Disease Pathway Management
Colorectal Cancer

The cancer journey
Better cancer services every step of the way

Draft Report
Regional Engagement Visits
2010
Executive Summary

In the following pages of this report we outline Cancer Care Ontario’s Disease Pathway Management process for the identification of priorities for action across all phases of the cancer journey, concentrating in this case on colorectal cancer. We address each phase of the colorectal cancer journey describing (and wherever possible providing data on) the current state of Ontario’s cancer system to develop the case for action.

We list the priorities for action for each journey phase (and transition between phases) identified by the Colorectal Cancer Team (CRCT) and validated by the broad range of participants at the Colorectal Cancer Symposium. Finally, we describe examples of initiatives underway at CCO and within the regional cancer programs that address some of the key priorities for action. The initiatives described are not meant to represent an all-inclusive list, nor are they intended to address all priorities for action, but are meant as examples to encourage further action throughout the province. We provide contact information for the leaders involved in each initiative that we describe throughout the document and in Appendix B.

This report represents one part of Cancer Care Ontario’s regional engagement strategy associated with colorectal cancer disease pathway management. The second major component of the strategy is a set of regional engagement sessions that we are planning with clinicians and cancer program administrators from across province. These sessions are meant to link the priorities for action and some of the initiatives underway described in this report, with the current state and specific needs of each regional cancer program. We will present region-specific colorectal cancer data for each phase of the cancer journey and lead discussions around the priorities for action most relevant to a specific region and explore tailored regional solutions. The discussion will be focused on identifying opportunities rather an evaluation of current performance.

We hope that we clearly describe the case for action in improving colorectal cancer care, the excellent progress that has been made, and the outstanding work available to build upon.

Please do take the opportunity to either contact your colleagues listed in this report or the disease pathway management team, as your region moves toward implementing initiatives to further improve colorectal cancer care across the cancer journey.

Thank you.

We look forward to continued and accelerated progress toward improving all aspects of the colorectal cancer journey.

The Colorectal Cancer Team Leadership.

Andy Smith, CRCT Chair  Amanda Hey, CRCT Vice-chair  Raquel Shaw Moxam
Cancer Care Ontario, Acting Director, Clinical Programs, Disease Pathway Management Secretariat

The Colorectal Cancer Team would like to thank Cindy Nhan from Cancer Care Ontario, for her dedicated support in the preparation of this report and our regional engagement strategy.
Specific Objectives of this Report:

1. Provide a call to action
   - Describe the current Ontario colorectal cancer context
2. Set focus on discrete areas with urgent need for action
   - Describe priorities for action identified by colorectal cancer Disease Pathway Management team
3. Provide examples to build upon
   - Describe selected initiatives aimed at improving identified priorities

Objectives of Companion Regional Engagement Strategy

1. Discuss select region-specific data for each phase of the colorectal cancer patient journey in a provincial context
2. Suggest specific opportunities for collaboration and action
   - Describe potential improvement initiatives for each stage of the colorectal cancer journey
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Section 1: The Colorectal Cancer Call to Action

Colorectal cancer is Ontario’s third most commonly diagnosed cancer...
An estimated 8100 Ontarians were diagnosed with colorectal cancer in 2009. This represents an estimated 12% of all new cancer diagnoses in the province. Colorectal cancer is the third most commonly diagnosed cancer behind prostate cancer (17%) and breast cancer (13%).

…and Ontario’s second leading cause of cancer death...
An estimated 3300 Ontarians died from colorectal cancer in 2009. This represents approximately 12% of deaths due to cancer in the province, with only lung cancer accounting for more deaths (25%). Breast and prostate cancer account for 8% and 6% of cancer deaths respectively.

…but there appears to be an opportunity for improvement.
When detected early there is an estimated 90% likelihood of curing colorectal cancer. Yet, Ontario’s current relative 5-year survival rate is only 63%.

The Ontario incidence and mortality statistics alone provide a compelling case for the need to continue to improve colorectal cancer prevention and care in the province. A second and perhaps equally important reason to focus on colorectal cancer is the excellent progress that has taken place in Ontario over the past decade.

