

Signature Event Recommendations and Proceedings Report

CQCO

Cancer
Quality
Council
of Ontario



COLLABORATE to ACTIVATE

Empowering patients and providers
for improved self-management

Cancer Quality Council of Ontario
November 18, 2015
Ramada Plaza Downtown Toronto



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Executive Summary

The Cancer Quality Council of Ontario (CQCO) is an arm's-length advisory group that was established in 2002 to guide Cancer Care Ontario and the Ministry of Health and Long-Term Care in their efforts to improve the quality of cancer care in Ontario. CQCO's mandate is to monitor and publicly report on the quality of cancer services in Ontario and to improve cancer system quality by identifying quality gaps and, through the use of international expertise and advice, commissioning special studies to address them.

The CQCO Signature Event series is one of four key tools used to achieve its mandate. The annual Signature Event brings practice leaders, policymakers, providers, patients and family representatives together with international and national experts to provide practical solutions to address a quality gap and to identify areas of opportunity for improving the quality of health service delivery within Ontario.

The CQCO's twelfth annual Signature Event—*Collaborate to Activate: Empowering Patients and Providers for Improved Self-Management*—was held in Toronto on Wednesday, November 18, 2015. With a view to addressing important quality gaps in Ontario, the 2015 CQCO Signature Event focused on self-management, patient activation and patient empowerment in the cancer system. The event objectives were the following:

- learn from other best practice jurisdictions that have adopted and implemented a self-management program;
- receive feedback on Cancer Care Ontario's *Framework for Self-Management Education for Cancer Patients* and examine how we might implement self-management and patient empowerment; and
- provide practical solutions and recommendations for how Cancer Care Ontario can improve the quality of health service delivery within Ontario.

The Signature Event opened with a cancer survivor sharing her experience with cancer, including the many challenges she faced and the support she received from self-management programs. Virginia McLaughlin, Chair of CQCO, then introduced the Council and provided an overview of self-management and patient activation in Ontario's cancer system, tying the topics back to the Ontario Cancer Plan IV. This was followed by several presentations and facilitated discussions designed to achieve the event objectives listed above. Specifically, presentations included an introduction to define the key terms of the day (such as self-management and patient activation), an overview of their benefits and courses of action, a focus on health literacy and patient



education, and a review of lessons learned from developing and implementing self-management programs. Following these presentations, a facilitated discussion was held between speakers and the audience.

Further presentations provided national and international insight into self-management, including an assessment of the implementation of a chronic disease self-management program in Denmark and lessons learned from developing self-management support with health-care professionals in British Columbia. These presentations were followed by another facilitated discussion between speakers and the audience.

The day also included a debate on the opportunities for self-management. Following the debate, a rapid rounds session was held that showcased local self-management projects. The first portion of the session highlighted innovations in technology to support patient activation and self-management in Ontario; the second highlighted best practice examples from across Ontario.

To achieve the event's second objective of receiving feedback on Cancer Care Ontario's draft *Framework for Self-Management Education for Cancer Patients* and examining its implementation, a facilitated breakout session was held in the afternoon. Participants were broken up into groups to discuss initiating self-management in Ontario, embedding self-management into clinical practice and prioritizing these actions. Additionally, attendees evaluated Cancer Care Ontario's evidence-informed draft *Framework for Self-Management Education for Cancer Patients* and discussed its applicability in Ontario's health-care system (see Appendix 1 for the draft framework). The event concluded with closing remarks from Cancer Care Ontario's President and Chief Executive Officer, Michael Sherar, who expressed the organization's commitment to incorporating self-management, patient activation and patient empowerment into the cancer system.

Based on the themes that emerged from the presentations and discussions at the Signature Event, CQCO developed a set of seven recommendations to address self-management, patient activation and patient empowerment in Ontario. The recommendations can be found on pages 8–11.



1. Background

The Cancer Quality Council of Ontario (CQCO) is an arm's-length advisory group that was established in 2002 to guide Cancer Care Ontario and the Ministry of Health and Long-Term Care in their efforts to improve the quality of cancer care in Ontario. CQCO's mandate is to monitor and publicly report on the quality of cancer services in Ontario and to improve cancer system quality by identifying quality gaps and, through the use of international expertise and advice, commissioning special studies to address them.

The CQCO Signature Event is one of our four key tools for achieving that mandate, along with the following:

- The **Cancer System Quality Index**, an interactive web-based public reporting tool that tracks Ontario's progress towards better outcomes in cancer care and highlights where cancer service providers can advance the quality and performance of care. The Index has been released annually since 2005. More information can be found [here](#).
- The **Quality and Innovation Awards**, an annual competition first held first in 2006 that encourages and recognizes significant contributions to quality and innovation that enhance and improve the delivery of cancer care across the province. The Awards are sponsored by CQCO, Cancer Care Ontario and the Canadian Cancer Society—Ontario Division. More information can be found [here](#).
- An annual **Programmatic Review** that brings international experts to Ontario to share their best practices, review progress and analyze effectiveness being made by existing cancer system programs (or informing an emerging program). More information can be found [here](#).

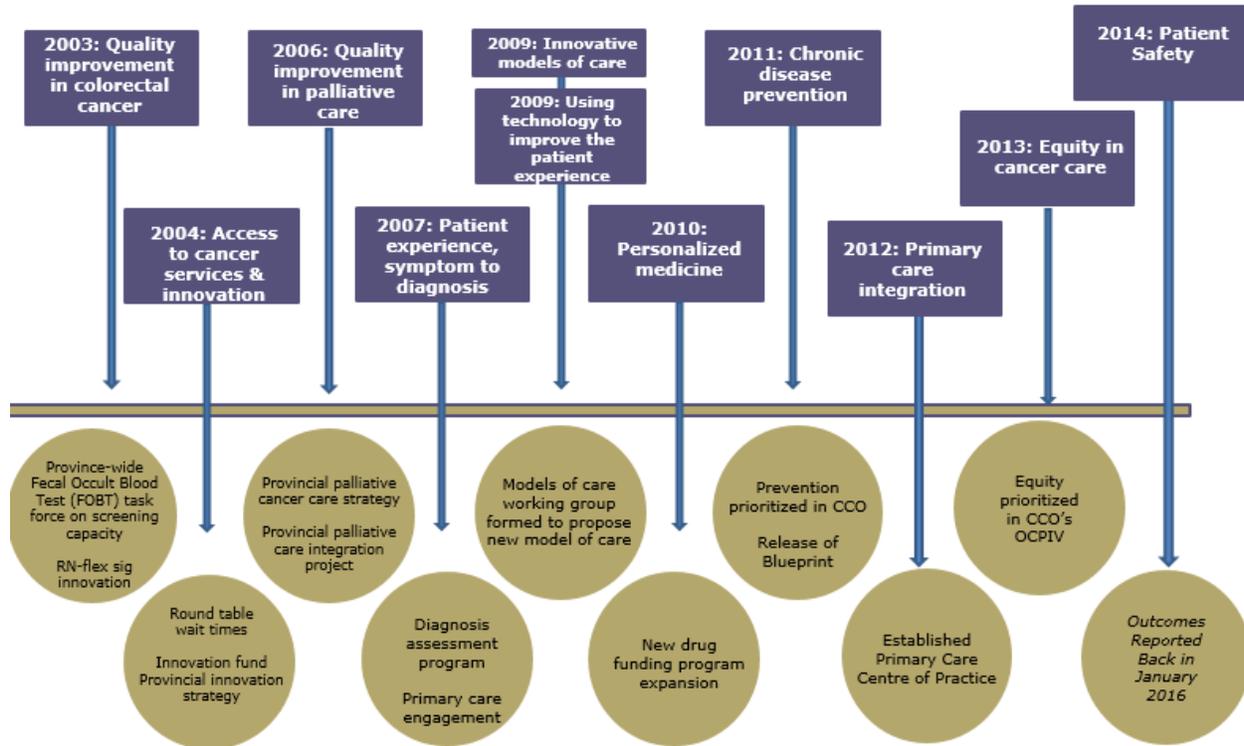
CQCO incorporates national and international benchmarking tools in all of its products to help monitor, report and enhance the performance of the Ontario cancer system.

1.1. CQCO Signature Event Series

As one of the four key tools used to achieve CQCO's mandate, the annual Signature Event brings together practice leaders, policymakers, providers, patients and family representatives together with international and national experts to provide practical solutions to address quality gaps and identify areas of opportunity for the improvement of the quality of health services delivery within Ontario. Figure 1 shows the themes and outcomes of the CQCO Signature Events from 2003 to 2014.



Figure 1: Areas of focus and outcomes of Signature Events from 2003–2014



1.2. CQCO's 2015 Annual Signature Event: Collaborate to Activate: Empowering Patients and Providers for Improved Self-Management

The CQCO's twelfth Signature Event—*Collaborate to Activate: Empowering Patients and Providers for Improved Self-Management*—was held on November 18th, 2015 in Toronto, Ontario. The specific objectives of the event were the following:

- learn from other best practice jurisdictions that have adopted and implemented a self-management program;
- receive feedback on Cancer Care Ontario's *Framework for Self-Management Education for Cancer Patients* and examine how we might implement self-management and patient empowerment in practice; and
- provide practical solutions and recommendations for how Cancer Care Ontario can improve the quality of health service delivery within Ontario.



The purpose of this report is to provide a summary of the proceedings, as well as a collection of recommendations based on the input from the panel discussions and breakout groups that occurred at the Signature Event, and from the international and local experts who attended.

3. Recommendations

One of the outcomes of the Signature Event was the creation of a set of seven recommendations for how Cancer Care Ontario can address patient activation and self-management. These recommendations were developed through feedback collected from participants during a breakout session at the Signature Event. Each recommendation is presented below, followed by a brief summary to provide context. Along with these, a number of enabling recommendations were developed to enhance the recommendations and provide guidance on next steps.

Cancer Care Ontario may determine partner organizations required to collaborate with on the below recommendations.

1. Develop and implement a provincial coordinated approach for integrating self-management into cancer care from the point of diagnosis.

Self-management by cancer patients is a fairly new undertaking internationally, nationally and in Ontario. As such, the establishment of a provincial steering committee would provide a platform for collaboration among the various stakeholders who are currently working on self-management.

Enabling recommendations:

- Cancer Care Ontario's Person Centred Care portfolio should consider forming a provincial steering committee that includes individuals across Cancer Care Ontario's Person Centred Care programs (e.g. psychosocial oncology, patient education, patient reported outcomes, patient experience, etc.) along with other clinical programs such as systemic and radiation treatment. The steering committee should include representation from Cancer Care Ontario staff, patients, family members, and caregivers, clinicians and other allied healthcare workers, as well as administrative leaders, academics/researchers and government representatives. It should steer the development and implementation of self-management programs in Ontario and be able to prioritize this work alongside other Person Centred Care priorities. The steering committee should take on the following responsibilities:
 - Set clear goals and outcomes for what the Steering Committee hopes to achieve
 - Work with existing, successful Ontario self-management programs to focus on how to scale and spread programs



- Endorse a standard definition of self-management (such as the Institute of Medicine’s definition) and adapt it to the Ontario context
- Build on the existing Self-Management Patient Education evidence summary
- Integrate health equity, health literacy and relationship building throughout the provincial self-management strategy.
- To integrate self-management from the point of diagnosis onward, Cancer Care Ontario should consider enabling a pilot and evaluation of self-management program(s) beyond the survivorship phase of the cancer trajectory.

2. Include patients, family members, caregivers, and front line healthcare providers as partners at each step in the development of the self-management strategy, tools and resources.

A self-management approach requires that a variety of people work in collaboration to provide the best possible care. This includes a partnership between healthcare providers, patients, family members and caregivers.

Enabling recommendations:

- Cancer Care Ontario should provide evidence and recommendations on how to deliver self-management programs. Self-management programs, tools and resources need to incorporate a self-tailoring aspect to make the programs, tools and resources as user friendly as possible.
- The collection and use of feedback from patients, family members, and caregivers should align with best practices to ensure that feedback is collected and used appropriately.
- Consideration needs to be given to how these tools will be adopted and embedded in existing front-line practice by healthcare providers from the onset.

3. Develop a multi-pronged provincial self-management education strategy for patients, family members, caregivers and healthcare providers.

Self-management programs have traditionally been offered in the survivorship phase of the cancer continuum. Self-management programs for cancer may however be more useful to introduce at the point of entry into the cancer system (time of diagnosis) to improve outcomes and reduce side-effects of treatment.

Enabling recommendations:

- Develop best practices for healthcare staff competencies in self-care management.



- Clarify roles and responsibilities of healthcare staff for different points in the patient continuum.
- Include family members and caregivers of cancer patients in self-management education and programming, starting at the point of initial cancer diagnosis. Consider transition points for patients as points to connect them to existing programs, as well as patients' identified needs (e.g. pain).
- Build on existing peer programs in Ontario for patients and families and consider how to connect patients to these existing opportunities.
- The education strategy should be mindful of equity divergence (i.e. if a resource is provided in several languages but a patient does not know how to read or understand the information then the resource will be underutilized) as well as health literacy.
- Focus on relationship building and engagement as part of the education strategy since there are under served /resourced communities (e.g. Aboriginal communities, new immigrant communities) that will require building of rapport and an understanding of the barriers the community faces.

