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# Envisioning mechanisms for success: Evaluation of EBCD at CHEO

Kristina Rohde

*Children's Hospital of Eastern Ontario Research Institute, krrohde@cheo.on.ca*

Mireille Brosseau

*Children's Hospital of Eastern Ontario, mbrosseau@cheo.on.ca*

Diane Gagnon

*University of Ottawa, dgagnon001@gmail.com*


Jennifer Schellinck

*Carleton University, jschellinck@sysabee.com*

Christine Kouri

*Children's Hospital of Eastern Ontario, ckouri@cheo.on.ca*

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## **Cover Page Footnote**

This work was supported by the Canadian Foundation for Healthcare Improvement (CFHI). As part of the “Partnering with Patients and Families for Quality Improvement” learning collaborative, CHEO, along with 21 other Canadian healthcare organizations, benefitted from financial, coaching and other support to engage patients and families in designing, delivering and evaluating healthcare services. CFHI is funded through an agreement with the Government of Canada. The views expressed herein are those of the authors and do not necessarily represent the views of CFHI or the Government of Canada.

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Kristina Rohde, *Children's Hospital of Eastern Ontario Research Institute, krohde@cheo.on.ca*

Mireille Brosseau, *Children's Hospital of Eastern Ontario, mbrosseau@cheo.on.ca*

Diane Gagnon, *University of Ottawa, dgagno8@uottawa.ca*

Jennifer Schellinck, *Carleton University, jennifer\_schellinck@carleton.ca*

Christine Kouri, *Children's Hospital of Eastern Ontario, ckouri@cheo.on.ca*

### Abstract

To advance patient engagement (PE) and more comprehensively involve patients, families, and staff in quality improvement (QI) at the Children's Hospital of Eastern Ontario (CHEO), the Experience Based Co-Design (EBCD) approach was piloted. Set against the backdrop of envisioning factors that would facilitate success, an evaluation was designed to assess five domains: strengthening of mutual understanding, collaboration, and partnerships between patients/families and staff; a greater involvement of patients, families, and staff in QI; satisfaction with the process; the ability of EBCD to generate clear and useful data to ascertain the patient/family and staff experience; and the ability of EBCD to generate clear and useful data to improve patient/family and staff experience. The King's Fund EBCD toolkit was followed to implement the approach. This involved observations and interviews to capture experiences; and feedback events to understand experiences and identify improvement areas. The resulting data was used to evaluate the process relative to the five domains of interest. The evaluation data supported the conclusion that the EBCD process usefully addressed each of the domains of interest, and facilitated PE in QI. In addition, the evaluation revealed important considerations to the success of such an initiative. Using EBCD allows for a more nuanced and comprehensive consultation than traditional methods employed. The research presented here informs the future spread and/or adaptation of EBCD by offering a case for using the approach, but also suggests modifications or considerations to integrate PE methods with existing structures for greater efficiency, success, and value.

### Keywords

Patient engagement, patient experience, patient- and family-centered care, staff engagement, staff experience, quality improvement, evaluation, mixed-methods

### Note

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### Introduction and Background

In 2013, the Children's Hospital of Eastern Ontario (CHEO) was looking to enhance the involvement of patients and families in quality improvement (QI). It was apparent that QI and patient engagement (PE) efforts were not fully integrated; PE within QI efforts took the form of collecting patient experience data via patient satisfaction surveys and focus groups; e-mail quick poll surveys on one issue; and family and youth advisory committees. CHEO wanted to include an approach that fostered a partnership between patients and families and staff throughout the QI cycle. This would allow for a more complete fulfillment of CHEO's philosophy of patient and

family-centred care to "involve families in all aspects of the hospital, including development and evaluation of programs, policy development and facility design."<sup>1</sup>

A working group was formed to determine what type of approach should be adopted to meet this aim. In a review of best and emerging practices, a list was formed of potential engagement opportunities CHEO had not yet explored including online patient consultation, redesigning name badges, consistently asking children and youth about their pain, nursing bedside handoffs, and Experience-Based Co-Design (EBCD) among others. EBCD was included as the approach was being adopted by a number of Ontario healthcare organizations and had positive

reports on the experience and results. There was a consultation and vote representing 165 stakeholders from 8 key groups such as the nursing and medical advisory teams, the youth and family forums, and a wide sample of families via survey. With a clear majority, CHEO decided to test the EBCD approach as it was complementary to other QI work at CHEO, and was appealing since it focuses on experiences of care from the perspectives of those who experience it, thereby providing an inclusive and holistic approach to healthcare improvement. It is a systematic multistage approach that involves patients (and/or their family members) and staff working together in a collaborative process to improve healthcare services and patient/family experience.<sup>2</sup> The approach is user-centered as the methods used to collect information about care experiences are narrative-based or ethnographic, such as videoed-interviews and observations.<sup>2</sup> Many have used EBCD internationally since its conception in 2006, to our knowledge, there has been no examination of the mechanisms within the EBCD approach that are meant to facilitate success with the method.<sup>3,4</sup>

This article documents the evaluation of EBCD at CHEO framing it amongst how our team defined success with EBCD, the techniques within EBCD that would facilitate these outcomes, and ultimately how this played out in practice. The current evaluation concentrates on the initial phase of the EBCD process designed to understand experiences in order to generate improvement recommendations. Work to co-design and implement improvements will be detailed in other papers.

Specifically, the evaluation is intended to address five questions regarding EBCD effectiveness on this front:

1. Does the EBCD process strengthen mutual understanding, collaboration, and partnership between patients/families and healthcare providers?
2. Does the EBCD process lead to greater involvement of patients, families, and staff in QI?
3. Were participants satisfied with the EBCD process?
4. Does the EBCD process generate clear and useful data to ascertain patient/family and staff experiences?
5. Does the EBCD process generate clear and useful areas for improvement and recommendations?

### Experience-Based Co-Design: The Intervention

Using the EBCD toolkit from the King's Fund,<sup>5</sup> the pilot was planned in three steps (see Figure 2): 1) capture patient and staff experiences through observations and interviews 2) deepen mutual understanding of experiences through patient/family, staff and joint patient/family/staff

'feedback events' and identify improvement areas 3) improve patient and family experiences. The first two steps, which we refer to as 'Phase I', were conducted between May and December 2014 and will be the focus of this paper.

A Theory of Change (TOC) model (see Appendix A) was developed to conceptualize what the "future state" might be based on the key facets of the approach. In order to examine the mechanisms within EBCD that would facilitate the changes we hypothesized as outcomes, we then developed a modified TOC (see Figure 1). This TOC was limited to our outcomes and what it was in particular about the activities within the EBCD process that would enable these critical outcomes to occur.