- A 9% improvement in five-year survival rate over the past decade.
- Continued increases in the number of people screened for colorectal cancer through the joint Ministry of Health and Long Term Care and Cancer Care Ontario (CCO) ColonCancerCheck program
- The implementation of quality improvement initiatives aimed at achieving better outcomes (e.g. increased lymph node retrieval and decreased surgical positive margins rates)

The above are a few examples of the progress being made across the province. The disease pathway management approach to colorectal cancer described in this report aims to identify and encourage actions that further improve colorectal cancer care. Regional opportunities to participate in activities that address key priorities for action are described throughout the remainder of this report.
The continuum of cancer care from prevention and screening, through diagnosis and treatment, on to survivorship or palliative care differs greatly from one type of cancer to another. The disease pathway management (DPM) approach brings together patients and disease-focused experts spanning all aspects of the continuum of care to map the patient journey, evaluate system performance, and develop an integrated program. It is aimed at improving:

- Quality of care
- Efficiency of processes
- Overall patient experience

These focus areas make CCO’s disease pathway management strategy a key program aligning with goal #5 of the Ontario Cancer Plan — Improving the performance of Ontario’s cancer system.

Colorectal Cancer was first in the Disease Pathway Management Sequence.

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**Year 1** – Pathway development, intense team and external stakeholder gap analysis and priority setting

**Year 2** – Pilot projects, evidence-based guideline development and regional engagement

**Year 3** – Dissemination and implementation of high impact projects and guidelines
In February 2008, the Colorectal Cancer Team (CRCT) consisting of 28 clinicians, patients and system stakeholders was formed under the leadership of Dr. Andy Smith and Dr. Amanda Hey. Great care was taken to select a geographically diverse, multidisciplinary team with varying experience and expertise spanning the entire colorectal cancer journey (see Appendix A for the CRCT membership list).

The team engaged in four day-long meetings aimed at:
- Mapping the colorectal cancer journey
- Identifying, selecting and ranking priorities for action

The efforts from the first year of the CRCT culminated in a symposium of diverse colorectal cancer stakeholders held in December 2008. The goals of the symposium were:
- To exchange knowledge on disease pathway management with emphasis on the colorectal cancer patient journey
- To solicit feedback on the priorities for action identified by the CRCT, expanding the inventory of priorities as required
- To build upon the work of the CRCT in establishing a collaborative agenda for colorectal cancer system improvements in quality, processes and patient experience

Never before had such a broad group of colorectal cancer stakeholders with an ability to influence all phases of the colorectal cancer journey been assembled. Participants included:
- Colorectal cancer focused patient advocacy groups and non-governmental organizations
- Health service researchers
- Clinicians (representing all areas of colorectal cancer care)
- Hospital and Regional Cancer Centre administrators
- Representatives from the Ministry of Health and Long-term Care

The Colorectal Cancer Symposium brought together over 125 Ontario stakeholders to develop a collaborative agenda to improve colorectal cancer care.

Section 2: Putting DPM into Perspective (cont’d)

“...a cancer system that engages the spectrum of health care providers and draws upon the depth and diversity of their professional experience and perspective to map out a seamless system will ultimately enhance the patient journey.”

Dr. Amanda Hey, Clinical Lead, Preventive Oncology and Screening, Hôpital régional de Sudbury Regional Hospital Regional Cancer Program
One of the main objectives of the Colorectal Cancer Symposium was achieved with the validation of a series of priorities for action. The priorities are outlined below. The figure indicates the phase (or transition point) in the colorectal cancer journey with which each priority aligns.

After the first year, CRCT membership continues to engage on specific initiatives.

Since the Colorectal Cancer Symposium, work has been underway (both provincially and regionally) aimed at addressing several of the validated priorities for action. Individual members of the CRCT have been instrumental contributors to (and often leaders of) this important work. Examples of this work are described throughout the report.

Since it has been just over one year since the Colorectal Cancer Symposium, we saw this as an opportunity to follow-up with a progress update. This report is part of the kick-off of a colorectal cancer regional engagement strategy, during which we will hold special sessions presenting region-specific data to build the case for regional action on the key provincial and region-specific priorities related to colorectal cancer.
Section 3: Prevention

Case for Action on Prevention

Approximately 8100 Ontarians were expected to be diagnosed with colorectal cancer in 2009, making it Ontario’s third most commonly diagnosed cancer. In 2009, an estimated 3300 expected deaths were attributable to colorectal cancer, making it Ontario’s second leading cause of deaths due to cancer.

Many CRC risk factors are modifiable and shared with other cancers.
Colorectal cancer shares the same modifiable risk factors with many other cancers and several other chronic diseases, such as:
- Diet—low in fibre, high in red or processed meats
- Sedentary lifestyle
- Obesity
- Excessive alcohol consumption

Priorities for Action on Prevention identified by CRCT
Through the efforts of CCO’s Prevention and Screening Program and Aboriginal Cancer Care Unit, regional public health units, community organizations, and regional hospital and institutions, work in the prevention domain is well underway. Although population-level improvements in these modifiable behaviours were recognized as being extremely important, the CRCT did not identify specific priorities for action in this area.