4. Develop standards for self-management programs, supporting tools and resources.

Self-management for cancer is a fairly new undertaking and understanding self-management work that is already underway in other chronic diseases across the province is an important first step in paving the way in this domain.

Enabling recommendations:

- Cancer Care Ontario should facilitate increased collaboration among stakeholders working in this area and increase understanding of best practices in self-management.
- Cancer Care Ontario should undertake a jurisdictional scan to understand what self-management programs, tools and resources exist across the province.

5. Develop a standardized assessment of both patients' and healthcare providers' ability to undertake a self-management programs.

The current provider centered approach to cancer care needs to shift as self-management programs lead to increased quality of life, increased decision making ability and lowered healthcare expenditures (e.g. emergency room visits decrease). The standardized assessment tool should be used throughout the patient continuum to collect feedback and continuously improve programs (akin to a PDSA cycle).

Enabling recommendations:



- Distinguish between standard self-management support provided by all health care providers and a self-management program.
- Adopt a measure such as the [Patient Activation Measure](#) to assess how ready a patient is for taking on a self-management program (or how 'activated' a patient may be). This could be extended to include family members and caregivers, as well as how to adapt this for healthcare providers. Consider how to embed and/or incorporate this type of measure with other measures already being collected.
- Provider training should be embedded into existing self-management training for providers (e.g. Choices and Changes Workshop).

6. Provide guidance on the elements of successful electronic platforms such as mobile apps to aid self-management.

There are a number of groups in Ontario who are working on building electronic solutions for self-management education and programming (i.e. Sunnybrook Health Sciences Centre, MARS). Using a collaborative approach may encourage innovative solutions and help to repurpose existing tools and resources to create online self-management tools and resources.

Enabling recommendations:

- Consider groups such as MaRS Excellence in Clinical Innovation Technology Evaluation (EXCITE) program as a source of expertise in the development of online self-management tools.
- Consider how and when to provide easy access to patients of their medical information outside their healthcare visit, that could enable decision making and self-management (e.g. lab data for diabetes decision making).

7. Develop a measurement strategy in collaboration with the Patient Experience and Patient Reported Outcomes programs, as well as other programs, to assess the outcomes of a provincial coordinated approach for integrating self-management.

Establishing a coordinated and consistent approach to measuring the implementation, delivery and outcomes of self-management programs will provide an opportunity to reflect on lessons learned and provide data and an evidence base from which to act on.



Enabling recommendations:

- The following measurements should be collected to gain a clear picture of the need for self-management programs and the eventual outcomes of a provincial self-management strategy:
 - Patients' overall sense of wellness after utilizing a self-management program
 - Symptom severity
 - Patient experience
 - Cost impact (e.g. decreased emergency room visits, decreased clinic visits, readmissions rates)
 - Burden of care for patients' family members and caregivers
 - Assess return to work in some patient populations (where it is relevant/appropriate).

4. Introduction to the Event

4.1. The Need for Patient Activation and Self-Management: A Patient's Perspective

Dawn Powell, eight-year cancer survivor and CQCO member, welcomed participants to the Signature Event. Following her welcome, Ms. Powell proceeded to set the tone for the event by sharing the story of her experience with cancer, the many challenges she faced and the support she received from self-management programs.

When she was diagnosed with cancer, Ms. Powell and her family sought out programs and assistance to support her through the cancer continuum of care. Ms. Powell noted that she was fortunate that her expenses were covered under her insurance; for many cancer patients, however, the financial impact of a cancer diagnosis can be devastating due to out-of-pocket treatment expenses and lost income. Furthermore, while Ms. Powell had daily access to health-care providers who could provide answers and advice at the cancer centre, that support was not always available outside of the centre. Ms. Powell also found herself dealing with multiple treatment side effects—such as loss of strength and stamina, chronic pain, digestive disorders and bone damage—and she and her family needed some way to manage them.

To help alleviate some of the side effects of her cancer treatment, Ms. Powell enrolled in various programs and workshops, such as the *WE-Can* program. *WE-Can* is a home-based exercise program for cancer patients during and after treatment that focuses on cardio, strength training, nutrition and peer support, and that involves continuous assessments. Due to the program's success, a follow-up program called *WE-Did* was created. Ms. Powell also took part in a program called *Healthy Change* at the North West Community Care Access Centre (CCAC) (formerly at St. Joseph's Care Centre). *Healthy Change* is a six-week workshop for patients with chronic diseases.



It focuses on topics such as pain and fatigue management and the creation of action plans. Ms. Powell found that these programs helped her regain physical and emotional strength.

Ms. Powell went on to say that the peer-to-peer support, goal setting, follow-up and exercise all were very important and that they went well for her. She did note, however, that improvements could be made to the self-management programs that she joined (which were self-management programs aimed at the diagnosis stage and booster programs that continue to follow up and reinforce concepts with cancer patients).

Ms. Powell's vision for self-management for cancer patients would be a single multidisciplinary program that addresses all stages of treatment (diagnosis to post-treatment), including providing both information on the short-term and long-term side effects of treatment and a "one stop shop for survivorship" clinic (where different services for physical, mental and emotional health would be available).

4.2. Introductions and Overview of the Day

Virginia McLaughlin, Chair of CQCO, thanked Ms. Powell for her story, welcomed participants and speakers to the event, and gave a brief description of CQCO, the Signature Event series and past Signature Event topics (see Appendix 2 for speaker biographies). Ms. McLaughlin introduced the event's theme of patient activation and self-management, and described the theme's alignment with [Cancer Care Ontario's Ontario Cancer Plan IV](#). Under the quality of life and patient experience domain in the Ontario Cancer Plan IV, the strategic objective of "supporting health-care providers, patients and families with training, tools and resources to improve communication, decision-making, self-management and quality of life" is presented under the goal of ensuring delivery of responsive and respective care, and of optimizing quality of life across the cancer care continuum.

Ms. McLaughlin continued by highlighting the event's objectives and scope. In-scope topics included the whole patient journey (from prevention through to recovery, survivorship and end-of-life care), symptom and toxicity management, patient education, self-management for chronic conditions (outside of cancer) and health literacy. To help focus the day and ensure that objectives were achieved out-of-scope topics included patient navigation and transitions of care (see Appendix 3 for the Signature Event agenda).

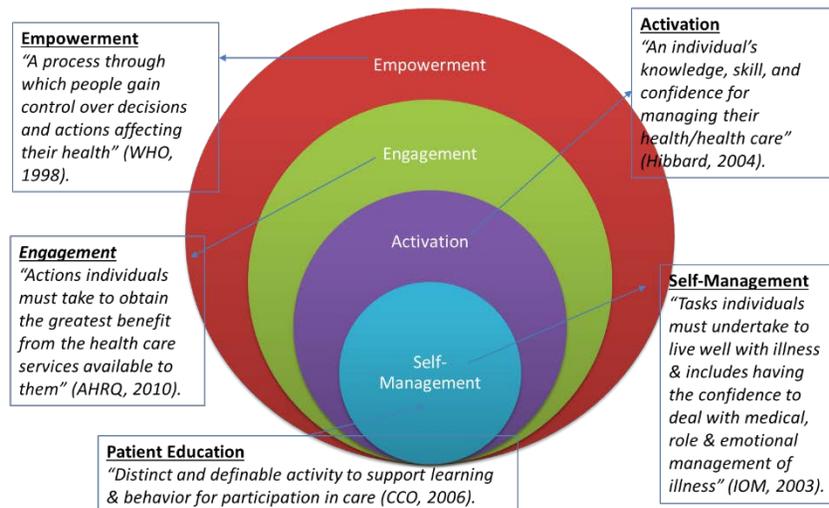


5. Defining Patient Activation and Self-Management

Dr. Robin McLeod, Vice-President of Clinical Programs and Quality Initiatives at Cancer Care Ontario, introduced Dr. Doris Howell, senior scientist at the Princess Margaret Cancer Centre, and Ms. Tamara Harth, Provincial Head of Patient Education at Cancer Care Ontario.

Dr. Howell began her presentation by defining self-management and patient activation, noting how these terms often are used interchangeably. Dr. Howell described the hierarchy of the terms related to self-management and patient activation (see Figure 2). She also highlighted the difference between self-management, self-care and patient education, noting that self-care describes an individual's daily actions, and that the term does not necessarily include elements of self-management (such as problem solving and goal setting). She went on to explain that while patient education is an essential component of self-management, it tends to focus more on dissemination of information than it does on decision-making.

Figure 2: Defining self-management terms



Dr. Howell explained how cancer is classified as a chronic disease and self-management is required during post-treatment and survivorship; she also suggested that cancer self-management programs need to be developed and available during the acute phase of cancer treatment.

Dr. Howell defined patient activation as an individual's knowledge, skill and confidence in managing their health and health care. She described the relationship between patient activation and self-management behaviours, where positive change in activation relates to positive change in self-management behaviours (and vice versa). Patient activation can be categorized into four

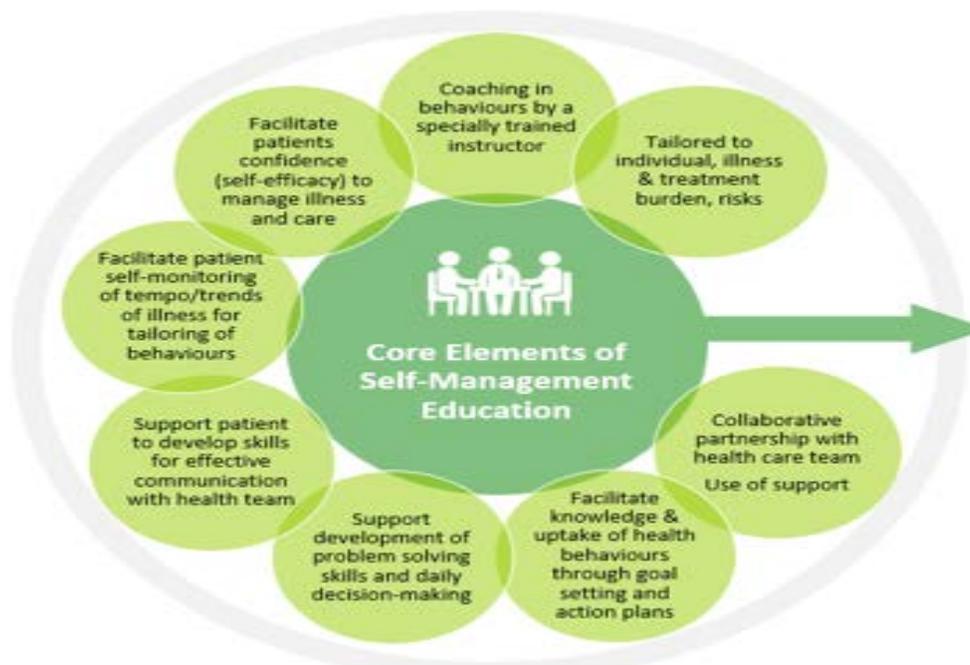


levels. The first level describes a patient with low knowledge of self-management skills who is passive in his/her role as patient. The second level describes a patient who is aware of self-management skills, but who still requires external support. The third level describes a patient who has knowledge of self-management skills and is applying them. The fourth and final level describes a patient who maintains new behaviours and persists through stress or change.

Dr. Howell noted that patient activation provides many benefits. For example, the literature indicates that the higher patients are activated, the higher their uptake of healthy lifestyles, screening and prevention activities. There also are clear clinical therapeutic outcomes: patients are able to recognize symptoms and adjust their behaviours, and overall, they have a better quality of life. Finally, there is a reduction in health care use, with potential cost savings in the billions.

Dr. Howell did note, however, that a challenge in self-management is that there are a variety of interventions and approaches, and that some are not in keeping with the core skills of self-management (Figure 3). Dr. Howell also indicated that these core skills may need to be tailored to individual patients because cancer is a complex, transitional disease, and a one-dimensional solution is not appropriate.

Figure 3: Core elements of self-management education



In order to integrate self-management, there must be a system-level change that begins with a self-assessment as a professional and as an organization. With that, it can move forward.



Ms. Tamara Harth began her presentation by defining patient education. Patient education is a distinct and definable activity that supports the learning and behaviour of patients; it includes all learning experiences that patients begin with the conscious goal of improving their understanding of their care so that they can become active participants in it. These learning experiences can be formal or informal, initiated by the patient or by the health-care provider, and they can include videos, mobile applications and learning modules.

