



Cancer Care Ontario

Patient-Reported Outcomes and Symptom Management Program

STRATEGIC FRAMEWORK 2016-2019



Ontario
Cancer Care Ontario

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Foreword

Since 2007, Ontario has been integrating Patient-Reported Outcomes (PROs) into routine clinical practice to improve cancer symptom screening and management across the province.

PROs facilitate conversations with care providers and increase patient involvement in their care. This allows patients to focus on issues most relevant to their experience, help identify issues early, track symptoms over time, and ultimately improve patient outcomes. Cancer Care Ontario has declared its commitment to expanding the use of patient-reported outcome measurement tools, as outlined in the first goal of the Ontario Cancer Plan IV (OCP-IV) 2015-2019 to “ensure the delivery of responsive and respectful care, optimizing individuals’ quality of life across the cancer care continuum”.

We are proud to introduce the Patient-Reported Outcomes and Symptom Management Program Strategic Framework, which aligns with the overarching vision of OCP-IV, and highlights the program’s focus areas, initiatives, and evaluation for the next three years. The Framework outlines five key focus areas that are integral to implementing PROs and corresponding symptom management efforts for person-centred care across Ontario.

Creating the Framework was a collaborative process. We collected data from numerous sources and perspectives. We held a strategic planning workshop with multiple stakeholders to identify key themes and priority areas. We then shared the draft framework with key stakeholders, such as Patient and Family Advisors (PFAs) and the Ontario Collaborative for Symptom Management Committee (OCSMC), to ensure it captured a unified vision of PROs and symptom management in the province.

This Framework will guide the work of the PROs and Symptom Management Program at Cancer Care Ontario over the next three years as we demonstrate our commitment to improving patient outcomes and patient experiences.



Dr. Robin McLeod
Vice President,
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Dr. Lisa Barbera
Clinical Lead, Patient
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The Voice of the Patient

Throughout the cancer continuum, a patient can experience a myriad of side effects and symptoms. These symptoms, such as fatigue, pain, and anxiety can have a significant impact on a patient's quality of life.

The aim of the PROs and Symptom Management Program is to support the symptom management of patients as they navigate through the cancer continuum. The program is driven by Cancer Care Ontario's vision, which is to create the best cancer system in the world.

To improve the patient experience for those with cancer, the program needs to continue to engage and respond to patients and families. For this reason, patients and families have been engaged through the development of this plan to ensure their views and perspectives are captured and reflected in this document.

By speaking to patients, we understand that symptoms have an impact on their quality of life and that they want clinicians to provide them with the knowledge and tools they need to effectively manage their own care. We also understand that they are excited about the future directions of the PROs and Symptom Management Program and that they feel the program will have a positive impact on the experience of cancer patients.

"My hope is the framework will assist me in the getting the assistance I need to manage lymphedema – I suffer with this on a daily basis. My hope is that someone will pay attention to symptoms for this earlier in the trajectory of treatment for cancers like mine. That services will be offered sooner to the patient. That other patients will not have to wait as long as I have to get the support and services needed to manage their symptoms. That hospitals will partner with the community to give these much needed services to patients when they need them and are affordable."

– Joanne M., Cancer Care Ontario Patient and Family Advisory Council member



“It is important through the journey for the patient and caregiver to understand what to expect, how to mitigate, how to cope, and when it’s necessary to seek immediate medical attention (i.e., what is ‘normal’ vs. what is life threatening). Cancer can make one feel powerless: if one is at least able to manage one’s symptoms, it returns some control and power back to the patient.”

– Jane L., Cancer Care Ontario Patient and Family Advisory Council member

“I think this framework impacts one’s thinking about health care and symptom management in general, not just cancer care. Whether it’s a formal assessment tool such as ESAS or an individual recording their symptoms and results of treatment, it puts an onus on the patient to report symptom ‘data’ and for a primary care provider to listen to the data and respond accordingly. It’s a model I personally follow and I advocate for my friends and family to do the same, for any health concern.”

– Jane L., Cancer Care Ontario Patient and Family Advisory Council member

“Patients often deal with a lot of symptoms from treatment and the various surgeries and the cancer itself. It is important that we have the information, assistance and support we need to deal with these symptoms. They are often painful, debilitating and can have a huge impact on our quality of life.”