Examples of Initiatives Underway Addressing Prevention Issues

Aboriginal Cancer Care Unit program aims to increase awareness and to help prevent colorectal cancer.

Since the late 1960s, the incidence of colorectal cancer among Aboriginal (First Nations, Inuit, Métis) people has more than tripled. The risk of developing colorectal cancer among male Aboriginals is now higher than the Ontario average. Rates of modifiable risk factors including: smoking, obesity, and alcohol consumption, have been increasing among Aboriginal Ontarians and are now higher than rates for non-Aboriginal Ontarians. Aboriginal people also face distinctive health challenges which have resulted in lower screening rates, limited access to screening and cancer services, poorer health outcomes and survival rates.
Erie St. Clair program targets employee improvement in modifiable cancer risk factors.

In Fall 2008, Erie St. Clair Regional Cancer Centre launched a structured pilot program, *Your Health Matters*, designed as an education and cancer screening referral program aimed at encouraging their employees to improve their modifiable cancer risk factors.

The program consists of various tools to assist participants in monitoring progress against key risk factors, such as:

- An initial risk assessment survey
- A prevention and screening resource booklet
- A personalized tracking card for both modifiable risks and screening programs

This initiative fills an important knowledge gap, as 40% of participants indicated that they would not have received prevention information outside of this program, and only 53% of participants stated that they had discussed personal risk factors and screening options with their health care providers. As part of the program evaluation strategy, a six-month matched outcome survey was conducted to assess the program’s progress. The survey results revealed 35% of participants learned they were due for FOBT screening with 50% completing the testing in the subsequent 6 months.

For further information, please contact Elizabeth Dulmage, Manager, Prevention and Screening, Erie St. Clair Regional Cancer Program at elizabeth_dulmage@wrh.on.ca.

Cancer Care Ontario has developed a toolkit promoting Screening and Prevention in the workplace.

This toolkit includes resources such as posters, fact sheets and an interactive game for health promoters practicing in the workplace setting. The materials promote cancer prevention behaviours and raise awareness of screening. For additional information on these complementary resources: www.cancercare.on.ca/workplacetoolkit
ColonCancerCheck – the first program of its kind in Canada.

Launched in 2008, ColonCancerCheck is a province-wide, population-based colorectal screening program. It is the first cancer screening program of its kind in Canada, and is a joint effort between the ministry and CCO. Colorectal cancer is the second deadliest cancer in Canada. Ontario has one of the highest rates of colorectal cancer in the world, and thousands of men and women die from colorectal cancer each year. Yet, if detected early 90% of colorectal cancer cases are estimated to be curable.

For the two-year period prior to the launch of the ColonCancerCheck Program, Ontario’s colorectal cancer screening rate was under 17% for the population between the ages of 50-74. Between 2006 and 2007, Fecal Occult Blood Test (FOBT) screening rates increased by nearly one-third to 24%. More recent data will be presented in the ColonCancerCheck annual report, which will be released in the Spring of 2010.

Ontario CRC screening rates are improving in Ontario.

Population modeling has shown that screening with FOBT saves lives. As depicted in the adjacent figure, screening 50% of the eligible population is expected to save over 3000 lives in Ontario by 2025.

Ontario targets an FOBT screening rate of 40% of the eligible population by 2011. Even the highest performing Local Health Integration Network (LHIN) had not yet reached this target by 2007 (27% screening rate), with the lowest performing LHIN having a screening rate of less than half of the target rate in 2007 (18%).
Priorities for Action on Screening Identified by CRCT

Given the high impact that colorectal cancer screening has on patient outcomes, the CRCT identified several priorities for action associated with the screening phase, and screening to diagnosis transition of the cancer journey, such as:

- Improving FOBT screening rates
- Improving colonoscopy access processes
- Improving FOBT and colonoscopy quality

Examples of Initiatives Underway Addressing Screening Issues

Program uses technology and works with family physicians to increase colorectal cancer screening rates.

In October 2009, the ColonCancerCheck program reached another level through the first release of InScreen, an innovative IT solution enabling the proactive identification of over three million Ontarians eligible for colorectal cancer screening.

In addition to identifying eligible Ontarians, this technology is used to invite them to discuss colorectal cancer screening options with their family physicians, to remind them when they are due for screening, and to notify patients of screening results. In 2009-10, invitations were sent to the rosters of 100 family physicians. It is expected that this will increase to rosters of 1000 family physicians in 2010-11.

