



## Self-Management in Cancer | Quality Standards

PATIENT EDUCATION PROGRAM, CANCER CARE ONTARIO

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# Introduction & Overview

In November 2015, the Cancer Quality Council of Ontario (CQCO) brought together a group of international experts for a Signature Event, entitled “Collaborate to activate: Empowering patients and providers for improved self-management”.

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## Objectives of the Signature Event

- Learn from other jurisdictions
- Receive feedback on Cancer Care Ontario’s Framework for Self-Management Education for Cancer Patients
- Provide practical solutions and recommendations to Cancer Care Ontario

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Through feedback gleaned from this event, the CQCO provided Cancer Care Ontario with a list of recommendations for future work. From this comprehensive list of recommendations, the CQCO and Cancer Care Ontario agreed upon a more refined list that included:

1. Develop a provincial steering committee for self-management.

2. Define self-management and self-management support for oncology in Ontario.

3. Develop a set of quality standards that will guide how self-management support will be developed, implemented and measured in Ontario.

4. Work with the regions across Ontario to begin implementing the standards through projects and programs, and measuring their impact.

The definitions and quality statements in this document aim to articulate the desired foundation for this work by giving providers and administrators a concrete and consistent starting point and by giving patients a consistent standard of what to expect when receiving care. The quality statements together provide the recommended standard for the development and implementation of self-management and self-management support in cancer care throughout Ontario.

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## Definition of Self-management and Self-management Support

A consistent definition for self-management and self-management support for oncology care in Ontario is needed in order to establish the scope of what the standards cover and refer to.

### **Self-management:**

Cancer self-management is what a person does, in collaboration with their healthcare team, to manage the symptoms, medical regimens, treatment side-effects, physical changes, psychosocial consequences, and lifestyle changes following a cancer diagnosis and/or treatment. It includes self-management activities and behaviours aimed to prevent or reduce health risks and optimize health and quality of life.

### **Self-management support:**

Self-management support involves a collaborative relationship between patients and healthcare providers to identify the

need for education and supportive interventions. The identification of patient needs includes: regular assessment of progress and problems, problem-solving support, goal setting and action planning. The aim of self-management support is to enhance patient skills and confidence in managing their health and well-being. Self-management support is underpinned by effective communication skills of healthcare providers and is augmented by patient education resources and tools that reinforce learning and behaviours.

Definitions have been adapted from Barlow, Bodenheimer and Lorig (1-3).

A note about the term 'patient' – for the purpose of this document the term 'patient' includes family members, friends and anyone else in a social role that is impacted by the patient's diagnosis of cancer.

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## Background

Self-management and self-management support are well known concepts in the chronic disease literature and although relevant and important, are less studied in the context of cancer care. Exemplars of cancer self-management and self-management support relate to behaviours such as active participation by the patient in symptom management and engaging in a wide range of generic and condition specific tasks (1). These tasks include medical management of illness such

as adhering to oral treatment regimens managing changes in roles and relationships, and the emotional consequences of cancer. Depending on the type of cancer and treatment patients receive they also may have specific self-management tasks to master such as ostomy care, pharmacological management of erectile dysfunction, or care and cleaning of a G-tube.

Advances in diagnostic tools and treatment, an aging population, and other factors, have led to an increased incidence of cancer in Ontario, with greater numbers of people surviving their disease and living with the effects of illness (4). Supporting this growing number of cancer patients and survivors more effectively is a global concern. Self-management and self-management support have been shown to improve access to and the quality, safety and value of healthcare services (1, 5). In addition, a person-centred approach to oncology care, including seeking patient input in care decisions and increasing patient engagement, improves the patient experience and is a key component of self-management. As such, attention has turned to self-management support as a means of facilitating patients' ability to effectively self-manage throughout the cancer continuum from the point of diagnosis through treatment and beyond to prevent or reduce health risks and optimize health and quality of life (6-8).

Evidence is emerging to support the use of chronic disease self-management (CDSM) approaches in cancer self-management. However, as cancer is a unique set of diseases with varying treatments and approaches to care depending on the specific diagnosis and stage of disease, the CDSM approach may be relevant but needs tailoring to cancer as both an acute and chronic illness. Cancer Care Ontario, in collaboration with the Program in Evidence-Based Care, released 'Self-Management Education for Patients with Cancer: Evidence Summary' in January 2016 (7). This summary identified the need for further study in the area of cancer self-management and showed that self-management support interventions may help to reduce symptoms of fatigue, depression, anxiety and emotional distress, and improve overall quality of life.