– Joanne M., Cancer Care Ontario Patient and Family Advisory Council member

“I am looking for services to be made available to me to assist and support me in managing my pain and symptoms. I need these services to be offered earlier in my treatment – not wait until I am in so much discomfort that I can’t function on a daily basis. This is my hope for the ideal outcome.”

– Joanne M., Cancer Care Ontario Patient and Family Advisory Council member

“Simply stated, symptoms experienced before, during and after cancer treatment affect quality of life. It is an ongoing reminder that one is fighting cancer, and it degrades the quality of day to day living, the ability of the patient and his/her family to live life as they once did. Dealing with multiple symptoms is emotionally and physically draining for the patient and caregiver. Proper symptom management will help the patient and family to live as well as possible during and after treatment.”

– Jane L., Cancer Care Ontario Patient and Family Advisory Council member

Patient Reported Outcomes and Symptom Management in Ontario

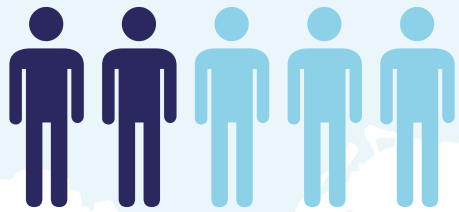
The Landscape, Ongoing Need, and Opportunity

The landscape

Cancer incidence rates have more than doubled since 1984

1984

2015



2 in 5

Ontarians will develop cancer in their lifetime¹

Up from
↑ 56 to 63%

In just 15 years, advances in cancer screening, detection and treatments have increased **five-year relative survival rates** from 56–63%.

A Patient Reported Outcome (PRO) is a measurement of any aspect of a patient's HEALTH status that comes **directly from the patient**

What are the most common symptoms?

Tiredness or fatigue

75%

Issues of wellbeing

71%

Depression

50%

What Patients Report

83%

of patients reported that their health care team treats/ manages their physical symptoms

78%

of patients reported that their health care team responds to their worries, concerns, or feelings of sadness

86%

of patients reported that their health care team includes them in decisions about how to treat/manage their symptoms

¹ Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2013. Canadian Cancer Society, 2013 [cited 2014 April]. Available from: <http://www.cancer.ca/~media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/canadian-cancer-statistics-2013-EN.pdf>

Ontario's cancer symptom screening program using ESAS

The only population-based cancer symptom-screening program in North America

14

regional
cancer centres

49

hospitals

261,991

unique patients
screened in 2015

30,000

unique patients
screened per month

Created the largest
cancer symptom
database in the world.

3.4 million

ESAS screens collected
since 2007

Developing the tools to give patients a stronger voice

Patients tell care
providers about
1 in 3 severe
symptoms during
their clinical visit

This makes it
harder for health
professionals to
help alleviate them.

When symptoms
aren't addressed,
they can worsen.

ESAS and other
PROs can make a
difference on a
patient's quality
of life

A person-centred approach

This model empowers clinicians to work with
patients to better manage symptoms by:



1. Looking beyond disease or treatment outcomes and focusing on whole person outcomes.



2. Respecting patients' right to communicate and focusing on the impacts of cancer that matter most to them.



3. Evaluating each patient's symptoms and developing a tailored care plan.



4. Empowering patients to participate in their own care.





Progress to Date

PROs and Symptom Management Program Approach to Date

Ontario is an international leader in adopting and implementing standardized symptom screening and symptom management strategies to enhance the quality of life of cancer patients. Since 2007, over 3.4 million symptom screens have been completed by Ontario patients, demonstrating the breadth of the PROs and Symptom Management Program.

