

# Improving the integration of care for patients with cancer – an Ontario perspective

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# Contributors

We'd like to thank the following organizations and programs for contributing their input and expertise during the development of this Report.

CCO:		Canadian Partnership Against Cancer
•	Diagnostic Assessment Programs	Champlain Regional Cancer Program / / The
		Ottawa Hospital
•	Disease Pathway Management	Health Quality Ontario
•	Palliative Care	Institute for Clinical Evaluative Sciences
•	Patient and Family Advisory Council	North York Centre Health Link

Person-Centred Care
 St. Elizabeth Home Care

Radiation Treatment Toronto Central Community Care Access Centre

Surgical Oncology Toronto Central Regional Cancer Program

(North)

• Primary Care Trillium Health Centre

Survivorship

Systemic Treatment

Thank you to Melissa Tamblyn and Amanda Chudak for their consulting support in the development of this Report.

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# A Message from the Clinical Lead



As clinicians, we are all looking for system solutions that help provide better quality of care, empower patients, help with system efficiencies and help us manage our practices better. A structured approach for achieving this goal should begin at the planning stage but often clinical priorities, the nature of the work, urgency of care moves us straight into active management of patients that we never come back to doing the planning in a detailed manner. Integrated care plans can help achieve the system priorities and can be initiated even after the urgent issues have been dealt with; however, having tools, knowledge and a structured approach will enable this work to start. This report presents these details and below I pose a few questions that were key to this project.

#### What did I learn?

I learned that terminology was an important issue; many terms exist to describe similar constructs to Integrated Care Plans, but are neither synonymous nor inter-changeable, e.g.: care plans, care pathways, protocols, etc. It was therefore an important exercise to validate these terms with various clinical groups, in order to solidify a definition of integrated care plans that resonate with practitioners and that is grounded in the literature.

"...different specialists don't have the same information, they don't know your story, you don't know what to tell them or what's relevant for them...more integration from a patient point of view would be a marvelous step forward in the process."

~ Karen, cancer survivor

Developing the patient scenarios from real patient data was an eye opening experience, as it was truly surprising to see the large number of health care team members that can be involved in caring for patients with cancer. Typically, one focuses largely on that which occurs within one's own institution, however these scenarios have elucidated the fact that the number of individuals in a patient's circle of care move beyond the walls of one single institution. Presenting the information as such provides a more patient-centred perspective.

Finally, I learned that in most cases where the patients are quite complex, an integrated care plan could be optimized and best facilitated by a dedicated nurse navigator.

# What was challenging?

As a whole, a true integrated care plan that spans the trajectory of the patient's care, from diagnosis to survivorship/end-of-life, is a lengthy endeavor where the bar is set rather high. Clearly of high value when well executed, but not an easy task – and yet there remains quite little detailed work on the development and implementation of integrated care plans in a Canadian context. As it stands, the current challenges are three-fold: 1) culture – as physicians, we don't inherently have time talk to one another nearly enough in our daily practice, nor do we explicitly define our clear roles within the circle of care; 2) patient goals of care are not always explicitly discussed, but should be brought to the forefront; 3) resources to

do this work – as in many cases, patients are interacting with physicians that may not be in close proximity with one another, additional resources need to become available to facilitate this communications, e.g.: electronic solutions. An interesting opportunity to make this kind of progress would be to especially in scenarios where there is not close proximity (e-solutions).

# What was exciting?

It was particularly exciting to be able to complete an endeavor like documenting the process and requirements for integrated care planning for patients with cancer. Moreover, since policy is a significant enabler in the development and implementation processes for integrated care plans, there is an opportunity for CCO to influence cancer care policy in Ontario towards standardizing an integrated approach to care planning. This is currently relatively well done in scenarios of close proximity, short or simple evaluation and in non-complex cases, as evidenced from the literature.

There is also great potential for this work if commenced with a more reasonable scope – to define complex patients or complex patient outcomes, and begin the process of integrated care planning with a smaller, pre-defined population in a step-wise manner.

# What are potential future directions for this work?

It will be important to develop and implement pilot projects in the near future; these can be created in a structured step-wise manner that address certain portions of the integrated care plan process and patient trajectory. Beginning with a structured treatment plan for systemic treatment could open the door to the possibility of later integrating this model into a larger, more comprehensive integrated care plan.

There is a strong need to improve technology as an enabler of the process, outcome and data capture/measurement. The patient scenarios that have been outlined in this report could be leveraged as "use cases" to understand the features and functionality required to integrate care planning into existing systems, such as Personal Health Records, Health Information Exchange, Patient Portals etc. Much work is needed in order to truly understand where current systems can be modified, and what additional e-solutions must be developed to facilitate adequate communication between providers and patients.

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# Introduction

Integrated care has recently emerged as an important priority across various jurisdictions, including international health organizations such as the National Health Service (NHS) in England, and the Institute for Healthcare Improvement (IHI) in the United States. In 2013, the NHS made several commitments to supporting local areas in delivering integrated care and supporting a system-wide 'shared commitment' to this endeavor (1); the IHI has released multiple reports on integrating care between healthcare providers and community organizations (2). From an Ontario perspective, the Ministry of Health and Long-Term Care has made a renewed commitment to integrated care through its Patients First: Action Plan for Health Care, highlighting "more coordinated care for patients with complex medical conditions" as a key priority (3)

At Cancer Care Ontario (CCO), there is a particular strategic focus within its Corporate Strategy for Integrated Care; its goal is to drive integrated care delivery by strengthening accountability across healthcare settings. The Integrated Care corporate strategy has therefore been defined as being grounded in improving patient care, focusing on transitions in and out of the healthcare system and coordination of treatment. Paramount to this objective is to ensure that this coordinated approach is person-centered, whereby care is designed with and for the patient and family; continuous, where providers plan and navigate with the patient to adjust the care based on changing needs; and collaborative, where interdisciplinary teams work together to provide personalized care for each patient.



Integrated Care for complex patients involves collaboration between community and primary care providers as well as hospital specialists, with the patient at the center

The delivery of integrated care across the cancer care continuum in particular has been highlighted as an important goal for CCO in the Ontario Cancer Plan (OCP) IV. The OCP IV's strategic objective and "by 2019" statement that aligns with this particular goal is to "ensure that standardized care plans are developed and communicated to all members in the care team, and across the care continuum to facilitate an integrated approach to care that is centered around the patient. By 2019 standardized care plans will be available for selected disease sites, treatments, and patient populations, across care settings. These plans will be used to improve communication around goals of care and expected outcomes among patients/families and providers." Many CCO programs are also currently planning or working on initiatives aimed at improving patient navigation (i.e. Diagnostic Assessment Programs, Systemic Treatment, Nursing, Palliative Care, Models of Care, ACCU) and developing care plans (i.e.

Diagnostic Assessment Programs, Systemic Treatment, Palliative Care, Survivorship, Primary Care, ORN).

Lastly, the development of an improved approach to integrated care and care planning is a priority for patients. The CCO Patient and Family Advisory Council lists patient navigation as a top priority. In addition, results from the 2015 Ambulatory Oncology Patient Satisfaction Survey (AOPSS) show that only approximately 50 per cent of patients say their providers are aware of their medical history, more than 80 per cent of patients say they are given confusing or conflicting information, and only approximately 60 per cent of patients say their family doctor knows enough about their cancer care<sup>1</sup>.

There is hence an expressed need to develop a common understanding of what an integrated care plan for cancer patients should entail, and how it may be developed, implemented and evaluated in support of the provincial agenda, CCO strategic and operational goals, and patient needs.

Cancer patients represent an increasingly growing and complex patient group in Canada, with approximately 2 in 5 Canadians expected to develop cancer during the course of their lives, and about 1 in 4 Canadians dying of cancer (4). Estimates indicate that roughly 190,000 Canadians will develop cancer annually (4), with about 82,200 new cancer cases expected to be diagnosed in 2015 in Ontario alone (5). Like other high-needs patient groups, cancer patients utilize a wide range of services from multiple providers across diverse settings at various points along the continuum of care, including non-cancer specialists, primary care physicians, nurses, pharmacists, physiotherapists, allied health professionals, etc. This complexity extends beyond the care of the cancer itself, as 55% of cancer patients have been found to have two or more comorbid conditions (6). This complexity requires services from several healthcare providers across settings, which has been shown to be delivered in a more fragmented and uncoordinated way (7). Additionally, there is evidence that suggests that cancer patients with multiple comorbidities can have a higher mortality rate, poorer treatment adherence and may have a delayed cancer diagnosis (8).

Recent research has examined complexity of cancer patients, and reported that the costs associated to patients' healthcare utilization before, during and after a cancer episode is strongly linked to the number of co-morbidities and to a lack of continuity in the care of the patient (6). Given their high cost and the complexity of their evolving needs including multiple transitions of care across providers and settings

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<sup>&</sup>lt;sup>1</sup> The Ambulatory Oncology Patient Satisfaction Survey results are shared annually with CCO, and the 2015 results were obtained from this data holding at CCO.

over the disease trajectory, cancer patients require integrated care from medical, nursing and allied-health practitioners in both hospital as well as community settings (7).

In light of the diverse range of health care providers and settings involved in care delivery and management of cancer patients (9,10), there has been a strong emphasis on the use of care plans (9) to enable a more streamlined and patient-centered approach towards coordinating the delivery of care across providers at various stages in the disease trajectory (12-15). Care pathways, which are also referred to in the literature as clinical pathways, critical pathways, care plans, integrated pathways, patient journeys or care maps, are considered as tools to design and improve care processes from a patient-centered lens, support the implementation of clinical governance, promote adherence to best evidence and enable the efficient and effective delivery of care (16-18).

The evidence suggests that integrated care planning has the potential to have a positive impact on:

- Supporting the management of medically and psychosocially complex patients
- Enhancing continuity of care across the patient journey
- Improving communication and information exchange across providers, disciplines and setting
  of care, as well as between patients and providers
- Having a positive impact on the patient and their family (experience, symptom management, quality of life, clinical outcomes of care), provider (satisfaction, experience) and health-care system (efficiency of care delivery, appropriate resource utilization)

Building on this foundation, CCO set out to better understand the evidence around integrated care planning and design an approach to move toward a process for integrated care planning that could be advanced by a variety of program areas within the organization.

In 2015, in response to the OCP IV's identified priorities, as well as program areas bringing this issue to light, CCO initiated the Integrated Care Plans Project. It began with a review of the evidence to scope the integrated care planning landscape. This review revealed key features, benefits and enablers of integrated care planning and set forth a draft definition for integrated care plans that set them apart from other types of care planning. Following on this work, the results of the Scoping Review were used to develop a toolkit and generic process for integrated care planning, as well as a set of case studies to illustrate the benefits and outcomes of integrated care planning at the clinical point of care. This Report highlights the work completed to date to advance the integrated care planning agenda across all of CCO and its program areas.

# Part 1: Scoping Review

#### 1.0 Purpose

There is limited consensus around what constitutes a care plan for cancer patients (or similar constructs, i.e., care pathway or care map etc.), which key stakeholders should be involved in its conception and implementation, and at what stages they should be engaged in care plan development and/or use. This gap in existing literature is further compounded by a lack of consensus on a common definition for the term 'care plan', including how it may be distinguished from other concepts, including care protocols, care pathways or care maps etc. Previous work on elucidating an appropriate definition for a care plan involved a concept analysis on a term outlining a similar process: *clinical pathway*. This analysis found 84 different definitions that had been used to describe the concept and the authors concluded that their analysis was unable to achieve general consensus on the basic tenants of a *clinical pathway*, emphasizing the need for further work to harmonize across definitions and perspectives thus achieving a common understanding of the concept of a clinical pathway (19). A clear distinction between these terms and the elements that compose care planning is a beneficial first step from a CCO perspective towards integrating care planning throughout the patient's cancer journey.

