



Our future health built with care

# Building a Culture of Person-Centred Care in Ontario

PERSON-CENTRED CARE ANNUAL REPORT 2014/15





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# Person-Centred Care: The Future of Healthcare in Ontario

At CCO, we believe in a person-centred approach to health, developed in partnership with patients and healthcare providers. Since the publication of our 2011-2014 report, *Improving Ontario's Health System through Patient and Family Engagement*, CCO has continued to partner with patients and families and healthcare providers across the province to build a healthcare system that is designed with patients. This year's report focuses on: the steps CCO has taken to advance a person-centred care culture; initiatives to support the effective measurement of patient experience; CCO's engagement with Patient and Family Advisors; and highlights of achievements across the regions.

The Minister of Health and Long-Term Care has identified person-centred care as a top priority with a commitment to "putting patients at the centre of healthcare by providing the right care, in the right place at the right time," while also highlighting the need to partner with patients. This commitment reinforces the fact that patients in Ontario are the real owners of healthcare, and it's up to us as healthcare practitioners and system administrators to act as the custodians of patient care by enabling their experience across our healthcare systems. One of our main achievements this year has been the release of a Person-Centred Care Guideline, which outlines the level of care that any person (i.e., patient, family member, caregiver) accessing adult oncology services in Ontario should expect to receive. Cancer Care Ontario is also continuing to expand and evolve its Patient and Family Advisor community, embedding the voices of the patient and caregiver in new initiatives and everyday practices.

With similar goals in mind, the Ontario Renal Network will soon pilot and evaluate the implementation of a standardized approach and associated decision aids to support decision-making that is shared among patients, their families and their healthcare teams. The Ontario Renal Network is gaining momentum in driving the adoption of a person-centred approach to care across the chronic kidney disease system in Ontario with the establishment of its own Patient Advisory Council.

Integrating person-centred care across Ontario's healthcare system will be achieved through the collaboration of healthcare providers and system administrators, working in partnership with patients and families. We all benefit from a shared commitment to putting patients at the centre of care. This approach will result in greater job satisfaction for care providers, better outcomes for patients, and a more active role for patients and their families in their care.

For me, as an oncologist practicing in Ontario, person-centred care is why I come to work every day. It is about always putting the patient at the centre and partnering with patients to achieve our vision of working together to create the best healthcare systems in the world.

*"We all benefit from a shared commitment to putting patients at the centre of care."*



**DR. SIMRON SINGH, CLINICAL LEAD,  
PERSON-CENTRED CARE**





**DR. MICHAEL SHERAR**, *President, CEO, CCO*

**DR. ROBIN MCLEOD**, *VP Clinical Programs, Quality Initiatives, Cancer Care Ontario*

SECTION 1

# Creating the Culture

# Growing the Person-Centered Care Culture

Person-Centred Care (PCC) is increasingly recognized as a guiding principle in the design, delivery and evaluation of healthcare, both in Ontario and around the world. Such a pivotal, system-wide shift requires a parallel cultural transformation among those who support the healthcare system. Read more about CCO's PCC model.

**Within the organization, some key actions have taken place:**

1. Launch of an e-learning module for all CCO staff to complete;
2. Creation of a system-wide PCC Guideline.

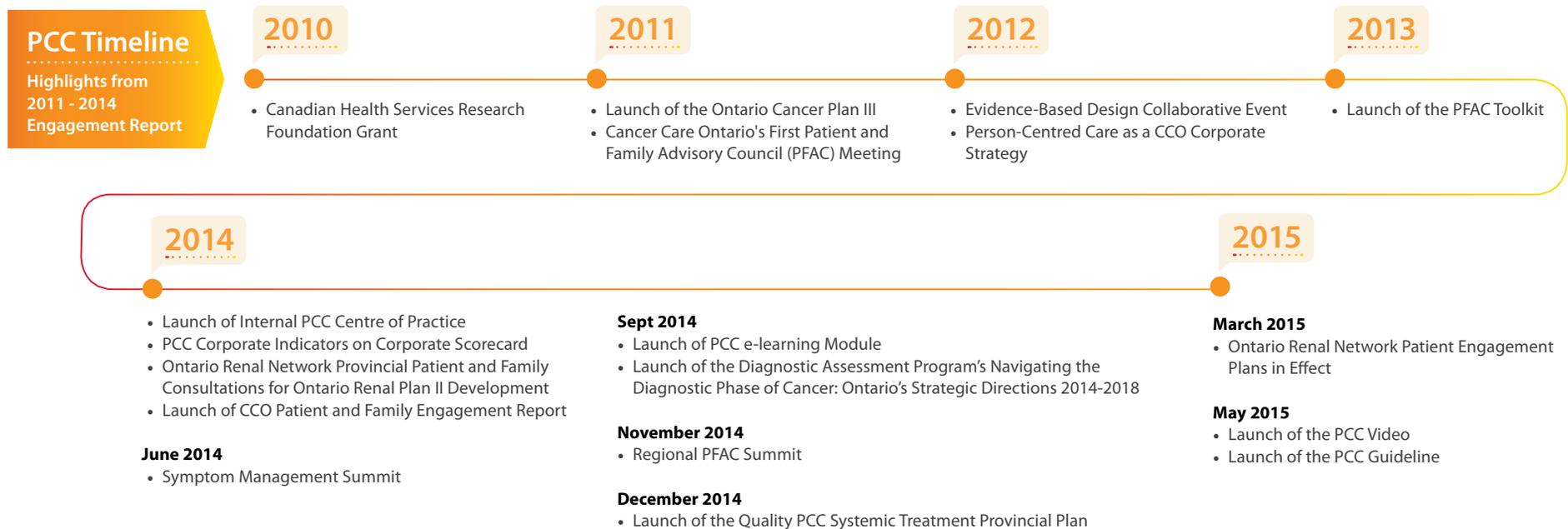
CCO has rolled out the following key initiatives to support stakeholders across all levels of the healthcare system in advancing PCC.



"In the Clinical Programs Quality Initiatives portfolio we work with our partners, including patients and families, to drive quality, value and sustainability of cancer care in Ontario through evidence, measurement and innovation to improve outcomes for patients. Measuring and improving the patient experience is one of our core commitments at CCO and we believe strongly in gathering data to identify gaps. This report will give you an overview of the many approaches CCO and the Regional Programs are taking to continually improve the performance of our services and to build a person-centred system that measures and acts on what matters to patients and their families."

**DR. ROBIN MCLEOD**, VP, Clinical Programs Quality Initiatives, Cancer Care Ontario

**FIGURE 1** | PCC Timeline



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# Organization-wide e-Learning Module Launched

As the first in a series of initiatives to advance a corporate culture of person-centred care, CCO disseminated an e-learning module to staff across the organization. This module helps orient staff to the person-centred care model and describes the internal resources available to help align their work with the principles and approaches of this corporate priority.

The Person-Centred Care e-Learning Module was first launched in Access to Care, a service area of CCO Analytics and Informatics, and was successfully completed by 100% of staff.

This was followed by a series of employee engagement workshops in which employees generated 35 unique ideas to incorporate the principles and approaches of person-centred care into the day-to-day business of Access to Care.

The e-learning module has now been disseminated across the rest of CCO, including Cancer Care Ontario and the Ontario Renal Network.



# Release of a Person-Centred Care Guideline

In May 2015, Cancer Care Ontario released its Person-Centred Care (PCC) Guideline, which establishes the standard of care that any person (i.e., patient, family member, caregiver) using adult oncology services in Ontario should expect to receive. This guideline is the most recent initiative for advancing a person-centred approach to care delivery and improving patient experience across Ontario.

Person-centred care is complex. Bringing it into daily practice requires standardizing the way we think about being person-centred in our work and distilling this guiding principle into manageable parts. The PCC Guideline consists of 5 key domains. Each defines specific person-centred care practices and behaviours.

## Person-Centred Care Video Increases Understanding and Awareness

To support healthcare providers in their efforts to integrate PCC Guideline recommendations into their roles, CCO developed a person-centred care training video and made it available to more than 900 key stakeholders including nurses, psychosocial oncology providers, radiation therapists, oncologists, administrators and patients.

The video defines the fundamental concepts of PCC. It includes two surveys (at the beginning and end of the video) to assess current awareness and understanding of the principles of PCC. Preliminary results show that after watching the video, 93.5% of viewers rated their understanding of PCC as 8 or higher on a scale of 10. By collecting these evaluations over the course of 2015, CCO will be able to assess the current state of PCC awareness across the province.





"The Person-Centred Care Guideline reminds everyone who provides care that patients bring with them their values, beliefs, hopes, fears and past experiences, all of which influence how they experience care. The guideline serves as a reminder to see the whole person and not just the disease."

**RHONEL B**, Cancer Care Ontario Patient and Family Advisor,  
Person-Centred Care Guideline Endorsement Working Group member



SECTION 2

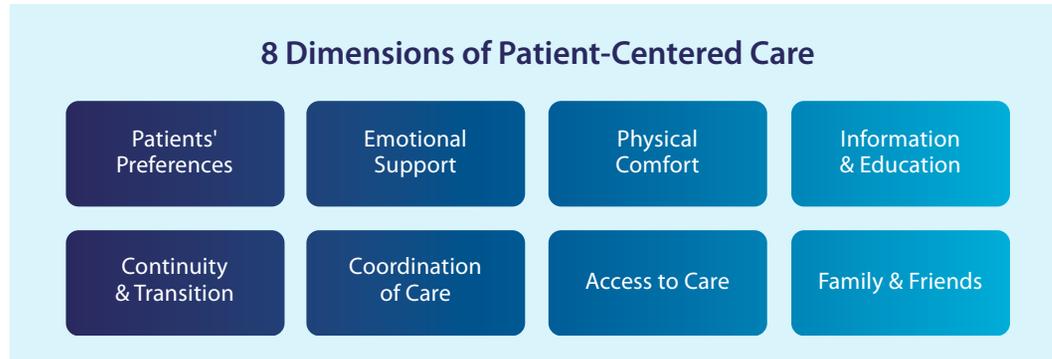
# Patient Experience

# Direct Feedback from Patients

One way Cancer Care Ontario measures the extent and effectiveness of person-centred care within the Regional Cancer Programs is by asking patients about their experiences with the healthcare system. When patients report on their experiences and interactions along the cancer care continuum, we can then implement quality improvement initiatives addressing areas of concern that are reflective of the patient voice.

In addition to developing and implementing treatment-specific tools to measure patient experience, CCO is working to standardize core criteria for the measurement of patient experience across the organization.

**FIGURE 2 |** 8 dimensions of Patient-Centred Care



Adapted from Canadian Patient Experiences Survey developed by Canadian Institute for Health Information (CIHI) and National Research Corporation Canada (NRCC). <http://nationalresearch.ca/products-and-solutions/patient-and-family-experience/>

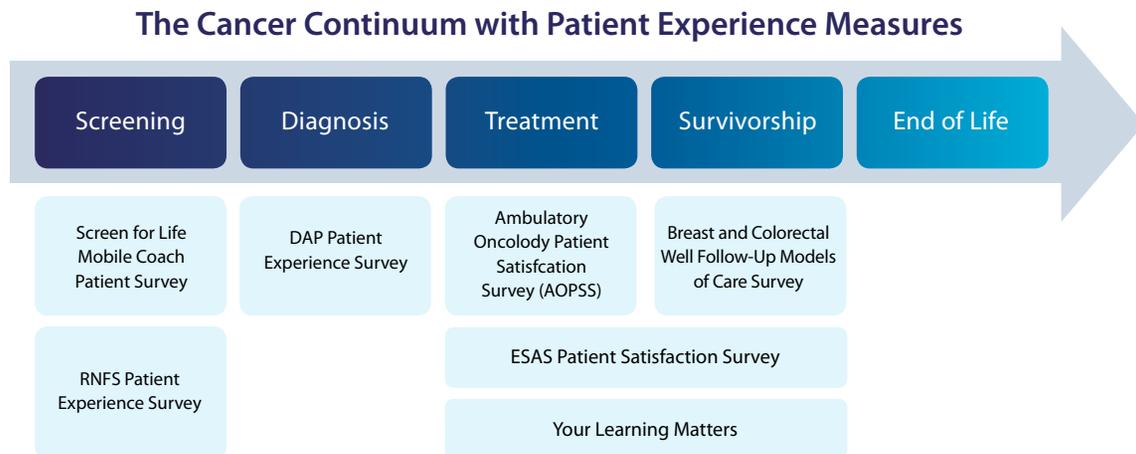
## Ontario Cancer Plan IV

Measuring the patient experience is essential to improving the quality of care provided to patients.