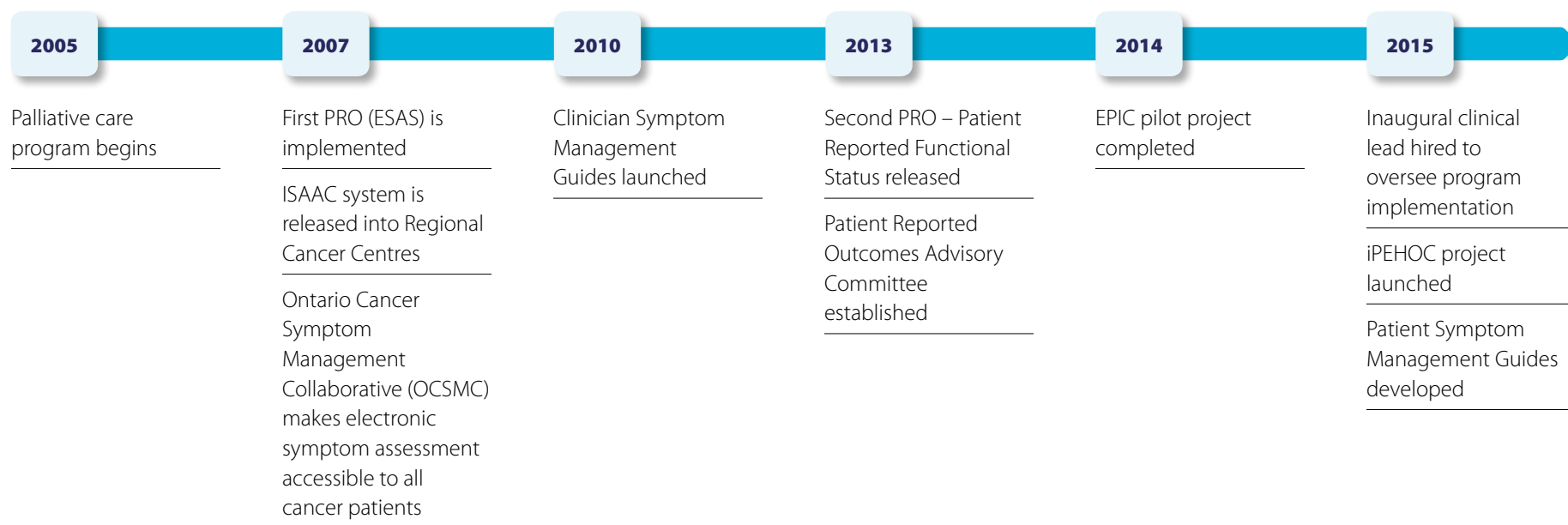
The program has matured and grown significantly since implementing ESAS, Ontario's first PRO measure, in 2007. The Interactive Symptom Assessment and Collection (ISAAC) system was also launched in Regional Cancer Centres in 2007, which allowed patients to electronically report their symptoms. In 2013, a second PRO measure was implemented, the Patient Reported Functional Status (PRFS), and the program conducted a pilot test of the Expanded Prostate Cancer Index Composite (EPIC) in 2014. In 2015, the program collaborated with Quebec to pilot test symptom-specific measures, such as the Generalized Anxiety Disorder (GAD-7) scale, the Patient Health

Questionnaire (PHQ-9) for depression, the Brief Pain Inventory (BPI) and the Cancer Fatigue Scale (CFS) through the Improving Patient Experience and Health Outcomes Collaborative (iPEHOC) project.

To further improve symptom management, the Clinician Symptom Management Guides were launched in 2010 and the Patient Symptom Management Guides were collaboratively created in 2015. To address the growing scope of the program, the Patient Reported Outcomes Advisory Committee was established and the first ever PROs Clinical Lead was appointed at Cancer Care Ontario.

Despite the progress of the program, opportunities exist across the province to better equip patients and clinicians with the tools needed to respond effectively to the symptom burden of Ontario's cancer patients. The expansion of the program, through both the roll-out of new PROs and continued strides toward better symptom management, will help improve patient experience throughout the care trajectory.

TIMELINE



About the Strategic Framework

Introduction to the Strategic Framework

The 2016-2019 Strategic Framework will guide the PROs and Symptom Management Program over the next three years. It is aligned to OCP-IV, with a particular focus on quality of life, patient experience, and person-centred care. It is an ambitious yet actionable plan that focuses on enhancing the quality of care and experience of patients and their families as they interact with the cancer system.

The Framework outlines how the program will focus its efforts to support the implementation of PROs and symptom management tools across the province. The efforts will focus on five strategic priorities, each with their own set of key initiatives.

The Strategic Framework provides the PROs and Symptom Management Program with the foundation necessary to meet new challenges and transform symptom management across the province. More importantly, it ensures a focused and measurable approach to improving cancer care for patients.

