Improving Quality in Ontario’s Cancer System –
progress in cancer service delivery and performance

Terrence Sullivan PhD
Farrah Prebtani, MA
Carol Sawka, MD
Michael Sherar, PhD
Linda Rabeneck, MD
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1. INTRODUCTION

Ontario’s cancer services system has gone through significant changes in a short time period. Many of these changes have been transformative and have resulted in improvements in cancer services and patient care.

The late 1990s and early 2000s were marked by great turmoil for the cancer system as it was unable to plan and manage the growing demand for cancer services. Public confidence in the system declined as long wait times for radiation therapy resulted in the re-referral of large numbers of patients elsewhere in Canada and to the US for treatment. The system was described as being highly fragmented, limited in scope and unable to deliver high quality care. As a result, the Cancer Services Implementation Committee (CSIC) was created to recommend ways to improve the integration of cancer services at the local level that would result in improved efficiency, productivity and quality of care [1]. The evolution and organization of the cancer system today was is in large part informed by the advice from this Committee.

This paper describes the progress that has been achieved in both the management and delivery of cancer services in Ontario over the past decade. A brief introduction to the history and evolution of cancer services will follow and we describe the changes that have been implemented in the cancer system which resulted in the improvements currently being observed across the continuum of cancer control. We highlight how the system is beginning to display the characteristics of a high performing health system.

2. HISTORY OF CANCER SERVICES

The cancer control system in Ontario was originally created over six decades ago in response to the recommendations of the Cody Commission of 1932 to develop a centralized function for cancer control in Ontario. Established in 1943 through the Cancer Act, the Ontario Cancer Treatment and Research Foundation (OCTRF) was set up as the first provincial, cancer agency charged with the operation of the three existing radiation treatment facilities. While this set up resulted in the development of a strong radiation program and cancer surveillance system through the Ontario Cancer Registry, the ‘comprehensive care centres’ envisioned by Cody did not flourish. Additionally, due to limited research and knowledge on what constitutes best practice, variations in practice were evident. The details of the history of cancer services are well characterized elsewhere [2,3 ADD DON COWAN REFERENCE ].

In 1997, OCTRF was born under the new name, Cancer Care Ontario (CCO). As an operational agency of the government, CCO was charged with improving the coordination and alignment of cancer services in Ontario through the development of a strong provincial and regional cancer program encompassing the full continuum of cancer control including prevention and supportive care as originally envisioned. CCO continued operating the provincial breast cancer screening program established in 1990 and the 8 Regional Cancer Centres providing radiation and systemic therapies. While CCO’s role was expanded, the problems of fragmentation and lack of integration of cancer services persisted. This was in large part due to the majority of cancer services and funding remaining outside of the organized cancer system, with half of systemic therapy and all of cancer surgery under the control of hospitals receiving funding directly from government.
3. NEW GOVERNANCE MODEL

In 2003, the cancer system underwent significant restructuring following the recommendation of the CSIC [1,4]. The restructuring involved the devolving of the operational services of the 11 Regional Cancer Programs, previously independent of their host hospitals to become integrated programs within host hospitals, with a contract to provide services, data and quality information under contract with Cancer Care Ontario. The regional programs were now linked to form Integrated Cancer Programs (ICPs) with a broader role in service delivery including screening, radiation therapy, systemic therapy and surgery. While continuing to remain as principle advisor and accountable to the government on all cancer matters, CCO moved away from being a direct provider to become a commissioner of cancer services, with a focus on better data, performance and quality. Direct patient care now rested with the ICPs as providers of the regional centres previously directly employed by CCO were now employees of their host hospitals. In its new role, CCO became accountable for providing leadership and direction in the planning, management and championing of a quality cancer agenda. Following a master negotiation, contractual agreements were formalized between CCO and the host hospitals which set out the terms of accountability and provision of service volumes and quality in exchange for funding [Figure 1].

As the demand for cancer services has increased, so too has the number of centres providing care. Today, 14 ICPs have been established in local health integration networks (LHINs) to align with the regionalization efforts in Ontario. CCO quickly recognized that to achieve its new mandate with sustained improvement, both a culture shift and changes to the way it was organized both provincially and regionally were required. Unlike health system reforms elsewhere in Canada, CCO adopted a clinical governance model that integrates both administrative and clinical accountability approaches in its pursuit of quality [5]. This approach has recently gained increasing relevance and acceptance as a mechanism for improving quality of care. This new approach has been endorsed by CCO’s board and adopted by all levels of the organization. To support this new model, Regional Vice Presidents (RVPs) were employed in each of the regional cancer centres with formalized roles and dual accountability to CCO and their respective hospitals. In this role, the RVPs through relationship building and support from all cancer providers in their region (LHIN) and they are responsible to ensure local planning and coordination of cancer services aligned with provincial priorities. In addition RVPs set specific access, volume and quality objectives which are the subject of quarterly performance reviews with provincial leadership at CCO.

Additionally, at the provincial level, clinical leadership was employed for each of the 10 major program areas along the cancer continuum including primary care, stage capture, pathology and laboratory reporting, radiation therapy, systemic therapy, surgical oncology, palliative care, psychosocial oncology, oncology nursing and patient education with their regional counterparts established in each of the regional cancer centres. The regional clinical leadership has clearly established roles with responsibility to CCO as well as their RVP, and in many cases receives modest stipend funding to carry out its function. While traditionally clinicians are solely held for professional accountability through direct patient care, this new role confers additional responsibility by further holding them accountable for improving quality of care for the entire patient population in their region through the development and local implementation of targeted quality initiatives and through the ongoing identification of quality issues.
Figure 1: Restructuring the Cancer System to Drive Quality Improvement

<table>
<thead>
<tr>
<th>2000/01</th>
<th>2010/11</th>
</tr>
</thead>
<tbody>
<tr>
<td>provider of patient care</td>
<td>purchaser of services</td>
</tr>
<tr>
<td>managing service delivery</td>
<td>managing system performance</td>
</tr>
<tr>
<td>treatment orientation</td>
<td>Prevention, screening and reduced total burden</td>
</tr>
<tr>
<td>radiation and systemic therapy programs</td>
<td>full continuum of cancer services including prevention and screening, primary care, improved stage capture and surveillance, pathology and laboratory medicine, radiation treatment, systemic treatment, surgical oncology, palliative care, psychosocial oncology, oncology nursing, patient education</td>
</tr>
<tr>
<td>measuring volumes</td>
<td>measuring access and quality</td>
</tr>
<tr>
<td>patient based approach</td>
<td>population based approach</td>
</tr>
<tr>
<td>opinion based decision making</td>
<td>evidence based decision making</td>
</tr>
<tr>
<td>professional accountability</td>
<td>integrated clinical and administrative accountability</td>
</tr>
<tr>
<td>fragmented care</td>
<td>integrated and coordinated care</td>
</tr>
<tr>
<td>internal reporting</td>
<td>public reporting by center and provincially</td>
</tr>
<tr>
<td>limited information management systems</td>
<td>mature and comprehensive information technology (data) systems</td>
</tr>
<tr>
<td>8 regional cancer centres + Princess Margaret Hospital</td>
<td>14 integrated cancer programs</td>
</tr>
<tr>
<td>single disease agency</td>
<td>multi-service agency (cancer, access to care, chronic kidney disease)</td>
</tr>
<tr>
<td>$284 million funding</td>
<td>$750 million funding</td>
</tr>
</tbody>
</table>

4. BUILDING A QUALITY AGENDA

High performing health care systems have been described as those that are patient centric, equitable, efficient, accessible and recognize quality as a systems property [6-8]. These systems have created effective frameworks and systems for improving care that are applicable to different settings and sustainable overtime [6]. Common frameworks for achieving high success in health care, as well as specifically for the cancer system have been developed [6,9]. CCO’s governance model is grounded in a performance improvement cycle [10] that displays the common attributes of high performing health systems – performance measurement and accountability mechanisms, clinician integration, incentives and information management systems - each of which are key enablers to continuous quality improvement. This tool recognizes the importance of data and information systems in helping administrative and clinical leadership to understand the state of quality in the system and use this information to generate and disseminate knowledge to the broader community to drive system improvement. The impact
of these implementation activities is further evaluated through continuous performance management where progress against established indicators is measured, quality gaps are identified and new priorities and quality initiatives are set. This tool has been critical in keeping quality top of mind. Both administrative and clinical leadership are heavily involved throughout this process to varying degrees and have been crucial to its successful implementation [Figure 2].

This section will describe the common elements embedded in the performance improvement cycle in further detail and show how they have resulted in key improvements in access to and quality in the cancer system that we see today. We have previously described some of the early progress that has been made following the implementation of the new governance model [11].

Figure 2: Clinical and Administrative Integration for Continuous Quality Improvement

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**a. Performance Management**

As manager of the provincial cancer system, Cancer Care Ontario has legal contracts with each of the 14 ICPs as well as all non-cancer centre hospitals providing cancer services. These agreements set out the foundation for a culture of quality improvement by holding various individuals within the hospitals, from providers to the hospital CEOs accountable for improving the quality of cancer services within their regions. Contractual agreements were initially established with regional cancer centres providing radiation therapy and systemic therapy and laid out conditions of funding to meet volume requirements to improve access to care. Over the years, as the system has moved towards a more comprehensive and integrated model of service delivery, these contracts have evolved to cover the spectrum of care and include
expectations around participation in quality initiatives and submission of data for program and performance measurement and management against provincial and regional targets.

Throughout the year, CCO engages in discussion with the RVPs of the integrated cancer programs who are accountable for ensuring the terms and conditions set out in the contractual agreements are met and targets for quality indicators are achieved. Through quarterly reviews, regions have an opportunity to discuss progress and challenges in meeting forecasted service volume requirements. In circumstances where a hospital may not achieve expected service levels, funds are reallocated to neighbouring centres that pick up additional volumes above their expected levels. Additionally, to promote quality and patient safety, CCO has begun to financially penalize centres such as those performing thoracic surgery that do not meet the standard of a designated centre (see surgical oncology section below). These reviews serve as a forum to monitor progress for key indicators tied to quality initiatives compared to provincial and regional levels, and identify areas of underperformance. While there are no financial incentives for good performance, this ongoing review and public reporting mechanism ensures a continuous cycle of quality improvement and has served as a stimulus to improve performance. In 2010, Cancer Care Ontario will experiment with a pay for performance model for wait time achievements by rewarding centres that meet and exceed wait time targets for their centre. Research shows that hospitals that are involved in public reporting and pay for performance fare better in quality than those engaged in public reporting only [12]. Whether this will translate into better care in the cancer system is yet to be seen.

b. Clinician Engagement

It has been observed that a high performing health system ensues when clinicians “own” improvement [6]. At CCO, clinician leadership is the cornerstone of the new governance model as physicians are engaged in the development of evidence to guide clinical practice and throughout the process of priority setting, indicator development, program implementation and evaluation [10 and Figure 2]. Clinician engagement in each of these areas has been facilitated through investments from the provincial office in infrastructure and structures to drive the quality agenda forward. This includes investments in provincial and regional clinical leadership with clear roles and accountabilities for driving quality as described earlier, investments in data systems and information technology, formal networks for knowledge development such as the Program in Evidence-Based Care (PEBC) to support guideline development and networks of communication and information sharing such as the Clinical Council comprised of provincial and regional clinical leadership from each of the regional cancer programs. More informally, the organization also brings together communities of practice of interested practitioners to support implementation of priorities. The impact of clinician engagement in driving quality improvement through this model has been significant.

For example, the PEBC, established by CCO, is endorsed internationally for its rigorous approach to developing and disseminating up-to-date evidence based guidelines and standards for clinical care and organizational delivery through the mobilization of numerous disease site and clinical program experts and various stakeholders [13]. The successful development and implementation of over 180 standards and guidelines to date have been the result of the leadership and efforts of local clinician champions.

In 2005, the first Cancer Plan, a three year road map that sets out the strategic direction for the province across the continuum of cancer control was created. This initiative involves an elaborate engagement process that includes jurisdictional reviews and consultations with clinicians and other experts at the international, provincial and regional levels to establish goals,
priorities and an action plan that is innovative and aligned with evidence and best practice. Each year, a progress report is released publicly that assesses the activities of the previous year against its goals and identifies current pressures to address in the coming year. Currently, the organization is in the process of developing its third Cancer Plan that is expected to build on the work that is currently underway and chart the course for organizing cancer care over the coming years.

Each year, as part of CCO’s performance management cycle, a series of engagement processes take place internally involving the executive leadership and provincial clinical department heads, who reflect on the previous year’s performance and evaluate progress of the Ontario Cancer Plan’s goals against established measures and targets. Each program establishes priorities for the upcoming year while developing new indicators and revisiting and resetting annual performance targets that are achievable and aligned with the provincial strategy. These priorities are brought to the provincial clinical leadership table for endorsement as well as to the executive team at CCO for approval. Once the strategic priorities are established, it is the clinical leadership that facilitates the implementation of these priorities and evidence based standards in their region through avenues such as communities of practice (see surgical oncology program below) and through disciplines such as project and program management that focus on an organized and cost effective approach to the execution of the planned interventions.

c. Funding

The ability to influence change at a local level through a funding lever is an attribute unique to CCO that distinguishes it from other agencies or organizations of government. As one of the largest agencies of the provincial government, Cancer Care Ontario currently oversees $750 million for the organization and delivery of cancer services across Ontario compared to $284 million a decade ago [1]. These funds flow to various programs across the provincial cancer control system with over half expended for cancer treatment. This increase over the past decade has largely been a result of the growth in regional cancer services and restructuring efforts across the province resulting in an increase in scope of services within the organization’s purview. Whereas Cancer Care Ontario was responsible for oversight of three quarters of radiation therapy and half of systemic therapy services in early days, this represented only 20% of cancer funds, the remaining 80% flowing through the government directly to hospitals responsible for the operation of the remainder of radiation and systemic treatment including all of cancer surgery [1]. Additionally, a moderate portion of funds have been allocated to support infrastructure investments and change management in regions including the recruitment of administrative and clinical leadership to put provincial priorities into action as well as start up funds for implementation of information technology systems to improve data capture and facilitate quality patient care.