In alignment with the focus on quality of life and patient experience in the Ontario Cancer Plan IV ([ocp.cancercare.on.ca](http://ocp.cancercare.on.ca)), Cancer Care Ontario is using several patient-reported experience-measurement tools to help capture patient experience across the cancer continuum (see Figure 3). Some examples include:

- **Screening:** The Registered Nurse Flexible Sigmoidoscopy (RFNS) Patient Experience Survey (pg. 13)
- **Treatment:** The Ambulatory Oncology Patient Satisfaction Survey (pg. 46)
- **Treatment and Survivorship:** Your Learning Matters
- **End of Life:** Patient Experience at the End of Life Survey (pg. 12)

**FIGURE 3 |** Patient Experience Data generated from measurement tools will be analyzed according to 8 dimensions of Patient-Centred Care.



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# The Registered Nurse Flexible Sigmoidoscopy Patient Experience Survey

Flexible sigmoidoscopy is a procedure for examining the lining of the rectum and sigmoid colon (lower third of the colon) that can be used for colorectal cancer screening. It allows for the detection, biopsy and removal of small polyps.

Since 2005, Cancer Care Ontario has supported the establishment of RNFS clinics, which are now operational in 9 hospitals across the province. The RNFS program has continually surveyed participants to assess their level of satisfaction with their care. Last year we enhanced the survey to focus on each participant's individual experience. Work is now underway to test the new survey in the RNFS program, to ensure that it will be user-friendly and will capture the information required to make effective improvements before formal implementation.

In parallel, the Cancer Screening Program is working to incorporate the measurement of participant experience into our breast cervical cancer screening program. The results will enable the Cancer Screening Program to identify opportunities for meaningful program improvement in response to the voice of Ontarians.

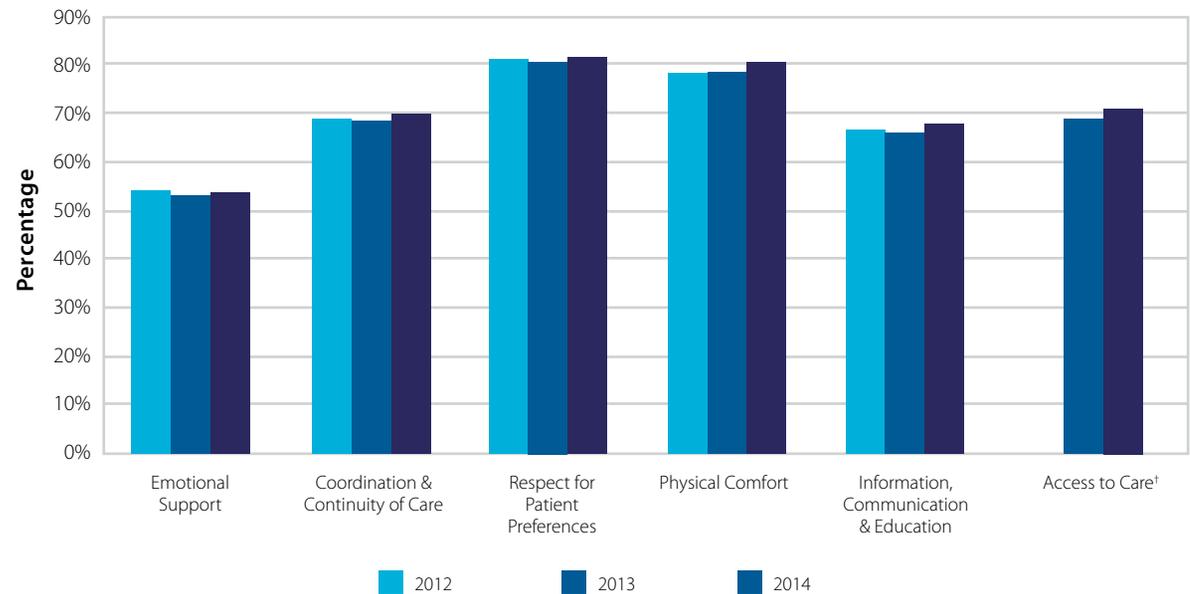


# Outpatient Oncology Survey Measures 6 Dimensions of Patient Experience

The Ambulatory Oncology Patient Satisfaction Survey (AOPSS) is mailed to a random sample of cancer patients from each Regional Cancer Centre. Patients are asked to complete the 95-question survey within 6 months of receiving their cancer treatment. Their responses are analyzed according to 6 dimensions of patient experience, which correspond with a subset of AOPSS questions. The Regional Cancer Centres receive AOPSS reports quarterly, enabling them to assess their performance in terms of these dimensions and identify opportunities for improvement. Each region can also use these reports to develop and implement programs for improving patient care.

In 2015, Cancer Care Ontario's Person-Centred Care Program selected a new indicator based on 3 dimensions of person-centred care: communication, self-management and support for shared decision-making. The data indicates that Ontario cancer patients treated in outpatient settings continue to report a reasonably high degree of overall satisfaction with most aspects of their experience, but gaps and opportunities for improvement still exist within individual experience domains.

**FIGURE 4 |** Percent of questionnaire respondents who responded positively to forty-four questions within six dimensions of care.



Report date: February 2015  
Data source: Ambulatory Oncology Patient Satisfaction Survey (AOPSS)  
Prepared by: Analytics and Informatics, Cancer Care Ontario

Note: All disease includes the following type of cancers: Brain, Breast, Cervix/Uterine/Ovarian, Colorectal/Bowel, Head/Neck, Hematology, Lung, Lymphoma, Melanoma, Prostate/testicular, Sarcoma, Stomach, Kidney and other diseases

<sup>†</sup>Question text changed starting in 2013 for Access to Care domain

# Rapid Feedback from Patient Survey

In partnership with the Regional Cancer Centres, Cancer Care Ontario is implementing a rapid feedback patient experience survey that will allow patients to provide feedback about their experience with the cancer system. Patients will have the opportunity to complete this survey after their visit to a Regional Cancer Centre. The centres will be able to access timely reports of patient experience data that provide a snapshot of what patients are experiencing in the Regional Cancer Centre. This information can help drive quality improvement initiatives and data-based prioritization within the system.

## Benefits of Rapid Feedback from Patients:

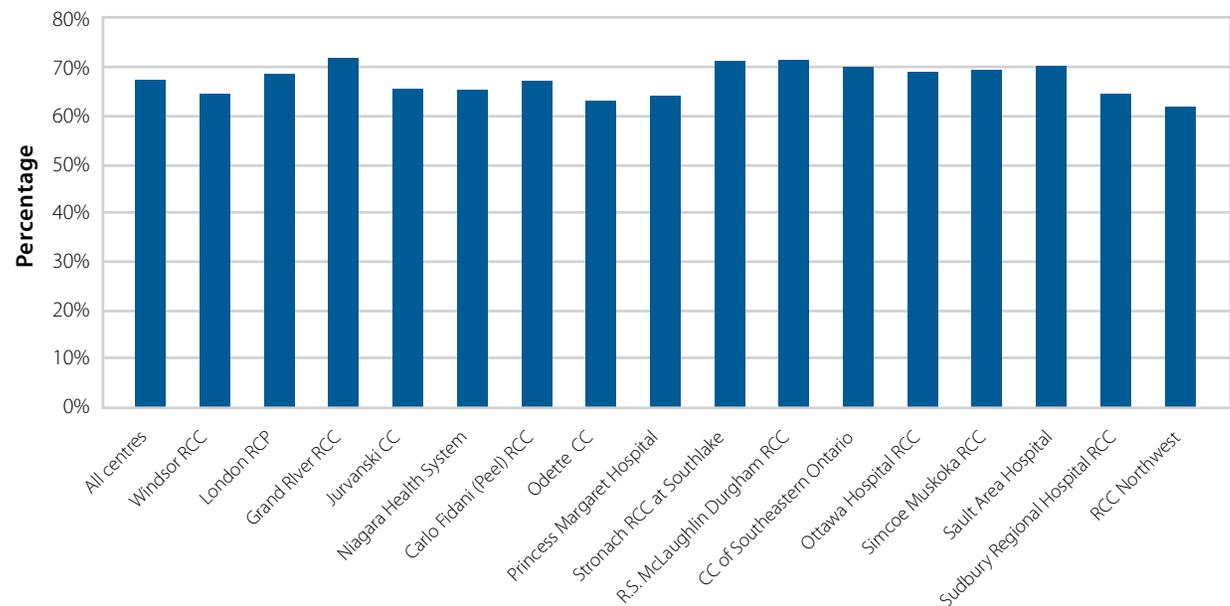
### For patients and families:

- Provides cancer patients (and their families) with the opportunity to provide feedback on their experience soon after their actual experience with care, and acts as a gateway to empowerment;
- Enhances the engagement of patients and families in their care; and
- Makes accountability for patient experience possible through the reporting of overall rapid feedback measurement survey scores.

### For healthcare providers:

- Improves processes, systems and services associated with patient experience throughout the cancer care continuum; and
- Makes accountability for patient experience possible through the reporting of real-time measurement survey scores on regional scorecards.

**FIGURE 5 |** Percent of positive responses to selected questions based on three dimensions of care – communication, self-management and support for shared decision-making, by RCC and select partner sites, Ontario, 2014



Report date: February 2015  
 Data source: Ambulatory Oncology Patient Satisfaction Survey (AOPSS)  
 Prepared by: Analytics and Informatics, Cancer Care Ontario

### For Cancer Care Ontario

- Provides an important source of data for the measurement of patient experience and expands our capacity to use data to improve Ontario's cancer system.

## Patient Experience Report Provides International Comparisons

The Cancer System Quality Index monitors and reports publicly on the performance of the cancer system and provides international comparisons and benchmarking so Ontario healthcare providers and administrators can learn from other jurisdictions. Patient experience measures, alongside screening, wait times and access measures, contribute to the larger picture of performance ([www.csqi.on.ca](http://www.csqi.on.ca)).



## SECTION 3

# Engagement: Patient and Family Advisors



## Joanne M.

Joanne is a two-time breast cancer survivor, and when she retired a few years ago she decided that she wanted to make a bigger commitment to partnering with CCO to help make our healthcare system the best in the world. For the past 4 years, she has been Co-Chair of Cancer Care Ontario's Patient and Family Advisory Council (PFAC), Co-Chair of the Ontario Cancer Plan IV Executive Sponsor group and a strong champion for improved information and communication between healthcare providers and patients. Joanne has also been engaged with the Ontario Steering Committee for Cancer Drugs and served as an expert panel member for the development of Person Centered Care Guidelines. She has also participated in four Cancer Quality Council of Ontario (CQCO) Programmatic Reviews.



## Michael M.

Mike is a Patient and Family Advisor (PFA) working with the Ontario Renal Network since 2011. Having spent the past 27 years on dialysis, he was inspired to become an advocate for people with chronic kidney disease. He is a strong believer in patients being educated about and involved in their care. In addition to his role on the Patient Advisory Committee formed for the development of ORP II, Mike has also been engaged with the Primary Care Chronic Kidney Disease (CKD) Delphi Panel which was responsible for identifying indicators of CKD, which are important to primary care providers in increasing early detection in at-risk populations. He has assisted on numerous initiatives related to independent dialysis, participating in the development of strategies and initiatives to support patients to dialyse at home. He has also spoken at the Body Access/Independent Dialysis conference and the public launch of ORP II and OCP IV.

Mike and Joanne are two of a community of close to 100 Patient and Family Advisors who partner with CCO to ensure the patient perspective is embedded into the organization's work. If you are interested in learning more about becoming a PFA, visit [cancercare.on.ca/PFA](https://cancercare.on.ca/PFA) or email [patientfamilyadvisors@cancercare.on.ca](mailto:patientfamilyadvisors@cancercare.on.ca) / [pfa@renalnetwork.on.ca](mailto:pfa@renalnetwork.on.ca)

# Through the Eyes of Patient and Family Advisors

Having experienced the cancer and chronic kidney disease health systems in Ontario first-hand, we, along with our fellow Patient and Family Advisors (PFAs), are in a unique position to provide a wealth of knowledge to health system providers and administrators. We are firm believers that stories can lead to change. The stories of our experiences help providers and system administrators to learn and understand where areas of improvement in the health system are needed. As part of CCO's commitment to advancing person-centred care, staff are encouraged to weave patient and caregiver perspective into their daily work.

We've both had the opportunity to be engaged in the development of the Ontario Cancer Plan IV (OCP IV) and the Ontario Renal Plan II (ORP II) and seen the impact of partnering with patients through the development phases to identify priorities. Patient and caregiver stories were woven throughout these final system plans which grounded them in the real world of the people who are engaged in the cancer and renal care systems.

Last year, CCO produced the report, Improving Ontario's Health System through Patient and Family Engagement to demonstrate what patient and family engagement looks like, why it is important and the value seen so far. This year's report shifts to focus on advancing person-centred care. Below is each of our perspectives on the impact of advancing a person-centred care approach at the system level.

## **Q: Why is it important for Ontario to foster a person-centred care culture in chronic disease health systems?**

**MICHAEL:** Person-centred care, if planned, implemented and administered properly, can have positive outcomes for both patients and for system administrators. By involving patients at the system level, chronic care systems can operate more efficiently to deliver medical services to the right people at the right time.