This work aims to summarize the literature and extract key themes, and formulate a conceptual framework for integrated care planning for cancer patients. As such, key objectives include: review of existing literature to extract themes and develop the framework and to conduct internal stakeholder interviews to obtain consensus and clarity around nomenclature and language used across the organization to define integrated care plans.

#### 1.1. Research questions

While previous literature on this topic has examined the impact associated with the use of care pathways in a variety of settings (20,21), there has yet to be an exclusive focus on care plans used specifically in cancer care. This review is meant to offer a more detailed understanding of the components/activities and contextual features (barriers and facilitators) associated with the design and use of integrated care plans in and along the continuum of cancer care. Furthermore, this review will examine what types of indicators are used to assess the impact of integrated care plans at three distinct levels: patient, provider and system-level. The key research questions guiding the review, outlined a priori, are as follows:

- 1. What are the key elements (i.e. planning/design features, components) of integrated care plans that are intended to improve the organization and delivery of cancer care?
- 2. Which types of indicators may be used to assess the use, impact and benefits of integrated care plans at a patient, provider and system level?
- 3. What are the key facilitators and barriers that support or inhibit the development and use of integrated care plans for cancer patients?

#### 1.2 Literature review project scope

The scope of this project is multi-staged; the first step was to formulate a working definition for an integrated care plan, the second step was to conduct a scoping review of the literature on integrated care plans using the developed definition. Internal stakeholder consultations were also conducted to socialize emerging themes from the literature and to validate the nomenclature for an integrated care plan, while ensuring no overlap with other key terms often used both in the literature and across programs at CCO.

# 2.0 Methodology

#### 2.1 ICP Definition

The literature search to develop the integrated care plan definition was performed using a number of key search terms across multiple databases (MedLine, Web of Science, Cochrane, Scopus, and Google Scholar) including: care plans, care maps, care plans, care pathway, patient care planning, individualized care plans, clinical pathway, or critical pathway. The search leveraged peer-reviewed literature, grey literature as well as policy documents authored by other research groups and cancer agencies such as American Society of Clinical Oncology (ASCO), Canadian Association of Nurses in Oncology (CANO), Ontario Medical Association (OMA) and Agency for Healthcare Research and Quality (AHRQ). A list of the definitions that were used to guide the initial development of the definition is available in Appendix A.

#### 2.2 Scoping Review

The approach and process for conducting this review was based on scoping review methodology by Arksey and O'Malley (2005) and Levac et al. (2010) (22). A summary of the research process and stages of the review is available in Appendix B.

#### Search strategy

Articles published between 1995 and 2015 were searched using the following search terms (developed following an iterative process): care map, care pathway, care plans, critical pathway, patient care planning, critical path/pathway, individualized care plans, patient care plans, advance care planning, or

patient care conferences, and cancer or neoplasms, in Medline, CINAHL, Embase, PubMed and HealthStar. Articles were reviewed if their plans were developed for adults with cancer, for any disease site, but that began following the cancer diagnosis (screening and diagnostic phase was out of scope). Figure 1 outlines the inclusion/exclusion criteria that were applied to the retrieved articles.

Figure 1: Summary of Inclusion and Exclusion Criteria

INCLUSION	EXCLUSION
<ul> <li>Cancer focus</li> <li>Care plans/pathways or a similar construct, i.e., care planning, clinical pathways, critical pathway or care map etc., was the primary intervention</li> <li>The definition of the ICP (or similar constructs) aligns with the ICP definition developed at the outset of the project</li> <li>ICPs begins once a diagnosis has been made</li> <li>All disease sites</li> <li>All study designs</li> <li>Published between 1995 and 2015</li> <li>Published in English</li> </ul>	<ul> <li>ICPs used in pediatric populations, including transitions between childhood and adulthood*</li> <li>ICPs focused on the prevention, screening or diagnosis of cancer</li> <li>Commentaries, protocols, newsletters, and review articles (i.e., systematic and realist reviews etc.)</li> <li>Published before 1995 or after March 2015</li> <li>Published in a language other than English</li> </ul>

<sup>\*</sup> Articles with a focus on adolescents and young adults were flagged but were not included in the analysis

#### Article selection

Articles were screened at the abstract level, and remaining articles were then reviewed at the full-text level by two independent reviewers to minimize bias (22). Additional details regarding the screening criteria at each level are provided in Appendix C.

#### Data extraction and analysis

Articles retained following the full-text reviews were evaluated in order to extract data on a pre-defined list of variables necessary for the thematic analysis. The thematic analysis yielded categories of common themes as they pertain to: planning and design of an integrated care plan, key components, outcome measurement, and facilitators and barriers (23). The themes were developed by analyzing the extracted data using NVIVO<sup>2</sup> - a qualitative analysis software tool that is commonly used in conducting literature reviews.

#### 2.3 Stakeholder engagement

Following the review of the included articles, and synthesis of the common themes, an internal review of program objectives, and definitions used across CCO were explored to examine concordance and

<sup>&</sup>lt;sup>2</sup> NVivo. (2016). Melbourne, Australia: QSR International.

ensure alignment with the integrated care plan project goals as a corporate initiative. Furthermore, the definition of an integrated care plan, the purpose and intended deliverables of this project were shared with multiple program areas and refined based on the feedback that was received. Programs that were actively consulted prior to the initiation of the review and engaged throughout are as follows:

- Disease Pathway Management (DPM)
- Palliative Care
- Survivorship
- Systemic Treatment Program (STP)
- Primary Care
- Patient Centred Care
- Radiation Treatment Program (RTP)
- Surgical Program
- Specialized Services Oversight Complex Hematology/Shared Care Models

Following the completion of synthesizing the emerging themes from the literature review, findings were presented to the above CCO programs. Structured consultations with these programs yielded particular themes that highlight the importance of the development of an integrated care plan conceptual framework from a strategic standpoint.

#### 3.0 Results

Figure 2 outlines the number of articles retained across both levels of screening and for data extraction and analysis. Supplemental details on each level of review are provided in Appendix C. A total of 68 articles were retained for thematic analysis.

Figure 2: Flow of Literature Review and Data Extraction

Screening Level	Number of articles
Level 1 screening Title and abstract review	Total reviewed n = 1061
Level 2 screening Full text review	Included n = 249, Excluded n = 812
Data extraction and analysis	Included n = 68, Excluded n = 181

#### 3.1 Integrated care plan theoretical definition & nomenclature

A review of peer-reviewed and grey literature was initially conducted to better understand existing terminology in this topic area, and to develop a theoretical definition for an 'integrated care plan' in the

context of our organizational mandate and strategic priorities. Following this stage of the literature review, consensus was reached on a definition for an integrated care plan for cancer patients:

#### An Integrated Care Plan:

- Acts as a model to structure, organize and monitor patient-centered care delivered longitudinally and can be adapted and individualized/tailored as needed
- Outlines the goals and elements of care to: improve patient-level outcomes (i.e., clinical, functional, and experience etc.), enhance patient/family and provider experience and enable greater efficiency in care delivery
- Ensures continuity and coordination of care during or across stages, disciplines and/or organizations involved in the patient's circle of care

During the process of developing the definition, a number of comparable concepts also emerged from the literature with overlapping ideas, including: clinical pathway, care pathways, disease pathway, care maps and clinical guidelines etc. An important secondary objective of developing a definition for the purposes of this project involved obtaining a better understanding of how these constructs are used both in published literature, and within CCO's organizational boundaries. Figure 3 outlines that the proposed nomenclature for an integrated care plan is therefore the combination of core patient-centric elements of personalized care planning with the sequential nature of care/clinical/disease pathways and treatment plans, and the management components of clinical protocols/guidelines. Figure 3 represents the conceptualization of how the definition of an integrated care plan falls in the overlap of clinical guidelines, treatment plans, personalized care plans, and disease pathways.

#### In essence, integrated care plans:

- 1. Serve as a model for organizing and delivering care longitudinally;
- 2. Are used across sites, providers and settings, and;
- 3. Are both process oriented and evidence informed.

Figure 3: Overview of existing definitions

Concept	Definition
Clinical Protocol, Clinical Guideline, Care Protocol	Management of clinical aspects of patient care e.g. medications, tests
Personalized Care Planning or Individualized Plans of Care	Support organizing care that is patient-centric and incorporates patient/caregiver's goals and preferences
Care Pathways, Clinical Pathways, Disease Pathways, Pathway Maps	Outline a sequence for assessment and interventions to be used in the care of patients with a particular diagnosis; typically disease/stage specific
Treatment Plans (ie: Survivorship/Palliative)	Documentation and coordination of cancer treatment to facilitate provider-to-provider and provider-to-patient communication

This definition for integrated care plans informed the review and data extraction process as it helped construct a robust set of data elements deemed important to extract from included studies.

#### 3.2. Key Descriptive findings

The included studies were examined for certain descriptive factors that characterized the kinds of plans that were being evaluated, including the setting that they were being developed and implemented, the part of the patient disease pathway that was the primary focus, the variety of cancer disease sites that created the patient cohorts, and the method of delivery of the integrated care plan (paper vs. electronic). A summary of these characteristics follow:

#### 3.2.1 Settings

A variety of settings for integrated care planning implementation was referenced in the literature, including one or more of the following: primary care, hospice care, hospitals and cancer centres, as well as in a number of health systems, including both public and private payer system designs. Most of the articles that met the inclusion criterion were based in healthcare organizations in the United States (37%), followed by the United Kingdom (13%) and Canada (10%).

#### 3.2.2 Cancer patient pathway phases

Different phases of the patient pathway were represented in the included studies. Integrated care plans were either designed for one particular point in the cancer journey, or they were comprehensive, in that they were meant to facilitate and coordinate a patient's transition from one phase into another (i.e.: transition from active treatment to survivorship). No studies were found to have designed or implemented an integrated care plan for the entire patient pathway (from diagnosis to either palliative or survivorship). Forty-one percent of the included studies evaluated integrated care planning during the active treatment phase of the cancer trajectory, with 40% for surgical cases and 1% for systemic treatments cases. Thirty-five percent of the studies investigated the use of care planning during the survivorship phase of the

cancer pathway, and 16% of studies focused on palliative and end-of-life care plans. As mentioned, only 7% of the studies focused on transitions between different phases (comprehensive).

#### 3.2.3 Disease Sites

A variety of different cancer diagnoses were represented in the included studies, the most common disease sites are as follows:

- Breast (28%)
- Multiple cancers (19%)
- Esophagus (9%)
- Colorectal (7%)
- Gynecological (4%)
- Head and Neck (6%)
- Prostate (6%)
- Gastrointestinal (4%)

#### 3.2.4 Method of Delivery

Twenty-nine percent (29%) of the included studies evaluated the use of integrated care plans that were paper-based, while 7% used electronic care plans. Fifteen percent (15%) implemented a combination of both paper-based and electronic, however in 49% of the studies, the mode was not indicated explicitly.

Of those studies that indicated a combination of both electronic and paper format of their integrated care plan, there was a considerable degree of variation. For instance, one study that focused on care planning for head and neck cancer patients, hard copies of the pathway were developed and posted in the patients' rooms to facilitate communication between patients, families, and members of the care team, while an electronic version of the pathway was created and incorporated into the hospital computerized order entry system (24). Whereas in another study, the patient received a partially completed survivorship care plan during a check-In with the nurse practitioner following treatment, and the patient takes the ICP document home, and a copy is scanned into the patient's electronic medical record (25).

#### 3.3 Integrated Care Planning Themes

Five main themes emerged from the thematic analysis, highlighting different stages of developing and implementing integrated care plans in a clinical setting, as well as measures to evaluate their effectiveness, and potential barriers and facilitators within organizational uptake. Figure 4 outlines the

emerging themes and the characteristics that were highlighted among studies included for review are summarized. The 5 emerging themes are as follows: 1. Planning and Design: factors involved in the planning phase of an integrated care plan; 2. Components: key features activities and elements of the care plan itself; 3. Outcome Measurement: indicators used to evaluate success of an integrated care plan; 4. Facilitators: factors that support design, uptake and implementation; and 5. Barriers: Challenges associated with development and use.