Through formalized relationships with regional cancer programs and cancer service hospitals, the organization now has fiscal control over services across the full continuum of cancer care albeit to varying degrees. The power to control funds no matter how small has proven to be significant in the ability to drive change and quality improvement at the system level. For example, although CCO funds only a small proportion of hospital colonoscopies (approximately 6%) due to program indications, it oversees over 70% of all hospitals colonoscopies in the province through contractual agreements with these facilities, requiring them to meet certain quality requirements as a condition of funding for all colonoscopies performed in their facility whether or not they are performed for screening or diagnosis. This lever has made it possible to
work towards standardizing care across the province as can be demonstrated across the cancer journey (see below).

d. Information Management & Technology

A fundamental element of the performance improvement cycle is the recognition that data and information management and technology systems and expertise are key enablers to improving quality and system efficiency. One of the biggest challenges in the cancer system was the absence of reliable, comprehensive and timely data making it difficult to make informed decisions regarding resource allocation, system planning, and performance. The data that was available was either not fully exploited, limited to surveillance information through the Ontario Cancer Registry and radiation and systemic therapy delivered only within regional cancer centres [14]. Through its Chief Information Office, CCO has expanded its data holdings and developed the expertise to develop and deploy information systems to accelerate improvements and invested in Informatics proficiency to ensure quality data and to support complex analysis. CCO’s plan to advance the cancer agenda through information management and technology through informatics is well articulated in their Information Strategy and Cancer Plan [15,16].

Today, the organization has increased its breadth and scope of data sources and now has more complete data for radiation therapy. CCO has a robust understanding of cancer surgery volumes and demand in the province and an emerging understand of the quality of cancer surgery that is being performed. In addition, population based data for stage capture making it possible to report on more measures of quality across the entire clinical continuum. Further, CCO has started to expand on screening and palliative care data sources. Deliberate investments have been made both provincially and regionally in information technology systems to facilitate the capture of data at multiple points along the cancer journey as well as to enable quality patient care such as through standardized pathology reporting and stage capture, safe care through computerized drug order entry and to understand the patient experience through electronic symptom assessment. This data is accessible to various users including policymakers and health system planners through CCO’s web-based analytic tool and through working with informatics staff with skills in the area of data modeling, data quality, forecasting, predictive analytics, capacity planning and reporting. There continues to remain gaps in data for upstream care such as prevention as well as systemic therapy treatment for those patients remaining outside of the cancer system. Additionally, most of the data that is being reported is based on process and long term outcomes measures such as wait times, survival and mortality with less focus on immediate and intermediate outcomes including those patient focused measures of quality of life and impact of health care interventions [Figure 3 and Appendix 1].

One of the most notable gains have been in the development and deployment of the provincial Wait Times Information System that makes it possible to report wait times information for cancer surgery and other procedures outside of the cancer system which was not previously available. The success of this initiative has resulted in the organization garnering support to expand the system to areas outside of the cancer system including alternate levels of care and emergency department visits. As the linkages to various data sources improve, we will have a better picture of quality of care that spans the patient journey.
**Figure 3:** Scope of Data Collection & Coverage across Cancer Continuum

<table>
<thead>
<tr>
<th>CANCER PROGRAM</th>
<th>DATA TYPE</th>
<th>2004</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention</td>
<td>Risk Factor</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Screening</td>
<td>Breast Screening</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Colorectal Screening</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Cervical Screening</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Stage at Diagnosis</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Pathology Reporting</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Colonoscopy</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Imaging (CT &amp; MRI)</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Treatment</td>
<td>Radiation Treatment</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Systemic Treatment</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Surgery</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Supportive Care</td>
<td>Psychosocial Oncology</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Oncology Nursing</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Patient Education</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>End-of-Life</td>
<td>Palliative Care</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Symptom Management</td>
<td>○</td>
<td>●</td>
</tr>
</tbody>
</table>

Legend:  ● Population-based  ○ Significant Coverage  ◦ Limited Coverage  ○ No data

*For more details on data coverage, data sources and gaps, refer to Appendix 1.

e. Public Reporting

Public reporting has become a common phenomenon within the health care sector and is an important lever and motivation for change [17]. Cancer Care Ontario endorses a high quality cancer system by promoting accountability and transparency in the system. In 2002, CCO with the Ministry of Health and Long Term Care established the Cancer Quality Council of Ontario, as an arm’s length, advisory body to CCO, to monitor and publicly report on the performance of Ontario’s cancer system and guide quality improvement efforts [18]. As a first line of business, the Cancer Quality Council set out to assess the state of cancer service delivery and performance in the province and released a book that takes stock of the strengths, challenges...
and quality gaps in cancer system. [3]. This initial analysis has served as a critical guide to map out key priorities and determine where investments should be targeted. To fulfill its role in performance reporting, the Cancer Quality Council convened a working group to establish a set of key system performance indicators tied to the organization’s strategic goals [19] which are used today to monitor progress on the performance of the cancer system through an annual Cancer System Quality Index (CSQI) that is reported publicly on the CCO website.

The CSQI has evolved over time and is currently in its sixth year of release with annual updates. As data capacity and quality continue to improve, it has become possible to report on more measures to monitor system wide improvement and track trends overtime. To date, the index reports on nearly 30 indicators at the system, LHIN and regional levels along the continuum of care from prevention to palliative care, and are being used by health care providers, policy makers and health system planners throughout the province. In the coming years, the index will begin to report on integration of cancer services with the health care system. Only recently, have measures of cancer services integration been developed to monitor and improve system performance. [20]

In addition to the CSQI, the regional cancer centres receive a more frequent, performance scorecard throughout the year, which provides a more detailed picture of how well facilities in their region are doing in implementing quality improvement programs and meeting targets for key performance indicators. This report serves as an internal management tool for the quarterly reviews with CCO and provides an opportunity to identify gaps and have meaningful discussions on areas that are underperforming. Additionally, by drawing comparisons with other regions, this mechanism fosters healthy competition among regions and provides an incentive for them to continuously track their progress and improve their position. One of the greatest achievements to date has been in the surgical oncology program, where reporting is now being done at the provider level. While public reporting occurs at a regional and hospital level wait time data as well as quality performance data is monitored at a provider level. This allows interaction with provider for performance improvement and with the ongoing support from clinicians, wait times for cancer surgery as well as quality performance will result in an overall improvement in the cancer surgery system with a focus on an improved access to quality care. The pathology program is expected to follow suit with physician level reporting.
5. LOOKING FORWARD

As the organization continues to expand its scope of influence across the broader spectrum of care; marked gaps continue to exist including those for the diagnostic phase of the cancer journey as well as improving integration and the patient experience - key areas requiring further momentum. As well, it is imperative to continue to innovative to keep pace with demand and ensure a sustainable system in the long run. To meet these challenges, the following initiatives are being pursued:

*Diagnosis Phase*

The diagnosis phase of the cancer journey - the time from suspicion of cancer or abnormality in test result to diagnosis is a time of great anxiety for patients particularly, as they suffer long waits for confirmation of diagnosis in a highly fragmented stage of the cancer continuum. To improve the patient experience and quality of care in this phase of the journey, the Cancer Quality Council, in 2007, engaged a series of stakeholders to identify gaps in the system and determine ways to improve care coordination and patient outcomes [21]. As a result, in 2008, CCO experimented with Diagnostic Assessment Programs, to provide a one-stop shopping for patients to receive all required diagnostic tests at one time, which has shown promising results in improving access and reducing wait times. This approach integrates both primary and specialty care, typically working in silos, to provide a multidisciplinary approach to caring for patients prior to entering the cancer system. Today, DAPs have been implemented in all regions focusing on the most common cancers including breast, lung, colorectal and prostate. In addition, the Program in Evidence Based Care has developed a set of organization standards to guide the implementation of DAPs across the province [22].

*Disease Pathway Management*

In an effort to improve the patient journey, standardize care approaches and ensure a seamless transition from one phase of the cancer continuum to the next, CCO has embarked on a new initiative, disease pathway management. This approach aims to identify gaps in quality of care, processes and patient experience along the entire continuum of care for specific cancers, recognizing the unique path and approach required to care for people with different cancers. This initiative uses a broad stakeholder engagement process and multidisciplinary team of experts in the disease specific area, administrators and patients to develop critical care path that leads to the identification of gaps in patient care and areas for improvement which can include the implementation of quality initiatives or changes in provider practice, development and implementation of evidence based guidelines where they may be lacking and development of quality indicators to better monitor patient care. Through the mapping of the colorectal cancer journey, it was observed that there were variations in practice across the province in how best to care for patients in the ‘survivorship’ phase, following treatment. As a result, the PEBC has been engaged to develop a set of follow up guidelines which will identify the appropriate follow up regimen including frequency of appointments and testing, long term effects of late treatment and testing for potential recurrence. Additionally, after recognizing that a large proportion of lung cancer patients suffer from dyspnea resulting in emergency department visits, 6 dyspnea clinics have been piloted across the province to better manage these patients. The
DPM approach is being adapted for prostate cancer and will further be extended to other cancers in the coming years.

Models of Care

As the demands on the cancer system increase through an increase in the number of new cancer cases and increased survivorship of cancer patients, it has become increasingly evident that the current way of delivering care is no longer sustainable. In 2009, the Cancer Quality Council of Ontario engaged stakeholders to discuss innovative models of care delivery that identified the current challenges in the system and initiatives that have been successful. Through the support of the MOHLTC, CCO has recently embarked on an initiative and received funding from the MOHLTC to explore and recommend new models of care delivery within the cancer system where there exists the greatest opportunity to impact change and maximize quality of patient care and system efficiency. Three workstreams have been identified and working groups established to move this agenda forward: 1. Models of Care which will identify and implement series of pilot projects across Ontario to maximize existing scopes of practice, support patient education and self care management through electronic tools and improve follow up care through group visits; 2: Alignment & Accountability which will suggest alternate funding mechanisms for oncologists that will align with new models of care and incentivize best practice; and 3. Prediction & Planning which will develop a planning tool to understand current and predict future health human resource capacity requirements. The first phase of this project involves development of workplans and frameworks for each of these streams, with implementation following in the second phase and coming years.

6. SUMMARY

In just a decade, the cancer control system in Ontario has gone through a significant transformation from a system whose ability to meet demand was questioned to one that is now providing high quality care across a broader spectrum of the cancer continuum. This has been achieved through the reorganization of the cancer system to a stewardship model embedded in a quality improvement matrix with clinician engagement as a focal point resulting in greater transparency, accountability and a focus on continual quality improvement. Key improvements have been made in the surgical oncology, stage capture and pathology and radiation treatment programs. While some strides have been made in the colorectal cancer screening and palliative care programs, there is more work that needs to be done to fully incorporate the upstream and downstream components of the patient journey as well as those areas outside of the organized cancer system. Through increased informatics capacity, technology deployment expertise and program management proficiency, we have improved our ability to report on more quality indicators and monitor quality which has not previously been possible. There continues to be work done to focus on the patient experience including the patient journey as well as patient focused outcomes which the organization is now embarking on. As we continue to make improvements to the cancer system, the Ontario Ministry of Health and Long Term Care has supported CCO’s leadership in leveraging the cancer model to other areas such as chronic kidney disease to improve the integration and coordination of dialysis services in the province.
7. REFERENCES


13. Cancer Care Ontario: Program in Evidence Based Care [http://www.cancercare.on.ca/toolbox/qualityguidelines/pebc/]


## 8. APPENDIX 1 – Scope of Data Coverage across Cancer Continuum

<table>
<thead>
<tr>
<th>Cancer Program</th>
<th>2004</th>
<th>Data Coverage &amp; Gaps</th>
<th>Data Sources</th>
<th>2010</th>
<th>Data Coverage &amp; Gaps</th>
<th>Data Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PREVENTION</strong></td>
<td></td>
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<tr>
<td>Breast</td>
<td></td>
<td>• Data only on women participating in Ontario Breast Cancer Screening Program (OBSP)</td>
<td>ICMS, OHIP</td>
<td></td>
<td>• Data only on women participating in OBSP (~63%, up from 47% in 2004), Expansion of InScreen to support Integrated Cancer Screening underway, including access to OHIP data and results on non-OBSP screening</td>
<td>ICMS, OHIP</td>
</tr>
<tr>
<td>Colorectal</td>
<td></td>
<td>• No organized screening in place, opportunistic screening data available via OHIP only but inaccessible to CCO.</td>
<td>OHIP</td>
<td></td>
<td>• No results data for patients/labs not participating in ColonCancerCheck program (non-branded FOBT)</td>
<td>Laboratory Reporting Tool, OHIP, CIRT</td>
</tr>
<tr>
<td>Cervical</td>
<td></td>
<td>• Screening result only from 4 community labs providing data to Cytobase</td>
<td>Cytobase</td>
<td></td>
<td>• Only 4 community labs providing data</td>
<td>Cytobase, OHIP</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Issues</td>
<td>Data Sources</td>
<td>Solutions</td>
<td></td>
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<tr>
<td>Cancer Stage</td>
<td>• Accuracy and timeliness of data was limited</td>
<td>• OHIP</td>
<td>• TNM from RCCs</td>
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<tr>
<td></td>
<td>• Limited information on stage at diagnosis (~30% coverage)</td>
<td></td>
<td>• Full population based data by stage for 4 most common cancers (lung, breast, colorectal, prostate) and significant coverage for other cancers</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Target 90% population coverage for all cancers by 2012</td>
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<td></td>
<td></td>
<td></td>
<td>• TNM data from Regional Cancer Centres (RCC)</td>
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<td></td>
<td></td>
<td></td>
<td>• Collaborative staging data from all hospitals providing cancer services</td>
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<tr>
<td>Pathology Reporting</td>
<td>• With implementation of PIMS, narrative reports in electronic format for 80-90% of cancer cases</td>
<td>• PIMS</td>
<td>• Expect 90% population based data for all cancer cases via electronic reporting in synoptic format by 2012</td>
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<tr>
<td></td>
<td>• Remainder of reports available in paper format</td>
<td></td>
<td>• Limited data on benign/precancerous pathology</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Underreporting of select cancers in community labs</td>
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<tr>
<td>Colonoscopy</td>
<td>• Data captured in OHIP inaccessible to CCO</td>
<td>• OHIP</td>
<td>• Full population data on counts of colonoscopies</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Data on all colonoscopies performed and results from ColonCancerCheck funded hospitals</td>
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<td></td>
<td></td>
<td></td>
<td>• No data on results from non-funded hospitals and private clinics</td>
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<td></td>
<td></td>
<td></td>
<td>• Limited data on alternative diagnostic tests from CT and MRI following positive FOBT</td>
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<td></td>
<td></td>
<td></td>
<td>• Implementation of PET program in 2010 will provide data from non-funded procedures</td>
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<tr>
<td>Diagnostic Imaging</td>
<td>• Data captured in OHIP inaccessible to CCO</td>
<td>• OHIP</td>
<td>• Data on wait times of all cancers from all hospitals participating in Wait Time Strategy</td>
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<td></td>
<td></td>
<td></td>
<td>• Data by specific type of cancer not available</td>
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<td></td>
<td></td>
<td></td>
<td>• Volumes, results data on imaging procedures not available</td>
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<td></td>
<td></td>
<td></td>
<td>• WTIS</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• PET Registry</td>
<td></td>
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<tr>
<td>Treatment</td>
<td>Systemic</td>
<td>Radiation</td>
<td>Surgery</td>
<td>Supportive Care</td>
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</tr>
</tbody>
</table>
| Systemic  | • Volume data from CCO funded regional cancer programs only  
           • Limited data to support measurement of wait times, patient safety and quality improvement  
           • Data captured in OHIP not accessible to CCO | • Good coverage on consultations performed, treatment volumes and wait times | • Partial data on volumes of cancer surgery and limited data on access and quality of care  
           • Data captured in OHIP not accessible to CCO | • Limited data on patient activity, quality and patient satisfaction in existing databases but inaccessible to CCO |
|           | • RCCs  
           • OHIP | • RCCs | • DAD  
           • OHIP | • Hospital & physician records |
|           | • Population level volume data on all patients receiving systemic therapy and related procedures  
           • Expanded depth of coverage for wait times in RCCs, additional information about compliance with standards for quality monitoring and patient safety  
           • Data on drug prescribing from both RCCs and non RCCs implementing OPIS (~65% of all chemotherapy treatments)  
           • No clinical or wait times data from non-cancer centres not using OPIS 2005  
           • Data on chemotherapy drug utilization from hospitals reimbursed through New Drug Funding Program  
           • Limited capture of oral chemotherapy in RCCs | • Full population level data on patients receiving radiation treatment  
           • Captures data from hospitals seeking reimbursement from brachytherapy  
           • Expanded depth to include data on wait times, compliance with standards for quality monitoring, system efficiency | • Full population data on counts of patients with all cancer surgeries  
           • Expanded depth of coverage on wait times from consult to treatment, compliance with guidelines for quality monitoring  
           • Limited data on immediate surgical outcomes required for collaborative staging  
           • Lack of information on wait time from referral to consultation - initiative currently underway | • Ambulatory oncology clinic patient satisfaction data from RCCs  
           • Pilot project in RCCs to capture supportive care activity & family visits  
           • Limited data on patient experience | • AOPSS Survey (CCO) |
|           | • RCC  
           • NACRS  
           • NDFP  
           • OPIS in non-RCCs | | | |
<table>
<thead>
<tr>
<th>Palliative Care</th>
<th>Hospital &amp; physician records</th>
<th>Data on palliative clinic visits from RCCs only, and lacking from home and community based services</th>
<th>End-of-life service utilization available from DAD</th>
<th>Limited data on symptom assessment from patients only in RCCs that are using ISAAC</th>
<th>Symptom assessment outside of RCCs lacking and inconsistent</th>
<th>ISAAC expansion to additional centres underway</th>
<th>RCC</th>
<th>DAD</th>
<th>Symptom Management Data Base</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Minimal data and accessibility from existing databases</td>
<td>• Hospital &amp; physician records</td>
<td>• Data on palliative clinic visits from RCCs only, and lacking from home and community based services</td>
<td>• End-of-life service utilization available from DAD</td>
<td>• Limited data on symptom assessment from patients only in RCCs that are using ISAAC</td>
<td>• Symptom assessment outside of RCCs lacking and inconsistent</td>
<td>• ISAAC expansion to additional centres underway</td>
<td>• RCC</td>
<td>• DAD</td>
<td>• Symptom Management Data Base</td>
</tr>
</tbody>
</table>
APPENDIX 2 – Rebalancing Services along the Continuum of Care

