



Provincial Health Services Authority

Patient Experience Program

# Patient and Family Engagement

Annual Report 2020

Joyce Lee

Provincial Lead, Patient & Family Engagement

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## Executive summary

This document reports on the engagement activities of the BC Cancer Network of Patient and Family Partners that were implemented between April 1, 2019 and March 31, 2020. 73 provincially- and regionally-led engagement initiatives in BC Cancer were reported to and evaluated by the Patient Experience Program. There was a diversity of engagement techniques used, ranging from one-time individual interviews to annually renewable committee memberships. As at March 31, 2020, 27 engagements were completed, 44 were in progress and 2 were on hiatus. Responses from the Partners and from the health professionals leading the initiatives were sought at midterm (6 months) and at the end of the engagement, using evaluation questionnaires comprising scales and reflection questions.

In assessing their confidence and readiness in the engagement, Partners agreed that they were able to share or seek information readily. On communication, Partners reported that the purpose of the engagement activity had been clearly explained to them, although the use of their input from the activity was not always clearly understood. To strengthen communication in the engagement, Partners suggested that health professionals use accessible language, take time to clarify engagement progress discussed at the meetings and update Partners on engagement progress. Reflecting on the partnership with health professionals, Partners indicated they were able to share their perspectives freely and felt that their views were heard. Partners appreciated the opportunity to contribute to care improvement while learning about the organization challenges and opportunities in care delivery.

Partners have largely felt supported to participate in the engagement and that the input they have provided would be considered in decision-making. At the same time, Partners said they wish to see more diverse Partners participating in the engagement and prompt uptake of actions to improve service delivery. Partners also highlighted the need to see the results of their inputs, emphasizing the importance of reporting back to Partners the influence they have had on decision-making.

The Partners further identified that the key strengths of the engagement were centred on the collaborative relationship and facilitation of the engagement by health professionals. Partners felt that their feedback was sought, acknowledged and acted on to improve care. They were particularly appreciative when health professionals included the Partners in conversations, took time to address the Partners' questions, and treated the Partners as valued members of the team. On ways to enhance the engagement, Partners reiterated the importance to clarify goals and roles in the engagement, update

Partners promptly on changes in meeting schedule/leadership/timeline, and explain terminology/acronyms used in the engagement.

Among the health professionals, there was agreement that engagement was a good use of their program resources. The Partners' input was also deemed useful where it could be integrated in practice and outputs from the engagement could influence decision. Reflecting on the strengths of the engagement, health professionals commented that the collaboration between health professionals and Partners was meaningful and synergetic and engaging. Partners have contributed to patient-centred care. To improve on the engagement experience, health professionals identified the importance of matching Partners with experiences that aligned with the engagement topic, being clear about the amount of influence Partners have in the engagement and more education about the process of matching Partners to an engagement.

In December 2019, the Patient Experience Program established the *Partners to Partners Connect Networking Group* (P2P Connect) in an effort to strengthen peer support and mentoring in engagement. Partners contributed to the phone and virtual meetings by making recommendations for discussion topics, co-facilitating meetings and presenting and providing feedback at the meetings. With increasing interest, a team of five Patient and Family Partners was formed to lead and shape P2P Connect. The five Partner-Leads represented diversity in role (patient/family caregiver), age, gender, culture and ethnicity and engagement experience.

This is the second year of evaluation of patient and family engagement at BC Cancer. Improvements made to last year's reporting included collecting Partners' demographic data during their enrolment to the Network and the use of a similar set of scale questions at both midterm and end-of-engagement evaluations. The changes have resulted in a more complete reporting of Partners' background information and increased efficiency in data collection.

Patient and family engagement in BC Cancer continues throughout the COVID-19 pandemic, where Partners participate through phone and video conferencing. The learning and support from peers at the monthly network group meetings provided further opportunities for Partners to be more engaged at BC Cancer at this uncertain time.

Overall, the Partners' and health professionals' evaluation of their engagement demonstrates their commitment to this work. Their experience, as reported here, provided insights into BC Cancer's continuous efforts to include the patient's voice in care improvement.

## Introduction

The Network of Patient and Family Partners was established in May 2017 under the governance of the Patient Experience Program. The Partners are patients and their loved ones who have experienced cancer care. Through the Network, Partners are matched to BC Cancer initiatives, bringing their voices to improve cancer care for all patients and families across the province.

### What is engagement?

“...a process by which people are enabled to become *actively and genuinely involved* in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action *to affect change.*” - *World Health Organization*

Patient and Family Engagement is part of providing person-centred health care. It is an intentional strategic approach that we use to give patients a voice in the design and delivery of health care. Aligned with BC Cancer’s commitment to person-centred care, we engage patients and families because we want:

- health services that are accessible and responsive to the needs and preferences of patients and families
- improved understanding of how people navigate health services
- improved understanding of supports and barriers experienced by patients and families
- to uphold accountability to the public in the designing of their care

See Appendix A for definitions, Appendix B for references and Appendix C for links to resources in engagement.

There are five types of engagement in the spectrum of public participation: *inform, consult, involve, collaborate, empower*. Each type of the engagement delivers a promise, using different techniques (activities) that are congruent with the goals of the engagement. See Appendix D for the spectrum of engagement showing the types, techniques and promises of engagement. Engagement techniques used at BC Cancer in the reporting period is listed in Appendix E.

As at March 31 2020, 139 cancer patients and family caregivers across BC were enrolled in the Network. In the reporting period of April 1, 2019 to March 31, 2020, 73 engagement initiatives in BC Cancer were reported to the Patient Experience Program. The initiatives encompass provincially- and regionally-centered projects and committees. The health professionals who led the internal initiatives include multidisciplinary practitioners and administrators.

The midterm engagement questionnaire and end-of-engagement (closure) questionnaire used for evaluating the engagement initiatives were adapted from the Public and Patient Engagement Evaluation Tool (PPEET)<sup>1</sup>. See Appendix F to M for evaluation questionnaires. Engagement evaluation was conducted at two time points: midterm (6 months after engagement start date) and end-of-engagement with the Partners and the health professionals who led the initiatives (initiative lead). Partners and health professionals were asked to complete questionnaires encompassing scale and reflection questions. Partners provided feedback to the scale questions relating to their self-assessment on confidence/readiness, communication between the Partners and health professionals in the engagement, the strength of the partnership, support needs and the Partners' perceived influence on decisions made. Health professionals were asked to respond to the scale questions regarding resource usage, impact on practice change and decision-making and training needs. Reflection questions on the strengths of the engagement, areas for improvement and support needs were posed to the Partners and health professionals at the end of the engagement.

As of June 2019, revised midterm questionnaires (version 2) were used to evaluate the Partners' and the health professionals' experience in the in-progress engagement initiatives. The scale questions in the revised Partners' and health professionals' midterm questionnaires are similar to those in the end-of-engagement questionnaires.

The end-of-engagement evaluation included response from Partners who had resigned from an in-progress engagement initiative. Engagements at provincial and regional levels that were not reported to the Patient Experience Program are not included in this report. Where Partners and health professionals did not complete the evaluation, no responses are reported.

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<sup>1</sup> The Public and Patient Engagement Evaluation Tool has been licensed under a Creative Commons Attribution---NonCommercial---Share Alike 4.0 International License. ©2018, Julia Abelson and the PPEET Research---Practice Collaborative. McMaster University. All rights reserved.



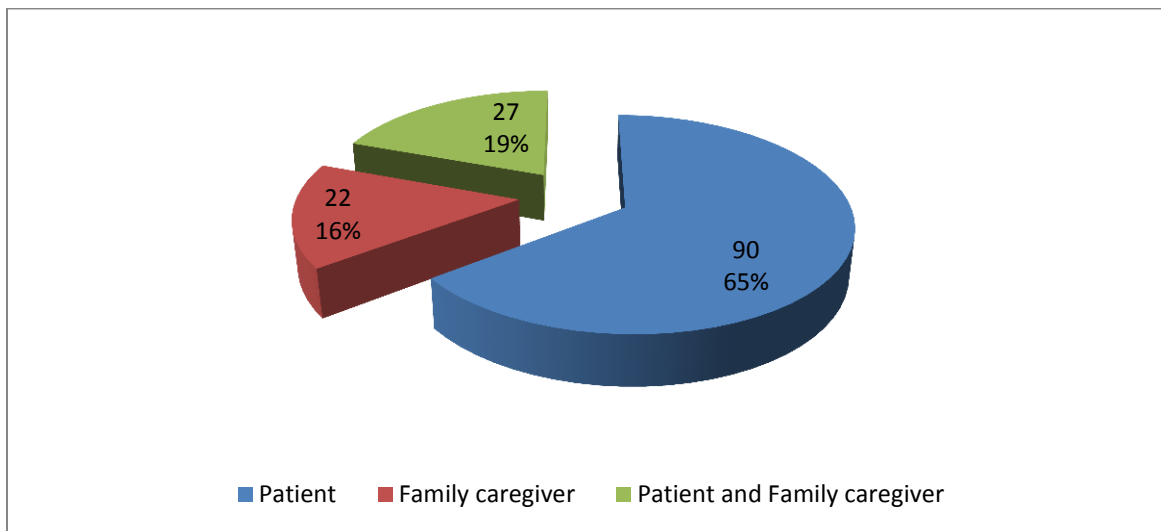
The report provides an overall description of the Partners in the Network as at March 31, 2020. The engagement status of the initiatives in each regional centre is discussed. The evaluation results were analyzed, quantitative responses were aggregated, and emerging themes were drawn from the qualitative responses. Further, respondent comments were quoted to reflect the quantitative results and the identified themes. Learnings from a new initiative, Partners to Partners (P2P) Connect, undertaken by the Patient Experience Program to strengthen Partners connection and engagement at BC Cancer, is also reported. The document concludes with a discussion on the improvements over last year, limitations in engagement evaluation and considerations to improve future reporting.