Figure 4: Common Themes and Characteristics Extracted from Thematic Analysis

Planning and Design: Factors involved in planning phase	Components: Key features/activities	Outcome measurement*: Indicators to evaluate success	Facilitators: Factors that support design, uptake and implementation	Barriers: Challenges associated with development and use
<ul> <li>Multidisciplinary teams at the core of ICP development and implementation</li> <li>Iterative development process</li> <li>Evaluation and concordance analyses</li> <li>Comprehensive training for all staff in patient's circle of care</li> <li>Implementation point of contact within the team/organization</li> <li>Adaptation of ICP to local context</li> </ul>	<ul> <li>Multi-disciplinary delivery of care (2 or more)</li> <li>Sequencing of care activities</li> <li>Role clarity</li> <li>Accountability across providers in circle of care</li> <li>multi-disciplinary case conferencing</li> <li>Patient needs assessment</li> <li>Transitional care planning</li> <li>Follow-up post treatment</li> <li>Documentation of care delivery</li> <li>Patient and/or caregiver education</li> <li>Information/communication n exchange</li> <li>Symptom/outcome monitoring</li> <li>Patient and caregiver engagement</li> <li>Point of contact for patients/providers</li> <li>Customization of ICP based on patient needs</li> <li>Establishing goals of care</li> </ul>	<ul> <li>Patient-level</li> <li>Patient or caregiver satisfaction</li> <li>Symptom management</li> <li>Quality of Life</li> <li>Anxiety</li> <li>Unmet needs</li> <li>Extent of cancer care coordination</li> <li>Provider-level (Team or Process)         <ul> <li>Uptake of ICP by providers</li> <li>Analysis of pathway variance/deviation</li> <li>Provider satisfaction</li> <li>Communication within and across provider teams etc.</li> </ul> </li> <li>System-level (Clinical or Financial)         <ul> <li>Postoperative complications</li> <li>In-hospital mortality</li> <li>Length of Stay (LOS)</li> </ul> </li> </ul>	<ul> <li>Patient/Provider level (Micro)</li> <li>Strong provider buy in</li> <li>Multi-stakeholder representation in development stages</li> <li>Patient and caregivers engaged and educated on ICP purpose</li> <li>Organization level (Meso)</li> <li>Quality improvement plan/strategy at an organizational level</li> <li>Oversight of implementation process (dedicated staff/team)</li> <li>Resource availability (i.e., funding and/or IT support)</li> <li>Policy (Macro)</li> <li>National integrated oncological care policy</li> <li>Incentives to support adoption/maintenance of ICP</li> </ul>	<ul> <li>Limited provider buy-in/adherence</li> <li>Staff turnover</li> <li>Patient complexity limits the use of standardized care plans (e.g. fast-track surgical protocol)</li> <li>Lack of IT support (e.g. integrated Electronic Health Records)</li> <li>Time and resource intensity</li> </ul>

Planning and Design: Factors involved in planning phase	Components: Key features/activities	Outcome measurement*: Indicators to evaluate success	Facilitators: Factors that support design, uptake and implementation	Barriers: Challenges associated with development and use
		<ul> <li>Cost (Total cost - typically in-patient cost of care)</li> </ul>		

<sup>\*</sup>list of indicators and tools available in appendix D

#### 4.0 Conclusions

There is a growing emphasis on the use of care plans to guide the organization and delivery of cancer care across CCO. To that end, this review was able to identify key considerations for the design and implementation of integrated care plans. The review was unable to identify a single integrated care plan that spanned across all stages of the cancer journey in a comprehensive manner; most plans had a vertical focus in that they often reflected a single stage, and few included a transition to a second stage. It was also shown that very few studies are investigating the use of an integrated care plan during the active cancer treatment phase, particularly with respect to systemic and radiation treatment. Although the literature on this topic is seemingly in its early stages, the themes extracted from the analysis proved to be valuable concepts that informed the creation of a conceptual framework. Additionally, the stakeholder consultations as well as these gaps in the literature, bring to light key issues being experienced by oncological and primary care providers in caring for cancer patients and the need for a more horizontal approach to integrated care planning.

# Part 2: Toolkit and Scenarios

# 1.0 Purpose

This section of the Report builds on the key findings of the Scoping Review to further illuminate a tangible path towards initiating integrated care planning for cancer patients in Ontario. It provides a toolkit of materials and establishes a practical definition and process for integrated care planning that can be used across CCO programs for the purposes of planning, and to guide program-level efforts at improving patient navigation and care planning. The toolkit is supported by scenarios that demonstrate how integrated care planning may be introduced at the point of care through an alignment with existing clinical workflows and resources. Finally, the Report offers a view of readiness for integrated care planning in the cancer system and population, and outlines priority next steps for moving this agenda forward.

# 2.0 Methodology

This work was undertaken between January and April 2016, with the initial goals of validating the findings of the Scoping Review (outlined in Part 1 of this report) and developing a set of scenarios to illustrate integrated care planning in action for four cancer patients. In the course of meeting these goals the work was extended to include the construction of a generic process for integrated care plan development and implementation. This was considered a necessary step, both to enable the inclusion of a future state view of integrated care into the scenarios and to extend the high-level findings of the Scoping Review towards a more tangible depiction of integrated care planning for cancer patients in Ontario.

This work was conducted with reference to the Scoping Review and CCO operational models, and included an informal literature review, semi-structured interviews with a broad range of CCO staff and external stakeholders, clinical validation of scenarios, and consensus building, using the following approach:

#### 1. Review and documentation of evidence

The work began with a thorough examination of the Scoping Review and its key findings, including a strong emphasis on the developed theoretical definition that informed the data extraction process, and the emerging themes from the literature. These themes outlined the key features, benefits and enablers associated with integrated care planning based on the experience of other organizations in Canada and around the world.

A broad review of additional literature on integrated care plans and the process of integrated care planning was also conducted to better understand the context for integrated care planning and to inform the approach to this work. This review revealed three important concepts that became foundational to our methodology:

- Complex patients benefit from integrated care planning. The literature demonstrated the
  value of continuity of care for complex patients, defined as those patients whose care
  experience transcends multiple phases of care, providers and / or settings.
- Cancer patients are complex, even beyond their cancer. Work by the Institute for Clinical and Evaluative Sciences (ICES) (26) analyzed healthcare utilization and cost amongst patients newly diagnosed with any cancer in Ontario, grouping patients into ten trajectories of care according to the cost and nature of their healthcare before, during and after cancer treatment. The work reported that 55 per cent of this cancer cohort had two or more comorbid conditions that resulted in frequent transitions between the cancer system, primary care providers and other community care providers during and after cancer treatment (6).
- The value of integrated care planning is best illustrated through the lens of "real" patients. The Esther Project (27) used the persona of "Esther" an elderly woman with chronic conditions and occasional acute care needs to rally doctors, nurses and other healthcare providers in working together to improve patient flow and coordination across six municipalities in Sweden. The three-year project resulted in impressive reductions in hospital admissions, length of stay and wait times. The team credits the use of a "real" patient whose needs can be easily understood and imagined as key to their success.

Based on these findings, it was concluded that this work should be rooted in four clinical care scenarios based on actual complex patient cases.

#### 2. Validation of emerging themes from the literature and approach to work

Consultations were conducted with a broad range of CCO leaders and staff as well as selected external stakeholders to seek input on the theoretical integrated care plans definition and the key themes that emerged from the Scoping Review. Concurrent to these consultations, selected external stakeholders were consulted on exemplar programs for integrated and coordinated care planning in Ontario. CCO stakeholders included representation from Disease Pathway Management, Diagnostic Assessment Programs, Surgical Oncology, Systemic Treatment, Radiation Treatment, Survivorship, Palliative Care, Primary Care and Person-Centred Care, the Ontario Renal Network, as well as CCO Directors. External stakeholders included patient and family representatives as well as representatives from the CCO

Integrated Care Advisory Panel (with members from the Canadian Partnership Against Cancer, Health Quality Ontario, the Institute for Clinical Evaluative Sciences, St. Elizabeth Home Health, and Trillium Health Centre), the North York Centre Health Link, the Toronto Central Community Care Access Centre, and the Champlain and Toronto Central Regional Cancer Programs. A full list of CCO staff and external stakeholders consulted can be found in Appendix E.

These consultations yielded general support for the findings of the Scoping Review, as well as key insights into integrated care planning processes and tools currently in use and available in Ontario. Specifically, the consultations uncovered that:

- Integrated care planning is both a process and a tool; that is, integrated care planning is
  composed of both the methods used to enable integrated care (e.g. to engage a patient,
  convene a care team, set roles and responsibilities, exchange information, etc.) and the content
  used to enable integrated care (i.e. information documented and shared).
- Several models of integrated care planning are currently being tested across the province at a
  regional and organizational level, including the Health Links initiatives and several survivorship
  initiatives. However, these models are limited to pockets of integrated care; most do not span
  the full journey of care or the continuum of providers and settings accessed by cancer patients.
- Several electronic information systems exist across the province to support integrated care
  planning at a regional or organizational level. Examples include the Integrated Assessment
  Record (IAR), Hospital Report Manager (HRM), connectingGTA (cGTA),
  connectingSouthWestOntario (cSWO), and the Client Health and Related Information System
  (CHRIS), to name a few. However, none of these systems are yet available province-wide, nor
  are they integrated with existing electronic medical records or across all settings of care.
- Several tools are available and in use to support the documentation and exchange of important patient information, including Diagnostic Assessment Program standard referral forms, the Health Links Coordinated Care Plan (28), the American Society of Clinical Oncology (ASCO) Treatment Plan (29), the ASCO Survivorship Plan (30), the INTEGRATE Project Primary Care Form (28) and the Liverpool Care Pathway for the Dying Patient (32). However, none of these tools capture information that spans the full care journey and rarely are the tools shared across all of the providers involved in an individual cancer patient's care.

#### Development of model for integrated care planning

With a validation of the Scoping Review as a foundation, the draft definition and emerging themes from the literature were used as a starting point for the initial documentation of the concept, features, benefits and enablers of an integrated care plan.

Concurrent to this documentation, attention was turned to developing an integrated care planning scenario framework. The ICES work on the healthcare utilization and cost of the cancer population was once again referenced as a source of patient vignettes based on actual clinical cases, including data such as gender, age, pre-existing conditions, cancer assessments and diagnosis, cancer treatment, emergency department visits and care team members (26). Four complex patient cases were selected, reflective of the following healthcare utilization trajectories before, during and after cancer treatment:

- **Low-Treated-High**: A patient with low initial healthcare costs who was diagnosed with cancer, treated for cancer, and survived cancer with high ongoing healthcare costs.
- High-Ongoing: A patient with high initial healthcare costs who was diagnosed with cancer and whose treatment for cancer was ongoing over a period of more than one year.
- **High-Treated-High**: A patient with high initial healthcare costs who was diagnosed with cancer, treated for cancer, and survived cancer with even higher ongoing healthcare costs.
- **High-Died**: A patient with high initial healthcare costs who was diagnosed with cancer, was given palliative and end of life care, and who died within one year of their cancer diagnosis.

From these cases, basic patient profiles were documented as a starting point for the reconstruction of each patient's journey and an assessment of the current state of integrated care (i.e. a view of patient care without integrated care planning).

A generic process for the development and implementation of an integrated care plan was also created to serve as the basis for the future state of integrated care (i.e. a view of patient care with integrated care planning) for each scenario.

Finally, a draft list of information elements were compiled from existing coordinated care planning tools as a starting point for discussion around the key patient data that should be collected and shared with patients and providers across the care journey in support of integrated care.