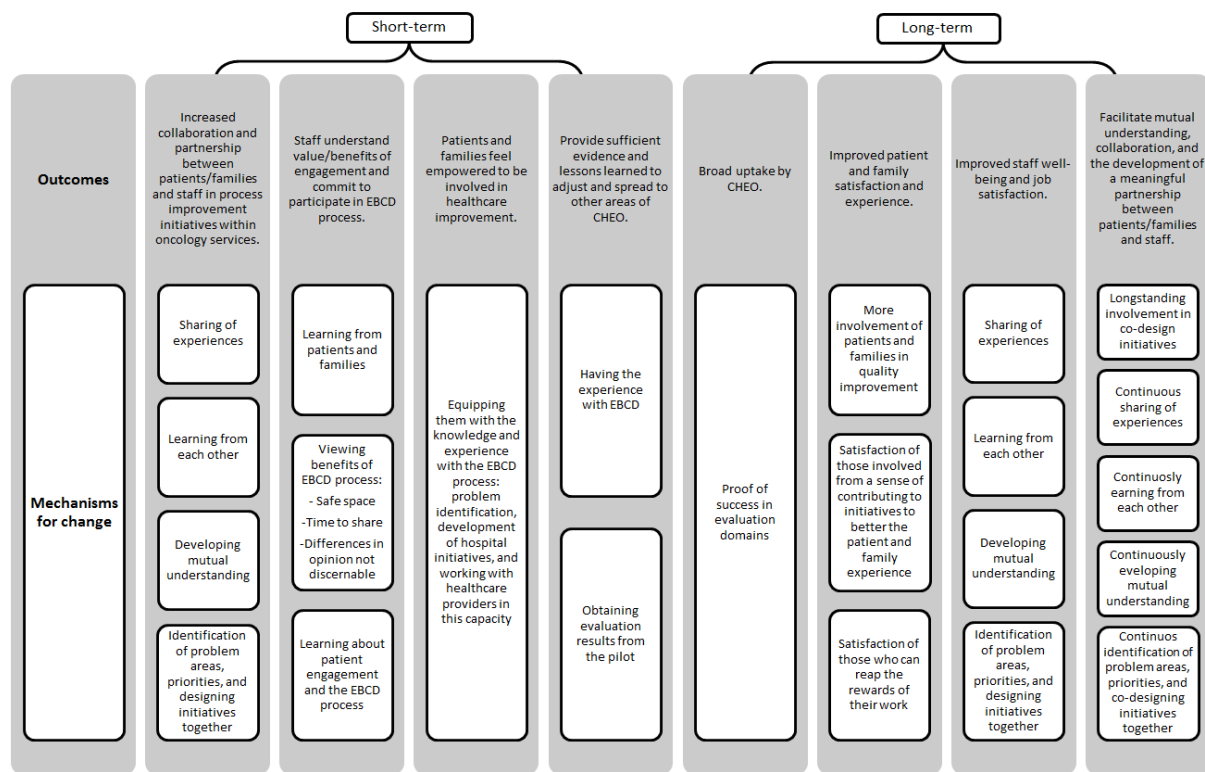
Oncology was chosen because: 1) the inpatient services team was familiar with process improvement practices, and 2) a group of oncology families had expressed a desire to work with staff to improve care processes and their patient/family experience. The group of staff participants included 15 individuals: 5 staff nurses, 2 social workers, 2 care facilitators, 1 case manager, 1 oncologist, 1 pharmacist, 1 child life specialist, 1 clerk, and 1 interlink nurse. Likewise, the patient and families group represented a range of ages, diagnoses, and stages of treatment and included 12 families (24 parents, 5 youth and 2 siblings).

The EBCD process proceeded as outlined in Figure 2. Observations were done on both inpatient and outpatient units to become familiar with the oncology environments, care processes, and the personal interactions patients and families had with staff. The 15 semi-structured interviews conducted with staff members focused on staff experience, their perceptions of patient/family experiences, and their improvement ideas. These were open-ended where interviewees were encouraged to provide a narrative account of their experiences. Three feedback sessions were held to deepen mutual understanding of patient and staff experiences and identify opportunities for improvement by sharing themes from the data gathered in the EBCD process and allowing meaningful discussion. A collective exercise ensued to prioritize improvement recommendations.

### Evaluation Methods

During the EBCD process, in addition to gathering data for the process itself, multiple lines of inquiry were utilized to address each evaluation question. Data was gathered through questionnaires at the end of each feedback event. Questions pertained to the events themselves, as well as participant experiences and initial perceptions of the EBCD approach. For some questions, respondents were asked to rate their experiences on a 5 point Likert-type scale and for other questions respondents were simply asked to provide feedback.

Figure 1: Modified TOC - Mechanisms for change



Workshop notes were kept by project team members participating in each feedback event. And finally, follow-up telephone and in-person semi-structured research interviews were conducted with 9 family members (8 parents and 1 adolescent patient) and 11 staff members (4 nurses, 2 care facilitators, 2 social workers, 2 other specialized allied health care professionals, and 1 physician) involved in the larger EBCD process to reflect on the process. The Evaluation Framework in Figure 3 delineates the indicators, data sources, data collection methods, and comparators for each evaluation question.

**Results**

Data analysis of the quantitative data consisted of examining frequencies and descriptive statistics, while qualitative data was grouped according to each major evaluation question and general themes or patterns sought out through a process of thematic analysis.<sup>6</sup> The following results will address the extent to which data gathered during the EBCD process provides evidence for the five evaluation questions.

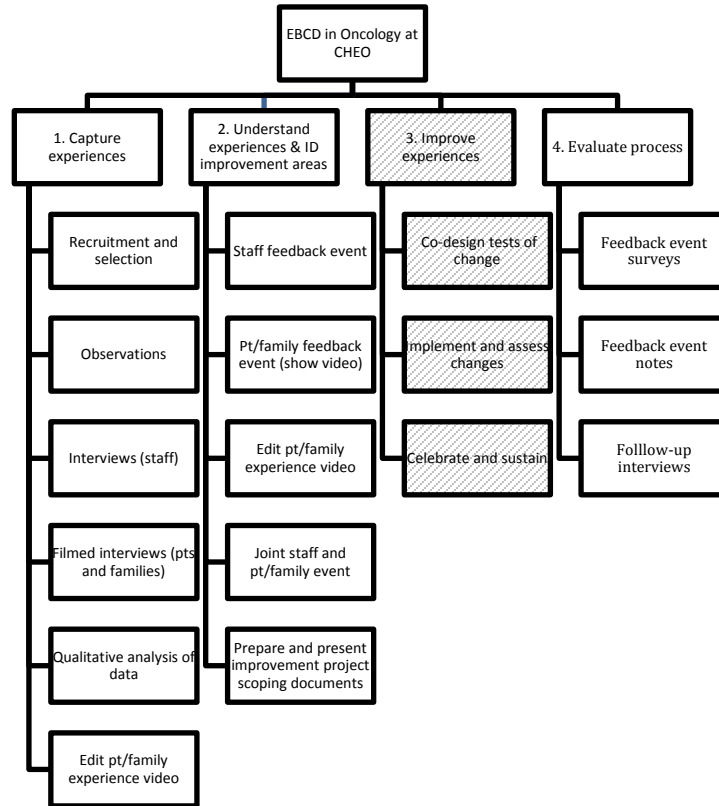
*Does the EBCD process strengthen mutual understanding, collaboration, and partnership between patients/ families and healthcare providers?*

Data relevant to this evaluation question highlighted an improvement in terms of efforts to collaborate, understand, and partner with those different groups that participated in the EBCD process overall but also within different sub-groups.

