



Provincial Health Services Authority

Patient Experience Program

Patient and Family Engagement

Annual Report 2021

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Contents

- Executive summary..... 3
- Introduction..... 5
- Characteristics of Partners 8
- Engagement initiatives13
 - Provincial13
 - Abbotsford15
 - Kelowna.....15
 - Prince George.....16
 - Surrey.....16
 - Vancouver.....17
 - Victoria.....17
- Partners evaluation of engagement.....19
 - Communication, partnership, support and influence19
 - Communication19
 - Partnership.....20
 - Support needs21
 - Influence in decision-making22
 - Strength and improvement.....23
 - Strengths.....23
 - Opportunities for improvement24
- Health professionals evaluation of engagement27
 - Resource usage, impact and training27
 - Resource usage27
 - Impact on practice change and decision28
 - Training and education support30
 - Strength and improvement.....30
 - Strengths.....31
 - Opportunities for improvement31
- Partners to Partners Engagement Connect Networking Group.....35

Learnings from P2P Connect	35
Conclusions.....	38
Appendices	39
A. Definitions.....	39
B. References	40
C. Resources links.....	41
D. Spectrum of engagement	42
E. Engagement techniques	43
F. Partners midterm engagement questionnaire.....	44
G. Partners end-of-engagement questionnaire	45
H. Health professionals midterm engagement questionnaire	46
I. Health professionals end-of-engagement questionnaire.....	47

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, 2020 and March 31, 2021. 60 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, 2021, 31 engagements were completed and 29 were in progress. 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 communication in the engagement, 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 stressed the need for health professionals to use accessible language and to keep Partners updated 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 highlighted the impact of ongoing changes in leadership on the engagement progress. Partners also reiterated their wish to see prompt uptake of actions to improve service delivery.

The key strengths that Partners identified were centred on the collaborative relationship and facilitation of the engagement by health professionals. Partners felt listened to, and that their feedback was sought, acknowledged and acted on to improve care. Health professionals also included Partners in conversations, treating the Partners as valued members of the team. On ways health professionals could enhance the engagement, Partners reiterated the importance of reaching out to engage them. Partners reiterated the need to promptly update them on the outcomes of the engagement, so that they will know how they have made a difference and how they can continue to contribute to the initiative.

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 Partners contributed by bringing their experience, as well as their skills, to improve care. Health professionals also highlighted trusting relationships with Partners as a contributing factor to a successful engagement.

To improve the engagement experience, health professionals identified the need to be clear about the purpose of the engagement, the role and expectation of the partners and of the initiative leads, and the amount of influence that Partners have in the engagement. Further, it'll be important that Partners understand the scope of the engagement, before participating in the initiative.

Partners continue to connect with peers through the *Partners to Partners Engagement Connect Networking Group* (P2P Connect) monthly virtual meetings throughout the pandemic. Under the purview of the Patient Experience Program, P2P Connect was established in 2019 to provide a platform for Partners to network and learn from peers on ways to improve their engagement experience. Partners contributed by making recommendations for discussion topics, co-facilitating meetings, co-presenting and participating in discussions at the meetings. A team of four Patient and Family Partners helped to plan and lead the monthly meetings.

Overall, the Partners' and health professionals' evaluation of their engagement demonstrates their commitment to this work. An area of improvement noted in the 2020/2021 evaluation reporting is the higher response rate from health professionals, compared to the past 2 years of evaluation. The readiness to respond may be attributed to the email reminders. At the same time, it reflected the commitment of the health professionals to engaging Partners, of which evaluation is a key component of engagement.

Despite the slower uptake of engagement activities in the reporting period, members of the Network of Patient and Family Partners at BC Cancer continues to be engaged through different means of communication during the pandemic. Partners also had further opportunities to interact with peers through the monthly network group meetings. The Partners' and health professionals' evaluation of their engagement experience will be pivotal to BC Cancer's continuous efforts to engage patients and families in their care.

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 2021, 109 cancer patients and family caregivers across BC were enrolled in the Network. In the reporting period of April 1, 2020 to March 31, 2021, 60 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)¹. See Appendix F to I 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 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.

Midterm questionnaires were used to evaluate the Partners' and the health professionals' experience in the in-progress engagement initiatives. The scale questions in the 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.

¹ 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.

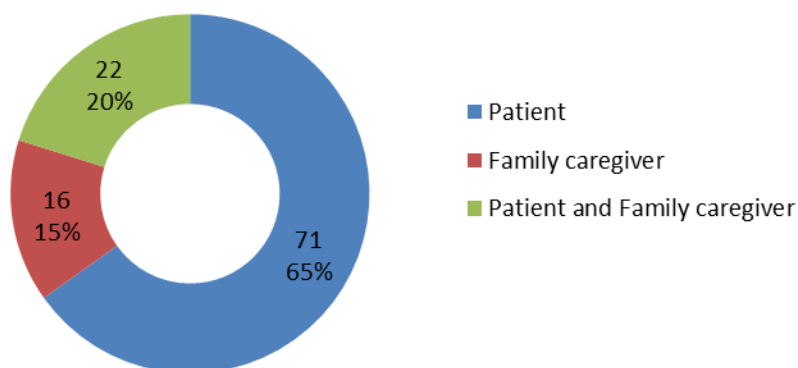
The report provides an overall description of the Partners in the Network as at March 31, 2021. The engagement status of the initiatives in each regional centre is discussed. The evaluation results were analyzed, quantitative responses were aggregated, and emerging themes were drawn from the qualitative responses. Further, respondent comments were quoted to reflect the quantitative results and the identified themes. Learnings from a recent initiative, Partners to Partners (P2P) Connect, undertaken by the Patient Experience Program to strengthen Partners connection and engagement at BC Cancer, is also reported.