**JOANNE:** Patients come to health care providers with a lot of concerns on top of the fear associated with being diagnosed with a life-threatening disease. If we are partners in decision-making, we will be equipped with the information we need to make decisions about our own care.

## **Q: What are the benefits of patient engagement at the system level?**

**JOANNE:** Patient engagement at the system level keeps the focus on the needs and values of the patient when developing programs and forging partnerships between patients, families and healthcare providers.

**MICHAEL:** Since patients diagnosed with chronic kidney disease face treatment for life, even when facing renal replacement therapy, they are a tremendous resource at all levels of the renal journey, including at the system level.

## **Q: What impact do you think your partnership with CCO in the development of the system plans will have on the healthcare system in Ontario?**

**JOANNE:** The many partnerships between CCO and patients and caregivers demonstrate that patients and families have a lot to contribute in the development of programs and planning for the future.

**MICHAEL:** The Ontario Renal Network is relatively new when compared to our colleagues at Cancer Care Ontario. Patient engagement is just being formalized in ORP II, which will see the development of a permanent Patient Advisory Council, whose primary task will be to contribute to the implementation of system plan.

## **Q: Based on your engagement with CCO, can you share one or more examples of a challenge and success you've experienced?**

**MICHAEL:** I've worked on some initiatives to support patients dialysing at home by highlighting the needs of patients transitioning onto dialysis. The greatest success I have experienced has been my contribution to the development of ORP II.

**JOANNE:** When I joined the working group for the development of the OCP IV in addition to acting as Co-Chair of the Executive Sponsor Group, I initially saw this opportunity as a challenge, concerned that my voice at the table wouldn't be valued but my perspective quickly changed. The group was welcoming and encouraging and together we produced a plan that clearly demonstrates that patient and family perspectives were present in every step of its development.

# Patient and Family Advisors Create a Community With Broad Experience

As CCO's community of Patient and Family Advisors (PFAs) continues to grow, so too has CCO's dedication to patient and family engagement.

The benefits of PFA engagement can be clustered into 3 main areas:

## INTEGRATION

- Changing how we communicate about our work, both internally and externally;
- Increasing collaboration and interaction between patients, families, clinicians and the system; and
- Adding relevance for our key audiences – patients, their families and caregivers.

## WORK IMPACT

- Making person-centred design and content changes to project materials;
- Enhancing project design, planning, conceptualization and usability;
- Modifying our data collection and methodologies;
- Focusing our efforts on improving patient experience and person-centred care; and
- Identifying areas in which clarification and context are needed.

## ADDED VALUE

- Raising awareness of the priorities of patients and their families;
- Personalizing the work that we do, increasing its meaningfulness;
- Affirming and/or deepening our understanding of patients' experiences and needs; and
- Increasing our credibility with external stakeholders.

The evolution of CCO's partnership with PFAs is particularly evident in the transformation of the Patient and Family Advisory Council (PFAC) from a group that depends on Cancer Care Ontario's programs and seeks advice to a body of volunteers with a set of priorities that complement current System Plans and Corporate Priorities. On the following page

is more information on the growth of CCO's PFA community followed by information on the process and impact of developing a set of PFAC priorities .

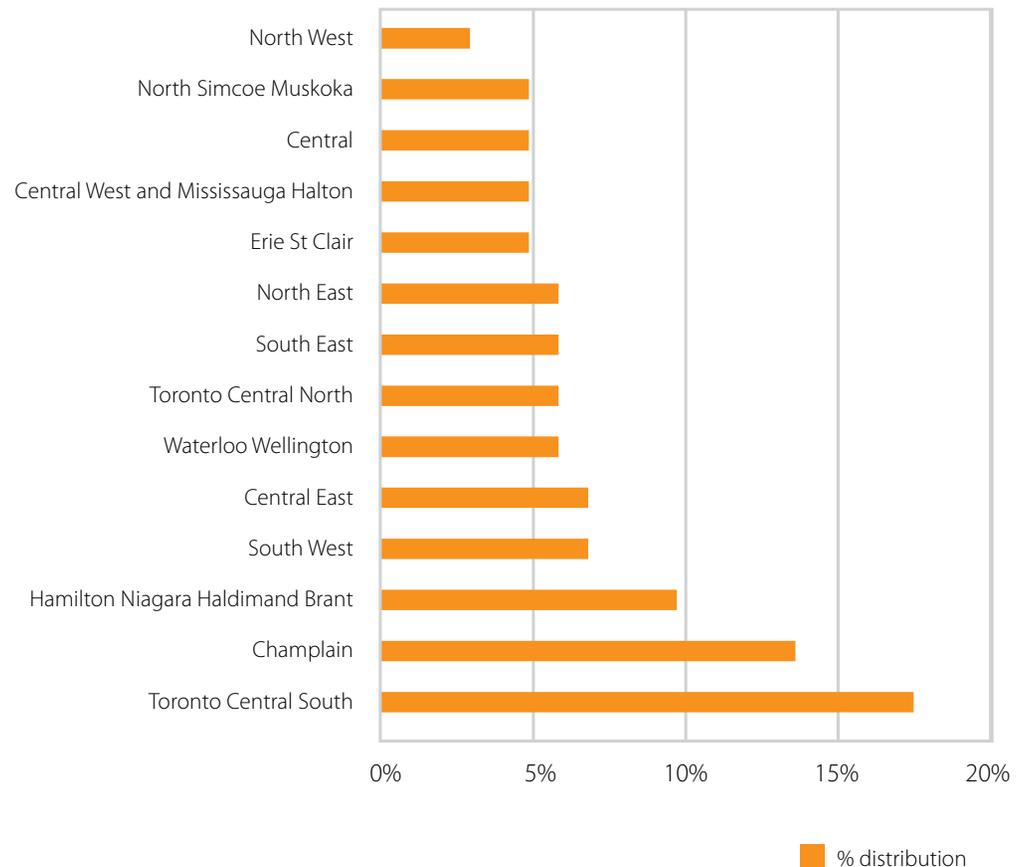


# Province-Wide Patient and Family Advisor Community

CCO's Patient and Family Advisor (PFA) community is made up of individuals across the province with a diverse range of ages, backgrounds and experiences with the healthcare system. Some have moved through the system as patients receiving treatment, while others have been caregivers to patients. As seen in the Person-Centred Care timeline, our community of PFAs has grown significantly since Cancer Care Ontario's first Patient and Family Advisory Council meeting in 2011. It now includes a broad group that has experienced either the cancer care continuum or the chronic kidney disease journey. The Ontario Renal Network's PFAC is in its formative stage and is building on the success of Cancer Care Ontario's PFAC, while shaping their PFAC to better reflect the kidney care system in Ontario.

Here are some key characteristics of our expanding PFA community (data is as of March 31, 2015):

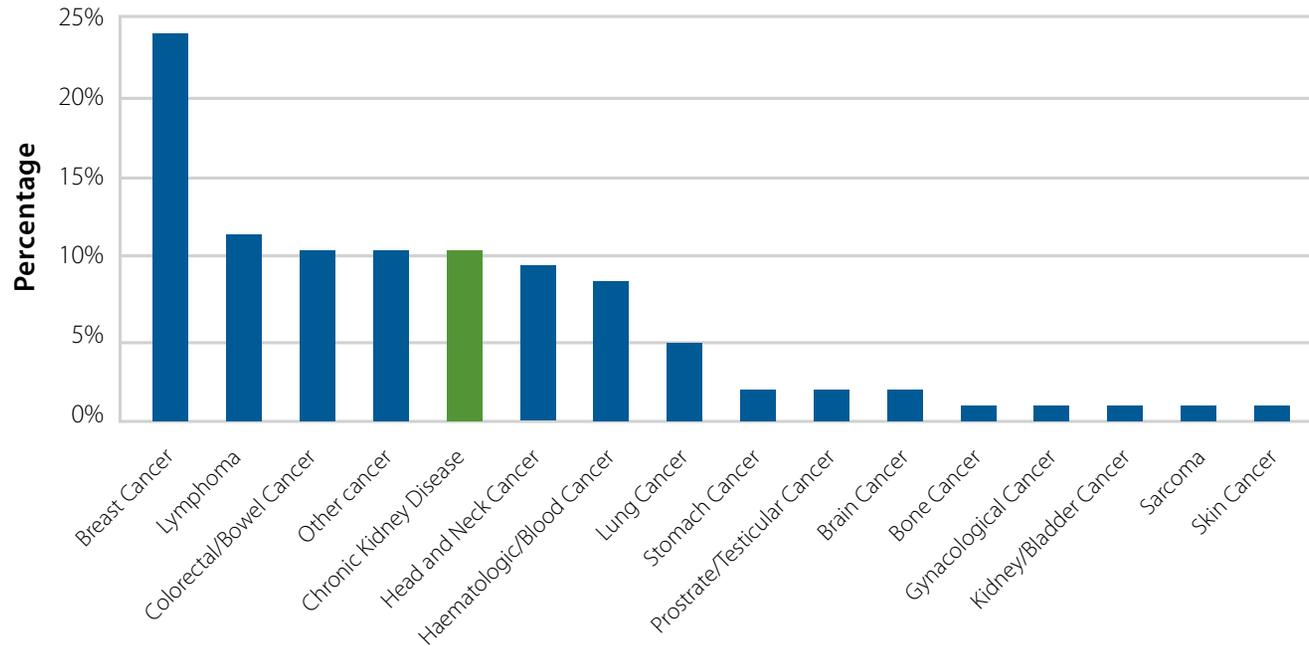
**% of CCO PFAs from each Ontario Region**



**FIGURE 6** | Distribution of PFAs in Ontario

## Types of Disease Experiences Represented

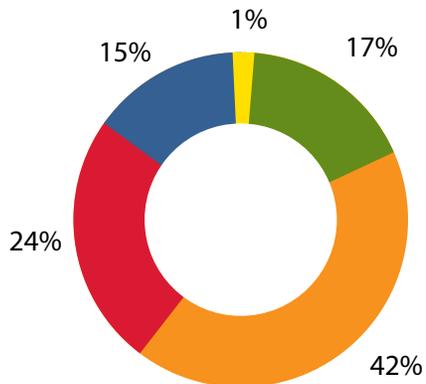
(Cancer and Chronic Kidney Disease)



**FIGURE 7** | Just over half of Cancer Care Ontario PFAs have had experience with cancers such as breast, colorectal, and lymphoma

*\*multiple PFAs have experience with multiple types of diseases*

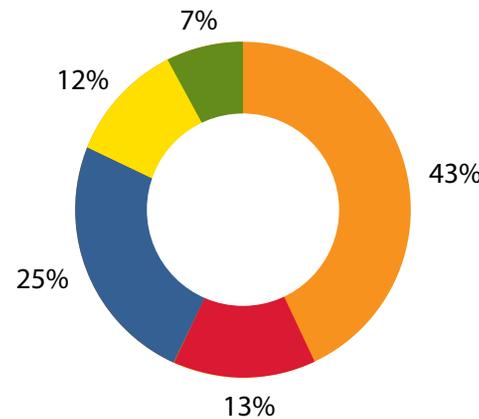
## Age Ranges of PFAs Represented



**FIGURE 8** | The majority of PFAs are older than 40 years of age.



## How long PFAs have been working with CCO



**FIGURE 9** | Just under half of current PFAs have been working with CCO for less than 1 year.



# Province-Wide Patient and Family Advisor Community

## Key Stats from April 1, 2014 to March 31, 2015:

**FIGURE 10** | A snapshot of the types of "ongoing" engagements from January 2015 to March 2015 includes:

Ongoing engagement type	# of PFAs*
Advisory Committee (includes the Cancer Care Ontario PFAC)	52
Working Group	46
Steering Committee	38
Provincial Program Committee	3
Other (includes user groups and expert panels)	4

\* Multiple PFAs could be members of multiple groups.

## Surveys Show Strong Satisfaction among PFAs

Asking PFAs about their experience working with CCO is an important step in strengthening our engagement efforts. The following indicators are just 2 of the many ways we can evaluate how well teams are able to engage the PFAs that work with them on an ongoing basis

71%

strongly agree or agree with the statement: "I am a partner in decision-making"

89%

strongly agree or agree with the statement: "My insights and personal experiences are taken into consideration"

## How You Can Get Involved:

To learn about becoming a PFA with Cancer Care Ontario, please visit [cancercare.on.ca/pfa](http://cancercare.on.ca/pfa)



# 9 Priorities for the Patient and Family Advisory Council

Following its inception in 2011, Cancer Care Ontario's Patient and Family Advisory Council (PFAC) operated as a consultation body, providing input for existing program objectives and initiatives at Cancer Care Ontario. The PFAC was being driven by the needs of Cancer Care Ontario rather than developing its own priorities in partnership with the organization.

