners and resources to make it a reality."

This coordinated work among provincial cancer agencies and health ministries, the Canadian Council of Cancer Registries, Statistics Canada, the Public Health Agency of Canada and the Canadian Association of Pathologists is a powerful example of collaboration, as it draws on long-standing sources of important cancer knowledge in Canada. Currently, provinces are leading their implementations based on what already exists in their jurisdictions and contributing financial and in-kind resources as needed. The three territories will report stage data through the provincial cancer registries.



"The collection of standardized stage data will provide a more complete picture of cancer in Canada," says Lee Fairclough, the Partnership's VP of Knowledge Management.

Through the National Staging Initiative, stage data is being collected for prostate, lung, breast and colorectal cancers diagnosed January 1, 2010, or later, with a goal of collecting national standardized stage data for 90 per cent of these cases. It is expected that this data will be available beginning in 2012. ■

¹ Canadian Cancer Society's Steering Committee: *Canadian Cancer Statistics 2010*. Toronto: Canadian Cancer Society, 2010, p. 12.

For regular updates from the Partnership, sign up for the monthly e-Bulletin at: www.partnershipagaincancer.ca

Canadian Partnership Against Cancer
1 University Ave., Suite 300
Toronto, ON M5J 2P1

info@partnershipagaincancer.ca
1-877-360-1665

This newsletter is intended as a twice-yearly update on the Partnership for all individuals and organizations in the cancer arena in Canada.

Production of this newsletter has been made possible through a financial contribution from Health Canada. The views expressed represent those of the Canadian Partnership Against Cancer. Ce bulletin est disponible en français.

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