



Provincial Health Services Authority

Patient Experience Program

# Patient and Family Engagement

Annual Report 2019

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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 January 1 2018 and March 31 2019. Seventy-one 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 interview to annually renewable committee membership. As at March 31, 2019, 36 engagements were completed; 35 are in progress. Responses from the Partners and health professionals leading the initiatives were sought at midterm (6 month) and at the end of the engagement, using evaluation questionnaires comprising scale and reflection questions.

In assessing their confidence and readiness in the engagement, Partners agreed that they were able to be engaged in the meeting discussion. 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. Reflecting on the partnership with health professionals, Partners indicated they were able to express their view freely and felt that their views were heard. Particularly, they appreciated the collaboration with the leadership team and the opportunity to contribute to care improvement.

Partners have largely felt supported to participate in the engagements. Evaluating their perceived influence on decision-making, Partners felt that the input they provided in the engagement would be considered and that their participation in the engagement would make a difference. 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. At the same time, Partners suggested opportunities for improvement to strengthen communication and the quality of 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, although the impact on decision-making may be limited by organizational constraints. Reflecting on the strengths of the engagement, health professionals commented that the engagements were highly valued, the matching of Partners to the engagement was streamlined, and that the Partners had contributed to the improvement of the care initiatives. To improve on the engagement experience,

health professionals recognized the need for diverse Partners perspective, consistent communication with the Partners and more clarity on meaningful engagement in committees.

This engagement evaluation is the pioneering work of the Patient Experience Program to report on the status and progress of patient and family engagement in BC Cancer. Limitations and areas of improvements have been identified and will be addressed in future reporting. The program is committed to continue providing important insights on patient and family engagement, upholding the BC Cancer mandate to deliver person-centred care.

## Introduction

The Network of Patient and Family Partners was established in May 2017, under the governance of the Patient Experience Program and the Patient Experience and Interprofessional Practice Portfolio. 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.

*“Patient and Family Engagement is part of providing person-centred health care. It’s an intentional strategic approach that we use to give patients a voice in the design and delivery of health care.” - Bernice Budz, VP Patient Experience and Interprofessional Practice*

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

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 1 for the spectrum of engagement showing the types, techniques and promises of engagement.

As at March 31 2019, 95 cancer patients and family caregivers across BC were enrolled in the Network. In the reporting period of January 1 2018 to March 31 2019, 71 engagement initiatives in BC Cancer were reported to the Patient Experience Program. The engagements encompass provincially and regionally led initiatives. 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 engagements were adapted from the Public and Patient Engagement Evaluation Tool

(PPEET)<sup>1</sup>. Engagement evaluation was conducted at two time points: midterm (6 month 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.

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.

The report provides an overall description of all Partners in the Network, as at March 31, 2019. The engagement status of the initiatives in each regional centre is also reported. The evaluation results were analyzed, quantitative responses were aggregated, and emerging themes were drawn from the qualitative responses. Further, respondent comments were quoted to highlight the identified themes. The document concludes with a discussion of the limitations of the current report and recommendations for future reporting, as gleaned from the Partners' and health professionals' feedback.

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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.

## Characteristics of Partners

Ninety-five patients and family caregivers were enrolled in the BC Cancer Network of Patient and Family Partners, as at March 31, 2019. The Partners were predominantly referred to the Network by BC Cancer staff/health professional (72.15%). Other sources of referral were: community collaborators (11.39%), Online-website/social media (10.13%) and Partners' word of mouth (6.33%).

Sixty percent of the Partners enrolled were cancer patients and about 16% were family caregivers. Almost a quarter of the Partners in the Network identified as both cancer patients and carers of a loved one (family/friend) diagnosed with cancer.

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. Over 50% of the Partners resided in Greater Vancouver, and more than 20% were from Vancouver Island. About 12% of the Partners lived in Interior BC and less than 10% were from Northern BC.

