

ENGAGE! CREATING A FRAMEWORK FOR PATIENT AND FAMILY ENGAGEMENT
FOR A HEALTH CARE ORGANIZATION

By

RHANDALL TYDD-WHITING

BScN, Laurentian University, 2009

SCHOLARLY PRACTICE ADVANCEMENT RESEARCH PROJECT
SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES
(School of Nursing)

THE UNIVERSITY OF BRITISH COLUMBIA
(Vancouver)

August 2020

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Abstract

Background: Patient and family member engagement (PFE) is the ‘hands-on’ collaboration between patients, family members and health professionals. Meaningful engagement that incorporates patients’ voices into health care planning and delivery is considered a key strategy for achieving the “Triple Aim” of quality health care: improvement of the patient experience, better health outcomes and lower costs. Providence Health Care (PHC) has made a strong commitment to patient- and family- centred care (PFCC) but has not yet developed a framework to guide PFE. **Purpose:** The purpose of this Scholarly Practice Advancement Research (SPAR) project was to create a PFE framework for PHC through collaboration with patient-family partners. **Methods:** A virtual workshop was held with patient-family partners from PHC to inform the creation of a PFE framework. **Findings:** Workshop participants provided a range of insights regarding existing PFE frameworks that highlighted areas that could be strengthened in order to further support patients and family members during the engagement process. Critiques were synthesized into six themes: purpose of the framework, the engagement spectrum, patient- and family- centred language, visuals, PHC mission, vision and values, and combining frameworks. **Outcomes:** The integration of best available evidence, clinical expertise, PHC’s mission, vision and values, and patient-family voices resulted in *The PHC Person and Family Engagement Framework*. My experience of the engagement process provided an opportunity to reflect on PFE in practice, which may provide insight for other novices in clinical leadership.

Key words: Patient and family member engagement, patient- and family- centred care, patient-family partners, engagement framework, organization

Table of Contents

Abstract	ii
Table of Contents	iii
List of Tables	v
Acknowledgements	vi
Chapter 1: Background & Purpose	1
Background	2
Purpose	3
Summary	3
Chapter 2: A Focused Literature Review	5
Definition of Patient and Family Member Engagement	6
Essential Elements of PFE Frameworks	7
Appraising the Selected Frameworks	10
B.C. Ministry of Health Patient, Family, Caregiver and Public Engagement Framework	11
B.C. Renal Patient & Family Engagement Framework	12
Ontario's Patient Engagement Framework	14
Summary	15
Chapter 3: Methods for Adapting a Patient and Family Engagement Framework	16
Workshop Preparation	16
Workshop Facilitation	18
Synthesis of Workshop and Questionnaire Findings	19
Care Experience Strategic Direction Advisory Committee Presentation	19
Summary	20
Chapter 4: Workshop and Questionnaire Findings	21
Purpose of the Framework	21
The Spectrum of Engagement	22
Patient- and Family- Centred Language	23
Visuals	23
PHC's mission, vision and values	24
Combining Frameworks	24
Summary	27
Chapter 5: Discussion	28
Overview of the Framework	28
The Framework Goal	29
Enablers of Engagement	30
Guiding Principles of Engagement	31
The Engagement Spectrum	33
Personal Reflections	36
Misalignment in Understanding	36
Lessons Learned	38
Limitations	39
Conclusion	40

References.....	42
Appendix A: Glossary of Terms	45
Appendix B: Framework Matrices.....	46
Appendix C: Workshop Materials	48
Workshop Invitation	48
Workshop Participant Agenda & Zoom Etiquette	49
Pre-Work Information Booklet for Participants	51
Zoom Participant Guide.....	60
Follow-Up Questionnaire for Participants	62
Appendix D: Summary of Findings.....	65
Appendix E: The Providence Health Care Person and Family Engagement Framework	69

List of Tables

Table 1. Summary of participants' likes/dislikes of the selected frameworks.....	26
Appendix B: Framework Matrices	
Table 2. B.C. MoH Framework Matrix.....	46
Table 3. BC Renal Framework Matrix.....	46
Table 4. Health Quality Ontario Framework Matrix.....	47

Acknowledgements

There are many extraordinary people who helped me to complete this degree.

First, I would like to thank my partner, Nathan, for the love and support you have given to me through every step of this process. Your patience allowed me to grow and learn in unexpected ways.

I would like to express my gratitude to my supervisor, Dr. Maura MacPhee. Your insights helped to shape this project in ways that furthered both my academic and professional growth. I have appreciated your genuine kindness and encouragement throughout this process.

Also, my thanks to my committee member Dr. Martha Mackay, I sincerely appreciate your thoughtful advice and constructive feedback. I hope to continue to find opportunities to learn from you.

I must thank Kate McNamee and Larry Mroz, for their expert knowledge and feedback. Without Kate McNamee's support there would be no engagement framework! Kate, I have enjoyed collaborating with you.

I am grateful to many wonderful friends who provided encouragement along the way. Thank you for all the listening ears, shoulders to cry-on, happy dances, messages, cups of coffee and glasses (bottles) of wine! I would not have made it through without such an incredible support system.

Finally to my family, Mum, Dad, Riley and Rogan, thank you for cheering me on, listening, reading papers and assisting with new technology! Even from afar you are a source of strength and love that gives me the confidence to succeed. I am grateful for you all.

Chapter 1: Background & Purpose

Patient- and family-centered care (PFCC) is defined as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families” (Ahmann, Abraham & Johnson, 2003 p. i). A patient- and family-centered approach to health care represents a significant, system-wide paradigm shift from paternalistic, disease-centric practices to more holistic care that fosters equitable relationships between patients, family members¹ and the health care team (Institute of Medicine, 2013; Olding et al., 2016). In 2001, the Institute of Medicine’s report *Crossing the Quality Chasm* catalyzed this culture shift by identifying PFCC as one of the six foundational elements of delivering high-quality health care. Despite several decades of support for PFCC, health care organizations struggle to fully embrace this approach because of difficulties engaging patients and family members in meaningful partnerships with health care workers (Carman et al., 2013; Olding et al., 2016).

Whereas PFCC is a philosophical approach to health care culture, patient and family member engagement (PFE) represents the pragmatic, ‘hands-on’ collaboration between patients, family members and health care workers (Carman et al., 2013). Through PFE, the opinions, preferences and values of patients and family members help to inform the planning, delivery and evaluation of health care (Abelson, Humphrey, Syrowatka, Bidonde, & Judd, 2018; Frampton et al., 2017). Evidence has consistently shown that including the needs and preferences of patients and family members in health care planning and delivery results in better outcomes, lower costs and a better patient experience, commonly known as the “Triple Aim” of high-quality health care

¹ Throughout this paper, family member is defined as any individual(s), related or unrelated, identified by the patient as someone who provides support and with whom they share a significant relationship (Davidson et al., 2017). This definition is widely recognized in PFCC literature.

(Abelson et al., 2018; Frampton et al., 2017; Institute of Medicine, 2013). Thus, engaging patients and family members in decision-making is a critical determinant of meeting modern health care demands for better quality at a lower cost.

Although both PFCC and PFE are considered fundamental to improving the overall quality of health care, several challenges continue to frustrate efforts to engage patients and family members in partnership. These challenges include clinicians' fears of loss of control and demands on their time; lack of organizational support and resources to support PFE; and clinician confusion over what exactly PFCC and PFE are (Abelson et al., 2018; Frampton et al., 2017; Institute of Medicine, 2013). For patients and family members, the challenge of engagement can begin with whether an invitation to participate is even extended. Some studies note that health care organizations tend to favour patients and family members that are considered more 'desirable' because they are able to volunteer their time, hold higher levels of post-secondary education and have fewer health barriers for inclusion, such as cognitive impairment or behavioural health issues (Black et al., 2018; Frampton et al., 2017). However, during engagement, patients and family members often face challenges gaining access to the financial and educational support that is needed in order to make impactful contributions (Black et al., 2018; Frampton et al., 2017). Given the challenges noted, patients and families often assume passive versus active roles in organizational activities and research (Carman et al., 2013; Frampton et al., 2017; Institute of Medicine, 2013).

Background

Providence Health Care (PHC) has been recognized both nationally and internationally for their commitment to PFCC (Ahmann et al., 2003; Canadian Foundation for Healthcare Improvement, 2020). Clinical leaders at PHC consider the Family Presence policy to be a significant step in changing organizational culture by recognizing the needs and preferences of

patients and family members. PHC has reinforced their commitment to PFCC by signing the “Better Together Pledge”, an initiative through the Canadian Foundation for Healthcare Improvement (2020) that recognizes patients and family members as allies in creating quality and safety within the health care system. In addition, PHC has included language of the “Triple Aim”, enhancing the patient experience, population health improvement and fiscal sustainability in their current strategic planning (PHC, 2019). Despite these strong indicators of organizational support, PHC has not yet defined or created a framework for PFE. A significant body of literature indicates that organizational guidance for PFE practices would help PHC achieve their strategic plan and meet their commitments to PFCC (Institute of Medicine, 2013).

Purpose

The purpose of this Scholarly Practice Advancement Research (SPAR) project was to actively engage patient and family representatives in the adaptation of a PFE framework that strengthens PFCC and provides a foundation for the creation of PFE guidelines within one health care organization.

Summary

Currently PFE in health care is considered one of the best strategies to improve the quality of care delivered. Evidence indicates that engaging patients and family members improves the patient experience, promotes better overall health and lowers health care costs (Carman et al., 2013; Frampton et al., 2017; Institute of Medicine, 2013). PHC has been a provincial and national leader in supporting patient and family-centered practices; however, the organization has not yet clearly defined or created a framework for PFE. The goal for my SPAR project outputs was to fill this gap in organizational practice. Completion of a literature review

and evaluation of existing frameworks guided the creation of a practical, usable framework for PFE intended for implementation across PHC.

Chapter 2: A Focused Literature Review

For this SPAR project, I conducted a focused literature search to locate a definition of PFE and potential frameworks. Both peer-reviewed documents and grey literature were used to identify the essential elements of PFE. My preliminary literature search revealed that PFE is widely supported but often confused with PFCC and other synonymous terms for engagement (Abelson et al., 2018; Carman et al., 2013; Frampton et al., 2017). In order to discover a range of PFE literature I searched the following CINAHL and Medline terms: engagement, stakeholder participation*, family involvement*, consumer participation*, patient participation*, activation, patient-centered, family-centered and shared-decision making. Framework and organization were combined with ‘engagement’ terms using the Boolean operator “AND”. I also located reports, position statements and practice recommendations through governments, professional organizations, advocacy groups and institutions that monitor health care quality. To be considered for inclusion in the literature review, all resources were less than 10 years old, written in English, and focused on organization or system-wide PFE initiatives, as opposed to nursing unit-specific initiatives.

Using the elements of PFE identified from the literature review, as well as PHC’s vision, mission and values, I located three PFE frameworks that could be considered suitable for adaptation to this health care organization. The three PFE frameworks in closest alignment with PHC’s vision and mission are the *B.C. Ministry of Health (MoH) Patient, Family, Caregiver and Public Engagement Framework*, *B.C. Renal Patient & Family Engagement Framework*, and *Ontario’s Patient Engagement Framework* (B.C. MoH, 2018; B.C. Renal, 2019; Health Quality Ontario, 2016). The literature review findings helped to inform the comparison between

advantages and disadvantages of each framework with respect to planned development of an organization-wide PFE framework for PHC.

Definition of Patient and Family Member Engagement

A clear definition of PFE distinguishes the concept from PFCC and provides direction for the development of a practical and usable framework. Carman et al (2013) define PFE as, “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system – direct-care, organizational design and governance, and policy making – to improve health and health care” (p. 24). This article is widely referenced among engagement literature and frameworks, which makes this definition commonly accepted by experts in PFE (Abelson et al., 2018; Baker, 2014; B.C. MoH, 2018; Frampton et al., 2017; Health Quality Ontario, 2016; Health Research & Educational Trust, 2013). This definition distinguishes PFE as actions taken in practice where patients, family members and health professionals work together to achieve a common goal, as opposed to an overarching approach to health care delivery.

The key feature of PFE is active partnership between patients, family members and health professionals. All definitions of PFE retrieved from the literature describe health professionals *working with*, rather than *doing for* patients and family members (Abelson et al., 2018; Baker, 2014; Black et al., 2018; Carman et al., 2013; Frampton et al., 2017; Greene et al., 2015). An active partnership between patients, family members and health professionals results in a bi-directional flow of information and perspectives, as well as shared responsibility for decision-making (Carman et al., 2013; Frampton et al., 2017; Olding et al., 2016). The aspirational aim of PFE is shared decision-making; however, best available evidence, the patient’s biological condition, and the patient or family member’s preferences, values and life circumstances may determine to what extent patients and family members are able to engage (Carman et al., 2013;

Frampton et al., 2017; Institute of Medicine, 2013). In keeping with the philosophy of PFCC, patients and family members need to be given choice over their involvement in the engagement process (Carman et al., 2013; Institute of Medicine, 2013).

Essential Elements of PFE Frameworks

The purpose of PFE frameworks is to outline the active partnership between participants across the different levels of health care, and to identify supportive strategies and behaviours for the engagement process (Carman et al., 2013; Frampton et al., 2017). The following section describes the essential elements of PFE frameworks that were identified from the literature review. Language used to describe the essential elements of PFE varies across the literature and different frameworks; therefore, a Glossary of Terms was created to help clarify the different terms (See Appendix A).