#### Consultation on toolkit and scenarios

Consultation on the toolkit and scenarios was conducted with CCO staff and took part in three phases:

 Consultations focused on expanding the four draft patient profiles into valid clinical scenarios that included a full patient journey and assessment of the current state of integrated care.

- Consultations focused on validating the generic process for integrated care plan development and implementation, and the draft list of information elements to be documented as part of this process.
- Consultations focused on applying the generic process for integrated care plan development and implementation to each of the four clinical scenarios to produce future state views of integrated care, including the identification of roles and responsibilities for integrated care and a possible future state clinical workflow relating to each patient journey.

The results of these consultations allowed for the development of a final integrated care plan toolkit and four integrated care planning scenarios.

#### Final validation and discussion of next steps

A final round of consultation was conducted with CCO staff to validate the overall findings of this work and to obtain input and agreement on next steps. These consultations produced both a preliminary readiness assessment for the initiation of integrated care planning for cancer patients in Ontario and a shortlist of priority opportunities for the advancement of integrated care planning in the cancer population.

#### 3.0 Results

The results of the informal literature review and consultations led to the development of a toolkit for integrated care planning, including a more refined, practical definition of integrated care planning, a process for integrated care planning development and implementation, and four integrated care planning scenarios based on real patient cases.

#### Definition

Consultations with CCO staff and external stakeholders produced a final working practical definition of both integrated care and integrated care planning that leverages both the theoretical definition outlined in the Scoping Review, and the definition set out in CCO's Corporate Strategy.

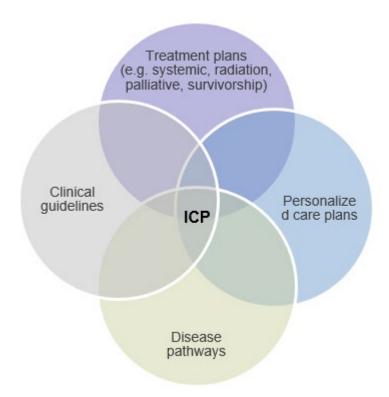
**Integrated care** is grounded in improving patient care, focusing on transitions within the healthcare system and coordination of treatment. This coordinated approach should be person-centered, continuous and collaborative.

**Integrated care planning** provides a process and a structure to organize the goals and elements of a complex patient's care. It establishes roles and responsibilities to facilitate coordination and continuity at

the point of clinical care and across settings, providers and stages of care, and includes the measurement of outcomes.

Conceptually, an integrated care plan is the intersection between a disease pathway, clinical guidelines, a treatment plan, and a personalized care plan. Unlike disease pathways and clinical guidelines, which outline a standard of care for a group of patients, integrated care plans focus on the needs of an individual patient at the point of clinical care. While treatment plans also focus on the individual patient, they are most often limited to one phase of care. Integrated care plans transcend specific treatments to encompass the overall needs and goals of the patient across multiple stages of the care journey, including transitions into, within, and out of the cancer system. Based on this person-centred approach, integrated care plans also encompass elements of personalized care planning.

Figure 5: Integrated Care Plan Concept



This work also validated a set of features uncovered by the Scoping Review that characterize successful integrated care planning. These include:

- A person-centred approach
- The inclusion of a patient needs assessment

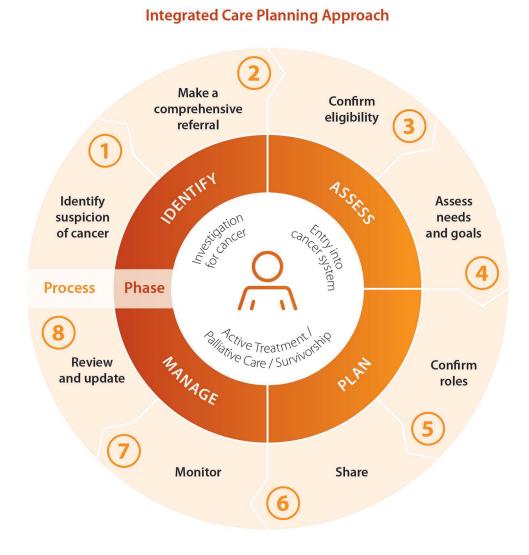
- Planning and delivery by a multidisciplinary team with role clarity and sequencing of care activities
- Early planning for transitional care
- Patient and caregiver education
- An iterative and progressive approach to plan development
- Ongoing plan evaluation and outcomes measurement

•

Building on the definition of an integrated care plan and its features, a generic four-phase, eight step, person-centred process for the initiation, development and implementation of an integrated care plan for cancer patients emerged.

The process for integrated care planning was mapped against the National Health Service (NHS) Identify, Assess, Plan, Manage model (33) for alignment with other CCO integrated care initiatives. Key to the process is the use of the integrated care plan for an individual complex patient at the point of care. Complex patients often have multiple conditions or other factors that contribute to high healthcare utilization, frequent transitions between care providers and settings, low health literacy, or the risk of poor outcomes. At its core, this process is aligned to the cancer patient journey and focuses on key methods to increase the continuity of care, improve communication and information exchange across patients and providers, phases of care and settings, and enable a positive impact on the experience and outcomes of the patient.

Figure 6: Process for developing and implementing an integrated care plan, with high-level documentation elements



Below are the details of the integrated care planning process:

- Identify a suspicion of cancer based on symptoms, a positive screening result, or incidental findings.
- Make a comprehensive referral by supplying the information needed to perform an assessment
  of the patient's integrated care plan eligibility, and to support future integrated care planning and
  improve clinical care. Currently, referrals to the cancer system often exclude important patient
  information, such as information about pre-existing conditions, medications and other care team

members. This can create difficulty in properly assessing the patient's complexity and planning care.

- Confirm the patient's eligibility for an integrated care plan based on either (1) a diagnosis of cancer plus the presence of two or more comorbid conditions or (2) expected outcomes. Through this latter criterion, an integrated care plan may be deemed beneficial based on a number of factors, including age, social determinants of health, frailty, the diagnosis of a complex or advanced cancer, the high toxicity of treatment, or a palliative intent of treatment.
- Assess the patient's needs and goals by engaging the patient in a discussion of their personal goals of care and plan for future situations. At this stage, a formal assessment of lifestyle factors, psychosocial status, functional status and symptoms should be conducted, along with a medication reconciliation. Following these assessments, an initial view of the potential risks and issues to be addressed through the integrated care plan should be evident.
- Confirm roles by identifying the members of a core care team who will participate in integrated care planning and take responsibility for monitoring and managing the patient's side effects, symptoms, treatment and general health during and after cancer treatment. The core care team is also responsible for considering patient needs and goals to determine planned interventions, key points of information exchange, and the targeted outcomes of the integrated care plan.
- Share the integrated care plan with the patient, their family, and the core care team. At this time, an integrated care planning lead provides the patient and the core care team with an orientation to the integrated care plan and its associated roles and responsibilities. The lead may also provide patient resources and education.
- Monitor concordance against the integrated care plan as well as patient symptoms and
  outcomes to determine if adjustments to the care plan are needed. At this step, both the patient
  and the core care team have roles, with the patient self-monitoring for symptoms and the core
  care team monitoring the patient according to their confirmed responsibilities. Outcomes are
  measured using the "indicators to evaluate success" identified through the Scoping Review.
- Review and update the integrated care plan as needed for patient or family needs, new goals of
  care, changes in the patient's treatment plan, medications, condition or care team, hospital
  admissions, Emergency Department visits, new phases of care, or desired outcomes.

Throughout this process, important information about the patient must be documented and shared with the patient and the core care team to enable integrated care. A series of existing tools used to coordinate and manage patient care were reviewed as part of this work. While the data elements included in these tools did overlap to some extent, none of the tools included a full set of data elements to support patient care across the entire cancer journey, from referral to treatment to survivorship or end of life. A draft list of integrated care plan documentation elements was compiled by bringing together the data elements from the existing tools into a single view. This list could be used as a starting point to develop a common tool for integrated care planning. The full draft list of documentation elements and their sources can be found in Appendix F.

#### Scenarios

Based in work by the ICES on the complexity of the cancer population and supported by the generic process for integrated care plan development and implementation, four integrated care plan scenarios were developed based on real patient cases.

Figure 7: Summary of patient cases

#	Patient	Healthcare utilization trajectory	Pre-cancer diagnosis comorbid conditions	Cancer diagnosis	Post-cancer treatment comorbid conditions
1	Sue (female, aged 65)	Low-Treated-High	Stable coronary heart disease, hypertension	Stage 1 breast cancer	Depression, heart attack
2	Vince (male, aged 72)	High-Ongoing	Arthritis, asthma, depression, diabetes, hypertension	Multiple myeloma	Not applicable, treatment ongoing
3	Russell (male, aged 74)	High-Treated-High	Arthritis, GERD, diabetes, hypertension	Stage 2 prostate cancer	Congestive heart failure, renal disease
4	Sabine (female, aged 74)	High-Died	COPD, hypertension	Stage 4 lung cancer	Not applicable, died

Each scenario was composed of three main parts:

- A patient profile, which provided key data about the patient, including gender, age, pre-exiting conditions, cancer diagnosis, healthcare utilization, and care team members.
- A current state, which provided a detailed patient journey based on the patient profile and an assessment of the current state of care for the patient without integrated care planning.
- **A future state**, which provided an ideal view of care for the patient and highlighted some of the key benefits and outcomes that could be achieved through integrated care planning.

In examining the current state of integrated care in cooperation with clinicians, and in applying a future state integrated care planning process to each patient profile, a number of current challenges and potential future benefits and outcomes of integrated care planning were uncovered.

Figure 8: Current challenges and potential future benefits / outcomes of integrated care planning

	•		
Cı	urrent state (without integrated care planning)	Fu	uture state (with integrated care planning)
CI	hallenges	Po	otential benefits
•	Referrals are often incomplete (e.g. lack patient history and information about pre-existing conditions and care providers), leading to difficulty in assessing patient complexity, coordinating care, and bringing the patient to timely treatment	•	A comprehensive referral includes details of patient history and comorbid conditions to allow for a fulsome assessment of patient complexity and needs, triggering integrated care planning activity and improved care planning
•	Patient engagement in discussion of goals of care and plan for future situations is ad hoc or absent, resulting in a lack of patient input into the care planning process	•	Patient is engaged to discuss / assess their goals and needs and to perform a medication reconciliation, and this information is used to inform treatment planning
•	Patient assessment (e.g. for lifestyle factors, psychosocial factors, functional status, symptoms) and medication reconciliation are ad hoc or absent, meaning that treatment planning	•	A core care team is identified and brought together for care planning that takes into consideration the patient's goals, needs, cancer diagnosis and other conditions
•	often takes place without careful consideration of the full scope of patient needs  Care planning is fragmented between various community and cancer care providers, meaning that treatment planning and management often	•	A tool is available with a common set documentation elements that can be used to capture, update and share information across the patient journey and between providers of care
•	take place in silos by patient condition  There is no tool available to capture and share patient information that is relevant and useful across the care journey and all providers of care	•	Each core care team member's role in the monitoring, management and documentation of the patient's treatment, symptoms and side effects is clearly defined and communicated to allow for maximization of clinical care delivery, appropriate use of resources, and
•	Roles and responsibilities related to monitoring and managing the treatment, symptoms and side effects of the patient's cancer and other comorbid conditions are seldom confirmed or communicated, resulting in a lack of	•	comprehensive monitoring  Core care team members are given information about the expected symptoms and side effects of cancer treatment
	coordination, duplication and / or gaps in patient care, and patient confusion about where to go for help	•	The patient is oriented to their integrated care plan, including their prognosis, goal of treatment, and the roles and responsibilities of their core care team members, and given
•	Care plans are not shared with the patient or across all care providers, leading to a lack of awareness and understanding of the patient's prognosis and goal of treatment		resources and education to support self- monitoring, reporting and management of potential symptoms and side effects

prognosis and goal of treatment

#### **Current state (without integrated care planning)**

- Patient and community care providers are not given thorough information about the potential symptoms and side effects of cancer treatment
- Patient education lacks coordination and often excludes information related to self-monitoring, management and reporting of symptoms
- There is no built-in, standardized measurement and assessment process to monitor and evaluate patient needs and outcomes
- New information about the patient's needs, treatments, medications, etc. are often not communicated to the patient and all care providers, resulting in disconnects in the patient's care

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#### **Future state (with integrated care planning)**

 Core care team members monitor and manage the patient according to their confirmed roles and responsibilities and a defined measurement framework, and update other care team members when the patient's needs or care changes

#### Potential outcomes

- Enhanced continuity of care across the patient journey
- Improved communication and information exchange across providers, disciplines and settings of care
- Improved patient and family experience •
   Improved symptom management, quality of life and clinical outcomes of care
- Improved provider satisfaction and experience
- Increased efficiency of care delivery
- More appropriate resource utilization

Specific improvements in clinical outcomes of care were realized in each scenario. These positive outcomes varied in nature based on the patient journey and the specific challenges being addressed by the patient's integrated care plan. The scenarios also served to identify key care team members and their roles relating to participation in the integrated care planning process and the care of the patient.

