Institute for Clinical Evaluative Sciences

Integrating care for Cancer patients: An evidence-informed analysis

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Executive Summary

Overview

The current corporate strategy of Cancer Care Ontario involves five important focus areas, including: (1) patient-centered care; (2) prevention of chronic disease; (3) integrated care; (4) value for money; and knowledge sharing and support. An important priority for integrating care among cancer patients is to ensure 'seamless' transition along the continuum of cancer care as patients navigate through the health care system.

This report addresses the integrated care focus of CCO's strategy, where the primary aim to is to drive integrated care delivery by strengthening accountability across healthcare settings through partnerships and innovative models of care. A particular focus of the Integrated Care strategy is developing a systems view of how complex cancer patients interact with health care providers and opportunities for improvement. From a patient and family perspective, integrated care is experienced when providers work with patients and families to manage individual care needs for all health conditions including, but not limited to, cancer. Integrated Care at CCO is therefore looking to implement models for cancer patients with complex needs to enable improved coordination of care, collaboration and patient and family experience.

The aim of this report is to summarize the current state of health status and system utilization among cancer patients that are complex, and through a review of the literature establish certain indicators that could best evaluate the integration of care among complex cancer patients. This report will ultimately contribute to CCO's ability to improve patient care experiences and health outcomes and empower health providers to ensure that care is optimized and occurs in the setting that provides best care for complex patients and value to the health system.

The report summarizes the results of three related components:

1) a literature review of peer-reviewed and grey literature on definitions of integrated care, and indicators aimed at evaluating the integration of care in various health systems;
2) an analysis of health system utilization by cancer patients through health administrative data;
3) clinical vignettes that present comprehensive investigations into a small set of cancer patients, created and analyzed to identify particular points during their care that could have benefited from a focused integrative approach, and to provide the basis of recommendations for the care of complex patients.

All three components of the report were steered by an Integrated Care Advisory Panel (and a subgroup of this panel forming a clinical expert panel). The preliminary approach for each of component was to create and present a broad framework to the advisory panel, and following incorporating iterative feedback while completing the project the project components, results were discussed with the clinical expert panel. Clinical meaningfulness of the findings was validated with this group and results of the

final report were discussed with the Integrated Care Advisory Panel for further discussion, questions and modifications.

Results

Literature Review

Dimensions of integrated care identified in the literature address five different dimensions of coordinated patient care:

1. Coordinated across health professionals within a patient care team;
2. Coordinated across facilities;
3. Coordinated across patient care teams and community resources;
4. Continuous over time;
5. Continuous between visits.

The primary measures of coordinated care that can be measured using health administrative data are the Usual Provider of Care (UPC) and Continuity of Care (COC) measures.

In addition to administrative data, survey data can be used to measure dimensions of patient-centered care to include care that is:

- Tailored to the patients' needs, meaning the extent to which patients' needs and values are considered while managing care;
- Shared responsibility between patients and providers where care is not only informed by providers, but also engages patients and their caregivers in decision-making with respect to managing care.

Empirical Analyses

Analyses of health administrative data found that:

- In the year prior to cancer diagnosis, approximately 36% of the cohort was complex, based on their being in the top 10% of health care spending in the year prior to cancer.
- Approximately 75% of patients survived cancer, while 18% died during treatment and 7% continued to receive treatment. In the year following cancer treatment, 27% of survivors were high cost, 37% were low cost, while 10% died.

Based on these results, 10 trajectories of care were identified to summarize cancer trajectories. Five of these trajectories, representing 70% of all cancer patients were developed for further investigation in empirical analyses and to develop vignettes to make clinical care recommendations. The five trajectories examined in detail included patients whose complexity (costs) prior to cancer was either low or high cost, patients who survived or died during cancer and patients who had either low or high complexity after cancer treatment ended.

Patients with high post-treatment complexity or who died during cancer treatment generally tended to be older, have higher severity of cancer staging, have a greater number of comorbid chronic conditions,

a greater number of physician visits per month and number of unique specialists in their circle of care as well as a larger proportion of patients who were emergency department user.

Recommendations

Based on vignettes and a deliberative dialogue, a clinical panel distinguished key roles of primary care physicians and cancer specialists over the course of the cancer care trajectory. The recommendations fell into four categories: 1. Recommendations for primary care; 2. Recommendations for cancer care; 3. Recommendations for shared responsibility between primary and cancer care; and 4. Recommendations for patient engagement in their care. Most of these recommendations focused on improving communication of diagnoses and particularly treatment plans as well as clear identification of roles and responsibilities for care after cancer treatment. Primary care physicians particularly need to know more about side-effects of cancer treatments and likely / potential medication interactions for patients during their cancer treatment phase.

Consultations with the clinical panel and the integrated care advisory panel, including with patients and caregiver representatives highlighted the need to better coordinate and share care between cancer care system and primary care providers. While there was relatively little specific discussion of home care service, one recommendation voiced by panel members was earlier identification and referral of palliative care patients. A second key recommendation was that coordination of care considerations should include rationalizing testing and multiple visits for tests and visits. Finally, responsibility for coordinating testing results needs to be clearly defined and communicated between cancer and primary care providers.

Further research is needed to better understand the relationship between measures that can be assessed with health administrative data such as the UPC and COC and positive cancer care outcomes.

1.0 Introduction & Context

Due to the increasing population of cancer survivors, cancer is becoming increasingly recognized as a chronic illness that needs to be managed across several phases, from diagnosis to treatment to survivorship or end of life care, often involving multiple providers of care. Cancer care requires a specialized, integrated approach to ensure that patients receive life-long surveillance of potential recurrence, monitoring of long-term effects resulting from treatment, including, psychosocial support, and management of comorbid conditions. From a patient perspective, integrated care is about managing individual care needs for all health conditions, not only cancer. An important priority for integrating care among cancer patients is to ensure 'seamless' transition along the continuum of cancer care as patients navigate through the health care system. Another distinct feature of cancer care is end-of-life care, as many jurisdictions aim to reduce significant health system costs and improve quality of palliative care in the community [1,2].

The current corporate strategy of Cancer Care Ontario involves five important focus areas, including (1) patient-centered care; (2) prevention of chronic disease; (3) integrated care; (4) value for money; and knowledge sharing and support. This report addresses the integrated care focus of CCO's strategy, where the primary aim to is to drive integrated care delivery by strengthening accountability across healthcare settings through partnerships and innovative models of care. A particular focus of the Integrated Care strategy is developing a systems view of how complex cancer patients interact with health care providers and opportunities for improvement. From a patient and family perspective, integrated care is experienced when providers work with patients and families to manage individual care needs for all health conditions including, but not limited to, cancer [1,2]. Integrated Care at CCO is therefore looking to implement models for cancer patients with complex needs to enable improved coordination of care, collaboration and patient and family experience.

2.0 Rationale and Objectives

Provincial and international work on costing patient interaction with the health care system has identified a large proportion of health care costs being used by very small subsets of the population. In a report describing healthcare costs per patient in Ontario, it was found that approximately 80% of health care costs are being used by 10% of the population [3,4]. Although cancer was noted as one of the top 5 diagnosis within the 10% in this analysis, it was unclear which cancer patients fell within this qualification of complexity and if there was any variation of complexity.

The aim of this report is to summarize the current state of health status and system utilization among cancer patients that are complex, and through a review of the literature establish certain indicators that could best evaluate the integration of care among complex cancer patients. This report will ultimately contribute to CCO's ability to improve patient care experiences and health outcomes and empower health providers to ensure that care is optimized and occurs in the setting that provides best care for complex patients and value to the health system.

The overall project consisted of three related components with the following objectives:

1) a literature review of peer-reviewed and grey literature on definitions of integrated care and complexity, and indicators with the objective of evaluating the integration of care in various health systems, and establishing a working list of indicators
2) an analysis of health system utilization by cancer patients through health administrative data with the objective of quantifying complexity and varying patient trajectories through the healthcare system;
3) clinical vignettes that present comprehensive investigations into a small set of cancer patients, created and analyzed with the objectives of identifying particular points during their care that could have benefited from a focused integrative approach, and to provide the basis of recommendations for the care of complex patients.

3.0 Methods

All three components of the report were steered by an Integrated Care Advisory Panel (and a subgroup of this panel formed a clinical expert panel) (members listed in Appendix A). The preliminary approach for each of component was to create and present a broad framework to the advisory panel, and following incorporating iterative feedback while completing the project the project components, results were discussed with the clinical expert panel. Clinical meaningfulness of the findings was validated with this group and results of the final report were discussed with the Integrated Care Advisory Panel for further discussion, questions and modifications. Detailed methods for each component of this project are outlined below.

3.1 Literature Review

We conducted a literature synthesis regarding indicators for integrated cancer care and particularly coordination of care between cancer and non-cancer related health care providers. Among these indicators, we explicitly aimed to highlight specific care integration measures and appropriate data sources for indicators that could be measured using health administrative data in Ontario. Measures that can be ascertained using clinical administrative databases were used to inform our empirical analyses.

Search strategy

We performed a review of peer-reviewed and grey literature using PubMed Central® database and Google® between November 2013 and March 2014. Searches for peer-reviewed sources included the use of relevant MeSH terms where possible. Terms such as "Neoplasm" or "cancer", were paired with terms such as "continuity of patient care", "quality indicator", "health care", "administrative data", "delivery of health care", "survivor", "patient satisfaction", "physician role", "delivery of health care, integrated", "physician, primary care", "assessment, outcomes", "integrated health care systems", "measurement", and "performance". Publications from the year 2000 onward were retrieved primarily from different fields of study, including general medicine and oncology, health policy, and health service research, in English. We conducted an environmental scan of grey literature using Google® to identify indicators currently recommended or monitored by organizational websites, such as official non-governmental organizations (e.g. Manitoba Centre for Health Policy) and health quality councils in Canada or internationally. Key themes found in the literature were defined using thematic analysis.

Inclusion criteria

The search strategy and preliminary search results were reviewed with a clinical panel. Publications were reviewed if the title or abstract suggested that measures or indicators of continuity, coordination and/or integration were examined, either as process, structural or outcomes measures. Figure 1 outlines the selection process of the literature search, indicating a total of 547 titles were found through PubMed and Google, and following exclusions, 19 studies were retained for analysis.
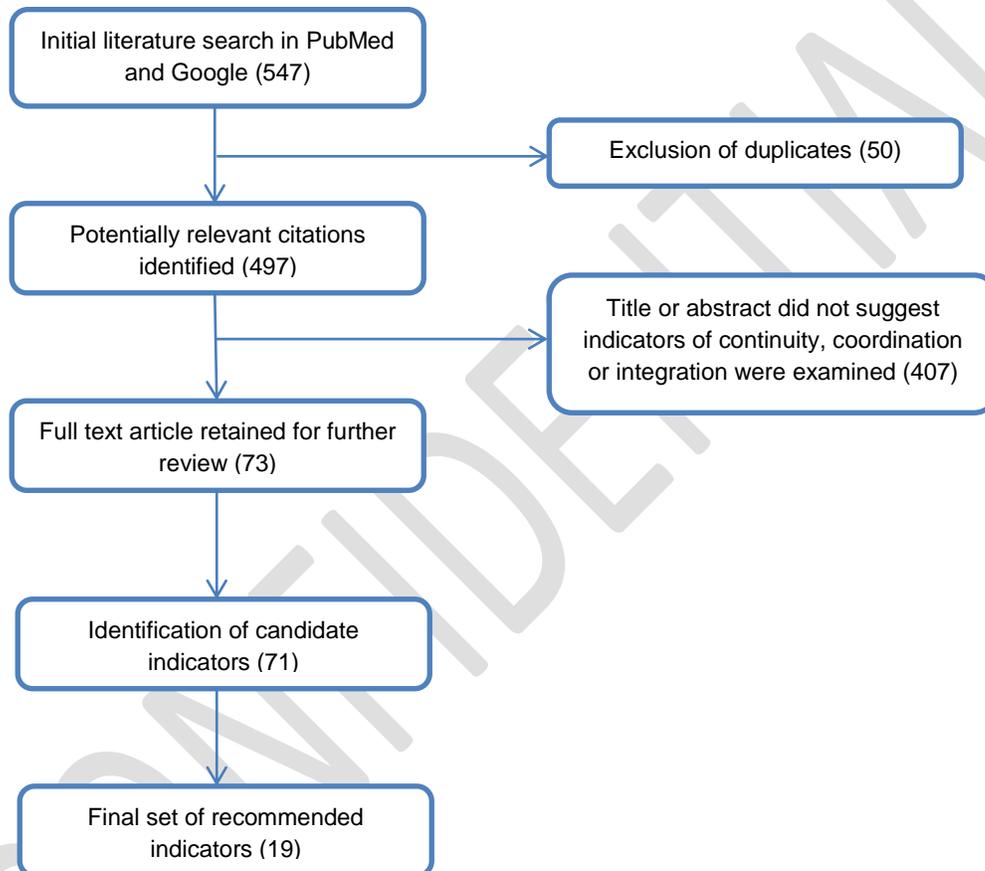
Figure 1: Flow Chart of Study Selection Process

3.2 Empirical Analyses

A retrospective cohort study was conducted using administrative data among adults, aged 18 and over, who were newly diagnosed with cancer between April 1st, 2009 and September 30th, 2010. The purpose was to understand the proportion of cancer patients who were complex and high users of the health care system prior to, during and after their cancer treatment.