The Continuum of Engagement. Within PFE frameworks the continuum of engagement outlines the different ways patients, family members and health professionals may participate in active partnerships (B.C. MoH, 2018; Carman et al., 2013; Health Quality Ontario, 2016; International Association for Public Participation, 2014). Generally, at one extreme of the continuum, patients and family members have limited power over decision-making and a less active role in their health care (Carman et al., 2013). Moving along the continuum, patients and family members take on more active roles across the health care system, such that responsibilities and power over decision-making are shared with health professionals (Carman et al., 2013). Although shared decision-making is usually considered the pinnacle of PFE, one way of engagement is not necessarily considered better than other ways of engaging (Baker, 2014; Carman et al., 2013; Institute of Medicine, 2013). Instead, the level of activity chosen from the continuum should reflect the purpose of engagement and the patients' and family members' capabilities, interests or goals (Carman et al., 2013; Institute of Medicine, 2013).

Originally developed for civic engagement, The International Association for Public Participation (IAP2) Spectrum (2014), has been utilized in PFE frameworks by health care organizations as a continuum of engagement (Baker, 2014; B.C. MoH, 2018; BC Renal, 2019). The IAP2 Spectrum begins with ‘Inform’, in which the goal is to provide information to the public that enhances understanding of the problem, and finishes with ‘Empower’, in which final decision-making is placed in the hands of the public. Although the IAP2 Spectrum depicts ways of engaging with the public, these methods may not be suitable for PFE. Not all aspects of the IAP2 Spectrum, like ‘Inform’, support the active partnership between patients, family members and health professionals, which is the key feature of PFE. Furthermore, ‘Empower’ on the IAP2 Spectrum does not take into account complexities, like patient condition, financial constraints and practice standards that may limit patients’ and family members’ power over the final decision.

Levels of Engagement. Another essential element of PFE frameworks are the levels of engagement, which describe the domain of health care where active partnership occurs (Carman et al., 2013; Health Quality Ontario, 2016). The goal of PFE is to improve both health and health care; therefore, engagement is not limited to direct patient care (Baker, 2014; Carman et al., 2013; Frampton et al., 2017; Institute of Medicine, 2013). Engagement can occur at any level of health care including direct-care, nursing units, organization governance or policy making and community programs (B.C. MoH, 2018; Carman et al., 2013; Health Quality Ontario, 2016; Institute of Medicine, 2013). In fact, leveraging patient and family members’ experience can help to improve design and delivery of health care organizations and systems (Baker, 2014; Institute of Medicine, 2013). Many PFE frameworks identify three levels of engagement in health care: an individual or direct-care level, an intermediate level and a macro level (B.C. MoH, 2018; Carman et al., 2013; Health Quality Ontario, 2016). Differentiating between the levels of engagement helps to identify the priorities for engaging as well as appropriate methods for

involving patients and family members (Carman et al., 2013; Health Quality Ontario, 2016; Institute of Medicine, 2013).

Factors Influencing Engagement. Across the PFE literature a multitude of factors were identified that influence to what extent patients, family members and health professionals are able to engage. For patients and family members knowledge of their health condition, level of health literacy and beliefs about their role are just a few of the factors that can influence their capacity for engagement (Carman et al., 2013; Frampton et al., 2017; Institute of Medicine, 2013). Only two articles discussed the impact of the social determinants of health on PFE, indicating that patients at a lower income level or who lack proficiency in English may be less likely to be invited to participate in engagement (Black et al., 2018; Carman et al., 2013). A few articles highlighted health professionals' knowledge, attitude and beliefs surrounding engagement, which can also influence whether opportunities for PFE are created (Baker, 2014; Frampton et al., 2017; Institute of Medicine, 2013). In all of the literature retrieved there was agreement that organizational foundations have the most significant impact on the extent to which PFE can occur (Baker, 2014; Carman et al., 2013; Frampton et al., 2017; Institute of Medicine, 2013). Supportive organizational foundations include policies that encourage PFE, leadership practices that align with PFCC and a philosophical conviction that patient and family member participation is “the right thing to do” (Frampton et al., 2017).

All frameworks identify supportive behaviours or strategies to guide engagement, thus mitigating barriers to PFE (B.C. MoH, 2018; Carman et al., 2013; CIHR, 2014; Frampton et al., 2017; Health Quality Ontario, 2016). A common element included in PFE frameworks is guiding principles, which are a set of shared values that must be followed in order for meaningful engagement to occur (CIHR, 2014). Some frameworks identify organizational values and behaviours that further support PFE, including leadership practices and educational supports for

patients and family members (B.C. MoH, 2018; BC Renal, 2019; CIHR, 2014; Health Quality Ontario, 2016). By outlining relevant values and behaviours within PFE frameworks, organizations can both help to create or strengthen a culture that supports meaningful engagement, and provide guidance to individuals on practices that foster patient and family member involvement in care.

Appraising the Selected Frameworks

My criteria for selecting potential PFE frameworks for adaptation to PHC included demonstration of commitment to improving health care planning and delivery, utilization of the essential elements of engagement and alignment with the organization's mission, vision and values. PHC's vision, "driven by compassion and social justice, we are at the forefront of exceptional care and innovation", underpins the organization's overall strategic direction (PHC, 2019 p.2). Furthermore, according to the Institute of Medicine (2013), PFE is key to developing a continuously learning health system that delivers better care at a lower cost. Accordingly, the selected frameworks, *B.C. MoH Patient, Family, Caregiver and Public Engagement Framework*, *B.C. Renal Patient & Family Engagement Framework*, and *Ontario's Patient Engagement Framework*, were chosen for their overarching goal to improve health and health care through the involvement of patients and families in the decision-making process (B.C. MoH, 2018; B.C. Renal, 2019; Health Quality Ontario, 2016). Their alignment with PHC's mission, vision and values is discussed further, below.

The literature findings formed the basis for my appraisal of the selected frameworks. In addition, consideration was given to how PHC's mission, vision and values were captured in each framework. Three matrices were developed to outline my initial thoughts about each framework's strengths and weaknesses, and alignment with PHC's mission, vision and values (See Appendix

B). The following discussion summarizes the advantages and disadvantages of the selected frameworks and how they articulate PHC's mission, vision and values.

B.C. Ministry of Health Patient, Family, Caregiver and Public Engagement Framework.

The primary advantage of the *B.C. MoH Patient, Family, Caregiver and Public Engagement Framework* (2018) is its focus on patients and family members as participants in care. This framework clearly states that engagement is about doing 'with' rather than doing 'for' patients and family members, which is a key feature of the definition of PFE (Carman et al., 2013; Frampton et al., 2017). The B.C. MoH explicitly states that this framework is aimed at patients, family members and caregivers as well as health care leaders. Also, the framework provides clear guidance for when engagement is an appropriate strategy to guide decision-making and when it is not appropriate, e.g., when a decision must be made urgently. Guidance regarding when to utilize engagement helps to clarify the patients' and family members' role in the engagement process. Of note, role clarity has been associated with more positive engagement experiences for patients and family members (Abelson et al., 2018; Black et al., 2018).

Unfortunately, the B.C MoH (2018) framework does not help to address health inequities that can be perpetuated by PFE. Several articles highlight that PFE attracts a certain type of patient or family member who tend to have a higher level of education, availability to dedicate their time to volunteering and are proficient in English (Black et al., 2018; Frampton et al., 2017). Within this framework's guiding principles of engagement, there is no clear reference to diversity or consideration of the patients' and family members' cultural experience. Furthermore, cartoon graphics utilized to depict the continuum of engagement, only have white faces. This lack of attention to inclusivity is a significant disadvantage for making all patients and family members feel like important participants in the engagement process.

Overall the *B.C. MoH Patient, Family, Caregiver and Public Engagement Framework* fits PHC's mission to meet the physical, emotional and social needs of patients by seeking out their perspectives and including them in the decision-making process. Also, the guiding principles of engagement within this framework include respect, dignity and trust-based relationships. This language aligns with the PHC's values of Respect and Trust, which promote dignity and support for all patients and family members.

B.C. Renal Patient & Family Engagement Framework

The second framework selected is the *B.C. Renal Patient & Family Engagement Framework* (2019). The B.C. Renal framework has well defined guiding principles that clearly describe how the engagement process will be supported by patient partners, B.C. Renal staff and health professionals. The B.C. Renal guiding principles include both Responsiveness and Support. Responsiveness is described as a commitment to acknowledging and responding to the voices of patients and families with open and honest (or transparent) communication (B.C. Renal, 2019). Transparent communication that opens channels for patients and family members to share their needs and perspectives is an organizational practice that is important for fostering meaningful engagement (Frampton et al., 2017). Without honest responses to patient and family voices, the engagement process can become tokenistic and may not contribute to improving health care (Frampton et al., 2017). Also, the guiding principle of Support describes learning, training and mentorship opportunities as well as financial reimbursement for patients and family members that participate in engagement (B.C. Renal, 2019). The supports outlined in this B.C. Renal guiding principle are unique among the other frameworks. A lack of either financial and educational support has been found to be a significant barrier for PFE (Black et al., 2018; Frampton et al., 2017). Making a strong commitment to financial and educational support for patients and family members helps to address some of the inequities encountered during

engagement with health professionals. Following this guiding principle, the B.C. Renal Framework outlines efforts that can support patients' and family members' participation in meaningful engagement.

Despite strong support for patients and family members, the B.C. Renal (2019) framework has significant gaps that may diminish the uptake of PFE in practice. First, the domains of health care where PFE may occur are not explicitly identified; however, examples used within the framework point to PFE being utilized at the level of organizational governance. Defining where PFE takes place is important for setting the priorities and determining appropriate activities of engagement (Carman et al., 2013). Opportunities for PFE may be missed if the domains of engagement are not identified for health professionals seeking guidance surrounding engagement at the direct-care level or within smaller community projects. Furthermore, B.C. Renal does not outline the support available for staff and health professionals, as opposed to patient and family member support, which is clearly described. Like patients and family members, health professionals need education and practice resources that provide them the knowledge and skills to support meaningful engagement (Frampton et al., 2017). Organizations that support PFE practices recognize the interdependence of all participants and have supportive resources available for patients, family members and health professionals (Frampton et al., 2017; Institute of Medicine, 2013).

Principally, the B.C. Renal framework is aligned with PHC's commitment to improving population health. Stewardship is a PHC value that acknowledges the shared accountability for the well-being of the community. Specific examples of PFE within the B.C. Renal (2019) framework demonstrate the positive impact that patient and family involvement has had on provincial kidney care. Therefore, adopting a PFE framework that supports patient and family

involvement at the level of organizational governance could help PHC achieve the organizational goal of improving community well-being.

Ontario's Patient Engagement Framework

In contrast to the other PFE frameworks, *Ontario's Patient Engagement Framework* includes language that supports active partnership between patients, family members and health professionals across the continuum of engagement activities (Health Quality Ontario, 2016). The B.C. MoH (2018) and B.C. Renal (2019) frameworks utilize the IAP2 Spectrum of civic engagement that begins with 'Inform' where information is provided to the public. However, active partnership between patients, family members and health professionals is fundamental to PFE and implies that valuable information, input and perspectives are exchanged between participants (Carman et al., 2013; Frampton et al., 2017). In recognition of this, *Ontario's Patient Engagement Framework* has developed a unique continuum of engagement that begins with 'Share', as opposed to 'Inform', in which information and perspectives are exchanged between patients, family members and health professionals (Health Quality Ontario, 2016). By changing the description of the continuum of engagement in this way, Ontario's framework supports active partnership in all forms of engagement and pushes health professionals to recognize the value of patients' and family members' lived experience.

Although *Ontario's Patient Engagement Framework* acknowledges financial and cultural inequities in PFE, no specific resources or guiding principles are identified to support broader engagement. Financial and cultural inequities are significant barriers to PFE and can impact which voices are heard and valued in the health care system (Black et al., 2018; Frampton et al., 2017; Institute of Medicine, 2013). Legislation and provincial practice recommendations can help to promote the necessary shift in organizational structure to address these inequities (Frampton et

al., 2017; Institute of Medicine, 2013). A strong recommendation for financial support in a well-developed provincial PFE framework could help shift traditional practices surrounding PFE.

Several aspects of *Ontario's Patient Engagement Framework* align with PHC's mission and values. First, this framework states the importance of engaging with social groups that have been disadvantaged by the health system (Health Quality Ontario, 2016). This strong statement for social justice in health care speaks to PHC's mission and vision, which both recognize the importance of compassion and social justice to providing innovative and high quality care (PHC, 2019). Furthermore, the guiding principles and supportive strategies for engagement included in Ontario's framework coincide with almost all of PHC's values including Trust, Integrity, Excellence, Stewardship and Respect. Overall, the language used throughout this PFE framework was most closely aligned to PHC's mission, vision and values for social justice, continuous learning and compassionate care.

Summary

In summary, through this focused literature review a commonly used definition of PFE was located and the essential elements of PFE frameworks were identified. The essential elements of PFE frameworks include a continuum of engagement activities, different levels at which engagement can occur, and guiding principles or supportive strategies that underpin meaningful engagement. These elements, along with PHC's mission, vision and values, helped to inform my selection of three frameworks that may be suitable for adaptation to the organization. Overall, the findings from the literature provide a succinct outline of the elements for inclusion in a PFE framework for PHC. Further steps taken to adapt the selected frameworks for PHC are discussed in the following chapters.