In April 2014, with support from a skilled facilitator, the PFAC identified 9 priority areas that would serve to focus the group's work over the coming years. These priority areas are unique to and owned by the PFAC, and they are in alignment with CCO's Strategic Directions and the Ontario Cancer Plan IV.

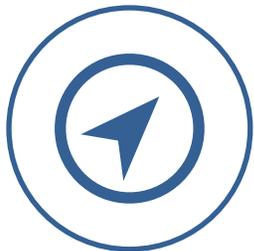
These priorities may adapt and change as new information about existing and current work is discovered.

**Prioritization of these 9 areas by our PFAC members enables more meaningful and measurable patient and family engagement by:**

- **Tracking PFAC Impact:** Now that outcomes are related to specific objectives within defined priority areas, tracking PFAC impact is less dependent on feedback received from a third party and therefore more reliable.
- **Demonstrating PFAC Impact:** Reporting on the output and outcomes of the work done by the PFAC allows for a meaningful experience for PFAC members, and signals to the organization the impact and value of patient-centred care and the patient voice.



# 9 Priorities



Navigation



Transition for Younger Patients



Support Caregivers



Improve Equity



Symptom Management in Survivorship



Person-Centred Care



Urgent Care



Patient Engagement



Technology

- 1. Navigation:** Create a patient navigator role and assign it to an individual who understands the healthcare system and who crosses care settings.
- 2. Transition for Younger Patients:** Assist young people who have cancer in terms of:
  - a. Understanding the transition from the pediatric system into adult services;
  - b. Dealing with the long-term effects of the symptom and treatment burden in survivorship; and
  - c. Understanding the possibility of recurrence.
- 3. Support Caregivers:** Enhance the support for caregivers who are caring for their loved one experiencing cancer.
- 4. Improve Equity:** Work to achieve greater equity in the continuity of care from region to region in terms of:
  - a. Wait times (e.g., diagnostics, mobile units);
  - b. Access to quality services (e.g., psychosocial oncology); and
  - c. Expert knowledge and support (e.g., multidisciplinary case conferences and telemedicine).
- 5. Symptom Management in Survivorship:** Provide information to patients and their families on the long-term effects of cancer treatment.
- 6. Person-Centred Care:** Define person-centred care behaviours in the cancer system.
- 7. Urgent Care:** Offer urgent care support that is delivered by providers who have oncology expertise.
- 8. Patient Engagement:** Improve processes for staff at Cancer Care Ontario and the Regional Cancer Programs for engaging with patients and families.
- 9. Technology:** Help design and evaluate better technology for patients in the cancer system, especially self-management tools.



SECTION 4

Collaborative  
Regional  
Programs  
Drive Best  
Practices

Networking and collaborating with Regional Cancer Programs and Regional Renal Programs on person-centred care across the province are imperative for successful engagement.

CCO has engaged with the Regions to build bridges, open lines of communication, form synergies and develop a united approach in our efforts to advance person-centred care.

**Articles in this section**

- Environmental Scan
- Regional PFAC Summit
- Person-Centred Care Provincial Committee
- Ontario Renal Network Patient Engagement Plans



“Cancer Care Ontario’s Patient and Family Advisory Council (PFAC) has, for a number of years, brought together individuals from across the province to assist in the development of programs and offer strategic advice and voices from all regions in Ontario. This has been a remarkably successful endeavour from both the organization’s and the PFAC members’ viewpoints. In November 2014, CCO brought together clinicians, hospital administrators, and family and patient advisors at a Regional PFAC Summit. The facilitated exchange of ideas and information among those involved in regional programs provided a unique opportunity for the sharing of best practices, networking and collective input into mapping the way forward in the promotion of person-centred care in Ontario.”

**BRIAN MCKEE**, *Cancer Care Ontario PFAC member and Regional PFAC Summit Co-Chair.*

# Environmental Scan Identifies Provincial Baseline

Cancer Care Ontario conducted an environmental scan in order to gain an understanding of the current state of person-centred care in the province and develop a provincial baseline and regional categorization of these activities at the Regional Cancer Centres and partner hospitals. We interviewed over 65 individuals working within all 14 Regional Cancer Programs to determine the baseline.

Support for person-centred care included resources, staff engagement and education, and proper Patient and Family Advisor selection and onboarding. Barriers included cultural attitudes, lack of time, competing demands and the absence of a common person-centred care definition.

Overall, results show that Cancer Care Ontario can play an integral role in working with organizations to facilitate and support the provision of person-centred care. This has significant implications for person-centred care activities within health organizations and provides evidence to help inform the regional person-centred care strategy.

## Results from the Environmental Scan, Winter 2014

**80%** of Regional Cancer Programs in Ontario shared a common goal of embedding person-centred care

**58%** of hospitals had a person-centered care strategy and dedicated hospital staff

**36%** of Regional Cancer Centres had a specific strategy for person-centred care

**12%** of hospitals and

**29%** of Regional Cancer Centres did not have a person-centred care strategy or designated staff

**27%** of hospitals had not yet engaged patients

The environmental scan will be repeated in 2016 to measure the significant progress made.

# First Regional Patient and Family Advisory Council Summit

Across the province, Patient and Family Advisory Councils (PFACs) play a key role in implementing and overseeing work relating to person-centred care and patient and family engagement. Throughout Ontario's Regional Cancer Programs and Regional Renal Programs, dedicated Patient and Family Advisors (PFAs) work to ensure that their engagement in program activities leads to an improved experience for every patient. To capitalize on this enormous effort, as well as the variety of innovative tactics and approaches being undertaken, CCO convened the first PFAC Summit.

Held in Toronto on November 10, 2014, the summit brought together Regional PFAC co-chairs and administrative and clinical leaders from across the province to collaborate and network in order to engage patients and families and advance person-centred care.

The summit concluded with the articulation of concrete next steps that will support continued, meaningful engagement of patients and their families in advancing person-centered care. Work is underway to design initiatives relating to each step.

In 2015, Cancer Care Ontario will partner with provincial and regional PFACs, and the Person-Centred Care Provincial Committee in ongoing efforts to build a collaborative PFAC network that will effectively advance the engagement of patients and family members in Ontario.

FIGURE 11 | Breakdown of attendees, by role

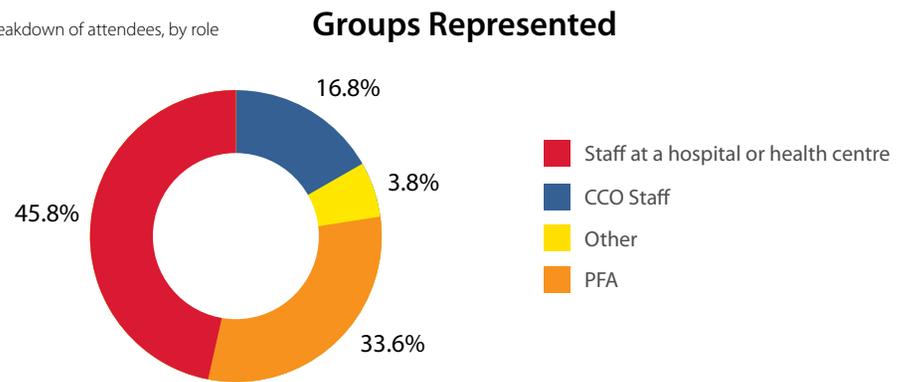
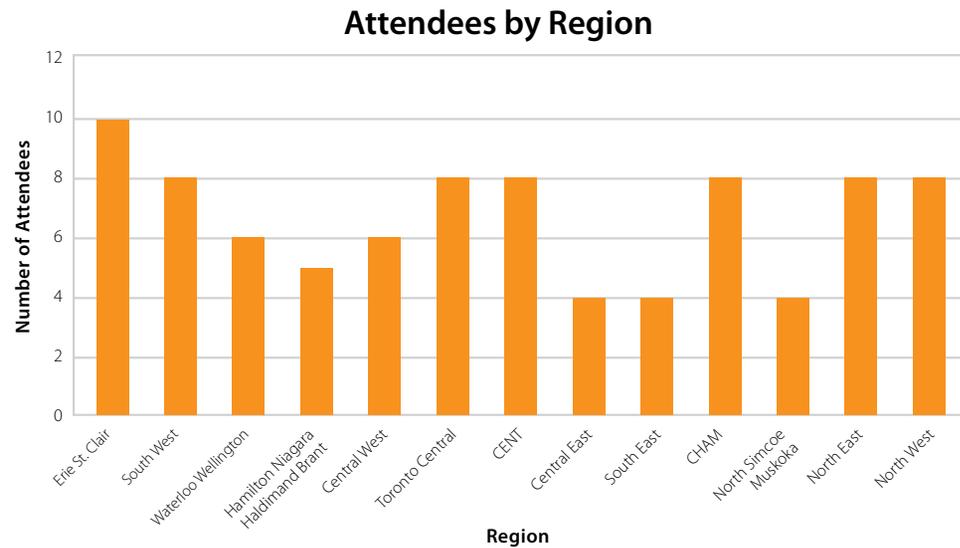


FIGURE 12 | Attendees represented each of the 14 regions



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## 119 attendees

**72%** agreed that the summit helped build their network of Patients and Family Advisors; and

**85%** agreed that the summit helped advance person-centred care in Ontario

**500,000 Twitter**  
**2,600 Facebook**

accounts were reached through the launch of CCO's first Report on Patient Engagement at the event

## PFAC Summit Outcomes:

Presentation of results of summit to CCO and regional stakeholders

Dissemination of full report to Regional Person-Centred Care Champions and summit participants

Establishment of a Cancer Care Ontario Person-Centred Care Provincial Committee

Articulation of terms of reference for a forum to identify standard provincewide definitions, roles and responsibilities in practicing person-centred care



# Committee Promotes Collaboration Across Province

In 2014, Cancer Care Ontario connected with regional and provincial partners to identify approaches to advancing the adoption of patient and family engagement and person-centred care in Ontario.

This revealed a need for greater collaboration, which led to the establishment of the Person-Centred Care Provincial Committee. This committee provides a forum for person-centred care leaders across the province to:

***Advance the mission and vision of Cancer Care Ontario and its Regional Cancer Programs by contributing to the development and implementation of provincial and regional work plans involving person-centred care and patient and family engagement in order to drive local and system-level quality improvement.***

The committee will make substantial contributions at both the regional and provincial levels by clearly assigning specific responsibilities to Cancer Care Ontario and committee members. The articulation of the committee's terms of reference is a first step towards defining the terms of a shared dialogue on person-centred care and patient and family engagement in Ontario.

The provincial committee will also assume responsibility for a number of critical functions and tasks for which accountability for person-centred care was previously undefined, including:



- Sharing information between the Regional Cancer Programs and Cancer Care Ontario;
- Informing regional stakeholders of provincial initiatives on an ongoing basis;
- Developing and implementing the Person-Centred Care Program's annual work plan;
- Increasing capacity for bringing local, national and international person-centred care and patient and family engagement best practices to Ontario; and

- Promoting a shared understanding and definition of the approach to practicing person-centred care.

The committee has begun work on specific work plan assignments this year, including playing an integral role in the rollout of the Person-Centred Care Guideline across all of the Regional Cancer Programs and developing a plan for the meaningful measurement of person-centred care.

# Regional Renal Programs Developing Patient and Family Engagement Plans

In recognition of the importance of patient and family engagement and in order to provide clear direction at the local level, the Ontario Renal Network worked with regional administrative and clinical leaders to define a standard minimum set of expectations for patient and family engagement.

This laid the foundation for a new requirement: all Regional Renal Programs must develop a Regional Patient and Family Engagement Plan. These regional plans articulate how each program will move forward and begin to embed patient and family engagement practices within its regular operations. The plans provide an understanding of the current landscape of patient and family engagement and promote sharing of lessons learned across Regional Renal Programs. Plans were submitted in March 2015 and will be refreshed on a quarterly basis.

**FIGURE 13** | Snapshot of the Regional Patient and Family Engagement Plan template used by Regional Renal Programs

PATIENT ENGAGEMENT PLAN - INSERT PROGRAM NAME HERE - - INSERT DATE HERE -			
Activity	Status	Description of current/planned activity If applicable, identify any barriers to implementation	Implementation Timeline
<b>Priority Setting</b>			
1. Identify and communicate patient and family engagement as a strategic objective/goal/priority in annual planning exercises	Choose an item.		
<b>Education, Training and Resources</b>			
2. Provide CKD <u>staff</u> with access to education and/or training programs on patient and family engagement <i>Consider: Is there a consistent definition of patient and family engagement that program staff know and understand?</i>	Choose an item.		
3. Provide CKD <u>patients and their families</u> with access to education and/or training programs on patient and family engagement	Choose an item.		
<b>Communication, Participation and Information Sharing</b>			
4. Provide a mechanism(s) for patients and their families to offer input regarding their care on an ongoing basis (e.g. through feedback, surveys, etc.) <i>Consider: Do you have strategies to overcome barriers to patient and family participation?</i>	Choose an item.		