*Pre-EBCD state.* When asked what they liked best about their work, 13 of the 15 staff at the beginning of the EBCD process referenced the positive relationships they have with patients and/or families. One staff member remarked that she valued the “the closeness we have with our families.” While another stated about a patient, “She runs down the hall with her hands back like she’s going to fly like a bird into my arms. When you have that with the kids, what more could you want?” Other staff members referenced positive relationships with colleagues, “we’re a small, cohesive team.” That being said, there was a general sense from staff that time and workload pressures impacted their relationships with families,

*“The social interactions are not what they used to be. We don’t have time anymore to sit and chat. Sometimes I don’t even know the parents’ names and their child*

Figure 2: the EBCD process at CHEO



*has been my patient for four months – I have not had time to get to know them.”*

The positive regard for the relational aspects of oncology services did not emerge as a consistent thread in the initial family interview data. While some families noted the dedication and compassion of clinical and support staff, others also spoke about not being heard,

*“I think the biggest opportunity to make things better is to make sure people know how to work as a team .... Let’s work together to get that done versus assuming that CHEO knows best .... Make sure that the family is part of it.”*

Each group was surveyed after their respective feedback events. As shown in Figure 4, patients and families were quite variable as to how they rated the extent to which they had experienced meaningful and effective partnerships between oncology patients, families, and healthcare providers prior to the EBCD process. The feedback provided from the patient and family event highlighted the need for “better communication and partnering” and that “... there’s room for improvement, communication, exchange of information.” At the staff event, staff rated partnerships and collaboration more

positively, but there was mixed feedback regarding how collaborative their overall team was with the following noted, “there is always room for improvement; not everyone meshes together,” and “I feel there is overall a healthy climate of mutual respect, collaborative partnerships.”

Participants reported noticing differences in several dyads: between the patients and families themselves, between the staff themselves, and between patients and families and staff overall.

*Family-Family Dyad.* Between the families involved, there was an appreciation of their similar experiences and the connection families felt to each other because of this. Survey feedback from the patient and family feedback event from one family indicated “it was good to know that other people felt the same way we did.” Parents also valued the collaboration between patients and families at different stages in the treatment process, “you don’t have a lot of opportunities to deal with the families who are off treatment or behind you” (Family Research Interview-5).

*Staff-Staff Dyad.* Several staff referenced the EBCD process furthering the connection between the staff themselves. Different areas of contention were noted, for example

Figure 3. Evaluation Framework

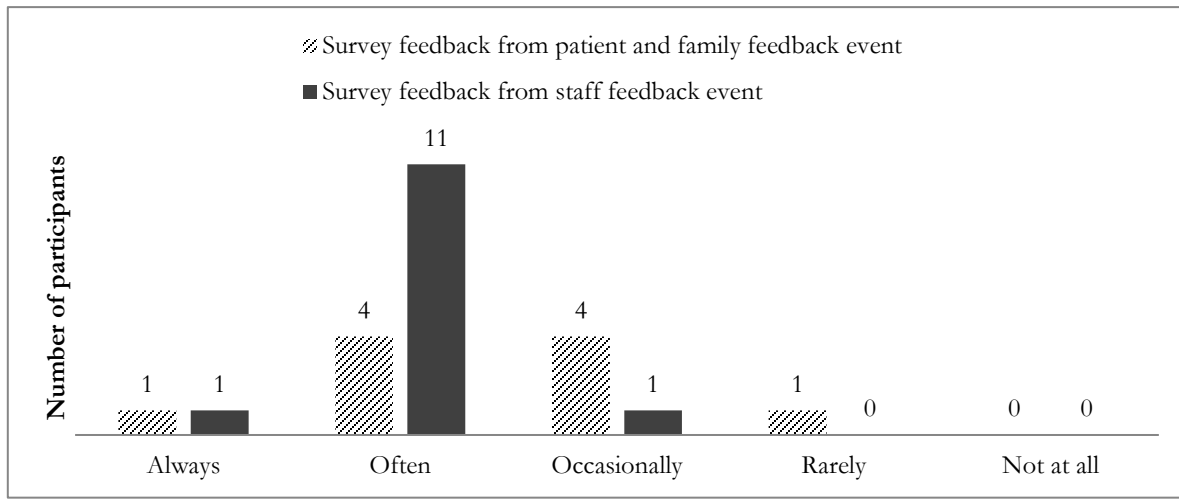
Evaluation Issues/Questions	Indicators	Data Source	Data Collection Methods	Bases for Comparison
<b>Assessment of Process</b>				
1) Does the EBCD process strengthen mutual understanding, collaboration, and partnership between patients/ families and healthcare providers?	<ul style="list-style-type: none"> <li>▪ Patient and family experiences</li> <li>▪ Healthcare provider experiences</li> <li>▪ # of shared workshops and co-design groups</li> <li>▪ EBCD process manager opinions</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients and families</li> <li>▪ Healthcare providers (Oncology staff and physicians)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Follow-up interviews</li> <li>▪ Feedback questionnaires</li> <li>▪ Workshop notes</li> </ul>	<ul style="list-style-type: none"> <li>▪ Project theory of change model</li> <li>▪ Initial reflections on past experiences from interviews and notes</li> </ul>
2) Does the EBCD process lead to greater involvement of patients, families, and staff in quality improvement?	<ul style="list-style-type: none"> <li>▪ Patient and family experiences</li> <li>▪ Healthcare provider experiences</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients and families</li> <li>▪ Healthcare providers (Oncology staff and physicians)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Follow-up interviews</li> <li>▪ Feedback questionnaires</li> </ul>	<ul style="list-style-type: none"> <li>▪ Project theory of change model</li> </ul>
3) Were participants satisfied with the EBCD process?	<ul style="list-style-type: none"> <li>▪ Participant level of satisfaction</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients and families</li> <li>▪ Healthcare providers (Oncology staff and physicians)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Follow-up interviews</li> <li>▪ Feedback questionnaires</li> </ul>	<ul style="list-style-type: none"> <li>▪ Other methods of ascertaining the patient experience.</li> </ul>
<b>Assessment of EBCD Outputs</b>				
4) Does the EBCD process provide clear and relevant information to accurately ascertain the patient and staff experience?	<ul style="list-style-type: none"> <li>▪ Patient and family opinions</li> <li>▪ Healthcare provider opinions</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients and families</li> <li>▪ Healthcare providers (Oncology department MDs, RNs, others)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Follow-up interviews</li> <li>▪ Feedback questionnaires</li> <li>▪ Workshop notes</li> </ul>	<ul style="list-style-type: none"> <li>▪ Project theory of change model</li> <li>▪ Other methods of ascertaining the patient experience.</li> </ul>
5) Does the EBCD process generate clear and useful areas for improvement and recommendations?	<ul style="list-style-type: none"> <li>▪ Patient and family opinions</li> <li>▪ Healthcare provider opinions</li> <li>▪ EBCD phase 1 report</li> </ul>	<ul style="list-style-type: none"> <li>▪ Patients and families</li> <li>▪ Healthcare providers (Oncology department MDs, RNs, others)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Workshop notes</li> <li>▪ Final recommendations</li> </ul>	<ul style="list-style-type: none"> <li>▪ Other methods of pinpointing areas for process improvement at CHEO.</li> </ul>

between the different disciplines as one staff noticed “the disconnect between in and out-patient [staff]” (Staff Research Interview-3). Feedback from the staff feedback event included staff describing that “it was reassuring to see common themes emerge-that you are not the only one feeling a certain way.” One staff member explained the benefits of the EBCD process for staff collaboration as,

“it was a good exercise for colleagues, different disciplines to understand where we’re struggling and how we get frustrated on a day to day basis and how we can support each other better with families” (Staff Research Interview-10).