Twenty-six 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 (28.45%), followed by brain cancer (10.34%) and prostate cancer (6.9%). Partners also reported experience with rare cancers, and several have had diagnoses of multiple cancers. See table 1 for characteristics of Partners.



**Table 1: Characteristics of Partners**

Characteristics	Number	%
<b>Role:</b>		
Patient	57	60.00
Family caregiver	15	15.79
Patient and Family caregiver	23	24.21
Total number of Partners	95	100
<b>Geographic location</b>		
Greater Vancouver	55	57.89
Interior BC	11	11.58
Northern BC	8	8.42
Vancouver Island	21	22.11
Total number of Partners	95	100
<b>Cancer type</b>		
Bladder	2	1.72
Bone	1	0.86
Brain	12	10.34
Breast	33	28.45
Cervical	1	0.86
Colon	7	6.03
Endometrial	1	0.86
Gestational trophoblastic neoplasia	1	0.86
Head/neck	5	4.31
Intestine	1	0.86
Leukemia	3	2.59
Liver	1	0.86
Lung	4	3.45
Lymphoma	6	5.17
Melanoma	3	2.59
Multiple Myeloma	7	6.03
Ovarian	7	6.03
Pancreatic	2	1.72
Prostate	8	6.90
Pseudomyxoma Peritonei	1	0.86
Rectal	2	1.72
Renal	1	0.86
Rhabdomya Sarcoma	2	1.72
Testicular	2	1.72
Thyroid	2	1.72
Uterine	1	0.86
Cases reported by Partners	116	100

## Engagement initiatives

Between January 1 2018 and March 31 2019, 71 BC Cancer engagement initiatives were reported: 35 have been completed and 36 are in progress. Provincial programs constitute more than half of the engagement initiatives (60.56%). The remaining initiatives were led by health professionals in each regional centre: Abbotsford (4.23%), Kelowna (4.23%), Prince George (2.82%), Surrey (7.04%), Vancouver (11.27%) and Victoria (9.86%). See table 2 for the proportion of BC Cancer engagement initiatives by program/regional centre.

**Table 2: BC Cancer engagement initiatives between January 1 2018 and March 31 2019**

Program/Centre	Completed	In progress	Total	%
Provincial	24	19	43	60.56
Abbotsford	1	2	3	4.23
Kelowna	0	3	3	4.23
Prince George	1	1	2	2.82
Surrey	3	2	5	7.04
Vancouver	4	4	8	11.27
Victoria	2	5	7	9.86
Total	35	36	71	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 interview to annually renewable committee membership. See Appendix 2 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 43 provincially-led engagement initiatives, 24 have been completed and 19 are in progress. The initiatives engaged between 1 and 25 Patient and Family Partners using various engagement techniques. Partners enrolled in the provincial initiatives participated in committees, review of patient education material and forms, photo shoots and filming, Word Cafés, conferences, working groups, consultation groups, interviews, focus groups and/or surveys. See table 3 for the characteristics of engagement initiatives led by the provincial program.