3.2.1 Data sources

This study was conducted at the Institute for Clinical Evaluative Sciences (ICES), where anonymized health information for all Ontario residents eligible for the Ontario Health Insurance Plan (OHIP) is held. Patients newly diagnosed with cancer were identified through the Ontario Cancer Registry (OCR). A computerized process linked individual records from identified patients from hospitals discharges, specialized treatment institutions (e.g.: regional cancer centres), pathology reports, and death certificates. These sources are used to identify cancer site, histology, date of diagnosis, diagnostic and treatment procedures, for each case [5].

Other data sources included chronic disease registries and administrative datasets that contained information related to hospital admissions, emergency department visits, and physician billings. For this study, the following databases were used:

- **Ontario Cancer Registry (OCR):** The OCR is a population-based cancer registry with all new cases of cancer since 1964 registered, except non-melanoma cancer. The OCR is representative of 95% of the population. Main data elements include details of cancer diagnosis, such as date of diagnosis and site of primary cancer.
- **Registered Persons Database (RPDB):** The RPDB provides demographic information, such as age, sex, neighbourhood income level, and residence of all individuals that have ever held a valid Ontario health card number (OHIP), as well as death information such as date of death.
- **National Ambulatory Care Reporting System (NACRS):** The NACRS dataset captures information on outpatient visits to the hospital and community-based ambulatory care centres, including day surgery, outpatient clinics, and emergency department visits.
- **Discharge Abstract Database (DAD):** The DAD dataset contains information on all hospitalizations at acute care institutions in Ontario. Each record represents an inpatient separation and includes information related to admissions, length of stay, and disposition.
- **Home Care Database (HCD):** HCD is a clinical client-centered dataset that captures information on encounters between clients, service providers, and the Ontario Community Care Access Centres (CCACs). Examples of data elements in HCD include the types of services provided (nursing, social work, etc.), assessment data, and admission/discharge information.
- **Ontario Health Insurance Plan (OHIP):** The OHIP claims database contains data on fee-for-service claims made by Ontario physicians that are covered and paid for by the OHIP. Each record in the database represents a single service and a diagnosis associated with that service. Elements used from this database included date and code of the service/procedure provided, as well as diagnoses associated with the service.

- **ICES Physicians Database (IPDB):** The IPDB is comprised of information from the OHIP Corporate Provider Database (CPDB), and the OHIP database of physician billings. Information from IPDB is used to identify physician characteristics, notably their specialty type.
- **Client Agency Program Enrolment (CAPE):** The CAPE dataset indicates the enrolment of patient with a specific practitioner or group, which may be part of a fee-for-service or blended capitation primary care model.
- **Interactive Symptom Assessment and Collection Tool (ISAAC):** The ISAAC database was used to capture patient-reported information on severity of symptoms, such as pain, nausea, and anxiety, as well as measures of functional status.

3.2.2 Measures

The measures that were captured on this cohort of patients with cancer included some demographic and clinical information, as well as information regarding the each patient's health system utilization. Measures included in analyses are listed below:

Demographic Characteristics:

Demographics were obtained from the RPBD database.

- age
- sex
- neighbourhood income quintile
- rural vs. urban residence: based on the Rurality Index of Ontario

Clinical Characteristics:

Clinical characteristics were obtained from the OCR database.

- Primary cancer site
- Stage of cancer at diagnosis
- Cancer treatment episodes**:** during the study period, episodes of cancer care were created based on the first observed occurrence. Sequential cancer-related physician and acute care visits for each patient were examined from the date of cancer diagnosis to March 2012. Episodes started from the date of diagnosis continuing through cancer-related visits within at least three months of each other, ending when three months would pass without a cancer-related visit. Additional groups were created to categorize those that died during or following treatment, and those with ongoing treatment. If a patient had record of a new cancer diagnosis in the OCR after three months of their last cancer-related visit, they were considered to be receiving ongoing cancer treatment.
- Symptom severity**:** assessed during cancer treatment using the Edmonton Symptom Assessment Symptom (ESAS). Symptoms assessed included: pain, tired, nausea, depression, anxious, drowsy, appetite, well-being, shortness of breath.

Patient Complexity:

Patient complexity was evaluated using a proxy as defined by resource intensity, or health care expenditures. Patients were characterized as a high or low resource user according to whether their overall system costs fell within or below the top 10%. The approach that was used to determine the total system costs were defined by the accumulation of community-based and institutional health system encounters (based on data from the NACRS, DAD, HCD and OHIP databases), using the following thresholds [3].

Figures for high-cost (90th percentile) threshold, based on annual health system costs				
Complexity category	2007-08	2008-09	2009-10	2010-11
High cost (90th percentile)	$ 3,041	$ 3,620	$ 3,764	$ 3,668

High or low complexity was then assigned to each patient based on their resource intensity prior to, during and following treatment for their cancer.

Comorbidities:

At the time of cancer diagnosis, using a look back period from 2001 to diagnosis, patients were evaluated for the presence of comorbid chronic conditions, including: congestive heart failure, chronic obstructive pulmonary disorder, asthma, osteoarthritis or other arthritis, rheumatoid arthritis, osteoporosis, chronic coronary syndrome, acute myocardial infarction, hypertension, cardiac arrhythmia, diabetes, dementia, depression, stroke, or renal failure. The number of comorbid conditions was calculated for each patient and were categorized at 0, 1, 2, 3, 4, 5-16. Diagnostic codes for these conditions were ascertained from DAD, OHIP and NACRS databases.

Health System Utilization:

Measures to evaluate the level of system utilization were evaluated for each patient as follows:

- **Visits to primary care physicians** (general practitioners, family physicians), were identified using OHIP claims data and RPDB to identify physician specialty. Visits that were cancer-related were flagged using specific diagnostic codes.
- **Specialist visits** were also identified using OHIP claims data and RPDB data. They were considered cancer-related if the visit was billed by radiation or medical oncologist, or hematologist.
- **Acute care use** included cancer and non-cancer related emergency department visits and acute care hospitalizations, identified using information from the main problem or most responsible diagnosis fields in NACRS and DAD.
- **Home care use** included visits from service provider, coordinated through the CCAC, and were identified using HCD.

- **Continuity of care** was calculated using two methods and data from OHIP – to capture physician claims, and IPDB - to determine the specialty of the physician:
    - Usual Provider of Continuity (UPC) Index which measures the proportion of visits made to a usual provider of care (one provider);
    - Continuity of Care (COC) Index, which measures the concentration of visits to multiple providers and aims to identify whether there is a 'dominant' provider to whom a significant portion of visits can be attributed.

3.2.3 Analysis

The patient cohort for this study included Ontario adults aged 18 and over, newly diagnosed with cancer between April 1st 2009 and September 30th, 2010.

Using the measure for patient complexity (categorized as *high* or *low* based on the resource intensity of each patient) prior to and following cancer treatment, as well as outcomes of cancer care (survived, died, ongoing treatment), ten trajectories of cancer care were created. These groupings reflected all of the patients in the sample, and were formed to better organize the data and to perform focused analyses on patient and system utilization characteristics. This report will highlight the patient and system utilization characteristics among five of the ten trajectories, which reflect 70% of the patient sample. For each of the highlighted trajectories, patient characteristics, clinical characteristics continuity of care, and patterns of health service use were compared.

3.3 Expert Panel

Clinical review of patient vignettes

Patient vignettes were created based on the highlighted five health system trajectories from our quantitative analysis, and provided insight on patients' journeys and experiences throughout the continuum of cancer care. Each vignette represents the 'median' patient with respect to age, emergency department visits, hospital admissions, primary care and specialist visits, and chronic comorbid conditions. In other words, half of the patients within the respective trajectory have more complex care, while half were less complex.

Specifically, 5 patients were identified in the health administrative data from within each respective vignette who had the single most prevalent cancer type and stage within the trajectory and then the median (or within a narrow range of the median) score on each of the above-named measures. With these 5 specific patients, the exact physician types and billings by type of physician were explored during the cancer episode. The exact number and cause for ED visits and acute hospital admissions were similarly examined. The exact conditions present prior to and newly diagnosed during the cancer episode were also extracted. Where the condition or type of visit was present for at least 3 of the 5 patients, it was included in the vignette description. This information was used to create a vignette of a representative patient which was presented to the clinical expert panel along with vignette-specific

questions. In addition to the individual vignettes, we also summarized the five most common reasons for ED visits for the entire population within each of the vignettes to determine whether any of these visits might be potentially avoidable.

The clinical expert panel provided feedback throughout the project including reviewing review of the initial empirical trajectories and cancer classifications, suggesting refinements to the trajectories and cancer classifications, and identifying important measures to be considered in describing the populations. The role of the clinical expert panel was to provide expert review of the analyses, and to guide the selection of specific cancer populations for the focus of our research. Members were presented with five patient vignettes and cancer care trajectories from the empirical analyses as well as a summary of indicators based on the results from our literature synthesis. Using this information, the expert panel identified recommendations to improve integrated care for cancer patients represented in each vignette. After review and modifications based on the clinical panel, the advisory panel was consulted including input from patient and caregiver representatives.

4.0 Results

4.1 Literature Review
This section provides an overview of the current literature themes related to integrated cancer care, and identifies existing measures of integration, providing a foundation for future indicator development.

4.1.1 Defining Integrated Care and Coordination
The term 'integration' has been used widely and defined in a number of contexts. In this section, we provide an overview of how integrated cancer care has been defined and measured in the literature in a clinical context.

Singer and colleagues (2011) describe integrated care as "patient care that is coordinated across professionals, facilities, and support systems; continuous over time and between visits; tailored to the patients' needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health." In other words, integrated can be defined as care that is multidimensional in that it is patient-centered, coordinated across care providers (inter-professional), and continuous [6]. Integration involves a common structure among multiple care providers, each with their unique involvement, in order to better facilitate the coordination of patient care [7].

According to the Agency of Healthcare Research and Quality (AHRQ), coordination may be measured from different perspectives, including that of the provider, the patient, and the overall health care system [8]. From the perspective of patients and caregivers, coordinated quality care is described as any activities that support their needs for information sharing, decision-making, and personal treatment needs and preferences, especially during points of transition across sectors within the health care system [8]. Health care professionals view coordinated care as effective and efficient patient-navigation through the health care system. Components of effective and efficient navigation include information-sharing among providers, managing provider involvement and responsibilities, and directing patients

towards appropriate services or providers. Coordinated care from a provider perspective suggests that medical, psychosocial, informational, and financial concerns have been identified. From a systems perspective, the goals of coordinated care are to integrate health personnel, information and other resources required to ensure efficient and effective health care delivery, within and across sectors of the health care system [8].

Singer (2011) and colleagues recommend the use of the following seven dimensions of integrated care, categorized under two broader categories used to define integration; coordination; and patient-centered. They suggest that these dimensions guide the development of a measurement framework to evaluate integrated care among patients with multiple or complex chronic conditions.

Singer and colleagues discuss five different dimensions of coordinated patient care which are defined as care that is:

1. Coordinated across health professionals within a patient care team, in other words, the degree to which providers within a care team are aware and informed of each other's decisions and care delivery;
2. Coordinated across facilities, in other words, the degree to which health care teams are consistent and aware of the delivery of other patient care teams;
3. Coordinated across support systems, meaning the coordination of activity between patient care teams and community resources. This definition of integration reflects health care providers' knowledge and utilization of local support resources;
4. Continuous over time, which measures the degree to which care providers are familiar with a patient's history as well as the degree of care provided to the patient in the past;
5. Continuous between visits, in that patient receive ongoing follow-up, home care, phone calls. This additionally reflects responsiveness to patient's care needs.

Dimensions of patient-centered care include care that is:

- Tailored to the patients' needs, meaning the extent to which patients' needs and values are considered while managing care;
- Shared responsibility between patients and providers, in other words, care that is not only informed by providers, but also engages patients and their caregivers in decision-making with respect to managing care.

