



Improving Ontario's Health System  
*through Patient and Family Engagement*



# Partnering for Success

A profound shift has taken place in our health system: we have gone from an approach where care is system or provider centred to one where care is centred around the patient and their family. Cancer Care Ontario (CCO), like most healthcare organizations, recognizes the importance of working with patients and families and engaging them in everything we do.

This report has been developed to demonstrate what patient and family engagement looks like, why it is important and the value we have seen so far. Over the past three years, CCO has committed to meeting our strategic priority in the Ontario Cancer Plan III (OCP III) to continue to assess and improve the patient experience. We asked ourselves whether patients can have an influence on the cancer and renal systems at a strategic level – the answer is yes, they can.

Since the launch of CCO's Patient and Family Advisory Council (PFAC) in 2010 with initial support of one of the first Patient Engagement Project grants from the Canadian Health Services Research Foundation (CHSRF, later renamed Canadian Foundation for Healthcare Improvement, CFHI), this group of engaged patients and family members has grown into a broader Patient and Family Advisor Community with representation from across the province.

For us, patient engagement is about building strong, sustainable partnerships between patients, family members, health professionals and community groups to plan, deliver and evaluate health services. We believe excellence in care requires more than just the best care in diagnosis and treatment; it also requires care that addresses every aspect of a patient's experience. As you will see in this report, increased patient engagement has already begun to result in greater value for patients and health system providers alike.

Our vision is to build the best health systems in the world. As you will see in this report, we have built a strong foundation for patient and family engagement in our work across the cancer spectrum, and as we look ahead, of equal importance, is our commitment to growing our engagement with patients and families experiencing chronic kidney disease.

We are moving forward, but there is still work to be done. By engaging in meaningful dialogue, together we can collectively design a health system that will result in better outcomes and increased patient and provider satisfaction.



*Michael Sherar*

**Michael Sherar**  
President and CEO  
Cancer Care Ontario



*Joanne MacPhail*

**Joanne MacPhail**  
Co-Chair, Patient  
and Family Advisory  
Council (PFAC)  
Cancer Care Ontario

.....  
**“We asked ourselves whether patients can have an influence on the cancer and renal systems at a strategic level – the answer is yes, they can.”**  
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# Setting the Stage: Person-Centred Care Strategy

Our goal is to partner with patients and healthcare providers to advance a person-centred approach to health.

Person-Centred Care is the evolution of patient-centred care. Our Patient and Family Advisors (PFAs) encouraged CCO to rename the strategic priority to signal to the system the importance of being treated as a person first, recognizing that patients are not defined by their disease. It recognizes that true high-quality care with direct impact to the patient experience requires a fundamental shift in our approach to healthcare.

In Ontario, there are a number of policy and legislative initiatives helping to drive this shift from a healthcare culture in which patients and their families are expected to fit into existing services and patients have little input into the design or delivery of the services they receive, to one that centres care on the healthcare and personal needs of the individual receiving the care.

## Strategic Focus

CCO identified Person-Centred Care as one of five areas of strategic focus in its new Corporate Strategy. By continuing to drive improvement through Person-Centred Care in the cancer and chronic kidney disease health systems, CCO committed to:

1. Actively partnering with Ontarians in identifying, designing, planning and improving healthcare services;

2. Developing and implementing programs and resources that drive the adoption of Person-Centred Care approaches to service delivery;

3. Embed expectations for evidence-based, person-centred, quality care into our performance improvement approaches.

## A Model of Person-Centred Care

The adoption of a model of Person-Centred Care requires a different conceptualization of how patients, those going through screening programs, family members, caregivers and providers are engaged with and work with healthcare providers. Person-Centred Care is an approach (Figure 1) to the planning, delivery and evaluation of healthcare that involves mutually beneficial partnerships between healthcare providers, patients and families to:

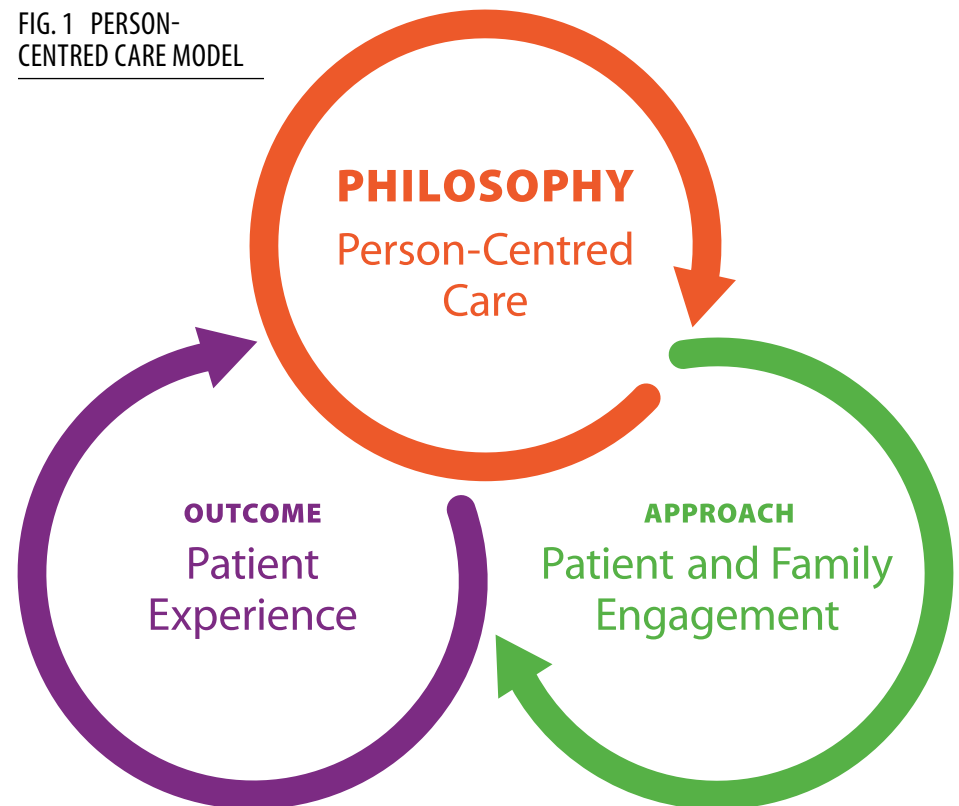
1. Give patients a voice in the design, delivery and evaluation of the care they receive; and
2. Enable patients to be more active in their care experience in order to deliver better outcomes and greater value through wiser use of resources.



Catherine  
Patient and Family Advisor

**“Patients are the experts in how they experience the disease. The members of the healthcare team are the experts in treating and managing the disease. There’s a role for both to play. Two parts can work together to make a better whole.”**

FIG. 1 PERSON-CENTRED CARE MODEL



# Our History: The Evolution *of Patient and Family Engagement at CCO*

**“Having patients as part of our work can be important in moving away from provider-centric decisions to ones that are inclusive of patient impressions and wishes. It allows us to consider the patient experience using real-life examples instead of assumptions of what patients want.”**

Sean Molloy,  
Program Manager, Symptom Management



# Charting Our Progress

Cancer Care Ontario's Patient and Family Advisory Council (PFAC) was founded under the direction of the Ontario Cancer Plan III in May 2011.