Characteristics of Partners

A hundred and nine patients and family caregivers were enrolled in the BC Cancer Network of Patient and Family Partners as at March 31, 2021. About two-thirds of the enrolments were referred to the Network by BC Cancer staff/health professional (63.3%). About 15% of the referrals were from community collaborators. Other sources of referral were online-website/social media (7.3%) and Partners' word of mouth (5.5%).

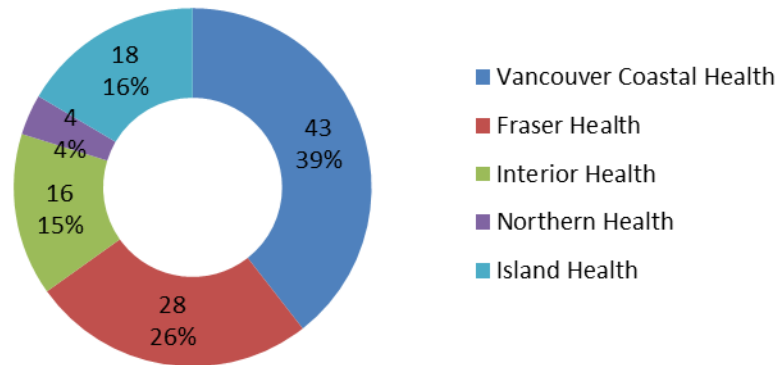
Almost two-thirds (65%) of the Partners enrolled were cancer patients; 15% were family caregivers. About one-fifth (20%) of the Partners in the Network identified themselves as both cancer patients and carers of a loved one (family/friend) diagnosed with cancer. See Graph 1 on Partner's role.

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



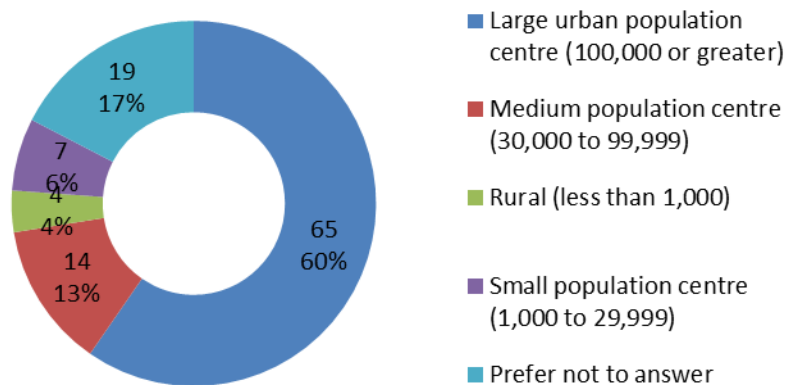
The Patient and Family Partners have predominantly received care in a BC Cancer regional centre; those who were not identified as BC Cancer patients received care in their local hospital or community clinic. Almost 40% of the Partners resided in the Vancouver Coastal Health region; 26% were from the Fraser Health region. 15% of the Partners lived in the Interior Health region; 16% were from the Island Health region, and 4% were from the Northern Health region. See Graph 2 on characteristics of Partners by geographic location.

Graph 2: Characteristics of Partners – Geographic location by health authority, n=109

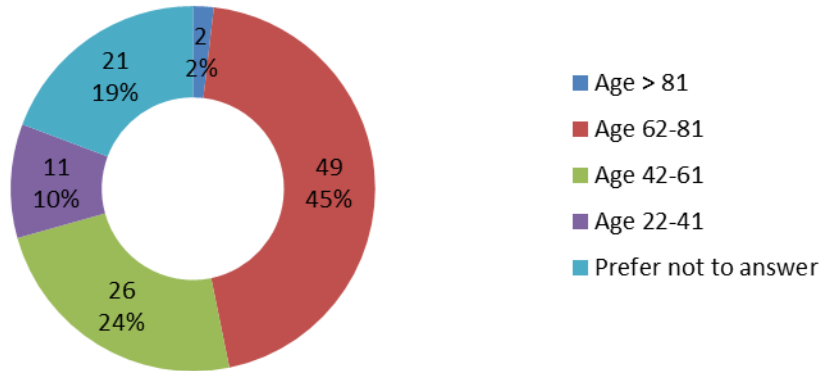


Among the Partners who provided further demographic information, the majority (60%) were identified as residents of a large urban population (100,000 or greater), compared to 4% from rural communities (less than 1000). On the Partners’ ages, close to 50% (47%) were over 61, with 10% under 42. A majority of the Partners also identified as female (54%) and have university education (56%). While 33% reported that they have retired, over 30% 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.