The purpose of the scenarios was to bring to life an aspirational future state view of integrated care planning for cancer patients in Ontario. In reality, the implementation of integrated care planning at the point of clinical care will vary widely by location, for alignment with a range of clinical workflows and resources. These scenarios serve to identify four possible options for the implementation of integrated care planning at the point of clinical care, identifying key resources and roles as examples.

#### **SCENARIO #1: Patient Profile**

Patient – Sue (female, aged 65)

NA	Pre-cancer diagnosis care journey	Cancer diagnosis care journey	Post-cancer treatment care journey
Conditions	Stable coronary heart disease, hypertension	Stage 1 breast cancer	Depression, heart attack
Healthcare utilization	Low	Treated	High
trajectory	Infrequent primary care and specialist care involvement	Cancer assessment and treatment = ultrasound, MRI, biopsy, surgery In community; hormonal therapy, radiation treatment at Cancer Centre	Increased ongoing home care, primary care, and specialist care involvement
Care Team In Cancer centre	NA	Pathologist, Medical oncologist, Radiation oncologist, Radiation therapist, Pharmacist, Nurses	NA
Care Team In community hospital	NA	Radiologist, nuclear medicine specialist, Anesthesiologist, General surgeon, Nurses	NA
Care Team In other community setting	Family doctor, Cardiologist, Pharmacist, Family and friends	Family doctor, Cardiologist, Pharmacist, Nurse navigators, Home care workers, Family and friends	Family doctor, Cardiologist, Pharmacist, Home care workers, Family and friends

# SCENARIO #1: Current State (without integrated care planning)

Cancer journey	Current State
Investigation for cancer  Stable coronary heart disease Abnormal screening mammogram Ultrasound, MRi and biopsy Diagnosis of breast cancer confirmed  Entry into cancer system Referral to general surgeon at community hospital Partial mastectomy, sentinel node biopsy Home care initiated Emergency Department Visit for surgical site infection Stage 1 breast cancer diagnosis  Active treatment / survivorship Referral for radiation treatment Radiation treatment (four weeks) Assessment for adjuvant therapy Tamoxifen regimen begins Depression, fatigue, pain on right side of chest Heart attack, hospital admission	<ul> <li>Abnormal screen identified by Ontario Breast Screening Program</li> <li>Nurse Navigator assigned. Automatic referral to Breast Assessment Program for cancer assessment</li> <li>Entry into cancer system</li> <li>No assessment for pre-existing conditions. Patient assumed non-complex due to nature of cancer. Patient frustrated that providers seem unaware of medical history.</li> <li>Informal assessment of symptoms and functional status but not shared with family doctor. No medication reconciliation or psychosocial assessment.</li> <li>Care planning fragmented Family doctor and cardiologist not informed of potential cardiac side effects of cancer treatment. No roles confirmed.</li> <li>Active treatment / survivorship</li> <li>Lack of complete patient record. Patient and care team do not receive shared documentation or orientation to roles</li> <li>No coordinated monitoring of side effects, symptoms, outcomes</li> </ul>
Depression, fatigue, pain on right side of chest	shared documentation or orientation to roles

# SCENARIO #1: Future State (with integrated care planning)

Duran	Process Future State				
		Future State			
Inve	stigation for cancer	Investigation for cancer			
•	identify suspicion of cancer	Abnormal screen identified by Ontario Breast Screening Program (OBSP) ar	าd		
•	Make a comprehensive referral	reported to family doctor. IC plan lead – family doctor.			
Entr	y into cancer system	Entry into cancer system			
•	Confirm eligibility	Nurse navigator documents information for assessment of complexity,			
•	Assess needs and goals	including pre-existing conditions. Orients primary oncology nurse. IC plan	า		
•	Confirm roles	lead – OBSP nurse.			
		Primary oncology assesses patient complexity. Patient eligible for an IC	plan		
Activ	ve treatment / survivorship	based on comorbid conditions. IC plan lead – Primary Oncology nurse			
•	Share	Patient engaged in assessment, discussion of goals and medication			
•	Monitor	reconciliation. Findings incorporated into treatment plan. IC plan lead –			
•	Review and update	Primary Oncology nurse			
	·	Active treatment / survivorship			
Core	Care Team (Members and their role in care)	Core care team identified. Cancer treatment plan and expected outcome			
•	Family doctor – monitor / manage general health and	documented at core care team discussion. Roles confirmed. IC plan lead	i —		
	depression	Primary Oncology nurse			
•	Cardiologist – monitor / manage cardiac health	Primary Oncology Nurse shares copy of IC plan with patient and core ca      The provides arientation and highlights releasing patient advection.			
•	Primary oncology nurse – Lead IC plan. Monitor / manage	team, provides orientation and highlights roles, gives patient education. I	C		
	symptoms.	plan lead – Primary Oncology nurse			
•	General surgeon – monitor / manage surgical symptoms,	Core care team monitors symptoms and outcomes according to roles. He Care Workers addresses would ED visit avoided IC plan lead Prima			
	outcomes.	Care Workers addresses wound, ED visit avoided. IC plan lead – Prima Oncology nurse, Cardiologist, family doctor and home care workers.	ıy		
•	Medical Oncologist – monitor / manage systemic treatment		4		
	symptoms, outcomes	Cardiologist alerts Primary Onc. Nurse to blood pressure increase. Heart attack avoided. Survivership plan initiated after period of survivership plan initiated after period of survivership plan initiated after period of survivership. IC.			
•	Radiation Oncologist - monitor / manage radiation treatment	attack avoided. Survivorship plan initiated after period of surveillance. IC plan lead – Primary Oncology nurse, Cardiologist, family doctor and hom			
•	Radiation Therapist - monitor / manage radiation treatment	care workers.	1 <del>C</del>		
	symptoms, outcomes.	outo workers.			
•	Home Care workers – monitor / manage symptoms				

#### **SCENARIO #2: Patient Profile**

Patient – Vince (male, age 72)

	Pre-cancer diagnosis care journey	Cancer diagnosis care journey
Conditions	Arthritis, asthma, diabetes, hypertension, depression	Multiple myeloma
Healthcare utilization trajectory	High. Frequent primary-care and specialist care involvement. Moderate home care involvement.	Ongoing (treatment). Cancer assessment and treatment = blood and other laboratory tests, chemotherapy at Cancer Centre. High home care, primary care and other specialist care involvement.
Care Team In Cancer centre	NA	Hematologists (several), Radiologists (several), Pathologists (several), Medical oncologists (x3), Chemotherapy Nurse, Emergency medicine specialists (x2), Internists (x2), Pharmacist, Nurses
Care Team In community hospital	NA	NA
Care Team In other community setting	Family doctor, Cardiologists (x4), Dermatologist, Endocrinologist, Ophthalmologist, Pharmacist, Home care workers, Family and friends	Family doctor, Cardiologists (x4), Dermatologist, Endocrinologist, Ophthalmologist, Pharmacist, Home care workers, Dentist, Family and friends

# SCENARIO #2: Current State (without integrated care planning)

Cancer journey	Current State
Investigation for cancer	Investigation for cancer
<ul> <li>Arthritis. Asthma, diabetes, hypertension</li> <li>Back pain</li> <li>Blood test shows anemia and abnormal protein</li> <li>Referral to hematologist at Cancer Center</li> </ul>	<ul> <li>Suspicion of cancer identified by Family Doctor via blood test</li> <li>Family Doctor makes referral to hematologist. Missing key information including previous conditions.</li> </ul>
<ul> <li>Entry into cancer system</li> <li>Additional assessments</li> <li>Diagnosis of multiple myeloma confirmed</li> <li>Cancer Center Consult</li> </ul> Active treatment / survivorship <ul> <li>Chemotherapy (9 cycles of 4 weeks on and 1 week off)</li> <li>Prescription of steroids and bone protectant</li> <li>Frequent blood tests</li> <li>Medication-related loss of diabetic control</li> <li>Emergency department visit for hyperglycemia, dehydration, peripheral neuropathy</li> <li>Diarrhea, fatigue, bone pain, low immunity</li> <li>Progression of cataracts</li> </ul>	<ul> <li>Entry into cancer system</li> <li>No assessment for pre-existing conditions. Patient frustrated that providers seem unaware of medical history.</li> <li>Medication reconciliation conducted but not shared with Family Doctor. No assessment of patient symptoms, status, needs or goals.</li> <li>Care planning fragmented. Family doctor, Specialists not informed of potential side effects of medications and cancer treatment. No roles confirmed.</li> <li>Active treatment / survivorship</li> <li>Lack of complete patient record. Patient and care team do not receive shared documentation or orientation to roles</li> <li>No coordinated monitoring of side effects, symptoms, outcomes across providers and settings. Lack of diabetes monitoring</li> <li>Limited exchange of information between providers. Patient unsure of who to call for symptoms, changes in condition.</li> </ul>

# SCENARIO #2: Future State (with integrated care planning)

	(with integrated care planning)			
Proce		Future State		
Investigation for cancer		Investigation for cancer		
•	Identify suspicion of cancer  Make a comprehensive referral	<ul> <li>Suspicion of cancer identified by family doctor via blood test. IC plan lead – Family Doctor</li> </ul>		
Entry •	into cancer system Confirm eligibility Assess needs and goals Confirm roles	<ul> <li>Family Doctor makes referral to hematologist, documents pre-existin conditions and current treatment plan. IC plan lead – Family Doctor</li> <li>Entry into cancer system</li> <li>Primary oncology assesses patient complexity. Patient eligible for an IC plan based on comorbid conditions and expected outcomes. IC</li> </ul>		
Active	e treatment / survivorship Share Monitor Review and update	<ul> <li>plan lead – Primary Oncology nurse</li> <li>Patient engaged in assessment, discussion of goals and medication reconciliation. Findings incorporated into treatment plan. IC plan lead – Primary Oncology nurse</li> </ul>		
Coro	Care Team (Members and their role in care)	Active treatment / survivorship		
Core	Care Team (Members and their role in care) Family doctor – monitor / manage general health and pre-existing conditions Cardiologist – monitor / manage cardiac health Endocrinologist – monitor / manage diabetes Primary oncology nurse – Lead IC plan. Monitor / manage symptoms. General surgeon – monitor / manage surgical symptoms, outcomes. Medical Oncologist – monitor / manage systemic treatment symptoms, outcomes Radiation Oncologist - monitor / manage radiation treatment Radiation Therapist - monitor / manage radiation treatment symptoms, outcomes. Home Care workers – monitor / manage symptoms	<ul> <li>Core care team identified. Cancer treatment plan and expected outcomes documented at Multidisciplinary Cancer Conference. Role confirmed. IC plan lead – Primary Oncology nurse</li> <li>Primary Oncology Nurse shares copy of IC plan with patient and cor care team, provides orientation and highlights roles, gives patient education. IC plan lead – Primary Oncology nurse</li> </ul>		