Initially focusing only on only a few aspects of the cancer control system, CCO has broadened its scope to encompass the cancer continuum from screening to diagnosis to treatment to palliative and supportive care [Figure 4]. This section describes how the organization has leveraged its new governance model and quality framework to make improvements in quality and access to care in each of the program areas. The most notable gains can be seen in the surgical oncology and stage capture and pathology programs with more recent improvements in the colorectal cancer screening and palliative care programs.

Figure 4: Cancer Control Pathway

a. Primary and Secondary Prevention

Evidence shows that nearly 30% of cancers can be attributed to modifiable risk factors such as smoking, diet, physical inactivity and obesity [1]. In an era where the incidence of cancer is expected to increase and more people are living longer with the disease, it is not only important to improve treatment regimens for these individuals but to focus on both primary and secondary efforts to prevent cancer altogether. Over the past decade, Cancer Care Ontario has supported provincial initiatives aimed at reducing the risks of cancer through promotion of the Smoke-Free Ontario Strategy which has made major gains in reducing smoking rates in Ontario, the development of Healthy Eating, Physical Activity and Healthy Weights guideline [2], as well as development of the Cancer 2020 Action Plan [3,4] to identify strategies, actions and targets to improving cancer prevention and increase screening activities. Most recently, CCO launched the largest and first of its kind, longitudinal health study in Ontario, which will track Ontario adults over the course of a decade to better understand the role risk factors and the interplay between the environment and genetics in causing cancer, leading to more effective prevention strategies. Additionally, the Occupational Cancer Research Centre was recently launched in 2009, to understand the burden of occupational and environmental risks leading to cancer with the aim of preventing cancer through healthy workplaces.

Screening for cancer has shown to have significant benefits in reducing the likelihood of progression. Today, CCO administers three organized screening programs: breast, cervical and colorectal cancer and has set goals and targets to improving these rates over the coming years. Both the breast and cervical cancer programs have been existence for some time, but despite this, screening rates have only steadily increased over the years and have reached a plateau (66% and 72% respectively) [5]. In 2009, CCO in partnership with the Ministry of Health and Long-Term Care launched the Integrated Cancer Screening Strategy to improve the screening rates for all three cancers. This strategy includes reaching out to vulnerable and under screened populations, administering recalls and reminders to patients as well as giving providers information on their screening populations and tools to increase rates. This initiative will give
primary care leads an integral role in implementing these strategies within their regions. Below is an example of the how CCO’s business model has been leveraged to make an impact on improving quality and screening rates for colorectal cancer.

Case Example: Colorectal Cancer Screening

i. Background

It is well known that colorectal cancer is 90% curable if detected early [6]. The stage capture project (section b), has shown that 20% of all new cases of colorectal cancer seen in Ontario in 2007 had metastatic disease at presentation [Figure 8]. Landmark randomized control trials beginning in the early 1990s have shown the effectiveness of regular screening using fecal occult blood test (FOBT) in reducing mortality and incidence of colorectal cancer [7]. In 1999, Ontario was the first province in Canada to recommend a colorectal cancer screening program for average-risk persons aged 50 years and older using FOBT as the primary screening test [8]. This was further echoed a few years later by the Canadian Task Force on Preventive Health Care [9]. However, despite this, colorectal cancer screening was not a major government priority until very recently. As a result, colorectal cancer screening rates have remained low and inconsistent across Ontario [5,10].

Recognizing the importance of screening in reducing the burden of colorectal cancer, the Cancer Quality Council of Ontario hosted its first signature event in 2003 to discuss how best to improve screening and management of colorectal cancer [11]. Two years later, CCO submitted a proposal and received political support to launch a colorectal cancer screening program in Ontario. In April 2008, Cancer Care Ontario jointly with the Ministry of Health and Long-Term Care launched Colon Cancer Check, the first province wide, organized, population based, colorectal cancer screening program in Canada. Already, a number of initiatives have been developed to ensure a high quality program and improve screening rates including the implementation of colonoscopy and FOBT standards, a primary care strategy and a colorectal cancer screening registry. Additionally, FOBT screening rates are slowly starting to improve and have reached 30% in 2007/08 compared to 15% in 2003/04 [Figure 5] [5].

ii. How did we Improve Quality?

1. Performance Management

One of the implications of implementing a fecal occult blood test (FOBT) screening program is that about 4% of persons screened will have a positive FOBT requiring a follow up colonoscopy [12]. To meet this expected increase in demand for colonoscopies, Cancer Care Ontario formalized relationships with 72 hospitals in 2008/09 through contractual agreements to provide additional funding to perform the increased volumes. In exchange, hospitals are required to implement and adhere to colonoscopy standards, provide data monthly on wait times and other quality measures for all hospital based colonoscopies performed in their facility through the Colonoscopy Interim Reporting Tool, an automated tool that captures data electronically from the hospital systems. Collection of data on number of colonoscopies would now make it possible to manage the program performance and measure colonoscopy quality. As of 2009/10, 94,000 additional colonoscopies have been funded to meet the increased demand.

2. Clinician Engagement

a. Evidence Based Standards
One of the concerns identified through the FOBT Pilot Study was the variation in quality and practice of screening for colorectal cancer due to lack of standards on appropriate care. In 2007, the Program in Evidence Based Care, primary care leaders and other experts in the province were engaged to develop standards for the delivery of colonoscopies [13] and laboratory standards around the use of FOBT [14] to ensure a consistent, high quality colorectal cancer screening program across Ontario based on best practice and timely information. The colonoscopy standards outlined physician, institutional and performance requirements including a recommendation that colonoscopies should only be performed by physicians that perform 200 or more colonoscopies per year. Additionally, in response to the recommendations in the FOBT standards, the Ministry and Ontario Association of Medical Laboratories (OAML) signed an agreement to utilize approved FOBT screening kits and ensure laboratories adhere to certain standards and protocols. These standards were necessary to ensure a high quality screening program that was consistent across.

b. Primary Care and Cancer Strategy

The success of the ColonCancerCheck is highly dependent on the participation of family physicians through which patients are invited to participate in the screening program and receive FOBT screening kits. Patients that do not have a family physician, can access an FOBT screening kit via their local pharmacy, telehealth or Colon Cancer Check and may be referred to a primary care provider via the program if a colonoscopy is required for follow up of a FOBT positive. The Ontario FOBT Pilot Study launched in 2003, demonstrated the importance of public awareness, education and involvement of primary care providers in improving screening rates. Research demonstrates that increased contact with a family physician is associated with a greater likelihood of being screened [15].

As such, in October 2008, Cancer Care Ontario launched a Primary Care and Cancer Strategy and recruited a provincial primary care lead and regional primary care leads to better integrate family practice within the cancer care system and to focus on improving the cancer screening and participation rates beginning with colorectal cancer and subsequently moving to an integrated model encompassing breast and cervical cancer screening. By leveraging the existing primary care structure in Ontario via Primary Care Networks, regional leads are working with other family physician and primary care providers in their region to improve awareness of the Colon Cancer Check program, educate them on the benefits of screening, promote use of evidence based standards and improve their capacity to participate in the program.

3. IM/IT - InScreen

In September 2009, a colon cancer screening information system, InScreen, was launched in response to the recommendations of the Cancer Screening Uptake Expert Panel, to increase provider and patient participation in the screening program [16]. The system integrates data from various sources including hospitals, laboratories and the Ontario Cancer Registry to identify and invite eligible patients for screening, support family physicians in managing their patients by sending out invitations, reminders and recalls to over 3 million patients, and serves as a performance management tool. Participating physicians receive primary care screening reports to monitor screening activity for their patient population, compare progress against their peers as well as against the provincial target. To date, the system has been piloted to 100 family physicians and their 14,000 eligible patients in primary health care teams across Ontario. The next phase will include broader primary care engagement and patient participation. The system will also be leveraged to improve screening rates for breast, cervical and colorectal cancer and ultimately broadened to other chronic diseases.
4. Public Reporting

Though the ColonCancerCheck program is still in its infancy, the CSQI is already beginning to track trends in colorectal cancer screening participation at a provincial and regional level as well as measure progress against the provincial target. Additionally, Ontario is the first province in Canada to measure colonoscopy quality and report on wait times for colonoscopies. This information is being used to assess whether patients requiring this procedure are receiving it within accepted timeframes as well as ensuring that the increase in volumes due to increased screening rates do not have the unintended consequence of longer waits for persons with symptoms. This is the first time that data for all colonoscopies performed in hospitals participating in the program including those that are used for diagnosis are being captured.

**Figure 5**: Biennial Fecal Occult Blood Test (FOBT) Participation Rate, individuals aged 50-74 years

*age standardized to 1991 Canadian population

Source: OHIP Claims History Database (MOHLTC), Registered Persons Database (MOHLTC)
REFERENCES


b. Pathology and Laboratory Medicine

i. Background

The Pathology and Laboratory Medicine Program (PLMP) focuses on the screening and diagnostic components of cancer care. Almost all cancer patients begin their involvement with the cancer system through a series of diagnostic tests. Pathology is the medical specialty that principally deals with the examination of these tissues and cells under the microscope to arrive at a diagnosis and in many cases to provide prognostic and predictive information. The vision of the PLMP is to have a system in place across the province that allows pathologists and other laboratory medicine providers to effectively and efficiently perform analyses of samples and provide appropriate medical consultations. This will allow patients to be diagnosed or have cancer ruled out accurately and quickly, ensure that the right treatments are selected for their specific cancer, and allow necessary monitoring of the effectiveness of the treatment.

Through the PLMP we work to strengthen the quality of pathology and laboratory medicine services across Ontario with a focus on the following elements of quality: measurement, standard setting, continuous quality improvement, knowledge translation and exchange, accountability and performance monitoring.

Following are examples of two initiatives of the PLMP quality agenda. HER2/Neu testing for breast cancer patients is an example of an early initiative that led to the inclusion of Pathology and Laboratory Medicine as an area of clinical focus for CCO, developed into a volume-based funding program tied quality criteria and accountability agreements, and has emerged as a funding and quality assurance model for emerging molecular oncology tests in the world of personalized medicine. The Stage Capture and Pathology Reporting Project each look to improve the quality and completeness of data collection based on standards. For the Pathology Reporting Project the Provincial adoption of a common reporting standard by Ontario’s pathologists is unprecedented for a jurisdiction of this size and complexity. The data collected from these projects is being used to report on quality indicators, is shared with hospitals for their own internal quality assurance practices and the system level uses of the data include surveillance, projections and system planning.

ii. How did we Improve Quality?

1. HER2/Neu Testing for Breast Cancer Patients

Advances are being made in the development of systemic treatment to include testing for biomarkers that can predict treatment response and that have prognostic value. This growing field is known as personalized medicine and uses a person’s genetic information to tailor cancer treatment to their disease. Before the days that ‘personalized medicine’ was part of our vernacular, CCO’s Pathology and Laboratory Medicine Program was overseeing the administration and quality framework for a genetic test that predicts response to a systemic therapy. HER2/Neu is a genetic biomarker proven to be a prognostic marker for breast cancer and predictive of response to the breast cancer drug trastuzumab (Herceptin). Over expression of HER2/Neu (“HER2+”) is predictive of response to trastuzumab, more commonly known as Herceptin, a drug used to treat patients with breast cancer [1]. In August 1999, Herceptin was funded for use in Ontario patients with metastatic breast cancer who were HER2+.