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SECTION 5

# Key Success Highlights

CCO

CCO approaches patient and family engagement in a variety of ways. Engagement frameworks, such as the International Association of Public Participation Canada, and Health Canada’s Policy Toolkit for Public Involvement in Decision-Making have been useful in planning and in setting expectations for patients, family members, caregivers and staff about how engagement works.

The following are select examples of successful person-centred care initiatives at CCO where patient and family engagement plays a central role.

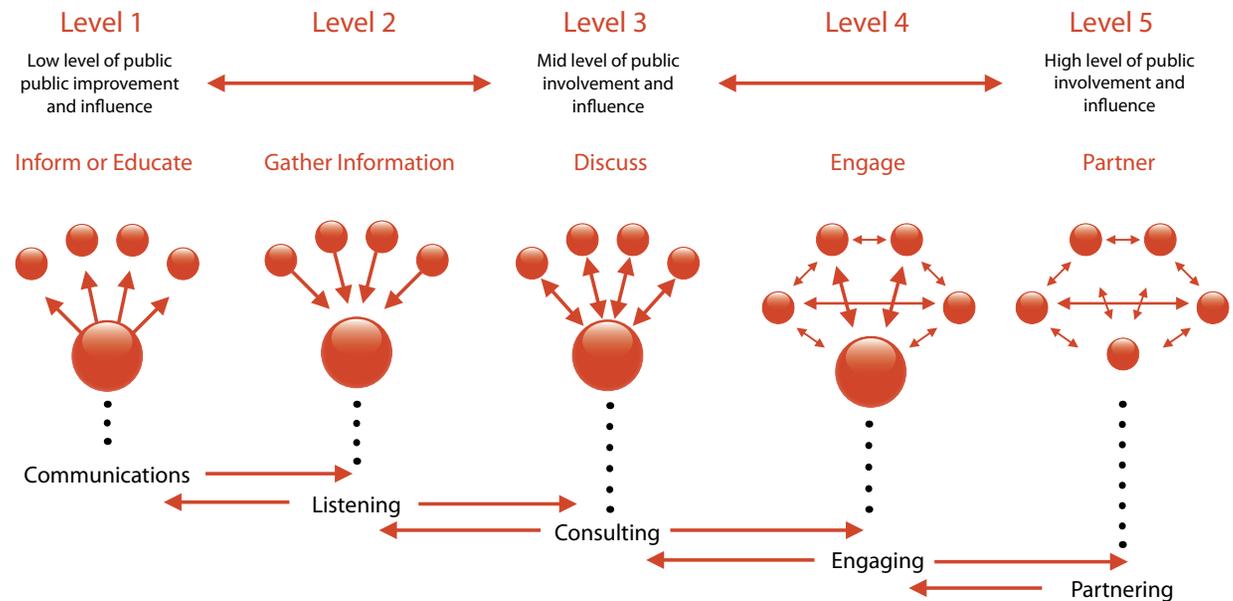
The stories are categorized along the engagement spectrum below:

- Listening
- Engaging
- Consulting
- Partnering

“Cancer Care Ontario is committed to working with Patient and Family Advisors to improve the design, delivery and evaluation of healthcare. Our mandate is to build the evidence base and provide the tools that will enable healthcare providers and staff to work with advisors to build meaningful and mutually beneficial partnerships for success.”

**LESLEY MOODY, (A) Director, Person-Centred Care, CCO**

**FIGURE 14 |** Patient and Family Engagement Framework



Adopted from Health Canada Public Participation Toolkit 2000. <http://www.hc-sc.gc.ca/>

# Public Participation in Cancer Screening

## Patient and Family Engagement

A focus group of 6 Ontarians who are eligible for cancer screening (colorectal, breast, or cervical), and 2 Patient and Family Advisors discussed what a successful partnership would look like and where their engagement would be most valuable and have the biggest impact.

## Outcomes/Next Steps

The outcome of this consultation was a key input into the development of a plan to ensure that Ontarians who are eligible for cancer screening continue to be involved in the planning and implementation of our work.

“The Cancer Screening Program is a gift. Consultations with patients and families will help Cancer Care Ontario determine how to best give this gift to Ontarians.”

**ANONYMOUS**, *Focus Group attendee*



# Enhancing Communication through Synoptic Reporting

## The Initiative

The Cancer Imaging Program is developing synoptic reports, a method of standardizing data that improves the completeness and clarity of cancer imaging reports.

## Patient and Family Engagement

In order to develop report templates that meet the needs of both patients and clinicians, Cancer Care Ontario interviewed a number of Patient and Family Advisors (PFAs). These interviews elicited their thoughts on the format and content of an imaging report for lung cancer staging, their experience with imaging reports, and the type of information they would like to receive. Using this feedback in the design of imaging report templates will ensure patients receive the type of information they need, in the format they want. This provides them with another approach to discussing their care with clinicians.

The perspectives and experiences shared in these interviews were so powerful that in February 2015, at the Synoptic Radiology Reporting Symposium, the organizers invited a PFA to deliver the opening remarks for the day. Quotations from PFAs were used throughout the presentations to emphasize the importance synoptic reporting has across the cancer continuum.

## Outcomes/Next Steps

The Synoptic Radiology Reporting Project is a multi-year, multi-phase project and the Cancer Imaging Program plans to engage PFAs in the development of other templates and the details of future implementation.



"Our family believes in the importance of 'giving back'. My husband is alive today because of the dedication of many, many people. We are only too happy to share our experience, especially when we know it has a chance to make a real difference."

**ANNE N.**, Patient and Family Advisor

"When breaking down silos in healthcare, we need to ensure that the patients are not left out. Patients need to be engaged in every step of their care, including the development of strategies and policies. Patients have brought valuable insight and perspectives to our projects. We are learning that better patient outcomes come from better patient engagement and input."

**DR. JULIAN DOBRANOWSKI**, Provincial Lead of Cancer Imaging Program and Staff Radiologist, St. Joseph's Healthcare Hamilton

# 2015 Symposium – Patients as Partners in Managing Treatment-Related Toxicity

## The Initiative

Each year, the Systemic Treatment Program hosts a symposium to encourage dialogue among medical oncologists, nurses, pharmacists, administrators, patients and caregivers regarding systemic treatment quality and safety in Ontario. The theme of the 2015 symposium was Patients as Partners in Managing Cancer-Treatment-Related Toxicity.

## Patient and Family Engagement

Patients and their families were involved in the event planning committee and were engaged as attendees and panelists at the event, which included a prioritization and validation exercise. They helped draft the agenda and the session topics and also supported the orientation of the Regional PFAs who attended the event. This orientation helped prepare these attendees to participate and contribute to the symposium. Overall, PFAs reported that they felt their thoughts and ideas were well received by those in attendance.

## Outcomes and Next Steps

The 2015 symposium provided Cancer Care Ontario with direction regarding the areas of focus for toxicity management, which include greater access to care, further standardization and improved communication.



“Telling my story and the challenges I faced during my treatment provided cancer clinicians and system administrators the opportunity to learn about less-than-optimal patient outcomes. Sharing real stories allows for the opportunity to learn and improve.”

**ANDY C.**, PFAC member and speaker at the Safety Symposium

“This was the first time we asked patients and their family members to participate alongside healthcare providers and administrators from across Ontario. I am confident their input before and during the event was a major contributor to its success. The overwhelmingly positive evaluation results have confirmed what we felt, and we will continue to take a person-centred approach with subsequent symposia.”

**DR. MONIKA KRZYZANOWSKA**,  
Clinical Lead, Quality and Access, Systemic Treatment, Cancer Care Ontario and Medical Oncologist, Princess Margaret Cancer Centre

# Symptom Management Summit Addresses 4 Key Objectives

## The Initiative

The Symptom Management Program hosted a one-day summit, that brought together healthcare providers, administrators and patients and family members to work collaboratively in designing solutions that will improve symptom management for patients.

### *The summit addressed the following objectives:*

- To define what effective symptom management means to patients and providers;
- To identify who is responsible and accountable for symptom management;
- To gain multidisciplinary alignment around issues that each region faces; and
- To reach consensus on major efforts and initiatives that need Cancer Care Ontario's support.

## Patient and Family Engagement

Prior to the summit, Patient and Family Advisors (PFAs) were encouraged to ask questions in order to provide the patient and family perspective during breakout discussions. Participants then had the opportunity to work with their cancer centre team and cross-regionally with peers to identify opportunities and strategies for improving symptom management outcomes. The event offered an opportunity for individuals to learn from each other and develop solutions that could improve patients' experiences as they move through the cancer care continuum.

## Outcomes/Next Steps

Each of the 14 Regional Cancer Program teams attending the event developed a Regional Improvement Charter. These have helped to inform the development of priorities and strategic directions for the Symptom Management Program at CCO for 2015 to 2018 and beyond. Regional Quality Improvement Plans in Symptom Management, which link specific improvement projects to performance measurement and accountability, will be among the key deliverables beginning in the spring/summer of 2015.

*"As a system, there is an opportunity to improve responsiveness with respect to our patients' symptom management needs. The Symptom Management Summit provided an opportunity for key stakeholders from across the province to share best practices and lessons learned."*

**TOM MCHUGH**, *Regional Vice President, Central East Regional Cancer Program, and Co-Chair, Symptom Management Summit Planning Committee*





“When someone is ill, the thing they desperately want is to feel better. By better managing the distressing symptoms and side effects the patient is experiencing, their worry and anxiety are lessened, caregiver burden is minimized, confidence in the healthcare team is increased, and a positive outlook and quality of life are renewed.”

**LIANNE D.**, *PFAC member and Symptom Management Summit participant*

# Making Wait Times Information More Meaningful

## The Initiative

In early 2014, Access to Care, a service of CCO Analytics and Informatics, was given the opportunity to review the current website on which the Ministry of Health and Long-Term Care (MOHLTC) publicly reports on wait times. One goal of the review was to make recommendations that would support the website in adopting a more person-centred perspective.

## Patient and Family Engagement

During a focus group held in May 2014, a number of Patient and Family Advisors (PFAs) reviewed the surgical, diagnostic imaging and emergency room wait times sections of the website and gave their perspectives on how the data could be reported in a more meaningful way. A summary of these recommendations was provided to MOHLTC in October 2014.

## Outcomes/Next Steps

The PFAs were a strong voice in the dialogue on provincial wait times, and the end result was a comprehensive list of 27 recommendations on how the usability of the public reporting website could be improved. These recommendations were shared with MOHLTC for consideration as part of an ongoing review of this wait times website.



“For patients and families, wait time information supports more informed conversations with their physicians. With this information, patients can source alternate locations to receive care.”

**ARLENE H.**, PFAC member and Focus Group Participant

“This was our first experience working with PFAs, and it provided relevant feedback on an existing project, developing recommendations on potential changes to the Ontario Wait Times public website. As a result of this positive experience, we are excited to now have 3 PFAs to help Access to Care further embed person-centred care principles into our day-to-day work and projects.”

**CLAUDIA ZANCHETTA**, Group Clinical Manager, Surgery and Diagnostic Imaging Wait Times and Efficiencies Program, Access to Care

# Focus Group Provides Patient Insights on Patient Engagement in Funding Reform

## The Initiative

Health System Funding Reform (HSFR) began advising the province to move towards a patient-based funding (PBF) model in 2012. With this new model, funding for health service providers will be based on how many patients they look after, the services they deliver, the evidence-based quality of these services and the specific needs of the population they serve.

## Patient and Family Engagement

In January 2014, CCO's Funding Unit met with the Cancer Care Ontario Patient and Family Advisory Council (PFAC) to explore opportunities for engaging patients and their families in funding reform. PFAC's recommendation was to create a focus group to develop ideas and options for patient engagement in HSFR. The goal was to develop an understanding of patient's thoughts, perceptions and questions about HSFR and how they would like to be engaged in HSFR at Cancer Care Ontario.

## Outcomes/Next Steps

The focus group's findings were shared with the Cancer Care Ontario PFAC.

### *The next steps could include:*

- Adding Patient and Family Advisor (PFA) representation on HSFR-related committees, especially those focusing on quality;
- Creating a PFA section in the Funding Unit website and newsletter;
- Developing further targeted focus groups;
- Providing PFAC with an annual HSFR update; and
- Developing patient and family value principle statements for HSFR.

"I didn't know a lot about health system funding reform, but the CCO Funding Unit spent time explaining how it works and answered our questions. They were very knowledgeable and willing to listen to our concerns. They were very respectful and, most importantly, they listened to us. I gained a better understanding of funding and the challenges the healthcare system faces."

**JOANNE M.**, PFAC Co-Chair and focus group participant

"Working with PFAs has been enlightening because it is a reminder to us that the people of Ontario are directly affected by the work we do and the decisions we make. We were pleased to obtain several ideas on avenues for PFA engagement in our work. None of this would have been possible without the generosity of the PFAs and we look forward to our ongoing engagement with these volunteers."