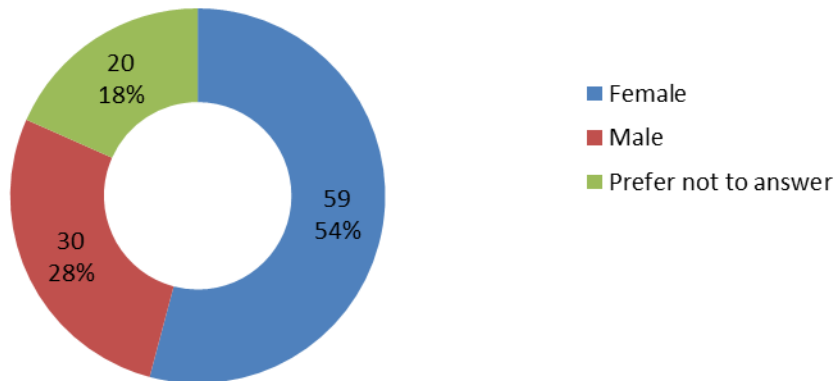
Graph 3: Characteristics of Partners – Geographic unit, n=109



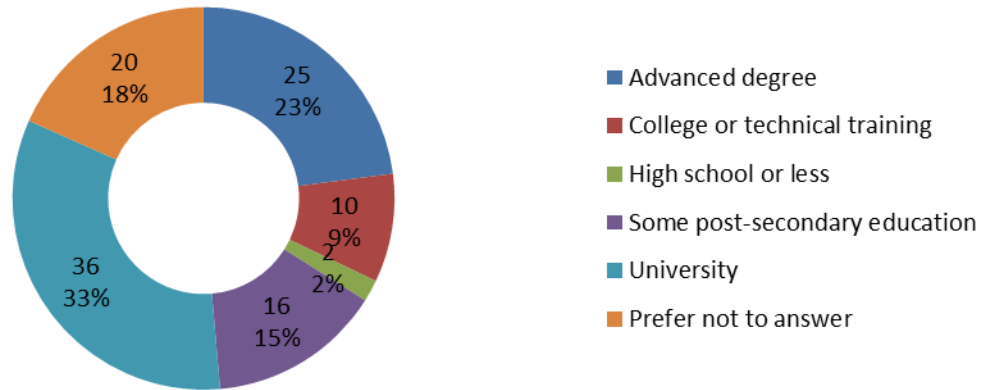
Graph 4: Characteristics of Partners – Year range of birth, n=109



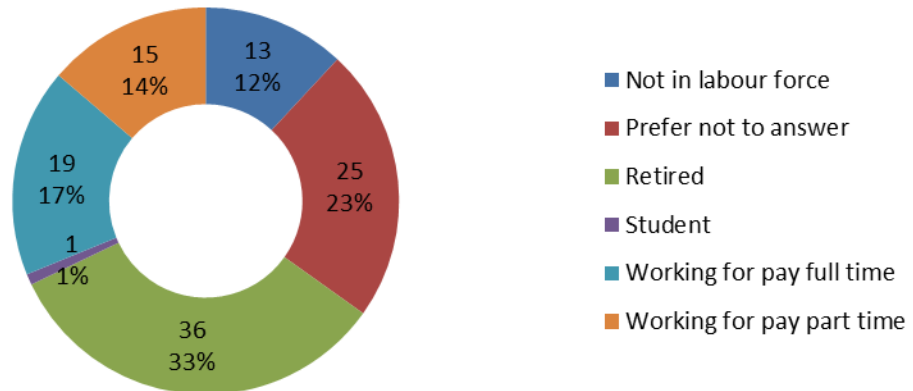
Graph 5: Characteristics of Partners – Gender, n=109



Graph 6: Characteristics of Partners – Education, n=109



Graph 7: Characteristics of Partners – Work status, n=109



Twenty seven 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 (38.83%), followed by head/neck (14.56%) and prostate cancer (11.65%). 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: Cancertype

Cancer type	Number	%
Breast	40	38.83
Head/Neck	15	14.56
Prostate	12	11.65
Lymphoma	9	8.74
Colon	8	7.77
Lung	7	6.80
Ovarian	7	6.80
Leukemia	5	4.85
Others (< 5 cases)	36	34.95
Total cases reported by Partners	139	100.00

Note: 1. Cancer types of less than 5 cases reported: appendix, bladder, bone, cervical, colorectal, endometrial, gallbladder, leiomyosarcoma, liver, melanoma, myelofibrosis, myeloma, pancreatic, rectal, renal, rhabdomyosarcoma, small intestine, stomach, testicular.

Engagement initiatives

Between April 1, 2020 and March 31, 2021, 60 BC Cancer engagement initiatives were reported: 32 have been completed and 28 were in progress. Provincial programs constituted more than half of the engagement initiatives (63.33%). The remaining initiatives were led by health professionals in each regional centre: Abbotsford (3.33%), Kelowna (5%), Prince George (5%), Surrey (6.67%), Vancouver (11.67%) and Victoria (5%). See Table 2 for the proportion of BC Cancer engagement initiatives by program/regional centre.

