



# Engaging Patient and Family Advisors in Health-Care System Planning: Experiences and Recommendations

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## Abstract

**Background:** Patient and family advisors (PFAs) contributed to the development of the Ontario Cancer Plan IV (OCP IV), a 4-year strategic plan for Ontario, Canada's cancer system produced by Cancer Care Ontario. **Objective:** To understand the barriers and facilitators PFAs experience when they are engaged in health-care system planning and provide recommendations for future engagement. **Method:** Patient and family advisors who had an ongoing involvement in the development of the OCP IV were invited to take part in an interview. Qualitative data were analyzed for emergent themes and recommendations were generated. **Results:** Key emergent themes highlighted necessary elements for effective engagement of PFAs. These included rapport (feeling valued, included as an equal and having supportive interpersonal relationships), communication (clarity and transparency, shared language and understanding, feeling heard, and effective teleconferencing), and leadership (from PFAs and staff). Recommendations for optimizing PFA engagement in health-care system planning were generated. **Conclusion:** Patient and family advisors can be effectively engaged in system-level strategic planning by building reciprocal rapport, effective communication, and strong leadership. Notably, developing "systems literacy" in PFAs is key to ensuring the voices of patients and their families are heard and reflected in health-care system plans.

## Keywords

patient engagement, patient and family advisors, health-care system planning, quality improvement

## Background

Engaging patients and their families in health-care improvement has been increasing across many jurisdictions (1,2). Patient engagement in quality improvement and system redesign has led to initiatives that have improved care, processes, outcomes, and patient experience measures (3). However, rigorous evaluation to establish the unique contribution of patient engagement in terms of its utility, cost-effectiveness, and impact is scant (1,2,4,5). Whether or not engaging patients and families results in measureable improvements to health care, it is desirable in that it represents patient-centredness in health-care design (2,4,6). It also provides the unique perspective that only patients and their caregivers can provide. As a result, establishing best practices for engaging with patients and families is important to ensure that these engagements are mutually beneficial (7,8). A recent review reports key factors for patient engagement in the design, delivery, and evaluation of health services. These factors relate to how the engagement

was undertaken/designed, how participants were recruited and then involved in the engagement, the presence of a receptive context, and leadership involvement (9).

Cancer Care Ontario (CCO), the cancer advisor to the Government of Ontario in Canada, directs and oversees \$1.5 billion in spending within a single-payer health

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system. As a strategic priority, CCO engages with patients and their families in order to advance a person-centered approach to health care. In April 2014, CCO released the Ontario Cancer Plan IV 2015 to 2019 (OCP IV), a 4-year strategic plan for Ontario's cancer system (10) that was developed in consultation with a vast network of partners—including patient and family advisors (PFAs). This was the first time a cancer plan in Ontario partnered with PFAs in its development. The intent of the engagement with PFAs was to ensure that plan would be meaningful to patients and families and help to improve the quality of care and patient experience. During the OCP IV development, CCO PFAs were informed of the various opportunities for engagement that were available and invited to participate. Those PFAs expressing interest were embedded throughout the process including cochairing the executive sponsor group, being members of working groups, and attending an all-day planning meeting. The PFAs were also consulted during Patient and Family Advisory Council (PFAC) meetings, regional sessions, and review events. By providing input on key issues, desired outcomes, and expectations, PFAs helped shape the content of the strategic goals, objectives, and system-level initiatives in the OCP IV.

The current study aimed to elucidate facilitators, barriers, successes, and limitations of CCO's engagement with PFAs on the OCP IV and provide insight and recommendations regarding how best to engage with patients and their families in health-care system planning. Unlike other research on patient engagement which focuses on patient empowerment/activation with regard to their own care or patient involvement in quality improvement of direct health-care service delivery, this study investigates engagement of patients and their families in system planning and investigates if there are unique considerations for engagement at the system level.

## Methods

Patient and family advisors who had an ongoing involvement in at least one of the working groups regarding the development of the OCP IV (N = 9) were invited to take part in a one-time, 1 hour, in-depth, semi-structured telephone interview that explored PFAs' experience of engagement on the OCP IV project (Table 1). Interviews were conducted by an CCO staff member who was not directly involved in OCP-IV development or with PFA recruitment. All interviewees were informed that their comments would remain anonymous. Interviews were audio recorded and transcribed verbatim. Data extraction and interpretation were guided by qualitative description (11,12) which is a foundational, data-driven method that offers a rich description of the data that are summarized and interpreted in a manner that is close to the participant's own words. Results were shared with PFAs to ensure that they were an accurate reflection of what was shared in the interview.