2010

## CANADIAN HEALTH SERVICES RESEARCH FOUNDATION GRANT

- **December 2010** Funding was received to support the development of CCO's PFAC

2011

## ONTARIO CANCER PLAN III LAUNCH

- **May 2011** CCO's PFAC was founded under the direction of the Ontario Cancer Plan III
- Strategic priority "continue to assess and improve the patient experience" includes a commitment to ensuring patients' interests are represented through "a forum to advise on initiatives to improve the patient experience"

## FIRST CCO PFAC MEETING/ORIENTATION/ STRATEGY DEVELOPMENT – MAY 2011

- **May 2011** 16 members from across the province gathered in Toronto to participate in the initiation of PFAC, learning about the process and developing the first set of priorities

2012

## EVIDENCE-BASED DESIGN (EBD) COLLABORATIVE EVENT

- **June 2012** Experience-Based Design (EBD) leaders from the United Kingdom National Health Service facilitated a two-day event where staff and PFAs from Regional Cancer Programs came together to launch an EBD training session for 200 people

2012

## PERSON-CENTRED CARE AS A CCO CORPORATE STRATEGY IS LAUNCHED

- **June 2012** Advancing Person-Centred Care is formally announced to CCO staff as the first strategic focus for the organization

## EXPANSION OF PFAC MEMBERSHIP

- **September 2012** Recruitment and orientation of 12 new PFAs to ensure adequate geographical representation on the Council

2013

## LAUNCH OF PFAC TOOLKIT

- **January 2013** Online toolkit launched for organizations to create their own PFACs based on lessons learned from CCO's experience

## CANCER QUALITY COUNCIL OF ONTARIO (CQCO) SIGNATURE EVENT: PATIENT EXPERIENCE PROGRAM FORMATIVE PROGRAMMATIC REVIEW

- **January–June 2013** Joint process with CQCO and the Patient Experience Program
- Literature review, environmental scan, internal and external stakeholder interviews
- Culminating in June retreat to create recommendations

## EXPANSION OF PFA COMMUNITY

- **September 2013** Recruitment and orientation of 25 new PFAs within the community to expand the ability to bring the patient and family voice to more tables at CCO

## CCO'S PERSON-CENTRED CARE ESTABLISHED

- **October 2013** Dedicated staff to enable Person-Centred Care practices at CCO are hired. The team sits under the Patient Experience Portfolio in Clinical Programs and Quality Initiatives

2014

## EXPANSION OF PFA COMMUNITY

- **February 2014** Expanded our PFA community with 15 new PFAs

## LAUNCH OF INTERNAL PERSON-CENTRED CARE CENTRE OF PRACTICE

- **March 2014** An internal online resource was launched to assist CCO programs with planning and implementing their patient and family engagement activities

## PCC CORPORATE INDICATORS ON SCORECARD

- **April 2014** Reporting to the CCO Executive Leadership on Patient and Family Engagement indicators that map to the strategic focus of Advancing Person-Centred Care to develop accountability within the organization and continue to grow its efforts in this area

## INAUGURAL CCO PATIENT AND FAMILY ENGAGEMENT REPORT

- **November 2014**

## ENABLERS OF OUR BEGINNING

This initiative began when CCO received one of the first Patient Engagement Project grants from Canadian Health Services Research Foundation (CHSRF, later renamed Canadian Foundation for Healthcare Improvement, CFHI). The research

grant was a co-design and partnership with University Health Network's Centre for Health Wellness and Cancer Survivorship. Regional Cancer Centre site coordinators assisted in the recruitment of members and facilitated

submissions to local Research Ethics Boards. In May 2011, PFAC members participated in a two-day orientation to the Council, their role and CCO's Patient Experience Program.

# Form Meets Function: Structuring Our PFAC

The purpose of CCO's PFAC is to create a forum where patients and family members provide insight into how to improve the quality of the patient and family experience. The PFAC advises CCO on the direction and content of current and future strategies and initiatives that directly impact those outlined in the Ontario Cancer Plan III.

**The scope of the PFAC is to provide partnership and advice relevant to and based on patient/family member/caregiver experience in order to:**

- improve the patient and family cancer care experience;
- develop the vision and scope of Person-Centred Care;
- generate areas of focus and priorities;
- advise on strategies for actively partnering with patients and families to design, plan and improve healthcare services (such as experience-based co-design);
- review evaluation methods to help define the measurement of system-level success.

**“Though some other organizations and hospitals have done great work in building successful PFACs, CCO has led the way in building a PFAC at the system level. We are the leaders in this space who other jurisdictions come to for advice when building their own PFACs. I feel enormous satisfaction about the leadership that we have provided in creating and sustaining a PFAC and in building a PFA community across the system.”**

**Esther Green**  
Co-Chair, PFAC and Provincial Head, Nursing and Psychosocial Oncology,  
Cancer Care Ontario

**The PFAC's membership is comprised of cancer patients with and living beyond cancer, family members, caregivers of patients and CCO staff:**

- a minimum of two representatives from each of the 14 Regional Cancer Programs across Ontario;
- CCO's PFAC is jointly co-chaired by a Clinical Leader, currently CCO's Provincial Head of Nursing and Psychosocial Oncology, and a PFA;
- a PFAC administrative team that supports the PFAC functions: PFA Engagement Specialist and the Person-Centred Care Senior Manager;
- other members of PFAC from CCO include: Directors, Communications staff and one Vice-President. The number of CCO staff is fewer than the number of PFAC members, emphasizing the value of patient and family engagement and partnership.

**“We, the patients, along with our families, are the ‘Face of Cancer’... We have a story to tell and share. If you think of this partnership for just one moment – with the people who have the knowledge, research and training, plus the patients and their families who have experienced or are experiencing the cancer journey – the care can only get better and better. This is our hope and this is our passion.”**

**Joanne**  
PFAC Member

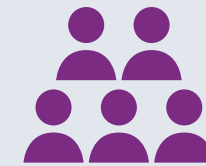
## ELEMENTS OF PFAC

**3**  
years

The term for a PFAC member is three years

**28**  
members

From each of the 14 Ontario Regions



**NEW**



**EXPERIENCED**

CCO is constantly striving for new and experienced members representing the diversity of Ontarians to maintain a balance of family and patient experience



Interview with at least one of the co-chairs to confirm areas of interest

Selection of new members is conducted by a formal recruitment process through the Regional Cancer Programs, and includes a Call for Participation, completion of an application outlining interest and experience, and an interview with at least one of the co-chairs to confirm areas of interest. New PFAC members are approved by the PFAC co-chairs.

# What is the PFAC Toolkit?

## A Toolkit for Building a PFAC

The CHSRF grant and collaboration culminated in the development of the PFAC Toolkit. This toolkit provides support for the development and growth of PFACs throughout Ontario and within the Regional Cancer Programs. It is intended to provide organizations in Ontario and beyond with a structured approach to engaging patients and their families in order to improve services and the overall patient experience.

The PFAC toolkit contains samples, templates, and multimedia tools to foster information sharing, increased participation and effective learning. The toolkit can be found online at:

[www.cancercare.on.ca/toolbox/pfac](http://www.cancercare.on.ca/toolbox/pfac)





ONLINE PFAC TOOLKIT  
CONTENT USAGE

**The PFAC toolkit outlines content that includes:**

- key lessons learned from CCO's PFAC and the Patient Engagement Project grant;
- published research on engaging patients and families in advisory councils;
- discussions with leaders of existing councils as well as organizations focused on Person-Centred Care.