Chapter 3: Methods for Adapting a Patient and Family Engagement Framework

The work of adapting a practical and usable PFE framework for PHC primarily focused on collaboration with patient-family partners who have previously participated in engagement strategies and who are members of the Care Experience Strategic Direction Advisory Committee (CESDAC) – a hybrid patient-family advisory committee and leadership group. Working closely with the PFCC Practice Consultant for PHC, I was able to gain valuable insight into the needs of PHC, and liaise with patient-family partners and the CESDAC. In addition, I shared my work with a provincial expert in patient engagement and knowledge translation to gain insight into their experiences with engagement practices. The collaboratively agreed-upon PFE framework will serve as a foundation for ongoing co-development of PFE organizational guidelines by patient-family partners and PHC leadership. To deliver a practical and usable PFE Framework for PHC, I carried out the following:

1. Developed a virtual workshop and questionnaire for patient-family partners to share their opinions on PFE frameworks
2. Facilitated the virtual workshop to gather the opinions of patient-family partners about PFE frameworks
3. Synthesized findings from the workshop and questionnaire responses to draft a PFE Framework for PHC
4. Presented a draft of *The PHC Person and Family Engagement Framework* to the CESDAC for further feedback

Workshop Preparation

Engagement frameworks provide guidance for the practical application of PFCC, which values patient and family input at all levels of the planning and delivery of health care. Therefore,

a PFE framework for PHC would not be practical or usable without the input of patient-family partners guiding its development. The preparation and facilitation of a workshop for patient and family partners at PHC was critical to the development of a practical and usable engagement framework. Working with PHC's PFCC Practice Consultant, I planned for and conducted a two-and a half-hour workshop to gain patient-family partners' insights on the selected PFE frameworks that could be adapted for PHC.

An invitation to the workshop was sent to patient-family partners at PHC through the PFCC Practice Consultant (See Appendix C for Workshop Materials). The PFCC Practice Consultant is in contact with patient-family partners across PHC's programs including the Heart Centre, mental health programs, long-term care facilities and other in-patient and out-patient programs, so the invitation was able to reach a diverse group of potential participants. The maximum number of workshop participants was limited to 15 because of the virtual delivery over Zoom. Due to the perceived complexities of engagement and the selected frameworks, the decision was made to invite patient-family partners who had either previously or were currently participating in a PHC initiative. I believed that the experiences of patient-family partners familiar with engagement would bring valuable insight to how a framework might be shaped to align with PHC's values and what might need to improve in order to support meaningful engagement.

Although a novice to workshop facilitation, I quickly learned that preparation and planning are key to a successful workshop. I utilized several online resources and met with a provincial research leader in patient engagement from the B.C. Patient Support Unit to help plan my workshop agenda and activities (Appendix C). My discussions with the researcher leader helped to refine my agenda to think critically about the input I was seeking, and to consider how I would elicit these insights from the workshop participants. Through the University of British

Columbia's Centre for Instructional Support I met with an Education Technology Assistant who provided valuable insight on how to utilize Zoom for the delivery of a workshop. On the day of the workshop, two technology support persons were in attendance to assist with any major technical issues.

To further prepare the participants for the workshop discussions, I created and sent out pre-workshop materials including an information booklet, Zoom instruction guide and agenda (Appendix C). The information booklet provided key information about the concept of patient engagement and helped to familiarize participants with the selected frameworks. Each of the selected frameworks was summarized on one page that included a link to the full framework document. The pre-workshop materials were emailed to each participant the week before the workshop with an invitation to submit any questions or requests for clarification prior to the workshop.

Recognizing the limitations of a virtual workshop, I developed a questionnaire that mirrored the workshop activities (Appendix C). The purpose of the questionnaire was to allow participants to supplement the workshop discussion with their own insights. Zoom can be a difficult platform through which to facilitate large group discussion. The questionnaire provided an opportunity for participants to add to their critiques of the existing frameworks and to identify language that was meaningful to them for supporting PFCC and engagement. The questionnaire and a feedback survey were emailed to participants after the workshop. Completion of the questionnaire and survey was voluntary.

Workshop Facilitation

The goal of the workshop was to elicit opinions about the selected PFE frameworks from patient-partners to identify a framework or a combination of framework qualities that could be adapted into a practical, usable framework for PHC. The workshop involved short presentations

on the common elements of engagement frameworks and the importance of guiding principles. Working in three breakout rooms, small groups discussed the perceived strengths and weaknesses of one of the selected frameworks. Large group discussion helped to build consensus around qualities to include within a PFE frameworks and areas that could be improved. As the workshop progressed, discussion within the large group focused on identifying guiding principles that were deemed supportive of meaningful engagement with patients and family members. The findings from the workshop and follow-up questionnaire are presented in Chapter Four.

Synthesis of Workshop and Questionnaire Findings

The findings from the workshop and questionnaire were synthesized to develop a PFE framework for PHC. Qualitative notes from the workshop and questionnaire responses were organized into a table to visualize the most common areas of agreement among participants.

Care Experience Strategic Direction Advisory Committee Presentation

The final stage of developing PHC's framework was a presentation over Zoom of a draft of *The PHC Person and Family Engagement Framework* to the CESDAC. The CESDAC committee is comprised of eight patient-family partners and eight clinical practice leaders. One patient-family partner who participated in the workshop is a member of the CESDAC. The purpose of my presentation was to seek feedback to further refine the adapted framework for PHC. After the presentation, feedback was immediately solicited through a large group discussion over Zoom. To encourage thoughtful critique of the framework, members of CESDAC were invited to contribute their feedback via email for up to 10 days after the presentation. Of note, none of the clinical practice leaders on the CESDAC provided feedback. Responses were received from patient-family partners, which helped to further refine the final recommendation

for a PFE framework for PHC. The final framework is presented in Appendix E and each section of the framework is discussed in Chapter Five.

Summary

Utilizing the methods described in this chapter, I was able to adapt a combination of features from the B.C. MoH (2018), B.C. Renal (2019) and Health Quality Ontario (2016) PFE frameworks into a practical and usable PFE Framework for PHC. The following chapters discuss in depth the major findings from the patient-family partner responses and how those responses shaped the final framework.

Chapter 4: Workshop and Questionnaire Findings

Given that PFE seeks to incorporate patient and family perspectives into the planning and delivery of health care, the development of a practical and usable PFE framework would not be valid without the input of patient and family members. Thus, the most significant component of developing a PFE framework for PHC was the patient-family partner workshop and questionnaire. The synthesis of patient-family partners' perspectives from the workshop and questionnaire was carried out through critical reading of notes and questionnaires, and organization of feedback into tables and brief qualitative summaries (See Appendix D: Summary of Findings). From this synthesis, six key themes from the patient-family partner perspectives were identified. The key themes are: purpose of the framework; the spectrum of engagement; patient- and family- centred language; visuals; PHC's mission, vision and values; and combining frameworks. These themes shaped the development of the PFE framework for PHC and are discussed in detail in this chapter.

Purpose of the Framework

The most common question during the workshop was “*What is the purpose of this framework?*” Several participants asked this question and expressed confusion surrounding why PHC needs a specific engagement framework. I explained how a PFE framework could strengthen PHC's support for PFCC and better patient experiences. Some participants, however, were not convinced that a framework would alter current practices (i.e., the status quo). One participant stated, “*If this [framework] is to uphold the status quo [of PFE] then this [initiative] is not really patient-family centred!*” Confusion among the participants about the purpose of a PFE framework highlights gaps that may exist between organization practices and patient-family engagement experiences.

The Spectrum of Engagement

Both the workshop discussion and questionnaire responses were critical of the spectrum of engagement used in the B.C. MoH (2018) and B.C. Renal (2019) frameworks. Within the B.C. MoH framework, a few participants liked how the spectrum of engagement “*mirrored a patient’s journey, as they gain more control and independence over their care.*” The majority of the workshop participants and questionnaire respondents, however, did not like the step-wise representation of different ways of engaging. Participants recognized from their own experience with engagement that several different methods of engagement may be used simultaneously, “*Aren’t you using ‘Inform’ and ‘Consult’ when you ‘Involve’ patients and family? I think that could be clearer.*” According to the participants, a step-wise representation implies that a single method of engaging is associated with specific types of patient-provider experiences. However, this approach did not correspond with their experiences. Participants were concerned that a step-wise or linear representation of engagement would be misleading to patients and family members.

Participants had issues with the language of the engagement spectrum utilized by the B.C. MoH (2018) and B.C. Renal (2019) frameworks. Both of these frameworks use adaptations of the IAP2 Spectrum (2014), which includes inform, consult, involve, collaborate and empower as the methods of engagement. The IAP2 Spectrum is meant for civic engagement but has been adapted by several Canadian health care systems and organizations to guide PFE. The workshop participants and questionnaire respondents did not feel that the language of the IAP2 Spectrum captures PFCC, especially the use of the term ‘inform’, which implies a one-way direction of giving information, generally from health professionals to patients or family. Several participants argued that ‘empower’ should not be a method of engagement, but rather needs to underlie all engagement activities, “*It needs to be clear that it’s [PFE] a collaboration and the patient will*

be consulted and listened to along the way.” There was consensus from the workshop participants and questionnaire respondents that patients and family members must have equal voice in discussions and decisions related to them, and that their input must be recognized and respected as having equal weight to health professionals’ input.

Patient- and Family- Centred Language

While literature does not clearly identify specific patient- and family- centred language, the workshop and questionnaire participants were quick to identify phrasing in the selected frameworks that they did not consider to be patient-family focused. As outlined in the previous theme, participants did not think that the IAP2 Spectrum (2014), which is intended for civic engagement, captured the inclusion of patients and family that is supported by PFCC and PFE. Use of words like ‘inform’, ‘consult’ and ‘we will’, sounded like “power over” to them rather than “power with”, “*You need to start with empowerment and work from there since the framework [language] doesn’t make patients feel equal and doesn’t value transparency.*” Some terms associated with examples of engagement, such as ‘deliberative polling’, were described as abstract, intangible and irrelevant to them.

Visuals

Several comments from the questionnaire and during the workshop focused on visuals of the selected frameworks. The most significant critique about *Ontario’s Patient Engagement Framework* (Health Quality Ontario, 2016) was that the white writing on a coloured background was not easy for participants to read, especially if they had a visual deficit. There was also agreement that the B.C. Renal (2019) framework was not visually appealing because of the large amount of small print. The visuals for the B.C. MoH (2018) framework were considered to be clear, colourful and easy to understand. Several participants, however, noted that the examples in

the B.C. MoH framework focused only on direct-care delivery and all the people in the graphics had white faces. Overall, the participants liked the info-graphic format of the B.C. MoH framework, although they noted that a trade-off of info-graphics is lack of examples of types of engagement.

PHC's mission, vision and values

One of the objectives of the workshop was to have participants identify how the PHC mission, vision and values could be incorporated into a PFE framework. There was not time during the workshop to meet this objective, and the questionnaire responses only confirmed that the framework should support the mission, vision and values of PHC, as well as the organization's commitment to PFCC. Some questionnaire respondents suggested incorporating PHC values into a guiding principles section for the adapted framework. The PHC values that were recognized by participants as supportive of meaningful engagement were Excellence, Respect and Trust. These values were seen as enabling engagement by creating a culture of continuous learning and inquiry, respecting the experiences of all those participating in the engagement process, and building relationships that value honesty. These PHC values were also ranked most highly in the section of the questionnaire that asked respondents to identify the guiding principles of engagement that were important to them.

Combining Frameworks

The primary purpose of the workshop and questionnaire was to determine from the participants' perspectives if there was one clear framework that could be adapted for PHC. The workshop discussion and questionnaire responses strongly indicated that no single framework met the requirements for a PHC framework. Instead, participants identified a combination of qualities from each framework that could be adapted into a practical, usable framework for PHC.

During the workshop and through the questionnaire, participants were asked to identify their major likes and dislikes for each of the selected PFE frameworks. Critiques covered a range of qualities from each framework including visual format, examples of engagement, methods included within the spectrum of engagement, and choice of language. The following table summarizes the participants' chief likes and dislikes regarding each of the selected PFE frameworks.

Table 1. Summary of participants' likes/dislikes of the selected frameworks

Framework	Likes	Dislikes
<i>B.C. MoH Patient, Family, Caregiver and Public Engagement Framework (2018)</i>	<ul style="list-style-type: none"> • Visual presentation of engagement spectrum: all one info-graphic, colourful, black print • Clear that engagement is “nothing about me without me” 	<ul style="list-style-type: none"> • Info-graphic doesn't capture engagement at the community or system level. • Info-graphic implies a hierarchy of engagement methods • Graphics are all white faces
<i>BC Renal Patient & Family Engagement Framework (2019)</i>	<ul style="list-style-type: none"> • Used specific examples of engagement activities • Clear explanations of each method of engagement 	<ul style="list-style-type: none"> • More targeted to community/organization than to direct care • Some examples were abstract/irrelevant • Language like “we will” and “Inform” implies “power over”
<i>Ontario's Patient Engagement Framework (2016)</i>	<ul style="list-style-type: none"> • Clear sections that describe overall approach to engagement; especially Guiding Principles and Enabled By sections • “Share” as a method of engagement, gives the impression health professionals are listening to patient/family input 	<ul style="list-style-type: none"> • Not visually appealing • Difficult to read white print on coloured squares • Could have better examples of engagement for each method on the engagement spectrum

According to the participants, the strongest quality of the B.C. MoH (2018) framework was the simple, colourful visual layout. Most participants agreed that the use of colour to

highlight different areas within the framework helped to clarify the domains and methods of engagement (See Appendix A for a Glossary of Terms). The use of graphics was perceived to make the framework more appealing to participants by reducing the use of abstract language, and depicting patients and family members as central to engagement. Several participants agreed that the graphic layout of the B.C. MoH (2018) framework methods of engagement was easiest to visualize and to relate to their own experiences. Despite the positive responses to the visual format, the majority of participants did not think this framework captured all opportunities for PFE because the examples of engagement were all from direct-care delivery.

