

**Understanding the Process of Patient Engagement in Planning and Evaluation of Health
Services: A Case Study of the Psychosocial Oncology Program at the Ottawa Hospital**

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Dedications

To my father's memory, and my beloved family and friends for always supporting, helping, and standing by me.

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PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

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Abstract

The underlying philosophy of patient-centred care (PCC) advocates for patients to have an active role in all areas of their care, including broader areas of the health care system such as planning and evaluation. Despite efforts made in the past decade that would see greater patient engagement, conventional evaluation approaches continue to dominate the landscape in health services evaluation. To date, limited empirical research has examined the effects of patient engagement or the best approach to engage patients (Abelson et al., 2015; Baker, 2014; Baker, Judd, Fancott, & Maika, 2016). Furthermore, a relative lack of collaboration and shared knowledge exists between the evaluation community and health sector in the rapidly developing area of patient engagement and the development of best practices. Consequently, health organizations continue to struggle with how best to involve patients (i.e., process) in health service improvement initiatives, as well as learn from patient experience (Baker, 2014; Baker, Judd, et al., 2016; Luxford et al., 2011).

This dissertation responded to some of these challenges and through this intervention study, the specific purpose of the thesis study was to gain a better understanding of the process of patient engagement in planning and evaluation by addressing the following research questions:

1. What are the facilitators and barriers of engaging patients in planning and evaluation of health services and why?
2. What did the process of engagement look like with respect to Cousins and Whitmore's (1998) three dimensions of collaborative inquiry?
3. What are the observed effects of the engagement process?

This longitudinal qualitative case study began with the creation of the Patient and Family Engagement Committee (PFEC) at the Ottawa Hospital Psychosocial Oncology Program (PSOP) and completed an evaluation project over a period of six months. The research study occurred in parallel with the evaluation project and was designed to gain a better understanding of the process of patient engagement and the role that evaluation plays in this context. The study consisted of three phases and data collection relied on multiple sources.

Facilitators that influenced the patient engagement process include: accommodating participant needs, commitment, orientation meeting, designated lead with evaluation skills, homework between meetings, and mutual respect. Having a designated lead, mutual respect, and commitment to the project were the three most highly endorsed facilitators at the end of the project.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Conversely, barriers identified include time and resources, imbalanced participation, change in health status, and living at a distance. Time and resources was endorsed as the most significant barrier to the patient engagement process across all three phases of the study. Motivations for participant involvement revolved around giving back, improving health services, learning, commitment to research/evaluation, and providing or hearing a unique perspective. The study examined participatory aspects of the focal evaluation using Cousins and Whitmore's (1998) three fundamental dimensions of process in collaborative approaches to evaluation: stakeholder diversity, control of evaluation process, and depth of participation. Findings revealed that intended benefits of participant involvement included reach to decision-makers, improved health services, increased diffusion of patient/family engagement, improved access/awareness of services, and a follow-up to assess influence of engagement. Participants' experiences of being involved invoked enthusiasm for the project, were personally rewarding, instilled a sense of optimism that the project would have an influence, closed the loop on healing, contributed to a shift from a personal to broader health care focus, and contributed to learning.

Further research is needed to gain a better understanding of the processes involved or evaluation approaches that could contribute to translating patient engagement into improved outcomes. The findings of this study have enhanced understanding of key contributions that patients, family members, health professionals, and evaluators bring to the patient engagement process, and enriched understanding of key facilitators and barriers to ensure successful patient engagement.

Table of Contents

Dedications	ii
Acknowledgments	iii
Abstract	v
List of Tables.....	xiii
List of Figures	xv
List of Acronyms and Abbreviations	xvi
Chapter 1: Introduction	1
Statement of the Problem	1
Overview of Thesis.....	2
Chapter 2: Literature Review	4
Patient-Centred Care	4
Patient Engagement	9
Facilitators of Patient Engagement	12
Barriers to Patient Engagement.....	14
Participatory Approaches to Program Evaluation	15
Research Purposes and Approach	19
Conceptual Framework	20
Focal Intervention and Research Questions.....	22
Chapter 3: Methods	25
Research Overview.....	25
Epistemological Orientation.....	25
Research Approach and Design.....	27
Case Description.....	28
Participant Recruitment.....	29

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Research Ethics	32
Data Collection	32
Program Documents	33
Participant Observation	33
Independent Interviews	33
Reflective Journal	35
Focus Group	35
Data Analysis	36
Ensuring Quality	37
Construct validity.	38
Internal validity.	39
External validity.	39
Reliability.	39
Chapter 4: Phase I Findings	41
Phase I Timelines and Overview	41
Phase I Interview Findings	41
Contextual Factors	42
Motivations for patient engagement involvement.	42
Facilitators to patient engagement.	44
Barriers to patient engagement.	48
Patient Engagement Process	51
Diversity of members.	51
Depth of participation.	56
Control over evaluation process.	58
Improving the engagement process.	61
Consequences of the Patient Engagement Process	61
Intended benefits.....	61
Participant experience.....	64

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Phase I Participant Observation and Researcher Reflection Findings	66
Contextual Factors	66
Patient Engagement Process	69
Consequences of Patient Engagement	69
Chapter Summary	70
Contextual Factors	70
Patient Engagement Process	71
Consequences of the Patient Engagement Process	72
Chapter 5: Phase II Findings	73
Phase II Timelines and Overview.....	73
Phase II Interview Findings.....	74
Contextual Factors	74
Facilitators to patient engagement.....	74
Barriers to patient engagement.....	78
Patient Engagement Process	80
Diversity of members.....	80
Depth of participation.....	81
Control over evaluation process.....	85
Improving the patient engagement process.....	89
Consequences of the Patient Engagement Process	91
Intended benefits.....	91
Participant experience.....	93
Unintended outcomes.....	96
Phase II Participant Observation and Researcher Reflection Findings	96
Contextual Factors	96
Patient Engagement Process	99
Consequences of Patient Engagement Process	100

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Chapter Summary	100
Contextual Factors	101
Patient Engagement Process	101
Consequences of the Patient Engagement Process	102
Chapter 6: Phase III Findings	103
Phase III Timelines and Overview	103
Phase III Interview Findings	104
Contextual Factors	104
Facilitators to patient engagement.	104
Barriers to patient engagement.	107
Patient and Family Engagement Process	109
Diversity of members.	109
Depth of participation.	110
Control over evaluation process.	113
Improving the engagement process.	116
Consequences of the Patient Engagement Process	117
Intended benefits.....	117
Participant experience.....	121
Unintended outcomes.	124
Phase III Participant Observation and Researcher Reflection Findings.....	124
Contextual Factors	124
Patient Engagement Process	126
Consequences of Patient Engagement Process	126
Chapter Summary	127
Contextual Factors	127
Patient Engagement Process	127
Consequences of the Patient Engagement Process	128

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Chapter 7: Phase IV Validation of Research Findings.....	130
Focus Group Process	130
Focus Group Findings	130
Motivations for Patient Engagement Involvement	130
Facilitators and Barriers to the Patient Engagement Process.....	131
Improving the Engagement Process.....	133
Diversity of PFEC	133
Depth of Participation	134
Control over Evaluation Process.....	135
Intended Benefits of the Engagement Process	135
Participant Experience	136
Unintended Outcomes.....	137
Conclusion.....	137
Chapter 8: Discussion.....	139
Motivation for the Study	139
Overview of the Study.....	139
Summary of Findings by Research Questions.....	141
Question 1: Facilitators and Barriers of Patient Engagement	141
Motivations for patient engagement involvement.	141
Question 2: Process According to Dimensions of Collaborative Inquiry	145
Control over evaluation process.	145
Diversity of PFEC.	147
Depth of participation.....	147
Improving the engagement process.	148
Question 3: Observed Effects of the Engagement Process	149
Intended benefits of the engagement process.	150

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Participant experience.....	150
Unintended outcomes.	151
Observed outcomes and process dynamics	152
Relevant Findings Contributing to the Literature.....	152
Contextual Factors	155
Patient Engagement Intervention/Process.....	158
Consequences.....	162
Limitations of the Study	163
Implications for Research.....	165
Implications for Practice and Policy.....	167
Genuine Commitment for Genuine Engagement.....	168
Participant Recruitment for Patient Engagement.....	168
Let's not reinvent the Wheel.....	169
Policy Makers and Organizational Decision-Makers	170
Conclusion.....	170

List of Tables

Table 1 <i>Definitions of PCC and Health Care Context Represented</i>	6
Table 2 <i>Summary Description of Study Participants</i>	31
Table 3 <i>Justification of Data Sources</i>	32
Table 4 <i>Interview Timelines</i>	33
Table 5 <i>Case Study Tactics for Quality Tests</i>	37
Table 6 <i>Motivations for Patient Engagement Involvement</i>	42
Table 7 <i>Facilitators to Patient Engagement in PFEC during Phase I</i>	45
Table 8 <i>Barriers for Participation in PFEC during Phase I</i>	48
Table 9 <i>Diversity of PFEC Members during Phase I</i>	52
Table 10 <i>Depth of Participation in Engagement Process during Phase I</i>	56
Table 11 <i>Control over Evaluation Process during Phase I</i>	59
Table 12 <i>Intended Benefits of Engagement Process during Phase I</i>	62
Table 13 <i>Participant Experience of PFEC Involvement during Phase I</i>	64
Table 14 <i>Meetings II, III, and IV: Evaluation Work Completed Prior to Phase II Interviews</i>	74
Table 15 <i>Facilitators to Patient Engagement during Phases I and II</i>	75
Table 16 <i>Barriers to Participation in PFEC during Phases I and II</i>	78
Table 17 <i>Diversity of PFEC Members during Phases I and II</i>	80
Table 18 <i>Depth of Participation during Phases I and II</i>	82
Table 19 <i>Control over Evaluation Process during Phases I and II</i>	86
Table 20 <i>Recommendations for Improving the Engagement Process during Phase II</i>	89
Table 21 <i>Intended Benefits during Phases I and II</i>	91
Table 22 <i>Participant Experience during Phases I and II</i>	93
Table 23 <i>Meetings V and VI: Evaluation Work Completed Prior to Phase III Interviews</i>	103
Table 24 <i>Facilitators to Patient Engagement during Phases I, II, and III</i>	104
Table 25 <i>Recurring Themes: Barriers for Participation in PFEC during Phases I, II, and III</i> .	107
Table 26 <i>Diversity of PFEC Members during Phases I, II, and III</i>	110
Table 27 <i>Depth of Participation in Engagement during Phases I, II, and III</i>	111
Table 28 <i>Control over Evaluation Process during Phases I, II, and III</i>	113
Table 29 <i>Recommendations for Improving Engagement Process during Phases I, II, and III</i> ..	116

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Table 30 <i>Intended Benefits during Phases I, II, and III</i>	118
Table 31 <i>Participant Experience during Phases I, II, and III</i>	121
Table 32 <i>Facilitators and Level of Endorsement Across all Three Phases</i>	143
Table 33 <i>Barriers and Level of Endorsement Across all Three Phases</i>	144
Table 34 <i>Control over Evaluation Process and Level of Endorsement across Three Phases</i>	146
Table 35 <i>Diversity of PFEC Members and Level of Endorsement across Three Phases</i>	147
Table 36 <i>Depth of Participation and Level of Endorsement across Three Phases</i>	148
Table 37 <i>Recommendations to Improve Process and level of endorsement across Three Phases</i>	149
Table 38 <i>Intended Benefits and Level of Endorsement Across all Three Phases</i>	150
Table 39 <i>Participant Experience and Level of Endorsement Across all Three Phases</i>	151

List of Figures

Figure 1. A multidimensional framework for patient engagement in health and health care 12

Figure 2. An integrated set of principles for use in guiding collaborative approaches to evaluation..... 17

Figure 3. Dimensions of form in collaborative inquiry..... 18

Figure 4. Conceptual framework: contextual factors, intervention, and consequences. 21

Figure 5. Revised conceptual framework..... 154

List of Acronyms and Abbreviations

CFHI: Canadian Foundation for Health Care Improvement

IAPO: International Alliance of Patients' Organization

IOM: Institute of Medicine

PCC: Patient-Centred Care

PFEC: Patient and Family Engagement Committee

P-PE: Practical Participatory Evaluation

PSOP: Psychosocial Oncology Program

T-PE: Transformative Participatory Evaluation

Chapter 1: Introduction

Statement of the Problem

Health organizations are increasingly making efforts to offer patient-centred health services that are more responsive to patient preferences, values, and needs. The underlying philosophy of patient-centred care (PCC) advocates for patients to have an active role in all areas of their care, including broader areas of the health care system such as planning and evaluation of health services (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Stewart et al., 2000). The conceptualization of PCC emerged during the 1950s and is widely used in health organizations to refer to an essential component of quality health care. The concept of PCC was originally introduced as a rejection of the traditional model of care that tended to be more disease- and physician-focused, towards health care that is more holistic in nature and aims to improve the patient experience. Studies have demonstrated that PCC, with its emphasis on being responsive to patient preferences and needs, has positive outcomes on the quality of health care and is strongly desired by patients and families (Agency for Health Care Research and Quality, 2005; Little et al., 2001; Rao, Weinberger, & Kroenke, 2000). However, despite considerable quality improvement efforts, health organizations have had mixed results in implementing widespread patient-centredness (Luxford, Safran, & Delbanco, 2011; Shaller, 2007).

The Institute of Medicine's ([IOM], 2001) report *Crossing the Quality Chasm* has been influential and has received widespread support within health care with respect to applying more patient-focused quality improvement strategies. These strategic efforts to increase patient engagement are geared towards addressing some of the gaps identified in the use of conventional quality improvement strategies as well as improving the quality of patient-centred health services. More recently, a sharp increase has been seen in the number of government organizations sponsoring and advocating for greater patient engagement activities across all levels of health care (e.g., quality improvement, accreditation, strategic planning, research). For example, the *Patients First: Action Plan for Health Care*, which made a commitment to expand patient engagement in Ontario (Ministry of Health and Long-Term Care, 2015), and *Canada's Strategy for Patient-Oriented Research*, which provides an opportunity for engaging patients in identifying research priorities, as well as integrating research findings into patient care and health policy (Canadian Institutes of Health Research, 2016). There are also examples within the

private sector that engage patients to help inform some of the work that they do. For example, Calprise (2017) examined the actions that pharmaceutical companies could take “to positively influence clinical trial participation and impressions of the clinical trial experience, and to increase the relevance of clinical trial results to patients” (p. 9). With greater attention and efforts made towards patient engagement in the planning, design, and evaluation of health services, it is critical to identify strategies that continue the advancement of patient engagement as complementary to improving patient-centred health services. Health organizations have attempted to increase patient engagement efforts, but some of these developments have not always been as productive and effective as originally intended.

To date, limited empirical research has examined the effects of patient engagement or the best approach to engage patients (Abelson et al., 2015; Baker, 2014; Baker, Judd, Fancott, & Maika, 2016). Furthermore, a relative lack of collaboration and shared knowledge exists between the evaluation community and health sector in the rapidly developing area of patient engagement and the development of best practices. Consequently, health organizations continue to struggle with how best to involve patients (i.e., process) in health service improvement initiatives, as well as learn from patient experience (Baker, 2014; Baker, Judd, et al., 2016; Luxford et al., 2011).

The overarching objective of the present longitudinal case study was to address this gap by learning more about the process (what helps or hinders) of involving patients and families to work collaboratively with health professionals to improve health services. The study also examined the patients’ and family members’ perspectives, as well as those of health professionals involved in the program improvement process. Through an intervention study of patients, family members, health professionals, and decision-makers engaged in a sustained strategic planning initiative, this study a) examined the benefits of patient engagement, b) explored the experiences of patients and families, as well as health professionals, with the collaborative inquiry process, and c) investigated the efficacy of the collaborative processes used.

Overview of Thesis

Chapter 2 contextualizes the study in the relevant literature and synthesizes a more detailed examination about what is known about patient-centred care, patient engagement, and the sorts of processes or approaches in which we might expect patient engagement to prosper. Chapter 2 also describes the conceptual framework used to bind the inquiry and the overall

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

objectives of the study including the research questions. Chapter 3 provides an account of the research methods including the epistemological orientation that guided the study, study design, description of the case study, and data collection and analysis procedures for all three phases of the study. Chapters 4, 5, and 6 present detailed descriptions of the findings associated within the three phases of data collection. Phase I findings are described in Chapter 4 and include baseline data collected after the orientation meeting but before project goals had been established. Phase II findings, when the project was at mid-point of completion and well established, are described in Chapter 5, and Chapter 6 presents the findings of Phase III at the completion of the evaluation project. Chapter 7 presents the Phase IV findings of the validation exercise that took the form of a focus group following the completion of the project and review of the preliminary findings. Lastly, Chapter 8 presents a detailed discussion of the findings, implications for practice and research, and a conclusion.

Chapter 2: Literature Review

The purpose of this literature review is to situate the thesis in the current body of knowledge in the following three areas: patient-centred care, patient engagement in planning and evaluation of health services, and participatory approaches to program evaluation. In addition to surveying the landscape in the area, I critique the quality of the knowledge base and identify substantive and methodological gaps that may be worth pursuing. I begin by providing an overview of the evolutionary trajectory of PCC, providing a conceptual perspective for discussing some of the facilitators, barriers, and approaches to patient engagement.

Patient-Centred Care

The conceptualization of PCC emerged during a time of substantive change in health care, changes that saw the introduction of new technologies, specialties, and patient populations. PCC is entrenched in health organizations to refer to an essential component of quality health care. Despite difficulties defining the term, by the late 1990s some general principles were associated with PCC, many of which were based on seminal work by the *Picker Commonwealth Program for Patient-Centred Care*, now known as the *Picker Institute*, which is considered to be one of the more influential organizations for advancing PCC (Shaller, 2007). The Picker inquiry, led by Gerteis et al. (1993), conducted a wide range of focus groups with recently discharged patients, family members, physicians, and non-physician hospital staff and reviewed pertinent literature related to PCC. Seven key principles of PCC were identified through this work, which culminated in the publication of a book entitled *Through the Patient's Eyes* (Gerteis et al., 1993). The fundamental PCC principles identified in this work are as follows:

- Respect for patients' values, preferences, and expressed needs;
- Coordination and integration of care;
- Information, communication, and education;
- Physical comfort;
- Emotional support and alleviation of fear and anxiety;
- Involvement of family and friends; and
- Transition and continuity. (p. 223)

Subsequent to the publication of this book was a significant increase in the interest in PCC across health care systems and significant uptake in efforts to define PCC (International Alliance of

Patient Organization, 2007). For example, in its landmark report, *Crossing the Quality Chasm* (Institute of Medicine, 2001), it includes PCC as one of their six aims for health care improvement and declares that “making care more patient-centred means adjusting nearly every aspect of practice, in every realm from the administrative to the clinical to the technological” (p. 1).

Despite the prominence given to PCC within the health care system, implementation of effective PCC practices remains a challenge (Luxford et al., 2011; Shaller, 2007). Identification and distinction of PCC definitions within the different health care contexts in which it is being applied could assist health care providers with respect to improving the implementation of PCC. For example, Robinson, Callister, Berry, and Dearing (2008) indicate that most PCC definitions are derived from the following four distinct sources:

- *Economic perspective*: Based on the premise that the patient is a consumer of health care. This perspective is not as relevant in Canada as it is in the United States.
- *Clinical perspective*: Addresses patients’ expectations of being actively involved with their health care provider in decisions related to treatment.
- *Patient perspective*: Relates to how patients expect to be treated by health care professionals when receiving health services.
- *Public policy perspective*: Helps shape the vision of health care and provides the basic concepts for building a quality health care system.

The PCC perspectives that Robinson et al. (2008) suggest deconstruct the PCC concept into more manageable and context-specific components. Table 1 provides examples of PCC definitions within each of the four areas of health care. These four proposed PCC perspectives challenge health organizations to focus their efforts at all levels of the health care system and are useful for articulating the strategic vision of PCC from “boardroom to bedside” (Shaller, 2007, p. 10). Significant efforts have been made in the past decade, using a bottom-up approach, to improving PCC practices within the *patient* and *clinical PCC perspectives* that take place at the individual patient level. However, one area of development that deserves greater attention is exploring PCC practices aimed at the broader organizational level of health programs and organizations (International Alliance of Patient Organization, 2007).

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Table 1

Definitions of PCC and Health Care Context Represented

Health Care Context	Definition
Public Policy Perspective	Placing patients at the centre of the system of care and developing good services that revolve around them (Mallett, 1996).
Economic Perspective	Patients and their families receive evidenced-based, cost-effective quality care that maximizes health, alleviates discomfort, and is safe and free from avoidable errors (National Health Council, 2004 as cited in International Alliance of Patient Organization, 2007).
Patient Perspective	An approach to care that consciously adopts a patient's viewpoint. This perspective can include such dimensions as respect for patients' values, preferences, and expressed needs in regard to coordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, involvement of family and friends, and transition continuity (US Agency for International Development, 1999 as cited in International Alliance of Patient Organization, 2007).
Clinical Perspective	A collaborative effort consisting of patients, patients' families, friends, the doctors, and other health professionals... achieved through a comprehensive system of patient education where patients and the health care professionals collaborate as a team, share knowledge, and work toward the common goals of optimum healing and recovery (International Alliance of Patient Organization, 2007).

Robinson et al. (2008) refer to this as the *public policy perspective* of PCC, and it serves as the foundation for all other PCC practices and sets the strategic direction for PCC across health care. Mallet's (1996) definition of PCC as "placing patients at the center of the system of care and developing good services that revolve around them" (p. 10) is a good example of a PCC definition addressing this perspective and will be used to guide this patient engagement study. For the purpose of this study, the PCC public policy perspective put forth by Robinson et al. (2008) was modified to specifically address the broader organizational level of a health program or health organization and will not address public policy.

Luxford et al. (2011) identify key organizational facilitators for promoting successful implementation of PCC. The most important of these are (a) a strong and committed leadership

(i.e., CEO and board of directors), which is critical for achieving sustained delivery of PCC; (b) a strong and clearly communicated strategic vision, which is constantly communicated to every member of the organization; (c) systematic measurement and regular feedback to health service providers (e.g., front-line staff, decision makers, etc.) of patient experience data with high specificity; (d) involvement of patients and families at multiple levels (e.g., service redesign, partners in care, patient and family advisories, representation on medical executive committees, etc.); and (e) a culture that strongly supports change and collective learning identified as a powerful enabler to PCC.

Current strategies used for the assessment and monitoring of PCC and patient experience tend to be primarily based on performance measurement and patient/family feedback (Baker, 2014; Davies & Cleary, 2005). For example, patient satisfaction surveys are commonly used for reporting on the quality of health services as well as informing decision-making. Considered one of the *gold standards* in health care quality improvement, a wide range of validated patient satisfaction surveys are available and are low-cost, can gain large amounts of feedback, can be easily implemented, and can provide hospitals with an opportunity to receive post hoc feedback from patients (Canadian Foundation for Healthcare Improvement [CFHI], 2012; Veillard et al., 2005). Yet, as reported by the CFHI, there is a myth in health care that “high patient satisfaction means high quality care” (2012, p. 1). Martin and Ronson (2007) caution that an approach in which health organizations rely on patient satisfaction surveys to identify areas that need improvement and to learn more about the patient experience is insufficient. They conclude that “fifty years of patient satisfaction research has found that in study after study between 80 and 90% of patients are satisfied” (2007, p. 8). Some of this can be explained by the fact that most patient satisfaction surveys tend to ask surface-level questions (i.e., discrete, categorical questions about delivery of care), are subject to self-selection and literacy bias, and are therefore limited in capturing the patient experience beyond the questions being asked (CFHI, 2012; Williams, Coyle, & Healy, 1998). Other forms of feedback commonly used to tap into the patient experience include interviews, complaints, and patient or family narratives. These are beneficial for capturing patient experience information, but tend to focus on individual issues, are resource intensive, and often challenge decision-makers with respect to how to incorporate the resulting data into quality improvement plans (Baker, 2014).

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Another common practice in health care quality improvement efforts is the use of performance measurement systems, which monitor the performance of the broader health care system using statistical data to determine progress toward specific defined objectives such as PCC (Adair et al., 2006). Health decision-makers gather performance monitoring data by monitoring selected indicators and targets to help assess their performance over time and to make comparisons with other health institutions that offer similar services. Performance data serve an important role in ensuring health organizations meet accountability requirements established by their funding agencies. They are also regularly used to help inform health professionals and decision-makers with respect to how health consumers use the health system (e.g., number of emergency department visits, wait times) as well as to establish strategic directions. However, an important limitation is the relative lack of health performance systems that include indicators that can further our understanding of patients' health service experiences, which are integral to improving PCC (Canadian Institute for Health Information, 2015). One explanation may be that patients or family members are not regularly involved or consulted in the development of health services indicators; that is, performance indicators are typically developed through provincial or state requirements, research evidence, and consensus of an expert panel usually comprising health professionals without input from patients or family members (Baker, Fancott, Judd, & O'Connor, 2016). As a result, performance data often fall short in terms of informing decision-makers about issues that are of importance to patients and families. For example, administrators, clinicians, and patients give importance to different aspects of care, and their ideas on quality health services differ (Kötter, Schaefer, Scherer, & Blozik, 2013). Administrators tend to be concerned with *operational efficiency* (e.g., bed occupancy, budget), clinicians are interested in *clinical efficiency* (e.g., mortality rates, complications), and patients are more concerned with the health care experience and interpersonal interactions with health providers (Ioan, Nestian, & Tiță, 2012). Arguments have been made for greater involvement of patients and family members in indicator development and selection to collect performance data that are more reflective of patient and family priorities and to better understand the patient experience (Gagliardi, Lemieux-Charles, Brown, Sullivan, & Goel, 2008a, 2008b; Kötter et al., 2013). Recently, the CIHI (2016) has taken the lead in efforts to address the indicator gaps related to measuring patient experience and are in the process of developing "a set of indicators to measure patient experience, inform performance improvements over time, and support benchmarking across Canada" (p. 2). This is

an important contribution to health performance systems and will certainly advance the ability of health professionals and decision-makers to consider and better understand patient experiences. However, key challenges that will remain are the ability to gain a true understanding of the local context of patient experience and to explain the variance in results.

The use of performance measurement and patient feedback is well entrenched within the health sector and highly valued by decision-makers. These strategies serve important functions in terms of meeting accountability requirements and monitoring patient satisfaction. Yet, despite efforts to collect these forms of data, the application of quality improvement strategies that would facilitate patient-centredness across organizations remains a challenge and has had mixed results (Baker, 2014; International Alliance of Patients' Organizations, 2007; Ponte et al., 2003; Robinson et al., 2008). For example, Baker (2014) reviews how patient engagement contributes to improved care, reporting that decision-makers feel challenged in linking these data sources to answer key priority questions. Overall, efforts made towards developing sophisticated measures for capturing patient experience have not led to improved knowledge on how to apply these results as a means to improve the patient experience. As Baker (2014) notes, "while data and stories about patients are important sources of information, they may be insufficient to motivate and focus improvement in many contexts" (p. 2).

While the concept of PCC is well entrenched in health care, there continue to be challenges with respect to its meaning and implementation. The factors contributing to successful implementation of PCC outlined in this section may provide some insight into practices that elevate the norm. In response to the continuing challenge of incorporating widespread patient-centredness across health organizations, momentum is building and there is commitment within the health sector to seriously support activities that engage patients in health care quality improvement efforts.

Patient Engagement

This leads us to a body of knowledge that promotes *patient engagement* in planning and evaluation as a means of addressing PCC at the broader level of a health program or organization. The terminology surrounding patient engagement, patient involvement, public engagement, and public involvement in health care is quite varied (Dyess-Nugent, 2018; Finset 2017; Higgins, Larson, Schnall, 2017). All of these terms share the common goal of seeking public or patient input and guide health system decision-making on specific health care issues

(Abelson et al., 2016). The term *public engagement* appears to be used as an umbrella term in the literature for public involvement in health decision-making; other terms such as *patient engagement/involvement* tend to have more limited specific meanings and different intensities of engagement (Hill, O’Grady, Millar, & Boswell, 2000; Mitton, Smith, Peacock, Evoy, & Abelson, 2009). Abelson et al. (2015, p. 2) describe *public and patient engagement* as a “term to capture a wide range of efforts aimed at actively involving citizens and patients in various domains and stages of health system decision- making”. This research is only concerned with the patient perspective rather than the broader societal public perspective; therefore, the term *patient engagement* will be used to represent the active engagement of patients, including family members, in health service planning and evaluation. The CFHI (2017) has been at the forefront of supporting patient engagement initiatives and describes patient engagement as

...initiatives that engage patients and families in designing, delivering and evaluating health services, with the goal of improving the quality of care. Co-designing improvements with patients and families leads to new insights and better results than providers and leaders working on their own. (para. 1)

“Making explicit the meanings expressed by the concept will improve communication between healthcare entities through a shared understanding of the core aspects and variations of patient engagement (Higgins, et al., 2017).

Patient engagement gained considerable attention in North America and Europe more than a decade ago, and the practice of patient engagement for health service improvement has evolved considerably in Canada (Abelson et al., 2015; CFHI, 2017; Crawford et al., 2002; van de Bovenkamp, Trappenburg, & Grit, 2009). The United Kingdom and the Netherlands have been at the forefront of developing strategies for patient engagement (e.g., experience-based co-design; Bate & Robert, 2007) and conducting empirical studies examining the effects of patient engagement (Crawford et al., 2002; Fudge, Wolfe, & Mc Kevitt, 2007; Van de Bovenkamp et al., 2009).

In Canada, efforts towards greater patient engagement for improving the patient experience have been more recent. For example, the Advisory Panel on Healthcare Innovation (2015), chaired by Dr. David Naylor, was tasked with identifying “the five most promising areas of innovation in Canada and internationally that have the potential to sustainably reduce growth in health spending while leading to improvements in the quality and accessibility of care” (p. 2).

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

One of the report's recommendations calls for "creating incentives for greater patient engagement at the organizational and system level, with the goal of improving models of care and system design" (p. 55). The Change Foundation (2010), an independent policy think tank, includes a strategic priority "to engage patients in a meaningful way when changes are being conceived, contemplated and introduced" to their 2010–2013 strategic plan (p. 4). The Ontario Cancer Plan (2015) for 2015-2019 identifies as a priority to "continue to foster strong partnerships with our many stakeholders, especially patients and families, while also building new connections. We will seek opportunities to combine our competencies and assets with our partners to achieve common goals and priorities" (p. 37). And finally, the *CFHI* (2011), which has been at the forefront of developing best practices for patient engagement, identifies this area as one of their strategic research priorities, funded patient engagement case studies across Canada, and developed executive training programs to improve patient and family involvement in care (Baker, Judd, et al., 2016). Efforts towards increased patient engagement in quality improvement have become priorities for many health organizations as a means to improve patient-centred care and experience, but progress has been limited (Baker, 2014; Baker, Fancott, et al., 2016; Baker, Judd, et al., 2016).

Carman et al. (2013) made significant contributions to defining and describing what is involved with patient engagement and proposed a multidimensional framework for patient engagement in health and health care. The framework describes the levels at which patient engagement can occur across the health care system, from direct care to patient engagement into organizational design, evaluation, governance, and policy-making. The framework (Figure 1) depicts how much information is exchanged between patient and provider, as well as how active a role the patient plays along the continuum of engagement. For example, at the continuum's lower end, which tends to be consultative in nature, "patients are involved but have limited power or decision-making authority. Providers, organizations, and systems define their own agendas and then seek patients' input. Information flows to patients and then back to the system" (Carman et al., 2013, p. 224). At the higher end of the patient engagement continuum, "engagement is characterized by shared power and responsibility, with patients being active partners in defining agendas and making decisions. Information flows bidirectionally throughout the process of engagement, and decision-making responsibility is shared" (p. 224)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

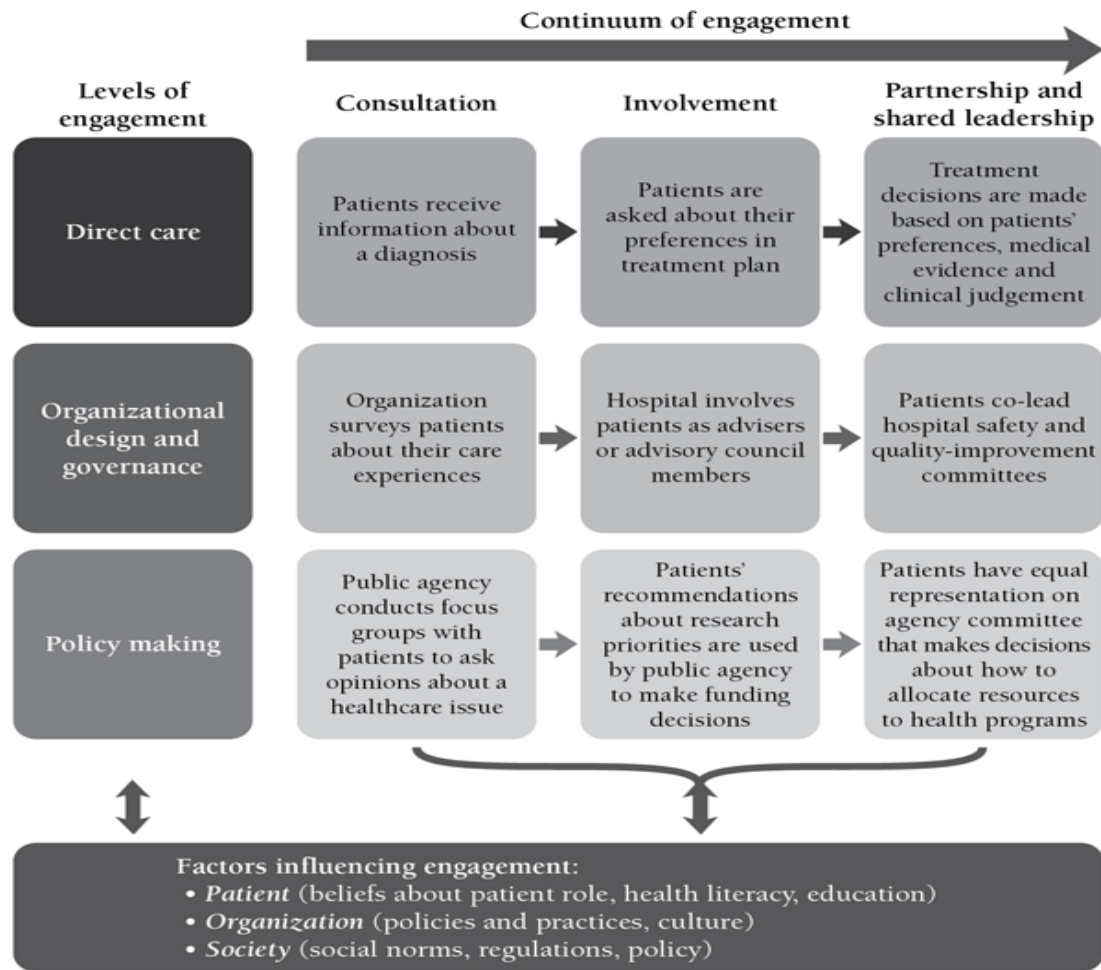


Figure 1. A multidimensional framework for patient engagement in health and health care, from Carman et al. (2013). Reproduced with permission.

Limited empirical research has examined the process, effects, and best approaches for engaging patients in health organizational design/governance, evaluation, and policy (Armstrong, Aveling, & Martin, 2013; Baker, 2014; Baker, Fancott et al., 2016). The following section provides an overview of the literature on the facilitators and challenges of patient engagement in the planning and evaluation of health services that go beyond direct care.

Facilitators of Patient Engagement

Baker and Denis (2011) identify initiatives meant to better respond to patient needs and expectations, indicating this is a priority area for system change within Canada. They also suggest that patient engagement is increasingly being seen as a “potentially strong lever to shift

the system toward improvement and to align the perspectives and activities of different practitioners” (p. 25).

A review of patient engagement studies indicates a positive impact in the following areas: improved educational or tool development (Baker, Fancott, et al., 2016; Baker, Judd, et al., 2016; Bombard & Baker, 2011), possibly improved clinical care outcomes or service delivery (Baker, 2014; Baker, Fancott, et al., 2016; Baker, Judd, et al., 2016; Rathert, Wyrich, & Boren, 2013), informed policy or planning initiatives as well as accelerated work and its visibility (Baker, 2014; Bombard & Baker, 2011), and improvement in patient experience (Baker, Fancott, et al., 2016; Baker, Judd, et al., 2016). Some facilitators identified in the literature to enhance patient engagement or patient-centred care initiatives include (a) a clear rationale for patient engagement and identifying the correct patient engagement approach to achieve the desired outcomes, (b) a dedicated champion and/or committed leadership that communicates strategic focus across the organization, (c) building staff capacity to work with patients, (d) adequate resources, (e) an organizational culture committed to change, (f) learning and involving patients in a meaningful way, and (g) clear roles and responsibilities (Armstrong et al., 2013; Baker, 2014; Baker, Fancott, et al., 2016; Baker, Judd, et al., 2016; Luxford et al., 2011; Shaller & Darby, 2009). Crawford et al. (2002) report that staff attitudes towards collaborating with patients became more favourable compared to baseline, and that the organizational culture became more open to working with patients as a result.

The public and patient engagement evaluation tool recently developed by Abelson et al. (2015) could be an important facilitator in advancing patient engagement and evaluating its impact. The tool was developed through a collaborative process that involved a review of the literature as well as input from public and patient engagement researchers and practitioners. The four principles identified as critical for the evaluation of public and patient engagement are as follows: (a) *Integrity of design and process* (i.e., diverse range of views, clear communication between organizers and participants, and support to enable participation), (b) *Influence and impact* (i.e., informs planning/decision-making, learning, and increased confidence and trust), (c) *Participatory culture* (i.e., organizational support for patient engagement, leaders informed on patient engagement, and demonstrated use of patient engagement work), and (d) *collaboration and common purpose* (i.e., plan and coordinate collaboratively to address concerns of people they serve). Despite the strengths of patient engagement in health service planning and

evaluation, it does not come without its unique challenges. This next section will discuss some of the challenges faced when engaging patients in planning and evaluation initiatives.

Barriers to Patient Engagement

The vagueness of the concept of *patient engagement* and the lack of clarity of purpose, structures, and roles amongst patients and health professionals involved in a patient engagement initiative are reported to challenge the patient engagement process (Armstrong et al., 2013; Baker, 2014; Baker, Judd, et al., 2016; Bombard, & Baker, 2011; Crawford et al., 2002; Fudge et al., 2007; Gagliardi et al., 2008a; Tedford-Gold, Abelson, & Charles, 2005). Some view patient engagement as a quality issue that can contribute to service improvements, but others see it as an accountability requirement that can be accomplished with a single consultation.

Studies examining patient experiences with engagement are mixed; some patients report that the process was rewarding and appreciated their involvement, while others report dissatisfaction with the process and lack of interest in health improvement initiatives (Fudge et al., 2007; Gagliardi et al., 2008b). Some health professionals are reluctant to support shared decision-making (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). The variations in the valuing of patients' experiential knowledge resulted in some studies reporting a significant gap between their intentions to involve patients and what actually occurred. Finally, appropriate guidelines or approaches for engaging patients in health service planning and evaluation are quite lean. Participatory evaluation and research approaches to patient engagement have been suggested as a good starting point, but there is little published evidence that such approaches have been used or evaluated (Armstrong et al., 2013; Baker, Judd, et al., 2016; Bate & Robert, 2007; Bombard & Baker, 2011).

Methodologically, few studies have examined the effectiveness or quality of their patient engagement approaches (Baker, Judd, et al., 2016). Most studies examining patient engagement approaches are descriptive and generally restricted to the authors' reflections on the strengths and limitations of their engagement process. To date, most patient engagement in program improvement initiatives have been consultative in nature rather than representing genuine interactive engagement sustained over time. Very few studies examined the patients' experiences or the impact of the engagement process on patients and health professionals involved in the patient engagement process; considering that the intent of patient engagement is to be more patient-centred, this is somewhat ironic (Baker, Judd, et al., 2016; Bombard & Baker, 2011;

Fudge et al., 2007; Gagliardi et al., 2008a). Also of concern is the relative lack of collaboration and shared knowledge between the evaluation community and health sector related to patient engagement.

Many of the strengths and challenges discussed in the patient engagement literature have a long history in the evaluation literature. Evaluators have unique skills and evaluation approaches that could make significant contributions with respect to ensuring that patient engagement prospers and ultimately improves the patient experience. The next section provides an overview of participatory approaches to evaluation, and discusses how such approaches could serve to improve patient engagement processes and strengthen partnerships between patients and health service providers.

Participatory Approaches to Program Evaluation

Abelson et al. (2015) describe *public and patient engagement* as a term that captures “a wide range of efforts aimed at actively involving citizens and patients in various domains and stages of health system decision-making” (p. 2). The very nature of actively involving patients in different areas and stages of health system planning, decision-making, and evaluating suggests that the use of collaborative and participatory approaches could facilitate the engagement process. Yet, one of the barriers to patient engagement in health service planning and evaluation is the limited knowledge on how to put such approaches into practice (Fudge et al., 2007). Patient engagement provides patients with an opportunity to dialogue with health professionals about what is of importance to them as well as being actively involved in decisions for improving health services, a key principle of PCC. However, recurring weaknesses from the patient engagement literature are the lack of guidance or approach to implementing patient engagement into practice, the gap between intentions to involve patients and their actual involvement, and patient engagement tending to be more consultative than collaborative (Bombard & Baker, 2011; Fudge et al., 2007; Tedford-Gold et al., 2005). For example, in Gagliardi et al.’s (2008a) study, one of the suggested recommendations made by participants was that the patient engagement “process should be ongoing and interactive rather than single, passive efforts to enable information sharing, and foster mutual understandings of perspective among patients and health professionals” (p. 239). This type of recommendation bodes well for a patient engagement approach that is collaborative in nature.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Recent developments in the evaluation community, particularly with regard to the development and validation of principles for collaborative approaches in evaluation (CAE) (Shulha, Whitmore, Cousins, Gilbert, & al Hudib, 2016), offer useful guidance. CAE seeks to develop a partnership between the evaluator and members of the program or intervention community such as program developers and managers or service users (e.g., patients). Evaluators bring technical expertise and knowledge of evaluation professional standards of practice to the planning and evaluation process, and patients bring experiential knowledge with the interventions and a rich knowledge of the context in which the interventions are implemented (Cousins & Chouinard, 2012; Cousins & Earl, 1995; Stevahn, King, Ghore, & Minnema, 2005). A key element to CAE is that stakeholders (e.g., patients, family members, health professionals) are actively involved in decision-making and are able to see tangible evidence of their contributions. Of equal importance in CAE is attention to capacity-building designed to assist program community members with understanding the evaluation process and their role in it. Cousins and Earl (1995) and Cousins and Chouinard (2012) view participatory approaches to evaluation as a means of enhancing the *use* of evaluation findings and working towards creating an organizational culture that is committed to learning and improvement. Learning not only involves quantitative standards from performance indicators, but from genuine collaboration between health practitioners/researchers and patients/family or process use (Patton, 1997).

Figure 2 elucidates the eight evidence-based principles to guide CAE recently developed and validated by Shulha et al. (2016). A growing number of participatory approaches fall under the CAE umbrella (e.g., practical participatory evaluation [P-PE], most significant change technique, rapid rural appraisal). Common to them all is that evaluators work in partnership with members of the program community. Three important considerations are associated with these principles: first, they are to be considered as a set, not as a pick-and-choose menu for application; second, they are well differentiated from yet overlap and interconnect with one another; finally, they are not intended to imply a linear sequence, although there is a loose temporal order beginning with “clarify the motivation for collaboration”. The principles can be used most importantly as a guide to CAE practice but also to retrospectively analyze projects, review evaluation policy, and inform professional development, among other applications.

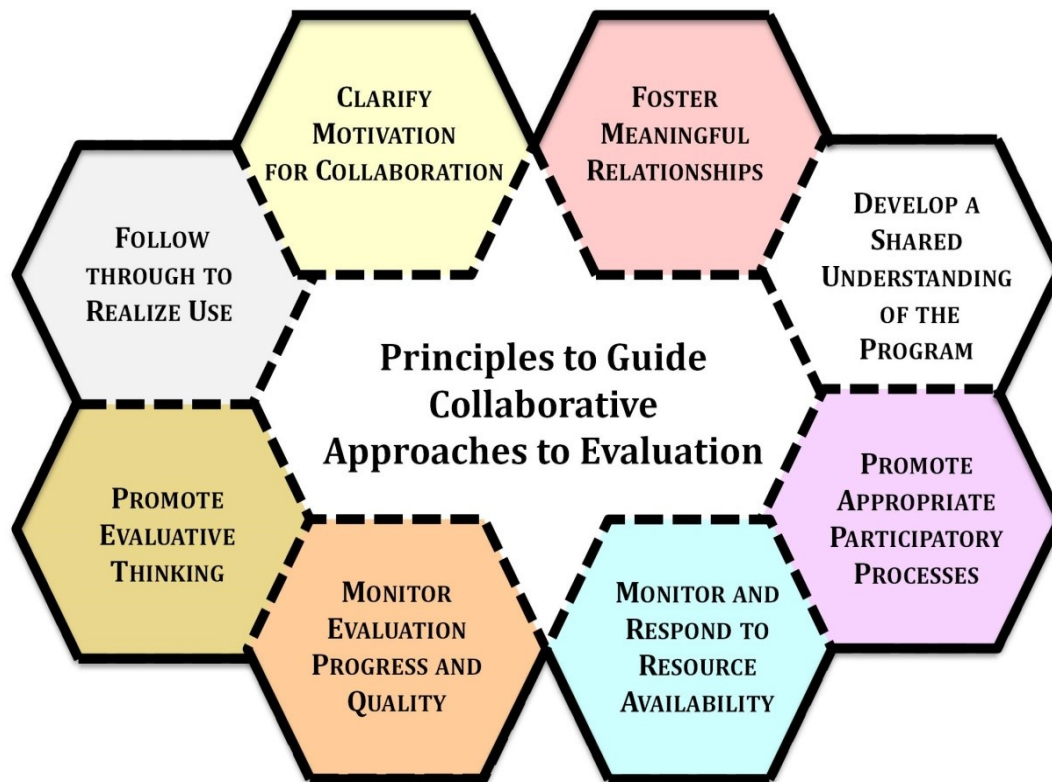


Figure 2. An integrated set of principles for use in guiding collaborative approaches to evaluation, from Shulha et al. (2016). Reproduced with permission.

In the present case, the emphasis placed on the *participant's* central role in the evaluation process is of great interest because it parallels Mallett's (1996) definition of PCC, which emphasizes placing patients in the centre of the system of care. Importantly, many types of CAE involve other stakeholders such as managers and implementers in evaluation processes, although many do engage intended service or intervention beneficiaries as would be the case in the context of PCC.

In considering justifications for CAE, Cousins and Whitmore (1998) identify two streams of participatory evaluation: (a) *Practical Participatory Evaluation (P-PE)* and (b) *Transformative Participatory Evaluation (T-PE)*. P-PE supports program or organizational decision-making and its main function is to foster evaluation *use*: "The core premise of P-PE is that stakeholder participation in evaluation will enhance evaluation relevance, ownership, and thus utilization" (p. 6). The second rationale, T-PE, seeks to empower members of community groups who are less powerful and "invokes participatory principles and actions in order to democratize social change; it has quite different ideological and historical roots from P-PE" (p. 7). For the purpose of this study, the proposed use of participatory evaluation approaches would

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

adhere to the P-PE rationale. Despite the element of empowerment in patient engagement, the overall goal is to improve the quality of care while recognizing that the process has a very practical aspect to it. In addition, P-PE promotes utilization of evaluation results by having decision-makers involved throughout the evaluation process. However, note that capacity building and empowerment outcomes may also occur in P-PE, and that transformative and practical outcomes are by no means mutually exclusive.

Cousins and Whitmore (1998) identify three fundamental dimensions of process in CAE, which are also affirmed by others (e.g., Daigneault & Jacob, 2009). These dimensions, appearing in Figure 3, are considered orthogonal and represent decision points that help to shape the CAE process. The first is *control over evaluation process* — who controls the decision-making related to the technical aspects of the planning and evaluation process: researchers/evaluators, organizational decision-makers (health professionals)/service users (patients), or some balance between the two? The second dimension is *stakeholder diversity* — who (e.g., program decision-makers, patients, family, program staff) within the program or organization should be involved in the planning and evaluation process? The final dimension is *depth of participation*, implicating the intensity of involvement in the evaluation process, ranging from light touch consultation to significant engagement with all phases of evaluation planning and implementation.

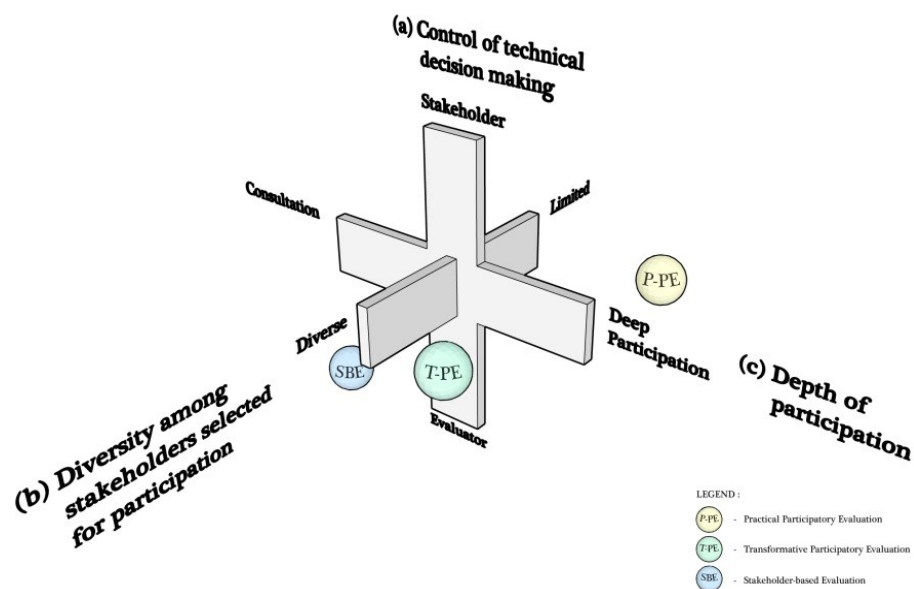


Figure 3. Dimensions of form in collaborative inquiry, from Cousins & Chouinard (2012). Reproduced with permission.