Models of care and across the continuum of cancer care

There is a growing body of literature which focuses on models of care and involvement of physicians in general and cancer-specific roles during the continuum of cancer care; starting from diagnosis to advanced or survivorship phases to end of life. US-based studies have shown that the number of visits to oncologist decline significantly within five years following cancer treatment, and number of individuals that see an oncologist annually post-treatment is low [9-11]. Whether this is due to lack of

resources or related to access is unclear; however, these findings have important implications for the delivery of coordinated care.

Different general medical roles include management of comorbid conditions, evaluation and treatment of depression, establishing DNR status, referral to hospice, and pain management. Cancer roles include establishing treatment and prognostic goals, assessment of patient treatment preferences, determine initial treatment, decisions on use of surgery/ radiotherapy/ chemotherapy, and discussions of clinical trial participation [12].

Studies on physician involvement have shown that primary care physicians play a key role in managing comorbid conditions and treatment of depression, which are highly common among patients undergoing cancer treatment and survivors [12]. These aspects of care have been previously found to be unidentified in cases where cancer care management was primarily assumed by specialists [13]. Models of care, based on previous work by Norman and colleagues (2001) have been described in the literature as: (1) sequential, where there less primary care involvement, majority of care is managed by an oncology team; (2) parallel, primary care physician is mainly involved in management of non-cancer related issues; and (3) shared, where both primary care and oncology teams are involved in management of cancer care [14]. There is evidence to support that co-management, or shared care models particularly during the survivorship phase are associated with patients receiving increased surveillance, ongoing screening, and preventive care, compared to those in models led by either physician alone [12;15]. Similarly, patients in shared models of care are more likely to receive end-of-life services, for example, referral to hospice care [12]. Primary care physicians and specialists functioning in a co-management capacity may be indicative of a high-quality, coordinated approach to cancer care which facilitates the transition from treatment to post-approach [12;13;16]. Shared models of care appear to be most common during advanced or survivorship phases, whereas more parallel models of care are observed during treatment, as primary care physicians are more involved in follow-up of non-cancer related issues [17;18].

Given the optimal approach of coordinated cancer care, studies on physicians' expectations and preferences for models of care suggest discordance, in that oncologists expect primary care physicians to be involved during pre-post-treatment periods, while primary care physicians prefer being involved throughout all phases of care [7;12;16;18]. Clarification of roles and improved communication between primary care and oncology specialists is undoubtedly an opportunity to improve the coordination of care [6].

Despite the important benefits and patient preferences for shared models of care, having multiple providers often results in confusion among patients, and their understanding of provider responsibility for certain aspects of care. Though many patients tend to report their family physician as their main provider, a significant number report their cancer specialist as a main provider as well [15]. Sisler and colleagues (2012) suggest that the extent to which transfer of information and care responsibility to family physicians during survivorship is unclear. To this regard, other findings show that such discrepancies are associated with overuse of surveillance tests, calling for a greater clarity in survivorship care plans, benefiting patients and providers. They highlight that coordination of care

between providers is especially important for those with psychosocial and physical symptoms following cancer treatment during survivorship [15].

Patient experience in continuity of care

Research has shown that favourable perceptions of continuity of care are correlated with better health outcomes. Though subjective, measures of experienced continuity are reflective of consistency in care, timeliness, attention, coping strategies, confidence in treatments, and knowing what to expect [19; 20]. King and colleagues found that experienced continuity of care during a given phase of treatment was predictive of lower supportive care needs in the following phase. Other studies have shown that the timeliness, meeting informational needs particularly at discharge, and knowing what to expect, are associated as positive experiences of collaboration between primary care physicians and specialists [7;21].

Patient-centered care during the course of cancer care is important as a result of the emotional, physical and social challenges experienced by patients. In addition, patient-centered, coordinated care in an important quality indicator [22]. Poor patient perceptions of coordination of care may be indicative of a lack of access for supportive care needs or emotional support [23, 22]. Measures of patient satisfaction, collected using the Ambulatory Outpatient Satisfaction Survey (AOPSS) developed by NRC Picker, are available in seven Canadian jurisdictions, including Ontario. The 2012 Cancer System Performance Report highlights that across Canada, patient satisfaction was lowest on the domain of emotional support [22].

The purpose of measuring patient experiences with cancer care is to understand the degree to which the cancer system is meeting patients' supportive care needs in terms of physical comfort, respect for patient preferences, access to care, coordination and continuity, informational needs, and emotional support. Further, it is important to assess these needs across all phases of care, from diagnosis to advanced or survivorship care.

4.1.2 Quality health care delivery: system-level

Medical records and administrative health data sources are used to objectively define and measure continuity of care using standard approaches. Continuity of care from a system-level perspective is often measured through outcomes such as health service use, including measures of emergency department visits, hospital admissions, and hospital length of stay. High continuity is not only associated with increased satisfaction and the lower use of health services, but better quality of preventive medicine such as screening tests and outpatient consultations [24]. The latter may be reflective of faster referral processes under a regular source of primary care [24].

A number of methods currently exist to measure continuity of care, each focusing on different indices of relational continuity, in other words, the ongoing patient-provider relationship [25;26]. Indices of relational continuity include the duration of patient-provider relationships, which simply measures the

length of time with a provider; density of visits, dispersion or frequency of care, and sequence of visits [25;26]. Examples of density, dispersion, and sequence of care indices most commonly found in the literature are outlined below.

Density: Usual Provider Continuity Index (UPC)

The UPC index is the most commonly used indicator of continuity in the literature [20;25]. This index measures the proportion of visits made to a regular provider of care or the physician that was visited most frequently if the patient does not have an identified provider of care [24;25;27]. While the UPC measure takes into account that the usual provider of care may be a primary care physician or a specialist, the focus is on the strength of the relationship with a single provider, and therefore may not consider visits to multiple providers [27]. For example, a patient who sees their specialist frequently, to whom they were referred by their primary care physician, may appear to have a lower UPC when in fact they are receiving continuous care [245;27].

Dispersion: Continuity of Care Index (COC) & Modified Continuity Index (MMCI)

The COC index measures the concentration and dispersion of visits between providers, while the MMCI measures the dispersion of visits but focuses less on the number of providers seen [2;25-27]. Both measures take into account that patients see numerous providers and have multiple visits; however the COC index is more widely used than the MMCI. The COC index captures whether there is a 'dominant' provider to whom a significant portion of visits can be attributed; or the contrary, where the distribution of visits to multiple providers is more equally or evenly spread, signalling lower continuity of care [25-27]. Because COC index factors the overall number of providers seen, they are considered measures of continuity from a management perspective [25].

Sequence: Sequential Continuity Index (SECON)

The SECON index, which is not as commonly used as the UPC and COC indices, takes into account the proportion of visits consecutively made to the same provider [26;27]. The SECON measure is considered useful in understanding the need for information-sharing and communication among providers. The SECON index also provides a measure of the degree of immediate follow-up with a certain provider, as well as the transition between two providers [24;25;27]. Sequence measures are seen as taking a patient-centered view, in that it considers the sequence in which providers are seen, signaling potential inconsistency. Therefore, a patient that sees multiple providers through less sequential visits is likely to experience lower continuity of care [25;26].

4.1.3 Quality of palliative and end-of-life care

A number of studies we found focused on the quality of end-of-life cancer care, particularly focusing on access to palliative care programs and health service utilization near the end of life. Much of the literature related to integrated care was focused specifically on palliative and end-of-life care patients. End-of-life cancer care is becoming increasingly recognized as an important part of the continuum of

cancer care [28]. However, has been noted that palliative care services are introduced much later during the course of end-of-life cancer care, if at all [28].

There are a number of concerns related to the appropriateness of care close to death, for example, the overuse of chemotherapy at a time where supportive services, such as hospice care, should be put in place [28-31]. Other forms of aggressive care practices or inappropriate interventions near death include emergency department visits, hospitalizations, and admissions to the ICU; these are often considered to be poor indicators of quality end-of-life care [28;30;32]. Negative care processes such as overuse of the emergency department, ICU admissions and hospitalizations during end-stage cancer may delay hospice admission [30]. Another focus of end-of-life care is location of death; though the majority of palliative patients prefer dying at home in a favourable environment with family and friends present, the majority die in hospital [22;31;32]. Whether these care processes and/or outcomes are indicative of poor access to palliative or hospice care resources, acceptance of terminal illness, or lack of supportive care needs are uncertain.

Using administrative and data, studies have shown associations between the use of community and outpatient services such as home care, outpatient palliative care assessments, and physician house calls, with better continuity measured through fewer emergency department visits, hospitalizations and ICU admissions among end-of-life cancer patients [28;33]. Greater continuity and use of community services, in particular home care, has been shown to also be associated with lower likelihood of dying in hospital [33].

4.1.4 Indicator Selection Process
From 73 sources, we completed an inventory of 150+ indicators. A subset of these indicators was chosen based on (1) how frequently they were found in the literature; (2) their alignment to the key objectives of this project; and (3) consultation with our expert panel. Table 1 describes the chosen indicators, and is organized to outline some of the technical specifications of each indicator, such as the level of measurement or perspective from which the indicator is measured; data type (survey, administrative data); and indicator type (process, structural, outcome). Process indicators are direct measures and are more sensitive to the quality of care that is being delivered to patients. Outcome indicators reflect all aspects of care, though not necessarily a direct measure of quality [34;35].

Table 1: Summary of Proposed Indicators from Literature Review

Indicator Name	Domain	Dimensions/Constructs	Indicator Description	Level of measurement	Type	Data type	Tools/Instruments	Jurisdiction	Source
Physician involvement throughout the cancer trajectory	Physician experience	Coordination, emotional support, information transmission, symptom relief	Measures physician involvement (primary care, oncologist) during different phases of cancer (diagnosis, primary treatment, stability, progression/relapse, advanced/terminal or survivorship), across dimensions of care. Types of involvement include: (1) sequential - no PCP involvement, most care from oncology team; (2) parallel - PCP involved mostly for non-cancer issues; (3) shared - involvement of PCP and oncologist in cancer.	Provider	Process	Survey	2004 Canadian National Family Physician Workforce Survey	Ontario, Quebec	[7;18]
Physician involvement in general medical and cancer care roles during cancer treatment	Physician experience	• General medical roles: Establish DNR status; evaluate and treat depression; manage comorbid conditions; prescribe opiates for pain management; refer to hospice. • Assessment of patient treatment preferences; use of chemotherapy; use of radiotherapy; use of surgery; determine initial treatment; clinical trial participation; establish treatment and prognostic goals	Measures physician involvement (%) in general medical roles and cancer care roles during the active phase of treatment	Provider	Process	Survey	Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)	Ontario, Canada; United States	[7;12]
Family physician involvement in cancer care	Patient experience	Coordination, emotional support, information transmission, symptom relief	Measures physician involvement (primary care, oncologist) across different phases of cancer (diagnosis, primary treatment, stability, progression/relapse, advanced/terminal or survivorship), and aspects of care (coordination, emotional support, information transmission, symptom relief). Types of involvement include: (1) sequential - no PCP involvement, most care from oncology team; (2) parallel - PCP involved mostly for non-cancer issues; (3) shared - involvement of PCP and oncologist in cancer.	Patient	Process	Survey	Primary Care Assessment Tool	Quebec, Canada	[17]
Patient experience of care collaboration between GPs and specialists	Patient experience	GP approach, GP referral, specialist approach/feedback, overall collaboration	Measures patients' experience of care collaboration between GP and specialists. Included 36 items on how patients were approached and referred by the GP, approach and feedback by the specialist, and overall collaboration	Patient	Process	Survey	Consumer Quality Index (CQ-index) Continuum of Care	Netherlands	[21]