## Characteristics of Partners

A hundred and thirty-nine patients and family caregivers were enrolled in the BC Cancer Network of Patient and Family Partners as at March 31, 2020. About two-thirds of the enrolments were referred to the Network by BC Cancer staff/health professional (67.5%). Referrals from community collaborators constituted almost a fifth of the enrolment (17.89%). Other sources of referral were online-website/social media (6.5%) and Partners' word of mouth (8.13%).

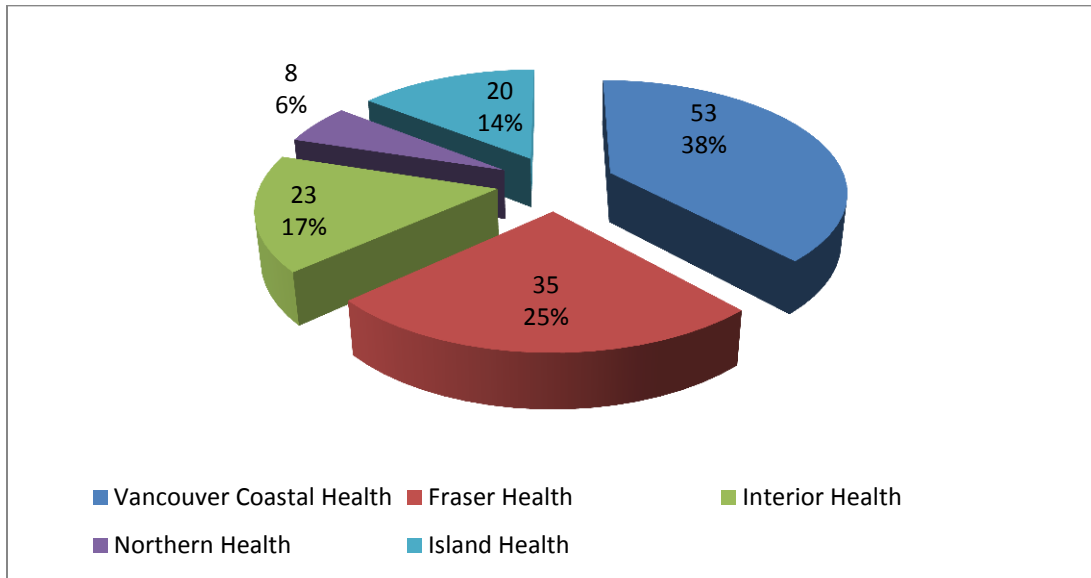
Almost two-thirds (64.75%) of the Partners enrolled were cancer patients; more than 10% (15.83%) were family caregivers. About one-fifth (19.42%) of the Partners in the Network identified themselves as both cancer patients and carers of a loved one (family/friend) diagnosed with cancer. See Graph 1 on Partner's role.

**Graph 1: Characteristics of Partners – Role identified, n=139**



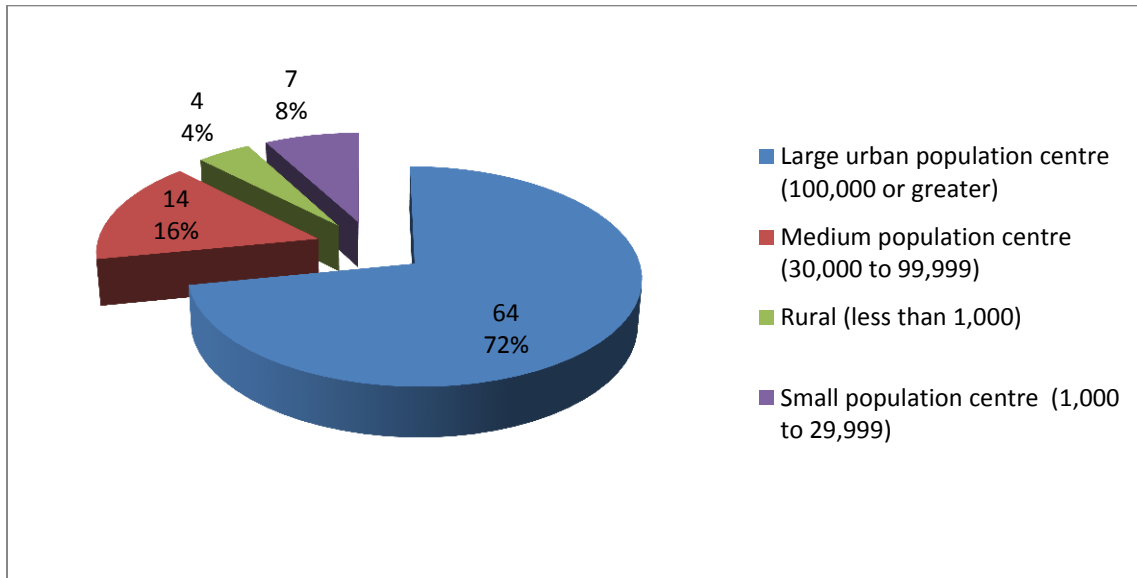
The Patient and Family Partners have predominantly received care in a BC Cancer regional centre; those who were not identified as BC Cancer patients received care in their local hospital or community clinic. Almost 40% of the Partners resided in Vancouver Coastal Health region; 40% were from the Fraser Health region. About 16% of the Partners lived in the Interior Health region; 14.39% were from the Island Health region, and 5.76% were from Northern Health region. See Graph 2 on characteristics of Partners by geographic location.

**Graph 2: Characteristics of Partners – Geographic location by health authority, n=139**

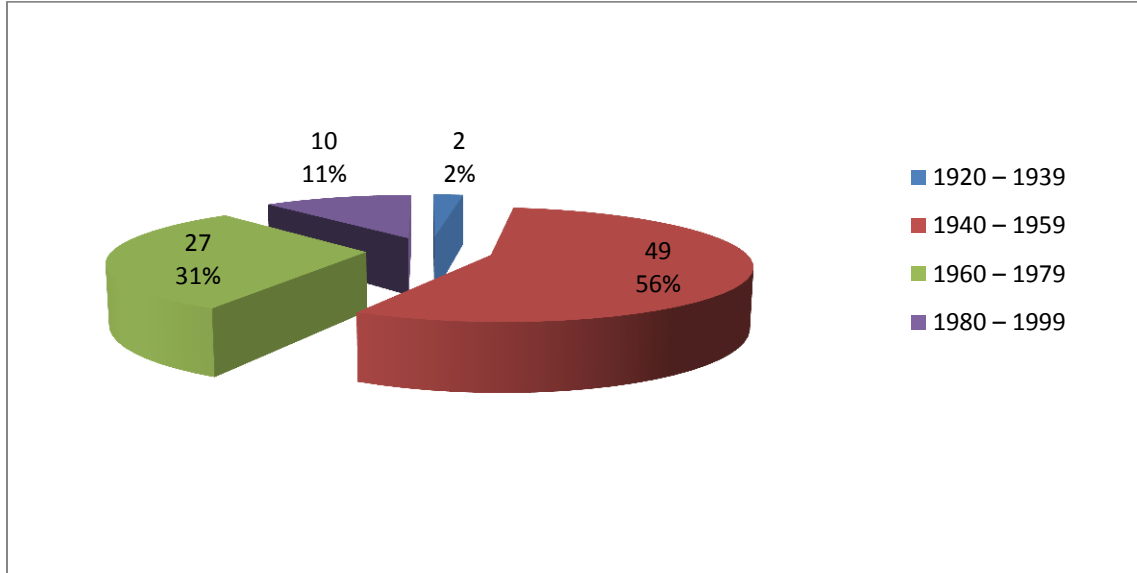


Among the Partners who provided further demographic information, the majority (72%) were identified as residents of a large urban population (100,000 or greater), compared to 4% from rural communities (less than 1000). On the Partners' ages, almost 60% were over 60, with 11% under 40. A majority of the Partners also identified as female (66%) and have university education (67%). While 40% reported that they have retired, close to 40% were in the labour force. See Graph 3-7 on characteristics of Partners by geographic unit, year range of birth, gender, education and work status.