I argue that widespread use of CAE in the context of PCC is lacking, but has enormous potential to assist health organizations to leverage patient engagement in meaningful and sustainable ways. I advocate practical CAE approaches to broaden decision-making and problem-solving by engaging a range of *key* stakeholders in planning and conducting evaluation toward the end of service quality improvement. Intended service beneficiaries (i.e., patients/family) would be the central figures among participating stakeholders, making the approach compatible with the principles of PCC. CAE, specifically P-PE, has the potential to provide health organizations with a powerful means of enhancing services and strengthening programs through a more meaningful creation of useful evidence than is currently offered by conventional approaches to evaluation.

Research Purposes and Approach

As described above, current research on patient engagement in planning and evaluation of health services is inconclusive. Despite efforts, the extent to which patients are engaged is mostly limited to various forms of single time-point consultation. As a result, few studies have examined the process of engagement, patients' experiences with engagement activities, or the effects of patient engagement on the improvement of health services (Abelson et al., 2015; Bombard & Baker, 2011; Canadian Health Services Research Foundation [CHSRF], 2011; Fudge et al., 2007; Gagliardi et al., 2008b). Most studies examining patient engagement approaches are descriptive and restricted to authors' reflections. How do patients, health providers, and decision-makers feel about their engagement experience? Do we know what approach is best suited to engage patients in the evaluation process? What are some of the factors that facilitate or restrain patient engagement? The present research study responded to some of these challenges and examined in depth the nature, contextual factors, and consequences of the patient engagement process. The literature on participatory evaluation (e.g., Cousins & Chouinard, 2012) suggests possibilities for using participatory approaches to guide the patient engagement process in a manner that is compatible with PCC; this is the approach used in this intervention study.

Conceptual Framework

To assist in bounding the inquiry, the conceptual framework appearing in Figure 4 informed this study by explicating the key constructs to be studied, as well as the presumed or suggested relationships among them (Miles & Huberman, 1994). This framework supports my view that methodological decisions of social inquiry should be driven by, as Greene and Caracelli (1997) argue, the “inquiry problem’s practical demand” (p. 8) in an attempt to address research questions that arise. I developed the framework based on what we know from the published literature and my clinical and evaluation experience as a researcher.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

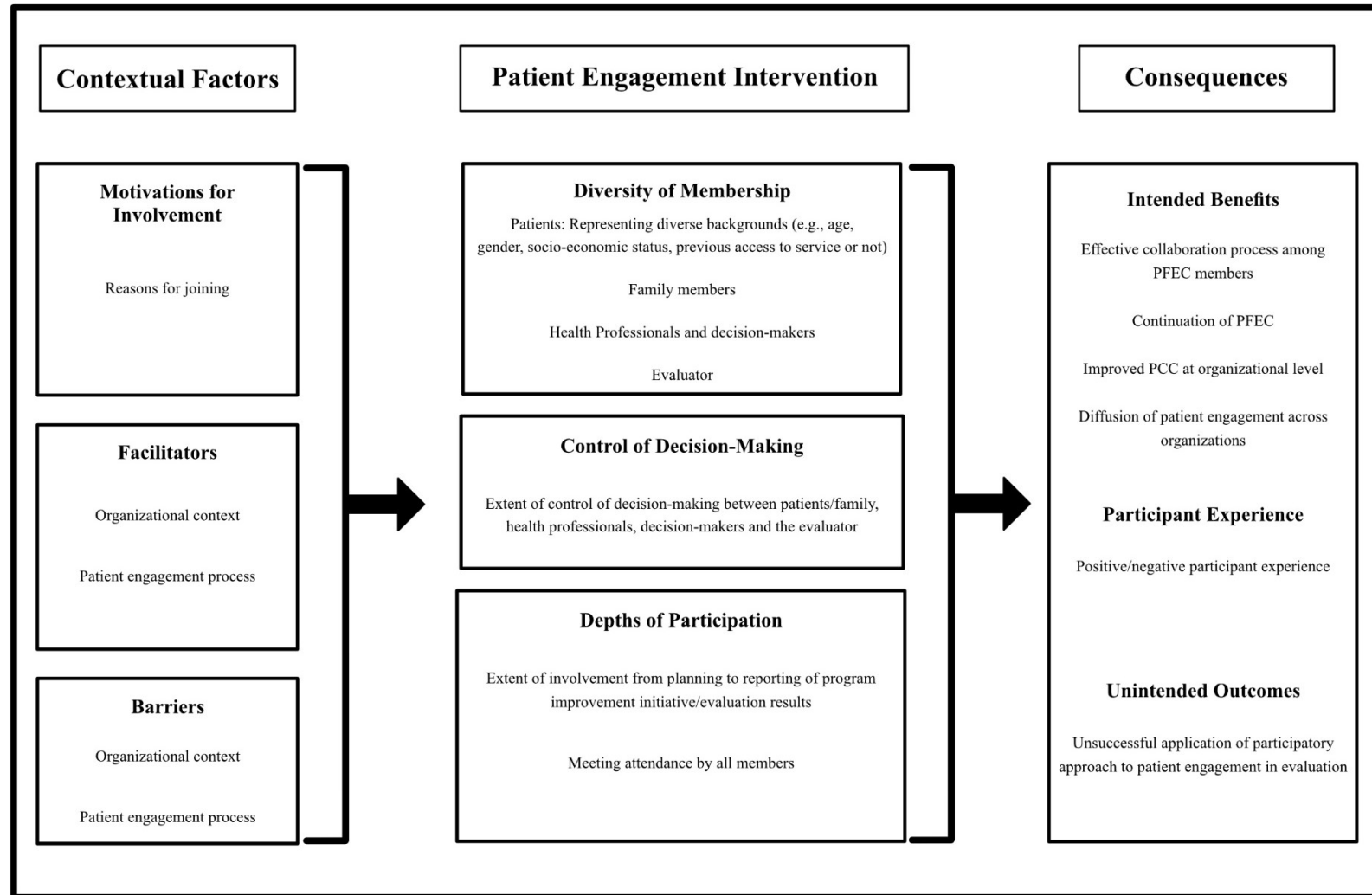


Figure 4. Conceptual framework: contextual factors, intervention, and consequences.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

As shown in Figure 4, the first aspect of the study examined the contextual factors, which included facilitators and barriers impacting the patient engagement intervention. Contextual factors that might impact the patient engagement process include health professionals' attitudes towards involving patients or family members in program improvement activities or the level of representation from diverse patient groups (e.g., age, gender, culture). These factors were envisaged to influence and shape the patient engagement process corresponding to the three dimensions of form in collaborative inquiry set out by Cousins and Whitmore (1998): diversity of participation (i.e., PFEC membership [see next section]), control over technical decision-making, and depth of participation. The third panel of the framework lays out the intended consequences of the patient engagement intervention in terms of the sustainability of the PFEC, the patient/family members' experience, level of collaboration using participatory evaluation approaches, and, ultimately, the level of diffusion of patient engagement across the cancer program/organization and improved patient-centred health services. Note that the study also considered unintended outcomes.

The framework was integral to this research, guiding instrument development; data collection, analysis and interpretation; and reporting. However, the research was open to refinement based on emerging observations, constructs, and relationships (Baxter & Jack, 2008; Miles & Huberman, 1994). For further elaboration of the constructs presented in Figure 4, refer to Appendix A.

Focal Intervention and Research Questions

The intervention began with the creation of a Psychosocial Oncology Program (PSOP) Patient and Family Engagement Committee (PFEC). The PSOP is a program within the Ottawa Hospital Cancer Program (hereafter the Cancer Program) that offers multidisciplinary health services (e.g., physiotherapy, social worker, psychology, psychiatry) to support patients with cancer and their families by providing mental health and rehabilitation services to ensure patients receive comprehensive clinical services (Ottawa Hospital, 2012). As a means of partnering with patients and family members, the PFEC collaborated on a needs assessment that would assist the PSOP in identifying priority areas and recommendations to move forward over the next few years. More specifically, through conversation with multiple program stakeholders with unique experiences and expectations, the goal was to learn from one another and find ways to continuously improve the services offered.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Membership included patients, family, and PSOP staff. Once the PFEC was established, collaborative work on a program needs assessment took place over a 12-month period using a P-PE approach (Cousins & Whitmore, 1998); the PFEC determined the specific areas of focus for the needs assessment. I worked in collaboration with the PFEC on all phases of the program improvement initiative. Most decisions about the overall areas of focus for the needs assessment, the approach used for working together, how to collect input from the committee members, recommendations to move forward, and reporting methods were made collaboratively. I acted as both project lead and evaluator. This involved setting up meeting agendas, chairing the meetings, taking meeting minutes, contributing technical evaluation skills to the committee, and taking the lead in writing the final project report.

Through a series of discussions and priority sort exercises, three broad priority areas were identified, each containing specific areas of concern for PSOP patients/family and staff. Key recommendations to address these issues were also identified collaboratively. Due to time constraints, committee members did much of the committee work at home between the meetings. I sent monthly questions to each of the members by email to be answered one week before the next meeting, and I consolidated the responses and shared them with the group two days before each meeting in preparation for group discussion. This approach proved valuable in focusing meeting discussions on identifying key challenges and recommendations for each of the priority areas identified. The final product of the project included a 37-page project report (Appendix B) disseminated to key decision-makers at the Ottawa Hospital Cancer Program.

Through this intervention, the specific purpose of the thesis study was to gain a better understanding of the process of patient engagement in planning and evaluation by addressing the following research questions:

1. What are the facilitators and barriers of engaging patients in planning and evaluation of health services and why? Did these change as the process unfolded?
2. What did the process of engagement look like with respect to Cousins and Whitmore's (1998) three dimensions of collaborative inquiry? Specifically, (a) to what extent were patients and other program community members in control of decision-making?; (b) what was the range of stakeholder involvement in the inquiry in terms of different roles and interests?; and (c) to what extent did program

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

community members engage with the full range of planning and evaluation tasks and challenges? Did these change as the process unfolded?

3. What are the observed effects of the engagement process? Specifically, (a) what are the intended benefits of engaging patients in the planning and evaluation process?; (b) what are the unintended effects, if any, of engaging patients in the planning and evaluation process?; and (c) to what extent did these observed outcomes depend on process dynamics?

In the next chapter, I provide an explication of and justification for the research methods employed. It is important to recognize that the research occurred in parallel with the development and implementation of the focal intervention. Despite the highly collaborative nature of the focal intervention, the research process was, by design, collaborative only in limited ways.

Chapter 3: Methods

Research Overview

The data collection approach I used for this study consisted of four phases. The first three phases sought to explore changes that occur over time associated with context, process, and consequences of patient engagement in the planning and evaluation process. In these phases, I collected data at baseline, mid-project, and at the end of the project; the primary sources of data were program documents, participant observation, interviews, and a research journal. An independent interviewer conducted the interviews to reduce observer bias, and interview data were withheld from me until the completion of the evaluation project. Preliminary data analysis of the first three phases was then conducted and I completed a case study profile report. In Phase IV, I shared the case study profile report with all members of the PFEC. A focus group was then conducted with all members of the committee for validation of the case study profile findings and to collect new information that represented the entire group's perspective regarding the patient engagement process.

The sections that follow provide a description of the epistemological underpinnings of this research, and then the research strategy applied and my rationale for its use. Details are also provided with respect to the research design, which also includes the case used for this study, research ethics requirements, and data collection methods, including participant recruitment. Finally, the analytic strategy that I used for this study is outlined in detail.

Epistemological Orientation

It is good practice to make one's epistemological orientation explicit to help clarify the underlying assumptions and values guiding your research. My early academic foundation in health sciences was predominantly influenced by what is commonly labelled as positivism. That is, that the researcher is independent from what is being studied, inquiry is value free, generalizations from inquiry are time and context-free, and that there is a single reality (Biesta, 2010). As McMurtry and McMurtry (2016) describe "the traditional notion that learning is a thing that can be acquired and transferred is deeply entrenched in our professional cultures. As is the notion that we must talk about the things we learn in terms of their objectivity or subjectivity" (p. 1091). In the early stages of my health care career, I often found myself conflicted between the dichotomies that knowledge is either objective, and provides an accurate

representation of reality, or subjective, which is strictly socially-constructed. As Biesta (2010) describes, this type of traditional view “leads to fractions, oppositions, and a polarization of the discussion rather than interaction and exchange. Paradigm thinking also tends to give research students (but not only them) the impression that they need to adopt a particular paradigmatic stance” (p. 6). However, as my work has taken a greater focus in the area of program evaluation and research on evaluation, I recognize the need for capturing program context, learning from stakeholder experience, and using this learning to practically improve particular health services rather than focussing on the generalizability of findings. I believe that decisions about methodology for social inquiry need to be guided by the research questions that arise from the practical demand of the inquiry’s problem (Greene & Caracelli, 1997). As a result of my professional and academic experiences, I have evolved towards an orientation that is sympathetic to pragmatism and moved away from thinking about knowledge according to the traditional dichotomy (i.e., objective versus subjective). John Dewey’s theory of knowledge offers an understanding that knowing does not start from what he saw as the ‘impossible question’ or premised on the dualistic mind-world scheme.

Instead, Dewey put forward a framework that starts with interactions—or, as he later preferred to call it, transactions—taking place in nature and in which nature itself is understood as a moving whole of interacting parts. Whereas *transactions* refers to interactions taking place in nature more generally, *experience* refers to the transactions of living organism and their environment. What is distinctive about these transactions is that they constitute a double relationship. . .As consequence the changes produced in the environment react upon the organism and its activities. The living creature undergoes, suffers, the consequences of its own behavior. This close connection between doing and suffering or undergoing forms what we call experience. (Biesta, 2010)

Pragmatism begins by asking “what are our lived experiences”; its approach to knowing and research is rooted in life itself rather than starting with assumptions based on objectivity or subjectivity (Morgan, 2014). As Morgan (2014) points out, pragmatists believe that research is not fundamentally different from what we do in our day to day life. That is, we try things out, reflect on our experiences, construct understanding or beliefs of it, test out that understanding, and see what happens. That is, it is a process of examining areas that have become problematic and through action trying to resolve it by asking and answering questions. Therefore, the

pragmatists do not concern themselves with whether the inquiry responds to some subjective reality or objective truth, but rather uses this “continuous process that may involve many cycles between beliefs and actions before there is any sense of resolution” (Morgan, 2014, p. 1047). The systematic approach of pragmatic inquiry fits well with my research questions and examining the engagement process, the consequences of the evaluation project, as well as the lived experience of all participants involved in the engagement process. The intent of this research is to learn from the engagement process and to contribute practical and ethical improvements related to patient and family engagement, in the hopes of improving the process and patient and family health service experience.

Research Approach and Design

In this study, I applied a longitudinal qualitative research approach to explore the research questions. This research approach responds to the methodological gaps identified in the previous chapter. Specifically, this approach emphasizes exploring processes of change using a participatory evaluation approach that occurred over a sustained period of time and the processes associated with these changes (Farrall, 2006). A qualitative research approach allowed emphasis to be placed on questions that explored how the social experience of being a PFEC member was created and given meaning (Denzin & Lincoln, 2011). A strength of the longitudinal qualitative approach

...is the ability to link the micro to the macro, especially during periods of sustained and dramatic change. Social or organization change, especially if it is dramatic and either takes some time to unfold often involves a change in the relationship between an individual and larger social organizations or institutions. (Farrall, 2006, p. 7)

Considering that patient engagement in planning and evaluation of health services is a relatively new approach in health care, it was important to explore the precise facilitators/barriers that contributed to a successful or less-than-successful patient engagement process and experience. Exploring these specific mechanisms, contexts, and outcomes required consideration of how particular processes work ‘on the ground’ at an individual level over time (Farrall, 2006; Pawson & Tilley, 1997). As such, I used a longitudinal single case intervention study design, which is particularly useful when trying to address ‘how’ and ‘why’ research questions about real-life events and when phenomenon and context are not readily separable (Yin, 2009).

The strength of case study is the opportunity to learn about the particularity and complexity of a phenomenon within its context (Stake, 1995). According to Flyvbjerg (2011), case studies are typically intensive and comprise richness, detail, and variance — that is, depth — for the unit of study. Engaging patients in the evaluation process within a health care context is not straightforward, and the effects are not well known (Bombard & Baker, 2011). As such, understanding this phenomenon encompassed important contextual conditions. Learning the particularities of patient engagement using collaborative approaches to evaluation within a health care context justified the selection of the case study approach for this study.

Case Description

The case organization I selected for this study is the PSOP at the Ottawa Hospital; refer to Appendix C for the Ottawa Hospital Psychosocial Oncology Program Organizational Chart. The PSOP comprises a multidisciplinary team at the Ottawa Hospital that supports patients with cancer and their families by providing mental health and rehabilitation services to ensure patients receive comprehensive clinical services. The program's multidisciplinary team comprises physiotherapists, social workers, psychologists, nutritionists, speech therapists, rehabilitation therapists, and psychiatrists to assist patients in coping with many of the challenges of cancer (Ottawa Hospital, 2012). The vision for the PSOP is “to lead the country as an integral part of the provision of excellent inter-professional care to enhance the experience of people living with cancer” (Ottawa Hospital, 2012).

Oncology patients and/or family members access these services through physician or self-referral. Patients and family members receiving services at the PSOP live within the Champlain Local Health Integration Network (LHIN), Ontario's easternmost region (e.g., Ottawa, Hawkesbury, Cornwall, Pembroke, Deep River).

Within the case organization, the PFEC intervention defined the principal boundaries of the research case. The creation of the PFEC is a result of a few contributing factors. First, the PSOP celebrated its fifth anniversary in 2013 and took pause to reflect on its achievements and how it could continue to improve services to better respond to patient and family needs. At the same time, the program closely reviewed the recommendations made in the Ottawa Hospital's Consultations on Cancer Program Transformation Report (Ottawa Hospital, 2011), which included the results of a largely unprecedented effort to engage patients and families in frank discussions about improving patient experiences and adopting a more patient- and family-centred

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

approach to care at the Cancer Program. The development of a PFEC aligned well with a number of overall recommendations that were highly relevant to the PSOP. They included:

- Increasing patient participation;
- Adopting a whole-patient approach (i.e., expand psychosocial support; create a rehabilitation and wellness clinic that would include exercise, physiotherapy, and massage therapy; and develop program seminars to provide information and training to patients and family members on nutrition and exercise); and
- Improving system navigation.

As one of the programs that participated in the Ottawa Hospital's consultations on Cancer Program transformation, the PSOP was in the process of brainstorming ideas on how their program could maintain the momentum of the consultation process. At this time, I was introduced to the program manager and clinical director of the PSOP by a colleague who knew of my research interests. We had a number of meetings in the early planning phases of this project to discuss our mutual interests, and the PSOP was very keen to collaborate with me on the intervention that would form the basis for my research project. I would assist them in the recruitment and establishment of the PFEC and offer my technical skills in leading the needs assessment for the PSOP and, in turn, and in parallel, I would study the process of engaging patients and family members in an evaluation project.

Participant Recruitment

Recruitment strategies were developed through discussions with the PSOP staff involved in the project, which consisted of the program manager, the clinical director, and a clinical psychologist, who also became members of the PFEC as staff representatives. A fourth staff person, a social worker, was later recruited to the PFEC but was not part of the original steering committee involved in the planning and approval of the project.

Patient and family member participants recruited for the PFEC and this study were over the age of 18 and living within the Champlain LHIN catchment area. All patient participants were either current or recently discharged (i.e., within one year) from the PSOP and had received a minimum of two visits. Family member participants had to have accessed PSOP services within two years from the time their family member had passed away. Efforts were made to have representation from diverse groups of patients and family members (e.g., male/female, younger/older, urban/rural, cultural diversity) as well as the more vulnerable (e.g., low income,

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

without family support). In addition, emphasis was placed on recruiting one or two patients who received cancer treatment external to the Cancer Program (e.g., patients with blood cancers), but did not have access to PSOP services. These patients would offer a unique perspective in terms of the psychosocial services they wish they had received.

By using the inclusion criteria identified above, in consultation with PSOP staff, my goal was to recruit 10–12 (70%) patients/family to be members of the PFEC along with 4–5 (30%) health care professionals from the PSOP. I identified potential PSOP patients and family members who met the inclusion criteria using the PSOP Mozaic database. I used Cancer Program data to determine the number of letters to be sent out to achieve proportional representation of patients with different cancer sites to reflect the actual cancer population seen at PSOP. Once potential members were identified, I took the following steps for study recruitment:

- A general recruitment letter (Appendix D) was sent through direct mailing, advising the patient about the study and inviting them to contact me if they wanted further information.
- Patients and family members who did not receive PSOP services contacted the program directly after they had seen one of the recruitment posters (Appendix E) within the Ottawa Hospital or were recruited through referral.
- Recruitment letters (Appendix F) were handed out directly by the PSOP speech language pathologist to patients with head and neck cancers. These patients, in general, tend to belong to more vulnerable patient population groups, so additional efforts were made to recruit them beyond the main recruitment strategies.
- Participants who indicated interest in participating in the study following a telephone conversation with me were emailed a detailed information sheet describing the study, as well as a consent form that was completed before the first orientation meeting (Appendices F and G).
- There were no inducements for participation in the PFEC. However, members were provided refreshments and a light snack because meetings were held immediately after work hours. Participants were reimbursed for parking or local travel expenses.

The recruitment period lasted approximately six weeks, and a total of six patients, two family members, and four PSOP staff consented to be part of the PFEC and corresponding study.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Only four of the six patients attended the orientation meeting; all PSOP staff and family members recruited attended. I had a follow-up conversation with the two patients that did not attend the first meeting, and it became clear that they were unsure about their ability to attend monthly meetings considering their health status. They voiced concerns about their role in a program improvement project and the possibility of their involvement having a negative impact on their clinician/patient relationship in the future. These are important concerns to be considered when developing best practices for patient engagement and are discussed in the final chapter of this thesis.

A total of four patients, two family members, and four PSOP staff were recruited and participated in all phases of the project and research study. I made efforts to recruit two more patients after the orientation meeting, but was unsuccessful due to time constraints and the challenges of patient recruitment. Despite having two fewer patients than originally planned, the steering committee felt the PFEC had acceptable diversity among members and good representation of different cancer sites. To respect confidentiality, I did not collect biographical information from participants; however, Table 2 provides a general description of the PFEC participants recruited.

Table 2

Summary Description of Study Participants

Staff	Staff 1	Staff 2	Staff 3	Staff 4
Gender	Female	Female	Female	Female
Role	Program manager	Clinical director	Social worker	Psychologist
Patients	Patient 5	Patient 6	Patient 7	Patient 8
Gender	Female	Female	Female	Male
Ethnicity	Caucasian/Immigrant	Caucasian	Caucasian	Caucasian
Occupation	Professor	Public Servant	Homemaker	Dentist
Age range	50–60 years	50–60 years	30–40 years	40–50 years
Services	Yes	Yes	Yes	No
Cancer site	GI/Remission	Unknown/Remission	Breast/Active	Blood/Remission
Residence	Ottawa	Orleans	Ottawa	Ottawa
Family	Family member 1	Family member 2		
Gender	Male	Female		
Occupation	Engineer	Retired		
Age range	30–40 years	50–60 years		
Residence	Ottawa	Renfrew area		

Research Ethics

The University of Ottawa Ethics Board and the Ottawa Health Science Network Research Ethics Board granted full ethical approval prior to the recruitment of study participants. A Collaborative Research Project Agreement between the University of Ottawa and the Ottawa Hospital Research Institute was also approved. The researcher and the independent interviewer involved in the study attained certificates of completion for the Tri-Council Course on Ethical Conduct for Research Involving Humans.

Data Collection

Data were collected from multiple sources, including program documents, participant observation, interviews, the focus group, and a reflective research journal that I completed throughout the study. One of the advantages of multiple sources of evidence is the development of converging lines of inquiry (Yin, 2009). Table 3 summarizes each of these data sources along with the justification of their use related to each of the research questions.

Table 3

Justification of Data Sources

Data Source	Comments
Program Documents	Program documents to corroborate and augment evidence from other sources.
Participant Observation	An observation checklist was used to guide the observation process. This checklist ensured consistency of observations across all PFEC meetings. A detailed audit trail of the methods, procedures, and decisions made throughout the study was also kept.
Reflective Journal	Reflective journal promoted self-reflexivity related to all three research questions.
Interviews	Interviews offered rich and extensive data on the context (Q1), process (Q2), and consequences (Q3) of patient engagement. An interview guide was developed and pilot tested.
Focus Group	The focus group offered rich and extensive data on the context (Q1), process (Q2), and consequences (Q3) of patient engagement. This data source allowed for checking back with participants about the preliminary interview findings and generated information that represented the entire group's perspective.

Program Documents

In the initial stages of research, PSOP documents were reviewed to describe the case program under study. Along with the documents, the program patient data system was reviewed to identify current and recently discharged patients of the PSOP for potential recruitment. Finally, meeting minutes or any other program information that provided context for the intervention being observed were also collected.

Participant Observation

I conducted participant observations through all stages of the study immediately after each PFEC meeting and recorded them as field notes. Data obtained assisted in gaining a better understanding of the case by describing the physical, social, and cultural contexts in which the study took place, as well as validating other findings. I generally focussed observations on behaviours and other factors that were most relevant to the research questions. I used general categories of information as an observational template during all sessions, as outlined in Appendix H. This mode of observation is unique because, as the researcher, I was not a passive observer but rather assumed a variety of roles within the case study.

Independent Interviews

During the project, 30 independent interviews were conducted with members of the PFEC (i.e., three interviews per PFEC member). I developed the interview timelines described in Table 4 based on the research questions being explored and evaluation project milestones to be completed. I opted for the Phase I interviews to be conducted following the orientation session but before meeting II to establish a baseline of members' understanding and expectations of the PFEC to be analyzed at the end of the project. The mid-project interviews (Phase II) were completed following the completion of meetings II, III, and IV, and the end-of-project interviews (Phase III) were conducted after meetings V and VI.

Table 4

Interview Timelines

Interview	Corresponding evaluation
Baseline interviews (Phase I)	Following orientation session and prior to meeting II
Mid-project interviews (Phase II)	Following meetings II, III, and IV and prior to meeting V
End-of-project interviews (Phase III)	Following meetings V and VI

An independent interviewer was used to reduce the potential for participant observer bias for this data collection method. Robinson and Cousins (2004) used a similar research approach in which an independent interviewer uninvolved in the project conducted the interviews. Importantly, all interview data were withheld from me until the evaluation and the final set of interviews were completed, after which I received access to all interview data, completed a preliminary data analysis of the interview data, and prepared a case study profile that would be shared with all members for discussion in the focus group.

The independent interviewer was selected based on discussions with my advisor about potential candidates who would have the appropriate research skills to conduct semi-structured interviews; have experience working in the health care system; possess strong communication and interpersonal skills to interview patients, family members, and staff of PSOP; and be available for the duration of the study. The independent interviewer met all requirements: she was a PhD candidate with the Faculty of Education with a strong evaluation background, had previously been involved in some evaluation and project management work for a health care organization, had excellent communication and interpersonal skills, and was available for the duration of the study. The independent interviewer and I collaborated on pilot testing and finalizing each of the interview guides used at baseline, mid-project, and end of project. I provided her with a recording device and the contact information for each of the PFEC members to assist in the scheduling of interviews. Remuneration was provided to the independent interviewer following each set of interviews by her invoicing me directly for the services rendered.

The independent interviewer used guiding rather than structured questions during all three sets of interviews (see Appendix I for the interview guides). The interviews allowed participants to discuss their perception of their participation and that of the other members at the beginning, mid-point, and end of the research project. Before the first interview with participants, I pilot tested the interview guide with health professionals of the PSOP and two patient advisors at the Ottawa Hospital Cancer Program that were not involved in the study. Questions that appeared redundant to participants were removed and questions that were confusing or misinterpreted were modified. A second pilot test was conducted with the revised interview guide with a member of the Centre for Research on Educational and Community

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Services to ensure clarity of the questions and to provide the interviewer with an opportunity to practice the interview process.

Each interview took between 30 and 60 minutes to complete and was audio recorded; all participants granted permission to be recorded. Prior to each interview, participants were asked to read an information sheet explaining the study (Appendix J) and consent to the interview by reviewing and signing the consent form (Appendix K).

Reflective Journal

Throughout all phases of the study, I used a reflective research journal to facilitate reflexivity of personal assumptions and biases, and to clarify and challenge personal assumptions. The process I used involved documenting my reflections of the meeting process immediately after each PFEC meeting to ensure I captured accurate thoughts and perceptions of the meeting process. On two occasions, I captured my thoughts using an audio recorder immediately after the meeting and transcribed my reflections at a later time. This process served as a way of making my “history, values, and assumptions open to scrutiny” (Ortlipp, 2008, p. 698). Further, through reflective writing, I was more likely to preserve the multiple perspectives of the people involved in the study (Stake, 1995).

Focus Group

A focus group was conducted in Phase IV with all members of the PFEC approximately three months following the completion of the patient engagement project. The primary purpose of the focus group was to review the draft case study profile, which included the preliminary research findings, and to generate information represented by the entire group’s perspective regarding the patient engagement process. The focus group guide was developed based on the preliminary case study profile findings (Appendix L). The focus group was facilitated by my thesis supervisor, Dr. Brad Cousins, and the independent interviewer who conducted all of the study interviews, neither of whom were involved in the evaluation project. As the evaluator/researcher of this project, I participated in the focus group discussion with the PFEC members, which proved to be a very valuable exercise in validating preliminary findings, clarifying ideas, and celebrating the work that the PFEC had completed.

Data Analysis

The conceptual framework that formed the basis for the development of the research questions, design, and data collection methods guided the analytic strategy for this study. As Leshem and Trafford (2007) suggest, the conceptual framework offers “a self-audit to ensure cohesion and appropriate conceptualization for research conclusions” (p. 101) and may evolve as the research evolves. I aimed to make the process of data analysis as visible and transparent as possible through continuous self-reflection on the research objectives, conceptual framework guiding the study, approaches, and decisions made (Ortlipp, 2008; MacNaughton, 2001; Stake, 1995).

Prior to data collection and analysis, a preliminary database was created to effectively organize all raw data. I transcribed all sources of data to text and entered them into NVivo qualitative software, including reflective notes and participant observations. Initially, all data from the interviews, my reflective notes and participant observations were read and explored to gain a general understanding; memos were created as a first step to assist in the development of codes, themes, and a preliminary codebook. The second step was the coding process, which involved grouping and attending to all sources of evidence, coding the data by labelling ideas, and developing themes from similar codes to reflect increasingly broader perspectives (Creswell & Plano Clark, 2011; Miles & Huberman, 1994; Yin, 2009). Once a theme was identified, I explored and compared whether each theme emerged across all sources of data (i.e., interviews, reflective notes, personal observations). This process of triangulation, ensured that the key themes that emerged from the data analysis is strong and is supported by more than a single source (Stake, 2010; Yin, 2009). Additionally, key themes identified from the interview data were further explored to examine if they were representative of a cross section of the groups' views or did it emerge more strongly in one particular group of participants (i.e., staff versus patient/family). To make this determination, I developed the following evidence rule: a theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants. The 75% threshold was used to confirm overall strong support for the theme associated with a particular group. The final step of the analysis consisted of interpreting and validating the results using the *explanation building* analytic technique as well as the creation of

rival explanations, both designed to address the research questions (Yin, 2009). Preliminary results were summarized in a case report and sent to participants for feedback (Appendix N).

Ensuring Quality

Efforts were made to ensure the trustworthiness and authenticity of findings. As such, tactics developed by Yin (2009) to improve the quality of case study research were applied to this study. Each of these case study tactics, with relevance to this study, is summarized in Table 5 and briefly described.

Table 5

Case Study Tactics for Quality Tests

Tests	Case Study Tactic	Phase	Tactics Used for the Study
Construct Validity	Multiple sources of evidence	Data collection	Triangulation: multiple sources of evidence provided through observations, document review, and interviews with PFEC members.
	Establish chain of evidence	Data collection, analysis, and case study profile	Peer review of research design & emergent results (congruency with raw data).
	Member check of key information	Review of case study profile by members and focus group	Key informants review the case study profile.
Internal Validity	Member check of key information	Data collection, analysis, review of case study profile and focus group	Ensured research design supported research questions and inferences were well supported.
External Validity	Use theory in single-case studies	Research design	As per Yin (2009), analytical generalizability applies to case studies, not statistical generalizability. This study was based on the theory of PCC, the validated <i>dimensions of form in collaborative inquiry</i> (Cousins & Whitmore, 1998), and the concept of patient engagement.
Reliability	Use of case study profile	Data collection	This study followed a standard case study protocol as outlined by Yin (2009). This ensured all of the research questions and procedural steps were well documented.
	Develop case study database	Data collection	I created a detailed audit trail that describes the methods, procedures, and decision points throughout the study.

Note 1. Case study tactics for quality adapted from R. Yin, *Case study research: Design and methods* (3rd ed.), 2009, p. 41, Figure 2.3, Case Study Tactics for Four Design Tests.

Construct validity. A number of strategies identified by Yin (2009) were used to ensure the construct validity of this qualitative study, which Yin describes as “identifying correct operational measures for the concepts being studied” (p. 40). In other words, I ensured that the research design, data collection tools, data collection process, data analysis, and results were appropriate for answering the research questions (Leung, 2015).

I used multiple sources of evidence in this study, including three sets of interviews with 10 participants, a focus group, participant observations, program documents, and a reflective journal I kept during all phases of the study, all triangulating on the same set of research questions. Triangulation of evidence aims to increase confidence that the evidence is strong and is supported by more than a single source (Stake, 2010; Yin, 2009).

Another tactic used to reduce potential problems with construct validity is investigator triangulation (Patton, 2002; Yin, 2009). Despite this study being conducted by a single investigator, myself, multiple aspects of the study design were peer reviewed by clinicians and academics. For example, the research proposal was reviewed and approved by my doctoral research committee, which consists of four professors, each offering different expertise. This was followed by a thesis seminar that involved presenting the research proposal to professors and graduate students of the Faculty of Education and engaging in a collaborative discussion about its strengths and weaknesses, which contributed to improving the quality of the proposed study. Once the research proposal was finalized, it was reviewed for approval by the program manager, medical clinical director, and psychologist for the PSOP.

I also used member checking to increase construct validity and to maintain the chain of evidence. As Miles and Huberman (1994) point out, “one of the most logical sources of corroboration is the people you have talked with and watched” (p. 275). Preliminary data analysis of all sources of data was completed following the last set of interviews and written up in a case study profile, which was shared electronically with all participants, including the independent interviewer and my supervisor. This was followed by a focus group, the main objectives of which were to discuss the case study profile and assess whether the conclusions from the preliminary data analysis resonated with participant experiences on the PFEC. The secondary objective was to generate information represented by the entire group’s perspective regarding their experiences with the PFEC. Following the focus group, I presented the findings at the University of Ottawa, with all members of the PFEC, the independent interviewer, my

supervisor, and members of the Faculty of Education and Faculty of Social Sciences invited to attend. This presentation provided an overview of the research study as well as the findings for each of the research questions, and was another form of verification; that is, PFEC members, the independent interviewer, and my supervisor, all present at the focus group, were provided the opportunity to question the research findings and request additional clarity if they had concerns.

Internal validity. According to Yin (2009), concerns over internal validity relate mainly to explanatory or causal studies, and can be defined as “seeking to establish a causal relationship, whereby certain conditions are believed to lead to other conditions, as distinguished from spurious relationships” (p. 40). Exploratory studies, on the other hand, are not concerned with causal relations, but rather the broader problem of making inferences and whether they are correct. As described in the construct validity section above, I conducted extensive member-checking strategies throughout this study to ensure inferences were well supported.

External validity. To improve the external validity of this case study research, a conceptual framework was developed to help guide the research process. This conceptual framework is based on the theory of patient-centred care, the validated dimensions of form in collaborative inquiry developed by Cousins and Whitmore (1998), and the concepts of patient engagement emerging in the literature. The findings of this case study have contributed to the refinement of the conceptual framework and further clarified the concept of patient engagement.

Reliability. As Yin (2009) describes, “one way of approaching the reliability problem is to make as many steps as operational as possible and to conduct research as if someone were always looking over your shoulder” (p. 45); here, the aim was to minimize errors and biases in the case study. I used several tactics to strengthen the reliability of this study, some of which have already been discussed. Additional tactics included a detailed audit trail, which Yin (2009) describes as a chain of evidence that clearly identifies the data collection methods used, research procedures, and key decision points throughout the study. A case study database was developed to organize all raw data collected. The case study database was developed using NVivo 11, which was also used to assist in the data analysis component of the study.

The chapters that follow present the findings from each of the research phases, including the results from the follow-up validation focus group. This will be followed by the final chapter

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

that discusses the findings related to each of the research questions, along with limitations of the study and implications for future research in the area of patient engagement.

Chapter 4: Phase I Findings

The purpose of this chapter is to highlight the findings of the study from Phase I, which was the preparatory stage of the evaluation project from recruitment to the orientation meeting. The intention of Phase I was to establish a baseline to explore participant opinions and expectations about the project before the project work began. These findings provided the data needed to subsequently examine any changes in PFEC members' opinions and experiences during the patient engagement process.

The first section of this chapter provides a summary of Phase I timelines and evaluation project milestones, which will provide context for the baseline findings. The subsequent section describes the findings of Phase I interviews conducted with all members of the PFEC, and concludes with a description of the findings from my participant observations and reflections captured during the baseline phase of the study.

Phase I Timelines and Overview

The baseline phase consisted of a period of approximately one month, from November 6, 2013, to December 4, 2013. During this period, participants provided informed consent and attended a PFEC orientation meeting at the Ottawa Hospital PSOP. The main objectives of the orientation meeting consisted of providing background information about the PSOP and the purpose of the PFEC, and discussing their role as committee members. The draft terms of reference for the PFEC were shared with the committee before the orientation meeting, and members were given the opportunity to suggest changes or seek clarity before the final version was shared for approval at the first meeting. The meeting ended with every committee member introducing themselves and sharing their personal experience with PSOP and/or the Ottawa Hospital Cancer Program. The goal was for committee members to get to know each other, but also to appreciate the different perspectives that members brought to the committee.

Phase I Interview Findings

This section begins by reporting the contextual factors that impacted the patient engagement intervention, then describes what the process of engagement looked like with respect to Cousins and Whitmore's (1998) dimensions of collaborative inquiry, and concludes by reporting on the observed effects or consequences of the engagement process.

Contextual Factors

In this study, contextual factors are historical, cultural, political, and economic factors in the internal or external environment that impact the context of the PSOP as well as the PFEC and how it operates. In Phase I interviews, I explored the motivations of participants wanting to be involved in a patient engagement project and the facilitators and barriers to participation on the PFEC; that is, what were some of the factors that positively influenced or restrained patients, family members, and health professionals with respect to becoming involved with the PFEC?

Motivations for patient engagement involvement. Participants shared a number of different reasons or motivations for joining the PFEC and wanting to get involved; each of these is listed in Table 6 and described below.

Table 6

Motivations for Patient Engagement Involvement

Theme	Participant Group
Way of giving back	All
Improving health services	All
Commitment to research & evaluation	Staff
Offering a unique perspective	All
Learning and revisiting assumptions	Staff

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Way of giving back. Overall, most patients and family members joined the PFEC as a “way of giving back” to the program and/or the hospital for the care they had or were continuing to receive. Patients were very appreciative of the services received, and joining the PFEC was one way of helping other patients. One patient/family member explained that “I had a very positive experience here, and if there’s anything that I could do for the PSOP, then I would, so here I am”. Based on her clinical experience of working with patients and family members in support groups and education sessions, one staff participant shared that patients/family have a change of thinking and perspective over the course of their illness and often develop a strong sense of wanting to help others in similar situations.

Improving health services. Despite being satisfied with the health services received, a number of patients and family members wanted to contribute to the project as a means of further improving services for others. As one family expressed, “otherwise, why am I here, right? Why

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

would I be participating if it's not going to make a difference?". A common reason and motivation given for wanting to be involved with the PFEC was to make access to PSOP services for other cancer patients and their families easier through greater awareness of the program or a more streamlined referral system. As two patient/family participants explained:

I got so much benefit from the services that were offered here, and so I thought there's got to be a way to maybe help others to figure out that these services are available, and that they can really help, even when you don't think you need help. (Patient/Family)

I've had some experiences that were really good and some experiences that were not so good. I guess, you get to a point where you wish you could try to make the whole process a little easier for someone else coming after me. (Patient/Family)

Staff participants also shared that one of their main motivations for joining the PFEC was to review their program and hear from patients and family members how they can further improve the program. One staff participant shared the following about her motivations for joining:

By using their feedback, we would like to improve our services, which would then go to improve the experience and services of many other patients in the future, so it would have major impact potentially . . . at the end of the day, it's all about service delivery and providing excellent patient care. (Staff)

Commitment to research and evaluation. This theme emerged uniquely from the PSOP staff and relates to some staff having research and evaluation responsibilities for the PSOP and felt the PFEC was a good direction to take to begin collaborating with their patients. There had been a desire among PSOP staff to involve patients and family members in a program improvement initiative, but the PSOP did not have the resources to commit to this type of project. When I approached the program to discuss a patient engagement project for my doctoral research study, it became possible and mutually beneficial for the program and myself to proceed with this project. The reality for most of the PSOP staff is that their clinical responsibilities are so demanding that committing to a longer-term project without protected time or having an evaluator take the lead is difficult. A staff member explained that "having [the evaluator] here with her expertise in program evaluation, and also this idea of a PFEC that would work on actual program evaluation outcomes, seemed timely and very fitting with my role here". Another staff member shared that patient and family engagement "is something that I really believe in;

however, we've had really competing priorities on trying to get something like this going".

Offering a unique perspective. All participants felt strongly that hearing the patient and family perspective about their health care experience was important with respect to improving the PSOP. Emphasis was placed on the lived experience of patients and family members having gone 'through the system'. Patient and family participants shared that they have a unique perspective on health services and can offer suggestions for improvement and areas of priority that staff may not have considered. For example, as one patient shared, "I know how the hospital works, because you know things aren't always absolutely perfect. If any feedback I give can help improve things, I think that's good". A family member expressed that having patient and family members involved in health service improvement projects "creates awareness — the practitioners who are ultimately delivering services to be aware of what the patient and family is going through". One staff member commented that "we are trying to improve services . . . but we're not even consulting the stakeholders. So I think an awareness that we probably would benefit from asking them what their opinion is, asking them some ideas and some feedback".

Learning and revisiting assumptions. In general, PSOP staff became involved because of their desire to learn from their patients and family members on ways to improve their program. There was acknowledgement that, when trying to improve services, professionals can sometimes make assumptions without consulting stakeholders. As one staff participant shared, "I'm going to do the same thing over and over and over again. Nobody ever tells me that, hey, this doesn't work . . . How am I going to know, because you get in your own little system".

Some staff members had experience working on projects related to improving PCC at the Ottawa Hospital, so this evaluation project was a natural fit. One staff member discussed the importance of program staff "getting a better sense of what's the difference between clinical research and program evaluation . . . it'll be personally rewarding to be involved in a process of something that could potentially result in improvement and change". Patient family members were also excited to be involved in a project that is "near and dear to [their] heart" and viewed their participation as "a different learning and growth experience".

Facilitators to patient engagement. Beyond asking why participants joined the PFEC, I was also interested in exploring participant perceptions on the positive influences that facilitated their ability to participate in this project in the early phase. Table 7 illustrates the five factors that emerged as important facilitators to their involvement in the project.

Table 7

Facilitators to Patient Engagement in PFEC during Phase I

Theme	Participant Group
Accommodating participant needs	All
Commitment to project	All
Orientation meeting	Patient/Family
Designated lead with evaluation skills	Staff

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Accommodating participant needs. The most frequently identified factor identified by participants as having influenced their ability to participate on the PFEC was the effort made to accommodate their schedules and needs. For example, during the recruitment phase of the project, all potential participants were asked what day of the week would be most and least accommodating if they were to join the PFEC. It was challenging to strike the delicate balance of accommodating the needs of such a diverse group of participants. For example, some participants were in treatment for their cancer, some lived outside the City of Ottawa, others worked during the day, some were retired, and others had young children in their care. A key facilitator for determining the most accommodating day and time to have the monthly meetings was the commitment of the PSOP staff to prioritize the patient and family participants' schedules first. Their efforts to accommodate their schedules accordingly is revealed in the following excerpts from staff and patient participants.

I'd say in terms of timing, we have tried to come up with a time that was a compromise between all of the stakeholders . . . People have to drive in [and] pay for parking, so there may be different issues for them that are harder. So in that sense, it may be easier for us to just come in this room and participate but it just makes me think more of commitment. It makes me think that this did require some commitment and passion. (Staff)

One of the things that I've encountered in my 18 months of experience with cancer treatment is that so many services, whether they're voluntary or part of the hospital or whatever, are available Monday to Friday from 8:00 till 3:00 or 4:00. I was already missing so much work for appointments and treatment, and all sort of stuff that I just can't miss anymore . . . it really comes down to the hours right now. (Patient/Family)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Patient and family participants also made efforts to be as accommodating as possible, recognizing and appreciating that an attempt was being made to have a committee with “people participating from as many different groups as possible”. As such, participants were willing to change their schedules when possible to accommodate other potential participants to participate on the PFEC. For example, one patient/family member shared that, during their conversation with the evaluator, “I basically said, don’t worry too much about me. I’m sure you’re going to have people much more difficult to accommodate, so I’ll work around it”.

Another positive factor identified as facilitating participation was providing food at the orientation meeting. For example, some participants shared that having food contributed to making the orientation meeting feel welcoming, for others it helped to have food because of their health status, and others appreciated that food was offered at the end of a work day. For example, as one participant noted: “I really appreciate that they provide food, drinks, and coffee, it’s really important for me, very important, because of my sickness, I have to eat often, and I’m always hungry, so these things are important”.

One participant talked about appreciating the PFEC organizers’ efforts to offer teleconferencing to those who live at a distance or are unable to attend a meeting in person. One family participant who lives on the outskirts of Ottawa appreciated having the option for teleconferencing, but felt it was important to attend the meetings in person if possible: “[The evaluator] has offered to arrange teleconferencing, but again I think I could participate more if in person, so it is worth it for me. So any meetings that I can make I will drive in”.

Commitment to project. A close second to accommodating participant needs in facilitating participation on the PFEC was the commitment each participant made to the program improvement project and improving health services for future patients and their families. Some staff expressed they made the commitment because they believed it was a valuable project and wanted the patient and family perspective included before making program changes:

I think that it speaks to the commitment I have, because I am willing to extend my day. It also speaks to the fact that I think this is a meaningful project. If I didn’t think this was important, I’d say, “oh, sorry, I can’t participate.” To me, this was important so it’s worth making that extra effort. (Staff)

Patients and family members, on the other hand, expressed their commitment as a result of gratitude to a program that was very helpful to them during a difficult time. For example, one

family member indicated that “the PSOP helped me to participate in the project by, you know, by playing a major role in my own recovery after losing my wife”. Some patients expressed making a commitment to join the PFEC to improve the referral process to PSOP for future patients. Specifically, they were appreciative of the services received by the PSOP, but the process to get referred was challenging and they wanted future patients to have an easier time accessing PSOP services. As one family expressed, “I am strongly motivated to do this. It’s almost like you want to prevent other people of going through the pain that I went through, but you can’t, so you got to just do the next best thing”.

Orientation meeting. The first meeting consisted of an orientation for participants to review consent forms and terms of reference for the PFEC, discuss roles, meet committee members, and learn more about the evaluation project. The most frequently identified benefit of the orientation meeting according to participants was meeting the other members, gaining an understanding of their motivations to be involved, and hearing everyone’s stories. During these introductions, members were asked to introduce themselves and share their motivations for wanting to be involved on the PFEC; participants were encouraged to only say what they were comfortable sharing. The majority of participants shared that hearing everyone’s experiences with the program was critical to beginning to form group cohesion and understanding the perspective from which everyone was coming. Here is one example of how participants described the importance of sharing their story:

I think for the patient and family members, it is also important to sort of have a personal introduction and we probably took too long doing that. But I still think that was in a way necessary for everybody to feel comfortable being together in the room, talking together in that room. (Patient/Family)

Participants shared that the orientation meeting was helpful in terms of clarifying logistics, expectations, and providing an overview of the goals of the PFEC. A patient member said that “it helped me to understand what the project is going to be all about”. Some participants shared that the orientation meeting increased their eagerness to be part of the PFEC and they were excited to know more about the objectives of the evaluation project. For example, one family member said that “I actually got anxious, well no not anxious, but enthusiastic about what our project is going to be? Where are we going with this? I like to get at it!”. A staff member shared that the “first meeting is about getting to know one another, trying to form that kind of

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

group cohesion, and feeling excited about embarking on something together, and talking a little bit about what we hoped to do together as a group”.

Designated lead with evaluation skills. All staff participants and one family member identified that having a designated lead with evaluation skills coordinating the evaluation project and taking the lead on the meeting logistics was a key facilitator to their participation on the PFEC. One family member shared that “having someone do all the administration and facilitator work is kind of nice. That is why I wanted to do this because it is totally different than anything I have already done in the past”. For staff in particular, they emphasized the challenges of leading this type of project due to competing clinical demands on their time and the challenge of conducting an evaluation project without evaluation experience. One staff member described having an evaluator as making it a “heck of a lot easier for us as a group ... I think that, in and of itself, is a gift to us”. Another staff member shared that we “believe in what she’s doing, and how she’s gone about it; the thought that she’s put into it. We have no major agenda here; it’s just about improving the patients’ experience”.

Barriers to patient engagement. Despite the positive perceptions that facilitated participants’ ability to participate on the PFEC, a few barriers and concerns were identified. Despite the early stage of this program improvement process, participants were able to identify four factors as potential barriers to patient engagement, which are identified in Table 8 below.

Table 8

Barriers for Participation in PFEC during Phase I

Theme	Participant Group
Time & resources	All
Imbalanced participation	Patient/Family
Change in health status	Patient/Family
Living at a distance	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Time and resources. As touched upon in the previous section, finding the time to participate on the PFEC does mean making sacrifices. Staff participants identified having to extend their work day by a couple of hours was a significant barrier they had to overcome. They also identified having competing clinical demands and non-protected time to do this type of work

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

made it challenging to complete some of the work associated with the evaluation project. In one participant's words:

When I participate, that's extra time. I take that out of my own personal time . . . because I'm still doing my day from 8:00 to 4:00. So I think it's just workload issues. Timings of the meetings, which I totally support, need to be at the end of the day, just to meet the needs of the patients and families. It'd be great if it was during a workday, but it isn't, and I accept that. I think workload is really it. (Staff)

Staff also shared that if the evaluator was not leading this process for the program, it would be unlikely that any staff member could take on this type of long-term patient engagement project. Staff felt strongly that having an evaluator leading this project made it more feasible for them to participate. The lack of financial and human resources to support this type of work was also identified as a barrier to doing such work in the future. Staff shared that they have a supportive manager who is finding innovative ways to arrange funds within the program budget to support this project, but it was unlikely that financial resources could be secured to provide staff with protected time to continue the work being conducted by the evaluator/researcher.