Based on advice from CCO the Ministry of Health & Long-Term Care (“Ministry”) implemented volume-based funding to provide testing for metastatic patients (approximately 6% of patients diagnosed with cancer [2]) and established a reference network structure for HER2/Neu testing.
to provide quality oversight. The HER2/Neu testing program aims to improve quality in the delivery of cancer services by testing all new breast cancer patients to ensure that only the patients likely to benefit from treatment receive it, the toxic side effects and costs are avoided for those not likely to benefit, setting quality criteria for labs performing the testing and linking funding to the quality criteria.

HER2/Neu is an early example and model for how cancer treatment can be tailored to the patient at the individual level and how an overall quality based service delivery system can be implemented at the system level.

For the breast HER2/Neu testing program performance is managed in multiple ways. An expert panel was convened to monitor volumes, changes in the testing environment, emerging evidence, quality criteria, oversee external quality assurance (EQA) testing and provide advice to CCO. A reference network structure for HER2/Neu testing was established to provide quality oversight for EQA testing, educational support for labs within their network and has evolved into a community of practice. EQA testing is performed twice a year and labs provide quarterly volume reporting to CCO. This data is used to track against projections, identify issues, and shift testing volumes amongst labs as necessary.

As per recommendations from the 2008 CCO Molecular Oncology Task Force [3] volume-based funding has been put forth as a mechanism to deal with rapidly emerging evidence which is expected to continually alter or replace existing tests, as well as adding new tests. The breast HER2/Neu testing program is the first volume-based funding program to be administered by CCO on behalf of the Ministry. From inception, CCO developed a quality framework for testing which included a reference centre structure for EQA testing, and linked funding to performance and quality criteria. The reference centre structure has been successful in fostering a strong community of practice amongst the testing centres.

As more and more drugs come to market with accompanying biomarker tests that either predict treatment response or have prognostic value, there is increasing interest to have a mechanism that addresses the funding and quality assurance aspects of the testing. The approach used for breast HER2/Neu testing could be replicated for other molecular oncology tests.

2. Stage Capture and Pathology Reporting Project

Cancer stage refers to the extent or severity of an individual’s cancer based on the extent of the primary tumor and spread in the body [4]. Determining stage allows clinicians to assess prognosis and the appropriate treatment for patients resulting in better quality of care and outcomes. It provides a common language for communication and is beneficial at a population level for a variety of purposes including planning cancer services, evaluating health care interventions, and assessing quality of care against evidence based standards and research. Two interrelated processes are required to stage patients including clinical staging which occurs prior to surgery and involves abstraction of data from various medical and laboratory charts, and pathologic staging which is documented by pathologists when analyzing tissue samples obtained from a cancer surgery or biopsy. Given that the majority of cancers are diagnosed based on findings in a cancer pathology report – these clinical reports are not only used by clinicians to determine prognosis and guide treatment but also serve as key inputs for Ontario’s Cancer Registry for tumour registration. The ability to ensure effective cancer surveillance depends on the availability of critical information at a population level related to cancer incidence, stage and tumour pathology.
In an effort to improve the completeness and usability of cancer stage data and pathology reporting in Ontario, CCO embarked on a multi year stage-path initiative beginning in 2004 with the following objectives: 1. To enable a semi-automated capture of cancer stage at diagnosis for 90% of all eligible new cases using collaborative staging minimum data set; 2. To ensure electronic cancer pathology reports are received in a synoptic format by Ontario’s Cancer Registry with discrete data fields and are 90% complete based on College of American Pathologists (CAP)cancer checklists.

In the short time period since the inception of the stage capture project, the stage capture rate for all incident cancer cases in Ontario has increased from 36% for the 2005 diagnosis year to 75% for 2008 [Figure 6] [5]. In September 2010 automated stage capture was successfully implemented leveraging CCO’s e-Path repository of synoptic pathology reports to enable more efficient and effective cancer staging for the 2009 diagnosis year forward.

In the period since the inception of the pathology reporting project, we have seen considerable changes in the practice and spectrum of pathology reporting in the province from narrative reporting in a single text field with no College of American Pathologists (CAP) content (level 1 reporting) to reporting synoptically using a standardized CAP nomenclature with all principal data elements entered in discrete data field format with automated back-end encoding with CAP specific composite keys (C-Keys) and/or SNOMED CT codes [Figure 7][6]. From May 2008 to September 2010 cancer pathology reporting in Ontario has evolved significantly - 86 hospitals have implemented synoptic reporting e-tools and are electronically reporting against the CAP standard to the Ontario Cancer Registry for five common cancer resections (breast, lung, prostate, colorectal and endometrium). At the present time, 9 hospitals have transitioned to Level 6 reporting using the electronic CAP Cancer Checklists (eCCs) for all mandated CAP disease sites and it is expected that by 2012 the majority of acute care cancer reporting facilities in the province will be reporting in this format. For those hospitals reporting at Level 5, the percent of pathology reports for five common resections submitted in discrete data fields (DDF synoptic format between May 2008 and July 2010 is 94% (13,704/14,541). Reporting in discrete synoptic format facilitates completeness in pathology reporting resulting in 94% (12,936/13,704) of all DDF reports found to be complete against CAP cancer checklist standard for applicable disease sites. By comparison, a recent American College of Surgeons audit of US cancer centres showed completeness rates of just 69% [7]

Today, CCO is recognized as a world leader in being the first jurisdiction of this size and complexity to demonstrate full interoperability between a centralized cancer registry and all cancer treating hospitals for cancer pathology reporting. Interoperability was enabled with the adoption of internationally endorsed CAP content and data standards with HL7 messaging standards based on the National Association of Centralized Cancer Registries ePath standard.

3. Performance Management

As part of contractual agreements with CCO, regional cancer centres and hospitals providing cancer surgery were now obligated to participate in a number of quality initiatives and work towards achieving targets in addition to increasing volumes of services performed in exchange for funding dictated under the Cancer Surgery Agreement (CSA). These included ensuring that all eligible cancer patients are staged according to the globally accepted standards of the International Union against Cancer (UICC) [8] and the American Joint Committee on Cancer (AJCC) [9] and that this data is submitted to CCO. Hospitals performing surgery were further required to electronically submit discrete synoptic pathology reports and ensure that 90%
completeness in pathology reporting against the CAP standard [10]. Additionally, all centres were required to appoint both clinical and administrative leadership for each of the stage capture and pathology programs to facilitate implementation of the program goals and serve as a point of contact to CCO. Lastly, it was essential for all centres to work collaboratively with a provincial implementation team. Implementation of monthly reporting to hospital based leads on the completeness of stage capture and pathology reporting was a key tool used for performance management to advance project goals and enable quality improvement.

4. Clinician Engagement

a. Stage Capture

One of the key aims of the stage capture project is to improve the quality of stage data from regional cancer centres and to expand stage capture to all cancer treating acute care hospitals. Prior to this, stage data was available from regional cancer centres providing radiation and systemic therapy but did not include patients receiving care outside a cancer centre or only receiving surgery at the host hospital of the cancer centre.

It was recognized that to successfully implement this program and effect changes in staging practice, a multifaceted strategy that utilized local champions, multifaceted knowledge transfer strategies and audit and feedback loops were required [11,12]. Each regional cancer centre and host hospital identified clinician mentors, stage physician leads and health records leads who were responsible for implementing a plan to meet the target for stage capture rate in their region, promoting uptake of the program through knowledge transfer activities and collecting and processing the data respectively. These key internal leadership roles were supported with external facilitation by CCO project team members. Successful implementation of the program required collaboration and ongoing communication at both the local and provincial levels. Orientation sessions were held for clinician mentors outlining the purpose of the project, their roles and expectations and knowledge transfer activities to engage other physicians. In turn, regional education sessions were held with local leadership describing the purpose and value of the program and strategies for increasing data capture. Monthly conference calls for clinician mentors and health records leads with CCO leadership provided an opportunity to discuss progress, challenges and mutually resolve issues. The details of these activities have been well documented [12].

b. Pathology Reporting

Each year CCO receives over 100,000 surgical pathology reports electronically by over 400 pathologists from more than 100 hospital laboratories in Ontario. Given the number of players and institutions involved, the participation of local clinical leadership was paramount to the successful implementation of the pathology reporting project. This was achieved through the implementation of communities of practice for each specialty area bringing together people sharing a common expertise and passion [13]. Regional pathologist leads and laboratory information system data leads were implemented at all of the pathology labs in Ontario who served as local champions in implementing quality standards in pathology reporting through various outreach and knowledge transfer strategies with hospital stakeholders. Shortly after the inception of this program in 2004, CCO conducted a series of audits on pathology reports received electronically, finding variations in the format within which data is submitted and completeness against internationally recognized CAP standards. One of the key features of the educational sessions was the provision of feedback of these reports. Additionally, a hospital working group consisting of each of the pathology leads were formalized which participated in
regular teleconferences and meetings with the provincial pathology lead and other CCO leadership to obtain guidance and leadership. Further, pathology leads were linked with CCO’s RVPs at each of the regional cancer centres to promote collaboration and stakeholder engagement at a local level.

5. IM/IT

The success and sustainability of both the stage capture and pathology projects was highly dependent on the implementation of information technology. Previously, CCO has invested in a pathology information management system (PIMS) which enabled electronic transmission of pathology reports from hospital systems; an achievement over paper based data capture. After engagement with hospital stakeholders, it was evident that further investments were required for a technical solution that facilitated capture of pathology requirements in the new standardized format. Synoptic reporting electronic tools have been implemented in hospitals resulting in the submission of pathology data that is consistent and comparable with other hospitals.

Additionally, CCO has moved to a more sophisticated level of capturing stage data called collaborative staging, an internationally recognized standardized data set which enables complete and timely stage data capture. This process currently involves a semi-automated data capture of pathology related stage data elements from the provincial PIMS repository of synoptic pathology reports housed at CCO. The data collection system also uses a centralized system and data abstractors housed at CCO with remote linkages to all cancer patient hospital records across the province to enable centralized data abstraction of non-path staging information from imaging, surgical reports and clinical notes. The collaborative staging data collection system has been implemented in 85 cancer treating hospitals across Ontario, starting with the collection of data for the four most common cancers – lung, breast, prostate and colorectal. The ultimate goal is to have fully electronic data capture for all cancer sites and all cancer centres and hospitals participating by 2012.

6. Public Reporting

All Ontario cancer treating hospitals and cancer centres receive location specific reports on their progress against provincial targets including stage capture rate and completeness of pathology reporting. Additionally, this data is publicly reported at both a regional and provincial level, which allows for comparison across regions and shows progress against provincial targets. One of the key drivers in engaging physicians and regions in adopting the new approach to data collection and reporting was by demonstrating the value and utility of this new data beyond clinical diagnosis to system performance measurement and quality of care. For example, stage distribution of incident cancer patients by disease site measures efficacy of screening programs by showing the proportion of patients in late stage cancer [Figure 8]. The aim is to capture patients in early stage to improve survival rates. The data shows that only 5% of incident breast cancer patients are in late stage cancer compared to 20% of incident colorectal cancer patients [5]. This can be explained by the fact that a provincial breast cancer screening program has existed for over a decade while the provincial colorectal cancer screening program was recently implemented. Additionally, standardizing pathology reporting into discrete synoptic format has facilitated more complete and standardized reporting and has resulted in the development of new quality indicators that assess the quality of surgical practice. It is now possible to easily capture the number of lymph nodes harvested after colorectal cancer resections and gauge if these are meeting evidence based standards. This information in turn is useful for providers in improving quality of care.
Figure 6: Percentage of Cancer Cases in Ontario with Valid Stage

Source: Ontario Cancer Registry, Collaborative Staging Database

Figure 7: Percentage of Ontario Hospitals Reporting Cancer Pathology by Level of Standardization from Narrative to Synoptic
<table>
<thead>
<tr>
<th>Reporting Level</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
<th>Level 5</th>
<th>Level 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>• Narrative • No CAP content • Single text field data</td>
<td>• Narrative • CAP content • Single text field data</td>
<td>• Level 2 • Synoptic-like structured format</td>
<td>• Level 3 • Electronic reporting tools using drop down menus</td>
<td>• Level 4 • Standardized reporting language • Data elements stored in discrete data fields</td>
<td>• Level 5 • Common data and messaging standards with C-Keys, SNOMED CT or other encoding</td>
</tr>
<tr>
<td>% Ontario Hospitals 2004-05</td>
<td>5%</td>
<td>40%</td>
<td>50%</td>
<td>5%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>% Ontario Hospitals 2006-07</td>
<td>0%</td>
<td>5%</td>
<td>70%</td>
<td>25%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>% Ontario Hospitals 2008-09</td>
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<td>0%</td>
<td>65%</td>
<td>17%</td>
<td>18%</td>
<td>0%</td>
</tr>
<tr>
<td>% Ontario Hospitals 2009-10</td>
<td>0%</td>
<td>0%</td>
<td>20%</td>
<td>2%</td>
<td>78%</td>
<td>0%</td>
</tr>
<tr>
<td>% Ontario Hospitals January 2011</td>
<td>0%</td>
<td>0%</td>
<td>20%</td>
<td>2%</td>
<td>69%</td>
<td>9%</td>
</tr>
</tbody>
</table>

Source: Cancer Care Ontario, Pathology Information Management System ePath Database
**Figure 8:** Distribution of New Cancer Cases by Stage at Diagnosis, four highest volume disease sites, diagnosed in 2008

Source: Ontario Cancer Registry, Collaborative Staging Database
REFERENCES


**Multidisciplinary Cancer Conferences**

Research has provided patients and clinicians with more options to treat and cure cancer yet selecting the best option for the disease and patient circumstance places a significant weight on individual medical staff and health professionals. Multidisciplinary Cancer Conferences (MCCs) are a method to bring health professionals together to discuss individual patient treatment options.

MCCs result in improved care.
- Evidence suggests that patient cases reviewed at a MCC are more likely to receive evidence-based care and have all treatment options considered.
- MCCs are also a mechanism for peer review (quality assurance) of pathology reports and diagnostic images.
- They foster the development of a multidisciplinary culture across health care disciplines.
- They encourage hospitals across regions to work together – the majority of Ontario MCCs use videoconferencing where expertise can be shared between hospitals.
- MCCs are standard of care in the United Kingdom, the USA, Australia and Belgium.

