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# Healthcare Quarterly

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# Improving Quality and Performance in Ontario's Cancer Services: Lessons for Constructing a Learning Healthcare System

Terrence Sullivan

## Abstract

**Cancer Care Ontario as a provincial agency has undergone a significant transformation in the last 10 years. This paper documents a predictable crisis of radiotherapy capacity at the turn of the millennium, creating an imperative for transformative change. This transformation occurred included a divestment of existing cancer centers to large local host hospitals while retaining service obligations through a financial, quality and performance contract. The paper documents the simultaneous introduction of quality and access measures and the creation of a continuously evolving improvement panel of metrics which underpin the performance of local centers and population-wide reporting of Cancer Control. The recent successful expansion to include renal services is referenced.**

## Ontario's Cancer Services in Historical Context

The story of Cancer Care Ontario (CCO) is rooted in its early origins as the Ontario Cancer Treatment and Research Foundation (OCTRF, a thumbnail history is sketched briefly in Appendix A [see [www.longwoods.com/content/24002](http://www.longwoods.com/content/24002)]). Some of the early evolution and more recent challenges are documented, respectively, by Cowan (2008), Hayter (1998) and Sullivan et al. (2003).

The history of relevance begins with the discovery of radium, the appointment of a provincial medical registrar for cancer and the creation of a small number of regional cancer centres co-located on the site of academic health science centres, but housed separately and governed separately from the hospital

services on which much ancillary care was dependent. Following the Cody Commission recommendations (1932), OCTRF came into existence through an act of the provincial legislature in 1943, and the statute remains the governing legislation to this day.

The policy legacy of this early organization was to create a cancer system with a strong radiation oncology orientation with little attention to surgery and no real structure for the broader arsenal of cancer control. These early arrangements created what political scientists call institutional "lock in," which results in durable institutional designs that are challenging to change (Pierson 2000). While the original institutional designs of OCTRF were suitable to the management and controlled introduction of radium as a source of treatment for cancer, the unintended effect of this design was to create very significant resistance to the evolution of mature, multi-disciplinary approaches to cancer control from prevention to palliation.

## Predictable Emergence of an Access Crisis in Radiation Oncology

Starting in the early 90s, there was concern within the agency that the expansion of radiation capacity within Ontario (and many other provinces) was not sufficiently fast or large enough to respond to the epidemiologically inevitable and dramatic rise in cancer cases largely associated with a growing and aging population.

The work of the cancer agency at that time began in the late 90s in earnest to deal with multiple crises (inadequate supply of

a range of professionals and technical staff, insufficient capital investment in radiation treatment machinery and inadequately short hours of operation). The consequence was inevitable, as clinicians properly decided that patients with several types of cancer were waiting too long for treatment, a re-referral office was established at CCO to expedite referrals between centres with long waits and centres with shorter waits, as well as to offer treatment in neighbouring border cities within the United States. In addition, a privately managed team led by Dr. Tom McGowan established under contract with CCO, an after-hours radiation treatment program at Sunnybrook Hospital to improve the internal re-referral process within Ontario, as many cancer patients were unable or unwilling to travel to the United States for treatment. All centres began running longer hours to deal with the backlog. Compounding the challenges, Princess Margaret Hospital (PMH), the largest and most research-intensive cancer centre in Canada, was not integrated with the family of CCO cancer centres within Ontario.

Viewed in retrospect, this crisis was in no small measure tied to the reluctance of successive provincial governments of all stripes to deal with the expensive capacity expansion required in the cancer sector. It was tied also to the apparent inability of the agency leadership to convey, directly and responsibly, to the public, the scale of imminent crisis as a way to motivate appropriate political action to rapidly enlarge capacity.

In June of 2001, when I joined CCO as vice president of prevention and cancer control, the front-page headlines in major Ontario newspapers announced that the province had decided to dismantle the cancer agency because of the serious political fallout arising from its inability to care for the population it was intended to serve. Predictable public outcry ensued against such a dismantling, and a committee of wise people was assembled to provide guidance on how to refocus the agency in a more solution-oriented fashion. In late 2001, Alan Hudson was asked to chair the Cancer Services Implementation Committee (CSIC) and gave able leadership to the development of a set of recommendations to improve cancer services within Ontario (Hudson 2001). Shortly after the release of this report, Dr. Hudson was appointed the CEO of the agency, until the fall of 2004 when he stepped out of the CEO role to lead the provincial wait-time strategy as part of a transformation team established by the Premier of Ontario. I was appointed CEO in the fall of 2004.

The CSIC report laid out a number of areas for transformation and improvement, and we worked vigorously to refine the redesign details as we moved over the course of two years. These included the divestment of assets and staff to regional hospitals through a complex legal and administrative transfer. The arrangement had elegant simplicity administratively. The agency transferred these assets to the hospitals through a master service agreement that allowed the agency to continue holding

the funding levers for the services, and hospitals agreed to certain performance and data delivery obligations as part of the agreement. In a short period of approximately 18 months, the agency moved from a service delivery organization to a fund-holding agency with a strong focus on quality and performance, with purchasing authority for cancer services within Ontario. The story of getting the transfer done was well-told in a short piece by Thompson and Martin (2004) and the overall transformation by Sullivan et al. (2005). We took counsel from Ken Kizer early on his pace-setting experience within the Veterans Health Administration system in the United States as we pushed forward the reform of cancer services in Ontario. Ken Kizer advised we get the right folks on the team to make the transformation, and he also advised us to document and study the transition from the “old” CCO with a narrow focus on radiation and chemotherapy, to the “new” CCO with a broader focus on disease control from prevention to palliation, with a carefully instrumented series of metrics.

### **Reengineering Cancer Services**

One of the early tasks that the “new” CCO undertook was to establish a Quality Council, which to this day plays a quasi-independent role in capturing and reporting publicly on performance metrics across the spectrum of cancer control, to drive necessary improvements. It also ensures that the public and policymakers have visibility into the real performance of their cancer services with independent input from members of the quality council. To the best of my knowledge, the Cancer System Quality Index was the first jurisdiction-wide reporting on a comprehensive set of clinically vetted cancer system performance and quality measures, informed by an earlier stock-taking of the problems in performance and access (Sullivan et al. 2003; Greenberg et al. 2005).

With the realigned accountability and contract agreements in place and an initial picture built on the quality of care and performance, the first provincial three-year cancer control plan in Canada was rolled out in 2005 to address the major capacity problems in the sector and build out a more comprehensive cancer control plan that spanned the spectrum.

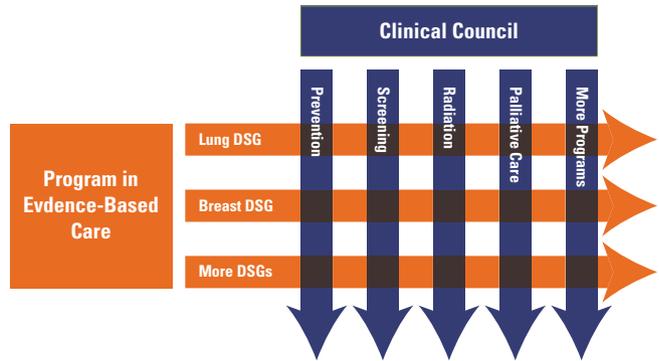
This plan called for and detailed a very expensive capital program to grow the number of cancer programs in Ontario from 7 to 14, which were aligned to regional boundaries established for local health integration networks in Ontario. This expansion, supported very actively by the provincial government as laid out in the 2005 plan, is more or less complete. It has resulted in a large expansion of roughly 50%, which closes the gap in provincial radiation capacity. Moreover, the technology has been upgraded to intensity-modulated radiation therapy to create more precise targeting of disease in radiation medicine.

Following Ken Kizer's advice, the executive structure of CCO was realigned around three important councils and

there was a more or less complete turnover in the executive leadership. The councils comprised the Quality Council noted earlier, which assembles and reports publicly on a provincial and regional picture of performance and quality; and a new Clinical Council to ensure engagement of specialty discipline and disease site leaders; a regional Provincial Leadership Council that brings the regional vice presidents together to align overall planning, performance measurement and reporting activities and to ensure continued momentum to link access and quality metrics to executive accountability regionally and provincially. The then chief of operations at Princess Margaret Hospital (Dr. Bob Bell) was selected to chair the Clinical Council, effectively integrating Princess Margaret Hospital with all the other cancer centres in Ontario for the first time. This ensured that all cancer centres in Ontario had full and active participants in the provincial cancer control agency and in population-based cancer control. There has been no looking back.

The Clinical Council was and remains a central vehicle to ensure that medical, radiation, and surgical oncology developed improvement plans and targets. As part of the reform, the leadership in the allied oncology disciplines of pathology and laboratory medicine was established, and for the first time, other allied disciplines central to the cancer control agenda were drafted in provincial leadership roles. The pathology team displayed great leadership in early conversion of paper registration of cancer to e-pathology and synoptic reporting consistent with American College of Pathology checklists. These included imaging, nursing, primary care, palliative care, screening and preventive oncology. Between 2005 and now, successive professional leaders have been identified for each of these disciplines. They in turn interact with and have built network relationships with equivalent leads in each of the regions to both align efforts and ensure an overall clinical governance model for cancer within the province of Ontario. Figure 1 illustrates how the clinical council is effectively embedded with the Program in Evidence-Based Care to generate systematic reviews of emerging evidence in specialty care and site-specific disease state management to advance priority improvement initiatives through a Plan-Do-Study-Act cycle, on a quarterly and annual basis.

**FIGURE 1.** Clinical accountability structures at CCO



In the past few years, CCO introduced a more articulated clinical governance model to increase accountability for quality within the CCO network and to ensure the advancement of an evolving and dynamic clinical leadership culture with CCO (Duvalko et al. 2009). In addition, the introduction of participation in quality activities as a recognized professional activity in the radiation and medical oncology alternate payment plans was key to committing oncologists to the quality agenda, as was the introduction of quality in the academic surgical oncology alternate payment plans.

CCO as an organization has forged ahead with a revitalized model of disease state management for cancer, with reasonably good clinical microsystems for instrumentation of the patient journey and with the elements of a learning healthcare system, and a high-performance delivery organization (Sullivan et al. 2008, Krzyzanowska et al. 2013).

**Seizing Opportunities: A Few Examples**

CCO has many firsts that it can celebrate, and a longer story is told in an online document (see: Appendix A at [www.longwoods.com/content/24002](http://www.longwoods.com/content/24002)). Here are just a few highlights.

**Wait Times: Access to Care**

As a consequence of Alan Hudson playing a lead role in the wait-time reduction efforts on the part of Ontario, CCO took on the role of designing and deploying hospital information systems to capture a range of waiting intervals, eventually including emergency room and surgical wait times for key procedures enumerated by the provinces as part of the 2005 First Ministers' accord on improving access to such procedures (Sullivan 2009). The development and expansion of wait-times measures and their implementation in Ontario was a fortuitous opportunity to build on CCO's already well-developed registry and information systems capacity to provide another province-wide service. It also allowed some experimentation with linking wait-time reductions with modest incentives to do a quality job. If quality standards were not met, then payment could be withheld. While

**LIST OF ACRONYMS**

Acronym	Description
CCO	Cancer Care Ontario
OCTRF	Ontario Cancer Treatment and Research Foundation
PMH	Princess Margaret Hospital
CSIC	Cancer Services Implementation Committee
CKD	chronic kidney disease
FNIM	First Nations, Inuit and Metis
ORN	Ontario Renal Network

this option was rarely exercised, it allowed a range of escalation measures before money was raised and presented a powerful impetus to do a better job.

With the wait-times initiative in motion, the newly invigorated surgical oncology program flourished as an aligned provincial leadership with corresponding responsible regional surgical leaders to drive stepwise improvements in quality in a range of areas from thoracic and hepatobiliary-pancreatic procedures to sentinel lymph node biopsy in breast cancer to improvements in colon and rectal surgery, to margins in prostate surgery, to mention just a few. These initiatives (and more are emerging) were developed with strong clinician engagement along the way.

While progress was made in the past decade in Ontario on reducing and managing wait times for a number of key surgical and diagnostic procedures with quality improvement along the way, the current absence of a strong and provincially mandated leadership voice on access to care remains a vexatious problem. Our country remains an international outlier on access problems in primary care and in specialty care. We and our governments must push harder to deal with these problems directly and in a timely manner. These access issues have much less to do with supply and much more to do with the organization of and payment methods for our professionals (Lewis and Sullivan, 2013).

### **Renal Services in Ontario**

Not unlike cancer, chronic kidney disease (CKD) in Ontario evolved regionally in an inequitable manner with few quality and performance standards. In 2009, the Ministry approached CCO to see if it might be possible to support the development of a better disease state management program for the rapidly growing number of patients with CKD in Ontario. Not surprisingly perhaps, the patient and clinical community was ready to engage. A strong information platform was built with good clinical leadership, common measures of quality and performance were specified and the entire renal community is now pushing towards stronger performance and quality based on targeted improvements across the range of indicators set by the community and publicly reported by the community (ORN 2013).

### **What Is Next for CCO?**

CCO has built a strong and clinically aligned platform for advancing the disease-state management of cancer with strong clinical involvement, good planning and informatics capacity, strong political support and public reporting against explicit goals. The addition of Access to Care and the Ontario Renal Program to the agency marks the evolution into a de facto, multi-service agency. This places the organization in a strong position. The provincial government has further sanctioned this status by entrusting CCO with leadership now on some Quality-

Based Payment initiatives to advance quality and sustainability of services in Ontario. These facts ensure its continued vitality and relevance in a world of competing priorities.

With these considerations in mind, CCO faces a promising future and will have to struggle with the evolution of a coherent identity and legal mandate as an organization with its feet strongly in the disease-state management arena. It is an organization and a network committed to illustrate the features of a learning health system that can adapt and evolve with changing evidence and changing imperatives for learning and improvement (Olsen et al. 2007). This collection lays out some thoughts on new directions, informed by recent history and the explicit public commitments in planning that have been made by the agency.

### **Outline of the Volume**

Ten years after service integration, CCO has moved fast and far from its days of access crisis at the turn of the millennium in Ontario. A new approach to primary prevention focussed on advancing chronic disease prevention is well-outlined in the paper “Primary Prevention – Recent Developments in Policy and Support” by Rabeneck and others (see: [www.longwoods.com/content/24003](http://www.longwoods.com/content/24003)). This approach to enable policies for the reduction of major risk factors for multiple chronic diseases follows naturally on CCO's significant legacy and leadership in supporting the development of a smoke-free Ontario in the past decade.

The emergence of an integrated screening effort, built on ColonCancerCheck – the first organized colorectal screening program in Canada, allows the organization to send invites and reminders to men and women to increase screening participation rates and follow-up for breast, cervical and colon cancer screening, including the new addition of a focused screening effort for women with elevated risk for breast cancer. That story is laid out in “Successes and Challenges in Population-Based Cancer Screening” by Rabeneck and colleagues (see: [www.longwoods.com/content/24004](http://www.longwoods.com/content/24004)).

As a consequence of building a number of province-wide electronic platforms, CCO is in the position of beginning to build better analytic capacity to “instrument” the patient journey from prevention to palliation within the cancer and renal services it supports. This effort, which offers further promise of greater integration and better evidence-based intelligence to inform both patients and providers, is detailed in “Strategic Analytics: Towards Fully Embedding Evidence in Healthcare Decision-Making” by Garay and others (see: [www.longwoods.com/content/24005](http://www.longwoods.com/content/24005)).

The challenges of building a stronger focus on a more integrated, patient-centred approach to care, with a particular focus on prevention to palliative care, are explored in some greater detail in “Integrating Cancer Care Beyond the Hospital

and Across the Cancer Pathway: A Patient-Centred Approach” by Evans and others (see: [www.longwoods.com/content/24006](http://www.longwoods.com/content/24006)). A large part of the rationale for reforming cancer services in 2004 was to integrate services more closely for patients. While progress has been made within the cancer services community, better integration of primary, home and community care, with the patient at the centre, remains challenging, and palliative care for patients is particularly in need of greater attention. The presence of a primary care network attached to CCO has been a strong foundation on which to advance this objective.

CCO has been fortunate enough to host an aboriginal cancer services unit, which has built a strong focus on improving equity. While incidence rates remain slightly lower in the FNIM community in our country, there is a enormous effort required to close the gap in disparities with First Nations, Inuit and Metis (FNIM) people and the rest of Ontario, as cancer incidence and numerous chronic disease rates are rising and life expectancy is poorer among FNIM people. The paper “Improving Health Equity for First Nations, Inuit and Métis People: Ontario’s Aboriginal Cancer Strategy II” by Kewayosh (see: [www.longwoods.com/content/24007](http://www.longwoods.com/content/24007)) and others lays out the elements of a new Aboriginal cancer strategy.

The major challenges and the need to develop adaptive policies and strategies for personalized medicine are tackled by Pollett and others in “Personalized Medicine: CCO’s Vision, Accomplishments and Future Plans” (see: [www.longwoods.com/content/24008](http://www.longwoods.com/content/24008)). The genomic revolution arrived first in cancer, and the manner in which we shape the policies for quality standards in test, the evaluation and payment for companion diagnostics and the challenges of the cost of new cancer agents will set the pace for other areas of medical care.

Woodward and others detail nicely in “Implementation of an Agency to Improve Chronic Kidney Disease Care in Ontario: Lessons Learned by the Ontario Renal Network” (see: [www.longwoods.com/content/24009](http://www.longwoods.com/content/24009)) the early phase of the Ontario Renal Network (ORN), a brand new entity service for patients with CKD within the CCO corporate umbrella. This new enterprise has benefitted from good clinical and administrative leadership and the refinement of existing information systems. In three short years, the ORN has begun to make important differences in the quality of care, the distribution of different modalities of care for patients with CKD and providing public reporting on progress.

Adalsteinn Brown, who gave vigorous early and ongoing counsel in the development of strategic indicators for CCO, has laid out nicely in “The Challenge of Quality Improvement at the System Level. Whither CCO?” (see: [www.longwoods.com/content/24010](http://www.longwoods.com/content/24010)) the key organizational processes and policy elements that have allowed CCO to make progress, and how the features of performance and quality measurement, clear goals and engaged clinical leadership, with good data support, can lead to significant gains in service quality.

Last and importantly, Michael Sherar and team took on the task of where to from here for CCO (see: [www.longwoods.com/content/24011](http://www.longwoods.com/content/24011)). While much has been accomplished, important challenges remain going forward, to ensure a vibrant and innovative future for an adaptive organization working to model a learning healthcare system.

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# Primary Prevention – Recent Developments in Policy and Support

Mary Spayne, Linda Rabeneck, Loraine Marrett and Alice Peter

## Abstract

The focus of Cancer Care Ontario (CCO)'s renewed prevention strategy is to provide evidence-based support and policy advice for risk factor reduction and cancer prevention. As cancer shares several key modifiable risk factors with other major chronic diseases, CCO's prevention efforts also benefit the goals of chronic disease prevention. CCO's ability to successfully provide policy advice is dependent on timing and the ability to respond to current and emerging policy and legislative issues.

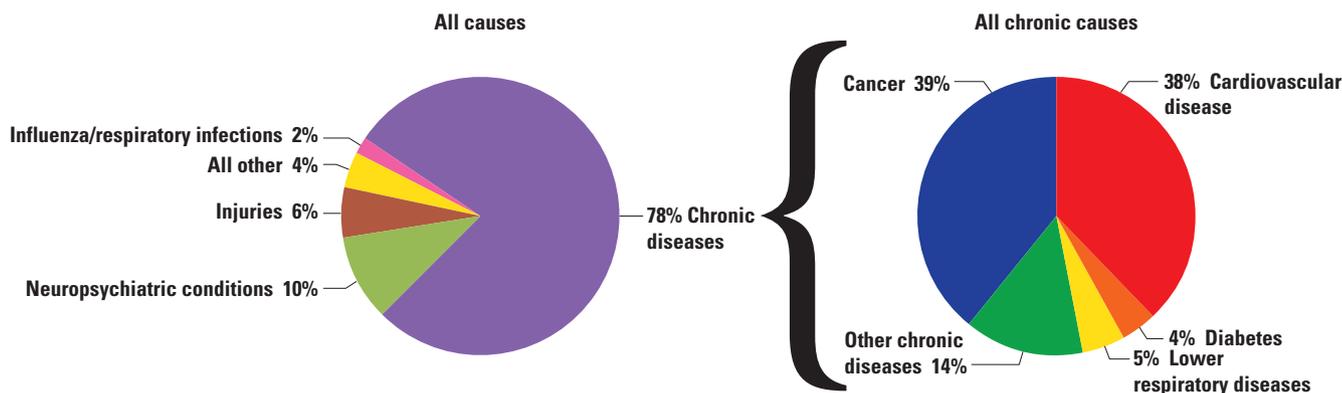
## Background

Primary prevention, which focuses on reducing exposure to risk factors and targets the well population before they are diagnosed with cancer, is an essential component of a cancer control strategy. Cancer shares several key modifiable risk factors – meaning that they can be affected by intervention or behaviour change – with other major chronic diseases including cardiovascular disease, chronic respiratory disease and diabetes. Because of this overlap, prevention initiatives at Cancer Care Ontario (CCO) also benefit the goals of chronic disease prevention.