Patient and family participants also identified having to make some sacrifices to attend the meetings. For example, one patient shared that "right now my life is extremely busy, so that doesn't make it easy, but I knew that going in, so that's okay", while another commented that "if it means I have to go back to work afterwards, that's what I'll have to do".

Imbalanced participation. Most participants recognized that the first meeting had a strong focus on getting to know each other and gaining an understanding of the participant role and goals of the PFEC. Overall, participants were very pleased with the meeting process, but some did observe the varied amounts of time participants took to introduce themselves and share their motivations for joining the PFEC. For example, one family member shared that "there were definitely people that took less time than others, but I don't feel like anyone was rushed; everyone had time to say what they wanted to say". In general, most participants acknowledged that it was only the first meeting, and perhaps some had more to share than others, but two participants had a cautionary concern that it was something to pay attention to in future meetings. One patient commented that "they're going to have to be reined in, but that's every group. There's always someone, you know; it's just people". Another patient/family participant said that "to a certain extent you need to allow for some personal elaboration just because people need to

have their experiences recognized I guess, or to feel comfortable. But, I still do think that the focus needs to be watched carefully”. Overall, participants were optimistic that members would be respectful in future meetings and give everyone a chance to speak, but a few did share that this would have to be closely monitored.

Change in health status. Another important factor identified as a potential barrier to participating on the PFEC was the health status of patient participants. Specifically, participants recognized that a number of members were still in active treatment, or in remission with the possibility of relapse. For example, one patient shared that one barrier for her to attend meetings is “my personal situation, for example, if I go for a surgery or for a treatment that would make me to miss one meeting”. Participants shared they were pleased with the messaging that they should not feel pressure to attend all meetings and should feel comfortable participating at the level at which they were capable.

Some participants discussed the importance of being well enough psychologically and physically to participate on the PFEC, but not so far removed from their experience that it was no longer relevant. One family member shared that his social worker said “it was a concern when people were being recruited, that you were mentally stable enough, that you weren’t going to be terribly upset by being there, for instance. So I certainly wasn’t that”. One staff member shared that

we know that going through treatment and early recovery from treatment, people are fatigued, they’re still working out a lot of existential issues around what they’ve been through, so sometimes to catch people this early is a challenge; . . . however, I think to get the true feedback from patient experience, people have to be fairly close to the experience. (Staff)

Living at a distance. Some members shared their concern about living out of town and having to commute to the meetings, which adds further complexity to participating on the PFEC. One patient/family member shared her experience arriving at the first orientation meeting:

I just remember I was really, really stressed because I got stuck in traffic and it took me forever to get there coming from outside town and I was late. My first little while there, I was just catching my breath I guess. (Patient/Family)

Some participants addressed concerns about the first meeting ending a little later than expected, especially for those who live out of town and have to travel late at night. A family member

commented that “staying on time is important to me because driving an hour and half back and forth is significant and I am getting home in the dark; it’s not the end of the world, but can be difficult”.

Patient Engagement Process

Recurring weaknesses identified in the patient engagement literature are the lack of guidance or approach to implementing patient engagement into practice, the gap between intentions to involve patients and their actual involvement, and patient engagement tending to be more consultative rather than collaborative (Baker & Bombard, 2011; Fudge et al., 2007; Tedford Gold et al., 2005). As such, I was interested in examining participant experiences at different times during the patient engagement process. Specifically, I was interested in exploring each of the three dimensions of collaborative inquiry proposed by Cousins and Whitmore (1998): (a) their perceptions of the diversity of the PFEC membership, (b) the depth of participation PFEC members perceived having in the evaluation process, and (c) their thoughts on their role as well as the evaluator’s role in relation to the technical decision-making that occurred during the project. Participant views on the engagement process in Phase I are limited to their experience at the first meeting (orientation meeting), but offer some interesting perspectives of their initial impressions as well as their expectations moving forward with the project.

Diversity of members. The first dimension examined was the diversity of the PFEC members (i.e., stakeholder diversity); that is, who within the program or organization should be involved in the planning and evaluation process? Participants were asked their views about the value of the different roles on the committee and who they thought was missing. Table 9 provides a summary of themes that emerged; a description of each with examples follows.

Who is missing? Overall, participants noted the value in having a diversity of opinion and as many perspectives as possible contributing to the program improvement project. The majority of participants acknowledged that they were fairly homogenous group with respect to socioeconomic status, education, language, etc. However, they appreciated that each member represented a different cancer site and the good diversity in terms of age, gender, and staff-to-patient/family ratio.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Table 9

Diversity of PFEC Members during Phase I

Theme	Participant Group
Who is missing	
Vulnerable populations	All
Patients with head and neck cancer	Staff
Need for more heterogeneous group	All
Family members of patients in active treatment	Patient/Family
Value of evaluator role	
Facilitator/organizer	All
Evaluation skill set	Staff
Value of staff role	
Context and reality check	Patient/Family
Ability to affect change	All
Value of patient/family role	
Contextual knowledge from lived experience	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

One participant shared these thoughts about the diversity of the group:

From my layman's perspective, I mean, I guess when you look at the facts, you've got male/female, you've got age, disease site, socio-economic situation, like I don't know the answer really . . . but again, I think over time, it'll become more evident who is missing.
(Patient/Family)

Most participants appreciated the efforts made to recruit patient and family members that represent certain groups; however, the majority recognized that certain patient groups were not represented on the PFEC. For example, patients from different cultures, belonging to a lower socioeconomic group, with head and neck cancer, or considered more vulnerable were not represented. Two patients commented that they appreciated having family representation on the committee because this group is often neglected during the treatment process. They also suggested that having a family member whose loved one is currently in active treatment might add a slightly different perspective from a family member who has lost a loved one to cancer. Here are sample comments shared by participants about who might be missing from the PFEC:

I think the big one that we felt may have been missing is the head and neck population
...The head and neck [patient] is the one thing that I know—we were aware that we had

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

not been able to—we did try, but we were not able to get. (Staff)

I'm a patient going through treatment, I have my perspective, but my wife for instance she has her perspective and she's still looking at it from the point of view of somebody that's dealing with somebody in treatment not somebody who's passed on.

(Patient/Family)

However, some members acknowledged the challenges of recruiting some of those groups and that more creative approaches would perhaps need to be used to include them in the future. Here is an example of what one participant shared:

There were certain more “vulnerable” groups missing. And I suppose, unfortunately it's the nature of this kind of project that you don't get them as easily . . . but what would you do? How would you get to them? I don't know; maybe you will have to seek them out in a different way. (Patient/Family)

Value of the evaluator role. The majority of participants saw the evaluator role as facilitating the program improvement project. When asked to clarify, participants described the evaluator as leading the evaluation project by facilitating the process, chairing the meetings, and taking charge of all of the organizational tasks that go along with project management. Typical comments from participants included the following:

She's the brains behind the whole operation, basically. She's the one who's organizing each meeting, deciding how to go about it. I mean, we have a broad idea what we want to do, but she's the one who's going to execute it, give us these thought exercises. (Staff)

[The evaluator] ensured that all of us were able to talk, but even in open conversation, there was really a good mix of participation between both the members from patient families but also from administration or from PSOP. So there was a good exchange. I think everyone seemed to have a chance to talk. (Staff)

Staff expressed that the evaluator role added value in terms of level of engagement obtained from patients and family members participating in the program improvement project. As one staff member described,

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

None of us would have done it in this way. We might have pulled the committee together, but none of us would have done it as thoughtfully and thoroughly . . . this is taking patient engagement to another level for us, it really is. (Staff)

Staff seemed to particularly appreciate the systematic process that moved the project along from one meeting to the next. One staff member suggested they were hopeful that having an evaluator lead the project would ensure a more objective process and give credibility to the findings and recommendations: “I would expect the evaluator to be a neutral or unbiased person who would be able to really examine the process from the outsider perspective. I think it’s more in terms of the validity of the information”.

The majority of members of the committee saw the evaluator’s role as interfacing with decision-makers and being somewhat of a ‘change agent’, that is, someone who can bring recommendations forward to decision-makers and advocate for program improvements identified based on evaluation findings. One patient saw value in having the evaluator present results, but recognized that “it will be a challenge because she is working within a bureaucratic system”.

Value of the staff role. Based on the first meeting, the majority of PFEC members felt that the role of staff on the PFEC was critical. Specifically, members recognized the importance of having members with a strong understanding of the program and hospital (context); that is, staff can provide a ‘reality check’ to patient and family members, so the project outcomes and recommendations are realistically achievable. While the committee identified the program/hospital context as important, committee members also identified other expertise that staff bring to the committee, such as having oncology experience and experience within each of the different specialties represented (i.e., social work, psychology, administration, and medicine). One patient/family participant shared that “I could imagine patients/family sharing a perspective or an idea that might not be feasible . . . I assume that this will be facilitated in a way that we’re kept on track in terms of realistic outcomes”.

Another valuable aspect of having staff on the committee is learning. As one family member shared, “I can certainly see the benefits of the psychiatrist and the psychologist and the program manager, because they can learn from this”. Participants recognized that working in partnership with each other could offer important learning opportunities that go beyond conventional feedback tools regularly administered at the program/hospital level. They hoped that this learning could benefit not only their clinical practice, but also be brought back to the

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

program level and decision-makers. For example, one staff participant shared that “I’ve done it this way for a while, maybe I need to change it up a little bit. That’s on a personal practice issue for me as a practitioner”.

Value of patient and family role. Participants felt that the patient and family role was critical for this program improvement project. Specifically, participants shared that patient/family members have lived experience with the PSOP and Cancer Program that other key stakeholders do not. Members discussed the importance of having both patients and family members because the health care experience is very different. For example, two patient/family members shared the following:

The family members because they’ve experienced it as well, and often, in some ways far more, in some ways more intense way than the patients, because we know people, caregivers actually can have levels of depression that are higher than the patients themselves, because of the feelings of inability to change the situation, grief and loss, so I think their input will be central. (Patient/Family)

What I’ve seen happen to others around me, I have had quite a wide range in experience with my cancer. I’ve been intimately involved in surgery, chemotherapy, and radiation, all twice. . . . So I think I have maybe a better idea than a lot of people on the different areas for improvement. (Patient/Family)

Participants spoke of a partnership between staff and patient/family members that is critical to capture what is important to patients/family members and to help staff learn from their experience. The majority of participants shared that collaborating with patients/family members offers a real perspective on what the health care experience is really like. For example, one patient/family member shared that one of the reasons she joined the PFEC was to make the program aware of the impact cancer had on her children and family:

I think, I will bring a perspective from a family point of view. That’s one thing I was thinking about when I wanted to join, was how this experience has impacted not just me, but my kids and my husband. And how, in my view the PSOP hasn’t really considered that. Or at least if it has, it hasn’t been available to us. I’m bringing a different perspective from the family, and children and husband point of view. (Patient/Family)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

A small number of participants discussed the importance of having patients and family members with recent experiences with the PSOP so that their contributions are relevant. Some members felt that some hospital committees have patient/family representatives whose health service experience is too far removed to be able to accurately share a relevant lived experience.

Depth of participation. The second dimension is *depth of participation*, implicating the intensity of involvement in the evaluation process, ranging from light-touch consultation to significant engagement with all phases of the PFEC project. Keeping in mind that these findings are at the early stages of the project, Table 10 provides a summary of the three most commonly identified themes related to intensity of project participation. Included below the table is a description of each of the themes with examples.

Table 10

Depth of Participation in Engagement Process during Phase I

Theme	Participant Group
Evaluator facilitating process	All
Staff providing program context/reality check	All
Contextual knowledge from lived experience	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered to be endorsed by both groups.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Evaluator facilitating process. The majority of participants saw the evaluation role as facilitating or guiding the project. For example, a family member shared that “hopefully [the evaluator] can take in all that she hears from the different perspectives, and then turn it around to be patient and family centred, in the way that it is presented to the decision-makers”. Others viewed the role as critical to moving the program improvement project forward by listening to the different perspectives within the PFEC and facilitating consensus among the group in terms of program improvement recommendations to be presented to decision-makers. However, one participant asked, “Could you explain to me . . . more of what a program evaluator does?”. After the interviewer gave an explanation, the participant shared the following:

I would assume that if she’s evaluating things, then she would provide a lot of input to the evaluation process and hopefully some sort of recommendations could come out of it. It seems kind of obvious that her role would be very central to the whole thing.
(Patient/Family)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Several participants indicated that the evaluator role was critical to ensuring everyone is heard and that their voice is represented.

Staff providing program context/reality check. Patient and family members shared that staff provided some program background information at the orientation meeting, but that they spent most of the meeting listening to what the patient/family members shared about their experience. Patient/family members shared that having staff involved was critical for understanding the program issues and for developing realistic recommendations. Staff members felt their role was to provide historical and contextual information about the PSOP and the hospital organization. Staff also shared they felt their role was critical to providing ‘reality checks’ during the process to ensure realistic recommendations were being developed.

Contextual knowledge from lived experience. A significant component of the first orientation meeting was to introduce members and devote time to allow members to share their personal experience with the PSOP, either as a patient, family member, or staff. A staff member shared, “I think it was important to understand why people were at the table and what they had to bring”. PFEC members were very transparent and open about their motivations for wanting to be involved in this patient engagement project and in sharing their personal experience, for example:

We went around the table, and everybody took a couple of minutes to explain who they were, and what their association with the PSOP was. To be honest, I’m humbled by all these people, and feel for everyone who’s still going through this in some way; but, yeah, it’s definitely a good way to get to know each other. I’m glad that we had that, I’m glad that we got to hear everyone’s story, and I guess I wouldn’t have expected that, so it was a nice introduction. (Patient/family)

As a result of some members sharing personal and difficult experiences with PFEC members, some staff felt challenged in terms of how much to share with committee members. As the evaluator, I began by introducing myself to the group and shared that I had experience at the Cancer Program with my father who had recently died of cancer. As the evaluator of the project, I felt it was important to be transparent about my recent experience, because it impacted my understanding of the Cancer Program and services available. Reflecting on my introduction, one family member said that “she has her personal experience with her own father, so you know; it’s not just a professional contribution” and a staff member noted that “I think [the evaluator] brings

her experience in program evaluation and also her personal experience of her father navigating the system and being a support to him”. For some participants, this gave credibility to my motivation to do this type of research. Here is an example of a staff member’s thoughts about transparency of the evaluator and staff:

Well, [the evaluator] went first, and she shared personal information. So as the evaluator sharing, it was completely appropriate. It gives a context. I think it helps to build that cohesion. I’m sure that the patients, I don’t know what they’ll say, but I have a suspicion that maybe they appreciated knowing that. Like as opposed to our titles and our roles in the program, what is it that personally leads us to be involved in cancer care, in particular, and wanting to be involved in such a committee. So that was interesting.
(Staff)

Some staff members felt unsure about how much they should share about their experience with the program because of their professional relationships with patients and family members on the committee. It was challenging for some to hear such personal stories from patients and family members and not share more about themselves. As one staff member noted:

Patients introduced themselves and their story and their reasons for being there and then professionals also introduced themselves. There was a bit of — on some people’s part — how personal do you get when you’re the professional in the room when the patients are sharing their personal stories? And of course as professionals we all have personal lives, so that was interesting to notice, the variation in terms of professionals, in terms of how much personal information they disclosed. I wonder about how people felt in the situation. Like if they disclosed more than they — if they felt any pressure to disclose personal information. (Staff)

This quote highlights the new territory that health professionals and patient/family members are entering in this new collaborative working relationship. Overall, staff seemed comfortable with the extent to which patients and family members shared, but some struggled with remaining neutral or reserved in a committee setting compared to a clinical setting.

Control over evaluation process. PFEC members were asked to reflect on a series of questions related to who controls the evaluation process, recognizing that only one orientation meeting had occurred at the time of the interview. For example, participants were asked if they

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

felt their voice and opinions were being heard, how they would like to see decisions made, and their understanding of the project goals and how they were determined. Table 11 provides a summary of the most commonly identified themes about participant views related to control over the evaluation process and what they hoped would unfold during the project.

Table 11

Control over Evaluation Process during Phase I

Theme	Participant Group
Mixed clarity of project goals	Patient/Family
Democratic/majority rule decision-making	All
Respectful and collaborative	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Mixed clarity of project goals. When the patient and family members were recruited to participate on the PFEC, they were informed by telephone and an information letter that the purpose was “to be involved in a program improvement initiative that is identified as important to the PSOP”. The PSOP staff and I met on numerous occasions to discuss some broad objectives that the PSOP would like to achieve with the PFEC and overall approach. The staff decided to undergo a needs assessment of the program to identify areas that most need improvement and those areas identified by all members of the PFEC. At the time of the orientation, the majority of the patients and family members were unclear on the specifics of the needs assessment, because identification of areas of improvement would not begin until the next meeting. Below is an example of how one patient/family participant described the objectives of the PFEC.

I think that what [the evaluator] is trying to do is to figure out a way to integrate the PSOP into the care plan for patients and family members. I think that’s what the ultimate objective is, is to determine where the best times, like temporarily where the best points are to insert PSOP, and for how long, and what services can actually be provided. That, I think, is the essence of what she’s trying to do. Maybe I’ll come to a different conclusion when I read more. I don’t know. (Patient/Family)

In contrast, the PSOP staff participants had more clarity about the overall goals of the project, without knowing specifically what areas of the program would be identified by the PFEC for

further analysis and recommendations for improvement. Having had a number of meetings to discuss overarching objectives for the PFEC, the staff participants had a better understanding of the project goals.

Democratic/majority rule decision-making. Participants were asked what process or approach they would like to take in making decisions as a committee. All participants shared that they would like to use a democratic style of decision-making, which was often described as decisions made by the group rather than one person or a select few on the committee. One staff member described wanting decisions to be made “through brainstorming and consensus. You look at the advantages and disadvantages of different things, and then decide what the priorities are collectively”. However, some patient/family members emphasized that they hoped decisions would be made democratically but appreciated that staff members have contextual knowledge about the program and the hospital that needs to be taken into consideration when making a group decision; that is, patient/family members do not want to put forward recommendations that are not feasible or realistic, so staff opinion was highly valued in that regard. Here is an example to illustrate this view:

It’s not like a jury where you have to have 100% unanimous, because that’s not realistic in something like this, especially with the number of different viewpoints involved . . .

There are going to be some things that maybe we could recommend, but the staff members on the committee may understand, but frankly will never work. Really what it comes down to is you try for a best consensus. (Patient/Family)

Overall, participants seemed committed to making decisions collaboratively, but at the same time recognized the importance of being pragmatic about certain decisions to ensure realistic project outcomes.

Respectful and collaborative. Participants were asked if they felt their opinions were valued and their voices heard at the orientation meeting. All participants felt the meeting atmosphere was respectful and that all members appeared genuinely interested in hearing what everyone had to say. Staff appreciated being with patients and family members in a non-clinical role wherein they could collaborate as partners, rather than in the traditional clinical relationship role. For example, one staff member noted that “just being at the table with them at more of an equal level, that’s been kind of nice”.

A small number of participants commented on how the staff members were quieter

compared to the patient and family members, but felt they were trying to give patient and family members the opportunity to speak and be heard. One patient expressed that the staff members are naturally very good listeners because of the nature of their work in psychosocial oncology. In one patient/family member's words:

I thought it was good that the psychologists and the working people here from the hospital allowed the patients and family to speak the most. I thought that was really nice. But I guess that's what they do for a job too, so that they're good at that anyways.
(Patient/Family)

One staff member commented that "I also felt that my voice wasn't necessarily the most important voice to hear. So, my voice was probably heard less because there were other people that I think needed to have that opportunity to speak". In general, participants were pleased by the members' level of openness and felt their opinions were valued and appreciated.

Improving the engagement process. Participants were asked if they had any suggestions to improve the patient engagement process. The majority of participants commented that it was too soon to make improvement suggestions, but overall were pleased with the recruitment process and how the first meeting unfolded. However, a few suggestions were made by individual participants:

- Adding more meetings to the overall project because there might not be enough time to thoroughly address all of the objectives. (Staff)
- Begin project work at initial meeting. (Patient/Family)
- Finalize broad objectives sooner, because the process seemed rushed. (Staff)

Consequences of the Patient Engagement Process

While I examined the contextual factors and the patient engagement process, an additional objective was to identify the consequences of the process. I wanted to explore the intended benefits and unintended outcomes of the patient engagement intervention (i.e., member expectations of the PFEC) and the participants' experience with the engagement process thus far. Intended benefits are discussed below; no unintended outcomes were identified in Phase I.

Intended benefits. Participant views on the consequences of the project in Phase I focused on the expectations of participants with respect to being a member of the PFEC and what they hoped would be the consequences of the evaluation project. Table 12 outlines the four most common themes identified by participants.

Table 12

Intended Benefits of Engagement Process during Phase I

Theme	Participant Group
Reaching decision-makers	All
Improving PSOP services	Staff
Increased diffusion of patient/family engagement	All
Improving awareness/access of PSOP	Patients/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Reaching decision-makers. The most important intended consequence participants identified for their participation is that the results of their work would reach decision-makers. This included staff, who were hopeful that having patients and family members involved in this project elevated its credibility and hence the findings would more likely be welcomed by decision-makers. As one staff member noted:

I have fair optimism in that we are facing a difficult time in terms of economics, so it's a more difficult or more challenging system to work with in general, but despite that, the focus is very much on the patient experience at the moment. Coming in with a suggestion or a request or a plan that is based on patient advice or patient and family advocacy I think will have more weight, so I think they will be taken maybe more seriously. (Staff)

Some patients and family members wanted to have a follow-up with the program upon completion of the project to be updated on the progress made based on the recommendations brought forward in the report. This follow-up would help hold the program and decision-makers accountable and reinforce the importance that participants place on their engagement being genuine.

Improving PSOP services. Staff participants are hopeful that their participation on the PFEC will help guide the PSOP in terms of the direction it should take in the next few years to continue to improve the patient experience. Staff participants expect they will be able to implement program-level recommendations, but recommendations at the organizational level (e.g., increase human resources, program accessibility) might be more difficult but nevertheless possible because they have been co-developed with patients and family members. One staff

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

member shared the following thoughts about the expected consequences of their involvement on the PFEC:

So at the program level, I think definitely there are, for some components, very easy changes that can be made. But at the broader level, I think certainly the suggestions would be taken much more seriously with the patient inclusion in there. (Staff)

Patient/family members spoke of identifying program areas that need to be improved, but also the importance of identifying the strengths of the PSOP program. For example, one noted the following: “I hope we can make some suggestions where strong elements of the PSOP process can be adhered to or identified as optimal, basically, and then areas where there may be weaknesses that could potentially be modified”.

Increased diffusion of patient/family engagement. Finally, participants were hopeful that the work conducted by the PFEC will serve as an example of genuine engagement and collaboration. They were hopeful that the lessons learned from this process will help further develop best practices for patient and family involvement in quality improvement initiatives and that more programs will see the value of collaborating with patients and family members. This was summarized by one participant as follows:

I don’t know if it’s a movement per se, but certainly we’re in an era where patients are taking control. Patients are informed, patients are encouraged to self-manage. I think so there is a culture shift, I think, in health care. So I think both are coming in parallel but I think in response to the same culture shift that’s occurring. (Staff)

Improving awareness/access to PSOP. Some patient participants spoke of the need for greater visibility of the PSOP within the Cancer Program and quicker access to services. Participants shared the challenges they faced navigating the health care system and how things would have been easier had they been referred to the PSOP sooner or been made aware of their services at diagnosis. One patient/family member shared that “I hope that it will gain some visibility, and perhaps gain some funding and be available to more people earlier in their experience. It took me a long time to get to see anybody and I needed it from day one”.

PSOP staff also hoped that awareness of the PSOP could be elevated by having patients and family members working on the PFEC and being advocates for the program within and outside the hospital organization. One staff participant noted that “there’s a general perception of the value of PSOP within the cancer program, and I think having patients and families on board

to be the advocate or being the champion has a real benefit to us as an organization”.

I now turn to participant views about their experience on the PFEC.

Participant experience. Participants were asked to comment on their experience of involvement on the PFEC. The experiences described are based on the orientation meeting only, but the responses capture participants’ initial reaction to the first meeting and their perspective on future meetings. Overall, participants described the experience as being positive and did not identify any negative experiences with their involvement. Table 13 outlines the four most common themes identified by participants; included below the table is a description of each of the four themes with examples.

Table 13

Participant Experience of PFEC Involvement during Phase I

Theme	Participant Group
Shift from personal focus	All
Enthusiasm for project	All
Closing the loop and healing	Patient/Family
Personally rewarding	Staff

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered to be endorsed by both groups.
 Note 2. Identified themes are listed in the order most frequently identified by participants.

Shift from personal focus. The majority of patient/family members shared that the experience of hearing everyone’s experience at the orientation meetings was very moving, and many described it as “humbling”. Hearing the different experiences and perspectives made some members realize that other people have also had difficult experiences and significant loss, which helped them see this project from the perspective of others with very different experiences. One patient/family member shared the following about this perspective:

My experience with cancer treatment is going to be different from somebody with breast cancer, or colon cancer, or something like that, it’s going to be different from one of the family members who have lost somebody. I think it’s good to know where people are coming from . . . Sometimes it might temper your disagreement; I guess you could say if you can understand where they’re coming from. (Patient/Family)

Enthusiasm for project. All participants felt enthusiasm and excitement about the work the PFEC was planning to undertake and looked forward to the next meeting. For example, one

patient said “I like listening to people tell their stories. Some of them have such adversity, and yet they still are optimistic. I love that, that part of life”. Some people were impressed by the enthusiasm and commitment of members on the PFEC and felt it would be a good group to work with. In the words of one staff member:

I thought it was a really good first meeting, I was surprised at the calibre of people who came forward, it tended to be quite articulate, they tended to be very thoughtful, and they came ready to work. . . . I’m not quite sure what was I expecting, but it was a good meeting, it was a hopeful meeting. (Staff)

Overall, participants were ready to work and looking forward to ‘rolling up their sleeves’ and contributing to the project. A few participants hoped the first meeting would have included some project work, but understood the importance of an introductory meeting.

Closing the loop and healing. A few patient/family members felt in some indirect way that participating on this PSOP project was a way of not only giving back but also closing the loop on their cancer experience. Some also suggested being involved in this type of work could help the healing process and recovery from a challenging experience by allowing them to share their experience and be heard; as one patient noted, “it could be a chance for some people perhaps to connect and get to feel less isolated in their situation”. Another patient/family participant shared the following:

I think it just helps you heal too. It just helps close the loop, and whether or not you’ve had a good experience or a not-so-good experience with the system, it allows you to have that voice. Some of us do it because we felt we were treated so well and we’re so grateful to be alive. And others had a terrible experience — whether or not it was even in the minds of the people treating that person, something they even remembered that they did, or didn’t do, it’s important that that person be heard. (Patient/Family)

Some participants felt that being involved in this type of program improvement project could benefit them personally in terms of being surrounded by people that have had similar experiences and relating to each other’s experiences.

Personally rewarding. Staff participants shared that a personal benefit of their involvement was seeing how well some of their previous patients were doing. They talked about the personal satisfaction they received from hearing about their experience and how much they appreciated and benefitted from the PSOP. Many of the staff spoke of the affirmation they

received that their work was making a difference to patients' lives. As one staff member described, a "number of people had obviously been through an awful lot of trauma and turmoil, and then they seemed to have come out the other end, so, yeah, I think it's grounding, I think it's reaffirming, it's helpful". Another staff member shared that

On a personal level, it's a very valuable experience because it's getting feedback on the work that you do. So we all do our work. We have our patients who come in and see us — maybe for a short time, maybe for a long time . . . You get to know them over a period of time and you think you know what the benefit is to the work that you do. But when you hear people speak around the table, it's very touching first of all. And secondly, you think, "you know what? I have made a difference, I can make a difference". (Staff)

In the next section, I report on the data from my personal observations and reflective notes from the first orientation meeting.

Phase I Participant Observation and Researcher Reflection Findings

This section reports on the findings from the reflective notes and participant observations collected immediately following the orientation meeting. Similar to the interview findings, these data are reported according to the *contextual factors* that I perceived to influence the patient engagement process, the dimensions of form in collaborative inquiry (Cousins & Whitmore, 1998) impacting the *patient engagement process*, and the *consequences* of patient engagement.

Contextual Factors

According to my participant observations and reflective notes, a number of contextual factors either facilitated or inhibited the patient engagement process. PFEC members were given the opportunity to describe their reasons/motivations for wanting to be involved on the PFEC; key reasons described at the meeting included:

- Improving health services following a difficult referral process. (Patient/Family)
- Wanting to give back to the program for appreciation of services. (Patient/Family)
- Ability to provide a patient/family perspective about health services. (Patient/Family)
- Learning from patients and family members to improve PSOP services and challenging assumptions. (Staff)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

- Hopeful that PFEC recommendations will reach organizational decision-makers who highly value patient/family feedback. (Staff)

My observations from the meeting highlighted that most participants joined the PFEC to improve health services for future patients. Staff also “felt strongly that higher-level decision-makers greatly value the patient/family voice, so they are very hopeful that this project will help bring forward strong recommendations to improve care for cancer patients”.

The orientation meeting had a lot of positive energy and enthusiasm. Upon reflection following the meeting, I observed the following contextual factors that contributed to the positive meeting atmosphere:

- Food and beverages were appreciated and facilitated socialization.
- There was a sense of enthusiasm and keenness about the project by all participants.
- Staff demonstrated genuine warmth and appreciation towards patients and family members.
- Participants voiced appreciation for the meeting organization.
- Transparency and openness from patients and family members sharing their experiences about the PSOP.

My observations highlighted the openness, transparency, and warmth that participants displayed to one another. Here is a sample of my reflective notes illustrating these observations:

I’m completely taken aback by how open the patients and family members were in sharing their experiences with cancer and the services they received at the PSOP. There was a real sense of trust and warmth among members that was palpable, despite the fact that this was our first meeting. It was fascinating to see how some PSOP staff went beyond talking about their professional role with the PSOP to explain why they were passionate about psychosocial health services.

I felt it was important to be transparent about the fact that my father had recently passed away of cancer and that he had received services as the Cancer Program. I realized early in my conversation with patients/family members and staff that it would be very difficult to hide the fact that I had had experiences at the Cancer Program, so it was important to be honest and transparent about it.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

I also observed potential barriers that need to be considered when engaging patients and family members in health service improvement projects:

- Meeting times and locations need to be carefully considered to accommodate patient and family members, especially patients undergoing active treatment.
- Short time frames to complete project can be challenging.
- Risk of not hearing everyone's perspective and poor collaboration if the lead does not have strong facilitation skills.
- Discomfort shifting from a clinical relationship to a working relationship.

My observations from the first meeting also included concerns over patient participant fatigue and overburdening them while in or recovering from treatment. To illustrate, here is an excerpt from my reflective notes:

One patient participant arrived approximately 15–20 minutes into the meeting and looked a little exacerbated after struggling to find parking and looking for the meeting room.

When she walked in, she apologized for being late and blamed her struggles with finding the room on 'chemo brain'. I know she is still in active treatment and a mother of young children.

I also reflected on the challenges of facilitating this type of evaluation project, which involves patients undergoing serious cancer treatment and family members who have lost loved ones to cancer. As a result, the discussions at the orientation meeting were at times difficult to facilitate because the emotions of some participants were still quite raw. "It was an incredibly moving discussion and a few members shed tears, so it was challenging at times for me to maintain my professional role [facilitating the process], but at the same time remain empathic". There is a delicate balance that I knew I had to meet in order to be effective with the PFEC.

My observations from the orientation meeting included the fact that the patients and family members were welcomed warmly when they arrived; most had not seen each other since the patients had received treatment at the PSOP. I noted that the interaction between the staff and the patient and family members was warm and there seemed to be genuine happiness in seeing each other again, but "I observed a mild awkwardness or insecurity on the part of all participants during this initial interaction. I wonder if the awkwardness was a result of the different circumstances in which they were seeing each other again". Many of the patient and family members had clinical relationships with the staff, so seeing them again in a totally different

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

context, might have been initially uncomfortable for all participants: “It’ll be interesting to see the transition in that relationship as the project unfolds”.

Patient Engagement Process

The PFEC discussed the *diversity of members* involved with the PFEC, and my reflective notes identified the following observations from those discussions:

- The PFEC is generally satisfied with the diversity of the group in terms of age, gender, and cancer site.
- Future efforts should be made to recruit vulnerable populations, patients with head and neck cancer, and oncologists.
- The patient-to-staff ratio is satisfactory, but if more people are to be recruited they should be patient or family members.

In terms of the *depth of participation* and *control of decision-making*, my observations and reflections were of “participants arriving to the orientation meeting with enthusiasm, and I could sense their eagerness to learn more about the project, their role, and what the PFEC was going to focus on as an evaluation project”. Overall, the meeting ran very smoothly, and we were able to address every agenda item: “I was pleased with the questions and discussion about the terms of reference because they involved patients and family members questioning the goals and outcomes of the PFEC”. I described participants as being “attentive to what members were saying” and “very respectful of each other’s views”.

The discussions between the PSOP staff, the patient/family members and I were very collaborative: “I think it was very refreshing for the staff to see patients and family members who are so keen and serious about their role on the PFEC”. Allowing participants the time to share what they experienced over the course of their illness or their family member’s illness “appears to have helped the group bond. The staff were also very open about their experiences with PSOP and their interests in cancer care, which patient/family members seemed to really appreciate”.

Consequences of Patient Engagement

Participant discussion about reasons why they were motivated to join the PFEC were often interlinked with the *intended consequences* the PFEC would hopefully achieve. Key consequences identified in my reflective notes were as follows:

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

- Project is meaningful and will lead to improving health services: easier access to PSOP services.
- Reach decision-makers.
- Staff hope to learn from patient/family members and have greater patient engagement in the future.

“There was a clear sentiment among patients and family members that they wanted to ensure that the work that the PFEC embarked on would be useful and would lead to improved health service”.

Chapter Summary

This chapter provides the findings for Phase I of this three-phase study. To begin, an overview of the evaluation tasks completed and meeting timelines is provided. This is followed by the interview, participant observations, and reflective journal findings conducted in the early phase of the evaluation project. The *contextual factors* that impact the engagement process are first reported responding to the first research question; they include the reasons participants joined the PFEC and the facilitators and barriers to the engagement process.

Contextual Factors

Overall, participants described the following motivations for wanting to be involved on the PFEC during the interviews: a) way of giving back, b) improving health services, c) commitment to research and evaluation, d) offering a unique perspective to the PFEC, and e) learning and revisiting assumptions. My participant observations and reflective journal findings identified the majority of those themes, with two exceptions. First, my reflective notes and participant observations did not identify research and evaluation commitment as a reason for joining the PFEC. Second, my observations include one of the reasons for staff joining was to reach decision-makers more effectively; that is, staff believe that organizational decision-makers greatly value patient and family feedback, which is at times more powerful than staff input.

The interview findings identified a number of facilitators in the early stages of the project (i.e., accommodating participant needs, commitment to the project, the orientation meeting, and having a designated lead with evaluation skills). My participant observations and reflective journal findings were similar in that they identified accommodating participant needs and commitment to the project as facilitators, but also identified having food and beverages, genuine

warmth and appreciation from staff towards patient/family participants, and transparency and openness in sharing participant experiences. My observations also included participants voicing appreciation for strong meeting organization, which could be related to having a designated lead with evaluation skills as identified during the interviews.

Four barriers were identified from the interview data that may contribute to having a negative impact on participation in the process (i.e., time & resources, imbalanced participation, change in health status, and living at a distance). Participant observations and reflective journal findings identified very similar findings to those from the interviews, but also highlighted the need for the evaluation lead to have strong facilitation skills and recognition that the patient/clinician relationship needs to shift to a working relationship, which can create some initial discomfort when interacting in a different context.

Patient Engagement Process

Next, I reported on the findings of the second research question that relates to participant experience with the engagement process according to the three dimensions of collaborative inquiry (Cousins & Whitmore, 1998). Two salient themes that emerged from all data sources included having (a) an evaluator facilitating the process to ensure everyone has an opportunity to contribute and (b) having participants share their personal experience/story to provide the opportunity for everyone to participate equally at the first meeting.

Participant perceptions on the *diversity of the PFEC* membership included interview findings on who is missing (i.e., vulnerable populations, patients with head and neck cancer, need for more heterogeneous group, and family members of patients in active treatment) and the value of the different roles on the committee. My participant observations and reflective notes identified similar themes, but included having an oncologist on the PFEC.

Finally, I reported on the most commonly identified themes about participants' views related to *control over the evaluation process*. Participants hoped for (a) greater clarity of project goals at the next meetings, (b) a democratic or majority rule decision-making process, and (c) members to be respectful and collaborative. My observations and reflective notes indicated that the orientation meeting demonstrated early signs of collaboration and respect among members and attentive listening from all members. I also noted good discussion and constructive debate when seeking clarification related to the project goals at the first meeting.

Consequences of the Patient Engagement Process

Later in the chapter, consequences of the engagement process were reported to respond to the third research question. Specifically, the findings from all data collection sources identified the most important intended consequences for participation were (a) reaching decision-makers, (b) improving PSOP services, (c) increasing diffusion of patient/family engagement, and (d) improving awareness and access to PSOP. This was followed by a description of participants' experiences of being involved on the PFEC, which included: (a) having to make a shift from a personal issues focus to a more general (i.e., program level) issues focus, (b) feeling enthusiasm for the project, (c) closing the loop and healing, and (d) being personally rewarding. In the next chapter, Chapter 5, the findings for Phase II are reported using the same format as Chapter 4 with the inclusion of reporting on the changes occurring from Phase I to Phase II.

Chapter 5: Phase II Findings

This chapter highlights the interview findings of Phase II, which correspond with meetings II, III, and IV. The purpose of Phase II was to examine whether participant opinions and expectations about the project had changed by the midpoint of the evaluation project in comparison to Phase I. Phase II timelines and evaluation project milestones are described in the first section of this chapter, followed by reporting of Phase II interviews, participant observation and reflective journal findings, and concluding with a summary of the chapter.

Phase II Timelines and Overview

Phase II of the study consisted of an approximate two-month period from December 4, 2013, to February 5, 2014. During Phase II, the PFEC members completed some work from home to identify strengths and weaknesses of the PSOP based on their experience as a patient, family member, or clinician. Based on this work, I prepared a summary document of the strengths and weaknesses identified and the most common themes were highlighted; this summary was shared with the PFEC prior to meeting II. Based on the most common weaknesses identified, the PFEC undertook a priority sort exercise to further narrow areas that the PSOP would work towards improving in the next year or two. Meetings III and IV focused on fine-tuning the priority areas identified and beginning the work of identifying the issues needing improvement and collaboratively developing recommendations. The PFEC members advocated for preparatory work to be completed between meetings in order to use the meetings for discussion and decision-making, rather than brainstorming of ideas. That is, after each meeting a series of questions for reflection and comment were sent to members to begin the discussion for the upcoming meeting. Once all members provided input via email, I consolidated and summarized all responses and included a summary of key themes for each of the questions/issues being addressed at the meeting. This allowed members the time to reflect on their experience and the opportunity to have their opinions represented without influence from other members. Members reviewed the summary documents prior to attending each meeting, which provided the groundwork for further informed discussion and decisions related to the priority area being addressed at each meeting. Table 14 provides a summary of work completed in Phase II.

Table 14

Meetings II, III, and IV: Evaluation Work Completed Prior to Phase II Interviews

Meeting Number	Evaluation Work Completed
Meeting II	Reviewed PSOP logic model including data sources and updated by PSOP.
Meeting II	Reviewed 2011-2015 Cancer Care Ontario Strategic Plan and Work plan to establish common understanding of provincial priorities.
Meeting II	Priority sort activity conducted to prioritize areas for PSOP to focus on. Reviewed PSOP priority areas identified for focus of the PSOP needs assessment.
Meeting III	Reviewed wait time targets/expectations to receive PSOP services, identified gaps/weaknesses in process and recommendations.
Meeting III	Reviewed <i>Ottawa Hospital Cancer Program Psychosocial Oncology Program Priority Setting, Waiting List and Discharge Guidelines</i> , identified gaps/weakness in guidelines and recommendations.
Meeting IV	Reviewed PFEC member feedback on <i>Navigation of the TOH Health Care System</i> and <i>Navigation Education Session slides</i> . Identified gaps/weaknesses and recommendations.

The PFEC accomplished a significant amount of ground work in meetings II-IV in preparation for identifying key recommendations to put forward in the evaluation report. Patient/family members were given the opportunity to learn more about the program/organizational context and staff learned from the patient/family members about the lived experience of receiving services at the PSOP.

Phase II Interview Findings

This section follows the same format used to describe Phase I findings in Chapter 4. I report on the Phase II contextual factors impacting the patient engagement process, describe the patient engagement process according to the dimensions of collaborative inquiry, and conclude by reporting findings related to the consequences of the patient engagement process.

Contextual Factors

The contextual factors described below include participants' perception of any positive influences that assisted in or any restraining influences to the patient engagement process.

Facilitators to patient engagement. Participants were asked, "what helps the process of working collaboratively on this project?". Four themes emerged in Phase II, but only one of the

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

four themes was new when compared to Phase I (i.e., homework) and one theme identified in Phase I was no longer present in Phase II (i.e., orientation meeting). Table 15 displays all new and recurring themes, ordered most common to least common, identified in Phases I and II that facilitate working collaboratively. A description of new themes follows with a brief discussion of the recurring themes.

Table 15

Facilitators to Patient Engagement during Phases I and II

Themes	Phase I	Phase II	Participant Group
Homework	○	●	All
Commitment to project	●	●	All
Accommodating participant needs	●	●	All
Designated lead with evaluation skills	●	●	Staff
Orientation meeting	●	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Homework. Participants referred to the set of activities, usually in the form of reflective questions, assigned to PFEC members by the evaluator as ‘homework’. This theme was the only new theme to emerge in Phase II and was the strongest theme identified by all members as contributing to the collaborative evaluation process. Participants discussed the importance of being productive and continuing the momentum of the committee work between monthly meetings to keep everyone engaged in the process. Here is an example, shared by one of the participants:

[Homework] also had this secondary benefit that it added a feeling of engagement because people were communicating between sessions and asking questions, maybe going a little bit deeper . . . they’ll send some emails to give feedback or to ask more questions, and again, it builds on the continuity of that working group. (Staff)

Most participants discussed how the homework increased the productivity of the committee. Everyone recognized that the small number of meetings could be a limiting factor to accomplishing our evaluation goals.

According to the majority of participants, one of the main benefits of doing additional committee work from home was establishing a good understanding of the issues to be discussed at the meeting. Being prepared to have thoughtful discussions going into each meeting was

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

highly valued by all participants because much of the committee brainstorming was completed in advance of the meetings. Participants expressed the importance of being as efficient as possible between meetings in order to have productive meetings whereby informed decisions could be made and recommendations developed. One patient/family member noted that “if we can at least get some of the thinking points established before the meeting... we can take full advantage of the limited time we do have”. Another patient/family member emphasized the following:

We have a limited amount of time to hear everyone’s ideas, which is why I suggested giving us “homework” as early as possible, so that we could try and circulate responses well before meeting again, so that we could think about each other’s responses.

(Patient/Family)

Staff participants were initially hesitant to ask patient and family members to do additional work between meetings. They were cognisant that some members were still undergoing treatment and others had family and work responsibilities, so they did not want to overburden them. Some staff participants expressed surprise at how ‘eager’ and committed the patient and family members were about the project and began to recognize that doing additional work from home was important to them. Staff also became more comfortable with the idea of asking more of patient/family members because “[the evaluator] always reinforced that the homework was voluntary and that no one should feel any pressure to complete it if they were incapable”. Here is an example where one staff member explained how she felt conflicted about asking more of patient/family members:

I guess there’s kind of been this tension between us not wanting to burden patients and patients saying, “please burden us”. I think that’s been handled well too, because [the evaluator has] heard this. So what she does is, she suggests things to be done outside of the sessions, but makes it very clear there’s no obligation to do that. So people do what they can, and what they feel that they’re able. (Staff)

Overall, assigning additional work to committee members between meetings appears to have significantly improved the committee’s productivity, but with the added benefit of keeping committee members engaged between meetings and feeling more prepared and informed to participate effectively at each meeting.

Recurring theme: Commitment to project. Participants identified commitment to the project as a key facilitator in helping the collaborative engagement process. As identified in

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Phase I of the project, participants described committee members as being committed to the success of the PFEC project; this included being committed to attending meetings as much as possible, eagerly doing committee work outside of meetings, and having a desire to improve PSOP services for future patients and family members. One area of commitment that was highlighted in Phase II that was not as prevalent in Phase I was participants' description of the mutual respect they have for each other and the desire to ensure participants felt safe to voice their thoughts and opinions to optimize the quality and success of the project. For example, one patient shared that "everybody is on the same page and has the same goal in mind. We just want to see some improvements". A family member added that "the fact that everybody's prepared to listen, and see what that opinion is — the respect that everybody has around the table" contributes to the collaboration among PFEC members.

Recurring theme: Accommodating participant needs. Participants continued to share the importance of accommodating participants as much as possible as a factor for improving collaboration among members. As discussed in Phase I findings, participants appreciated efforts made to accommodate one of the members living outside of Ottawa by having teleconference capabilities when required. Participants also continued to appreciate having food and drinks when arriving at the meetings because it made them feel welcome and encouraged socialization before and after meetings. A staff member commented that the evaluator "brings in food; it is an extra, but it's important. It helps people feel appreciated".

Recurring theme: Designated lead with evaluation skills. Similar to Phase I, participants thought that having a designated lead with evaluation skills facilitating the evaluation project was helpful in terms of enhancing collaboration. Participants noted that the evaluator ensured participants had the opportunity to voice their opinions and were comfortable with the meeting process and decisions made; as one staff member shared, "I think also [the evaluator] has been able to make the group feel comfortable". One staff participant also shared that the evaluator's role in recruiting key stakeholders on the PFEC may have contributed to the collaborative atmosphere of the group. As part of the screening process, the participants were asked about their reasons for wanting to join the PFEC and what contributions they could bring to the committee. Participants expressed appreciation that the evaluator regularly checked in with PFEC members to see if anyone had questions, concerns, or something to add. For example, one family member commented that "I think [the evaluator] is consistent in asking — do you have anything to add?"

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Are you okay with that part? So, she goes out searching for confirmation that the other person is feeling good”.

Barriers to patient engagement. Participants were asked about what hindered the process of working collaboratively on the project. Table 16 identifies two themes present in Phase I (i.e., time & resources, inability to participate equally) that continued to be present in Phase II; no new barriers were identified. However, two barriers identified in Phase I were no longer identified in Phase II (i.e., change in life status, living at a distance).

Table 16

Barriers to Participation in PFEC during Phases I and II

Themes	Phase I	Phase II	Participant Group
Time & resources	●	●	All
Imbalanced participation	●	●	All
Change in health status	●	○	Patient/Family
Living at a distance	●	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered endorsed by both groups. Identified themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present ● Theme absent ○

Recurring theme: Time & resources. As identified in Phase I, participants voiced concern about the lack of protected time for staff and program resources to do this type of evaluation project. Staff reiterated that this project would not be possible without the designated lead evaluator and more funding.

Participants remained concerned about the limited amount of time the committee had to work towards accomplishing their project goals. Some participants voiced frustration that the process was too slow and bureaucratic. Interestingly, patient/family members shared that the evaluation process was slowed at times due to hospital policy and bureaucracy, but a small number of staff shared that it was important for staff to recognize that the evaluation process may take a little longer when working with patient/family members to ensure that all perspectives are heard and understood. Here are two such examples of these differing views:

I would say the whole sort of bureaucratic process, but I don't know if that's anything that can be greatly changed, but just the speed at which things are working at. A formal agenda is a good thing in terms of keeping people on track . . . Maybe part of it also the fact that we can only meet once a month. (Patient/Family)

I don't think we're having trouble getting to decisions. I think the bottom line is that we just had thought we could accomplish more than we can. And so, I suppose one thing that we've learned is that when you involve patients, you have to adjust expectations, because these are, of course, people who have experiences and they need to be given a voice and be able to share. (Staff)

Participants continued to see the restricted number of meetings as a potential factor for hindering the collaborative process in that there was not always enough time to thoroughly debate or discuss an issue.

Recurring theme: Imbalanced participation. Factors affecting participants' abilities to participate equally continued to be identified as hindering the collaborative process. The most common example given by participants was members 'going off on tangents' and not recognizing that they may be off topic or not allowing others the opportunity to speak. The majority of participants were sympathetic to the reality that some participants have had difficult experiences and that it can be challenging to redirect the discussion back to the agenda item. Others shared that the evaluator was in a challenging position having to redirect people when they were sharing very personal experiences; here is one example of a participant's thoughts:

I feel like there's not always time to speak because some people really get going and it's very difficult to turn them off for a little bit, because [the evaluator] doesn't want to just cut them off because they're talking about their really personal experiences and even I wouldn't cut them off. But I do get kind of, "Okay, wrap it up!" [Chuckles].
(Patient/Family)

One participant shared that meeting III was a little more challenging because members had developed a real sense of comfort with each other and there was a level of eagerness and excitement about the issues being discussed. Some participants recognized at meeting III that greater structure would need to be established to ensure everyone felt they had time to share their opinions and be more productive as a group. One staff member explained that, at the midpoint of the evaluation,

group cohesion has formed, people are not shy anymore, they're really engaged. . . . So, I think at some point we realized oh my gosh, we have to be careful to control or guide the work we're doing, because we could just talk and talk and talk and it could go on, right?

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

(Staff)

Most participants shared that meeting IV was more structured, and that participants seemed to respect the need to take turns and recognize that this was important in order to accomplish the committee goals.

Patient Engagement Process

I was interested in examining the participants' experiences at different times during the patient engagement process. Participant views on the engagement process in Phase I are limited to their experience at the first meeting (orientation meeting) and their expectations, but Phase II includes three subsequent meetings with some substantial evaluation work completed.

Diversity of members. Participants were asked their views about the value of the different roles on the committee and who they thought was missing. Participant views about the composition of the PFEC membership and the value of each role did not change from Phase I to Phase II (Table 17). However, one new theme did emerge in Phase II: participants' thoughts about the value of having a diversity of opinions on the PFEC.