Effective self-management depends on information provision. This involves tailoring information to the patient's needs and making sure that information is understandable, actionable and engaging. This is tied to the concept of health literacy. Health literacy describes the key skills needed to find, understand and evaluate health information, and it involves making health decisions using that information. Ms. Harth noted that 60% of Canadians over the age of 16 years have low health literacy; that number increases to approximately 88% in Canadians over the age of 65 years. Low health literacy is associated with poorer health, increased chronic disease, more medication errors, less preventative care, more emergency care, increased hospitalization and higher senior mortality.

Ms. Harth explained that it is necessary to pay special attention to health literacy in the context of self-management because there should be an expectation that patients will be activated and health-care providers will be involved with coaching and goal setting to help patients self-manage. Health-care providers should be able to identify patients with low health literacy and help them increase it so they can self-manage. Ms. Harth advocated for a "universal precaution" approach to low health literacy, which is based on the assumption that anyone in the health-care system may have low health literacy. To further emphasize the consequences of low health literacy, Ms. Harth presented a video about a patient's unfortunate journey that led to an unwanted surgical procedure, which was partly a result of low health literacy.

6. Developing and Implementing Self-Management Programs

Dr. Kate Lorig, Director of the Stanford Patient Education Research Center and Professor of Medicine in the Stanford School of Medicine and a cancer survivor, began her presentation by describing her journey as a cancer patient. Working with the University of Hawaii, Dr. Lorig developed a self-management internet program called *Cancer: Thriving and Surviving*. The program is a six-week interactive group session or online workshop for cancer survivors who have completed treatment within the last five years. The program is facilitated by two trained cancer survivors and does not require high levels of literacy.



From this intervention, Dr. Lorig found that cancer survivors were worried about returning to previous activities (such as work), and they also worried about recurrence, emotional support (or a lack thereof), side effects from treatment, pain, walking, doctors, medical scans and the future.

The *Cancer: Thriving and Surviving* program teaches participants core self-management skills. These include action planning with feedback, problem-solving and decision-making. Dr. Lorig noted that action planning with feedback was one of the most valued assets gained by participants. Program participants also discussed a variety of topics ranging from stress and symptom management to depression.

Three studies were performed to evaluate the *Cancer: Thriving and Surviving* program. For the internet workshop portion, studies were based in the United States and England. In the United States, a randomized controlled trial found that participants were sleeping better and exercising more after six months in the program. Participants who benefited the most were those who were two years following treatment. The study was replicated in England as a longitudinal study with the Macmillan Cancer Support team. Results included lower rates of depression, less fatigue, reduced stress and fewer oncology visits. For the face-to-face group session, a randomized controlled trial in the United States found similar results among participants who had spent six months in the program.

Dr. Lorig highlighted several methods of reaching underserved populations, including self-tailored interventions. In self-tailored interventions, participants are given a general structure of self-management; they are then free to tailor the intervention to their individual needs. Dr. Lorig noted that programs should be tailored to the specific population, where presenters and facilitators represent the population served and patients can contribute to building the program (such as through a self-management website's home page). Social media should be utilized to share the program. Lastly, community agencies and sites should be involved, as they represent better avenues for reaching participants than clinics and hospitals.

Early findings on engagement in the programs found that participants who actively participate online have better outcomes. Dr. Lorig also noted that completed action plans for self-management predict positive change in specific behaviours.

6.1. Highlights of the Facilitated Discussion with Dr. Doris Howell, Ms. Tamara Harth and Dr. Kate Lorig

Following the presentations by Dr. Howell, Ms. Harth and Dr. Lorig, Dr. Darren Larsen, Vice-Chair of CQCO, facilitated a discussion between the speakers and the audience. It was noted during the discussion that one of the biggest challenges when measuring cancer self-management is the



ability to measure specific behaviours and link them to outcomes of self-management programs. It also was noted that self-management programs need to be provided in more languages, and they must be made more culturally relevant because Ontario has a very diverse population. In addition, there is a need for clarity about the roles of physicians and patients.

7. A Critical Appraisal of the Implementation of Denmark's Chronic Disease Self-Management Program

Nicolaj Holm Ravn Faber, Chief Consultant at the Danish Committee for Health Education, provided a critical appraisal of Denmark's Chronic Disease Self-Management Program (CDSMP). In 2006, Denmark reorganized from 298 municipalities down to 98. The new, larger municipalities were made responsible for disease prevention, health promotion, rehabilitation after sickness leave and support for people with long-term conditions. The new municipalities also had to finance 20% of hospitals costs related to the readmission of patients with chronic conditions.

These responsibilities created a financial incentive for municipalities to reduce readmission rates and thus motivated efforts to help Danish citizens dealing with challenges related to long-term conditions. The National Board of Health, in collaboration with the Danish Arthritis Association, implemented the CDSMP in municipalities across Denmark. The Danish Committee for Health Education, closely tied to the National Board of Health, was chosen as the national centre for CDSMP. The first version of the CDSMP was piloted in 2003–2005; since 2006, the Committee has been working on the dissemination and quality assurance of the Stanford CDSMP program.

Many challenges were faced when implementing the CDSMP in Demark. Funding for the national roll-out of the program was difficult to obtain, and due to a scarcity of human resources, there was minimal time for patients and health-care providers to interact (patients generally received seven minutes of time with general practitioners). Mr. Faber also noted that health-care professionals largely believed they should not manage the lives of patients; rather, they felt they should only assist patients in managing their illnesses, even if patients wanted to know more. Peers also were a challenge: they might not have time to participate in the workshops, and peers sometimes became frustrated and workshops did not go as planned.

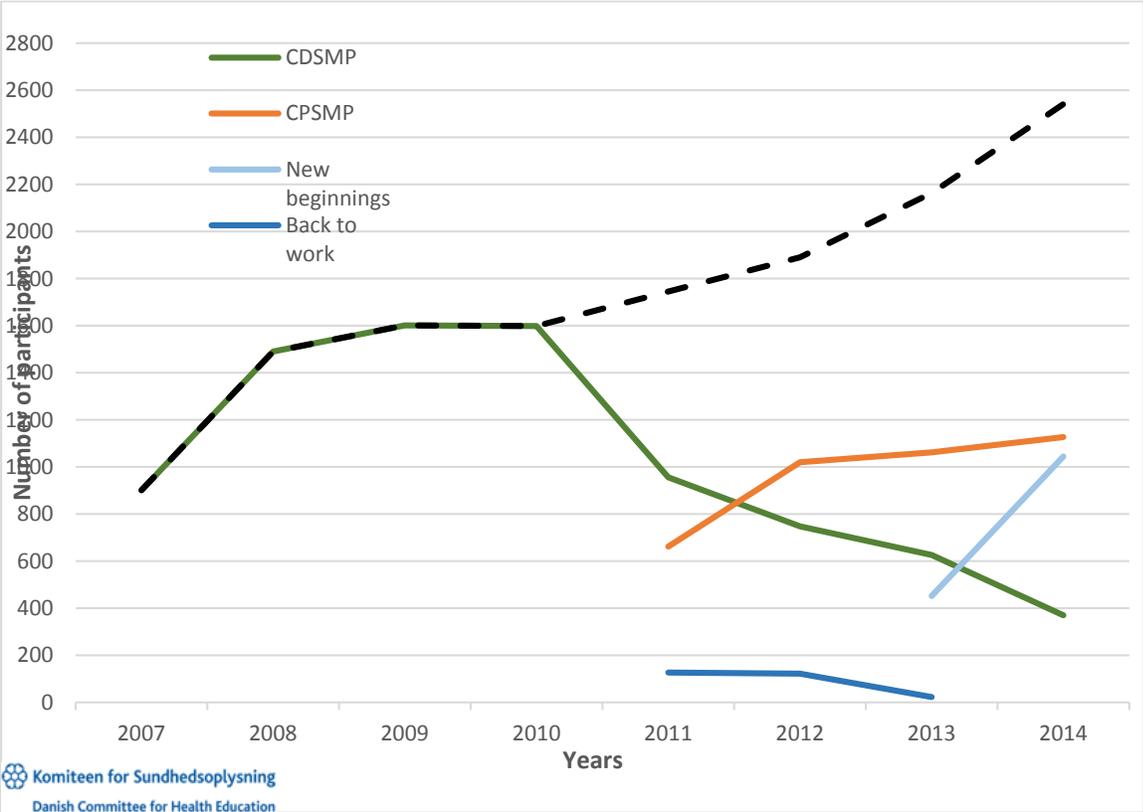
Mr. Faber discussed solutions to these challenges that included the following:

- building capacity among health-care professionals;
- creating a solid platform for peers, largely through annual gatherings that create opportunities for peers to address problems and share new knowledge; and
- utilizing results from randomized control trials to inform programming.



Mr. Faber noted that CDSMP participation has been declining in Denmark since 2010. This can be attributed to the introduction of the Chronic Pain Self-Management Program (CPSMP), which is specific to managing pain and the mental health workshop New Beginnings, which targets anxiety and depression (see Figure 4). The Back to Work project, which also is documented in Figure 4, is a study aimed at increasing the speed at which people return to work; it is now undergoing a randomized control trial. Figure 4 below illustrates that introducing self-management into the system is a long journey, not a quick fix.

Figure 4: Chronic disease self-management program participation in Denmark



Denmark’s next step is to approach hard-to-reach groups by focusing on drop-in centres, social housing areas and youth with mental health issues. In conclusion, Mr. Faber stated that Ontario needs to work with a platform of peers, and it must change the mindset of health-care professionals, informing them that self-management is an essential supplement to clinical treatment.

8. Self-Management Supports: Building Capacity among Health-Care Professionals

Dr. McGowan, Professor at the School of Public Health and Social Policy at the University of Victoria, presented on building capacity for self-management support among health-care



professionals in British Columbia. Dr. McGowan started to work on and implement self-management programs in British Columbia in 1987. Since then, five different self-management programs in various communities and multiple languages have trained over 5,500 people to become self-management leaders and teachers.

According to Dr. McGowan, self-management support refers to how individuals are supported in their self-management goals and activities by health-care professionals. As a result, training health-care professionals in self-management is essential. This is done through the use of the so-called 5A's framework: Assess, Advise, Agree, Assist and Arrange. In British Columbia, multiple organizations provide self-management training and are able to develop strategies to implement self-management support. Despite this, health-care professionals do not always apply the training and strategies they learn. This can be attributed to the belief that the physician knows best, concerns about risk and liability, and a lack of knowledge about wider community resources. Additional barriers include a lack of senior-level support and commitment, a lack of initiative, poor alignment with larger organizational priorities and insufficient systematic resources.

Dr. McGowan went on to describe a project to integrate self-management support into clinical practice in the Diabetes Health Education Centres in the Fraser Health Region of British Columbia. The objectives of the project were to fully incorporate self-management support in the vision of the centres, staff training and staff meetings. The outcome of the project was to provide educators with the ability to support patients using self-management strategies by creating action plans, providing feedback, measuring and recording self-management support activity, and connecting patients to other community programs. Based on these objectives, a basic logic model was developed to uncover perceived barriers (including knowledge, attitude and resource barriers). Then the electronic patient record system was modified to capture the SMS activities used with patients. Results were collected using the Patient Activation Measure and scores were recorded at baseline and six months post-implementation. In addition to addressing barriers, it was found that project participants also moved into higher activation levels, which is associated with positive outcomes.

Dr. McGowan concluded by noting that to integrate self-management support, consideration must be given to clinician expertise, patient values, best practices and working context. Self-management support can be delivered through community programs, but also by health-care professionals using self-management strategies.



8.1. Highlights of the Facilitated Discussion with Nicolaj Holm Ravn Faber and Patrick McGowan

Following the presentations by Mr. Faber and Dr. McGowan, Dr. Darren Larsen facilitated a discussion between the speakers and the audience. In the discussion, it was noted that when a self-management program is implemented, a standard approach must be taken to ensure the program is implemented as intended. After the implementation, the intervention then can be tailored to suit various populations. It also was noted that goal setting is an important activity for both health-care professionals and patients because it provides a mutual platform for understanding the desired goals of both parties. In fact, the act of setting and achieving goals is more important than the content of the goals themselves.

Participants also noted that it is important for health-care professionals to have knowledge of community resources for referrals. It also was mentioned that continuous evaluation and learning from both successes and failures is crucial for improving self-management programs and reaching desired goals.

9. **Debate: Bringing Self-Management from Theory to Practice**

Following the morning presentations, a debate was held to discuss bringing self-management from theory to practice. The debate was facilitated by Ms. Tamara Harth. Debate panelists included: Andrew Choate, Patient and Family Advisor at Cancer Care Ontario; Heather Sinardo, Senior Manager at the Canadian Cancer Society; Josie Barbita, Director of Professional Practice at the Toronto Central CCAC; and Dr. Doris Howell.

Ms. Harth asked the debate panelists several questions, and each panelist was given an opportunity to provide his or her perspective. Below is a summary of the main discussion points for each panelist.

