



Our future health built with care

**Person-Centred
Care: A Year in Review**
together we will

A PCC Partnership

“Creating the best health systems in the world requires ongoing and active collaboration of all our partners, from patients and families, to frontline care providers, to health system planners and administrators. Together, we are creating a system that puts patients at the centre of everything we do.”

Michael Sherar,
President & CEO, CCO



From left to right: **Brian McKee**, Patient & Family Advisory Council Chair, Cancer Care Ontario; **Rebecca Harvey**, Vice President, Ontario Renal Network; **Vivian Bethell**, Patient & Family Advisory Council member, Ontario Renal Network; **Shamara Baidoobonso**, Team Lead, Cancer Screening, Cancer Care Ontario; **Simron Singh**, Provincial Head, Person Centred Care, Cancer Care Ontario

Our Work

As the Ontario government's principal advisor on cancer and kidney care, as well as on access to care for key health services, CCO recognizes the importance of involving Ontarians in the design, delivery and evaluation of the care they receive.

“CCO is guided by a set of principles, the first of which is a commitment to put the people of Ontario at the core of everything we do and every decision we make.” – Dr. Simron Singh, Provincial Head, Person-Centred Care

PATIENT REPORTED EXPERIENCE MEASURES AND YOUR VOICE MATTERS

Patient Reported Experience Measures (PREMs) are used to capture patients' experiences while receiving cancer treatment. They give Cancer Care Ontario and regional cancer centres data for benchmarking and implementing quality improvement initiatives to improve the patient experience. Cancer Care Ontario's electronic-PREMS system measures the patient experience through a questionnaire called Your Voice Matters: We Are Listening. Your Voice Matters is a tool designed for outpatient oncology, and is used to measure the patient experience at point of care (as close to real time as possible). Since the tool was released in March 2016, we have collected over 13,000 responses from patients who were able to give feedback on their cancer treatment experience.

“If you want to be part of change, resist the urge to be part of the silent majority. Your voice matters!” – Arlene H., Patient and Family Advisory Council Vice-Chair, Cancer Care Ontario

ENGAGEMENT MEASUREMENT: LAUNCH OF ADVISOR EXPERIENCE SURVEY

Evaluating the experience of advisors is essential to ensuring meaningful patient, family and public engagement and value. A working group of CCO staff, Regional program representatives and Patient and Family Advisors (PFAs) participated in a four-step process: 1) A literature review to identify relevant engagement experience questions, 2) Gathered input on the chosen questions from a panel of experts, 3) Evaluated the questions to build consensus among multiple stakeholders, 4) Held cognitive interviews to ensure that the questions were clear and understandable. The final product, a 12-question Advisor Experience Survey, will evaluate the continuous engagement experience of advisors in the Ontario cancer and kidney care systems.

“These working group meetings demonstrated the most effective patient and family/caregiver engagement I have seen in more than two years as a patient advisor at the regional and provincial level. With CCO staff facilitating the meetings, PFAs responded as equal partners.” – Derek F., Patient & Family Advisor, Cancer Care Ontario

QUALITY MANAGEMENT PARTNERSHIP

As co-leaders of the Quality Management Partnership (the Partnership), Cancer Care Ontario and the College of Physicians and Surgeons of Ontario are working closely with stakeholders to implement quality management programs for three health service areas: colonoscopy, mammography and pathology. Once in place, these programs will ensure people receive consistent high-quality care no matter where it's accessed. These programs will also improve public confidence in the processes to measure and ensure quality, and increase transparency in the quality of care provided across Ontario.

The Partnership is committed to a person-centred approach and delivers on this principle by involving patients and service users in the design and delivery of quality management programs. Over the past year, the Partnership recruited 10 patients and service users for its newly created Citizens' Advisory Committee. This advisory committee will provide guidance on the overall implementation and evaluation of quality management programs as well as on patient engagement, patient experience measurement and public reporting approaches.

PATIENT ENGAGEMENT AT THE ONTARIO RENAL NETWORK

The patient engagement program at the Ontario Renal Network was established in 2015 and continues to grow. In addition to participating on the Patient and Family Advisory Council (PFAC), Patient and Family Advisors (PFAs) contribute as partners in improving kidney care by providing input on initiatives such as symptom assessment and management, peer support, patient experience measurement and the development of organizational standards. To date, PFAs have been involved in over 25 different aspects of the work done at the Ontario Renal Network, including participating hiring panels for new staff and speaking at quality improvement forums.

We value the patient voice and look forward to building a diverse community of PFAs. By partnering with patients and families, we are making changes to the kidney care system that benefit our most important stakeholders.

SYMPTOM ASSESSMENT AND MANAGEMENT FOR PATIENTS WITH CHRONIC KIDNEY DISEASE (CKD)

The Renal Symptom Management Project team is developing and piloting a standardized approach to symptom assessment and management for people living with CKD. The project will implement a validated patient-reported symptom screening tool and provider education on symptom management.

The goals of the Renal Symptom Management Project are to improve patient, family and care team awareness of and engagement in symptom assessment and management. The project provides an opportunity for patients and caregivers to engage in meaningful conversations about their symptoms and actively participate in decisions around managing these symptoms. The information collected during the project will also provide valuable insight about the symptom burden of Ontario's CKD population and enable the Ontario Renal Network to prioritize areas that require greater focus.