Table 17

Diversity of PFEC Members during Phases I and II

Themes	Phase I	Phase II	Participant Group
Who is missing			
Vulnerable populations	●	●	All
Patients with head and neck cancer	●	●	Staff
Need for more heterogeneous group	●	●	All
Family members of patients in active treatment	●	●	Patients/Family
Value of evaluator role			
Facilitator/organizer	●	●	All
Evaluation skill set (level of engagement, credibility, change agent, and use)	●	●	Staff
Value of Staff role			
Context and reality check	●	●	Patient/Family
Ability to affect change	●	●	All
Value of patient/family role			
Contextual knowledge from lived experience	●	●	All
Value of diversity of opinions	○	●	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Value of diversity of opinions. Most participants strongly valued the diversity of opinions within the PFEC. Participants shared that differences in opinion do slow the process down, but acknowledge that having a range of opinions is important. For example, one family member shared “that it would be useful [to always share the same opinions], but I think it’s important to grab perspectives from more people”. Another participant shared similar views:

Yes, sometimes that process can take a while to get everyone in the same direction; especially when it is a new group of people and everyone is getting to know each other and you are trying to tackle some pretty involved issues in what ultimately is a very short period of time. (Patient/Family)

A patient participant shared the following: “I like hearing different perspectives; it really helps you get a fuller picture”. Similarly, a staff participant noted that “there’s definitely been some difference of opinion on things, but that’s part of the process. That’s what we want; you don’t necessarily want a committee where everybody sits around and agrees with one another all the time”.

Overall, participants recognized the value of having a wide range of opinions to gain a more complete understanding of an issue.

Depth of participation. To explore the intensity and depth of participation at the midpoint of the evaluation process, I asked participants to describe the level of participation from each of the members in the project thus far and how patient/family members, PSOP staff, and the evaluator/researcher have influenced the project thus far. Table 18 shows that two themes present in Phase I remained present in Phase II (i.e., evaluator facilitating/organizing process, contextual knowledge from lived experience). Five new themes emerged to describe the contributions and intensity of participation of committee members based on their role on the PFEC.

Contributions of evaluator. Two themes emerged in Phase II to describe the depth of participation and contributions of the evaluator. One was a recurring theme from Phase I that the evaluator had a key role in facilitating/organizing the evaluation process. The second was a new theme that the evaluator had an important evaluation skill set that enhanced the evaluation process.

Table 18

Depth of Participation during Phases I and II

Themes	Phase I	Phase II	Participant Group
Contributions of evaluator			
Facilitating/organizing process	●	●	All
Evaluation skill set	○	●	All
Contributions of staff			
Context and reality check	●	●	All
Ability to affect change	○	●	Patient/Family
Contributions of patient/family			
Challenge status quo	○	●	Patient/Family
Contextual knowledge from lived experience	●	●	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered endorsed by both groups. Themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present ● Theme absent ○

Evaluation skill set. Participants shared that the evaluator had a key role in consolidating participant ideas and feedback, summarizing information in a useful way, and bringing it back to the committee for consideration and discussion. Some participants felt that the evaluator role was critical in terms of seeing different perspectives and challenging one's own ideas. In particular, participants noted that the evaluator contributed to the evaluation process by taking a leadership role in terms of their approach/process. That is, participants appreciated the approach used to capture participant input outside of meeting times, brainstorming exercises, offering suggestions on next steps to move the process along, and keeping all members informed of member contributions between meetings.

Recurring theme: Facilitating/organizing process. Similar to Phase I, participants had strong views about the evaluator heavily contributing to facilitating the evaluation process to ensure all members have the opportunity to contribute and have their opinions heard and respected. Participants felt the evaluation process was collaborative and respectful. Participants also described a strong organizational component to the evaluator role. For example, one participant said "she's been key, she's the pivotal person, because she brings it together, she chairs it, she organizes it". Overall, participants felt strongly that the evaluator had a key role in moving the evaluation process forward, ensuring meetings are well organized, and keeping participants informed about evaluation progress.

Contributions of staff. One new theme emerged in Phase II to describe the depth of participation and contributions of staff to the evaluation project. Participants continued to identify that staff contribute program context and a reality check, but also identified that staff have the ability to affect change.

Ability to affect change. Participants discussed that staff PFEC members have the ability to affect change through learning from patient/family members and making immediate changes to their clinical practice. One family member said it was encouraging to witness a staff member coming to new realizations and understandings about the program following discussions with patient and family members. Some staff participants learned from patient/family members through their involvement in the evaluation process and, in some cases, were able to make immediate simple changes to their practice to improve patient care. One staff member shared the following:

So as a staff person in addition to whatever formally comes from this, I also bring stuff, from what I hear at the meeting. You know, whether it's — one individual spoke about the nature of an intervention that he had with a social worker, which he felt was really positive, and felt it could be something that could benefit other staff, or other patients and families. So that's something I can bring to my work. When we talked about the navigating group, which I facilitate with my colleague, I was able to bring some of those suggestions. I haven't made major changes, but it's just some thought process and things that we can do differently, in the meantime. You know it's kind of at the moment. (Staff)

All participants recognized that staff have a unique opportunity and ability to help advance recommendations put forth by the committee to all PSOP staff and hospital decision-makers. One family member shared that it was interesting to hear the background information from staff and that “they can complement this and know who owns what. So they can make the link to what happens next as a direct action”. This was recognized as an important contribution to the evaluation process because staff could guide the committee in terms of advising on the best approaches to reach certain decision-makers and how to position certain recommendations to increase the committee's success in affecting change.

Recurring theme: Program context and reality check. The majority of participants identified that one of the key contributions of staff to the evaluation process is their understanding of the program and organizational context. This was highly valued by participants

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

because the PFEC wanted to affect change and therefore it was important to the group to put forth recommendations that could realistically be implemented by the program and hospital.

Here is an example shared by a patient/family member:

Staff members can provide more background about what the limitations in the system are, what are their current plans to improve things, what has been tried in the past or we are not going to go down that route because we have tried that before. I think the staff participation is critical. (Patient/Family)

Participants described discussions whereby patient and family members would suggest certain changes or improvements and staff would provide a ‘reality check’ on whether or not they thought it would be feasible to implement. Some participants voiced mild frustration at times when staff would explain why certain changes would be difficult to implement (e.g., lack of funding, outside program mandate, bureaucracy), but appreciated staff being up-front and pragmatic about the realities of the program and organization. Here is an example given by one of the participants describing how staff provided background and limitations related to changing the parking fees at the hospital:

They were able to bring more background that a lot of people have complained about [parking] and here is the reason why it is what it is and why it can’t change that much or it’s not going to change quickly. Obviously, parking provides income that is necessary for the hospital. It would be such a shame to drill into this topic without the staff — it would be a complete waste of our time. (Patient/Family)

Overall, patients and family members thought staff had a key role in the evaluation process because of their contextual knowledge, and a few patients and family members said they would not be interested in working on an evaluation project without staff being involved.

Contributions of patient/family. Two themes emerged in Phase II, the strongest of which was the contextual knowledge from lived experience that patient/family members bring to the process; this was also identified in Phase I. Challenging the status quo was a weaker theme that emerged in Phase II, but seen by some members as an important contribution to the evaluation process.

Challenge status quo. A small number of participants, mainly patients and family members, discussed the importance of patients and family members challenging the status quo of health service delivery. This was seen as a positive contribution to the evaluation process in that

it forced deeper reflection and discussion about certain issues and provided a different perspective on how health services could be delivered.

Recurring Theme: Contextual knowledge from lived experience. Similar to Phase I, all participants felt strongly that the most important contribution patient and family members make to the evaluation process is the contextual knowledge from lived experience. Some participants described that hearing patients' and family members' lived experiences was critical in terms of describing key issues being addressed in the evaluation and developing recommendations to address some of the challenges they had experienced. Another important factor identified was the learning that occurred by all members of the committee when hearing about someone's experience. Staff shared that hearing patient and family experiences with cancer and PSOP challenged their thoughts about their perceptions of health services being delivered; for example, one staff member noted the following:

We don't go through all the systems . . . I'd be at a loss myself. I don't know all of the steps of processes that are involved. So, we need to hear from people who have gone through it and we're here to learn that. I guess I'm kind of in my little bubble, I know what I do and I do it within the context of this program, but I'm not fully aware of everything that's going outside of this program, within the programming. (Staff)

In the next section, I discuss the findings related to control over the evaluation process at the midpoint of the project.

Control over evaluation process. At this point in the project, the evaluation project was well underway and we had developed a process of working together during our face-to-face meetings as well as between meetings. Interestingly, asking participants to describe how decisions were made elicited very homogenous views despite the fairly significant changes in emerging themes from Phase I to Phase II (Table 19). Specifically, three additional themes emerged in Phase II that were not present in Phase I (i.e., clarity of project goals, evaluator leading evaluation process, and delegation to staff and evaluator).

Table 19

Control over Evaluation Process during Phases I and II

Themes	Phase I	Phase II	Patient Group
Democratic/majority rule decision-making	●	●	All
Respectful and collaborative	●	●	All
Clarity of project goals	○	●	All
Evaluator leading evaluation process	○	●	All
Delegation to staff and evaluator	○	●	All
Mixed clarity of project goals	●	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Clarity of project goals. Participants had greater clarity of the evaluation project goals during Phase II compared to Phase I, which is to be expected considering the focus of the evaluation project was to be determined by PFEC members. During Phase I interviews, participants had some understanding of the broad objectives of the evaluation project, especially staff participants, but were unclear about the evaluation goals. In Phase II, participants had a more common understanding of the goals and the process involved in determining those goals. Most participants shared that an online question-and-answer exercise and priority-sort activity were used to identify key priority areas for the needs assessment. Following meetings II and III, participants had a good understanding of the priority areas the PFEC would address in the needs assessment. One participant discussed how the PFEC had to narrow the scope of the evaluation project to make it more manageable within our time frame:

We had to quickly pare that down to something more manageable. I think that was totally understandable and I think it was a good decision and I think we are ultimately focusing on the most important issues and the ones we can have ultimate impact. I feel the committee is working towards those goals. (Patient/Family)

Overall, the majority of participants voiced a common understanding of what the PFEC was working towards and a common understanding of the overall goals.

Evaluator leading evaluation process. A new theme that emerged in Phase II was participants noting that the evaluator had a key role in determining the process PFEC would use to advance the project goals, as well as draw final conclusions following participant consultations and discussions. One patient/family member shared the following:

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

I think the group discussions were the basis [of information for the evaluator to use to summarize to the group]. Summarizing the points, and then presenting them as potential decisions, or suggestions. Most of the time those things were accepted by the group.

Sometimes they were slightly tweaked to better represent what we thought that we meant, but I think the group as a whole did the decision, although the actual summarizing of it was done by [the evaluator]. (Patient/Family)

Most participants described a similar process that included consultation about key priorities using a question-and-answer format to begin the discussion between meetings, followed by face-to-face discussions at the monthly meetings based on the summary of findings. Participants were comfortable with the process in general, but ideally wanted more time to more thoroughly discuss each of the priority areas. The majority of participants also shared that, although the evaluator presented suggested recommendations and decision points based on PFEC consultations and discussion, there was always an opportunity to make changes if the group was uncomfortable with decisions being made. Participants also indicated it was important for the evaluator to provide the group with suggested recommendations based on the information collected by the group to be efficient as a committee, but also have someone summarize the information in a manner that best represents the majority of the participants' views.

Delegation to staff and evaluator. Most participants noted instances during the evaluation process when the PFEC delegated to the PFEC staff and evaluator to finalize decisions. For example, following the priority-sort exercise the PFEC recognized that, due to the tight timelines, the committee should further narrow the focus of the evaluation project. Rather than dedicating a full meeting to this process, the PFEC decided to let the staff and evaluator meet independently from the committee and determine what priorities would be most feasible to address in our timeframe and most clinically relevant to the program. One staff participant described the following:

Sometimes it was difficult for that many people to come to a consensus around priorities and sometimes they are multi-faceted and actually overlapping priorities. So some of the decisions were made with some fine tuning after the committee meeting with [the PFEC staff and evaluator], so it was a combination of the contribution of the bigger priorities, with the fine-tuning after the fact by those people. (Staff)

A small number of participants shared that one or two staff participants at times had very strong

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

opinions and views about certain aspects of the program. In some instances, these members dominated the conversation, which influenced the direction taken by the committee. One patient participant shared that “they have strong views, or at least I won’t say all of them, because maybe one or two of them have very strong views and I’m not sure that I agree actually with the views sometimes”. One patient participant noted frustration at times with staff views about the priority areas the PFEC should focus their attention on: “From my perspective, I’m starting to think I’m not really sure about the objectives and whether they’ve been predetermined”. This same participant also felt some rigidity at times in terms of exploring other possibilities or models for the PSOP; here is an example of this patient/family participant’s views:

I’m willing to go there because I don’t have expertise in the area, but in other instances I’m thinking well just wait a second, let’s take a step back. What has been done somewhere else? And what are the different models that we could look at? We’re assuming that this is a program that’s necessary for everyone. (Patient/Family)

This participant concluded by sharing that she recognized she may be in the minority with these views, but wished there was more time to more deeply explore some of these program issues.

Recurring theme: Democratic/majority rule decision-making. All participants continued to emphasize that the PFEC made decisions democratically using a majority-rules approach. As one patient participant shared, “I think they’re not consensus, but there is definitely majority, which I can live with. I don’t agree with some of the decisions, but well, heck, the other 10 people think one way”. Another participant noted that “not everybody will come to consensus but [the evaluator] helps us to identify the main priority in this discussion; where we should focus and what we can discuss”. Overall, all participants indicated they were comfortable with the decision-making process, despite some noting that some staff members voice strong opinions that may influence some decisions. Patient and family participants recognize that staff have a deep understanding of the program and the organizational culture; therefore, they trust that staff are advocating for recommendations that are implementable and realistic.

Recurring theme: Respectful and collaborative. As noted in Phase I findings, participants continued to feel that PFEC members were respectful of each other’s opinions in Phase II. All participants expressed a high level of mutual respect among members, despite having different experiences and views. Some members commented that the PFEC had a high degree of collaboration and mutual respect that is not always seen on other types of committees.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Here is an example of what one participant shared:

Not every committee has had that kind of respect actually. There's a strong desire certainly, in the family/patient, and probably with the hospital staff as well, that we want to make it better for the next person. If my volunteer work on this is to make any difference at all, then we have to be patient and listen to the other person and to offer valued legitimate opinions. (Patient/Family)

Participants also thought that members had a common goal of improving services for future patients and that this common goal made the process more conducive to collaboration. The following is an example of how one participant explained the high level of respect and collaboration among members:

I think we have a common goal, and often when you have a common goal and everybody has shared their stories — including the professionals — that acts almost like a level playing field because even for the professionals, they've shared their own experiences on how cancer has affected them . . . I think it breaks down barriers and it breaks the power differential. I think it has helped people have that understanding within our group. (Staff)

Overall, participants described experiencing a high level of respect and collaboration on the PFEC. Some of the many reasons for this were having a common goal, the evaluator's facilitation skills, and staff that work in an area that requires higher-than-average communication skills.

Improving the patient engagement process. Only a small number of participants offered suggestions for improving the meeting process in Phase I; however, most participants offered some recommendations in Phase II, including two themes outlined in Table 20 and described below.

Table 20

Recommendations for Improving the Engagement Process during Phase II

Theme	Phase I	Phase II	Participant Group
Additional time for evaluation project	N/A	•	All
Reinforce meeting etiquette at each meeting	N/A	•	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered endorsed by both groups. Themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present • Theme absent ○

Additional time for evaluation project. Most participants felt that more time was needed

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

to thoroughly examine each of the priority areas identified in the evaluation project. Most participants thought that the PFEC would have benefitted from an additional three to four meetings to reduce the time pressure members were feeling and to allow for greater discussion of priority areas that were more strategic in nature. For example, one patient participant shared that “it feels sometimes like you wish you had more time to go into more detail, or dig deeper in some issues, and the time just isn’t there”.

There were mixed feelings, especially among staff, about increasing the duration of the meeting from 1.5 to 2 hours. One staff member suggested a two-hour meeting might provide more discussion time and deeper exploration of each of the priority areas, but at the same time other participants acknowledged that adding two hours after a work day takes away from personal family time. Participants felt it was important to readjust the committee’s expectations and deliverables early on in the evaluation process to accommodate for the time restrictions.

Reinforce meeting etiquette at each meeting. More than half of the participants felt that some PFEC members monopolized some of the discussion and struggled to stay on topic. Stricter adherence to meeting etiquette was suggested by approximately half of the participants, but many acknowledged the risk of implementing too much formality to the meeting process and risk stifling good discussion. Many suggested the needs for a delicate balance of ensuring people are allowed to express their ideas and experiences but not at the cost of decreasing the productivity of the committee. Others thought that meeting III was more challenging in terms of keeping members on task, but that by meeting IV the evaluator reinforced meeting etiquette and began sending work to members between meetings. Below is an example of one participant’s views:

I think [the evaluator] realized that she had to rein the group in a little bit, watch time, but also be more focused and more organized. The other step that was taken for that, to improve that, is giving people homework in between. So, that made the session easier and more productive to manage or to handle, because people were not coming in with no information. They had already looked at it, thought about it, and digested it . . . Those are a few things that the [evaluator] changed, that I think is really ensuring that we’re much more productive. (Staff)

A small number of participants felt strongly that the meeting process should not be too rigid and formal. Specifically, these participants thought that, because of the nature of the discussions, it was important to remain flexible and allow for a productive discussion, despite it challenging the

meeting agenda. As one patient/family member noted, “I think because time is limited, and we never seem to have enough time; we have to be super focused. However, some of the best discussion comes out of that free exchange”.

Overall, the majority of participants reinforced the importance of reminding members of meeting etiquette at each meeting and ensuring no member monopolized the discussion. This needed to be done while keeping in mind the importance of remaining flexible and understanding that participants are sharing very personal experiences, which may require the meeting process to be more flexible.

Consequences of the Patient Engagement Process

This section will describe the Phase II findings related to the intended benefits of the PFEC work, participant experience, and unintended outcomes of being on the PFEC.

Intended benefits. Participant views on the intended benefits of the engagement process in Phase II did not change significantly from Phase I to Phase II (Table 21). The only change noted from Phase I to Phase II is that the level of endorsement for improving awareness and access to PSOP was stronger in Phase II compared to Phase I.

Table 21

Intended Benefits during Phases I and II

Themes	Phase I	Phase II	Participant Group
Reaching decision-makers	●	●	All
Improving awareness/access of PSOP	●	●	Patient/Family
Improving PSOP services	●	●	All
Increased diffusion of patient/family engagement	●	●	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Recurring theme: Reaching decision-makers. This theme is very similar to Phase I and continues to be the most important intended benefit of the engagement process. Participants hoped that the work of the PFEC would ultimately reach decision-makers and affect change. One family member shared the following after being asked if she thought the PFEC was reaching decision-makers: “I certainly feel that we have the right people in the room to take it to the decision-makers”. Another patient/family member was hopeful that the staff members on the PFEC were absorbing what they were hearing from patients and family members.

Recurring theme: Improving awareness and access of PSOP. This theme was also strongly supported by most participants as an intended benefit. Participants were hopeful that the work the PFEC was doing would have a positive impact on improving the integration of PSOP services in cancer care. At a minimum, participants hoped that cancer patients would have easier access to PSOP services and be made aware of them. For example, one staff member shared, “that’s why navigation is so important. People need to know how to work through the system and get the information they need”. A patient/family member shared that patient/family members need to have the necessary information about available services at diagnosis; here is an example of this patient’s views:

Ultimately, I hope that the whole experience for someone who goes to the Cancer Program and gets diagnosed that their whole experience would be better; that they will get the right information at the right time. That they will get access to the resources they need and because of that it would seem a little less threatening. (Patient/Family)

Overall, participants agreed that all cancer patients should, at a minimum, be made aware of PSOP services upon cancer diagnosis, and they hoped this project could help facilitate that process.

Recurring theme: Improving PSOP services. As discussed in the Phase I findings, participants continued to be hopeful that PSOP health services would be improved for future patients as a result of this evaluation project. When asked if they thought this process could improve PSOP services, one family member responded in the following way: “You know what; I have to think that it will happen. I have to believe that, because otherwise, why am I here, right? Why would I be participating if it’s not going to make a difference?”.

Recurring theme: Increased diffusion of patient/family engagement. Participants continued to express the importance of having more patient/family members involved in health service improvement projects. One patient/family member responded as follows when asked what he hoped would come out this evaluation project:

In a perfect world, we would provide useful feedback for immediate change of service and then perhaps even more importantly that the research on these interviews would yield ideas or data to suggest more efficient ways to run this kind of committee in the future to get even more out of the participants. I think that is the easiest way to sum it up.
(Patient/Family)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Staff expressed hope that some members of the PFEC would be able to continue doing this type of work with the PSOP or at the Cancer Program or participate in other quality improvement activities. One staff member hoped that more patients and family members could be involved in peer-support activities as a result of this project.

Participant experience. Participants were asked to comment about their PFEC experience at midpoint in the evaluation process. All participants described the experience as positive and did not identify any negative aspects of their involvement. As illustrated in Table 22, participants identified three main themes describing their experiences with the PFEC. One of the three themes was present in Phase I of the study (i.e., personally rewarding) and three themes from Phase I were no longer present at the midpoint of the project (i.e., shift from personal focus, enthusiasm for the project, and closing the loop and healing). Two new themes emerged in Phase II that were not present in Phase I: participants learning through their involvement and encouraged that the PFEC might have an impact.

Table 22

Participant Experience during Phases I and II

Themes	Phase I	Phase II	Participant Group
Personally rewarding	●	●	All
Learning through engagement process	○	●	Patient/Family
Encouraged PFEC might have an impact	○	●	All
Shift from personal focus	●	○	All
Enthusiasm for project	●	○	All
Closing the loop and healing	●	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be endorsed by both groups. Themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present ● Theme absent ○

Learning through engagement process. Participants appreciated the learning they were experiencing through their involvement in the project. Some of the learning they described was related to the health care system and the PSOP (e.g., referral systems, services available, navigation) and the experiences of other patients. One patient/family member shared that, through the evaluation process, he learned about some of the constraints that staff have to work within. Others appreciated learning about the program but also about other patients' experiences. Some participants felt grateful they had had such a good experience, as they learned that was not the case for everyone. Here is an example of what a patient/family member shared:

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

It makes me think about things that I had never thought about before. Because when you're going through your own experience, you just have your own experience to think things from. Now that I've seen the things that other people have had to deal with too, and I think, oh wow. I can see where PSOP would have been a big help to you, and how it would have been great for you to be able to access services easier, and how there's such a disparity in the way we're treated. (Patient/Family)

Most participants enjoyed the challenge of learning about a new area. Participants enjoyed brainstorming ideas and appreciated being challenged to develop solutions and recommendations to improve health services. Patient/family members hoped that staff members were learning through the engagement process as well. As one patient/family member shared, "I've learned a lot of what the PSOP is trying to do . . . I think that some of the staff have also had some stuff that they've learned from the patients, I hope". Another patient/family participant felt it was personally gratifying to see that staff seemed to be learning through this process, and one staff member shared that she was learning through her experience on the PFEC. Here is one example to illustrate these views:

What has been encouraging, more than once I have seen staff members' reaction where the patient or family perspective is new? Is [it] actually new information or [is it] an exciting discussion for them? You would have thought that they would have seen or heard everything and maybe that is the case, but perhaps we are drudging up things that they have not thought of for a while. (Patient/Family)

Overall, patient/family participants appreciated not only the learning they were achieving through the evaluation process, but also the learning that the staff members appeared to be experiencing as well. For patient/family members, witnessing the staff learning that was occurring was personally rewarding and made their experience more meaningful.

Encouraged PFEC might have an impact. By the midpoint of the evaluation, approximately half of the participants were expressing satisfaction that the work the PFEC was doing might have an impact in improving PSOP services in the future. At baseline, participants were hopeful that their work would have a meaningful impact in improving health services, but midway through the evaluation process half of the participants were hopeful that the PFEC would be successful. Here are two examples to illustrate:

I am pretty encouraged by our work so far along the lines of thinking that we could have

a potentially positive impact out of all of this. It would be easy to imagine that a group like this would be composed of staff members that were told to show up and not necessarily personally interested or engaged, and that is certainly not the case here. It certainly does not feel like it. And as I said, those people that volunteer want to be engaged anyway. Ya, I really do feel like we will or certainly have the potential to have an impact. (Patient/Family)

I was like, "Oh, maybe that's not, that's brilliant. Maybe we never thought of that, let's pursue that". So, it's been a nice experience, and I think we all like that we're all there for that common goal of improving patient experience and patient services. So, we're all there for the same reason, but we're coming about it from different angles. So, that's nice. (Staff)

Some of the reasoning given for this optimism is the genuine commitment and interest of all members working together and being committed to a common goal.

Recurring theme: Personally rewarding. As described in Phase I findings, participants continued to identify that their involvement on the PFEC was personally rewarding. The most significant difference in Phase II was that all participants, as opposed to only staff in Phase I, identified that their experience was personally rewarding. Furthermore, this theme was the weakest of the four themes identified in Phase I, but in Phase II was identified as the most important factor describing participant experience on the PFEC. This is a staff participant's description of why it is personally rewarding:

It's been really nice, actually, to meet with patients in that kind of a setting, and I think, what's nice is that certainly in my practice style as a [health professional] I don't perceive myself as being [collegial] there is a professional boundary between me and my relationship with the patient family that I'm working with. But there is never really the opportunity in a situation that's not professionally outside the intervention. To talk to people in a more relaxed way about their experience has been, and some of their experiences have been very touching, and people are coming to the table. They are sharing really life-changing, gut-wrenching experiences, very emotional things that have changed their life, and continue to change their life, and have done so very willingly and open heartedly. So it's lovely to meet people in all circumstances, and hear what they have to say. (Staff)

Unintended outcomes. Participants were asked to identify any negative experience during their involvement on the PFEC. Participants did not identify any unintended outcomes in Phase I, but one theme emerged during Phase II. A small number of participants shared that in learning more about the PSOP they discovered they may have been eligible for services they did not receive or could have received sooner. Here is an example of what a patient/family member shared:

Well, at some point it was very hard. I realized, and I told my husband, that according to the criteria of the patient's priority to access for PSOP, I should have been marked as priority number one . . . I was never recognized as one, and instead of being referred to the program immediately and hearing the feedback from the program within the first weeks, I was referred to it 15 months after. (Patient/Family)

Discovering that their experience could have been smoother was frustrating for these participants, but strengthened their resolve to improve the referral process for other patients.

Phase II Participant Observation and Researcher Reflection Findings

This section reports on the findings from my reflective notes and participant observations captured after meetings II, III, and IV. Similar to the interview findings, these data will be reported according to the *contextual factors*, *engagement process*, and the *consequences* of the patient engagement process.

Contextual Factors

According to my participant observations and reflective notes, I observed a few contextual factors facilitating as well as inhibiting the patient engagement process during meetings II, III, and IV. In terms of facilitators, the following factors helped the engagement process:

- Accommodating participant needs: adequate meeting space, technology, etc.
- Commitment to program improvement project and optimizing efficiency by giving homework.
- Mutual respect among commitment members.
- Humour and efforts to fostering relationships.
- Evaluator facilitating process and evaluation process.

Meetings II, III, and IV took place in the Cancer Program boardroom, which was a significant improvement from the meeting room used for the orientation meeting: "Everyone

seemed more comfortable sitting around the boardroom table and I was able to have all the food and drinks in the boardroom, which allowed members flexibility to get up and get food or drinks”. The boardroom also provided the ability to offer teleconference capabilities through telehealth for one of our members living outside of Ottawa. In general, teleconference was a good option for this participant because it allowed her the ability to participate without having to drive in winter conditions. However, the technology failed during meeting IV; the visual component of the teleconference was working, but we were unable to get the audio. The PFEC members were determined to have her participate and we had to improvise. Here is an example of my observations after meeting IV:

We were able to call her on the phone in the conference room where she was and each member spoke into the phone, so she could hear what was being said. Passing the phone around was by no means ideal, but I was pleased by the level of commitment on behalf of all committee members to find a solution to ensure she could be included in the meeting. I observed a real sense of cohesion among the committee members and a determination to hear her opinions and to have her fully engage in the meeting process, despite the inconveniences to the other members. Members could have been frustrated through this process, but rather found some levity in the situation.

We began the process of identifying priority areas that the PSOP should focus on for the next year or two to improve services for cancer patients and their family members. Based on some initial work completed by members from home, we were able to identify the key strengths and weaknesses of the program. Based on this preliminary work, we completed a priority-sort exercise as a means to narrow the identification of priority areas for the PSOP. I was very nervous that it might be too early to successfully complete this exercise in meeting II. I was worried that members might not be comfortable enough to voice their opinions during small group discussions. Would patients and family members feel intimidated to advocate for a priority area that staff members do not see as a priority? This is an excerpt from my reflections.

In the end, I think this exercise provided a real bonding experience for committee members; everyone seemed engaged in the process and were keen to participate. The group dynamics that I witnessed were very courteous, respectful and in general members were very open minded to hearing everyone’s opinion. There was a real sense of energy

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

in the room and members moved around from group to group and there was lots of laughter as well.

Through discussions and observations, it became evident that PFEC members were sensitive to the fact that we needed to be as productive as possible at each meeting, but also between meetings. To improve efficiency and productivity, patients and family members encouraged me after meeting II to give them ‘homework’. Here’s an example of my notes describing my ambivalence about having participants doing additional work at home:

The staff and myself hesitate to ask more of patient and family members especially for patients still undergoing treatment, but they all seem very eager to have what they call “homework” to do between meetings . . . I emphasized many times that this was not mandatory and did not want anyone to feel pressure or guilty if they could not complete additional work at home. For now, we will continue the process of doing preparatory work at home and sharing the results with committee members before the meeting and review monthly to ensure this is not too onerous on committee members.

PFEC members shared that they liked the preparatory work completed at home and felt it was critical to continue doing this type of work from home before each of [the] meetings, so the committee could focus [on] making decisions and recommendations based on the summary of work completed from home.

My observations indicate that members were better prepared for discussions at the meetings as a result of the preparatory work and thus our meeting efficiency improved.

I also observed barriers to the engagement process midway in the evaluation process, including:

- Limitations/challenges with technology for participants living at a distance.
- Challenges of balancing meeting etiquette with sensitivity to participants’ experiences and being afforded the time to share their experiences.
- Limited time and resources: human and financial resources.

The priority-sort exercise was useful to narrow the priority areas, but that process may have seemed a little rushed for some participants: “I was trying to strike the balance of making good inroads every month on the evaluation project, so members feel confident that we have accomplished work that is useful to the program, without compromising the process”.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Meeting III was challenging to facilitate and many lessons were learned. By meeting III, the priority areas to be addressed were identified and members were becoming more comfortable with each other. Part of our process in addressing each of the priority areas was to include contextual descriptions of the issues identified by the members in order to address these challenges with appropriate recommendations. Members were quite vocal about their understanding of the first priority area being addressed (wait times, priority standards for services, and discharge guidelines) and shared their personal experiences; here is an example of my reflections following meeting III.

As the moderator, it was challenging to give everyone the opportunity to speak because some members had very personal and difficult experience in this area, but I wanted everyone to have the opportunity to speak. I realized after the meeting after discussing my concerns with a staff member that I was hesitant to “cut people off” because their experiences were so raw that it felt insensitive to redirect the conversations to someone else. I realized this was something I would need to work on to ensure everyone felt their opinions and experiences were valued and not just those who were most vocal.

At the beginning of meeting IV, I emphasized the importance of everyone taking turns to share their opinions and reintroduced our basic rules for meeting etiquette. This meeting went much smoother and I think everyone recognized that meeting III had gone slightly ‘off the rails’ so all members were committed to improving our meeting process.

Patient Engagement Process

My reflections and observations related to the *diversity of members* did not change from Phase I. In terms of the *depth of participation* and *control of decision-making*, my observations and reflective notes from meetings II, III, and IV describe participants being very enthusiastic to contribute their opinions and experiences, as well as increasing their contributions by doing work from home. The meeting process continued to improve with each meeting and my observations and reflective notes indicate that staff and participants felt the work completed by myself before, during, and after our meetings was critical to keeping the group ‘on track’ and ensuring we ‘hear everyone’s opinions and perspectives’.

My reflective notes and participant observations identified having additional time for the evaluation project and reinforcing meeting etiquette as a key factor for improving the process in the future. Specifically, I noted that “engaging patients and family members requires that all

participants recognized that it's going to take more time. Patients need to understand the organizational/program contexts and staff also need time to understand the lived experience”.

Consequences of Patient Engagement Process

My observations during meetings III and IV indicated a continued shift from a more personal focus to a more general patient population focus. Following a program logic model review and Cancer Care Ontario strategic plan, I noted that it was an important process to go through with the committee, as it further emphasized the importance of committee members “to reflect not only on their experience with the PSOP, but also the needs of other patients and family members that may not have been relevant to them”.

Overall, my observations described participants appearing very happy to be involved on the PFEC and enjoying the ability to make contributions for improving the PSOP. For example, I noted in my reflections that “I’m surprised by how engaged everyone is in this process; every member seems invested in making a difference and believe they can make a difference”. My reflective notes and observations also emphasize that

participants continue to be very pragmatic about this process. They don’t want to come up with pie-in-the-sky recommendations that are not feasible. Staff provide reality checks about feasibility of suggestions and patient/family members respond with alternative suggestions to increase chances of success . . . Some patient/family members appear frustrated with the bureaucracy and realities, but continue to offer suggestions that might be considered by decision-makers.

I observed participants who were genuinely motivated to find realistic solutions for improving the PSOP and accepting of the limitations (e.g., bureaucratic, resources) identified by PSOP staff. Participants were noted to be collaborative with one another and always demonstrated respect for everyone’s ideas and opinions.

Chapter Summary

Chapter 5 describes the findings for Phase II (midpoint) of this study. The chapter begins with an overview of the evaluation tasks completed and meeting timelines are described. This is followed by the interview findings for the first research question, as well as participant observation and reflective journal findings.

Contextual Factors

Four facilitators were identified by participants at the midpoint of the evaluation project to facilitate participation (i.e., homework, commitment to project, accommodating participant needs, and having a designated lead with evaluation skills). My participant observations and reflective journal findings were similar, but I also identified having mutual respect among members as well as efforts to foster meaningful relationships including humor.

Three barriers were identified from the interview findings that may inhibit the engagement process (i.e., time & resources, imbalanced participation, and living at a distance). My reflective notes and observations identified similar barriers, specifically technological difficulties for participants living at a distance, challenges of balancing meeting etiquette with sensitivity to participants' experiences and being afforded the time to share their experiences, and limited time and resources.

Patient Engagement Process

Next, I reported on the findings of the second research question that relates to participant experience with the engagement process. Participant perceptions of the *diversity of the PFEC* membership did not change from Phase I to Phase II, except that participants identified the value of having a diversity of opinions as a positive aspect to the evaluation process. My reflective notes and observations related to diversity of membership did not change from Phase I to Phase II. Six themes emerged related to the *depth of participation* by each of the participant groups, including the evaluator facilitating process and having evaluation skill sets; staff having program context and providing a reality check and an ability to affect change; and patient/family members challenging the status quo and having contextual knowledge from lived experience. Findings from my reflective notes and observations identified similar themes, but also included participants being enthusiastic to participate in the discussions and wanting to genuinely understand the different perspectives.

Finally, I reported on the most commonly identified themes related to *control over the evaluation process*, including democratic and majority rule decision-making, respectful and collaborative, clarity of project goals, evaluator leading the evaluation process, and delegation to staff and evaluator. Data from my reflective notes and observations also identified participants as being respectful and collaborative with one another, and how the evaluator leading the process facilitates hearing everyone's opinions during the evaluation process. This section concluded

with identifying factors for improving the engagement process. According to the interview findings and my reflective notes and observations, this included having additional time for the evaluation project and reinforcing meeting etiquette at each meeting.

Consequences of the Patient Engagement Process

Consequences of the engagement process were also reported to respond to the third research question. Specifically, I reported about participants' thoughts related to the intended benefits of being on the PFEC, which included reaching decision-makers, improving PSOP services, increased diffusion of patient/family engagement, and improving awareness and access to PSOP. Data from my reflective notes and observations identified very similar findings, but emphasized that participants were very pragmatic in their decision-making approach and remained enthusiastic that their work together would have an impact. Next, I reported on participants' experiences of being involved on the PFEC; the interview findings and my reflections/observations identified that participants found the PFEC experience to be personally rewarding, learned through the engagement process, and encouraged that the PFEC might have an impact. In the next chapter, Chapter 6, I will report on the findings from Phase III.

Chapter 6: Phase III Findings

This chapter follows the same format used in Chapters 4 and 5. The first section of this chapter provides a summary of Phase III timelines and evaluation project milestones, followed by a description of findings from the interviews and my participant observations and reflections.

Phase III Timelines and Overview

Phase III of the study took place over a one-month period from March 5, 2014, to April 2, 2014. Table 23 provides a summary of what was accomplished during meetings V and VI during Phase III of the evaluation project.

Table 23

Meetings V and VI: Evaluation Work Completed Prior to Phase III Interviews

Meeting	Evaluation Work Completed
Meeting V	Committee members reviewed the response summary to questions related to access and awareness of the PSOP sent prior to the meeting. Members were asked to identify key issues/factors that struck them as important when reviewing the summary of responses to share with the committee.
Meeting V	Factors affecting access and awareness identified and recommendations developed to improve access and awareness of PSOP.
Meeting VI	Continuation of discussion related to access & awareness of the PSOP from the March PFEC meeting.
Meeting VI	Review of overall key recommendations and strategies to move recommendations forward.
Meeting VI	Discussed interest and possible opportunity of PSOP members to join the Cancer Program Patient and Family Advisory Committee.

During this time, PFEC members continued to advocate for preparatory work to be completed between meetings in order to be more efficient. Meetings V and VI primarily focused on discussing issues surrounding access and awareness of PSOP and developing recommendations to address these concerns. Meeting VI was devoted to finalizing and reviewing all recommendations to be included in the final evaluation report. The final meeting ended with committee members sharing their interests about continuing this type of work in the future for the PSOP or the Cancer Program's Patient and Family Advisory Committee.

Phase III Interview Findings

This section describes the Phase III interview findings, beginning with a description of the contextual factors impacting the engagement process, then reporting on the process according to the dimensions of collaborative inquiry, and concluding with the findings related to the consequences of the patient engagement process.

Contextual Factors

The contextual factors described below include participants' views on what facilitated or hindered the patient engagement process in Phase III.

Facilitators to patient engagement. At the end of the evaluation project, participants were asked to reflect on the following question: "What helps the process of working collaboratively on this project?". Table 24 displays all new and recurring themes identified in Phases I, II, and III that facilitated the engagement process. The most endorsed theme by participants in Phase III was having a lead with evaluation skills facilitate the engagement process, and the least endorsed was accommodating participant needs. Three themes identified in Phase III (i.e., designated lead with evaluation skills, commitment to project, and accommodating participant needs) were also present across all three stages of the evaluation project. The only new theme to emerge in Phase III was mutual respect.

Table 24

Facilitators to Patient Engagement during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Designated lead with evaluation skills	●	●	●	All
Mutual respect	○	○	●	All
Commitment to project	●	●	●	All
Accommodating participant needs	●	●	●	Patient/Family
Orientation meeting	●	○	○	Patient/Family
Homework	○	●	○	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Mutual respect. The topic of mutual respect among members was discussed during Phase II interviews (i.e., approach to decision-making and contributing to member's commitment to the

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

project). However, in Phase III interviews, participants specifically identified the mutual respect that members had for each other as facilitating the collaborative patient engagement process. Participants described how all members had the same goal of wanting to improve health services for future patients, which may have contributed to the mutual respect members had for each other. Here are two examples shared by members describing the common goal of wanting to improve services:

Because we all wanted to help, right? We were there for making it better for the next person that goes through, and that's why we were there. And I think as a team, sometimes you've got to let go of ego, and for the good of the group, we moved ahead . . .
Everybody had a good attitude. Everybody was trying hard and I think that that's key too. Everybody has to — if it was only going to be a gripe session, then that's not productive.
(Patient/Family)

I think just the sense of purpose, we wanted to see things improve, coming to the table. I think the patients and families were probably feeling quite privileged to be asked to participate and to give their feedback. So they came with very good intentions, as did other people around the table. (Staff)

Another patient mentioned how the evaluator and the PSOP staff set the tone for the collaborative process from the start of the evaluation process: “the collaborative nature of [the evaluator] and her colleagues [helped the collaborative process], they wanted us to tell them and they were truly interested”. Participants also discussed the delicate balance of not having meetings too loosely or overly structured to allow participants the ability to share and feel that their opinion/experience was valued. Here is how one patient described the working environment:

The whole environment was really great. That's what I'm saying. If we talk about the way the committee worked every meeting, it was very respectful, rather structured, but not very rigid. So it was structured enough. That is why I think the committee worked really well. (Patient/Family)

Overall, all participants described the high level of mutual respect as strongly contributing to the collaborative process during the project. Members described a working environment that was warm, welcoming, and safe, and which they highly valued.

Recurring theme: Designated lead with evaluation skills. PFEC members identified having a designated lead with evaluation skills as an important facilitator in all three phases of the evaluation project, but by Phase III this was noted as the most important facilitator to the patient engagement process. As discussed in Phases I and II, participants valued the role the evaluator played facilitating the meeting process, ensuring participants understood their committee role, ensuring multiple ways of participating, and setting the tone for a collaborative process. One patient shared that the evaluator “set it up so that we could have discussions that were useful”. A family member appreciated the evaluator’s ability to provide focus to the evaluation process: “I think when we hit a point where there was maybe too much information to work on, and finally [the evaluator] strategically brought it down, zeroed it to a couple of issues”. Finally, staff members appreciated “the preparation that went on before we started . . . I think the preparation helped the people’s understanding of what to expect”. Other staff members discussed the important role the evaluator had in recruiting members that were appropriate for the PFEC and committed to being involved in this type of evaluation project.

Recurring theme: Commitment to project. Similar to Phases I and II, participants spoke of the common commitment all members shared to improve health services for future cancer patients. One staff participant shared that participants “knew that they were there with a purpose in mind and they were going to make it beneficial. I think they really did, they as in everybody around the table, came with a purpose of enhancing the psycho-social oncology program”. According to participants, this shared commitment to the program and the project facilitated the collaborative process by ensuring compromise, respect for differing opinions, and overall resolve to develop recommendations that will improve PSOP health services.

Recurring theme: Accommodating participant needs. A consistent theme identified across all three phases of the evaluation project was the importance of accommodating participant needs. PFEC members discussed the importance of doing the ‘little’ things to make the working environment conducive to collaboration. Participants also spoke of the importance of the repeated message by the evaluator and staff to not feel any pressure to do work from home if they were unable to. Participants appreciated knowing they could come to meetings and participate without feeling guilty if they were unable to complete the reflective assignments sent by the evaluator. Members also shared the importance of making efforts to integrate members

outside the city using technology, especially during the winter months. Finally, all members appreciated having food and beverages available at the beginning of each meeting.

Barriers to patient engagement. Participants were asked at the end of the project to reflect on “what hindered the process of working collaboratively on this project”. Table 25 illustrates three themes (i.e., time & resources, imbalanced participation, and living at a distance) that emerged in Phase III. Similar to Phases I and II, time & resources remains the most significant barrier to the patient engagement process, as well as the ability to participate equally in meetings; living at a distance was identified as a barrier in Phase I and again in Phase III. No new factors were identified to hinder working collaboratively on the evaluation project in Phase III.

Table 25

Recurring Themes: Barriers for Participation in PFEC during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Time & resources	●	●	●	All
Imbalanced participation	●	●	●	All
Living at a distance	●	○	●	Patient/Family
Change in health status	●	○	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Recurring theme: Time & resources. All participants wished there had been more time to complete the evaluation project. One family member shared that “it feels like there’s a lot of work still to be done” and others said they wished the committee could remain intact to follow through with the recommendations put forward. Another concern related to time was the amount of material the committee was covering in a short period. Participants were pleased with the meeting structure and the level of efficiency the group had developed, but it was important to allow participants the time to express their experiences without feeling rushed. Overall, participants acknowledged that additional time would have benefitted the project, but members appreciated that a research project was associated with the evaluation project, which limited the ability to add supplemental meetings at the end due to research ethics approval requirements. Staff participants continued to share concerns that continuing this type of patient engagement project would require more protected time for staff and human/financial resources.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Approximately half of the participants said they were pleased and proud of the work the PFEC had completed in such a short amount of time, but wished the PFEC could have continued to do further program improvement work.

Recurring theme: Imbalanced participation. Similar to Phases I and II, participants identified the imbalanced participation at some meetings as a barrier to the engagement process. Some participants described it as “going on a tangent” and that some topics elicited more discussion and personal stories than others. Two participants described the difficulty at times to have a balanced discussion about program strengths and weaknesses due to some members having very strong opinions about the program or a strong influence on the direction a discussion would take. Here is an example of thoughts shared by a staff participant:

We’re used to being the chairs of committees, because we’re kind of the leaders in the program. We’re used to being the dominant ones who set the stage for how things are going to go. But in this case, we’re participants. And it’s important that we’re able to have our voices heard and our opinions heard; it’s also important that everyone else gets a chance for that to happen. (Staff)

Participants also shared that it was difficult to voice an opinion during some discussions in fear of cutting someone off who was sharing a very difficult experience; here is an example of one staff member’s perspective:

The patients and families are coming with a whole history of really challenging and difficult issues. So sometimes the group becomes a forum for them to discuss that in more detail than may be relevant to everybody around the table. When you’re looking at a very time-limited meeting, it’s not always appropriate for people to be tangential with regards to their particular issues . . . but sometimes you have to let people have that opportunity, because that’s important to them. So it’s a bit of a challenge. (Staff)

Overall, participants were sympathetic that members had experiences to share and those needed to be heard and respected, but at the same time acknowledged that it should not be at the expense of other members being unable to share their opinions.

Recurring theme: Living at a distance. Approximately half the participants noted that it would be an additional burden to have to drive long distances to attend a meeting in person, especially during the winter months. Some participants appreciated the efforts made to include one participant living out of town using Ontario Telemedicine Network (OTN), but questioned if

that participant was able to engage in the process as deeply as other members who could attend meetings in person. Despite the technological challenges of being at a distance, members overwhelmingly supported using technology to engage more participants that live outside the city, but acknowledged that it had its disadvantages as well.

Patient and Family Engagement Process

Consistent with Phases I and II, I explored participants' experiences related to the engagement process at the final stage of the evaluation project.

Diversity of members. Participants were asked their views about the value of the different roles on the committee and who they thought was missing; Table 26 provides a summary of the most commonly identified themes. Similar to the findings related to the diversity of PFEC members discussed in Chapter 4, there continued to be alignment with participant views about the “value of each role” (diversity of PFEC members) and their views about the “contributions each role brings” (depth of participation) to the evaluation project. There was no change in opinions about the diversity and value of the differing roles on the PFEC from Phases I, II, and III, and continued to be a strong similarity of views related to the contributions versus value of each role. As such, to reduce repetition of findings I direct the reader to the next section (depth of participation) for a description of the value or contributions of each of the members, and to Chapter 4 for a description of who is missing on the committee.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Table 26

Diversity of PFEC Members during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Who is missing				
Vulnerable populations	●	●	●	All
Patients with head/neck cancer	●	●	●	Staff
More heterogeneous group	●	●	●	All
Family with patient in active treatment	●	●	●	Patient/Family
Value of evaluator role				
Facilitator/organizer	●	●	●	All
Evaluation skill set	●	●	●	Staff
Value of staff role				
Context and reality check	●	●	●	Patient/Family
Ability to affect change	●	●	●	All
Value of patient/family role				
Contextual knowledge	●	●	●	All
Value of diversity of opinions	○	●	●	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Depth of participation. Table 27 shows that no new themes emerged to describe the contributions of participation of committee members based on their role on the PFEC. Two themes (i.e., evaluator facilitating/organizing process and patient/family challenging status quo) identified in Phase II were no longer present in Phase III. Participants in Phase III did not highlight the evaluator's role as facilitating and organizing the process, but rather spoke more generally about that contribution as being one of many evaluation skill sets. Also, patient/family participants no longer identified one of their contributions as challenging the status quo, but rather focused on providing contextual knowledge about their lived experience.

Table 27

Depth of Participation in Engagement during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Contributions of evaluator				
Evaluation skill set	○	●	●	All
Facilitating/organizing process	○	●	○	All
Contributions of staff				
Program context & reality check	●	●	●	All
Ability to affect change	○	●	●	Patient/Family
Contributions of patient/ family				
Contextual knowledge from lived experience	●	●	●	All
Challenge status quo	○	●	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Contributions of evaluator. *Recurring theme: Evaluation skill set.* Similar to Phase II, participants noted that the evaluator's evaluation skills were an important contribution to the evaluation process. Participants said the evaluator contributed by taking a leadership role capturing participant input, brainstorming exercises, offering suggestions on next steps to move the process along, and keeping all members informed of member contributions between meetings. Participants continued to indicate that the evaluator had a key role in consolidating participant ideas and feedback, summarizing information in a useful way, and bringing it back to the committee for consideration and discussion. PFEC participants also identified that the evaluator had a key role in continuing to ensure that the recommendations put forth by the committee reached high-level decision-makers for consideration and implementation.

Contributions of staff. *Recurring theme: Program context and reality check.* Participants continued to identify one of the key contributions of staff is their understanding of the program and organizational context. PFEC members wanted to affect change and therefore it was important to the group to put forth recommendations that could realistically be implemented by the program and hospital. Participants continued to appreciate the 'reality check' that staff would provide in terms of the feasibility of certain recommendations for change and improvement. On the other hand, some participants voiced that at times some staff members appeared defensive of

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

the program and of their attempts to improve certain issues, but overall participants appreciated that staff were up front and pragmatic about the realities of the program and organization.

Recurring theme: Ability to affect change. Similar to Phase II, participants continued to identify that staff have the ability to affect change through learning from patients and family members and making immediate changes to their clinical practice. Participants also identified that staff have the ability to advance recommendations put forth by the committee to all PSOP staff and hospital decision-makers. Participants were hopeful that staff members would be able to advocate for the PFEC recommendations. For example, one family member shared that the report “was well thought out, everyone contributed . . . and it would be good of the hospital to implement what we came up with”. Others shared that they would appreciate a follow-up meeting to get an update from the staff on what changes had been made. Here is an example of what one patient/family participant shared:

Whether it will work out; how much the hospital administration will listen to this is another matter . . . I would very much appreciate if we would come back, say, in a year or two and hear what has happened. (Patient/Family)

All members were hopeful that staff members would be able to affect some change, but were also cognisant of the organizational realities and restrictions staff are faced with.