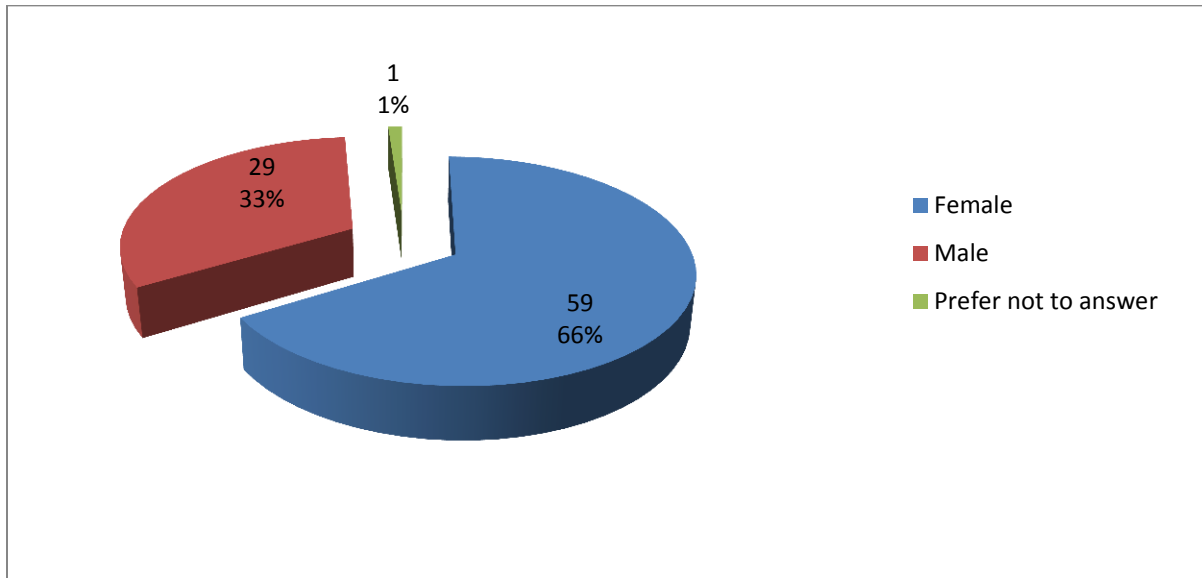
**Graph 3: Characteristics of Partners – Geographic unit, n=89**



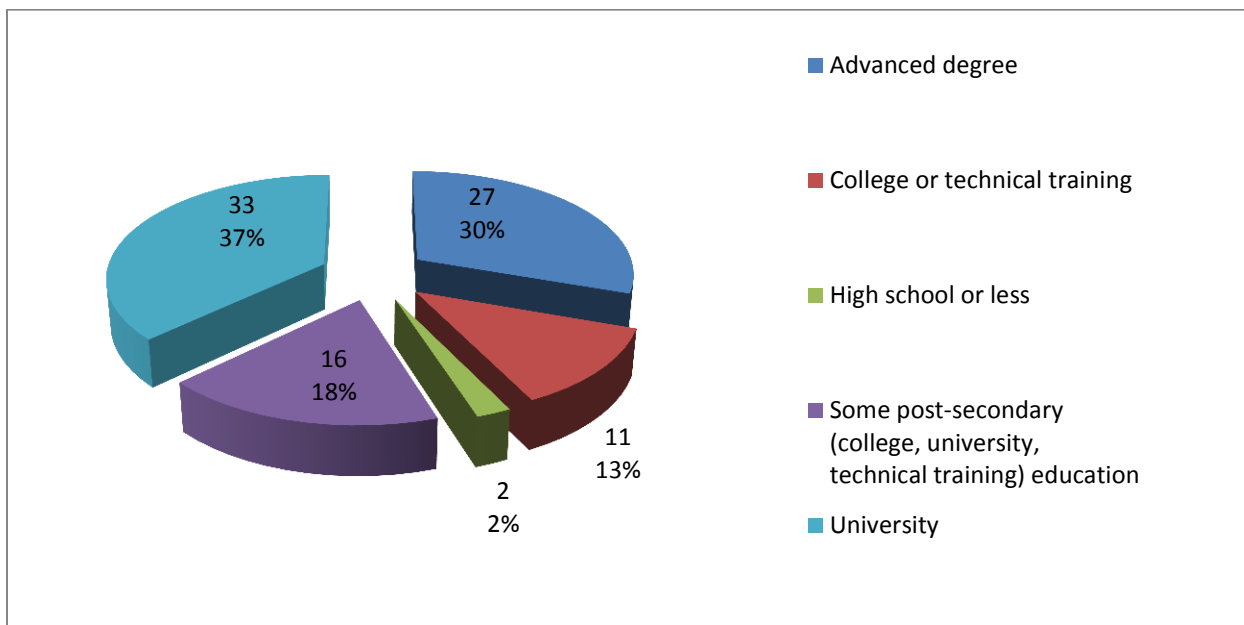
**Graph 4: Characteristics of Partners – Year range of birth, n=88**



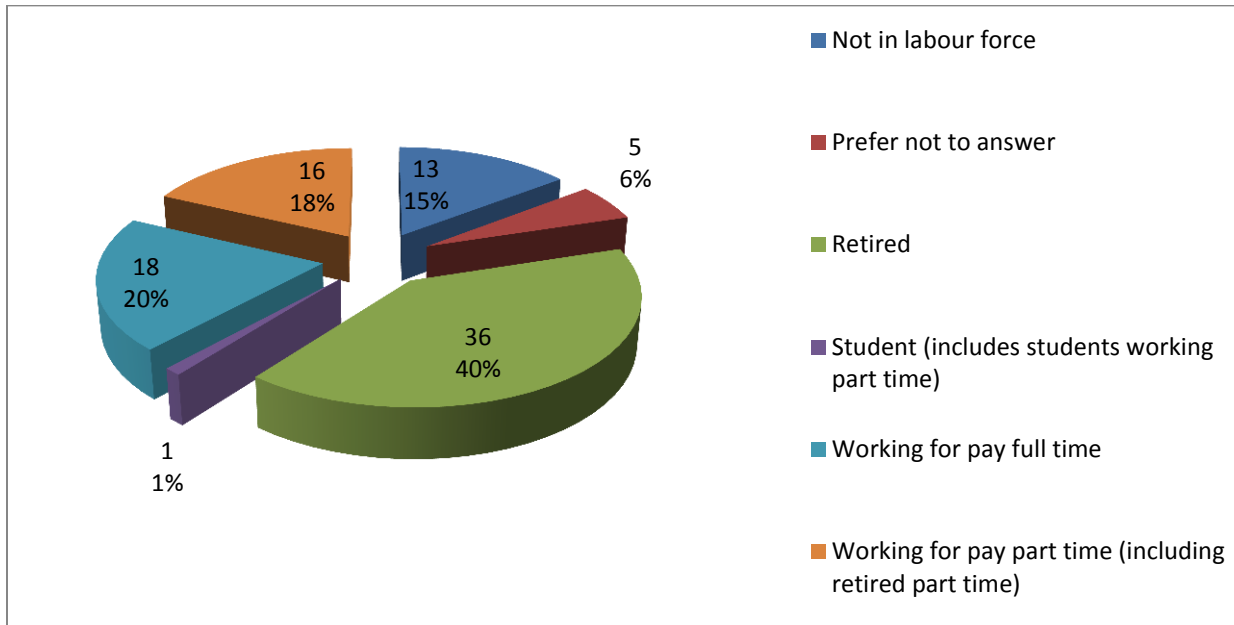
**Graph 5: Characteristics of Partners – Gender, n=89**



**Graph 6: Characteristics of Partners – Education, n=89**



**Graph 7: Characteristics of Partners – Work status, n=89**



28 cancer types were reported by the Patient and Family Partners, reflecting a diversity of cancer experience in the Network. Breast cancer was most commonly cited (29.41%), followed by colon (8.24%) and prostate cancer (8.24%). Partners also reported experiences with rare cancers, and several have had diagnoses of multiple cancers. See Table 1 for cancer type cases reported by Partners.

**Table 1: Cancer type**

Cancer type	Number	%
Brain	10	5.88
Breast	50	29.41
Colon	14	8.24
Head/neck	11	6.47
Leukemia	7	4.12
Lung	6	3.53
Lymphoma	9	5.29
Melanoma	7	4.12
Multiple Myeloma	5	2.94
Ovarian	8	4.71
Pancreatic	5	2.94
Prostate	14	8.24
Others <sup>1</sup>	24	14.12
Cases reported by Partners	170	100

Note: 1. Cancer types of less than 5 cases reported: amyloidosis, anal, appendix, bladder, bone, bone marrow, cervical, endometrial, leiomyosarcoma, liver, rectal, renal, rhabdomyosarcoma, small intestine, stomach, testicle, ureter.