**“CCO’s PFAC toolkit was the foundation document which allowed us to quickly and confidently move forward with establishing the key aspects of our own PFAC.”**

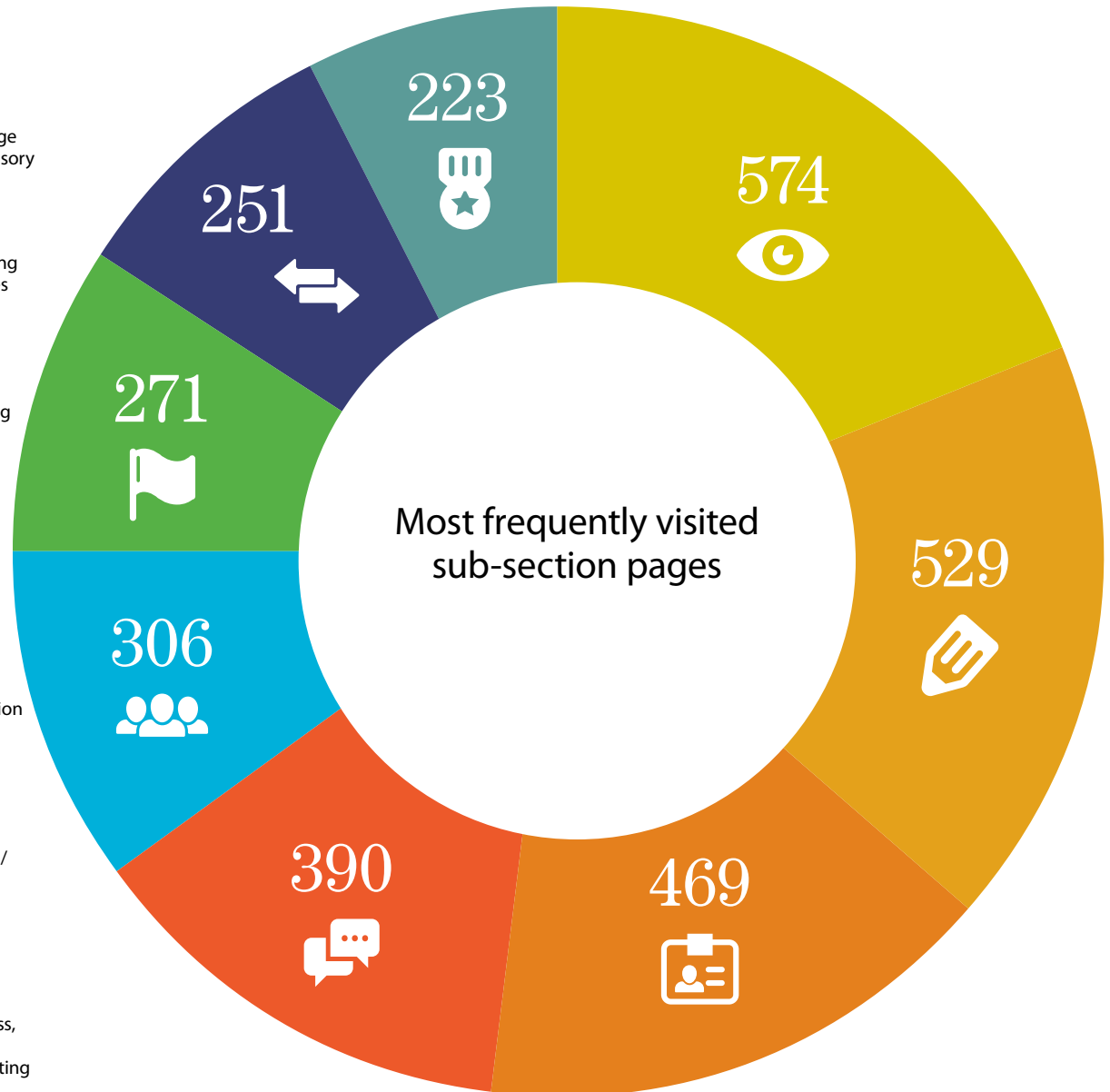
**Janet Ellis, MD, FRCPC**  
Regional Lead Toronto Central North LHIN  
Psychosocial Oncology, Sunnybrook Health Sciences Centre

**Tamara Harth**  
Program Manager and Regional Lead Toronto Central North LHIN, Patient Education,  
Sunnybrook Health Sciences Centre

**10,265**  
unique page views

**2,000**  
unique page views  
every quarter

-  **Contemplate**  
Preparing to engage patients in an Advisory Council
-  **Plan**  
PFAC creation planning – assigning tasks and resources
-  **Recruit**  
Council size and makeup, recruitment process – soliciting and collecting nominations
-  **Communicate**  
Verbal and written communications with council members
-  **Logistics**  
Hosting considerations (travel, meals), meeting preparation and technology support
-  **Form**  
Meeting other council members, training/ preparation
-  **Facilitate**  
Council meetings and interactions
-  **Sustain**  
Reflection, progress, recognition, mentorship, reporting



## MEETING FORMAT



Over the past three years, the total number of hours served by PFAC members during Council meetings was 1,606. In January 2014, due to increased demand for PFAC's engagement in the work at the system level, the meeting frequency increased to monthly, using alternating formats to

maximize attendance and convenience for members – a cycle of one-hour teleconferences, three-hour videoconferences and one full-day in-person meeting.