Andrew Choate

Mr. Choate's definition of self-management and patient activation included the following criteria for a clinician:

- 1) An evaluation to determine how the patient might engage in and tailor his or her own care. This includes consideration of the patient's preferred mode of communication, level of adherence, functionality, accessibility and external support.
- 2) Full disclosure of information with the patient or caregiver at an appropriate level of understanding.



Mr. Choate indicated that he was very active in learning about his condition and treatment, and that many patients are the same. As a result, technology can help patients know what to focus on and when take preventative or corrective action (if needed).

Mr. Choate hopes that patients will be able to participate in managing their own care, both by seeking credible medical information about their condition and treatment and by engaging with clinicians as support and decision-makers. He also hopes that patients will be able to obtain the best treatment as close to home as possible.

To support his case, Mr. Choate shared his experience of deciding to immediately undergo chemotherapy treatment. To make this decision, he needed sufficient knowledge about the treatment and strong communication with his hematologist. His hematologist was very willing to discuss the current state of research and details about the treatment, and this gave Mr. Choate the confidence to proceed with it. Mr. Choate continues to discuss the current state of research, and he looks forward to the day he can self-administer oral chemotherapy at home.

Mr. Choate mentioned that an excellent example of self-care in his community was a local diabetes clinic. He stated that the clinic counselled him on proper diabetes management and accommodated their care to his lifestyle. It also provided him with technology that helped him with self-care, including a blood glucose tester and test strips, the ability to trend blood glucose on a computer log, the self-administration of insulin using an injector, the ability to track results of a A1C performed at a local private lab using an online web application, and ongoing primary care oversight using his electronic medical record.

Mr. Choate stated that patients want access to their own electronic medical records. For him, it helps him decide when to take corrective action with his blood sugar for his diabetes, and it allows him to engage with his hematologist.

Mr. Choate stated that patients, caregivers, clinicians and community care providers need to be educated on self-management. He noted that the benefit of self-management needs to be demonstrated to both patients and health-care providers. Mr. Choate also noted that there needs to be alignment with technology with health services to inspire patients to self-manage while also reducing health-care consumption.

Heather Sinardo

Ms. Sinardo explained that there are different components of self-management care at the Canadian Cancer Society, where patients are able to get information they want when they want it. There are multiple tools and apps that can track progress. It can be challenge because the



frequency of information can change and it can be difficult to keep information up-to-date. As a result, a platform should be developed where patients can track their medical history in one place. Ms. Sinardo hopes that patients will be comfortable asking health-care teams about their care, and she noted that collaboration is crucial to providing self-management programs.

Josie Barbita

Ms. Barbita described a tele-homecare program for chronic obstructive pulmonary disease patients that operates at the Toronto Central CCAC, in collaboration with the Ontario Telemedicine Network. Once patients consent to the program, medical technology that monitors weight and vital signs is placed in their homes. The collected information is monitored by a nurse from the Toronto Central CCAC who is specifically assigned to the patient; the data also are sent to the patient's primary care provider. In addition to this, the nurse also provides the patient with health coaching, action and goal planning, and general daily support.

Ms. Barbita explained that the tele-homecare program is currently being evaluated by the Toronto Health Economics and Technology Assessment Collaborative at the University of Toronto. Data collected to date indicate a decrease in emergency room visits. Since the data collected are sent to primary care providers and clinicians, they help patients and providers, but they also help address challenges and barriers and allow for future adoption.

Ms. Barbita noted that, unlike brochures, technology can help us continuously update information. Furthermore, the rise of mobile apps means that technology can help connect and monitor larger groups of people, including family and peers.

Dr. Doris Howell

Dr. Howell emphasized that a standardized approach of explaining self-management is necessary because there are many terms and everyone is assumed to understand them. Dr. Howell also addressed the need to consider an inclusive, family-oriented approach, as cancer affects the entire family.

Dr. Howell mentioned that there are plenty of survival and mortality data when evaluating exercise and physical activity. Disease-specific studies also are being performed, but those do not always link to behaviour change, nor are there many studies that perform a cost analysis of behaviour change. This means that the financial benefits of such changes would not be known until they are performed. It is, however, reasonable to anticipate short-term increases in costs when patients shift to the care they require.



Dr. Howell stressed that self-management needs to be brought into patient's homes and communities because patients do not enjoy travelling back and forth to cancer centres. She also suggested that some programs focus too much on reading about self-management instead of focusing on building problem-solving skills through an online component.

Dr. Howell stated that health-care workers can use Edmonton System Assessment Scores (ESAS) scores to suggest self-management strategies for patients to change certain behaviours and alleviate certain symptoms. Dr. Howell concluded by noting that there is plenty of self-management literature, and that it is up to the health-care workers to incorporate self-management.

10. Rapid Rounds Session

Following the debate, a Rapid Rounds session was held, with 10 presenters providing a three-minute presentation on innovation in technology related to self-management and best practices in self-management across Ontario.

10.1. Innovations in Technology

Susana Neves-Silva

Susana Neves-Silva, Client Service Manager at the Toronto Central CCAC, provided a description of the Toronto Central CCAC's tele-homecare program. She explained that clients receive technology, such as a tablet and a blood pressure monitor that continuously transmits health information electronically to the tele-homecare nurse. Nurses respond to this information, relate it back to the client's action plan and share it with physicians; the information also helps clients learn about their chronic condition, which then enables them to take care of themselves at home. Reports found that in six months post tele-homecare program, clients had a 54% reduction in emergency room visits and a 67% reduction in hospital admissions. Tele-homecare clients have tripled since 2014 (up from 191 in 2014 to 630 in 2015).

Robert Kyle

Robert Kyle, a Toronto Central CCAC client, shared his experience with the Toronto Central CCAC's tele-homecare program. Mr. Kyle has faced many challenges, including heart failure, a tragic loss and providing care for a family member with diabetes. Participating in the CCAC's tele-homecare program provided a lifeline for him. He found he was not alone—that he could receive care in the comfort of his home and check in with a trained health-care provider regarding his



condition and care. Mr. Kyle is a graduate of the tele-homecare program and continues to advocate for it.

John Semple

Dr. John Semple, Surgeon in Chief at the Women's College Hospital, performs breast reconstruction for breast cancer patients. Complications usually occur 30 days post procedure, but Dr. Semple found that he was unaware of what happens with patients after they are discharged. As a result, a mobile app was created by QoC Health that enabled patients to answer a series of questions related to their symptoms and identify complications using a quality scale; it also made it possible for them to upload pictures of their wounds and track their daily progress. This information is then accessed by health-care professionals who provide follow-up care if needed. Early findings from a randomized controlled trial with the Canadian Institutes of Health Research found that the app helped reduce readmissions, and that it had the potential to produce cost savings.

Zayna Khayat

Zayna Khayat, Lead of MaRS Health and Director of MaRS EXCITE, began her discussion by describing the "Copernicus moment" we are experiencing in health care, where social services that would originally revolve around the system, institution or practitioner are now revolving around the patient. Ms. Khayat provided an overview of how we are working to shift from an industrial age medicine pyramid to an information age health-care pyramid, where self-care is encouraged rather than discouraged. Ms. Khayat highlighted some of the self-care startups that MaRS is involved with through a sharing economy, including SeamlessMD, QoC Health, MD Home Call, Self Care Catalysts and ManagingLife. She stated that there are hundreds of self-care initiatives worldwide, but that they yet are not as popular here in Ontario.

Deborah Kennedy

Deborah Kennedy, Program Development Manager at Sunnybrook Hospital's Holland Orthopaedic & Arthritic Centre, presented a mobile app called *myHip&Knee*. Hip and knee surgery patients wanted an app to address their learning needs throughout the procedure, especially after discharge. *myHip&Knee* performs a daily health check where patients answer questions about their symptoms and daily lives; the app then provides detailed recommendations. It also has a library of information about treatment and symptoms that can help patients on their journey.



Patients are given information about the app at the Surgery Assessment Centre: they download it and are shown how to use it. From the time between discharge and the post-op follow-up visit, patients use the app to help with self-management at home. At the post-op follow-up visit, patients complete a survey.

Kyle McKeown

Kyle McKeown, Senior Coordinator of Partnerships and Promotion at the Canadian Cancer Society's Smoker's Helpline, described a smoking cessation support text message service provided by his organization. The service sends registered users motivational and informational text messages regarding smoking cessation. The service also supports reactive texts, where users can text key words and receive instant advice or help. The service hopes to expand by incorporating an easier registration process and real-time support with an associate via text.

10.2 Best Practice Examples across Ontario

Lianne Dupras

Lianne Dupras, a Patient and Family Advisor at Cancer Care Ontario, explained how a cancer diagnosis can lead patients to a sense of loss: loss of time, routines, work status, control and physical appearance. Self-management, however, can be an effective way of recapturing some of that lost control. She proposed eight ways to help patients become activated and engaged:

- 1) Include a Patient and Family Advisor in projects and discussions.
- 2) Be patient: if at first you don't success, try again. Not all patients are motivated to self-manage at first, so health-care professionals need to allow time for some patients to ready themselves. When they are ready, the patients can be approached again.
- 3) Let patients know they are "seen." Be engaging and encouraging with patients; let them know you are rooting for them.
- 4) Take the time. Health-care professionals should spend time going through all of the different aspects of their self-management program. This strengthens the relationship between patients and health-care professionals, and it emphasizes the importance of good self-management.
- 5) Customize information and educational tools. Health-care professionals should have informational and educational tools that cater to different learning types, such as pictures for visual learners, chat sessions for auditory learners or props for hands-on learners.
- 6) Keep things simple. Information such as graphs, literature and educational materials should be clear, concise and easy to understand.



- 7) Show patients the value in their efforts. Health-care professionals need to acknowledge and commend the work that patients perform, including filling out questionnaires, history forms and ESAS reports.
- 8) Make it clear that self-management should complement health system supports, not replace them. Health-care professionals need to continuously remind patients that care will always be available to them, and that self-management is meant enhance their quality of life and health outcomes.

Monika Krzyzanowska

Dr. Monika Krzyzanowska, Clinical Lead of Quality Care and Access in the Systemic Treatment Program at Cancer Care Ontario, presented the Ambulatory Toxicity Management (AToM) pilot. Findings from Ontario databases showed that patients undergoing adjuvant chemotherapy had one or more emergency room visits during treatment. The current model of care is for patients to call in themselves if there are any complications, but the AToM pilot attempted to change that. Nurses followed-up with patients twice after each treatment cycle to talk about common side-effects and symptoms; the advice they provided was standardized and evidence-informed. Patients also were provided with a self-management booklet that contained information about common symptoms. Results from the pilot indicate that there was an 82% adherence to the calls, that 97% of patients indicated they liked receiving calls, and that 94% recommended the pilot be shared with all chemotherapy patients. The next step for the pilot is to perform a large-scale randomized control trial.

Denise Bryant-Lukosius

Denise Bryant-Lukosius, Associate Professor at the School of Nursing at McMaster University, explained that patient activation and self-management support are core components of new models of care, including urgent care, pain/symptom management and survivorship care. Knowing this, Ms. Bryant-Lukosius devised a descriptive study to examine health-care provider knowledge, skills, attitudes and practices related to the promotion of patient activation and the provision of self-management support. Working with the Juravinski Cancer Centre, all health-care providers filled out a self-report questionnaire that focused on self-management support, patient activation and patient-centeredness; the health-care providers also participated in an in-depth interview. The study used the *Clinician Support for Patient Activation Measure (CS-PAM)* and *Practices in Self-Management Support (PMS)* tools.

Preliminary survey results showed 164 of 363 providers participated, and that respondents represented a good range of health-care providers, including nurses, radiation therapists and oncologists. The survey found that 65% of participants had no prior education related to self-



management support, 49% of participants were aware of patient activation and self-management support concepts, and 37% of participants were novices in providing self-management support. The study's next steps are to complete survey accrual and analysis, and to make recommendations to help improve provider engagement in patient activation and self-management support. Ms. Bryant-Lukosius mentioned that a patient parallel study will be performed in the future.

Simron Singh

Dr. Simron Singh, Clinical Lead of Person-Centred Care at Cancer Care Ontario, began his presentation by providing an overview of the Quality of Life and Patient Experience goal under [Cancer Care Ontario's Ontario Cancer Plan IV](#). Dr. Singh described the strategic objectives within this goal, which address engaging patient and supporting health-care providers with training, tools and resources to improve communication, decision-making, self-management and quality of life. Dr. Singh explained that there was not a clear understanding of self-management among clinicians. To address this Dr. Singh and the Person-Centred Care team worked with the Program in Evidence-Based Care (PEBC) to develop the [Person-Centred Care Guidelines](#). Adapted from the United Kingdom's National Health Services recommendations, the Person-Centred Care Guidelines aimed to establish a standardized set of recommendations for providing person-centred care in the delivery of cancer care in Ontario. The overall recommendations from the guideline include:

- knowing the patient as an individual;
- essential requirements of care;
- tailoring health-care services for each patient;
- continuity of care and relationships; and
- enabling patients to actively participate in their care.