Development Process

The plan was created collaboratively by the PROs and Symptom Management team, internal partners within Cancer Care Ontario, patients and family advisors, and regional partners. Over the past year, the program engaged a broad range of stakeholders through interviews, surveys, and in-person sessions to obtain input on the program, its objectives, and how PROs and symptom management can be implemented to have a meaningful impact for patients. This engagement will continue as the Framework is implemented to ensure it responds to the ever-changing health care environment.



Strategic Framework

Program Goal, Mandate, Focus Areas

The Strategic Framework is anchored by PROs and Symptom Management Program's goal, mandate, and focus areas.

Goal: Ensure that patients receive responsive and respectful care that is based on best evidence and optimizes their quality of life across the cancer care continuum.

Mandate: To support the implementation of patient reported outcomes and symptom management to improve person-centred care across Ontario.

Focus Area	Selection & Implementation	Patient & Families	Symptom Management & Interdisciplinary Teams	Technology	Research & Improvement
Definitions	The defined method and oversight of how new PROs will be introduced and maintained in the Ontario cancer system	How patients and families will be educated, engaged and activated during the implementation of PROs	Support and engagement of the clinical team for the adoption of PROs and improvement in symptom management	The technology and information management tools and systems used to facilitate PROs data collection and analysis	How PROs and Symptom Management data are harnessed and leveraged to learn and improve
Outcome	Sustained adoption of suitable PROs in Ontario's cancer system	Patients and families who are activated to participate in the assessment and management of their symptoms	Clinical teams using PROs and symptom assessments to effectively respond to the symptoms of patients	Effective analytics capabilities and collaboration between IM/IT (information management/ Information technology) partners to ensure an excellent user experience	Using data effectively for research, quality improvement initiatives, outcome evaluation and planning
Initiatives	<ul style="list-style-type: none"> Develop a pipeline to support the selection, implementation and sustained adoption of suitable PROs Create a governance structure, core processes and guiding principles to support the implementation and roll-out of PROs Expand PROs to new settings to enhance the spread, scale and impact of PROs in Ontario while ensuring congruence among existing PROs and new PROs 	<ul style="list-style-type: none"> Support patients in self-management of their symptoms by implementing an approach to promote patient education that: <ul style="list-style-type: none"> - Allows patients and families to understand the value of PROs - Provides patients with the skills, resources and confidence to be activated in symptom management - Creates a patient-safe environment where patients can discuss their symptoms Create a strategy to effectively engage patient and family advisors in the implementation and evaluation of new and existing PROs to ensure a person-centred focus 	<ul style="list-style-type: none"> Implement a strategy to measure the clinical teams' response to PROs Implement relevant clinical toolkits that are adaptable to local settings Recruit and leverage Clinical Champions to promote the implementation of PROs Collaborate with internal partners to define roles and responsibilities to support symptom management Create a strategy to clearly articulate the value of PROs to clinician teams 	<ul style="list-style-type: none"> Develop IM/IT requirements for PROs through engagement with internal and external stakeholders Collaborate with IM/IT partners to define roles and responsibilities to support PROs implementation and facilitate symptom management Develop and enhance reporting and analytics capabilities to evaluate and report on PROs 	<ul style="list-style-type: none"> Leverage Cancer Care Ontario data assets to inform and improve the PROs implementation pipeline Develop a research strategy in collaboration with internal and external partners Embed an evaluation framework into appropriate initiatives Support local quality improvement projects and planning

Strategic Priorities

“It gives me hope that a symptom management program is being planned in a proactive and strategic manner, and that this program will attempt to meet the ever changing needs of the patient and provide information and supports we need so desperately.”

– Joanne M., Cancer Care Ontario Patient and Family Advisory Council member

Strategic Priority 1

Selection and Implementation

The program will achieve sustained adoption of suitable PROs in Ontario’s cancer system.