Ideally, prevention activities are embedded throughout the cancer system and are reflected in the operations of Regional Cancer Programs and in efforts to drive quality improvement and health-system sustainability. Key to CCO's primary prevention role is its ability to provide scientific, evidence-based advice to support the effective development and implementation of policy, leading to initiatives that promote action on prevention, increase the effectiveness of the prevention system and work towards health equity. CCO's capacity to generate new knowledge, interpret and summarize existing evidence and measure and report on progress in risk factor reduction is central to its strategic approach.

Cancer and other chronic diseases are common in Ontario, as they are in other provinces and around the world; cancer and cardiovascular disease together account for almost 80% of deaths in Ontario (Figure 1). In addition to causing premature death and affecting quality of life, cancer and chronic diseases also place a heavy burden on the healthcare system and increase health disparity (World Health Organization 2008).

**FIGURE 1.**  
Cancer mortality: Cause of death, Ontario, residents, 2009



Report date: January 2013, Source: Death, Ontario Ministry of Health and Long-Term Care, IntelliHEALTH ONTARIO

Prepared by: Cancer Care Ontario, Prevention and Cancer Control (Prevention and Surveillance)

Note: ICD10 categories adopted from World Health Organization Global Burden of Disease: data, source, methods and results. Available from: <http://www.who.int/healthinfo/paper54.pdf>.

Four key modifiable risk factors in the development of cancer are shared by other major chronic diseases – tobacco use, alcohol consumption, physical inactivity and unhealthy eating. A significant number of Ontarians engage in these behaviours or activities – 20% of Ontario adults smoke, 53% are overweight or obese, 9% drink alcohol in excess of cancer prevention recommendations, close to half are physically inactive or spend many of their leisure hours on the computer or watching television and almost two-thirds of Ontario adults consume fruit and vegetables less than five times per day (Cancer Quality Council of Ontario 2014).

Research has shown that one-third of cancers could be prevented if nobody smoked or was exposed to tobacco, and roughly another 20% by maintaining a healthy weight, consuming alcohol at or below cancer prevention guidelines and following healthy patterns of diet and physical activity (World Cancer Research Fund 2010). In addition, the four modifiable risk factors mentioned above are recognized as the most effective targets in reducing the burden of chronic disease at a population level (United Nations 2011). This article discusses CCO’s renewed prevention mandate, describes the approach recommended for chronic disease reduction in Ontario by the 2012 policy document *Taking action to prevent chronic disease: recommendations for a healthier Ontario* (“*Taking Action*”) (Cancer Care Ontario/Public Health Ontario 2012) and highlights CCO’s current evidence-based prevention initiatives.

### The Ontario Cancer Plan III - A Renewed Prevention Mandate

CCO’s primary prevention mandate – to develop evidence-based recommendations and initiatives with CCO partners that promote and support action on chronic-disease prevention – enables the organization to play a unique role in prevention activities in the province. In 2011, the *Ontario Cancer Plan III* was released (Cancer Care Ontario 2011). This plan for the cancer system outlined six goals; one of which specifically identified lessening Ontarians’ risk of developing cancer. In addition, prevention is one of the five pillars of CCO’s corporate strategy, and CCO has renewed its commitment

to prevention by dedicating approximately \$1 million yearly to the organization’s prevention work. The mandate’s emphasis on providing policy advice is supported by CCO’s experience in measurement and public reporting and its ability to maximize and leverage partnerships to achieve a common goal.

It is important to note that the impact of cancer prevention efforts/work/activity requires a long view. Many cancers take a long time to develop and even the most successful prevention initiatives may not demonstrate results in terms of reduced cancer incidence for 20 years or longer. For example, while smoking rates for Ontario males began to decline around 1960, lung cancer incidence rates continued to increase until 1982 (Cancer Care Ontario 2002), before starting to decline. In this way, similar delays may be expected when considering the effects of policies geared towards tobacco exposure and control, such as smoking bans in public places and tobacco taxation. Nevertheless, while long-term goals of cancer prevention programs and policies may not be reflected at a population level for many years, the significant health benefits of risk factor reduction at the individual level, such as those of smoking cessation, are well-documented. While it is not possible to show changes in cancer rates in the near term, CCO continues to monitor the prevalence of major cancer risk factors through health surveys such as the Canadian Community Health Survey and other ongoing data sources.

### Providing Evidence-Based Support and Policy Advice

In addition to the *Taking Action* initiative, CCO is instrumental in furthering provincial chronic disease prevention policy, such as tobacco control. As well, CCO frequently responds to emerging public health prevention issues and provides evidence-based support and leadership for diverse prevention activities. Key partnerships and initiatives are described in the following text.

### The Taking Action Initiative

*Taking action to prevent chronic disease: recommendations for a healthier Ontario* is a comprehensive strategy document consisting of 22 recommendations to the provincial government for policy interventions aimed at reducing chronic disease. Released in 2012, the report is the result of a year-long partnership between CCO and Public Health Ontario.

While several other factors play an important role in the development of cancer, including genetics, ultraviolet (UV) radiation exposure and exposure to environmental and workplace carcinogens, *Taking Action* focuses on the key modifiable risk factors of tobacco use, alcohol consumption, physical inactivity and unhealthy eating. This is in keeping with the United Nations report on non-communicable diseases and in order to achieve maximal chronic disease reduction at the population level. Recommendations are wide-ranging and

#### LIST OF ACRONYMS

Acronym	Description
CCO	Cancer Care Ontario
RCCs	Regional Cancer Centres
MOHLTC	Ministry of Health and Long-Term Care
PTCC	Program Training and Consultation Centre
CoP	Communities of practice
PSQI	Prevention System Quality Index
CSQI	Cancer System Quality Index

include actions targeted to education policy reform, taxation, socially responsible pricing, infrastructure and capacity, assessment and accountability and health equity (Table 1).

**TABLE 1.**  
**Taking action to prevent chronic disease: recommendations for a healthier Ontario**

Policy Recommendations and Interventions
1. Increase tobacco tax
2. Broaden and extend integrated tobacco cessation system
3. Implement a sustained social marketing campaign for tobacco
4. Ban smoking on unenclosed bar and restaurant patios
5. Maintain and reinforce socially responsible pricing for alcohol
6. Ensure effective controls on alcohol availability
7. Strengthen targeted controls on alcohol marketing and promotion
8. Increase access to brief counselling interventions
9. Require physical education credits for high school graduation
10. Evaluate daily physical activity in elementary schools
11. Support active transportation
12. Provide leadership through workplace physical activity policy
13. Create an Ontario food and nutrition strategy
14. Include compulsory food skills in curricula
15. Support healthy eating in publicly funded institutions
16. Implement mandatory menu labelling in food service operations
17. Adopt a whole-of-government approach
18. Improve measurement, increase accountability
19. Connect knowledge with practice
20. Implement a coordinated health communications campaign
21. Reduce health inequities
22. Address First Nations, Inuit and Métis health

Current approaches to reducing exposure to modifiable chronic disease risk factors demonstrate that social, physical, economic and environmental factors all play important roles in influencing exposure and that policy interventions targeting these factors enable long-term population health gains. For example, greater access to alcohol is related to increased alcohol consumption and health-related problems (Popova et al. 2009). Policies affecting availability and access, such as government-controlled alcohol outlets, appropriate taxation and minimum pricing, have been effective in lowering consumption and reducing alcohol-related chronic disease.

The report also recommends a centrally coordinated, whole-of-government approach to policy development with collaborations between ministries and integration across all levels of government. Currently, tobacco use is the only key chronic disease risk factor subject to a comprehensive prevention strategy

in Ontario – Smoke-Free Ontario (Cancer Care Ontario/Public Health Ontario 2012). For example, multiple government sectors, ministries and non-governmental agencies, in addition to the Ministry of Health and Long-Term Care (MOHLTC), are responsible for food and nutrition policy. To maximize effectiveness, *Taking Action* recommends a coordinated food and nutrition strategy that acknowledges the interconnectedness of food and nutrition programs and policies throughout agriculture, education, health, culture and social and economic development. Promising initiatives take into account the cross-sectorial nature of food and nutrition would be a cornerstone of a provincial food and nutrition strategy. For example, the government's pilot program, *Fresh from the Farm: Healthy fundraising for Ontario schools*, raises funds for schools by selling fresh Ontario produce to communities. The program delivers healthy food choices, encourages opportunities for learning about food and agriculture in the classroom and supports Ontario's farmers and the local economy. British Columbia and Nova Scotia have implemented provincially integrated food and nutrition strategies with good results (Cancer Care Ontario/Public Health Ontario 2012).

CCO is co-leading (with Dietitians of Canada and Sustain Ontario) the development of an Ontario Food and Nutrition Strategy. Through a collective impact model, more than 20 organizations have come together to design a strategy for the province that has the potential to support the health and well-being of Ontarians through a productive, equitable and sustainable food system. Strategic directions focus on: ensuring Ontarians access to healthy foods; providing opportunities to develop food literacy and skills; and enabling a diverse, healthy and resilient food production system that contributes to an equitable and prosperous economy (Sustain Ontario 2013).

In order for a whole-of-government approach to work, all sectors of the government must be engaged, as well as non-governmental partners and sectors outside of the traditional health system. So far, results are promising. Since the release of *Taking Action*, several milestones have been attained, including the planned renewal of Smoke-Free Ontario, a coordinated approach to smoking cessation in ambulatory settings at Regional Cancer Centres (RCCs), MOHLTC Healthy Kids Panel recommendations to reduce childhood obesity, a preliminary inter-ministerial meeting on food and nutrition programming and policies and the preparation of *Taking Action* recommendations designed in consultation with First Nations, Inuit and Métis in Ontario. A *Taking Action* report card, evaluating the progress of policy interventions, is planned for 2015.

### **Tobacco-Prevention Policy Advice and Support**

CCO's Program Training and Consultation Centre (PTCC) is recognized as a leader in evidence-based tobacco prevention advice and is instrumental in furthering tobacco control and

tobacco use reduction policy in support of the MOHLTC's Smoke-Free Ontario strategy. In partnership with the University of Waterloo, the PTCC conducts applied research, collecting and synthesizing scientific and practice-based evidence, to support tobacco control planning and decision-making. This expertise is used to provide training, technical assistance and knowledge exchange services to public health practitioners working in tobacco control. In addition, PTCC's health promotion specialists provide direct field support to Ontario's 36 public health departments and seven tobacco control area networks to assist them in effectively implementing tobacco control initiatives.

The PTCC also fosters knowledge exchange among decision-makers, practitioners and researchers through provincial communities of practice (CoP), through which groups of peers meet to deepen their understanding and build a collective knowledge base. The Tobacco Use Reduction for Young Adults CoP, for example, aims to enhance knowledge exchange and provide a platform for problem-solving and skill development in tobacco use reduction for young adults aged 18–34, the age group which has the highest smoking rate in Canada.

### **Policy Advice on Emerging Issues**

CCO's success in providing evidence-based advice is closely tied to its ability to respond to emerging issues. In early 2012, a bill was put forward to ban tanning bed use for individuals under age 18. Use of tanning equipment has been associated with the development of skin cancer, with increased risk for people who first use tanning beds before age 35 (International Agency for Research on Cancer 2012). Tanning bed legislation is already in place in five other provinces. In support of the bill, CCO prepared briefing notes summarizing the evidence. In 2013, the Skin Cancer Prevention Act was passed in Ontario, legislating the banning of tanning beds for individuals under age 18 and prohibiting youth-targeted marketing.

In relation to alcohol consumption, CCO recently used its expertise and published research to publicly counter the government's intention to expand liquor sales to grocery outlets and the sale of wine at farmers' markets, providing evidence that alcohol is carcinogenic and that policy actions to facilitate access have been demonstrated to increase consumption and, thereby, increase the associated chronic disease health risks.

### **Cancer System Quality Improvement through Measurement – A Prevention System Quality Index**

Building on its experience in metrics, measurement, surveillance and reporting, CCO is developing a framework for assessing the performance of the prevention system. The long-term goal of

assessment is to identify policy gaps and recommend actions, so that the prevention system can be improved to support reduction in risk factors and, ultimately, in cancer and chronic disease incidence. Measurement of prevention activity at the system level – encompassing legislation, strategies, policies and programs – is not currently coordinated in Ontario. CCO's Prevention System Quality Index (PSQI) envisages a set of metrics for reporting on these factors, where there is evidence that they influence risk factor prevalence.

For example, while the online Cancer System Quality Index (CSQI) currently reports on the proportion of Ontarians at risk due to higher than recommended levels of alcohol consumption it did not report on system-level factors that influence exposure, such as policy-related disincentives like alcohol pricing or retail access, until 2014.

Similar to the CSQI, the PSQI's intention is to enable the reporting of system-level indicators at the regional level over time, including comparison with other jurisdictions wherever possible. Public reporting will allow for successful efforts to be recognized as well as system improvement to occur. Where policy-related shortfalls or gaps are identified, actions such as monitoring, regulation and enforcement can be recommended. Initial system-level indicators related to alcohol policy and environmental exposures are included in the 2014 CSQI. To our knowledge, this is the first coordinated attempt at assessing primary prevention at a system level in the country.

### **Providing Evidence-Based Support for Risk Reduction**

#### **My CancerIQ**

Research suggests that individuals may over- or under-estimate their cancer risk and that there is a need for better cancer risk information and engagement among the public (Colditz et al. 2000). The MOHLTC funded CCO to create an online tool that will allow Ontarians to assess their personal cancer risk and learn about risk factors, disease prevention and cancer screening. In an effort to encourage Ontarians to engage in prevention activities, My CancerIQ provides links to provincial and community supports, such as programs geared towards smoking cessation and healthy eating. Built on an evidence-based algorithm, the first release (early 2015) of My CancerIQ focuses on lung, female breast, colorectal and cervical cancers. In addition to increasing Ontarians' knowledge about disease prevention, My CancerIQ can be used as a platform to inform discussions with healthcare providers and is intended to increase awareness and uptake of breast, colorectal and cervical cancer screening (Figure 2).

**FIGURE 2.**  
**My CancerIQ**

**Cancer Care Ontario**  
**Action Cancer Ontario**

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You can take action against cancer.

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**Complete a cancer risk assessment and get your personalized action plan now.**

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**ABOUT My CancerIQ™**  
Built by Cancer Care Ontario, this site shows Ontarians what steps they can take to help reduce their cancer risk. [More](#)

**FOR HEALTHCARE PROVIDERS**  
Learn how My CancerIQ helps support patient education and get links to downloadable resources. [More](#)

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Learn more about factors that can increase or decrease your risk for certain cancers, and find a list of helpful resources. [More](#)

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### Population Cancer Risk Factor Profiles

An important support provided by CCO to internal divisions, regional cancer programs and chronic disease partners is specific cancer risk profiles. In-depth analyses are conducted to provide a deep understanding of cancer risk factors as they occur over time, by sex, in youth (where data are available), among sub-populations and as they affect equity (e.g., median cigarette smoking by sex, age or income group). The analyses are used to inform prevention and policy work. For example, CCO's monthly Cancer Fact Sheets are often timed to coincide with public health and awareness campaigns on topics such as smoking cessation.

In addition, Cancer Risk Factors in Ontario – in-depth epidemiologic reports describing how specific risk factors influence the development of cancer and other chronic diseases in the province – are used to inform prevention recommendations, ensuring they are based on a foundation of evidence. Because the epidemiological analysis in the reports may reveal that a risk factor affects a particular sub-population disproportionately, the information can also be used to help plan interventions and as a baseline for reporting. Cancer Risk Factor reports on tobacco use and alcohol consumption were released in 2014 and provide scientific information to assist in informing the development of *Taking Action* policy recommendations and prevention initiatives.

## Sun Safety Messaging

Excess exposure to the sun and other sources of UV radiation increases the risk of skin cancer and some eye diseases. Melanoma, which is the main cause of skin cancer mortality, is the sixth most commonly occurring cancer in the country (Canadian Cancer Society 2013). Evidence shows that Canadians are spending an increasing amount of time in the sun without increasing their protection, suggesting that more needs to be done to inform them about the risks of UV exposure (The Ontario Sun Safety Working Group 2010).

In an effort to reduce overexposure to UV radiation, the Ontario Sun Safety Working Group (of which CCO is a member) has led a process to update public sun safety messages, identifying gaps and reflecting current evidence. CCO is working with relevant system partners (Canadian Cancer Society, Canadian Dermatology Association) to build a consensus process to ensure broad, national and cross-provincial agreement on and adoption of consistent, evidence-based sun safety messages.

## Conclusion

CCO's most important contribution to cancer and chronic disease prevention is its ability to provide scientific, evidence-based advice to support the effective implementation of policy, promote action on chronic disease prevention, increase the effectiveness of the prevention system and work towards health equity. CCO's expertise in generating new knowledge, summarizing evidence and measuring and reporting on progress in risk factor reduction is central to this process. The policy document *Taking action to prevent chronic disease: recommendations for a healthier Ontario* presents a strategy for policy interventions aimed at reducing chronic disease in the province and forms a platform for future prevention work. Maintaining the expertise and fluidity to respond to and support emerging legislative and policy developments and maximizing collaborations with external organizations and chronic disease partners to achieve common goals are key to the success of CCO's prevention work. **HQ**

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# Successes and Challenges in Population-Based Cancer Screening

Mary Spayne, Linda Rabeneck and Lynn Guerriero

## Abstract

**Cancer Care Ontario's (CCO's) organized breast, colorectal and cervical cancer screening programs are in different stages of development and maturity. Headed by clinical and scientific leads, the programs reflect a deep understanding of how to design, evaluate and report on programs based on evidence and best practice. Guided by a CCO–Ministry of Health and Long-Term Care ("the Ministry") joint committee and supported by recent investments in information technology infrastructure, the programs provide high-quality cancer screening to Ontario's eligible population.**

## Background – A Case for Organized Screening

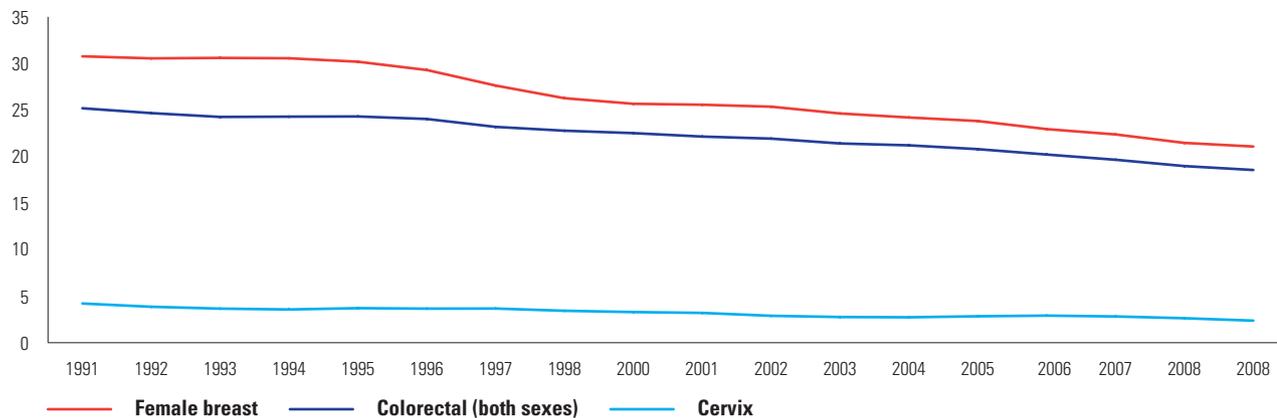
Overseen by Cancer Care Ontario (CCO), the Ontario Breast Screening Program (OBSP) and ColonCancerCheck (CCC) were launched in 1990 and 2008, respectively, and the Ontario Cervical Screening Program (OCSP) began as a province-wide initiative in 2000. Cancer screening and follow-up are conducted in primary care provider (PCP) offices, hospitals and affiliated centres of CCO's 13 Regional Cancer Programs (RCPs), headed by CCO regional vice-presidents. This governance model has been in place since 2003 – RCPs plan and coordinate services locally and undergo routine performance reviews with CCO. In 2011/2012, CCO spent \$92 million on cancer screening programs annually. This funding includes volumes for screening tests (breast and colorectal screening), funding for our regional cancer programs to deliver the screening programs, funding for our physician and scientific leads and running the operations of

all three screening programs across Ontario through the provincial office.