Contributions of patient and family. *Recurring theme: Contextual knowledge from lived experience.* Through all three phases of the study, participants felt strongly that the most important contribution patient and family members could make to the evaluation process is the contextual knowledge from lived experience. Participants described learning from hearing patient and family experiences; this was also a reminder to the committee that some participants were still undergoing treatment, which made the program improvement project ‘very real’ to them. One family member shared the following:

The patients and the family members couldn’t help but see the lady who was still going through chemo treatments for breast cancer, it was right in your face, she wasn’t going to be at every meeting, but, boy, there was a big contribution factor there, and the rest of us saw it as well. So, it’s really in your face. I was talking about the way it was with [my husband] and for those of us who’d lost a family member, but it was important to see that person, in your face, who is still going through it. (Patient/Family)

All members shared that the unique experiences of each patient and family member provided

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

helped ensure that members put forth recommendations that would improve health services for the majority of PSOP patients and family members, rather than a small cross-section of their patient population. Participants, especially staff members, shared that hearing different patient and family experiences challenged their thinking and preconceived ideas about service delivery and access. Overall, participants noted that the lived experience and knowledge that patients and family members bring to the evaluation process was critical, and contributed to developing a more patient- and family-centred evaluation report for decision-makers.

Control over evaluation process. Control over the evaluation process was also examined in Phase III. At the time of the final interviews, participants were very familiar with the committee's evaluation process, so their views about control over the process were more streamlined compared to Phases I and II; that is, in Phase II, participants identified five themes describing control over the evaluation process, but in Phase III participants narrowed it to four themes: three recurring themes and one new theme (see Table 28).

Table 28

Control over Evaluation Process during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Democratic/majority rule decision-making	●	●	●	All
Respectful and collaborative	●	●	●	All
Evaluator leading evaluation process	○	●	●	All
Need for voting procedures	○	○	●	Patient/Family
Mixed clarity about project goals	●	○	○	Patient/Family
Clarity of project goals	○	●	○	All
Delegation to staff and evaluator	○	●	○	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (i.e., Patient/Family or Staff) if the theme was identified 75% or more by a single group; otherwise, the theme would be considered endorsed by ALL participants.

Note 2. Identified themes are listed in the order most frequently identified by participants.

Two themes identified in Phase II were no longer identified in Phase III of the project (i.e., clarity of project goals and delegation to staff and evaluator). By the final phase of the project, participants shared that members were clear about the project goals and no longer needed clarification. Furthermore, participants no longer shared that some evaluation decisions were delegated to program staff or the evaluator. Three themes related to the control over the

evaluation process continued to be present in Phase III (i.e., democratic/majority rule decision-making, respectful and collaborative, evaluator leading evaluation process) and one new theme (i.e., need for voting procedures) was identified by participants.

Need for voting procedures. A small number of participants shared that the committee might have benefitted from having a more structured voting process in relation to decisions being made. Participants shared that the evaluation process was very collaborative and decisions were made democratically or by majority rule, but some participants expressed that they would have appreciated a formal voting process to increase the clarity of decisions and recommendations being put forward. For example, one participant shared:

I don't believe that there was ever a vote that I can think of. I feel that there was a little lack of clarity in terms of what are we putting forward because there wasn't any voting, that might have added clarification to the process. (Patient/Family)

One participant shared that having a more formal voting process provides an opportunity for members to formally agree or disagree with a decision or motion and have it on record.

I often felt like most people were on side. I'm just talking from my own perspective. I was thinking, I'm not exactly on side yet, but that was just me. I don't know, I couldn't get a sense of how others felt. (Patient/Family)

Overall, participants appreciated that the meetings were not too formal, which made for a relaxed atmosphere, but a small number of participants indicated that some level of formality for decision-making would have added clarity to the evaluation process.

Recurring theme: Democratic/majority rule decision-making. Participants continued to describe the decision-making process as democratic and majority rule. Participants were comfortable with the decision-making process and appreciated the diversity of opinions around the table. One patient/family member shared that "I think that was the strength behind this committee — the opposing viewpoints offered . . . Not everybody agreed necessarily, but there was a lot of agreement". A small number of participants were satisfied with the democratic and majority-rule style of decision-making, but would have appreciated a more formal voting process for decisions and recommendations being put forward in the final report. Patient and family participants continued to recognize that staff have a deep understanding of the program and the organizational culture, but that some staff participants had strong opinions that may have influenced some decisions. Overall, participants were satisfied using a democratic and majority-

rule approach to decision-making with a few participants suggesting increased formality for key decisions or recommendations being incorporated into the final evaluation report.

Recurring theme: Respectful and collaborative. Participants felt that PFEC members were respectful of each other's opinions through all three phases of the evaluation project. One staff member shared the following: "I think people were treated with great respect, great understanding, and that all contributed [to the collaborative process]". All participants expressed a high level of mutual respect among members, despite having different experiences and views. One staff member described the working environment in the following way:

I think it was just a very welcoming, comfortable group. We laughed a little bit; it was relaxed to some degree or another, but also people have strong feelings. This is a very significant event that they've experienced in their life . . . That has a lifelong impact, and they feel very strongly about the discussion and felt that they had a lot to offer and wanted to make that contribution. (Staff)

One patient/family member shared she had much respect for the staff PFEC members because she recognized that they were very busy and took the time to be part of the process, which in her view demonstrated the genuineness they had for learning from patients and family members. Similar to Phases I and II, participants shared that having a shared common goal of improving health services, an evaluator facilitating a collaborative evaluation process, and engaged staff and patient/family members contributed to the mutual respect among members.

Recurring theme: Evaluator leading evaluation process. Participants continued to share that the evaluator had a strong role in leading the evaluation process. Participants described that the evaluator had a key role in staying neutral and allowing all opinions to be heard. One patient/family member shared that "she managed to stay neutral, and I think she did move things along quite nicely". Others described the evaluator contributing to the evaluation process by asking key questions important to the evaluation between meetings and consolidating the information for discussion at monthly meetings. According to participants, the evaluator did make a substantial number of decisions, such as what meeting process/approach to use, development of monthly reflective questions, and recommendations based on analysis of written feedback and discussions, but all participants emphasized committee members always had the opportunity to review and voice objections to recommendations or decisions made. Overall,

participants viewed the evaluator role as important to the evaluation process and emphasized it was a key role for moving the process forward.

Improving the engagement process. Participants were asked if they had any suggestions for improving the engagement process in the future. The majority of participants were satisfied with the process, but were able to offer three recommendations for future consideration, as outlined in Table 29. Having additional time and reinforcing meeting etiquette continued to be identified in Phase III. A small number of participants shared one recommendation (i.e., clear project goals) that was not present in Phase II, but superficially discussed in Phase I interviews.

Table 29

Recommendations for Improving Engagement Process during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Additional time for evaluation project	●	●	●	All
Reinforce meeting etiquette at each meeting	○	●	●	All
Clear project goals at beginning of process	●	○	●	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme was considered to be endorsed by both groups. Themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present ● Theme absent ○

Clear project goals at the beginning of process. A small number of participants shared that it took two or three meetings to understand the project goals for the evaluation project. Some participants would have preferred if the PSOP staff had predetermined what priority areas would be included in the needs assessment versus going through a priority-sort exercise that some participants thought felt rushed. One patient/family participant shared that there was sometimes not enough time for detailed discussion about an issue: “I just don’t like snap decision-making when we’re going to be talking about changing policy within an institution or something. I think we should be careful so that we understand the different parts of what the implications are”. Most participants felt that the lack of clarity of project goals in the early stages of the project was ‘growing pains’ and to be expected. Overall, participants thought that clarity of project goals could have been improved by having PSOP staff predetermine the areas of focus based on their clinical judgement.

Recurring theme: Additional time for evaluation project. Most participants commented

across all three phases that the evaluation project would have benefitted from additional time to thoroughly discuss and examine each of the priority areas. Participants felt that the PFEC maximized the time they had together by doing work between meetings and coming to meetings prepared for discussion. Participants appreciated that staff were involved in the process to provide reality checks and prevent time being wasted working on unrealistic recommendations. As one patient/family member shared, “you know we have such limited amount of time to work together, so let’s get to a point in discussion that can benefit everyone, rather than, you know, rebuild the wheel and start over”. Participants indicated that the PFEC had to readjust its expectations and deliverables two or three meetings into the process to accommodate for the time restrictions. Participants felt that, with more time, some of the recommendations ideally could have been implemented while the PFEC continued to work with the PSOP. One staff member shared that, “if there was a patient and family engagement group that could continue on down the line . . . to look at continuing to collaborate and implement some of those suggestions and action plans and look at other issues that arise”, the likelihood of the recommendations being implemented would be higher. Overall, participants are hopeful that staff members will be able to continue the work of the PFEC, but implementation of the recommendations would be facilitated by an ongoing contribution from patients and family members.

Consequences of the Patient Engagement Process

Similar to Phases I and II, I wanted to explore what participants hoped would come from the work completed by the PFEC and what the overall experience was like for them.

Intended benefits. Participant views on the intended benefits of the engagement process did not change significantly throughout the evaluation process, except for one theme (i.e., follow-up to assess influence of engagement project) that emerged in Phase III. Table 30 displays all themes identified in each phase of the study, four of which were consistently identified in all three phases and one that emerged in the final phase.

Table 30

Intended Benefits during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Reaching decision-makers	●	●	●	All
Improving awareness/access of PSOP	●	●	●	All
Follow-up to assess influence of engagement project	○	○	●	Patient/Family
Improving PSOP services	●	●	●	All
Increased diffusion of patient/family engagement	●	●	●	All

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered to be endorsed by both groups. Themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present ● Theme absent ○

Follow-up to assess influence of engagement project. Participants felt hopeful at the end of the evaluation project that the work of the PFEC would improve PSOP health services; but, some participants voiced that it may be difficult to know the extent of the impact they will have had without a follow-up. Here is an example of patient/family participants' views when asked about PFEC's contributions to improving PSOP services:

It feels a little bit like the information is out there. Are the decision-makers going to implement it? I don't know. Did they hear it? I think they heard what we said, and will it be brought forward? I believe so. Is it going to go anywhere with it? I don't know.

(Patient/Family)

Patient and family participants were confident that some of their work has already had some impact in terms of improving health services at the PSOP. For example, patient and family members described feeling heard and valued by PSOP staff and described noticing staff learning from what they were hearing. However, due to time restraints and the committee dissolving, patients and family members would "like to find out what happens next, after I'm finished. I'd like to get some sort of idea of the results of it . . . like the recommendations, and if anything is implemented as a result of it". Most participants recognized that implementing some of the recommendations would take time; for example, one patient/family member said that "I'm hopeful that we did, but to really know whether or not we had impact or how useful it was is going to take some time". One patient/family member was motivated to do this type of work again, but needed to know that this type of work is having an impact.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Staff participants were hopeful they would be able to implement some of the recommendations, but acknowledged this would take time and only a few would be implemented before the end of the evaluation project. One staff member shared that “I think that with the report and with the involvement of patients, given the emphasis here on patient experience and input of patients, then that should help to facilitate things”.

Recurring theme: Reaching decision-makers. This theme continued to be the most important intended benefit for participants involved with the PFEC. Participants hoped the work completed by the PFEC would reach decision-makers and affect change. Patients and family members described their main motivation to participate on the PFEC was to share their experiences with decision-makers and help improve health services for future patients. One patient/family member shared the following after being asked if they influenced decision-makers:

I put it this way. So far, I didn't see another way of giving feedback to PSOP members, physicians, and other health care professionals. That was my way, my channel, to give them my feedback. And I think many other patients and family members were thinking in the same way. (Patient/Family)

The majority of patients and family members described feeling heard and that their opinions and experiences were valued. One patient/family member said that they gave PSOP “something to think about”, but whether their input would have an impact remains to be determined. Staff participants have some decision-making responsibilities, but most staff members felt that senior management would play a significant role in terms of implementing recommendations. Some staff described using the final PFEC report as a tool to negotiate change for PSOP, highlighting the importance that the recommendations were co-developed with patient and family members.

Overall, participants were hopeful that the work completed by the PFEC would reach decision-makers and be considered, especially given that patients and family members were involved in the production of recommendations. Staff participants were concerned that implementing some recommendations might be more challenging in the current organizational context (e.g., budget cuts, increased acuity of patients), but shared that recommendations co-developed with patient/family members will add credibility and urgency to their requests.

Recurring theme: Improving awareness and access of PSOP. This theme was strongly supported by the majority of participants as an intended benefit of the engagement process

during all three phases of the evaluation process. Participants shared that improving awareness and access to the PSOP for all cancer patients was an important outcome that they hoped the PFEC could influence. Participants spoke of better integration of PSOP services within the Cancer Program; that is, that psychosocial oncology services would be integrated into cancer care or at a minimum introduced to all patients and family members as a service available to them. Similarly, staff participants were not advocating for total integration of PSOP services for all cancer patients, but as one staff member described: “I’m not saying that we need to do it all, people just need to have the awareness of us. If they choose not to seek services, that’s fine. I just want them to know we’re here”.

Recurring theme: Improving PSOP services. Participants across all three phases of the study were hopeful that PSOP health services would be improved as a result of this evaluation project. Some participants continued to share that improving PSOP services was the main reason they decided to join the PFEC. Here is an example of how one patient/family member described it:

I would hope that the PSOP program will somehow be improved. It’s pretty basic, but that’s the whole reason I came on. I don’t criticize the program, but any program can be improved, so if we can help it improve somehow, then that’s great, that’s pretty much it.
(Patient/Family)

Overall, participants were hopeful that services would be improved by learning from patient and family experiences, reviewing program education modules, working with PSOP staff to improve patient navigation sessions, and co-developing recommendations with patients, family members, and staff.

Recurring theme: Increased diffusion of patient/family engagement. Participants continued to value the importance of having patient/family members collaborating with health professionals in health service improvement projects. Participants discussed the important roles patients, family members, and staff bring to quality improvement projects: patient/family members bring lived experience and staff bring organizational and clinical experience. At the end of the evaluation project, most participants saw value in this type of collaborative work. One staff participant shared that “I think the benefit of . . . going through that process, has left us with information and an experience that reminds us of the needs of patients and families”. Staff were

pleased that some members of the PFEC expressed interest in continuing to do this type of work at the Cancer Program or participating in other quality improvement activities.

Participant experience. I was interested in exploring what participants' experience of being involved on the PFEC was like through all phases of the evaluation project. Similar to Phases I and II, participants were asked if their involvement on the PFEC had been a positive or negative experience. All participants described the experience as being positive and did not identify any negative experiences with their involvement at any stages in the evaluation process. Furthermore, all participants were pleased they participated on the PFEC and would agree to participate on a similar committee in the future. Participants were also asked to describe the overall experience of being a member of the PFEC. Table 31 outlines all four themes that emerged related to participants' experiences of being involved.

Table 31

Participant Experience during Phases I, II, and III

Themes	Phase I	Phase II	Phase III	Participant Group
Personally rewarding	●	●	●	All
Learning through the process	○	●	●	All
Encouraged PFEC might have an impact	○	●	●	All
Enthusiasm for project	●	○	●	Staff
Shift from personal focus	●	○	○	All
Closing the loop and healing	●	○	○	Patient/Family

Note 1. Evidence rule: A theme would be considered endorsed by a single group (Patient/Family or Staff) if 75% or more identified the theme; otherwise, the theme would be considered endorsed by both groups. Themes are listed in the order most frequently identified by participants.

Note 2. Legend: Theme present ● Theme absent ○

Three themes related to participant experience in Phase II continued to be identified in Phase III (i.e., personally rewarding, learning through the engagement process, and encouraged PFEC might have an impact) and one theme re-emerged from staff participants from Phase I (i.e., enthusiasm for the project).

Enthusiasm for project: Staff participants described being pleasantly surprised and motivated by the level of commitment and 'keenness' from the patient and family members. Staff participants shared that witnessing the passion and commitment on the part of the patients and family members made their involvement more meaningful. This is how one staff member described her experience:

It meant a lot to them [patient and family members] . . . it almost came as a little shock.

In the hospital you drag yourself from one committee to the next, thinking "ah... thank

goodness that's over, I don't have to worry about it for another month or whatever," but these people were like give us more. [Interviewer: and that surprised you?]. In some ways, yes; that motivation and that energy was actually very good. (Staff)

Staff also shared that working with patients and staff participants that insisted on doing work between meetings and being so committed to improving PSOP service increased their commitment to the project as well. As one staff member shared, "they were very keen to do some readings in advance and it was really rich in terms of what each person contributed". Overall, staff members described being pleasantly surprised by the level of commitment and enthusiasm to do work compared to other committees they have been involved with in the past.

Recurring theme: Personally rewarding. Similar to Phases I and II, participants continued to identify that their involvement on the PFEC was personally rewarding. Staff described their participation as validating to the work they do at the PSOP. Here is an example of how one staff member described it:

It's very poignant, very personal. It makes it very real when you hear from patients and families. It also . . . really gives us a sense of justification in terms of the work that we do. It actually helps you feel good about the work that you do, because you realize you are on track in many ways, that you are sensitive to the needs of the patients. (Staff)

Patients and family participants described enjoying the committee environment because members were genuinely interested in what people had to say and everyone had the same goal of improving the PSOP, which made their involvement more rewarding.

Some participants described their experience as "refreshing" and "collaborative" compared to other committee work they have been involved with. The majority of patient/family members also described "feeling happy to take part, to try to give back to the system a little bit". "Giving back to the program/system" was an important part of why participants decided to join the PFEC initially, and this sentiment followed through until the end of the evaluation project.

Recurring theme: Learning through the engagement process. Learning through the evaluation process remained important for the majority of participants. Some of the learning they described was related to the PSOP and the overall health care system, while other learning related to the experiences of other patients. As one patient/family member shared, "I think there's a lot of intangible stuff that you always learn when you work with people, and you problem solve". Another patient/family member described that they "learned about all the

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

different areas that people entered the system — I had no clue, and that helps me and in my role on another committee”. Patients and family members described enjoying and being somewhat surprised by the different types of areas they learned about through their involvement on the PSOP.

Staff members also described learning through the engagement process and working with patients and family members. As one staff member noted, “I like group work, I learned a lot from patients. Even though you think you’ve heard it all, there’s always something new that you hear, because everyone’s different”. Staff participants described appreciating learning from patients and family members by hearing about their health care experiences, and their perspectives and suggestions for improving some of the weaknesses in the system.

Recurring theme: Encouraged PFEC might have an impact. By the final stage in the evaluation, over half of the participants were expressing satisfaction that the PFEC was already or would in the future have a positive impact. Participants recognized that it might take time for real change to occur, but at the same time indicated there was already some evidence that the PFEC work was contributing to some organizational learning. For example, one staff participant described the following sentiments related to the immediate impact of the work completed by the PFEC:

As an example, this one message of the lack of integration people feel, I’ve brought that up at meetings with administration, and when it comes from the patients, it seems as if it has more weight. So, I’ve actually repeated that a few times, this idea that, you know, it’s not just us as a program that we feel like we’re not integrated, our patients are actually telling us that, and so we need to improve. (Staff)

Overall, the majority of participants expressed interest in a follow-up meeting in a year’s time to evaluate the impact of the PFEC, but in the short term most participants were hopeful the committee would have contributed positively to the PSOP:

I guess at the end of the day, I feel like we could definitely have had a real concrete and positive impact. I would love to or I hope there’s some feedback mechanism, so that we know that or not. You know, I’m not sure what everyone’s motivation is for volunteering, but I would like you to know that I hope that my time goes into something with a real result. (Patient/Family)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

This patient/family excerpt represents the typical opinion of the majority of participants with regards to their PFEC experience. Participants were hopeful their time and efforts on the PFEC would contribute to meaningful results for improving the PSOP, but felt strongly that a feedback mechanism should be in place to keep members informed of progress made.

Unintended outcomes. Despite exploring with participants any unintended outcomes that may have occurred during the evaluation project, participants did not identify any additional unintended outcomes other than one identified in Phase II. If you recall, in Phase II a small number of participants identified it being challenging at times to discover the services that could have been available to them or their family member during their illness. Participants had moments of frustration comparing their experience to how services could have been delivered or accessed more effectively.

Phase III Participant Observation and Researcher Reflection Findings

This section reports on the findings from the reflective notes and participant observations captured after meetings V and VI. Similar to the interview findings, these data will be reported according to the *contextual factors*, *engagement process*, and the *consequences* of the patient engagement process.

Contextual Factors

During meetings V and VI, I observed a few contextual factors facilitating as well as inhibiting the patient engagement process; I identified the following factors as facilitating the process, some of which I also identified in Phases I and II:

- Accommodating participant needs: food/drinks, participating virtually using technology.
- Enthusiasm and commitment to the project.
- Mutual respect among members.
- Efforts to foster relationships: humor and empathy.
- Homework contributing to meeting efficiency.
- Appreciation by participants for consolidation of participants' feedback and identification of gaps by evaluator.

Meetings V and VI mainly focussed on finalizing the needs assessment and evaluation report to be shared with senior management at the Cancer Program. During the final two

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

meetings, I observed a strong connection among PFEC members. Here is a sample of my reflections following meeting VI.

It was interesting to see how comfortable committee members were with each and seemed to be genuinely happy to see each other at the beginning of each meeting. PFEC members were noticeably more social with each other at the beginning and end of each meeting, and it was evident that a strong group dynamic had been formed over the months working together.

Members seemed less concerned about seating arrangements and appeared comfortable to sit anywhere in the boardroom: “The boardroom continued to be an excellent place for our meetings because it provided comfortable seating for everyone, VPN access for our out-of-town member, and was big enough to allow food and drinks in our meeting area”.

There were times during each of the two final meetings that I worried “we might not be able to accomplish everything we had set out to do, but members seem very committed to meeting our objectives within our remaining timeframe”. According to my observations and reflections, meetings V and VI felt very productive and members’ ability to work collaboratively together was significantly stronger. Facilitating the final two meetings was less stressful than the previous meetings, in part because we had a “good meeting process in place and overall everyone wanted to give everyone the opportunity to share their ideas”.

I also observed barriers to the engagement process during meetings V and VI, including:

- Limited time and resources.
- Challenge facilitating group discussion when people are very passionate.
- Living at a distance.

The final two meetings focussed mainly on awareness and access to PSOP, and all members had strong opinions about this issue. But, overall, members were very respectful about the diversity of opinions and acknowledgement that all members had a different experience and perspective, which was an important contribution to the evaluation project. However, my observations and reflective notes indicated that “I found it challenging to facilitate the meeting at times. I really want to ensure everyone has the opportunity to share their opinions, but naturally some people are going to be more vocal”. I noted that meeting etiquette improved in meetings V and VI, but ensuring everyone had the opportunity to speak remained a challenge with such a passionate group of participants.

Patient Engagement Process

My reflections and observations related to the *diversity of members* did not change from Phases I or II. In terms of *depth of participation* and *control of decision-making*, there were times during the final two meetings where “some staff members seemed defensive of the program when hearing some of the issues and recommendations being brought forward by patient/family members”. In some instances, the defensiveness seemed to be related to the frustration of hearing patients and family members suggest solutions to issues they had already attempted to address as a program, but staff members still appreciated hearing their lived experience: “The frustration was never directed at the patient/family participants, but rather at the reality of knowing these issues exist and being unsuccessful in being able to address them adequately”. At the same time, patient/family participants also appeared to find it difficult to “make suggestions that staff did not think would be feasible”. Facilitating some of those discussions was not always easy; I wanted to make sure everyone felt heard, but at the same time I had to remain conscious of time and ensure we were moving forward in the evaluation process. Here is an excerpt of some of my reflections after meeting V:

These discussions were not always easy to facilitate, but in the end members acknowledged that it was important to have all the differing views developing recommendations; that is, staff acknowledged how important it was to hear about patient and family experiences with the program, and patient and family members appreciated the reality check of staff sharing the realities of hospital bureaucracy and the historical context of the program.

Despite the difficult topics of discussion, participants “remained committed to working collaboratively and there is tremendous mutual respect among all members”. Data from my reflective notes also identified having additional time for the evaluation project and reinforcing meeting etiquette as key factors for improving the process in the future.

Consequences of Patient Engagement Process

Meeting VI ended with members discussing how they were pleased with what had been accomplished as a group in such a short amount of time: “Overall, members and I would have appreciated having a few more meetings to further unpack some of the issues identified . . . but patients and family members seemed confident that staff members would do their best to move the recommendations forward”. Participants were hopeful that the work completed by the PFEC

would lead to improving access, awareness, and services of the PSOP. Overall, “I was pleased to hear from members how much they had appreciated their experience on the PFEC”. Some shared they would be interested in joining the Patient and Family Advisory Committee at the Cancer Program to continue this type of work and advocate for the recommendations in our evaluation report at the Cancer Program level. Moreover, “[m]y impression from staff is that they are pleased with the work completed and feel a sense of responsibility to ensure that the work completed by the PFEC leads to program improvement”. Overall, I am pleased that members seem proud of the work completed and that it appeared to be a positive experience for all members.

Chapter Summary

Chapter 6 described the findings for Phase III of this study. Similar to Chapters 4 and 5, the chapter began with an overview of the evaluation tasks completed and meeting timelines. This was followed by a description of the findings from interviews and my participant observation and reflective notes.

Contextual Factors

Participants identified four themes in the final stage of the evaluation project that facilitated participation in the engagement process: having a designated lead with evaluation skills, mutual respect, commitment to the project, and accommodating participant needs. My participant observations and reflective notes also highlighted the efforts being made by participants to foster strong working relationships as well as homework with respect to facilitating the engagement process. Participants identified three barriers that may negatively impact the engagement process (i.e., time & resources, imbalanced participation, and living at a distance); these were also identified in my observations and reflections.

Patient Engagement Process

Participant perceptions and my observations and reflections of the diversity of the PFEC membership did not change from Phase II to Phase III. Participants were consistent in stating that the following groups were missing from the PFEC: vulnerable populations, patients with head and neck cancer, family members of patients who are in active treatment, and a more heterogeneous group. My observations and reflective notes continued to identify the same missing groups as participants, but in addition I reported seeing the value in having an oncologist

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

involved in the work of the PFEC. Participants continued to see the value in involving an evaluator, staff members, and patient/family members. Overall, participants indicated the great value of having a diversity of opinions on the PFEC.

Four themes were identified by participants related to the depth of participation in the evaluation process by each of the participant groups: evaluator facilitating process and having evaluation skill sets; staff having program context and providing a reality check and an ability to affect change; and patient/family members having contextual knowledge from lived experience. My observations and reflections indicated similar findings, but also highlighted the challenges as an evaluator facilitating the engagement process during the discussion of difficult topics. The reality checks provided by the staff and the lived experience shared by the patients and family members required some strong facilitation skills to ensure the discussion remained productive and that differing views were heard and respected.

Finally, I reported on the most commonly identified themes about participants' views related to control of the evaluation process between meetings IV and VI: democratic and majority rule decision-making; respectful and collaborative; evaluator leading the evaluation process; and a need for voting procedures. My participant observations and reflective notes indicated similar findings, except that I did not include identifying a need for voting procedures; however, I did identify a defensiveness at times on the part of the staff when discussing program issues. I also noted that, as a result of some (although infrequent) defensiveness, some participants seemed hesitant or reluctant at times to share some of their perspectives on how to improve the program. Despite these challenging discussions, my reflective notes indicated that all participants remained respectful and committed to collaborating to improve the program.

This section concludes with participant recommendations for improving the engagement process; this included having additional time for the evaluation project, reinforcing meeting etiquette at each meeting, and having clear project goals at the beginning of the evaluation process. Data from my reflective notes also identified having additional time for the evaluation project and reinforcing meeting etiquette.

Consequences of the Patient Engagement Process

Consequences of the engagement process were also reported in Chapter 6, which include participants' thoughts about the intended benefits of being involved on the PFEC. Participants shared that reaching decision-makers, improving awareness and access to PSOP, having a

follow-up to assess the influence of the engagement project, improving PSOP services, and having increased diffusion of patient/family engagement in health care as important intended outcomes to their participation on the PFEC. Data from my reflective notes and observations indicate that participants appeared pleased with what they had accomplished as a group in such a short amount of time and were hopeful the recommendations put forward would reach decision-makers and result to improved awareness, access, and services of the PSOP.

The chapter concludes with a description of participants' overall views about the experience of being involved on the PFEC. All participants enjoyed their experience on the PFEC and would participate again in the future if the program improvement project was of interest to them. Participants were asked to describe their experience on the PFEC and identified the following consequences to their participation: personally rewarding, learning through the engagement process, encouraged the PFEC might have an impact, and enthusiasm for the project. Data from my reflective notes and observations support these findings, but also identify staff appearing to feel a strong sense of responsibility to move these recommendations forward to improve the program out of respect for the hard work completed by all participants involved. In the next chapter, Chapter 7, I will briefly report on the focus group findings that served to validate and enrich the findings reported in Chapters 4–6.

Chapter 7: Phase IV Validation of Research Findings

In the previous three chapters, I reported on the findings from Phases I–III. This chapter will briefly describe the results of the focus group conducted after completion of the evaluation project. The purpose of the focus group was to review the draft case study profile and ensure the preliminary findings resonated with participants. The focus group discussions provided strong validation of preliminary research findings shared through the case study profile, but also added value by providing the entire group’s perspective regarding the patient engagement process. This chapter will also briefly report on additional findings generated through focus group discussions.

Focus Group Process

The focus group was conducted three months following the end of the evaluation project. The focus group was co-facilitated by my academic advisor, Dr. Brad Cousins, and the independent interviewer who conducted the interviews. All PFEC members were present for the two-hour focus group, which was held at the PSOP. One week prior to the focus group, participants were sent a case study profile (see Appendix L) containing the preliminary findings from the three sets of interviews for review. The case study profile and focus group discussions were organized according to eight questions that closely aligned with the interview questions in all three phases of the study.

Focus Group Findings

In the following section, I discuss new insights related to the research questions that were generated from the focus group discussions. Some of these insights further reinforced or expanded upon the findings reported in Chapters 4, 5, and 6, but in some cases new data emerged from the discussion. I begin with the first research question that explored the motivation for participants joining the PSOP.

Motivations for Patient Engagement Involvement

Participants confirmed the findings from Phase I that described the reasons they gave for joining the PFEC; these included a way of giving back, improving health services, commitment to research and evaluation, offering a unique perspective, and learning and revisiting assumptions. Participants did not provide other motivations or reasons for their interests in joining the PFEC, but did emphasize that the most important reason for joining was as a way of

‘giving back to the system’. The group was very appreciative of the services received at the PSOP, and wanted to give back by helping the program continue to improve their psychosocial oncology services.

A second important reason the group shared was their motivation for making the process of accessing PSOP services easier. One patient participant had a very difficult time accessing PSOP services when she received treatments the first time, but once she was in the system and needed treatment a second time, it was a much smoother process. In her words, “I wanted to make it easier for patients the first time they go for treatment”.

Staff participants reinforced their views that they wanted to learn from the patients and family members, as well as revisit assumptions. One staff member hoped that patient and family members “could come up with solutions for things we were struggling with”. There was a very practical aspect to wanting to work with patients and family members; that is, they were often aware of some of the challenges patients were facing, but needed “fresh ideas or solutions” to try to adequately address them.

Facilitators and Barriers to the Patient Engagement Process

Participants had some strong views about what facilitated the evaluation process. Overall, participants agreed with the list of facilitators developed across the three phases of the study, which included (a) accommodating participant needs, (b) commitment to project, (c) orientation meeting, (d) designated lead with evaluation skills, (e) homework, and (f) mutual respect. One theme that was closely aligned with mutual respect that participants felt very strongly about was the high level of collaboration and valuing of people’s different experiences and perspectives. The participants spent a significant amount of discussion time exploring why the group worked so well together. One family member felt valued when “people were lining up to a telephone” when she was participating through teleconference and we had lost audio capabilities and could only communicate with her using the phone.

Others suggested the possibility that the PSOP staff are trained professionals (i.e., social worker, psychologist, and psychiatrist) who have strong communication and listening skills due to the type of work they do. Most participants agreed that having everyone “on the same page and wanting to improve the experience for other patients” helped the collaborative process. According to PFEC members, having a common goal motivated the group to work hard and be

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

as efficient as possible. One example given that demonstrated the group's commitment was finding ways to improve efficiency, such as "doing homework between meetings". All participants emphasized that the committee would have been far less productive without the additional work completed between meetings. Participants also appreciated the work completed between meetings by the evaluator, specifically sending out reflective questions, summarizing everyone's responses, and sending out the summaries a week before the next meeting. One staff member also suggested, and the group agreed, that the preparation completed before the first meeting by the evaluator and PSOP staff (i.e., recruitment process, recruitment interviews, and orientation meeting) most likely had a strong influence in terms of recruiting the "right kind of people with the proper motivations" for doing this type of work.

There was an interesting discussion around the suggestion that I, as the evaluator, played an important role in setting the tone of collaboration. For example, most participants voiced their appreciation that I was transparent in sharing at the orientation meeting that I was also a registered nurse and had had some experiences at the Cancer Program with my father who had recently passed away from cancer. I acknowledged at the focus group that I was concerned and conflicted about sharing my recent experiences, but felt it was important to be transparent and genuine. Participants appreciated this honesty and said it set the tone for them to share more "than just their name and diagnosis," but also what their experience had been like at the PSOP. Participants also reinforced that, despite my personal experiences with my father, they never felt I "pushed an agenda" and that I remained "neutral" in terms of listening to the overall group and summarizing what I was hearing. Overall, participants shared that the introductions by all PFEC members set a tone that contributed to the positive group dynamics that ensued.

In terms of barriers to the engagement process, participants agreed with the preliminary findings shared; they included time & resources, imbalanced participation, change in health status, and living at a distance. Participants emphasized the challenge of attending every meeting, especially when still undergoing treatment. Participants appreciated not feeling any "pressure or guilt" if they were unable to attend a meeting due to illness or having low energy. Staff participants reinforced the challenge of doing this type of work with the competing demands of clinical responsibilities and limited budget. Despite having to increase their workload by participating on the PFEC, staff members were pleased to be involved because the patients and family members were so passionate and keen to work.

Improving the Engagement Process

Suggestions for improving the engagement process identified during the evaluation process resonated with participants at the focus group. The following three themes were identified: (a) additional time for evaluation project, (b) reinforce meeting etiquette at each meeting, and (c) clear project goals at beginning of process.

Discussions surrounding the barriers and recommendations for improving the process were interesting. Participants were very vocal that any barriers identified would have been worked through if the committee continued to work together. One family member shared that “they weren’t so much hindrances, but minor details that would have resolved with some experience” and additional time. Another patient participant argued that “the lack of clarity about the project goals earlier on was a natural part of the process and that it was reasonable to expect it to take some time for adjustment”. Overall, participants did not identify additional barriers or recommendations for improving the process, viewed the barriers identified as minor, and felt they could have been addressed with adjustments over time.

Diversity of PFEC

Participants agreed with the preliminary results related to the diversity of members on the PFEC; that is, participants strongly agreed with the importance of having a professional evaluator leading the process and supported the participation of both PSOP staff from different specialties and different roles (i.e., clinicians versus administrators) as well as patient and family members with current lived experience with the program. Participants emphasized the importance of patients and family members having recent experience with the health care system in order for their experiences and contributions to be relevant. The risk is that patients may still be undergoing treatment and may need to miss some meetings due to illness or low energy. Despite that reality, participants felt having recent experience was critical. There was also some discussion about the possibility of having more patient members on the committee to compensate for the possibility of absenteeism due to illness, but the majority of participants agreed that “if [the committee is] too big the efficiency snowballs and [is] harder to control. Overall, meetings still go on if someone is missing”.

Participants confirmed that the PFEC had appropriate gender and age representation, as well as good diversity of patient participants with different cancer types (e.g., breast cancer, colon cancer, leukemia, etc.). Participants supported the conclusions of the preliminary findings

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

that greater efforts should be made in the future to include patients from vulnerable populations and patients with head and neck cancer, to create a more heterogeneous group in terms of education and socioeconomic status, and to have representation from family members of patients in active treatment.

Participants discussed the challenges of having greater representation of patients or family members from rural areas, and agreed it was critical to have “their voices at the table”. One staff member emphasized that “all the challenges that our out-of-town committee members have coming to a meeting is reflective of patients. It’s a reminder of the challenges that patients go through; it was a constant reminder for staff”. Participants emphasized the importance of continuing to use video conferencing technology (e.g., tele-health, Adobe Connect, etc.) to allow greater participation of people living in rural areas.

Participants also discussed and brainstormed ideas for having representation from vulnerable populations. One professional commented that patients who would be considered vulnerable are more likely to miss treatments or doctors’ appointments; therefore, joining a committee would offer even greater challenges. Suggestions were offered to increase recruitment of vulnerable patients or family members (e.g., going to their home or homeless shelter rather than having them come to us, getting their input while in hospital for treatment, consulting with professionals who work directly with this patient population, etc.). Overall, most participants agreed that, if another PFEC was to be created, some creative strategies would have to be considered to contact and incorporate these patient populations into the process.

Depth of Participation

General themes that emerged related to depth of participation by each member group during the evaluation process resonated with committee members. Participants agreed with the theme that the *evaluator contributed* to the evaluation process by providing evaluation skill sets, which included facilitating and organizing the meeting process, taking a leadership role capturing participant input, summarizing and analyzing feedback, offering suggestions on next steps to move the process along, keeping members informed, and advocating for PFEC recommendations to reach decision-makers for consideration and implementation. Participants also agreed with the themes identified related to staff contributions. Overall, participants agreed that the key *contributions made by staff* during the evaluation project included having a strong understanding of the program and organizational context, which provided the PFEC with ‘reality

checks' when recommendations were being discussed and put forward. Participants also identified that staff have the ability to affect change. Finally, participants agreed with the theme that the most important *contribution made by patients and family members* to the evaluation process is bringing the contextual knowledge from lived experience. Participants, especially staff members, shared that hearing different patient and family member experiences challenged their thinking and preconceived ideas about service delivery and access. Participants agreed with the theme that patients and family members have the ability to challenge the status quo and identify issues that might not otherwise be addressed without patient and family member input.

Control over Evaluation Process

Participants agreed with the general themes that emerged related to control over the evaluation process, which included mixed clarity about project goals, democratic/consensus decision-making, respectful and collaborative, clarity of project goals, evaluator leading evaluation process, delegation to staff and evaluator, and need for voting procedures.

One member clarified that decisions were made democratically and through a majority-rule approach rather than consensus. Participants discussed that they were comfortable with a majority-rule approach, because seeking consensus would be challenging with such a diverse group.

There was also some discussion surrounding “emotionally charged topics” that were at times challenging to facilitate. For example, some participants felt there were instances of “high sense of ownership or protectionism from program [staff]”, but most members interpreted this protectionism as “passion or caring”. One staff member shared that “sometimes what triggered that defensiveness was if we had tried that and were hit by a wall; it was not frustration at patients, but previous frustrations from the past”. Overall, patients and family members appreciated the reality checks and pragmatic discussions the committee had versus working on a direction or recommendation that was not realistic or had failed in the past.

Intended Benefits of the Engagement Process

Participants discussed their motivations for joining the PFEC and much of their motivation was also related to the intended benefits they hoped would be achieved by participating. All participants endorsed the themes presented in the preliminary results about the intended benefits of their participation, which included (a) reaching decision-makers, (b)

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

improving PSOP services, (c) increased diffusion of patient/family engagement, (d) improving awareness/access of PSOP, and (e) follow-up to assess influence of engagement project.

Participants discussed the importance of having “impact” in terms of the work they have completed with the PFEC. One family member shared that “giving back doesn’t happen until real change happens”. However, patients and family members clarified that they did not expect that all recommendations would be accepted and applied, and were realistic about some of the challenges being faced in health care. For example, one patient participant shared that “if a quarter of the recommendations come through that would be success — I think that is realistic. I think it’s impossible to think everything will be implemented”. Staff participants felt confident that some of these recommendations would be implemented. One staff member shared the following:

The real benefit is hearing from patients dealing with the system directly. Some of the recommendations are not resource intense, so we may be able to implement them, but hearing directly from patients and family is invaluable. Just the fact that you have educated us — the sharing part has had an impact. (Staff)

All members hoped that the priorities and recommendations would be thoughtfully considered by the PSOP and senior management. In general, most members described feeling “cautiously optimistic” that the PFEC work will affect change. Others described being content that they are “part of a movement” for greater patient and family engagement in health service quality improvement. One patient/family participant had the following sentiments:

We are affecting a cultural change. We are trying to move everyone forward and trying to educate our service providers as well. I don’t see this as a checklist [of recommendations to be implemented] at all, but rather broadening our community for greater patient engagement. (Patient/Family)

Participant Experience

All members of the PFEC shared that their participation with the PFEC was rewarding and would participate again in the future if the program improvement project was of interest to them. Participants endorsed the following general themes that emerged related to the participants’ experience of being a member: (a) shift from personal focus, (b) enthusiasm for project, (c) closing the loop and healing, (d) personally rewarding, (e) learning through the engagement process, and (f) encouraged PFEC might have an impact.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Staff participants discussed how rewarding it was to have time to reflect on their own professional practice and had already made some changes to their practice based on what they had heard. Patient and family participants discussed that “in some way it was therapeutic to hear other people’s stories”. One family member shared that “it helped me have some closure to losing my [name of spouse] and realizing that there are other people who have gone through this as well”.

Participants felt very comfortable from the first meeting, and noted that the dynamic of the group contributed to members feeling comfortable sharing intimate stories about their cancer experience. One patient participant shared that “cancer changes you or is life changing. It’s difficult not to be compassionate after going through this. People wanted to give versus take; that felt satisfying to me”.

Unintended Outcomes

Across all three phases of the study, as well as during the focus group, participants only identified one unintended outcome. In Phase II of the study, participants felt challenged at times discovering the possible services that could have been available to them or their family member during their illness. Participants had moments of frustration comparing their experience to how services could have been delivered or accessed more effectively. Many participants were able to relate to this feeling, but shared that it motivated them further to be involved on the PFEC to improve services and access to services for future patients.

Conclusion

The focus group offered the opportunity to confirm preliminary findings as well as provide additional insights about the engagement process. The focus group ended with a group photo and a light snack to allow participants to say their goodbyes and spend time together socially. The overwhelming sentiments shared by the PFEC members were a sense of gratitude that the group dynamic was so strong among all members, celebration of the work we had completed together, and emphasis of the critical areas that are of importance to all members. I found the opportunity to member check with PFEC participants through this focus group to be beneficial to all involved in ways that proved to be beyond methodological quality control. In Chapter 8, I will discuss each of the research questions in light of these research findings and the

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

relevant literature on patient engagement, as well as the implications of these findings for research and practice.

Chapter 8: Discussion

This chapter provides a discussion of the key findings responding to the research questions guiding this study. This is followed by a discussion of the implications of these findings for the conceptual framework presented in Chapter 2 and the contributions to the broader literature on patient engagement. I conclude this chapter by discussing the limitations of this study and further implications for research and practice. I begin by providing a brief overview of the motivation and purpose of the study to set the stage for this discussion.

Motivation for the Study

As presented earlier, there is little research on best approaches to use when patients and family members collaborate with health professionals on a program improvement initiative such as a program evaluation. The literature is inconclusive on what the experience is like for patients, family members, and health professionals involved in this type of collaborative process or the impacts on the program (Baker & Denis, 2011; Canadian Health Services Research Foundation, 2011; Crawford et al., 2002; van de Bovenkamp, Trappenburg, & Grit, 2009). For example, studies that did report on the patient engagement experience were generally descriptive in nature and limited to reflections on the strengths and limitations of the engagement process without examining the effectiveness of their patient engagement approaches or what the experience was like for patients, family members, and staff. Furthermore, most of the patient engagement initiatives reported in the literature have been consultative in nature rather than representing genuine interactive engagement sustained over time (Bombard & Baker, 2011; Fudge et al., 2007; Gagliardi et al., 2008b). This study responded to those methodological gaps and used a qualitative research approach that allowed for continuous examination of the patient engagement process and experience of participants over a six-month period. Thirty individual interviews were conducted at three points in time during the evaluation project with all members of the PFEC, and the nature, contextual factors, and consequences of the patient engagement process were examined in depth.

Overview of the Study

This study aimed to answer the following research questions:

1. What are the facilitators and barriers of engaging patients in the planning and evaluation of health services? Did these change as the process unfolded?

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

2. What did the process of engagement look like with respect to Cousins and Whitmore's (1998) three dimensions of collaborative inquiry? Specifically, (a) to what extent were patients and other program community members in control of decision-making?; (b) what was the range of stakeholder involvement in the inquiry in terms of different roles and interests?; and (c) to what extent did program community members engage with the full range of planning and evaluation tasks and challenges? Did these change as the process unfolded?
3. What are the observed effects of the engagement process? Specifically, (a) what were the intended benefits of engaging patients in the planning and evaluation process?; (b) what are the unintended effects, if any, of engaging patients in the planning and evaluation process?; and (c) to what extent did these observed outcomes depend on process dynamics?

To answer these questions, I used a longitudinal single case intervention study design and data collection approach, which consisted of four phases. Phases I to III sought to explore changes that occurred over time associated with context, process, and consequences of patient engagement. In these phases, data were collected at baseline, mid-project, and at the end of the project; the primary sources of data were program documents, participant observation, interviews, and a research journal. An independent interviewer conducted the interviews to reduce observer bias, and interview data were withheld from me until the completion of the evaluation project. Preliminary data analysis of the first three phases was then conducted and I completed a case study profile report. In Phase IV, I shared the case study profile report with all members of the PFEC, and a focus group was conducted with all members of the committee for validation of the preliminary findings, as well as to collect new information that represented the entire group's perspective regarding the patient engagement process. These findings were reported in Chapters 4 through 7.

The methodological choices made for this qualitative research served to respond to some of the methodological gaps in the patient engagement literature; they also spoke to appreciation for pragmatism as a paradigm for social research with its focus on understanding human experience and its reliance on a process-based approach to gaining knowledge, in which inquiry is the defining process (Morgan, 2014). Examining the sustained interactivity of the patient engagement process during the course of the evaluation, using a combination of data collection

methods, most notably 30 independent interviews, further enriches our understanding of the effects of patient engagement, not only for patients but also family members and health professionals involved in the process. This research approach was process-based, and allowed for the examination of an engagement process that was highly contextual, emotional, and social. Using this form of inquiry, I was able to explore a continuous engagement process of an evaluation that involved many cycles between beliefs and actions/decisions, as a means to gaining an understanding of the process itself and the consequences of patient engagement on participants and the program (Morgan, 2014). I now turn to providing a summary of the findings of this qualitative research study.

Summary of Findings by Research Questions

In this section, I address each of the research questions based on the findings reported in Chapters 4–7. Considering the detailed reporting of findings presented in Chapters 4, 5, and 6, and the summary of findings reported from the focus group, to reduce redundancy I focus here on providing an overview of the findings according to each of the research questions.

Question 1: Facilitators and Barriers of Patient Engagement

In this section, I provide a brief summary of findings responding to the first research question examining the contextual factors (i.e., facilitators and barriers) that impacted the patient engagement process. Of equal interest, although not identified specifically as a research question, were the reasons why participants joined the PFEC.

Motivations for patient engagement involvement. During the Phase I interviews, I was interested in examining the reasons why participants joined the PFEC. Patients/family members and staff participants identified five main motivations for wanting to join the PFEC, which can be summarized as follows: (a) way of giving back, (b) improving health services, (c) commitment to research and evaluation, (d) offering a unique perspective, and (e) learning and revisiting assumptions.

The most endorsed theme by all participants related to reasons for joining the PFEC was as a *way of giving back*. Patient/family members described being appreciative of the services received at PSOP and joining the PFEC was a way of giving back to the program. Staff participants shared that patient/family members appeared to have a sense of satisfaction of giving

back to the program and suggested that their involvement could contribute to continuing the healing process. The second-most endorsed theme was their *desire to improve health services for future patients*. Most patient/family participants received very good services at the PSOP, but the process of navigating the system or being referred to the PSOP was difficult, and therefore patients wanted to be involved in an evaluation project to improve that process. Staff members shared that the program had recently celebrated its fifth anniversary and felt it was the opportune time to re-examine the program and work with patient/family members to further improve its services. Third, staff participants shared that being involved with the PFEC assisted them with their commitments to research and evaluation. Some staff have research and evaluation responsibilities for the PSOP and this project was a good opportunity to begin collaborating with their patient/family members. The fourth-most endorsed theme was the importance of patients/family members *offering a unique perspective* to the program about their health care experience. Both patient/family members and staff believed there was great value in hearing directly from those receiving health services about their lived experience. The final theme, *interest in learning and revisiting assumptions*, was highlighted by the majority of staff who were interested in challenging their own assumptions and recognizing the importance of being open to learning from patient/family members.

Facilitators and barriers to patient engagement. Participants identified facilitators and barriers that impacted the engagement process during all three phases of the study. Participants identified six factors that facilitated the engagement process, three of which emerged during all three phases of the study: (a) accommodating participant needs, (b) commitment to project, and (c) having a designated lead with evaluation skills. Each of these facilitators varied in terms of intensity of participant endorsement depending on the phase of the study. The three remaining themes (i.e., orientation meeting, homework, and mutual respect) were present exclusively in one of the three phases of the study. Table 32 lists all six themes identified during the study and their relative endorsement level by participants.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Table 32

Facilitators and Level of Endorsement Across all Three Phases

Themes	Phase I	Phase II	Phase III
Accommodating participant needs	1	3	4
Commitment to project	2	2	3
Orientation meeting	3	x	x
Designated lead with evaluation skills	4	4	1
Homework	X	1	x
Mutual respect	X	x	2

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

Not surprisingly, the intensity of endorsement of certain themes generally reflects where the PFEC was at during the evaluation process. For example, some themes such as accommodating participant needs received the highest level of endorsement during Phase I and remained present during subsequent phases, but with decreasing importance over time. In the early phases of the project, significant effort was placed on identifying how to best *accommodate participant needs*, but by Phase III these efforts and accommodations became normalized within the process. Another example is the decision to do evaluation work between meetings, *homework*, to increase the productivity of the committee. This change in our working process occurred after meeting II and was highlighted in Phase II interviews, but by Phase III doing homework became status quo and was not identified; however, it was highlighted as an important facilitator during our focus group. Interestingly, having a *designated lead with evaluation skills* was identified as a facilitator to the engagement process during all phases, but received the highest endorsement by the end of the evaluation project. This might be explained by the fact that many participants were unclear about the role of an evaluator early on in the project, but as the evaluation project progressed participants recognized the value of having a lead with evaluation skills. *Commitment to the project* was identified as an important facilitator and its endorsement level was fairly consistent across all three phases. *Mutual respect* was an interesting theme that was only identified in the final stage of the engagement process, but received very high endorsement from all participants during interviews and the focus group. Participants shared that the mutual respect participants had for each other was key to the

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

successful collaboration, and for many participants the level of mutual respect was higher than they had experienced with other volunteer or working committees.