The Evidence Summary also identifies fundamental core skills for self-management that are applicable to cancer self-management programs:

1. Problem-solving (identification, finding solutions, implementing them and evaluating their effectiveness)
2. Decision-making (applying knowledge about condition and recognizing symptoms to make judgements and adjust behaviours accordingly)
3. Developing awareness of resources and how to use them effectively
4. Building patient-provider partnerships that foster shared decision-making
5. Taking action in the form of making short-term goal setting and action plans and carrying them out

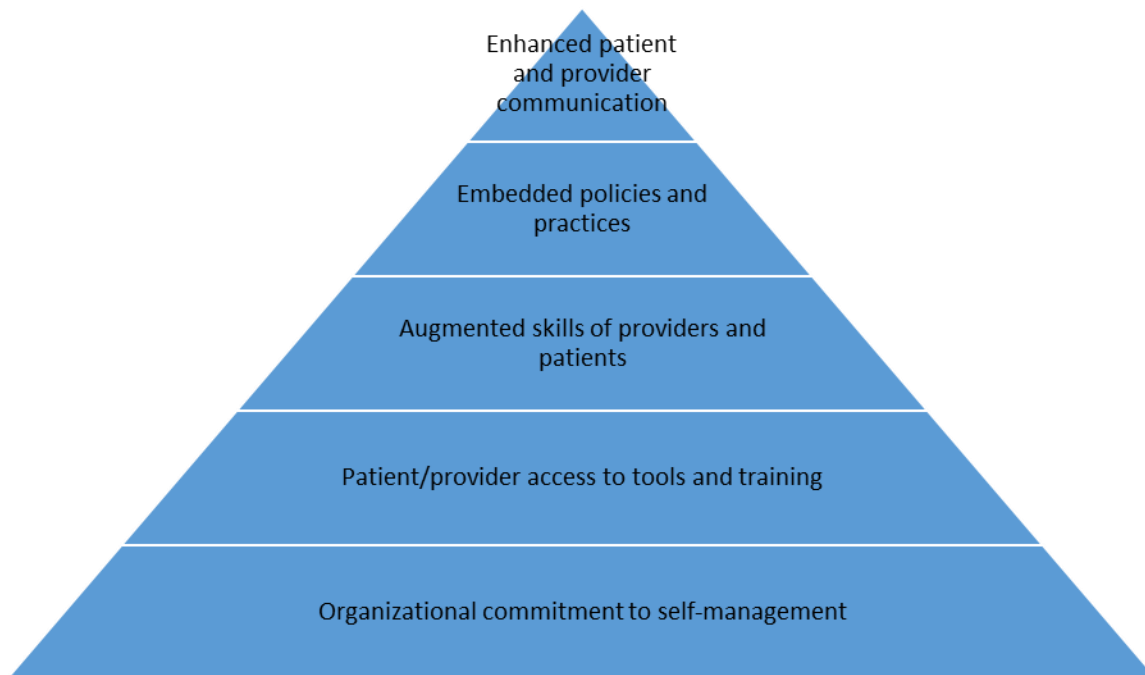
The development and implementation of training programs for healthcare providers in the provision of self-management support must:

- Aim to cultivate collaborative care relationships that support and engage patients in self-management. To do this, healthcare providers require skills in the following areas: understanding the role of health literacy and self-efficacy in patient engagement, and self-management communication skills including speaking in plain language, active listening and teach-back.
- Aim to build patient competencies in core self-management skills of problem solving, decision-making, effective use of resources (i.e. system navigation), building partnerships with healthcare providers and taking action (behaviours).

Figure 1 illustrates the hierarchy of outcomes of an organization that invests in and prioritizes building patient and provider skills in self-management and self-management support.

**FIGURE 1**

**Framework for attributes of organizations that prioritize self-management and self-management support.**



(Adapted from How Can Health Care Organizations Become More Health Literate?) (9)

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## Approach

Cancer Care Ontario, as recommended by the CQCO, convened a Self-Management Steering Committee in the spring of 2016 to identify key deliverables with regard to self-management in Ontario. The Steering Committee comprised key stakeholders including: patient and family advisors, oncologists, nurses, allied health professionals, regional administrative leadership, Cancer Care Ontario clinical program staff, and subject matter experts.

The Committee and Cancer Care Ontario staff consulted several landmark documents to inform the direction of these quality statements, including:

- Self-management education for patients with cancer: Evidence summary (Program in Evidence-Based Care/Cancer Care Ontario, 2016) (7)
- National standards for diabetes self-management support and education (American Diabetes Association, 2012) (10)
- How can organizations become more health literate? : Workshop summary (Institute of Medicine, 2012) (9)
- Supporting self-management: summarising evidence from systematic reviews (National Voices, 2014) (11)
- Strategies to support self-management in chronic conditions: Collaboration with clients (Registered Nurses Association of Ontario, 2010) (12)

Through a series of meetings, the Committee came to a consensus about the priority areas to include in the quality statements, as informed by the above documents, additional evidence and opinions from subject matter experts.