Patient satisfaction with care	Patient experience	Physical comfort; respect for patient preferences; access to care; coordination and continuity of care; information, communication and education; emotional support	Indicator examines the degree to which cancer patients feel that they are well supported and cared for throughout their cancer care journey.	Patient	Outcome	Survey	Ambulatory Oncology Patient Satisfaction Survey (AOPSS) - NRC Picker	Alberta, British Columbia, Manitoba, Nova Scotia, Ontario, Prince Edward Island, Saskatchewan	[22;36;37]
Patient perceptions of continuity of care	Patient experience	Information transfer, relationships in the community, management of forms, management of follow-up, management of communication among providers	Measures patient perceptions of continuity of care at time of discharge from hospital to the care of community providers. Focus is in assessing continuity of care between the cancer center and primary care after the end of cancer treatment (at oncology-primary care interface)	Patient	Outcome	Survey	Patient Continuity of Care Questionnaire (PCCQ)	Manitoba, Canada	[15]
Integration of patient care	Patient experience	(1) coordination within care team; (2) coordination across care teams; (3) coordination between care teams and community resources; (4) continuity - familiarity with patient over time; (5) continuity - proactive and responsive action between visits; (6) patient-centeredness; (7) shared responsibility		Provider		Survey	Patient Perceptions of Integrated Care (PPIC) survey	United States	[38]
Continuity of Care Index (COCI)	Health system/ utilization	Index used to measure the dispersion of visits; quantifies the number or percentage of visits to distinct providers	Measures both the dispersion and concentration (frequency) of visits among all providers seen.	System		Administrative data			[20;24-27;39]
Usual Provider of Care (UPC) Index	Health system/ utilization	Index used to identify the most frequently visited physician. Measures highest density (frequency) of a patient's visits to a physician, quantified as the number or percentage of visits over defined period of time.	Measures the proportion of visits to a usual/regular provider in a given period over the total number of visits to similar providers	System		Administrative data			[20;24-27;39]
Emergency department visits	Health system/ utilization		Measured as a potential outcome of continuity of care	System	Outcome	Administrative data		Quebec, Canada	[40]
Hospitalizations	Health system/ utilization		Measured as a potential outcome of continuity of care	System	Outcome	Administrative data		Quebec, Canada	[41]
Acute care length of stay	Health system/ utilization			System	Outcome	Administrative data		Ontario, Canada	[37;42]
Start of a new chemotherapy regimen in the last 30 days of life	Quality of palliative care			System	Process	Administrative data		United States	[30]

Received chemotherapy in the last 2 weeks (14 days) of life	Quality of palliative care		• Any chemotherapy in the last 14 days (% of those receiving chemotherapy); • Proportion receiving any chemotherapy in the last 14 days (% of whole cancer cohort)	System	Process	Administrative data		Ontario, Canada; Nova Scotia, Canada; United States	[28;30;31]
Hospital/Inpatient admissions	Quality of palliative care		• At least one hospitalization in the last 30 days; 14 days of life • # of hospital admissions • # of hospital days at end-of-life (inpatient LOS)	System	Process	Administrative data		Manitoba, Canada; Quebec, Canada; Nova Scotia, Canada; United Kingdom; United States	[29-33;36;38;43]
Frequency of emergency department (ED) visits	Quality of palliative care		• > At least one ED visits in last 30 days; 14 days. • Average # of ED visits in the last 30 days; 6 months of life. • Average # of ED visits per available day in last 30 days	System	Process	Administrative data		Nova Scotia, Canada; Quebec, Canada; United States	[29-31;33;37;44]
Location of death	Quality of palliative care		(home, hospice, hospital)	System	Process	Administrative data			[22;29-33;38;43]
Access to palliative care	Quality of palliative care		Enrollment in a palliative care program	System	Process	Administrative data			[31;37]
Enrollment in palliative care near death	Quality of palliative care		Admission to hospice < 3 days before death	System	Process	Administrative data		Nova Scotia, Canada; United States	[29-31]

4.2 Empirical Analyses: Trajectories of Cancer Care

This section summarizes the results of the empirical analyses using ICES administrative data, augmented by the CCO ISAAC data. A cohort of 88,749 individuals aged 18 to 105 years, newly diagnosed with cancer between April 1st 2009 and September 30th 2010 was identified. Among these individuals, the most common types of cancer were cancers of the digestive system (21%), followed by male genital cancers (15%), breast (14%) and respiratory system cancers (14%), as described in Exhibit 1.

Exhibit 1. Distribution of primary cancer sites among Ontario adults newly diagnosed with cancer (n=88,749) between April 1st 2009 and September 30th 2010.
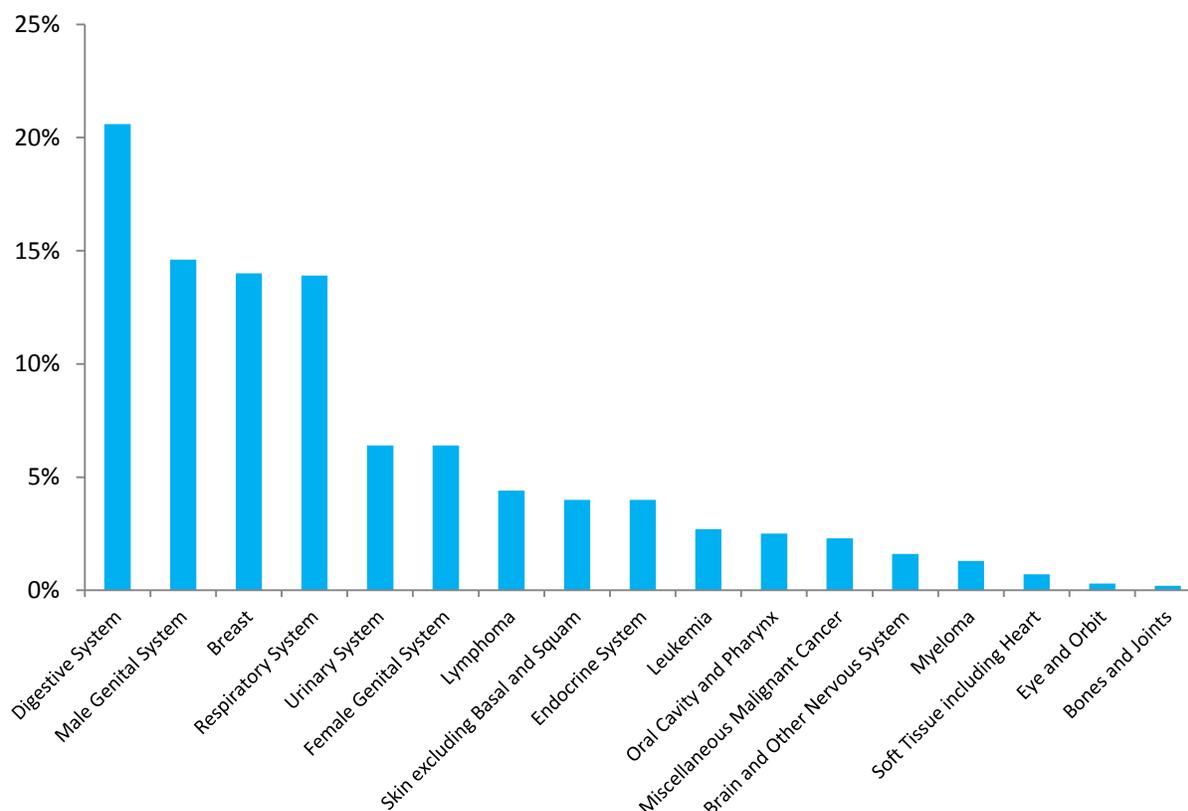
The percentage of patients that fell into each category of complexity prior to, and following treatment, as well as their outcomes either during cancer treatment or after, are described in Exhibit 2. It should be noted that 18.3% of the population that died during treatment, and 7.2% of those receiving ongoing treatment are not represented in the *post-cancer* categories, which solely includes those that survived their treatment (74.5%).

Exhibit 2. Resource intensity and outcomes of Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010, before, during and after cancer treatment.
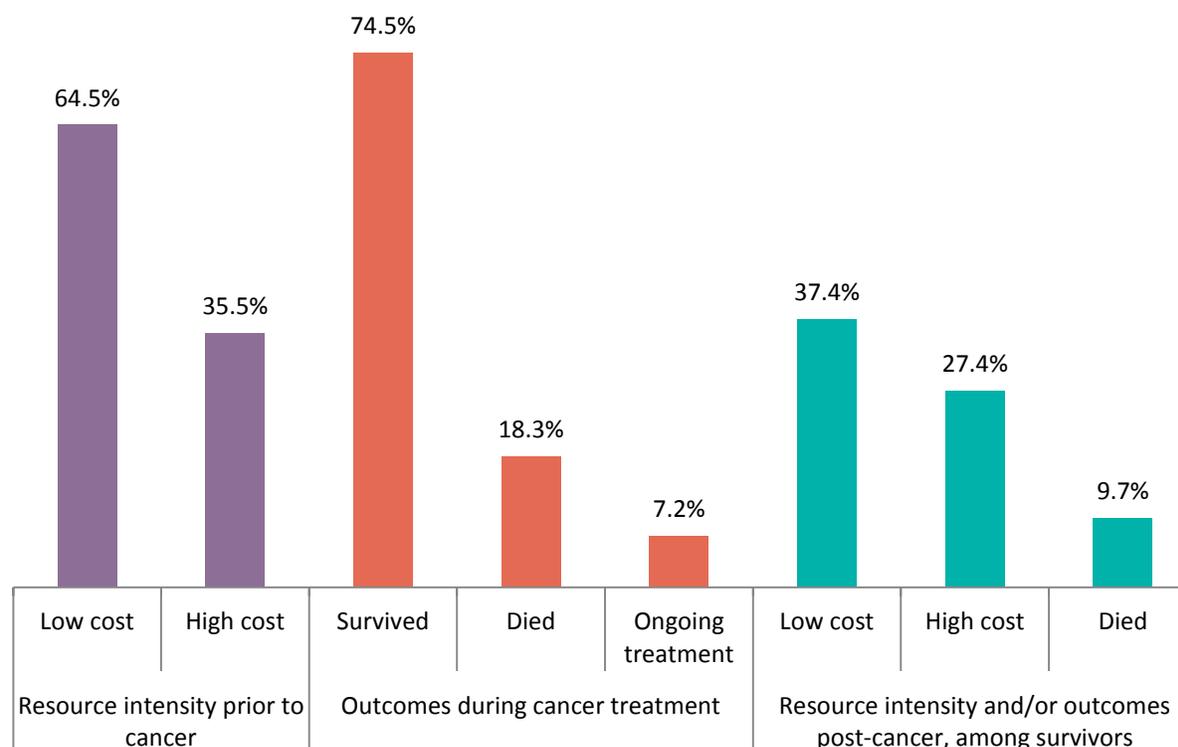
Summary of findings:

- In the year prior to cancer diagnosis, approximately 36% of the cohort was complex (based on their being high-cost). These findings differ considerably from that of the Ontario population, where only 10% of the general Ontario population are considered to be high cost.
- Approximately 75% of patients survived cancer, while 18% died during treatment and 7% continued to receive treatment. In the year following cancer treatment, 27% of survivors were high cost, 37% were low cost, while 10% died.
- The rate of mortality during cancer was 18% while mortality in the year after cancer treatment among patients who survived was nearly 10%. This compares to a 10% general mortality among patients in the highest 5% of spending in the province.

The distribution of the patient cohort within each of the 10 trajectories that were formed from complexity and outcome assessment are outlined in Exhibit 3. The trajectories that were selected for further analysis (and for the patient vignettes) based on their frequency and recommendations from the clinical expert panel are bolded and indicated with an *. In this report, demographic, clinical and health system utilization characteristics will be summarized only for these trajectories.

Exhibit 3. Frequencies of 10 trajectories among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.

Resource intensity prior to cancer	Cancer outcome	Resource intensity post-cancer	N	%
*Low	**Treated**	**Low**	**27,896**	**31%**
*Low	**Treated**	**High**	**13,004**	**15%**
Low	Treated	Died	3,779	4%
High	Treated	Low	5,258	6%
*High	**Treated**	**High**	**11,322**	**13%**
High	Treated	Died	4,837	5%
Low	Ongoing	-	4,518	5%
*High	**Ongoing**	**-**	**1,869**	**2%**
Low	Died	-	8,054	9%
*High	**Died**	**-**	**8,212**	**9%**

*selected for patient vignettes

Summary of findings:

- Based on all of the trajectories of care, nearly one-third (31%) of patients newly diagnosed with cancer were low cost in the year prior to cancer, completed their treatment, and continued to be low cost in the year following cancer (*low-treated-low*). The following trajectory (15%) represents patients that were low cost in the year prior, completed their treatment, but were high cost in the year following treatment (*low-treated-high*).
- Only 4% of patients that were low cost prior to cancer and completed their treatment, died in the year following treatment (*low-treated-died*), while 5% of those that were high cost prior to cancer and completed their treatment, died (*high-treated-died*).
- Patients that were complex prior to and following cancer accounted for 13% of the cohort population (*high-treated-high*).
- Among the 18% that died during cancer treatment, half were complex prior to treatment while the remaining half was not (*high-dead, low-died*).

Exhibit 4 outlines the five most commonly diagnosed cancer sites and stages across the five highlighted trajectories of complexity/cancer care.

Exhibit 4. Top 5 most commonly diagnosed cancer sites and stage, by trajectory of cancer care among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.