Table 2: BC Cancer engagement initiatives (between April 1, 2020 and March 31, 2021)

Program/Centre	Completed	In progress	Total	%
Provincial	21	17	38	63.33
Abbotsford	1	1	2	3.33
Kelowna	2	1	3	5.00
Prince George	1	2	3	5.00
Surrey	2	2	4	6.67
Vancouver	4	3	7	11.67
Victoria	1	2	3	5.00
Total	32	28	60	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 38 provincially-led engagement initiatives, 29 have been completed and 17 were in progress. The initiatives engaged between 1 and 6 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 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, 2020 and March 31, 2021)

No.	Engagement title	Engagement technique	No. of Partners	Status
1	Advance Care Planning Committee	Committee	2	Completed
2	BC Cancer Primary Care Learning Sessions	Committee	4	Completed
3	BC Cancer Provincial Ethics Advisory Council	Committee	3	Completed
4	BC Cancer Quality Improvement Facilitation and Advisory Group	Committee	2	Completed
5	BC Cancer Smoking Cessation Initiative	Working group	2	In progress
6	Caregiving for colorectal cancer patients - Primary caregiver reported outcomes	Working group	3	In progress
7	Chemotherapy and Patient Quality of Life Project	Working group	3	Completed
8	Clinical Trial Protocol Review Committee	Committee	3	Completed
9	Conversations with pharmacy residents on patients' perspectives of cancer care	Consultation group	2	Completed
10	Digital Health Steering Committee	Consultation group	1	In progress
11	Early Palliative Integration into Cancer Care	Committee	3	In progress
12	Exploring the use and performance of Zoom in smaller B.C. communities	Consultation group	4	Completed
13	Grant application for clinical trial in ovarian cancers	Review	3	Completed
14	Gynecologic Cancer Initiative - Clinical Trials Group (GCI-CTG)	Working group	2	In progress
15	Gynecologic Cancer Initiative Patient and Family Advisory Council	Committee	6	In progress
16	Gynecologic Oncology Systemic Therapy Group - Patient Reported Outcomes	Consultation group	1	In progress
17	Improving the Model of Care in Breast Cancer Clinic (Extra Project)	Committee	2	Completed
18	Lung Cancer Screening Program - Patient Pathway Working Group	Working group	1	In progress
19	Outpatient Cancer Care Patient Survey Consultation Group	Committee	2	In progress
20	Patient and family experience evaluation metrics (CST)	Working group	2	Completed
21	Patient Experience Committee	Committee	2	Completed
22	Patient Experience Survey Focus Group	Focus group	6	Completed
23	Patient Results Letter in Familial Pancreatic Cancer Program	Review	4	Completed
24	Patient-Centred Measurement Innovation Group	Committee	3	In progress
25	Performance Management Advisory Committee	Committee	1	In progress
26	Primary care lung cancer clinical guideline working group	Working group	1	In progress
27	Provincial Interprofessional Practice Council Patient and Family Consultation Group	Consultation group	3	Completed
28	Provincial Systemic Therapy Program Committee	Committee	1	Completed
29	Radiation Therapy Video Series	Photo shoot/filming	2	In progress
30	Review of BC Cancer library website for gender-	Review	1	Completed

No.	Engagement title	Engagement technique	No. of Partners	Status
	neutral language			
31	Review of supportive cancer care brochures	Review	4	Completed
32	Review of Zoom Patient Resource Infographic	Review	2	Completed
33	RT Patient and Family Consultation Group	Consultation group	3	In progress
34	Simulated Interactions Between Patient/Family and Pharmacist Student in Training	Consultation group	3	In progress
35	SOGIE Working Group	Working group	2	In progress
36	Virtual Health Advisory Committee, PHSA	Committee	3	Completed
37	Virtual Interpreter Project	Consultation group	2	Completed
38	Working Group: Follow-Up Care for Patients on Capecitabine Oral Chemotherapy	Working group	2	In progress

Abbotsford

Two engagement initiatives were reported in Abbotsford, one of which has been completed and one was in progress. Each of the initiatives engaged two Patient and Family Partners. Both initiatives were committees. See Table 4 for the characteristics of engagement initiatives led by Abbotsford centre.

Table 4: Abbotsford engagement initiatives (between April 1, 2020 and March 31, 2021)

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Abbotsford Regional Patient Experience Committee	Committee	2	Completed
2	Patient and Family Advisors for Patient-centred Measurement Assessments project	Committee	2	In progress

Kelowna

Three engagement initiatives were reported in Kelowna; two have been completed and one was in progress. Between 1 and 4 Patient and Family Partners were engaged in the initiatives. The initiatives involved committee membership and review of patient education material. See Table 5 for the characteristics of engagement initiatives led by Kelowna centre.

Table 5: Kelowna engagement initiatives (between April 1, 2021 and March 31, 2021)

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Regional Patient Experience Council, Kelowna	Committee	4	In progress
2	Review of a patient handout on checking balloon water volume in retention feeding tubes	Review	1	Completed
3	Review of a patient symptom diary for immunotherapy patients	Review	2	Completed

Prince George

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

Table 6: Prince George engagement initiatives (between April 1, 2020 and March 31, 2021)

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

Surrey

Four engagement initiatives were reported in Surrey; two have been completed and two were in progress. Between 1 and 3 Patient and Family Partners were engaged in the initiatives. The initiatives constituted committees and working groups. See Table 7 for the characteristics of engagement initiatives led by Surrey centre.