## Results

Six PFAs were interested in, provided informed consented for, and completed an interview (67% response rate). However, one transcript was removed from the analyses as the participant failed to remember the OCP IV engagement specifically. Participants were female, reflected both the patient and family member perspective, and represented the age ranges of 26 to 39, 56 to 64, 65 to 75, and older than 80 and above years old. Their involvement included regular participation in at least one working group (a series of at least three 1 hour meetings) and most also attended CCO Spring Planning Day (a 1 day event) as well as regular PFAC meetings where the OCP IV was discussed. Interview analysis revealed 3 key emergent themes that described the engagement of PFAs in the development of the OCP IV: rapport, communication, and leadership. Recommendations related to each of these themes are presented in Table 2 and discussed below. Patient and family advisors also reported that they believed their contributions had an impact on the OCP IV and the health-care system; these comments are also discussed below. All participants' names have been anonymized through the use of pseudonyms to ensure the confidentiality of the data.

### Rapport

Establishing reciprocal rapport between CCO staff and PFAs ensured that PFAs felt valued, included, and supported.

*Feeling valued and included as an equal.* Prior to their engagement in OCP IV development, most PFAs feared experiencing "tokenism." This fear echoes a finding in the literature regarding the risk of using patient participation to endorse an initiative rather than to meaningfully engage in a substantive manner (5). In this case, PFAs reported that these fears quickly dissipated. Most PFAs described feeling like an equal team member and described the staff as being inclusive, minimizing power differences. Participants described feeling valued because they were asked meaningful questions, which they believed demonstrated that their contributions were seen as important and taken seriously by other team members. Several participants also mentioned senior executives (eg, vice presidents) and clinicians reaching out to them to convey recognition or to check in to see how they felt about the process. In describing what made her feel valued, Karen commented, "It is just how your presence at the table is perceived and whether the people at the table who are not patients or family members have bought into you being an integral part of the process."

Specific behaviors that made PFAs feel valued and respected included: being directly called on for input, being listened to, being kept informed, "being considered every step of the way" (Sharon), and having the staff explain decision-making (ie, specifically making an effort to describe what decisions were made and why). These findings

**Table 1.** Interview Protocol.

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1. What led you to become involved with Cancer Care Ontario (CCO) as a patient and family advisor (PFA)?
    - Was there something about your experience of cancer (your own or someone else's) that led you to become involved? If yes, what was that?
    - Were you hoping that your experience might be valuable to others? If yes, in what way?
    - What were there changes you were hoping to make?
  2. What were your expectations of being involved as a patient/family advisor?
    - What, if anything, did you know about the program at the outset?
    - What kinds of activities did you expect to be involved in?
    - What were you hoping to get out of the experience?
    - In what ways were you hoping to contribute?
    - Did you have prior experience with being a PFA that motivated you to get involved?
  3. Tell me about your experience of participating in Ontario Cancer Plan (OCP) IV.
    - What was your role and what did it involve?
    - What kinds of activities did you participate in?
    - Was it easy to participate? (could probe about staff facilitating participation)
    - Did you feel comfortable?
    - Did you feel prepared? (could probe about working at system level)
    - Did you feel like your contribution was important? Why/why not?
    - How did you see yourself in relation to the other people involved?
    - Did you feel like an equal player? Why/why not?
    - Did you feel like your contribution was well integrated or well reflected into the process? Why/why not?
    - Did you feel valued as a participant? What made you feel that way? (or not)
    - Did you feel heard?
    - Did you feel respected?
  4. Based on your experience, how would you describe the impact of including PFAs on the development of OCP IV?
    - Do you think that PFAs were an important part of the process? In what ways?
    - Can you think of any examples that could help us understand how and why PFAs were important?
    - How might things have been different without PFA involvement?
    - If you feel like PFAs were not very influential, why do you think that was?
    - What was it about the process that meant that the involvement of PFAs didn't seem to have much impact?
    - Were your contributions included in the work you were a part of? Can you provide a specific example?
    - How would you describe the impact of being involved in the OCP IV on you and other work that you do?
    - How has been involved in the OCP IV compared to other engagement opportunities at CCO?
  5. If you were in charge of future OCPs, what would you keep from the current process and what would you change?
    - What worked and could be built on?
    - What didn't work and how would you change it?
  6. Is there anything else about your experience of participating in OCP IV that was important to you that we haven't talked about that you would like us to be thinking about?
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are consistent with previous reports of how patients were effectively engaged on an advisory committee (6).