Furthermore through InScreen, the program is able to generate screening activity reports for physicians enabling them to better manage their performance in terms of practice level screening rates and in terms of identifying individuals who are due for screening or who may have been lost to follow-up.

These interventions are expected to increase screening rates, leading to earlier detection of colorectal cancer and ultimately to better patient outcomes.

For further information, please contact Marnie MacKinnon, Director of Policy and Planning for Prevention and Screening, Cancer Care Ontario at marnie.mackinnon@cancercare.on.ca.
**Section 5: Diagnosis**

**Case for Action on Diagnosis**

*The pre-diagnosis phase of the cancer journey is often fraught with uncertainty and stress.*

The time between the discovery of an abnormality, or the experience of symptoms by a patient, and the diagnosis of cancer is a time of uncertainty and stress. Patient interviews and focus groups indicate that this phase of the cancer journey would be a difficult time, even with a near perfectly coordinated system. Difficult entry into the system, extended colonoscopy and imaging wait times, and the less than transparent diagnostic pathway that can sometimes characterize colorectal cancer diagnosis, can exacerbate these feelings.

Although ColonCancerCheck is creating a screening pathway into the diagnostic system, currently, the majority of colorectal cancer cases are first identified when a patient presents to a health care provider with signs or symptoms. This poses two main challenges:

- CRC signs/symptoms are complex and it can be difficult to predict what is urgent and needs referral
- Many diagnostic processes are used to investigate symptoms; some are more predictive than others

**Priorities for Action on Diagnosis Identified by the CRCT**

The CRCT recognizes these challenges, and has identified several priorities for action aimed at improving the diagnostic phase of the journey and the transition to treatment for patients diagnosed with cancer, such as:

- Measuring and shortening the time to diagnosis.
- Standardizing reporting of diagnostic imaging.
- Expanding and improving multidisciplinary case conferences.
- Establishing staging standards.

**Examples of Initiatives Underway Addressing Diagnosis Issues**

*Primary care referral guidance aims to streamline suspected colorectal cancer patient entry to cancer system.*

Primary care providers often assess a full spectrum of ailments in a variety of patients; however, it is likely that they only see a small number of patients suspected to have colorectal cancer. Furthermore, the signs and symptoms of colorectal cancer can be subtle and not necessarily specific. Cancer Care Ontario, through its Regional Primary Care Network, has engaged Ontario and international family physicians and specialists to create a set of evidence-based guidelines for family physicians and primary care nurse practitioners to refer to when they are suspicious that a patient may have colorectal cancer. These guidelines specify:

- Which signs and symptoms warrant referral
- Which investigations would be helpful
- Within what timeframe a consult with a specialist and a definitive diagnosis should occur

For further information, please contact Dr. Cheryl Levitt, Provincial Primary Care Lead, Family Practice Program, Cancer Care Ontario at cheryl.levitt@cancercare.on.ca.
Structured diagnostic assessment programs aim to streamline colorectal cancer diagnostic testing.

In order to improve access to better and more rapid diagnosis of colorectal cancer, CCO and the ministry are funding and supporting implementation of diagnostic assessment programs (DAP) in each region of the province. The main goals of the DAPs are to improve patient outcomes, improve diagnostic services and improve patient experience. The components of these programs are described in the figure below.

A piece of work underpinning the development of DAPs is the development of standard diagnostic pathways. Many members of the CRCT have dedicated time to the development of draft pathways that are currently undergoing consultative review.

Over the coming years, the Regional Cancer Programs will work with CCO to plan, implement and evaluate colorectal cancer DAPs. In some regions, work is already underway. In October 2007, the Ages Cancer Assessment Clinic at the Ottawa Hospital began its regional diagnostic program for colorectal cancer. Achievements in the early stages of this program include: reduced wait-times, fewer required visits, reduced duplication of tests, and improved transitions from screening and into the cancer centre for treatment.

For further information on diagnostic assessment programs, please contact Melissa Kaan, Program Manager, Diagnostic Assessment Program, Cancer Care Ontario at melissa.kaan@cancercare.on.ca.

For further information on the development of colorectal cancer diagnostic pathways, please contact Nathalie Assouad, Program Manager, Disease Pathway Management, Cancer Care Ontario at nathalie.assouad@cancercare.on.ca.