I was also interested in the barriers to the engagement process. Participants identified four themes across all three phases of the study: time & resources, imbalanced participation, change in health status, and living at a distance. Table 33 lists all four barriers and their relative endorsement level by participants during each phase.

Table 33

Barriers and Level of Endorsement Across all Three Phases

Themes	Phase I	Phase II	Phase III
Time & resources	1	1	1
Imbalanced participation	2	2	2
Change in health status	3	x	x
Living at a distance	4	x	3

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

The most endorsed barrier by participants to the patient engagement process across all three phases of the study was *time & resources*. Participants all shared that the PFEC would have benefitted from additional meetings to allow for greater discussion during the evaluation process. Staff also struggled with balancing the competing demands of clinical, research, and administrative responsibilities and being involved on the PFEC. Insufficient human and financial resources were also identified as important barriers to continuing to do this type of work in the future. The second-most endorsed theme was *imbalanced participation* among members due to challenges at times in redirecting the conversation when a patient/family member was sharing a difficult and personal experience. Participants recognized the delicate balance of ensuring everyone had the opportunity to share their story while also keeping the meeting process moving forward. Another theme identified during the early phases of the project was the potential challenge for patients still undergoing treatment to attend all meetings if there is a *change in their health status*. This theme did not reoccur after Phase I, but some participants did mention that they appreciated not feeling any “pressure or guilt” if they were unable to attend a meeting due to illness or low energy. Finally, *living at a distance* was identified as a barrier to

participation in Phases I and III for any participant living outside the city, especially during the winter months.

Question 2: Process According to Dimensions of Collaborative Inquiry

The second research question focused on the engagement process according to Cousins and Whitmore's dimensions of collaborative inquiry: "what did the process of engagement look like with respect to Cousins and Whitmore's (1998) three dimensions of collaborative inquiry? Specifically, (a) to what extent were patients and other program community members in control of decision-making?; (b) what was the range of stakeholder involvement in the inquiry in terms of different roles and interests?; and (c) to what extent did program community members engage with the full range of planning and evaluation tasks and challenges?". Additionally, although not a specific research question, I was interested in learning from the participants how the engagement process could be improved.

Control over evaluation process. I was interested in examining how decisions were being made during the evaluation process and how participants felt about their ability to contribute to the process during and between meetings. Participants identified seven major themes related to control over the evaluation process: (a) mixed clarity about project goals, (b) democratic/consensus decision-making, (c) respectful and collaborative, (d) clarity of project goals, (e) evaluator leading evaluation process, (f) delegation to staff and evaluator, and (g) need for voting procedures. Table 37 presents all seven themes identified in each of the study phases. Only two themes (i.e., democratic/majority rule decision-making and respectful and collaborative) were consistently identified in all three phases with relatively high endorsement in all three phases.

Table 34

Control over Evaluation Process and Level of Endorsement across Three Phases

Themes	Phase I	Phase II	Phase III
Mixed clarity about project goals	1	x	x
Democratic/majority rule decision-making	2	1	1
Respectful and collaborative	3	2	2
Clarity of project goals	X	3	x
Evaluator leading evaluation process	X	4	3
Delegation to staff and evaluator	X	5	x
Need for voting procedures	X	x	4

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

Mixed clarity of project goals was identified as the most endorsed theme in Phase I, but was not identified during Phase II or III interviews. This is most likely because the orientation meeting could only provide an overview of the overall project goals, but as the project evolved to Phase II the theme “clarity of project goals” emerged. *Democratic/majority rule decision-making* was the most endorsed theme by all participants during the last two phases. Overall, participants’ felt that decisions were made by the overall group and efforts were taken for them to be made democratically. Participants identified the engagement process as *respectful and collaborative* across all three phases of the study, but this was most pronounced in the two last phases. By Phases II and III, participants shared that the *evaluator was leading the evaluation process* by facilitating the discussions, summarizing findings, developing reflective questions for discussion, etc. However, participants noted that they did not feel the evaluator was controlling the decision-making, but took a lead role in the collaborative process. *Delegation of decisions to staff and evaluator* was a theme that emerged in Phase II when patient and family members encouraged staff and the evaluator to review the priority issues identified by all PFEC members and prioritize them based on their clinical expertise. Subsequent to that process, all decisions were made collectively, which explains why this theme was absent in Phase III. Finally, at the end of Phase III, some participants identified that there could be some value in having *official voting procedures*. Although members acknowledged that decisions were made democratically/ by majority rule, some participants felt it was important to have a tighter voting process for critical decisions that might be contentious.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Diversity of PFEC. Diversity of PFEC. Participants strongly supported the importance of having as diverse representation as possible on projects related to evaluation of health services. Table 35 presents who participants felt were missing and the level of endorsement for each theme across all phases.

Table 35

Diversity of PFEC Members and Level of Endorsement across Three Phases

Themes	Phase I	Phase II	Phase III
Who is missing			
Vulnerable populations	1	1	1
Patients with head and neck cancer	2	2	2
Need for more heterogeneous group	3	3	3
Family members of patients in active treatment	4	4	4

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

Participants shared that the PFEC had appropriate gender and age representation, as well as good diversity of patient participants with different cancer types. Participants felt strongly that in future projects greater efforts should be made to include *vulnerable populations, patients with head and neck cancer, a more heterogeneous group in terms of education and socioeconomic status, and family members of patients in active treatment.*

Depth of participation. Participants were asked to share their thoughts about the depth of participation and contributions being made by the different member groups on the PFEC. As discussed earlier, participants strongly supported diversity on projects related to the evaluation of health services. Table 36 presents the major themes and level of endorsement for each theme across all phases.

Participants shared that the evaluator was deeply involved in *facilitating and organizing the evaluation process* and contributed *evaluation skills* throughout the process. Interestingly, participants' views about the evaluator's contributions changed slightly across the three different stages of evaluation. For example, in the early phases of the evaluation process, participants emphasized the facilitator/organizational contributions of the evaluator, but as the evaluation evolved participants valued specific evaluation skill sets the evaluator was contributing to the project. Participants equally valued the level of involvement and contributions of the staff to the evaluation project.

Table 36

Depth of Participation and Level of Endorsement across Three Phases

Themes	Phase I	Phase II	Phase III
Contributions of evaluator			
Facilitating/organizing process	1	1	x
Evaluation skill set	x	2	1
Contributions of staff			
Context and reality check	2	1	1
Ability to affect change	x	2	2
Contributions of patient and family			
Contextual knowledge from lived experience	3	2	1
Challenge status quo	x	1	x

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

Specifically, participants felt across all three phases of the project that one of the strongest contributions staff made was providing *program and organizational context* and, in the final two phases of the study, participants also felt that staff had the *ability to affect change*. Finally, in all phases of the study, participants shared that patient/family members contributed to the project by providing *contextual knowledge about their lived experience*, and in Phase II identified the importance of patient/family members being able to *challenge the status quo* by probing questions about the program/system.

Improving the engagement process. During all three phases of the study, participants were asked to identify recommendations for improving the engagement process. For example, I was interested in exploring ideas for improving collaboration among members, maximizing productivity of the group, taking the best approach for decision-making, accommodating members, etc. The following three themes were identified by participants: (a) additional time for evaluation project, (b) reinforce meeting etiquette at each meeting, and (c) clear project goals at beginning of process. Table 34 displays the level of endorsement for each theme during each phase of the study.

Table 37

Recommendations to Improve Process and level of endorsement across Three Phases

Themes	Phase I	Phase II	Phase III
Additional time for evaluation project	1	1	1
Reinforce meeting etiquette at each meeting	X	2	2
Clear project goals at beginning of process	2	x	3

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

The most highly endorsed theme across all three phases of the study was having *additional time for the evaluation project*. As a result of the limited number of meetings, some participants felt a sense of urgency to ensure the committee met its objectives. Participants recognized that having patient/family members collaborating with staff required more time, especially in the early phase of the project. For example, patient/family members shared their personal experiences with the health care system with staff and staff shared the organizational context with patient/family members, both of which were critical to gaining a mutual understanding of the issues, but this did require more time. The second-most endorsed theme was *reinforcing meeting etiquette* to encourage participants to stay on topic and allow others the opportunity to voice their opinions. The third recommendation by participants was to have *clear project goals at the beginning of the evaluation process*. Staff and I had scoped broad project goals before the beginning of the first meeting, but defining the specific program issues to be addressed in the evaluation project was done collaboratively with patients and family members. Some patients and family members shared that the specific project goals could have been predetermined by staff, but staff felt strongly that patient/family input on program issues to be addressed should be collaboratively determined.

Question 3: Observed Effects of the Engagement Process

The third research question focused on the observed effects of the engagement process: “What are the observed effects of the engagement process? Specifically, (a) what were the intended benefits of engaging patients in the planning and evaluation process?; (b) What are the unintended effects, if any, of engaging patients in the planning and evaluation process?; and (c) To what extent did these observed outcomes depend on process dynamics?”. I begin by

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

summarizing the intended benefits of the engagement process and participants' experiences of being involved on the PFEC.

Intended benefits of the engagement process. Participants discussed their motivations for joining the PFEC, many of which were related to the intended benefits they hoped would be achieved by participating. Participants identified four themes consistently across all three phases of the study and a new one emerged in the final phase (Table 38).

Reaching decision-makers and improving PSOP services remained the two most highly endorsed themes across the three phases of study. Having increased diffusion of patient/family engagement in program improvement initiatives and improving access and awareness of PSOP fluctuated between the third- and fourth-most endorsed themes across all phases. *Reaching decision-makers* and *improving PSOP services* remained the two most highly endorsed themes across the three phases of study. Having *increased diffusion of patient/family engagement* in program improvement initiatives and *improving access and awareness of PSOP* fluctuated between the third- and fourth-most endorsed themes across all phases.

Table 38

Intended Benefits and Level of Endorsement Across all Three Phases

Themes	Phase I	Phase II	Phase III
Reaching decision-makers	1	1	1
Improving PSOP services	2	2	2
Increased diffusion of patient/family engagement	3	4	5
Improving awareness/access of PSOP	4	3	4
Follow-up to assess influence of engagement project	X	x	3

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

A final theme emerged at the end of the project and reflected participants' desire to know what *impact or influence the PFEC work would have* on the PSOP and the Cancer Program. Ideally, participants would have appreciated *a follow-up meeting* at six months or one year to evaluate the progress made with respect to implementing some of the recommendations developed in the evaluation report.

Participant experience. All members of the PFEC shared that their participation was rewarding and they would participate again in the future if the program improvement project was

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

of interest to them. Table 39 identifies all six themes that emerged at different phases of the study as well as the level of endorsement for each theme.

Table 39

Participant Experience and Level of Endorsement Across all Three Phases

Themes	Phase I	Phase II	Phase III
Shift from personal focus	1	x	x
Enthusiasm for project	2	x	4
Closing the loop and healing	3	x	x
Personally rewarding	4	1	1
Learning through engagement process	X	2	2
Optimism engagement project will have influence	X	3	3

Legend: 1 having highest level of endorsement and 4 having the least and x indicating theme was not present

The first four themes (i.e., *shift from personal focus*, *enthusiasm for the project*, *closing the loop and personally rewarding*) were all identified in Phase I, with *shift from personal focus* being the most highly endorsed theme. Participants expressed surprise by the impression left on them after hearing other patient and family members' health care experiences; they described feeling a shift from personal focus from their own experience to realizing other people had very different and often more difficult experiences. The remaining two themes (i.e., *learning through the engagement process* and *optimism engagement project will have an influence*) emerged in Phases II and III. All participants learned through the engagement process. Staff learned from hearing patient/family member experiences, which challenged some of their assumptions, and patient/family members learned about the health care system, which changed their perception of contexts surrounding health care and the challenges many patients/family face within health care. Members described being involved on the PFEC as being *personally rewarding* and felt optimistic that the work of the PFEC might have an impact on the PSOP, but also across the organization.

Unintended outcomes. Unintended outcomes (i.e., negative experiences) were explored during all phases of the patient engagement project, but only one was identified across all three phases. Two participants shared that, by learning more about the PSOP, they discovered they may have been eligible for services they did not receive or could have received sooner. Discovering that their experience could have been smoother was frustrating at times for them,

but strengthened their resolve to improve the referral process for other patients. In the next section, I share the relevant findings that make contributions to the patient engagement literature.

Observed outcomes and process dynamics. Participants shared across all three phases that they felt that their contributions were valued and that there was a strong sense of mutual trust and respect amongst committee members that contributed to the positive experience of being involved on the PFEC. Participants emphasized the importance of having shared goals and motivations as a contributing factor to the positive outcomes of the engagement process. Having an evaluator facilitate the process and accommodating participant needs were identified as key facilitators to the engagement process. Overall, participants shared that the process dynamics of the PFEC improved with each phase of the study and positively impacted the experience of being involved on the PFEC as well as the productivity of the committee.

Relevant Findings Contributing to the Literature

Key areas discussed in the literature review in Chapter 2 related to patient engagement in the planning and evaluation of health services can be informed by the findings of this study. Overall, this study makes important contributions to the body of knowledge on patient engagement. This qualitative case study of a Canadian patient engagement project in an acute care hospital examined the contextual factors, process, and consequences of using a P-PE approach. The results of this study are summarized in the revised version of the conceptual framework (Figure 5), initially presented in Chapter 2 (Figure 4), that was used to assist in bounding the inquiry and explicating the key constructs under study. As illustrated in this visual representation, the results of this study highlight the influence of contextual factors on all aspects of the engagement process — the facilitators, barriers, motivations for patient engagement (PE) involvement, the process, and the consequences.

The arrows from contextual factors (i.e., facilitators, barriers, and motivations for PE involvement) to patient engagement intervention (i.e., process) and continuing on to consequences demonstrate the pervasive effect that the contextual factors have on all three dimensions. The bi-directional arrows between facilitators/motivations for PE involvement and diversity of membership represent the influence each of these dimensions has on the other; that is, the findings of this study highlight that the facilitators and motivations for PE involvement have a strong influence on the diversity of members/stakeholders, but that the stakeholders

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

involved in this project also have a strong influence on the contextual factors that facilitated the process.

In this next section, I highlight the relevant themes (shown in italics) in the framework that make important contributions to the patient engagement literature and the field. This discussion is organized according to the three distinct panels included in the conceptual framework, which include contextual factors, the intervention/process, and consequences. I begin by highlighting the influence of context and its effects on the patient engagement process and consequences.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

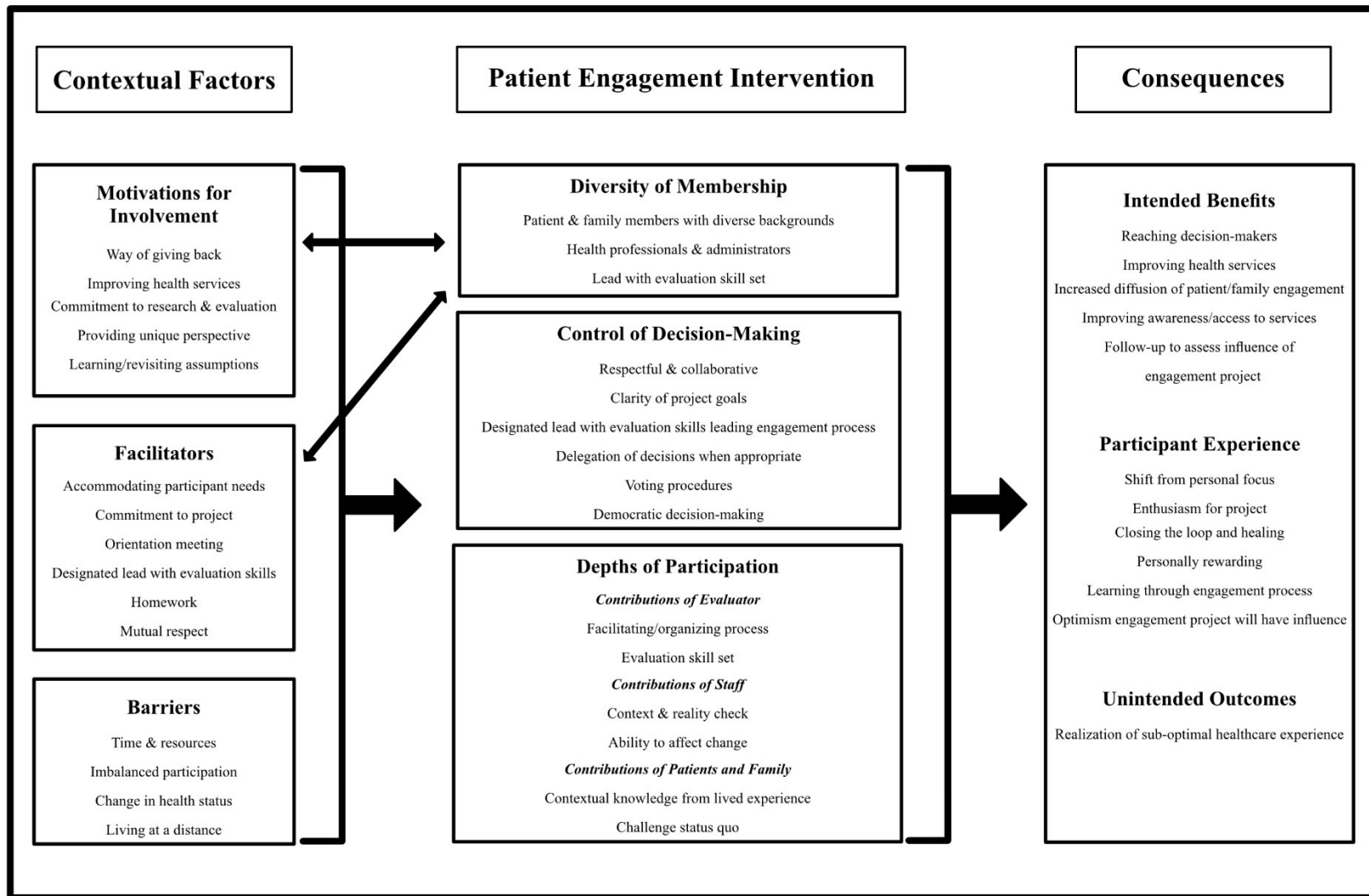


Figure 5. Revised conceptual framework

Contextual Factors

Six contextual variables were identified across all three phases of the study that facilitated successful implementation of a patient engagement project; having a *designated lead with evaluation skills* emerged as the most endorsed facilitator in the final stage of the project. Some authors indicate that having a dedicated champion and/or committed leadership and building staff capacity to work with patients are important facilitators (e.g., Baker, Fancott, et al., 2016; Luxford et al., 2011). The results of this study build on Luxford et al.'s (2011) findings that key facilitators to improving PCC are building the capacity of staff in the areas of communication, learning about the values of PCC, and customer service/leadership skills; that is, participants in this study specifically identified evaluation skills as critical to the process in terms of a) leading and facilitating the engagement process, b) ensuring project goals were developed to reflect the needs of the program and PFEC members, c) remaining neutral and allowing a diversity of opinions to be heard, d) asking key questions to stimulate discussion, e) having strong understanding of participatory approaches to planning and evaluation, and f) consolidating and disseminating information for discussion. Although participants described the engagement process as collaborative and that most decisions were made democratically, they felt the evaluator made a substantial number of technical evaluation decisions during the project, such as what meeting process/approach to use, developing a process for members to complete work between meetings, summarizing recommendations based on analysis of written feedback and discussions of members, etc. Overall, participants viewed the evaluator role as important to the engagement project and emphasized it was key for moving the engagement process forward.

Baker, Judd, et al. (2016), Crawford et al. (2002), and Luxford et al. (2011) report that staff attitudes towards collaborating with patients became more favourable compared to baseline through doing work together, and that the organizational culture became more open to working with patients as a result. The findings of this study further support those claims in that *mutual respect* became the most endorsed facilitator to patient engagement, despite only being superficially discussed in the first two phases of the study. When participants of this study were probed regarding why mutual respect among members was so high, participants could not answer that question conclusively, but speculated on a few factors that may have contributed to this outcome. For example, staff participants involved in the study are clinicians in the area of psychosocial oncology, which requires health professionals to have strong communication skills

(i.e., active listening) and to work within a multidisciplinary team; this is in contrast to many acute care models. Staff participants suggested that the recruitment process of patient and family members was rigorous and most likely contributed to having patient/family members that were committed to doing this type of work. Other participants shared that the *orientation meeting* was critical for setting the tone for the collaborative atmosphere. Specifically, participants identified the importance of being given the time to share their story with other committee members as a critical factor for members to have a better understanding of their motivations for joining the PFEC and what their health care experience had been like. Participants shared that hearing about other members' experiences shifted their focus from an individual perspective to a broader perspective, and made them more aware of issues that were not necessarily relevant to their experience but equally important. Finally, participants also discussed the approach used by the evaluator to facilitate the collaborative engagement process may have contributed to mutual respect among members. Participants appreciated efforts made to accommodate their needs (e.g., having food/beverages, teleconference, etc.) and felt their voices and opinions were valued. Ultimately, no single factor was identified but, as Shulha et al. (2016) propose as one of the principles for guiding CAE, efforts put forth to foster meaningful relationships (e.g., building respect, trust, transparency) all contribute to the successful implementation of a collaborative engagement processes.

Monitoring and responding to resource availability (i.e., time, budget, and personnel) is one of the principles I identified for guiding CAE (Shulha et al., 2016), and this study adds further empirical evidence to its importance, in that the lack of *time and resources* emerged as the most significant barrier to successful patient engagement. While previous research has identified the importance of organizational support, such as having a dedicated budget, staff training, and committed leadership (Abeslson et al., 2015; Baker, Judd, et al., 2016; Gagliardi et al., 2008a; Luxford et al., 2011), this study's findings extend the current literature on the successful implementation of patient engagement; that is, participants shared more specifically the types of support needed to successfully engage patients in a quality improvement project. Specific organizational support identified in the data as critical to successful engagement include: (a) protected time from clinical/research/administrative responsibilities for all staff who participate or lead patient engagement activities; (b) sufficient budgetary allowance to support administrative costs of the engagement project (e.g., food/beverages for participants,

parking/travel reimbursement, etc.); (c) meeting space with teleconference capabilities for out-of-town patient/family members; and (d) sufficient project time to allow patients/family members and staff to collaborate on realistic and sustainable program improvements. As Shulha et al. (2016) note, when participants are committed to meaningful engagement and there are process and capacity-building goals, CAE such as patient engagement may take more time to be implemented compared to conventional approaches.

Another contextual variable identified as a barrier in this study was the *imbalanced participation* at certain points in the meetings. Many authors reported on the importance of shared decision-making when collaborating with patients and family members on a quality improvement project, as well as ensuring views from all stakeholders are heard and respected (e.g., Baker, Fancott, et al., 2016; Baker, Judd, et al., 2016; Gagliardi et al., 2008a). What the data show in this study is that participants found it challenging at times, especially in the early phase of the project, when some members dominated the conversation and affected the ability of others to participate equally. Some participants described these challenges as the “growing pains” of any collaborative work; that is, it takes time for teams or working groups to establish efficient ways of working together, especially when members are new to one another. Participants shared that, in the earlier phases of the project, some staff members were more vocal justifying program decisions made and that some patients/family members required more meeting time to share personal health care experiences; but, as the group became more familiar with each other, imbalanced participation became less of an issue. The data from this study show that participants accepted the “messiness” of the early stages of the collaborative process and argued that it takes time to establish efficient and effective ways of working as a group. Overall, participants noted the importance of flexibility within a meeting to create a safe space for all voices to be heard, as well as the understanding that conventional meeting procedures might need to be adjusted for successful collaboration between patients, family members, and staff.

The findings of this study also offer important insights into the motivations driving patients, family members, and health professionals to undertake this type of collaborative quality improvement work. Shulha et al. (2016) emphasize clarifying the motivation for collaboration (e.g., purpose, information needs, expectations) and what this means in practice. An important consideration in the early phases of a patient engagement project (e.g., recruitment of participants, making expectations around collaboration explicit) is “learning about the extent to

which stakeholders will welcome engagement and be prepared to work at fostering the approach” (Shulha, 2016, p. 200).

Findings from this study revealed that patients and family members were motivated to do this type of work a) as a way of giving back, b) to improve health services, and c) to offer a unique perspective. Staff were motivated to a) learn and revisit assumptions, b) be involved in commitment to research and evaluation, c) improve health services, and d) learn from the unique perspectives of patients and family members. These findings suggest that patient/family participants were highly motivated to participate on the PFEC as a way of ‘paying it forward’ for good care received and/or as a way of improving health services for future patients by sharing their experience with decision-makers. Staff participants were motivated to challenge their own assumptions and learn from patients and family members through the evaluation process as a means to improve PSOP services. The reported motivations for doing this type of work differ from those reported by Fudge et al. (2007), which focus mainly on meeting personal health care needs (e.g., meeting others in similar situations, accessing health/social care services, having a say about the services they use); in contrast, my study findings centre on giving back to the system, learning, and improving health services for others. The findings of this study support the claims made by Armstrong et al. (2013) and Baker, Fancott, et al. (2016) that engagement activities need to have clear goals and be value-based, specifically engaging patients and families on issues that are important to them individually and to the organization. Based on the findings of this study, I argue that the same claims should be extended to include health professionals involved in patient engagement activities. Engaging patients, family members, and health professionals early on about the motivations for working collaboratively does not guarantee successful collaboration, but the process of discussing how the collaboration will unfold can help all stakeholders articulate the assumptions and needs that the patient engagement project is intended to address (Shulha et al., 2016).

Patient Engagement Intervention/Process

An ongoing weakness noted in the patient engagement literature is the lack of guidance or approach for successful implementation of patient engagement into practice, as well as the gap between the intended level of interactive and ongoing involvement of patients and their actual involvement, i.e., consultative versus collaborative (Baker & Bombard, 2011; Fudge et al., 2007; Tedford-Gold et al., 2005). Participatory evaluation approaches to patient engagement have been

suggested for successful implementation of patient engagement, but there is little evidence that such approaches have been successfully used or evaluated (Armstrong et al., 2013; Baker, Judd, et al., 2016; Bate & Robert, 2007; Bombard & Baker, 2011). The findings of this study contribute to the research on best approaches or process for the implementation of patient engagement by adopting a practical-participatory evaluation (P-PE) approach and examining the effects of this approach on participant experience and project outcomes. The use of a P-PE approach was motivated by the core premise that stakeholder participation “will enhance evaluation relevance, ownership, and thus utilization” (Cousins & Whitmore, 1998, p. 6).

The participatory approach used for this study was examined using Cousins and Whitmore’s (1998) three fundamental dimensions of process in collaborative approaches to evaluation: (a) *stakeholder diversity* (e.g., program decision-makers, patients/family staff), (b) *control of evaluation process* (e.g., who controls the decision-making related to the technical aspects of the evaluation/engagement process), and (c) *depth of participation* (e.g., intensity of involvement of members in the evaluation/engagement process). These three independent dimensions (Figure 3) helped shape the collaborative patient engagement process and offered a practical aid or decision points in determining and evaluating the integrity of the patient engagement design and process (Cousins & Whitmore, 1998). This study also provides empirical evidence to support and enhance Abelson et al.’s (2015) *tool for the evaluation of the public and patient engagement* by applying the three dimensions of process in CAE (Cousins and Whitmore, 1998). For example, some of the prioritized outcomes for successful engagement proposed by Abelson et al. (2015) include having participants representing a diverse range of views, access to supports to enable genuine participation, and an engagement process that informs planning/decision-making, all of which contribute to learning.

Overall, participants were generally satisfied with the *diversity of stakeholders*, with the exception of a few groups that were not represented despite recruitment efforts (e.g., vulnerable populations, patients with head and neck cancers). The findings of this study related to the diversity of the PFEC group (e.g., who was missing) revealed some interesting ideas around who should be involved in patient engagement activities and suggested tactics for recruiting certain groups that might be more challenging to access (e.g., homeless population, single mothers, etc.). However, the most interesting findings that emerged related to the diversity of stakeholders were participants’ thoughts about the positive dynamics of the PFEC. Participants shared in all three

phases of the study and particularly at the focus group that the group dynamics were “unusually strong” and “not what we are used to”, especially considering the diversity of the group and the short amount of time participants worked together. As displayed in the conceptual framework (Figure 5) with bidirectional arrows between *motivations for PE involvement/facilitators* and *diversity of membership*, this theme arose during the interviews and focus group. Participants debated whether it was the process or the people involved that contributed to fostering such a positive group dynamic and process; one participant questioned the following:

I wonder if you would consistently get this, if, say, you repeated the exercise with a different set of people. Would you consistently get that result or is it an accident how the dynamics of the group panned out because of the individuals? And perhaps because of the way the first meeting just went when we all introduced ourselves? (Patient/Family)

What the data do show is that the reasons why the PFEC members developed strong group dynamics, mutual respect, and trust were multifaceted. Participants shared that the orientation meeting was the “foundation for the whole process . . . and why we got this feeling of being warm and kind of respectful” (Patient/Family participant). Others believed it was related to methods used for the proper selection of good, motivated, and compassionate people, as well as the collaborative patient engagement approach used during that evaluation process that contributed to fostering these interpersonal relationships. The role of leadership, shared decision-making, building staff capacity to work with patients/family, clear roles/responsibilities, genuine engagement vs. consultation, and building trust have been identified as strong facilitators to successful patient engagement (Abelson et al., 2004; Baker, Judd et al., 2016; Fudge et al., 2007; Luxford et al., 2011). The findings of this study support Shulha et al.’s (2016) claim that a successful CAE, such as patient engagement, relies on the quality of the relationships that patients, family members, health professionals, and the evaluator are able to develop and sustain. This requires purposeful and transparent efforts on behalf of all stakeholders to develop trust among members and to foster meaningful working relationships.

Questions surrounding *control of decision-making* in patient engagement can be difficult to manage. Issues concerning control of decision-making are often associated with less-than-successful patient engagement activities (e.g., Fudge et al., 2007; Gagliardi et al., 2008a; Luxford et al., 2011). Some of these challenges arise due to differing opinions on the meaning and purposes of patient engagement. Patient engagement can involve a broad range of quality

improvement activities and differing levels of involvement; it can also vary with respect to the degree of contribution by patients and family members (Baker, Judd et al., 2016). Carman et al. (2013) identify three levels of engagement—direct care, organizational design and governance, and policy-making—and describe a continuum of engagement for each of these levels. For example, patient engagement activities tend to be consultative in nature at the continuum's lower end but characterized by shared power and responsibility at the higher end. In this patient engagement study, participants described the decision-making process as democratic and were generally comfortable with the decision-making process, but felt that more formal voting procedures should be implemented for contentious decisions. The evaluator also had a key role in leading the engagement process with regards to the technical aspects of the engagement process. Furthermore, participants shared that certain decisions were delegated to staff and the evaluator for pragmatic reasons; that is, some decisions related to the prioritization of key issues identified by the entire group were streamlined by the staff and evaluator because patients and family members felt strongly that they were best equipped with the organizational and program contextual knowledge to make decisions that would be most beneficial to the program.

The patient engagement literature strongly advocates that health organizations build staff capacity to work with patients and help them recognize the value of collaborating with patients and family members (Baker, Judd et al., 2016; Fudge et al., 2007). Other key facilitators to successful engagement are preparing patients and family members involved in health service improvement activities to their roles and responsibilities (Armstrong et al., 2013; Baker, Judd et al., 2016) and ensuring they are engaged in issues that are of value to them (Armstrong et al., 2013). Baker, Fancott et al. (2016) describe how patients and family members are experts by experience based on their health care experiences as users. The findings of this study strengthen the scholarly research in this area by identifying key contributions related to specific stakeholder roles involved in patient engagement activities. For example, as outlined in Figure 5 in the *depth of participation dimension*, the contributions of the evaluator, patient and family members, and staff are outlined. Participants identified that the key contributions of the *evaluator* were organizing/facilitating the process and having evaluation skill sets and for *staff* were providing program and organizational context and reality checks as well as the ability to affect change. Participants viewed that *patient and family members* contributed most by providing contextual knowledge of lived experience and challenging the status quo. These study findings offer further

support to Armstrong et al. (2013), who contend that patients can challenge the status quo or, in their words, be a “technology of persuasion”, challenging assumptions that everything is fine and resolving contestation about whether a proposed change is appropriate.

Consequences

What are the observed effects of patients, family members, and staff collaborating on a health service improvement project and to what extent did these observed outcomes depend on process dynamics? Despite longstanding calls to learn from practical experience through empirical study (e.g., Baker, Judd et al., 2016; Bombard & Baker, 2011; Fudge et al., 2007; Gagliardi et al., 2008b), to my knowledge this exploratory study represents the first longitudinal case study of its kind examining the intended benefits, unintended outcomes, and participant experiences using a participatory approach. The findings of this study reveal that participants involved in this patient engagement quality improvement project expect that the intended benefits of their involvement will include (a) reaching decision-makers; (b) improving health services; (c) increasing diffusion of patient/family engagement activities across the program/organization; (d) improving access and awareness of services; and (e) a follow-up to assess influence of engagement project (e.g., how did their contributions inform planning/decision-making, improve health services, etc.). The results are supportive of Abelson et al.’s (2015) contention that successful public and patient engagement informs planning and decision-making, supports ongoing quality public/patient engagement in strategic planning, policy and service delivery, and demonstrates how participants’ input will be used in decision-making. Due to study timelines approved by the PSOP program, Cancer Program, and research ethics, there was no flexibility to follow-up with the PSOP at a later date (i.e., 6–12 months) to assess the influence of the patient engagement project on practical or transformative outcomes at the program or organizational level. During the focus group, staff participants were able to identify some practical outcomes that were influenced from the work conducted by the PFEC. For example, two clinicians provided concrete examples of how they had made changes to their practice based on what they had learned through the engagement process. PSOP staff also shared with patients and family members that they had changed their program signage to ensure it was more visible within the Cancer Program. The physician on the committee confirmed sharing the PFEC report with the Cancer Program’s Medical Advisory Committee in hopes of influencing decision-makers to support some of the recommendations made by the PFEC. Despite the short

duration of this patient engagement project and the inability to assess long-term practical outcomes, there is some anecdotal evidence of short-term practical outcomes. Furthermore, based on our focus group discussions with staff, I am optimistic that the patient engagement process will continue to influence practical and transformative outcomes across the cancer program.

Studies examining the participant experience of those involved in a patient engagement project have been mixed. For example, some report the engagement process was rewarding and participants appreciated being involved while others report patient dissatisfaction with the process and lack of interest in being involved in health improvement initiatives (e.g., Fudge, 2007 & Gagliardi et al., 2008b). Frosch et al. (2012) and Gagliardi et al. (2008a) report in their studies some reluctance on behalf of some health professionals to support shared decision-making with patients. *Participant experiences* in this patient engagement project were reported to a) be personally rewarding, b) have optimism that the engagement project will have a positive influence on the program and organization, c) have enthusiasm for the project, d) close the loop on healing, e) shift from personal to broader health care focus, and f) contribute to learning through the engagement process. These findings further support Armstrong et al.'s (2015) findings that making patient involvement work well in practice requires a non-hierarchical structure among members, with a strong emphasis on learning from one another.

Limitations of the Study

As with any research study, this study has limitations that should be taken into consideration. These include the study's scope, selected methodology, and interpretations of its findings.

The unique focus on the out-patient PSOP as the case under study for this exploratory research has generated findings that are unique to this program and not necessarily applicable to other health care programs (e.g., in-patient programs, long-term care, etc.). The focus on this specific program allowed for a deeper examination of the contextual factors impacting patient engagement as well as its consequences, and increased the relevance of the conceptual frameworks for other out-patient multidisciplinary health programs, but may not be relevant to other types of health service programs. Furthermore, staff participants by nature of their role within the PSOP have highly developed communication skills and work within a multidisciplinary model, which requires collaboration with other specialties. These skill sets may

have contributed to the positive patient engagement process and PFEC dynamics, and not necessarily be representative of the collaborative nature of the majority of health professionals.

The present study used an exploratory research approach as a result of the limited empirical knowledge related to the contextual factors that influence patient engagement, best approaches for implementing patient engagement, and the possible positive and negative consequences of patient engagement. This research laid the groundwork for future studies and allowed for flexibility to explore the contextual factors, patient engagement process, and consequences of patient engagement within the bounds of the conceptual framework. While this process allows for flexibility in the identification and interpretations of unexpected and unanticipated findings, it is necessarily limited in its ability to do so.

As a result of this study being associated with my doctoral research, the time available to investigate the research problem and to measure change over time was constrained. As a result, this study was unable to examine the long-term impacts or outcomes that the patient engagement project will have on the program and organization. Some anecdotal evidence was provided with respect to short-term practical outcomes related to the work completed by the PFEC, but long-term outcomes could not be examined.

Another limitation of this study concerns the possibility of bias, considering I was involved in the evaluation process but at the same time analyzing the process as the researcher. Several steps were taken to minimize this potential bias:

- An independent interviewer was hired to conduct all participant interviews, and data were withheld from me until the end of the evaluation project.
- A focus group with all research participants was conducted three months following completion of the research project. A case study profile was created and shared with all members. This process offered validation that the preliminary findings resonated with research participants as well as the independent interviewer. It also gave participants the opportunity to clarify the findings and make changes if required.
- Extensive use of direct quotations in this thesis from the interviews to compare and contrast participant data allow the reader to draw their own conclusions.

The role of the researcher must be considered as well. As a graduate student and research assistant, registered nurse, and family member affected by cancer, I brought my own ideas and bias to the study of patient engagement at the Ottawa Hospital PSOP. These same biases would

also influence the analysis and interpretation of the data. I attempted to reduce this bias in many ways. First, I maintained a researcher's reflective journal throughout the study to promote self-reflection and critically think of alternative explanations for my observations, feelings, and perceptions during the research process. Second, as previously discussed, a focus group was conducted to review and validate preliminary research results with all research participants, the independent interviewer, and my supervisor. Third, triangulation was performed to ensure construct validity. Multiple sources of evidence were used in this study, which included three sets of interviews, a focus group, participant observations, program documents, and a reflective journal, all triangulating on the same set of research questions. Triangulation of evidence aims to increase confidence that the evidence is strong and is supported by more than a single source (Stake, 2010; Yin, 2009). Despite efforts to reduce bias, some may remain and findings should be interpreted with that caveat in mind.

Implications for Research

The findings of this study provide several opportunities for further research. While this study provides a first step towards a better understanding of contextual factors (i.e., facilitators, barriers, and motivations for wanting to engage in patient engagement activities), it also highlights the possibilities for continued research to shed further light on some of these findings. Despite emerging evidence that suggests patient engagement leads to improved PCC and organizational improvements (Baker, 2014), we need to explore and gain a better understanding of the processes involved or evaluation approaches that could contribute to translating patient engagement into improved outcomes. The following research objectives and questions are provided to help guide future researchers.

- What are the long term effects of engaging patients/family members in health service improvement initiatives? Improved patient experience or patient centeredness?
- Despite significant effort, the extent to which patients have been engaged in health care quality improvement has mostly been limited to various forms of single time point consultation, rather than a genuine interactive partnership based on principles of CAE. Of interest would be examination of the applicability of the *Principles for Guiding CAE* developed by Shulha et al. (2016) to the development of effective

engagement processes. Such activities have significant potential to leverage evidence-based decision-making in the interest of service improvement.

- More research is required to assess different approaches to patient engagement in the planning and evaluation of health services. Principles of CAE implicate the development of deep understandings of context and the nature of interventions to inform subsequent process decisions, such as (a) who controls the technical evaluation decision-making in patient engagement projects (lead with evaluation skills, health professionals, patients/family); (b) who from the health care community (e.g., health care managers, caregivers), apart from patients, should be involved in patient engagement activities and why; and (c) how intensive (light touch, deep involvement) patient engagement should be in the planning and evaluation of health services.
- The findings of this study demonstrate that participatory approaches can be effective with respect to the implementation of patient engagement activities. What other approaches could lead to effective patient engagement? Would the application of participatory approaches to patient engagement be effective in other health care settings?
- It is important to understand patient engagement consequences in the health care setting context. What are the observed effects of the engagement process? Has improved patient experience or patient-centredness been achieved? What are the practical and transformative outcomes of engaging patients and family members in the planning and evaluation process? To what extent did these observed outcomes depend on process dynamics? Researchers should consider field testing the public and patient engagement evaluation tool developed by Abelson et al. (2015); it is a good first step and would benefit from further refinement based on empirical study.
- I am of the view that alternative methodological approaches are required to assess patient experience and the effects of patient engagement beyond measurement and patient feedback (i.e., patient satisfaction surveys, patient narratives). Performance data often fall short with respect to informing decisions about issues that are of importance to patients, and patient satisfaction surveys are limited in terms of identifying areas that need improvement or learning about the patient experience. I

suggest complementing these strategies with ones that provide deeper understanding of the patient experience and help focus improvement efforts — for example, qualitative approaches — as a means of giving primacy to what is meaningful to patients and focus improvements. In short, we need to move beyond the reflective narrative in describing the patient engagement process and its impacts on PCC.

- The findings of this study enhance our understanding of key contributions that patients, family members, health professionals, and evaluators bring to the patient engagement process. Further research is needed to explore key competencies and/or characteristics required by those who lead patient engagement projects as well as those who are involved.

Implications for Practice and Policy

Despite the present study being exploratory in nature, it accrued significant knowledge about the contextual factors that positively or negatively impact patient engagement activities as well as the influence of process or approach on the consequences of patient engagement on participants and the program/organization. Collaborative approaches to evaluation for improving patient-centered care

The findings of this study contribute to the empirical literature on patient engagement as well as patient-centered care. The results of this study support the use of collaborative approaches to evaluation as an effective method to engage patients and family members to work collaboratively with health professionals on quality improvement initiatives with the goal of improving patient-centered care. If health organizations want to truly be patient-centered, patients and family members must be given opportunities to influence the delivery of services through engagement in planning and evaluation of health services. We have learned from this study that health professionals collaborating with patients and family members gain a better understanding of the patient experience through this type of collaborative work and make practice changes based on this learning. The findings of this study also suggest that health professionals recognized the value of working with patients and family members in challenging traditional assumptions about health service delivery and value the innovative ideas patients and family members brought to the discussion.

These study results also bring to light the consequences of adopting collaborative approaches as a process to patient and family engagement. That is, collaborative approaches to engagement have shown to be well suited for patient and family engagement in quality improvement initiatives, but in order to be effective they do require a certain level of organizational commitment, time, resources, and willingness on the part of health professionals for shared decision making. These facilitators enable the engagement process to be ongoing rather than single, passive efforts and help foster strong working relationships among patients and health professionals.

Genuine Commitment for Genuine Engagement

The findings of this study contribute to the empirical literature on patient engagement. Organizational decision-makers and program managers should pay particular attention to the contextual factors (i.e., facilitators, barriers, and motivations for involvement) identified in this and other studies to positively or negatively influence the patient engagement process. A key theme for successful implementation of patient engagement is the importance of commitment; that is, is the commitment to being involved in patient engagement for the right reasons — is it for the purpose of learning from patients/family, to improve health services, or strictly to meet accountability requirements? Are health professionals committed to partnering or collaborating with patients and family members in a genuine interactive engagement sustained over time that supports shared decision-making? Is there a commitment to take the time to adequately orient health professionals and patients/family members regarding their roles and responsibilities and level of involvement to be expected with this type of work? Finally, there also needs to be a commitment to support patient engagement with dedicated resources. For example, will health professionals be given protected time from clinical/administrative responsibilities for training and doing this type of work? Will there be a commitment to provide staff with sufficient budgetary allowances to support the administrative costs of conducting an engagement project (e.g., food/beverages for participants, parking/travel reimbursement, etc.).

Participant Recruitment for Patient Engagement

Consideration needs to be given to participant recruitment methods to ensure characteristics of potential participants reflect the form that patient engagement takes; that is, attention needs to be paid to reducing inequalities of groups being given opportunities to be

involved as it might be more difficult for some. Creative strategies need be considered if we are to do a better job at involving patients and family members who have important contributions to make about their experiences, but may not be reached using traditional recruitment methods or engagement strategies. Of equal importance is proper screening of potential patient/family participants for relevant and recent health care experience to ensure that their interests for involvement align with those of the patient engagement project. Health professionals also need to be screened to ensure their professional interests are in alignment.

Let's not reinvent the Wheel

I argue that there is a relative lack of collaboration and shared knowledge between the evaluation community and health sector in the rapidly developing area of patient engagement and the development of best practices; that is, health organizations continue to struggle with how best to involve patients (i.e., process/approach) in health service improvement initiatives as well as learn from patient experience. I make the argument that the evaluation community can make significant contributions in these areas; why would we ‘reinvent the wheel’ and develop ‘new’ collaborative approaches to patient engagement when collaborative approaches have been optimized by others in the evaluation community? Participatory approaches to guide patient engagement have been recommended in the patient engagement literature and are supported by the findings of this study. I encourage health care practitioners who have limited experience in the areas of participatory or collaborative approaches to evaluation to broaden their review of the literature outside of the health field and expand their understanding through examination of the evaluation literature.

I offer for consideration “a set of evidence-based principles to guide evaluation practice in contexts where evaluation knowledge is collaboratively produced” (Shulha et al., 2016, p. 193). The development of these principles drew on the expertise of 320 evaluators to identify key factors/characteristics that enhance or impede success in collaborative approaches in evaluation. Three possibilities for use of these principles within a patient engagement context could be as “(a) a guide to planning and implementing CAE [i.e., patient engagement]; (b) a basis for retrospective reflection on completed projects (with an eye to surfacing lessons learned); (c) a framework for structuring [patient engagement] education, training, and professional development” (p. 212).

Policy Makers and Organizational Decision-Makers

A cultural shift is occurring within the Canadian health care system, requiring patients to be engaged in health service planning and evaluation. Examples of this shift taking place are patient engagement policies being developed across different levels of health care, the creation of patient and family advisories, involvement of patients in the development of clinical guidelines, and patient-oriented research initiatives. For patient engagement to be accepted and effective, policy-makers and organizational decision-makers interested in establishing patient engagement strategies must be prepared to debate why patient engagement is desired and what is hoped to be achieved. Policy and organizational leaders need to be committed to encouraging health professional acceptance of patient engagement in planning and evaluation activities. Additionally, policies need to assist and direct health care organizations to go beyond conventional methods for capturing patient experience (e.g., patient satisfaction surveys) and adopt a strategic organizational approach to patient engagement.

Conclusion

My hope is that the results of this thesis will contribute to increased successful implementation of patient engagement and generate new research questions in the study of patient engagement in planning and evaluation of health services. To date, limited empirical research has examined the effects of patient engagement, investigated the best approach to engage patients, or systematically evaluated patient engagement implementation. To my knowledge, this is the first patient engagement study to prospectively examine the various constructs involved in patient engagement using a participatory approach. The use of multiple data collection methods, particularly the 30 independent interviews at multiple time points during the engagement process, enhances our contextual understanding of key factors impacting the process of engagement and its consequences for participants. Strengths of this prospective qualitative study were that it allowed for examination of participants' experiences through the course of the evaluation project and could identify changes occurring over time.

This study also identified important areas where I believe the evaluation community can play a significant role in continuing to advance the body of knowledge and practice of patient engagement. My intention has been to explicate some options for more collaborative practice and to inform a future research agenda that will add new insights and advance our understanding of patient engagement. In the end, my hope is that research on patient engagement will help

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

highlight the importance of including patient and family perspectives to create a more responsive health care system. I leave you with some final thoughts shared by a staff research participant who expressed her thoughts on why she felt the PFEC had been successful:

I think the success is probably due to multiple factors. It's proper selection of good, motivated, and compassionate people. It's the way that the meetings were run, so there was a clear goal and purpose. It was productive; the feedback was collected and analyzed well. I think what made the group also feel good and successful was part of the process and how that was managed. So, I think those are the two pieces of it, and it feels empowering! (Staff)

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Appendix A

Description of Key Constructs of the Conceptual Framework

Term	Definition
Contextual Factors	Refers to historical, cultural, political, and economic factors that are in the internal or external environment that impacts the context of PSOP as well as the PFEC and how it operates.
Consequences	Refers to the stakeholders' perception of the impact of the PFEC, which will be directly influenced by the perceived benefits and drawbacks of the PFEC.
Intervention	The creation of the PFEC within the PSOP is the intervention under study.
Facilitators	Refers to stakeholders' perception of any positive influences that assist in the patient engagement process.
Barriers	Refers to stakeholders' perception of any restraining influences on the patient engagement process.
Intended Benefits	Refers to stakeholders' perception of any positive impacts that have occurred as a result of the PFEC.
Patient Engagement	A health care system that "recognizes the capacity of patients to discuss issues, generate options and participate in the design, delivery and evaluation of health services. The term 'patient' includes the individuals receiving treatment and/or those that support them throughout their care journey, such as their family members, friends and their community" (CHSRF, 2011, p. 2).
Patient-Centred Care (PCC)	A health care system that places patients at the centre of the system of care and develops good services that revolve around them (Mallett, 1996).
Stakeholders	People who have a stake, a vested interest, in the PSOP evaluation findings.
Diffusion of patient engagement across organization	Extent to which Patient engagement in planning and evaluation will take hold within the Cancer Program and spread through the organization.

Appendix B

Ottawa Hospital PSOP Patient and Family Engagement Committee Report

2



July, 2014

**The Ottawa Hospital's
Psychosocial Oncology Program
Patient and Family Engagement
Committee Report**

Program Priorities and Recommendations

Report Prepared by: Nathalie Gilbert, University of Ottawa

In collaboration with: Jane deSnaijer, Agneta Gertenfel, Dr. Caroline Gérin-Lajoie, Dr. Cheryl Harris, Simon Hind, Michele Holwell, Diane Manii, Jonathan Mayer, Jennifer Shamess and Marina Sokolova



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2

PSOP Priorities and Recommendations

21

TABLE OF CONTENTS

Foreword	3
Preface	4
Acknowledgements	5
Executive Summary	6
Introduction and Background	10
Beyond Patient and Family Engagement: Studying the Process	11
The PSOP Patient and Family Engagement Committee Process	12
PSOP Priority Areas and Recommendations	16
Conclusion	24
References	25
Appendix A: Inclusion and Exclusion Criteria for the PSOP PFEC	26
Appendix B: Terms of Reference for the PSOP PFEC	27
Appendix C: Strengths of the PSOP	30
Appendix D: Issues/Priority Areas for the PSOP	31
Appendix E: <i>The Ottawa Hospital Cancer Centre Psychosocial Oncology Program Priority Setting, Wait Listing and Discharge Guidelines</i>	32

List of Acronyms

CCO: Cancer Care Ontario

ESAS: Edmonton Symptom Assessment System

PSOP: Psychosocial Oncology Program

PFEC: Patient and Family Engagement Committee

TOH: The Ottawa Hospital

Foreword

The Psychosocial Oncology Program (PSOP) has always prided itself on providing person centred care. However the development of the Patient and Family Engagement Committee really allowed us to truly examine this premise with the involvement of a very committed, informed, and motivated committee of patients and family members, as well as staff members and a physician. It was a meaningful learning opportunity. I was amazed at how quickly and succinctly the group focused on some of the biggest challenges for the program, and most significantly on how psychosocial oncology must be an integrated part of person centred care.