Of the three frameworks, B.C. Renal (2019) received the strongest criticism because of its implied “power over” language. Similar to the B.C. MoH (2018) framework, participants did not agree with the use of ‘Inform’ and ‘Consult’ on the spectrum of engagement because these words were not felt to align with the active partnership that underpins engagement activities. Unlike the B.C. MoH framework, the B.C. Renal framework has specific examples of engagement activities and this was determined by participants to be the best quality of this framework.

Ontario’s Patient Engagement Framework (Health Quality Ontario, 2016) received the most positive comments regarding patient- and family- centred content. Participants preferred the use of ‘Share’ within the spectrum of engagement because this language was perceived to describe a more active exchange of information between all those involved. Participants preferred the inclusion of Guiding Principles and Enablers of Engagement as distinctive sections within this framework. These two aspects of this framework were thought to be helpful for patients, family members and health professionals; to raise awareness of the ways to support collaborative engagement in different contexts. A few participants criticized the use of ‘buzzy words’ that lacked clear examples or definitions. For example, there were no specific examples of ‘Share’ as a method of engagement, although most participants assumed that ‘Share’ meant an exchange of

information between patients, family members and health professionals. These opinions support participants' emphasis on incorporating concrete examples of engagement within a framework.

The majority of participants did not like the Health Quality Ontario's (2016) framework use of graphics or the format. Several participants agreed that of all the frameworks, Health Quality Ontario's framework was the most difficult to read due to the use of white print. Even though participants liked the content within the Health Quality Ontario framework there was not sufficient agreement that this framework alone should be adapted for PHC.

Summary

The findings from the workshop and follow-up questionnaire discussed in this chapter have informed the creation of a practical and usable framework for PHC, based on the strengths of three separate frameworks. The following chapter will discuss how these findings informed the final framework for PHC and discuss lessons learned from this project about creating meaningful engagement with patient-family partners.

Chapter 5: Discussion

The purpose of this chapter is to discuss the final construction of a practical and usable PFE Framework for PHC as well as my personal reflections of the overall engagement experience. While empirical knowledge regarding PFE derived from traditional research methods continues to grow, there is much that can be learned from the experience of engaging (Frampton et al., 2017). The findings from my focused literature review, my personal critique of the selected frameworks and expert knowledge of engagement from health care leaders provided some insight into the strengths and weaknesses of the selected frameworks. However, it was the input from patient-family partners through the workshop discussion and questionnaire responses that were most significant to the adaptation of the final recommended framework for PHC. Through my experience of engaging with patient-family partners I have used their insights in the development a PFE framework. I also gained experiential knowledge of engagement that may be useful for furthering practice that supports novice clinical leaders looking to meaningfully engage with patients and family members.

Overview of the Framework

The PHC Person and Family Engagement Framework (Appendix E) is two pages long and reflects foundational elements of engagement from PFE literature, insights gained from consultation with health care leaders in PFE and the perspectives of patient-family partners. Along with information from these knowledge sources, language that is reflective of PHC's mission, vision and values was incorporated into the framework to help highlight and strengthen the organization's commitment to meaningful engagement. The patients' and family members' critiques of phrases and language used in the selected frameworks highlighted how traditional power dynamics between health professionals and patients and family can be reinforced through

choices of wording that have not been thoughtfully vetted by patients and family members.

Language in a practical and usable PFE framework must acknowledge the patient-family partners as a central audience of the framework (Frampton et al., 2017). Language choices need to reflect the active partnership between patients, family and health professionals, both in the methods of engaging and sustaining engagement throughout the health care experience.

The framework is separated into four sections: The Framework Goal, Enablers of Engagement, Guiding Principles of Engagement, and The Engagement Spectrum. These sections capture the fundamental elements of engagement outlined in the literature, including contextual factors influencing engagement, the domains of engagement and continuum of engagement. Each section of the framework is discussed in detail, including specific features believed to promote its utilization and practical application.

The Framework Goal

The most significant feedback from the patient-family partner workshop participants was to question the purpose of a PFE framework for PHC. Some of the framework's impact will be determined by its socialization and implementation, which is beyond the scope of this project. However, a goal can help to clarify the purpose of a PFE framework and guide users towards upholding a culture of PFCC (Health Quality Ontario, 2016). All the PFE frameworks found in the literature review had a goal or guiding purpose that set out to strengthen patient and family involvement within the system or organization in order to improve outcomes (B.C. MoH, 2018; B.C. Renal, 2019; CIHR, 2014; Health Quality Ontario, 2016).

The goal of the framework was adapted from PHC's strategic direction regarding PFCC. After consulting with the PFCC Practice Consultant for PHC, the decision was made that the framework goal needed to align with PHC's strategic direction in order to promote uptake and implementation. The language from PHC's strategic direction focuses on improving the patient

and family experience, enhancing the quality of health care delivery and increasing patient and family capacity to manage their health. Simultaneously, PHC's strategic direction appears to align with the "Triple Aim" of health care improvement, better health outcomes, lower costs and a better patient experience, which PFE helps to achieve (Institute of Medicine, 2013). Thus, sharing language from PHC's strategic direction with the framework goal further supports the organization's commitment to PFCC and achievement of the "Triple Aim" of high-quality health care delivery.

Enablers of Engagement

An organization's support for engagement is considered the most significant factor that influences to what extent patients, family and health professionals are able to engage (Carman et al., 2013; Frampton et al., 2017). Although literature identifies the importance of organizational support, there are few recommendations about how to foster this type of support for engagement (Carman et al., 2013). Two of the three frameworks identified system-wide supports for engagement, but only *Ontario's Patient Engagement Framework* embedded "Enablers of Engagement" into their framework summary (Health Quality Ontario, 2016). Patient-family partners that participated in the workshop and those who submitted questionnaire responses identified "Enablers of Engagement" as a feature they liked within Health Quality Ontario's (2016) framework because this section clearly identifies what must be in place to support meaningful engagement with patients and family.

Ontario's Patient Engagement Framework defines enablers of engagement as foundational values and ethics, infrastructure and resource support, and knowledge and understanding that support environments capable of meaningful patient engagement activities (Health Quality Ontario, 2016). PHC's mission, vision and values provide foundational values and ethos of the organization's culture. Therefore, to create an Enablers of Engagement section

for this framework, I drew from PHC's existing mission, vision and values that already provide support for systems-wide engagement. The Enablers of Engagement section for PHC reminds health professionals, patients and family members of the values embedded within the organizational culture that support meaningful engagement and strengthen the framework's applicability to practice.

Guiding Principles of Engagement

The guiding principles of a PFE framework are a shared set of values that guide the overall approach to engagement and must be followed by all those participating in order to carry out successful engagement activities (CIHR, 2014; Health Quality Ontario, 2016). Like enablers of engagement, guiding principles influence to what extent meaningful engagement can occur, depending on the commitment put forth by participating individuals to uphold the values that are stated. Guiding principles are the values that underpin the engagement process, whereas enablers of engagement are embedded in the organization's culture and help set the stage for engagement to take place (Frampton et al., 2017; Health Quality Ontario, 2016). To select the guiding principles for the framework, both PHC's values and the values identified by the three selected PFE frameworks were considered. The guiding principles from the selected frameworks were considered for inclusion, because these values were selected by a broad group of patients, family members, health professionals and researchers, and were often shared between the frameworks, which demonstrated their validity. The workshop and questionnaire participants agreed that guiding principles were important to help direct the way health professionals, patients and family members approach the engagement process.

When the participants were asked to select the guiding principle most important to them, the majority chose Mutual Respect. Mutual respect is in alignment with the selected PFE frameworks, which all include respect for patient experiences and knowledge as a guiding

principle (B.C. MoH, 2018; B.C. Renal, 2019; CIHR, 2014; Health Quality Ontario, 2016).

Looking further, a previous study that explored patient-research partners' experiences found that the research team atmosphere could range from inclusive to dismissive of patient-research partner input and that mutual respect helps to create positive conditions for meaningful engagement by eliminating behavioural barriers that impede collaboration (Black et al., 2018). This study, along with the workshop participants' responses, suggests that respect for patients' and family members' knowledge varies across health professional teams and significant power imbalances still determine to what extent patients and family members are able to engage. The inclusion of mutual respect as a guiding principle in the PHC framework will support an engagement process that acknowledges the experiences and expertise of all participants and promotes shared power with patients and family members.

Both the workshop participants and the CESDAC patient-family partners discussed sharing power during the engagement process, but with differing perspectives. The workshop participants strongly recommended that all engagement activities should be guided by the principle of empowerment that allows patients and family members to have control over the final decision. Several questionnaire respondents chose empowerment as a guiding principle to underpin the engagement process. In contrast, the CESDAC patient-family partners felt that use of the word empowerment implied that health professionals were gatekeepers of power, which does not acknowledge the autonomy patients and family members have over their health and to what extent they may choose to participate in engagement.

On consultation with leaders in PFE, there was further disagreement about whether empowerment could be supported as a guiding principle or as a method of engagement.

Realistically, within the health care system, decisions are not entirely controlled by the patient and family due to an abundance of barriers that may include, but are not limited to, the medical

options available, adherence to practice standards and financial resources (Institute of Medicine, 2013). One study found that despite reservations surrounding patients' power over organizational decision-making, having patients engage at this level gives voice and promotes a sense of trust in the governance process (DeCamp et al., 2019). Taking into account the opinions of the patient-family partners, experts and available evidence, I tried to select a guiding principle that would promote agency for patients and family members, where they are able to share perspectives with impunity and confidently make informed decisions. Trust, a PHC value, is defined by the organization as behaving in ways that promote safety, inclusion and support, aligned with patient and family agency. Trust is associated with transparency and sharing (DeCamp et al., 2019). The other PHC value used in the framework, therefore, is trust, a guiding principle to support the inclusion of patients' and family members' perspectives in the engagement process.

The Engagement Spectrum

The final section of the framework is an info-graphic that captures the different ways of engaging across three domains within the organization. To develop the info-graphic, I combined essential elements of engagement identified in the literature with the major findings from the workshop participant discussion and their questionnaire responses. The 'Ways of Engaging', at the top of the info-graphic, coincides with the continuum of engagement from the literature, which describes the active role that patients and family members have in care decisions and the flow of information between participants during different activities (Carman et al., 2013). As the reader moves to the right across the 'Ways of Engaging', power and responsibilities within the engagement process are increasingly shared between patients, family members and health professionals. The 'Domains of Engagement' identify where different engagement activities may occur. In the literature the domains of engagement are defined as micro, meso and macro levels (Carman et al., 2013). For this spectrum, the included domains are Direct Care (micro), Program

Level (meso) and Organization Governance (macro). Further refinement of The Engagement Spectrum was based on the workshop discussion and questionnaire responses.

Overall, The Engagement Spectrum is intended to be patient-family centred and easy to understand so that patients, family members and health professionals can realize the practical application of engagement. The use of black print, colourful shapes and generic icons reflected the workshop participants' critiques about the ease of readability and lack of diversity in the B.C. MoH (2018) engagement framework. Also, the participants wanted pragmatic patient-family centred examples of engagement as opposed to abstract examples, like deliberative polling, which were used in the B.C. Renal (2019) framework. Clearly, examples of engagement utilized in a PFE framework should reflect pragmatic, concrete ways that patients and family members can participate in the planning and delivery of their health care. Accordingly, within the centre of The Engagement Spectrum are current examples of PFE at PHC. I tried to select routine practices, such as gathering information about how patients are managing their pain or patient-partners participating in organization-wide committees, to demonstrate the accessibility of involving patients and family members in the planning and delivery of care. All of the examples reflect current practices across PHC, with the intent that recognition of real and accessible ways of engaging will inspire all areas of the organization to continue growing the involvement of patients and family members through active partnership.

In addition to the examples of engagement, the 'Ways of Engaging' were changed to reflect patient- and family- centred language that was chosen by the workshop participants. Language used on the spectrum of engagement by the B.C. MoH (2018) and B.C. Renal (2019) frameworks was adopted from the IAP2 Spectrum (2014), an organization focused on the broader process of civic engagement. Findings from the workshop participants' responses demonstrated that the B.C. PFE frameworks did not characterize the active partnership that patients and family

are expecting to experience during the process of engagement. Workshop participants felt that inclusion of 'Inform' and 'Consult' as methods of engagement, place the control over the flow of information in the hands of health professionals and minimize the contributions of patient input. Once again, this finding alludes to significant concerns over how patients and family are included in health care decision-making and whether their voices are being respected. Instead of having 'Inform' and 'Consult' on the 'Ways of Engaging', participants chose 'Share' and 'Gather Information' in order to portray a bi-directional exchange of information and perspectives between health professionals, and patients and family. Moving away from the traditional language used in PFE frameworks may help to represent patients and family as respected and active members in the engagement process.