**Table 3: Provincial program engagement initiatives (between January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement technique	No. of Partners	Status
1	Advance Care Planning Committee	Committee	2	In progress
2	Ask Me 3 handout review	Review	4	Completed
3	BC Cancer Excellence Awards	Committee	1	Completed
4	BC Cancer Foundation In-Centre Awareness Campaign	Review	4	Completed
5	BC Cancer Patient and Family Photo Shoot	Photo shoot	5	Completed
6	BC Cancer Radiation Oncology Lymphoma Retreat	World Café	1	Completed
7	BC Cancer Summit	Conference	8	Completed
8	Breast density primary care	Working group	2	In progress
9	Cannabis For Cancer-Related Symptoms - Clinical Trial Document Review	Review	3	Completed
10	Chemo smart book	Interview	4	Completed
11	Consultation group for the BC Ambulatory Oncology Patient Satisfaction Survey	Committee	2	In progress
12	Designing a relaxation video for people with cancer working group	Working group	1	Completed
13	Early Palliative Integration into Cancer Care	Committee	4	In progress
14	Early Palliative Integration into Cancer Care - Patient Experience Survey	Focus groups	8	In progress
15	Film/Photo Shoot for Patient and Family Counselling Services	Photo shoot	3	Completed
16	Gynecologic Oncology Systemic Therapy Group - Patient Reported Outcomes	Working group	2	In progress
17	Health Ethics Council	Committee	3	In progress
18	Hiring package	Review	3	Completed
19	Interprofessional Nutrition Committee	Committee	1	Completed
20	Lung Cancer Screening Focus group	Focus group	4	Completed
21	Medical Cannabis handbook	Review	14	Completed
22	Nutrition Patient Education Material Review	Review	5	Completed
23	Patient and Family Needs Assessment form - Fatigue	Review	5	Completed
24	Patient Experience Committee	Committee	4	In progress
25	Patient intake form working group	Working group	2	In progress
26	Patient Reported Outcomes Committee	Committee	2	In progress
27	Performance Management Advisory Committee	Committee	1	In progress
28	Photo shoot for publication, Psychosocial	Photo shoot	4	Completed
29	Provincial Systemic Committee	Committee	2	In progress
30	Psychosocial resource editing	Review	4	In progress
31	Radiation Therapy Patient and Family Consultation Group	Consultation group	3	In progress
32	Radiation Therapy Safety Strap Working Group	Working group	3	In progress

No.	Engagement title	Engagement techniques	No. of Partners	Status
33	Radiation Therapy Skin Care Education Video	Review	2	In progress
34	Resources Editing and Advisory Committee - Psychosocial Oncology	Committee	1	In progress
35	Review of BC Cancer policies, procedures and patient handouts	Review	5	Completed
36	Safety package review	Review	4	Completed
37	Spiritual Health Model of Care Advisory Committee	Committee	1	In progress
38	Supportive Cancer Care Focus Groups	Focus group	8	Completed
39	Supportive Care Committee	Committee	1	Completed
40	Test a BC Cancer patient experience survey	Survey	25	Completed
41	Tiers of Service Provincial Working Group	Working group	1	Completed
42	Virtual Health Steering Committee	Committee	2	In progress
43	Website review	Review	11	Completed

## Abbotsford

Three engagement initiatives were reported in Abbotsford, two of which are in progress. Between 1 and 4 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committee and consultation group. See table 4 for the characteristics of engagement initiatives led by Abbotsford centre.

**Table 4: Abbotsford engagement initiatives (between January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Advanced Care Planning Committee	Committee	1	In progress
2	Digital Display Project	Consultation group	4	Completed
3	Regional Patient Experience Committee	Committee	2	In progress

## Kelowna

Three engagement initiatives were reported in Kelowna; all are in progress. Between 2 and 4 Patient and Family Partners are engaged in the initiatives. All initiatives involved committee membership. See table 5 for the characteristics of engagement initiatives led by Kelowna centre.

**Table 5: Kelowna engagement initiatives (between January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Interior Regional Oncology Council	Committee	3	In progress
2	Regional Patient Experience Council,	Committee	4	In progress
3	Triage Steering Committee	Committee	2	In progress

## Prince George

Two engagement initiatives were reported in Prince George; one has been completed and another is 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 January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Clinical Trial Advisory Group	Committee	1	In progress
2	Milestone/End of Treatment Bell and Location Change	Consultation group	2	Completed

## Surrey

Five engagement initiatives were reported in Surrey; three have been completed and two are in progress. Between 2 and 6 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees, consultation groups and a review of patient forms. See table 7 for the characteristics of engagement initiatives led by Surrey centre.