*Supportive interpersonal relationships.* One benefit of engagement is the opportunity to form new relationships (6). In this case, building relationships was important to many PFAs who had hoped to meet like-minded people through their role. Patient and family advisors reported these relationships made them feel comfortable, welcomed, and integrated into an environment where people shared their desire to improve the cancer system. Participants also appreciated working in a diverse team and the opportunity to learn from the other individuals at the table. As Paula shared, "I liked interacting with the different players at the table, whether they were clinicians or CCO staff or nurses or other PFAs... It was interesting to hear the perspectives at this one little table." Many participants believed that the learning was reciprocal, as Sharon stated, "I learned a lot from them and they learned from me."

### Communication

Patient and family advisors reported that communication between themselves and CCO staff was overall effective, characterized by clarity, transparency, efforts to establish a shared language and understanding, and a feeling of being heard. They also reported that logistics around teleconferencing needed to be appropriately managed.

*Clarity and transparency.* As reported elsewhere (13), participants involved with the OCP IV described open, clear, and transparent communication as contributing to their positive experience of engagement. Information was regularly shared with PFAs before and after meetings. All participants felt they were given material with enough time to review and had the opportunity to clarify information. One participant expressed "If we are not prepared it is pretty much our own fault because we've had everything given to us" (Carol). This is in keeping with a previous observation in the

**Table 2.** Summary of Recommendations for Engaging Patient and Family Advisors (PFAs) in Health-Care System Planning.**Reciprocal rapport**

- Include opportunities to build rapport between PFAs and other team members to minimize power differences
- Informally and formally, verbally recognize PFAs for their contributions
- Cultivate a culture that values the participation of PFAs
- Provide opportunities for PFAs to work alongside and develop relationships with other PFAs

**Effective communication**

- Spend time developing a shared language and a common understanding
- Orient PFAs with detailed background information to increase their sense of preparedness and systems literacy
- Routinely spell out acronyms the first time they are used in all documents and avoid acronyms when speaking in meetings
- Provide PFAs with clear, direct and transparent communication. When choosing communication channels, be mindful of the fact they may not be as well connected electronically as internal staff
- Be responsive and keep PFA team members updated on work taking place outside of meetings
- Consider how communication (ie, teleconferences) can be more inclusive and accessible
- Provide multiple opportunities for communication (eg, premeeting orientations, debrief meetings)
- Consider making premeeting orientations optional or eliminate altogether if the content does not add to materials that were circulated via e-mail
- Communicate with PFAs early in the process as it can be challenging to engage in opportunities with short timeframes as it takes time to learn the role and determine how to contribute meaningfully

**Strong leadership**

- Demonstrate clear and respectful leadership with clarity around procedures, roles, timelines, responsibilities, and expectations
- Have strong leaders/chairs to facilitate well organized meetings with clear purposes and ensure everyone has the opportunity to contribute to the discussion
- Directly ask PFAs for their input and ask PFAs meaningful questions about their contributions

**Represent diversity**

- Include both patients and family members; family member experiences and perspectives are different from those of patients
- Strive to increase diverse voices and perspectives, reflective of the population.
- Include more than one PFA in each engagement opportunity to help ensure continuity if a PFA can no longer be involved as originally planned
- Recognize barriers for PFA involvement, including time constraints (eg, meetings during business hours), and how this may impact the ability of PFAs from different perspectives to participate

literature that educational opportunities and reference material empower patients to be collaborators (14). Sharing information before meetings made it easier for participants to contribute as they understood what the objective of the meeting was and what was expected of them; this sense of understanding has also been noted in other reports as a key aspect of effective engagement (3).

Premeeting orientations and debriefing meetings were also appreciated by PFAs. When the premeeting orientations shared context and background information that went beyond the information shared in the materials circulated via e-mail, the meeting was perceived as being “crucial.” However, at times premeeting orientations were a “reading of the slide deck,” which was less useful. One participant recommended making these meetings optional or asking PFAs what questions they would like addressed in advance of the meeting.