Table 7: Surrey engagement initiatives (between April 1, 2020 and March 31, 2021)

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

Vancouver

Seven engagement initiatives were reported in Vancouver; four have been completed and three 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, 2020 and March 31, 2021)

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	BC Cancer - Vancouver/Vancouver Coastal Health Joint Cancer Care Strategy Engagement	Consultation group	2	Completed
2	Cancer Care Implementation Working Group - A Palliative Approach to Care in Vancouver Centre	Working group	1	In progress
3	Explore issues and solutions for child care for patients and families at BC Cancer-Vancouver	Consultation group	1	Completed
4	Patient Experience Council, BC Cancer-Vancouver	Committee	6	In progress
5	Patient Experience mapping (3 partners)	Working group	2	Completed
6	Review of letter to family on radiation therapy for pediatric patients	Review	2	Completed
7	Spiritual Health Advisory Committee	Committee	1	In progress

Victoria

Three engagement initiatives were reported in Victoria; one has been completed and two were in progress. Between 1 and 3 Patient and Family Partners were engaged in the initiatives. The initiatives

constituted committees and consultation group. See Table 9 for the characteristics of engagement initiatives led by Victoria centre.

Table 9: Victoria engagement initiatives (between April 1, 2020 and March 31, 2021)

No.	Engagement title	Engagement techniques	No. of Partners	Status
1	Island Regional Cancer Care Strategy Council	Committee	1	In progress
2	Multidisciplinary Care for Patients with a GU Cancer	Consultation group	1	Completed
3	Regional Patient Experience Council – Victoria / Vancouver Island	Committee	3	In progress

Partners evaluation of engagement

Between April 1, 2020 and March 31, 2021, 78 Partners participated in at least one of the engagement initiatives reported to the Patient Experience Program. At midterm evaluation, 130 evaluation questionnaires were sent to the Partners who were participating in the in-progress initiatives; we received 90 responses, yielding a response rate of 69.23%. At end-of-engagement evaluation, 88 evaluation questionnaires were sent to the Partners who completed the engagements; we received 56 responses, and the response rate was 63.64%. 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.

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 4.17 to 4.67 at midterm and from 4.14 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 have largely agreed that the purpose of the engagement activity had been clearly explained to them, with overall mean of 4.47 at midterm and 4.46 at end-of-engagement. Partners commented that the initiative leads were organised and prepared, took time to address their questions and shared information with them. Positive comments from Partners included:

- “The initiative lead has consistently been well prepared, open for questions and considerate of our time and effort.”

- “Great listening and clarification. Minutes and agenda. Listing names of participants and their roles. Staying within the agreed upon time.”
- “Open, honest and constructive dialogue between the project lead and the other partner involved.”
- “Answering my questions during meetings, and providing feedback and supporting information to help me understand all the elements in decision-making at the agency.”
- “Both Dr. ___ and Dr. ___ are excellent listeners, treat patient partners with patience as peers, as do all members of the committee. This initiative has opened up other opportunities for participation as a patient partner which has expanded my knowledge and understanding of the topic.”

Partners’ understanding of the use of their input from the activity was relatively lower (midterm mean 4.17; end-of-engagement mean 4.27). To strengthen communication in the engagement, Partners stressed the need for health professional to use accessible language and to keep Partners updated on engagement progress:

- “Provide Patient Partners with a list of all the acronyms that are used by professionals in discussions because it's very difficult to follow the conversation when you have no idea what they're talking about!”
- “Send the materials in advance, use less jargon and acronyms and introduce themselves before presenting.”
- “More updates as to why my participation makes or can make a difference.”
- “Would like to know what is going on that I, as a PFA (Patient Family Advisor), might contribute to.”
- “Covid-19 and many changes to the senior leadership halted the work of this committee. Keeping me informed would have helped.”

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 4.60; end of engagement mean 4.52). Partners appreciated the opportunity to contribute to care improvement while learning about the organization challenges and opportunities in care delivery:

- “When I share the experiences I have through my engagements, I receive acceptance and encouragement. I have more confidence to be part of the committee.”
- “The willing sincerity and enthusiastic engagement shared by health professionals, patients and caregivers regardless of the complex range of topics/subjects under consideration.”
- “Meeting a variety of health care providers and gaining an understanding of the issues that concerned them for which they wanted patient partner input. Also, being able to bring forward issues of concern to me.”
- “The committee has persisted in spite of the change in the BCCA management and the turnover of the chairs. It has also continued during the devastation of the pandemic. This indicates there is value in this committee and the input of its members.”
- “I wouldn't so much call it a low point but gaining the knowledge to work with very technical and research oriented terms has taken awhile. It's not a low point as all learning is good but until there is more confidence in understanding you have a tendency to hold back from fully expressing a view. The committee members never made putting up your hand for more information or clarification as a bad thing and were very patient as we moved along our learning curve.”