It is well established that detecting cancer early when it is easier to treat decreases cancer mortality, and a reduction in mortality is the key goal of a cancer screening program (Cancer Care Ontario 2013). Between 1990 and 2009, mortality reductions for breast cancer, colorectal cancer and cervical cancer were all statistically significant. Breast cancer mortality decreased by 32% in Ontario as a whole and by 37% for women aged 50–74 as a result of increasing numbers of women being screened and advancements in treatment (Cancer Care Ontario 2013). Mortality rates for colorectal cancer also fell in this period, but not as substantially, at 26%. Mortality rates for cervical cancer fell the most drastically by approximately 44% between 2000 and 2009, in part due to widespread screening with the Papanicolaou (Pap) test (Canadian Cancer Society 2013).

Significant gains have been made over the past two decades and mortality rates for these three cancers in Ontario are comparable with those of other provinces (Canadian Cancer Society 2013); statistical analysis shows no levelling off of trends in Ontario (Figure 1). Ontario's population is rapidly growing and aging. The effectiveness of CCO's cancer screening programs is therefore ever more important, as the programs face the challenge of serving increasingly large numbers of screen-eligible Ontarians while upholding their mandate of providing optimal, evidence-based screening services and their goal of decreasing cancer mortality.

**FIGURE 1.**  
**Mortality rates for breast, colorectal and cervical cancer in Ontario (per 100,000 people)**



Source: Cancer Care Ontario (Ontario Cancer Registry, 2012)

Prepared by: Cancer Care Ontario, Prevention and Cancer Control (Prevention and Surveillance)

\*Rates are per 100,000 and standardized to the age distribution of the 1991 Canadian population.

Females breast (ICD-10 C50), Colorectal (ICD-10 C18-C20, C26.0), Cervix (ICD-10 C53). Cervical cancer rates are calculated with hysterectomy-corrected population at risk.

Screening for other cancers, such as lung and prostate, is also under investigation. CCO has begun economic and technical evaluations for screening those at high risk for developing lung cancer, and is planning to conduct pilots to determine the feasibility of implementing organized screening for this population. At the time of writing, CCO does not have a plan to move forward with organized prostate cancer screening using the prostate-specific antigen (PSA) test due to the lack of evidence that such a program would be beneficial when the harms and benefits are weighed against each other.

### Evidence-Based Practice – The Foundation of Our Work

To achieve and sustain high levels of participation, a successful organized screening program must be built on clinical guidelines for screening and test result follow-up, invitations of eligible individuals for screening and regular re-screening, programs to ensure quality in each of these activities and an infrastructure to support them (World Health Organization 2005). Further, screening programs must continue to keep up with best practices, move the public and physicians from awareness to adoption and stay current with emerging issues. Administering a successful screening program is a complex, multi-layered undertaking, which in Ontario involves multiple stakeholders, including the Ministry of Health and Long-Term Care (MOHLTC), practitioners, RCPs, screening and assessment sites, clinical professional organizations, laboratories, advocacy groups and the public.

CCO’s cancer screening programs are headed by clinicians and scientific leads. Work is supported by CCO’s Program in Evidence-Based Care (PEBC), a guideline development body

that assists clinicians and policymakers with practice and policy decisions. This organizational structure has helped CCO develop a deep understanding of how to design, evaluate and report on evidence-based programs.

Ontario’s screening programs and outcomes are routinely evaluated and compared with national and international benchmarks, where available, and CCO continually makes changes to improve program effectiveness. Screening programs also face systematic and environmental challenges – some screening occurs outside of organized programs, the process of changing a screening test or technology involves many stages and multiple partners, changing provider behaviour is complex and public engagement is crowded by numerous organizations.

In a constantly evolving environment, CCO has found that engaging the government early and regularly is key. Therefore, CCO and the MOHLTC have created a screening program joint committee made up of senior leaders from both organizations, which monitors progress and provides direction to Ontario’s cancer screening programs. Key issues are addressed, such as funding and reporting requirements, program performance, privacy concerns and approvals. The committee also helps maintain open communication between both parties, making it easier to address issues and mitigate risks.

To facilitate knowledge transfer and increase cancer screening according to guidelines, CCO offers continuing medical education modules, and develops a suite of tools for PCPs and other specialist audiences. Tools are disseminated to providers primarily through their professional organizations (e.g., the Ontario Medical Association, the Nurse Practitioners’ Association of Ontario) and include clinical guidelines summaries, decision support tools, handouts and e-bulletins.

CCO recently implemented its first mobile screening tool for providers – an app for the updated cervical cancer screening guidelines and followup of abnormal laboratory results.

Additionally, CCO has created a toolkit encouraging providers to boost their screening efforts. In 2013, PCPs working in teams were required to submit Quality Improvement Plans to the MOHLTC. In response, CCO designed a toolkit enabling these teams to evaluate and report on their screening practices. The toolkit is based on the “Plan, Do, Study, Act” cycle of improvement (Langley et al. 1996) and has been well-received.

## Translating Evidence to Practice

### Example: Updating Guidelines for Cervical Cancer Screening

Cervical cancer is highly preventable with regular screening; 49% of invasive cervical cancers in Ontario in 2009–2011 occurred among women who were not screened in the 5 to 10 years previous to diagnosis, or who were never screened (Cancer Care Ontario 2014). Updated in 2012, CCO guidelines recommend that women aged 21–69 screen with a Pap test every three years until age 70 if they are or have ever been sexually active (Murphy et al. 2011). In addition, the guidelines recommend moving to the human papillomavirus (HPV)-DNA test as the primary cervical cancer screening tool for women aged 30–69. CCO has funded planning and pilot work to determine an implementation strategy for Ontario.

## LIST OF ACRONYMS

Acronym	Description
CCO	Cancer Care Ontario
OBSP	Ontario Breast Screening Program
CCC	ColonCancerCheck
OCSP	Ontario Cervical Screening Program
RCPs	Regional Cancer Programs
PSA	Prostate-specific antigen
PEBC	Program in Evidence-Based Care
PCPs	Primary care providers
HPV	Human papillomavirus
MRI	Magnetic resonance imaging
DR	Direct radiography
CR	Computed radiography
CSQI	Cancer System Quality Index
gFOBT	Guaiac-based faecal occult blood test
FIT	Faecal immunochemical test
FNIM	First Nations, Inuit and Métis
SAR	Screening Activity Report
PEMs	Patient enrolment models

The issuance of new guidelines in 2012 was well received by PCPs because it provided them with the ability to screen based on the latest evidence and recommendations. Previously, many PCPs tested women yearly to coincide with their routine medical examination, regardless of the 2005 guidelines, which recommended screening annually until the achievement of three negative screens and then every two to three years. The MOHLTC supported uptake of the new guidelines by aligning provider fee schedules with CCO’s recommendations. For example, PCPs are not reimbursed for performing a Pap test during the time interval between recommended screens unless a woman is symptomatic. CCO notes that the overall volume of Pap testing dropped dramatically in the latter half of 2012 and through 2013 as adherence to guidelines increased. The updated guidelines were timely because they coincided with the launch of the correspondence initiative for the OCSP. In particular, the implementation of the participant recall letters greatly supported the new extended interval for cervical screening.

### Example: Implementing a Breast Cancer Screening Program for Women at High Risk

In July 2011, the OBSP implemented a new program that screens women aged 30 to 69 who are at high risk for breast cancer. The expansion was supported by PEBC clinical practice guidelines that indicated that women at high risk (due to genetic factors, medical or family history) would benefit from annual screening with mammography and magnetic resonance imaging (MRI) within the context of an organized screening program (Warner et al. 2004). Seventy-seven percent of the cancers detected in screen-eligible, high-risk women in 2011–2012 were invasive and none were found using mammograms alone, making the addition of the MRI essential to the high-risk program. To our knowledge, Ontario is the first jurisdiction in the world to incorporate this type of protocol into an organized breast cancer screening program. An evaluation of the program’s first year revealed that women at high risk for breast cancer were under-referred to the program (Chiarelli et al. 2014). CCO and the MOHLTC are making efforts to address this issue and expect to increase referrals in the coming years.

### Example: Transitioning to Direct Radiography Technology

Continued monitoring of evidence has led to an important change in mammography technology. In 2013, a CCO scientist found that mammography using screen film technology and digital mammography using direct radiography (DR) are better at detecting breast cancer than digital mammography using computed radiography (CR) technology (Chiarelli et al. 2013). The MOHLTC accepted CCO’s recommendation to transition all CR machines to DR technology (i.e., both within and outside of the OBSP), and completed this transition by early 2014.

### Program Performance – How Are We Doing?<sup>1</sup>

Incorporated into Ontario's cancer screening programs are performance evaluation frameworks, with provincial and regional indicators published routinely in the Cancer System Quality Index (CSQI) (Cancer Quality Council of Ontario 2014). This continuous cycle of evaluation, in addition to other regular regional reporting, works well to identify issues, allowing for performance management and recommendations for improvement. Public reporting also enables regional comparison and has led to healthy competition among regions.

Among Ontario women, breast cancer is the most frequently diagnosed cancer and the second leading cause of cancer deaths after lung cancer (Cancer Care Ontario 2013). In 2011–2012, the two-year period over which indicators were calculated, approximately 1.1 million women were screened (within and outside of the OBSP), comprising 60% of eligible women in Ontario compared with the national target of 70% for women screened in a two-year period (Public Health Agency of Canada 2013). Almost three-quarters of women (74%) were screened at OBSP-affiliated centres. Retention rates within the OBSP – women who had a mammogram in 2010 and returned for screening within 30 months of their previous mammogram – were high at 84%.

During the three-year period 2010–2012, 64% of eligible women in Ontario were screened for cervical cancer. The *Ontario Cancer Plan 2011–2015* sets out an ambitious target of 85% for Ontario women screened every three years for cervical cancer (Cancer Care Ontario 2010). Screening retention rates (women screened within 36 months of a 2009 Pap test) were 80% and have remained steady since 2006 (Cancer Care Ontario 2014).

Colorectal cancer is the second leading cause of cancer-related deaths in Ontario after lung cancer (Canadian Cancer Society 2013). CCO recommends screening for average-risk individuals aged 50 to 74 every two years using the guaiac-based fecal occult blood test (gFOBT), followed by colonoscopy for those with abnormal test results. The guidelines recommend screening with colonoscopy for individuals at increased risk due to a family history of colorectal cancer (defined as one or more first-degree relatives diagnosed with the disease). In 2011–2012, 30% of eligible Ontarians were screened with the gFOBT, an increase from 19% from 2005–2006 before the implementation of the organized program. However, when all colorectal screening tests are taken into account (i.e., gFOBT, flexible sigmoidoscopy, colonoscopy), results were better, with 42% of eligible Ontarians being due for colorectal cancer screening. Retention rates were 26% for Ontarians who were screened by gFOBT in 2010 and returned for a subsequent gFOBT within the recommended 24-month period, but jumped to 63% within a 30-month period.

A challenge encountered by the ColonCancerCheck program has been physician opinion surrounding the gFOBT because

some believe it is unreliable for screening. Colorectal cancer can be cured when found early, and current screening participation and retention rates represent a missed opportunity in reducing cancer morbidity and mortality. CCO is examining ways to improve participation, including replacing the gFOBT with the fecal immunochemical test (FIT) for average-risk individuals. The FIT is not only a more sensitive test for detecting colorectal cancer and pre-cancerous lesions (Rabeneck et al. 2011), but is also easier to use, so better physician uptake and participant compliance is expected.

To achieve optimal cancer screening, it is critical that screening and follow-up of abnormal test results be complete and timely. While Ontario's screening programs specify benchmarks for followup of abnormal results (e.g., individuals having an abnormal gFOBT should complete a colonoscopy within eight weeks), followup intervals can be affected by many factors, which we are in the process of investigating. Ontario's cancer screening programs have improved performance for completeness of followup, reflected in the proportion of individuals completing followup diagnostic procedures within six months of their abnormal test result, although there is some room for improvement. In 2012, approximately 43,500 OBSP-screened women (98%) with an abnormal screening mammogram were diagnosed (breast cancer or benign) within six months of their abnormal mammogram result. Approximately 14,500 Ontarians with an abnormal gFOBT (76%) received a followup colonoscopy within six months of their abnormal gFOBT, up from 66% in 2009 (nearly 8,000 or 42% had a followup colonoscopy within the eight-week benchmark, up from 32% in 2009). Approximately 4,700 (81%) Ontario women had a followup procedure (colposcopy or definitive treatment) within six months of a high-grade abnormal Pap test. These numbers do not reflect the screening activity of people who fall outside the recommended screening guidelines. Ineligible Ontarians are not invited to participate in our programs, but they can make a personal decision to get screened after consulting with their healthcare provider.

### Under-Screened and Never-Screened Populations – Initiatives to Improve Participation

There are sub-populations in Ontario and Canada who are under screened for a variety of reasons, including age, ethnicity, socioeconomic status and geographic location.

For example, Ontario data (Cancer Quality Council of Ontario 2014) indicate that women living in the lowest-income areas participate less in breast and cervical cancer screening than women in the highest-income areas; women living in areas with a high percentage of immigrants participate less in cervical screening than women in areas with fewer immigrants. Ontario's First Nations, Inuit and Métis (FNIM) populations also

participate less in screening, are more overdue for screening and receive less diagnostic followup care than non-FNIM populations. Data for cervical screening, for example, indicate that 50% of women needing followup after an abnormal Pap test and living in areas with a high percentage of Aboriginal Peoples received a colposcopy or treatment within six months, compared with 81% in areas with fewer Aboriginal Peoples (Cancer Quality Council of Ontario 2013).

CCO has recently undertaken a series of initiatives to try to address these imbalances, including two areas of focus: a commitment to Ontario's FNIM and pilot projects focused on public engagement.

As part of CCO's efforts to better serve FNIM populations, it has funded four community-based under-/never-screened regional pilot projects and one provincial research project (there is a fifth pilot in Toronto that does not focus on FNIM groups). The pilots involve developing and administering tailored screening invitations to Aboriginal populations in northern communities, and hiring a screening outreach worker in Sioux Lookout, Ontario, to provide outreach and education to community members and healthcare providers.

The public engagement pilots focus on building capacity and evidence for improving immigrant access to screening, supporting the patient-provider relationship to encourage screening and maximizing other reminder programs, such as correspondence and clinic-based interventions.

These pilots were designed based on a comprehensive literature review, a cross-jurisdictional environmental scan, regional consultations with RCPs and other partners, development of a decision-making framework to support implementing interventions and a plan for how to move from strategy to pilots to execution. Examples include computer tablets featuring educational breast screening videos that patients can view while waiting for their provider, using electronic medical records to identify patients who are due for cervical screening and reminding them by phone and creating cancer screening materials designed for immigrants.

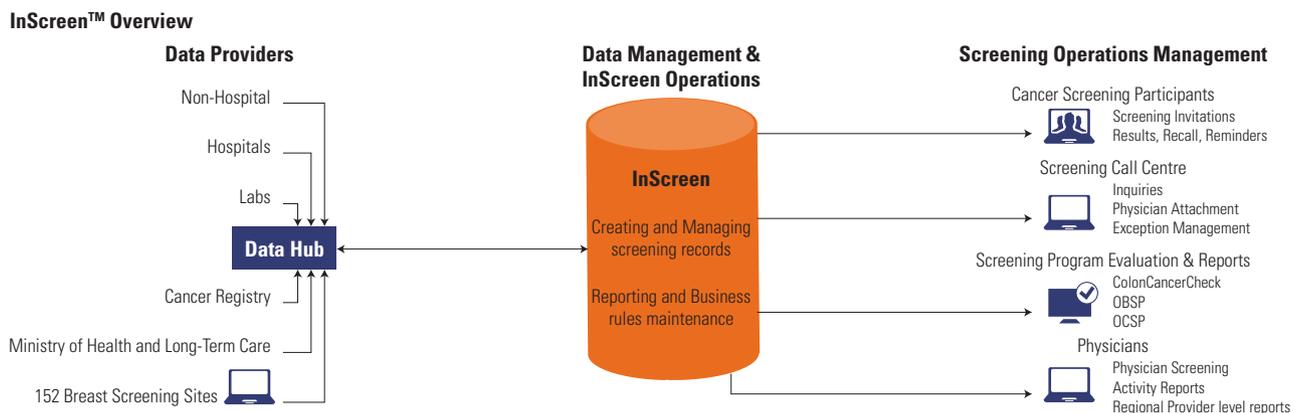
Access to screening is also challenging for women living in geographically isolated areas. The OBSP mobile screening mammography coach addresses this barrier and has served more than 30 Northwestern Ontario communities since 1992. Under the new "Screen for Life" program name, a second coach was launched in Southwestern Ontario, which serves women facing similar screening barriers. Building on their success, the coaches added cervical and colorectal cancer screening services.

### Enabling Technology – Supporting Physicians and the Public

From the outset, an important component of CCC has been its information system (InScreen™), which enables the collection of colorectal cancer screening data for the purposes of reporting and evaluation, and serves as a platform for participant correspondence and physician reporting. Over the past few years, CCO has prioritized integrating all Ontario screening data into one information system. Breast and cervical cancer screening information was fully incorporated into InScreen in spring 2013, allowing for the generation of correspondence.

The functionality and capacity of InScreen has evolved, growing exponentially with the addition of population-based and clinical data sets. As of December 2013, the annual volume of correspondence for CCC was approximately 1.7 million letters. Screening correspondence for the OCSP launched in 2013 and generated over one million letters between August and December. Population-based correspondence began for the OBSP in March 2014. Evidence indicates that contacting individuals by mail continues to be one of the most effective methods of reaching target populations (Camilloni et al. 2013). CCO is exploring electronic methods of contacting individuals in the future (e.g., email), which would enable CCO to provide patients with additional information via electronic links. Electronic correspondence would also be more efficient and possibly cost-saving. The complexity of the InScreen architecture, including data inputs and operations required to arrive at system goals, is illustrated in Figure 2.

**FIGURE 2.**  
**Integrated cancer screening at CCO**



A second key feature of InScreen is its ability to support physicians. The Screening Activity Report (SAR), assembled using InScreen data and built on an electronic reporting platform (eReports), helps physicians manage cancer screening by letting them know which of their patients have been screened, which are overdue for screening and which need follow-up after abnormal test results. It also allows them to compare their performance with their regions and the province.

Launched in 2013 to deliver information on colorectal cancer screening, the online SAR is available to PCPs working in patient enrolment models (PEMs). Since primary care reform in 2000, most PCPs in Ontario practice in PEMs and, to date, over 4,200 are enrolled in the SAR program. In April 2014, breast and cervical screening data were added, allowing providers to assess in one place the screening status of all of their patients. As CCO provider reports evolve, the potential to use the eReports platform to track screening is promising (Figure 3).