	Select Trajectories of Cancer Care, n(%)				
Pre	**Low**	**Low**	**High**	**High**	**High**
Treatment	**Treated**	**Treated**	**Treated**	**Died**	**Ongoing**
Post	**Low**	**High**	**High**	**n/a**	**n/a**
N (%)	**27,896 (31%)**	**13,004 (15%)**	**11,322 (13%)**	**8,212 (9%)**	**1,869 (2%)**
1	Male genital system, stage 2	Male genital system, stage 2	Male genital system, stage 2	Respiratory system, stage 4	Digestive system, stage 3
2	Breast, stage 1	Breast, stage 1	Digestive system, stage 2	Digestive system, stage 4	Digestive system, stage 4
3	Breast, stage 2	Breast, stage 2	Digestive system, stage 1	Respiratory system, stage 3	Respiratory system, stage 3
4	Female genital system, stage 1	Digestive system, stage 2	Breast, stage 2	Digestive system, stage 3	Respiratory system, stage 4
5	Digestive system, stage 2	Digestive system, stage 3	Respiratory system, stage 1	Digestive system, stage 2	Digestive system, stage 2
Length of treatment, days (mean± SD)	196.42 ± 146.88	198.66 ± 153.54	164.04 ± 139.43	138.10 ± 150.93	551.72 ± 144.40

Summary of findings:

- Among the top three trajectories of care cancer, male genital system cancer (stage 2), was the most commonly diagnosed.
- Stage one and two breast cancers were the second and third most commonly diagnosed among the top two trajectories, both of which were low cost prior to cancer treatment, however differed in complexity in the year following cancer. Neither of these cancers was viewed as "complex" by the clinical panel.
- Digestive and respiratory system cancers were most common in trajectories where patients were high cost in the year prior. Those with longer episodes of cancer treatment, i.e. receiving ongoing treatment, or that died, were most likely have more advanced stages of cancer.
- The average treatment length, was considerably higher among those who continued to receive ongoing treatment, at 552 days. Those that died had a treatment length of 138 days, the shortest across all trajectories.
- The complexity of the trajectories was reflected in the complexity of the cancer sites. Cancer stages, however, seemed to increase with increasing complexity.

Demographic characteristics for each highlighted trajectory are described in Exhibit 5 including: median age, sex, income quintile and rurality of residence.

Exhibit 5. Demographic characteristics of Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.

Prior to cancer Cancer Outcome Post-treatment N(%)	Low Treated Low 27,896 (31%)	Low Treated High 13,004 (15%)	High Treated High 11,322 (13%)	High Died n/a 8,212 (9%)	High Ongoing n/a 1,869 (2%)
Age at diagnosis (median)	59	65	74	74	69
Sex					
Female	14,773 (53.0%)	6,120 (47.1%)	5,405 (47.7%)	3,894 (47.4%)	907 (48.5%)
Male	13,123 (47.0%)	6,884 (52.9%)	5,917 (52.3%)	4,318 (52.6%)	962 (51.5%)
Income Quintile					
Q1 (lowest)	4,212 (15.1%)	2,289 (17.6%)	2,434 (21.5%)	1,840 (22.4%)	401 (21.5%)
Q2	5,231 (18.8%)	2,591 (19.9%)	2,399 (21.2%)	1,751 (21.3%)	373 (20.0%)
Q3	5,496 (19.7%)	2,529 (19.4%)	2,202 (19.4%)	1,557 (19.0%)	343 (18.4%)
Q4	6,172 (22.1%)	2,697 (20.7%)	2,138 (18.9%)	1,562 (19.0%)	374 (20.0%)
Q5 (highest)	6,685 (24.0%)	2,862 (22.0%)	2,108 (18.6%)	1,476 (18.0%)	370 (19.8%)
Rurality Index of Ontario					
Rural	3,654 (13.1%)	1,863 (14.3%)	1,577 (13.9%)	1,173 (14.3%)	270 (14.4%)
Urban	24,220 (86.8%)	11,135 (85.6%)	9,740 (86.0%)	7,036 (85.7%)	1,599 (85.6%)

Summary of findings:

- Results highlighted in the table above suggest that age increases with complexity. The median age of patients from the low-complexity trajectory (*low-treated-low*), was 59 years, as compared to the highest complexity trajectories, (*high-treated-high* and *high-died)*, where both had a median age of 74 years.
- Patients that were receiving ongoing treatment tended to be younger, with a median age of 69 at diagnosis.
- There did not seem to be any marked differences among sexes, income quintile, or rurality of residences across trajectories, however there were slightly more patients in the higher income quintile in the low-complexity trajectory (*low-treated-low)*

The number of comorbid chronic conditions as assessed prior to each patient's cancer diagnosis, were calculated based on the list of conditions listed in Section 3.2.2. The proportion of each trajectory that fell into the following categories is indicated in Exhibit 6: 0, 1, 2, 3, 4, 5-16.

Exhibit 6. Number of comorbid chronic conditions among Ontario adults newly diagnosed with cancer between April 1ˢᵗ 2009 and September 30ᵗʰ 2010.
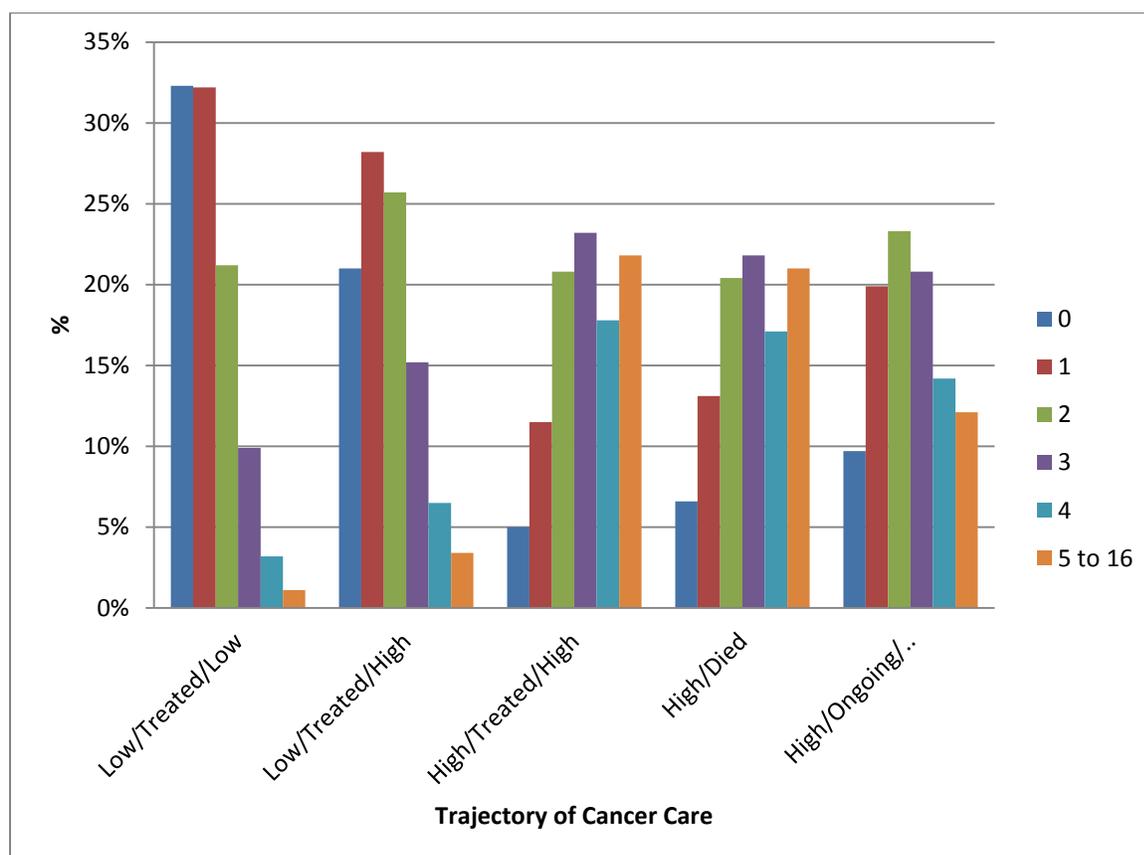
Summary of findings:

- The number of comorbid chronic conditions varied considerably according to complexity and outcomes; the number of patients with many comorbid conditions increased with increasing complexity.
- The largest proportion of patients with the highest number of comorbid conditions was found in the high complexity trajectories, where 22% of patients in the *high-treated-high* group and 21% of the *high-died* had 5-16 comorbid conditions.
- Overall, findings suggest that multimorbidity clearly relates to resource intensity before, during and after cancer treatment.
- In the Ontario population, other research has found that just over 25% of the entire population have just one of these same 17 conditions (16 plus cancer) while 12% have two conditions, 6% have three, 3% have four and just under 3% had five or more conditions [45]. These numbers highlight the increased complexity of all cancer patients as compared to the general population.

A more thorough look into the particular diagnoses afflicting patients in each trajectory was performed and is outlined in Exhibit 7. The six most common diagnoses were evaluated.

Exhibit 7. Most common comorbid chronic conditions among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.
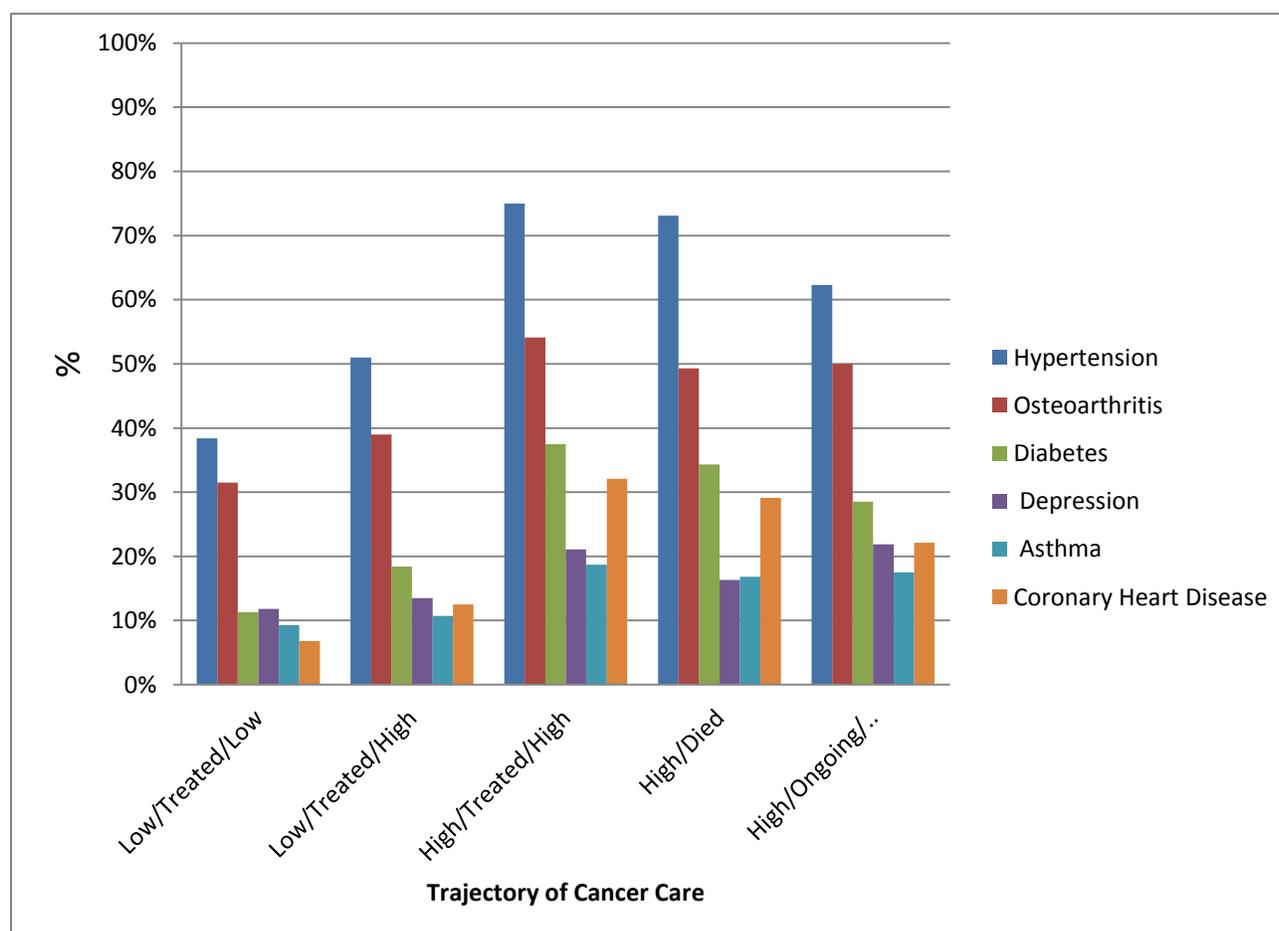
Summary of findings:

- Patients did not appear to differ with regard to the type of comorbid conditions. Across all trajectories, regardless of complexity or outcome, hypertension and osteoarthritis were the most common comorbid conditions; while the prevalence of each condition varied substantially.
- In the Ontario population, other research has found that the prevalence of these conditions is: Asthma (29%), Arthritis (24%), Hypertension (16%), and Depression (15%), Diabetes (6%) and CHD (3%) [45]. 75% of the most complex patients (*high-treated-high)* were found to be hypertensive and consistent with previous comparisons to the general Ontario population, this reflects a much larger proportion (vs. 16% of Ontario population).