**Figure 4: Survey feedback - to what extent there are meaningful and effective partnerships between oncology patients, families, and healthcare providers**



*Family-Staff Dyad.* The most profound experiences in terms of a shared mutual understanding and strengthening of the collaboration and partnerships were between the patients and families and staff. Through the various shared meetings during the EBCD process, families and staff cited developing a mutual understanding of experiences describing the process as a bonding experience. One family remarked, “it’s nice to be able to see the staff as people and not just someone on the other side of the thing and vice versa” (Family Research Interview-1). Many staff noted appreciation for where families were coming from, “it gave me a better understanding of where families are coming from and also I don’t know that you really get a chance as staff to express some of our positives and negatives of what we do and how we interact with patients and families and what we do for them” (Staff Research Interview-5).

A realization cited by six participants in the interviews and four in the joint feedback event survey was how similar the perspectives of both groups were. One staff member described the biggest success of the process as “how much patients, families, and staff were on the same page as to what they saw as weaknesses in the system and also what they saw as strengths” (Staff Research Interview-5). Moving forward several staff now feel as though they are more sensitive to the experiences of patients and families, “there is now a common understanding of what staff do and what patients need from them and when that doesn’t mesh, there is some understanding of why because we both know each other’s side a bit better, more than you would from just working with them on a day shift or a night shift” (Staff Research Interview-4).

*Does the EBCD process lead to greater involvement of patients, families, and staff in QI?*

Evaluative data highlighted a positive recognition by participants that EBCD facilitated a greater consultation of their experiences and needs.

*Appreciation of involvement.* Qualitative data revealed that families and staff appreciated being involved, one family remarked that “they are working more with staff team and feel more heard” (Family Research Interview-1). Families felt the process was empowering, “there is very little control or input opportunities” (Family Research Interview-5). Staff also appreciated being involved because they often feel voiceless when they raise concerns that don’t go anywhere. Survey feedback from the staff feedback event revealed staff felt appreciative to be involved: “a rare opportunity during my 10 years at CHEO,” and “it’s great to know that our opinions/ideas are really valued.”

*EBCD versus traditional PE at CHEO.* Eight interview participants offered direct comparisons to previous methods of inciting patient engagement (PE) at CHEO and felt that there was indeed a greater involvement. One family remarked, “this goes so far beyond that survey that CHEO has a habit of sending out” (Family Research Interview-1). Another family similarly noted, “what was most significant was that we had space to speak and express our thoughts, which is much more than we can give by filling out surveys. There is a direct line of communication. It was easier and more accessible” (Family Research Interview-3).

Staff echoed similar sentiments that it is rare for them to go to patients directly and ask what their needs are. One



staff noted that CHEO's family advisory committee is not enough in terms of patient and family engagement, and that decisions usually come top-down. Incidentally, this perception of greater patient and family involvement in QI appeared to facilitate further buy-in from the staff group, "the minute you involve families, there's immense ownership to move the project forward whereas a lot of projects here just fall to the wayside," "no obligation or commitment to make things better for staff, but the minute patients involved, there's commitment to make things better for them which inadvertently makes things better for staff" (Staff Research Interview-4). Another reflected that "you need to hear from the client, you can't define the needs, clients have to define those needs" (Staff Research Interview-10).

#### *Were participants satisfied with the EBCD process?*

Impressions from the evaluative data suggested that participants of the process enjoyed their involvement; reflecting on particular elements that contributed to that experience but also what could be done to improve.

*Positive experience with EBCD events.* Feedback from the respective group and joint feedback events were predominantly positive. The joint feedback event was rated particularly favourably. Figures 5 and 6 depict results from the post-event survey of some of the questions designed to ascertain perception of the experience. All of the participants rated their comfort level sharing and talking about experiences positively (either excellent or good). That said, open ended comments revealed that the majority (14/18 participants) also felt more time was needed for the event.

Both quantitative questionnaire data and qualitative data from interviews revealed a strongly positive impression of the process. Families saw the process as a source of affirmation, "it's been very affirming as they have got to

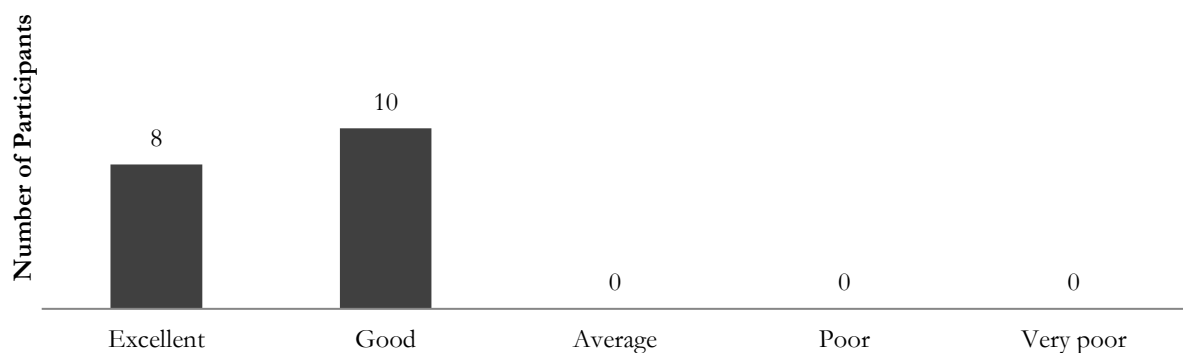
see feedback actually turn into projects" (Family Research Interview-1). Many families and staff shared the same sentiment that the process should be hospital-wide and repeated as things evolve.

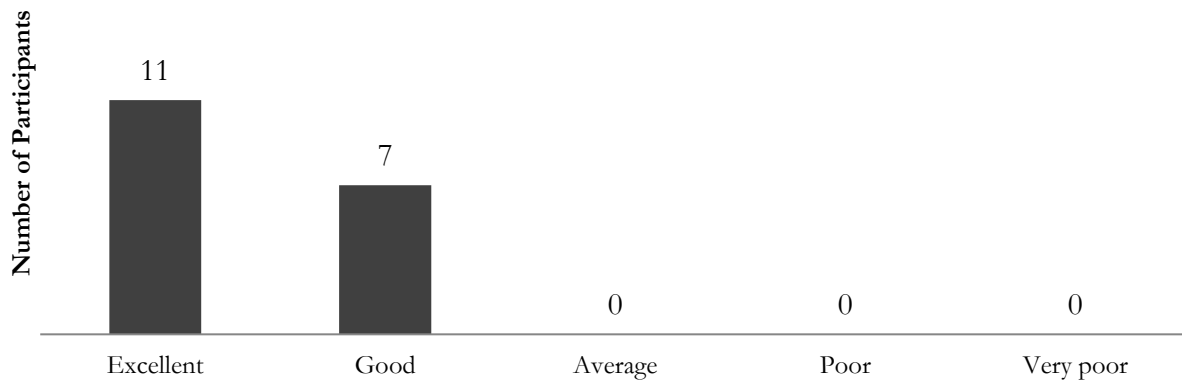
*Positive leadership.* It was recognized by both groups that leadership during the process and the subsequent ability to influence change was a key feature to success and impacted the way they perceived the process. One participant reflected on the leadership of the event itself, "the way [the EBCD facilitator] greeted everyone in respect of backgrounds, histories, experiences they had gone through" (Family Research Interview-6). Whereas other staff noted that momentum is difficult to maintain, and that good leadership helps to advocate for actionable change. One staff member described the EBCD facilitator, saying that she "made participants feel as though it was going somewhere," and "if anyone else had led this project, it wouldn't have been as successful" (Staff Research Interview-4).