## Engagement initiatives

Between April 1, 2019 and March 31, 2020, 73 BC Cancer engagement initiatives were reported: 27 have been completed, 44 were in progress and 2 were on hiatus. The initiatives on hiatus were for reasons of priority and leadership change. Provincial programs constituted more than half of the engagement initiatives (63.01%). The remaining initiatives were led by health professionals in each regional centre: Abbotsford (5.48%), Kelowna (4.11%), Prince George (2.74%), Surrey (6.85%), Vancouver (8.22%) and Victoria (9.59%). See Table 2 for the proportion of BC Cancer engagement initiatives by program/regional centre.

**Table 2: BC Cancer engagement initiatives between April 1, 2019 and March 31, 2020**

Program/Centre	Completed	In progress	On hiatus	Total	%
Provincial	19	26	1	46	63.01
Abbotsford	1	2	1	4	5.48
Kelowna	2	1	0	3	4.11
Prince George	0	2	0	2	2.74
Surrey	1	4	0	5	6.85
Vancouver	1	5	0	6	8.22
Victoria	3	4	0	7	9.59
Total	27	44	2	73	100.00

The health professionals who led the internal initiatives included multidisciplinary practitioners and administrators. The techniques of engagement used ranged from one-time individual interviews to annually renewable committee memberships. See Appendix E for the engagement techniques used.

Characteristics of the engagement initiatives in the provincial programs and in the regional centres are reported in the following section. Initiatives that are related to Clinical and Systems Transformation (CST) are also indicated in the engagement listing.

### Provincial

Of the 46 provincially-led engagement initiatives, 19 have been completed, 26 were in progress and 1 was on hiatus. The initiatives engaged between 1 and 10 Patient and Family Partners, using various engagement techniques. Partners enrolled in the provincial initiatives participated in committees, working groups, consultation groups, review of patient education material and forms, photo shoots and



filming, Word Cafés, conferences/presentations and/or focus groups. See Table 3 for the characteristics of engagement initiatives led by the provincial program.

**Table 3: Provincial program engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement technique	No. of Partners	Status
1	Advance Care Planning (ACP) Committee	Committee	2	In progress
2	BC Cancer Primary Care Learning Sessions	Committee	4	In progress
3	BC Cancer Quality Improvement Facilitation and Advisory Group	Committee	2	In progress
4	BC Cancer Smoking Cessation Initiative	Working group	2	In progress
5	BC Cancer Website Testing	Review	5	Completed
6	BCC Summit 2019	Conference/presentation	6	Completed
7	Breast density primary care	Working group	2	Completed
8	Caregiving for colorectal cancer patients - Primary caregiver reported outcomes	Working group	3	In progress
9	Chemotherapy and Patient Quality of Life Project	Working group	3	In progress
10	Clinical Trial Protocol Review Committee	Committee	3	In progress
11	Early Palliative Integration into Cancer Care	Committee	3	In progress
12	Early Palliative Integration into Cancer Care - Patient Experience Survey	Focus group	8	Completed
13	Exploring the Occupation of Patient Engagement at BC Cancer	Working group	1	Completed
14	Film Shoot for Patient and Family Counselling Services	Photo shoot/filming	3	Completed
15	Gynecologic Cancer Initiative - Clinical Trials Group (GCI-CTG)	Working group	2	In progress
16	Gynecologic Oncology Systemic Therapy Group - Patient Reported Outcomes	Consultation group	1	In progress
17	Health Ethics Council	Committee	2	In progress
18	Hereditary Cancer Family Letter Update	Review	2	Completed
19	Improving the Model of Care in Breast Cancer Clinic	Committee	2	In progress
20	Lymphoid Cancer Education Forum Speaker	Conference/presentation	1	Completed
21	Model of care for adolescent and young adult cancer survivors	Working group	1	Completed
22	Online access to pathology results	Focus group	10	Completed
23	Outpatient Cancer Care Patient Survey Consultation Group Meeting	Committee	2	In progress
24	OVCARE Patient and Family Advisory Committee	Committee	3	In progress
25	Patient and family experience evaluation metrics (CST)	Working group	2	In progress
26	Patient Centered Measurement Committee (formerly Patient Reported Outcomes Committee)	Committee	2	In progress

No.	Engagement title	Engagement technique	No. of Partners	Status
27	Patient Experience Committee (formerly Patient and Family Engagement and Experience Committee)	Committee	3	In progress
28	Patient speaker for BC Cancer Nursing Orientation	Conference/presentation	6	In progress
29	Patient symptom self-assessment tool	Review	5	Completed
30	Patient Video Series	Photo shoot/filming	3	Completed
31	Performance Management Advisory Committee	Committee	1	In progress
32	Primary care lung cancer clinical guideline working group	Working group	1	In progress
33	Provincial Interprofessional Practice Council Patient and Family Consultation Group	Consultation group	3	On hiatus
34	Provincial Systemic Committee (Chemotherapy)	Committee	1	In progress
35	Psychosocial resource editing	Review	4	Completed
36	Radiation Therapy Safety Strap Working Group	Working group	3	Completed
37	Radiation Therapy Skin Care Education Video	Review	2	Completed
38	Resources Editing and Advisory Committee - Psychosocial Oncology	Committee	1	Completed
39	Retreat about improving care for advanced cancer patients	World café	1	Completed
40	Review Patient Pamphlets about Infection Control	Review	6	Completed
41	Review of supportive cancer care brochures	Review	4	In progress
42	Radiation Therapy Patient and Family Consultation Group	Consultation group	4	In progress
43	Using wearable sensors to assess functional status in cancer patients project	Working group	2	Completed
44	Virtual Health Advisory Committee, PHSA	Committee	3	In progress
45	Virtual Health Steering Committee	Committee	2	In progress
46	Virtual Interpreter Project	Consultation group	2	In progress

## Abbotsford

Four engagement initiatives were reported in Abbotsford, one of which has been completed, two were in progress and one was on hiatus. Up to three Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees and review of patient forms. See Table 4 for the characteristics of engagement initiatives led by Abbotsford centre.

**Table 4: Abbotsford engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Abbotsford Regional Patient Experience Committee	Committee	2	In progress
2	Advanced Care Planning Committee, Abbotsford	Committee	0	On hiatus
3	Information Referral Form, Abbotsford	Review	3	Completed
4	Patient and Family Advisors for Patient-centred Measurement Assessments project	Committee	3	In progress

## Kelowna

Three engagement initiatives were reported in Kelowna; two have been completed and one was in progress. Between 2 and 7 Patient and Family Partners were engaged in the initiatives. The initiatives involved committee membership and working group. See Table 5 for the characteristics of engagement initiatives led by Kelowna centre.

**Table 5: Kelowna engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Interior Regional Oncology Council	Committee	3	Completed
2	Referral Project Working Group - Kelowna (formerly Triage Steering Committee)	Working group	2	Completed
3	Regional Patient Experience Council, Kelowna	Committee	7	In progress

## Prince George

Two engagement initiatives were reported in Prince George; both of which were in progress. The initiatives engaged up to 2 Patient and Family Partners in a committee and in a consultation group. See Table 6 for the characteristics of engagement initiatives led by Prince George centre.

**Table 6: Prince George engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Clinical Trial Advisory Group, BC Cancer-Prince George	Committee	1	In progress
2	Patient experience in witnessing the ringing of the 'milestone' bell	Working group	2	In progress

## Surrey

Five engagement initiatives were reported in Surrey; one has been completed and four were in progress. Between 1 and 5 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees, working groups and a review of patient material. See Table 7 for the characteristics of engagement initiatives led by Surrey centre.

**Table 7: Surrey engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Advanced Care Planning Quality Improvement Project, Surrey	Working group	5	In progress
2	Joint BC Cancer / Fraser Health Cancer Care Strategy Council – Surrey	Committee	1	In progress
3	Malignant Hematology Working Group, Surrey	Working group	1	In progress
4	Radiation Therapy Prostate Information Session Presentation, Surrey	Review	1	Completed
5	Regional Patient Experience Council - Surrey	Committee	2	In progress

## Vancouver

Six engagement initiatives were reported in Vancouver; one has been completed and five were in progress. Between 1 and 6 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees, consultation group, working groups and review of patient material. See Table 8 for the characteristics of engagement initiatives led by Vancouver centre.

**Table 8: Vancouver engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	BC Cancer - Vancouver/Vancouver Coastal Health Joint Cancer Care Strategy Engagement	Consultation group	2	In progress
2	Cancer Care Implementation Working Group - A Palliative Approach to Care in Vancouver Centre	Working group	1	In progress
3	Patient Experience Council, BC Cancer-Vancouver	Committee	6	In progress
4	Patient Experience mapping	Working group	2	In progress
5	Review travelling for cancer treatment handout	Review	3	Completed
6	Spiritual Health Advisory Committee	Committee	1	In progress

## Victoria

Seven engagement initiatives were reported in Victoria; four have been completed and three were in progress. Between 1 and 3 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees, consultation groups and a conference speaking engagement. See Table 9 for the characteristics of engagement initiatives led by Victoria centre.