**PASCALE LAJOIE**, Senior Specialist, Funding, Planning and Regional Programs, Cancer Care Ontario

# Over 3,000 Participants in Patient Education Survey

## The Initiative

The Patient Education Program believes that effective health education empowers cancer patients and their families to better manage their care and make more informed decisions. From November 2014 to March 2015, the Patient Education Program rolled out the “Your Learning Matters” survey in partnership with the 14 Regional Cancer Centres and the Walker Family Cancer Centre.

The results of the 10-question survey will improve our understanding of the type of education and information that patients and families receive, and whether it is useful. This will help Cancer Care Ontario identify gaps in cancer education.

## Patient and Family Engagement

Patient and Family Advisors (PFAs) on the Provincial Patient Education Committee provided guidance on the current gaps in patient education and offered suggestions on how to phrase the survey questions, and what kinds of communication materials and implementation strategies would help ensure the survey was a success. They are also helping with the interpretation of the responses.

## Outcomes and Next Steps

Each centre reached the target of 150-200 responses, with many centres collecting more. In total, the program collected 3,060 responses. The results will provide a better understanding of the current state of oncology patient and family education across Ontario, inform quality improvement initiatives at a local level within the Regional Cancer Centres, and help set the provincial agenda moving forward.



“Upfront education for cancer patients helps ease the journey. You know what’s coming down the road.”

**PATRICIA P.**, PFAC member and Provincial Patient Education Committee member

“Input from those who have lived the cancer experience is essential to ensuring the cancer system provides the highest quality, most effective patient education services to Ontarians. As a result of our PFAs’ input, we now have a tool that will allow us to assess the state of cancer-related patient education services across the province. This will help us empower and engage people effectively by providing them with innovative, accessible and timely education about their cancer at the point of care and beyond.”

**TAMARA HARTH**, Provincial Head, Patient Education, Cancer Care Ontario and Program Manager, Patient and Family Education at the Odette Cancer Centre

# Enhancing Person-Centred Systemic Treatment

## The Initiative

The Systemic Treatment Provincial Plan 2014 - 2019 serves as a road map for the delivery of safe, high-quality, accessible systemic treatment of cancer across Ontario.

## Patient and Family Engagement

Patient and Family Advisors (PFAs) were involved in the development of the plan from the beginning, participating in working groups alongside physicians, nurses, pharmacists and administrators through to the plan's endorsement at the Cancer Care Ontario Patient and Family Advisory Council. Their experiences and perspectives helped ensure that the content and format of the plan recognized the needs and preferences of patients and family members. Their stories, quotes and insights also enhanced the final document.

## Outcomes/Next Steps

The Systemic Treatment Provincial Plan was launched in December 2014, and work has already started on implementing many of its recommendations. PFA involvement with these initiatives continues.



"Our involvement as Patient and Family Advisors in the Systemic Treatment Provincial Plan is an opportunity to bring our insight and voice to the table to inform the clinical and administrative team about the challenges experienced by the patient and caregiver during treatment and follow-up care."

**CATHERINE C.**, Patient and Family Advisor  
**AND DONNA E.** Patient and Family Advisor (photo not shown)

"As we set out to develop the strategy for systemic treatment over the next 4 to 5 years, we knew it would not be successful without integrating input from patients and family members from the outset. The Patient and Family Advisors grounded us with their practical and poignant contributions, and helped us to deliver an excellent road map for the program. We thank each of the advisors, and look forward to continuing to work alongside them and others as we implement the recommendations in the plan."

**DR. LEONARD KAIZER**, Provincial Head, Systemic Treatment, Cancer Care Ontario, and Medical Oncologist, Trillium Health Partners

# Patient Voice Key to Steering Committee

## The Initiative

The Cancer Performance Steering Committee guides the execution of consistent, effective cancer system performance management at Cancer Care Ontario, including setting policy and developing cancer system performance indicators. Its work has the potential to advance person-centred care by helping to drive quality improvements in the cancer system. The committee meets 5 times per year, setting key priorities at a planning meeting each April.

## Patient and Family Engagement

At the 2015 planning meeting, 2 Patient and Family Advisors (PFAs) presented their perspectives on gaps they saw in Cancer Care Ontario's performance measurement and management. Their questions and ideas generated excellent discussion around the table. The patient voice helped remind committee members of what is most important when decisions are being made about setting targets for performance improvement and determining which indicators will be prioritized.

## Outcomes and Next Steps

The impacts of this discussion are already becoming apparent. At least one Cancer Care Ontario program has adjusted its planning for 2015/16 to address an issue raised by the PFAs.



"In a busy workday filled with opinions from hospital executives, government officials, healthcare staff and physicians, the Patient and Family Advisors provide us with a sober second thought so we can get it right the first time."

**GARTH MATHESON**, Vice President, Regional Programs and Planning, Cancer Care Ontario

"As a Patient and Family Advisor, I am able to have a direct impact on how well cancer system services in Ontario provide for the needs of patients. The cancer system administrators and clinicians know that the system is not perfect and rely upon our input to identify gaps. As a patient, I feel that I bring to this committee the human side of good performance."

**ANDY C.**, PFAC member and Cancer Performance Steering Committee member

# PFAs Co-Design Shared-Care

## The Initiative

In order to improve access to high-quality care, the Acute Leukemia Steering Committee recommended the development of a shared-care program that would allow appropriate patients to receive portions of their care at both Princess Margaret Cancer Centre and a partner cancer centre closer to home.

## Patient and Family Engagement

In 2014, Patient and Family Advisors (PFAs) began to work with the steering committee on the development of patient and provider communication materials, patient navigation and appointment tracking tools and, very importantly, a patient experience measurement survey. This survey will collect patient feedback on the quality and coordination of care they experience as part of the shared-care program, which will inform potential enhancements to the program.

## Outcomes/Next Steps

Moving forward, Cancer Care Ontario will continue to work with regional partners and others, including PFAs, to expand the Acute Leukemia Shared-Care Program



"I can already see from my own experience as a patient and a clinic volunteer that the shared-care model is working. Being diagnosed with cancer is hard enough without adding travel, bad weather and a strange environment to the mix. In many ways, these variables have been reduced, if not eliminated."

**ANNA L**, Patient and Family Advisor and Acute Leukemia Implementation Steering Committee member

"Leukemia patients and their caregivers will receive the best care closer to home when possible and will enjoy the success of our shared-care program, as it has evolved and been built with the help of our PFAs."

**DR. TOM KOUROUKIS**, Provincial Hematology Disease Site Lead, Cancer Care Ontario, Division Head, Malignant Hematology, Juravinski Cancer Centre and Associate Professor, McMaster University, Department of Oncology

# Focal Tumour Ablation Report Released

## The Initiative

In 2014, Cancer Care Ontario created a Focal Tumour Ablation Advisory Committee to consider the organization and delivery of selected focal tumour ablation services in Ontario, with a focus on access, quality and funding. With clinicians, administrators and Patient and Family Advisors (PFAs) at the table, the committee was asked to develop a recommendations report.

## Patient and Family Engagement

2 PFAs participated on the advisory committee, lending their voices to the development of the recommendations report by sharing their individual experiences, discussing what they had learned from other patients and family members, and providing suggestions for improvement. The PFAs reviewed the report and helped make it understandable and relevant from a person-centred perspective. For example, the addition of a glossary of terms was one valuable suggestion that was adopted in the final report.

## Outcomes and Next Steps

The Focal Tumour Ablation in Ontario: Recommendations Report was released in March 2015. Cancer Care Ontario continues to engage with members of the advisory committee on the development of additional evidence summaries and is working with the Ministry of Health and Long-Term Care and regional stakeholders to determine how to move forward with the recommendations.



"It moves me to see how much work the committee put into this recommendations report, which may make focal tumour ablation an integral part of delivering more comprehensive cancer care in Ontario. I have been so impressed with the level of care and expertise shown by this group. It has been an honour to be a part of it."

**BRIGITTA B.**, Patient and Family Advisor

"Our team worked diligently to recruit Patient and Family Advisors from the relatively small number of people impacted by these conditions/treatments. I'm proud of our success in doing so and look forward to the continued valuable contributions of the PFAs."

**ERIC GUTIERREZ**, Clinical Programs –  
Diagnosis and Treatment, Cancer Care  
Ontario

# Measuring Patient Experience at the End of Life

## The Initiative

CCO is undertaking a number of palliative care initiatives. The Patient Experience Measures at the End of Life project was intended to identify a way to measure the person's experience and the care that was received at the end of life. The project team adopted the disease-agnostic VOICES survey, which is completed by bereaved caregivers and focuses on the patient's last 3 months of care. The survey includes questions specific to various healthcare settings (including primary care, hospital, Regional Cancer Centre and hospice), as well as the health system as a whole.

## Patient and Family Engagement

2 Patient and Family Advisors (PFAs) joined the working group and attended 8 months of teleconference meetings. Their contributions were clear and well thought out and their ideas determined the final shape of the project. For example, on their advice, questions were added to enable CCO to measure the extent to which advance care planning is occurring for cancer patients at the end of life.

## Outcomes/Next Steps

The survey is currently being tested in the hospice setting by a research team at McMaster University, with plans for a phased approach that will roll out the survey to other healthcare settings in the province.



*"My hope is that by engaging the families of people who have died, through thoughtful interviews and surveys, and then involving advisors in creating new processes, we can approach our own deaths with the confidence that everything possible will be done to help us maintain dignity, comfort and connection, to the end, and that our families will be supported in their sorrow afterwards."*

**ANYA H.**, Patient and Family Advisor and member of the Patient Experience Measures at the End of Life project team

*"It is because of our PFAs' contributions to a number of cancer care contexts that I better understand how critically important it is to co-evolve our healthcare system with individuals who find themselves in it or having gone through it. The pace of making change and the breadth of perspective are far greater because of [their] participation."*

**DR. JEFF MYERS**, Palliative Care Physician, Sunnybrook Hospital

# 8 Cancer Patient Symptom Management Guides Developed

## The Initiative

Patient-focused symptom management guides provide information for people who are experiencing cancer-related symptoms before, during or after cancer treatment. Building on the success of Cancer Care Ontario's Patient Pathways, these guides are another example of an evidence-based resource created specifically for patients and their families.

The guides were developed using best practices for patient education. They help patients and families gain more knowledge about cancer-related symptoms and learn how they can better manage these symptoms themselves. This work demonstrates Cancer Care Ontario's commitment to move from a provider-centric model to one focused on the needs of patients and caregivers.

## Patient and Family Engagement

Collaboration between healthcare professionals and Patient and Family Advisors (PFAs) was integral to developing these evidence-based guides. From the outset of the project in August 2013, PFAs were involved as equal partners whose contributions were essential to achieving a remarkable comprehensiveness in the documents.

### Together the group:

- Set the terms of reference;
- Identified and evaluated existing tools;
- Developed the content of the guides; and
- Reviewed design templates.

Along with healthcare providers from across the province, Cancer Care Ontario's PFA community also participated in an external review of the guides before endorsing them for publication.

## Outcomes and Next Steps

In 2015/16, symptom management guides will be published for fatigue, nausea and vomiting, pain, anxiety and depression, shortness of breath, bowel care, loss of appetite and oral care.

"It would have been nice to have these symptom management guides when I was in treatment. You want to know the challenges you will have to face. It is great to have this information in plain language, because sometimes you are overwhelmed when you hear all of this from a doctor or staff member in a hospital setting. It is nice to go home and have the information at your fingertips."

**ANONYMOUS**, external review participant

"The success of the symptom management guides started with a need, voiced by patients and families. The resourcing, researching and composing of the guides involved dedicated champions who represented every aspect of symptom care. This project illustrates how we can partner with patients and families and create a powerful and motivated province wide team to make positive things happen, together."

**DR. ALEXANDRA GINTY**, Regional Primary Care Lead for Mississauga/Halton, Cancer Care Ontario, Family Physician and Adj. Assistant Clinical Professor, McMaster University

# PFAs Provide Key Input to Ontario Cancer Plan IV

## The Initiative

The Ontario Cancer Plan IV (OCP IV) serves as a road map that shows how Cancer Care Ontario, the Ministry of Health and Long-Term Care, healthcare providers and the Regional Cancer Programs will work together to develop and deliver cancer care services over the next four years.

In developing OCP IV, Cancer Care Ontario consulted with an extensive network of stakeholders, including internal staff, all Regional Cancer Programs, Patient and Family Advisors (PFAs) and provincial partners, as well as international cancer and health system experts. Their insights helped identify the high-level themes of OCP IV, shaping the plan's goals, strategic objectives and "By 2019" statements.

## Patient and Family Engagement

PFAs were involved in every step of the development of OCP IV. This provided an unprecedented opportunity to shape the plan so that it would be more person-centred and responsive to the needs and challenges of individuals directly affected by cancer.