#### **SCENARIO #3: Patient Profile**

Patient – Russell (male, age 74)

NA	Pre-cancer diagnosis care journey	Cancer diagnosis care journey	Post-cancer treatment care journey
Conditions	Arthritis, GERD, diabetes, hypertension	Stage 2 prostate cancer	Congestive heart failure, renal disease
Healthcare utilization trajectory	High. Frequent primary-care and specialist care involvement.	Treated. Cancer assessment and treatment = PSA test, ultrasound, pelvic x-ray, prostate biopsy in community; CT, bone scan, radiation treatment at Cancer Center. Moderate home care, primary care and other specialist care involvement.	High. Increased ongoing homecare, primary care, and specialist care involvement.
Care Team In Cancer centre	NA	Pathologist, Radiologist, Radiation oncologist, Radiation therapist, Pharmacist, Nurses	NA
Care Team In community hospital	NA	Radiologist, Urologist, Nurses	Urologist
Care Team In other community setting	Family doctor, Cardiologist, Dermatologist, Pharmacist, Family and friends	Family doctor, Cardiologist, Dermatologist, Pharmacist, Home care workers, Family and friends	Family doctor, Cardiologist, Pharmacist, Home care workers, Family and friends

# SCENARIO #3: Current State (without integrated care planning)

Cancer journey	Current State
Investigation for cancer	<ul> <li>Current State</li> <li>Investigation for cancer</li> <li>Suspicion of cancer identified by Family Doctor via PSA test</li> <li>Family Doctor makes referral to urologist. Missing key information including previous conditions.</li> <li>Entry into cancer system</li> <li>No assessment for pre-existing conditions. Patient assumed non-complex due to nature of cancer. Patient frustrated that providers seem unaware of medical history.</li> <li>Informal assessment of goals but not shared with Family Doctor. No assessment of patient symptoms, status or needs. No medication reconciliation.</li> <li>Care planning fragmented. Family doctor not informed of potential side effects of medications and cancer treatment. No roles confirmed.</li> <li>Active treatment / survivorship</li> <li>Lack of complete patient record. Patient and care team do not receive</li> </ul>
<ul> <li>Prescription of medications for erectile dysfunction</li> <li>Urinary retention, catheterization and home care initiated</li> <li>Decreased kidney function</li> <li>Emergency department visit for proctitis</li> <li>Renal Disease and congestive heart failure</li> </ul>	<ul> <li>Lack of complete patient record. Patient and care team do not receive shared documentation or orientation to roles</li> <li>No coordinated monitoring of side effects, symptoms, outcomes across providers and settings. Delays treatment for urinary retention.</li> <li>Limited exchange of information between providers. Patient unsure of who to call for symptoms, changes in condition.</li> </ul>

# SCENARIO #3: Future State (with integrated care planning)

(with integral	ted care planning)
Process	Future State
Investigation for cancer  • Identify suspicion of cancer	<ul> <li>Investigation for cancer</li> <li>Suspicion of cancer identified by family doctor via PSA test. IC plan lead –</li> </ul>
<ul> <li>Make a comprehensive referral</li> <li>Entry into cancer system</li> </ul>	<ul> <li>Family Doctor</li> <li>Family Doctor makes referral to urologist, documents pre-existing conditions and current treatment plan. IC plan lead – Family Doctor</li> </ul>
<ul><li>Confirm eligibility</li><li>Assess needs and goals</li><li>Confirm roles</li></ul>	<ul> <li>Entry into cancer system</li> <li>Primary oncology assesses patient complexity. Patient eligible for an IC plan based on comorbid conditions. IC plan lead – Primary Oncology nurse</li> </ul>
Active treatment / survivorship	Patient engaged in assessment, discussion of goals and medication reconciliation. Findings incorporated into treatment plan. IC plan lead – Primary Oncology nurse
Core Care Team (Members and their role in care)  • Family doctor – monitor / manage general health and pre-	Active treatment / survivorship     Core care team identified. Cancer treatment plan and expected outcomes documented at core care team discussion. Roles confirmed. IC plan lead – Primary Oncology nurse
<ul> <li>existing conditions</li> <li>Cardiologist – monitor / manage cardiac health</li> <li>Primary oncology nurse – Lead IC plan. Monitor / manage symptoms.</li> </ul>	Primary Oncology Nurse shares copy of IC plan with patient and core care team, provides orientation and highlights roles, gives patient education. IC plan lead – Primary Oncology nurse
<ul> <li>Urologist - monitor / manage urinary symptoms, outcomes</li> <li>Home Care workers – monitor urinary health</li> <li>Radiation Oncologist - monitor / manage radiation treatment</li> </ul>	<ul> <li>Core care team monitors symptoms and outcomes according to roles. IC plan lead – Primary Oncology nurse, Urologist, Radiation Oncologist and Family Doctor</li> </ul>
Radiation Therapist - monitor / manage radiation treatment symptoms, outcomes.	<ul> <li>Patient alerts Primary Onc. Nurse to urinary symptoms, Core care team informed. Renal disease progression avoided. IC plan lead – Primary Oncology nurse, Urologist, Radiation Oncologist and Family Doctor</li> </ul>

### **SCENARIO #4: Patient Profile**

Patient – Sabine (female, age 74)

NA	Pre-cancer diagnosis care journey	Cancer diagnosis care journey
Conditions	COPD, hypertension, diabetes	Stage 4 lung cancer
Healthcare utilization trajectory	High. Frequent primary-care and specialist care involvement. Moderate home care involvement.	Died. Cancer assessment and treatment = chest x-rays, laboratory tests in community, chemotherapy, radiation at Cancer Center.
Care Team In Cancer centre	NA	Nurse navigator, Radiologists (x3), Pathologists (x2), Respirologist, Palliative Care consultant, Medical oncologist, Chemotherapy Nurse, Radiation oncologist, Radiation therapist, Pharmacist, Nurses
Care Team In community hospital	NA	Radiologist, Nurses
Care Team In other community setting	Family doctor, Cardiologists, Endocrinologist, Pharmacist, Home care workers, Family and friends	Family doctor, Cardiologist, Endocrinologist, Pharmacist, Home care workers, Community palliative care nurse (x2), Family and friends

## **SCENARIO #4: Current State**

(without integr	ated	care	planning	)
	Cur	rent !	State	

Cancer journey Current State		
Cancer journey		
Investigation for cancer	Investigation for cancer	
COPD. diabetes, hypertension	Suspicion of cancer identified by chest x-ray at community hospital	
Pneumonia, admission to community hospital	Family Doctor makes referral to Lung Diagnostic Assessment Program	
Chest x-ray		
Referral to Lung Diagnostic Assessment Program		
	Entry into cancer system	
	No assessment for pre-existing conditions. Patient assumed non-complex	
Entry into cancer system	due to nature of cancer. Patient frustrated that providers seem unaware of	
Additional assessments	medical history. Diagnosis and prognosis not communicated to patient.	
Diagnosis of stage 4 cancer	Assessment of patient symptoms, status, needs conducted but not shared	
	with Family Doctor. No medication reconciliation. No advance care plan.	
Active treatment / survivorship	Care planning fragmented. Family doctor, specialists not informed of	
Palliative chemotherapy and radiation initiated	potential side effects of medications and cancer treatment. No roles	
Fatigue, nausea, vomiting, lack of appetite, shortness of breath	confirmed.	
Blood test results delivered late Friday show haemoglobin at 60		
Emergency Department visit for transfusion	Active treatment / survivorship	
Aggressive treatment continues	Lack of complete patient record. Patient and care team do not receive	
	shared documentation or orientation to roles. No caregiver support given.	
Emergency Department visit for severe shortness of breath     Liganital admission and death	No coordinated or after hours monitoring of side effects, symptoms,	
Hospital admission and death	outcomes across providers and settings. Treatment despite declining status.	
	Limited exchange of information between providers. Patient unsure of who	
	to call for symptoms, changes in condition.	

# SCENARIO #4: Future State (with integrated care planning)

# Process Investigation for cancer

- Identify suspicion of cancer
- Make a comprehensive referral
- Entry into cancer system
- Confirm eligibility
- Assess needs and goals
- Confirm roles

#### Active treatment / survivorship

- Share
- Monitor
- Review and update

#### Core Care Team (Members and their role in care)

- Family doctor monitor / manage general health/ palliative / after-hours care
- Community Palliative Care Coordinator and Primary oncology nurse – Lead IC plan. Monitor / manage symptoms.
- Endocrinologist monitor / manage diabetes
- · Cardiologist monitor / manage cardiac health
- Palliative Care Consultant monitor / manage palliative care
- Chemotherapy nurse and Medical Oncologist monitor / manage systemic treatment symptoms, outcomes
- Radiation Therapist and Radiation Oncologist monitor / manage radiation treatment symptoms, outcomes
- Community Palliative Care Nurse and Home Care workers monitor / manage general health

#### **Future State**

#### Investigation for cancer

- Suspicion of cancer identified by chest x-ray at community hospital and reported to Family Doctor. IC plan lead Family Doctor
- Family Doctor makes referral to Lung DAP, Nurse Navigator assigned.
   Documents information for assessment of complexity. IC plan lead DAP Nurse Navigator

#### Entry into cancer system

- Primary oncology assesses patient. Patient eligible for an IC plan based on expected outcomes. Diagnosis and prognosis confirmed with patient. IC plan lead – Primary Oncology nurse
- Patient and family engaged in assessments, discussion of goals and medication reconciliation. Findings incorporated into palliative care plan. IC plan lead – Primary Oncology nurse

#### Active treatment / survivorship

- Core care team identified. Palliative care plan and expected outcomes documented at Multidisciplinary Cancer conference. Roles confirmed. IC plan lead Primary Oncology nurse
- Primary Oncology Nurse shares copy of IC plan with patient / family and core care team, provides orientation and highlights roles, gives patient and family education and support. IC plan lead – Primary Oncology nurse
- Core care team monitors symptoms, status, goals at palliative care community rounds, and according to roles. IC plan lead – Primary Oncology nurse, Family Doctor, Community Palliative Care Coordinator
- Community Palliative Care Coordinator core care team to declining status.
   Hospital admission avoided. Patient dies in hospice. IC plan lead Primary Oncology nurse, Family Doctor and Community Palliative Care Coordinator

#### 4.0 Conclusions

This work has provided a broad a set of tools that has the potential to set a provincial standard for integrated care planning in the cancer population. It is expected that these tools will be used to guide CCO program efforts aimed at improving patient navigation and care planning. It is also expected that these tools will be applied at the point of clinical care to improve the continuity of care, experience, and clinical outcomes of cancer patients in Ontario.

To frame CCO's go-forward approach, a preliminary readiness assessment was conducted. The results of this assessment helped to determine priority opportunities and immediate next steps to advance the integrated care planning agenda.

#### Readiness assessment

Findings from the Scoping Review showed a number of key enablers that are essential to the support of integrated care planning:

- Policy
- Buy in / use by team and patient
- Dedicated navigator aligned with existing clinical workflow and resources
- Tools for patient assessment
- Staff training
- Ongoing relationships and team continuity
- Integrated information systems and tools for data collection, information exchange, reporting and evaluation

Using these enablers as a framework, a preliminary readiness assessment was conducted to determine the strengths, challenges and opportunities that currently exist for integrated care planning in the cancer population. The assessment revealed that while a number of supports and tools already exist to enable integrated care planning, these supports and tools generally occur in pockets by location, organization or

phase of care. Currently, none of the enablers are fully supported across the entire cancer journey and all settings of care.