The resulting set of five quality statements are based on the best evidence for self-management in oncology and other chronic disease populations and practical needs and concerns expressed by Committee members from across Ontario.

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## Intent

The intent of these quality statements is to drive the development of strategies to implement self-management and self-management support in cancer care throughout the cancer continuum. It is also to encourage administrators and individual providers to begin to examine how self-management and self-management support can be implemented and measured in their individual organizations and practices.

This document does not prescribe how organizations and individuals should achieve compliance with the statements, but it establishes a standard for how care should be optimally designed to support self-management in Ontario.

The quality statements outline the level of service that any person (patient, family member or caregiver) using adult oncology services in Ontario should expect to receive with regard to self-management support.

The quality statements address healthcare provider-to-patient collaboration and pertain primarily to activities within the Regional Cancer Programs.



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# List of Quality Statements

## **Quality Statement 1:**

Regional Cancer Programs promote self-management and self-management support as an organizational responsibility.

## **Quality Statement 2:**

Regional Cancer Programs prepare healthcare providers to be knowledgeable about self-management and equipped to provide self-management support.

## **Quality Statement 3:**

Regional Cancer Programs have adequate infrastructure to provide patients with appropriate, high-quality self-management support enriched by patient education resources throughout the cancer continuum.

## **Quality Statement 4:**

Regional Cancer Programs promote equitable access to quality self-management support throughout the cancer continuum.

## **Quality Statement 5:**

Regional Cancer Programs foster a culture of continuous quality improvement, and invest in the evaluation of self-management and self-management support strategies.

## Quality Statement 1

Regional Cancer Programs promote self-management and self-management support as an organizational responsibility.

### Description

Organizational structures and programming across the cancer system (i.e. Cancer Care Ontario and the Regional Cancer Programs) foster a culture of self-management and self-management support.

This includes a culture shift that recognizes and values the role of the patient in their care. For example, patients should be equipped by their healthcare team to recognize changes in their health states that require attention and know how to access healthcare services appropriately. The essence of the necessary culture shift can be adapted from the Health Foundation's (13) rephrasing of a key question that guides care decisions from, "what is the matter with you?" to "how can we work together to make sure you get the best possible care?"

### What this looks like:

- A commitment to self-management is reflected in the strategic goals, objectives and work plans of the Regional Cancer Programs and Cancer Care Ontario, and linked to the Ontario Cancer Plan as appropriate.
- Self-management and self-management support are included in quality improvement measures of the Regional Cancer Programs.
- Administrative and clinical leadership, and champions for self-management, are identified and supported.
- Patients are part of the governance structure of an organization and will be engaged in all levels of planning and decision-making with regard to self-management and self-management support.

## Quality Statement 2

Regional Cancer Programs prepare healthcare providers to be knowledgeable about self-management and equipped to provide self-management support.

### Description

Regional Cancer Programs educate, prepare and enable healthcare providers to provide self-management support. In doing so, an acknowledgement is made that most healthcare providers are not currently equipped to provide self-management support, and a commitment is made to work toward preparing healthcare providers in self-management and self-management support.

Healthcare providers need to be knowledgeable about the clinical benefits of self-management to their patient population (where applicable as supported by evidence). They should receive appropriate training which may include how to identify important self-management skills, and to develop curricula to engage and prepare patients for self-management.

### What this looks like:

- Healthcare providers are required to have specialized skills and competencies to provide self-management support during treatment and along the continuum of care, and are adequately supported in acquiring those skills.
- Healthcare providers are equipped to identify opportunities for patient self-management along the pathways of care. This includes critical points of care such as care transitions and other times when patients are at risk for safety incidents or complications. Healthcare providers are able to provide adequate self-management support either through program referrals or providing direct self-management support. The concept of self-management and skills to provide self-management support are integrated into relevant orientation programs and continuing education opportunities for healthcare providers.
- Healthcare providers are able to assess patient readiness and capacity to self-manage including an assessment of patient activation, self-efficacy, and patient confidence in communicating with healthcare providers.
- Healthcare providers have strong plain-language communication skills to support patients, enable conversations about self-management and build a self-management plan where appropriate.

### **Quality Statement 3**

Regional Cancer Programs have adequate infrastructure to provide patients with appropriate, high-quality self-management support enriched by patient education resources throughout the cancer continuum.