Three main components of the DAP program

1. **Diagnostic Processes**
   - Reduce diagnostic wait times
   - Increase diagnostic volumes
   - Coordinate diagnostic processes
   - Reducing system waste

2. **Electronic Pathway Solution**
   - Reduce anxiety & confusion
   - Increase access to service
   - Increase system efficiency
   - Increase capacity to properly manage patients with suspicion of cancer

3. **Diagnostic Wait Times**
   - Validate the diagnostic wait times parameter
   - Develop cancer system indicators to monitor access & quality of care in diagnostic phase
   - Develop priority levels for testing

*Improve the patient experience, improve patient outcomes & quality of cancer diagnostic services*
The use of a clinical synoptic report can facilitate communication between physicians. Synoptic means “summarized” and refers to presentation of information in a tabular rather than narrative form. Synoptic reports not only help to ensure completeness, but also consistency in reporting. Implementation of pathology synoptic reporting is underway across the province of Ontario. Complete, accurate and easily understandable pathology reporting is critical to diagnosing cancer, determining treatment options and assessing quality of treatment.

For further information, please contact Dr. John Srigley, Provincial Head of Laboratory Medicine and Pathology, Cancer Care Ontario at jsrigley@cvh.on.ca.

Magnetic Resonance Imaging (MRI) reporting is the most accurate widely available imaging modality for rectal cancer staging and pre-operative planning. Currently, synoptic reporting for MRIs is not used in Ontario. As a result of keen interest of the Colorectal Cancer Surgery and Pathology Champions, a project led by Dr. Erin Kennedy of University Health Network is in the process of developing a synoptic MRI report for primary rectal cancer that can eventually be implemented across Ontario. This project is being funded through an innovation grant provided by the Cancer Services Innovation Partnership (CSIP), a collaboration between the Ontario Division of the Canadian Cancer Society and CCO.

Further opportunities to participate in this important work exist. For further information, please contact Erin Kennedy, University Health Network at erin.kennedy@uhn.on.ca.

Recognizing the critical role that imaging plays in the diagnosis and treatment planning for colorectal and other types of cancer, CCO has established the Cancer Imaging Program. This new addition to the clinical programs portfolio is led by Dr. Julian Dobranowski, who is currently refining a program work plan and selecting regional leads.

For further information, please contact Dr. Julian Dobranowski, Provincial Head of Cancer Imaging Program, Cancer Care Ontario at julian.dobranowski@cancercare.on.ca.
Section 6: Treatment

Case for Action on Treatment

It is widely acknowledged that adequate preoperative assessment (primarily staging) leads to optimal treatment. Pathology reporting is also important in patient prognostication and in guiding adjuvant treatment. In the case of colorectal cancer, patients with curable disease generally undergo surgery. Adjuvant radiation treatment and chemotherapy is often used to complement treatment and can lead to better outcomes. Through ColonCancerCheck and advances in population screening, the number of colorectal cancer patients eligible for surgery with curative intent is expected to increase over the coming years. In fiscal years 2004/05 to 2005/06, over 8500 colon and rectum cancer resections were performed in Ontario.

Priorities for Action Identified by the CRCT

The CRCT identified several priorities for action in the domain of treatment. These priorities include:

- Developing initiatives to improve surgery quality
- Improving surgery reporting
- Ensuring consideration of adjuvant chemotherapy where warranted
- Developing standardized approach to treating liver metastases
- Providing improved ostomy support

Many initiatives are underway aimed at addressing the priorities, some of which are outlined below.

Examples of Initiatives Underway Addressing Treatment Issues

Regional Pathology and Surgery Champions – a cornerstone of CCO’s colorectal cancer knowledge translation strategy.

With the launch of the Optimization of Surgical and Pathological Quality Performance in Radical Surgery for Colon and Rectal Cancer: Margins and Lymph nodes guideline, a strong and multifaceted knowledge translation strategy has been implemented. The guideline demonstrates the integral link between surgery and pathology in patient care.

Surgery and Pathology Champions were nominated from each region. Their role is to work together to build a multidisciplinary community of practice across the region for colorectal cancer. This is no small task and requires energetic and dedicated individuals. CCO’s Surgical Oncology Program supports the Champions by providing educational slide decks and data from an audit of pathology reports as tools to be used within the regions. The Program also brings the Champions and radiology and radiation oncology representatives together in quarterly meetings; the guidance from these meetings influences and informs the next steps to improving the care of colorectal cancer patients.

Under the leadership of Drs. Robin McLeod, Andy Smith and David Driman important initiatives have resulted from this strategy, including an online multidisciplinary List Serv discussion group involving pathologists, surgeons, radiation oncologists, medical oncologists and radiologists.