**Conclusion**

Ontario’s breast, colorectal and cervical cancer screening programs have made significant progress since their launch. Providing comprehensive, high-quality cancer screening to Ontario’s eligible population, the screening programs are based in evidence and guided by clinician/scientist leads. Programs perform well for key indicators and in comparison with other Canadian jurisdictions (Cancer Quality Council of Ontario 2014; CPAC 2012). Evaluation occurs on an ongoing basis and programs continue to evolve in response to scientific research, evidence-based recommendations and changes in the screening environment. There is still much progress to be made, particularly in increasing screening participation to decrease mortality and maximize screening benefits. CCO’s approach in translating evidence to practice, finding innovative solutions to screening barriers and creating a high-quality information technology infrastructure to support its work has positioned it to better achieve this goal and make continued progress in the field of cancer screening. **HQ**

**FIGURE 3.**  
**The Screening Activity Report**

Screening Activity Report (SAR) as of 30-Nov-2013  
Dashboard

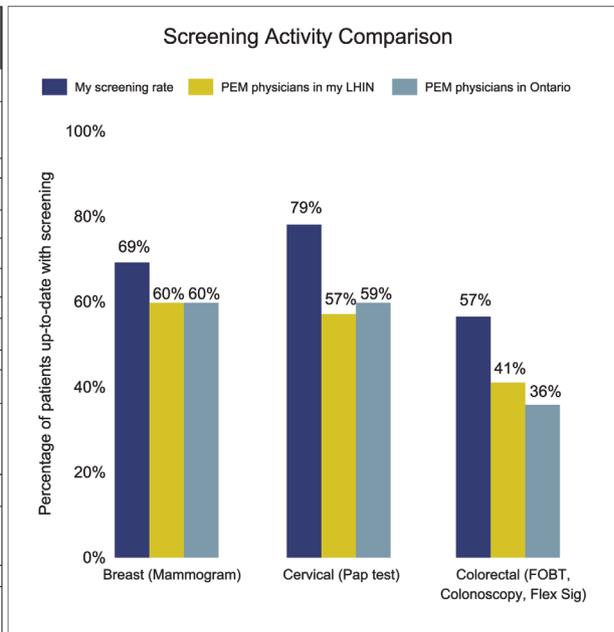
[Go to Summary](#)

Physician: HG-308 HS-22

CPSO: 790822

LHIN: North Simcoe Muskoka

Physician Level Summary	Breast Screening	Cervical Screening	Colorectal Screening
Total eligible individuals	13	14	23
Total excluded individuals (due to previous cancer, surgery or OBSP high risk)	8	4	3
<b>Action required</b>	<b>4</b>	<b>6</b>	<b>12</b>
Abnormal screen, followup needed	2	3	2
Invalid results, retest required	N/A	1	2
Overdue for screening	2	2	8
<b>Due for screening ≤ 6 months</b>	<b>2</b>	<b>2</b>	<b>2</b>
<b>Physician review required</b>	<b>4</b>	<b>5</b>	<b>7</b>
Colonoscopy in the last 10 years or Flexible Sigmoidoscopy in the last 5 years	N/A	N/A	3
Review patient history	2	3	3
Abnormal screen, followup underway or completed	2	2	2
<b>No screening action required: normal screen</b>	<b>2</b>	<b>1</b>	<b>2</b>



Note: Data is reported as of the cut-off date. Recent screening and assessment activities may not be included due to date lag.

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## Note

1. Performance data in this section have been excerpted from the *Cancer System Quality Index (CSQI) 2014*, which can be viewed at <http://www.csqi.on.ca>.

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# Strategic Analytics: Towards Fully Embedding Evidence in Healthcare Decision-Making

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## Abstract

**Cancer Care Ontario (CCO) has implemented multiple information technology solutions and collected health-system data to support its programs. There is now an opportunity to leverage these data and perform advanced end-to-end analytics that inform decisions around improving health-system performance. In 2014, CCO engaged in an extensive assessment of its current data capacity and capability, with the intent to drive increased use of data for evidence-based decision-making. The breadth and volume of data at CCO uniquely places the organization to contribute to not only system-wide operational reporting, but more advanced modelling of current and future state system management and planning. In 2012, CCO established a strategic analytics practice to assist the agency's programs contextualize and inform key business decisions and to provide support through innovative predictive analytics solutions. This paper describes the organizational structure, services and supporting operations that have enabled progress to date, and discusses the next steps towards the vision of embedding evidence fully into healthcare decision-making.**

## Introduction

Cancer Care Ontario (CCO) supports quality improvement in prevention, screening and patient care, including patient experience. The agency's work ranges from monitoring and evaluating health-system performance to leading the design and implementation of new healthcare practices and models.

## CCO's Information Technology, Tools and Databases

To support quality improvement, CCO has implemented multiple information technology (IT) solutions to collect, manage and report on health system data. Within CCO, there are over 170 data holdings, which include data CCO collects from external partners (e.g., Ministry of Health and Long-Term Care [MOHLTC], Canadian Institute for Health Information and Institute for Clinical Evaluative Sciences), as well as data collected from Ontario health providers and organizations, which is then enriched and linked within the agency. Some examples of these enriched datasets are:

The Interactive Symptom Assessment and Collection (ISAAC) tool is designed to capture patient-reported, cancer-related symptoms primarily through touch-screen kiosks located at hospitals and Regional Cancer Centres. The extensive and timely data collected through ISAAC are communicated to patients' healthcare providers to help them monitor and manage their patients' symptoms. As of February 2014, approximately 285,000 unique patients submitted over 2.1 million symptom screens into the ISAAC database, providing CCO with the largest patient-reported cancer symptom dataset in the world.

Using a web-based application, the Ontario Renal Network (ORN) collects pre-dialysis, acute dialysis and chronic dialysis patient-level data from across the healthcare system

for the Ontario Renal Reporting System (ORRS). This dataset is used to report on a range of chronic kidney disease (CKD) indicators to health professionals, policy-makers and researchers.

The Wait Time Information System (WTIS) is a web-based tool used to collect and to report wait time information for over 190 procedures in 13 key surgical areas and diagnostic imaging cases. Over 665,700 surgical cases and more than 1.7 million diagnostic imaging cases were entered into the WTIS during fiscal year 2012–2013, making it the most comprehensive wait time information database publicly available in Canada. Approximately 3,100 clinicians use the WTIS to help manage wait times in 96 hospitals across Ontario. Policymakers and planners also use it to inform funding decisions and resource allocation, as well as to identify performance improvement opportunities. Moreover, WTIS is used to collect near real-time data on Alternate Level of Care patients, a designation given by a physician to a patient who is occupying a bed in a hospital, but who does not require the intensity of resources or services provided in that particular care setting.

### CCO's Data Strategy

CCO's role in quality improvement has steadily expanded over the past several years. This has been accompanied by a simultaneous growth in both the volume and type of data collected in the organization. As that data expansion continues, there is a need to explore information flow throughout the organization, from its collection and infrastructure to its management and reporting. Additionally, there is an opportunity to link together and leverage this information for program and capacity planning, implementation and evaluation. As such, CCO is engaging in the first comprehensive data-focused organizational and stakeholder review to gauge current and future data needs, both from an institutional and patient-focused perspective. The application of data for operational planning and reporting has always been a clearly identified priority. However, the application of data to predict and model future state is, to a large degree, in its infancy. This will lead to the development of CCO's first enterprise-wide data strategy. The organization will place a significant focus on utilizing current data and driving future acquisition, to significantly increase capacity for predictive modelling and strategic analytics (SA) for system planning and evaluation.

### CCO's Strategic Analytics Practice

In recent years, the resource constraints experienced by health systems across Canada have increased the need for innovations that improve the efficiency and effectiveness of the management and delivery of healthcare. At CCO, the intersection of these trends with the agency's data infrastructure has led its programs to an increasing pursuit of data-driven insights, such as the Cancer System Quality Index (CSQI), iPort and iPort Access.

The first of its kind in North America, CSQI helps drive CCO's mission of improving services and outcomes related to cancer within Ontario. The tool is produced with and on behalf of the Cancer Quality Council of Ontario and tracks Ontario's progress in a number of evidence-based quality measures and informs policymakers, physicians and researchers where quality improvements are needed. For example, the CSQI has highlighted improvements in access to care through decreased wait times for cancer services and in the effectiveness of care through improved surgical outcomes by consolidating complex care for cancers of the lung, esophagus, pancreas and liver (Anas et al. 2012). Now in its 11th year, CSQI continues to shine a light on areas for improvement in Ontario's cancer system.

iPort and iPort Access are secure, web-based tools developed to help provide accessible information about cancer surveillance and activity at the provincial, regional and Local Health Integration Network (LHIN) level, as well as wait time and surgical efficiency data collected through the WTIS. These tools are helpful for health system planning using analytical reports encompassing a number of key metrics. Individuals with access

#### LIST OF ACRONYMS

Acronym	Description
CCO	Cancer Care Ontario
IT	information technology
MOHLTC	Ministry of Health and Long-term Care
ISAAC	The Interactive Symptom Assessment and Collection
ORN	Ontario Renal Network
ORRS	Ontario Renal Reporting System
CKD	chronic kidney disease
WTIS	Wait Time Information System
SA	strategic analytics
CSQI	Cancer System Quality Index
LHINs	local health integration networks
RCPs	Regional Cancer Programs
SAAP	Strategic Analytics Advisory Group
gFOBT	Guaiac-based Fecal Occult Blood Test
FIT	faecal immunochemical test
ID	independent dialysis
PAO	Privacy and Access Office
PHIPA 2004	Personal Health Information Protection Act
IPC	Information and Privacy Commissioner of Ontario

to these tools can generate detailed analytic reports that include information with respect to geography, time, age and diagnosis time. Additionally, users can access comprehensive dashboards for up-to-date information on health system performance. An example of a dashboard is the Cancer Regional Performance scorecard, which is a performance management tool that monitors and measures the performance of the Regional Cancer Programs (RCPs) against provincial priority indicators and targets. The purpose of the scorecard is to help drive system improvement and address poor performance, as part of CCO's quarterly performance review process. The electronic Scorecard enables users to view the underlying data supporting each metric, allowing for more detailed analysis to support performance improvement. Users are able to visualize trends in performance, make regional comparisons against targets and gain an overall picture of provincial performance where RCPs are ranked 1 through 14.

### Strategic Analytics Advisory Group

To oversee the development of the SA practice, an external advisory panel was instituted in 2012. The Strategic Analytics Advisory Group (SAAP) is composed of nine thought leaders from across the healthcare sector. The panel was established to have leaders in the healthcare information space, external to CCO, act in an advisory capacity to offer strategic insights, thus propelling CCO's achievement of its goal to enhance healthcare decision-making by generating richer evidence. The SAAP meets with the SA team and members of the CCO leadership three times a year to help identify opportunities for advanced analytics based on their understanding of the nuances of analytics and the challenges facing the healthcare system.

### Strategic Analytics Projects

Since its inception, SA has led a number of projects. One recent example involved working with Access to Care (one of CCO's main programs) on the development of a model to support the province's LHINs in predicting the required number of hip and knee replacement surgeries to meet and sustain wait time targets during fiscal years 2013–2014 and 2014–2015. The model relied on WTIS data for up-to-date wait list information, and used time-series forecasting to predict wait list arrivals, seasonal variations to estimate monthly surgical volume and queuing theory to estimate the average and 90th percentile wait times.

Another example is a current project with CCO's cancer program in support of the Ontario Cancer Plan III's commitment to develop patient-centred models of care (Cancer Care Ontario, 2011). The project involves developing an interactive decision support tool that is heavily based in CCO's data holdings. The resulting model enables users to assess the impacts of followup care devolvement, as well as repatriation or centralization of specific types of care, to determine the required number of medical, gynaecological and radiation oncologists.

CCO's Cancer Screening team is also engaged in a SA project to predict the impact on the Ontario healthcare system associated with switching from the current colorectal cancer screening test (Guaiac-based Fecal Occult Blood Test, or gFOBT) to the more sensitive Fecal Immunochemical Test (FIT). A multi-component system impact model is being built to support the planning activities around the implementation of FIT. One component of the model will predict volume shifts in cancer cases based on important Ontario-specific cancer screening parameters as identified by CCO. The other component of the model uses these results to build a final demand model using multiple CCO data sources, which focuses on predicting changes in the patterns of health system use associated with cancer screening.

In 2013–2014, SA developed a strategic regional capacity planning tool that encompasses a mathematical model of the CKD health system. The tool projects future patient net population growth over the next 12 years using time series forecasting at the sub-LHIN level, and translates it into capacity requirements at each dialysis facility. This is accomplished through a series of allocation algorithms that determine the care modality and location of all patients receiving dialysis. These algorithms leverage spatial analysis and optimization routines to ensure that they are calibrated to the population and service characteristics of each dialysis regional program, and to the individual facilities that provide the care.

Much of the data from ORRS is used throughout the model to project future capacity requirements. This data is supplemented with data from the Ontario Health Insurance Plan claims payment system to provide robust forecasts based on 14 years of data. The model parameters can be easily refreshed as new data becomes available.

In addition to population growth, the model accounts for changes in the patient journey. Specifically, target independent dialysis (ID) rates obtained from each regional CKD program are used to estimate the number of patients receiving dialysis at home, thereby lessening the burden on in-facility capacity requirements. By accounting for the transition and retention characteristics of ID patients in each program, the model is able to translate annual ID targets to program-specific quarterly referral goals. The model also accounts for the return of home patients to facility-based dialysis temporarily or permanently, often as a result of medical complications requiring close attention. As such, it can provide guidance on how much capacity each regional program must reserve within their hospitals to accommodate home patients who unexpectedly return.

The model creates a multi-level, system-wide view of the CKD healthcare system, informing a variety of decisions and allowing them to be made in a consistent, evidence-based manner. The primary output is the predicted surplus or shortage of dialysis stations at each treatment facility, which is used to support capacity expansion proposals, and as evidence for need

of new treatment facilities. However, other model outputs are also relevant. For example, the model also projects the required patient-based funding to support the annual request for MOHLTC funding.

The model's interface has allowed it to be used as a flexible tool in planning processes, rather than as a static source of information. It allows users to manipulate input parameters, which has facilitated ongoing conversation between ORN and local planning stakeholders. In 2013, ORN provided baseline results from the model to regional planning stakeholders, who responded with input of certain model parameters and assumptions, including projected growth rates and patient travel patterns. ORN planners are now able to take the feedback from the regional planning stakeholders and make the necessary changes via the interface to re-run the model and produce an updated set of results. ORN can also use the model to test hypothetical planning scenarios, such as the effect of opening new facilities on capacity requirements at nearby facilities.

## Conclusions

The ORN model is an excellent example of the capacity that CCO is committed to developing across the organization and within the healthcare system. Through the development of a robust data infrastructure and enterprise data strategy, acquisition of new data sources and exploration of automated operational reporting, CCO will direct greater focus to developing this expanded planning capacity.

Establishing the SA team at CCO is a journey that has merely begun. In this journey, we are guided by three principles: relevance, agility and positive user experience. We strive to support relevant clinical, management and policy decisions that have a real impact on healthcare performance; to provide the solutions in an agile manner to empower timely decision-making; and to enable a positive user experience that allows decision-makers to interact with and adopt solutions to support their decision-making.

The backbone of these solutions is robust analytics that go beyond historical descriptive analytics towards predictive and prescriptive analytics. While the general perception of such advanced analytics is that they require a lengthy process to develop, we are constantly learning and adopting agile approaches, such as machine learning, that expedite the process. Furthermore, we are currently working on optimizing the backbone of our analytical processes through standardization of methodologies and analytic steps, as well as our infrastructure set-up, in order to reduce project delivery times further.

CCO has come to understand the importance of supportive and entrenched policies and analytic processes, joint governance of the projects with CCO programs and mutual collabora-

tive efforts with the Privacy and Access Office (PAO). It is by maintaining these success factors that we can move towards our vision of fully embedding evidence into healthcare decision-making.

## Insert: The Future of Privacy: Privacy by Design

In leveraging CCO's rich datasets and technological and software assets to bring advanced insights to clinical programs, CCO must meet its privacy law-related mandate, including obligations pursuant to the Personal Health Information Protection Act (PHIPA 2004), as well as those set by its regulator, the Information and Privacy Commissioner of Ontario (IPC). Close collaboration with the Privacy and Access Office at CCO has enabled CCO to ensure its datasets are used in a way that minimizes the chance for any privacy breaches.

Moreover, CCO is currently moving towards a Privacy by Design (Information and Privacy Commissioner 2011) model, whereby all future privacy controls will be embedded seamlessly into every analytics approach. Privacy by Design is a concept that was developed by the IPC to address the growing and systemic effects of IT and of large networked data systems. To accomplish Privacy by Design, the following seven principles must be applied:

1. It is proactive not reactive such that it anticipates privacy issues before they occur.
2. It sets privacy as the default setting, ensuring that personal data are automatically built into the IT system.
3. It is embedded into the design and architecture of systems without diminishing functionality.
4. It aims to accommodate all interests such that it results in positive sum, not zero sum.
5. It extends throughout the life cycle of the data (from start to finish), including destruction.
6. It seeks to ensure that all operations remain visible and transparent.
7. It requires architects, operators and users of the data to keep the interests of the individual first and foremost.

CCO's PAO at CCO is continually working with the SA – and all the agency's programs – to embed these principles throughout the entire data life cycle. **HQ**

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# Integrating Cancer Care Beyond the Hospital and Across the Cancer Pathway: A Patient-Centred Approach

Jenna M. Evans, Garth Matheson, Sandy Buchman, Marnie MacKinnon, Elaine Meertens, Jillian Ross and Hardeep Johal

## Abstract

**Cancer patients constitute one of the most complex, diverse and growing patient populations in Canada. Like other high-needs patient groups, cancer patients desire a more integrated approach to care delivery that spans organizational and professional boundaries. This article provides an overview of Cancer Care Ontario's experience in fostering a more integrated cancer system, and describes the organization's emerging focus on patient-centred models of integrated care through the whole cancer pathway, from prevention to end-of-life care and survivorship.**

## Introduction

Patients with multiple co-morbidities, frequent hospitalizations and physical, mental or psychosocial challenges often bear the brunt of fragmented healthcare systems (Hollander and Prince 2008; Kodner and Spreeuwenberg 2002). These complex patients require services from several healthcare providers and organizations that frequently operate in silos. A lack of communication and coordination across professional and organizational boundaries can result in poor quality of care, wasted resources and dissatisfied patients (Enthoven 2009). Complex patients also have a significant impact on healthcare costs, as demonstrated by their health-service utilization patterns. In Ontario, over 80% of annual healthcare expenditures are linked to the healthcare services provided to only 20% of the

population (Wodchis et al. 2012). This group of high-cost, complex patients includes accident/trauma survivors, individuals at the end of their lives and those with one or more chronic illnesses, most notably cancer (Wodchis et al. 2012).

Cancer patients constitute one of the most complex, diverse and growing patient populations in Canada, as a result of higher rates of cancer incidence and improved detection, treatment and survival. Nearly 190,000 new cancer cases are diagnosed annually in Canada, of which approximately 40%, or 74,000 cases, are in Ontario (CSQI 2013). Cancer patients utilize a range of diagnostic, treatment and supportive-care services in different settings delivered by a multitude of professionals, including multiple non-cancer specialists, primary care physicians, nurses, pharmacists, physiotherapists and psychosocial workers. Like other complex patient groups, cancer patients require *integrated care* from medical, nursing and allied-health practitioners across hospital and community settings.

The delivery of integrated care requires coordination and collaboration across various organizations, care settings and professionals to ensure patients receive the right care, in the right place, at the right time. Canadian and international integrated care models (which typically involve case-managed multidisciplinary team care, organized provider networks and financial incentives) have demonstrated a range of positive outcomes. These include reduced emergency department (ED)

visits and nursing home placements, lower institutional costs, higher patient satisfaction and improved health outcomes (Curry and Ham 2010). Another common feature of these models is their focus on the frail elderly and those with chronic diseases. The academic literature suggests that integration initiatives focused on complex patient populations will yield greater quality, efficiency and patient satisfaction when compared with broader, generic approaches to integration (Burns and Pauly 2002; Kodner and Spreeuwenberg 2002; Leutz 1999).

Cancer patients who experience disease progression have particularly complex health and social needs, as they often present with multiple co-morbidities. In Ontario, almost 40% of all deaths are related to cancer, and the percentage of cancer patients who visit an ED during their last two weeks of life or who die in an acute care hospital remains high (43% and 53%, respectively) (CSQI 2013). The early introduction and integration of palliative care into patients’ cancer journeys therefore has the potential to improve quality of care and the patient experience, while reducing or maintaining healthcare costs (Barbera and Dudgeon 2010; Klinger et al. 2013; Temel et al. 2010).

This paper summarizes Cancer Care Ontario (CCO)’s integration efforts across the patient journey from prevention to end-of-life care and survivorship and discusses the organization’s emerging focus on a patient-centred integrated model of care.

### **Integrated Cancer Care in Ontario**

CCO’s integration efforts to date have focused primarily on hospital and provider partnership strategies. These institution- and provider-centred approaches to functional, organizational and clinical integration reflect similar steps taken towards integrated care in various other jurisdictions (Evans et al. 2013).

In the 1990s, Ontario’s cancer system had reached a critical point and was under intense pressure to change. As the incidence of cancer continued to grow, the cancer system was fragmented and unable to meet patient demands. In addition, limited information existed about access, quality of care and

outcomes for cancer patients at the provincial and regional levels, making quality improvement on a provincial scale a challenge (Hudson 2001).