The Renal Symptom Management Project kicked-off in June 2016 and will begin implementing at select Regional Renal Centres in early 2017. The Project will inform broader provincial implementation.

PERSON-CENTRED CARE INDICATORS TO MEASURE THE PATIENT EXPERIENCE

The Ontario Renal Network is seeking to understand whether patients feel well informed about their treatment options and are engaged in the development of their care plans. We will measure this by developing two indicators to assess how well patients feel they are engaged and included in their healthcare decisions:

1. Proportion of patients and families who are informed about treatment options, including dialysis modality, comprehensive conservative care, dialysis access and transplant.
2. Proportion of patients who have the opportunity to participate in the development of their care plans. By understanding the level of patient engagement in their healthcare decisions, the Ontario Renal Network can determine gaps in the care process and identify ways to ensure that care is delivered in a more person-centred way.

Indicator development is well underway, and instruments have been chosen for each of the indicators.

PCC Initiatives: across the regions

THE OTTAWA HOSPITAL CANCER PROGRAM ENHANCES CULTURAL AWARENESS

Enhancing cultural awareness to develop a more person-centred approach to care delivery.

Cultural diversity and awareness is an important component of providing person-centred care, as cultural sensitivity can have a significant impact on patient experience. The goal of this initiative was to enhance staff understanding of and respect for the cultural beliefs and values of others. The working group planned to accomplish this by implementing a cultural awareness self-assessment survey and enhancing cultural awareness through workshops.

Results of the self-assessment indicated that 64 percent of respondents wanted to learn more to decrease barriers with patients, and 61 percent wanted to improve their ability to communicate with those from other cultures (n=260).

After the workshops, 119 participants completed evaluations: 93 percent found the workshop to be very informative. Overall, these efforts have improved the healthcare team's understanding of cultural differences and encouraged them to be more sensitive to the needs of their diverse patient population.

"Competency in effective cross-cultural and two-way communication is essential to give patients the safest and most effective of care. Cultural assumptions, stereotypes and communication barriers should not stand in a patient's way of understanding their situation. Training in cross-cultural communication should be today's standard for all front-line members of a patient's health care team."

- Chantal Batt, Patient & Family Advisory Council Member

CENTRAL REGIONAL CANCER PROGRAM IMPROVES THE PATHWAY FOR ESOPHAGEAL CANCER PATIENTS

Newly diagnosed esophageal cancer patients have a streamlined process to get access to specialist clinicians.

The diagnosis and treatment phase of care for esophageal patients can be complex as they meet multiple healthcare providers through many appointments to manage their care.

The goals of this project were to improve patients' health outcomes by providing dedicated navigational support right at time of referral to reduce patient anxiety and provide guidance for managing their cancer journey.

Initially, patient stories were gathered to identify common opportunities for improvement. As part of a collaborative event, representatives from the Stronach Regional Cancer Centre, the Surgery Team, community partners, allied health team and patients and family members mapped out the current patient journey any gaps in the process, and co-designed solutions from all perspectives.

As a result of this project, early referral to dietitians improved patients' nutritional status and their bodies' ability to respond to additional treatments and therapies, as well as reducing emergency room visits and unplanned hospital readmissions.

Results showed that 72 percent of patients were satisfied with the information, communication, and education they received through a personalized Esophageal Patient Pathway binder.

"It was tremendous and encouraging to have everyone from across the organization come together for an uncommon cancer to raise awareness of the importance of providing person centred care. Having the opportunity to tell my story and to see how everyone genuinely wants to make a difference and work together with compassion to optimize the best possible person centered care was wonderful."

- L.D., Patient Advisor, Project Planning Group

PERSON-CENTRED CARE GUIDELINE TWITTER CHATS

Using social media to engage communities

The South East Regional Cancer Program tested and applied the principles of CCO's Person-Centred Care Guideline through the use of Twitter chats. The program hosted regular chats using topics decided by patient advisors, and invited patients and families to join and ask questions and share feedback on their healthcare experiences with staff, including specialists. The program also used it as a tool to share information online with patients and families in the community, enabling them to:

- Engage members of the public, as well as healthcare providers in conversations to understand how the South East Region can provide the right care, at the right time, in the right place.
- Support improved access to services for specific populations, including equitable access to information.
- Increase the availability of relevant clinical information to patients and providers across care settings.

Key accomplishments include a growth in Twitter followers from approximately 600 to 1,100 and continual growth of approximately five percent after each Twitter Chat. It was found that specialists enjoyed the experience and said they would do it again.

Established Provincial Person-Centred Care Committee: A group of partners in PCC across the Regional Cancer Programs who advise, consult and support implementation of initiatives

SPEAK UP FOR YOUR HEALTH!