**Table 9: Victoria engagement initiatives (between April 1, 2019 and March 31, 2020)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Island Regional Cancer Care Strategy Council	Committee	2	In progress
2	Multidisciplinary Care for Patients with a GU Cancer	Consultation group	1	In progress
3	Oncology Nutrition Patient/Family Representatives, Victoria	Consultation group	2	Completed
4	PET/CT Program Opening, Victoria	Consultation group	2	Completed
5	Regional Patient Experience Council – Victoria	Committee	3	In progress
6	RT Quality Committee – Victoria	Committee	1	Completed
7	Vancouver Island Oncology Conference	Conference/presentation	2	Completed

## Partners evaluation of engagement

Between April 1, 2019 and March 31, 2020, 97 Partners participated in at least one of the engagement initiatives reported to the Patient Experience Program. At midterm evaluation, 121 evaluation questionnaires were sent to the Partners who were participating in the in-progress initiatives; we received 61 responses, yielding a response rate of 50.41%. At end-of-engagement evaluation, 89 evaluation questionnaires were sent to the Partners who completed the engagements; we received 50 responses, and the response rate was 56.18%. In the following section, responses from Partners who have completed the midterm and end-of-engagement evaluation questionnaires are reported. The feedback constitutes both quantitative and qualitative data. Partner responses to scale questions (1=Strong disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree) were aggregated, and mean scores are presented by program/centre, with “n” denoting the number of responses. Where Partners had completed an engagement initiative and did not provide response to the evaluation, no response is reported.

### Self-assessment of confidence and readiness

Partners scored high in their self-assessment of their confidence and readiness for the engagement at the midterm evaluation. Partners who participated in provincially-led and/or regionally-led engagements agreed that they took initiative to seek information and prepare for meetings, with overall mean scores of 4.17 and 4.25 respectively. The ability to contribute to agenda items scored slightly lower, with overall mean score of 3.67. See Table 10 for the Partners’ self-assessment of their confidence and readiness.

The reasons for the lower mean score on co-developing agendas may not be reflective of Partners’ level of engagement. Given the diverse types of engagement, some may not involve agenda development (e.g. a working group with a narrow scope of participation). The following section on the Partners’ evaluation of communication, partnership and their influence in the engagement provides further insights to the quality of the engagement.

**Table 10: Partners midterm evaluation (mean score)**

	As needed, I prepare for meetings by reviewing material in advance. <sup>1</sup>				If I lack information, I take the initiative to get it. <sup>1</sup>		I occasionally suggest topics for future meeting discussions or agenda items. <sup>1</sup>		
Overall (n=12)					4.17		3.67		
Provincial (n=12)	4.25				4.17		3.67		
	The purpose of the activity was clearly explained. <sup>2</sup>	The supports I needed to participate were available. <sup>2</sup>	I had enough information to contribute to the topic being discussed. <sup>2</sup>	I was able to express my views freely. <sup>1,2</sup>	I feel that my views were heard. <sup>2</sup>	I feel that the input provided through this activity will be considered by the organizers. <sup>2</sup>	I understand how the input from this activity will be used. <sup>2</sup>	I think my participation in this activity will make a difference. <sup>2</sup>	Overall, I was satisfied with how I participated in this activity. <sup>2</sup>
Overall (n=61)	4.46	4.35	4.21	4.66	4.53	4.49	4.06	4.00	4.31
Provincial (n=40)	4.44	4.30	4.20	4.73	4.60	4.60	3.90	3.70	4.10
Abbotsford (n=4)	4.75	4.05	4.50	5.00	4.75	4.75	4.00	3.50	4.25
Kelowna (n=5)	4.40	4.20	4.60	4.80	4.60	4.60	4.20	4.20	4.60
Prince George (n=1)	4.00	4.00	4.00	5.00	5.00	5.00	4.00	4.00	4.00
Surrey (n=2)	3.50	3.50	3.00	4.00	3.50	3.50	3.50	3.50	3.00
Vancouver (n=6)	4.17	4.17	3.83	4.50	4.33	4.17	4.00	4.00	4.17
Victoria (n=3)	4.00	4.00	4.00	4.67	4.67	4.33	3.67	3.67	4.67

Note. 1. Questions in version 1, Apr 2019-May 2019. 2. Questions in version 2, Jun 2019-Mar 2020. n = number of responses. Ranking: 1=Strong disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree.

## Communication, partnership, support and influence

At midterm and at the end of their engagement, Partners were asked to rank their agreement to statements reflecting communication between the Partners and health professionals in the engagement, the strength of the partnership, support needs and the Partners' perceived influence in the outcome of the engagement. The overall aggregated mean scores of these aspects of engagement across the provincially- and regionally-led engagements were high, ranging from 4 to 4.66 at midterm and from 4.32 to 4.64 at the end-of-engagement. See Table 10 and 11 for the aggregated mean scores of Partners evaluation at midterm and at the end of the engagement.

### Communication

Partners reported that the purpose of the engagement activity had been clearly explained to them, with overall mean of 4.46 at midterm and 4.64 at end-of-engagement. Positive comments from Partners included:

- “We have a full description and back ground history provided of the subject, this allows me to be more informed.”
- “The project lead is very good at contacting me outside of the meetings to try and ensure that I understand what is being talked about.”
- “Those involved were totally professional; explained what was going to take place, how the material would or could be edited to make the end product the best possible.”

Partners' understanding of the use of their input from the activity was relatively lower (midterm mean 4.06; end-of-engagement mean 4.46). To strengthen communication in the engagement, Partners suggested using accessible language, taking time to clarify engagement content and keeping Partners updated on engagement progress:

- “Has been improving of late but early on so theoretical and acronym heavy that I felt a patient Partner was of no help. Now I feel I am able to offer some insight.”
- “Maybe an orientation session for the patient participants in advance of the first multi-shareholder session. This would help patient participants dive into the deep end with a bit more grounding on the project, what it is trying to achieve and its various stages.”
- “When I cannot fully understand the topic or I missed part of it during my absence. I wish they can update me what I have missed.”



## Partnership

Reflecting on the partnership with health professionals in the engagement, Partners reported that they were able to express their views freely (midterm mean 4.66; end of engagement mean 4.64) and felt that their views were heard (midterm mean 4.53; end of engagement mean 4.50). Partners appreciated the opportunity to contribute to care improvement while learning about the organization challenges and opportunities in care delivery:

- “My experience 5 years ago at this facility was so stressful. I am hoping to offer a welcome, gentle kindness, encouragement and shape the introductory experience for others. The projects I have helped to shape seem to be aiming to do this.”
- “Opportunity to be heard by the team and key stakeholders in the initiative. Personally my engagement has also given me the opportunity to learn more about the challenges and opportunities BC Cancer faces in making the type of change contemplated by this initiative.”
- “Being able to have a voice in an area that has much potential for altering the way patients interact with their information and resources.”

## Support needs

Partners have largely felt supported to participate in the engagement initiatives. Particularly, they agreed that the supports were available to them (midterm mean 4.35; end of engagement mean 4.54), and they had enough information to contribute to the topics discussed at the engagement meetings (midterm mean 4.21; end of engagement mean 4.62). At the same time, Partners have also identified areas where support could be enhanced:

- “I would appreciate an org chart of BC Cancer to see how the staff and services are structured.”
- “I need more context and simpler language on some of the issues.”
- “Patient partners should be provided with a list of acronyms ahead of time since they're constantly bandied about by professionals and we have no idea what they're talking about!”

## Influence in decision-making

Evaluating their perceived influence on decision-making, Partners felt that the input they have provided in the engagement would be considered (midterm mean 4.49; end-of-engagement mean 4.48) and that their participation in the engagement would make a difference (midterm mean 4.00; end-of-

engagement mean 4.32). Partners reiterated their wishes to see more diverse Partners participating in the engagement initiatives and prompt uptake of actions to improve service delivery:

- “I feel challenged to fairly represent a more global patient perspective of the cancer treatment experience at the agency. It is important that I provide my feedback and my perspective, but I am only one person and my experience does not necessarily reflect what others have gone through. I think more involvement by patients on this committee reflecting other ages, cancers, genders, etc. would give a broader, more thorough picture.”
- “Endorsement of the project outcomes by those responsible for the delivery of the outcome(s) in a timely fashion.”
- “Health services providers that are participating in projects might consider developing generally accepted project management core competencies to deliver project objectives on budget and on time.”

Further, Partners highlighted the need to see the results of their inputs, reiterating the importance of reporting back to Partners the influence they have had on decision-making.

- “The organizer didn't follow up after two weeks as he had indicated in his last communication. It felt like we've been left out of the finished product.”
- “After providing my input (which took considerable time and thought), I never heard back from those leading the project.”
- “I did hear back from the Initiative lead, with the final letter form, so she did receive my contribution.”