In response to growing concerns, CCO worked with the Ministry of Health and Long-Term Care (MOHLTC) and regional partners to plan for system-wide changes in the administration of cancer services. In January 2004, the governance and leadership structures at the ambulatory care Regional Cancer Centres (RCCs), and those of their co-located hospitals, were integrated. On the path towards achieving organizational and functional integration, CCO devolved its operational authority over the RCCs and made their host organizations accountable for delivering cancer services under an overarching CCO-led strategy, the Ontario Cancer Plan. CCO also led provider-level integration by building clinical leadership at the provincial and regional levels to facilitate the development and implementation of shared guidelines for cancer care across organizations and regions. The adoption of Multidisciplinary Cancer Conferences (MCCs) by CCO is one example of how clinical leads champion new evidence-based programmatic initiatives. MCCs are regularly held in cancer programs, where interprofessional oncology teams review individual cases and collectively determine treatment plans. Patients whose cases are reviewed at an MCC are more likely to receive treatment according to clinical guidelines (Forrest et al. 2005). In a study of almost 14,000 women with breast cancer, MCCs improved survival by 11% and reduced variation in survival among hospitals (Kesson et al. 2011). In 2012/2013, 32,000 patients were discussed at MCCs throughout Ontario. In 2008, CCO expanded its clinical leadership model to include primary care and launched the Provincial Primary Care and Cancer Network (PPCCN) (Levitt and Lupea 2009). The initial focus of the network was on increasing the rates of colorectal cancer screening and has since expanded to improving care and the patient experience across the entire cancer pathway from prevention to end-of-life care and survivorship.

Over the past 10 years, evidence has emerged suggesting equivalent outcomes for appropriately selected cancer survivors whose care is transitioned from oncologist-led models to nurse-led models in cancer clinics or primary care-led models in the community (Grunfeld et al. 1999; Grunfeld and Earle 2010; Lewis et al. 2009; Sussman et al. 2012; Wattchow et al. 2006). Primary care providers are often willing to assume followup care with proper guidelines and a clear transition of care for their patients, and are more likely than oncologists to provide preventive interventions directed at non-cancer conditions (Del Giudice et al. 2009; Grunfeld and Earle 2010). Based on these observations, funding was provided in 2012 to support the development and evaluation of models to transition appropriate breast and colorectal cancer survivors from medical oncology-led practice to primary care settings.

#### **LIST OF ACRONYMS**

<b>Acronym</b>	<b>Description</b>
CCO	Cancer Care Ontario
ED	Emergency department
RCCs	Regional Cancer Centres
MCCs	Multidisciplinary Cancer Conferences
PPCCN	Provincial Primary Care and Cancer Network
MOHLTC	Ministry of Health and Long-Term Care
CCACs	Community Care Access Centres
ESAS	Edmonton Symptom Assessment System
ORN	Ontario Renal Network

### **Integrated Patient-Centred Care**

Recent literature and evolving patient needs demonstrate that patient centredness and community-based health and social services are the next frontiers for healthcare integration (Evans et al. 2013; Singer et al. 2011). As such, the definition of integration has recently been extended to incorporate not only the concept of coordination, but also the concept of patient centredness (Singer et al. 2011). According to Singer and her colleagues (2011: 113), integrated patient care is:

- coordinated across professionals, facilities and support systems;
- maintained over time and between visits;
- tailored to patients' needs and preferences; and
- based on shared responsibility between the patient and caregivers for optimizing health.

This explicitly patient-centred model of integration targets the well-documented challenges faced by complex patients and their families – and provides the framework for CCO's efforts to improve cancer services integration. The province-wide focus on integrated care, led by the MOHLTC's Transformation Secretariat, provides a supportive and enabling context for CCO's integration initiatives. It offers unique opportunities for collaboration with the work of the MOHLTC's recent initiative for Health Links, which integrate services for high-needs patients.

### **Beyond Hospitals and into the Community**

Integration strategies are becoming an increasingly timely and common element of health-system redesign and reform efforts as populations age, the burden of chronic disease deepens, financial constraints tighten and new technologies and treatments are developed (Tsisis et al. 2012). The academic literature increasingly emphasizes the need to move beyond integrating tertiary-care services to integrating home- and community-based services (Valentijn et al. 2013). Research indicates that health systems that are supported by a strong primary care foundation result in better health outcomes at lower total health-service costs (Starfield et al. 2005). Yet, the largest gaps in quality of care, identified in following text, occur where patients transition from one provider to another (Coleman 2003).

Three key areas of focus for improving integrated care for complex patients have been identified.

#### **Focus 1: Care Transitions**

A lack of communication and coordination at transition points contributes to numerous quality and safety problems, including suboptimal chronic disease management, adverse events, medication errors, unnecessary declines in patient health and functional status and preventable hospital readmissions and

costs (Coleman 2003). Therefore, the first area of focus is to improve transitions in care for patients as they move across settings and providers, particularly from the hospital back into the community.

#### **Focus 2: Care Outside Hospitals**

Many patients and caregivers prefer the convenience of home- or community-based care, and empirical evidence confirms that several cancer treatments can be safely delivered outside of the hospital (Boothroyd and Lehoux 2004; Luthi et al. 2012). Some services are also more cost effective when delivered in the community or in patient homes rather than in hospital (Boothroyd and Lehoux 2004). The second area of focus is to enable the provision of safe treatment and care outside of hospitals, such as chemotherapy infusions and wound care in community settings or patients' homes.

#### **Focus 3: Palliative Care**

The third area of focus is to promote early identification of patients who can benefit from an integrated, interprofessional approach to palliative care. Palliative care refers to services that improve the quality of life of patients who have a serious or life-threatening disease by preventing or treating, as early as possible, the symptoms of the disease and the side-effects of the treatment, in addition to addressing the related psychological, social and spiritual needs of patients and their families (National Cancer Institute 2014). Cancer patients at the end of life have complex health and social needs that, if not adequately addressed, result in poor patient outcomes and experiences, as well as high costs to the system due to inappropriate utilization of acute care services (CSQI 2013). Despite the significant potential benefits of palliative care, patients continue to be referred to palliative care programs in low numbers and late in their cancer journey (Hui et al. 2010). In the remainder of this article, we discuss CCO's approach to integrating palliative care for cancer patients as a central component of CCO's integrated care improvement work.

#### **Early Access to Integrated Palliative Care Services**

A common misperception about palliative care is that it is appropriate only at the end of life. In Ontario, 53% of cancer patients died in an acute care hospital in 2009, and 8.3% of these patients were referred to palliative care only in the last two weeks of life (CSQI 2013). Identifying the need for palliative care only at the end of life has significant negative implications for patients, including unnecessary prolonged suffering from pain and other symptoms, a lack of preparedness for the end of life and the inappropriate and unwanted use of acute care services. Early implementation of palliative care, meanwhile, has been proven to provide benefits to both patients and their families, which

include less depression and anxiety, better quality of life, less aggressive treatment and lowered healthcare costs (Temel et al. 2010; Howie and Peppercorn 2013; Zimmerman et al, 2014). A Canadian public survey found 87% believe that a palliative approach to care should be available early on in the course of a disease; and 93% believe palliative care services should be available in the setting of their choice (The Way Forward 2014)

CCO is implementing the INTEGRATE Project, a pilot project that incorporates integrated models of palliative care for early identification of palliative care, assessment and management of patients across settings. Interdisciplinary teams that include primary care, MCC teams and Community Care Access Centres are participating in this pilot. The surprise question, “Would you be surprised if this patient were to die in the next year?” (Free et al. 2006) will be leveraged to promote early identification of patients in the primary care and cancer centre settings. This approach will be tested from 2014 to 2017 in select regions of Ontario. To support these integrated models of palliative care, existing CCO and other evidence-based infrastructure, resources and tools will be utilized, including symptom management guides and validated symptom assessment tools, such as the Edmonton Symptom Assessment System (ESAS). ESAS assesses pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. This approach requires education for all care providers on the appropriate use of the tools and the development of process maps between care providers for information flow.

## Conclusion

While great strides have been made in the early detection and treatment of cancer, cancer patients continue to represent one of the most complex, diverse and growing patient populations in Canada. The provincial and regional structures that have been established in Ontario’s cancer system in recent years provide a strong foundation for interdisciplinary care, evidence-based practice, continuous quality improvement and performance management. However, much remains to be done to provide truly patient-centred integrated care across the cancer continuum.

Together with existing and new partners, CCO is building on past work to integrate hospital-based services to design a care system that provides integrated care across multiple settings. The current focus on palliative care is aligned with the provincial government’s transformation agenda and offers an opportunity to have an impact on growing system costs while improving experience and outcomes for this underserved segment of the population. The Ontario Renal Network is also working with CCO to further advance integrated palliative care for renal patients, leveraging alignment across the organization. It will be possible to achieve high-quality, cost-effective integrated care by looking beyond the four walls of hospitals and into the community, and by integrating palliative care earlier in the

patient journey. Improving services for complex and vulnerable individuals may also contribute to system-wide enhancements in integrated care for all patients by highlighting innovative and successful patient-centred models that can be applied more broadly. **HQ**

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# Improving Health Equity for First Nations, Inuit and Métis People: Ontario's Aboriginal Cancer Strategy II

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## Abstract

**Cancer incidence is increasing more rapidly and cancer survival is worse among Ontario's First Nations, Inuit and Métis (FNIM) populations than among other Ontarians. Cancer Care Ontario's Aboriginal Cancer Strategy II aims to reduce this health inequity and to improve the cancer journey and experience for FNIM people in Ontario. This comprehensive, multi-faceted strategy was developed and is being implemented with and for Aboriginal Peoples in Ontario in a way that honours the Aboriginal Path of Well-being.**

## Introduction

First Nations, Inuit and Métis (FNIM) people represent the fastest-growing segment of the Canadian population. Between 2006 and 2011, the number of people self-identifying as Aboriginal increased by 20.1%, compared with Canada's overall growth rate of 5.3%; in 2011, 1,400,685 people (representing 4.3% of the total Canadian population) self-identified as Aboriginal. Ontario has Canada's largest number of Aboriginal people in any province or territory: 301,425 (representing 2.2% of Ontario's population) or 21.5% of the country's total Aboriginal population. Within Ontario, 67% of those reporting an Aboriginal identity are First Nations (FN), 29% are Métis and just over 4% are Inuit (Statistics Canada NHS 2011).

FNIM people are the original inhabitants of Canada, possessing rich and diverse traditions, distinct practices and

beliefs and unique understandings of health and wellness. FNIM political and governance structures, processes and decision-making practices are also unique to the three nations. Rather than being categorized as an ethnic group, FNIM people are distinct nations constitutionally recognized by the Government of Canada. The Constitution Act (1982, Section 35-1) protects Aboriginal and treaty rights and recognizes that Aboriginal peoples include "... the Indian (First Nations), Inuit and Métis people of Canada" (Aboriginal Affairs and Northern Development Canada 2013a). "First Nation" may refer to specific communities, or as an adjective to describe an individual or a group; the term "First Nation" is often used to replace the terms "bands," or "Indian" (AANDC 2013b). In Ontario, there are 133 First Nation communities (also known as "reserves"), with First Nation governments. Métis people are of mixed First Nation and European ancestry, and their history and culture draws on diverse ancestral origins such as Scottish, Irish, French, Ojibway and Cree (AANDC 2013c). Inuit are Aboriginal people primarily from Northern Canada, such as Nunavut, Northwest Territories, Northern Quebec (Nunavik) and Labrador; there are no Inuit communities in Ontario, but the Inuit that do live in the province predominantly reside in Ottawa (AANDC 2013d).

Health disparities continue to exist between indigenous and non-indigenous populations in developed nations. While there

has been notable improvement in the United States, Canada and New Zealand, more needs to be done (Cunningham 2011; Ring 2003).

In 2003, the Institute of Medicine released its report called *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, noting that “the majority of studies find that racial and ethnic disparities remain even after adjustment for socio-economic differences and other healthcare access related factors” (IOM 2003: 5). The report’s authors observed that the evidence pointed to disparities in cancer care and that those disparities were associated with higher death rates among minorities. That same year, in their First Ministers’ Accord on Health Renewal, Canada’s First Ministers acknowledged the gap in health status between Aboriginal and non-Aboriginal Canadians (Health Canada 2003). Ten years later, the Health Council of Canada reported that “despite significant investments to address inequities in the health status and health outcomes of Aboriginal Peoples, the impact of these initiatives is unclear” (Health Council of Canada May 2013a: 35).

In this paper, we examine the incidence of cancer among FNIM people in Ontario, and we address the social determinants contributing to health inequity in those groups. Next, we outline the Aboriginal Cancer Strategy II (ACS II) (Cancer Care Ontario, 2012), a multi-faceted approach to reducing risk, prevention and improving the cancer journey for Ontario’s FNIM people, and we provide details about three of its six priorities. Our paper concludes by discussing several of the policy-related initiatives that will, in the coming years, help to advance the ACS II’s objectives.

**LIST OF ACRONYMS**

Acronym	Description
FNIM	First Nations, Inuit and Métis
FN	First Nations
ACS II	Aboriginal Cancer Strategy II
MOHLTC	Ministry of Health and Long-Term Care
CCO	Cancer Care Ontario
JOACC	Joint Ontario Aboriginal Cancer Committee
ACCU	Aboriginal Cancer Control Unit
PTOs	Political Territorial Organizations
SAR	Screening Activity Report
RCPs	Regional Cancer Programs
ATP	Aboriginal Tobacco Program
TFNHSOC	Trilateral First Nations Health Senior Officials Committee

**Disparities Affecting Health Equity among FN, Inuit and Métis in Ontario**

**Disparities in Cancer Burden**

Globally, cancer mortality is higher for indigenous people. For example, in Australia, cancer mortality for indigenous people is 45% higher than for other Australians (Whop 2012). In Cottrell’s analysis of cancer profiles and survival of Aboriginal and non-Aboriginal people in South Australia, she notes “the survival results reflect the multitude of obstacles confronting Aboriginal patients with cancer compared with non-Aboriginal cancer patients” (Cottrell 2007: 495).

Similarly, in Canada, people with any Aboriginal origins have been found to have higher age-standardized mortality rates than people with no Aboriginal ancestry (Marrett and Chaudhry 2003; Wilkins 2008). Mortality rates have been found to be highest among Registered Indians (those who are registered as Indians under the Indian Act) (Wilkins 2008).

While there are no specific data on the cancer burden among Ontario’s Inuit and Métis people, cancer patterns differ significantly between the province’s FN people and general populations. Cancer incidence rates for major cancers are increasing more rapidly among FN people and cancer survival is worse in this population compared with other Ontarians (Marrett and Chaudhry 2003; Nishri et al. 2015). For example, while incidence rates for breast cancer have stabilized in the general population, the incidence of breast cancer among Ontario’s FN women continues to increase. A recent study examining reasons for poorer breast cancer survival in FN women compared with non-FN Ontarians identified later stage at diagnosis and greater co-morbidity as the two major determinants of survival differences (Nishri et al. 2015; Sheppard et al. 2010). There are also major disparities in cancer risk factors, with, for example, significantly higher rates of cigarette smoking in FN and Métis Ontarians, compared with the non-Aboriginal population (Cancer Care Ontario 2014). These portend a growing cancer burden in Aboriginal Ontarians and growing inequalities.

**Disparities in the Social Determinants of Health**

Broad determinants of health contribute to the unique cancer burden faced by Ontario’s FNIM people. Generally, FNIM people are younger, more mobile, less educated and more often unemployed than non-Aboriginal people. They also earn less and are more likely to be incarcerated, and there are proportionally more Aboriginal single-parent families compared with non-Aboriginal families (34.4% vs. 17.4%, respectively) (Statistics Canada 2011). The median income per Aboriginal household is \$46,865, which is significantly lower than Ontario’s median household income of \$73,290. The Aboriginal unemployment rate in Ontario is 12.3%, and about 57% of the FNIM population over 15 years of age is working. Conversely,

the provincial rate of unemployment is 7.2%, representing almost half the level of unemployment among FNIM Ontarians (HRSDC 2013). Thirty-eight percent of FNIM Ontarians have no post-secondary certificate, diploma or degree, and 61.8% have only a high school diploma or less.

Other socio-cultural factors, such as poor housing, language barriers, cultural differences and geographic isolation, likely also contribute to health-related disparities (Health Council of Canada 2013a). Twenty-eight (21%) of the 133 FN communities in Ontario are isolated (i.e., no regular flights, no year-round road access), with an approximate total population of 90,000 individuals. Thirteen of those 28 remote FN communities are accessible only by air, making it difficult to procure healthy, affordable food and access mainstream health services. With limited healthcare services in many communities, medical travel is a frequent necessity; however, given the higher unemployment and lower income levels, medical travel costs can be prohibitive.

Many FNIM people delay seeing a healthcare professional until they are seriously ill because they are afraid their diagnosis will mean they will be sent away for care and never return. If they do seek help and the care is not culturally safe, they may not return for followup appointments or continue with their treatment plans (Health Council of Canada 2013a). Jurisdictional issues of federal versus provincial accountability also arise in the provision of healthcare for FN people living on-reserve.

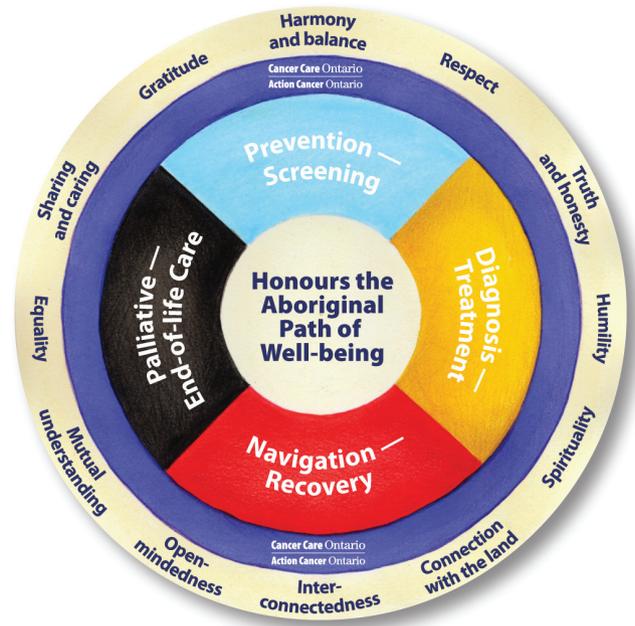
### Cancer Care Ontario's Aboriginal Cancer Strategy II

In Ontario today, the equitable distribution of healthcare is set within the 2010 Excellent Care for All Act, which established the foundation for improving healthcare quality and affirmed the value of a patient-centred health system. In keeping with this statute, Ontario's Ministry of Health and Long-Term Care (MOHLTC 2013) developed a Health Equity Impact Assessment tool to support improved health equity and identified FNIM people as a group that may experience significant unintended health impacts as a result of policies, programs and initiatives.

One of Cancer Care Ontario's (CCO) goals is to improve the performance of the cancer system with, and for Aboriginal people in Ontario in a way that honours the Aboriginal Path of Well-being (Figure 1). The Aboriginal Path of Well-being involves: a balance and harmony between and within the four aspects of a person's nature, which are mental, physical, spiritual and emotional; responsibility for each individual's own health and lifestyle choices; respect for others and the application of traditional Aboriginal practices with integrity, acceptance and empowerment; and an understanding of individual growth and development as it pertains to the Path. Whereas traditionally the basis for the Western health model could be seen as linear and disease- or illness-focused, the Aboriginal model by

contrast involves a circular perspective and a focus on health and wellness (Stewart 2014). The steps to the Aboriginal Path of Well-being include, but are not limited to, the following aspects (Hill 2008):

**FIGURE 1.**  
The Aboriginal Path of Well-being



1. Health in balance: giving equal importance to all aspects of health
2. Wellness: both emotional and spiritual
3. Active choice: one's ownership for health decisions
4. Holistic approach: balance the mind, body and spirit with community and environment
5. Understand root causes: past and present aspects that impact health
6. Joint and personal responsibility: health and well-being is the responsibility of the individual, family and community

The data addressed above pertaining to disparities affecting the health of FNIM people underscore the need for a specific FNIM-focused cancer control strategy that includes both improvements to surveillance and research data in order to better document the current state and progress, as well as actions to improve cancer control across the cancer journey. Launched in 2012, the ACS II is a component of the broader Ontario Cancer Plan and builds on the foundation of the first Aboriginal Cancer Strategy (2004–2009). The ACS II aims to adhere to the principles of the Aboriginal Path of Well-being, while establishing an Aboriginal cancer system that is community-based, holistic in its approach, culturally competent and inclusive.

Acknowledging that FNIM people are distinct, constitutionally recognized groups with Aboriginal and treaty rights, CCO engaged directly with individual FNIM nations, communities and organizations across Ontario to develop the ACS II. This extensive engagement to establish strong, positive relationships with FNIM groups and communities was designed to ensure a shared agenda that extends beyond the strategy's development.