**1 hour**  
monthly  
teleconferences



**3 hours**  
quarterly video  
conferences



**1 day**  
bi-annual  
in-person meetings

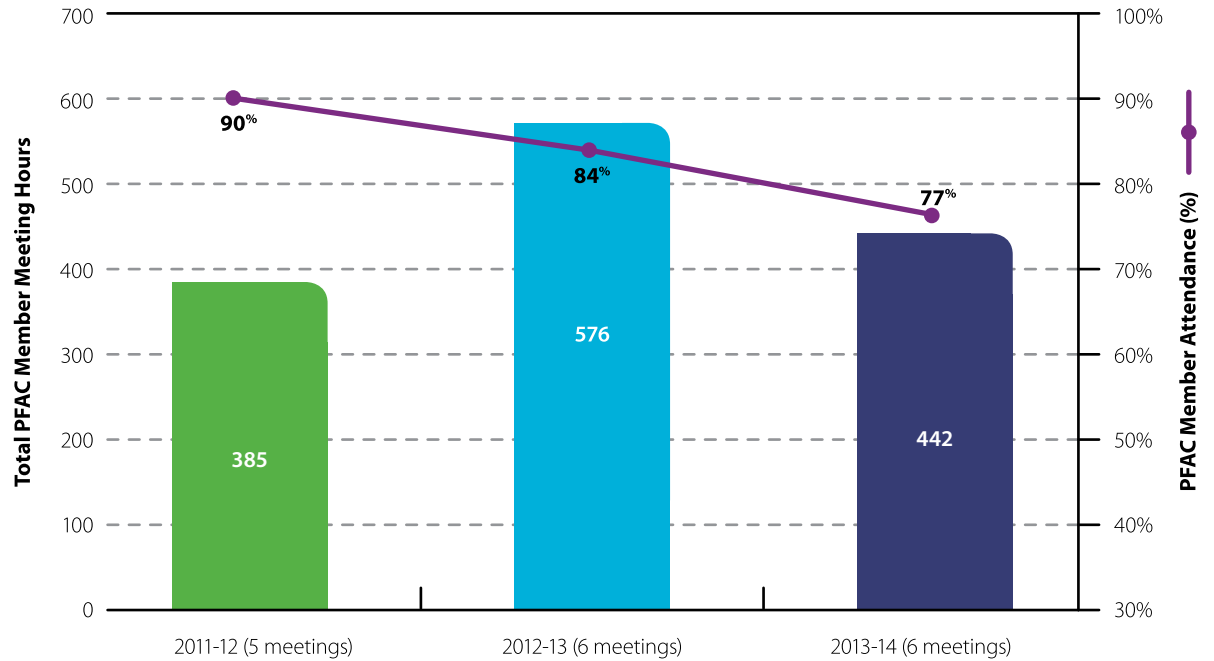


Patricia  
PFAC Member

**“I think the establishment of the PFAC is one of the most important things leading to the best cancer system in the world, and that is because patient and family voices are listened to and heard. The support of the CCO staff is paramount in this and is never lacking. This is not a token move on the part of CCO because we are able to see the differences this Council is helping to make.”**

# PFAC Meetings

FIG. 3 PFAC MEETINGS: HOURS AND ATTENDANCE



## PFAC QUICK STATS 2011/12–2013/14

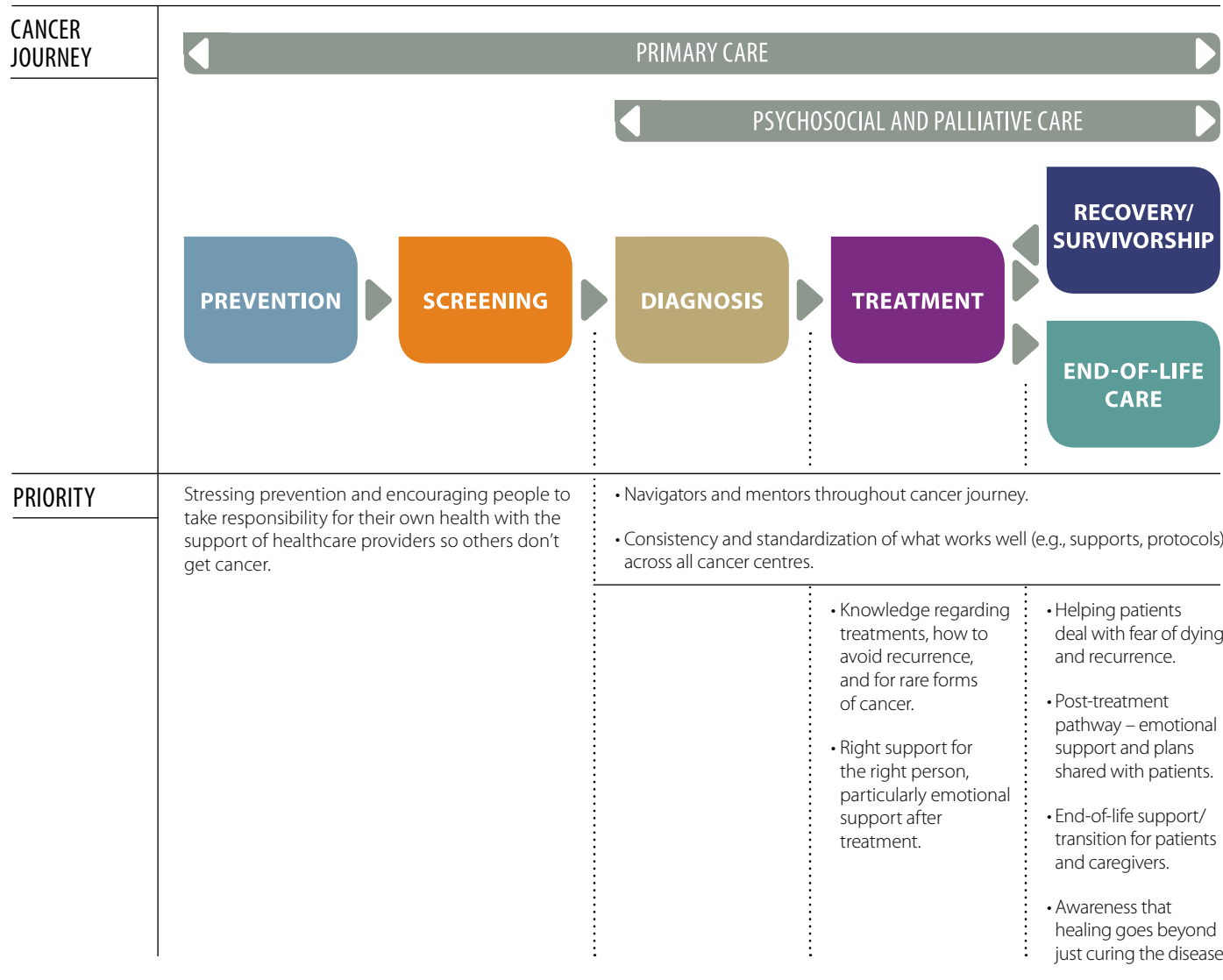
**3** orientations

**17** PFAC meetings

**75%+** attendance

**1,606** total number of hours served by PFAC members (as of March 31, 2014)

# Setting the Agenda: Patient and Family Advisory Council Priorities



**Anya**  
PFAC Member

**“If patients were connected at diagnosis to palliative care – which means relieving suffering, not necessarily facing death – then they and their families would get the benefit of this support throughout their illness. We all need that. We need the attention, the relief, the connection and the continuity of dealing with people who understand the consequences of cancer, who will stay with us from the shock at the beginning through the whole process, regardless of the prognosis.”**



**Pat**  
PFAC Member

**“For me, PFAC membership has meant listening to others who have experienced the cancer continuum and learning from them with the hope that we will make a difference in the delivery of care for patients and their families in the future.”**

Since the beginning, PFAC members have been engaged to provide direction on priority areas of focus. The PFAC's priorities identify key healthcare elements, such as emotional support, coordination of care and navigation during all phases of the cancer journey.

# Partnering with CCO Programs

At CCO, our goal is to partner with PFAC and collaborate with the membership in a significant and impactful capacity that goes far beyond information-sharing, soliciting feedback and potentially integrating their input into our work.

**To monitor and evaluate the nature and quality of PFAC engagement activities, CCO uses a spectrum of engagement to qualify each activity that is presented to the Council.**

The spectrum of engagement is adapted from Health Canada and IAP2 to categorize engagement activities at one of the following four levels:

- Level 1: Informing;
- Level 2: Consulting;
- Level 3: Engaging;
- Level 4: Partnering.

In the graphs to the right we have captured the level of engagement of each activity and opportunity presented to the PFAC since it was established, and have displayed this data first by level of engagement within fiscal years (Figure 4). Figure 4 presents a slightly skewed impression of the growth and movement of PFAC engagement activities because the number of meetings and therefore activities varies each year. However, the growth of PFAC in terms of the total number

of engagement activities is underway. Though gradual, there is a clear increase in the number of PFAC activities that are at a Level 4 (Partnering) in terms of engagement. Figure 5 shows the proportion of all 86 agenda topics, where more than a quarter (28%) were in the higher end of the engagement spectrum (Engaging or Partnering).