**Table 7: Surrey engagement initiatives (between January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	End of Treatment Bell	Consultation group	4	Completed
2	Exam room computer (CST)	Consultation group	3	Completed
3	Joint BC Cancer / Fraser Health Cancer Care Strategy Council	Committee	2	In progress
4	Regional Patient Experience Council	Committee	2	In progress
5	Treatment Summary and Care Plan Review	Review	6	Completed

## Vancouver

Eight engagement initiatives were reported in Vancouver; four have been completed and four are in progress. Between 1 and 6 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees, consultation groups and working groups. See table 8 for the characteristics of engagement initiatives led by Vancouver centre.

**Table 8: Vancouver engagement initiatives (between January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Art therapy	Working group	1	In progress
2	Brain Tumour Patient and Family Advisory Council	Committee	2	In progress
3	Experience with Radiation Therapy	Consultation group	3	Completed
4	Patient and Family Counselling reception area	Consultation group	2	Completed
5	Patient Experience Council	Committee	6	In progress
6	Patient Experience mapping	Working group	2	Completed
7	Radiation therapy discussion: Full bladder	Consultation group	1	Completed
8	Vancouver/Vancouver Coastal Health Joint Cancer Care Strategy Engagement	Consultation group	3	In progress

## Victoria

Seven engagement initiatives were reported in Victoria; two have been completed and five are in progress. Between 1 and 5 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 January 1 2018 and March 31 2019)**

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Chemo room reconfiguration (CST)	Consultation group	1	Completed
2	Multidisciplinary Care for Patients with a GU Cancer	Consultation group	1	In progress
3	Oncology Nutrition Patient/Family Representatives	Consultation group	2	In progress
4	PET/CT Program Opening	Consultation group	2	In progress
5	Radiation Therapy Quality Committee	Committee	1	In progress
6	Skype for Virtual Health	Consultation group	5	Completed
7	Vancouver Island Oncology Conference	Conference	2	In progress

## Partners evaluation of engagement

Between January 1 2018 and March 31 2019, 78 Partners participated in at least one of the engagement initiatives reported to the Patient Experience Program. At midterm evaluation, 58 evaluation questionnaires were sent to the Partners who were participating in the in-progress engagements; we received 42 responses, yielding a response rate of 72.4%. At end of engagement evaluation, 61 evaluation questionnaires were sent to the Partners who completed the engagements; we received 39 responses, and the response rate was 63.9%. In the following section, responses from Partners who have completed the midterm and final 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 and did not provide response to the evaluation, no responses are reported.

## Self-assessment of confidence and readiness

At midterm, Partners scored high in their self-assessment of their confidence and readiness for the engagement. The Partners’ scores ranged from 4 to 5, with 1 being strongly disagreeing and 5 being strongly agreeing to the statements about initiative-taking and participation in an engagement. Partners who participated in provincially-led and/or regionally-led engagements agreed that they were able to share or seek information readily. The ability to contribute to agenda items scored slightly lower, ranging between 3 and 4.67. See Table 10 for the Partners’ self-assessment of their confidence and readiness at the midterm evaluation.

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 of which 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 will provide further insights to the quality of the engagement.



**Table 10: Partners self-assessment of confidence and readiness at midterm evaluation (mean score)**

	As needed, I prepare for meetings by reviewing material in advance.	If I lack information, I take the initiative to get it.	I was able to express my views freely.	I occasionally suggest topics for future meeting discussions or agenda items.
Overall (n=23)	4.57	4.38	4.54	3.70
Provincial (n=20)	4.70	4.39	4.43	3.61
Kelowna (n=3)	5.00	4.33	5.00	4.67
Prince George (n=1)	4.00	4.00	4.00	4.00
Surrey (n=3)	4.67	4.67	4.67	3.33
Vancouver (n=6)	4.00	4.33	4.67	3.83
Victoria (n=1)	4.00	4.00	5.00	3.00

Note. 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 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 aggregated mean scores across the provincially and regionally led engagements were largely high, ranging from 3.75 to 5. See Table 11 for the aggregated mean scores of Partners evaluation at the end of the engagement.