Finally, another important feature of The Engagement Spectrum is in the representation of the 'Ways of Engaging'. During the workshop discussion, many participants raised issues with a step-wise depiction of the different methods of engaging. The participants recognized that meaningful engagement depends on context as well as patient choice, and that multiple ways of engaging may be used during a project. The insights of participants inspired me to change the graphic used to represent the 'Ways of Engaging' so that the methods of engagement are not isolated from one another and no single 'Way' is viewed more favourably. To capture the participants' voices, I developed a graphic of puzzle pieces to depict the 'Ways of Engaging' because the pieces are not hierarchical: they can be viewed as distinct activities but are not necessarily carried out in isolation. Ultimately, changing the visual representation of the 'Ways of Engaging' is a practical way to convey that any one of the described engagement activities can contribute to improving the patient and family experience.

Personal Reflections

Several important learning moments occurred during the patient-family partner workshop. The workshop participants and their follow-up questionnaire responses provided invaluable insights that shaped the development of a practical and usable PFE framework for PHC. By involving patient-family partners in the development of the final recommended framework, I was able to gain experience in the process of engagement while researching and writing about the topic. As a novice to clinical leadership, my experience of engaging with patients and family provided many learning opportunities that may be useful to others in a similar position.

Misalignment in Understanding

Approximately one hour into the patient-family partner workshop a participant asked; “*What is the purpose of this project?*” This question caught me off guard. I was confident that I had stated the purpose of the workshop in the PowerPoint presentation, pre-workshop information materials and my email communications. I tried to reiterate the purpose of the project, which is to develop a PFE framework adapted for PHC that strengthens their culture of PFCC. My explanation was met with further push back when a different participant said; “*If this [framework] is to uphold the status quo [of PFE] then this [initiative] is not really patient-family centred!*” During the preparation for the workshop, I had assumed that all patients and family members would want a framework that supports their participation in health care planning and delivery. Questions surrounding the purpose of the project and how a framework would impact PFCC at PHC proved challenging for me to answer as a novice to facilitating a project and leading change. The participant concerns over the impact a PFE framework on their experiences with PHC dominated the workshop discussion, making me realize how important it is that concepts expressed in a framework are operationalized in practice and evaluated by patients and families with respect to their health care experiences.

Reflecting on how I responded to these surprising questions and comments, I considered how my preparation for the workshop affected the development of written information and my confidence as a facilitator. Meaningful PFE that fosters partnership and transparency requires adequate time and resources (Bellows, Kovacs Burns, Jackson, Surgeoner, & Gallivan, 2015). The timing of the CESDAC meeting and my employment schedule limited my time to prepare for the workshop and develop written materials. I used an internet tool to check written materials for their language level and readability but not all of my written materials met plain language standards. Likely with more time to develop written materials, I could have focused on the use of plain language to state the purpose more clearly and avoid some of the confusion among participants. Also, technical difficulties at the beginning of the workshop diminished some of my confidence as a facilitator. With more time to prepare, I could have mitigated technical difficulties by increasing my familiarity with the technology and resources available for support.

Another part of my reflective process was sharing my workshop experience with health care leaders that have expertise in PFE. These leaders reassured me that patient-family partners have questioned the purpose of their projects and that this misalignment in understanding is a common part of the engagement process. Furthermore, studies have found that patient partners approach engagement with a different understanding of their role and expectations from health professionals (Bellows et al., 2015; Black et al., 2018). Knowing that this experience is somewhat common, I have started to question whether there is something missing from how the patient role in the engagement process is described. Even though many engagement frameworks are developed in collaboration with patients and families, literature on PFE and framework development is generally written by and published for an audience of clinical leaders and not readily accessible to public (Frampton et al., 2017). Arguments have been made for moving away from traditional forms of evidence and knowledge transition to promote inclusion of patients and

family members in developing the field of PFE (Frampton et al., 2017). Changing the methods used to share knowledge and evaluate outcomes so that patients and family are meaningfully included may help to close the gap in expectations between health professionals and the public. While developing the PFE framework for PHC, I did my best to include the patient-family partners insights into all major decisions, so that the final recommendation is practical and usable for patients and family members as well as health professionals.

Lessons Learned

Prior to this project I had never facilitated a workshop, -virtual or otherwise. Through this experience I learned the importance of preparation, being familiar with the technology and utilizing available resources. When all else fails, adaptability is an imperative skill for a facilitator to have. At one point, I was unable to share a website that was critical for small group activity. Utilizing the technology I had and some help from the small group members, I was able to adapt the activity and still gained substantial information from the discussions. In the future, I would ensure I had more alternative strategies planned in case of technical difficulties or unforeseen challenges.

Leading discussion through a virtual workshop was more difficult than I anticipated. During the workshop there were instances where verbal or written comments disrupted the ongoing discussion. Some of the verbal comments were not in a tone that suited a professional environment. In the moment, I struggled to reorient the discussion and set boundaries with disruptive participants. Mutual respect was highly valued by the participants during the workshop discussion and in the responses to the follow-up questionnaire, which fits with findings in the PFE literature (Bellows et al., 2015; Black et al., 2018). I think as a novice facilitator I did not hold everyone accountable for maintaining a respectful workshop environment, even through a

virtual platform. As I build my clinical leadership skills, I will try to focus on setting and maintaining boundaries that support mutual respect by developing my communication skills.

Limitations

The PHC Person and Family Engagement Framework should be considered a recommendation that may require further refinement before implementation and socialization across the organization. The development of the PHC framework was limited by the virtual delivery of a workshop, a dearth of staff feedback, and the project time constraints. As discussed in my personal reflections, the virtual delivery of a workshop was challenging due to technical difficulties and limitations of interactions. Different circumstances or activities may have changed the outcomes of the workshop discussion. I hope that the follow-up questionnaire allowed participants to share their opinions openly and further contribute their perspectives. Despite the challenges of delivering a virtual workshop, I believe the participants made significant contributions to the development of the recommended framework.

In contrast, the recommended framework does not reflect feedback from various PHC staff. The PFCC Practice Consultant for PHC, was available for consultation and provided helpful feedback throughout the project, however no feedback was received from PHC leaders who are members of the CESDAC. A period of ten days was given to all CESDAC members to submit feedback about the framework. Although patient-family partners provided comments there was no response from the PHC leaders on the committee. The lack of response from PHC leaders could mean they have no issue with the recommended framework or that further refinement will be necessary before it is taken up across the organization.

Finally, the project time constraints prevented further refinement of the recommended framework and the development of PFE guidelines. A SPAR project is intended to be completed in a 12-week semester. The project time limitations definitely impacted the workshop

preparation, the analysis of workshop findings and consequently the development of the final framework. Despite the time constraints that impacted the project, a PFE framework is a living document that should change as organization culture and patient-family needs evolve (B.C. MoH, 2018). Instead of a completed work, the recommended framework that I have developed should be considered a launch point for strengthening PFE at PHC, and is open for further development as PFCC and support for engagement evolves.

Conclusion

This project not only resulted a PFE framework but also embodied the process of engagement by seeking out patient-family partners' perspectives to shape the final recommendation. Active partnership with patients and family members is the fundamental element of engagement; therefore, development of a practical and usable framework would not be complete without the involvement of patient-family partners. Furthermore, PHC's strong commitment to PFCC made the inclusion of patient and family member voices and choices a requirement of the project. Drawing from the patient-family partners' insights to shape the final framework supports its application across PHC and for a broad audience. More work may need to be done to determine how patients, family members and health professionals will utilize the PHC framework. Providing guidance on how to use the framework to support meaningful engagement is a significant piece that needs to be addressed to improve the patient and family experience.

Ultimately, *The PHC Person and Family Engagement Framework* represents a synthesis of best available evidence, the expertise of health care leaders specializing in engagement, and the perspectives of patient-family partners. Combining these credible forms of knowledge, I have created a practical and usable engagement framework that is in alignment with PHC's mission, vision and values. The goal of this framework is to strengthen PHC's culture of PFE and

commitment to PFCC. As the PHC framework is taken up, active partnerships with patients and family will help to change the way health care is delivered.

References

- Abelson, J., Humphrey, A., Syrowatka, A., Bidonde, J., & Judd, M. (2018). Evaluating patient, family and public engagement in health services improvement and system redesign *Healthcare Quarterly*, 21, 61–67.
- Ahmann, E, Abraham, M.R., Johnson, B. (2003). *Changing the concept of families as visitors: supporting family presence and participation*. Institute for Patient and Family Centered Care: Maryland, Virginia.
- Baker, G. R. (2014). *Evidence boost : A review of research highlighting how patient engagement contributes to improved care*. Canadian Foundation for Healthcare Improvement: Toronto, Ontario. Retrieved from <http://www.cfhi-fcass.ca/sf-docs/default-source/reports/evidenceboost-rossbaker-peimprovedcare-e.pdf?sfvrsn=8>
- B.C. Renal (2019). *B.C. Renal patient and family engagement framework*. Retrieved on April 1, 2020 from http://www.bcrenalagency.ca/resource-gallery/Documents/Pt_Engagement_and_Family_Engagement_Framework.pdf
- Bellows, M., Kovacs Burns, K., Jackson, K., Surgeoner, B., & Gallivan, J. (2015). Meaningful and effective patient engagement: What matters most to stakeholders. *Patient Experience Journal*, 2(1), 18–28. <https://doi.org/10.35680/2372-0247.1069>
- Black, A., Strain, K., Wallsworth, C., Charlton, S. G., Chang, W., McNamee, K., & Hamilton, C. (2018). What constitutes meaningful engagement for patients and families as partners on research teams? *Journal of Health Services Research and Policy*, 23(3), 158–167. <https://doi.org/10.1177/1355819618762960>
- British Columbia Ministry of Health. (2018). *Patient, family, caregiver and public engagement framework 2018*. Retrieved on April 1, 2020 from

<https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>

Canadian Foundation for Healthcare Improvement (2020). *Better together pledging organizations*. Retrieved on April 8, 2020 from <https://www.cfhi-fcass.ca/WhatWeDo/better-together/pledging-organizations>

Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies evidence and potential. *Health Affairs*, 32(2). <https://doi.org/10.1377/hlthaff.2012.1133>

CIHR. (2014). *Strategy for patient-oriented research: Patient engagement framework*.

Retrieved from

<http://www.himss.org/ResourceLibrary/genResourceDetailPDF.aspx?ItemNumber=28305>

Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., ... Curtis, J. R. (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Critical Care Medicine*, 45(1), 103–128. <https://doi.org/10.1097/CCM.0000000000002169>

DeCamp, M., Dukhanin, V., Hebert, L. C., Himmelrich, S., Feeser, S., & Berkowitz, S. A. (2019). Patients' views about patient engagement and representation in healthcare governance. *Journal of Healthcare Management*, 64(5), 332–346. <https://doi.org/10.1097/JHM-D-18-00152>

Frampton, S. B., Guastello, S., Hoy, L., Naylor, M., Sheridan, S., & Johnston-Fleece, M. (2017). Harnessing evidence and experience to change culture: a guiding framework for patient and family engaged care. *NAM Perspectives*, 7(1). <https://doi.org/10.31478/201701f>

- Greene, J., Hibbard, J. H., Sacks, R., Overton, V., & Parrotta, C. D. (2015). When patient activation levels change, health outcomes and costs change, too. *Health Affairs*, 34(3), 431–437. <https://doi.org/10.1377/hlthaff.2014.0452>
- Health Quality Ontario. (2016). *Ontario's patient engagement framework: creating a strong culture of patient engagement to support high quality health care*. Retrieved on April 1, 2020 from <http://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>
- Health Research & Educational Trust. (2013). *A leadership resource for patient and family engagement strategies*. Retrieved from www.hpoe.org
- International Association for Public Participation. (2014). IAP2 spectrum. Retrieved on April 1, 2020 from [https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20\(1\).pdf](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf)
- Institute of Medicine. (2013). *Best care at lower Cost: the path to continuously learning health care in America*. Washington, DC: National Academies Press.
<https://doi.org/10.17226/13444>
- Olding, M., McMillan, S. E., Reeves, S., Schmitt, M. H., Puntillo, K., & Kitto, S. (2016, December 1). Patient and family involvement in adult critical and intensive care settings: a scoping review. *Health Expectations*. Blackwell Publishing Ltd.
<https://doi.org/10.1111/hex.12402>
- Providence Health Care (2019). *The Providence plan: achieving our vision*. Retrieved April 22, 2020 from <http://www.providencehealthcare.org/about-providence/accountability/reports-plans/strategic-plan>

Appendix A: Glossary of Terms

Activities of engagement – refers to specific examples of how engagement takes place between patients, family members and health professionals, i.e. patient satisfaction surveys, participation in a quality and safety committee, (Health Quality Ontario, 2016).

Continuum of engagement - outlines the different ways patients, family members and health professionals may participate in active partnerships. Moving along the continuum of engagement, responsibilities and power over decision-making become more shared between patients, family members and health professionals (Carman et al., 2013)

Domains of engagement – describes where engagement can occur in the health care system. Usually in PFE frameworks domains are divided into a micro-, meso- and macro-systems (B.C. Ministry of Health, 2018).

Levels of engagement – describes where engagement can occur in the health care system. (see domains of engagement).

Methods of engagement – refers to more general descriptors of how engagement happens between patients, family members and health professionals. Usually found on the continuum of engagement, i.e. Inform, Share, Consult, Involve, (B.C. MoH, 2018).