The nature of PFAC engagement activities has evolved over the years since the Council was established. In 2011/2012, engagement activities that involved Engaging (Level 3) or Partnering (Level 4) with PFAC were smaller in scale and project-specific, such as engaging with the Disease Pathway Management Program staff to build and propose sample patient-friendly pathway maps for particular disease sites.

FIG. 4 NUMBER OF EACH TYPE OF PFAC ENGAGEMENT ACTIVITY WITHIN FISCAL YEARS

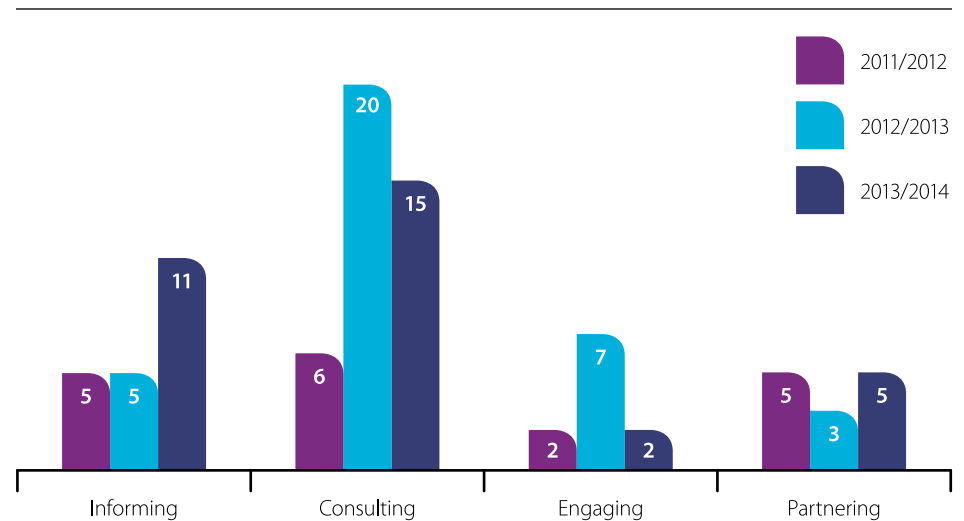
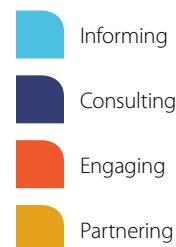


FIG. 5 DISTRIBUTION OF EACH TYPE OF PFAC ENGAGEMENT ACTIVITY ACROSS FISCAL YEARS

- 2011/12 to 2013/14
- 17 meetings
- 86 agenda topics



# PFAC Impact

A debriefing interview is conducted with each CCO program member or other individuals after they have made a presentation to the PFAC. These interviews help us understand and articulate the impact of their experience with the PFAC. Understanding the effects of PFAC feedback in the transformation of healthcare design, delivery and evaluation is invaluable in measuring patient and family engagement at the system level.

## The following questions were posed in the interviews:

1. How did you incorporate the input/ feedback received from the PFAC?
2. Have those interactions changed the course of your work?
3. How would you describe the value of having the PFAC input into your work?

The responses were grouped by impact into three areas: Integration, Work Impact and Added Value.

### Integration

- including PFAs as members of program committees or groups or on interview panels;
- changing how we communicate about our work, both internally and externally;
- increasing collaboration and interaction between patients, families, clinicians and the system;
- incorporating the voices of patients into our work;
- 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 the patient experience and Person-Centred Care;
- identifying areas that require clarification and context.

### Added Value

- raising awareness of the priorities of patients and their families;
- putting a face on the work that we do and increasing its meaningfulness;
- affirming and/or deepening our understanding of patients' experiences and needs;
- increasing our credibility with external stakeholders by including PFAC input;
- providing an opportunity to talk to patients and understand their experiences.



Subi  
PFAC Member

**“If our healthcare system is designed for the patients and the caregivers, then it is imperative that the voice of the patient be heard. CCO staff can gain tremendous insights from the patients’ stories. These insights can help them identify specific opportunities to improve the health system and enhance the patient and caregiver experience.”**

**“Because we don’t work directly with patients in front-line care, it’s an amazing thing to hear their voices at the table. Instead of just wondering what patients want, we get to ask. It changes the conversation in a really positive way.”**

Junell D’Souza  
Planning Officer, Cancer Planning and Regional Programs

# The Community *of Patient and Family Advisors* (PFAs)

**“I hope my work as a PFA will bring awareness of the significant value of our cancer experiences to the development and delivery of cancer services. It is exciting to watch service providers embrace the patient and/or caregiver as a valued resource and to improve healthcare delivery with this in mind.”**

Janet, PFAC Member



# Growing the Community of PFAs

In addition to the current PFAC membership, CCO has grown to include 33 volunteer PFAs from across the province of Ontario. PFAs provide a valuable contribution to CCO's programs and initiatives.

Figure 6 illustrates the increase in PFAs from 2011 to 2014.

**As part of a structured orientation session, a PFA Orientation Manual with PFA guiding principles and specific role descriptions for both PFAC and PFA members has been created.**

- Our PFAs have found these orientation sessions very valuable: *"I feel like all of my questions were answered and feel ready to contribute as a PFA."*
- The need for guidance on how to articulate each PFA's unique experience in the healthcare system in order to translate it into making broad system change was highlighted. As part of the orientation, a skill-building session, complete with worksheets, was developed on "How to tell your story with impact."

FIG. 6 THE GROWTH OF THE PFA COMMUNITY

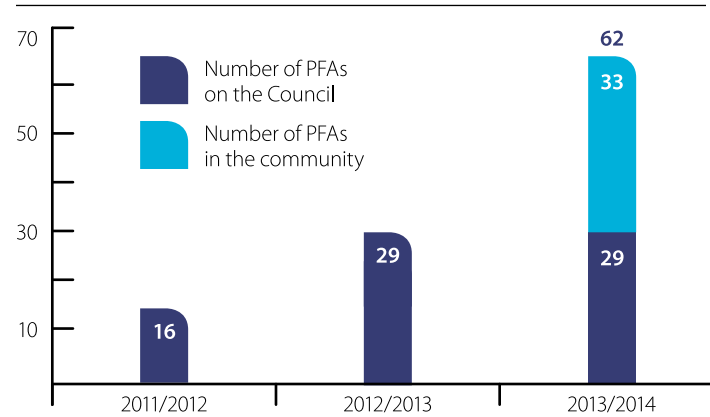
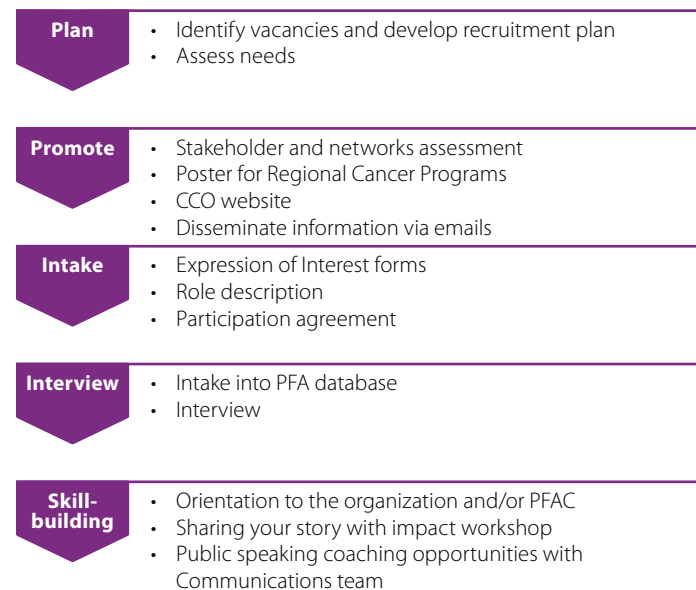
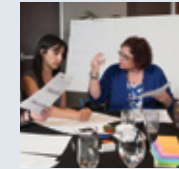


FIG. 7 RECRUITMENT AND ONBOARDING PROCESS

CCO has adopted a five-step process for successful recruitment and onboarding of PFAs.