For further information, please contact Amber Hunter, Program Manager Surgical Oncology Program at amber.hunter@cancercare.on.ca
Multidisciplinary cancer conferences bring clinicians together to ensure patients get optimal care.

In Multidisciplinary Cancer Conferences (MCCs) groups of clinicians prospectively review individual cancer patients, and make recommendations on best management, keeping in mind that individual physicians are responsible for making the ultimate treatment decision. The primary purpose of the MCC is to ensure that all appropriate diagnostic tests are done, all suitable treatment options are considered, and the most appropriate treatment recommendations are made for each cancer patient. Implementation of MCCs is a priority for CCO.

Under Dr. Frances Wright’s leadership, the team has made significant progress:
- Understanding the state of MCCs in each region
- Setting and monitoring performance targets
- Fostering a community of MCC coordinators to share best practices
- Developing guidelines for determining which colorectal cancer patients would benefit most from a MCC discussion

Evidence shows that for many colorectal cancer patients, outcomes are improved through adjuvant chemotherapy or radiation treatment. Occasionally, there are appropriate reasons for non-guideline-concordant care. Ontario data from the Cancer Services Quality Index (CSQI) showed significant variation in the use of guideline concordant care for adjuvant chemotherapy in 2009. Regular gastrointestinal MCCs represent a way that appropriate treatment recommendations are generated for each cancer patient.

For further information, please contact Amber Hunter, Project Manager, Multidisciplinary Cancer Conferences at amber.hunter@cancercare.on.ca.
Case for Action on Palliative Care

Most palliative care work relevant to all cancer disease sites.

Palliative care and cancer symptom management is a major focus of activity for Cancer Care Ontario across all cancer disease sites. Work in this area directly impacts progress against Goal # 4 of the Ontario Cancer Plan – to understand and improve the patient experience. Much of the work aimed at this important phase of the cancer journey (e.g. the Ontario Cancer Symptom Management Collaborative (OCSMC)) is directed against all disease sites. As such, the CRCT did not have recommendations for priorities for action specific to colorectal cancer. Therefore, this section of the document focuses primarily on survivorship issues.

The overall goal of the OCSMC, led by Dr. Deb Dudgeon and Esther Green, is to promote a model of care that allows for earlier identification, documentation and communication of symptoms, optimal symptom management and coordinated palliative support. This initiative uses CCO’s Interactive Symptom Assessment and Collection (ISAAC) software, which enables cancer patients to record their own symptoms in a standardized manner. The program is also focused on developing standardized tools to aid clinicians in using this patient-reported information to achieve optimal symptom control. The program originally focused on lung cancer patients, but is now used for all cancer patients. There is work underway to identify symptom control issues specific to patients with colorectal cancer by analyzing CRC patient symptom assessment scores in comparison to those of other cancer patients.

For more information, please contact Susan King, Provincial Improvement Coordinator, Ontario Cancer Symptom Management Collaborative, Cancer Care Ontario at susan.king@cancercare.on.ca.

Case for Action on Survivorship

Population of cancer survivors in Ontario is increasing.

In the year 2017, an estimated 83,220 Ontarians are expected to be diagnosed with cancer, which represents a 32% increase compared to 2007. Due to advances in early detection and screening, and improved treatments, people are living longer after cancer diagnosis and treatment. In 2017, over 406,000 Ontarians are expected to be living with a personal history of cancer.

Colorectal cancer survivors make up a large proportion of the survivorship population; this proportion is expected to increase.

Colorectal cancer patients are estimated to comprise between 10% and 12% of people living with a cancer diagnosis. If caught early, 90% of colorectal cancer cases are estimated to be curable. In Ontario, work is underway through the ColonCancerCheck program to improve early detection, leading to an expected increase in the number of colorectal cancer survivors. Colorectal cancer follow-up treatment and survivorship issues will be of increasing importance in the future.

Priorities for Action on Survivorship

The CRCT and other attendees at the Colorectal Cancer Symposium recognized the need for an improvement in care during the time interval following active treatment, but before recurrence of the primary cancer, development of another cancer, or death. For the purposes of this report, we call this phase of the patient journey survivorship.
Examples of Initiatives Underway Addressing Survivorship Issues

Need for guidance on survivorship care for colorectal cancer exists.

For almost all cancers, care during the survivorship period varies across Ontario. Published (and soon to be published) cohort study results from Grunfeld and colleagues demonstrated both overuse and underuse of post-treatment imaging tests and follow-up visits. Furthermore, many people who have received treatment for one type of cancer do not receive recommended screening for other cancers. This variability has several patient, clinician and system consequences. These are described in the figure below.