In 2006, CCO released the *Multidisciplinary Cancer Conferences Standards* [1] which describe the purpose, format, cases to review, and team members’ roles and responsibilities and institution responsibilities. Since then a provincial-wide implementation project ensued with a plan encompassed facets of CCO’s performance improvement cycle. The objective is to implement a province-wide strategy that ensures all appropriate cancer patient cases have access to a high-quality MCC discussion.

Project Achievements include:
- **Engagement:** Obtaining feedback and input from clinicians across Ontario has been instrumental to the projects accomplishments. Stakeholders included clinicians from multiple disciplines (surgery, medical oncology, radiation oncology, pathology and radiology) who participate and chair MCCs, hospital administration who encourage participation and MCC coordinators. Indeed few hospitals outside of academic centres held MCCs prior to 2006.
  - Engaged a multidisciplinary, province-wide expert panel to develop informed recommendations for the formation and maintenance of MCCs.
  - Held a workshop that consulted practitioners and administrators in Ontario to define the goals of the MCC project. This workshop also developed the minimum evaluation requirements for a MCC including: Chair and coordinator assigned, prospective case review, weekly or bi-weekly frequency, a 75% participation rate from surgery, medical oncology, radiation oncology, pathology and radiology.
  - Consulted disease site expert panels to a) refine MCC requirements based on disease and b) offer advice on which patients may benefit most from an MCC discussion.
  - Created and fostered the MCC Coordinator Provincial Network (conferences, online community) to address barriers, share best practices across regions and set future direction.
  - Launched an MCC Resource page which provides regional partners access to MCC tools to not only implement but sustain MCCs in their regions (FAQs, best practices, etc.). Includes:
    - Medico-Legal opinions on MCC participation
    - How to accredit an MCC for Royal College credits
    - MCC Coordinator job description
• Performance management: In 2009 regions began collecting information about the minimum criteria of an MCC, being able to measure has allowed the project to facilitate a culture of continuous improvement through the Quarterly review process.
  o In FY09/10 63% of existing MCCs met the minimum criteria
  o It is estimated that 17,000 patients received a multidisciplinary discussion of their treatment options in FY09/10 and this is expected to continue in FY10/11. On average 6-7 patients are discussed at an MCC.
  o As more is known, the measurement of MCCs continues to be refined. For example, originally a hospitals reported on MCCs where the hospital received Cancer Surgery Agreement funding while moving forward hospitals will be asked to expand the number of MCCs they have to include disease sites with at 35 patients per year.

• Public reporting: With the collection of data from each of the regions, the project publically reported preliminary performance results on the Cancer Service Quality Index in 2010.
  o The Percentage of hospitals providing cancer services reporting at least one MCC (50%) and Adherence to Standards Criteria of reported MCCs (64%)

• Funding:
  o Each region has a designated regional MCC Coordinator who works to collect attendance and patient data, improve practices and organize meeting materials. This role is the ‘glue’ that holds the MCC together. This position is funded by the MOH.
  o The implementation of MCCs is a requirement in the Cancer Surgery Agreements and the Medical Oncology hospital agreements.
  o The project has sponsored investment in regional funding projects which make practical improvements within the regions to facilitate implementation of MCCs.
    ▪ 12 regions made investments in videoconferencing or information technology to improve the quality and speed of meetings. Including: laptops, microphones, screens, slide image cameras, telemedicine carts, and database developments.
    ▪ 11 regions have held regional workshops, education sessions and/or conducted site visits with the hospitals in their LHIN. The goal of the sessions included:
      • Educating on MCCs
      • Developing consensus to improve discipline attendance from across the region
      • Gaining feedback on process improvement and streamlining logistics and/or share best practices and uses resources and time efficiently
      • Investigate new technology for documentation
  o The project worked with the Ministry of Health and Long Term Care and the Ontario Medical Association to develop an OHIP billing code. In October 2010, the code was introduced representing a substantial milestone. There is a code for the MCC Participant and a code for the MCC Chair.
REFERENCES

c. RADIATION TREATMENT

i. Background

Beginning in the early 1990s and continuing into the turn of the century, there were public concerns about the long wait times for radiation treatment as many patients were sent out of province and country to receive treatment. While the early focus of the OCTRF was on improving access to radiation treatment, the growing incidence of cancer patients requiring treatment and inadequate supply of radiation equipment to meet demand resulted in the wait times for all cancers (median 5-7 weeks) exceeding acceptable targets established by the Canadian Association of Radiation Oncologists (4 weeks) [1]. The issue was further complicated by the shortfall in radiation oncologists and other providers required to deliver radiation therapy. It was evident that a multifaceted approach including investments in health human resources, capital and process improvements were required to improve access.

Since 2005, there has been a 26% increase in patient treatment capacity with Ontario surpassing the federal target for radiation therapy wait times. Today, 95% of new cancer patients are receiving radiation treatment within four weeks of being ready to treat compared to 76% in 2005 [Figure 9]. Additionally, CCO has further established targets by urgency rating to identify access issues regionally and is also focusing on improving radiation treatment utilization as well as developing a quality program through and promotion of appropriate and safe treatment such as intensity modulated radiation treatment.

Another major effect of inadequate treatment capacity and prolonged waiting times for treatment was that many patients who could have benefitted from treatment were not referred for consultation. Even as more facilities for treatment became available and waiting times reduced, these patients were not referred for consideration of treatment – leading to decreased use of RT as a treatment modality. Cancer Care Ontario has recognized this problem of low utilization of RT in Ontario (currently 35.5%) and is working actively to get to the provincial target of 48%.

ii. How did we Reduce Wait Times and Improve Quality?

1. Performance Management

Contractual agreements with regional cancer centers and host hospitals, known as integrated cancer programs, were established in 2004, and set out the new relationship between CCO and the 10 cancer programs at the time, providing radiation treatment with providers now directly employed by the individual programs. As part of their agreement, each regional cancer program was required to recruit a radiation oncology lead that was accountable to CCO and their regional vice president for establishing a high quality radiation treatment program that was aligned with the provincial radiation treatment program goals. Overtime, the relationship between regional cancer programs and CCO has evolved to include requirements around provision of increased volumes for funding as part of the wait times initiative, submission of data on wait times and other indicators to measure progress against provincial targets, and participation in quality initiatives such as multidisciplinary cancer conferences and intensity modulated radiation treatment (IMRT) programs.
2. Capital Plan

To improve access to radiation treatment and ensure referrals are closer to home, large investments have been made by the Ministry of Health and Long Term Care under the consultation of Cancer Care Ontario to increase the number of regional centres and radiation treatment units to meet projected needs. Since the late 1990s, six additional regional cancer centres were opened across Ontario bringing the total to 14 centres today providing radiation treatment, with expansions in Peel, Durham and Ottawa. Additionally, portable radiation facilities or bunkers have also been established in Barrie and Ottawa to bring care closer to home. To date, 92 radiation treatment machines are in operation across the province compared to 74 in 2005, an increase of 20% with a capacity to treat close to 40,000 patients. Most recently, Southlake Regional Cancer Hospital was opened with three machines and further new centres and expansions are expected over the next few years potentially bringing the total number of machines to 115 by 2015 [Figure 10].

In addition to increasing the number of treatment units large investments have been made by the Ministry of Health and Long Term Care in new technology implementation throughout the province. Intensity Modulated Radiation Therapy has been phased in over a 3 year period – ensuring that all patients who could benefit from this approach have it available to them [2]. This required a considerable capital investment by the Ministry, in addition to a considerable investment in educational initiatives to ensure the safe application of this new approach. The evaluation of the Gamma Knife installed in 2003 at the Toronto Western Hospital is ongoing and 2 Cyberknifes have become operational in 2010 – in Ottawa and Hamilton – and this exciting new technology will be evaluated over the next 3-5 years.

3. Investments in Health Human Resources

An effective radiation treatment program requires an adequate mix of radiation oncologists, radiation therapist and physicists, without which, results in inefficiencies and compromises the quality and safety of patient care [3]. In 1999, the Task Force on Human Resources for Radiation Services delivered a plan to the Minister of Health detailing the health human resource requirements to deal with the increasing waits for radiation treatment services and future increase in incident cancer patients requiring radiation treatment. [3].

Investments in health human resources were an important strategy in improving access to radiation treatment services. In 2002, through negotiations between the Ontario Medical Association and Ontario Ministry of Health and Long-Term Care, the payment model for radiation oncologists changed from one that was primarily salary based to a hybrid model that included a base salary and fee for service billing similar to other physician groups. The new fee schedule now accommodated the complexity of planning and treatment and incentivized radiation oncologists to treat more patients as well as participate in more complex therapy such as IMRT. Additionally, investments were made to increase the number of residency spots in radiation oncology training programs annually to meet the projected increase in incident cancer patients requiring radiation. In 2008, the number of radiation oncologists practicing in Ontario was 172 compared to 126 in 2002. There are now 3 radiation therapy schools operating in Ontario, including one in Northern Ontario (as compared to only one in 2002).

Similarly, to attract and retain individuals in the radiation therapy and medical physics profession, required adjustments in salaries of these professions, increasing the number of training spots as well as providing opportunities for career growth and development through further education and research opportunities. A Professional and Research Masters Program in radiation therapy has started at the University of Toronto and there are ongoing plans for the
development of a new Clinical Specialist Radiation Therapy akin to the Advanced Practice Model in Nursing. CCO has committed annual funding for a training program for physicists to ensure appropriately trained physicists. A training program established for physicists four decades ago is now funded by CCO.

4. Public Reporting

One of our major advances in the radiation treatment program area has been the ability to capture data on all patients receiving radiation treatment in the province which has been an important lever for improvements to access and quality. Access to a province-wide database has also made it possible to gauge data quality, completeness and accuracy. Public reporting of wait times data began with radiation treatment, when in 2004, provincial median wait times were first reported on the CCO website. Wait times data continues to be reported monthly by regional cancer centre and disease site. In 2007, median wait times started to be reported at two intervals, from the time between patient referral and consultation with a specialist (wait 1), and time between being ready to treat and starting radiation treatment (wait 2) and progress was measured against provincial targets [4]. Regional cancer centres also have access to wait times data for their region by priority rating based on urgency. Through this level of reporting, it is possible to identify where wait times issues lie and where resources should be allocated. Data and trends on radiation treatment wait times are also tracked annually in the CSQI along with utilization rates. The data shows that radiation therapy is underutilized in Ontario as only 36% of cancer patients receive this form of therapy [4] whereas it has been suggested that the appropriate rate of utilization for Ontario should be closer to 50% [5]. Reporting on utilization rates across regions can work towards improving patient referrals for treatment to optimize usage. The province has also started to share anonymized data on number of incidents reported at regional cancer centres and incidence reports to all centres regardless of where the incident occurred, in an effort to improve patient safety, share lessons learned and prevent reoccurrences.

Figure 9: Federal-Provincial-Territorial Benchmark: Percentage of Radiation Patients treated within 28 days from Ready to Treat to Start of Treatment

Source: Cancer Care Ontario, Activity Level Reporting / Data Book
Figure 10: Number of Current Operating and Planned Radiation Treatment Units across Regional Cancer Centres

*radiation treatment units currently planned under CCO’s Capital Strategy

Source: Cancer Care Ontario - Capital Projects Office
REFERENCES


d. SYSTEMIC TREATMENT

i. Background

Systemic treatment was one of the early areas of the cancer system under the control of Cancer Care Ontario as it was focused on improving access to cancer treatment delivered in the regional cancer centres. Although progress in this area has been slow to develop, there have been significant improvements in the last few years. Historically, approximately half of systemic treatment was delivered outside of the organized cancer system, mostly in community hospital settings. This challenge in the ability to understand and improve access and quality of care in the entire system was further exacerbated by the lack of standards on appropriate care and limited province wide data on the use and quality of systemic treatment [1].

Over the past few years, the addition of three new community cancer centers with two more planned to open soon, as well as the development of the Regional Systemic Treatment Program (RSTP) has completely changed the organization of systemic treatment in the province. Another noteworthy achievement has been in the development and deployment of the largest electronic drug order entry system in Canada that has been implemented in 36 hospitals across Ontario with high success [Figure 11]. Additionally, a number of efforts are underway to improve quality and standardize care across the province including the development and implementation of evidence based guidelines on optimal drug use and development of standards around the safe handling, labeling, and administration of chemotherapy. To date, wait times have remained steady over the past few years. However, as the incidence of cancer is expected to increase, the demand for complex therapy will rise making it important to ensure that access to treatment is available to those that need it.

ii. How did we Improve Quality?

1. Performance Management

As one of the earlier programs managed by Cancer Care Ontario, contractual agreements had been established initially with the 8 Regional Cancer Programs and have now been expanded to the 14 integrated cancer programs providing systemic treatment in the province. Initially, these agreements set out the conditions of funding which included the submission of data on volumes and wait times information as well as the recruitment of regional leads with the regional cancer centres to drive the implementation of initiatives that are aligned with provincial priorities. In 2007, through the PEBC, CCO published a set of evidence based standards for organizing and delivering systemic treatment in Ontario [2] followed by the RSTP provincial plan in 2009, outlining the actions needed to implement those standards and measure their impact [3]. These standards require that all facilities providing systemic treatment in Ontario become part of an integrated provincial system with formal regional partnerships. As of September 2010, there are 80 designated RSTP facilities. Furthermore, CCO has outlined requirements to participate in quality improvement initiatives, implement program guidelines, and monitor wait times to ensure timely access to treatment. The standards identify 4 levels of hospital service ranging from complex highly specialized chemotherapy given in level 1 and 2 cancer centers to low risk treatment given in level 4 general community hospitals under the direction of an oncologist. The standards around the organization of systemic therapy across the province also include participation in other provincial priorities such as multidisciplinary cancer conferences as well as the submission of data for a number of indicators tied to quality initiatives through stage physician and health record leads. These measures serve as the basis of quarterly performance reviews with RVPs and CCO. Formal agreements have also been established with community
hospitals providing systemic treatment as well as centres that have implemented CCO’s Oncology Patient Information System for electronic prescription drug ordering.

2. New Drug Funding Program (NDFP)

Cancer Care Ontario administers the New Drug Funding Program, which provides funding for injectable cancer drugs through a network of hospitals and provincial cancer centres. As the costs and utilization of cancer drugs has increased, the path to reimbursement for new cancer drugs has changed considerably.