## ROLE OF PFAs



As active participants in the cancer system, patients and families provide unique perspectives and valuable feedback on the standard of care they receive. Their insight and experience helps to inform programs and practices aimed at improving the patient experience and advancing Person-Centred Care.

PFAs are individuals with experience in the Ontario cancer system who partner with staff to provide direct input into policies, programs and practices that affect patient care and services.

### PFAs bring value to our work by:

- Sharing personal cancer care experiences in a variety of media (e.g., video, prose) and forums (e.g., CCO meetings, interview panels);
- Vocalizing and providing insight into patient interests, needs and backgrounds beyond their own experience (where possible);
- Providing input and making recommendations based on their experience of the Ontario cancer system; and
- Assisting with achieving clarity about the discussion topics and meeting objectives.

**"I was lucky to be one of the first PFAs because we all learned our roles together. As members of a Systemic Treatment Provincial Plan Working Group, medical professionals, CCO staff and PFAs all sat around the table trying to figure out how to make cancer treatment better in Ontario."**

**Donna**  
Patient and Family Advisor

## Growing *the Culture* at CCO

**“If you have the opportunity to engage PFAs in your work, I would say do it. It’s a great experience and you meet wonderful people along the way. It’s not often that you get the opportunity in other organizations to work so closely with patients and family members on projects. In my experience I have found their input to be extremely valuable in moving our program initiatives forward. It’s their perspectives that ground our work and give it meaning.”**

Wenonah Mahase  
Project Lead, Symptom Management





# Key Highlights of Patient and Family Engagement

## Diagnostic Assessment Program (DAP) Strategic Planning

As a member of a working group for the Diagnostic Assessment Program (DAP) strategic plan entitled Navigating the Diagnostic Phase of Cancer: Ontario's Strategic Directions 2014–2018, PFA Debora provided ongoing advice and direction on the strategic priorities and objectives, as well as reviewing the draft of the strategic document. Strategic directions were also sought from CCO's PFAC to seek broader feedback. This ensured patient needs would be addressed in the diagnostic phase by delivering on the strategy. It also helped to present the plan in a manner that would resonate with patients.

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**“Without their feedback, we would not have been able to address the challenging issue of sharing patient results during the diagnostic phase in an actionable manner that meets the needs of all stakeholders.”**

Melissa Kaan,  
Manager, Diagnostic Assessment Program

## Survivorship Program

The involvement of seven PFAs in the development of the care pathway was essential to the creation of the Survivorship Program's Colorectal Cancer Follow-Up Care Patient-Friendly Pathway – a resource developed based on identifying the needs of patients. Applying the Experience-Based Design approach (EBD) helped us understand the patient experience and we used this information as a basis for re-designing services. Three workshops were conducted over the course of five months where information was collected from participants, in addition to teleconferences to validate the feedback and work through a draft document with participants. In partnership with other healthcare professionals such as primary care physicians, nurses, patient education representatives, oncologists and administrators, a truly collaborative resource is now in use within the Regional Cancer Programs for patients who are transitioning to primary care providers for their ongoing follow-up care.

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**“The end product demonstrates the value of inviting the patient to tell their story, capturing that story and sharing it with others. Thanks to the patients, family members and caregivers who were involved in this work, we now have a meaningful resource to guide cancer survivors through the follow-up phase of the cancer journey.”**

Maria Grant  
Program Manager, Survivorship

## A TOOLKIT FOR ENABLING PFA ENGAGEMENT



**The CCO Patient Engagement toolkit is designed to provide CCO staff with:**

- A simple step-by-step approach to patient engagement at CCO;
- An understanding of the roles and responsibilities in the patient engagement process; and
- Tools, guides, forms and templates to assist in planning and implementing patient engagement activities at CCO.

## FIVE-STEP APPROACH FOR CCO STAFF



Learn how engagement is relevant.



Identify your engagement approach and needs.



Get everyone on the same page before working together.



Establish communication ground rules.



Measure your success in partnership.

## Symptom Management Program

There are two major initiatives with PFA involvement: the Ontario Cancer Symptom Management Collaborative (OCSMC) and the Patient Reported Outcomes (PROs) Advisory Committee.

Within OCSMC, there are five patients included on the provincial team that is made up of representatives from each of the 14 regions. Members of this collaborative share ideas on how to improve symptom management and it is important to have patients at the table with us in this work. In addition, patients are now included in sub-initiatives of this work including our Chart Audit Working Group, Patient Satisfaction Survey Working Group, the Symptom Management Summit Planning Committee, the ISAAC User Group and in contributing to conference and journal abstract submissions.

There are four PFAs as part of the Patient Reported Outcomes Advisory Group, who meet with CCO on a quarterly basis to move forward our work related to PROs. PFAs in this group have also become involved with CCO's CPAC grant related to PROs, which has three PFAs involved and on our EPIC prostate cancer project, which has two PFAs involved. PFAs have also contributed to abstracts and journal submissions on this work.

The Symptom Management Program promotes the use of standardized tools that allow patients to self-report their symptom information and treatment effects to improve communication with their care providers and enable the system to measure what patients are experiencing throughout their cancer journey. The essence of the work is extremely patient-centric and it is important that we include PFAs in the design of our work to ensure their views and input guide decisions made regarding practice.

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**“All of us want to do the best we can for our patients, but sometimes culture and resistance to change can be difficult to overcome. The PFAC has provided direct input into symptom management. This support is invaluable as we work to improve the quality and consistency of symptom management for all patients across the care journey.”**

Sean Molloy  
Program Manager,  
Symptom Management

.....  
Involving patients in decisions made regarding symptom management and the ways in which we strive to improve in these areas is essential so that our work matches the needs of patients and their families. It is a completely natural fit for our work and to not engage patients with us is not an option we are willing to consider.

PFAs have been with us on calls, at in-person meetings, at face-to-face workshops and conferences, as part of working groups, committees and planning groups, at the table when decisions are made, contributed to abstracts and conference submissions, developed terms of reference, contributed to funding deliverable outputs like chart audits and satisfaction surveys and have been included in strategic planning. They are completely involved in all of our work.

Having patients, caregivers and family members involved as partners in our work has been very rewarding for our team. Their eagerness and willingness to contribute to our improvement initiatives gives our team energy and helps us to succeed. I have heard of some resistance to this, but when we view patients as customers or clients in healthcare, how can we not want them involved to tell us what works and what does not? It is what every business in the world does and should become a standard way of operating in healthcare so that all of our work meets the needs of patients and drives improvement in the areas that are most important to them. This involvement is now routine, and our program is much improved because of it.