Although the CRCT and Colorectal Cancer Symposium attendees did not provide advice on specific issues within the survivorship phase of the cancer journey, a survivorship expert panel convened by CCO identified standardizing follow-up care in colorectal cancer as a top priority.

In addition to high variability in follow-up care, some colorectal cancer survivors have unique issues around stomal care. This was also recognized as a priority for action by the CRCT.

Variability of follow-up practice causes issues for patients, clinicians, system

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<td>• Guidelines that exist often variable and open to interpretation, limited guidance on late effects of treatment</td>
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<td>• Care planning and documentation ad-hoc in nature</td>
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<tr>
<th>Patient issues</th>
<th>Limited clarity/understanding of follow-up care ahead</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Risk and long-term impact of follow-up testing</td>
</tr>
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<td></td>
<td>Unclear expectation with respect to late effects of treatment</td>
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<tr>
<th>Clinician issues</th>
<th>Rarely identify recurrence during follow-up, usually symptoms</th>
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<tbody>
<tr>
<td></td>
<td>Limited authoritative guidance for most types of cancer</td>
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<tr>
<td></td>
<td>Reimbursement and time required for care planning</td>
</tr>
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<table>
<thead>
<tr>
<th>System issues</th>
<th>Opportunity and financial cost of unnecessary testing</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>• Many follow-up tests characterized by limited resources (e.g. colonoscopy, imaging)</td>
</tr>
</tbody>
</table>

Effort underway to develop standardize colorectal cancer follow-up care.

There is limited definitive evidence-based and consensus-based guidance on the optimal follow-up regimen for colorectal cancer. This lack of guidance drives much of the variability in practice, as well as the uncertainty felt by patients around colorectal cancer follow-up.

Cancer Care Ontario in association with McMaster University’s Program in Evidence-Based Care has started developing evidence and expert consensus-based follow-up guidelines for colorectal cancer. This guidance will extend to issues such as: the chronic effects of colorectal cancer and related treatments, long-term late effects of treatment, and follow-up visits and testing required to detect potential recurrence. These guidelines will be adapted into clinician and patient tools to assist in the management of life beyond colorectal cancer.

For more information, please contact Dr. Craig Earle, Director, Health Services Research, Cancer Care Ontario at craig.earle@ices.on.ca or Raquel Shaw Moxam, Acting Director, Clinical Programs and Disease Pathway Management, Cancer Care Ontario at raquel.shawmoxam@cancercare.on.ca.
Section 8: Cross Journey Initiatives

Case for Action Across the Entire Cancer Journey

Historically, quality improvements in cancer have been highly functional in nature, aimed specifically at a particular discipline (i.e. radiation treatment or surgery) or a particular phase of the patient journey. In recent years, great strides have been made in the care of colorectal cancer in Ontario, such as a provincial screening program, advances in diagnostics and improved quality of (and options for) treatment, to name but a few. Furthermore, CCO has developed Provincial Programs, notably in psychosocial oncology and patient education, that align with the Ontario Cancer Plan goal of improving the patient experience across the entire cancer journey. One of the main objectives of Disease Pathway Management is to take a similar patient-centred view across the entire journey, but to apply this approach to a specific disease type (in this case colorectal cancer). This enables the team to identify specific priorities for action addressing multiple phases of the colorectal cancer journey concurrently along with the most critical transition points.

Priorities for Action Spanning the Cancer Journey

The CRCT identified several priorities for action spanning the patient journey, which were subsequently endorsed by key stakeholders at the 2008 Symposium. These priorities include:

- Measuring the patient experience – identifying CRC prevalent issues
- Developing and implementing supportive care tools
- Designing and implementing a patient navigation system
- Developing standardized approach to treating liver metastases
- Building provider registries

Example of Initiatives Underway Addressing Cross Journey Issues

Patient navigation has been a hallmark of many successful diagnostic assessment programs across the province. Navigators can include: electronic tools, hospital volunteers, clerical staff and clinicians (primarily nurses) depending on patient needs (i.e. coordination, support, clinical information) and the setting.

In January 2010, the Nursing Secretariat of the Ministry of Health and Long-Term Care in conjunction with Cancer Care Ontario funded seven pilot studies across the province. These pilot studies were aimed at developing and evaluating the role of nurse navigators in the diagnostic phases of colorectal and lung cancer. Although these pilot studies focus on diagnosis (often the most complex phase of the colorectal cancer journey), there is a vision in many of the programs to expand the navigation role to span other phases of the care continuum.