Participants provided a few examples of when communication was not effective, where they did not feel considered, or they “fell through the cracks.” These examples included instances where e-mails were not responded to, where there was confusion regarding engagement specifics, and where there was a lack of logistical support. Patient and family advisors noted that while they were members of the working group, they were not employees and therefore did not have access to the same tools, infrastructure, and resources as

staff. For example, when meetings were canceled or rescheduled, extra effort needed to be made to ensure PFAs received the notification. Additionally, if PFAs required assistance with meeting logistics, effort was needed to coordinate with internal stakeholders to ensure PFAs’ full participation (eg, setting up a teleconference line).

**Shared language and understanding.** Shared language and understanding is needed to facilitate engagement (3). In the current study, one language barrier was an overall reliance on acronyms. Although participants reported that CCO staff made an effort not to use acronyms at the first meeting of the various working groups and committees, many PFAs developed their own acronym dictionaries or relied on one that was provided to them. Premeeting orientations and debriefing meetings were also useful for clarifying language and acronyms.

Additionally, PFAs reported that there were times it felt as though they and CCO staff were ascribing different meanings to the same words. It became important for groups to work together to clarify the meaning of words and concepts that were used. Over time, a shared language and understanding was developed and clarified through ongoing discussion. Some participants reported that they believed including patient and family perspectives served to humanize administrative, clinical, and systematic language used

by CCO and that made the OCP IV more accessible to a broader audience.

**Feeling heard.** One of the most successful engagement tactics identified by participants was directly calling on PFAs to share their perspectives during meetings.

It seemed to me that the OCP IV table was equal from the beginning, there was no question. If I, or the other PFA hadn't spoken in a while, somebody would say "What do you think?" or "How does this look to you" and then we could voice what we had been thinking about. (Karen)

Once PFAs spoke in meetings, they described that their contributions were often referred to and discussed by others. This active discussion of their contributions made participants believe that they had been heard, that their voice was important, and that their input was "changing the discussion." The sense of feeling valued and heard has been reported elsewhere in the literature as important for effective engagement (6). A key factor in helping PFAs feel heard was the presence of strong meeting chairs. As Karen stated, "if you don't have a good chair, you're gone. You are just lost." A few participants described that meeting chairs were effectively able to moderate meetings, manage individuals who monopolized conversations, and ensure that everyone's voice was heard.

The PFAs also felt heard as a result of the staff's responsiveness to PFAs' contributions. Following up with PFAs to let them know how and why their feedback was or was not incorporated and keeping PFAs informed of work taking place outside of the meetings led to an increased sense of rapport with staff and left participants feeling like integral team members.

**Teleconferencing.** All participants preferred face-to-face meetings over teleconferencing, although they recognized the resource constraints that made it impossible for all meetings to be held in person. Teleconferencing challenges described by participants included a lack of their own technological skills, lack of equipment, and the limitations imposed by not being able to read someone's facial expressions and body language. This finding needs to be weighed against other observations from the literature that suggest the ability to attend meetings virtually increases participation, particularly among those who are in remote locations (6).

### Leadership

Patient and family advisors noted that leadership, both on the part of themselves and among CCO staff, was important for effective engagement.

**Patient family advisors as leaders.** Patient and family advisors bring to the engagement not only their experience with health care but also their own skills and expertise. These

attributes contribute to a sense of leadership that can facilitate productive engagement (7,15). Many participants in the OCP IV development felt they were able to draw upon relevant professional/volunteer experience in addition to their personal experience with cancer and the health-care system. Most participants felt that participating in the development of the OCP IV allowed them to use and develop their skills, while contributing to making positive change and drawing from their first-hand experience.

All participants described engaging in the development of the OCP IV as a steep learning curve. Many participants took the initiative to develop the background knowledge they felt they would need in order to fully participate. Given this learning curve, most participants recommended that the PFA orientation be more comprehensive when engaging PFAs in future planning efforts, such as the OCP V.