Patient and family member engagement - patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system – direct care, organizational design and governance, and policy making – to improve health and health care (Carman et al., 2013, p. 24)

Spectrum of engagement – Used interchangeably with continuum of engagement. This term outlines the different ways patients, family members and health professionals may participate in active partnerships. Moving along the spectrum of engagement, responsibilities and power over decision-making become more shared between patients, family members and health professionals (Health Quality Ontario, 2016).

Ways of engaging – considered a plain language term to describe both general and specific examples of how engagement takes place between patients, family members and health professionals, i.e. a patient satisfaction survey, Involve (Carman et al., 2013).

Appendix B: Framework Matrices

Table 2. B.C. MoH Framework Matrix

Strengths	Weaknesses	Fit with PHC's Mission/Vision/Values
clear about when not to use engagement	defines engagement as exchange between pts, families, HCP but then describes inform as one way communication from HCP	focused on promoting continuous learning in health care
has domains of engagement	depiction of framework largely focuses on direct care. Less focus on higher domains of engagement	guiding principles include respect trust
specifically mentions engagement is doing "with" rather than doing "for"	size of information	
outlines 6 underlying principles to guide engagement	Lacks inclusiveness of cultural competence - white people only in info-graphic on engagement spectrum!	
provides some guidance for 'how to' do engagement - champions, context		

Table 3. BC Renal Framework Matrix

Strengths	Weaknesses	Fit with PHC's Mission/Vision/Values
guiding principles present	includes one way 'inform' on spectrum of engagement	guided by similar principles: community stewardship, integrity, respect
from a provincial agency	doesn't define engagement	promotes continuous learning
focuses on operationalizing engagement : The engagement process	no domains of engagement focused on organization level	
	engagement process very focused on pt/fam education not HCP/organization education	
	length of document	
	Some difficult language for patients & family	
	Not very mindful of cultural competence	

Table 4. Health Quality Ontario Framework Matrix

Strengths	Weaknesses	Fit with PHC's Mission/Vision/Values
defines engagement	should empower be on the spectrum or a guiding principle?	considers social justice/community stewardship
framework guided by a goal	doesn't fit PHC domains, more oriented to the provincial system	focuses on interdependence of pts, families and HCP
has all the elements of engagement: domains, enablers, spectrum	no guidance around process of engagement	focused on continuous learning in health care
guiding principles embedded in framework	Size of document	
doesn't use language of inform - discusses sharing	no specific mention of Indigenous culture	
considers circumstances/social justice of persons involved		
empower is a principle of engagement rather than on the spectrum, this implies every engagement activity can be empowering		

Appendix C: Workshop Materials

Workshop Invitation

Hello,

My name is Rhandall Tydd-Whiting. I'm a student in the Masters of Science in Nursing program at UBC. For the final project of my Masters, I'm working with Kate McNamee to develop a Patient and Family Engagement Framework for Providence Health Care. As a patient-family partner, your experience is very important to the development of this framework.

You're invited to share your perspectives on patient and family engagement through a dynamic virtual workshop. **The workshop will be held via Zoom on Monday June 15, 2020 from 1:00-3:30pm.** Please RSVP to this event by replying to this email. Space is limited to 15 people due to the non-traditional workshop format.

The purpose of the virtual workshop is to work together to:

- adapt an existing Patient and Family Engagement Framework for Providence Health Care.
- utilize a variety of activities to discuss what engagement with patient and families can look like at Providence Health Care.

Materials for you to review and a conference link with instructions will be emailed to you by Wednesday June 10, 2020. Please take a few moments to review these materials before June 15th, as they will be the focus of the discussions.

If you decide to participate, please note that the workshop will be recorded. All information shared will be kept confidential. Once the project is complete, the workshop recording will be destroyed.

I hope to connect with you over this unique virtual experience. Feel free to reply to Kate McNamee kmcnamee@providencehealth.bc.ca or me, rtyddwhiting@providencehealth.bc.ca if you have questions on the workshop. I look forward to working together to create a framework that can be used to support Providence Health Care in their goal to meaningfully engage with patients and families.

Warm Regards,
Rhandall Tydd-Whiting, RN

Workshop Participant Agenda & Zoom Etiquette

Patient and Family Engagement Workshop

Workshop Goal

- To adapt an existing Patient and Family Engagement Framework for Providence Health Care (PHC)

Agenda Item	Virtual Tools/Overview	TIME
Introduction	-Log into Zoom - Facilitator will share screen for activity	15 Minutes
Engagement Frameworks	-Shared Screen -Overview of selected frameworks	10 Minutes
Critiquing a Framework	-Using Zoom “Breakout Rooms” -Small groups discuss one selected framework	20 Minutes
Group Discussion	-Returning to main chat room -Each group will share their ideas	20 Minutes
BREAK		15 Minutes
Guiding Principles of Engagement	-Shared Screen -Overview of Guiding Principles	10 Minutes
Idea Challenge	-Facilitator will share a link to an online poll - Poll results will be shared and guide discussion	10 Minutes
Group Discussion	-Returning to main chat room -Facilitator will share poll results and guide discussion	30 Minutes
Wrap-Up	-Review of decisions made -Feedback	10 Minutes

Important Zoom Etiquette:

Here are a few simple guidelines to help foster respectful Zoom etiquette and give everyone a chance to participate:

1. Please mute your microphone when you are not speaking. This will help to minimize disruptions or distracting noises during discussion.
2. We would like to use video as much as possible to capture non-verbal communication. When using video please be mindful of your background to help minimize distractions.
3. Please use the '*Raise your hand*' button under the **Participant icon** if you have a question or are waiting to speak.
4. Remember that in most cases everyone can read your chat, so please be respectful. The Host will monitor the chat and try to help everyone in a timely manner.
5. There may be some technical challenges! Please be patient and we'll work together to overcome these challenges.

Pre-Work Information Booklet for Participants**PATIENT AND FAMILY ENGAGEMENT VIRTUAL WORKSHOP
PRE-WORK MATERIALS**

TABLE OF CONTENTS

Providence Health Care Mission, Vision and Values	3
Summary of Engagement Frameworks	4
Overview of Engagement Frameworks:	
<i>B.C. Ministry of Health Patient, Family, Caregiver and Public Engagement Framework</i>	5
<i>B.C. Renal Patient and Family Engagement Framework</i>	6
<i>Ontario's Patient Engagement Framework</i>	7
Guiding Principles of Engagement Frameworks	8
References	9

Providence Health Care Mission, Vision and Values

The mission, vision and values of Providence Health Care (PHC) are fundamental to who we are and what we do. The purpose of adapting a patient and family engagement framework for PHC is to capture the spirit of the mission, vision and values in our document. As we collaborate on adapting a framework for PHC please reflect on the following:



Inspired by the healing ministry of Jesus Christ, Providence Health Care is a Catholic health care community dedicated to meeting the physical, emotional, social and spiritual needs of those served through compassionate care, teaching and research.

Driven by compassion and social justice, we are at the forefront of exceptional care and innovation.

VALUES

Spirituality

We nurture the God-given creativity, love and compassion that dwells within us all.

Integrity

We build our relationships on honesty, justice and fairness.

Stewardship

We share accountability for the well-being of our community.

Trust

We behave in ways that promote safety, inclusion and support.

Excellence

We achieve excellence through learning and continuous improvement.

Respect

We respect the diversity, dignity and interdependence of all persons.



Summary of Engagement Frameworks

PHC has made Person and Family- centred Care an important part of their organization's culture but has not developed a framework for patient and family² engagement. It is important to recognize that person and family- centred care is different from the 'hands-on' partnership of patient and family engagement. The purpose of this summary is to provide a definition of patient and family engagement and identify common elements of engagement frameworks.

Carman et al. defines patient and family engagement as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system – direct care, organizational design and governance, and policy making – to improve health and health care” (2013 p. 224). This definition recognizes that active partnership is essential for meaningful engagement. Studies have shown that better engagement between patients, families and health professionals can improve health outcomes, contribute to improvement in quality and safety, and help control health care costs.

Elements of Engagement Frameworks

- ***The spectrum of engagement*** describes the different levels of engagement that promote and support active partnerships. Moving along the spectrum, the decision-making power of patients and families increases until responsibility is shared with health professionals. The spectrum recognizes that engagement is not “one size fits all”. It is important that patients and families have the right to choose their level of participation.
- ***Domains of engagement*** are the different levels of health care where engagement can occur. There are opportunities for engagement between patients, families and health professionals at the level of direct care, unit or program design, and organization policy and governance.
- ***Contextual factors of engagement*** refers to the factors that can influence engagement. Contextual factors may include the organization's culture, support from leaders, cultural competence and finances.

As you review the selected frameworks, try to make note of the elements of engagement that each of the organizations chose to include. If you want to read the full documents that accompany the selected frameworks, a link is provided at the end of each summary page.

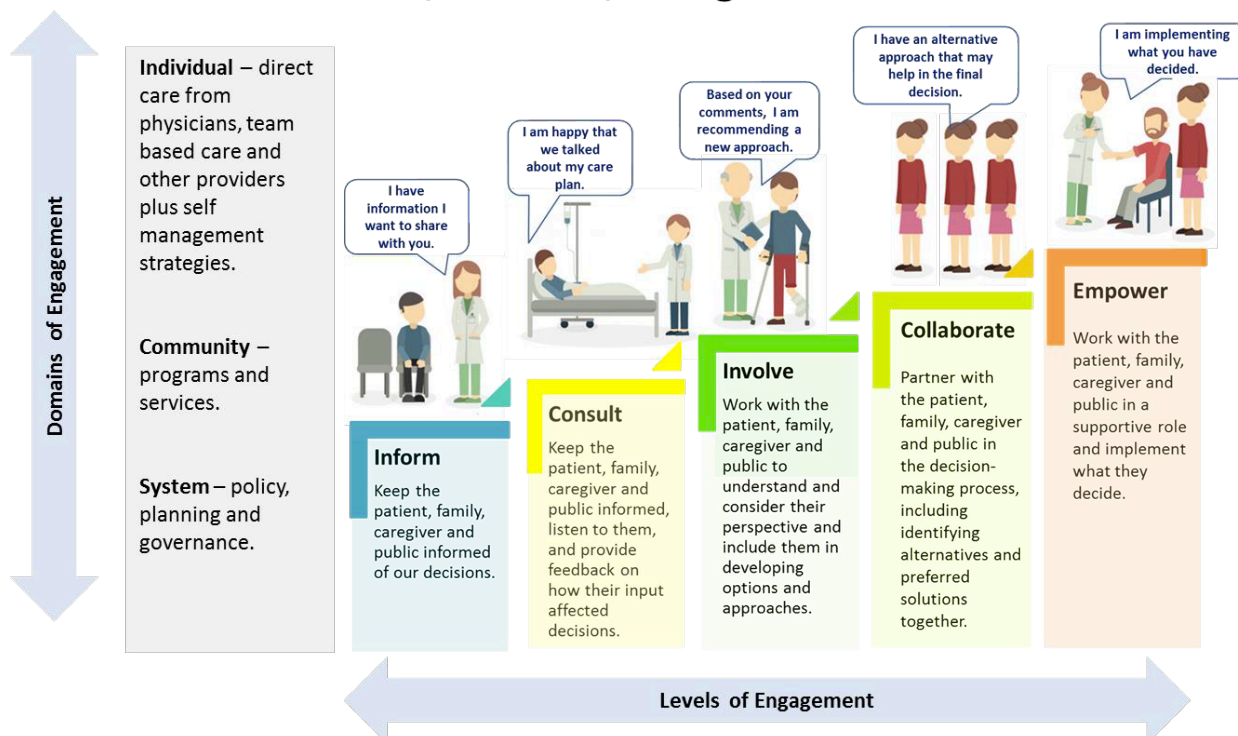
² Family is defined as any individual(s), related or unrelated, identified by the patient as someone who provides support and with whom they share a significant relationship (Davidson et al., 2017).

OVERVIEW OF ENGAGEMENT FRAMEWORKS

1. B.C. Ministry of Health Patient, Family, Caregiver and Public Engagement Framework

The B.C. Ministry of Health's framework goal is to improve patients' care experiences, improve the health of populations and reduce the per capita cost of health care.