### Communication

Partners reported that the purpose of the engagement activity had been clearly explained to them, with mean ranging from 4.55 to 5. Positive comments from Partners included:

- “open and honest communication between patient/family members and staffers”
- “well-managed activity, benefited by concise, practical notes”

Partners’ understanding of the use of their input from the activity was relatively lower; the mean ranged from 3.75 to 5. To strengthen communication in the engagement, Partners’ suggestions included:

- “The scope of the project could have been more clearly explained and issues that were not addressed but remain under consideration for future phases should be specified.”
- “In the future, I would find it helpful to get a clearer "why does this matter" statement in the description of the engagement opportunity. Then patients and staff know that their time is valued and they will be able to contribute where it really matters.”

### Partnership

Reflecting on the partnership with health professionals in the engagement, Partners reported that they were able to express their view freely (mean range 5 to 4.5) and felt that their views were heard (mean range 4 to 5). Partners appreciated the collaboration with the leadership team and the opportunity to share their cancer experience and contribute to care improvement. Some comments, including ways to enhance the partnership, were:

- “Having senior management demonstrate their support for patient centred care and support by extending an invitation to patient.”
- “Listening to and being listened to. The level of compassion and respect was a definite plus for both staff and family and patient members to speak freely about experiences, values, social, economic and cultural concerns.”
- “1:1 calls would give Family/Patient partners more time to give valuable input. This committee was very large with little time for each member to give input.”

### Support needs

Partners have largely felt supported to participate in the engagements. Particularly, they agreed that the supports were available to them (mean range 4 to 5) and they had enough information to contribute to the topics discussed at the engagement meetings (mean range 4.5 to 5). At the same time, Partners have also identified areas where support could be enhanced:

- “A list of stakeholders their roles, on the project and in the organization, and acronyms to keep handy during meetings might be helpful.”
- “If they can speak louder and slower, but it will be quite unnatural for people who can speak English fluently.”
- “Clarity and understanding. Some participation opportunities are patronizing and clearly seek needed input rather than thoughtful input that may well help both practitioners and patients

and family embrace the reality of progressing through diagnosis and treatment. Those of us who are willing to share and reflect have much to share.”

### **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 (mean range 4 to 5) and that their participation in the engagement would make a difference (mean range 3.75 to 5). Partners reiterated their hope to see their input affecting recommendations and health professionals taking leadership in implementing changes, resulting in streamlined patient care and communication among care providers:

- “I would like our input carefully considered, evaluated for effectiveness and efficiency, and implemented where suitable.”
- “I hope that feedback from patient partners will be taken into consideration in designing programs. That said, I also think that ultimate responsibility rests with the staff who are designing and carrying out these initiatives.”
- “Continue embracing opportunities to support staff, at all levels to develop routines that further streamline patient care, communication among and between cancer centres and provincial health zones.”

Further, Partners highlighted the need to see the results of their inputs, reminding us of the importance of reporting back in engagement:

- “It would be beneficial to see final result as to how collective review process impacted the final documents.”
- I hope the suggested edits were helpful but wouldn't know unless I received copies of the final materials.”

## Strength and improvement

Partners agreed that they were satisfied with their participation in the engagements overall (mean range 4 to 5. See Table 11 for mean scores in provincially and regionally led engagements). Partners appreciated hearing different perspectives in the topics of discussion and using their skills to address issues, all of which contributed to “positive and fulfilling” experiences in engagements.