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 4.34; end of engagement mean 4.45), and they had enough information to contribute to the topics discussed at the engagement meetings (midterm mean 4.29; end of engagement mean 4.43). At the same time, Partners have also identified areas where support could be enhanced. They included updates on meeting schedule, support for virtual meetings and overview of BC Cancer care system:

- “Know when next meeting will be so I can put it in my day book.”
- “I need to follow through and learn how to ZOOM ... in the meantime telephone links are essential.”
- “Nothing specific. However, as I am not employed in government or healthcare getting a general overview of how the system works (organizationally) ahead of time might have been useful.”

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 4.48; end-of-engagement mean 4.45) and that their participation in the engagement would make a difference (midterm mean 4.20; end-of-engagement mean 4.14). At the same time, Partners highlighted the impact of ongoing changes in leadership on the engagement progress. Partners also reiterated their wish to see prompt uptake of actions to improve service delivery.

- “The continual turnover of the leads - first it was ____, then ____, then ____, then ____ and now _____. This certainly adds complexity to building trusting relationships between the lead and the patient-partner. Also, the disruption loses momentum. Also, the continual change in the scope of the Committee's mandate - wastage of time, and never certain if anything will ever get implemented when we constantly press the "reset" button.”
- “The managerial changes in the organization of the agency appears to have impacted momentum and progress of this group’s initiatives.”
- “Retain consistency in the team chairmanship and keep focus on a few key initiatives.”
- “The lengthy, time-consuming process needed to adjudicate committee ideas, proposals or recommendations. Typical of administrative efforts in all large organizations, unfortunately.”
- “Yes my thoughts are being heard, however the length of time by which things are being formulated and implemented at the front line and within the organization takes a while.”

Strength and improvement

Overall, Partners agreed that they were satisfied with their participation in the engagement initiatives (midterm mean 4.37; end-of-engagement mean 4.25). 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. Commenting on the “high points” of their involvement in engagements, Partners appreciated having opportunities to contribute and influence decision-making, gain knowledge and learn, and interact with care providers. On the other hand, the frequently mentioned “low points” were not seeing prompt uptake of implementation plan, interruption to engagement meetings during COVID-19 pandemic and the lack of in-person meetings.

Strengths

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

- “They (health professionals) really listen and allow me to offer perspectives from a patient’s point of view. They also are patient in answering my questions when the discussion gets more technical.”
- “(Health professionals) Address me by my name, seeking my opinions, and giving me feedback!”
- “Asking myself and the other patient partner on the team lots of questions, actively seeking our input in meetings and in written.”
- “In reviewing some very complicated research applications, Dr. ___ was able to put in lay person's terms for the patient partners and that greatly assisted in our being able to provide input that was value-added and informed.”
- “The leader and members are intelligent, thoughtful, committed and caring. They create a comfortable environment for discussion and education, which creates a positive experience at every meeting. I like that there are sometimes sub groups established to look at some issues before reporting back to the larger group. This allows everyone to be involved as much as they want.”

Opportunities for improvement

On ways health professionals could enhance the engagement, Partners reiterated the importance of reaching out to engage them. Partners reiterated the need to promptly update them on the outcomes of the engagement, so that they will know how they have made a difference and how they can continue to contribute to the initiative. Elaborating on their suggestions, some of the Partners' comments were:

- “More initiatives and reach outs from health professionals asking for our help, participation and feedback.”
- “Perhaps more questions to me as a Patient Partner to 'check out' my experience in the system.”
- “There was a need for better communication and periodic updates.”
- “Keep members apprised of project schedule targets so that completion can be expedited.”
- “I'd like to look at the end result: more patients in remission, more personalized treatment offered, longer better quality life for all cancer patients.”

Table 10: Partners midterm 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=90)	4.47	4.34	4.29	4.67	4.60	4.48	4.17	4.20	4.37
Provincial (n=67)	4.49	4.39	4.33	4.67	4.61	4.48	4.22	4.22	4.37
Abbotsford (n=2)	5.00	5.00	4.00	5.00	4.00	4.00	4.00	3.00	4.00
Kelowna (n=4)	4.50	3.75	4.25	4.75	4.50	4.25	4.00	4.00	4.50
Prince George (n=3)	4.00	4.00	4.00	4.00	4.00	4.67	3.33	4.00	4.00
Surrey (n=1)	4.00	4.00	4.00	4.00	4.00	4.00	4.00	4.00	4.00
Vancouver (n=7)	4.43	4.29	4.14	4.86	4.57	4.57	4.29	4.43	4.43
Victoria (n=6)	4.50	4.33	4.33	4.83	5.00	4.67	4.00	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.