A Multi-Dimensional Health Sector Engagement Framework for Patients, Families, Caregivers and the Public

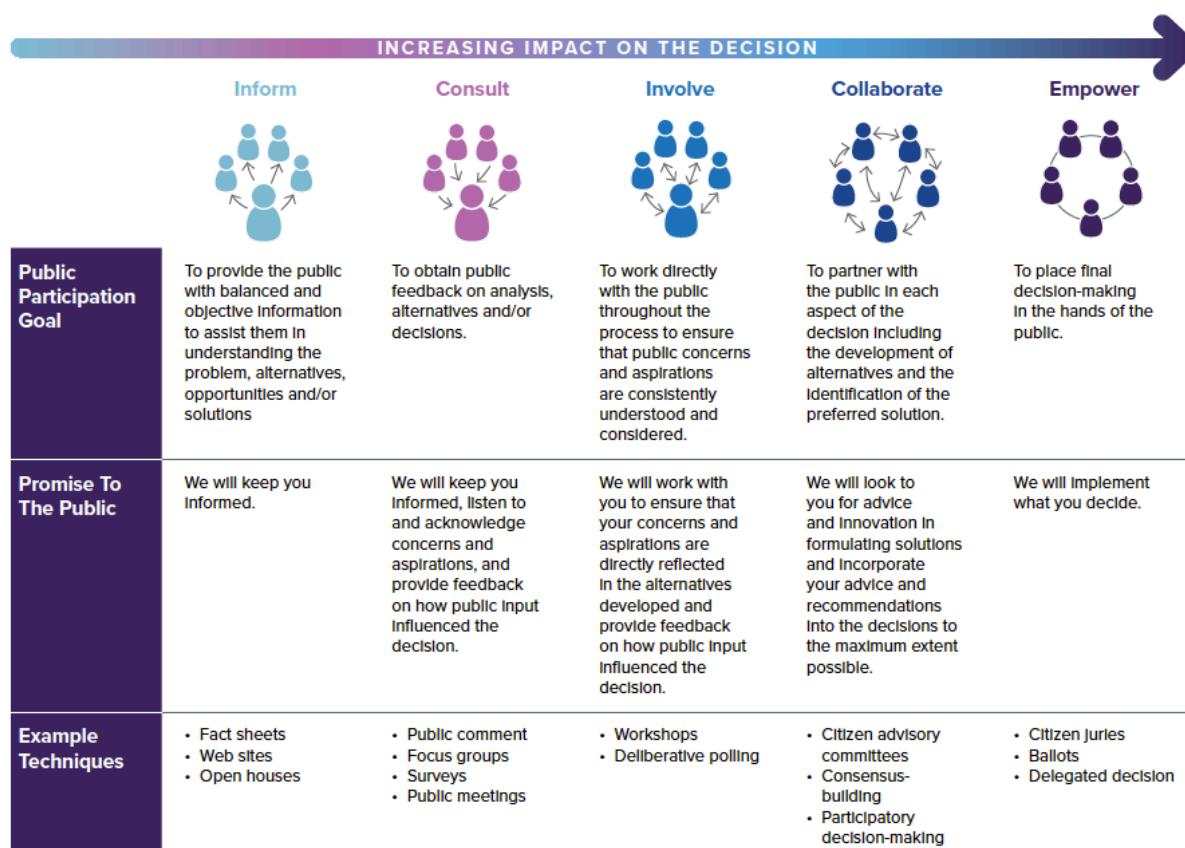


(B.C. MoH, 2018)

Link to full document: <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>

2. B.C. Renal Patient and Family Engagement Framework

The B.C. Renal framework goal is to optimize patient experiences and outcomes. In their full document, B.C. Renal describes their three domains of engagement as input from patients and families, co-design with patients and families, and capacity-building with patients and families.

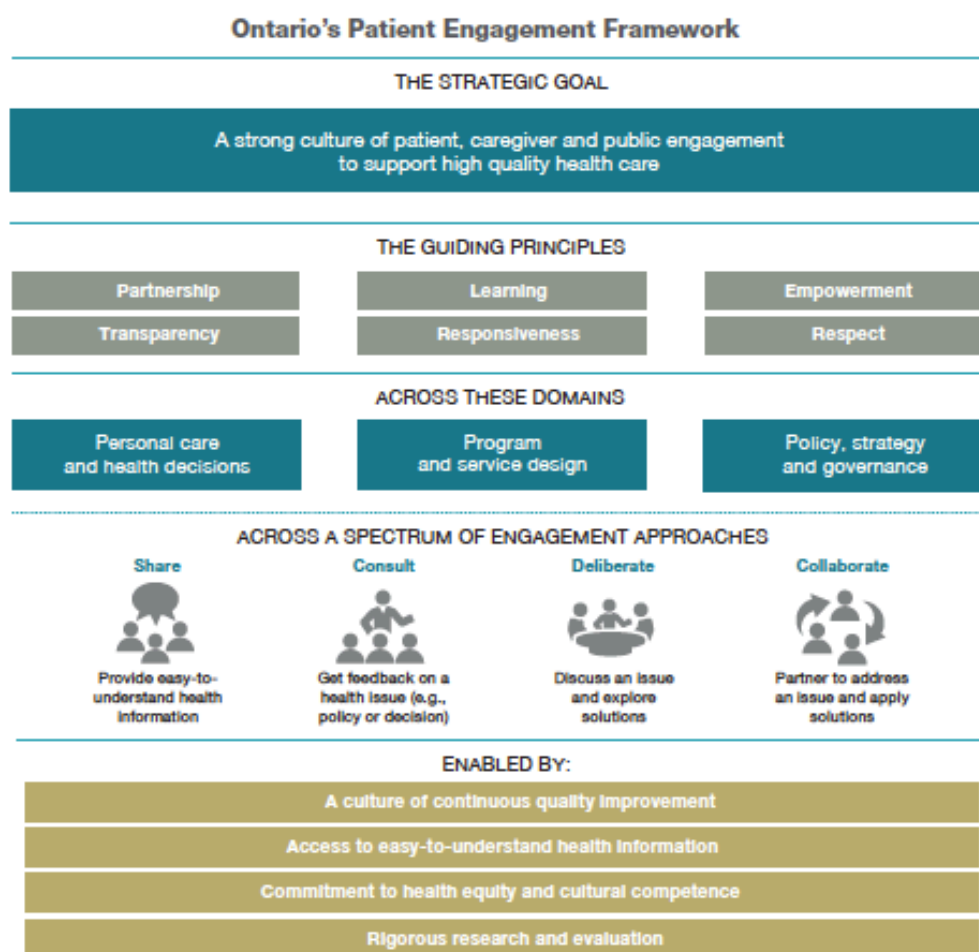


(BC Renal, 2019)

Link to full document: http://www.bcrenalagency.ca/resource-gallery/Documents/Pt_Enga-Patient_and_Family_Engagement_Framework.pdf

3. Ontario's Patient Engagement Framework

Ontario's Patient Engagement Framework was created by Health Quality Ontario, a provincial government agency that is focused on making health care more effective, affordable and efficient. In one page, this framework clearly states their strategic goal, domains of engagement, enablers of engagement, and a set of guiding principles.



(Health Quality Ontario, 2016)

Link to full document: <https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

Guiding Principles of Engagement

Guiding principles of engagement are a set of shared values that must be followed in order to support meaningful engagement among patients, families and health professionals. Here, I have summarized guiding principles that are shared among many engagement frameworks (BC Renal, 2019; CIHR, 2014; Health Quality Ontario, 2016) for your consideration.

Inclusiveness: Engagement brings together a diversity of patient and family perspectives, and outcomes are reflective of their contributions.

Support: Adequate support and flexibility are provided to patients and family to ensure that they can contribute fully to discussion and decisions. This includes creating safe environments that promote cultural competence, training, education and financial compensation.

Mutual respect: Patients, families and health professionals acknowledge and value each other's expertise and experiences.

Co-Build: Patients, families and health professionals work together to identify problems, set priorities, and produce and carry out solutions.

Partnership: Meaningful engagement requires authentic and mutually beneficial relationships between patients, families, health professionals and the organizations they work with.

Learning: All participants in engagement should expect to learn – about each other's perspectives, about the issue at hand, and about how things may improve.

Empowerment: patients and families need to feel empowered to openly express their needs, perspectives and concerns without fear of reprisal, and to make informed decisions with confidence.

Transparency: Health professionals and organizations are honest about their apprehensions, resource limitations and knowledge gaps when it comes to engaging with patients and family.

Responsiveness: Health professionals and organizations commit to acknowledging and responding to the voices of patients and families. This includes being clear about the purpose of engagement from the outset and embracing open and honest communication throughout the entire process.

References

- B.C. Renal (2019). *B.C. Renal patient and family engagement framework*. Retrieved on April 1, 2020 from http://www.bcrenalagency.ca/resource-gallery/Documents/Pt_Enga-Patient_and_Family_Engagement_Framework.pdf
- British Columbia Ministry of Health. (2018). *Patient, family, caregiver and public engagement framework 2018*. Retrieved on April 1, 2020 from <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>
- Canadian Institute for Health Research (2014). *Strategy for patient oriented research. Patient engagement framework*. Retrieved on April 3, 2020 from https://cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf
- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies evidence and potential. *Health Affairs*, 32(2). <https://doi.org/10.1377/hlthaff.2012.1133>
- Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., ... Curtis, J. R. (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Critical Care Medicine*, 45(1), 103–128. <https://doi.org/10.1097/CCM.0000000000002169>
- Health Quality Ontario. (2016). *Ontario's patient engagement framework: creating a strong culture of patient engagement to support high quality health care*. Retrieved on April 1, 2020 from <http://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>
- Providence Health Care (2019). *Mission: Forward. Providence Health Care Strategic Plan*. Retrieved on June 5, 2020 from <https://www.missionforward.ca/wp-content/uploads/2019/09/STRAT-PLAN-book-FULL-s.pdf>

Zoom Participant Guide

How to Join a Zoom Meeting:

You do not need a Zoom account to attend the workshop, but you will need to install the Zoom application on your device. You can do this ahead of time by following the prompts when you click on the link included in the Zoom invite. Once you have installed the Zoom application:

- Join the Workshop session by clicking the link included in the Zoom invite
- Click 'open zoom.us app' on the Pop-up

**Tips: Close all background programs for better connectivity. Join the Workshop a few minutes early to test your computer audio and video.*

How to Participate During the Workshop:

A tool bar at the bottom of the Zoom meeting screen will display ways of engaging with the group. Use the picture below to see the icons available in Zoom:

1. Share audio by clicking the **Microphone icon**. This icon will mute/unmute your audio.
2. Share video by clicking the **Video icon**. This icon will turn your webcam on and off.
4. Use the **Participants icon** to raise your hand or ask the Host to slow down.
6. Chat by text with 'Everyone' or individual participants by clicking the **Chat icon**.
Feel free to use the **Chat icon** if you want to write a question or ask for assistance.
8. Share basic reactions (like giving thumbs up) with the **Reaction icon**.

**Tips: Try to find a quiet, well lit spot for joining the session. For using video it is best if light is coming from in front of you or at an angle. Light (like a window) coming from behind will shadow your face. If you experience any lag time during the session you may need to turn your video off.*



1 2 3 4 5 6 7 8 9

How to Participate in Breakout Rooms:

During the workshop the Host will use breakout rooms for small group discussions. The Host will invite you to a break out room and you must click **Join**. Once you are in the breakout room:

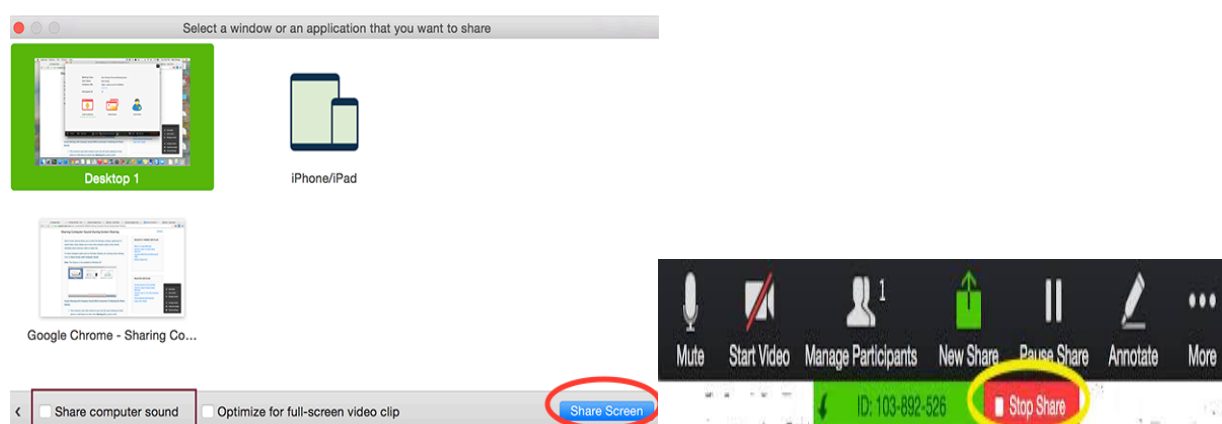
- You can participate using the same icons as in the main room.
- If you need assistance in the breakout room, click the **Ask for Help** button to let the Host know

- Once the Host ends the breakout room for you, you will be given the option to return to the main session immediately or in 60 seconds so that you can wrap up discussion.

How to Share Your Screen:

During small group sessions, you may want to share your screen within your group. To share your screen:

- Click the **Share Screen icon** (icon 5 in the picture above).
- Select what you would like to share. You can share your whole desktop or just your internet screen.
- Click **Share Screen**.
- When you are done click the red **Stop Share** button



Zoom Tutorials

If you would like more instructions for using Zoom check out the following websites and YouTube videos:

Providence Health Care Zoom Instructions for Patients

<http://covid19.providencehealthcare.org/medical-staff/resources-medical-staff/virtual-health/how-can-i-use-zoom-virtual-visits>

Zoom Tutorials <https://support.zoom.us/hc/en-us/articles/206618765-Zoom-Video-Tutorials>

Downloading Zoom & Joining a Meeting <https://www.youtube.com/watch?v=kh50kValdAY>

Meeting Controls

https://www.youtube.com/embed/ygZ96J_z4AY?rel=0&autoplay=1&cc_load_policy=1

Follow-Up Questionnaire for Participants

Patient and Family Engagement Questionnaire

Thank you for taking the time to fill in this questionnaire. Your answers will be combined with the discussions from the Virtual Workshop to inform the creation of an engagement framework for Providence Health Care (PHC). Please email your completed questionnaire to rtyddwhiting@providencehealth.bc.ca by June 20, 2020. I will share my progress on the engagement framework with participants via email by July 3, 2020.