For example, CCO's existing organized screening and diagnostic assessment programs provide excellent navigational support to patients during the diagnostic phase of their journey, as well as comprehensive referral structures; however, these programs capture only a small subsection of the total cancer population. Navigation support does, in fact, exist at several points across the care journey, but gaps between these points of navigation remain and no end-to-end approach has yet been instituted. Similarly, several tools and information systems exist to support the documentation and exchange of information, but these too are limited to specific locations, providers, phases of care, or settings, and lack integration with other existing clinical information systems. There are also several existing forums for care teams to connect, including multidisciplinary cancer conferences and communities of practice, but these forums are mostly limited to cancer care providers and exclude primary care and other community care providers. On a positive note, patients are asking for better continuity of care, as demonstrated by the Patient and Family Advisory Council's ongoing prioritization of patient navigation and the 2015 AOPSS results, implying strong patient support for integrated care planning efforts. The details of the full preliminary readiness assessment can be found in Appendix G.

The key moving forward lies in a bridging of existing supports through a coordinated and integrated effort amongst CCO programs. Strong support will be required from both clinical and administrative leadership. Following these initial efforts, pilot testing of integrated care planning at the point of clinical care may be initiated.

## **Appendices**

# Appendix A: Scoping Review Detailed Theoretical Integrated Care Plan Definition

Our review of the literature was guided by the following theoretical definition for an integrated care plan for cancer patients:

- An ICP acts as a model to structure, organize and monitor patient-focused care that is delivered longitudinally to a well-defined group of patients
- The overarching objectives of an ICP include:
  - Enabling the delivery of patient-centered 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" (Singer et al., 2011)
  - Explicitly outlines the goals and key elements of care based on evidence-informed guidelines, emerging best practices, as well as patient and caregiver expectations
  - o Improving patient-level outcomes (i.e., clinical, functional, and experience of care etc.)
  - Reducing risks to patient safety
  - Increasing provider satisfaction/experience
  - o Improving the efficiency of care delivery to reduce inappropriate resource utilization
- ICPs may be used to ensure continuity of care during a specific stage or over multiple stages of an illness, and across practice/professional disciplines and settings/organizations involved in the patient's circle of care (i.e., engages two or more providers AND/OR is being used in two or more settings)

## Appendix B: Scoping review research methodology (22)

STAGE	DESCRIPTION
Clarifying purpose and identifying research questions      Identifying relevant studies	<ul> <li>A number of key research questions were developed in alignment with organizational strategic plan and guidance of the project committee and clinical lead.</li> <li>Iterative refinements to questions to help balance feasibility with breadth and comprehensiveness of the review</li> <li>Clear deliverables were identified to ensure accountability</li> <li>Development, testing and refinement of search strategies and selection of relevant databases</li> <li>Establishing and testing inclusion and exclusion criterion for screening</li> <li>Refining scope based on reviewing results of various search strategies</li> </ul>
3.Study selection	<ul> <li>Independent application of screening criterion at two levels - title and abstract review (Level 1) and full article review (Level 2) by two reviewers</li> <li>Regular communication at the start, midpoint and end stages of screening</li> <li>Refinements to screening criterion as appropriate following team discussion</li> <li>Resolution of disagreements by a third to establish final inclusion</li> </ul>
4: Data extraction	<ul> <li>Development of a data extraction template in alignment with research questions and study purpose</li> <li>Revising data extraction template based on project team feedback</li> <li>Independent quality testing of data extraction template by two reviewers to ensure consistency in</li> <li>Applying data extraction tool to articles retained following Level 1 and Level 2 screening</li> </ul>
5: Data analysis	<ul> <li>Summarizing descriptive results; conducting a numerical analysis of articles screened and extracted, and exploring descriptive variables (i.e., disease sites, types of ICPs etc.</li> <li>Thematic analysis of extracted data in reporting results, and considering the implications of study findings to policy, practice, or research</li> </ul>
6: Incorporating consultation with key stakeholders within CCO	<ul> <li>On-going engagement of key internal stakeholders including multiple program areas, clinical leads and directors</li> <li>Sharing results with internal stakeholders for feedback on appropriateness and relevance to portfolios to support alignment at an organizational level</li> <li>Development of a KT strategy which involves sharing of the framework with external stakeholders for validation will be conducted once the framework has been developed</li> </ul>

# Appendix C: Overview of inclusion and exclusion criterion for Level 1 and Level 2

#### Level 1 - Title and abstract review

Inclusion Criteria:

- Studies involving the use or development of ICPs (or alternate terms) in the diagnosis, treatment and/or management of cancer in adults (aged 18 or above)
- Peer-reviewed journal articles
- Systematic reviews and meta-analyses (these will be hand searched to ensure that our pull has not missed any relevant articles)
- Published in English from January 1995 onwards

**Exclusion Criteria:** 

- Studies published prior to 1995
- Not published in English
- Protocols, conference abstracts, case reports, and editorials etc.
- Studies where the patient population are below age 18 (i.e., children, adolescents)
- Studies focused on the design, implementation and evaluation of a treatment option/algorithm to support clinical decision-making
- Studies that do not involve the use of an ICP for cancer diagnosis/treatment/management

#### Level 2 - Full article review

**Inclusion Criteria:** 

Study must meet AT LEAST the first criteria AND EITHER 2 OR 3.

- The description of the ICP used meets at minimum 2 out of the 4 features, and at least the first feature (a):
- The ICP involves a structured multidisciplinary plan of care that engages two or more providers (cross-disciplinary) OR is being used in two or more settings
- The ICP involves care planning longitudinally over a specific stage or across stages of a particular illness, i.e., survivorship, end of life, or advanced care planning for cancer patients
- The ICP outlines specific steps to guide a patient's course of treatment/care in a plan, pathway,
   algorithm, guideline, protocol or similar "inventory of actions" into local structures/care processes

- The ICP seeks to enhance the delivery of care for a specific condition/clinical problem in a specific
  population through a series of mechanisms including improved communication between
  providers/key stakeholders in the patient's circle of care, better coordination of roles/tasks across
  settings, stages or over time, sequencing of care activities, identification of required resources,
  and/or improved documentation and greater accountability within and across care settings
- The study reports on outcomes associated with the use/implementation of the ICP (patient, provider and/or system – including cost analyses/effectiveness)
- The study discusses key facilitators, barriers, challenges, and/or the implementation process (i.e., how the ICP was developed and implemented/operationalized etc.)

#### **Exclusion Criteria:**

- No clear definition of a care plan/pathway is provided
- The definition of the ICP does not meet the minimum criterion for inclusion
- Study focuses on a single activity within a broader ICP (we examined the source article discussing the ICP if provided)

## Appendix D: Outcomes and measurement tools

For patients:

For patients:	
Outcome type and indicators	Tool/approach
HRQOL	<ul> <li>Short Form 36 Physical and Mental Component</li> <li>Short Form 12 (SF-12) (76)</li> <li>The European Organization for Research and treatment of Cancer quality-of-life questionnaire QLQ-C30 instrument (26,76)</li> </ul>
Patient satisfaction	<ul> <li>Medical Outcomes Study-Patient Satisfaction Questionnaire [MOS-PSQ] (27)</li> <li>System Usability Scale (SUS) (65)</li> <li>Patient's Perceived Quality of Care survey (67)</li> </ul>
Anxiety/distress (patient-reported)	<ul> <li>Spielberger State-Trait Anxiety Inventory (STAI-I) (61)</li> <li>Brief Symptom Inventory (BSI-18)</li> <li>Cancer Survivors Unmet Needs scale (26)</li> <li>Impact of Events Scale assesses distress anchored to a specific event (27)</li> <li>Profile of mood states (27)</li> </ul>

For caregivers:

Outcome type and indicators	Tool/approach
Caregiver satisfaction	<ul> <li>Toolkit After-Death Family Interview' (Toolkit) (39)</li> <li>Views of Informal Carers Evaluation of Service (VOICES) survey (90)</li> <li>Evaluating Care and Health Outcomes—for the Dying (ECHO-D) (80)</li> <li>Family Satisfaction Survey (30)</li> </ul>

For system:

i di dydicili.	
Outcome type and indicators	Tool/approach
Length of stay	Number of nights spent in the hospital after surgery
Post-operative complications	Post-operative complication rates
Mortality	In-hospital mortality
Readmission rates	Readmission rates (30 days)
Costs	<ul> <li>Total costs of hospital stay (includes in-house services received)</li> <li>Total cost of delivering ICP (i.e., staff resources)</li> </ul>
	Cost-effectiveness of ICP use (i.e., QALYs gained for cost incurred)

#### **Appendix E: Internal and external stakeholders\***

\*Consulted on IC Plan definition, emerging themes from the literature, toolkit and scenarios

#### CCO

- Sandy Buchman Clinical Lead, INTEGRATE Project
- Sara Urowitz Manager Ontario Palliative Care Network
- Angelika Gollnow Director Ontario Palliative Care Network, Survivorship and Primary Care Engagement
- Suzanne Strasberg Provincial Lead Primary Care
- Jonathan Sussman Chair Survivorship Advisory Committee
- Maria Grant Manager Survivorship
- Jonathan Irish Provincial Head Surgical Oncology and Models of Care
- Leigh McNight Acting Manager Surgical Oncology
- Leta Forbes Provincial Head (incoming) Systemic Treatment
- Leonard Kaizer Provincial Head (outgoing) Systemic Treatment
- Erin Redwood Manager Systemic Treatment
- Padraig Warde Provincial Head Radiation Treatment
- Eric Gutierrez Manager Radiation Treatment
- Elaine Meertens Director Clinical Engagement Programs
- Lesley Moody Director Person-Centred Care
- Jill Ross Director Cancer System Quality Improvement Initiatives
- Melissa Kaan Manager Diagnostic Assessment Program
- Rebecca Anas Director Cancer Quality Council of Ontario
- Gillian Bromfield Director Program Design and Cancer Screening
- Irene Blais Director Funding and Financial Analytics

- Alex Iverson Director Renal Clinical Programs
- Jackson Wood Director Strategy and Business Management
- Phil Holm Acting Director Policy, Planning and Evaluation, Ontario Renal Network

#### External

- Theresa Agnew, Executive Director, Trillium Health Centre & Member of the CCO Integrated Care Advisory Panel
- Subhash Bhandari Patient & Family Representative, CCO Patient and Family Advisory Council & Member of the CCO Integrated Care Advisory Panel
- Gail Dobell Director of Evaluation, Health Quality Ontario & Member of the CCO Integrated Care Advisory Panel
- Paula Doering, Vice President of Clinical Programs and Champlain Regional Cancer Program at The Ottawa Hospital
- Rheta Fanizza Senior Vice President, St. Elizabeth Home Health & Member of the CCO Integrated Care Advisory Panel
- Jodeme Goldhar Chief Strategy Officer Toronto Central Community Care Access Centre
- Esther Green Director, Person-Centred Perspective, Canadian Partnership Against Cancer & Member of the CCO Integrated Care Advisory Panel
- Tory Merritt Project Manager North York Centre Health Link
- Patricia Pottie Patient & Family Representative, CCO Patient and Family Advisory Council & Member of the CCO Integrated Care Advisory Panel
- Jan Stewart, Director, Regional Cancer Program Planning, Toronto Central Regional Cancer Program (North)
- Walter Wodchis Health Economist, Institute for Clinical Evaluative Sciences & Member of the CCO Integrated Care Advisory Panel

## Appendix F: Draft integrated care plan documentation

Sources

Information elements	Health Links Coordinated Care Plan	ASCO Treatment Plan	ASCO Survivorship Plan	INTEGRATE Primary Care Report	Liverpool Care Pathway for the Dying Patient
Referral Elements	Yes	Yes	Yes	Yes	Yes
Patient Goal / Plan Elements	Yes	Yes	Yes	NA	Yes
Treatment and Symptom  Management Elements	NA	Yes	Yes	Yes	NA
Survivorship Elements	NA	NA	Yes	NA	NA
Palliative and End of Life Elements	NA	NA	NA	Yes	Yes

#### Referral elements

Reason for communication (list TBD)
Action items (list TBD)
Communicated to (list TBD)

Note: All sections below will include a "last verified" (date) and "verified by" (name) fields.