The work started has been significant as those patients and families who receive support have some of the highest psychosocial needs. I want to thank Nathalie Gilbert for her very thoughtful, respectful, and collaborative approach to leading this initiative and committee. We hope that this final report will provide direction for further work. I also want to thank those patients and family members who attended this committee for their willingness to share their experience and commitment to improve the services for others coming through the Cancer Program.

Diane Manii, MSW RSW,
Clinical Manager and Regional Lead
Psychosocial Oncology Program,
The Ottawa Hospital Cancer Centre

PREFACE

In May 2009, The Ottawa Hospital (TOH) embarked on a quality improvement journey with a vision to become a top 10% hospital in North America. Central to its vision is the provision of excellence in patient care and patient experience. But how can an organization truly become patient-centred without directly involving the patients and families it cares for?

The Psychosocial Oncology Program (PSOP) at The Ottawa Hospital Cancer Centre was developed in 2008. Its mandate is to reach the TOH and University of Ottawa's goals of excellence in clinical services, academic work, teaching, and research. But, to continue improving on these goals and to ensure that our outcome measures were truly meaningful, we realized that we needed to start working with "the real experts" ...the Cancer Centre's patients and families.

Through a collaboration lead by Nathalie Gilbert from the Centre for Research on Education and Community Services at the University of Ottawa, a Patient Engagement Committee was formed. This working group included members from the PSOP, as well as cancer patients and family members. Its mandate was to provide feedback about the PSOP's challenges, priorities, services and evaluation.

This experience was enriching, informative, and the feedback collected will help guide the PSOP's next steps for quality and service improvement. Thank you to the patients and family members who took the time to participate in this important initiative. You will be making a difference in the care of cancer patients and families at TOH. We also hope that other clinical programs across TOH will consider replicating this model and start involving patients in their work.

Caroline Gérin-Lajoie, MD, FRCPC
Psychosocial Oncology Program,
The Ottawa Hospital Cancer Centre

ACKNOWLEDGEMENTS

I take this opportunity to express my profound gratitude and deep regards to all members of the PSOP Patient and Family Engagement Committee for your exemplary guidance and contributions to this project. To the PSOP staff committee members, despite competing responsibilities, thank you for your unwavering commitment to your patients and the incredible support you have demonstrated throughout this project. To the patient and family committee members, thank you for taking time from your busy lives to contribute to this project; your contributions to this project have been invaluable. The learning that you have imparted on all members of the PFEC by so openly sharing your experiences will have an impact beyond this project.

I am obliged to all staff members of the Psychosocial Oncology Program, for their valuable assistance and information provided by them in their respective fields. I am grateful for their cooperation. Each of them, Josée Charlebois, Geneviève Côté, Solange Hosselet, Isabelle McIntosh and Dr. Patricia Poulin, deserving of profound gratitude for their assistance at different stages of this project. I must also acknowledge Paula Doering, Senior Vice-President, Perioperative Services, Cancer and Diagnostics and Cathy Degrasse, Clinical Director for the Ottawa Hospital Cancer Program for their support, without which this project could not have been possible.

I also take this opportunity to express a deep sense of gratitude to Dr. Brad Cousins from the University of Ottawa, for his commitment to this project as well as his encouragement, mentoring and guidance along the way.

I am also grateful to the Centre for Research on Education and Community Services at the University of Ottawa and the PSOP for financial support of this project.

Nathalie Gilbert, PhD Candidate
Centre for Research on Educational and Community Services
University of Ottawa

EXECUTIVE SUMMARY

INTRODUCTION AND BACKGROUND

In response to the Psychosocial Oncology Program's (PSOP) 5th anniversary milestone, the program took pause to reflect on their achievements as well as embarked on a new program initiative that included the creation of the *PSOP Patient and Family Engagement Committee* (PFEC). As a means to partnering with their patients and family members, the PFEC collaborated on a needs assessment that would assist PSOP in identifying priority areas and recommendations to move forward over the next few years. More specifically, through conversation with multiple program stakeholders that have unique experiences and expectations, the goal was to learn from one another and find ways to continuously improve the services being offered.

BEYOND PATIENT & FAMILY ENGAGEMENT: STUDYING THE PROCESS

There was a unique opportunity to embark on this type of work with a doctoral candidate, Nathalie Gilbert from the University of Ottawa, who has a research interest in understanding the process of patient and family engagement in planning and evaluation of health services. More specifically, she wanted to examine the process (facilitators/barriers) of involving patients and family members in working collaboratively with health professionals in improving health services as well as to learn more about their perspective on involvement in this type of activity.

THE PSOP PATIENT & FAMILY ENGAGEMENT COMMITTEE PROCESS

The PFEC membership comprised of four patients and two family members who had recently received PSOP services within the last year, and four PSOP health professionals from different specialties (psychology, social work, management and medicine). The facilitator for the PFEC was the principal investigator for the study, Nathalie Gilbert.

The preliminary meetings involved identifying the strengths of PSOP and priority areas for PSOP to focus on for improving the patient's experience. In order to complete this task, the PFEC committee members were asked to respond to a series of questions related to services received at PSOP or their work at PSOP. A content analysis of the responses was performed by the facilitator and summarized in two separate documents: strengths of the PSOP (Appendix C) and priority areas for PSOP to focus on to improve patient experience (Appendix D). This report will share the findings of the PSOP needs assessment which includes the identification of priority areas along with recommendations to guide future directions for PSOP. The data analysis for the research component of this project is in progress and will be forthcoming.

PSOP PRIORITY AREAS AND RECOMMENDATIONS

Through a series of discussions and priority sort exercises, three broad priority areas, each containing specific areas of concern for PSOP patients and family members, were identified. Key recommendations to address these issues were also identified collaboratively which have been highlighted below.

1. Wait Times and Expectations to Access PSOP Services

- ☐ Time constraints on PSOP services due to demand
- ☐ Delays and difficulties in referral process
- ☐ Development of key outcome measures to demonstrate PSOP impact

Key Recommendations:

1. Patients scoring above 4 (moderate to severe) on the *Edmonton Symptom Assessment System* (ESAS) should have a discussion with their clinicians about their symptoms and consider a referral to PSOP if appropriate. If ESAS scores are high, clinicians should refer to PSOP rather than manage their patients' psychosocial symptoms.
2. Psychosocial oncology services should be integrated into cancer care to reduce the number of referral delays. PSOP needs to be more visible (i.e., patient testimonials, brochures, etc.) within TOH.
3. Most patients are seen by PSOP within an appropriate timeframe once the referral reaches PSOP; however, in some cases, patients do not receive services from the appropriate health professional. Further revisions of the wait time strategy, in particular the intake assessment, may need to be further refined to ensure patients are receiving services from the appropriate healthcare professional.
4. Development of key outcome measures to better meet the needs of patients and to assess impact of services.

2. Navigation of TOH Healthcare System after Cancer Diagnosis

- ☐ Awareness of PSOP services
- ☐ Fear and feeling of isolation as an in-patient

Key Recommendations:

1. Overall, the PFEC felt that the navigation education slides/package offered by PSOP is excellent and covers important information that many of the patient/family committee members would have appreciated receiving when they or their loved one was first diagnosed. The overall consensus was that general navigation information and cancer specific information needs to meet the needs

of patients in a broader way and should be disseminated using multiple platforms. The PFEC and PSOP acknowledges that in order to implement some of these recommendations a significant increase in financial and human resources would have to be directed towards improving the navigation of TOH healthcare system for patients after cancer diagnosis.

2. There was a general agreement that patients are different and therefore, often have different needs. For example, one form of information dissemination (i.e., handouts, navigation session, etc.) could benefit a certain patient population but not others. In general, the committee agreed that any information about available services is better than nothing; this allows the patient to decide what is and is not relevant to them.
3. Efforts need to be made to provide navigation education and community resources information to all cancer patients at TOH (e.g., patient education handbook, Maplesoft, etc.).
4. Some patients diagnosed with cancer are directly admitted as in-patients; efforts should be made to provide navigation education to those patients and family members to reduce fear and feelings of isolation.

3. Psychosocial Oncology Services Should be Integral to Cancer Care

- ☐ Awareness and access of PSOP with TOH and regionally
- ☐ All PSOP service related concerns (i.e., increase uptake of group sessions and/or workshops, help with family dynamics during stressful treatment period, etc.)

Key Recommendations:

1. There should be a more systematic approach to making patients and family members aware of PSOP within TOH Cancer Centre as well as a more consistent approach to the referral process. We also need to be cognizant that there is variability in terms of how patients enter the system (multiple entry points) and need to meet the needs of these patients as well. In order for patients to self-refer or ask for support, they must be aware of the symptoms and services offered at PSOP and in the community.
2. Improve the frequency and consistency of ESAS completion with patients in the Cancer Centre and increase the frequency of clinicians (nurses and physicians) reviewing the screening results with their patients in the clinics. If a patient scores high on anxiety, there should be some sort of direct feedback/mechanism to alert the patient that their anxiety score is considered high and to consider having a conversation with their healthcare provider.
3. Because patients manifest distress in many different ways, there needs to be a judgment made on the part of the health professional in determining whether a patient is experiencing distress or not. For that reason, consistent mention and

- offering of PSOP services to cancer patients could better meet the needs of all patients regardless of how they demonstrate distress.
4. There is significant variety in terms of how patients are made aware of and referred to PSOP. Ideally, patients will be made aware of PSOP by health professionals at multiple times along the course of a patient's treatment and using a variety of approaches. The issue of access and awareness needs to be approached using a more multidirectional approach rather than a linear approach. It is also important to ensure that patients and family members are also aware of services offered in the community.
 5. The PFEC acknowledged that there would be value in collecting data upon entry to PSOP (i.e., how the patient was made aware of PSOP, how they were referred, etc.); however, the resources to support this type of work (data entry) in the program are limited.

CONCLUSION

Three overarching priority areas for PSOP have been presented with corresponding recommendations to help guide the PSOP's next steps for quality and service improvement. These priorities and recommendations are based on the collaborative work of the PSOP Patient and Family Engagement Committee during 6 face to face working meetings as well as preparatory work completed individually. This committee composed of patients, family members, clinicians, a program administrator and an evaluator/researcher has identified (i) improving wait times to access PSOP services, (ii) improved navigation of TOH healthcare system after cancer diagnosis, and (iii) the importance of integrating psychosocial oncology services into cancer care as priorities for improving the cancer patient experience. The recommendations are based on patient and family experiences and anchored by PSOP staffs' contextual understanding and knowledge of PSOP and TOH Cancer Centre. We are very much aware that this is neither a full nor a finished set of recommendations for these priority areas. We rather like to see it as a work-in-progress and look forward to continuing this dialogue. We hope that this project serves an example of how patients and family members can collaborate on program improvement initiatives with the goal of improving services and the patient and experience.

INTRODUCTION AND BACKGROUND

The Psychosocial Oncology Program (PSOP) recently celebrated its 5th anniversary and took pause to reflect in the *PSOP Newsletter* (September, 2013) on its achievements thus far and on how the program can continue to improve services to better respond to patient and family needs, and to improve patient experience and outcomes. The PSOP, comprised of a multidisciplinary team, supports patients with cancer and their families by providing mental health and rehabilitation services to ensure patients receive truly comprehensive clinical services. This concept is clearly stated in the vision for PSOP, which is “to lead the country as an integral part of the provision of excellent inter-professional care to enhance the experience of people living with cancer” (PSOP Newsletter, September 2013).

In response to the program’s 5th anniversary milestone and as a means to partnering with their patients and family members, PSOP embarked on a program needs assessment by creating a *PSOP Patient and Family Engagement Committee* (PFEC), which had its first meeting in November, 2013. The overall purpose of the PFEC was to collaborate on a needs assessment that would assist PSOP in identifying priority areas to focus on and would provide recommendations to move forward over the next few years. More specifically, through conversation with multiple program stakeholders that have unique experiences and expectations, the goal was to learn from one another and find ways to continuously improve the services being offered. At the same time, it was felt that this initiative aligned well with a number of overall recommendations identified in *The Ottawa Hospital’s Consultations on Cancer Program Transformation Report* (MASS LBT, 2011) that were highly relevant to PSOP, which included:

- ☐ Increase patient participation.
- ☐ Adopt a whole-patient approach to health:
 - Expand psychosocial support;
 - Create a rehabilitation and wellness clinic that would include exercise, physiotherapy, massage therapy; and
 - Develop program seminars to provide information and training to patients and family members on nutrition and exercise.
- ☐ Improve system navigation.

Further to this, the *2011-2015 Ontario Cancer Plan* (Cancer Care Ontario [CCO], 2011) identified as one of their six strategic priorities to “continue to assess and improve the patient experience” (pp. 37–40). More specifically related to PSOP, the Ontario Cancer Plan indicates that every cancer patient in Ontario will:

- ☐ Have access to tools to help navigate the cancer system and manage their own journey.

- Have the opportunity to give feedback on their experience throughout their cancer journey.
- Receive care in a timely manner for physical and emotional symptom scores flagged through symptom screening.
- Have their interests represented at a Patient Advisory Council, a forum to advise on initiatives to improve the patient experience.
- Have access to psychosocial resources, standardized across the province and based on international best practices.

Upon reviewing the above recommendations and strategic priorities for psychosocial health and cancer care, PSOP prioritized the creation of the PFEC. By engaging with patients and family members, the PFEC aimed to identify priorities or gaps in PSOP services and develop recommendations for The Ottawa Hospital (TOH) to strive to better meet the needs of their patients.

BEYOND PATIENT & FAMILY ENGAGEMENT: STUDYING THE PROCESS

There is little research into the best approaches to use when patients/family members partner with health professionals on a program improvement initiative. It is not clear what impacts this type of collaboration has on programs or on patients, family members, and health professionals involved in this process (Baker & Denis, 2011; Canadian Health Services Research Foundation, 2011; Crawford et al., 2002; van de Bovenkamp, Trappenburg, & Grit, 2009). There was a unique opportunity to embark on this type of work with a doctoral candidate, Nathalie Gilbert from the University of Ottawa, who has a research interest in understanding the process of patient and family engagement in planning and evaluation of health services. More specifically, she wanted to examine the process (facilitators/barriers) of involving patients and family members in working collaboratively with health professionals in improving health services as well as to learn more about their perspective on involvement in this type of activity. This was a mutually beneficial opportunity for PSOP and the researcher. The researcher took the lead in collaboration with key PSOP staff to create the PSOP Patient Engagement Committee and facilitate the process and subsequent meetings. As part of the research study, an independent interviewer interviewed all members of the PFEC at three separate intervals (baseline, mid-project and completion of project) during this project to examine the research interests addressed above.

As a result of there being a study attached to this program initiative, the project proposal was submitted to the Ottawa Health Science Network Research Ethics Board and the Office of Research Ethics and Integrity of the University of Ottawa for approval before we could begin recruitment of committee members. Inclusion and exclusion criteria for recruitment were established (Appendix A) and potential committee members for the PFEC were identified using the PSOP Mozaic database. Once potential

members were identified, a general recruitment letter was sent out through direct mailing advising them about the project and inviting them to contact the researcher if they were interested in receiving more detailed information. Recruitment posters were also posted within TOH Cancer Centre and in the PSOP. There were no inducements for participation on the PFEC, but members were reimbursed for parking. The final PFEC membership comprised four patients and two family members who had recently received PSOP services within the last year, and four PSOP health professionals from different specialties (psychology, social work, management and medicine). The facilitator for the PFEC was the principal investigator for the study, Nathalie Gilbert from the University of Ottawa. The PFEC met once a month at TOH Cancer Centre Board Room from 4:30pm to 6:00pm for a total of six working meetings. One committee member joined the meetings via video conferencing during the winter months to eliminate driving.

The research component of this project is still ongoing; therefore, the findings are not reported in this report. This report will share the findings of the PSOP needs assessment which includes the identification of priority areas along with recommendations to guide future directions of PSOP in order to continue improving the services they offer.

THE PSOP PATIENT & FAMILY ENGAGEMENT COMMITTEE PROCESS

The first PFEC meeting consisted mainly of an orientation, with the main focus being on providing background information about the PSOP, the purpose of the PFEC, and their role as committee members. The draft Terms of Reference for the PFEC were shared with the committee prior to the first meeting and members were given the opportunity to suggest changes or seek clarity before the final version was shared for approval at the first meeting (Appendix B). Finally, the meeting ended with every committee member having the opportunity to introduce themselves and share their personal experience with PSOP and/or TOH Cancer Program. The goal was for committee members to get to know each other, but also to appreciate the different perspectives that members bring to the committee. Committee members appeared to appreciate having this opportunity not only to share their story but also to elaborate on the reasons why they joined the PFEC.

Following the orientation meeting, the PFEC was eager to get to work and were committed to fully engaging in the process of identifying priority areas for the program and developing some recommendations to address them. In order to maximize our working time at the meetings, committee members were in agreement to do some preparatory work for each meeting. It was made very clear to all members to do only what they were able to do and not feel any pressure to complete work if unable to. The typical PFEC working process was to have committee members reflect on a particular topic related to the PSOP, usually in the form of questions sent to them via email that they answered before our meetings. The PFEC facilitator asked for their responses a few

days before the scheduled meeting and conducted a content analysis of all the responses and shared the findings/summary with the committee members at the meeting. This approach worked very well and served three purposes: (i) allowed all committee members an opportunity to provide input in a thoughtful way that they may not have otherwise felt comfortable doing in a committee setting, (ii) provided members an opportunity to contribute despite having to be absent from a meeting, and (iii) it was an efficient approach to maximizing our productivity at our meetings.

The preliminary meetings involved identifying the strengths of PSOP and priority areas for PSOP to focus on for improving the patient's experience. In order to complete this task, PFEC committee members were asked to respond to the following questions:

Questions for Patient and Family Members

Question 1: *From your perspective, please reflect and identify 3–5 personal experiences/services that had a positive impact on your ability to adjust to living with cancer or living with someone who had cancer. Alternatively, please identify 3–5 experiences that made it more difficult to adjust to living with cancer or living with someone who had cancer (within PSOP or not).*

Question 2: *For the second part of this exercise, imagine how someone close to you would respond to these same questions. Try to take your family member's perspective and answer the same questions from their point of view. For example, if you are a patient who has survived cancer, how is one of your family members (spouse, child, parent, etc.) likely to respond to the same questions (you can go ahead and ask them)? If you are a family member who supported someone with cancer (spouse, child, parent, etc.) how do you think they would have answered the same questions? Your family member would likely identify different strengths and limitations of the services received in meeting their different and separate needs.*

Questions for PSOP Staff PFEC Members

Question 1: *From your professional experience, please reflect and identify 3–5 key strengths and limitations of PSOP in assisting patients and family members to adjust to living with cancer or living with someone who had cancer.*

Question 2: *From your professional experience, imagine how a patient or family member (please identify by circling: patient or family member) would respond to question 1 above.*

A content analysis of the responses was performed by the facilitator and summarized in two separate documents shared with the PFEC. One document included the content analysis findings identifying the strengths of the PSOP (Appendix C) and the other

summarized the priority areas for PSOP to focus on to improve patient experience (Appendix D). The PFEC reviewed and discussed the strengths and priority areas of the program. Below is a sample of some of the overall strengths of PSOP identified by the committee members:

- ☐ A high functioning inter-professional team with clinical expertise in mental health and rehabilitation disciplines.
- ☐ Program recognizes global impact of cancer on patients' lives as well as the impact post treatment with survivorship issues.
- ☐ One on one consultation with highly trained professionals.
- ☐ Having continued access to a program after a family member dies, which is reassuring for a patient to know that their loved one will continue to be supported.
- ☐ Reduces isolation and gives outlet.
- ☐ Provides information about services available outside of program (i.e., finances, community physiotherapy, etc.)

A more detailed list of the identified strengths can be found in Appendix C. Although the PFEC acknowledges the importance of identifying the strengths of the program and "what works well", this exercise mainly served as an aid to critically reflect on the identification of potential gaps in the program. For this reason, this report does not provide a detailed description of the strengths of the program, but rather attempts to provide a general sense of where the program strengths lie when cross referencing some of the priorities and recommendations identified in this report.

Within the same exercise, the PFEC members identified 19 priority areas for PSOP that they felt PSOP could focus on to enhance patient care. For feasibility and manageability of the project, the PFEC engaged in an exercise to identify which of the 19 priority areas were the most critical to focus on as a committee. In order to accomplish this task, the committee facilitator asked the members to divide up into two groups (combinations of patients, family members and PSOP staff) to participate in a group priority sort activity, which draws on the combined knowledge of diverse participants to provide the information needed to identify the highest priority items (Jacobson et al., 2011; McGuire and Zorzi, 2011). Each group had to sort each of the 19 priority items into one of five piles, #1 being less important and #5 being more important. By the end of the meeting, the committee had engaged in thoughtful discussions and debate and identified 10 priority areas that PSOP should focus on in the short term; these can be seen in Table 1.

Table 1: Priority Areas for PSOP

1. Navigation of the TOH healthcare system after cancer diagnosis	2. Lack of awareness of PSOP services within TOH
3. PSOP should be considered integral to cancer care	4. Waiting time to receive PSOP services
5. Fear and feeling of isolation as an in-patient	6. Development of key outcome measures to demonstrate impact of PSOP
7. Increase uptake/participation of group sessions/workshops	8. PSOP services (i.e., 1-1 counselling/workshop) need to provide constructive steps or actions
9. Help with family dynamics during stressful treatment period	10. Time constraints on PSOP services due to demand

The 2 highest priorities for the PSOP identified by both groups from this list of 10 priorities were: (1) Navigation of the healthcare system after cancer diagnosis and (2) PSOP should be considered integral to cancer care. The groups ranked waiting time to receive PSOP services as a 4 (very important) and 3. One group ranked lack of awareness of the PSOP services within TOH at 5 (most important) and the other group at 1 (least important). The PFEC reviewed the list of 10 priorities identified and recognized that there was significant overlap and that addressing each priority individually would not be feasible or practical. Therefore, we grouped the priority areas within 3 broad categories and addressed them more generally within each category.

1. Wait Times and Expectations to Access PSOP Services

- ☐ Time constraints on PSOP services due to demand
- ☐ Development of key outcome measures to demonstrate impact of PSOP

2. Navigation of TOH Healthcare System after Cancer Diagnosis

- ☐ *Awareness of services also addressed in Navigation
- ☐ Fear and feeling of isolation as an in-patient

3. Psychosocial Oncology Services Should be Integral to Cancer Care

- ☐ Awareness and access of PSOP with TOH and regionally
- ☐ All PSOP service related concerns (i.e., increase uptake of group sessions and/or workshops, help with family dynamics during stressful treatment period, etc.)

With these priority areas in mind, we now turn to further defining/contextualizing what the issues are that makes these priorities for PSOP, along with some accompanying recommendations for each of the overarching priority areas.

PSOP PRIORITY AREAS AND RECOMMENDATIONS

Wait Times and Expectations to Access PSOP Services:

To explore the issue of wait times at PSOP, PSOP staff committee members gave the PFEC an overview of *The Ottawa Hospital Cancer Centre Psychosocial Oncology Program Priority Setting, Wait Listing and Discharge Guidelines* (Appendix E), which has been in development over the last three years. This wait time strategy was developed by PSOP as a means to having: (i) a systematic referral process (intake); (ii) referral to the appropriate professional; and (iii) ensure that patients are seen in an acceptable timeframe based on the priority needs for each discipline. PSOP's work has contributed to the development of the Cancer Care Ontario (CCO) wait time strategy. CCO's expectation for wait times is that a referral be reviewed and addressed within 72 hours of receiving the referral and that those patients be seen within 2 weeks regardless of discipline. CCO will start publishing wait times for psychosocial oncology in Ontario. Subsequent to this presentation, the PFEC committee members had the opportunity to review the guidelines and were asked to reflect and respond to the following two questions in preparation for the next meeting:

Question 1: *When reviewing the different priority levels (1–4) for each discipline, to the best of your knowledge and personal experience, do you think they are appropriate and satisfactory? If not, please indicate why and which discipline you are referring to.*

Question 2: *Do you have any suggestions that could improve these guidelines?*

A content analysis of the responses indicated that overall the PFEC felt that the PSOP wait time strategy was appropriate and meets the needs of most patients and family members once the referral reaches PSOP. There were a few suggestions made to improve the guidelines that have since been communicated with the steering committee responsible for the continued improvement of the guidelines, three of which are:

1. *Psychology discipline, Priority 2:* This priority level will be reviewed by PSOP for patients given a terminal prognosis and referred to PSOP. Currently, the wait time is up to 8 weeks. **Recommendation:** For this particular patient situation, the priority should be more immediate.
2. *Social work discipline:* It was suggested by the committee that the guidelines should clearly address the needs of patients who are caregivers. **Recommendation:** Include in Priority 1 or 2 descriptions that include patients as primary caregivers, i.e., of young children, elder parents, disabled husband, etc.

3. *Clarity of guidelines:* Some committee members suggested that areas of the guidelines lacked clarity. **Recommendation:** The guidelines should clearly indicate who is responsible for the initial intake assessment and who should assign the priority code.

Further discussions concerning the PSOP wait times led the committee to realize that delays in receiving PSOP services were mainly related to the referral not being sent within an acceptable timeframe or not reaching PSOP. Some of these issues relate to access and awareness of PSOP services, discussed in the section below. The following issues and recommendations address the longer wait times faced by some patients needing psychosocial oncological services:

- The symptom management screens in the waiting areas of the Cancer Centre are intended to identify patients who have moderate to severe levels (between 4–10) of stress according to the *Edmonton Symptom Assessment System* (ESAS). **Recommendation:** Patients scoring above 4 should have a discussion with their clinicians about their symptoms and consider a referral to the PSOP if appropriate. If ESAS scores are high, clinicians should refer to PSOP rather than manage their patients' psychosocial symptoms.
- Cancer patients should be made aware of PSOP services whether they require them or not. **Recommendation:** Psychosocial oncology services should be integrated into cancer care to reduce the number of referral delays. PSOP needs to be more visible (i.e., patient testimonials, brochures, etc.) within TOH.
- Most patients are seen by PSOP within an appropriate timeframe once the referral reaches PSOP; however, in some cases, patients do not receive services from the appropriate health professional. **Recommendations:** Further revisions of the wait time strategy, in particular the intake assessment, may need to be further refined to ensure patients are receiving services from the appropriate healthcare professional.

Navigation of TOH Healthcare System after Cancer Diagnosis

The *Ottawa Hospital's Consultations on Cancer Program Transformations Report* (2011, p. 35) recommended improving the system navigation to improve patient and family experience. CCO also included in their strategic plan "that every Ontario cancer patient will have access to tools to help navigate the cancer system and manage their own journey" (p. 39). PSOP staff members were also hearing from their patients that navigating through the TOH healthcare system after cancer diagnosis was an additional burden during an already difficult period in their lives. In responding to this service gap for TOH cancer patients, PSOP both listened to patients and took into consideration the recommendations made in the aforementioned report. PSOP took on the role of providing *Navigation Education Sessions*, led by two PSOP social workers. The resources available for this service are limited, since the two social workers leading this

initiative continue to have heavy clinical caseloads. PSOP management is very supportive of this initiative and recognizes its importance but fully recognizes that it will require more resources in order to expand its services and impact a greater number of cancer patients.

To better understand the needs of cancer patients related to navigation of the healthcare system, a social worker leading the navigation education sessions shared anecdotally some reoccurring themes she has witnessed with cancer patients she interfaces with in her clinical practice and at the navigation education sessions. The main stressors for newly diagnosed patients that she identified include:

- ☐ Pre-diagnostic is a very stressful time. For example, it's a long process of seeing doctors and getting tests.
- ☐ Diagnostic phase is also stressful. For example, how is this going to affect my/family life?
- ☐ Entering the medical world is stressful: medical terminology can be overwhelming, a feeling that the system is big, not sure who to go to in order to get the answers needed quickly, who to trust, etc.
- ☐ As treatment unfolds patients begin to think about how this illness is going to impact them on a day-to-day basis (physically and emotionally).
- ☐ When people are highly stressed, they don't always retain and understand information, so we need to offer multiple methods of offering navigation information.

The navigation education sessions are intended to reduce some of the stressors listed above and provide patients and family members with information to help them navigate through their cancer treatment as smoothly as possible. The PFEC was provided with an overview of the education information and a copy of the PowerPoint (PPT) slides used for the navigation education sessions. The intent of this exercise was to assess whether there were any gaps in the information being presented to patients. Committee members were then asked to respond to specific questions related to the PPT slides and navigation of the TOH healthcare system in preparation for the next meeting:

Question 1: *Could you reflect on your personal experience and briefly outline/describe some of the most challenging navigation issues you or your family member had to face following diagnosis?*

Question 2: *What information would you have appreciated receiving and when?*

Question 3: *What did you like or appreciate most about the material in the presentation?*

Question 4: *What did you like the least or find the least helpful from the presentation slides?*

Question 5: *What information is missing or would be important to add to this presentation?*

Responses to the reflective questions were consolidated in one document and shared with all committee members, including the co-lead for the navigation education session at the PSOP. Here is a sample of the responses received:

“The new system (the hospital and cancer centre) became so important so quickly and not knowing how to navigate the system was a stressor for us.”

“We were very lucky to both have time, background and skills to dedicate to researching information...with an advocate a patient stands a much better chance to navigate to the point of ‘full service’.”

“Most challenging navigation issues following diagnosis would have been as a layperson trying to understand medical terms used to describe cancer conditions. Who do I see for what? ... What is normal? I felt pressure to ‘get it right’ as my family member’s life depended on it.”

“Although there were times when I felt I was not being given enough information regarding the details of my treatments or the next steps, the truth is I don’t think I could have processed it sufficiently. I would characterize my receipt of information as ‘just in time’.”

Responses to the above questions served as a starting point for discussion on how PSOP can improve navigation of TOH healthcare system for newly diagnosed cancer patients. Important issues and recommendations were identified:

- Overall, the group felt that the navigation education slides were excellent and covered important information that many of the patient/family committee members would have appreciated receiving when they or their loved one was first diagnosed. **Recommendations:** Some suggestions were made for some minor improvements in content, and these were shared with the co-lead of this initiative. The main area of concern was finding strategies to disseminate this information in multiple formats to increase accessibility for all patients at TOH Cancer Centre.
- Committee members suggested that a hard copy of the information offered at the navigation education session could be offered to newly diagnosed patients. **Recommendation:** The PPT information would need to be repackaged to make it appropriate and understandable as a handout. Some patients may find that amount

of information overwhelming and consequently not read it. Others want all the information they can receive. Therefore, a general information package of key information might be most suitable (including links to community resources in the community). There have been discussions about developing a *patient education booklet* at TOH Cancer Centre that could benefit from some of the information developed from the navigation education sessions.

- Timing to receive navigation information? Some members felt strongly that they would want patient information specific to their cancer at their first meeting with their Patient Designated Nurse or oncologist. There was recognition however, that some people would feel overwhelmed by receiving too much information and that to a certain extent patients do need to have a certain level of self-direction in obtaining the information that they need. **Recommendations:** There was a general agreement that patients are different and often have different needs. For example, one form of information dissemination (i.e., handouts, navigation session, etc.) could benefit a certain patient population but not others. In general, the committee agreed that any information about available services is better than nothing; this allows the patient to decide what is and is not relevant to them.
- The PFEC identified a gap in services for those cancer patients that are not treated at TOH Cancer Centre and may not have the same level of access to the navigation education session and/or the PSOP (i.e., hematology cancer patients and patients requiring surgical cancer treatment). **Challenges:** To access services at TOH Cancer Centre the patient needs to be registered (needs specific K code) at the Cancer Centre. There are limited resources at the Cancer Centre to meet the needs of all cancer patients at TOH. This gap in service has been identified and there have been attempts to resolve it. Some improvements have been made with patients from the hematology department. However, other cancer patient populations at TOH do not have the same access to the services offered at TOH Cancer Centre. **Recommendation:** Efforts need to be made to provide navigation education and community resources information to all cancer patients at TOH, for example via a patient education handbook, community resources, Maplesoft, etc.
- The overall consensus was that general navigation information and cancer specific information needs to meet the needs of patients in a broader way and should be disseminated using multiple platforms. **Suggestions from the committee include:**
 - ❖ Upload navigation education session information onto the PSOP and TOH Cancer Centre websites (it would need to be repackaged to be suitable for the website). Also upload the handouts (list of community resources, links to websites, telephone numbers, etc.). **Challenge:** The web-based system at TOH is limited in terms of adding information to the website. PSOP leads for this

initiative have been working with Information Technology to get more information online.

- ❖ Need to ensure that the information remains current and relevant, which will require increased resources.
- ❖ Provide patients and family members with the ability to access the navigation presentation via a webinar for those who cannot come to TOH Cancer Centre to attend a session.
- ❖ Run navigation education session/information videos on TV screens in the Cancer Centre waiting area. Could also look into running these videos in a designated patient information/resource room.
- ❖ Provide navigation/cancer specific information on compact disks or USB keys.

The PFEC and PSOP acknowledges that in order to implement some of these recommendations a significant increase in financial and human resources would have to be directed towards improving the navigation of TOH healthcare system for patients after cancer diagnosis.

Psychosocial Oncology Services Should be Integral to Cancer Care

This overarching priority encompassed many important issues for the PFEC, such as access and awareness of the PSOP and key services that members felt were important during their cancer journey. Prior to our discussions about this issue, committee members were asked to reflect and respond to the following questions:

Question 1: *How and when after your (or your family member's) cancer diagnosis were you made aware of PSOP services?*

Question 2: *How difficult or easy was it to get referred to PSOP? What made it challenging/smooth in your opinion?*

Question 3: *Do you have any suggestions on how access to and awareness of PSOP could be improved over and above what we have already discussed as a committee?*

Here is a sample of the range of responses related to access and awareness of PSOP by PFEC members:

"It took a long time and I didn't know to ask for it. It wasn't until a relative who's a psychologist suggested I'd get on antidepressants and to help wean myself off benzodiazepines that I thought to ask my oncologist."

"My personal experience was that I received a referral and then an appointment in a timely manner."

“I’d say it is pretty tough to be referred to PSOP.”

“I saw women with Look Good, Feel Better gift bags and picked up the ad for the program. Then called the number, etc.”

“I was made aware of PSOP when I had a meltdown in front of (my doctor); he and I both realized that I needed help.”

A summary of responses was shared with the committee and PFEC members were each asked to identify key issues/factors that struck them as important in relation to access to and awareness of PSOP. Below are the issues identified as important and some recommendations to address them:

- The *variability* of responses was striking in terms of how quickly PSOP patients/family members were referred and/or received PSOP services. Some members felt they were served promptly and effectively when services were required, but others had to wait almost 5 months for services and/or referral. In the latter case, it is difficult to determine whether or not a referral was sent to PSOP at the initial time of need. Regardless, for some members the amount of time between when they needed PSOP services and when they received them was too long. Members agreed that there isn’t enough consistency in terms of how and when referrals are made, or in the level of awareness of PSOP services. As one member mentioned “there is too much randomness about how people are referred or find out about the PSOP.” **Recommendation:** There should be a more systematic approach to making patients and family members aware of the PSOP within TOH Cancer Centre as well as a more consistent approach to the referral process. We also need to be cognizant that there is variability in terms of how patients enter the system (multiple entry points) and need to meet the needs of these patients as well.

- There is a challenge within TOH Cancer Centre in that the ESAS is not consistently completed or reviewed in the clinics. Some clinicians consistently review the ESAS and refer when the symptom screening is high, but in other cases it is not reviewed. Some of the reasons discussed include heavy caseloads in clinics, a lack of time to review screening scores, and individual judgment on the part of the clinician whether to refer to the PSOP. Some physicians indicated to PSOP management that they intentionally decreased their referrals because they were under the impression that the PSOP was over capacity in terms of the number of patients they could treat. **Recommendation:** Improve the frequency and consistency of ESAS completion with patients in the Cancer Centre and increase the frequency of clinicians (nurses and physicians) reviewing the screening results with their patients in the clinics. If a

patient scores high on anxiety, there should be some sort of direct feedback/mechanism to alert the patient that their anxiety score is considered high and to consider having a conversation with their healthcare provider.

- People manifest distress in many different ways. While some patients are able to verbalize the symptoms they are experiencing others may internalize them, making it more challenging for clinicians to determine if a patient is experiencing distress. **Recommendation:** Because patients manifest distress in many different ways, there needs to be a judgment made on the part of the health professional in determining whether a patient is experiencing distress or not. For that reason, consistent mention and offering of PSOP services to cancer patients could better meet the needs of all patients regardless of how they demonstrate distress. Someone might be internalizing symptoms but take a physician up on the referral to PSOP.
- The summary of responses in terms of how patients accessed PSOP services shows that the problem of access to and awareness of PSOP varies greatly amongst patients. **Recommendation:** There is significant variety in terms of how patients are made aware of and referred to PSOP. Ideally, patients will be made aware of PSOP by health professionals at multiple times along the course of a patient's treatment and using a variety of approaches. The issue of access and awareness needs to be approached using a more multidirectional approach rather than a linear approach.
- At the initial time of diagnosis, patients and family members tend to be overwhelmed by the diagnosis and all that is attached to it (information on treatment options, how this will affect their life, etc.). Some patients accessing PSOP have shared that they do not remember when they were first informed about the PSOP. Interestingly, they admit that they might have been made aware of these services upon first entry into the system, but they only realized that the PSOP existed when they were feeling distress and needed these services. **Recommendation:** Repeatedly making patients and family members aware of PSOP services during their cancer journey is critical. There is a lot of information given upon initial diagnosis and patients can only retain what is vital to them at the time. Informing patients/family members of the PSOP at multiple points in time and using multiple methods (pamphlets, bulletin boards, physicians, nurses, website, video, navigation session, USB key, QR code, etc.) will hopefully improve awareness and access to PSOP for people experiencing distress.
- It is a challenge to identify patients that are not accessing or being made aware of the PSOP. Hospital patient satisfaction surveys address some of this, but there are limitations to the survey in that it is retrospective and the results are not made available in a timely fashion. **Recommendation:** The committee acknowledged that there would be value in collecting data upon entry to PSOP (i.e., how the patient

was made aware of PSOP, how they were referred, etc.); however, the resources to support this type of work (data entry) in the program are limited.

- Committee members suggested that beyond cancer patients being aware of PSOP services, they should be aware of key symptoms related to psychosocial distress. **Recommendation:** In order for patients to self-refer or ask for support, they must be aware of the symptoms and services offered at the PSOP. One member said, “*it can’t be subtle.*” *For example, posters advertising PSOP should be very clear/blunt about what services they offer and for what symptoms*”. Another suggestion was to have a Quick Response Code (QR code) on posters and other advertisements that a patient can activate with their cell phones to access the PSOP website.
- Module L has patients complete a quality of life screening tool, but it is not linked to PSOP. **Recommendations:** There have been a few referrals to PSOP with the Quality of Life Screening Tools attached to the referral, so this is an area that could be pursued further.
- PSOP services are not a requirement for all cancer patients; it is entirely dependent on each patient’s circumstances. **Recommendation:** It is important to ensure that patients and family members are also aware of services offered in the community (e.g., education sessions, counselling, etc.).

CONCLUSION

Three overarching priority areas for PSOP have been presented with corresponding recommendations to help guide the PSOP’s next steps for quality and service improvement. These priorities and recommendations are based on the collaborative work of the PSOP Patient and Family Engagement Committee during 6 face to face working meetings as well as preparatory work completed individually. This committee composed of patients, family members, clinicians, a program administrator and an evaluator/researcher has identified (i) improving wait times to access PSOP services, (ii) improved navigation of TOH healthcare system after cancer diagnosis, and (iii) the importance of integrating psychosocial oncology services into cancer care as priorities for improving the cancer patient experience. The recommendations are based on patient and family experiences and anchored by PSOP staffs’ contextual understanding and knowledge of PSOP and TOH Cancer Centre. We are very much aware that this is neither a full nor a finished set of recommendations for these priority areas. We rather like to see it as a work-in-progress and look forward to continuing this dialogue. We hope that this project serves an example of how patients and family members can collaborate on program improvement initiatives with the goal of improving services and the patient and experience.

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Appendix A

Table 1: Inclusion and Exclusion Criteria for PFEC

Inclusion Criteria	Exclusion Criteria
Patients or family members will be over the age of 18.	Patients or family members younger than 18 will be excluded.
Patients or family members will have accessed PSOP services at least twice.	Patients or family members that accessed services only once will be excluded.
Patients currently receiving PSOP services or received services within a year of the establishment of the advisory group will be included.	Patients that received PSOP services greater than a year after the establishment of the advisory group will be excluded.
Family members currently receiving PSOP services or received services within a year of the establishment of the advisory group.	Family members that received PSOP services greater than a year after the advisory group was established will be excluded.
Family members currently accessing PSOP services or within the last two years of a deceased family member.	Family members of a deceased patient that received PSOP services greater than two years after the establishment of the advisory group will be excluded.
All patients and family members will live within the Champlain Local Health Integration Network (LHIN) catchment area.	Patients and family members living outside the Champlain Local Health Integration Network (LHIN) catchment area will be excluded.
Select members must be able to attend the orientation session.	Select members unable to attend the orientation session will be excluded.

Appendix B

THE PSYCHOSOCIAL ONCOLOGY PROGRAM (PSOP) PATIENT & FAMILY ENGAGEMENT COMMITTEE - TERMS OF REFERENCE

BACKGROUND

The Psychosocial Oncology Program (PSOP), comprised of a multidisciplinary team, supports patients with cancer and their family by providing mental health and rehabilitation services to ensure patients truly receive comprehensive clinical services. This concept is clearly stated in the vision for the PSOP which is *“to lead the country as an integral part of the provision of excellent inter-professional care to enhance the experience of people living with cancer”*.

The PSOP recently celebrated its 5th anniversary and is committed to continuing to offer the best possible psychosocial oncology services for their patients and family members. The PSOP *Patient and Family Engagement Committee* (PFEC) has been created as a means of partnering with patients and family members in reviewing the program goals as well as the current services being offered by the program. Through this program review, the PSOP hopes to identify gaps in their services and develop recommendations for The Ottawa Hospital to continuously strive to better meet the needs of their patients.

PURPOSE OF THE PFEC

Overall, the purpose of the PFEC is to collaborate on a program improvement project that will assist in improving the patient and family experience across the cancer journey. Through conversation with multiple stakeholders of the program that have unique experiences and needs (patient, family member, clinician, management, etc.), the goal is to collaborate on finding ways to continuously improve the services being offered by PSOP.

CORRESPONDING RESEARCH STUDY

In recent years, there have been increased efforts in partnering patients and family members in the improvement of health services. However, there is little research into the best approaches to use when patients/family members partner with health professionals on a program improvement initiative. Further, the impacts of this type of collaboration/partnership on health programs is not clear as well as the impact it has on patients/family members/health professionals involved in this process.

In conjunction with this PFEC program improvement project, a research study, conducted by Nathalie Gilbert, will be examining the process (what helps or hinders) of involving patients and family members in working collaboratively with health professionals in improving health services. More specifically, patient and family

member perspectives as well as those of health professionals involved in the PFEC will be examined.

SCOPE

The scope of the PFEC is to share ideas based on patient/family member experience to:

- ☐ Review the existing vision, goals, and logic model of the PSOP. Do they remain relevant?
- ☐ Identify areas of improvement/issues affecting the patient and family experience in psychosocial health during their cancer journey. How can the psychosocial services offered at The Ottawa Hospital (TOH) be made more patient and family centred? Specific attention will be given to the navigation of cancer care education sessions offered by the PSOP.
- ☐ Provide recommendations for each of the identified areas of improvement/issues on how psychosocial services can be made more patient and family-centred at TOH.
- ☐ A final report and updated PSOP logic model will help guide the next phase of PSOP's program improvement efforts.

MEMBERSHIP

- ☐ Chair –Nathalie Gilbert, PhD Candidate, University of Ottawa.
- ☐ Patient and Family members living within the Champlain LHIN catchment area (8 members)
- ☐ Selected PSOP health professionals (5 members)

TERM

- ☐ The term is a maximum of 1 year membership.
- ☐ Members may withdraw from membership at any time and by any means (i.e. written or verbal).

MEETINGS

- ☐ Monthly meetings from November to April (4:30pm-6:00pm) as well as one focus group in June 2013.
 - First meeting: November 6th, 2013= PSOP Group Room C1115
 - Second meeting: December 4th, 2013=Cancer Centre Board Room C2445
 - Third meeting: January 8th, 2014 (Second Wednesday of the month due to Xmas holidays) Cancer Centre Board Room C2445
 - Fourth meeting: February 5th, 2014 Cancer Centre Board Room C2445
 - Fifth meeting: March 5th, 2014 Cancer Centre Board Room C2445
 - Sixth meeting (if required): April 2nd, 2014 Cancer Centre Board Room C2445

- ☐ The agenda, minutes and related materials will be provided by Nathalie Gilbert at least one week prior to the meeting date.
- ☐ Members may be asked to review and comment on relevant documents circulated electronically between meetings.
- ☐ Recommendations will be made by consensus of the members.

ACCOUNTABILITIES OF MEMBERS

- ☐ Collaborate and contribute to PFEC agenda items.
- ☐ Regularly attend and be an active participant in committee meetings.
- ☐ Prepare for meetings as well as review and comment on minutes and reports.

Appendix C

Strengths of the Psychosocial Oncology Program

- ☐ Clinical expertise of the PSOP professionals that includes professionals from mental health and rehabilitation disciplines.
- ☐ High functioning interprofessional team.
- ☐ Genuinely want to provide good care to their patients and family members. They seem to really care.
- ☐ Try to schedule appointments to correspond with other medical appointments if possible.
- ☐ Program recognizes global impact on patients' lives/recognizes the impact post treatment with survivorship issues.
- ☐ Serve as advocates.
- ☐ One on One consultation with highly trained professionals.
- ☐ Workshops and education sessions (look good, feel better; Coping with Holiday Stress workshops).
- ☐ Allowing family members to participate in appointments.
- ☐ Ability to call nurse anytime to support haematologist (outside of PSOP, but very helpful).
- ☐ Kindness and empathy of support staff.
- ☐ Cheerfulness and energy of staff on the 5th floor (outside of PSOP).
- ☐ Assistance with driving
- ☐ Volunteers throughout the hospital to help direct people.
- ☐ Intake and triage process of PSOP to identify those with highest need.
- ☐ Hopefully feel responded to in a timely manner.
- ☐ Comes to a place that hopefully supports many of patients' needs.
- ☐ PSOP specialist helps guide you through cancer journey.
- ☐ Having continued access to program after family member dies as well as reassuring to patient to know loved one will continue to be supported.
- ☐ Access to homecare.
- ☐ Wig salon
- ☐ Exercise specialist and dietician gave a focus and something to work on.
- ☐ Recognize impact of caregivers and offer support to them.
- ☐ Reduces isolation and gives an outlet.
- ☐ Provides information about services available outside of program (i.e., finances, community physio, etc.).
- ☐ Beautiful location and lovely fireplace.
- ☐ Can self-refer to program.
- ☐ Access to many multidisciplinary services free of charge.

Appendix D

Issues and Priority Areas for the PSOP

1. Navigation of Health Care System After Cancer Diagnosis
2. Lack of Awareness of the PSOP Services within TOH
3. Waiting Time to Receive PSOP Services
4. Fear and Feeling of Isolation as an In-Patient
5. Development of Key Outcome Measures to Demonstrate Impact of the PSOP
6. Feeling Overwhelmed with Responsibility of Caring for Loved One (i.e., multiple meds, appointments, care, etc.)
7. PSOP not Considered Integral to Cancer Care
8. Help with Time Management with Multiple Appointments/Services
9. Help with Family Dynamics during Stressful Treatment Period
10. Help with Physical Limitations (i.e., energy, pain, feeling stoned from meds.)
11. Help with Loss of Ability to Drive/Limited Volunteer Drivers
12. Lack of Access to Services Required (i.e., West End does not include all specialities)
13. Time Restraints on PSOP Services due to Demand
14. Referral to the PSOP does not always Connect Patients/Family Member to Services/Specialist Required
15. Increase Uptake/Participation of Group Sessions/Workshops
16. PSOP Services (i.e., 1-1 counselling/workshop) Need to Provide Constructive Steps or Actions (Do Not Want to be Passive Participants)
17. Difficulty to Connect with People that may have Similar Illness (i.e., learn from their experience, what to expect, etc.)
18. Parking Costs & Difficulty getting there with Physical Limitations

Appendix E

The Ottawa Hospital Cancer Centre Psychosocial Oncology Program Priority Setting, Wait Listing and Discharge Guidelines (Abbreviated version)



The Ottawa Hospital Cancer Centre Psychosocial Oncology Program Priority Setting, Wait Listing and Discharge Guidelines (Abbreviated version)

Each professional discipline has established service parameters indicating when a patient will be discharged from our services. As a team mandated to provide care for complex and acute needs, we must endeavour to refer patients to community resources as appropriate according to the level of needs.

The following were the proposed levels of PSO care with wait times from CCO as of May 2012:

Level	Assessed level of Stress	ESAS	Intervention	Provider	Timeline
1	Minimal	-	Informational and basic practical support	Health care team, patient education	Within 4 weeks
2	Mild	0-3	Emotional, spiritual and peer support	Nursing, social, worker, psycho-education, peer-support, chaplain	Within 4 weeks
3	Moderate	4-6	Counseling, time limited therapy, skills training, specialized therapy for depression, anxiety, relationship problem	Psychologist, social worker, advanced practice nurse, chaplain, psychiatrist, advanced practice nurse, social worker, couple/family therapist	Within 1-4 week
4	Severe	7-10	Intensive or comprehensive therapy for acute and complex problems	Mental health team, psychiatrist	Within 24 hours

All disciplines except social work indicated that these criteria were too vague to base priorities and waitlist times on.