Please refer to the Pre-Work Materials information booklet to complete this survey.

1. For each framework in the material you received, identify three things you liked and three things that could be improved.

B. C. Ministry of Health:

BC Renal:

Health Quality Ontario:

2. Thinking about the things you liked in each framework, what qualities do you think must be included in an engagement framework for Providence Health Care?

3. Is there one framework that stands out to you that we could use or perhaps change slightly to use at Providence Health Care?

4. Which statement should guide our PHC Patient Engagement framework?

a. A **goal** statement: The goal of our framework is to create a strong culture for person and family member engagement at PHC that supports our commitment to exceptional care and innovation.

b. A **vision** statement: The people we serve and their families are active partners in achieving PHC's vision to be at the forefront of exceptional care and innovation.

c. Create your own statement:

5. The levels/components/pillars of engagement describe the ways patients, families and health professionals can engage together. For the Providence Health Care framework, we can choose the words we like best to describe the different levels/pillars/components.

For the following questions, highlight or circle your response:

ii) What word would you choose to describe the first level of engagement?

a. Share

b. Educate

iii) What word would you choose to describe the second level of engagement?

a. Consult

b. Gather Information

iv) What word would you choose to describe the highest level of engagement?

a. Empower

b. Partner

6. The Guiding Principles of Engagement and PHC Values are listed in the box below. Please circle or highlight a total of 6 words. (You may want to refer to your Pre-Work Materials for the description of each word).

Inclusiveness	Mutual respect	Partnership
Spirituality	Trust	Stewardship
Support	Co-Build	Learning
Excellence	Integrity	Empowerment
Responsiveness	Transparency	Respect

6. Please rank your 6 choices from 1 to 6. (1-being most important and 6-being least important).

1.

2.

3.

4.

5.

6.

Any further comments:

Thank you for completing this questionnaire. Please email your responses to rtddwhiting@providencehealth.bc.ca by June 20, 2020.

Appendix D: Summary of Findings

Critiques of Each Framework

B.C. Ministry of Health

Workshop Findings	
<i>Likes:</i>	<i>Dislikes</i>
Lay out	Doesn't capture community or system levels of engagement
Language fairly clear	Implies a hierarchy of engagement
Captures significance of empowerment	Too focused on the individual/direct care
Increasing levels imply weight – representative of shared decision-making	

Questionnaire Findings	
<i>Likes:</i>	<i>Dislikes:</i>
Visual presentation – all one graphic, colourful, black print	Not clear if all 'levels' of engagement apply to every person in every situation
Clear examples of each method of engaging	If inform is used, need to be clearer that this is not informing people of the a decision made but advising them of options
Level and domains of engagement well illustrated	PCC doesn't occur in progressive steps
Patient-centred : clear that engagement is “nothing about me, without me”	HCP do not just inform – inform is not strong enough PCC language
Visuals help to increase understanding of framework for all that are involved	Need better examples of what inform can be
Simple language	Graphics of people are all white faces
Arrow going back and forth implies engagement can move in different directions	Missing guiding principles
	Only describe individual domain in examples

BC Renal

Workshop Findings	
<i>Likes:</i>	<i>Dislikes:</i>
The goal of Empowerment is patient-centered	IAP2 spectrum is not really patient/health centered
Good example of what not to do	Doesn't relate to people with kidney disease
	Not visually appealing (too generic)
	Need to start with empowerment and work from there since the framework doesn't

	make patients feel equal and doesn't value transparency
	Would like to see "Share" at the beginning rather than inform
	Very bureaucratic language "we will" that is not patient centered

Questionnaire Findings	
<i>Likes</i>	<i>Dislikes</i>
Info on one graphic	Written for HCP/BC Renal employees as a opposed to patients as equal partners
Better explanation of Inform than BC MOH	Missing guiding principles
Used specific examples of engagement	Seems more targeted to community/organization then direct care
Black print	Some examples of empowerment were abstract – "what is deliberative polling?"
Explanations clear of engagement levels	Language is not patient centered – didn't feel appropriate for patients or geared to promoting transparency
Goals and promises made to public	
All three domains can use single graphic (implied)	

Health Quality Ontario

Workshop Findings	
<i>Likes:</i>	<i>Dislikes:</i>
Overall content – clear sections	Visually poor for patient audience
Word choices (share rather than inform)	Not enough examples (especially for guiding principles)
Especially like the 'Enabled by' section	
Structured well for different audiences, patients, families or health professionals	

Questionnaire Findings	
<i>Likes</i>	<i>Dislikes</i>
All info on one page	Impossible to read white print on coloured squares – consider people with vision problems
Explains approach to engagement indepth but simply	Could have better examples under each of the engagement approaches
Enabled by section identifies supports for engagement	Didn't like the word Share
4 levels of engagement much more PCC	Graphic is not visually appealing – too many words that are not connected together
Share gives the impression HCP is	Graphic isn't understandable unless

listening	someone is explaining it to you
Liked the goal statement – strong culture of engagement across the different domains	“lots of buzz words” without examples – ‘very little trust in something that shows a lot of words but no promises, no actual direction’
Guiding principles clearly identified and how they are applied	‘doubt any one would use this – the approach is hidden in the framework – actual steps to achieve the goal are not emphasized’
Empowerment as a guiding principle as opposed to way of engagement	

Guiding Principles

Workshop Findings:	<p>The top rated guiding principles were: (in order)</p> <p>Mutual Respect Inclusiveness Transparency Partnership Empowerment Responsiveness</p>
	<ul style="list-style-type: none"> • Excellence just missed the cut for top spot but an argument was made that Excellence as a guiding principle would drive approach to engagement and push everyone to do better, not stagnant on the ‘status quo’ of engagement • Another point was made that if we have Transparency and Mutual Respect these guiding principles help to build trust

Questionnaire Findings:	<p>The guiding principles chosen by the questionnaire included:</p> <p>Mutual Respect (chosen by everyone/highest rank 3/4 respondents) Trust Transparency Empowerment Excellence Responsiveness Partnership (chosen but not ranked) Inclusiveness (chosen but not ranked)</p>
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	Learning Support Stewardship
	<ul style="list-style-type: none"> • 3/4 respondents selected Excellence • Mutual Respect came out as a strong guiding principle

Other Questionnaire Findings:

Qualities to include on a framework:

- 5 section approach like Health Quality Ontario Framework
- Clear about all patients being partners “nothing about me, without me”
- Emphasis on PHC mission, vision and values
- Examples to show how PHC will apply the approaches
- Patients upfront in visuals and examples as they are significant part of approaches and concepts
- The idea that it’s a collaboration and the patient will be consulted and listened to along the way.

Which framework(s) to use?

- BC MOH/Health Quality Ontario Combo
- BC MOH as template
- BC MOH

Vision or goal statement:

one respondent = vision

one respondent = goal

Level of engagement wording:

No clear consensus. Different respondents chose wording all over the map: Share (2), Educate, Gather Information (2), Consult, Empower, Partner (2)

There was a common opinion that levels of engagement weren’t really ensuring partnership or promoting PCC

This says to me there is a lot of confusion and disconnect around how we are engaging and what patient-family partners want from methods of engagement. How can we rethink/come together more on these methods.

Miscellaneous findings:

- Needed a clearer explanation of why the project is important/purpose, what will the impact be
- Can’t engagement start with involve

Who comes to these types of workshops? They are usually white privilege.

Appendix E: The Providence Health Care Person and Family Engagement Framework

The Providence Health Care Person and Family Engagement Framework

The Framework Goal:

The goal of our framework is to:

1. Provide an exceptional patient¹ and family² experience
2. Create highly engagement capable environments
3. Work together to develop the tools & resources needed for patients and families to be full partners in their own care

Enablers of Engagement

Meaningful engagement at Providence Health Care is enabled by the values we live everyday:

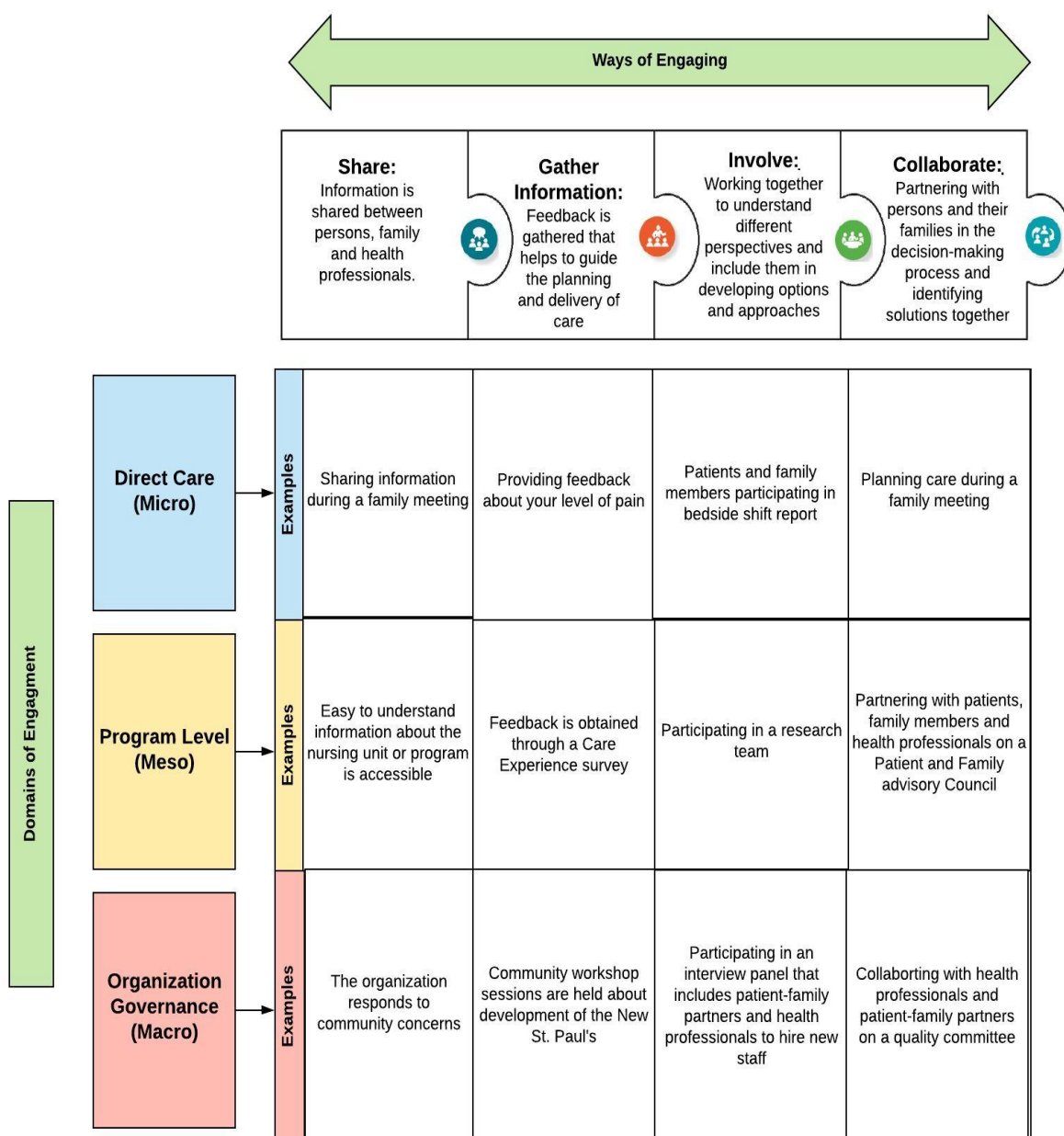
- A culture that is dedicated to learning and continuous improvement
- Recognition that patients and family members are equal and important partners in care
- As a faith-based organization, consideration for the spirituality and compassion that dwells within us all
- Acknowledgement that we are part of shaping the health and well-being of a larger community

Guiding Principles:

Underpinning this framework are guiding principles that all patients, family and health professionals must follow in order to support meaningful engagement activities:

- *Mutual Respect* - Patients, families and health professionals acknowledge and value each other's expertise and experiences.
- *Transparency* - Health professionals are honest about their apprehensions, resource limitations and knowledge gaps when it comes to engaging with patients and family.
- *Inclusiveness* - Engagement brings together a diversity of patient and family perspectives, and outcomes are reflective of their contributions.
- *Partnership* - Meaningful engagement requires authentic and mutually beneficial relationships between patients, families, health professionals and Providence Health Care
- *Trust* - patients and families need to feel that they are supported to openly express their needs, perspectives and concerns without fear of losing quality care, and to make informed decisions with confidence.
- *Responsiveness* – Providence Health Care, and its health professionals, commit to acknowledging and responding to the voices of patients and families. This includes being clear about the purpose of engagement from the outset and embracing open and honest communication throughout the entire process.

The Engagement Spectrum



¹Patient is an individual under the care of the hospital/residential care setting who has his or her own set of beliefs and habits, and his or her own unique family and support group. In this framework the term patient is intended to be inclusive of clients, residents and tenants served by Providence Health Care.

²Family is defined by the patient. When the patient is unable to define family, the patient's substitute decision maker provides the definition. Family members are the people who provide the primary physical, psychological, or emotional support for the patient. Family is not necessarily blood relatives. Family members are integral to the overall well-being of the patient.