#### **Patient identifiers**

- Name (given name, preferred name, surname)
- Gender
- Date of birth
- Health card number
- Mailing address (street address, city, province postal code)
- Telephone number
- Alternate telephone number
- Email address
- Preferred contact by
- Mother tongue
- Official language
- Ethnicity/culture
- Religion
- Marital status
- People who live with patient
- People who depend on patient
- Primary contact (name, relationship to patient, telephone number)
- Emergency contact (name, relationship to patient, telephone number)

#### **Baseline vitals**

- Height
- Weight
- Blood sugar

#### Allergies and intolerances

- No known allergies (checkbox)
- Allergies and intolerances (for each: substance, type, symptoms, severity)

#### Recent health assessments

• List of assessment types (for each: name, date completed, score, actions taken)

#### **Health issues**

• Conditions (for each: name, description, clinical description, date of onset, stability, notes)

#### **Medications**

- Last medication reconciliation (date, performed by)
- Taking medication (aids, challenges)
- Last medication change (type, how it made patient feel)
- Medications (for each: name, dose, route, direction, reason, pharmacy, start date, change date, prescriber)
- Special notes/instructions

#### Other treatments

- Significant surgeries or implanted devices
- Health education or counselling (next planned date)
- Assistive devices
- Self-monitoring routines
- Other treatments

#### Care team

- Members (for each: name, role, organization name, telephone number, email address)
- The people the patient relies on most at home are feeling (blank)
- Supports and services (for each: contact name, organization name, services provided, telephone number, email address, start date)

#### Patient goal/plan elements

Reason for communication (list TBD)

Action items (list TBD)

Communicated to (list TBD)

Note: All sections below will include a "last verified" (date) and "verified by" (name) fields.

#### **Cancer assessment**

Type of assessment (for each: name, date, results)

#### **Recent hospital visits**

Most recent visit (hospital name, type of visit, visit date, date of discharge, reason for visit, complications, hospital physician name and telephone number, advice from hospital physician, follow up appointment with/date)

#### Lifestyle factors

- Employment status, adequacy of income
- Supplementary benefits (list)
- Diet, adequacy of food
- Mode of transportation, level of difficulty in traveling
- Level of difficulty in reading and understanding health information
- Adequacy of housing
- Tobacco use (number of cigarettes/day, number of packs/year, quit date)
- Alcohol use (number of drinks in one sitting, number of drinks/week)
- Other substances (name, how recently, how frequently)
- Gambling activity (level of responsibility, most recent date gambled, number of days in last 90 days)
- 30 minutes of physical activity five days/week (Y/N)
- Social interaction within last seven days (Y/N)
- Other considerations

#### Plan to achieve goals for care

- Care team members who contributed to plan
- What is most important to patient right now
- What concerns patient most about healthcare right now
- Goals (for each: what patient hopes to achieve, suggested by, what can be done to achieve it, who is responsible, expected outcome, barriers and challenges, results achieved so far, review date)

#### Plan for future situations

- Situation (for each: what I will do, what I will not do, who will help me + telephone number, review date)
- Patient has received information about advance care planning (Y/N)
- Patient has completed advance care plan (Y/N)
- Location of advance care plan
- Patient understanding of advance care plan
- Substitute decision maker (name, relationship to patient)
- Power of Attorney for personal care (Y/N)

- Power of Attorney (name, relationship to patient, telephone number)
- Location of Power of Attorney document

+ updates to all previously populated elements, as required

#### Treatment and symptom management elements

Reason for communication (list TBD)

Action items (list TBD)

Communicated to (list TBD)

Note: All sections below will include a "last verified" (date) and "verified by" (name) fields.

#### **Cancer diagnosis**

- Cancer type/location/histologic type
- Diagnosis date
- Tumor size
- Lymph nodes
- Metastasis
- Stage (I, II, III, IV, not available/applicable)
- Other information, new cancer or recurrence, estimated survival duration)
- Has the patient been notified of diagnosis? Y/N

#### **Cancer treatment plan**

- Goal of treatment (cure the cancer and relieve symptoms/side effects, slow growth of cancer and relieve symptoms/side effects)
- Surgery (Y/N, for each: date, procedure/location)
- Radiation (Y/N, area of body to be treated, number of treatments over number of weeks, end date)
- Systemic therapy (Y/N)
- To be given *before* surgery or radiation, i.e. neoadjuvant (Y/N, name of regimen/agents used, number of cycles/planned frequency, end date)
- To be given after surgery or radiation, i.e. adjuvant (Y/N, name of regimen/agents used, number of cycles/planned frequency, end date)
- Additional information

#### Symptoms and side effects during cancer treatment

- Symptoms / side effects common during treatment (checklist, for each: most responsible provider in charge of management)
- Other concerns that may arise during cancer episode (checklist, for each: most responsible provider in charge of management)
- Conditions that warrant immediate communication with Oncology Team

• Lifestyles / behaviours that affect ongoing health (checklist, for each: most responsible provider in charge of recommendations)

#### Resources

TBD

#### Referrals made

- Type
- Contact
- Document attached

#### Goals of integrated care plan

- Expected outcome
- Method of measurement

+ updates to all previously populated elements, as required

#### Survivorship elements

#### Reason for communication

- Patient has progressive / non curative disease
- Rapid deterioration expected / noted
- · No further active treatment recommended
- Update on status
- Other

Note: All sections below will include a "last verified" (date) and "verified by" (name) fields.

#### **Estimated survival duration**

Select: not discussed, days to weeks, weeks to months, months to years

#### Follow up care plan

- Need for ongoing (adjuvant) treatment for cancer (Y/N, additional treatment name, planned duration)
- Schedule of clinic visits (coordinating provider, when/how often)
- Cancer surveillance and other recommended tests (coordinating provider, what/when/how often)

#### **Action items**

- See patient for follow up appointment by
- Continue goals of care and advance care plan with patient
- Review patient's palliative care needs
- Patient referred to Palliative Care Team, consider shared care
- Refer to local community services, as required
- Other

#### Symptoms and side effects after cancer treatment

- Persistent symptoms or side effects at completion of treatment (Y/N, types, for each: most responsible provider in charge of management)
- Symptoms / side effects common after treatment (checklist, for each: most responsible provider in charge of management)
- Other concerns that may arise after cancer episode (checklist, for each: most responsible provider in charge of management)
- Conditions that warrant immediate communication with Oncology Team
- Conditions that warrant a visit to the Primary Care Provider
  - Lifestyles / behaviours that affect ongoing health (checklist, for each: most responsible provider in charge of recommendations)

#### **Communicated to (list TBD)**

- Patient
- Family care / support
  - Substitute decision maker

#### Familial cancer risk

- Genetic/predisposing risk factors or predisposing conditions
- Genetic counselling (Y/N)
  - Genetic testing results

#### Resources

TBD

#### Referrals made

- Type
- Contact
  - Document attached
  - + updates to all previously populated elements, as required

### **Appendix G: Preliminary readiness assessment**

Enabler #1: Policy

Strengths

 Integrated care / patient navigation / care planning are priorities in Government of Ontario strategy, CCO Corporate Strategy, and many CCO program strategic plans

Challenges

 Integrated care / patient navigation / care planning are priorities in Government of Ontario strategy, CCO Corporate Strategy, and many CCO program strategic plans

Enabler #2: Buy in / use by team and patient

Strengths

- Support from community-oriented health administrators and clinicians (e.g. Primary Care, Survivorship, Palliative Care)
- Support from nursing at all levels
- Patients are asking for better continuity of care, as demonstrated by Patient and Family Advisory
   Council and NRC Picker

Challenges

- Limited evidence of impact on clinical outcomes
- Cancer treatment providers focused on issues internal to cancer system / complexity of cancer alone

Enabler #3: Dedicated navigator aligned with existing clinical workflow and resources

Strengths

- Nurse navigators in OBSP / DAPs (breast, colorectal, lung, prostate) provide highly organized entry and transition into cancer system
- HealthLinks care coordinators
- Family Health Team nurse navigators / coordinators
- Advance practice nurses in palliative care
- CCAC case coordinators
- Cancer system is highly organized by disease site and treatment modality
- Cancer system has done extensive process mapping (e.g. disease pathways and workflows

#### Challenges

- No end-to-end navigation
- Nurse navigation provided through DAPs ends at varying points in care journey, depending on disease site and region / location
- Limited navigation between and across cancer treatment modalities and phases of care, including out of the cancer system
- Lack of information exchange / rounding for shared patients
- Duplication of effort across navigators inside and outside of the cancer system
- Clinical workflow processes vary by region / location

#### Enabler #4: Tools for patient assessment

#### Strengths

- Comprehensive nursing assessment captures general health information, lifestyle factors and psychosocial status during Initial Consult for cancer treatment
- Edmonton Symptom Assessment System (ESAS) and functional status captured routinely at many hospitals during cancer treatment
- Some Cancer Centres are using the surprise question to identify patients who would benefit from a palliative approach
- Documentation of curative or palliative intent is mandatory prior to treatment

#### Challenges

- Assessments are not routinely shared outside of the cancer system or between settings of care
- No assessment for the complexity of the patient based on comorbidities
- No standard process / tool for medication reconciliation
- Patient goals not routinely discussed, documented or shared
- Advance care planning generally limited to end of life
- Documentation of intent is used primarily for treatment funding, rather than pathway development or conversation with patient

#### Enabler #5: Staff training

#### Strengths

- Several existing forums for staff training:
- CCO has had mandatory training for nurses for chemotherapy that is reported on regional scorecard
- CPAC INTEGRATE Project has LEAP Program for palliative care that is multidisciplinary
- Survivorship has developed medical school curriculum for well follow up that encourages information exchange between oncology and primary care

#### Challenges

- Many training programs address only a single phase of care
- Few training programs are multidisciplinary

Enabler #6: Ongoing relationships and team continuity

#### Strengths

- Multidisciplinary cancer conferences create team-based forum for collaboration amongst cancer treatment providers
- Caner communities of practice bring together multidisciplinary group of cancer treatment providers around some disease sites

Strong oncologist relationships exist within Cancer Centres
 Challenges

- There is often limited or incomplete information about members of the care team beyond the Cancer Centre
- Roles are not clearly defined, especially for the management of side effects and symptoms
- No established forum of communication between Cancer Centre and community beyond dictated notes
- Limited to no team continuity between phases of care or treatments
- When the Cancer Centre makes a referral to the CCAC, it bypasses the Primary Care Provider

Enabler #8: Systems and tools for data collection, information exchange, reporting, and evaluation Strengths

- Several external paper tools exist for patient data collection (i.e. HealthLinks Coordinated Care Plan, ASCO Treatment Plan, ASCO Survivorship Plan, CPAC INTEGRATE Project Primary Care Report, Liverpool Care Pathway for the Dying Patient)
- Some regional electronic systems exist that collect and facilitate sharing of information across providers and settings (e.g. IAR, HRM, cGTA, cSWO, CHRIS, survivorship program systems)
- Some electronic systems exist that provide patient access to care records (e.g. Sunnybrook's My Chart)

#### Challenges

- While there are many systems and tools, they are poorly integrated
- Most data collection is organized by phase of care or treatment
- Limited provincial electronic systems to enable sharing of information across providers, settings and phases of care
- Even within hospitals, cancer records are often not integrated with other hospital records

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