Until the mid-1990s, hospitals faced pressure to fund new, expensive intravenous cancer therapies from their own global budgets. When it became obvious that access to treatments varied based on a hospital’s ability to pay, there was recognition that a new funding model was necessary. The New Drug Funding Program was established at CCO in 1997, using a model where the funding followed the patient. A Policy Advisory Committee (PAC) was established to provide funding recommendations to government, based on evaluations of funding requests from clinician-led Disease Site Groups and supported by what would become the Program in Evidence-Based Care (PEBC). The PEBC’s rigorous approach ensured that each drug considered for funding was accompanied by a systematic review and practice guideline.

In the early 2000’s, the Ontario Ministry of Health and CCO began a collaboration to make more coordinated funding decisions on cancer drugs. The Ministry’s decision-making process was comprised of a Drug Quality and Therapeutics Committee (DQTC) that considered the clinical and pharmaco-economic arguments for submissions for oral and subcutaneous cancer drugs initiated by pharmaceutical companies. The CCO process lacked a formal pharmaco-economic evaluation, but incorporated clinical practice guidelines and the leadership of clinical experts.

In 2005, the DQTC-CCO Subcommittee (now Committee to Evaluate Drugs (CED)-CCO subcommittee) was established to enhance the review of all cancer drugs (injectable and oral), incorporating a review of clinical and pharmaco-economic evidence, as well as practice guidelines developed by the PEBC. Disease Site Groups, as well as pharmaceutical manufacturers, can make funding requests through this new process. Recommendations from the Subcommittee flow to the CED, where cancer drugs are considered from the perspective of the broader health system. Final decisions for all cancer drugs are now made by the Executive Officer of Ontario Public Drug Programs.

The integrated process championed by CCO has supported significant government investments in cancer drug funding. The NDFP has grown from reimbursing 6 drugs for 8 indications in 1997/98, at a cost of $8 million, to reimbursing 25 drugs for 58 indications, at a cost of about $200 million, in 2009/10.

While the consistency and rigour of provincial decision-making has been enhanced by the CED-CCO process, there continues to be significant differences between provinces in cancer drug access. In 2007, the CED-CCO Subcommittee formed the basis of an interim Joint Oncology Drug Review (iJODR), where all provinces receive recommendations from the CED-CCO evaluation process, and then make their own funding decisions. In early 2010, a formal decision was made to replace iJODR with a permanent pan-Canadian Oncology Drug Review (pCODR), a national commitment to improve the consistency of cancer drug decision-making across Canada. Once implemented, pCODR will ensure that all provinces make funding decisions based on a common evaluation of the clinical and cost-effectiveness data supporting a cancer drug.
3. Clinician Engagement

Evidence Based Standards

The evidence based organizational standards in the Regional Models of Care for Systemic Treatment in 2007 have helped to optimize the quality and efficiency of treatment delivery. In addition, through the PEBC, clinical experts on multidisciplinary provincial Disease Site Groups have been involved in the review of evidence and drafting of guidelines to support the optimal use of systemic treatment. More than 90 specific evidence based advice documents in 10 different disease areas form the foundation of systemic treatment practice in the province. Additionally, while CCO does not have control over oral drugs which is regulated by the provincial government, it does play a critical role via clinician input on the disease site expert panels of the PEBC to develop standards of care around appropriate prescribing and utilization, thereby impacting quality of care.

4. IM/IT – Oncology Patient Information System (OPIS) and Drug Formulary

Electronic drug prescribing systems have been shown to reduce medication errors in primary care settings [4]. In an effort to optimize cancer drug prescribing and improve patient safety, Cancer Care Ontario developed and implemented the Oncology Patient Information System (OPIS 2005), a computerized physician order entry system in regional cancer centres to be used by health care providers to facilitate patient care [5]. OPIS has played a key role in supporting patient care. OPIS 2005 functionalities include online drug profiles, prompts for potentially adverse drug interactions, and real-time electronic communication between physicians, nurses and pharmacists about drug orders and changes in dose. Regular and ongoing engagement with system users and system upgrades ensure OPIS 2005 remains current and supports user needs. Additionally, the system facilitates performance management, by providing data back to CCO on the use of drugs in the cancer system, and adherence to best practice, and by providing standardized drug regimens for order by practitioners. This is an important feature in improving quality of care and patient safety given that there are numerous guidelines on cancer drugs, making it otherwise difficult to keep up with current practice. By 2008, OPIS 2005 had been expanded to 36 systemic therapy treatment facilities across Ontario with 66% chemotherapy drugs prescribed through this system, compared to 46% adoption rate in 28 centres in 2004 [6]. The system is being used by over 1000 physicians, 750 nurses and 250 pharmacists, managing over 50,000 cancer patients. Canada is recognized as the first jurisdiction to implement an electronic cancer prescribing system in multiple institutions. Expanding OPIS 2005 to the remaining systemic therapy institutions is one of the goals of the Provincial Systemic Treatment Plan with full implementation expected by 2013 [3].

The CCO Drug Formulary is a publicly available information resource which serves as a reference for clinicians, administrators and patients reflecting best practices, standardized language and safe use of drugs in the Ontario cancer system. The Drug Formulary section of the CCO website is the highest traffic area of the CCO website; from March 20th to May 31st 2008, the online Drug Formulary has had 35,990 visits, composing 18.26% of the overall CCO website visitors for that time period. Drug Formulary continues to expand to accommodate the growing information needs associated with the expansion of systemic treatment.

5. Public Reporting

The performance of systemic treatment programs in regional centers is reported annually in the CSQI at the provincial and regional level for a number of indicators. Wait times for systemic treatment are also reported on a monthly basis. Initially reported from the time of patient referral
to first chemotherapy treatment, in 2009 these indicators were refined into two intervals: time from referral to the medical oncologist to time of consult; time from consult with the medical oncologist to first chemotherapy treatment. This helps to better identify which factors, such as human resources, hospital infrastructure, or others, are responsible for longer waiting periods. [6]. Regions are able to compare their own performance against the provincial average, provincial and regional targets and other regional programs. Additionally, by reporting patient safety and quality indicators, such as uptake of computerized physician order entry systems, drug utilization, compliance with best practices, and emergency department visits after systemic treatment, it is now possible to measure and assess improvements in quality of care for patients receiving systemic treatment. Data from many systemic treatment hospitals outside of regional cancer centres is not comprehensive, therefore it is difficult to gauge quality of care and wait times practice in these centres. As the CPOE adoption increases and Regional Systemic Treatment Programs are put into place it will become possible to get a more complete provincial picture of systemic treatment delivery. The Provincial Regional Systemic Treatment Plan has set a target to capture data on wait times for all centres delivering systemic therapy by 2012 [3].

Figure 11: Percentage of Systemic Treatment Visits (and number of hospitals) Supported by Computerized Physician Order Entry (OPIS)

Source: CIHI, National Ambulatory Care Reporting System
REFERENCES


e. SURGICAL ONCOLOGY

i. Background

Surgery spans the entire cancer continuum as it is often required for diagnosis, staging, treatment or palliation. It is usually the first point of contact for patients with the cancer system and 80% of cancer patients can expect to undergo a surgical intervention (resection or biopsy)[1]. As a result, the quality of surgical care can greatly impact the patient journey. Research beginning in the early 1990s showed that there were variations in surgical rates in Ontario with limited evidence to evaluate access and appropriateness. These issues were further echoed a decade later suggesting the need for better information, quality standards and indicators for surgery to measure access and appropriateness of care, monitor wait times, understand the reasons for variation in practice and improve the quality of cancer services. [2,3]

The provincial Surgical Oncology Program (SOP) was initially created in 1998 in response to the Ontario government’s request to establish departments of surgical oncology in all regional cancer centres in an effort to develop a knowledge network to increase the number of referrals to these regional centres for multidisciplinary consultation and treatment [2]. In 2003, CCO’s Board further renewed the mandate of the SOP to assess the quality of surgical care and to develop and implement strategies to improve delivery of surgery services. Through this initiative and as lead in the government’s Wait Times Strategy, CCO has improved both the access and quality of surgical oncology services in Ontario over the past 7 years. This includes the development and uptake of evidence based guidelines and standards for a number of surgical procedures, development and implementation of system standards for surgical care (eg. Thoracic and Hepatico-Pancreatic-Biliary [HPB] surgery), development of communities of practice and implementation of the Wait Times Information System across hospitals in Ontario. Moreover, over 27,000 additional surgeries have been performed since the launch of the Wait Times Strategy and wait times for all cancer surgeries from the decision to proceed with surgery to the surgery being performed have improved by 30% from 81 days in 2005 to 57 days in November 2010 with three-quarters of these performed within target [Figure 12] [4,5].

ii. How did we Reduce Wait Times and Improve Quality?

1. Performance Management

As part of the government’s Wait Times Strategy, CCO was asked to advise on the allocation of additional surgical volumes to reduce wait times for cancer surgery [6]. Since the inception of the strategy in 2004, Cancer Surgery Agreements have been signed with up to 47 hospitals annually including regional cancer programs. The Wait Times Strategy was a driving force behind improving the quality of surgical oncology services. Participating hospitals were required to sign accountability agreements with CCO to meet long-term quality and access improvements which include development of a regional surgical oncology program, implementation of quality standards and guidelines for surgery, implementation of system standards of care such as Thoracic Surgical Oncology Standards and the HPB Surgical Oncology Standards which recommend hospitals performing these complex surgeries meet a minimum volume of procedures each year. Furthermore the agreements require participation in quality of care communities of practice and regular reporting of data on cancer surgery volumes, wait times and other quality indicators. To carry out these requirements regions received funding to appoint a physician lead for surgery as well as meet the stating and pathology requirements described earlier. The 14 Regional Cancer Programs providing surgery were also
required to participate in the provincial surgical oncology program and meet the above requirements through their RVPs and surgical oncology leads. The RVPs in turn were responsible for ensuring these contractual obligations are fulfilled while advising on the allocation of funding for additional cases. Each regions performance on these requirements are monitored quarterly and/or annually through the performance management cycle.

2. Clinician Engagement

a. Evidence based standards

One of the barriers to quality cancer surgery services was the lack of research and evidence on optimal surgical care for cancer [2, 7]. To address this, the provincial SOP partnered with CCO’s Program in Evidence Based Care to develop a series of surgical oncology standards to organize cancer surgery services in hospitals and to guide clinical decision making. This has resulted in the development of a number of standards and guidelines just over the past five years including those for: thoracic cancer surgery; laparoscopic colorectal cancer surgery; hepatic, pancreatic and biliary tract cancer surgery; colorectal cancer surgery; prostate cancer surgery; and sentinel lymph node surgery for breast cancer as well as for multidisciplinary cancer conferences [8-15] which are being implemented across the province. The thoracic surgical oncology standards for example, set out the requirements for optimal organization and delivery of hospital services, providers and staff as well as the conditions for facilities to perform surgery. The evidence showed a volume-outcome relationship which resulted in the expert panel recommendation that thoracic surgery should be performed in level 1 facilities (minimum of 150 lung cancer surgeries and 20 esophageal surgeries) or level 2 facilities (minimum of 50 lung cancer surgeries and 8 esophageal surgeries). Other centers that were previously performing these surgeries were encouraged to build partnerships with Level 1 centres. Since the development of this standard in 2005, over 80% of thoracic cancer surgeries have been performed in designated centres [Figure 13]. Significant improvements in quality of surgical care have also been observed across all disease sites for which guidelines and standards have been developed [5].

b. Physician Engagement & Communities of Practice

Cancer surgery is performed by various general oncology and specialty surgeons and takes place in close to 100 academic and community hospitals including regional cancer programs. About half of the cancer surgery volumes are performed in a community setting [1]. In order to engage the numerous surgeons who perform cancer surgery the SOP has nominated regional champions from each of the 14 LHINs. The strategy is focused within disease sites. For example, with the release of a prostate cancer surgery and pathology guideline which focuses on appropriate surgical and pathological techniques to accurately report positive margins after prostate cancer surgery, surgery and pathology champions from each region were nominated to attend provincial meetings and discuss guideline implementation and issues specific to their region. The champions then met with surgeons and pathologists in their regions to develop regional initiatives for quality improvement. As an offshoot, a provincial and many regional communities of practice are developed. Results show that the provincial positive margin rate has decreased by over 10% and been sustained over time. Ongoing meetings of the provincial group have resulted in identifying other areas for potential improvement (eg. prostate biopsy guideline).

This strategy has also been adopted in colorectal cancer, thoracic and hepatic, biliary and pancreatic (HPB) cancers. The SOP implemented communities of practice as a mechanism to
connect surgeons across the province to support knowledge transfer and uptake of evidence based guidelines and best practice, establish relationships across LHINs, and facilitate ongoing sharing of knowledge and expertise. Communities of practice in surgery have improved awareness and acceptance of quality surgical initiatives and facilitated implementation across regions [16]

3. IM/IT - Wait Times Information System (WTIS)

The development and implementation of a provincial Wait Times Information System (WTIS) was a key driver behind improving access to surgical cancer services and reducing wait times. Prior to this, there was limited data on how long patients waited for treatment and what the acceptable wait time should be. Waiting lists that did exist were based on older data and managed in paper based format in individual clinician’s offices with hospitals allocating operating room without sufficient knowledge of access. Recognizing the long wait times and lack of transparency and accountability in the system, the Ontario government made this a top priority in 2004 and launched the Wait Times Strategy with the aim of improving access to health care services starting in five priority areas by December 2006: cancer surgery, cardiac surgery, cataract surgery, high and knee total replacement and MRI and CT scans.

CCO was quickly recruited to lead this initiative which included the development of a Wait Times Information Strategy resulting in the development of standardized definitions of wait time waypoints, priority level targets and the implementation of an electronic Wait Times Information System across Ontario [1, 17-18]. Today the WTIS collects accurate, near-real time data, centrally from 3100 clinicians’ offices and 92 hospitals. Given the success of this initiative [19], the WTIS has been expanded to other adult and pediatric surgeries. Further, the system is also being leveraged to capture other wait times along the continuum including the time a patient is referred from their primary care provider to their specialist for assessment (Wait 1), as well as the time a patient receives treatment and is designated to an alternate level of care (ALC) facility to the time of discharge to the ALC facility. While significant progress has been made in a short period of time, there remains work to be done to realize the full potential of the WTIS to effectively manage waiting lists which will require knowledge of wait lists from the level of the surgeon, hospital and region to more appropriately allow the mapping of hospital resources to demand [20]. This work is already underway within the surgical oncology program.