**Leadership of CCO staff.** Generally, participants gave positive feedback about the leadership skills of CCO staff. Staff were described as being "on top of things," transparent and providing substantial clarity in procedures, roles, goals, timelines, responsibilities, and expectations. Staff members were also seen as strong facilitators. Participants appreciated introductions at the beginning of meetings, felt that meetings were well chaired, and noted that agendas were well organized with appropriate time allotted for each item. These attributes made for more productive meetings and increased participants' sense of preparedness as they knew what was expected of them, at what time, and why.

### Impact of Engaging PFAs

Overall, PFAs had a positive experience and felt that their contributions made a positive impact on the development of the OCP IV. Participants felt that including patient and family voices changed the discussion by broadening the perspectives included in system planning and focusing on patient and family needs. As Sharon reflected "Engaging PFAs has given them [CCO] . . . an 'Aha!' moment. Like 'I didn't really thinking of it that way.'" Many participants felt that their voices humanized the strategic planning process and were able to see their contributions reflected in the discussion. Additionally, participants believed that including PFAs in the development process enhanced the visibility and awareness of the OCP IV; as the PFAs shared their experience with OCP IV development with their peers within their networks, many other patients and families across the province learned of the existence of the OCP and the value that CCO places on working with patients and families to improve the system.

### General Discussion

Overall, results from this evaluation reveal that the experience of engaging with PFAs on the OCP IV has many similarities to other reports of patient engagement (2,6–9). However, there is a key difference between engaging

patients and their families in system-level planning and in designing the delivery of clinical care. Namely, system-level planning requires those engaged to not only reflect on and convey their own experiences but also to consider their experiences within the larger system context and provide conceptual feedback on plans for the broader system. This difference is reflected in the results of this evaluation, primarily within the domain of communication, where PFAs articulated the need for clarity, transparency, shared language and understanding, and education in order to adequately prepare patients and their families to contribute. Patient and family advisors noted that there was a “learning curve” to their engagement. This would not be the case when patients and families are relating their personal experiences. As such, developing a certain degree of “systems literacy” in PFAs involved in health-care planning is key to this type of engagement. Systems literacy, encompassing knowledge, and understanding of how health-care systems operate and interact, could be developed in PFAs prior to or during engagements in order to address the knowledge gap between PFAs and other stakeholders more familiar with system-level health-care planning.

### Limitations

Like all evaluations, this qualitative exploration has some limitations that may impact the generalizability of the findings. First, the direct impact of the PFA engagement on the OCP IV has not been established and may be difficult to determine. Also several months had passed between participants’ engagement in OCP IV development activities and the time of the interviews. Given this time gap, some participants commented that they did not clearly remember all aspects of their engagement in the OCP IV.

The participants interviewed for this evaluation were enthusiastic and had a positive experience with engagement. This may have introduced a positive bias in the findings as individuals with less positive experiences may have been less motivated to participate in the interviews. Additionally, the interviewer was a member of CCO but was not involved with OCP IV development or the facilitation of PFA engagement. All interviewees were told their comments would be kept anonymous. Nevertheless, some PFAs may have not been as forthcoming in their comments as they would have been with a completely independent interviewer (ie, external to CCO).

Finally, in some ways the participants were homogeneous. All participants were female, many were retired, well-educated and had professional backgrounds, which may have provided them with comfort and confidence interacting with an organization focused on system-level planning. The experience of engaging with CCO (and thus recommendations for engagement) may be different for a more diverse group of individuals who would be more representative of the broad spectrum of Ontarians. The extant literature describes similar concerns around representativeness in the course of patient engagement (7,8).

Based on the results and limitations of this study, recommendations for engagement with PFAs in health-care system planning were developed (Table 2).

### Conclusions

Establishing reciprocal rapport, effective communication, and strong leadership are key elements suggested by the current study to ensure successful engagement with PFAs in health-care system planning. Additionally, including diversity to reflect the breadth of experience of patients and their families is suggested. Despite the small sample size, these emergent themes are largely consistent with other reports and reviews in the literature describing best practice in engaging with patients (2,6–9). However, in the current study, there was particular emphasis on aspects of effective communication, learning and education, and developing systems literacy to adequately prepare PFAs to contribute to strategic planning. This finding suggests that a key difference between engaging PFAs in health-care system planning versus clinical care improvement may be the background preparation required to support the engagement. Future research aimed at evaluating the utility of developing systems literacy is warranted to ensure patients and their families feel valued, supported, and empowered to contribute to improving health-care systems.


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