Building on this collaborative network, in the two years since its launch, the ACS II has been used to formalize the communication and engagement structures necessary to maintain and achieve strategic objectives within a framework of mutual respect, recognition of traditions and practices and honour for the history, culture and diversity of FNIM people. A Joint Ontario Aboriginal Cancer Committee (JOACC) is in place, with representatives from each of the FNIM nations and organizations. Its mandate is to ensure engagement and partnerships with FNIM groups and communities, build trust and a shared agenda, improve accountability and ensure an FNIM-centric perspective in the identification, development and implementation of solutions. The ACS II is supported by the wisdom and guidance of FNIM leaders, elders, cancer survivors and the knowledge and expertise of FNIM health program leads and other health professionals. The core strength of the ACS II is that it is not a pan-Aboriginal initiative, but rather an engagement tool that facilitates direct engagement with FNIM leaders and health networks, recognizing and respecting the differences between diverse and distinct Aboriginal cultures.

The ACS II comprises the following six strategic priorities:

1. Building productive relationships
2. Research and surveillance
3. Prevention
4. Cancer screening
5. Palliative care and supportive care
6. Education

In this paper we focus on three of the six strategic priorities: building productive relationships, research and surveillance and prevention.

### **Building Productive Relationships**

Building productive relationships is the ACS II's first strategic priority. These relationships based on respect and understanding are critical to the success of the ACS II. The foundation is the Relationship Protocols between CCO and each of the FNIM organizations and governance structures, including Political Territorial Organizations (PTOs). Relationship Protocols are agreements that acknowledge the unique history and ways of life of FNIM communities in Ontario, and establish and formalize the collaborative relationship between CCO and FNIM people. These protocols build trust and mutual respect, and create mutual accountability.

In 2013, two Relationship Protocols with CCO were signed: Grand Council Treaty #3 (May 2013) and the Union of Ontario Indians (June 2013). In 2014, two further Relationship Protocols with CCO were signed: The Ontario Federation of Indigenous Friendship Centres (July 2014) and the Nishnawbe Aski Nation (August 2014). The approval and signing of the remaining Relationship Protocols are anticipated in 2015, including the Association of Iroquois and Allied Indians, the Métis Nation of Ontario and with Inuit health service providers in the Ottawa region.

Understanding and adhering to FNIM protocol and governance structures is a vital component of working respectfully, and effectively, with FNIM communities. When considering specific initiatives with FN, CCO will seek the guidance and direction of the First Nation Leadership, through the PTO and, when community-specific, through the Chief and Council. This ensures that CCO has the full, prior and informed approval of the political leadership in each community before any work begins.

This approach was important in the development of a community-based colorectal cancer Screening Activity Report, which helps to ensure that residents are up-to-date with their colorectal cancer screening, and can facilitate early identification and prevention of colorectal cancer. CCO provided an overview of the project and sought community approval and support throughout the project. Engagement of the community's Chief and Council ensured greater awareness and recognition to address colorectal cancer screening in the community. Key resources and community members were engaged and aware of the project and importance of cancer screening. The success of this project was demonstrated in positive feedback received from community leadership, physicians and healthcare team members who found the approach of community engagement as respectful and effective. The report was noted as an important tool to support cancer screening in the community.

Establishing the roles of Aboriginal Cancer Leads and Aboriginal Navigators in 10 of Ontario's 13 Regional Cancer Programs (RCPs) with a higher FNIM population also helps to ensure local implementation and capacity to establish local solutions to address FNIM barriers to care. The Aboriginal Cancer Lead is the local champion in the implementation of the ACS II in each health region. The development of Regional Aboriginal Cancer Plans, through close partnerships between CCO, the RCPs and FNIM health tables (e.g., boards, advisory committees and community groups), ensures that each Regional Aboriginal Cancer Plan addresses the unique challenges and barriers faced by FNIM people in accessing cancer-related services. This collaborative approach is designed not only to make the cancer system function more effectively for FNIM people in each region, but also to ensure ongoing respectful, sustainable and productive relationships and an FNIM voice in the planning of the delivery of cancer services in each region.

The role of the Aboriginal Navigator is founded on the recommendations following CCO's Aboriginal Cancer Care Needs Assessment (2002), to provide support and advocacy for Aboriginal patients and their family members, to address and promote awareness of the cultural needs of Aboriginal clients and to network with Aboriginal and non-Aboriginal health groups and organizations. The Health Council of Canada (2012) has identified growing evidence demonstrating that the use of navigators can improve access to Western and traditional health services; increase quality of care; increase knowledge, understanding and adherence to recommended treatments; improve trust of providers; enhance coordination of care; and increase patient satisfaction. Similar evidence has been demonstrated in other jurisdictions. In British Columbia, Aboriginal Patient Navigators have been credited with an increasing access to care through increasing community referrals to hospitals from 24% to 40% (Health Canada 2011). The establishment of Aboriginal Patient Navigators in Quebec was noted to "improve awareness of Inuit health issues among provincial staff, and improved trust and communication between service providers" (Health Canada 2011). Aboriginal Patient Navigators in Newfoundland have demonstrated reduction in patient stress/anxiety and enhanced coordination after care (Health Council of Canada 2012).

**Research and Surveillance**

The ACS II recognizes that data gathered through research and surveillance are needed to support the identification of priori-

ties for action, strategy development and resource planning. Recent work using population-based survey data has been able to provide a clearer picture of the current cancer risk factor and screening participation profiles among Ontario's FN and Métis groups separately, as well as in comparison with the province's non-Aboriginal population. Currently, however, limited surveillance data are available on cancer in Ontario's FNIM communities, and the information that does exist is generally not up-to-date. There is also a paucity of research data about why inequalities exist and what interventions are effective to reduce them.

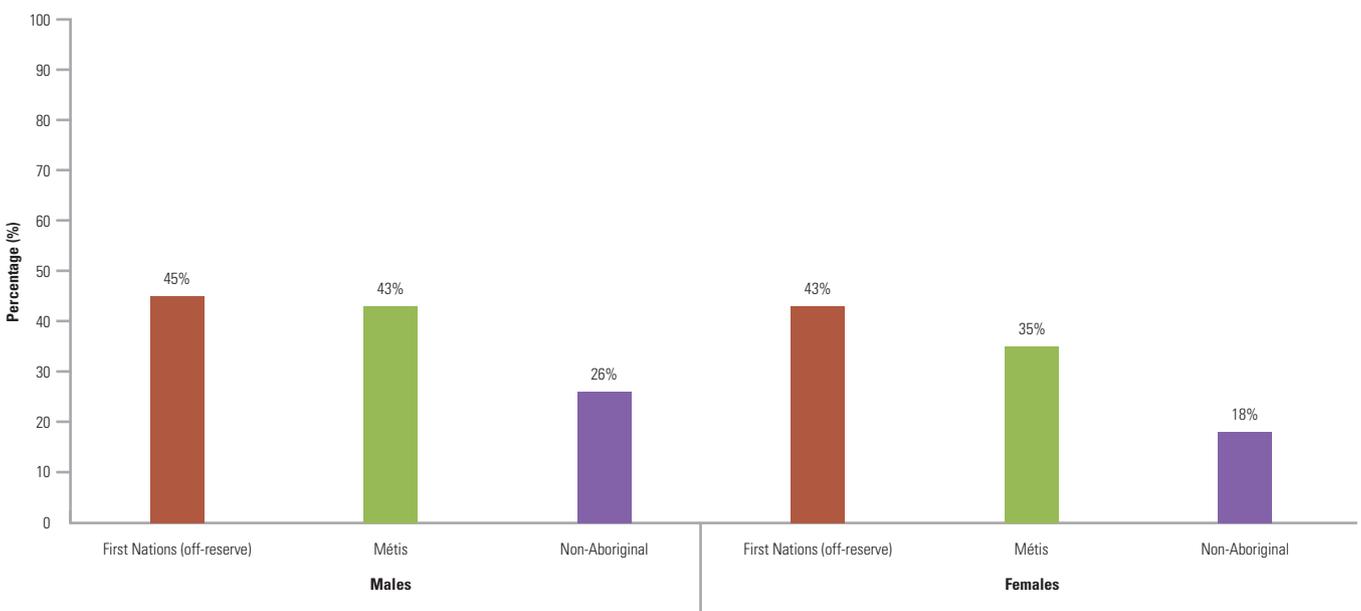
**Prevention**

Prevention offers the most cost-effective, long-term cancer control strategy. At least one-third of all cancer cases are preventable, and tobacco use is the single greatest avoidable risk factor for cancer mortality (WHO 2013).

Tobacco in Aboriginal communities has moved from its traditional ceremonial use to non-traditional, non-ceremonial use. Sacred tobacco represents a vital component of traditional practice for FN and Métis, dating back thousands of years. It is free of chemicals, held in the hand and offered to the earth and fire; it is not smoked. In many FN cultures, tobacco is a symbol of peace that is respected and honoured. It is one of the four sacred medicines (the other three are sage, cedar and sweetgrass) that are understood by FN people to have been offered to them by the Creator to assist them in their journey of life.

In Ontario, less than 18% of female and 26% of males report

**FIGURE 2.** Percentage of population who are current cigarette smokers – Ontario adults (aged 20+), by Aboriginal identity (off-reserve) and by sex, 2007–2011 combined



they are current smokers. However, the rate of non-traditional tobacco use among FNIM communities is as high as 49%, and Canada's Inuit have the highest lung cancer rates in the world (Physicians for a Smoke-Free Canada 2013). The rate of cigarette smoking is significantly greater among off-reserve FN and Métis people than among non-Aboriginal Ontarians (Figure 2). Furthermore, second-hand smoke exposure reported in the home, car or in public is significantly more common among off-reserve FN males and Métis females than non-Aboriginal Ontarians (Figure 3).

Combating the high prevalence of non-traditional tobacco use and exposure in FNIM communities requires culturally appropriate awareness and education initiatives. The primary goal of CCO's Aboriginal Tobacco Program is, therefore, to build capacity towards Tobacco-Wise FNIM communities, among both FNIM and non-FNIM policymakers, healthcare administrators and healthcare and social-care practitioners. A Tobacco-Wise community is one that understands the difference between commercial and sacred tobacco, has initiated discussions around smoke-free policies in the community and, once Tobacco-Wise, implements smoke-free policies. Tobacco-Wise leads advise and assist communities in designing their own non-traditional tobacco awareness and cessation programs. They also forge links with various local/community initiatives, such as the Tobacco-Wise Little Native Hockey League youth campaign to raise awareness among young people about the misuse of tobacco. In addition, smoking-cessation messages are broadcast (in translation) on local radio stations, which is an important conduit to remote communities.

### The Way Forward: Opportunities and Challenges

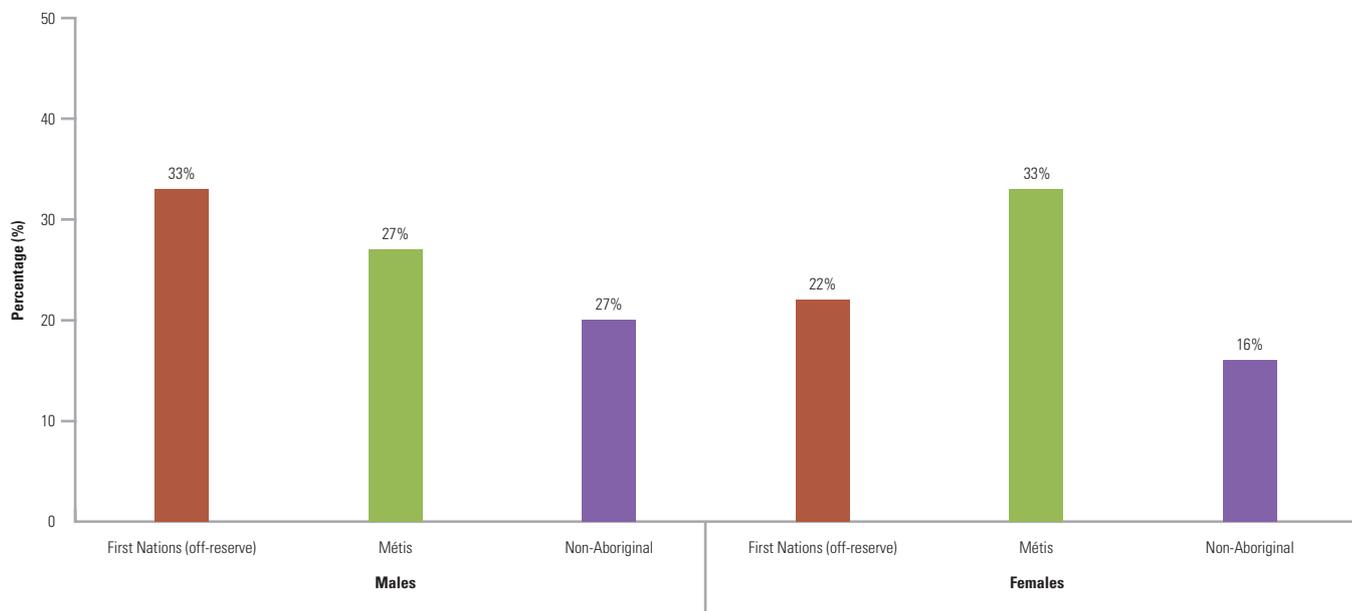
Improving the cancer journey for people in Ontario cannot be achieved overnight. It is a complex issue with many interconnected parts, and a multi-pronged approach that embeds an FNIM perspective is required to address this complex system issue.

The Aboriginal Path of Well-being outlined above incorporates a holistic understanding of the individual that is tied to FNIM values and traditions, and can be used as a framework for patient- and community-centred care.

A broader discussion regarding program and policy changes involving all levels of government is needed to ensure that cancer care is more equitable and accessible – from prevention and screening to treatment and palliative care. In 2011, the Trilateral First Nations Health Senior Officials Committee (TFNHSOC) was established in Ontario, aimed at enabling the three levels of government (Chiefs of Ontario and the provincial and federal governments) to collaborate on shared priorities. To date, these priorities include mental health and addictions, public health, data management and chronic disease prevention (with a focus on diabetes and cancer).

Further, there is an opportunity to develop regional capacity and more responsive programs and services by taking a more collaborative partnership approach with FNIM people than in the past. FNIM patients and families would function as design and quality improvement partners in the co-creation of programs and services. Balik (2012: 12) notes that this “doing with” model requires leadership, partnerships and infrastructure, “essential factors in the transformation from an

**FIGURE 3.** Proportion of population who are exposed to second-hand smoke (in home, car or public) – Ontario adults (aged 20+), by Aboriginal identity (off-reserve) and by sex, 2007-2011 combined



organizational-centred focus to a patient-and-family-centred one.”

Finally, improving the cancer journey for FNIM people requires improved surveillance and research. Extended surveillance data will allow for the identification of additional important research questions and, ultimately, promote actions to improve FNIM cancer control. To enable this, a number of data barriers will need to be addressed, including FNIM identification and community privacy. A key priority is, therefore, to identify FNIM data sources and assess their viability for integration into the current Ontario cancer data holdings for analysis.

At the same time, FNIM governance and self-government have implications for jurisdiction and control over FNIM-related research and information. According to the First Nations Information Governance Centre, “The First Nations Principles of OCAP™ (ownership, control, access, and possession) means that First Nations control data collection processes in their communities. First Nations own, protect and control how their information is used,” ([www.fnigc.ca/ocap.html](http://www.fnigc.ca/ocap.html)). A solution will need, therefore, to be mutually established between CCO and FNIM communities, organizations, data owners and data stewards of the various data holdings in order to develop an FNIM-identified surveillance system that permits FNIM-specific cancer research and control initiatives to be implemented. Doing so will require acknowledgement of the FNIM approach to privacy, which, unlike the standard Western industrialized model, emphasizes “community privacy” and group interests, while collaboratively addressing privacy concerns. **HQ**

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# Personalized Medicine: CCO's Vision, Accomplishments and Future Plans

Jennifer Guo, Suzanne Kamel-Reid, Michael Rutherford, Jennifer Hart, Saul Melamed and Aaron Pollett

## Abstract

**Personalized medicine is a rapidly expanding field, with the potential to improve patient care. Its benefits include increasing efficiency in cancer screening, diagnosis and treatment through early detection, targeted therapy and identifying individuals with an underlying genetic risk for cancer or adverse outcomes. Through the work of Cancer Care Ontario (CCO)'s Pathology and Laboratory Medicine Program, a number of initiatives have been undertaken to support developments in personalized medicine. In keeping with the momentum of recent accomplishments, CCO has led the formation of the Personalized Medicine Steering Committee to develop a comprehensive provincial genetics strategy for the future of cancer care.**

## Introduction

Cancer Care Ontario (CCO) pledged to “expand our efforts in personalized medicine” as a strategic priority in the latest Ontario Cancer Plan III (Cancer Care Ontario 2011: 45). Personalized medicine is a rapidly expanding field that uses genomics to increase efficiency in cancer screening, diagnosis and treatment. Understanding the underlying genomics allows for the identification of inherited cancer syndromes, focused implementation of screening activities resulting in the early detection and prevention of cancers and the prescription of molecularly targeted treatments and standard chemotherapies

that are most likely to benefit the individual patient (Butts et al. 2013; Hamburg and Collins 2010). Developments in molecular oncology have the potential to transform and enhance cancer care in the province. To ensure that Ontario's cancer system continues to be one of the best in the world, CCO is committed to leveraging state-of-the-art technologies, leading medical expertise and evidence-based best practices to promote Ontario as a leader in modern healthcare systems.

For Ontarians, personalized medicine has the potential to reduce the incidence of cancer, improve cancer survival rates and curtail costs associated with ineffective treatment and drug toxicity (Cancer Quality Council of Ontario 2011). CCO has been leading work that integrates an understanding of patients' genetic makeup and molecular changes into cancer prevention, diagnosis and treatment. Central to this work is CCO's Pathology and Laboratory Medicine Program, the clinical program that focuses on cancer diagnostic analysis and works to strengthen the quality of cancer pathology and laboratory medicine services across Ontario. This has included the provision of funding mechanisms for new genetic tests and close collaborations with Ontario's Ministry of Health and Long-Term Care (MOHLTC) to address genetics-related provincial and national policy issues. The aim is to have a system where Ontario patients have access to high quality, timely and personalized approach to cancer care.

## Current Developments in Personalized Medicine in Ontario

Ontario has been investing in large-scale research and infrastructure development in industry projects, private–public partnerships and hospital initiatives in personalized medicine (Invest in Ontario 2013). These funding commitments have supported application of new technologies, such as multi-gene panel testing and next-generation sequencing (NGS) platforms. The resulting advancements have expanded the ability of laboratories in Ontario to generate genomic data far beyond the molecular analysis of a single-gene, at a scale and accelerated pace that could not have been achieved a decade ago (Mardis 2013). To expand genetic testing to accommodate the clinical need, current funding and laboratory licensing models for emerging tests need to be continually updated to keep pace with the discoveries and developments of clinically validated molecular biomarkers.

Significant work has been done to pave the way for new paradigms in genetic testing, such as the coordination of predictive testing and treatment and the concept of “companion diagnostics,” or test-drug pairs. Given the efforts in widening the scope of available testing, progress towards more provincial oversight of genetic testing will be needed to ensure appropriate access and quality. Support for such initiatives will facilitate timely and efficient adoption of molecular testing into the clinical setting.

With an increased emphasis on integration of genetic testing into everyday clinical practice, healthcare providers will continue to require ongoing support, including updated practice guidelines and decision support tools, in order to effectively use these new technologies (Bonter et al. 2011; Cancer Quality Council of Ontario 2011: 9; Carroll et al. 2008). The availability of such tools will be critical for ensuring appropriate clinical utility of genetic testing as well as appropriate referral patterns to clinical geneticists and genetic counsellors.