Commenting on the “high points” of their involvement in engagements, the highlights included feeling included and appreciated for their contribution and acquiring knowledge about the topics in discussion, BC Cancer operations and the health care system. On the other hand, the frequently mentioned “low points” were the lack of communication about meetings schedules and project progress, and feeling overwhelmed with the specialized information transmitted 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. Particularly, Partners were impressed when the health professionals: were welcoming, respectful, authentic, inclusive and appreciative; reached out and ask for feedback, listened to and acted on Partners' suggestions; oriented Partners to the meetings/action items and took time to check-in over the course of the engagement. In the Partners’ words, the health professionals did well in engaging them when:

- “Treat(ed) me as someone who has valued contributions to make; I am never patronized or talked "down to"; recognition that I have a different perspective and that is one of the reasons a patient partner is on the committee; friendly/welcoming/willing to explain if I have a question or get stuck on a concept.”
- “By being very welcoming and expressing appreciation for the time and effort to complete the task. Providing information about the task and being available to answer any questions.”
- “They always take the time to answer questions and check to make sure we understand what's being said.”
- “(Health professionals) Pausing to ask if I don't offer comment where appropriate.

## Opportunities for improvement

On ways health professionals could enhance the engagement, Partners pointed out areas of improvement: proactively seek and listen to Partners’ feedback and engage Partners in implementation; clarify Partners’ roles and expectations, the engagement timeline, communication mode, terminology

and acronyms; follow-up with Partners promptly, especially following leadership change. Elaborating on their suggestions, some of the Partners' comments were:

- “Explore how patient partners might assist the team in a creative way. For example, create a list of information topics/values that patient partners might be able to provide to improve the process and from that list create a series of questions for patient partners to explore the topics in more depth.”
- “To be more involved in sub-committee work with a commitment to implementation.”
- “Continue to use non Centre language and involve us in discussions more. Since there are more staff, the patient partners are less willing to speak up out of turn.”
- “I think that the agenda items were too technical and not of interest for patient / family representatives involvement. The meeting discussions were managed well enough for patient / family representatives to contribute if you were a part of a medical team or department. I learnt a lot of acronyms, however felt of no value to the task at hand for this committee.”
- “I will continue to participate as long as I feel that I can make a meaningful contribution and that contribution will result in improved person-centred care and support. There is far, far, far, too much emphasis on visioning, frameworks, and rhetoric and not enough on optimal and feasible solutions to reduce the gaps and barriers that have been well identified for decades.”
- “I don't think they know yet what they are doing or where they are going - they have a new lead and that will take time to gel. I will wait another meeting, maybe two, to get a better idea of what they are doing and where they are going, and then I will ask the big question of, "What kind of feedback are you hoping I can provide? What insight are you hoping I have?"”

**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=38)	4.63	4.58	4.58	4.74	4.53	4.45	4.21	4.03	4.38
Provincial (n=20)	4.55	4.55	4.5	4.6	4.45	4.3	4	3.9	4.37
Abbotsford (n=1)	5	5	5	5	5	5	5	5	5
Kelowna (n=0)	--	--	--	--	--	--	--	--	--
Prince George (n=0)	--	--	--	--	--	--	--	--	--
Surrey (n=9)	4.56	4.78	4.56	5.00	4.78	4.78	4.56	4.44	4.56
Vancouver (n=4)	4.75	4.75	4.75	4.75	4.75	4.75	4.75	3.75	4.25
Victoria (n=4)	5	4	4.75	4.75	4	4	3.75	3.75	4

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 (January 1 2018 to March 31 2019), midterm evaluation questionnaires were sent to 25 health professionals leading the engagements. At the end of the engagement, evaluation questionnaires were sent to 23 initiative leads. 16 health professionals completed the midterm questionnaires and 15 completed the end of engagement evaluation; the response rates were 64% and 65.2%, 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. In view of the small sample size, results of the provincially and regionally led engagements were combined in the reporting to safeguard the confidentiality of all respondents. Qualitative responses/comments were summarized, with selected quotes to highlight emerging themes.

## Resource usage, impact and training

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-making, and training needs. The aggregated mean scores across these identified aspects of engagement quality were high, ranging from 4.08 to 4.69. See Table 12 for the means scores for each aspect in the combined sample.