*EBCD versus traditional PE at CHEO.* Many staff reflected on negative experiences they had with previous quality improvement (QI) efforts at CHEO and elsewhere that did not move forward and was done "just to say they involved staff but they were not really listened to" (Staff Research Interview-4). Another notes she cannot comment on whether she would recommend the process until she has seen the outcome, citing past negative experiences "I was part of the Lean process and there was no momentum for that ... without someone there pushing it, and pushing it, it lost momentum" (Staff Research Interview-7).

*Areas for improvement.* To improve the process, families, and staff called for a wider variety of participation with more and different staff and families. Further, there was mixed results in regards to the time commitment for the events.

**Figure 5: Survey feedback - Felt comfortable participating in the event and were able to contribute their own thoughts and experiences**



**Figure 6: Survey feedback - Talking about and sharing the different experiences of staff and patients/families**

Comments from the joint feedback event and several interview participants revealed that participants would prefer more time together (for reference, each session was four to five hours). Alternatively, nine interview participants indicated that they weren't able to attend as many events or initial interviews as they would have liked due to time commitments, sickness, or other factors. In addition, several interviewees also commented on the importance of stable participation and recognized it can be difficult to coordinate and that there were noticeable gaps in participation. A minority also felt there was too much lag time between steps, that more frequent gatherings would keep momentum going.

*Does the EBCD process provide clear and relevant information to accurately ascertain the patient and staff experience?*

Data highlighted that the EBCD process captured the patient and staff experience through its unique tools and methods.

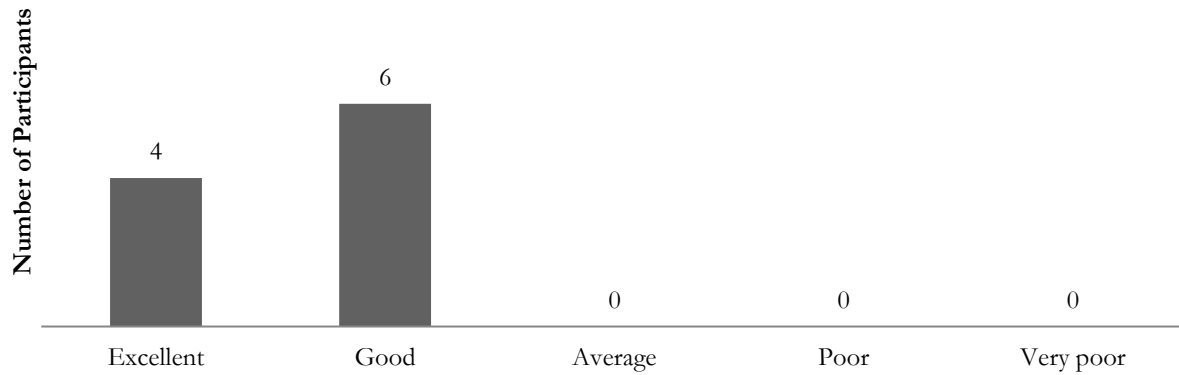
*EBCD tools.* The patient and family feedback event revealed that, overall, family members felt the video and themes generated from the data reflected many of their experiences. Figures 7 and 8 depict how patient and families rated each of the EBCD tools that collected information about the patient and family experience: the video, touch points, and emotion mapping exercise. Further, open-ended comments revealed that 10 of 12 participants indicated that the identified priorities reflected their own experiences.

Likewise, staff felt similarly. Notes from the staff feedback event demonstrate that staff felt as though themes that emerged from the initial EBCD Interviews reflected their experiences. Further, all staff participants during the staff feedback event felt that the priorities agreed upon at the end of the day reflected their own experiences.

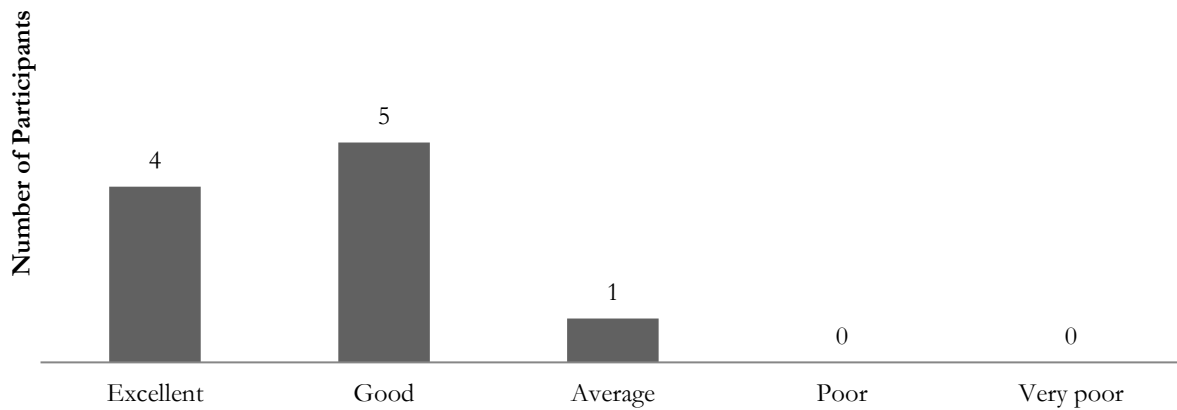
*Shared experience.* Data from the follow up interviews pointed to similarities in experiences. Families particularly enjoyed hearing experiences from other families that were similar to their own, "really neat to see other families who were saying the same things I would have or that you're not alone in your experiences" (Family Research Interview-1) and "it made us realize we're not alone, our stories are not unique" (Family Research Interview-5). Notwithstanding, there was also feedback shared during the interviews that the experiences focused on were not representative and geared towards easy administrative fixes rather than emotional issues. Staff pointed to a balancing of the experiences heard. One highlighted the need to include more patients, particularly teenagers as parents don't always speak for them "I think we got half the story" (Staff Research Interview-1). Staff also noticed the sharing of experiences were mostly negative, that they "heard a lot of the difficult experiences and not as many of the positive experiences" (Staff Research Interview-5).