### LIST OF ACRONYMS

Acronym	Description
CCO	Cancer Care Ontario
PMSC	Personalized Medicine Steering Committee
MOHLTC	Ministry of Health and Long-Term Care
NGS	Next-generation sequencing
MOAC	Molecular Oncology Advisory Committee
ALK	Anaplastic lymphoma kinase
BRAF	B-Raf proto-oncogene, serine/threonine kinase
KRAS	Kirsten rat sarcoma viral oncogene homolog
HCSSC	Hereditary Screening Cancer Sub-Committee
HBOC	Hereditary breast and ovarian cancer syndrome
VUS	Variants of unknown significance

## CCO's Accomplishments to Advancing Personalized Medicine

CCO contributes to the quality of medical genetics laboratory testing by advising the MOHLTC on emerging issues in molecular oncology and leading initiatives that support biomarker testing and up-to-date clinical criteria for genetic testing in cancer patients. In 2008, CCO struck the Molecular Oncology Task Force to develop an assessment of the province's genetic testing and counselling services in the field of oncology. The Task Force's report, *Ensuring Access to High Quality Molecular Oncology Laboratory Testing and Clinical Cancer Genetic Services in Ontario* (Cancer Care Ontario 2008), led to the formation of the Molecular Oncology Advisory Committee (MOAC) in 2010. MOAC is an advisory panel of leaders in medical and laboratory genetics. It plays an integral role in implementing provisions to ensure quality assurance and cost-effectiveness for strengthening molecular oncology laboratory and clinical cancer genetic services in Ontario. As of the writing of this article, MOAC has provided recommendations to MOHLTC that have led to CCO providing funding oversight for testing of several biomarkers, including ALK, BRAF and KRAS. MOAC's sub-committee, the Hereditary Cancer Screening Sub-Committee (HCSSC), is collaborating with CCO's Cancer Screening Program to support initiatives that screen for persons with known inherited cancer syndromes, such as hereditary breast and ovarian cancer syndrome (HBOC) – caused by alterations in the BRCA1 and BRCA 2 genes – and Lynch syndrome – caused by alterations in the MLH1, MLH2, MSH6 and PMS2 genes. In addition, the HCSSC is currently leading work in the development of an advice document to provide recommendations for clinical best practice to help drive consistency for identifying, analyzing and reporting genetic variants of unknown significance (VUS) in relation to testing for HBOC and Lynch syndrome. Other initiatives include the formation of ad hoc working groups that provide evidence-based and clinical expert advice to address pressing issues, such as the HER2/Neu Expert Panel Working Group. This expert panel provided recommendations for the testing of HER2 – a gene that when overexpressed promotes growth of breast cancer cells, while Herceptin – a targeted therapy against HER2 – was undergoing the approval process in Ontario (Cancer Quality Council of Ontario 2011: 22).

## CCO's Approach to Personalized Medicine

CCO established the Personalized Medicine Steering Committee (PMSC), consisting of oncology and pathology experts from across Canada, to advise on Ontario's strategy for personalized medicine in cancer care. Leveraging regional expertise, national leaders in the field, international networks and existing models of best practices, PMSC will provide leadership, guidance and input to advance personalized medicine into mainstream

medical practice, while working in alignment with MOAC, the Pathology and Laboratory Medicine Program and MOHLTC-supported working groups external to CCO.

Expected outcomes of PMSC's strategy for Ontario will include:

- Providing a proactive and comprehensive plan for the province to guide best practices in personalized medicine, such as incidental findings, VUS and use of information technologies.
- Supporting guideline development and knowledge transfer for healthcare providers to apply genomics as a central part of providing quality care to cancer patients.
- Collaborating with national and international groups to coordinate efforts to further best practice in personalized medicine.

### Concluding Remarks

Knowledge of genomic data is already being used by physicians to direct patients into screening and surgical risk reduction programs, advance new treatments that aim to inhibit the molecular target or genetic variant in the cancer cell genome of specific cancers and avoid costly treatments with limited benefits and possible side effects.

Ontario is moving towards a more comprehensive strategy to integrate the application of personalized medicine into mainstream medical practice for oncology. The strategy will include an approach to molecular diagnosis that spans from individual risk assessment to tumour analysis to disease management in the clinical setting.

This will require renewed focus to key policies, planning and approaches to genetics in the oncology field to enable the province's pathology and laboratory medicine programs to move cancer care beyond conventional standard guidelines and practices. The PMSC will embark on the next step to developing a strategy that will drive Ontario's approach in personalized medicine and bring the benefits of personalized medicine into clinical practice. **HQ**

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# Implementation of an Agency to Improve Chronic Kidney Disease Care in Ontario: Lessons Learned by the Ontario Renal Network

Graham L. Woodward, Alex Iverson, Rebecca Harvey and Peter G. Blake

## Abstract

**In 2009, Ontario's Ministry of Health and Long-Term Care initiated the transfer of oversight and coordination of chronic kidney disease (CKD) care to the Ontario Renal Network (ORN) under the auspices of Cancer Care Ontario (CCO). The aim was to replicate the quality improvement and change management practices used for cancer control within CKD. Much of the ORN's first three years were dedicated to building the infrastructure necessary to bridge the gap between provincial policy and clinical practice. This article explores the accomplishments, challenges and lessons learned over that period. The results, which are applicable to the management of chronic diseases in Ontario, Canada, and internationally, confirm that sustainable change takes time and requires strong leadership, transparency, accountability and communication, supported by a solid foundation of data and evidence.**

## Introduction

Prior to 2009, the province's chronic kidney disease (CKD) care system had been administered by the Ontario Ministry of Health and Long-Term Care (MOHLTC). This system consisted of 26 regional CKD programs that included over 90 sites caring for approximately 10,000 dialysis patients. Demand for services was outstripping supply in a number of regions, system planning was fragmented, provincial data on disease prevalence and

quality of care were absent and provincial improvement efforts lacked clinical leadership. A number of reports called for a more coordinated and integrated approach, including the creation of a provincial data set and agency (Kidney Foundation of Canada 2008; MOHLTC 2004, 2006, 2009). In 2010, the MOHLTC transferred provincial oversight and coordination of CKD to the Ontario Renal Network (ORN) under the auspices of Cancer Care Ontario (CCO). This transfer was formalized through the MOHLTC–CCO–ORN Accountability Agreement. This Agreement established areas of accountability for the ORN, deemed essential to building a strong foundation for improvement:

- Provincial and Regional Program Management: Establish an Ontario leadership team within CCO to inform the strategic direction, manage the provincial office and align and support province-wide implementation of improvements for the management of CKD. Establish regional leadership to drive the provincial CKD program agenda in every local health integration network (LHIN) and to align and support regional implementation of CKD quality improvement initiatives across Ontario.
- Performance Measurement and Management: Implement a performance measurement and management cycle to track the success of activities and strategies, and to improve

CKD program accountability and performance.

- Information Technology: Implement a provincial information system for clinical program and CKD system planning, management and funding.
- Communications and Stakeholder Relations: Establish the ORN as a transparent and accountable provincial entity within CCO, and engage a broad coalition of CKD stakeholders in its work.

### **Provincial and Regional Program Management**

The ORN's initial leadership consisted of a provincial medical director (nephrologist) and an executive lead; these individuals were supported by a small CCO-based secretariat (four FTE). Late in 2010, a CCO vice president with system-level management and policy experience was appointed. During this time, the regional leadership comprised a paid regional director (RD) and a volunteer regional medical leader (RML) associated with each LHIN region.

In 2010, Adeera Levin, Executive Director of the British Columbia Renal Agency, conducted an internal review of the ORN to inform the leadership on the current state of functioning, opportunities and challenges after one year of operation (Levin 2010). This review found that the leadership and advisory structure did not resonate well with stakeholders, and a number of recommendations were made to improve engagement with CKD providers and stakeholders. As a result, an ORN Executive Committee and Advisory Council were formed, and the provincial leadership was expanded to include physicians accountable for the ORN's priority areas: Vascular Access; Independent Dialysis; Early Detection and Prevention; Funding; Research; and Data and Reporting (ORN 2012a).

In 2012, ORN undertook a second review focused on the ORN's regional structure (ORN 2012b). This review found that the regional leadership was focused on administrative issues and lacked consistency across all the regions; for example, the RDs had inconsistent roles, responsibilities and remuneration, with some RDs lacking operational responsibilities within a regional CKD program. Regional leadership is a critical component of the CCO improvement model because it requires change leaders to be formally accountable at both provincial and regional levels. The RMLs were not remunerated and were much less engaged. Since 2013, a revised RD role description and contract has been implemented to improve consistency, and all RDs have management responsibilities within a regional CKD program. Similar to their RD counterparts, since 2013, the RMLs have been remunerated for half a day a week to improve accountability at both the provincial and regional levels. The regional leadership meet regularly with the provincial office to improve engagement.

Through discussion with both provincial and regional leadership, it has also become apparent that while many RDs, RMLs and provincial leads have held local leadership positions (e.g.,

Renal Program Director, Chief of Nephrology), few have had experience with policy or change management across a system of providers and stakeholders. As a result, ORN and CCO have improved access to continuing education and training, implemented stronger orientation practices and established a Centre of Practice to improve physician leadership recruitment and development (CCO 2014).

### **Performance Measurement and Management**

In 2010, the first accountability agreements between the ORN and the 26 hospitals with regional CKD programs were established. As a condition of funding, these agreements set out expectations for service volumes, reporting and quality improvement. These conditions, along with regular meetings with the CKD programs, RDs and RMLs, form the foundation of ORN's Performance Improvement Cycle for CKD care

As a commitment to public reporting and accountability, ORN also publishes performance metrics on its website ([www.renalnetwork.on.ca](http://www.renalnetwork.on.ca)). Public reporting of performance was new to many CKD care providers and resulted in considerable confusion and concern regarding its purpose and motivation. More explicit and direct engagement of care providers regarding the components and purpose of the performance improvement cycle was needed. Another expectation of the Agreement was for ORN to develop and implement a funding framework that is patient-based, reflects best practice and achieves greater funding equity across the province. At the time of ORN's inception, regional CKD program funding was based on self-reported service volumes, with little connection to quality or outcomes of care. Development of a new funding framework was based on transparent application of clinical and financial data; advice by clinicians, administrators and policymakers at both a provincial and regional level; and CCO's experience with case-based funding.

Implementation of the new framework, now part of the MOHLTC's Health System Funding Reform (MOHLTC, 2013), was completed in 2014. This funding transformation was supported by numerous tools and documents (e.g., workbooks to assess financial impact and help with budget transition, guides to describe purpose, methods and all funded services) and is governed by a panel representing ORN Provincial Office, RDs and RMLs (ORN 2014). Evaluations during implementation indicated that this approach was well-received by the regional CKD programs. Funding for CKD is being expanded in 2014 to include home and long-term care.

### **Information Technology**

Foundational to ORN's work is its ability to transform data into information useful for decision-making. In 2010, the Ontario Renal Reporting System (ORRS) was launched to provide timely data for CKD planning, funding and performance/quality reporting. Administered and managed by the

ORN Provincial Office, the ORRS collects data on all persons receiving dialysis and pre-dialysis care in Ontario. Essential to quick implementation of the ORRS was CCO's existing information management/information technology infrastructure, along with CCO's status as a prescribed entity within Ontario's Personal Health Information Protection Act (Service Ontario 2014). Regular enhancements to the ORRS continue, such as the roll out of direct access to the ORRS by each CKD program to improve data quality and disease monitoring and management at a local level (ORN 2014). Along with performance measurement, the ORRS and CCO's data analysis capacity was essential for the creation of an annual review of renal system capacity – another key deliverable in the Agreement. Based on the best available evidence, and developed in collaboration with the Institute for Clinical Evaluative Sciences (ICES), the Centre for Research in Healthcare Engineering and CKD programs, this review represents a shared understanding of the supply of and demand for dialysis services at a provincial and local level, and serves as a guide for future capital investment (ORN 2014). The most recent assessment includes capacity needs up to the year 2024, and was expanded beyond dialysis to include vascular/body access services and inpatient care.

### **Communication and Stakeholder Relations**

Since its inception, the development of a communications plan for regional CKD programs and physicians has been an important undertaking for ORN (Levin 2010). Initiatives such as the funding framework implementation, capacity assessment development and ORN Annual Planning Day continue to reinforce the need for intensive communication with stakeholders using a variety of methods such as newsletters, email, social media and meetings. A key feature of the ORN model has been to involve physicians in the management of renal care in Ontario. Historically, there had been a degree of distrust between the MOHLTC and nephrologists in the province. The introduction of physician co-management has helped to resolve this. Paid and accountable provincial and regional medical leads, the presence of four nephrologists on the ORN executive team and extensive nephrologist involvement in funding policy, organizational and clinical standards development and strategic planning initiatives have given physicians a central role in ORN governance. These changes mark a radical shift in the model of renal care delivery in Ontario.

### **Building on the Core Elements to Improve Quality**

In May 2012, ORN released the *Ontario Renal Plan*: the first comprehensive roadmap for CKD care in Ontario (ORN 2012a). Developed through consultation with the MOHLTC, CCO, LHINs, regional CKD programs and CKD organizations such as the Kidney Foundation of Ontario, the plan describes

our strategy to address the burden of end-stage renal disease, while improving the quality of care and treatment of current and future CKD patients. Framed by IHI's Triple Aim (Institute for Healthcare Improvement [IHI] 2014), seven priority areas (each with explicit targets) are described in the plan:

- Accountability to patients (AP)
- Early detection and prevention of progression (EDPP)
- Peritoneal and vascular access (VA) for dialysis patients
- Home or independent dialysis (ID)
- CKD infrastructure planning
- Research and innovation (RI)
- Funding aligned with quality patient-focused care.

Progress on these priority areas has been variable. As described earlier, funding and infrastructure planning have been successfully delivered and continue to be refined. For ID and VA, care coordinators have been established in every CKD program, an IHI-type collaborative (IHI 2003) has been implemented to support the coordinators along with provincial and regional leadership and information tools to track patient progress have been implemented. As a result of these activities, the proportion of dialysis patients using a home modality has begun to increase. However, a lack of consensus exists among nephrologists regarding the appropriate use of fistulas, compounded by issues of access to surgical care. As a result, a reduction in the percentage of haemodialysis patients using catheters has not yet been achieved. Improved data reporting has been implemented to study and improve issues of appropriateness, surgical access and performance

For EDPP, ORN initiated primary care practice pilots and partnered with the Electronic Medical Record Administrative Data Linked Database (EMRALD) project at ICES to evaluate CKD identification and management tools associated with their electronic medical records. As well, the EMRALD project will evaluate the effectiveness of performance scorecards for improving the management of chronic diseases by primary care (ICES 2014). To further support primary care, ORN has developed a CKD management algorithm and a standard referral form, and has carried out mentorship pilots that linked primary care providers to nephrologists for education and timely advice. Evaluation of the pilots demonstrated the need for greater peer support of primary care providers by their nephrology colleagues, as well as regular primary care educational opportunities (Cathexis 2014)

The RI and AP portfolios were slower to develop, but have made more recent progress. ORN is partnering in a number of research agencies to fill critical information gaps and with CCO has undertaken a corporate review of its research program to assess how we can better support CKD research needs. Under the guidance of CCO's Centre of Practice for Patient and

Family-Centred Care, ORN has begun to regularly and extensively engage patients and families in strategic and operational planning and will soon launch a provincial Patient and Family Advisory Council.

## Summary

ORN was created to plan and manage CKD system resources to ensure that high-quality care is available to those who need it, when and where they need it. As the system steward, ORN had to effectively bridge the gap between provincial policy and clinical practice. Bridging this gap required the implementation of numerous structures and processes. Provincial and regional leadership was required to define best practices and to champion these practices with front-line care providers. Valid, reliable and comparable data were required to measure performance and establish greater accountability. Methods for transparent communication and decision-making among the providers, policymakers and planners were launched to build trust and a shared purpose – the continuous improvement and sustainability of CKD care. ORN's progress towards goals and objectives identified in the first Ontario Renal Plan is evidence that numerous bridges have been successfully constructed. The second Ontario Renal Plan, due for release in the spring of 2015, will identify strategies to continue this progress as well as set out additional goals to improve the lives of all CKD patients and their families. 

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## Acknowledgements

ORN is a network. The early days were driven by a few dedicated people, but the concept only really began to take form when the linkages among a diverse and multidisciplinary group of administrators, providers and patients took hold. Thus, while this paper was written by a few, the successes it documents are the result of many. While we would love to name them, this runs the great risk of forgetting someone. Thanks to all of you for your dedication to improving the care of persons with CKD.

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# The Challenge of Quality Improvement at the System Level. Whither CCO?

Adalsteinn Brown

## Abstract

**Cancer Care Ontario has made significant strides in the improvement of access to high-quality cancer care by putting in place the basic elements of transformation: a clear plan, reporting against this plan and clinician engagement. However, as our health system changes so must improvement efforts. Greater focus on equity and population health will require a better understanding of the people served. The increasing need for improvement will put a premium on quality improvement skills. Finally, the need to re-engineer care across the patient journey will require attention to integration; attention that will have to come from government.**

## Background

In the decade since the release of the first cancer plan, Cancer Care Ontario (CCO) has made a number of efforts to improve the quality of cancer care and to build a platform for cancer control. These efforts are well-documented in other papers and include the creation of the Cancer Quality Council of Ontario (Sullivan et al. 2004), the creation of the first strategy-based cancer system scorecard (Greenberg et al. 2005) and its subsequent evolution into the Cancer System Quality Index (CSQI), the development of new programs designed to increase the effectiveness and appropriateness of care such as the deployment of synoptic pathology and the introduction

of the first integrated cancer screening program in Canada to meet the criteria for organized screening programs. All of these efforts build upon earlier work that laid a strong foundation for evidence-based care such as the Program in Evidence-Based Care (Browman 2012) and efforts to repatriate and increase access in Ontario to needed cancer care. In recognition of its success, CCO may point to its status as the longest-running independent health agency in the province and a growing list of responsibilities given to it by the government such as the Access to Care program, for all surgeries that was critical to the success of the Wait Times Strategy in Ontario, and the Ontario Renal Network that has brought about rapid and important improvements in the quality of dialysis care. Perhaps as importantly, CCO has published extensively on these efforts and consistently reported performance data, even when it showed poor results.

## Has Cancer Care Quality Improved?

In order to argue whether quality has improved, we should first define what we mean by quality. Although organizations like the Institute of Medicine have defined key dimensions of quality and the Excellent Care for All Act (2010) enshrines an even longer list in Ontario, our notion of what constitutes quality care has evolved over time. In the first several years of this century, quality of care was arguably focused on more and faster care. Following on the heels of substantial reductions in capacity and

streamlining, policy efforts at the federal and provincial level were focused on reducing wait times and increasing resources (facilities and professionals) available to provide care. Within this relatively narrow definition of quality of care, the quality of cancer care has improved. Wait times for cancer surgery have declined – and declined by more than some of the other priority areas identified by the federal and provincial governments in 2004 – and several new regional cancer centres have opened, while the capacity for radiation treatment has nearly doubled and improved in quality. Reports of cancer patients seeking care outside of Ontario seem to be less prominent, and most debates around access deal with new treatments for which evidence is inconsistent.

Although more and faster care was clearly the policy priority at the beginning of this century, the focus of efforts to improve quality has since expanded to include the technical quality (appropriateness and effectiveness) of care and, to a lesser degree, the extent to which this care is patient-centred. Once again, quality seems to be improving, although the evidence is less clear. Big dot indicators like hospital-specific mortality rates are declining in Ontario, and key cancer indicators related to the quality of care provided such as survival are at international benchmarks. Based on the CONCORD study that aggregates population-based cancer survival data from across dozens of jurisdictions, one- and five-year survival for the four most common cancers is as good in Ontario as in any other jurisdiction (Coleman et al. 2011). This performance is reflected in largely positive ratings on care in the CSQI (2014). It is also linked to major initiatives around measuring and improving the quality of surgical care, the appropriateness of radiation and chemotherapy and a continuing leadership role for clinicians in generating and adopting evidence on effective care. CCO has also led in this regard by implementing symptom assessment efforts that have improved the quality of life and patient experience measurement at all regional cancer centres.

More recently, however, the focus of quality improvement efforts has expanded to include broader goals. These have been variously defined as the Triple Aim (population health, patient experience and cost), value (a ratio of quality and cost) and even equity (reducible harm is eliminated across all populations and care is sensitive to the community). These perspectives on quality are captured in the CSQI. But we could argue that the current scope of measurement does not match the scope of these goals and the results, where they are measured, include some of the poorest ratings.

CCO is not alone in struggling to meet the challenges posed by these broader goals. It is clear that no jurisdiction or system has successfully met all of these goals. Major new policy initiatives around the world like Accountable Care Organizations in the United States or Health Links in Ontario are intended to

address some of these broader goals, but there is no silver bullet or even clear and compelling evidence on how to deal successfully with all of these challenges simultaneously. As CCO moves forward, it may be useful to consider what has helped drive its success through the first two evolutions of quality (more care and higher-quality care) and whether these lessons can shape CCO's and, more broadly, all health systems' strategies for improvement going forward.

### Stay the Course?

As always, the credit for past success goes to the people working in the cancer system at every level. Improvement happens because they do things differently, not because of policy or programs. But it may be useful to consider some of the important enablers that CCO has put in place that encourage and enable improvement. CCO has implemented a wealth of new programming, introduced new information systems and created new roles and goals. Perhaps most notably, CCO has also evaluated many of these innovations, keeping those that work while modifying some of the others. More fundamentally, CCO has also implemented what we have called the table stakes of transformation. In an earlier piece in this journal we suggested that successful health systems have gotten three things right: they have created a plan with clear goals, reported against those goals in a way that people had to pay attention and they have engaged clinicians in improvement efforts against those goals (Brown et al. 2012). CCO has met these tests.