### Resource usage

Health professionals agreed that the engagement was a good use of their program resources, with overall mean score of 4.62. Commenting on the contribution from the Partners, health professionals reminded that:

- “They (Partners) are key to this. Without them our group wouldn't exist.”
- “The input from our Patient Partner is valuable, however, the meetings occur once a quarter at this point so not that frequent.”
- “I feel they play a significant role in guiding our trajectory of work. I'd hope they say the same.”

- “The program has been able to achieve initial success with the patient partners' valued engagement and collaborative contribution throughout the planning and implementation of this project.”

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

The Partners’ input was deemed useful where it could be integrated in practice, with a mean score of 4.69. The Health professionals’ assessment of how the output from the engagement influenced decision-making was relatively lower (mean score 4.08). Reasons for the lower impact on decision-making include limitations in the engagement scope and organizational constraints:

- “I'm hoping to see more engagement as we start working on initiatives. Think it's a little too early to tell in terms of impact. Partners are attending regularly and participating where appropriate though.”
- “The patient partners have shared their perspectives. Where possible we have been able to incorporate their suggestions. Due to organizational constraints we can't make all of the changes the partners want to see.”

On their part, health professionals have adopted various approaches to report back to Partners on their influence on decision-making. The means of reporting back 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, and providing summary reports on the project progress at 6 month intervals.

### **Training and education support**

Health professionals have indicated that it would be helpful to participate in patient and family engagement training, to build their capacity in engagement (mean score 4.15). Areas for further training and education included:

- Types of frequently used engagements
- Facilitating engagement initiatives, especially in running large working groups
- Moving from consult/involve towards collaborate/empower in the spectrum of engagement
- Working with diverse populations
- Knowing when it is appropriate to engage patients and families, and planning for uptake



## Strength and improvement

Overall, health professionals indicated high satisfaction with the way they have engaged the Partners (mean score 4.69). See Table 12 on the health professionals' end of engagement evaluation (overall mean score).

### Strengths

There was agreement that the engagements were highly valued, the matching of Partners to the engagement was streamlined, and the Partners contributed to the initiative.

- “We appreciate the help we received... and this was a very positive experience for us. Connecting with the patient and family partners helped us improve our project and gave us new and fresh ideas we had not thought about.”
- “I really liked the initial intake form and phone call process to meet and clarify any questions.”
- “This is a great way to find first-hand, the patients' experiences. In every case, the patients were very pleased with their level of treatment and care and the spirit of the nursing staff that cared for them. If the occasion arose, I would like to experience patient interaction once again to determine areas that could be addressed.”

### Opportunities for improvement

At the same time, the health professionals recognized the need for more diverse perspectives, better communication with the Partners and more clarity on meaningful engagement in committees.

- “I think the one thing that would help is to increase our enrollment of patients with specific experience.” i.e. having “Partners from different backgrounds, ages, culture, socio-economic backgrounds.”
- “We would like to build on patient care by creating a more welcoming environment in the centre.”
- “I think continued reminder regarding what our partners can do for our committees, to bring this to the forefront of our minds the importance of involvement of patient partners.”

**Table 12: 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 enhanced decision making	I would like to participate in patient and family engagement training to build my capacity to do more of this work.
<b>Overall (n=13)</b>	4.69	4.62	4.69	4.08	4.15

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

## Feedback on evaluation questionnaires

Commenting on the evaluation questionnaires, Partners agreed that the evaluation played an important role in the engagement process. Particularly, Partners felt validated and supported, and valued the opportunity to provide feedback and raise issues to enhance their engagement experience:

- “Glad it was sent out as I have been questioning if I have added anything through the many calls.”
- “Thank you for creating this questionnaire. It validates my feeling that patient partners are important to the work the medical teams do.”
- “Well phrased! Great opportunity for reflection! I applaud the efforts and generosity of time and compassion those leading and participating and other professionals willing to listen and share thoughts and ideas give to, this, perhaps pivotal change in helping patients understand the complexity of this disease and of the tremendous energy BC Cancer is employing to treat and engage patients.”
- “It is good to have an opportunity to provide feedback and bring forward any concerns about the initiative.”