For further information, please contact Esther Green, Provincial Head, Nursing and Psychosocial Oncology, Cancer Care Ontario at esther.green@cancercare.on.ca.
Appendix A

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Cancer Care Ontario
Toronto, Ontario
raquel.shawmoxam@cancercare.on.ca
# Initiative List

<table>
<thead>
<tr>
<th>Phase</th>
<th>Initiative</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prevention</strong></td>
<td>Let’s take a stand against...colorectal cancer</td>
<td>Rina Chua-Alamang Manager, Health Promotion Aboriginal Cancer Care Unit</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:rina.chua-alamang@cancercare.on.ca">rina.chua-alamang@cancercare.on.ca</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alethea Kewayosh Director, Aboriginal Cancer Control</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:alethea.kewayosh@cancercare.on.ca">alethea.kewayosh@cancercare.on.ca</a></td>
</tr>
<tr>
<td></td>
<td>Your Health Matters</td>
<td>Elizabeth Dulmage Manager, Prevention and Screening Erie St. Clair Regional Cancer Centre</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:elizabeth_dulmage@wrh.on.ca">elizabeth_dulmage@wrh.on.ca</a></td>
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<tr>
<td></td>
<td>Screening and Prevention Toolkit</td>
<td>Complimentary resources available:</td>
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<td></td>
<td></td>
<td><a href="http://www.cancercare.on.ca/workplacetoolkit">www.cancercare.on.ca/workplacetoolkit</a></td>
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<tr>
<td><strong>Screening</strong></td>
<td>InScreen</td>
<td>Marnie MacKinnon Director, Policy and Planning for Prevention and Screening Cancer Care Ontario</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:marnie.mackinnon@cancercare.on.ca">marnie.mackinnon@cancercare.on.ca</a></td>
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<tr>
<td><strong>Diagnosis</strong></td>
<td>Primary Care Referral Guidelines</td>
<td>Cheryl Levitt Provincial Primary Care Lead Family Practice Program Cancer Care Ontario</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:cheryl.levitt@cancercare.on.ca">cheryl.levitt@cancercare.on.ca</a></td>
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<tr>
<td></td>
<td>Diagnostic Assessment Programs</td>
<td>Melissa Kaan Diagnostic Assessment Programs Cancer Care Ontario</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:melissa.kaan@cancercare.on.ca">melissa.kaan@cancercare.on.ca</a></td>
</tr>
<tr>
<td></td>
<td>Colorectal Cancer Diagnostic Assessment Pathways</td>
<td>Nathalie Assouad Program Manager Disease Pathway Management Cancer Care Ontario</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:nathalie.assouad@cancercare.on.ca">nathalie.assouad@cancercare.on.ca</a></td>
</tr>
<tr>
<td></td>
<td>Synoptic Pathology Reporting</td>
<td>Dr. John Srigley Provincial Head Laboratory Medicine and Pathology Cancer Care Ontario</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:jsrigley@cvh.on.ca">jsrigley@cvh.on.ca</a></td>
</tr>
<tr>
<td></td>
<td>Synoptic MRI Reporting for rectal cancer</td>
<td>Dr. Erin Kennedy University Health Network</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:erin.kennedy@uhn.on.ca">erin.kennedy@uhn.on.ca</a></td>
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</table>
| **Diagnosis** | Cancer Imaging | Dr. Julian Dobranowski  
Provincial Head,  
Cancer Imaging Program  
Cancer Care Ontario  
julian.dobranowski@cancercare.on.ca |
| | Regional Colorectal Cancer  
Champions | Amber Hunter  
Program Manager  
Surgical Oncology Program  
Cancer Care Ontario  
amber.hunter@cancercare.on.ca |
| | Systematic Review on Indications for  
Liver Resection | Amber Hunter  
Program Manager  
Surgical Oncology Program  
Cancer Care Ontario  
amber.hunter@cancercare.on.ca |
| | Multidisciplinary Cancer Conferences | Amber Hunter  
Project Manager  
Multidisciplinary Cancer Conferences  
Cancer Care Ontario  
amber.hunter@cancercare.on.ca |
| **Palliative Care/ Survivorship** | Ontario Cancer Symptom  
Management Collaborative | Susan King  
Provincial Improvement Coordinator  
Ontario Cancer Symptom Management  
Collaborative  
Cancer Care Ontario  
susan.king@cancercare.on.ca |
| | Follow-up Guidelines for Colorectal  
Cancer | Raquel Shaw Moxam  
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Clinical Programs and  
Disease Pathway Management  
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Cancer Care Ontario  
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