4. Public Reporting

Public reporting of wait times has been an important aspect of the Wait Times Strategy to improve public transparency and accountability in the system and an important lever for performance improvement. Since August 2005, wait times for cancer surgeries and other priority areas have been reported monthly on the Ontario government’s website at the provincial level as well as LHIN and hospital levels by disease site for those centres that receive additional funding to perform increased volumes with comparisons to the provincial targets [4]. Similarly, this data is also reported on CCO’s website as part of the annual reporting of the CSQI [5]. This data allows the opportunity to track trends and is used by hospitals and health system planners for resource planning and allocation. In 2009, CCO began to report on wait times for cancer surgery by priority access targets to more accurately reflect the patient wait time by level of complexity and urgency of need for care. This data shed light on the work that needs to be done to improve wait times for priority 2 and 3 cases and improvements in performance are already starting to be seen. In addition to wait times reporting, quality indicators tied to evidence based standards such as those for colorectal and prostate cancer continue to be reported annually in the CSQI at the provincial and LHIN levels. Hospital and LHIN administrative and clinical
leadership also receive reports on a number of other indicators such as deaths after surgery to evaluate outcomes of surgical interventions and guide effective decision making. Most recently, for the first time, wait times data is now being shared at the level of the surgeon to help regions to monitor performance, assess needs of surgeons and guide appropriate discussions for performance improvement including shifting of patients or resources to balance access issues.

**Figure 12:** Percentage of Cancer Surgeries Completed within Each Priority Target

![Figure 12](image)

Source: Wait Times Information System

**Figure 13:** Percentage of Thoracic (esophageal and lung) Cancer Surgeries Performed in Designated Centres

![Figure 13](image)

Source: CIHI, Discharge Extract Database
REFERENCES


f. PALLIATIVE CARE

i. Background

Palliative care has not received much momentum in Ontario until very recently. Historically, palliative care was provided in a piecemeal fashion by local institutions and providers without notable impact at the system level. The focus of the OCTRF had initially been on improving access to radiation therapy [1,2]. Similarly, this area was not an early priority for CCO as more attention was given to improving access and quality to cancer treatment. As a result, palliative care remained underdeveloped compared to other aspects of cancer control and issues such as lack of integration and coordination, lack of standards around appropriate pain and symptom management, inequitable access to providers and lack of a patient centered approach to care were evident. The evidence shows that over half of cancer patients die in an acute care setting despite evidence that the majority prefer to die elsewhere [3].

Throughout the years, the importance of palliative care across the patient’s journey was recognized both nationally and provincially [4,5]. In 2004, CCO made this an important strategic priority in the Ontario Cancer Plan [6] committing dedicated funding to this area. In the short time that has lapsed, CCO has begun to address some of these gaps through the development of a palliative care strategy and implementation of integrated palliative care programs and standardized patient symptom management tools, such as the Interactive Symptom Assessment and Collection (ISAAC) database, in all 14 LHINs. Ontario is the first province in Canada to use a web-enabled tool to report on cancer patient symptoms. The province is seeing some improvements in terms of the number of people screened and managed using ISAAC as well as in the level of patient satisfaction. In 2009, 57% of lung cancer patients were screened at least once per month, an increase of 20% from the previous two years. Additionally, 40% of all cancer patients are being screened at least once per month.

ii. How did we Improve Quality?

1. Performance Management

Each of the 14 Regional Cancer Programs in Ontario have contractual agreements with CCO to develop a Regional Palliative Care Program that is aligned with the provincial program and submit data to monitor progress. This includes fostering relationships with stakeholders in the field, working with hospitals within their LHIN to develop a comprehensive palliative care program, developing and promoting evidence based standards and collaborative care and symptom management practice guidelines, and fostering the implementation and expansion of ISAAC, an electronic patient symptom management screening system across facilities within their region. Additionally, the Regional Cancer Programs receive stipend funding, to recruit a Palliative Care Lead to develop and implement the palliative care program locally with support from their respective RVP. Each quarter, the Regional Cancer Program is assessed on its performance against these requirements as well as their progress against targets as they relate to use and expansion of the ISAAC screening tool.

2. Clinical & Stakeholder Engagement

a. Palliative Care Strategy

In 2004, CCO submitted a proposal to the Ministry of Health and Long-Term Care to support the implementation of palliative care integration programs across Ontario which was well received.
The first step required the development of a palliative care strategy, the success of which depended on support from other stakeholders in the field. Around the same time, the Ontario government had infused $115.5 million over three years into an End of Life Care (EOLC) Strategy [7]. While CCO focused on palliative care cancer patients, it was recognized that there was a clear overlap with the Ministry’s End of Life Care strategy that focused on end of life care for all patients but also included terminally ill cancer patients which naturally required that the two join forces. The provincial palliative care strategy was shared at a symposium hosted jointly by the Cancer Quality Council of Ontario and Cancer Care Ontario [8] and received endorsement by the palliative care community.

Recognizing the journey of a cancer patient and that appropriate referral and care requires earlier intervention, a more inclusive definition of palliative care was identified that went beyond end-of-life to encompass non-terminal patients as well as a vision that put the patient at the centre of all care decisions [8]:

“Every person, when faced with a cancer diagnosis, has the opportunity to live life fully, to receive timely and appropriate symptom management, to be supported along with his/her family with dignity and respect throughout the course of his/her illness, and in the face of incurable disease, to have the opportunity to live and die in a setting of his/her choice.”

With this vision in mind, the palliative care strategy was informed and validated by the regional palliative care leaders and other stakeholders in the province and included a focus on improving measurement through development of quality indicators, increasing the use of evidence by developing, implementing and disseminating evidence-based guidelines and standards and fostering the development and uptake of tools to increase efficiency.

The CCO palliative care strategy embraces a simultaneous approach to care [9]. A simultaneous approach to care supports the concept of palliative care being applicable early in the course of the disease, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy. This allows for earlier identification, documentation and communication of symptoms, thereby decreasing time to optimal symptom management and if necessary, referral to appropriate members of a multidisciplinary team. A recent study [10] showed the effect of palliative care when it is provided throughout the continuum of care for advanced lung cancer. Early integration of palliative care with standard oncologic care in patients with metastatic non–small-cell lung cancer resulted in survival that was prolonged by approximately 2 months and clinically meaningful improvements in quality of life and mood. Moreover, this care model resulted in greater documentation of resuscitation preferences in the outpatient electronic medical record, as well as less aggressive care at the end of life.

b. Ontario Cancer Symptom Management Collaborative (formerly the Provincial Palliative Care Integration Project)

Launched in 2006 through partial funding from the government, (as the Provincial Palliative Care Integration Project) the Ontario Cancer Symptom Management Collaborative built on the success of the Southeastern Palliative Care Project which utilized evidence based guidelines and standardized tools for patient symptom management, elements that were lacking in other parts of Ontario [11]. Initially expecting interest from only a few regions, this endeavour was widely supported by the community as all 14 Regional Cancer Centres and Community Care Access Centres quickly signed on. A provincial palliative care lead was identified to direct this program from a system level and regional palliative care physician leads and improvement coordinators were identified and embedded in the existing regional structures, End of Life Care
Networks, created by the Ministry to advance the program at a local level, which proved to be crucial to its success.

As the majority of the cancer population are cared for in palliative care teams, and palliative care covers the full spectrum of care involving many providers working within multiple settings from hospitals, long-term care homes, hospices, community care access centres and homes, the care coordination, consistency and continuity become important measures of quality for this population. Palliative care leads worked with palliative care providers to increase knowledge of palliative care and uptake of symptom management guidelines and common tools such as collaborative care plans and for optimal management of patients. The program was initially targeted to all lung cancer patients in Regional Cancer Centres and palliative care patients in the home, but now targets all cancer patients. The IHI’s renowned Model for Improvement and PDSA cycle [12] which outlines a series of steps to identify improvement aims and measures their impact was employed to accelerate change efforts. This process led to the development of provincial targets for appropriate care and symptom management that were linked to the broader strategic goals of the program.

c. Models of Palliative Cancer Care

In 2009, the Palliative Care Program proposed recommendations for the organization and structure of palliative cancer care services in Ontario [13]. The recommendations apply to the regional cancer programs and inpatient hospitals delivering palliative cancer care treatment within Ontario, and address: the types of providers and their roles, education of providers, service type/complexity, service volumes and quality improvement. The main goal of the recommendations is to create sustainable, accessible, quality palliative care and improve patient outcomes. The recommendations were developed to accommodate long-range needs and take into account the projected increase in palliative cancer care treatment over the next decade due to a growing and aging population. More importantly, these recommendations were developed with the goal of increasing accessibility to safe, equitable and quality palliative cancer care across the province that is based on four underlying principles:

- Patient centred care: optimizes outcomes for patients that are patient focused and are based on the patient’s need, as opposed to prognosis,
- Optimal care: optimizes systems and access to services within available resources to provide the best care for the patient that is high quality and safe,
- Interprofessional and intraprofessional collaboration; and
- Coordination and continuity of care

The recommendations are in accordance with the Canadian Hospice Palliative Care Association’s (CHPCA) [9] national principles and norms of practice and Accreditation Canada’s standards for hospice, palliative and end-of-life care services (Accreditation Canada). The recommendations outline three levels of care for the delivery of palliative cancer care treatment [14] [Figure 14]. The role of this document is to provide a framework for regional cancer programs and inpatient hospitals to achieve high quality care and service when delivering palliative care treatment in Ontario.

This report provides a benchmark for palliative care services in Ontario in terms of levels of service, role delineation and palliative care bed allocation. The model will help to define and formalize relationships in and between settings of care, for future health human resource planning in order to provide the appropriate mix of service levels to meet the needs of patients requiring palliative care services. The successful implementation of the model is intended to create sustainable, accessible, quality care and improve patient outcomes.
3. IM/IT - Interactive Symptom Assessment and Collection Tool (ISAAC)

One of the key aspects of this program was the development of an information technology platform, the Interactive Symptom Assessment and Collection (ISAAC) system which utilizes ESAS, a psychometric tool to allow patients to directly report the severity of nine common cancer symptoms on a scale of 0-10 through touch screen kiosks at regional cancer clinics or via phone or the internet at home prior to their clinic visit. Initially, five regional cancer centres had implemented these kiosks while the others administered paper based forms for their lung cancer and palliative care patients which has now been extended to all patients starting in 2008. Presently, all regional cancers use ISAAC kiosks or similar electronic means to capture patient symptom self-assessment scores. The purpose of the ISAAC tool is to enable integration and management of patient symptoms across providers groups and settings and promote early and appropriate referral through patient engagement. Its significance stems from the understanding that the patient self-report is the gold standard. When patients' scores exceed certain parameters, their clinicians are prompted via email to monitor symptoms, such as pain, and functional status over time. Clinicians also have access to patients scores electronically regardless of the setting in which it was completed. The tool has already started to show signs of success. Since implementation in 2007, there have been over 600,000 ESAS assessments [Figure 15]. The results of a patient satisfaction survey showed that 85% of patients thought ESAS was an important tool in helping providers better understand their symptoms and over 60% reported that their pain and other symptoms have been controlled to a comfortable level. Continued efforts are being made to manage patients with uncontrolled morbidity. The ISAAC system is now being adopted by the British Columbia Cancer Agency, to facilitate electronic screening and management of palliative care patients.

4. Public Reporting

Data collection and reporting is a new phenomenon in the domain of palliative care. Historically, performance indicators for palliative or supportive care have been lacking making it difficult to track use of support services and their impact. Through monthly data submissions by the regional centers, CCO has identified quality indicators and can routinely track the number of patients being screened by the ISAAC system and measure regional performance against provincial targets. Like the other programs, this data is reported at a provincial and regional level annually in the CSQI [3] and regions also receive monthly reports back for ongoing monitoring. Additionally, by tracking outcomes such as proportion of deaths in acute care hospitals and visits to the emergency department close to the end of life, it will be possible to determine if integrated palliative care programs are making a difference on improving quality of care and representing patient choice.
Figure 14

Providing Hospice Palliative Care (HPC) in Erie St. Clair – Conceptual Model

- **Description of Patient Need**
  - Requires medical/surgical interventions for issues such as bowel obstruction, etc.
  - Smallest volume of patients.
  - Complex physical, social, psychological, and/or spiritual needs that do not respond to simple or established protocols of care.
  - Requires highly individualized care plans.
  - HPC needs exceed those available from primary care providers.
  - Specific exacerbations of pain and other symptoms.
  - Coping Compromised.

- **Levels of Care/Expertise**
  - **Tertiary Interventions**
    - Clinical expertise in specialty areas (surgery, medicine, etc.)
    - Ideally working in concert with expert in HPC.
  - **Specialist/Tertiary HPC Expertise**
    - Consults to secondary and primary care.
    - Leads in training and advancing HPC.
    - Model of care may be:
      - Consultation only
      - Consultation and follow up
      - Direct care
      - Usually a shared care model with primary care.

- **Level 1 Primary Level HPC Expertise**
  - Requires basic understanding of HPC in order to identify and refer and provide core competencies of HPC.

- **Level 2 Secondary Level HPC Expertise**
  - Requires education in HPC.
  - Support primary providers.
  - Model of care may be:
    - Consultation only
    - Consultation and follow up
    - Direct care
    - Usually a shared care model with primary care.

- **Level 3 Specialist/Tertiary HPC Expertise**
  - Requires to define a patient to create a high level of expertise and create a single level of specialist care.

**Typical Settings of Care**
- Hospital based
- Acute care
- Ambulatory care
- Tertiary Palliative Care Unit

**Patient movement between levels**

Model developed for Erie St. Clair End of Life Care Network (ESOL-N) by Beth Lambe—Oncorad ESOL-N (Sept 2008, revised Dec 2008, Jun 2009)

This model incorporates concepts, design and content from:
- CMHSA Model (CMHC 56).
- Cancer Care Ontario—Regional Models of Care March 2010 (updated to reflect responsibility).  

*Figure 15: Total Number of ESAS Assessments for All Cancers per Month*

Source: Cancer Care Ontario, ISAAC Database

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**g. Psychosocial Oncology**

**i. Background**

Cancer patients may live for many years with the consequences of the disease or side effects of its treatment, and as such suffer social, emotional and psychological distress [1]. This may include permanent damage to physical health, alteration to normal development, emotional or mental health problems [2] or social problems (e.g. financial problems, reduced employment opportunities, stigma of disability, and social/spiritual support concerns). Approximately, 35% of people diagnosed with cancer experience clinically significant distress [3,4]. Families of cancer patients are also affected by the disease of their loved ones, often experiencing emotional distress, shifting of roles, financial burden, caregivers’ distress, and the fear of losing their loved one [5,6]. There is a well established body of evidence demonstrating that psychosocial interventions increase well being, improve adjustment and coping and reduce distress in people affected by cancer [7-10]. In the 2008-2011 Ontario Cancer Plan, CCO identified improving psychosocial care for cancer patients as a strategic priority for Goal #4 of the Plan to improve the patient experience along every step of the cancer journey and launched the provincial Psychosocial Oncology Program.