Since the first cancer plan in 2004, CCO has regularly updated the cancer plan and set both programmatic and outcome goals every year. This document is publicly available and widely distributed across the cancer system. Likewise, the first comprehensive cancer scorecard came out publicly in 2005 and has been updated every year, evolving over time to reflect many aspects of quality and the cancer patient journey. Clinical leadership and engagement in improvement efforts at every level from the board table to the bedside has continued to be a hallmark of CCO's efforts. These are critical elements to ensure quality, but will they be enough as the goals for improvement change?

One of the first things to consider is whether the health system has changed substantially enough that these elements should also change. The short answer is no. It is true that we have many more agencies working in the Ontario health system and many more sets of publicly reported indicators. But none of these changes would argue for more than a need for greater collaboration. Another issue worth consideration is whether we now know more about quality and quality improvement that invalidates what we have called above the table stakes. The short answer again is no. There has been excellent work over the past decade on key aspects of health system transformation

(Ham 2010; Baker et al. 2008). But again, none of these insights argue against the importance of a plan, reporting and clinical leadership. Rather, they provide additional and more refined advice on how to improve quality across health systems in a sustainable way that complements and reinforces the importance of plans, reporting and clinical leadership.

Finally, we must consider whether the goals of quality improvement have changed so much that the historic approach is no longer sufficient. Here, the answer is yes. The new goals require new measures and, perhaps more importantly, the acceptance of these measures as a point of meaningful accountability for managers and providers in the cancer system and, more broadly, the health system. If we want to pursue equity seriously in the health system, we need to know more about the people who need care and what they need. In contrast to the United States, we do not systematically collect information on the background of people seen in our system and we rely on ecological extrapolations from census data to know whether access is as good for the poor as it is for the wealthy. We know little about whether people understand the instructions for care given to them. Likewise, our efforts to engage patients meaningfully in defining what they need from care remain in their infancy. Moving beyond equity to a question of simple effectiveness, we should not underestimate the pace of technological change in care and the degree to which issues like personalized or precision medicine will fundamentally change what data we collect and what data we use to make decisions and even how we make these decisions at the bedside or in the boardroom. In this regard, CCO and cancer agencies in general can lead health systems as they did with wait times. Building off of its current information management policies, CCO can continue to stretch what data are collected and how they are used to make better decisions.

But more and better data will not be sufficient to meet the new goals of the quality movement. Success will also require increased leadership and improvement capacity. The broader goals require a level and breadth of improvement activity that is not yet common across most health systems. CCO has done an excellent job of engaging clinicians across the cancer system to shape and lead policy implementation. What is still missing – as it is in most systems – is the ability to engage a large portion of the professionals working in the system in improvement exercises. This is the oft-repeated mantra of Toyota and other organizations that everyone's job is to meet a standard and raise that standard. This vision of our system will require increased training in improvement as well as increased recognition that quality improvement is a portion of people's work that must be included when determining workload and compensation. CCO can lead on this goal but it will likely need to lead in partnership, as the capacity to train professionals in quality improvement rests elsewhere in the system. In this situation, CCO can

lead the entire system by increasing its focus on improvement and its recognition of the importance of improvement at all levels of the cancer system.

Finally, better data and more extensive improvement efforts will help achieve the current broader set of quality goals but two more transformations are critical. The first is a cultural shift. There is no single organization or individual who could credibly claim that they “have control over outcomes like cancer mortality or the equity of cancer mortality.” Rather, many providers influence these goals. This limits the willingness of any actor in the health system to accept accountability for this sort of big dot indicator. But if CCO cannot translate this sort of indicator into something meaningful and acceptable to providers, and if it cannot include these indicators in its accountability agreements, it will not be able to pursue these indicators in a meaningful way. This will be a cultural undertaking of great significance but a worthwhile one where CCO can again lead the health system.

The second shift is a structural shift. The broader sets of goals like the Triple Aim look to improve both health and cost. There is an increasing weight of evidence that this sort of goal is possible but in order to realize these goals, there needs to be a way of connecting the costs and benefits of improvement efforts. Øvretveit (2009) has noted that the costs and benefits of improvement are spread out across time and across stakeholders. If we look to improve the accuracy of cancer diagnosis and support more effective surgical treatment, we merely need to focus on the hospital and can achieve huge gains through improved surgical pathology alone. If we want to increase the value of care, the connection across the cancer journey must be much tighter and we must be able to share costs and benefits across that chain. Initial work here has been excellent – for example, the work to increase links with primary care – but in a siloed system like Ontario's, it has likely gone as far as it can. This is where the argument for structural reform that has to come from a ministry is critical. CCO can support this argument but it has likely done as much as it can here.

Broader health system transformation is not where we want it to be. This is as true in Ontario as it is in any other jurisdiction in Canada. We lag other systems. That being said, we should not ignore our successes. The table stakes for transformation were put into place at CCO years ago. They have borne fruit. We falter in many international scorecards, but Canada (and Ontario) do very well in international comparisons of cancer survival; undoubtedly one of the best indicators of the quality of a cancer care system. The challenge now is to move from re-engineering a cancer care system to creating a cancer control system. CCO, as well as other groups like the Canadian Partnership Against Cancer, can lead the way towards this goal, sometimes through action, sometimes through advocacy and always by establishing the evidentiary basis. **HQ**

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## Conflict of Interests

Member of the Cancer Quality Council of Ontario since 2007; involved in the development of the first Cancer System Quality Scorecard for CCO (2004) and Indicators of Quality Cancer Surgery (2005). No compensation received for these efforts.

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# The Opportunity and Strategy for Quality and Health-System Improvement Now and in the Future

Michael Sherar and Oonagh Maley

## Abstract

**Since 2004, Cancer Care Ontario (CCO) has played a leadership role in linking funding to quality of care, and in using evidence and administrative and clinical data to drive performance and quality improvement. This article describes how CCO has used its cancer and renal health system strategies to establish an environment of continuous health system improvement. The article also describes how CCO's Corporate Strategy is driving organizational improvement: evolving CCO's capacity and capability to drive quality and value across healthcare settings, and its ability to advance broader health system transformation in support of cancer and renal patients.**

We began this special issue by looking back in time to the 1990s and early 2000s when wait times for radiation therapy created a crisis and a platform for change in the Ontario cancer system. We end this issue by looking forward and contemplating how CCO is evolving to meet the emerging challenges in Ontario's healthcare systems. These challenges include reducing the rate of growth in healthcare spending, a distributed governance structure, a patchwork of information technology and funding for providers not well-aligned with quality. And this is on a backdrop of rising need for services due to an aging demographic and increasing exposure to risks for chronic disease including alcohol consumption, unhealthy eating and physical inactivity, and a decline in smoking rates that has stalled.

CCO can play an important role in meeting these challenges

for cancer and renal care while contributing more to broader health-system improvement in Ontario, by building on the approaches it has established for quality improvement. This article will summarize CCO's quality improvement approaches and achievements (until 2011), and then describe the corporate strategy that was developed and implemented over the past three years to position CCO to tackle broader quality improvement objectives that will enable cancer, renal and support broader health-system improvements.

## Background

Prior to 2004, CCO was the major provider of cancer services in Ontario through a system of regional cancer centres and with a focus on providing outpatient radiation and chemotherapy services. As a result of a provincial review in the wake of a crisis in access to radiation therapy (Hudson 2001), CCO ceased to be a provider of healthcare services, handing over operation of the cancer centres to the local hospitals with which they were co-located. CCO was to become a quality improvement organization combined with its role as a purchaser of cancer services. The intent was to maintain oversight of the budget for cancer services and through the development of a provincial quality plan, tie the provision of funding to quality of care. In 2005, CCO embarked on the implementation of the first Ontario Cancer Plan (OCP). The plan went beyond radiation and chemotherapy in hospitals, and took a population approach to cancer control and quality of care throughout the cancer journey

from prevention to survivorship or end-of-life care. Although initially CCO did not fund cancer services outside of radiation and chemotherapy, the Ministry of Health and Long-Term Care in Ontario (MOHLTC) began providing CCO the funding needed for growth in other cancer services (e.g., cancer surgery) as well as funding for quality improvement initiatives included in the OCP.

The first OCP (2005–2008) focused on establishing guidelines and standards for quality of care, the establishment of Regional Cancer Programs across the province and the gathering and use of information for performance measurement and quality improvement. The second OCP (2008–2011) broadened the scope of the work to strengthen Ontario's cancer screening programs, to streamline diagnostic assessment processes and to improve the patient experience. Throughout this period (2008–2011), several new cancer centres were built to improve access to services.

Significant improvements as measured through an annual Cancer System Quality Index were achieved through this approach, mostly in the quality of cancer care provided in hospitals. ([www.csqi.on.ca](http://www.csqi.on.ca)). As CCO embarked on consultations to develop the third OCP to begin implementation in 2011, it was recognized that more work was needed to improve the cancer system beyond the care provided during active treatment in hospitals. The effectiveness of prevention initiatives, cancer screening, diagnostic assessment, survivorship and palliative care all needed strengthening.

At about the same time, the MOHLTC asked CCO to develop and implement a plan for quality improvement in the care of patients with chronic kidney disease (CKD). To deliver on this new mandate, CCO established the Ontario Renal Network (ORN) in 2009. The rationale was that the approaches and infrastructure used to improve the cancer system could be leveraged to improve renal care. This was not without its challenges, including a renal care community suspicious of engaging with a cancer care organization and a cancer care community worried about a loss of focus. Nevertheless, four years later, improvements are now being made in renal care in Ontario while the breadth of work in cancer continues to expand. One example is the expansion of access to independent dialysis (dialysis provided outside of hospitals). Although much work remains, this access is now increasing.

## A Strategy for the Future

Once the third OCP was written, the ORN established and the first Ontario Renal Plan developed, CCO recognized in 2011 the need to plan strategically as to how best to achieve broader gains for the cancer and renal care systems in Ontario. Since 2005, CCO had focussed on the quality of care provided in hospitals. This involved working with a few hundred specialist

providers in surgical, radiation and medical oncology. To improve the system for prevention, screening, diagnostic assessment, survivorship and palliative care, a much wider group of providers including primary care and community organizations needed to be engaged. As CCO does not directly fund this broader set of services, we recognized that stronger partnerships were needed with other organizations that play a role in funding and quality improvement.

CCO's corporate strategy, developed in consultation with partners in 2011 and launched in 2012, was based on a recognition that CCO should retain a focus on cancer, CKD and access to care, while responding to opportunities for the use of CCO's assets and quality improvement approaches beyond these areas. We also recognized that to fully realize our vision for cancer and renal care, we must partner in or even lead broader health-system quality improvement. To leverage CCO's programs more generally in the health system to address quality issues, we decided to concentrate on developing those areas where there is a substantial cancer, renal or access to care footprint. As an example, it was recognized after a review of the quality of pathology services in some Ontario hospitals (McLellan et al. 2011) that a broad (not just cancer) approach to quality improvement in pathology was needed in Ontario (this example will be discussed in more detail later).

The CCO corporate strategy identifies five areas of strategic focus:

1. Person-centred care
2. Prevention of chronic disease
3. Integrated care
4. Value for money
5. Knowledge sharing and support

Person-centred care for CCO represents a shift to more indicators and measures of system performance based on the patients' view of their care, and involving patients and families more directly in our planning for system improvement. Measurements of quality from the patient's perspective include patient-reported outcomes such as quality-of-life indicators, how patients are supported throughout their care including emotional and physical supports and asking patients about their experience. The work to expand measurement of person-centred care is underway, and the more robust engagement of patients and families is having a significant influence on the development of OCP IV (2015–2019), which is being co-chaired by a member of CCO's Patient and Family Advisory Council.

However effective and efficient the healthcare system is, it does little to slow the increase in need for care due to the rising incidence of chronic disease including cancer and CKD. CCO's strategy recognized we could have a greater positive

impact on the incidence of disease, which links directly to the sustainability of our healthcare system. Through a focus on prevention of chronic disease, CCO can catalyze improved public policy with respect to exposure of the population to risk factors for chronic disease. Through this strategic focus, CCO will develop, assemble and analyze evidence and, on this basis, propose policies that the Ontario Government can enact to reduce the exposure of the population to the four most important risk factors for chronic disease: tobacco, alcohol, unhealthy eating and inactivity. An example of such policy advice includes a recent report on the effects of alcohol consumption that calls for a moratorium on increasing the density of sales outlets for alcohol. This report generated significant publicity at a time when the Ontario Government is considering increasing the number of premises licensed to sell alcohol in order to increase revenue. Part of the policy advice is based on a business case as to why foregoing increased revenue from alcohol sales makes economic sense for the province. There is now an opportunity, based on this report, to engage with the government to influence policy in areas such as alcohol sales. The ability of CCO to succeed in influencing broader public policy in chronic disease prevention particularly where the policy advice runs up against sensitive political issues, depends on the credibility of the advice and the quality of the supporting evidence..

The focus on integrated care is aimed at extending quality improvement across healthcare settings including primary care, hospital care, community care and home care, and making sure that care is seamless and effective for patients. To achieve this, CCO will work with organizations and providers of care to set standards for the delivery of cancer and renal care services in these settings. CCO will also develop indicators and measure the quality of care with a focus on how quality is experienced from the perspective of the patient as they cross settings. A challenge will be to develop clear accountability for performance with respect to patient care across healthcare settings, including the transitions of care. Accountability for transitions of care can be particularly complex in a jurisdiction such as Ontario, where many organizations with independent governance may be providing components of that care sequentially or even simultaneously. This is a significant shift for CCO, which has focussed the majority of its efforts to date on improving the quality of hospital care.

The fourth area of focus, value for money, is aimed at strengthening and broadening CCO's use of funding as a lever to drive quality improvement. This includes more tightly linking funding for services to quality at the patient level and stronger measurement and use of the data on how financial resources are used in Ontario's health system. The former goal is being achieved by CCO's central participation in a broader Health System Funding Reform (HSFR) initiative in Ontario,

which is changing how hospitals and then other organizations are to be funded, from block funding with few ties to quality, to patient-specific activity tied to quality standards. As part of HSFR, CCO is changing the way dialysis, chemotherapy and endoscopy are funded and also, as a result of these changes, the full funding envelopes for these services will flow through CCO to provider organizations. In the past, CCO has used a partial financial lever based on incremental or growth funding flowing through CCO, with the base of funding flowed through the block funding the hospital received from the Ministry of Health. The consolidation of funding into single envelope, and the more specific tie of that funding to standardized care pathways, is expected to result in a more effective application of the funding lever to drive quality improvement in the cancer and renal care systems.

CCO's focus on knowledge sharing and support goes back to the premise that to realize the best cancer and renal care systems, CCO needs to support broader health-system improvement in areas that have relevance for cancer and renal care but where broader transformation is required. One specific example in this focus area, CCO's partnership with the College and Physicians and Surgeons of Ontario, is described in more detail later.

### **Implementing the Strategy**

The five areas of strategic focus were a challenge to advance at CCO because they cut across programs (cancer, renal and access to care). They also required CCO to develop partnerships with other organizations such as Public Health Ontario, Health Quality Ontario, The College of Physicians and Surgeons of Ontario (CPSO) and the Ontario Medical Association, all of which oversee aspects of quality improvement in the areas identified, in order to achieve a coordinated approach. The strategy is taking CCO significantly beyond its' current activities both internally and with partners. To enable this change, an investment of up to 5% of CCO's annual central office budget was assigned to corporate strategy work each year for three years. And accountability for advancing each area of focus was assigned to a Vice President.

Internal challenges included a culture at CCO that was task-oriented. CCO was effective in carrying out the tasks associated with the current provincial cancer and renal plans but sometimes did not achieve the greatest leverage across programs. Achieving the goals of the corporate strategy relies on breaking down silos and achieving greater leverage of assets such as regional and clinical engagement, project management and informatics. The new corporate strategy's aim to build upon CCO's current model by broadening our activities and leveraging across programs was a challenging goal. It is sometimes easier to create and implement a new strategy when things are not going well. How do you, at the right pace, gradually change

an organization's focus? One tactic was to identify early-win initiatives and highlight initiatives that were already underway that we could point to as concrete examples of our work in each of the strategic focus areas. The work on health-system funding reform was an example of work underway that related directly to CCO's ability to measure and drive value for money in the health system. The partnership we developed with Public Health Ontario to produce the *Taking Action to Prevent Chronic Disease: Recommendations for a Healthier Ontario* report was an example of our work to provide policy recommendations to reduce the exposure of our population to risk factors for chronic disease. These were important signals to our staff at CCO and to our partners that we were committed to the change contemplated with the implementation of CCO's corporate strategy. Using these and other early-win projects, we began to build the teams that are enhancing our capacity in each of these areas and that will be key to sustaining the effort for the future.

One example of a new partnership that came from a broader view of CCO's role in health-system transformation in Ontario was the Quality Management Partnership (QMP), led in jointly by CCO and the CPSO. The initial trigger was the issue of the quality of pathology services in Ontario discussed earlier. The actual partnership opportunity was the result of a more comprehensive view of quality management across provincial, regional, local and down to individual physician performance. In 2013, the MOHLTC formally asked the two organizations to jointly develop provincial quality management programs for pathology, mammography and colonoscopy.

Why CCO and CPSO (CPSO is the regulator of physician services in Ontario)? The CPSO already had an established program for quality improvement of physician services. The CPSO also had a role for the quality of services provided in out-of-hospital premises. CCO was overseeing some aspects of quality in these services particularly as it pertained to cancer and mostly in hospitals. But no one could provide a comprehensive picture of quality for these services across all locations of service delivery and for all patients. It made sense to leverage the assets and programs from both organizations to develop integrated and comprehensive QMPs. But there were significant challenges.

As the regulator, the CPSO's main role is to ensure public safety and as such can suspend or ban a physician from practicing. The intent of the QMP is to develop non-punitive programs of quality improvement similar to the way mammography quality is overseen currently within the Ontario Breast Screening Program, which includes physician-level performance measurement and follow-up with respect to cancer detection. There was concern as to whether data on individual physician performance could now be used in an investigation by the CPSO that might lead to suspension of privileges. As it is, the CPSO

has very a clear "firewall" between "quality improvement" and "investigations," but nevertheless, there was a perception among some physicians that the new QMP could lead to punitive results. Also, CCO had well-established programs in each of the QMP areas (e.g., the Ontario Breast Screening Program for screening mammography), and so, the way in which these cancer-specific programs would dovetail with a broader QMP work that was looking beyond cancer to all services provided in each area needed to be understood. Similarly, CPSO had existing programs for quality improvement that currently captured some of the activity envisioned by QMP. The duplication of activities was to be avoided, but we also did not want to lose or slow the more detailed and specific quality work that was ongoing with respect to cancer-related services in these areas at CCO. There was concern that the pace of work in cancer would be slowed while the QMP got up and running. The exact operational structure for the QMP programs and the relationship to existing programs at CCO and CPSO will be confirmed as the QMP programs are launched in an operational way.

CCO (and the CPSO) have a central principle of engaging providers in the planning and implementation of quality improvement initiatives and this was particularly important for the QMP. Clinical leads and expert panels were selected to take on this planning work with the two partner organizations. Importantly, although the panels had substantial physician representation, they were multi-disciplinary, including other key healthcare professionals and patient representatives. At the time of writing, the panels have made recommendations for early quality initiatives that will be implemented in 2014/2015 as the first year of implementation of QMP in Ontario. The panels are now in the process of finalizing a broader set of recommendations for full implementation of the QMP. The early concern and hesitancy of physicians to engage in the building of QMP has now subsided. The signs are good that this initiative will launch successfully over the next couple of years.

## Conclusion

We started by outlining the major challenges for continued quality improvement in the health system and recognizing that although progress is being made overall acceleration is needed. Provincial approaches to cancer and renal care were implemented in part to reduce variation. It is clear that we needed more standardization based on evidence across these two areas in order for the system to be of most value to the public, as users of those services and as taxpayers. It is on this foundation of standard approaches that innovation can be encouraged, introduced and evaluated so that these standardized approaches can be rapidly improved upon. At the same time, approaches that are working to improve quality must be translated more broadly across the system and those that are not, discarded. This can

only be achieved if there is continuous and rigorous evaluation of quality improvement programs.

Also we need to turn more of our measurement of performance to indicators that patients, their families and the public feel are important in addition to clinical quality indicators. To do this effectively we must engage patients and the public much more in our work. And finally we must use stronger approaches to reduce the exposure of our population to risk factors for chronic disease if we are to sustain an excellent healthcare system for those who need it. **HQ**

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