Exhibit 8 reflects the severity of nine symptoms experienced by patients during cancer treatment as assessed by the Edmonton Symptom Assessment System (ESAS). Mean severity scores based on a scale of 1 to 10 for each symptom are presented across each trajectory.

Exhibit 8. Severity of symptoms experienced during cancer treatment, by Ontario adults newly diagnosed with cancer, between April 1st 2009 and September 30th 2010, based on earliest ESAS assessment.
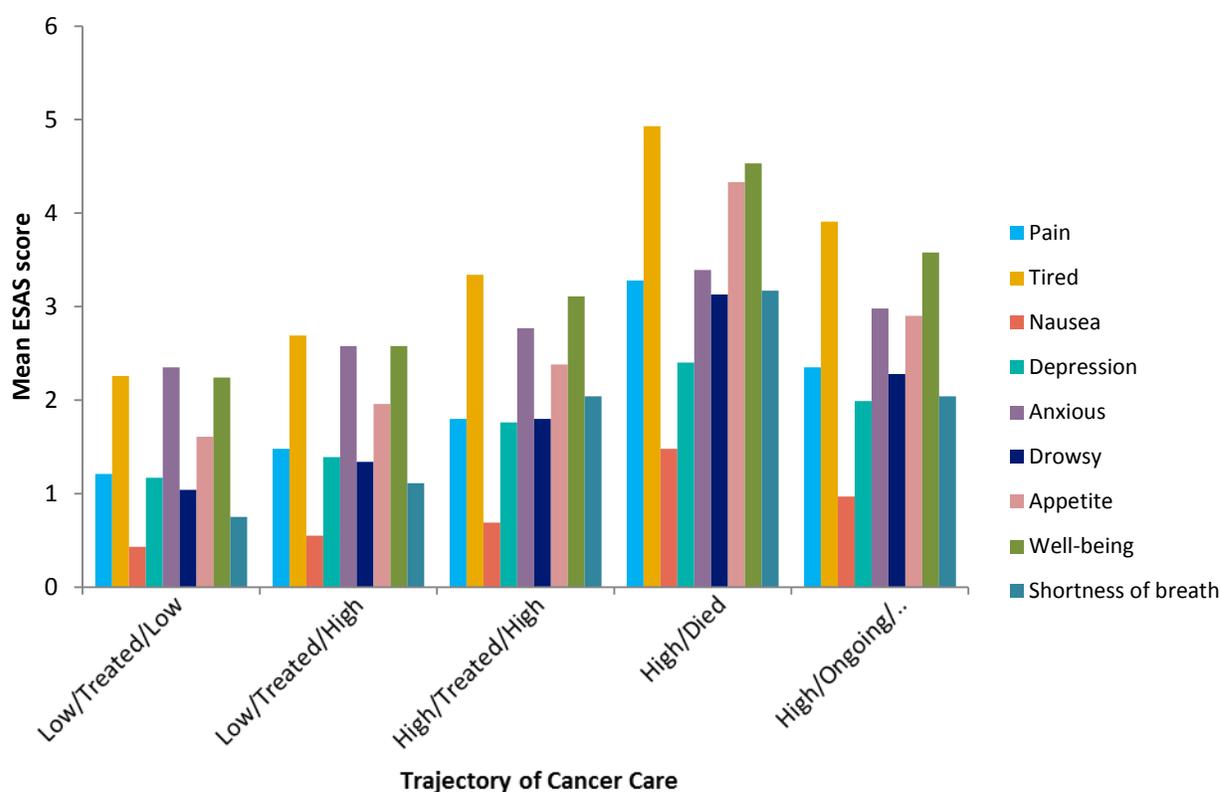
Summary of findings:

- Results indicate that tiredness, anxiety, and well-being were the most severe symptoms experienced by patients, in their early course of treatment, across all trajectories.
- All symptoms except for anxiety and depression have been shown to be positively associated with ED use among cancer patients with the well-being score associated with the highest odds of a subsequent ED visit [46].
- There is no clear difference among these symptoms across trajectories (with the exception of the *high-died* group) indicating that the complexity of each patient may not be associated with symptoms experienced during the treatment phase of cancer care.

Exhibits 9 and 10 present the results of analyses of health system utilization particular to primary care and specialist visits; Exhibit 9 outlines mean number of physician visits (primary care and specialist) and continuity of care during cancer treatment, per month. Exhibit 10 is a graphical depiction of the mean physician visits as indicated in the first two rows of the table below.

Exhibit 9. Health System Utilization: Average number of monthly physician visits and continuity of care during cancer treatment, among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.

Prior to cancer Cancer Outcome Post-treatment N(%)	Low Treated Low 27,896 (31%)	Low Treated High 13,004 (15%)	High Treated High 11,322 (13%)	High Died n/a 8,212 (9%)	High Ongoing n/a 1,869 (2%)
Primary Care Visits, mean (Q25-Q75)*					
Number of primary care visits, all causes	0.82 (0.24-1.00)	1.15 (0.30-1.25)	1.79 (0.42-1.83)	6.84 (1.51-9.69)	1.46 (0.58-1.83)
Number of primary care visits, cancer-related	0.24 (0.00-0.28)	0.32 (0.00-0.33)	0.38 (0.00-0.33)	4.25 (0.20-5.71)	0.68 (0.07-0.75)
Number of unique primary care physicians	1.78 (1.00-2.00)	2.04 (1.00-3.00)	2.08 (1.00-3.00)	3.70 (1.00-5.00)	4.28 (2.00-6.00)
Specialist Visits, mean (Q25-Q75)*					
Number of specialist visits, all causes	2.73 (1.46-3.07)	3.37 (1.67-3.75)	4.77 (2.08-5.32)	9.65 (3.46-14.05)	3.0 (1.84-3.69)
Number of specialist visits, cancer-related	1.19 (0.45-1.46)	1.20 (0.39-1.48)	1.37 (0.32-1.61)	3.44 (0.30-3.89)	1.07 (0.39-1.34)
Number of unique specialists	12.03 (6.00-16.00)	14.22 (6.00-19.00)	14.63 (6.00-20.00)	19.2 (9.00-26.00)	32.54 (21.00-41.00)
Continuity of Care, mean (Q25-Q75)					
Usual Provider of Care Index	0.31 (0.20-0.39)	0.3 (0.19-0.38)	0.3 (0.19-0.39)	0.29 (0.17-0.36)	0.26 (0.17-0.32)
Continuity of Care Index	0.17 (0.09-0.20)	0.16 (0.08-0.19)	0.16 (0.08-0.20)	0.15 (0.07-0.18)	0.12 (0.07-0.15)
Usual Provider of Care is GP/FP, N(%)	1,914 (6.9%)	1,082 (8.3%)	1,434 (12.7%)	3,118 (38.0%)	302 (16.2%)

*Average number of physician visits is standardized per month

Exhibit 10. Health System Utilization: Average number of monthly primary care and specialist physician visits (cancer and non-cancer) during cancer treatment, among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.
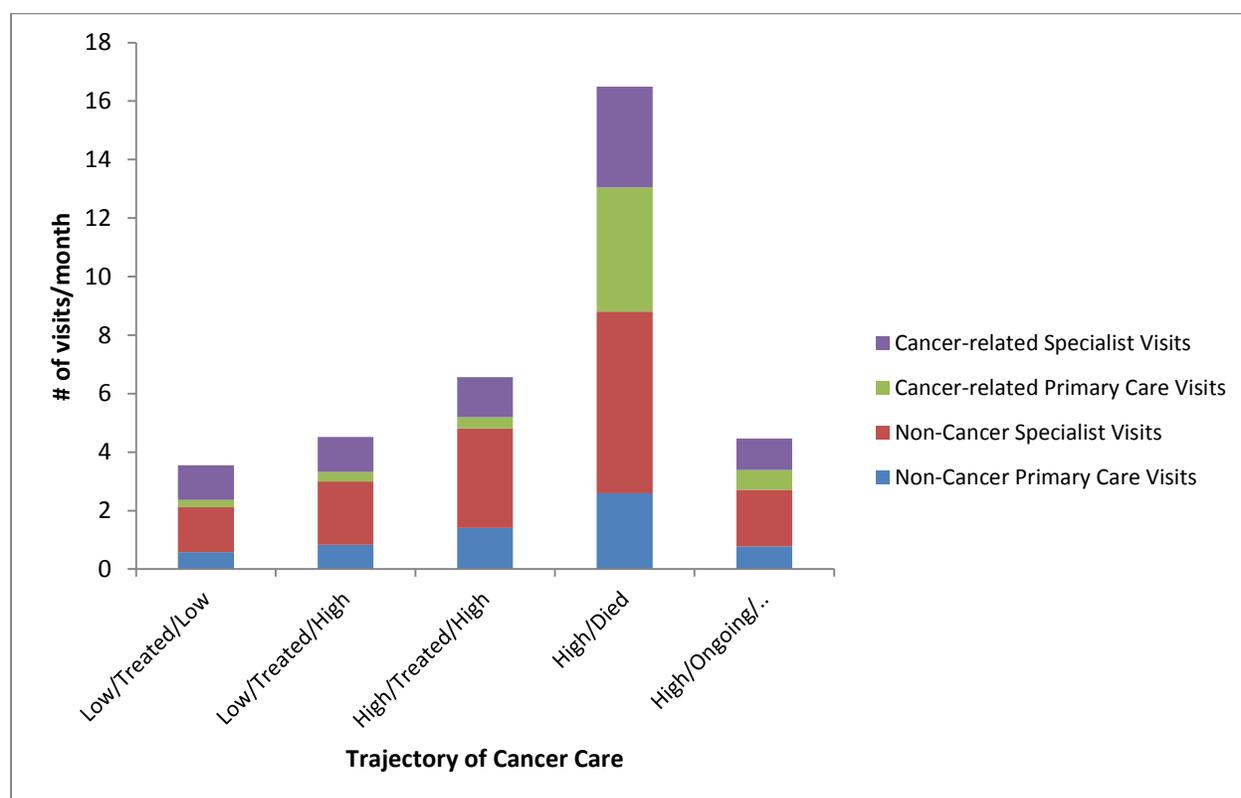
Summary of findings:

- There is an increasing gradient as complexity increases across: average number of primary care visits, average number of specialist visits, however, a smaller difference was found among cancer-related visits.
- The group of patients that were complex but died during treatment (*high-died)* had an average of 6.8 primary care visits per month, of which an average of 4.3 were cancer-related.
- The number of unique providers involved in patients' care (both primary care and specialist) increased with increasing complexity.
- The average number of specialist and primary care visits per month was highest among complex patients that died during treatment (*high-died)*. These patients, in total, had an average of 9.7 specialist visits per month, of which 3.4 were cancer-related, and .
- The number of unique specialists that were seen increased with complexity; complex patients receiving ongoing treatment (*high-ongoing)* saw an average of 33 specialists.
- Continuity of care, measured using the UPC and COC indices varied only slightly; however the proportion of *high-died* patients that identified a primary care physician as their main provider of care was 38%.

Exhibits 11 and 12 reflect health system utilization with regards to emergency department (ED) visits hospital admissions and home care use, during cancer treatment. Exhibit 11 provides the percentage of patients of each trajectory with any ED visits, hospitalizations or home care service usage, as well as the mean number of visits. Exhibit 12 is a graphical depiction of the ED visits across trajectories, and is presented to highlight the variation across complexities, and because ED visits tend to be a common indicator of care integration.

Exhibit 11. Health System Utilization- Emergency department visits, hospital admissions and home care services during cancer treatment, among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.