11. Breakout Session

Following the Rapid Rounds session, participants were divided into 12 groups. They were then given an opportunity to provide feedback on Cancer Care Ontario's draft *Framework for Self-Management Education for Cancer Patients* (see Appendix 1 for the draft framework); they also were asked to discuss steps for implementation and priority setting related to the roll out of self-management programs in Ontario (see Appendix 4 for a participant list). Participants received a glossary of terms to assist defining self-management terms; they also had received a set of five questions to review prior to the Signature Event to help them prepare for the discussion (see Appendix 5 for the Glossary of Terms and Appendix 6 for the breakout questions). A facilitator and note taker were assigned to each table to help stimulate discussion and record salient points.



Each table's feedback was reviewed and helped to shape the recommendations contained on pages 8–11 of this report.

12. Cancer Care Ontario's Commitment to Self-Management, Patient Activation and Empowerment in Cancer Care

Michael Sherar began by sharing some of the work that Cancer Care Ontario is undertaking to address the goals of quality of life and patient experience which are strategic objectives in the Ontario Cancer Plan IV. This includes support to health-care providers, patients and families with training, tools and resources in order to improve communication, decision making and strategies for patient self-management of care. Some examples are the development of a Person-Centered Care Guideline, Skin Care Reaction Guidelines and Best Practices and the development of printed and audio visual tools for managing side effects of treatment.

Dr. Sherar highlighted that the need for improvements in patient self-management and empowerment has increased due to the growing needs of an aging population. Cancer Care Ontario plays an important role in providing the tools which can be used to support patients across the cancer journey and allow them to feel confident, empowered and informed about their personal medical management. By doing so, it will also ensure they have a good understanding of what they need-both physically and emotionally from the health care system. Dr. Sherar explained that having a provincial level systems can be accomplished by forming partnerships.

In summary, Dr. Sherar reiterated that Cancer Care Ontario is committed to having self-management as an important component of cancer care in Ontario. This can only be accomplished by partnering with providers, patients, families and other stakeholders to plan and implement this initiative. Dr. Sherar went on to say that Cancer Care Ontario appreciates the work of all the participants and that we will use the recommendations to develop innovative solutions that are safe, effective and patient centered in order to allow our patients to participate in and manage their own care.

13. CQCO's Commitment to Self-Management, Patient Activation and Empowerment in the Cancer System

Ms. Virginia McLaughlin expressed her thanks to the speakers, facilitators and panelists for sharing their work and expertise in self-management and patient activation. Ms. McLaughlin went on to thank the Signature Event Steering Committee for providing advice and helping to shape the content of the Signature Event (see Appendix 7 for Steering Committee members). She also thanked Mr. Sherar and Cancer Care Ontario for their commitment to the work of CQCO and their ongoing support. She stated that CQCO will continue to hold Cancer Care Ontario



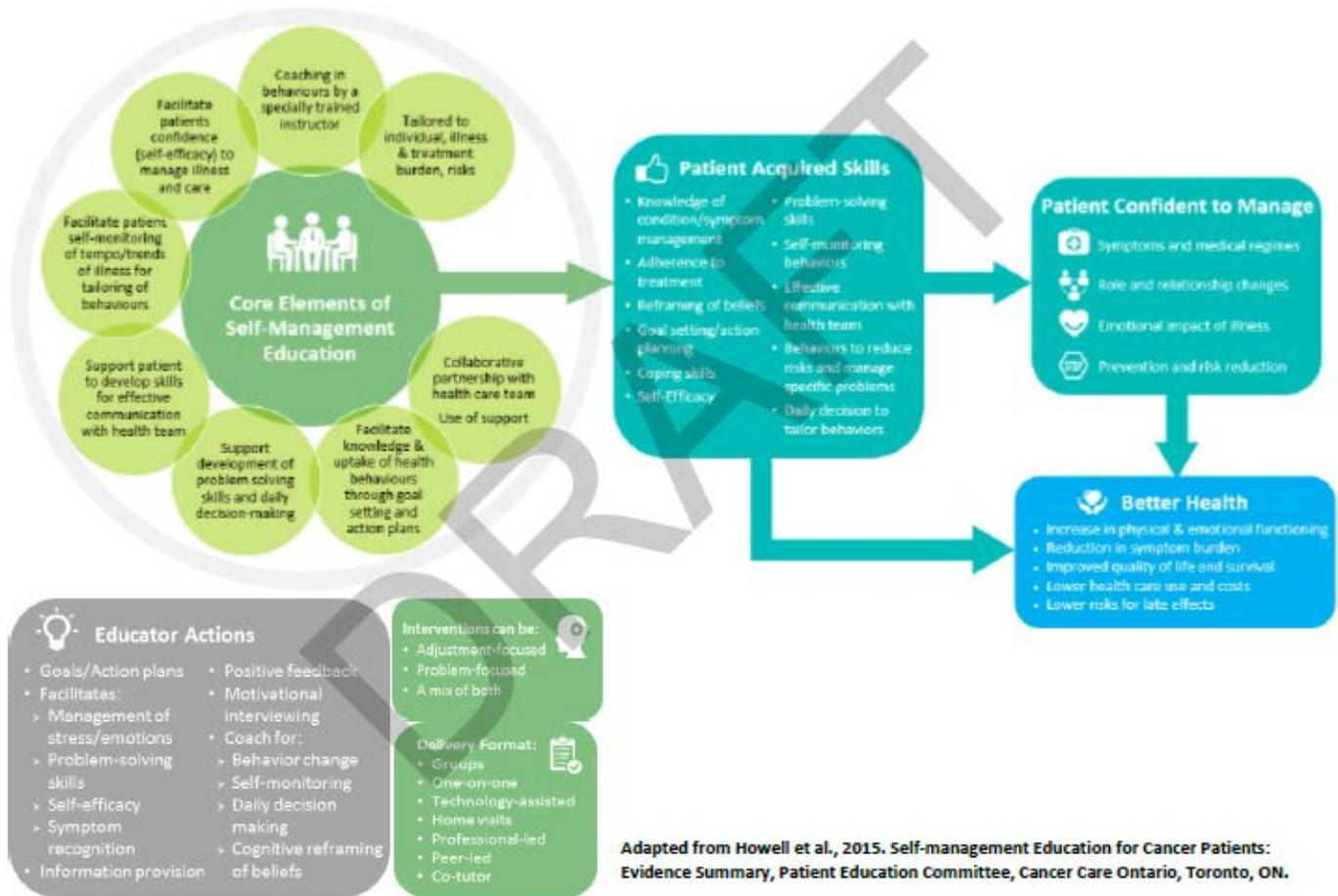
accountable for facilitating the implementation of self-management across the province. Finally, Ms. McLaughlin thanked the attendees for participating and sharing their experience in self-management and patient activation.



14. Appendices

Appendix 1: Draft Framework for Self-Management Education for Cancer Patients

An Emerging Framework: Self-Management Education Support for Cancer Patients





Appendix 2: Speaker Biographies

Dawn Powell, Patient Advisor and Member, Cancer Quality Council of Ontario

Dawn Powell is a 7-year cancer survivor. Because of the many challenges she encountered through treatment and beyond, she believes that her involvement as a PFA will make the system better for future cancer patients. She is actively involved in the Northwest Regional Cancer Centre offering a patient's perspective on numerous committees including the PFCC Leadership Council. Her vision of Cancer Care in 2014 formed the core for the Regional Cancer Care Plan III. She is actively involved as a PFA with the Thunder Bay Regional Research Institute. She also chairs a unique group of cancer patients and survivors called the Cancer Partnership who work with the Executive and Management of Cancer Care Northwest to improve the cancer journey for all involved. She is active on several committees within Cancer Care Ontario and is member of the Cancer Quality Council of Ontario.



Professionally, she is an accredited member of the Appraisal Institute of Canada and holds a MSC from the University of St. Thomas in Minneapolis. She has been appraising real property since 1978 and is the President of Powell Appraisals, specializing in commercial, institutional and industrial real property valuation since 1986. She enjoys motorcycling, photography and the great outdoors. She has been married to Eric for 28 years and they look forward many happy, healthy years together.

Virginia McLaughlin, Chair, Cancer Quality Council of Ontario

Virginia McLaughlin has been a member of CQCO since 2011 and has been serving as the Council Chair since 2013. She currently serves as a volunteer trustee on the Boards of trustees of the University of Guelph and the Canadian Museum of Science and Technology Corporation. In addition she is Honorary Lieutenant-Colonel of the 25 (Toronto) Field Ambulance. She is a past Chair of the Board of Directors, Sunnybrook Health Sciences Centre and a past chair of the Governance Leadership Council of the Ontario Hospital Association.



Prior to becoming a member of the Sunnybrook & Women's Board of Directors, Ms. McLaughlin was a member of the Board of Trustees, York Central Hospital (1985-1997) and Chair of the Board from 1995-97. She chaired the GTA/905 Healthcare Alliance from 1995-1998 and the York Region Tri-Hospital group from 1995-97. Ms. McLaughlin has also participated in governance for the Ontario Hospital Association as a member of the Regional Council Executive Committee for Region 3 (Toronto, York, Peel and Durham) 1998-2008, as chair of the RCEC 2000-2002, member of the OHA board of Directors 2000-2002 and chair of the OHA Advocacy Committee (2001-2002) and from 2004 until November 2007 was the Chair of the Ontario Hospital Association Governance Leadership



Council. Other recent volunteer commitments include Chair of the Board of Trustees of the University of Trinity College (2003-2005; member since 1999), Chair of Finance Committee (2000-2003) and member of Nominating Committee for the Provost (2001).

During the 1980's and early 1990's Ms. McLaughlin served as a volunteer member of the Toronto Symphony Board, Toronto Symphony Volunteer Committee and Junior Women's Committee and as a member of the Country Day School Board and Chair of the Junior School Curriculum Committee. In private life, Ms. McLaughlin is President of Helmhorst Investments Limited and Ferdinand Holdings Limited. She is married and has two adult children and three grandchildren.

Robin McLeod, Vice-President, Clinical Programs and Quality Initiatives, Cancer Care Ontario

As Vice-President, Clinical Programs and Quality Initiatives, Dr. Robin McLeod works with clinical leaders across the province to improve the quality and coordination of cancer care. Previously, she served for 7 years as Surgical Lead, Quality and Knowledge Transfer.

Robin received a BSc and MD from the University of Alberta. Following this, she completed training in general surgery at the University of Toronto, colorectal surgery at the Cleveland Clinic, and did training in clinical epidemiology at McMaster University before joining the faculty at the University of Toronto in 1985.



She is a Fellow of the Royal College of Physicians and Surgeons of Canada, a Fellow of the American College of Surgeons, and a fellow ad hominem of the Royal College of Surgeons of Edinburgh. She is a Diplomate of the American Board of Surgery and the American Board of Colorectal Surgery, a Professor in the Departments of Surgery and Health Policy Management and Evaluation, University of Toronto and Vice Chair, Quality and Performance in the Department of Surgery, University of Toronto. She has also led several multi-centre Canadian clinical trials in colorectal surgery and has authored more than 400 peer-reviewed articles and 40 book chapters.



Doris Howell, Senior Scientist, Princess Margret Cancer Centre

Dr. Doris Howell RN, PhD is a PhD graduate of the Department of Health Policy, Management and Evaluation, Outcomes and Evaluation Stream of the University of Toronto, Toronto, ON.

She is the RBC Chair, Oncology Nursing Research and Education at University Health Network (Princess Margaret Cancer Centre) & Co-Director of the Ontario-Patient Reported Outcomes Symptoms and Toxicity Research Unit, Ontario Institute for Cancer Research and a Senior Scientist, Ontario Institute for Cancer Research, Psychosocial Oncology and Supportive Care Division, Princess Margaret Cancer Centre, Toronto, ON.



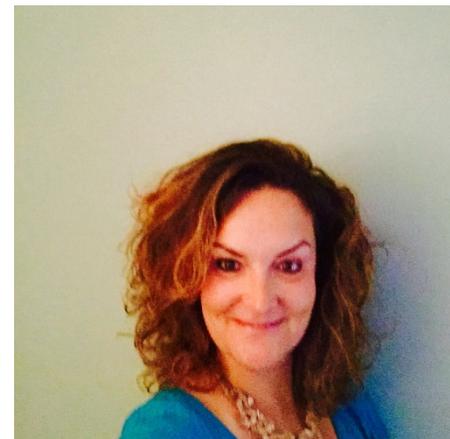
She holds faculty appointments as Associate Professor, Lawrence Bloomberg Faculty of Nursing, University of Toronto with Cross-Appointments in the Dalla Lana School of Public Health and the Department of Health Policy, Management and Evaluation. She is also a Diamond Jubilee Fellow at the University of Southampton in the United Kingdom.

Dr. Howell also holds Affiliate Scientist Appointments in the Institute for Clinical Evaluative Sciences, University of Toronto and the ELLICSR Wellness and Cancer Survivorship Centre at the Princess Margaret Cancer Center.