**ii. How did we Improve Quality?**

1. **Performance Management**

   Each of the 14 Regional Cancer Programs in Ontario has identified regional psychosocial oncology leaders tasked with driving change and innovation at the regional program level. This includes the development and implementation of practice and treatment guidelines; promotion of increased use of evidence and standards; improved measurement of quality standards; building strong collaborations across providers and settings; analysis and quality improvement planning related to results of the Ambulatory Oncology Patient Satisfaction Survey, in particular those areas related to symptom management and emotional support; development of process improvement related to ISAAC results i.e., referrals and interventions to respond to symptom distress; and the implementation of symptom management guides into practice.

2. **Clinical & Stakeholder Engagement**

   a. Psychosocial Oncology Program

   The vision of the Psychosocial Oncology Program is to provide psychosocial oncology services that will improve the patient experience through timely access to quality psychosocial oncology care and to reduce psychosocial morbidity related to unmet physical, emotional, practical and spiritual needs that may include but are not limited to distress, depression and anxiety. The vision of the Program was informed and validated by the provincial and regional psychosocial oncology leaders. The Program is focused on identifying, assessing, and addressing gaps in quality and access to psychosocial services for cancer patients.

   b. Evidence Based Standards

   Psychosocial oncology is an important aspect of cancer care [11, 12] and emotional distress, which is common in cancer patients, has been accepted as the sixth vital sign [11]. The Program partnered with the Program in Evidence Based Care to develop a series of guidelines to improve psychosocial care for cancer patients including guidelines on: depression;
communication; advance care planning; the adaptation of the Institute of Medicine’s (IOM) standard: Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs; and the adoption of national guidelines on the assessment of psychosocial needs for adults with cancer [13-17]. The guidelines are being used to develop performance indicators; to improve timely access to quality psychosocial oncology care and to reduce psychosocial morbidity among cancer patients and their families.

3. Measuring the Patient Experience

Since 2004 CCO has been measuring the patient experience in the outpatient setting through the Ambulatory Oncology Patient Satisfaction Survey (AOPSS). In 2009, 97% of outpatients who responded to the survey expressed a high degree of satisfaction with the care they received in the previous six months [18]. When asked to rate specific domains of care, 80% of patients indicated that health professionals showed respect for their preferences and decision making, while 79% said they were satisfied that their physical comfort was addressed. These two domains continue to have the highest ratings among the various domains of care [Figure 16]. For the first time, patients were asked about their perception of the safety of the care received and 98% of respondents rated the overall safety of their care highly. Emotional support has been a weak spot that continues to receive substantially lower scores than the other dimensions. Emotional support, rated as satisfactory by just over half (53%) of patients. Nonetheless, two areas rated quite positively: 72% of patients believed that the oncology provider went out of their way to help and 72% patients felt that they were told of their diagnosis in a sensitive manner. However, only 42% of patients reported that they received enough information about emotional changes resulting from cancer, and 46% reported not being informed adequately about potential changes in sexual activities. However, only a portion of patients actually responded to these two questions about changes in emotions or sexual activities. Similarly, only 45% said they were referred to professionals who could help them work through their anxiety and fear. Emotional support plays a crucial role in ensuring quality of life for those undergoing cancer treatment. For example, the majority of lung cancer patients who completed the Edmonton Symptom Assessment Scale (ESAS) at a regional cancer centre at the end of 2009 reported having symptoms of mild, moderate, or severe depression.

4. Public Reporting

The AOPSS is currently administered once a year to all regional cancer centres, including the developing centres (Niagara, Sault, RVH, Southlake). Results of the AOPSS are reported at a provincial and regional level annually in the CSQI. Regional Vice Presidents review and respond to data reports of AOPSS results for their centre. A review of the theoretical/conceptual literature indicates that the AOPSS does, in fact, reflect the “state of the art” in terms of capturing appropriate dimensions of the patient experience by measuring the 6 recommended dimensions of the patient experience – physical comfort, education/information needs, psychosocial/emotional support needs, respect for patient preferences, coordination and continuity of care, and access to care. By routinely measuring the patient experience CCO plans to raise the level and quality of psychosocial care for cancer patients thereby increasing the cancer patient experience.
Figure 16: Patient Satisfaction Rating on various Dimensions of Care for Outpatient Cancer Services

Source: Cancer Care Ontario, Ambulatory Oncology Patient Satisfaction Survey
REFERENCES


**h. Oncology Nursing**

**i. Background**

The specialty of oncology nursing is an essential component of health care services across the cancer continuum. Nurses in all practice settings are involved with the process of cancer care: prevention, detection, treatment, rehabilitation, recovery and palliative care. CCO established an Oncology Nursing Program with provincial and regional leadership with infrastructure support. The Vision of the Oncology Nursing Program is working collaboratively to advance cancer control through excellence in oncology nursing. The Oncology Nursing Program supports Ontario nurses to enhance excellence in oncology nursing practice, education, research and leadership. The Oncology Nursing Program is committed to: reducing variation in practice; improving the patient experience; building competency in oncology nursing through the use of evidence-based guidelines and standards; broadening the development and use of provincial standards and guidelines; increasing system capacity and access, advancing the coordination and focus of cancer research efforts in Ontario, optimizing advanced practice nursing roles and piloting new roles, building oncology nursing communities of practice to facilitate uptake of guidelines and standards, and identifying further opportunities for innovation, working with regional partners.

**ii. How did we Improve Quality?**

1. **Clinical & Stakeholder Engagement**

   a. **Evidence Based Standards**

   Partnering with the Program in Evidence Based Care (PEBC) the first nursing guideline was developed and published on the CCO website that focused on the management of central venous access devices in the cancer population [1,2]. An interdisciplinary working group led by nursing in partnership with PEBC developed the Cancer-Related Pain Management Guideline [3,4]. Nursing partnered with PEBC and the Systemic Treatment Program to develop two guidelines related to safety:

   - Safe Handling of Cytotoxic Agents (focused evidence to reduce staff exposure to chemotherapy in preparation and administration [5,6]
   - Safe Labeling of Chemotherapy (focused on minimizing the risk of error in medication delivery); [7,8].

   Both guidelines have been published in the literature. The Nursing Program worked in partnership with the Palliative Care Program on the development of Symptom Guides to Practice and Algorithms that focused on symptoms identified by patients through the use of the screening tool, ESAS (Edmonton Symptom Assessment System); or identified as problematic symptoms in home care or inpatient care (Delirium; Nausea and Vomiting unrelated to treatment).

2. **Education and Mentorship**

   To meet the complex care needs of the cancer patient population by developing nurses with the specialized knowledge and clinical experience to manage and care for cancer patients, the Ontario Ministry of Health and Long-Term Care established the de Souza Institute in 2008 with
$15 million in funding over 5 years (de Souza Institute http://www.desouzanurse.ca/index.shtml). CCO, the University Health Network and Princess Margaret Hospital are partners in the Institute that aims to provide specialized education for new graduates and nurses working in a variety of settings, including Public Health, screening programs, cancer programs, hospitals, home care/community agencies and hospice/palliative care. The Institute is the first of its kind in Canada, and its mandate is to develop, implement and evaluate innovative education, clinical fellowships, scholarships and mentorship programs for nurses to build capacity to meet the increasing incidence projected in the next 10 years.

The deliverables over the five years are to:

- Prepare 120-60 nurses to write the Canadian Nurses Association Certificate exam in Oncology or Hospice Palliative Care
- Develop programs for at least 1,000 Ontario nurses to participate in oncology nursing continuing education programs
- Train 50-80 new oncology nurse educators in communities across Ontario
- Ensure five per cent of new Oncology Certified Nurses are enrolled in a Masters program to prepare more Advanced Practice Nurses in Oncology

The de Souza Institute also provides a Mentorship Program that builds on a successful Mentorship Program launched for advanced practice nurses (APNs) in 2007 by the Ontario Oncology APN Community of Practice, CCO and the School of Nursing at McMaster University. With the support of the de Souza Institute, the program has been expanded to all Ontario nurses who care for patients and families at risk for or affected by cancer. This includes nurses involved in a variety of cancer related services such as: cancer prevention; early detection and screening; treatment; survivorship; and palliative and end-of-life care.

3. Investments in Health Human Resources

Canada currently recognizes two types of Advanced Practice Nurses (APNs): Clinical Nurse Specialists and Nurse Practitioners. There are over 100 oncology APNs in Ontario presently working in a variety of practice settings [9]. Oncology APNs enhance nursing practice and care delivery through the integration of knowledge and skills across five role dimensions, including: direct clinical care, research, education, organizational leadership and professional and scholarly development [10]. Research shows an impending demand for at least 150 new oncology APNs over the next five years – more than double the current oncology APN labour force in Ontario [10-12]. While there is substantial evidence supporting the effectiveness of APN roles on patient, provider and health systems outcomes, tools and resources are needed in order to plan for, recruit, implement and retain oncology APN roles more effectively [13, 14]. As a result CCO partnered with McMaster University, Laurentian University and the regional cancer centres in Sudbury and Hamilton to develop a Toolkit to guide health care planners, providers, administrators, managers, nursing leaders, APNs and policy makers from the point of defining their patient population and current model of care through defining a new model of care and implementing an APN role [9]. This project applies the PEPPA Framework, a participatory, patient-centered, evidence-based process that engages stakeholders in developing and evaluating APN roles [11].

CCO and the Ontario Ministry of Health and Long-Term Care (MOHLTC) have a partnership to implement a two year innovative pilot program to pilot a new role utilizing Registered Nurses (RNs) to assess patients, and implement Flexible Sigmoidoscopy to determine the presence of colon polyps, if patients meet the screening criteria. This inter-professional care model utilizes
RNs and physicians working inter-dependently to provide a valuable and under-utilized screening method for colorectal cancer detection. The statistics show that colorectal cancer screening rates need to be improved significantly as only 20% of the average risk population in Ontario are currently being screened. The ultimate goal of this program is twofold: to increase colorectal cancer screening rates for the Ontario population and to test the feasibility of RN-performed flexible sigmoidoscopy to enhance screening capacity.

The diagnostic phase of cancer care is an anxious time for patients. Patient navigation is a way of assisting and supporting individuals during this time. Gilbert et al., [15] conducted a review to explore patient navigation and its role in the diagnostic phase of cancer care. Patient care during the diagnostic phase requires various levels of navigation, according to individual informational, physical and psychosocial needs. Identifying those individuals who require more support - whether physical or psychosocial - during the diagnostic phase is of critical importance. In a new pilot project, seven specially trained registered nurses have been introduced in Diagnostic Assessment Programs throughout Ontario. Their main role will be to improve Ontario patients’ experience as patients undergo diagnostic assessment and testing for cancer. The purpose of this work is to build capacity in patient navigation in the diagnostic phase and to fully evaluate the role of nurses as navigators to improve the patient experience. Through a partnership with the de Souza Institute, a training course has been developed in patient navigation, designed to address the full continuum of cancer care, with a particular emphasis on the diagnostic phase. The Patient Navigation Project is being supported by the Ministry of Health and Long-Term Care, Nursing Secretariat and the Canadian Partnership against Cancer.

These roles and the evaluation of their effectiveness to improve the patient experience are critical as CCO develops new models of care to ensure the right provider for the right patient at the right time along the cancer journey.
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i. Patient Education

i. Background

Patient education is considered an essential component of patient care. Patient education provides patients with the information they need to actively participate in making decisions about their care throughout the course of their illness. Research has shown that effective patient education enhances patients’ knowledge and understanding of their disease and its treatment [1,2], while also improving treatment compliance [3] and symptom management [4], ability to cope, autonomy and confidence in the ability to self-manage their illness [5-7] and overall satisfaction with care [8-9]. There is also evidence that a well coordinated, programmatic approach to the delivery of patient education positively affects other areas including the use of health resources [10-12].

Formed in 2006/07, the Patient Education Program (PEP) aims to develop systems and frameworks for strengthening the delivery of cancer patient education across Ontario. The PEP is comprised of a Provincial Program Head and representatives from each of the Regional Cancer Programs. The work of the PEP work is rooted in the framework document “Establishing Comprehensive Cancer Patient Education Services: A Framework to Guide Ontario Cancer Education Services: Executive Summary”, published in 2006 by the PEP and CCO’s Program in Evidence-based Care. This document outlines nine components necessary to a Regional Cancer Patient Education Program. The document serves as the context for the PEP main program activities of capacity building within Regional Cancer Programs, stakeholder engagement and the current emphasis on expanded regional engagement.

ii. How did we Improve Quality?

1. Performance Management

The PEP is working to improve system competency across Ontario by developing, implementing and measuring the use of a framework to guide a programmatic approach to patient education throughout the 14 regions of Ontario. The Regional Cancer Programs were surveyed for uptake of the components of the framework document in 2007 and 2009. In 2007, while 100% of respondents were committed to developing a Patient Education program aligned with the framework, only six regions had established such a program with a Patient Education leadership position as compared with 2009, when nine regions have established a Patient Education program with a Patient Education leadership position. Since 2007, there has been an across the board increase in the patient education programming offered in the Regional Cancer Programs covering the following topics: patient orientation, general cancer information, treatment, rehabilitation, psychosocial support and clinical trials. While progress has been made, results for 2007 and 2009 cite lack of financial resources as a key barrier to full implementation of the framework.

2. Clinician Engagement

While health providers are good at managing their patients’ treatment and side effects, survey results suggest they need to improve their ability to determine what is important to patients. A course called "Maximizing Your Patient Education Skills" (MPES) was designed to help health
providers understand patients’ learning needs and communication styles, identify their preference for receiving information about their disease and care plans, and adopt a patient-centred approach to delivering education to patients and their families.

A train-the-trainer program was developed and training was provided to patient educators in each of the 14 regions, with the goal of implementing this skill-based competency program across all Regional Cancer Programs. A multi-site study in 2009 found that oncology healthcare providers’ knowledge of patient education theory, self-assessed competencies and skills was significantly improved after participating in this brief problem-focused and interactive workshop [13]. Efforts are now under way to further develop the MPES curriculum and to explore new technologies to deliver the program to a larger audience. CCO is working in collaboration with Toronto’s University Health Network and the de Souza Institute to convert part of the course into an online module, increase training and delivery capacity of the curriculum within the regions and deliver the workshop in all 14 regions.

3. Public Reporting

Results from the Regional Cancer Program survey conducted in 2007 and 2009 were reported in the 2010 Cancer System Quality Index (CSQI). The Regional Cancer Programs are set to be resurveyed in 2011 and the results could be included in a future CSQI.
REFERENCES