Prior to cancer Cancer Outcome Post-treatment N(%)	Low Treated Low 27,896 (31%)	Low Treated High 13,004 (15%)	High Treated High 11,322 (13%)	High Died n/a 8,212 (9%)	High Ongoing n/a 1,869 (2%)
Emergency Department Visits, N(%)					
At least one ED visit	8,165 (29.3%)	5,146 (39.6%)	4,792 (42.3%)	6,348 (77.3%)	1,506 (80.6%)
At least one cancer-related ED visit	557 (2.0%)	406 (3.1%)	301 (2.7%)	2,130 (25.9%)	272 (14.6%)
Number of all cause ED visits, mean (Q25-Q75)	0.56 (0.0-1.0)	0.87 (0.0-1.0)	0.97 (0.0-1.0)	1.99 (1.0-3.0)	3.34 (1.0-5.0)
Inpatient Hospital Admissions, N(%)					
At least one inpatient admission	16,108 (57.7%)	7,442 (57.2%)	7,248 (64.0%)	7,661 (93.3%)	1,489 (79.7%)
At least one cancer-related inpatient admission	14,388 (51.6%)	6,453 (49.6%)	5,958 (52.6%)	6,444 (78.5%)	1,203 (64.4%)
Number of all cause inpatient admissions, mean (Q25-Q75)	0.78 (0.0-1.0)	0.88 (0.0-1.0)	0.96 (0.0-1.0)	1.84 (1.0-2.0)	1.96 (1.0-3.0)
Home Care Services					
Home care service use, N(%)	9,315 (33.4%)	5,194 (39.9%)	4,573 (40.4%)	4,745 (57.8%)	1,406 (75.2%)
Number of home care service visits, mean (Q25-Q75)	6.08 (0.0-4.0)	10.79 (0.0-10.0)	13.63 (0.0-11.0)	23.31 (0.0-27.0)	55.55 (1.0-69.0)

Exhibit 12. Health System Utilization- Emergency department visits during cancer treatment, among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.
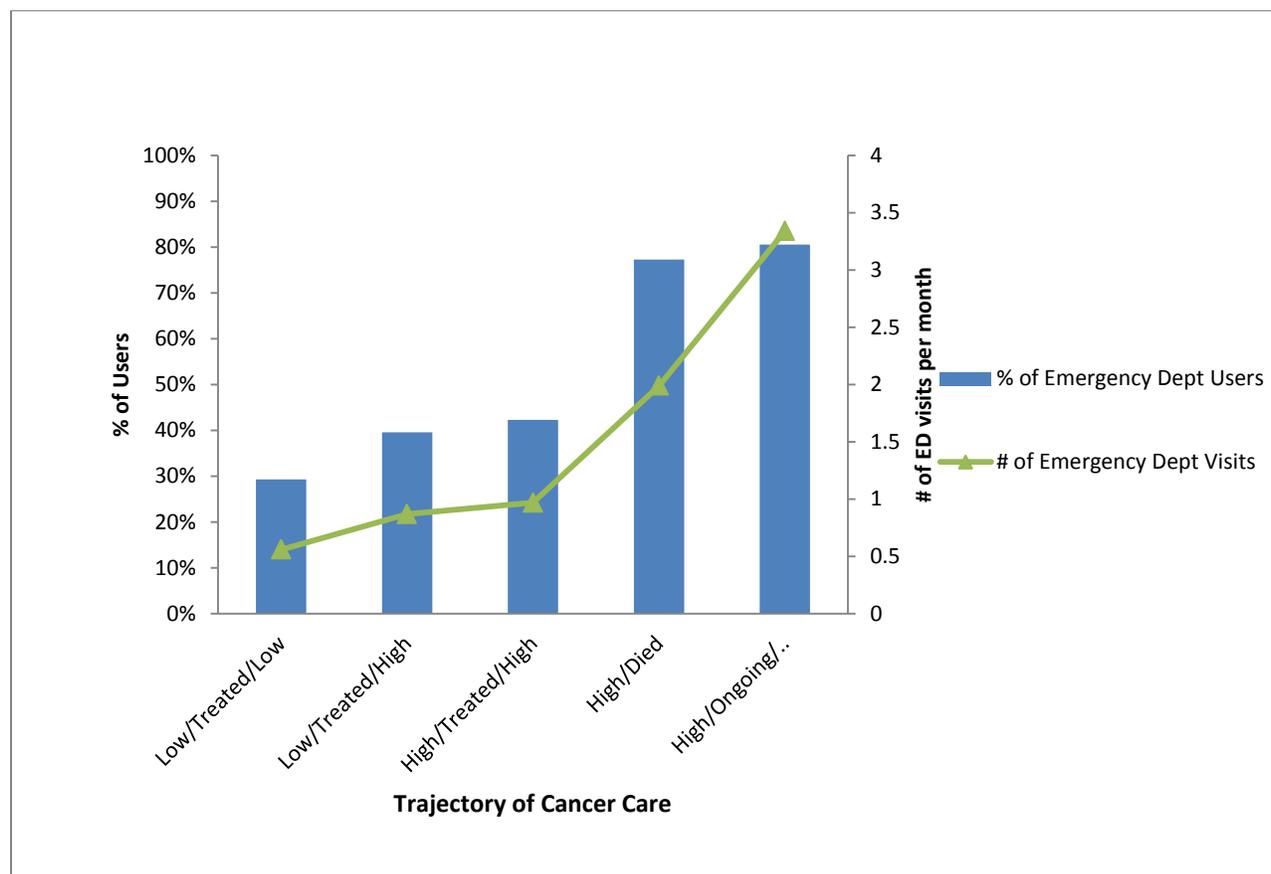
Summary of Findings:

- The proportion of patients that visited the emergency department (ED) increased with complexity, and ranged from 29% to 81%, suggesting that ED visits are common and are particularly present among patients that are high complexity. However, ED visits that were cancer-related were rare, and highest among complex patient that died (26%) (*high-died*).
- Inpatient hospital admissions were common with the majority of admissions being cancer-related, across trajectories. Cancer-related admissions were highest among more complex patients.
- The proportion of patients accessing home care services through Community Care Access Centres (CCAC) ranged from 33% to 75%, increasing with complexity and duration of care; this is indicative of the fact that patients are accessing home care services across all trajectories.

Total health system costs as determined prior to, during and following cancer treatment – that were used to categorize patients into high/low complexity categories are presented in Exhibit 13. Total costs are depicted graphically, and costs per person-day alive are provided in the subsequent table.

Exhibit 13. Total health system costs before, during and after cancer treatment, among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010.

	Low-Treated-Low	Low-Treated-High	High-Treated-High	High-Died	High-Ongoing
■ Pre-Cancer	$1,292	$1,699	$14,916	$16,521	$11,489
■ During Cancer	$54,385	$70,010	$107,664	$264,152	$48,728
■ After Cancer	$1,441	$15,352	$21,401		
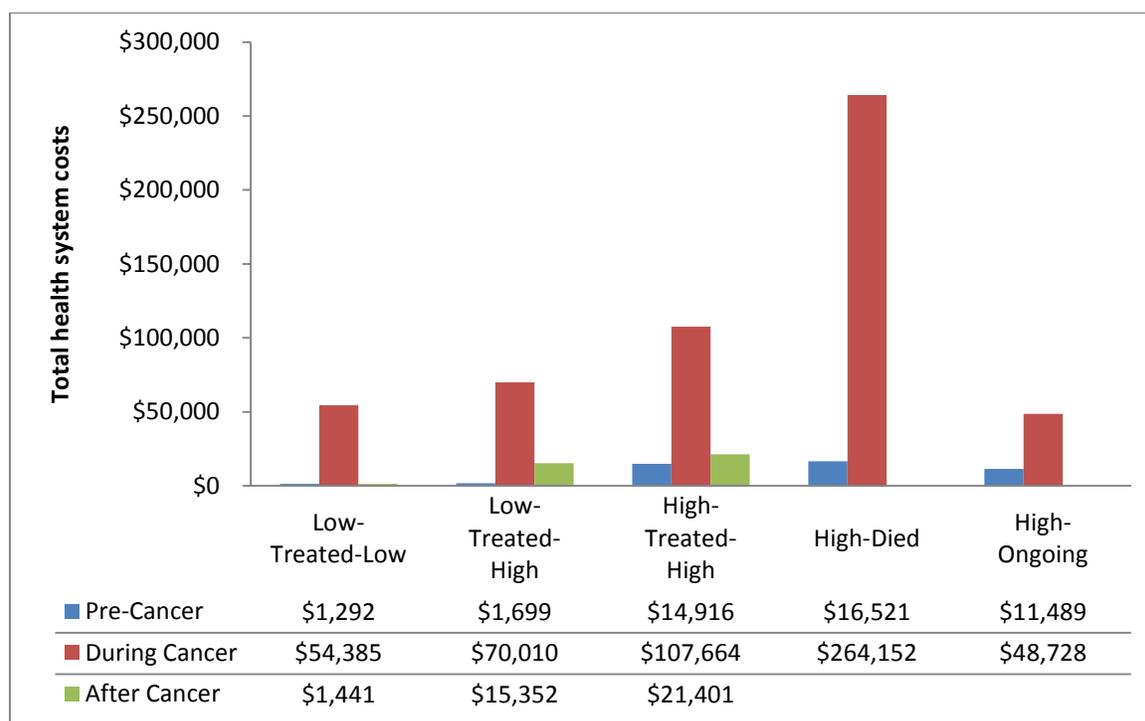
Total system cost, per person-day alive					
	Low-Treated-Low	Low-Treated-High	High-Treated-High	High-Died	High-Ongoing
Pre-Cancer	$3.54	$4.65	$40.87	$45.26	$31.48
During Cancer	$277.47	$351.81	$656.49	$1,914.14	$88.28
After Cancer	$4.04	$43.00	$59.61		

Summary of Findings:

- Health system costs were highest during cancer treatment across all trajectories, which reflect the notion that all cancer patients are considered complex during the treatment phase of their care. Health system costs reflect the use of health care resources, which were higher among patients that were highly resource intensive prior, during and after cancer treatment.
- Patients that died during treatment had the highest average health system cost, suggesting that they use a higher quantity of resources, which may include acute care, continuing care, primary care, home care, long-term care, etc.

- Patients that were high resource users and died during treatment cost an average of $558.00 per person-day alive across all periods; this estimate was substantially higher among this group.

4.2.1 Summary of Findings from Empirical Analyses

The results of analyses in this report demonstrated that all cancer patients are complex during treatment; however varying complexity of cancer patients is not based on their cancers, but on their number of comorbid chronic conditions. With the most complex patients defined as being high system users before and after treatment (*high-treated-high)* and the least complex as being low system users before and after treatment (*low-treated-low),* a comparative summary of these trajectories are described in Exhibit 14. Highlighted are the results that that age, cancer stage and number of comorbid conditions increased with complexity. The patients that were high system users prior to treatment but died of their cancer likely represents a patient sample that also had very complex cancers themselves, and the results therefore reflect similar numbers as *high-treated-high*.

Exhibit 14. Selected Patient trajectories summary statistics – Patient Characteristics.

	Low – Treated – Low	High – Treated - High	High - Died
Cancer Stage, Site	Stage 2: genitals/ breast	Stage 2: genitals/ digestive	Stage 4: respiratory/ digestive
Median Age	59	72	74
5-16 Chronic Conditions	1%	22%	21%
Specific Conditions	39% hypertension	75% hypertension	73% hypertension

Analysis on system utilization during treatment, outlined in Exhibit 15, reiterates the fact that ED usage was higher among the most complex patients (42% vs. 29%), and that although the number of cancer-related physician visits were relatively similar across trajectories, the monthly average number of non-cancer related physician visits among the *high-treated-high* patients was over double that of the *low-treated-low* patient group (4.8 vs. 2.1). The number of unique specialists in the circle of care over the course of cancer treatment was also slightly higher among the high complex patients (15 vs. 12). Evaluation on the total health system costs between 2009 and 2010 revealed a large difference between trajectories such that high complexity patients incurred costs nearly three times as high as the low complexity patients.

Exhibit 15. Selected Patient trajectories summary statistics – Health System Utilization.

	Low – Treated – Low	High – Treated - High	High – Died
% of ED users (total during treatment)	29%	42%	77%
# of Non-cancer physician visits/month	2.1	4.8	8.8
# of Cancer physician visits/month	1.4	1.8	7.7
# of Unique specialists in circle of care (total)	12	15	19
Total health system costs	$57,108	$143,981	$280,673

Through this report, the ten patient trajectories has revealed that among the patients that completed their cancer treatment during the follow-up period (where their treatment was not considered *ongoing*), 27% died, 37% survived their cancer and were considered *low* complexity after treatment, and 28% survived their cancer and were considered *high* following treatment. This delineation, depicted in Exhibit 17, highlights that while one third of the cancer population will die during or following their treatment and one third will complete their treatment as low users of the system, another third of these patients will exit the cancer system as high users.