*EBCD versus traditional PE at CHEO.* Ultimately, when making comparisons to other methods for ascertaining the patient experience, there is support to suggest that EBCD provides a truer picture. When speaking about the open forum as opposed to closed ended survey questions, one family noted "there are lots of different ways to gather feedback and evaluate services and this, though very intense, is giving the best truest picture of what the services are like for oncology" (Family Research Interview-1). Staff echoed similar feedback "rather than it just have it be like family forum, rather than it just being parents having a survey ... I think it's much better to have it be done where they are heard by the caregivers and the opportunity to feel comfortable" (Staff Research Interview-3).

**Figure 7: Survey feedback - The video a good representation of what it is like to be an oncology patient and/or caregiver**



**Figure 8: Survey feedback - touch points and emotional mapping exercise reflected their experiences identified priorities for improving the service**



*Does the EBCD process generate clear and useful areas for improvement and recommendations?*

Each respective feedback event resulted in the formulation of problem statements framed around a detailed and nuanced description of the challenges and opportunities for each (see Appendix B).

At the joint feedback event, families and staff collectively prioritized the improvement recommendations.

1. a. Development of an oncology patient/family orientation package: Patients/families often lack the

information that can help them navigate health services and be good “partners in care”.

b. Development of standard work to support orientation process: Patients/families often feel overwhelmed and/or disoriented during the early days of their admission and/or diagnosis; information is not always conveyed by the right person at the right time.

2. Optimization of orientation package and training for new staff: Inconsistencies in messaging, protocols and procedures conducted by staff increases anxiety and confusion among patients and their caregivers.
3. Development of “Know Me/Know Your Patient” tool: Staff often lack the detailed information needed

about patients and families to deliver care that is reflective of patient preferences and/or specific conditions or circumstances.

4. Revisit use of space and free space for private conversations with families: There is a lack of available space on the inpatient and outpatient units to provide counselling and/or hold private conversations with families.
5. Raise awareness of oncology patient/family experiences in the Emergency Department (ED) and identify improvement opportunities: Oncology patients/families frequently experience negative encounters in the ED as a result of staff having limited experience and expertise treating oncology patients.

Each recommendation was further developed into “project scoping documents” that used EBCD data to describe the current conditions, expected benefits, proposed action, stakeholders, and required resources.

Feedback from follow-up interviews suggested the EBCD process captured the big priorities and resulted in balanced solutions. Families and staff appreciated the tools EBCD employs, and one staff member spoke very highly of the emotion mapping exercise “that was huge for us to see and generated concrete areas to improve upon” (Staff Research Interview-2). Staff appreciated that recommendations were based on common messages and represented small changes such as the distribution of a hospital map. A minority of participants were critical that the EBCD process focused on larger administrative issues, as one staff member expressed, “much of the feedback was about systems” (Staff Research Interview-1).

#### *Other Lessons Learned*

When we look back on our modified TOC (figure 1), we can ascertain that we were mostly successful in meeting the short term outputs hypothesized. However, this success was limited to the group who participated throughout the entire process and many of these outcomes won't be fully realized until the co-design evaluation (phase II) is complete. In addition, it was apparent that the success in these factors ultimately hinges on momentum. Some staff are skeptical of quality improvement (QI) initiatives; which several research interview participants indicated do not move forward. Further, the constant moving target of patients and families is even more difficult to affect change on. Thus, it becomes important that not only is there momentum to carry the process forward, but that there is a commitment to keep the patient engagement (PE) in QI cycles moving, imbed new people in the process, and make it part of the organizational culture.

There are several other caveats that became evident that are integral to the success of EBCD at CHEO. A more

inclusive patient and family recruitment process would be beneficial. While a limited number of families were informed about the project via informational sessions, posters on the units, an Oncology newsletter, and one Facebook post, there was a reluctance from staff to share information about the project to all families (vs. approaching select families individually). Consequently, the recruitment of families took longer than expected. There should have been abundant and clear communication about the opportunity to as many families as possible to achieve a more inclusive and diverse sample of patients and families. As with any engagement, inspiring participation from all sectors of the population can be a difficult process.

Further, all efforts should be made to ensure that the EBCD process is a manageable process for all participants to sustain involvement. Multiple participants, both staff and families, in our project voiced that they could not be as involved as they would have liked to have been. Moreover, several others made suggestions to facilitate the involvement of participants in more manageable ways (e.g. by telephone, video conference, etc.). While this was true, the carryover of EBCD outputs like the video and emotion map into subsequent steps of the EBCD process helped participants to be mindful of collective rather than individual experiences. As a result, participants who missed an event still felt that final recommendations were reflective of their experiences.

Mechanisms for shared leadership would be also valuable. Information and project up-dates were shared on an ad-hoc basis with no mechanism or pre-established schedule for keeping stakeholders apprised of progress. Ownership and accountability stayed with the project manager which resulted in slower implementation.

## **Discussion and Conclusion**

This evaluation was designed to assess the value of the EBCD process to engage patients and families in quality improvement (QI) at CHEO. Findings suggest that strong leadership is imperative, not just to guide the process, but to incite momentum. In addition, there is a real distinction made between the perception of traditional patient engagement (PE) and QI efforts by CHEO employees, which involves minimal consultation and perceived inaction; and the comprehensive involvement of EBCD and the action participants envision could occur as part of the process. Further, given the paradox in comments regarding time commitments, perhaps a modification of process could be investigated in future. Other practitioners have developed an accelerated version of the EBCD approach which could be employed should the process be repeated by other practitioners.<sup>6</sup>

Notwithstanding, compared to past methods of engaging patients and families in QI at CHEO, the EBCD process inspired better collaboration in terms of the identification of areas for improvement with multiple perspectives included. In effect, our EBCD experience points to the relevance of Batalden et al.'s conceptual model of health service coproduction, which says that "healthcare services are always coproduced by patients and professionals in systems that support and constrain effective partnership."<sup>7</sup> It therefore makes sense to move beyond the notion of 'patient and family centred-care' to a more comprehensive 'relationship-centred-care' model where the focus is on improving the patient experience as part of a whole interconnected system of relationships: staff-patient/family, staff-colleagues, patient/family-patient community, and the potential for many others.<sup>8,9</sup>

The process facilitated a deeper mutual understanding between the two groups, via dialogues versus a one way endeavor such as a satisfaction survey. It also allowed for enhanced and larger representation of patient/family perspectives at a QI table versus one or two families within a larger table of staff and physicians. Results of the evaluation revealed that both groups seemed to appreciate the greater involvement the method afforded, making direct comparisons to dissatisfaction with existing PE and QI efforts.

We recognize that our sample size was quite small; focussing on a dwindling group of 46 participants. That said, this evaluation provides a unique case example from which support is generated for the EBCD process and could inform future use of EBCD activities. Future research should focus on the evaluation of the approach with different patient and staff populations, departments, and hospitals. We are also cognizant that the current evaluation focused on short term process outcomes such as satisfaction and perceptions on process. Future initiatives could expand on the literature investigating long-term outcomes such as patient and staff experience or care overall.