At the same time, some Partners suggested that evaluation be sought more promptly after the end of an engagement for clear recollection of their experience. Health Professionals added that scale questions could be used for assessing satisfaction and influence at the midterm evaluation, in addition to the questions on describing changes in Partners’ participation.

## Conclusions

The evaluation of BC Cancer patient and family engagement is the pioneering work of the Patient Experience Program. There are several limitations in this report:

- The evaluation result does not encompass all engagement initiatives in BC Cancer. Engagements that do not fall within the reporting period (January 1, 2018 – March 31 2018) are not included. 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 documentation.
- There was substantial missing data on the optional demographic questions in both the midterm and end of engagement questionnaires. Key demographic information including, age, gender, ethnicity and education, is not reported.

In the next report, the areas of improvement will include:

- Collect demographic data from all Partners at the point of enrolment to the Network. The required identifiable information will further facilitate matching Partners to engagements.
- Revise the evaluation questionnaires, incorporating scale questions for assessing satisfaction and influence.
- Collect evaluation data within a week of the engagement end date. To ensure timely data collection, it is recommended that the evaluation questionnaires to the Partners be communicated through the initiative leads.

Patient and family engagement in BC Cancer saw rapid growth in the past year, as membership in the Network of Patient and Family Partners continued to expand steadily. The engagement initiatives provided opportunities to partner with a diversity of patients and family caregivers in provincial programs and across the regional centres, as health professionals proactively sought out the perspectives of those receiving care. Partners responded and made their voices heard through an array of engagement activities, contributing to decision-making in enhancing cancer care. The Partners' and health professionals' evaluation of their engagement experience provided insights to BC Cancer's continuous efforts to uphold person-centred care. Engagement evaluation will remain a priority in the work of engaging patients and families in their care.

# Appendices

## I. Spectrum of engagement

	<b>Inform</b>	<b>Consult</b>	<b>Involve</b>	<b>Collaborate</b>	<b>Empower</b>
Definition	To give information	To get feedback	To understand	To work together	To give power to
Example techniques	Fact sheet Web site Open house	Survey Focus Group Public meeting	Conversation Dialogue	Working group Participatory- decision making	Referendum Delegated decision
Promise	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.

## II. Engagement techniques

Engagement techniques	Number of engagements	Explanation
Committee	25	Partner and health professional representatives meet in-person or by teleconference to provide input to planning process.
Conference	2	Partners selected to attend conference as invited panel speaker or as participant.
Consultation group	14	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	3	A group of Partners meet (in-person or phone) to participate in a planned discussion facilitated by a health professional.
Interview	1	Partners meet one-to-one (in-person or phone) with a health professional to provide feedback to specific questions
Photo shoot	3	Partners participate in a session of photo taking and/or filming with health professionals for purpose of BC Cancer service promotion.
Review (website, material)	13	Partners review BC Cancer resources prior to publication/posting by attending in-person/phone meeting or by email.
Survey	1	Partners participate in online surveys
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	8	An appointed group of Partners and health professionals working together on identified topics to achieve specific goals.

### III. Partners midterm engagement questionnaire

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

*Title of engagement:*

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*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.

#### IV. Partners end-of-engagement questionnaire

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:*

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	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.



#### IV. Health professionals midterm engagement questionnaire

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

*Title of engagement:*

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5. 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)?
6. Have any partners resigned from the initiative? If there was resignation, please provide the name of the individual and the reason for the resignation.
7. Thinking about how engaged 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.
8. How much influence do you think the partners have on this initiative?
9. Please explain how you are keeping the partners up to date on the initiative.

## V. Health professionals end of engagement questionnaire

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"/>