PFAC members at a Council meeting

## Interview Panels

In 2013, CCO programs began engaging PFAs to be a part of the hiring process by participating in interview panels for key leadership positions, including Vice-President of Clinical Programs and Quality Initiatives and Vice-President of Analytics and Informatics. Through their participation, the PFAs changed the conversation and asked the tough questions important to patients to ensure that CCO is hiring individuals whose vision and conduct are in alignment with our Person-Centred Care principles.

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**“Most people would say the cancer journey is a difficult one, but the silver lining is the opportunity to share this journey with those who are able to effect change in the cancer system. I believe that there is something good coming from a very difficult time.”**

Janet  
PFAC Member



## INTEGRATE Project

The INTEGRATE project focuses on implementing models for early identification of patients who can benefit from a palliative care approach in the primary care and cancer centre setting. Planning for the project implementation was set for October 2014, with the guidance and support of working groups and a steering committee composed of clinicians, administrative staff and PFAs.

PFAs have been engaged in defining the integrated models for each setting (primary care and cancer centre) through working groups and consultations. The PFAs have provided invaluable perspective to the project team and working groups, ensuring that the patient and family voice is

central in how we develop, implement and evaluate the project. Four PFAs participate in the INTEGRATE project through involvement in the following monthly groups: Provider Education, Primary Care Model, Cancer Centre Model and INTEGRATE steering committee. A total of 20 meetings have been conducted through in-person and teleconference engagement. PFAs have also attended pre-meetings before each meeting.

PFA involvement has allowed a patient perspective to be incorporated into the design of the integrated models. The PFA perspective has also provided clinicians and administrative staff on the working groups with a common understanding of patient and family needs and desires for implementing palliative care as well as reinforcing

the importance and value of having PFAs participate in this level of planning. One PFA shared her story with the steering committee, which helped to focus the group on the system changes that need to be made through the INTEGRATE project.

## The Disease Pathway Management Program

The Disease Pathway Management Program worked with members of the PFAC to draft patient-friendly pathways for particular disease sites. Their contributions led to the creation and publication of three patient-friendly pathways:

- Lung Cancer Diagnosis Patient Pathway
- Colorectal Cancer Screening and Diagnosis Pathway
- Colorectal Cancer Follow-up Care Pathway

These pathways are now available on CCO's website, and embedded in the Diagnostic Assessment Program's (DAP) Electronic Pathway Solution (EPS), at participating Regional Cancer Programs. The DAP-EPS is a web-based tool that connects patients, their families and healthcare providers during the diagnosis or rule-out of cancer, in addition to Patient Educators and DAP Navigators. Because of the positive experience with the PFAC, we've decided to include PFAs as members of our upcoming pathway working

groups and also on hiring panels for new clinical leaders. Patients and families are among our key audiences, so it is very important to keep them involved and present them with opportunities to make meaningful contributions.



The Patient Friendly Pathways are available on CCO's website at [www.cancercare.on.ca](http://www.cancercare.on.ca)

## Highlights of PFAs as Partners

The following are examples of events that were enriched by having PFAs in attendance as active participants:

**Models of Care:** A one-day meeting was held to determine how to extract the best value from nursing resources in healthcare. During this event, PFAs collaborated with administrators, clinicians and other healthcare staff in order to identify ways to maximize the efficiency of oncology nurses in meeting patients' needs. Different models of care pertaining to oncology nurses were brainstormed and discussed.

**Psychosocial Oncology (PSO) Meeting:** This in-person meeting served as a networking and relationship-building tool for the leaders in the Psychosocial Oncology department. During the event, various provincial PSO-related initiatives were discussed, followed by potential solutions to regional challenges.



Brad  
PFAC Member

.....  
"It has become evident to me that patients have become key stakeholders for CCO."  
.....

### Symptom Management Idea Lab:

The purpose of this event was to co-create symptom management improvement ideas with regional representatives, clinicians and PFAs. Key areas of opportunities and barriers to symptom management were discussed. Over 60 individuals participated in the event, eight of whom were PFAs. Together, participants engaged in activities that required collaboration and resulted in final deliverables that were presented to the whole room.

### Improving Patient Experience and Health Outcomes Collaborative Stakeholder Engagement meeting (funded by Canadian Partnership Against Cancer):

The purpose of this event was to foster engagement of the healthcare and patient community in striving for quality care through Patient-Reported Outcomes (PRO) measurements. Clinicians, administrators and PFAs from Ontario and Quebec collaborated in order to develop project plans for the implementation of PRO measures and evaluation metrics. This event included participation and experience sharing by the PFAs.



PFAC members at work

**Oral Chemo Think Tank:** This think tank event involved provincial and Canadian experts speaking on take-home cancer drug funding and drug delivery system design with the objective of orienting CCO's partners and stakeholders to the larger challenges with the existing model and to explore possible program and policy opportunities to enhance the safety, quality and equity of the entire system. The objective of the day was to identify opportunities, challenges, risks and costs of changes to the current framework. Recommendations that emerged from this event were used to inform CCO's guidance to the Ministry on this important issue.

**AGM:** CCO's AGM event is a way to engage our stakeholders in an educational session that celebrates what has been accomplished in the past year and looks forward to the next year. The 2014 AGM theme was Health System Transformation. CCO's President and CEO Michael Sherar highlighted key accomplishments of the past year through the lens of CCO's transformation over the past 10 years, and detailed how CCO's accomplishments link to, and support, the provincial government's transformation agenda as set out in the Action Plan for Health. The co-chair of CCO's PFAC, Joanne MacPhail, shared her personal experience in the system and provided examples of how patients like her and caregivers province-wide are assisting CCO in improving the patient experience by lending their voices to help transform the health system.



A real example of engaging patients took place at the Screening Town Hall in December 2013, when a PFA was asked to speak and share her story. In soliciting feedback from her peers afterward, Kathi comments, "In response to my question, 'what did you think of the patient that presented?', the most frequently used words, 'powerful', 'affirming of our work', 'grounding', and 'very emotional,' were used over and over again. In fact, the only criticism I heard was that a couple of people would have liked to have known so that they could have packed some Kleenex."

Kathi Carroll  
Senior Manager, Primary Care Centre of Practice

# Evaluation

**"I have the opportunity to be a partner with CCO in their quest for continuous improvement. Rather than being a vociferous critic of the system, I want to be a passionate contributor of solutions."**

Subi, PFAC Member



# Measuring Success

CCO has learned the importance of capturing both quantitative and qualitative feedback on the benefits of partnering with PFAs.

## How are we doing this?

Data on advancing Person-Centred Care is collected quarterly and reported on the Corporate Balanced Scorecard. Currently, two indicators are reported that speak to the growth of the PFA community at CCO, and also capture the extent to which our patients and families feel actively engaged in shared decision-making. In early 2014, the Person-Centred Care program launched a new survey tool to collect feedback from PFAs who are engaged in program work at CCO. Respondents are asked a number of questions regarding the CCO program they are involved with, and if they feel they are truly being engaged at a partnership level.