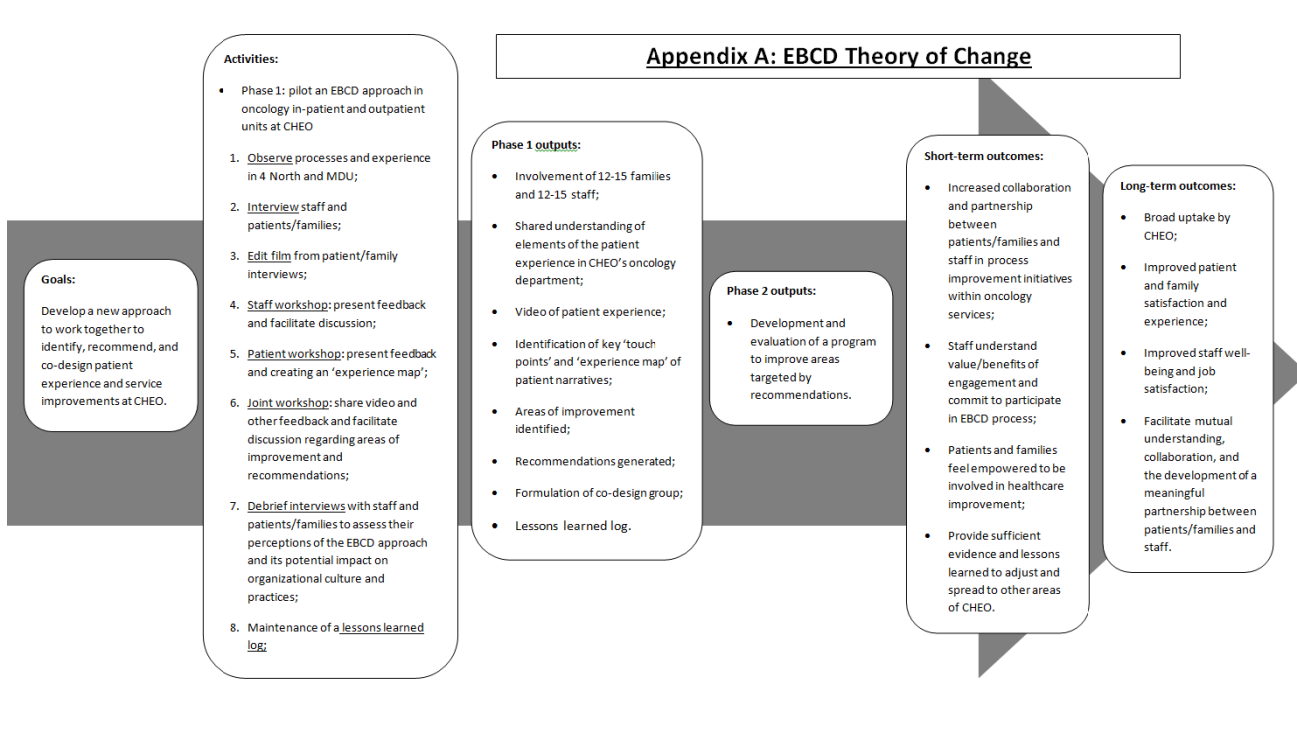
The results presented here suggest what may be the best option for CHEO to carry this forward, is a modified approach to co-design using for example different methods of data collection and consultation and an accelerated timeline rather than the full EBCD approach. Investigating, designing, and implementing change takes time, and as such the EBCD process loop has not yet been closed. While the subsequent phase where EBCD participants co-designed unit-based improvement initiatives is complete, the implementation, adjustment, and measurement of these improvements is on-going. Following these steps, administration will need to determine if co-design is a worthwhile endeavour for CHEO. Though this process was complex and lengthy, effective PE using EBCD requires investment, integration,

and momentum with the existing QI methodology of the healthcare organization.<sup>10</sup>

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## Appendix A. EBCD Theory of Change



**Appendix B: EBCD in Oncology Improvement Ideas**

S = Staff item

PF = Patient and family item

Item #	Problem statement	Challenges	Opportunities
<b>S1</b>	Staff feel tension between stressful work conditions and their capacity to provide best possible care to patients and families	<ul style="list-style-type: none"> <li>- Limited opportunities to give or receive recognition for work well done</li> <li>- Many changes and high staff turnover (esp. in 4N)</li> <li>- Lack of knowledge and understanding of one another's role and resulting difficulty re team effectiveness</li> <li>- Insufficient reserve in the system to account for unexpected though regular events (e.g. pts taking turn for worst)</li> <li>- Lack of opportunities for staff to hone skills and knowledge</li> </ul>	<ul style="list-style-type: none"> <li>- More team building</li> <li>- Staff shadowing staff</li> <li>- Reintroduce "Supergrams"</li> <li>- Ensure change initiatives involve the right people at the right time</li> <li>- Support staff self-care (e.g. taking breaks), team building and professional development</li> </ul>
<b>S2a</b>	Special treatment is given to some patients/families causing inequities in the provision of care	<ul style="list-style-type: none"> <li>- Consistent messaging and care to all families is difficult to maintain across disciplines with increased number of junior staff</li> <li>- Families that are either deemed "difficult" or more demanding of staff and the system will either be avoided or get what they want from staff who are under time constraints and/or want to avoid conflict</li> </ul>	<ul style="list-style-type: none"> <li>- Standardize tools and info for patients and staff to ensure people receive info in a consistent way and know what to expect</li> <li>- Have checklist at front of chart to indicate what teaching/information has been provided to pts/families</li> </ul>
<b>S2b</b>	Patients/families often lack the information or the opportunity to provide information that will allow them to be good "partners in care"	<ul style="list-style-type: none"> <li>- Not all families have the capacity to advocate for themselves and get what they want/need</li> <li>- Staff often do things for families that they might be able to do for themselves, given the proper tools and information</li> </ul>	<ul style="list-style-type: none"> <li>- Staff need to reinforce to pts/families that it is okay to speak about specific challenges/needs that, when addressed, can help them to be more proactive in their care</li> <li>- Provide pts/families with the right information at the right time</li> <li>- All staff need to probe regularly for issues and concerns, and connect pts/families with appropriate people/resources in a timely way</li> </ul>



Item #	Problem statement	Challenges	Opportunities
S3	Existing communication tools do not foster effective team work across disciplines and units	<ul style="list-style-type: none"> <li>- Electronic record is challenging for physicians; information is not consolidated in one place</li> <li>- Something like the old “Kardex” is missing to allow interdisciplinary communication about significant pt/family info on and between in-patient and out-patient units</li> <li>- Information about which patient is assigned to which staff member (e.g. social work) is not easily accessible</li> </ul>	<ul style="list-style-type: none"> <li>- Efforts should be made to include all team members at initial meeting with newly diagnoses pts/families (pics and role descriptions and support this when team members are not unavailable)</li> <li>- Find way for all staff to pts/family-team member assignment</li> <li>- Reintroduce something like the “Kardex”</li> </ul>
S4	There is a lack of space and privacy to provide optimal care, have discussions with families and provide therapeutic support	<ul style="list-style-type: none"> <li>- There are not enough bathrooms in MDU</li> <li>- There are no private spaces for counselling support</li> <li>- There is limited space to disclose diagnosis and maintain confidentiality</li> <li>- Clinic space for discussion of cases with learners is limited</li> </ul>	<ul style="list-style-type: none"> <li>- Additional space</li> <li>- More bathrooms in MDU</li> </ul>
S5	Previous efforts to increase efficiencies on both units have not been sustained	<ul style="list-style-type: none"> <li>- Workloads do not allow staff to provide what they consider to be good care</li> <li>- Staff often miss breaks and delay their lunches</li> <li>- Wait times for families in MDU</li> </ul>	<ul style="list-style-type: none"> <li>- Better alignment between staff assignments and patient care needs</li> <li>- Build in more reserve to accommodate unexpected (though common to oncology) events</li> </ul>
PF1	Pt/families are often unclear about the roles and responsibilities of healthcare team members including their own roles and responsibilities	<ul style="list-style-type: none"> <li>- Many health professionals are introduced in the early phases of treatment, but pt/family members often struggle to remember “who is who”</li> <li>- Pt/family members are often confused about what to expect or what they are supposed to do (i.e. we don’t know what we don’t know)</li> <li>- Family members feel lost, especially in the early days of their admission, and struggle to find their way</li> <li>- The “treatment road map” does not get regularly updated when the protocol has been modified</li> </ul>	<ul style="list-style-type: none"> <li>- Develop a standard approach to introduce healthcare team members to pts/families that is not overwhelming or stressful</li> <li>- Provide regular updates to keep pt/family members informed at every step (including updates to “treatment road map”)</li> <li>- Develop orientation booklet for oncology services</li> <li>- Develop checklists for both pts/families and staff that include items that need to be addressed by both</li> </ul>