Engaging a community to increase mammography participation

When looking to increase mammography participation, the TAIBU Community Health Centre (CHC) went right to the source and asked their clients for input. TAIBU CHC has a mandate to serve the black community in the General Toronto Area and the diverse, largely immigrant, community of Malvern. In order to reach the specific population that TAIBU serves, TAIBU CHC conducted surveys asking their current clients about barriers to mammography and ways to improve access. A follow-up focus group discussed the issues in further detail. After analyzing and summarizing the results, the team developed and implemented recommendations to support an increase in mammography participation. Since clients were interested in learning more information about cancer screening, CHC offered educational sessions. The centre also increased visible promotion of mammography by adding posters, videos and pamphlets to the waiting room. The end result was an increase in mammography participation by over five percent and the TAIBU CHC hopes that with a person-centred, culturally competent approach, it will be possible to have rates that are close to provincial rates over time.

"Promoting mammography to this community is essential, as breast cancer has a large impact on the black community. I recall one client in particular, an immigrant who hadn't been screened for many years. When she saw the information, her eyes popped and I know we reached her."

- Estella Williams, Health Promoter, TAIBU CHC

INCREASING CANCER SCREENING FOR HIGH-RISK INDIVIDUALS

Reaching out to marginalized patients with humour

The Nurse Practitioner-Led Clinic (NPLC) at Canadian Mental Health Association in Durham needed resources to educate their under-screened patients about the importance of cancer screening. They worked with the Central East Prevention and Cancer Screening program to develop brochures and tested them with focus group of people registered at the clinic. The brochures incorporated a humorous pun about the message, as testing found that clients enjoyed humour when discussing a sensitive issue. Focus group participants responded to the bright colours and descriptive images, and enjoyed point-form content that highlighted the most important information. The NPLC revised their health education strategy, displayed the new resources in the waiting room and created a comfortable education room to be used as part of the NPLC outreach program. The use of the resources helped to educate over 200 of their patients about cancer screening for breast, cervical and colorectal.

"Our clients are often marginalized and nervous of the healthcare system. By including them in this project, we were able to help validate their thoughts and feedback. They were excited to be part of the initiative."

- Sarah Logan, Outreach Registered Nurse

Published the Patient Symptom Management Guides: Guides that enable cancer patients to better understand and manage their own symptoms

FIRST NATIONS SUCCESS STORY

Transitioning to home treatment a first for remote First Nation community

In February 2016, the first patient from a remote (fly-in) Ontario community transitioned to home hemodialysis (HHD). Throughout the preceding year, the Ontario Renal Network and Thunder Bay Regional Health Sciences Centre worked closely with the community and the patient to help this individual return home to Kitchenuhmaykoosib Inninuwug (KI) First Nation, approximately 600 km north of Thunder Bay.

This initiative was co-designed closely with the patient to ensure this unique transition home met their needs and they were completely informed about this new model of care. This was a significant accomplishment in collaboration with a First Nations community in Ontario, as well as a considerable achievement in bridging the gap in access to healthcare for individuals in remote communities.

Developed new Patient Reported Outcomes (PROs) strategic framework: A framework with five key focus areas for implementing PROs and symptom management efforts across Ontario

LAKERIDGE HEALTH: PERSON-CENTRED CLINIC WALK-ABOUT

Identifying improvements with patients and families

The Lakeridge Health Kidney Care Clinic took a unique approach to engaging with patients and families by inviting PFAs to complete a clinic walk-about with the clinic's leadership team. The walk-about focused on reviewing various clinic areas, such as the waiting rooms and hallways, from the patient and family members' perspectives. The PFAs provided suggestions and feedback related to improving the patient and family experience and the flow of care. Many opportunities to improve the clinic space were identified, including: removing excess signage on walls, doors and windows; more prominently displaying bulletin boards to promote patient events and share information about patient engagement and peer support; changing the door handles on the bathrooms (to make it easier to identify if occupied or available); and, repositioning the patient weigh scale and furniture to improve flow. Lakeridge Health implemented the changes to improve the patient experience at their clinic.

NOTE FROM DR. ROBIN MCLEOD:

"CCO, along with our regional partners, is committed to creating and growing a culture of person-centred care across the province. The Clinical Programs and Quality Initiatives portfolio continues to expand person-centred care as a clinical standard in new areas of practice. In listening to patients and their families, we learn to build systems based on their needs. Collaborating with and supporting our partners across CCO and the province, and sharing best practices and stories with one another, we are working together to create a person-centred healthcare system for all."

- Dr. Robin McLeod, VP, Clinical Programs & Quality Initiatives, CCO

highlights from

2015/16

Launched PCC Guideline & Video: A guideline for the standard of care anyone experiencing cancer in Ontario should expect to receive (June 2015)

Enabled patients to maintain continuity in long-term care homes by providing dialysis care (June 2015)

Launched Ontario Renal Network Provincial Patient and Family Advisory Committee (October 2015)

Developed Sexual Health Guideline for Cancer Patients: A guide for healthcare providers with respect to sexual health for people living with cancer

Revised renal dietary guides to enhance understanding of the renal diet (January 2016)

Working together to
create the best health
systems in the world

**620 University Avenue
Toronto, ON M5G 2L7**

416.971.9800

accu@cancercare.on.ca

cancercare.on.ca

ocp.cancercare.on.ca



Ontario

Cancer Care Ontario