**The development of OCP IV began in early 2013 and was completed in March 2015. PFAs were involved throughout the process and in various working groups. For example:**

- OCP IV Executive Sponsor Group was co-chaired by a PFA;
- 2 PFAs participated in the OCP IV working group;
- PFAs participated in each of the theme working sub-groups;
- PFAs attended the 14 regional engagement sessions;
- A PFA participated in the International Advisory Panel meetings;

- Regular updates were provided at Cancer Care Ontario's Patient and Family Advisory Council;
- PFAs attended a spring planning day and the Cancer Quality Council of Ontario OCP IV review day; and
- PFAs shared their thoughts and stories for inclusion in the printed OCP IV document.

**PFAs contributed to the strategic planning process in several ways, such as:**

- Highlighting key issues in the cancer system and how they impact patients and their families;
- Ensuring the patient and family voice was heard as priorities were being set for the cancer system;
- Helping to foster better understanding of patient and family expectations of the cancer system; and
- Ensuring the language in OCP IV resonates with patients and families.

## Outcomes/Next Steps

OCP IV, which lays out the strategy for the Ontario cancer system from 2015 to 2019, was released in May 2015. The plan aims to improve the cancer system in the areas of:

- Quality of Life
- Patient Experience
- Safety
- Equity
- Integrated Care
- Sustainability
- Effectiveness.

"I want cancer patients and their families to know that they had a voice at the table as Cancer Care Ontario developed this plan. The Patient and Family Advisors really made a difference in determining how cancer care services are going to be provided over the next 4 years. Listening to patients - putting them at the centre of care - is a culture change that needs to spread across the healthcare system."

**PATRICIA P.**, PFAC member and OCP IV working group member.

"Patient and Family Advisors have been involved in the development of OCP IV right from the beginning, fully engaged in meaningful discussions that will shape the way cancer care is delivered in this province."

**GARTH MATHESON**, Vice-President, Regional Programs and Planning, Cancer Care Ontario

# Partnering with Patients for the Development of Ontario Renal Plan II

Between January and April 2014, the Ontario Renal Network embarked on its first provincial consultations with patients and families who are living with chronic kidney disease (CKD). The purpose was to hear directly from those most intimately impacted by CKD about their care, and what they thought should be addressed in the Ontario Renal Plan II (ORP II)

In total, feedback was collected from 82 patients and family members across 11 Ontario regions. Input was collected through in-person group sessions, group video-conferencing, one-on-one in-person and phone interviews and written submissions.

These patient and family perspectives were invaluable, revealing opportunities to improve the patient experience across the kidney care journey. Recognizing the need for continued engagement of patients in the development of the system plan, the Ontario Renal Network formed the Ontario Renal Plan II Patient Advisory Committee.

This group of 6 members met monthly to advise on the development of the plan and refinement of its goals, strategic objectives and initiatives so that they aligned with what is most important to patients and their families:

- Empowering and supporting patients and their family members to be actively involved in their care;
- Integrating care throughout the kidney care journey; and
- Improving access to kidney care.



“Having patients involved in the development and implementation of ORP II will result in a world-leading, patient-centred renal system in Ontario, where patients are engaged in all decision-making along the CKD care journey. I hope that by contributing my experiences to the project, I can help other patients succeed in managing CKD in their lives.”

**MICHAEL M.**, Patient and Family Advisor, Ontario Renal Network and ORP II Patient Advisory Committee member

“We met with and listened to hundreds of key stakeholders when developing the Ontario Renal Plan II. Of those hundreds of conversations, it was the voices of patients and families that highlighted the real opportunities to improve the kidney care system. I am so grateful that patients and families took time out of their lives to share their touching stories and challenges and suggest ways to make improvements.”

**CHRISTINA D'ANTONIO**, Business Strategist, Ontario Renal Network

# Partnering with Patients to Co-create Educational Materials to Support Shared Decision-Making

In July 2014, the Ontario Renal Network was successful in a proposal to the Canadian Foundation for Healthcare Improvement (CFHI) to participate in its collaborative, Partnering with Patients and Families for Quality Improvement.

With CFHI support, the Ontario Renal Network partnered with patient advisors and the renal program at The Ottawa Hospital to develop, implement and evaluate a skill-building video for healthcare providers on coaching patients' decision-making. The aim of the project is to reduce the scope of decisional conflict for patients and their families when they are selecting a renal replacement therapy by improving the skills of healthcare providers for engaging patients and families in shared decision-making.

Partnering with patients has been key to the project from its inception. A Patient and Family Advisor has been an active member of the project steering committee, providing input for the video script, helping to select the actors and supporting the introduction of the educational video at 2 pilot sites. This collaboration has been essential in ensuring the project accurately represents the thoughts, feelings and emotions often experienced by patients who are making decisions about renal replacement therapy. A complete project evaluation will be completed in December 2015.



"I was thrilled to be part of the shared decision-making project with The Ottawa Hospital and the Ontario Renal Network. In line with the objectives of the Ontario Renal Plan II, this project helps healthcare providers empower patients faced with decisional conflict by guiding them through a structured process that enables patients to come to a well-informed decision regarding renal replacement therapy. I know this process works because, as a patient myself, I was coached through the process and I know without a doubt that the renal replacement therapy I have chosen will be the best option for me when my kidneys fail."

**RANDY R.**, Patient and Family Advisor and member of the project team

"Patients bring their expertise about their life and situation and what's important to them: their circumstances, personal values and attitude to risk. Healthcare providers bring expertise on treatment options and the likelihood of a person experiencing a particular side effect. It is so exciting to be part of a team working together to better help and support patients, their families and those involved in their care."

**DR. MARY ANN MURRAY**, Advanced Practice Nurse, The Ottawa Hospital



SECTION 6

# Key Success Highlights

Ontario Regions

Successful person-centred care initiatives driven by patient and family engagement are evident not only in CCO programs, but also in the Regional Cancer and Renal Programs.

This section includes snapshots of person-centred care initiatives from a number of regions that demonstrate the impact of patient and family engagement.



"Across the province, there are many great examples of how we are engaging patients, family members and caregivers to drive meaningful change in how we deliver care. Cancer and renal programs have been promoting person-centred change on the ground, engaging with patients and families in better informed planning and initiatives for improving care quality. Changing patient-clinician interactions is integral to person-centred care, but equally important is ensuring we are building a person-centred system through meaningful partnerships with patients and families. Our thanks go to healthcare providers, patients and families across Ontario for the tremendous effort they are putting into improving the patient experience."

**DR. PETER BLAKE**, *Provincial Medical Director, Ontario Renal Network and Division of Nephrology Chair, London Health Sciences Centre*



# Ontario Regional Cancer Programs

CENTRAL WEST / MISSISSAUGA HALTON

## Trillium Health Partners

At Trillium Health Partners, patients and care providers collaborated to improve the quality of care by designing an oral chemotherapy care pathway. Patients were involved throughout the process, and offered vital insights for the development of improvement initiatives, including advice on process and materials. Patient and Family Advisors are also essential to the ongoing evaluation of this project, and they review regular reports on progress and key milestones.

“As the patient representative for this working group, and a patient who was taking an oral chemotherapy agent, I found that I benefited greatly from the resulting improvement to oral chemotherapy services. There is a lot of fear that surrounds cancer and chemotherapy treatment, and that fear can grow when you’re told to go home and take your chemotherapy drugs on your own. The patient education around safe handling, dosage and drug/food interactions helped tremendously with alleviating many of those fears. The handout also supported this and was a ‘go-to’ for me when I was in doubt. I am a patient who has endured both systemic and oral treatment, and I can definitely say, from experience, that I felt just as comfortable taking an oral agent at home as I did having a nurse administer intravenous treatment.”

**ANONYMOUS**, Patient and Family Advisor, Central West / Mississauga Halton Region



“We were fortunate to have a patient as a member of our team from the beginning of the development of our oral chemotherapy care pathway. She was an active member during all stages of the project, from the needs assessment/environmental scan to the development of educational material (care plans) and implementation of the new care pathway. As a patient who had recently had experience with both oral and intravenous cancer treatment, she was able to help identify some gaps in care that we had not previously considered. Her unique perspective was also valuable in the development of our teaching tools, particularly when addressing sensitive issues like how to clearly identify and communicate the intent of the oral cancer treatments.”

**DR. KATHERINE ENRIGHT**, Regional Lead, Quality Initiatives, Central West / Mississauga Halton Region

# Ontario Regional Cancer Programs

## CENTRAL

### Stronach Regional Cancer Centre at Southlake

In June 2014, the Stronach Regional Cancer Centre at Southlake conducted a value-stream mapping exercise with 3 main purposes:

- To develop a value statement in the voice of the patient that serves as the cancer care program's conscience in future work;
- To visualize the current cancer continuum and identify waste in the system; and
- To identify the gaps between the current and future state, and create a high-level action plan to define next steps.

The result was a value-stream map of the desired future state that encompasses the entire Stronach Regional Cancer Centre program and the steps needed to improve patient experience. The exercise brought together 40 staff members, physicians and volunteers and 4 patients over 2 days to go through a lean management process as a way to better understand the patient perspective and work towards system-level improvement.

During this process, patients and family members created a value statement, in the voice of the patient and charted their emotions across the cancer continuum on the process map. Following this event, 5 working groups were formed to review referral, navigation, standardization, assessment and patient experience.



By January 2015, 16 patients' stories had been collected and 2 projects were underway. One project that began in the patient experience working group was the redesign of the new patient chemotherapy teaching class. A Patient and Family Advisor worked with the group to create a patient satisfaction survey and tabulate the results. The redesigned class offers patients and family members more general information and involves other care providers, such as social workers, dietitians, pharmacists and the centre's chaplain.

"I had mixed emotions when asked to join, as this had been a very difficult time in my life. The idea of reliving that time was emotional but the experience has been life-changing for me. I feel that my voice is being heard and I can help bring about a change that will impact other people's lives based on my experience during a very difficult time. We recognized that patients were being asked a lot of questions, so we wanted to make sure we could get the most valuable feedback without overburdening them."

**STEPHANIE C.**, Patient and Family Advisor, Stronach Regional Cancer Centre and member of the Patient Experience Working Group

"Here at the Stronach Regional Cancer Centre we are highly focused on a value agenda - quality outcomes that are important to patients from their perspective, relative to cost and efficiency. We have been a very provider-dominated healthcare system, and we are trying to change the paradigm completely to make it a very patient-driven, patient-centred healthcare system."

**DR. DAVID FELL**, Vice-President, Patient Experiences, Regional Cancer and Cardiac Programs, Southlake Regional Health Centre, Regional Vice-President, Cancer Services and Central Regional Cancer Program, Cancer Care Ontario

# Ontario Regional Cancer Programs

ERIE ST. CLAIR

## Windsor Regional Hospital Cancer Centre

By partnering with patients, staff members and care providers, the Windsor Regional Hospital Cancer Centre learned that information, education and fitness can make a very big difference for anyone who is moving through the cancer continuum. The RENEW (Resources, Education, Nutrition, Exercise, Wellness) Education and Fitness Program is a partnership between the Windsor Regional Cancer Program and the University of Windsor Faculty of Human Kinetics.

The project's programs are offered either for free or at minimal cost to patients and their caregivers. These programs not only provide patients and families with important services, they bring these services together so that they lend invaluable support to one another. In the education program, experts from Windsor Regional Hospital's Cancer Program explain next stages in the cancer continuum including secondary screening, prevention and potential long-term side effects of treatment. A genetic counsellor instructs patients in drawing their family tree and discovering what cancer means for their families. A registered dietitian talks about healthy eating, nutrition and common myths about food and cancer. In addition, a certified cancer exercise specialist demonstrates the benefits of exercise and activity. The fitness program includes specially designed classes at a local fitness club, such as customized exercise and yoga group classes that can help patients re-establish an active lifestyle.

To ensure that it consistently responds to participants needs, the program partners with volunteer participants as members of the program committee or through focus groups. Committee members include cancer program staff and University of Windsor faculty of Human Kinetics Staff, as well as patients and caregivers (an equal number of staff and patients/caregivers). This provides the program with a variety of inputs, including ideas on how to advertise and areas for improvement and expansion.

**"Cancer is always there, and your biggest concern is keeping it away. There is a fear there. The RENEW Program gives you a focus. It helped to bring back my confidence and enhances my way of living."**

**DIANE M.**, *Patient and Family Advisor, and RENEW Education and Fitness Program Committee member*

**"Beating cancer is a true success story, and adding the benefits of a healthy lifestyle will take your success to an even higher level."**

**DR. KEN SCHNEIDER**, *Chief of Oncology, Windsor Regional Hospital*

HAMILTON NIAGARA HALDIMAND BRANT

## Walker Family Cancer Centre

Staff at the Walker Family Cancer Centre decided to make patients integral members of a team trying to make lymphedema care more person-centred by increasing access to the best educational and community resources. Following the experience-based design methodology, patients contributed extensively to the design of the project, ensuring that its objectives contributed to making their experience of care more positive. A Patient and Family Advisor helped the project team identify key learning points in the cancer continuum, from surgical pre-admission through chemotherapy and radiation treatments. With these key learning points in mind, the team helped develop pathways to guide patients to essential resources at the cancer centre and in the community. Finally, the patients' perspective was also instrumental in the design of pathways for caregivers, providing them with access to the right resources at the right time.