As of September 2012, we have been capturing the following data in Mosaik:

- ☐ date of referral;
- ☐ priority category;
- ☐ planned # of weeks on wait list;
- ☐ actual # of weeks on wait list; patient declining referral;
- ☐ patient requesting shorter wait time and/or priority category change due to circumstances; efficiencies upon appointment cancellations.
- ☐ We will thus be able to call up weekly reports to ensure that patients are not being held on the wait list longer than planned.

Letters will be sent out to patient for his/her information regarding the status of their referral but also interim services available when we know they will wait for at least three weeks.

Referral Process through Mosaik

Bucket 1 – UC	Bucket 2 – IC	Bucket 3 – UC/IC	Bucket 4 - Weekly
-Referral completed and sent via Mosaik - Pick-up from Modules and CTU	Receive through Mosaik notification: - IC to review the chart to clarify issues and help with priority category determination - IC to determine priority category in Mosaik - IC to determine the longest acceptable waitlist category - IC to assign to professional if there is a clinical reason	- UC (or IC in UC's absence) to assign within the priority category when possible and then within least amount of wait time as possible within the disease site when applicable. - E + P1 (without Wait Categories) should be assigned regardless of disease site.	Each week, UC to run Mosaik report weekly to find who is 'due' to be scheduled according to wait time allocation to avoid undue delays.

Discipline: Speech-Language Pathology

Priority Setting

Prioritization for assessment/management of consults to SLP is dependent on many factors and is dynamic; SLP frequently re-prioritizes cases depending on patients needs. SLP responds to interprofessional alerts

Priority 1 – wait list for up to 4 weeks

- ☐ Head and Neck cancers within clinic setting presenting with acute dysphagia (swallowing issues)
- ☐ Others disease sites presenting with acute dysphagia
- ☐ No previous SLP assessment

Priority 2 – wait list for up to 8 weeks

- ☐ Tracheotomised patient with acute dysphagia
- ☐ Dysphagia (swallowing dysfunction)
- ☐ Head and Neck cancers – no acute dysphagia; provision of preventative swallowing exercises
- ☐ Communication: dysarthria
- ☐ Communication: aphasia

All other referrals are reviewed and facilitated; referrals are made to the most appropriate out patient services (e.g. Montfort Hospital or Voice Disorders Program).

Wait Listing Guidelines

- ☐ When a patient is in active treatment, the radiation oncology team can alert SLP when an issue becomes acute.
- ☐ A Registered Dietitian may contribute and follow during daily treatment; if an issue becomes acute, she can alert SLP.
- ☐ Area of unmet needs: communication issues specific to CNS patients (e.g. brain tumours).
- ☐ If the patient is in follow up, i.e. not in active treatment, the risk areas are aspiration (choking, pneumonia), dehydration and feeding challenges.

Discharge Criteria

SLP attempts to follow Cancer Care Ontario (CCO) Guidelines for the Management of Health and Neck Cancer in Ontario. She continues to follow patients for approximately one year post completion of active treatment primarily regarding swallowing issues. She ensures a lead up to discharge at the 11th month post completion of treatment and if the patient's symptoms are stable she discharges the care following their 12 month follow up appointment in the Head and Neck clinic.

Ongoing active issues such as swallowing dysfunction, restricted diet and enteral feeding are followed indefinitely. If instrumental assessments are needed, those are completed. If symptoms are stable, care is discharged.

If new consult > 1 year post completion of therapy and not previously followed by PSOP SLP, the patient is referred to out patient dysphagia services at TOH, General Campus.

Discipline: Nutrition

Priority Setting

If referred patient has no issues upon referral he/she will be seen when treatment starts.

Emergency- same day: Out of town with priority 1

Priority 1 High risk- contact within 1 week

- ☐ Head and neck cancer, oesophageal, stomach, pancreatic cancer (combined chemo & RADS > 10 fractions);
- ☐ Stomach, on chemo only
- ☐ Bowel obstruction or fistula
- ☐ Unable to swallow (dysphagia)
- ☐ Tolerating only clear fluids x 5 days
- ☐ Tube feeding (on treatment)
- ☐ Severe acute symptoms interfering with oral intake and/or hydration status (such as mucositis, diarrhea, intractable vomiting)
- ☐ Severe weight loss: >2 %/1week or > 5%/ 1 month or >10%/ 6 months (patients that are not palliative)

Priority 2 Moderate risk – contact within 2 weeks

- ☐ Esophageal, stomach, pancreas (on chemo only)
- ☐ Other GI (colon, colorectal, hepatocellular, gallbladder)
- ☐ Lung (concurrent chemo & RADS > 10 fractions)
- ☐ Involuntary wt loss (>5% in 1/12 or >10% in 6/12)
- ☐ Radiation < 5weeks
- ☐ Moderate weight loss: 1-2%/ 1 week or 5 %/1 months or 10%/ 6 months

Priority 3 Low risk - contact as time permits (Nutrition classes ONLY)

- ☐ Carry over only (or at risk of developing only) diarrhea and/or nausea- Gyn/GU on RADS – Invite to Nutrition class for nausea/vomiting and diarrhea (“preventing dehydration”)
- ☐ Other mild - moderate side effects or complaints - Invite to “Nutrition During Treatment”
- ☐ No future treatment plans or no treatment for past 3 months

Priority 4 Prevention or Healthy eating (Nutrition classes ONLY)

- ☐ Cancer prevention & general nutrition information- “Invite to Nutrition After Treatment”

Inappropriate Referrals

- ☐ Issues unrelated to cancer/ cancer treatment: (i.e.: Weight management (requires weight loss); Diabetes management; Crohn’s)
- ☐ Referral to: Consulting Dietitians or community programs or TOH clinics (outpatient clinics)

Wait list: Invite to nutrition class or group patients with similar issues together (small group intervention)

Discharge

- ☐ Most patients are discharged after treatments are completed
- ☐ Patients are encouraged to call the Dietitian if issues/questions in future
- ☐ Patient on tube feedings are transferred to a Dietitian from Community Care Access Centre (CCAC) for ongoing follow up
- ☐ Only those with significant issues will be followed post treatment

Discipline: Physiotherapy

Priority Setting

- ☐ Priority 1 (within 1 to 3 weeks): acute respiratory issues; acute onset lymphedema; Safety issues and falls at home; pre-radiation with mobility issues (when possible)
- ☐ Priority 2 (within 4-6 weeks): Pain (related to cancer which is being addressed by MD); post-operation; pre/post-radiation
- ☐ Priority 3 (within 6-8 weeks): Have had Physiotherapy intervention for presenting problem already, chronic issues related to their cancer; general deconditioning secondary to pathology or long hospital stay (not unsafe at home)

Wait List Guidelines

PSOP Priorities and Recommendations

351

To ensure contact while they wait, patients who are referred for lymphedema and respiratory issues should be registered to the two associated education sessions, if this is timely. Appointments to be given in priority order according to date they are received.

Discharge Criteria

This is generally at the professional's discretion. Once the problem list is assessed, the treatment goals are established and the treatment plan is captured. This can and should be constantly re-evaluated throughout intervention as the scenario changes. Outcome measures are constantly monitored. Goals of treatment are usually achieved after 6-8 sessions. These sessions may need to be spaced out over an extended time frame, to promote measureable change. 10-12 sessions may be the upper limit of sessions provided to a patient.

Discipline: Psychiatry

The Psychiatric Services offered in the PSOP range from a psychiatric consultation with recommendations, to brief or short-term treatment with both psychotherapy and psychopharmacology approaches. The lack of resources does not allow provision of long-term follow-up.

EMERGENCY - Code E: [Wait time= 24-48 hours]

- ☐ Cancer patient with acute suicidal or homicidal ideation
- ☐ Agitation/aggression related to a psychiatric issues/disorder
- ☐ Psychosis
- ☐ Confusion/Delirium

-PSOP intake coordinator may be contacted for consultation and direction

PRIORITY 1 - Code P1W0 or P1W1: [Wait time= 1 week]

- ☐ Severely distressed patients
- ☐ Very significant/severe mood, anxiety or other psychiatric symptom
- ☐ Psychiatric symptoms that interfere with treatment, treatment compliance, refusal of treatment and significant conflict with the treatment team.

PRIORITY 2 - Code P2W0 or P2W1: [Wait time= 2-3 weeks]

- ☐ Moderately distressed patients
- ☐ Significant mood/anxiety or other psychiatric symptom

PRIORITY 3 - Code: P3W1 or P3W2: [Wait time= 4 weeks]

- ☐ Mildly distressed patients
- ☐ Mild mood/anxiety or other psychiatric symptom
- ☐ Review of medication or other recommendation

Discharge Criteria

- ☐ The number of sessions may range from 1 to 10, with 4-6 being the average.
- ☐ Discharge planning and clear goals will be discussed during the first session.
- ☐ Long-term follow-up is not available because of the lack of resources and Rx can only be renewed for a limited period of time.
- ☐ A letter or documentation will be forwarded to the family physician to optimize transfer of care back to the community.

Discipline: Psychology

Priority Setting

PRIORITY 1 - Code P1W1: [Wait time= 1 week]

Patient is not adhering to current treatment or current treatment is compromised due to anxiety (e.g., generalized anxiety, panic disorder, phobia, post-traumatic stress); depression (including suicidal ideation, although active suicidal ideation should be referred to the appropriate psychiatry service); fear of pain; conflict with medical team members etc.:

- ☐ Pt will be called by the unit coordinator or by a Psychologist for brief telephone assessment/intervention within 1 week.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

PSOP Priorities and Recommendations

361

- ☐ Patient will be assessed and recommendations will be made to help patient cope in the short-term, although the patient may have to wait to be seen in psychotherapy.

PRIORITY 1 - Code P1W2: [Wait time= 2 week]

Patient presenting challenge to the team due to interpersonal functioning difficulties:

- ☐ The team will be consulted within 2 weeks.
- ☐ Patient will be called by the unit coordinator or by a Psychologist for brief telephone assessment/intervention within 2 weeks.
- ☐ Patient will be assessed and recommendations will be made to help team members and the patient cope in the short-term, although the patient may have to wait to be seen in psychotherapy.

PRIORITY 2 - Code P2W8: [Wait time= up to 8 weeks]

Diagnostic assessment and psychotherapy for patients who have been referred by and are being followed by a Social Worker until Psychological services become available and 1) are newly diagnosed with cancer and/or in treatment and/or are palliative, and 2) are not also referred to Psychiatry:

- ☐ Patient will be seen within 2 months

PRIORITY 2 - Code P2W16: [Wait time up to 16 weeks]

Diagnostic assessment and psychotherapy for patients who have been referred by and are being followed by a Social Worker until Psychological services become available and 1) are in a survivorship phase, or 2) are also referred to Psychiatry:

- ☐ Patient will be seen within 4 months

GROUP – Time will be reserved to screen patients for group each week.

Wait Listing Guidelines

Patients are waitlisted by the intake coordinator according to priority categories. These are classified according to information from the referral but mostly from the social work assessment as it is assumed that the majority of patients will have been assessed by Social Work.

Treatment Guidelines and Discharge

Treatment is structured within a maximum of 10 session framework. In cases where the patient is making significant progress but treatment goals remain unmet and appropriate options for alternate treatment do not exist, the psychologist may offer an extension to psychotherapy services.

Discipline: Social Work

Social Work Services	Wait Listed 1 week	Wait Listed 2 weeks	Wait Listed 3 weeks	Wait Listed 4 weeks
Emergency ESAS scores: Anx. & Dep. = 7-10	Contact same day or within 48 hours			
Priority 1 ESAS scores: Anx. & Dep. = 7-10	2 weeks	3 weeks		
Priority 2 ESAS scores: Anx. & Dep. = 4-6	3 weeks	4 weeks	5 weeks	6 weeks
Priority 3 ESAS scores: Anx. & Dep. = 4-6	4 weeks	5 weeks	6 weeks	7 weeks
Priority 4 ESAS scores: Anx. & Dep. = 1-3	Directly to education sessions and groups			

Priority Setting

EMERGENCY - [within 24 hours]

- ☐ Overhead hospital codes at TOHCC/IGFCC
- ☐ Suicidal/ Homicidal Ideation
- ☐ Abusive situation (physical, emotional, sexual, financial) in the home
- ☐ Significantly high level distress (tearful, aggressive, agitated, overwhelmed)
- ☐ Emotional state that could compromise ability to start and/or follow treatment plan
- ☐ Practical assistance that could challenge compliance with treatment (transportation, medication, basic needs, homelessness)
- ☐ At immediate risk in the home (frail elderly, unable to care for themselves),

- ☐ Planning needed to avoid immediate hospital admissions
- ☐ Significant errors, near misses or patient safety issues with regards to clinical care
- ☐ These indicators are also important as they are the ones to base a decision to have a referral 'jump the queue'.

PRIORITY 1 - Code P1W1 to P1W3: [Wait time= 1-3 weeks]

- ☐ Abusive situation (physical, emotional, sexual, financial) in the home
- ☐ At risk in the home (frail elderly, unable to care for themselves, caregiver burnout), Planning to avoid hospital admissions
- ☐ High level of distress: ESAS scores of 7-10 on anxiety/depressive symptoms
- ☐ Non compliance with treatment, History of significant mental health issue that is compromising treatment
- ☐ Homeless/at imminent risk of eviction
- ☐ Out of town patients, geographic barriers to treatment
- ☐ Errors, near misses or patient safety issues with regards to clinical care.
- ☐ Urgent end of life planning
- ☐ Prognosis of less than 6 months and person has young children
- ☐ Financial difficulties (including complex insurance and drug coverage) hindering capacity to manage daily needs or impede tx
- ☐ HEM patients needing drug coverage for eminent BMT
- ☐ Motivated and asking for coping mechanisms

PRIORITY 2 - Code P2W1 to P2W4: [Wait time= 2-6 weeks]

- ☐ Individual, Family and Group cancer adjustment counselling, Caregiver burnout
- ☐ System Navigation and advocacy needs
- ☐ Recent, significant, losses that impact ability to cope with cancer
- ☐ Need for alternative living arrangements
- ☐ Non urgent end of life planning, future planning and legal issues (POA, SDM, Will, etc)
- ☐ Addictions that may compromise treatment
- ☐ Complex Drug coverage
- ☐ Medium level of distress (ESAS scores of 4-6 on anxiety and/or depression)

PRIORITY 3 - Code P3W1 to P3W4: [Wait time= 3-7 weeks]

- ☐ Resource information and community referral
- ☐ Survivorship/ Return to work/ vocational issues
- ☐ WSIB applications related to workplace exposure to known carcinogens
- ☐ Coping strategies & Individual, Family and Group cancer adjustment counselling
- ☐ Medium level of distress (ESAS scores of 4-6 on anxiety and/or depression)

Wait Listing Guidelines

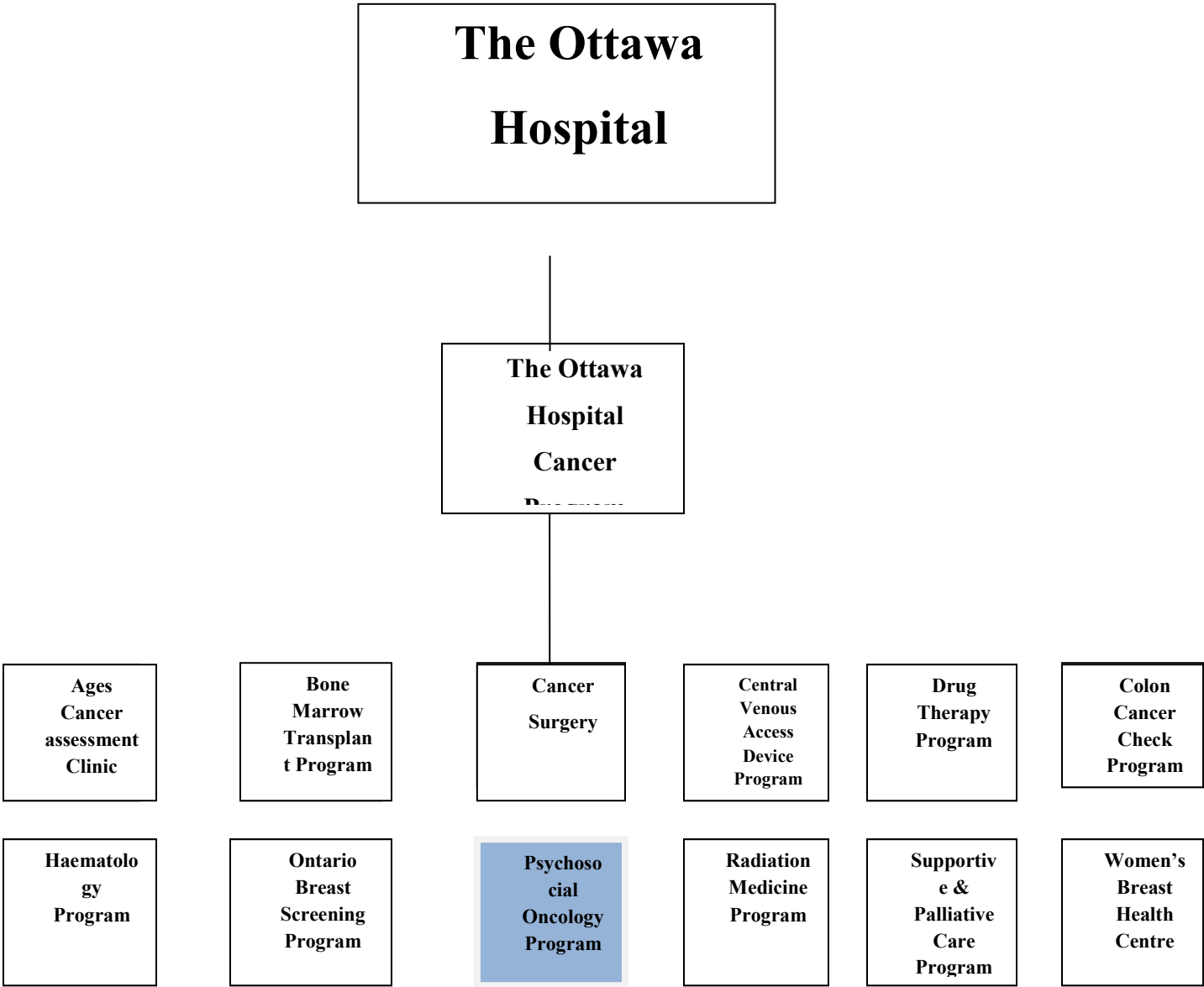
Each full-time social worker will not be assigned more than thirty new patients per month, which are no more than seven new patients per week with two extra over the course of one month likely to be assigned to cover emergencies.

Discharge Criteria

To ensure excellent patient-centred care, social workers must use their professional judgement to determine, with their client, the goals of the intervention and service they provide. In addition, the following guidelines should assist them in managing their caseload to ensure an efficient and clinically indicated flow through of patients.

- ☐ Brief intervention: one or two sessions or Short term counselling: 4-6 sessions
- ☐ Long term counselling: approximately 12 interventions over the course of their cancer trajectory, this may need to be reviewed for palliative patients.
- ☐ Discharge methodology and expectations: it is deemed sufficient to ensure that the last documentation on the patient's chart contains a short summary statement indicating the work done and the communication accomplished with the patient to ensure that they are aware of how to access services in the future as need arises.

Appendix C
Ottawa Hospital Psychosocial Oncology Program Organizational Chart



Appendix D

Initial Announcement Sent to Potential Participants



The Ottawa Hospital Psychosocial Oncology Program (PSOP)

**PARTICIPANTS NEEDED FOR
RESEARCH RELATED TO A PATIENT AND FAMILY ENGAGEMENT COMMITTEE**

Have you or one of your family members received care from the Psychosocial Oncology Program? If so, we are seeking your input as part of a new Patient and Family Engagement Committee. As part of the creation of this new engagement committee we would like to study the process of patients and family members working collaboratively with health professionals from the PSOP on a program improvement initiative.

As a participant in this study, you would be asked to be a member of the engagement committee, attend meetings at the Ottawa Hospital and be willing to be interviewed at three separate times during the project.

Your participation would involve attending approximately 5-6 working meetings of approximately 2 hours. Parking fees will be covered.

For more information about this study, or to volunteer for this study, please contact: ____, PhD Candidate, University of Ottawa at ____ or Email: ____

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Ottawa and the Ottawa Hospital.

Appendix E
Recruitment Poster



The Ottawa Hospital Psychosocial Oncology Program (PSOP)
PARTICIPANTS NEEDED FOR
Research related to a Patient and Family Engagement Committee

Have you or one of your family members received care from the Psychosocial Oncology Program? If so, we are seeking your input as part of a new Patient and Family Engagement Committee. As part of the creation of this new engagement committee we would like to study the process of patients and family members working collaboratively with health professionals from the PSOP on a program improvement initiative.

As a participant in this study, you would be asked to be a member of the engagement committee, attend meetings at the Ottawa Hospital and be willing to be interviewed at three separate times during the project.

Your participation would involve attending approximately 5-6 working meetings of approximately 2 hours. Parking fees will be covered.

For more information about this study, or to volunteer for this study, please contact:

(Name of student), PhD Candidate, University of Ottawa at (student telephone number)
OR Email: *(Student email)*

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Ottawa and the Ottawa Hospital.

Appendix F
Recruitment Letter

[PSOP Manager's signature block]

[Date]

Dear [name].

Greetings! We would like to invite you to consider being a member of the newly formed Psychosocial Oncology Program (PSOP) Patient and Family Engagement Committee. The engagement committee will consist of:

- 10-12 current or past patients or family members who received care from the PSOP;
- 4-5 PSOP health professionals; and
- an evaluator/researcher.

Our program is committed to providing the best care possible for our patients and therefore we have decided to create a committee that will engage our patients/family members and staff to work together on a program improvement project for the purpose of improving the health services that we offer.

Our program is working with (*student name*), a doctoral candidate at the University of Ottawa, who is conducting research on how best to involve patients and family members in the planning and evaluation of health services. As part of the creation of this new engagement committee we would like to study the process of patients and family members working together.

As a participant in this committee and research study, you would be asked to:

- Be a member of the engagement committee;
- Attend approximately 5-6 meetings at the Ottawa Hospital from April to the end of September, 2013;
- Be interviewed at three separate times during the project; and
- Consider continuing to be involved in the engagement committee after the study is completed in the fall of 2013 for another year and a half.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

If you agree to participate, your participation would be voluntary and would involve no risks, but there could be some inconveniences to you (e.g. attending 5-6 meetings and being interviewed three times). You may withdraw at any time. Please note that there will be no consequences to you for choosing not to participate or to withdraw from the study. As you no doubt have many questions, I have tried to anticipate some of them and have provided a response below:

What are the objectives of this study? Overall, the purpose of this research is to learn more about the process (what helps or hinders) of involving patients and families in working collaboratively with health professionals in improving health services. I am particularly interested in examining the patient and family's perspective as well as those of health professionals involved in the PFEC.

Who is the research team? This is my doctoral research project and I will be conducting the research myself, under the supervision of my thesis advisor, Professor Brad Cousins from the University of Ottawa, Faculty of Education. My committee consists of Professor Christine Suurtamm, Professor Angus McMurty of the Faculty of Education and Professor Roanne Thomas from the Faculty of Health Sciences.

What does participation imply? If you agree to participate in this research, I would ask you to be a member of the Patient and Family Engagement Committee for PSOP and to be involved in a program improvement initiative that is identified as important to the PFEC. Further, I would ask you to be involved in two independent interviews (beginning and end of research project) to be conducted by an interviewer that is not involved in the research study. The interview would be conducted at The Ottawa Hospital Cancer Program. The interview would be an estimated 60 minutes in length and with your permission it would be audio-taped to ensure accuracy. Upon completion of the data analysis, you will also have an opportunity to review the results of the case study.

How would the data be treated? All discussions are considered to be private and all of the information collected would be treated as confidential. Although I cannot guarantee anonymity within the group activities, I can assure you that I will be the sole person who has access to the data. There is a possibility that quotations may be included in reports arising from the research, however, your anonymity would be ensured (i.e., personally identifying information would be

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

removed and the contents of the quote would not reveal individual identities). Any data that has been collected will be stored and protected using password protected electronic files for electronic data, master recruitment list will only be stored on the hospital server, hard copy records (i.e., consent forms) will be stored in locked filing cabinets within the program and long-term storage of hardcopy records once the study is complete to an Ottawa Hospital Research Institute approved facility.

What would be the potential benefits of participation for you? I am hopeful that the findings arising from this research and your participation in the process will be useful to your continued participation in the PFEC by identifying what helps and hinders patients and family members being involved in planning and evaluation of health services. Furthermore, the results of this study and the evaluation initiative conducted by the PFEC will hopefully guide the PSOP. Our overall goal is for the PSOP Patient and Family Engagement Committee to continue well past the initial research study and to serve as a model for the rest of the Cancer Program and The Ottawa Hospital.

We would like an opportunity to speak with you to discuss our project; therefore, *(student name)* will call you within two weeks to determine your interest. For more information about this study, or to volunteer/decline to be a member of the engagement committee, please contact the principal investigator: *(student name)*, *PhD Candidate, University of Ottawa*, Tel: *(student number)* or Email: *(student email)*.

We look forward to the possibility of collaborating with you on this exciting project.

Sincerely,

XXXXXXXXXXXXXXXXXXXXX

Psychosocial Oncology Program,
The Ottawa Hospital Cancer Program,
Box #938, 501 Smyth Rd.
Ottawa, ON, K1H 8L6
Tel: 613-737-7700 ext. 7014

Appendix G
Consent Form

Study Title: Understanding the Process of Patient engagement in Planning and Evaluation

Consent to Participate in Research

I understand that I am being asked to participate in a research study that will involve being a member of the PSOP Patient and Family Engagement Committee (PFEC). With the creation of this new PFEC, this research study will examine the process of engaging patients and family members in a planning and evaluation initiative whose aim is to improve the quality of patient-centred health services. This study has been explained to me by the principal investigator, (*student name*).

I have read this 5 page Patient Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study. A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Date

Appendix H

General Participant Observational Template

Observational Category	Things to look for
Appearance	Clothing, age, gender, physical appearance
Verbal behaviour and Interactions	Who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice
Physical Behaviours and Gestures	What people do, who does what, who interacts with whom, who is not interacting
Physical Layout	PFEC Meeting room Seating area/set up Where people sit around the table (i.e. program staff on one side versus pats on the other) Use of technology Food and beverages
PFEC Formal Practices	# of people attending # of patients/family members # of team members # of decision makers Duration of meeting Administrative discussions Agreement/disagreement
PFEC Member Interactions	Informal patient-patient Informal patient-PSOP team member Informal with evaluator PFEC stories/events Who receives more attention than others

Adapted from N. Mack, C. Woodsong, K. M. MacQueen, G. Guest, & E. Namey, *Qualitative Research Methods: A Data Collector's Field Guide*, 2005, Table 3, p. 18.

Appendix I

Draft Interview Guide-Baseline

Introduction:

- Explain the purpose of the research-thank participant for agreeing to be involved
- Review informed consent for both interviews and ask about audio-taping
- Asked to interview you separately to get your opinion on how things are going up till now, since monitoring is only through (*student's name*) perspective.

Background:

- 1. First, I would like to know what made you decide to join the Psychosocial Oncology PFEC?**
- 2. Can you give me your overall perspective on the PFEC?**
 - a) How are things going? Are you comfortable with the setup?
 - b) What is your understanding of what the project goals are?
 - c) Do you think there is agreement on the project goals?
 - d) In general, are the group members fairly like-minded? Do they hold similar views
 - e) Do you perceive any factions or cliques forming within the group?
- 3. Now I would like to know about your perspective on the different roles within the committee?**
 - a) What is your understanding of your role within the PFEC?
 - b) What is your understanding of the roles of the PSOP staff/patients/family members on the engagement committee? How have they influenced the project thus far?
 - c) What do you consider the researcher's (*student's*) role to be on the committee? How has she influenced the project thus far?
- 4. How would you describe the way decisions are being made about the project?**
 - a) Who makes most of the decisions? Joint? Just a few of the health professionals on the team?
 - b) Do you feel like your voice and opinions are being heard?
 - c) Do you feel like you're making an impact?

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

5. What is your impression about the range of people involved in the PFEC?

- a) How do you feel about patients and health professionals working together on a program improvement project?
- b) What do you think about the membership of the engagement committee?

6. How would you describe the level of participation from each of the members in the project thus far?

- a) How have the patient/family members influenced the project thus far?
- b) How have the PSOP staff members influenced the project thus far?
- c) How has the evaluator/researcher influenced the project thus far?

7. What do you hope will come out of the work that the engagement committee is undertaking?

- a) Do you think this work will help contribute to improving the services PSOP offers?
- b) Do you think patients, family members, and staff working together on program improvement projects is a good approach to making health services more patient- centred?

8. What do you see as some of the main facilitators or barriers to continuing this kind of work in the future?

- a) What helped the process?
- b) What hindered the process?
- c) Do you have any suggestions on how the process or approach could be improved or changed?

9. Overall, what is the experience like for you being a member of the PFEC?

- a) Is it positive experience for you thus far? If so, why...
- b) Is it a negative experience for you thus far? If so, why...

10. Finally, is there anything else about the project you would like to comment on?

Thank you

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Draft Interview Guide-Midway

Introduction:

- Explain the purpose of the midway interview, thank participant for agreeing to be involved
- Review informed consent and ask about audio-taping
- Asked to interview you separately to get your opinion on how things are going up till now, since monitoring is only through (*student's name*) perspective.

Background:

- 1. First, I would like to know what made you decide to join the Psychosocial Oncology PFEC?**
- 2. Can you give me your overall perspective on the PFEC?**
 - f) How are things going? Are you comfortable with the setup?
 - g) What is your understanding of what the project goals are?
 - h) Do you think there is agreement on the project goals?
 - i) In general, are the group members fairly like-minded? Do they hold similar views
 - j) Do you perceive any factions or cliques forming within the group?
- 3. Now I would like to know about your perspective on the different roles within the committee?**
 - d) What is your understanding of your role within the PFEC?
 - e) What is your understanding of the roles of the PSOP staff/patients/family members on the engagement committee? How have they influenced the project thus far?
 - f) What do you consider the researcher's (*student's*) role to be on the committee? How has she influenced the project thus far?
- 4. How would you describe the way decisions are being made about the project?**
 - a) Who makes most of the decisions? Joint? Just a few of the health professionals on the team?
 - b) Do you feel like your voice and opinions are being heard?
 - c) Do you feel like you're making an impact?
- 5. What is your impression about the range of people involved in the PFEC?**

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

c) How do you feel about patients and health professionals working together on a program improvement project?

d) What do you think about the membership of the engagement committee?

6. How would you describe the level of participation from each of the members in the project thus far?

d) How have the patient/family members influenced the project thus far?

e) How have the PSOP staff members influenced the project thus far?

f) How has the evaluator/researcher influenced the project thus far?

7. What do you hope will come out of the work that the engagement committee is undertaking?

c) Do you think this work will help contribute to improving the services PSOP offers?

d) Do you think patients, family members, and staff working together on program improvement projects is a good approach to making health services more patient- centred?

8. What do you see as some of the main facilitators or barriers to continuing this kind of work in the future?

d) What helped the process?

e) What hindered the process?

f) Do you have any suggestions on how the process or approach could be improved or changed?

9. Overall, what is the experience like for you being a member of the PFEC?

c) Is it positive experience for you thus far? If so, why...

d) Is it a negative experience for you thus far? If so, why...

10. Finally, is there anything else about the project you would like to comment on?

Thank you

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Draft Interview Guide-Termination

Introduction:

- Explain the purpose of the termination interview-thank participant for agreeing to be involved
- Review informed consent for interview and ask about audio-taping
- Asked to interview you separately to get your opinion on how things are going up till now, since monitoring is only through (*student's name*) perspective.

Background:

- 1. Can you give me your overall perspective on the PFEC now that the project is complete:**
 - a) How did the project turn out? Were you comfortable with the setup?
 - b) Do you think there was agreement on the final recommendations?
 - c) In general, were the group members fairly like-minded? Did they hold similar views? Where did they differ most?
 - d) Did you perceive any factions or cliques forming within the group?
- 2. Now I would like to know about your perspective on the different roles within the committee?**
 - a) What do you think your role was within the PFEC?
 - b) What do you think the roles of the PSOP staff/patients/family members were on the engagement committee? How did they influence the project?
 - c) What do you consider the researcher's (*student's name*) role to have been on the committee? How did she influence the project?
- 3. What is your impression about the range of people involved in the PFEC?**
 - a) How do you feel about patients and health professionals working together on a program improvement project?
 - b) What do you think about the composition of the engagement committee?
- 4. How would you describe the way decisions were made during the project?**
 - a) Who made most of the decisions? Joint? Just a few of the health professionals on the team?
 - b) Do you feel like your voice and opinions were heard?
 - c) Do you feel like you made an impact?
- 5. How would you describe the level of participation from each of the members during the project?**

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

- a) How did the patient/family members influence the project?
 - b) How did the PSOP staff members influence the project?
 - c) How did the evaluator/researcher influence the project?
- 6. What do you hope will come out of the work that the engagement committee completed?**
- a) Do you think this work will help contribute to improving the services PSOP offers?
 - b) Do you think patients, family members and staff working together on program improvement projects is a good approach to making health services more patient-centred?
- 7. What do you see as some of the main facilitators or barriers to continuing this kind of work in the future?**
- a) What helped the process?
 - b) What hindered the process?
 - c) Do you have any suggestions on how the process or approach could be improved or changed?
- 8. Overall, what was the experience like for you being a member of the PFEC?**
- e) Was it a positive experience? If so, why...
 - f) Was it a negative experience? If so, why...
- 9. Finally, is there anything else about the project you would like to comment on?**

Thank you



Appendix J
Information Sheet

Study Title: Understanding the Process of Patient engagement in Planning and Evaluation

Principal Investigator: (*Student's name*) PhD Candidate, Tel. _____

Co-Investigators: Dr. Caroline Gerin-Lajoie and Dr. Cheryl Harris

Introduction and Purpose of Study:

You are being asked to become a member of the Psychosocial Oncology Program (PSOP) Patient and Family Engagement Committee (PFEC). We hope to recruit between 10-15 participants to be on the committee from the Ottawa hospital Cancer Program, including staff from the Psychosocial Oncology Program. In recent years, there have been increased efforts of engaging patients and family members in the improvement of health services. However, there is little research into the best approaches to use when patients/family members work with health professionals collaborating on a program improvement project. Further, the impacts of this type of initiative on health programs is not clear as well little is known about what the experience is like for patients/family members/health professionals of working together on program improvement initiatives.

What are the Objectives of this Study?

Overall, the purpose of this research study is to learn more about the process (what helps or hinders) of involving patients and family members in working collaboratively with health professionals in improving health services. More specifically, patient and family perspectives as well as those of health professionals involved in the PFEC will be examined.

What does Participation Imply? If you choose to participate in this research, you will become a member of the Patient and Family Engagement Committee for PSOP and be involved in a program improvement initiative. Further, you will be involved in three separate interviews (baseline, midway and at the end of the project) to be conducted by an independent interviewer that has not been involved in the project. The interviews will be conducted at The Ottawa Hospital Cancer Program or at a location that is convenient for you. The interviews would be an estimated 30-45

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

minutes in length and will be audio-taped to ensure accuracy. Two to Four months following the completion of the project, I would ask you to participate in a 2 hour focus group with all members of the PFEC to provide an opportunity for all members to review and discuss the preliminary results of the case study collectively.

How long will the study be? The study will last approximately 1 year, beginning from the initial meeting to the final focus group.

Are there any risks to participating? There are no risks to participating in this study, however, although individuals are asked to keep the identity of others and discussions in the focus groups confidential, this cannot be monitored.

What Would be the Potential Benefits of Participation for You? You may not receive any direct benefit from participating in this study. Your participation in this research may contribute to the development of best practices and approaches to engaging patients and family members in the planning and evaluation of health services. Furthermore, the results of this study will hopefully guide the PSOP to continue to engage their patients and family members in program improvement initiatives to better meet the needs of our patients.

Can I Withdraw From the Study? You do not have to participate in this research study. If you choose to participate, your participation would be voluntary. If you choose not to participate, your decision will not affect the care you receive at this Institution at this time, or in the future. You will not have any penalty or loss of benefits to which you are otherwise entitled to. You may withdraw at any time. You may also choose to not answer any question which makes you feel uncomfortable.

Will the study cost me anything? You will not be paid to participate in this research study; however, you will be reimbursed for parking for visits related to this study, with receipt.

What if there is New Information about the Study? You will be told of any new findings during the study that may affect your willingness to continue to participate on the PEC. You may be asked to sign a new consent form.

How Would Confidentiality Be Maintained? All personal health information will be kept confidential unless release is required by law. Once the session is audio recorded it will be moved onto the secure hospital server, and the recording will be deleted from the audiotape. All transcripts will be saved to a secure hospital server. Representatives of the Ottawa Health Science Network Research Ethics Board and the University of Ottawa Research Ethics Board may review relevant study records under the supervision of (*student's name*) staff for audit purposes.

You will not be identifiable in any publications or presentations resulting from this study. No identifying information will leave the Ottawa Hospital. All information which leaves the hospital will be coded with an independent study number.

The link between your name and independent study number will only be accessible by (*student's name*) and her staff. The link and study files will be stored separately and securely. Both files will be kept for a period of 10 years after the study has been completed. All paper records will be stored in a locked file and/or office. All electronic records will be stored onto the secure hospital server and protected by a user password, again only accessible by (*student's name*) and her staff. At the end of the retention period, all paper records will be disposed of in confidential waste or shredded, and all electronic records will be deleted.

Who do I Contact if I have Questions/Concerns about the Study? The Ottawa Health Science Network Research Ethics (OHSN- REB) and the University of Ottawa Research Ethics Board have reviewed this protocol. The OHSN-REB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Health Science Network Research Ethics Board at 613-798-5555, extension 14902.

Appendix K
Consent Form

Consent to Participate in Research

I understand that I am being asked to participate in a research study that will involve being a member of the PSOP Patient engagement Committee (PFEC). With the creation of this new PFEC, this research study will examine the process of engaging patients and family members in a planning and evaluation initiative whose aim is to improve the quality of patient-centred health services. This study has been explained to me by the principal investigator, (*student's name*).

I have read this 5 page *Patient Information Sheet* and *Consent Form* (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study. A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above research participant, to respect the rights

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Date

Appendix L

PSOP Patient and Family Engagement Committee Case Study Profile

Report prepared by: *(student's name)*, University of Ottawa

July, 2014

Background

In the fall of 2013 the Psychosocial Oncology Program (PSOP) created the **Patient engagement Committee (PFEC)** which consisted of PSOP staff, an evaluator/researcher and patient and family members who had received services from the PSOP. The overall purpose of the PFEC was to assist the PSOP in identifying priority areas and recommendations to guide PSOP in improving their services with the ultimate goal of improving the patient experience. More specifically, through conversation with committee members that have unique experiences and perspectives, the goal was to learn from one another and find ways to continuously improve the services being offered. The draft report on the identified priority areas and committee recommendations is currently with the PFEC members for review and feedback and is not addressed in this report.

In conjunction with this program improvement initiative there was a **concurrent doctoral research study** conducted by (*student's name*) from the University of Ottawa, who had a research interest in further understanding the process of patient engagement in planning and evaluation of health services. More specifically, she wanted **to examine the process of involving patients and family members in working collaboratively with health professionals in improving health services** as well as to learn more about their perspective on involvement in this type of activity. One of the data collection components for this study involved interviews with all members of the PFEC at three separate intervals (November, February and May). These interviews were completed by an independent interviewer, Barbara Szijarto, who was not involved in the PFEC process. We heard from: 4 PSOP patient representatives, 2 PSOP family representatives, 1 PSOP clinical manager, 1 PSOP psychiatrist, 1 PSOP psychologist and 1 PSOP social worker.

The interview questions were almost identical for each of the interviews with the exception of a few changes to reflect what stage the project was at (i.e., beginning, midway or end of project). The interview questions were focussed on gaining a better understanding of the process of patient engagement in evaluation or a program improvement initiative. For example, some questions related to the facilitators and/or barriers of patients and family members working collaboratively with health professionals. Other questions explored the intended and unintended effects of engaging patients in evaluation or the program improvement process. Finally, there was a set of questions that addressed different dimensions of working collaboratively (i.e., range of people on the PFEC, how decisions were made, roles, etc.). This next section presents a summary of what

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

was heard during the interviews from the PFEC as a whole. The purpose of sharing these summaries is to validate and possibly expand what has been heard in a focus group format. For each interview question a general response summarizing the group's overall thoughts has been provided.

Preliminary Findings

What were some of the reasons/motivations for joining the PSOP Patient and Family Engagement Committee?

Overall, most patients and family members joined the PFEC as a way of “giving back” to the program and/or the hospital for the care they had or are continuing to receive. Patients were very appreciative of the services received and this was one way of helping others in similar situations. Despite being very satisfied with the services received at PSOP, many patients wanted to contribute to the project to find strategies to assist other cancer patients and family members to be made more easily aware of PSOP and have an easier time getting referred to the program.

In general, PSOP staff became involved because of their desire to learn from their patients and family members on ways to improving their program. Some staff members had some experience working on projects related to improving Patient-Centred Care (PCC) at the Ottawa Hospital, so this was a natural fit with the work they were already involved with. Others had some research and evaluation responsibilities for PSOP and felt this was a good direction to take in order to begin collaborating with their patients. From the program perspective there was also an acknowledgement that sometimes when trying to improve services that professionals can make assumptions without consulting stakeholders. In general, they all felt that they could benefit from asking for their input and feedback about the program. Finally, there had been a desire to involve patients and family members but the program did not have the resources to commit to this type of project. When the evaluator/researcher suggested this project for her doctoral research it became possible and mutually beneficial for both the program and the evaluator/researcher.

What is your overall perspective of the PFEC?

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Overall, the PFEC members were very pleased to be involved from the beginning to the end of the project and many were disappointed that it was over. All members appreciated the first orientation meeting and felt it was essential that all members share their experiences and why they joined the PFEC.

In the early stages of the project there was some confusion and lack of clarity among some members about the overall goals of the program improvement project and the corresponding research objectives. The majority of the PFEC members were very pleased with the priority areas that the committee focussed on and felt that the committee was putting forth some good advice and recommendations to help PSOP improve their services. In general, the committee felt that it took 3 or 4 meetings to “really get going and get down to business.” The majority of the members felt that there should have been more time to work through the priorities and recommendations and would have liked to have addressed more issues identified during the first few meetings. All committee members expressed throughout the project that collaboration between patients, family members and staff is essential to improving services and PCC. Patients, family members and PSOP staff expressed strong opinions about the importance and responsibility of ensuring that these priorities and recommendations be considered by senior management for implementation. The majority of patients and family members voiced concern or uncertainty that these priorities and recommendations would be implemented due to the limited resources and system level challenges.

This committee is made up of representatives of patients, family members, an evaluator/researcher and PSOP staff, what do you think about.... the different roles and range/diversity of people on the committee (anyone missing), patients and family members working with health professionals?

Overall, most patients and program staff were very clear about their role and how they contributed to the PFEC throughout the project. Patients and family members expressed that they provided a unique perspective having experienced the program and services first hand. They were able to share some of the positive aspects of the care they had received as well as some of the challenges. For example, most patient and family members perceived their role on the committee as representing a certain demographic of people: a family member who lost a loved one to cancer,

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

representing those living outside the city, an immigrant with limited social support systems, a patient who received cancer treatment outside of the Cancer Program, etc. PSOP health professionals shared a similar view of the patient and family role. Patients and family members were also very keen to do “homework” as they called it to maximise the PFEC meeting time. As such, they contributed their monthly input by answering reflective questions related to scoping the priorities and recommendations which contributed to the development of the report.

PSOP health professionals felt their role was to provide information and context about PSOP, the Cancer Program, TOH and the region. Some PSOP staff in leadership roles felt it was important that they provide insights into some of the constraints they must work within as well as what initiatives have been tried in the past and why they did or did not succeed. Other PSOP staff shared that they offer a unique perspective by working on the front line with patients and their families. Patient and family members shared a similar view of the PSOP health professional role on the committee. They also shared that their role on the committee was essential, not only in providing program information, but also in guiding committee members towards priorities and recommendations that are realistic and feasible. Finally, PSOP staff contributed to the background work involved and meetings leading up to the creation of the PFEC. Staff members also provided input to the monthly reflective questions related to scoping the priorities and recommendations, but some share that this was challenging at times due to conflicting demands at work.

PFEC members were all in agreement that the evaluator/researcher role served as a facilitator of the committee and took the lead for the development of the PFEC (i.e., REB submission, recruitment of participants, interviews with potential PFEC members, etc.). In general, the PFEC felt that the evaluator/researcher role was neutral but served in directing the meeting process (i.e., agenda, minutes, communication, etc.), doing work behind the scenes in preparation for the next meeting such as sending reflective questions before each meeting and summarizing all the responses for committee members for discussion. Overall, members agreed that there needed to be an evaluator/facilitator to lead this type of committee, otherwise it could lose its focus. There was some hesitancy on behalf of some members to rotate the facilitator role between members. Two members suggested the possibility of having a professional facilitator/evaluator that is neutral to

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

the program that might be more at ease with interrupting members when discussions have gone off topic.

The members thought the range of people on the committee was well diversified. For example, the PFEC had good representation of patients with different cancer sites, male/female, younger and older members, one family member was from outside of Ottawa, etc. Members also shared that it was very important that patient and family members on the PFEC had recent PSOP or cancer treatment; some members were still undergoing treatment. Some members questioned whether the committee could have functioned as effectively with 1 or 2 less PSOP staff in relation to the number of patient and family members on the committee. The majority of the committee shared that the PFEC was not representative of the population of Ottawa or the patient population that they serve at PSOP. Most members agreed that there was a gap in terms of having representation from people outside of Ottawa, head and neck cancer patients and lower socioeconomic groups. There was acknowledgement from most members that there are significant barriers for recruiting from these groups. Overall, the majority agreed that if another PFEC was to be created some creative strategies would have to be considered to contact and incorporate these patient populations into the patient engagement process.

To what extent were patients and other program community members in control of decision-making?

In general, the members felt that most decisions were made democratically and through consensus. There were one or two occasions where the patient and family members delegated the PSOP staff members to make certain decisions with the evaluator/researcher (i.e., scoping of the program priorities). All members felt that their voice was heard and that everyone had the opportunity to speak and no factions existed within the committee.

In general, members felt that there were instances where some members went off topic or spoke for extended periods that consumed valuable meeting time. It was acknowledged that there is a fine line between allowing members the ability and respect to share their experiences and knowledge and redirecting the conversation to the agenda item. A few members also shared that

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

at times it appeared difficult for some PSOP staff to listen to some of the issues and recommendations being presented without feeling a certain level of advocacy or defensiveness for the program because of their close proximity and commitment to the program.

In general, most members believed that the decision makers within the PFEC heard and were usually receptive to opinions, issues and recommendations. There was however significant concern from the patient and family members that the priorities and recommendations put forth by the PFEC would not be considered past the leadership of PSOP, despite efforts and commitments to do so. This is due in part to the realization, on the part of the patient and family members, of the financial and human resource constraints as well as system level bureaucracy that the PSOP must function within. Conversely, PSOP staff members were cautiously optimistic that the priorities and recommendations put forth by the PFEC would be considered by senior management because they were identified and developed in collaboration with patients and family members. PSOP staff shared that the identification of these priorities is legitimized by the mere fact that they come from patients and family members. Finally, PSOP staff members feel that they have “justification” now for putting pressure for the implementation of some of the recommendations because they were developed by patients and family members of the program.

What do you hope will come out of the PFEC work?

All members hoped that the priorities and recommendations for PSOP would be thoughtfully considered by the PSOP and senior management. In general, the majority of members realize that it is highly unlikely that all recommendations will be implemented, but at a bare minimum hope that cancer patients will be more aware and have better access to PSOP in the future. They also hope that PSOP will be better integrated within the cancer care for all patients. In the end, they hope this is not simply an “academic exercise”. The majority of members also requested a copy of the report with the priorities and recommendations, update on the research study findings, and a 6 month or 1 year follow up with PSOP to be kept informed on the progress made with the implementation of recommendations.

What has helped or hindered your ability to participate on this committee?

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

Helped:

- Extremely keen and committed group of members who were all very passionate about PSOP and everyone working towards the common goal of improving the program for future patients.
- Food and beverages were very much appreciated as well as the time and location of the meetings was convenient.
- Kind and respectful nature of all the committee members.
- Neutral evaluator/researcher facilitating the process and collecting and synthesizing all the information in and out of the committee.
- Video conferencing was a good option, when it worked well.

Hindered:

- Driving in the winter for out of town members.
- Video conferencing was a challenge for one of the meetings.
- Lack of clarity of project goals early on in the project.
- At some points some members had difficulty staying on topic and the evaluator/researcher and committee members were challenged to bring the conversation back to topic.
- Ideally, the committee would have had more time to more thoroughly address the priorities and recommendations.
- Competing demands for PSOP staff to attend meetings with clinical responsibilities.
- Challenges for patients to attend meetings with energy levels are low due to treatment.

Ideas for consideration to improve the process of patient engagement in program improvement initiatives?

- The majority of committee members agreed that ideally the committee would have worked on this project longer (i.e. 8 months to a year minimum).
- We would need better representation from patients that tend to be more vulnerable (i.e., head and neck cancer patients, patients or family members in lower socioeconomic groups, etc.).
- More in-depth committee member training/orientation to specific roles on the PFEC, committee process rules of conduct, etc.

PATIENT ENGAGEMENT IN PLANNING AND EVALUATION

- Attention to seating arrangements: Have members of the committee sit beside someone who holds a different role than their own to increase integration.
- Although the goal was to work on a program improvement project that was meaningful to patient and family members, it might have facilitated the process to have a preselected project for the PFEC to work on. This may have improved the clarity of the project goals earlier in the process.

Overall, what was the experience like for you being a member of the PFEC?

All members found the experience of being a member very positive and would consider being on a similar committee, if it was on a topic of personal or professional interest to them. Overall, members did not experience any adverse effects to being on the committee. An unexpected positive outcome from the staffs' perspective was how keen and motivated the patient and family committee members were. Some PSOP staff shared that it reminded them of some of the challenges and difficulties that some of their patients have often faced and learned some things along the way that they have applied to their practice. PSOP staff also found it very rewarding to have committee members on the PFEC that had so deeply appreciated and benefitted from their services.

Most members found the experience to be very meaningful and enjoyed hearing the different perspectives from committee members. Some patient and family members shared that in some indirect way it was very therapeutic to hear other patient and family member's stories because they could relate. Patient and family members were also commented that they felt very good about their ability to give back to the program and the system.