## KEY MEASUREMENTS

**71%** agree or strongly agree that they are being engaged at a shared decision level

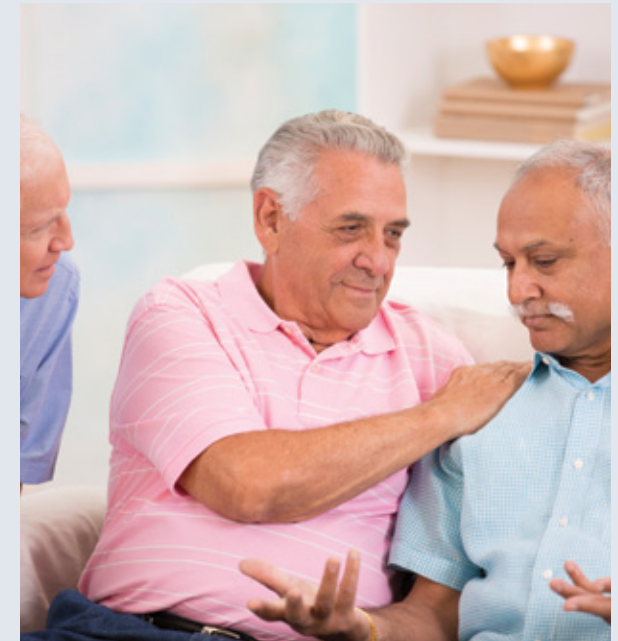
**138** instances of PFA engagement as of March 2014

**“I believe CCO is trailblazing in terms of patient and family involvement and engagement.”**

**Brian**  
PFAC Member

**“The benefit to me was bringing the patient perspective and voice to this important work. I believe with my input the focus became improving a variety of patient needs in the diagnostic phase. Overcoming the stress and the difficulty of navigating the system became top objectives. With the completion of the plan, I am confident that the difficulties have been addressed.”**

**Debora**, PFAC Member



# Key Lessons Learned

Since embarking on this journey in 2010, there have been a lot of learnings. CCO staff regularly gather insights from staff and PFAs to better understand how partnerships with patients and families can be improved.

Whereas some of these elements are widely recognized, others may reflect CCO's particular experience. Aside from logistical elements, organizations can build upon these foundational elements in order to facilitate setting up and working with a PFAC.

Patient stories are an essential success factor in highlighting PFAC's contribution to CCO's work. CCO has made a commitment to present patient stories across the organization. These stories are highlighted through videos, quotes and through the presence and work of our PFAs.

**1 Start with stories:** Patient stories have benefited CCO in a variety of ways. Patient stories provide CCO members with a deeper, clearer, more personal and meaningful insight into CCO's goal of improving the experience of patients and families affected by cancer. Patient stories provide an intrinsically human perspective to the healthcare system, contributing a wealth of personal evidence that can be utilized to plan for effective health services and foster patient healing. Lastly, stories remind us that patients are people, who want to be listened to and contribute meaningfully to their own recovery. Staff need to share their stories as well to level the playing field.

**2 Define what is in and out of scope:** Carefully defining the scope of the council's influence and decision-making is required. As advisors, the members serve the function of reviewing, engaging, collaborating and offering perspective that then needs to be taken into consideration for system change. However, decisions such as running programs, and, determining where resources are to be committed, are not the responsibility of PFAs; these are operational decisions.

**3 Visioning exercise with leadership in collaboration with PFAs:** Identify who your stakeholders are and get to the 'why' of bringing the Person-Centred Care philosophy to bear on organizational culture and operational decisions.

**4 Sustainability:** Making arrangements for reflections and lessons-learned conversations ensures building a sound evaluation strategy to demonstrate impact.

**5 Engage advisors early:** Advisors appreciate being engaged early on in a project before the decisions have been made. The engagement is more authentic and less likely to be seen as tokenism.

**6 Actively pursue advisors with different perspectives:** Diversity is important to foster a variety of perspectives and inputs. One size doesn't fit all. In addition, councils tend to attract similar people so it is important to think about engaging those who are hard to reach through other means.

**7 Orientation to the organization,** in terms of what it does and how it works, is critical. Without this solid understanding, the PFAs are not able to contribute effectively. This is especially important when working with an organization like CCO that is not a traditional service provider.

**8 Evaluate:** Use a continuous improvement approach to processes and ask yourself and your PFAs, "How can we do this better together?"

**9 Understand and appreciate organizational culture change:** Patients and families change the conversation. Many care providers are uncomfortable working with them in the room. Providers are used to the traditional clinician/patient relationship but not this new model. People need to be supported and oriented.

**10 Just do it!**



# Looking Forward

Over the past three years, CCO's patient and family engagement strategy has evolved into a corporate culture of truly partnering with PFAs in the design, delivery and evaluation of the healthcare system. As we have developed the strategic approach to partnering with PFAs within CCO, looking forward, our focus is on enabling Cancer Care Ontario, including the Ontario Renal Network, Access to Care and the Regional Cancer Programs to adopt a Person-Centred Care approach to care design, delivery and evaluation.

## THANK YOU FROM CCO STAFF

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To our Patient and Family Advisors, we cannot thank you enough for the time, energy, dedication, and commitment you continue to demonstrate in moving our healthcare system toward delivering Person-Centred Care. You have grown with us, learned alongside us and shared insights with us that only you can share. Your value is immeasurable and your generosity with your time is boundless. The staff at CCO could not do what they do without you and the perspective that you bring to the table as a partner with inside knowledge of what it is to traverse this complex system. The revisiting of emotional times and places you have experienced can be difficult, but you have done this willingly in order to improve the health experiences of others.

With sincere gratitude,  
All of the staff at Cancer Care Ontario

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**“On behalf of the patients I hope I am representing as they would wish, I thank the CCO staff for that support and for listening to patient and family voices.”**

**Patricia**  
PFAC Member

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# How You Can Get Involved

To learn more about becoming a Patient and Family Advisor with Cancer Care Ontario, please visit:

[www.cancercare.on.ca](http://www.cancercare.on.ca)

Alternatively, contact the Person-Centred Care team to learn more:

## Person-Centred Care Program

Cancer Care Ontario

620 University Ave.

Toronto, ON M5G 2L7

t. 416.971.9800

e. [patientfamilyadvisors@cancercare.on.ca](mailto:patientfamilyadvisors@cancercare.on.ca)



# What it Means to PFAs to be Engaged

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**“For me, being a PFA means that I am able to give back to the system that saved my life and hopefully provide input that can create change to improve the cancer journey for future patients.”**

**Tracy**  
PFAC Member

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**“Losing both my husband and a son to cancer, I sometimes saw a wonderful system with good intentions completely missing the mark. It’s clear to me now that the only way to fix that is to involve the people who receive the services. I hope that sharing my family’s experience and collaborating with policy makers will not only make things better for the next person, but will also help to establish a pattern in which patients and families are permanent partners in the design and delivery of healthcare.”**

**Anya**  
PFAC Member

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**“Becoming a PFAC member affords me the opportunity to bring my voice and that of my community back to CCO, which has the power to drive change for the patients and their families.”**

**Sandy**  
PFAC Member

**Left:** PFAC members driving priorities for the province

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**“During a time when I was giving up, being a Patient and Family Advisor restored my faith in the healthcare system. Working together and listening to each other helps make the changes that will benefit everyone. It’s the future of healthcare.”**

Lillian  
PFAC Member

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