**"We provided a perspective to the documentation, to the process and to the project's medical team that had never been considered. We were able to highlight the importance of repetition (of material and available resources), as patients may be looking for them at different times in their cancer experience."**

**LUCY S.** *Patient and Family Advisor and Lymphedema project team member, Walker Family Cancer Centre*

# Ontario Regional Cancer Programs

## CHAMPLAIN

### The Ottawa Hospital Regional Cancer Centre

At The Ottawa Hospital, person-centred care is not just a philosophy. Staff, administrators and even volunteers are expected to be person-centred in everything that they do.

To help integrate this practice into its culture, the hospital introduced the Patient and Family Advisory Council (PFAC) Award in 2014, recognizing a healthcare provider, support staff member, administrator, volunteer or team for outstanding achievements in advancing person-centred care. The first annual award was given to the members of the C.A.R.E. (Chronic Ascites and Recurrent Effusion) team, who recognized that patients suffering from chronic ascites repeatedly reported spending far too much time in the hospital while their condition was being managed. Partnering with patients to revise treatment and management protocols, the team was able to improve patients' ability to manage their own care at home, thus significantly decreasing time spent in the hospital and improving the overall patient experience.



**FROM LEFT TO RIGHT:**  
Dr. Kayvan Amjadi,  
Medical Director,  
Interventional  
Pulmonology; Lorraine  
Cake, RN; Lynn Kachuik,  
APN Supportive and  
Palliative Care

"With the PFAC Award, the members of the Champlain Regional Patient and Family Advisory Council have come up with a wonderful way to recognize care providers who truly live the values of patient-centred care."

**CATHY DEGRASSE**, Clinical Director, Regional Cancer Program

"Ultimately, we want to help effect cultural change by reinforcing those practices that contribute to our objectives of the best possible cancer care and service delivery. The PFAC Award is an opportunity for us to recognize and encourage those within the Champlain Region who have implemented sustainable, innovative and effective remedies that reflect our principles. And if any of these initiatives can be transferred geographically or to other diseases, then that is truly transformative."

**JENNIFER S.**, Patient and Family Advisor, The Ottawa Hospital Cancer Program

# Ontario Regional Cancer Programs

## NORTH SIMCOE MUSKOKA

### Simcoe Muskoka Regional Cancer Centre

At the Simcoe Muskoka Regional Cancer Centre (SMRCC), patients actively partnered with staff to talk about sexual health. A common concern for many patients and their partners, sexual health can often be overlooked by healthcare providers or brushed aside by patients who are trying to focus on active treatment. But since sexual health is an important component of overall well-being, the SMRCC Patient and Family Advisory Council (PFAC) recognized the need to start the conversation and make it a priority.

While conducting a review of previous patient satisfaction scores derived from both the Ambulatory Oncology Patient Satisfaction Survey (link to above section) and direct practitioner consultation with patients, the SMRCC PFAC partnered with leadership within the centre, and the concept of a sexual health clinic was born. The Sexual Health, Intimacy and Cancer (SHIC) clinic offers a pathway for cancer care providers to refer their patients to a social worker, nurse practitioner, urologist or radiation oncologist. All of these staff members are familiar with the inter-professional psychosocial oncology distance education courses on sexual health and cancer. Most importantly, patients and their partners can refer themselves to the clinic.

Implemented in June 2014 and fully operational by April 2015, the SHIC clinic has received overwhelmingly positive responses. In order to keep the momentum going, the SMRCC PFAC has

been involved in the implementation of a sexual health class. This will be offered to patients and their partners who may benefit from a general overview of common concerns and resolution strategies, rather than a formal SHIC clinic visit.

*"This clinic introduced me to a group of people who understood exactly what I am going through. They listened. They helped me. They changed my life! At the age of 43, with cancer, I thought I had lost everything. This clinic helped me understand that no matter what I am going through, I am a woman. I am worth it."*

**ANONYMOUS**

*"Patient feedback sparked a collaboration with multidisciplinary and interdisciplinary team members to develop a program that ultimately addresses the needs of our patients. This is just the beginning of more patient-inspired initiatives to come."*

**DR. CHRISTIAAN STEVENS**, *Clinical Director, Simcoe Muskoka Regional Cancer Program*

# Ontario Regional Cancer Programs

## TORONTO CENTRAL

### Sunnybrook Health Sciences Centre

The vision of the Quality Dying Initiative at Sunnybrook Health Sciences Centre encompasses person-centred care, embraces patient and family engagement, and began with a powerful patient story. The priorities of the initiative were drawn up in collaboration with families whose loved ones have died at Sunnybrook.

#### Areas of focus to date have included:

- Implementation of the Comfort Measures Strategy for persons who are very close to death;
- Development of 2 important family resources;
- Advance care planning; and
- The patient engagement video project.

The Quality Dying video was developed together with the Odette Cancer Centre and Cancer Care Ontario's INTEGRATE Project and highlights the stories of 2 families, who share what is most important for them at the end of life.

In the winter of 2014, the Odette Cancer Centre's newly formed Patient and Family Advisory Council (PFAC) had the opportunity to become engaged in the Quality Dying Initiative. The vision of improving care at the end of life resonated deeply with the members, affirming that conversations about value-based care, preferences and wishes are always in need of enhancement.

Other priorities identified by the PFAC include increasing awareness of and access to supportive care, improving navigation of the cancer continuum and providing effective patient education to manage the cancer experience. In the short time since the establishment of the PFAC, there has been tremendous interest expressed by healthcare teams and administrative staff across Sunnybrook in engaging with advisors to explore a variety of corporate strategic priorities. Patients and families who are involved with the PFAC have been the catalyst for change in the way the Odette Cancer Centre delivers care by promoting a culture of patient engagement and ensuring this concept is adopted throughout the program.

Members of the Odette Cancer Centre PFAC are now instrumental in advancing the Quality Dying Initiative priorities. They joined the Quality Dying Initiative Steering Committee as team members, are actively engaged in the development of the Advance Care Planning Strategy, and are now at the centre of patient and family resource development.

*"As the widow of a cancer patient, I know what information, conversation and emotional support I wish we had been offered during my husband's one-year illness. We need to talk about dying. We need to face the facts and the feelings. And we need to provide an environment, a community of support, to help the person who is dying and those they are leaving behind with broken hearts."*

**LAURELEA C.**, PFAC member, Odette Cancer Centre and member of the Quality Dying Initiative Steering Committee

*"Engaging patients and their families through the newly formed Patient and Family Advisory Council has been invaluable in terms of helping us better understand how we can deliver care in a person-centred way with the goal of improving the patient experience across the cancer care continuum."*

**JANICE STEWART**, Director of Operations and Regional Planning and Co-Chair, Patient and Family Advisory Council, Odette Cancer Centre

# Ontario Regional Renal Programs

## CENTRAL EAST

### Lakeridge Health

The Kidney Care Clinic at Lakeridge Health provides care to over 600 patients, half of whom also have diabetes. To address the frustration that many patients had expressed at having to visit 2 separate clinics and sometimes receiving conflicting recommendations, it was decided to integrate diabetes care into the kidney care clinic by providing support for staff members so that they could become certified diabetes educators and by adding endocrinology services. Utilizing experience-based design, Lakeridge Health partnered with chronic kidney disease patients and the University of Ontario Institute of Technology to develop the project plan and a survey to solicit patient and family feedback on this change. In total, 38 surveys and 6 telephone interviews were completed with patients and their families who were affected by this change. The results showed that they appreciated the integrated clinic. While the appointment time was longer, the benefits of the integration compensated for the longer clinic visit. The experience-based design approach was so informative that it has been utilized in 2 other quality improvement initiatives within the renal program.

**“When I was asked to be part of the process, I wasn’t sure what I could contribute. I was pleasantly surprised to be working collaboratively with other committee members. This was a familiar experience in my academic life. I found it to be stimulating.”**

**PAT S.,** Patient Advisor, Lakeridge Health

**“The Experienced-Based Design survey allowed us to focus on the patients’ experience. Knowledge of the experience in the clinic is only known by the patient; this is unique and very important. This survey allowed us to have a view of what our consumer or customer, our patients, were feeling about the integrated clinic.”**

**ANN MARIE ROBINSON,** Registered Nurse, Certified Diabetes Educator, Lakeridge Health

## CENTRAL

### Humber River Hospital

When Humber River Hospital (HRH) established a Dialysis Patient and Family Advisory Council (PFAC), its members identified the area most in need of improvement as communication and emotional support. Recognizing this need, along with its broader commitment to reinventing patient care, HRH launched Communicate with H.E.A.R.T.®, a training program developed by the Cleveland Clinic to improve the overall experience of patients and their families in the hospital and their interactions with hospital staff.

As decisions were made regarding the Communicate with H.E.A.R.T. training, the Dialysis PFAC was kept apprised of the evolving direction and was given a high-level overview of what the training would involve. Patients and their families shared examples of what helped them feel supported, and also what made them feel frightened and alone. Hearing directly from patients and their family members had a profound impact on staff members and supported the broader goal of cultivating a workplace of distinction by enabling delivery of high-quality, patient- and family-centred care.

**“A few kind words, a smile, a listening ear, these can all make a difference in turning a difficult hospital experience into a more positive one. We’ve heard that communicating with empathy is so important to our patients and their families, and we’re working to ensure that this is embedded in all of our interactions.”**

**MELANIE TREMBLAY,** Program Director, Humber River Hospital and Regional Director, Central Region, Ontario Renal Network

# Ontario Regional Renal Programs

## SOUTH WEST

### London Health Sciences Centre

As part of a person-centred care implementation strategy, leaders within the renal program at London Health Sciences Centre (LHSC) began working with staff and Patient and Family Advisors to identify vital behaviours. In order to properly communicate the principles of person-centred care, the team worked collaboratively to identify significant contact points between staff, patients and families that would provide the best opportunities for improving patient experience. For example, upon a visitor's arrival at the reception desk, it is important for the clerk to look up immediately, make eye contact and ask, "How can I help you today?"

Defining these vital behaviours has been a collaborative endeavour, bringing together staff members from across the program to reach a consensus and commit to realizing these behaviours. Patient and Family Advisors were integral, sharing stories and personal views on behaviours that made a real difference for them. This work has enabled staff members to develop a much better understanding of person-centred care principles, as well as the impact of working in partnership with patients. Staff will be held accountable for these behaviours, and it is the LHSC's expectation that they will be consistently enacted across the renal program.

"As I listened to staff share what they felt were crucial contact points with patients, I was given an opportunity to contribute my perspective as to whether I felt that was actually the case and hopefully they came up with a realistic set of behaviors to embrace."

**BONNIE F.** *Patient and Family Advisor, London Health Sciences Centre*

"Partnering with patients and having them at the centre of our discussions was a great way to understand the impact every one of us may have on a patient's journey. Even something as simple as helping a lost or wandering patient find their way helps to make their experience a positive one."

**DANIELA MARGHELLA.** *clerical staff member, London Health Sciences Centre*

# Ontario Regional Renal Programs

## HAMILTON

### Niagara Health System

Despite the fact that dialysis can require patients to be in a hospital several days a week, patients in the kidney care program at Niagara Health System (NHS) reported feeling isolated from one another, saying that noise pollution and the lack of physical proximity were barriers to interaction. These patients expressed an interest in making better connections with one another to strengthen their sense of community and feel more empowered in their decision-making.

Recognizing this opportunity for change, the NHS team launched an online community specifically for chronic kidney disease patients and their family members. A patient facilitator was engaged to moderate online chats and to work closely with the NHS project team, discussing ideas for service improvements and sharing news of relevant upcoming events and key pieces of information with community members. Given the current and widely shared focus on chronic disease management for community members, the project is providing valuable insight into the potential for extending this approach to other populations in the community requiring support to manage chronic conditions.

"My other social networks before this Kidney Care Online Community were places where I did not feel comfortable sharing my dialysis life freely. It was much too complicated to explain my struggles as a dialysis patient with my non-dialysis friends. When you are a dialysis patient, that part of you becomes a huge portion of your everyday life. For example: 'I had a rough long cold day stuck in that chair today,' other dialysis peers understand without an explanation".

**KIRSTEN E.**, *Patient Advisor*

"We are very excited to have this opportunity for partnering with our patients to provide support in this way. The possibilities are endless."

**CINDY BRYSON**, *Clinical Manager, Outpatient Kidney Care Program, St. Catharines Hospital*