Since the implementation of symptom screening using ESAS in 2007, the program has made significant progress and achieved substantial growth, including the development of the world’s largest cancer symptom screening database. As the program

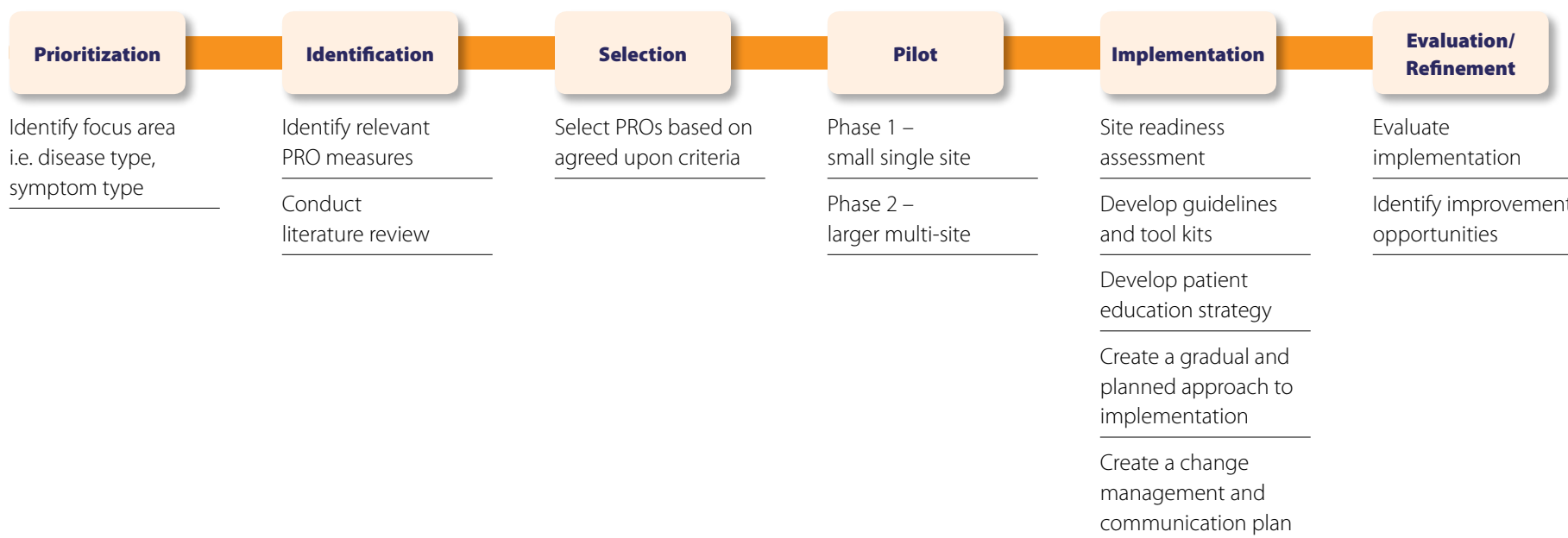
continues to evolve, there will be thought and intention in the selection and implementation of new PROs, to ensure that the tools, resources, and governance structures are in place to successfully expand PROs into new and existing settings. Over the next three years, the program will focus on the development of a streamlined and comprehensive process for the selection and implementation of PROs across Ontario.

The pipeline diagram below depicts the anticipated approach to the selection and implementation of new PROs and the evaluation and refinement of existing PROs.

Key Initiatives in this focus area include:

1. Develop a pipeline to support the selection, implementation, and sustained adoption of suitable PROs.
2. Create a governance structure, core processes, and guiding principles to support the implementation and roll-out of PROs.
3. Expand PROs to new settings to enhance the spread, scale, and impact of PROs in Ontario while ensuring congruence among existing PROs and new PROs.

PIPELINE



Strategic Priority 2

Patients and Families

The program will support the education, engagement, and activation of patients and families in the assessment and management of their symptoms.

Engaging patients and families in the design and delivery of PROs is essential to ensure that the program advances person-centred care as it grows and scales. The program will continue to foster an environment where patients can be activated in their care. Simply stated, patient activation is the knowledge, skills, confidence, and willingness of patients to manage their own health and care. To achieve this, the program will expand and refine its tools and supports so that patients can better self-manage their symptoms.

Key Initiatives in this focus area include:

1. Support patients in self-management of their symptoms by implementing an approach to promote patient education that:
 - Demonstrates the value of PROs to patients and families
 - Provides patients with the skills, resources, and confidence to be activated in their symptom management
 - Creates a patient-safe environment where patients can discuss their symptoms
2. Create a strategy to effectively engage patient and family advisors in the implementation and evaluation of new and existing PROs to ensure a person-centred focus.



Strategic Priority 3

Symptom Management and Interdisciplinary Teams

The program will improve clinical teams' ability to conduct symptom assessments and effectively respond to the symptoms of patients.