## Strength and improvement

Overall, Partners agreed that they were satisfied with their participation in the engagement initiatives (midterm mean 4.31; end-of-engagement mean 4.44). See Table 10 and 11 for the aggregated mean scores in the provincially- and regionally-led engagements at midterm and at the end of the engagement. Partners appreciated being a part of a team of diverse stakeholders, using their skills and experiences to address issues in cancer care.

Commenting on the “high points” of their involvement in engagements, the highlights included being able to contribute to care improvement, feeling valued and listened to and learning about challenges and opportunities in care delivery. On the other hand, the frequently mentioned “low points” were the lack of communication about project outcomes and feeling overwhelmed with the technical information and acronyms that health professionals used at the project meetings.

### Strengths

The key strengths that Partners identified were centred on the collaborative relationship and facilitation of the engagement by health professionals. Partners felt that their feedback was sought, acknowledged and acted on to improve care. Health professionals also included Partners in conversations and took time to address their questions, treating the Partners as valued members of the team. In the Partners’ words, the health professionals did well in engaging them when staff:

- “Ask for our input, so that everyone's voice is heard.”
- “Value my feedback, asking questions and being keen to hear the answers and incorporate my feedback.”
- “Explain technical terms and issues that I am unfamiliar with, and are patient with my questions and concerns.”
- “Asked for my comments during every meeting...thanked me for my contributions. I feel [I] belonged and treated as a valuable partner.”

### Opportunities for improvement

On ways health professionals could enhance the engagement, Partners pointed out areas of improvement: clarify project goals and Partners’ roles in the engagement; update Partners promptly when there are changes in meeting schedule, leadership, engagement timeline; explain terminology and

acronyms used in the engagement. Elaborating on their suggestions, some of the Partners' comments were:

- "Let me know what and how you are trying to achieve."
- "They can encourage me to contribute where my strengths can be of service."
- "Be mindful of last minute changes in schedule."
- "Staff changes resulted in need to clarify things."

**Table 11: Partners end-of-engagement evaluation (mean score)**

	The purpose of the activity was clearly explained.	The supports I needed to participate were available.	I had enough information to contribute to the topic being discussed.	I was able to express my views freely.	I feel that my views were heard.	I feel that the input provided through this activity will be considered by the organizers.	I understand how the input from this activity will be used.	I think my participation in this activity will make a difference.	Overall, I was satisfied with how I participated in this activity.
Overall (n=50)	4.64	4.54	4.62	4.64	4.50	4.48	4.46	4.32	4.44
Provincial (n=39)	4.69	4.62	4.69	4.69	4.56	4.54	4.51	4.38	4.49
Abbotsford (n=1)	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00
Kelowna (n=2)	4.50	4.50	4.50	4.50	4.50	4.50	4.50	4.50	4.50
Prince George (n=0)	--	--	--	--	--	--	--	--	--
Surrey (n=0)	--	--	--	--	--	--	--	--	--
Vancouver (n=2)	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
Victoria (n=6)	4.83	4.50	4.67	4.83	4.50	4.50	4.50	4.17	4.50

Note. n = number of responses. Ranking: 1=Strong disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree.

## Health professionals evaluation of engagement

In the reporting period (April 1, 2019 to March 31, 2020), midterm evaluation questionnaires were sent to 57 health professionals leading the engagements. At the end of the engagement, evaluation questionnaires were sent to 30 initiative leads. 29 health professionals completed the midterm questionnaires and 18 completed the end-of-engagement evaluation; the response rates were 50.88% and 60%, respectively.

In the following section, responses from health professionals who have completed the midterm and final evaluation questionnaires are reported. Health professionals' responses to scale questions (1=Strong disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree) were aggregated, with "n" denoting the number of responses. Where an engagement had ended and the health professionals did not provide response to the evaluation, no responses are reported. Qualitative responses/comments were summarized, with selected quotes to highlight emerging themes.

### Resource usage, impact and training

At the midterm and at the end of their engagement, health professionals were asked to rank their agreement to statements reflecting the quality of the engagement in terms of resource usage, impact on practice change and decision made in the engagement. The overall aggregated mean scores across the provincially and regionally led engagements regarding these aspects of engagement quality were high, ranging from 4.28 to 4.72. See Table 12 and 13 for the aggregated mean scores of health professionals' evaluations at midterm and at the end of the engagement.

#### Resource usage

Health professionals agreed that the engagement was a good use of their program resources, with overall mean score of 4.34 at midterm and 4.72 at end-of-engagement. Commenting on the contribution that Partners have made, health professionals said:

- "The Partner sat on the Planning Committee and made a lot of suggestions regarding the structure of the day (event) and its objectives. He was an active participant in all aspects of the event. He will be given an opportunity to provide feedback on the draft report before it is submitted to BC Cancer leadership."

- “Quite a bit, within the confines of the project. Their opinions and perspectives are highly valued, and we try and incorporate their suggestions and address any concerns arising.”
- “They provided very good insights that not only informed this particular project but how we market library services in general.”

### **Impact on practice change and decision**

The Partners’ input was deemed useful where it could be integrated in practice, with overall mean score of 4.41 at midterm and 4.61 at end-of-engagement. The health professionals also indicated that the output from the engagement would influence decision (midterm mean 4.28; end-of-engagement mean 4.44). On ways that Partners have contributed to practice change and decisions, health professionals highlighted:

- “This patient did have a positive influence that I felt changed the perspective. We included an introduction to all oncology team members during the patient information session as a result of the feedback.”
- “The input from the patient partner helped change the order that information was given and the terminology used.”
- “Their contributions resulted in significant changes to the tool and method. Very positive.”

On their part, health professionals have adopted various approaches to report back on the influence Partners had on decision-making. The means of reporting back to Partners included:

- Disseminating minutes of each meeting.
- Scheduling email/phone check-in with the Partners prior to the meetings.
- Emailing outputs to seek additional feedback from the Partners.
- Providing summary reports on the project progress at 6 month intervals and a final report at the end of the engagement.
- Scheduling follow-up phone meeting/debrief.

### **Training and education support**

At the end of the engagement, feedback on health professionals training needs was sought. While health professionals had not indicated high needs for training, they have identified ways to build their capacity in engagement (overall mean score 3.88). Areas for further training and education included:

- Planning for engagement and clarification on recruitment, engagement process and timeline.
- Frequently used engagements techniques, including surveys.
- Facilitating meetings and navigating conversations with Partners to ensure inputs are within the scope of the engagement.
- Managing Partners’ inputs that are important but are not in the scope of the engagement.
- Better identify opportunities or areas where Partner engagement is possible or appropriate.

## Strength and improvement

Overall, health professionals indicated satisfaction with the way they have engaged the Partners (midterm mean 4.10; end-of-engagement mean 4.61). See Table 12 and 13 for the aggregated mean scores of health professionals’ evaluations at midterm and at the end of the engagement.

### Strengths

There was agreement that the collaboration between health professionals and Partners was meaningful and synergetic, and the engagements have contributed to patient-centred care.

- “Very positive example of meaningful patient engagement from the perspective of partners and staff.”
- “This is the first time that patients have been included in the conference and response was extremely positive. We have been asked by other regions as to how they could integrate something similar into their regional conferences.”
- “I feel the partners have been a critical component and set-of-eyes on our work that has made our work better, and keeps our focus on the "patient-centred" in the work we do. I do want to acknowledge that many of our health care providers really advocate for the patient at the centre of our project, too--creating really great synergy.”

### Opportunities for improvement

At the same time, the health professionals recognized the importance to match Partners with experiences that aligned with the engagement topic, being clear about the amount of influence Partners have in the engagement and needing more education about the process of matching Partners to an engagement.



- “It is important to identify partners who resonate with the topic at hand. The partners for this project were a good fit, but I can see the value of the organization being really clear up front with the partners about the level of engagement hoped for, and being clear with themselves internally as well prior to moving forward with the partner engagement.”
- “I think it needs to be clear from the patient what they want to get out of the engagement, and to tell us (the leads) what exactly feeling and being engaged means to them (as this is different person to person).”
- “I found my first encounter with the patient experience program to be very smooth. The application process was not too onerous and the partners were lovely to work with. The only difficulty I had was that some portions of the application were difficult to fill out as there were unknowns at the time. Perhaps more advertising about the program so that more front-line projects could take advantage of this amazing resource.”

**Table 12: Health professionals midterm engagement evaluation (overall mean score)**

	Overall, I was satisfied with the way I/we engaged partners in this initiative.	This engagement activity is a good use of our program resources.	The partners' input is useful and can be integrated in practice	The output from this engagement will influence our decision
Overall (n=29)	4.10	4.34	4.41	4.28
Provincial (n=18)	4.17	4.39	4.39	4.44
Abbotsford (n=2)	3.00	3.50	4.50	3.50
Kelowna (n=3)	4.33	4.00	4.00	4.00
Prince George (n=0)	--	--	--	--
Surrey (n=3)	4.00	4.00	4.33	4.33
Vancouver (n=2)	4.00	5.00	5.00	3.50
Victoria (n=1)	5.00	5.00	5.00	5.00

Note. n = number of responses. Ranking: 1=Strong disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree.