#### **Description**

Regional Cancer Programs enable patients to take an active role in their care by educating, preparing, and empowering them to manage aspects of their care that can appropriately be optimized through self-management.

Infrastructure supports include:

- dedicated time for healthcare providers to receive self-management training
- clinic time to engage with patients in self-management support
- formalized patient education programs to collaborate with clinical subject matter experts in the development of patient-centred, health literate tools and patient education resources
- consumer health libraries with dedicated staff to manage and develop reliable and current cancer information collections.

#### **What this looks like:**

- Self-management support is integrated into routine cancer care which means that time for self-management support is adequately incorporated into clinic flow.
- Patient capacity to self-manage is built by healthcare providers around core knowledge, skills and competencies, for example, problem-solving, decision-making, resource use, building relationships with healthcare providers, and taking action on a plan (7).
- Patient-centred, health literate tools (e.g. symptom tracking diaries) and patient education resources (e.g. self-care video for tracheostomy, pamphlet on managing fatigue) are developed and incorporated into clinical care provision to help augment patient engagement in self-management.
- Access to self-management support including contact information of healthcare providers (for telephone and/or email) and patient education tools (online resources) are easily accessible.
- Appropriate web infrastructure is available to house patient education materials, that allows patients and caregivers to access and search for resources in an accepted number of clicks or amount of time on hospital or hospital supported websites.
- Access to after-hours web or telephone support to self-manage symptoms and disease outside of regular clinic hours to avoid the use of emergency services, when possible.

## **Quality Statement 4**

Regional Cancer Programs promote equitable access to quality self-management support throughout the cancer continuum.

### **Description**

Regional Cancer Programs ensure that the needs of the patient population are assessed, addressed and reflected in self-management and self-management support strategies. Self-management and self-management support should be tailored to individual needs, abilities and preferences. In doing so, an acknowledgement is made that systemic disparities in cancer care exist with underlying social advantages and disadvantages to patient groups, and a commitment is made toward mitigating disadvantages in self-management and self-management support.

### **What this looks like:**

- Regional Cancer Programs ensure that self-management programming in their region addresses the unique needs of the diverse patient populations they serve.
- Healthcare providers are trained to understand and appreciate how systemic disparities impact health and as such, are equipped to adapt self-management and self-management support strategies accordingly.
- Self-management programs and patient education materials are designed to support patients regardless of their information needs, health literacy levels and social determinants of health.
- Partnerships with community programs are formed as appropriate in order to address access issues or specific issues to the community they serve.

## **Quality Statement 5**

Regional Cancer Programs foster a culture of continuous quality improvement, and invest in the evaluation of self-management and self-management support strategies.

### **Description**

Regional Cancer Programs ensure that the development of strategies to assess the effectiveness of self-management and self-management support are reflected in quality improvement programming of the organization. These strategies should consider the impact on cost, outcome and experience of patients, healthcare providers and organizations, and should be measured in a meaningful way. In doing so, the knowledge and practice of self-management and self-management support in cancer care will expand and contribute toward more effective and patient-centered strategies to cope with the growing burden of disease.

### **What this looks like:**

- Self-management and self-management support is integrated into patient education and quality performance measures.
- Process and outcome measures are aligned with measurement of self-management effectiveness. This includes healthcare provider training and competency to engage in self-management support as well as evidence that patients are able to apply self-management strategies to manage the consequences of cancer (i.e. side effect management, emotional sequelae and relationship changes).
- Active inquiry into self-management and self-management support is cultivated, and partnerships in self-management and self-management support innovation through research are encouraged.

# Evaluation and Monitoring

Organizations implementing initiatives to comply with the quality standards set out in this document should consider how the implementation of any of these quality standards will be monitored and evaluated. The following table is adapted from the RNAO Clinical Best Practice Guidelines, Strategies to Support Self-Management in Chronic Conditions: Collaboration with Clients (2010) (12)

**Objective:** Evaluate the supports needed, the process involved and the impact of the quality statements for self-management and self-management support.