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=56)	4.46	4.45	4.43	4.64	4.52	4.45	4.27	4.14	4.25
Provincial (n=45)	4.53	4.51	4.47	4.64	4.53	4.47	4.29	4.13	4.31
Abbotsford (n=2)	4.00	4.00	4.00	4.50	4.50	4.00	4.00	4.00	3.50
Kelowna (n=4)	4.50	4.50	4.50	5.00	5.00	5.00	4.50	4.75	4.50
Prince George (n=0)	--	--	--	--	--	--	--	--	--
Surrey (n=5)	4.00	4.00	4.20	4.40	4.00	4.00	4.00	3.80	3.80
Vancouver (n=0)	--	--	--	--	--	--	--	--	--
Victoria (n=0)	--	--	--	--	--	--	--	--	--

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, 2020 to March 31, 2021), 60 midterm evaluation questionnaires were sent to the health professionals leading the engagements; 41 were completed. At the end of the engagement, 34 evaluation questionnaires were sent to the initiative leads; 29 were completed. The response rates for the midterm and end-of-engagement questionnaires were 68.33% and 85.29%, 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 ranged from 4.39 to 4.46 at midterm, and 4.07 to 4.28 at end of the engagement. 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 4.44 at midterm and 4.28 at end-of-engagement. Partners were active participants in the engagement meetings and have brought distinct perspective regarding their care experience. Commenting on the contribution that Partners have made, health professionals said:

- "We consider Patient Partners collaborative partners in the program. Specifically, their work is on the guidance council and working groups, and their input is sought on all aspects of program

initiatives to ensure that what we build and create incorporates their perspectives in all steps and stages of the program process.”

- “This group is meant to inform the development of cancer system performance metrics/indicators that should be monitored by BC Cancer. Patient partner perspective can offer a very different view from system administrators and program clinical leaders in terms of both what measures should be prioritized and how some measures should be measured (e.g. a provider vs patient perspective on a specific domain). As such patient/family representation on this group is, in my view as Chair, absolutely essential.”
- “All three partners are exceptional - they provide different perspectives, approaches and skill sets. They are involved in regular meetings, providing advice on other engagements and participating in other smaller engagements on an ad hoc basis.”
- “Our partner adds distinct, much appreciated perspective to our working group discussions and we appreciate him making the time and effort to participate.”
- “We are delighted to have had the opportunity to engage and to work with outstanding partners and program administrator. The end product and development process were enriched immensely. Thank you!”

Impact on practice change and decision

The Partners’ input was deemed useful where it could be integrated in practice, with overall mean score of 4.39 at midterm and 4.24 at end-of-engagement. However, the Partners’ capacity to contribute to discussion on system improvements may be more limited. As such, it is important that the initiative leads are clear about seeking the Partners’ perspective concerning their care experience. Where the content of the engagement meetings is most relevant to the Partners, the Partners can make the greatest impact on practice change.

- “Over time the engagement has helped to frame how we understand and respond to patient needs at each phase of the cancer experience. And we finalized a handout that will be used.”
- “The patient education information on the BC Cancer website will be more inclusive for transgender and gender-diverse population.”
- “Significant impact - added a new and essential insight to content and approach.”

- “My editor impacted the wording of my patient handout. She also encouraging me to improve the photos/images within the handout, thereby improving the patient's/readers understanding of the information.”
- “When we talk about how patients experience advance care planning, e.g. handouts and information, the partners can contribute meaningfully. However when we talk about system improvements, like development of a method to track and measure conversations, they can't contribute much. The meetings have to be specifically planned to address both "internal" and "patient-facing" issues so the content is relevant to the partners.”

The health professionals also indicated that the output from the engagement would influence decision (midterm mean 4.46; end-of-engagement mean 4.07). The amount of influence that Partners have on decision-making is determined by the scope of the engagement. Notably, Partners who were engaged from the beginning of the initiative were better positioned to contribute to the outputs and decisions made in the engagement.

- “HUGE impact!!! The templates are 100% better. I cannot say how happy I am with the results. Their work will benefit all the researchers and patients across PHSA who use these templates in the future. And your office was fabulous to work with.”
- “The partners are directly involved in reviewing funding applications - their input has been insightful and has influenced decision making.”
- Partner attends regular committee meetings and more recently has played a lead and pivotal role in developing and facilitating a workshop that is part of the Centre's top strategic priority.”
- “The partners requested a lot of things that were just not in the scope of the committee. They wanted to influence procedures at BC Cancer that are not within the sphere of influence for the committee.”
- “Patient partners have been engaged from the beginning of the Project on every single advisory council and working group (the project) runs. We anticipate Patient Partners will remain engaged until the end of the project in 2022. I see the role as collaborative: we consult and listen, and incorporate ideas, awareness, concerns, and any other input into our decisions, program development, and services.”

On the reporting outcomes of engagement back to the Partners, health professionals have adopted various approaches to update Partners on how they have influenced decision-making. The means of reporting back to Partners included:

- Disseminating agenda and minutes of each meeting.
- Scheduling phone/Zoom check-in with the Partners prior to the meetings.
- Emailing additional information, updates on project progress and outputs to seek additional feedback from the Partners.
- Including Partners on mailing lists to receive regular journals/newsletters.
- Providing summary reports on the project progress at 6 month intervals and a final report at the end of the engagement.
- Sharing project evaluation reports with the Partners.

Training and education support

At the end of the engagement, feedback on health professionals training needs was sought. Health professionals agreed that they would like to participate in patient and family engagement training to build their capacity to better engage Partners (overall mean score 4.08). Areas for further training and education identified were:

- Patient led vs patient participation initiatives
- Facilitating focus groups
- Engaging Partners in committee meetings
- Managing engagements that will meet project goals and partners expectation of meaningful interactions
- Successful ways to increase patient and family involvement and empowerment in health organizations.