**Table 13: Health professionals end-of-engagement evaluation (overall mean score)**

	Overall, I was satisfied with the way I/we engaged partners in this initiative.	This engagement activity was a good use of our program resources.	The partners' input was useful and could be integrated in practice.	The output from this engagement influenced our decision.	I would like to participate in patient and family engagement training to build my capacity to do more of this work.
Overall (n=18)	4.61	4.72	4.61	4.44	3.88
Provincial (n=16)	4.63	4.75	4.63	4.50	3.87
Abbotsford (n=1)	4.00	4.00	4.00	4.00	3.00
Kelowna (n=0)	--	--	--	--	--
Prince George (n=0)	--	--	--	--	--
Surrey (n=0)	--	--	--	--	--
Vancouver (n=0)	--	--	--	--	--
Victoria (n=1)	5.00	5.00	5.00	4.00	5.00

Note. n = number of responses. Ranking: 1=Strong disagree; 2=Disagree; 3=Neither agree nor disagree; 4=Agree; 5=Strongly agree.

## Partners to Partners Connect Networking Group

In December 2019, Patient and Family Partners from across B.C. had the opportunity to join the inaugural Partners to Partners Connect Networking Group (P2P Connect) teleconference.

The purpose of P2P Connect is to link BC Cancer Patient and Family Partners from across the province with one another and with the Patient Experience Program. P2P Connect provides a platform for Partners to network, share resources, and learn from peers on ways to improve their engagement experience. Partners meet monthly for an hour through telephone/video meetings. The goal is twofold: 1) To enhance Partners' engagement experience and 2) to increase participation in BC Cancer engagement initiatives.

In the first six months of the implementation phase, the meetings were chaired by the Provincial Lead of Patient and Family Engagement. With increasing interest to strengthen peer support and mentoring in engagement, a team of five Patient and Family Partners was formed in June 2020 to lead and shape P2P Connect. The five Partner-Leads represented diversity in role (patient/family caregiver), age, gender, culture and ethnicity and engagement experience. The Partner-Leads have participated in various engagement initiatives in BC Cancer and in the community, including national cancer care improvement initiatives. The Partner-Leads participated in an orientation/training with the Patient Experience Program before they began their leadership role in P2P Connect.

### Learnings from P2P Connect

Each month, a topic on engaging patients and families in cancer care was highlighted at the meeting. Attendance at the monthly meetings ranged from 12 to 19 Partners. Partners contributed to the meetings by making recommendations for discussion topics, co-facilitating meetings, presenting and providing feedback at the meetings. Between December 2019 and March 31, 2020, topics of discussion were as followed:

1. Partners' experience of BC Cancer Summit 2019
2. Update on BC Cancer supportive care resources
3. Communication between Partners and staff in engagements

Learnings from the Partners' responses to the discussion topics are summarised in the following section.

## **BC Cancer Summit 2019**

Six Partners who attended BC Cancer Summit 2019 shared their reflection on the event at the first P2P Connect meeting. The Partners enjoyed meeting other patients and family caregivers and having conversations with the health professionals during the 3-day conference. The Partners felt that their input was welcomed. They were able to contribute meaningfully to the discussion on addressing gaps in cancer care at the breakout sessions. Partners who were not at the Summit had the opportunity to respond to the Summit participants' reflections. A Patient Partner led the discussion on ways to better involve patients and family caregivers in the next Summit. Partners highlighted the importance of family caregivers' involvement, event timing, understanding of Partner role and session topic and communication with health professionals. The importance of peer support, including regular network meetings to connect with Partners, was also raised. Topics for next Summit were discussed. Ideas included better engagement with doctors, spiritual care, fertility and family planning, basics of cancer and post-treatment supportive care.

## **BC Cancer supportive care resources**

The Cancer Care Resource Social Worker presented on BC Cancer's new supportive care email newsletter. The presentation was followed by a discussion led by a Patient Partner on the usefulness and current gaps in supportive cancer care. In addition to using technology to reach patients and families, in-person communication was deemed necessary in providing quality care. Individuals who could bridge resources to care recipients include family doctors, peer volunteers and support navigators/ coordinators. The importance to reach out to patients and families in rural and remote community were highlighted, and the role of the family doctors in connecting the patients to cancer care was further discussed.

## **Communication between Partners and staff in engagements**

A Patient Partner talked about his experience co-chairing a patient experience committee and led the discussion with the Partners to address challenges and opportunities in engagement at BC Cancer.

Challenges identified included:

- The lack of continuity in engagement leadership
- Not knowing the direction of the engagements following a leadership change
- Lack follow-up with Partners who are unable to join the meetings in-person

The group identified best practices of communicating well in engagements, such as:

- Using clear and plain language
- Keeping Partners informed of decisions and leadership change
- Having regular committee meetings
- Using different communication media to connect with Partners
- Demonstrating respect by “actively” and “patiently” listening and acknowledging Partners (for their time and contribution)
- Clarifying meeting agenda and schedule
- Providing documentation on discussion and action items

## Conclusions

This is the second year of evaluation of BC Cancer patient and family engagement. Improvements were made to last year's reporting.

First, demographic data was collected from Partners when they were enrolled in the Network. This has resulted in more complete reporting of Partners' background information. The Partner demographic data also facilitates matching of Partners to engagement initiatives. Second, scale questions were used for assessing satisfaction and influence of engagement in decision-making at both midterm and end-of-engagement evaluations. This change has increased efficiency in data collection. The use of similar set of scale questions at the midterm and end-of-engagement intervals also provides indication of changes in engagement experience over time.

Notwithstanding the attempts made to improve the evaluation of engagement among Partners and health professionals, there are limitations in the reporting. The evaluation result does not encompass all engagement initiatives in BC Cancer. Engagement initiatives that were not matched to Partners in the Network were not implemented (withdrawn) or had not been reported to the Patient Experience Program were not included in this report. Further, there were time lapses between the ending of the engagement and the completion of the evaluation questionnaires by the Partners. While it was recommended that the questionnaires to the Partners be communicated through the initiative leads, the staff capacity to undertake this responsibility remained a challenge. The Provincial Lead for Patient and Family Engagement continues to collaborate with the engagement initiative leads, to keep current on the engagement status and follow up with evaluation at 6-month intervals (midterm and end-of-engagement).

Patient and family engagement in BC Cancer continues throughout the pandemic, engaging Patient and Family Partners through different means of communication. Partners also undertook increased opportunities to interact with peers through the monthly network group meetings. The engagement initiatives enable health professionals to partner with a diversity of patients and family caregivers across B.C., through provincially- and regionally-led initiatives. Partners responded and made their voices heard through an array of engagement activities, contributing to decision-making to enhance cancer care. The Partners' and health professionals' evaluation of their engagement experience provided insights to BC

Cancer's continuous efforts to partner with patients and families in care improvement. Evaluation continues to be a priority to strengthen engagement of patients and families in quality care.



## Appendices

### A. Definitions

**Engagement:** An intentional strategic approach used to give patients and families a voice in the design and delivery of health care, as part of providing person-centred health care.

**Initiatives:** Projects, working groups and committees that health professionals initiate and lead.

**Initiative lead:** Health professionals who request Partners for an engagement initiative. The requestor is also the contact person for the Partners and the Provincial Lead, Patient and Family Engagement (Provincial lead) for the duration of the engagement initiative.

**Matching:** The process of onboarding Patient or Family Partners to a specific engagement initiative.

**P2P Connect:** Partners to Partners Connect Networking Group

**Partners:** Patients and family caregivers who are enrolled in the BC Cancer Network of Patient and Family Partners.

**Person-centred Care:** Care that puts the persons at the forefront of their health and care, ensures they retain control over their own choices, helps them make informed decisions and supports a partnership between individuals, families, and health care services providers.

## B. References

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Vancouver Coastal Health (n.d.). Community Engagement Framework. Retrieved from <http://www.vch.ca/Documents/CE-Framework.pdf>

Baker R., Judd M. & Maika C. (Eds.). (2012). *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare*. Toronto, ON: Longwoods Publishing.