Her clinical research is focused on understanding complex cancer symptoms and the role of illness perceptions and testing the effectiveness of personalized symptom self-management interventions on symptom distress and health behaviours. She also conducts implementation science and health services research focused on improving the quality of health care and specifically the effects of integrating Patient-Reported Outcome measures in routine oncology practice on patient activation, health outcomes and patient experience.

Tamara Harth, Provincial Head, Patient Education, Cancer Care Ontario

Tamara Harth is the Provincial Head of Patient and Family Education at Cancer Care Ontario and the Program Manager and Lead for Patient Education at Sunnybrook Health Sciences Centre and the Odette Cancer Centre. In these roles, Tamara is responsible for setting, implementing and evaluating the strategic direction of patient education. She is very interested in health literacy and its impact on the development and implementation of patient education tools. Tamara has designed and provided workshops and talks on this topic to clinicians in a variety of disciplines. Her research interests are in the effectiveness of patient education in the context of self-management. She has received the distinguished service award from CPEN and recently was awarded the provincial distinguished support service award from the Canadian Cancer Society for her leadership in the development and implementation of a Patient Education Research Learning Centre.



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Kate Lorig, Director of the Stanford Patient Education Research Center and Professor of Medicine in the Stanford School of Medicine, California, USA

Kate Lorig is a Professor at the Stanford University School of Medicine, and Director of the Stanford Patient Education Research Center. She has a Master's in nursing and a doctorate in public health with a specialty in health education.

For more than two decades, using a public health approach, she has developed and evaluated community-based patient education programs in English and Spanish for people with chronic conditions. In recent years this work has been extended to similar programs offered via the Internet.



Darren Larsen, Vice Chair, Cancer Quality Council of Ontario

Over his 24 years as a comprehensive care Family Physician Darren has been involved in many provincial and national Health IT, Quality and Leadership initiatives. He has advised and acted in this space for OntarioMD, the Ontario Medical Association, and the Canadian Medical Association, and serves on e-health and quality committees for Health Quality Ontario, eHealth Ontario and Cancer Care Ontario. He is currently vice chair of the Cancer Quality Council of Ontario and works for the OMA as its Chief Medical Information Officer.

Darren obtained his BSc at the University of Alberta, MD at the University of Calgary and did residency at the University of Ottawa. He holds a Masters Certificate in Physician Leadership from York University's Schulich School of Executive Management. His happy place is on his snowboard, with his teenage kids, on the top of any mountain he can find.



Nicolaj Holm Ravn Faber, Chief Consultant, Danish Committee for Health Education, København, Denmark

Nicolaj Holm Ravn Faber holds a Master in Philosophy and Rhetorics from the University of Copenhagen. He holds a Process and Graphic Facilitator degree from Rambøll Management. Nicolaj has been working with the Danish Committee for Health Education since 2006 where he teaches and trains health care professionals in peer support and patient centered approaches. He is a T-trainer in the Chronic Disease Self-Management Program (CDSMP) and a developer of the CDSMP back to work program.





Patrick McGowan, Professor, School of Public Health and Social Policy, University of Victoria, British Columbia

Patrick McGowan is a Professor with the School of Public Health and social Policy at the University of Victoria. Patrick's research career over the last 30 years has focused on aspects of health education for persons experiencing chronic health conditions, particularly self-management. He has been implementing and researching effectiveness of self-management interventions with conditions such as: diabetes, arthritis, osteoarthritis, and tuberculosis. As well, he has been researching the feasibility, viability, acceptability and effectiveness of the Stanford University community programs. This research is being conducted at the community level (including the aboriginal, Punjabi and Chinese communities), and at provincial, national, and international levels. Patrick is also involved in integrating self-management support into clinical settings.



Dr. McGowan participates on provincial and federal and international committees. He is based in Delta, BC, where he directs the University of Victoria, Centre on Aging – Ladner Office.

Claire Foster, MacMillan Research Group, Southampton, United Kingdom

Prof Claire Foster obtained her PhD from the University of Exeter then spent seven years at the Institute of Cancer Research before moving to University of Southampton in 2004. She is Professor of Psychosocial Oncology in the Faculty of Health Sciences, University of Southampton, UK. She is Director of the Macmillan Survivorship Research Group and her research programme focuses on advancing understanding of the health outcomes and experiences of cancer survivors and developing supportive resources to enhance well-being and self-management following treatment. This includes large prospective cohort studies to understand the consequences of cancer over time, how this can impact on people's daily lives, and identifying areas for intervention. Her team is developing complex interventions, including web-based resources, to support self-management of cancer related problems such as fatigue following cancer treatment; and developing web-based decision aids to support younger women facing decisions about treatment and genetic testing.





Andrew Choate, Patient and Family Advisor, Cancer Care Ontario

Andrew Choate is a volunteer member of the CCO, Patient and Family Advisory Council. He was diagnosed with an incurable, rare form of Non-Hodgkin’s Lymphoma, Waldenstrom’s Macroglobulinemia, and he is managing Type 2 Diabetes. Andrew prefers not to be defined by his comorbidities and chooses to assist in bringing patient focus to the forefront in Ontario’s Health Care System.

Even in retirement, Andrew approaches many of life’s problems from a systems perspective. He spent in excess of 35 years in the nuclear power generation industry, implementing projects and managing various IT enterprise systems.



Andrew supports a Health Care Model that moves cancer treatment into the patient’s home.

Josie Barbita, Director, Professional Practice, Toronto Central Community Care Access Centre

Josie Barbita is the Director of Professional Practice with the Toronto Central Community Care Access Centre. She has more than 25 years of experience as a Health Services Administrator in both delivery and management roles. Her experience includes working in the acute care, primary care and community care sectors. Within her professional practice portfolio, Josie has responsibility for the planning, implementation and operations of the direct care nursing programs as well as managing the CCAC’s Interprofessional Specialty Team. She has led and implemented new models of care such as Telehomecare and most recently the implementation of a new community wound care strategy. Josie holds a Bachelor’s of Science degree in Nursing and a Master’s of Science degree in Health Administration.



Heather Sinardo, Senior Manager, Canadian Cancer Society

Heather Sinardo is the Senior Manager for the Canadian Cancer Society’s peer support programs, and has managed the nationwide telephone peer support program since its inception in 2003. She is also the Community Strategist for the Society’s online communities, CancerConnection.ca/ParlonsCancer.ca. Heather has been with the Society for over 15 years, is based in Toronto, and has a Master’s Degree in Nursing from the University of Toronto.





Robert Kyle, CCAC Client, Toronto Central Community Care Access Centre

After receiving a "new heart" through successful heart transplant surgery on October 17, 2014, Robert Kyle is now a 62-year-old, retired senior living in Toronto. He has a daughter Kandis also in Toronto and a son Darin who lives in Ottawa.



Susana Neves-Silva, Client Service Manager, Toronto Central Community Care Access Centre

Susana Neves-Silva is a Client Service Manager at Toronto Central Community Care Access Centre (CCAC) leading the organization's Telehomecare program.

A Registered Nurse with 18 years of experience assisting patients, Susana spent many years at St. Michael's Hospital in various areas, including Internal Medicine, In-Patient Mobility and in the Project Management Office.

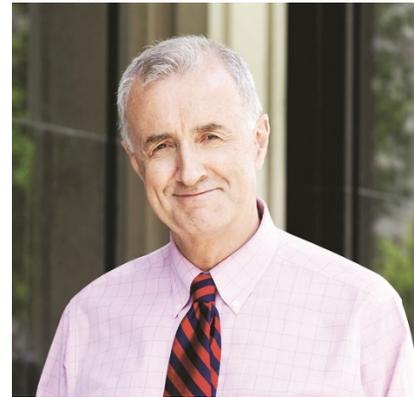
In addition to holding her BSc in Nursing from Ryerson University, Susana also holds certificates in Project Management and Leadership and Management in Nursing from the same institution. Since May of 2008, Susana has lent her skills to the CCAC in a variety of roles, including Hospital Care Coordinator and Hospital Preceptor for new staff. She has also actively engaged her team by mentoring them towards success and continues to work towards providing the highest standard of care and support to both her team and the clients that she serves.



John Semple, Surgeon in Chief, Women's College Hospital



Dr. Semple attended the Ontario College of Art and then completed a BSc in Medical Illustrating (Art as Applied To Medicine) at the University of Toronto. He received his MD degree at McMaster University and his surgical training in Plastic Surgery (FRCSC) at the University of Toronto. In addition he has a MSc in Experimental Pathology (U of T) and a clinical fellowship in microsurgery (TGH).



Dr. Semple is currently:

- Surgeon-in-Chief at Women’s College Hospital
- Professor, Department of Surgery at the University of Toronto.
- Chair in Surgical Research from the Canadian Breast Cancer Foundation
- Past President of the Canadian Society of Plastic Surgeons.

Dr. Semple has a special interest the development of affordable and appropriate mobile technology for solving problems in health care.

Zayna Khayat, Lead of MaRS Health and Director of MaRS EXCITE

Dr. Zayna Khayat is a senior advisor in health system innovation at MaRS Discovery District, an innovation hub in Toronto with a major focus on the health sector. She is also Director of the MaRS EXCITE health technology evaluation program. Zayna’s mission is to help healthcare systems in Ontario, Canada and around the world adopt health technology that improves public health while driving the Canadian knowledge economy. Dr. Khayat is also adjunct professor in health sector strategy at the Rotman School of Management at University of Toronto. Zayna was previously director of development at the Ivey International Centre for Health Innovation at Western University. Prior to this, she had an 11-year career in strategy consulting in the global health and life sciences sector, first with the Boston Consulting Group’s Toronto office from 2001 to 2010, and then as an associate principal with SECOR/KPMG. She holds a PhD in biochemistry from the University of Toronto and the Hospital for Sick Children, with a focus on insulin action and diabetes. She lives in Toronto with her husband and three children.





Deborah Kennedy, Manager, Program Development, Sunnybrook's Holland Orthopaedic & Arthritic Centre

Deborah is the Manager of Rehabilitation and MSK Program Development at the Sunnybrook Holland Orthopaedic & Arthritic Centre, an Assistant Clinical Professor in the School of Rehabilitation Science at McMaster University and Lecturer in the Department of Physical Therapy at U of T. She has a Master's Degree in Clinical Health Sciences and is a recognized expert in outcome measurement in the arthroplasty population. More recently, her research interests have focused on the evaluation of new models of care and patient education. Deborah is a tireless advocate for optimizing the patient experience.



Kyle McKeown, Senior Coordinator, Partnerships and Promotion, Canadian Cancer Society's Smoker's Helpline

Kyle McKeown has been working in tobacco control for more than a decade, with roles as varied as media spokesperson, webmaster, photographer, media analyst, copywriter, social media strategist and project manager.

After 8 years with the Media Network for a Smoke-Free Ontario at Cancer Care Ontario and a short stint in the private sector, Kyle joined Smokers' Helpline at the Canadian Cancer Society in 2010 to work on the highly successful Driven to Quit Challenge team. In 2011 and 2012, Kyle headed the pan-Canadian team responsible for the Health Canada-funded Break it Off initiative targeting young adult smokers, which showed significantly improved cessation outcomes are capable from an effective social media cessation campaign.



As Senior Coordinator of Partnerships & Promotions at Smokers' Helpline, Kyle is currently the cessation team lead working on an overhaul to the Smokers' Helpline Online and Text Message services, expected to launch in 2016.



Lianne Dupras, Patient and Family Advisor, Cancer Care Ontario

Lianne has been with Cancer Care Ontario's Patient and Family Advisory Council (PFAC) since September of 2012. She is on the Symptom Management Advisory Committee, the Patient Reported Outcomes Advisory Committee, the RTM Content Development Committee, the iPEHOC (Improving Patient Experience and Health Outcomes Collaborative), and the OCSMC (Ontario Cancer Symptom Management Collaborative). In addition to this she participates in various one-time events such as the OCP IV roadshow, telephone feedback, CRC Pathways, among other initiatives.



After months of feeling fatigued and of bruising easily, Lianne Dupras was diagnosed with Acute Promyelocytic Leukemia in June of 2000. Between June and November of 2000, she underwent several rounds of chemotherapy (3 different types administered simultaneously), lengthy stays in hospital in isolation and many, many blood transfusions. Serious complications arose as did some nasty side-effects from the treatments. Happily, a bone marrow biopsy showed that remission had been achieved in August 2000 and she has remained in remission since then.

Prior to her diagnosis, Lianne managed a Rob McIntosh China and Gifts and shortly after the birth of her first son in 1999, returned to her university studies—her favorite subjects being Sciences especially Anatomy and Physiology. Not long after finishing her first year back, she was diagnosed with leukemia. Lianne started volunteering weekly at her local cancer centre in 2002 and is still does. She has given presentations on the importance of blood donations, volunteers with various other cancer or blood donation related events and is a patient advisor on the Northeast Cancer Centre's Patient and Family Advisory Council.