Level of Indicator	Structure	Process	Outcome
<b>Organization</b>	<p>Self-management is reflected in the strategic goals and/or regional work plans and/or policies of the organizations within the Regional Cancer Program.</p> <p>Self-management support is discussed as an organizational priority during clinical orientation for various healthcare providers.</p>	<p>Clinical champions are identified and supported with appropriate resources.</p> <p>Healthcare providers and patient and family advisors are involved in the planning of self-management support.</p>	<p>Increased rates of self-management activity in the hospital.</p> <p>Programs and policies related to self-management support are consistent with the quality standards in this document.</p>
	<p>Supports are available in the Regional Cancer Program that allow healthcare providers to participate in the delivery of self-management support, including program</p>	<p>Percentage of time/number of minutes in clinic dedicated for self-management OR percentage of appointments dedicated to self-management.</p> <p>Percentage of patients who are given contact</p>	<p>Self-management support strategies are integrated into the process of care (including documentation of the self-management plan developed collaboratively between the patient and the provider).</p>

	development, where applicable.	information for after-hours clinical support.	
<b>Provider</b>	Availability of educational opportunities for providers to develop skills in and related to self-management support.	Percentage of healthcare providers trained in: <ul style="list-style-type: none"> <li>- self-management support (could be through a Local Health Integration Networks-based program)</li> <li>- plain language communication</li> <li>-assessing patients' readiness to perform self-management activities</li> <li>- cultural competence/safety</li> </ul>	Providers are knowledgeable and skilled in the provision of self-management support.
	Evaluation structures are in place to monitor effectiveness of education programs for healthcare providers.	Providers self-assessed knowledge of self-management support strategies.  Evidence that self-management program curricula meet best practices in patient teaching and core curriculum components.	Self-management competencies are included in job descriptions and performance reviews.  Further training opportunities are available as appropriate.
<b>Patient</b>	Availability of patient education opportunities related to self-management for cancer, including targeted interventions for patients who are at high-risk for adverse outcomes such as patient safety incidents	Percentage of patients with a self-management plan in place and whose self-management needs have been assessed using a standardized tool.	Patients demonstrate self-management knowledge regarding: <ul style="list-style-type: none"> <li>- medical management of their cancer</li> <li>- dealing with emotional consequences, role and relationship changes</li> </ul>



	<p>and emergency department use.</p> <p>Regional Cancer Program offers adequate programming to address the specific needs of patients in the LHIN.</p> <p>Computers, kiosks and resource centres are available to patients in the Regional Cancer Centre.</p>		<ul style="list-style-type: none"> <li>- medication and how to appropriately and safely take and dispose of medication</li> <li>- standard measures of health behaviours such as smoking cessation and physical activity</li> <li>- prevention or appropriate management of adverse events, such as safety incidents and unnecessary emergency department use</li> </ul>
<b>Resources</b>	<p>Provision of adequate financial resources for appropriate levels of staffing necessary to support the implementation of self-management support.</p> <p>Clinical champions are identified by leadership and supported with appropriate resources.</p>	<p>Cost required should be identified and budgeted.</p> <p>Percentage of research or quality improvement projects that are focused on self-management and/or self-management support.</p>	<p>Financial resources required for self-management support are clearly identified and specifically allocated for staffing, supplies and other associated costs for implementation and sustainability.</p>

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## Summary and Next Steps

These quality statements are intended to set the foundation for self-management support in Ontario and to foster the beginnings of a culture shift in oncology care towards empowering patients and providers to integrate self-management and self-management support into care. They give providers and administrators across the province the agency to tailor how they achieve the standards to their own unique organizational and regional needs. Furthermore, the standards are intended to foster more discussion and consultation with patients, providers and administrators about how to put the standards into practice in an effective and meaningful way.

As next steps, Cancer Care Ontario will support the Regional Cancer Programs to begin to define strategies for implementing the standards into practice and to develop a plan to measure their effectiveness.

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## Key Terms

**Activation:** Describes the knowledge, skills and confidence a person has in managing their own health and care (14).

**Health Literacy:** Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and make decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (15).

**Empowerment:** A process in which patients understand their role, are given the knowledge and skills by their healthcare provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation (16).

**Engagement:** Actions individuals must take to obtain the greatest benefit from the healthcare services available to them (17).

**Health Equity:** Equity is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. Health inequities therefore involve more than inequality with respect to health determinants, access to the resources needed to improve and maintain health or health outcomes (18).

**Self-Efficacy:** People's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection (19).

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## Acknowledgements

Cancer Care Ontario's Self-Management Steering Committee (see Appendix 1 for membership).

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# Appendices

## Appendix 1: Cancer Care Ontario Self-Management Steering Committee Membership

<p>Lesley Moody, MBA, PhD (c) (Co-chair)          Director, Person-Centred Care          Cancer Care Ontario</p>	<p>Janet Papadakos, MEd, PhD (Co-chair)          Provincial Head, Patient Education, Cancer          Care Ontario          Co-Director, Cancer Health Literacy Research          Centre; Associate Director ELLICSR Health,          Wellness and Cancer Survivorship Centre,          Princess Margaret Cancer Centre.</p>
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