## C. Resources links

[Pathway to Finding a Patient or Family Partner flowchart](#)

[Pathway to Becoming a Patient or Family Partner flowchart](#)

[Application form to request patient and family partners for your initiative](#)

[Online application form to become a patient or family partner](#)

[Patient and Family Partner Policies Handbook and Agreement](#)

[Orientation to Patient and Family Engagement online module](#)

Tip sheets:

 [Best Practices for Successful Engagement](#)

 [Diversity in Patient Engagement](#)

 [Engagement Methods](#)

 [How to Request Patient and Family Partners](#)

 [Matching Partners](#)

 [Planning Engagement](#)

 [Presenting With Patient Partners](#)

 [Reimbursing Partners](#)

## D. Spectrum of engagement

← INCREASING LEVEL OF INFLUENCE IN THE DECISION →

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
<b>Definition</b>	To give information	To get feedback	To understand	To work together	To give power to
<b>Example Techniques</b>	Fact sheet Web site	Survey Focus group	Conversation Dialogue	Committee Working group	Referendum Delegated decision
<b>Promise</b>	We will keep you informed.	We will listen to and acknowledge your concerns.	We will ensure that your concerns and goals are reflected in the decision.	We will incorporate your advice and recommendations into the decision as much as possible.	We will do what the group decides.

Adapted from the International Association for Public Participation (IAP2) Spectrum of public participation.

## E. Engagement techniques

Engagement techniques	Number of engagements	Explanation
Committee	29	Partner and health professional representatives meet in-person or by teleconference to provide input to planning process.
Conference	4	Partners selected to attend conference as invited panel speaker or as participant.
Consultation group	8	A group of Partner representatives meet (in-person or phone) with the committee chair to provide feedback to specific questions/issues brought to the consultation group by members of the committee.
Focus group	2	A group of Partners meet (in-person or phone) to participate in a planned discussion facilitated by a health professional.
Photo shoot	2	Partners participate in a session of photo taking and/or filming with health professionals for purpose of BC Cancer service promotion.
Review (website, material)	10	Partners review BC Cancer resources prior to publication/posting by attending in-person/phone meeting or by email.
World Cafe	1	Partners attend an in-person meeting with other stakeholders to participate in a series of Simultaneous conversations in response to predetermined questions
Working group	17	An appointed group of Partners and health professionals working together on identified topics to achieve specific goals.

## F. Partners midterm engagement questionnaire – V1. July 16, 2018

We are interested in your feedback about the following engagement initiative that you are participating in:

Title of engagement: \_\_\_\_\_

### A. Self- assessment

The questionnaire is composed of several statements. Please mark one box for each statement below.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
As needed, I prepare for meetings by reviewing material in advance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If I lack information, I take the initiative to get it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to express my views freely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I occasionally suggest topics for future meeting discussions or agenda items	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### B. Open-ended reflection

Please also provide additional feedback to the open-ended questions below.

- 1) What has been a high point of your involvement with this initiative?
- 2) What has been a low point of your involvement with this initiative?
- 3) What have the health professionals in the initiative been doing well to engage you?
- 4) What else can the health professionals in the initiative do to engage you?
- 5) What additional skills or support do you need right now to be able to engage in the way you want to?

All information you provide will remain confidential. Thank you very much for your participation.

## G. Partners midterm engagement questionnaire – V2. May 29, 2019

We are interested in your feedback about the engagement activity that you recently participated in. All information you provide will remain confidential. Thank you very much for your participation.

Title of engagement : \_\_\_\_\_

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The purpose of the activity is clearly explained.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The supports I need to participate are available.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have enough information to contribute to the topic being discussed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to express my views freely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my views are heard.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my input will be considered by the organizers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how my input will be used.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my participation in this activity will make a difference.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, I am satisfied with how I participated in this activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 1) What has been a high point of your involvement with this initiative?
- 2) What has been a low point of your involvement with this initiative?
- 3) What have the health professionals in the initiative been doing well to engage you?
- 4) What else can the health professionals in the initiative do to engage you?
- 5) What additional skills or support do you need right now to be able to engage in the way you want to?

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## H. Partners end-of-engagement questionnaire – V1. July 16, 2018

We are interested in your feedback about the engagement activity that you recently participated in. The questionnaire is composed of several statements. Please mark one box for each statement below. Please also provide additional feedback to the open-ended questions below.

All information you provide will remain confidential. Thank you very much for your participation.

*Title of engagement:* \_\_\_\_\_

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The purpose of the activity was clearly explained.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The supports I needed to participate were available.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had enough information to contribute to the topic being discussed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to express my views freely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my views were heard.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that the input provided through this activity will be considered by the organizers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how the input from this activity will be used.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my participation in this activity will make a difference.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, I was satisfied with how I participated in this activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Open-ended questions:*

1. How would you like the results of your participation to be used?
2. How do you think the results of your participation will be used?
3. What was the best thing about this engagement activity?
4. Please identify at least one improvement we could make for future engagement activities.

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## I. Partners end-of-engagement questionnaire – V2. May 29, 2019

We are interested in your feedback about the engagement activity that you recently participated in. All information you provide will remain confidential. Thank you very much for your participation.

Title of engagement: \_\_\_\_\_

If you have resigned from this engagement, please tell us the reason for your resignation.

\_\_\_\_\_

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The purpose of the activity was clearly explained.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The supports I needed to participate were available.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had enough information to contribute to the topic being discussed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to express my views freely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my views were heard.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel that my input will be considered by the organizers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how my input will be used.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my participation in this activity will make a difference.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall, I was satisfied with how I participated in this activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. What was the best thing about this engagement activity?
2. Please identify at least one improvement we could make for future engagement activities.

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## J. Health professionals midterm engagement questionnaire – V1. July 16, 2018

We are interested in your feedback about the engagement of the patient and/or family partners in the following initiative:

*Title of engagement:* \_\_\_\_\_

1. Please describe how the patient and/or family partners are engaged in this initiative. Are there any changes in the partners' role in the initiative, including the timeline of their involvement (end date of initiative)?
2. Have any partners resigned from the initiative? If there was resignation, please provide the name of the individual and the reason for the resignation.
3. Thinking about how engagement are the partners in the initiative (e.g. asking questions, communicating with you, attending the meetings), how satisfied are you with the engagement? Please describe any concerns.
4. How much influence do you think the partners have on this initiative?
5. Please explain how you are keeping the partners up to date on the initiative.

## K. Health professionals midterm engagement questionnaire – V2. May 29, 2019

We are interested in your feedback about the engagement of the patient and/or family partners in your initiative. All information you provide will remain confidential. Thank you very much for your participation.

*Title of engagement:* \_\_\_\_\_

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Overall, I am satisfied with the way I/we engaged partners in this initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This engagement activity is a good use of our program resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The partners' input is useful and can be integrated in practice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The output from this engagement will influence our decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. Please describe how the patient and/or family partners are engaged in this initiative. Are there any changes in the partners' role in the initiative, including the timeline of their involvement (end date of initiative)?
  
2. Have any partners resigned from the initiative? If there was resignation, please provide the name of the individual and the reason for the resignation.
  
3. Please explain how you are keeping the partners up to date on the initiative.
  
4. Are there any changes needed to improve the engagement?
  
5. Do you have further comments on the progress of the engagement?

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## L. Health professionals end-of-engagement questionnaire – V1. July 16, 2018

We are interested in your feedback about the engagement of the patient and/or family partners in your initiative. The questionnaire is composed of open-ended and summative questions. For the summative questions, please mark one box for each statement.

All information you provide will remain confidential. Thank you very much for your participation.

*Title of engagement:* \_\_\_\_\_

### *Open-ended questions:*

1. Please describe how the patient and/or family partners were engaged in this initiative.
2. Please describe what impact or influence the engagement input had on any decisions made within the organization. If the input did not have any impact or influence, please explain why you think this was the case.
3. Did you provide a summary report to the partners? How did you share it with the partners? If not please describe the plan for reporting back to the partners.
4. In what areas would you like to build your knowledge and skills to support future engagement of patients and families?
5. Please identify at least one improvement the patient experience program could make for future engagement activities.

### *Summative questions:*

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Overall, I was satisfied with the way I/we engaged partners in this initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This engagement activity was a good use of our program resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The partners' input was useful and could be integrated in practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The output from this engagement enhanced decision making	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would like to participate in patient and family engagement training to build my capacity to do more of this work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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## M. Health professionals end-of-engagement questionnaire – V2. May 28, 2019

We are interested in your feedback about the engagement of the patient and/or family partners in your initiative. All information you provide will remain confidential. Thank you very much for your participation.

*Title of engagement:* \_\_\_\_\_

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
Overall, I was satisfied with the way I/we engaged partners in this initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This engagement activity was a good use of our program resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The partners' input was useful and can be integrated in practice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The output from this engagement influenced our decision.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would like to participate in patient and family engagement training to build my capacity to do more of this work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. Please describe how the patient and/or family partners were engaged in this initiative.
  
2. Please describe what impact or influence the engagement input had on any decisions made within the organization. If the input did not have any impact or influence, please explain why you think this was the case.
  
3. Did you provide a summary report to the partners? How did you share it with the partners? If not please describe the plan for reporting back to the partners.
  
4. In what areas would you like to build your knowledge and skills to support future engagement of patients and families?
  
5. Please identify at least one improvement the patient experience program could make for future engagement activities.

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