Lianne values each and every day knowing that her initial chances for survival were slim (5%) because of the aggressive nature of this type of leukemia. She adores spending time with her loving husband and her 2 awe-inspiring sons, one born before her diagnosis and one after and their crazy cat and dog!



Monika Krzyzanowska, Clinical Lead, Quality Care and Access, Systemic Treatment Program, Cancer Care Ontario

Dr. Krzyzanowska is a medical oncologist and health services researcher at Princess Margaret Cancer Centre in Toronto. The overarching goal of her research program is to improve the quality of care received by cancer patients treated in routine care settings across the continuum of care. Her research has been supported by the Ontario Institute for Cancer Research, Canadian Institutes of Health Research, and the Canadian Breast Cancer Foundation. She is a previous recipient of an ASCO Young Investigator Award. She is the Provincial Clinical Lead for Quality Care and Access within the Systemic Treatment Program at Cancer Care Ontario and was previously Chair of the American Society of Clinical Oncology Quality of Care Committee. She is the Associate Editor for Journal of Oncology Practice.



Denise Bryant-Lukoslus, Associate Professor, School of Nursing, McMaster University

Denise is an Associate Professor in the School of Nursing and the Department of Oncology and the co-Director for The Canadian Centre for Advanced Practice Nursing Research (CCAPNR) at McMaster University. She is also a Scientist at the Escarpment Cancer Research Institute a joint venture between McMaster University and Hamilton Health Sciences. At Hamilton Health Sciences, Denise holds a cross appointment with the Juravinski Hospital and Cancer Centre as a Clinician Scientist and Director of the Canadian Centre of Excellence in Oncology Advanced Practice Nursing (OAPN) – which provides a unique a program of research, education, mentorship and knowledge translation activities to support the development of nursing roles in cancer control. As a health services researcher, Denise is involved in provincial, national and international initiatives designed to improve patient and health systems outcomes related to cancer and other chronic health conditions. Key areas of research focus on optimization of specialized and advanced nursing roles, evidence-informed decision-making, and the design and evaluation new models of care delivery. In addition to her education and research roles, Denise has national certification in oncology nursing and over 25 years of experience as a Clinical Nurse Specialist in Hematology/Oncology and urological cancers.





Simron Singh, Clinical Lead, Person-Centred Care, Cancer Care Ontario

In November 2013, Dr. Simron Singh joined Cancer Care Ontario (CCO) as the Provincial Head, Person-Centred Care responsible for the development and execution of CCO corporate strategic priority around person-centred care. Since February 2006, Dr. Singh continues to practice as a Medical Oncologist at the Odette Cancer Centre at Sunnybrook Hospital in Toronto. He is also an Assistant Professor on the Quality Improvement track in the Faculty of Medicine at the University of Toronto. In addition, Simron is a Principal Investigator with the Institute for Clinical Evaluative Sciences. Throughout Dr. Singh's professional work and academic studies, he has had a keen research interest in neuro-endocrine carcinomas as well as population health and cancer care utilization discrepancies.



Dr. Singh completed his BSc and MD at University of Alberta in Edmonton, Alberta. In addition, he completed his postgraduate training in Internal Medicine at Queens University in Kingston, Ontario and Medical Oncology at the University of Toronto. After completing his clinical training, Dr. Singh completed his Master's degree in Public Health from Harvard University in Boston, MA, USA.

Michael Sherar, President and CEO, CCO

Dr. Michael Sherar is President and CEO of Cancer Care Ontario. From 2006 to 2011, he was the provincial agency's Vice-President, Planning and Regional Programs, leading the development of Regional Cancer Programs, including capital planning for cancer services across the province. In this role, he led the development of the Ontario Cancer Plan 2011-2015.

Dr. Sherar is Professor of Medical Biophysics at the University of Toronto and Affiliate Scientist Techna Institute University Health Network where he carries out research and development of minimally invasive thermal therapy technologies for cancer including radiofrequency ablation.



In 2001, he was selected as one of Canada's Top 40 under 40 for achievements in leadership. He was previously Regional Vice President, Cancer Services, London for Cancer Care Ontario and Vice President, London Regional Cancer Program (LRCP), London Health Sciences Centre (LHSC).

Dr. Sherar received a BA in Physics from Oxford University in 1985 and his PhD in Medical Biophysics from University of Toronto in 1989.



Appendix 3: Signature Event Agenda

Morning Agenda

7:30 a.m.	REGISTRATION AND CONTINENTAL BREAKFAST	
8:30 a.m.	THE NEED FOR PATIENT ACTIVATION AND SELF-MANAGEMENT-A PATIENT'S PERSPECTIVE	Dawn Powell , Patient Advisor and Member, Cancer Quality Council of Ontario, Thunder Bay
8:45 a.m.	INTRODUCTIONS AND OVERVIEW OF THE DAY	Virginia McLaughlin , Chair, Cancer Quality Council of Ontario
8:55 a.m.	DEFINING PATIENT ACTIVATION AND SELF-MANAGEMENT FOR TODAY'S DISCUSSION	Introduction by Robin McLeod , Vice-President, Clinical Programs and Quality Initiatives, Cancer Care Ontario Doris Howell , Senior Scientist, Princess Margaret Cancer Centre Tamara Harth , Provincial Head, Patient Education, Cancer Care Ontario
9:40 a.m.	DEVELOPING AND IMPLEMENTING SELF-MANAGEMENT PROGRAMS	Kate Lorig , Director of the Stanford Patient Education Research Center and Professor of Medicine in the Stanford School of Medicine, California, USA
10:10 a.m.	FACILITATED DISCUSSION with Kate Lorig, Tamara Harth and Doris Howell	Facilitator: Darren Larsen , Vice Chair, Cancer Quality Council of Ontario
10:30 a.m.	MORNING BREAK	
10:45 a.m.	A CRITICAL APPRAISAL OF THE IMPLEMENTATION OF DENMARK'S CHRONIC DISEASE SELF-MANAGEMENT PROGRAM	Nicolaj Holm Ravn Faber , Chief Consultant, Danish Committee for Health Education, København, Denmark
11:15 a.m.	SELF-MANAGEMENT SUPPORTS: BUILDING CAPACITY AMONG HEALTHCARE PROFESSIONALS	Patrick McGowan , Professor, School of Public Health and Social Policy, University of Victoria, British Columbia
11:45 a.m.	FACILITATED DISCUSSION with Nicolaj Holm Ravn Faber and Patrick McGowan	Facilitator: Darren Larsen , Vice-Chair, Cancer Quality Council of Ontario



Afternoon Agenda

12:15 p.m.	LUNCH	VIDEO: SELF-MANAGEMENT IN THE UNITED KINGDOM Claire Foster , <i>MacMillan Research Group, Southampton, United Kingdom</i>
1:00 p.m.	DEBATE Bringing self-management from theory to practice	Facilitator: Tamara Harth , <i>Provincial Head, Patient Education, Cancer Care Ontario</i> PANEL SPEAKERS: Doris Howell , <i>Senior Scientist, Princess Margaret Cancer Centre</i> Andrew Choate , <i>Patient and Family Advisor, Cancer Care Ontario, Port Hope</i> Josie Barbita , <i>Director, Professional Practice, Toronto Central Community Care Access Centre</i> Heather Sinardo , <i>Senior Manager, Canadian Cancer Society</i>
1:45 p.m.	RAPID ROUND SESSION Highlighting best practice and innovations in patient activation and self-management across Ontario	RAPID ROUND PANELISTS: INNOVATIONS IN TECHNOLOGY Robert Kyle , <i>CCAC Client, Toronto Central Community Care Access Centre</i> Susana Neves-Silva , <i>Client Service Manager, Toronto Central Community Care Access Centre</i> John Semple , <i>Surgeon in Chief, Women's College Hospital</i> Zayna Khayat , <i>Lead of MaRS Health and Director of MaRS EXCITE</i> Deborah Kennedy , <i>Manager, Program Development, Sunnybrook's Holland Orthopaedic & Arthritic Centre</i> Kyle McKeown , <i>Senior Coordinator, Partnerships and Promotion, Canadian Cancer Society's Smoker's Helpline</i> BEST PRACTICE EXAMPLES ACROSS ONTARIO Lianne Dupras , <i>Patient and Family Advisor, Cancer Care Ontario, Sudbury</i> Monika Krzyzanowska , <i>Clinical Lead, Quality Care and Access, Systemic Treatment Program, Cancer Care Ontario</i> Denise Bryant-Lukosius , <i>Associate Professor, School of Nursing, McMaster University</i> Simron Singh , <i>Clinical Lead, Person-Centred Care, Cancer Care Ontario</i>
2:30 p.m.	AFTERNOON BREAK	
2:45 p.m.	FACILITATED BREAKOUT SESSION Determining next steps and priorities for implementation and review of Cancer Care Ontario's self-management education framework	
3:45 p.m.	WRAP UP	Virginia McLaughlin , <i>Chair, Cancer Quality Council of Ontario</i>
4:00 p.m.	COMMITMENT FROM CCO	Michael Sherar , <i>President & CEO, CCO</i>
4:15 p.m.	CLOSING REMARKS	Virginia McLaughlin , <i>Chair, Cancer Quality Council of Ontario</i>



Appendix 4: Signature Event Participants

First name	Last name	Organization
Rebecca	Anas	Cancer Quality Council of Ontario Secretariat
Danikah	Antaya	South West Regional Cancer Program
Chantel	Antone	South West Regional Cancer Program
Usman	Aslam	Cancer Care Ontario
Michelle	Aspden	Ontario Telemedicine Network
Megan	Bamford	Registered Nurses Association of Ontario
Sarah	Banbury	Mississauga Halton Central West Regional Cancer Program
Josie	Barbita	Toronto Central Community Care Access Centre
Hasmik	Beglaryan	Cancer Care Ontario
Chaim	Bell	Cancer Quality Council of Ontario; Mt. Sinai Hospital
Michael	Bell	South East Regional Cancer Program; Cancer Centre of Southeastern Ontario
Cathy	Bennett	Juravinski Cancer Centre
Leah	Bergstrom	North Simcoe Muskoka Regional Cancer Program
Subi	Bhandari	Patient and Family Advisory Council, Cancer Care Ontario
Joanne	Blyth	Southlake Regional Health Centre
Laurie	Bourne	Cancer Care Ontario
Susan	Boyko	Northeast Cancer Centre
Michael	Brundage	Cancer Quality Council of Ontario; Queen's University
Denise	Bryant-Lukosius	McMaster University; Juravinski Cancer Centre
Kirsten	Burgomaster	R.S. McLaughlin Durham Regional Cancer Program
Rodney	Burns	Association of Ontario Health Centres
Tory	Cadotte	Cancer Care Ontario
Scott	Campbell	Cancer Care Ontario
Kathi	Carroll	Cancer Care Ontario
Elizabeth	Carson	Cancer Care Ontario
Brenda	Carter	Cancer Centre of Southeastern Ontario
Jim	Chiarotto	R.S. McLaughlin Durham Regional Cancer Centre
Andrew	Choate	Cancer Care Ontario
Lillian	Clarke	Patient and Family Advisory Council, Cancer Care Ontario
Jenny	Cockram	Cancer Quality Council of Ontario; J. Cockram Associates Ltd.
David	Colgan	Central West Local Health Integration Network
Ruthe Anne	Conyngnam	Cancer Quality Council of Ontario; London Health Sciences Centre
Judie	Coutts	Cancer Quality Council of Ontario; Wellington Region/Hospice of Waterloo Region
Lindsey	Crawford	North Simcoe Muskoka Regional Cancer Centre



First name	Last name	Organization
Silvie	Crawford	Kingston General Hospital
Anthony	Dale	Ontario Hospital Association
Christina	Dantonio	Ontario Renal Network
Stacey	Daub	Cancer Quality Council of Ontario; Toronto Central Community Care Access Centre
Meghan	Davis	Hamilton Niagara Haldimand Brant Local Health Integration Network
Stefanie	De Rossi	Cancer Care Ontario
Lisa	Del Giudice	Toronto Central—North Local Health Integration Network
Debbie	Devitt	Durham Regional Cancer Centre/Lakeridge Health
Gail	Dobell	Health Quality Ontario
Paula	Doering	Ottawa Hospital Regional Cancer Centre
Winnie	Doyle	Cancer Quality Council of Ontario; St. Joseph's Healthcare Hamilton
Junell	D'Souza	Cancer Care Ontario
Monika	Duddy	Cancer Care Ontario
Charlene	Duliban	Walker Family Cancer Centre—Niagara Health System
Elizabeth	Dulmage	Windsor Regional Cancer Program
Lianne	Dupras	Cancer Care Ontario
Shari	Dworkin	Cancer Care Ontario
Craig	Earle	Institute for Clinical Evaluative Sciences
Kevin	Empey	Lakeridge Health
Katherine	Enright	Carlo Fidani Peel Regional Cancer Centre
Bill	Evans	Oncosynthesis Consulting Inc.
Lisa	Favell	Cancer Care Ontario
Brenda	Fleming	South West Regional Cancer Program
Jennifer	Foster	Toronto Central Community Care Access Centre
Colleen	Fox	Ontario Renal Network
Susan	French	North Simcoe Muskoka Local Health Integration Network
Debbie	Galet	Cancer Quality Council of Ontario; Baycrest Health Services
Sonal	Gandhi	Sunnybrook Health Sciences Centre
Jason	Garay	Cancer Care Ontario
Sophie	Georgas	Ministry of Health and Long-Term Care
Kelly-Jo	Gillis	Thunder Bay Regional Health Sciences Centre
Alexandra	Ginty	Mississauga Halton Local Health Integration Network
Angelika	Gollnow	Cancer Care Ontario
Esther	Green	Canadian Partnership Against Cancer
Sari	Greenwood	R.S. McLaughlin Durham Regional Cancer Centre
Carly	Griffin	Cancer Care Ontario
Eric	Gutierrez	Cancer Care Ontario