Measuring symptoms will not have a meaningful impact on patient's lives on its own. The success of the program depends on clinicians responding to identified symptoms and working with patients to adjust care plans accordingly. Through education, engagement, and advocacy we will communicate the value of PROs to clinicians so that each member of a care team understands the impact of symptom screening and their role in assessing and responding to the symptoms of their patients. The program will also equip clinicians with the tools and education they need to effectively respond to patient-identified symptoms.

Key Initiatives in this focus area include:

1. Implement a strategy to measure the clinician teams' response to PROs.
2. Implement relevant clinical toolkits that are adaptable to local settings.
3. Recruit and leverage Clinical Champions to promote the implementation of PROs.
4. Collaborate with internal partners to define roles and responsibilities to support PROs and symptom management.
5. Create a strategy to clearly articulate the value of PROs to clinician teams.

"If my healthcare team and I worked together to manage my symptoms my quality of life would be greatly improved – reduced pain and reduced anxiety. We need help in understanding our symptoms, assistance to manage our symptoms and education on how to control or avoid some symptoms. Our symptoms at times can be very debilitating and make day to day living very difficult. My hope is to wake up one morning 'symptom' and 'pain' free."

– Joanne M., Cancer Care Ontario Patient and Family Advisory Council member



Anya H., Cancer Care Ontario Patient and Family Advisory Council member

Strategic Priority 4

Technology

The program will create effective analytics capabilities and collaborations between IM/IT partners to ensure an excellent user experience with technology-enabled solutions that support PROs.

Technology is integral to the success of the program:

- it enables the collection of symptom data from patients through the ISAAC system
- it supports clinicians in tracking changes and responding to the symptoms of their patients
- it allows Cancer Care Ontario, researchers, and other system leaders to track progress, link measures to outcomes, and identify gaps in symptom management across the province using data and analytics

Collaborations with key stakeholders, such as the IM/IT team, will also guarantee access to the relevant information and data needed to implement and measure the success of PROs as they are rolled out across Ontario.

Key Initiatives in this focus area include:

1. Develop IM/IT requirements for PROs through engagement with internal and external stakeholders.
2. Collaborate with IM/IT partners to define roles and responsibilities to support PROs implementation and facilitate symptom management.
3. Develop and enhance reporting and analytics capabilities to evaluate and report on PROs.

Strategic Priority 5

Research and Improvement

The program will use data effectively for research, quality improvement initiatives, outcome evaluation, and planning.

As the program expands, it will be essential to evaluate effectiveness, monitor and report on performance, and incorporate learnings into program planning. The program will track performance against set goals and make adjustments as needed to enhance the approach and the implementation pipeline. The program will measure outcomes and encourage research and evaluation to demonstrate the impact of the program against system-level priorities such as health outcomes, quality initiatives, and patient experience.

Key Initiatives in this focus area include:

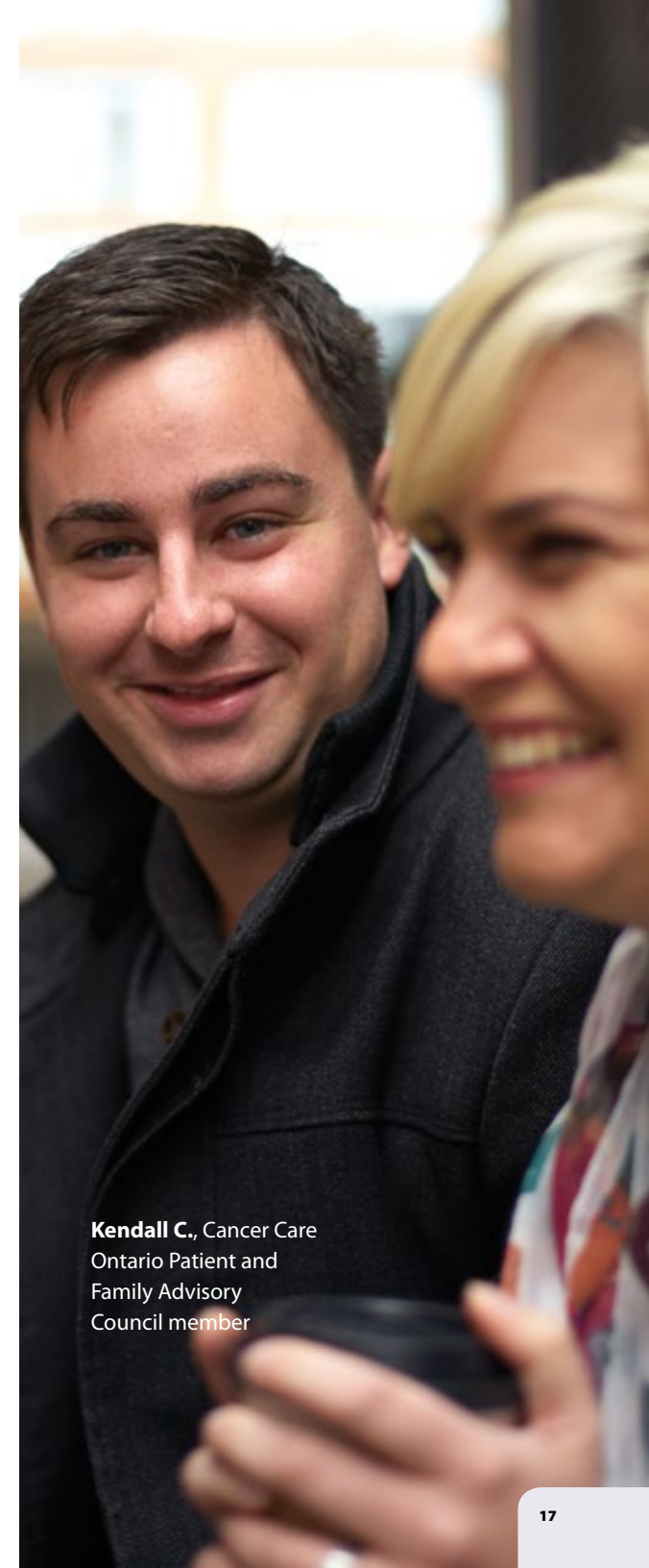
1. Leverage Cancer Care Ontario data assets to inform and improve the PROs implementation pipeline.
2. Develop a research strategy in collaboration with internal and external partners.
3. Embed an evaluation framework into appropriate initiatives.
4. Support local quality improvement projects and planning.

Looking Forward

Looking forward over the next three years, the vision is a system where clinicians are responding to patient's symptoms at every encounter. The PROs and Symptom Management Program will play an important role in enhancing the quality of care and experience of patients and their caregivers as they interact with the cancer care system.

To ensure success, the program will be nimble and flexible to adjust to the changing needs of the environment. The PROs and Symptom Management Program will continue to engage and collaborate with patients, caregivers, clinicians, and Regional Cancer Centres to drive forward the PROs and symptom management agenda in a meaningful way.

The PROs and Symptom Management Strategic Framework is an ambitious yet actionable plan which prioritizes quality of life and the patient experience through its focus on: selection and implementation, patients and families, symptom management and interdisciplinary teams, technology, and research and improvement. Indicators will be evaluated on a regular basis to ensure accountability and guide and refine actions over the next three years. The Strategic Framework provides the program with the foundation necessary to meet new challenges and deliver truly person-centred care. Together with the Regional Cancer Centres, the PROs and Symptom Management Program will improve the symptom management of cancer patients in Ontario.



Kendall C., Cancer Care
Ontario Patient and
Family Advisory
Council member





Cancer Care Ontario

About Cancer Care Ontario

Cancer Care Ontario – a division of CCO and the Ontario government’s principal cancer advisor – plays an important role in equipping health professionals, organizations and policy-makers with the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality patient care.

It does this by collecting and analyzing data about cancer services and combining it with evidence and research that is shared with the healthcare community in the form of guidelines and standards. It also monitors and measures the performance of the cancer system, and oversees a funding and governance model that ties funding to performance, making healthcare providers more accountable and ensuring value for investments in the system.

Cancer Care Ontario actively engages people with cancer and their families in the design, delivery and evaluation of Ontario’s cancer system, and shares Cancer Care Ontario’s mission of working together to improve the performance of Ontario’s cancer system by driving quality, accountability, innovation and value.

Cancer Care Ontario is committed to ensuring accessible services and communications to individuals with disabilities.

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Cancer Care Ontario

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create the best health
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