Exhibit 17. Proportion of patients who survived & died following treatment among Ontario adults newly diagnosed with cancer between April 1st 2009 and September 30th 2010
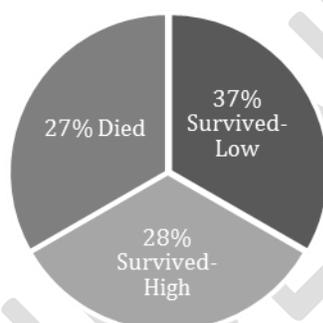
4.3 Analyses of Patient Vignettes

Vignettes were created and presented to the clinical expert panel along with vignette-specific questions that the panel responded to in advance of a meeting wherein panel comments were reviewed and consensus statements developed. For each of the vignettes a similar set of questions were posed to the clinical panel to consider and deliberate upon. These questions followed the general format of:

- What should the GP know about the patients' cancer treatment?
- What should a <specific non-cancer disease specialist> know about the patients' cancer treatment?
- How do the patient's comorbidities (and usual care for those conditions) affect their cancer treatment?
- If the patient did not visit their <specific non-cancer disease specialist> during the cancer period. Is this a problem?
- During the cancer episode, this patient had less than optimal <specific chronic disease> management based on commonly accepted laboratory testing quality measures. What is optimal <specific chronic disease> care for this patient?

- Is there anything that could be done to prevent new onset of <specific common new chronic conditions>?
- Is depression screening a normal part of cancer care and if so whose responsibility is this?
- How would we know whether this patient was on or off of the cancer care pathway?

And where applicable to trajectories with palliative patients …
- This individual seemed to be referred to the palliative care approach. What is the formal process for identifying and referring patients to palliative care?
- Is this process standardized across the province?
- Are the available palliative care resources and programs sufficient across the province?
- What are the available approaches to avoiding hospital admissions for palliative patients?

Vignette #1: Low-Treated-Low

The first vignette represents 31% of the cancer population. These patients were low cost/complex prior to cancer diagnosis, survived cancer, and were low cost/complex in the year following cancer treatment. The median patient in this vignette is female, age 59, and was diagnosed with stage 1 breast cancer. Comorbid conditions included hypertension.

During their cancer episode:

During the course of cancer treatment, this patient saw their primary care provider (PCP) three times; however all visits were unrelated to cancer. Other providers that were consulted during treatment included (1) cardiologist; (2) medical oncologist; (3) radiation oncologist; (4) anesthesiologist; and (5) general surgeon. Their PCP primarily billed OHIP for intermediate assessments (A007) and for an after-hours premium (Q012). Other services were billed by a diagnostic radiologist and nuclear medicine specialist.

Their cancer treatment involves undergoing surgery for a partial mastectomy and sentinel node biopsy, which was followed by radiation therapy.

In the year following cancer treatment, the patient was formally diagnosed with osteoarthritis.

Vignette #2: Low-Treated-High

Representing 15% of the cancer population, these patients were low cost/complex prior to diagnosis, survived cancer, and were high cost/complex in the year following cancer. The median patient in this vignette is male, age 65, with stage 2 prostate cancer. Comorbid condition included coronary heart disease and hypertension.

During their cancer episode:

In addition to their PCP, this patient saw four other specialists including (1) urologist; (2) anesthesiologist; (3) general surgeon; and (4) radiation oncologist. Their PCP billed OHIP for two intermediate assessments (A007) and two counselling visits (K013).

They were seen by the urologist twice for a partial assessment (A354); the radiation oncologist submitted four billing for partial assessments (A348); and the patient received two pelvis intra-cavitary ultrasounds (J138).

In terms of acute care use, the patient was admitted to hospital and underwent a radical prostatectomy (CMG 462). One week following discharge they visited the emergency department with a surgical site infection.

In the year following their cancer treatment they were formally diagnosed with depression (treatment unknown).

Vignette #3: High-Treated-High
The third vignette is representative of 13% of the cancer population, who were high cost/complex prior to cancer, survived cancer, and remained high cost/complex in the year after treatment. The median patient in this vignette is an older male, age 74, with stage 2 prostate cancer, with arthritis, hypertension, diabetes and colitis as comorbid conditions.

During their cancer episode:
During cancer treatment, this individual saw four other types of providers, (1) cardiologist; (2) urologist; (3) ophthalmologist; and (4) radiation oncologist, aside from their PCP. The patient made eight visits to their PCP, among which two were cancer-related. The PCP billed for two intermediate assessments (A007), two counseling visits (K013), and additional medical specific assessments (A343). The radiation oncologist saw the patient four times for partial assessments

The patient also had two intra-cavitary ultrasounds (J138), one pelvis x-ray, a prostate biopsy, and three laboratory medicine services for patient documentation and laboratory specimen collection fee.

They visited the emergency department once during their cancer episode for a flare up of their colitis.

In the year following their cancer treatment they developed renal disease and congestive heart failure.

Vignette #4: High-Died

The fourth vignette accounts for 9% of the cancer population, and represents complex patients that were older male, age 74, with stage 4 lung cancer and eventually palliative. Pre-existing comorbid conditions included chronic obstructive pulmonary disease (COPD), hypertension and diabetes.

During their cancer episode:
Half of the 12 visits this patient had with their PCP were for palliative care related to cancer, and included two home visits. Their medical and radiation oncologists also billed for weekly palliative care case management conferences. The patient had one consultation with a respirologist. During treatment, four different diagnostic radiologists read their four chest x-rays, and two different pathologists

examined samples. Extensive lab work was conducted including monitoring of creatinine, complete blood counts, calcium, phosphorous among others.

The patient received 12 home care visits for palliative care. They have one cancer-related emergency department visits, and one for anemia before being admitted to hospital for palliative care where they died.

Vignette #5: High-Ongoing

The final vignette represents 2% of the cancer population that are complex prior to cancer and have longer treatment duration. The median patient is older male, age 69, and was diagnosed with unstaged multiple myeloma. Pre-existing comorbid conditions include arthritis, depression, asthma and hypertension.

During their cancer episode:
During cancer treatment, this patient had a total of 18 visits with their PCP, of which five were cancer-related. They had 13 other physicians involved in their care, including six different specialists, such as (1) four cardiologists; (2) dermatologist; (3) two emergency medicine specialists; (4) two internists; (5) three medical oncologists; and (6) ophthalmologist. The total number of physician visits was 46, for which 13 were cancer-related.

Further, there were 18 other different physicians submitting claims for this patient, including hematologists, pathologists, and diagnostic radiologists. This patient had 37 blood tests, 20 chemotherapy treatments, and many, many other laboratory tests and assessments with a total of 240 OHIP claims over nearly two years of treatment.

In terms of health service use, the patient received home care services and has had 20 visits in total.

4.4 Summary of Clinical Expert Panel Findings

Results from empirical analyses and clinical vignette analyses were presented to the clinical expert panel for further consideration. A high-level discussion around the point of cancer diagnosis led to the panel distinguishing key roles of primary care physicians and cancer specialists. The recommendations fell into four categories: 1. Recommendations for primary care; 2. Recommendations for cancer care; 3. Recommendations for shared responsibility between primary and cancer care; and 4. Recommendations for patient engagement in their care.

Recommendations for Primary Care

They highlighted the need for primary care providers to communicate the patient's comorbid conditions to their cancer specialist. Primary care providers need to maintain involvement in treatment of medical and non-medical aspects of care; for example, optimizing dietary intake, blood pressure (hypertension) and renal function, as well as referrals to the appropriate specialists in order to avoid multiple ED visits. The panel also discussed the need to be managed by one primary care provider, and not several, as seen among some complex patients. They also maintained the importance of primary care providers' responsibility to review cancer treatment side effects while considering the patient's current comorbid conditions and chronic disease management.

Recommendations for Cancer Care

The role of the cancer specialists in this scenario would be to communicate the patient's treatment plan and risk of potential side effects to their primary care provider. In general, treatment plans should always indicate other comorbid conditions and identify any possible adverse interactions. Patient follow-up care plans should be available and identified upon discharge, with roles and responsibilities explicitly defined. The panel recommended that all cancer patients are referred to supportive care services, and highlighted the need to screen for symptoms such as depression and anxiety, using ESAS; for which results should be available to the patient, their primary care provider, and other members of the cancer care team.

Recommendations for coordination between cancer and primary care

The panel discussed the need for both the primary care physician and cancer specialist to share treatment information, and identify responsibility for prescriptions and testing. Scheduling for any tests that are required should be undertaken and assured by the physician requiring that test. Patient's scheduling of tests should be considered by each physician at the point of ordering a new test to see if consolidation of any planned testing is possible.

Recommendations for Patients

The patient should be informed of all treatment plans and responsibilities, and to optimize non-medical care.

5.0 Discussion, Conclusions & Limitations

Findings from the literature review suggest that there are important benefits in adopting a shared model of care approach between primary care providers and specialists in the coordination of cancer care. However, there are clear gaps in integrating care between physicians due to patient reports of confusion in understanding which physicians are responsible for their care as well as lack of clarity experienced by physicians with respect to transfer of care or responsibility as patients transition through phases of cancer care. Establishing continuous ongoing provider-provider and patient-provider relationships may have important implications in decreasing the likelihood of adverse of events, notably repeat hospitalizations, emergency department visits, and other forms of aggressive care practices – particular during end-of-life.

The empirical analysis with administrative data, although providing compelling results, was not without its limitations. Administrative coding, including diagnoses associated with physician visits, diagnosis associated with hospitalizations and visits to the ER are not always accurate, and due to conventions in physician billing cancer related and non-cancer related visits may have been miscoded. This should be considered when interpreting these findings.

Results from the empirical analyses showed high system utilization across all patient trajectories, indicating multiple providers, high ER use, frequent physician visits not related to their cancer. As well, the increasing number of comorbidities and high system utilization among the most complex patients highlights the potential for fragmentation of care to occur. These results are substantiated by the literature on the integration of patient care, which indicates that with more and more providers in a patient's circle of care there is an increased likelihood of fragmentation of patient care as well as poor coordination between health practitioners, particularly among patients with many chronic conditions who are undergoing complex treatments [38].The patient and family perspective of the high number of providers reflects challenges of needing to repeat their story, lack of communication regarding care or care plan between providers and care being organized for them, not with them. Multiple providers are involved in their care without having any single provider knowing their entire health story or helping them navigate the various specialists and appointments.

Ultimately, these findings highlight the importance of an integrated approach between primary care and cancer specialists, particularly among patients that are more complex. While it is certain that all patients benefit from a better integrated system, it has been shown that integrated care is only necessary for a subset of the population with complexities that require care from multiple providers and organizations [47]. By taking a stratified approach with an initial focus on complex patients, improvements to the delivery of care can be realized and lessons learned applied to benefit all patients.

Within CCO, there is currently a gap in terms of programs in place for patients that enter or leave the cancer system with high complexity due to multiple comorbities. New models of care that focus on the improvement of care for patients beyond their cancer treatment should be developed.

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Appendix A – Advisory Panel Members

Integrated Care: Advisory Panel Members		
Name	**Role**	**Organization**
Alex Iverson	Senior Manager, Health System Integration	Waterloo Wellington -LHIN
Candace Chartier	Chief Executive Officer	Ontario Long Term Care Association
Claudia Den Boer Grima	Regional Vice President Cancer Services	Cancer Care Ontario, Windsor Regional Cancer Program
Connie Twolan	Regional Director	Ontario Renal Network, Champlain
Deborah Simon	Chief Executive Officer	Ontario Community Support Association
Dr. Jonathan Sussman*	Clinical Lead, Survivorship Program	Cancer Care Ontario
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Dr. Suzanne Strasberg*	Provincial Lead - Primary Care	Cancer Care Ontario
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Sima Gandhi	Epidemiologist	Institute for Clinical Evaluative Sciences
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Gail Dobell	Director Evaluation Specialist	Health Quality Ontario
Jennifer Bowman	Vice President	North York General Hospital
Maggie Keresteci	Senior Director, Health System Programs	Ontario Medical Association
Neil Johnson	Regional Vice President Cancer Services	Cancer Care Ontario, London Regional Cancer Program
Patricia Pottie	Patient Representative	Cancer Care Ontario, Patient Family Advisory Council
Rheta Fanizza	Vice President	St. Elizabeth Home Health Care
Stacey Daub	Chief Executive Officer	Toronto, Community Care Access Centre
Subhash Bhandari	Patient family Member Representative	Cancer Care Ontario, Patient Family Advisory Council
Theresa Agnew	Executive Director	Nurse Practioner Association of Ontario

* Member of clinical expert panel