First name	Last name	Organization
Victoria	Hagens	Cancer Care Ontario
Farzana	Haji	Cancer Quality Council of Ontario Secretariat
Kiren	Handa	Cancer Care Ontario
Margaret	Hart	Lakeridge Health
Tamara	Harth	Cancer Care Ontario
Mark	Hartman	Northeast Cancer Centre/Health Sciences North
Rebecca	Harvey	Cancer Care Ontario
Caroline	Heick	Canadian Institute for Health Information
Malcolm	Heins	Cancer Care Ontario
Sherrie	Hertz	Cancer Care Ontario
Nicolaj	Holm Faber	Danish Committee for Health Education
Doris	Howell	Princess Margaret Cancer Centre
Gillian	Hurwitz	Cancer Care Ontario
Sarah	Hutchison	OntarioMD
Zahra	Ismail	Cancer Care Ontario
Hasina	Jamal	Cancer Quality Council of Ontario Secretariat
Neil	Johnson	London Regional Cancer Program
Barbara	Jones	Central Local Health Integration Network
Tracy	Jones	Ontario Home Care Association
Martin	Kabat	Canadian Cancer Society
Michelle	Karker	Cancer Quality Council of Ontario; East Wellington Family Health Team
Sue	Keller-Olaman	Public Health Ontario
Deborah	Kennedy	Sunnybrook Holland Orthopaedic and Arthritic Centre
Maggie	Keresteci	Ontario Medical Association
Zayna	Khayat	MaRS
Shoba	Khetrapal	Cancer Care Ontario
Paula	Knight	Cancer Care Ontario
Michelle	Krivel	Cancer Care Ontario
Monika	Krzyzanowska	University Health Network
Vishal	Kukreti	Cancer Care Ontario
Robert	Kyle	Toronto Central Community Care Access Centre
Helene	Lacroix	Saint Elizabeth Healthcare
Hugh	Langley	South East Local Health Integration Network
Antoinette	Larizza	Central East Local Health Integration Network
Darren	Larsen	Cancer Quality Council of Ontario; Ontario Medical Association/OntarioMD
Anne	Le Quang	Canadian Diabetes Association
Judy	Linton	Grand River Regional Cancer Centre



First name	Last name	Organization
Elizabeth	Lockhart	Cancer Care Ontario
Kate	Lorig	Stanford School of Medicine
Marnie	MacKinnon	Cancer Care Ontario
Kathy	MacLeod-Beaver	Central East Regional Cancer Program
Joanne	MacPhail	Patient and Family Advisory Council, Cancer Care Ontario
Jan	Macvinnie	Canadian Cancer Society
Catherine	Mahut	Southlake Regional Hospital
Allan	Malek	Ontario Pharmacists Association
Lorraine	Martelli	Juravinski Cancer Centre
Garth	Matheson	Cancer Care Ontario
Sarah	McBain	Cancer Care Ontario
Craig	McFadyen	Cancer Quality Council of Ontario; Carlo Fidani Peel Regional Cancer Centre
Patrick	McGowan	University of Victoria
Tom	McHugh	R.S. McLaughlin Durham Regional Cancer Centre
Kyle	McKeown	Canadian Cancer Society
Virginia	McLaughlin	Cancer Quality Council of Ontario
Robin	McLeod	Cancer Care Ontario
Scott	McLeod	Central West Local Health Integration Network
Sheila	McNair	McMaster University
James	Medeiros	Ontario Hospital Association
Elaine	Meertens	Cancer Care Ontario
Ralph	Meyer	Juravinski Cancer Centre
Nicole	Mittmann	Cancer Care Ontario
Lesley	Moody	Cancer Care Ontario
Dilshad	Moosa	Ontario Lung Association
Shelley	Morris	Ontario Telemedicine Network
Marjorie	Morrison	Canadian Cancer Action Network
Heather	Neilson-Clayton	Thunder Bay Regional Health Sciences Centre
Susana	Neves-Silva	Toronto Central Community Care Access Centre
Brett	Nicholls	Cancer Care Ontario
Linda	Novotny	Ministry of Health and Long-Term Care
Susete	Okada	Cancer Quality Council of Ontario Secretariat
Jason	Oliver	Odette Cancer Centre
Janice	Owen	South West Local Health Integration Network
Janet	Papadakos	Princess Margaret Hospital
Jillian	Paul	Ministry of Health and Long-Term Care
Naomi	Peek	Cancer Care Ontario



First name	Last name	Organization
Roseanne	Pegler	Stronach Regional Cancer Centre
Alice	Peter	Cancer Care Ontario
Aaron	Pollett	Cancer Care Ontario
Dawn	Powell	Cancer Quality Council of Ontario; Dawn M Powell Appraisals Inc.; Patient and Family Oncology Partnership Council, Thunder Bay
Melanie	Powis	University Health Network
Linda	Rabeneck	Cancer Care Ontario
Rami	Rahal	Canadian Partnership Against Cancer
Ratan	Ralliaram	Cancer Care Ontario
Robin	Reece	College of Physicians and Surgeons of Ontario
Jillian	Ross	Cancer Care Ontario
Susan	Ross	The Arthritis Society
Elham	Roushani	Cancer Care Ontario
Katrina	Santiago	Cancer Care Ontario
Kerseri	Scane	University Health Network
John	Semple	Women's College Hospital; Canadian Breast Cancer Foundation
Michael	Sharpe	Princess Margaret Hospital
Michael	Sherar	Cancer Care Ontario
Heather	Sinardo	Canadian Cancer Society
Simron	Singh	Sunnybrook Health Sciences Centre
Andy	Smith	Cancer Quality Council of Ontario; Sunnybrook Health Sciences Centre
Amy	Snow	Cancer Care Ontario
Monica	Staley	Windsor Regional Cancer Program
Janice	Stewart	Odette Cancer Centre
Robbie	Stewart	Cancer Care Ontario
Jennifer	Stiff	Cancer Quality Council of Ontario Secretariat
Harvey	Thomson	Cancer Care Ontario
Joshua	Tseng	Cancer Quality Council of Ontario Secretariat
Donna	Van Allen	Waterloo Wellington Local Health Integration Network
Joanna	Vautour	Toronto Central Regional Cancer Program
Chantelle	Vernon	Central East Local Health Integration Network
Kathy	Vu	Cancer Care Ontario
Maggie	Wang Maric	Cancer Care Ontario
Padraig	Warde	Cancer Care Ontario
Cori	Watson	North West Local Health Integration Network
Deanna	Wright	Grand River Regional Cancer Centre
Martha	Wyatt	Princess Margaret Hospital
Ella	Zarevich	Waterloo Wellington Community Care Access Centre



First name	Last name	Organization
Jennifer	Zelmer	Canada Health Infoway
Victoria	Zwicker	Cancer Care Ontario



Appendix 5: Glossary of Terms

This glossary was developed to ensure that all participants have an understanding of the various terms that will be used throughout the presentations and discussions at the 2015 Signature Event.

Patient activation

Those who are activated believe patients have important roles to play in self-managing care, collaborating with providers and maintaining their health. They know how to manage their condition and maintain functioning and prevent health declines; and they have the skills and behavioural repertoire to manage their condition, collaborate with their health providers, maintain their health functioning and access appropriate and high-quality care (Hibbard, Stockard, Mahoney, & Tusler, 2004).

Patient education

Patient education is a distinct and definable activity that supports the learning and behaviour of patients; and includes all learning experiences that patients engage in with the conscious intent of improving their understanding of and becoming active participants in managing their care. These learning experiences can be formal or informal, and initiated by the patient or health-care provider (Cancer Care Ontario, 2006).

Patient empowerment

The World Health Organization defines empowerment as a process through which people gain greater control over decisions and actions affecting their health and should be seen as both an individual and a community process (World Health Organization, 1998).

Patient experience

Patient experience has been defined as the sum of all interactions, shaped by an organization's culture, which influence patient perceptions and expectations across a continuum of care (The Beryl Institute, 2014).

Patient and family engagement

Working together with patients, family members, health-care providers and professionals to plan, deliver and evaluate health services. Engagement involves building strong, sustainable partnerships and relationships, and actively engaging stakeholders in meaningful dialogue to



drive system change and to create the best health systems in the world (Cancer Care Ontario , 2015).

Person-centred care

An approach to care that involves partnering with patients and health-care providers to do the following:

1. give patients a voice in the design and delivery of the care they receive; and
2. enable patients to be more active in their journey to deliver better outcomes and greater value through a wiser use of resources (Cancer Care Ontario , 2015).

Please see the below link for the Person-Centred Care Guideline:

https://www.cancercare.on.ca/pcs/person_centred_care/person_centred_care_guideline/

Self-management

Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions.

These tasks include having the confidence to deal with the medical management, role management and emotional management of their conditions (Institute of Medicine , 2003).

Self-management support

Self-management support is the systematic provision of education and supportive interventions by health-care staff to increase skills and confidence of patients when it comes to managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support (Institute of Medicine , 2003).

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Appendix 6: Breakout Group Questions for Discussion

Steps for Implementation and Priority Setting

1. From your perspective, how can we get started on improving the quality of health service delivery as it relates to self-management within the Ontario context?
 - a. Once you have identified the actions, please prioritize them.
2. What is required to successfully embed self-management in clinical practice?
3. How should we evaluate the priorities for patient activation and self-management that have been discussed (in Question 1) in order to measure its impact, outcomes and identify ongoing quality improvements to ensure its success?

Feedback on Cancer Care Ontario's Framework for Self-Management Education for Cancer Patients

4. Please provide feedback on Cancer Care Ontario's evidence-informed *Framework for Self-Management Education for Cancer Patients*.
5. From your perspective, how should/could this framework be applied to your work or experience in the cancer and health-care system to advance self-management and patient activation?



Appendix 7: Signature Event Steering Committee and Working Group Members

Signature Event Steering Committee members

First name	Last name	Organization
Virginia	McLaughlin	Chair, Cancer Quality Council of Ontario (CQCO)
Darren	Larsen	Vice Chair, CQCO
Ruthe Anne	Conygnham	CQCO member
Dawn	Powell	CQCO member
Robin	McLeod	Vice President, Clinical Programs and Quality Initiatives, Cancer Care Ontario and ex-officio CQCO
Monika	Krzyzanowska	Clinical Lead, Quality Care and Access, Systemic Treatment Program
Lesley	Moody	Acting Director, Person-Centred Care, Cancer Care Ontario
Tamara	Harth	Provincial Head, Patient Education, Cancer Care Ontario
Doris	Howell	Senior Scientist, Princess Margaret Cancer Centre
Martin	Kabat	CEO, Canadian Cancer Society
Erin	Redwood	Program Manager, Systemic Treatment, Cancer Care Ontario
Elizabeth	Lockhart	Team Lead, Radiation Treatment Program, Cancer Care Ontario
Chris	West	Patient and Family Advisor, Cancer Care Ontario
Carly	Griffin	Patient and Family Advisor, Cancer Care Ontario

Signature Event Working Group members

First name	Last name	Organization
Rebecca	Anas	Director, CQCO Secretariat
Michelle	Rey	Interim Manager, CQCO Secretariat
Jennifer	Stiff	Manager, CQCO Secretariat
Hasina	Jamal	Policy Lead, CQCO Secretariat
Tamara	Harth	Provincial Head, Patient Education, Cancer Care Ontario
Lesley	Moody	Acting Director, Person-Centred Care, Cancer Care Ontario
Zahra	Ismail	Program Manager, Psychosocial Oncology & Patient Education, Cancer Care Ontario
Junell	D'Souza	Planning Officer, Planning and Regional Programs, Cancer Care Ontario
Naomi	Peek	PFA Engagement Specialist, Patient Engagement, Cancer Care Ontario
Erin	Redwood	Program Manager, Systemic Treatment, Cancer Care Ontario
Elizabeth	Lockhart	Team Lead, Radiation Treatment Program, Cancer Care Ontario



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