Item #	Problem statement	Challenges	Opportunities
PF2	Pt/families have difficulty accessing psychosocial support when needed	<ul style="list-style-type: none"> <li>- There is some confusion about which health care professional is best positioned to provide this type of support (i.e. social worker, nurse or psychologist)</li> <li>- Social workers are not always available at the right time or the right place (unscheduled visits in the midst of medical treatment and the effects of treatment can be counterproductive)</li> <li>- Insufficient information about what might be available outside of CHEO</li> </ul>	<ul style="list-style-type: none"> <li>- Rethink how psychosocial services are offered and provided to oncology pts/families</li> <li>- Ensure that families know how to access psychosocial support internally and externally</li> <li>- Support should be offered at the right time (pt/family member receptive to it) and at the right place (in a private office rather than in room or hallway)</li> <li>- Empower staff to offer emotional support within the limitations of their roles/responsibilities and to help make connections with psychosocial professionals</li> </ul>
PF3	Standard practices and norms can get in the way of a more personalized approach to care	<ul style="list-style-type: none"> <li>- Staff don't always have the freedom or the information about patients to help them create a more optimal experience for patients and families</li> <li>- Staff don't always consider the fact that while the unit is their work environment, it is the pts/families' living environment</li> </ul>	<ul style="list-style-type: none"> <li>- Include at the front of the patient chart information that is important for staff to know about patients (e.g. afraid of needles, only speaks French, etc.)</li> <li>- Allow staff the flexibility to make decisions that are in the best interest of their patient</li> </ul>
PF4	Wait times in MDU and for certain procedures are seen as a result of poor planning and care coordination	<ul style="list-style-type: none"> <li>- Wait times in MDU are unpredictable and therefore difficult for families to make plans around these appointments</li> <li>- Parents do not understand rationale for coming in at 8 a.m. for lumbar puncture when these do not start before 10 a.m.</li> <li>- Waiting is difficult when there is no explanation for the delay or for what's next</li> <li>- Patient needs to be in MDU before starting chemo preparation</li> </ul>	<ul style="list-style-type: none"> <li>- Start lumbar punctures earlier to decrease length of time patients have to fast and wait</li> <li>- Allow parents to trigger chemo preparation by phone call prior to arrival</li> <li>- Keep parents informed of reasons for delay and next steps</li> <li>- Better scheduling of appointments</li> </ul>

Item #	Problem statement	Challenges	Opportunities
PF5	Many Emergency Department personnel have demonstrated insufficient knowledge and skill in treating oncology patients <sup>1</sup>	<ul style="list-style-type: none"> <li>- Wait times in ED to get admitted to 4N are long and stressful</li> <li>- Nurses commonly ask parents about procedures and proper equipment for accessing ports</li> <li>- Lack of empathy and patience demonstrated by nurses for patients who are frequently poked and prodded</li> <li>- ED nurses have not always complied with pt/parent requests to involve child life specialists</li> </ul>	<ul style="list-style-type: none"> <li>- Reconsider how oncology patients access oncology services when being admitted for complications such as febrile neutropenia</li> <li>- Provide in-service training to ED nurses by oncology nurses to develop skill set and increased understanding of this patient population and their unique needs</li> <li>- Provide access to child life specialists in ED</li> </ul>
PF6	Parents have been confused and overwhelmed about the decision they are asked to make about treatment options and clinical trials	<ul style="list-style-type: none"> <li>- Parents feel they lack the expert knowledge required to make such decisions</li> <li>- Some were overwhelmed with feeling that the decision was critical to their child's living or dying</li> </ul>	<ul style="list-style-type: none"> <li>- Oncologists should be very clear about what it is they are asking parents to decide</li> <li>- Oncologists should provide more guidance to pts/parents through decision making process</li> </ul>
PF7	Non-oncology patients and families on 4N are unaware of infection control precautions on the unit	<ul style="list-style-type: none"> <li>- Families have experienced awkward conversations with other families who were until then unaware of being on the oncology unit</li> <li>- Oncology parents have had to educate non-oncology families on the importance of infection control procedures</li> <li>- Healthcare professionals from other units coming to care for non-oncology patients do not always respect the infection control procedures</li> </ul>	<ul style="list-style-type: none"> <li>- Provide information to non-oncology pts/families about 4N and protocols that need to be respected</li> <li>- Signage should be visible to all that 4N is an oncology unit</li> <li>- Have visitors report to nurses' station to control access to unit</li> </ul>

<sup>1</sup> It has been noted with patients and families that improvements in the emergency department are outside of the scope of the EBCD in oncology project. Given the large number of patient/family stories that were heard about less than optimal care experiences in the ED, as well as the significance of these experiences in understanding the overall oncology patient/family experience, data has been collected on this touch point along with others in order to allow the emergence of improvement ideas in this area.

Item #	Problem statement	Challenges	Opportunities
PF8	Pt/family language preferences are not always taken into account by staff when providing verbal or written information	<ul style="list-style-type: none"> <li>- Parents are concerned about the ease with which visitors can walk on the unit without checking in at the nurses' station</li> <li>- There is a disconnect between asking about a patient's language of choice and following through with accommodating for this preference</li> <li>- Parents are told they can receive written information in French, but most often receive it in English</li> <li>- Difficult to understand information in second language, especially during critical touch points when stress is higher</li> </ul>	<ul style="list-style-type: none"> <li>- Greater efforts should be made to assign French speaking families to French speaking staff</li> <li>- Language of choice should be documented and visible by all staff who can help accommodate for preferences</li> <li>- If staff are unable to communicate in language understood by child, they should ask parents or bilingual staff to translate to child rather than speak directly to child in a language they do not understand</li> <li>- If unable to provide services in language of choice consistently, efforts should be made to do so at critical touch points (e.g. diagnosis, 1<sup>st</sup> chemo, etc.)</li> <li>- Psychosocial support should always be offered in the language of preference</li> </ul>