Strength and improvement

Overall, health professionals indicated satisfaction with the way they have engaged the Partners (midterm mean 4.12; end-of-engagement mean 4.21). 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 Partners contributed by bringing their experience, as well as their skills, to improve care. Health professionals highlighted trusting relationships with Partners as a contributing factor to a successful engagement, and there is more opportunity to develop these relationships in the longer term engagement.

- “In addition to their experiences as patients, both patient partners bring particular skills to their roles on the Committee and made important contributions to its foundational work.”
- “Each of the patient partners provided very different experiences, and it was very helpful that they were able to give insight to their emotions/thoughts/expectations during certain experiences. It has helped identify how to approach patient interactions, considerations to make.”
- “Having time to build a relationship with the Partners has been very helpful (long term engagement vs. one-off). I believe we have mutual trust and it makes it so much more meaningful to be able to involve them as advisors and 'senior' partners/leaders in this work.”
- “While the project may be progressing more slowly than anticipated the kindness and understanding from the partners have been phenomenal. Their contributions have been invaluable and have truly paved the way for the design of the project.”
- “I feel so blessed to have this Partner on our committee and personally, to have this Partner to be what I consider as a mentor in developing respectful and meaningful approaches to engaging and including patients in our work.”

Opportunities for improvement

To improve the engagement experience, health professionals identified the need to be clear about the purpose of the engagement, the role and expectation of the partners and of the initiative leads, and the amount of influence that Partners have in the engagement. Further, it'll be important that Partners understand the scope of the engagement, before participating in the initiative.

- “The committee itself needs to be more sure of its purpose and activities.”
- “I would say clear expectations around what we can each expect from these kinds of engagements.”

- “I would talk with potential partners a bit more prior to starting the engagement to determine if they understood the work they were being asked to participate in.”
- “As I write this I think I can dedicate a portion of each meeting to patient/family subjects and another portion to system/organisation subjects. Each meeting will have content that is relevant for the partners.”
- “It would be a good idea to review the role of partners in the committee - and link it to the role of the committee as a whole.”

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=41)	4.12	4.44	4.39	4.46
Provincial (n=31)	4.32	4.52	4.52	4.55
Abbotsford (n=0)	--	--	--	--
Kelowna (n=1)	4.00	4.00	5.00	5.00
Prince George (n=3)	3.67	4.33	3.67	4.67
Surrey (n=1)	3.00	3.00	3.00	2.00
Vancouver (n=4)	3.00	4.25	4.25	4.00
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=29)	4.21	4.28	4.24	4.07	4.08
Provincial (n=21)	4.19	4.29	4.24	4.05	4.15
Abbotsford (n=1)	3.00	3.00	4.00	4.00	2.00
Kelowna (n=2)	5.00	5.00	5.00	4.50	4.50
Prince George (n=1)	5.00	5.00	4.00	4.00	3.00
Surrey (n=3)	4.33	4.33	4.33	4.33	4.50
Vancouver (n=1)	3.00	3.00	3.00	3.00	--
Victoria (n=0)	--	--	--	--	--

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

Partners to Partners Engagement Connect Networking Group

Throughout the pandemic, Partners continue to connect with peers through the *Partners to Partners Engagement Connect Networking Group* (P2P Connect) monthly virtual meetings. Under the purview of the Patient Experience Program, P2P Connect was established in December 2019 to provide a platform for Partners to network, share resources and learn from peers on ways to improve their engagement experience. The goal of P2P Connect 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 led by the Provincial Lead for Patient and Family Engagement. Since June 2020, a team of four Patient and Family Partners helped in planning and facilitating the P2P Connect meetings. The Partner-Leaders have participated in various engagement initiatives in BC Cancer and in the community, including national cancer care improvement initiatives.

Learnings from P2P Connect

Each month, a topic on engaging patients and families in cancer care was highlighted at the Zoom meeting. The meetings were 90 minutes in duration, with attendance ranging from 12 to 27 Partners. Partners contributed to the meetings by making recommendations for discussion topics, co-presenting and providing feedback on ways to improve peers engagement experience. The topics explored at the meetings between April 2020 and March 2021 are listed in Table 14.

Table 14: P2P Connect discussion topics

2020	
April	Partner's story: i) Mental health in men living with a cancer diagnosis ii) Outreach to Indigenous cancer patients and families
May	Partner's story: Meaningful engagement during COVID-19 pandemic
June	Partner's story: Voices of LGBTQ patients in health care
July	Partner's story: Peer support and mentoring in engagement
August	Highlights of BC Cancer Network of Patient and Family Partners 2019/2020 engagement evaluation results
September	Partner's story: Selecting engagement opportunities to participate
October	Impact of engagement: The case of BC Cancer Smoking Cessation Program
November	Navigating through a process-oriented initiative: The case of Regional Patient Experience Councils
December	Addressing challenges in engagement: The case of the Early Palliative Integration into Cancer Care (EPICC) project
2021	
January	Vision of patient and family engagement at BC Cancer
February	Partner's story: Engagement beyond BC Cancer
March	Meaningful engagement with patients living with advanced cancer

From the monthly conversations, the strengths, needs and opportunities for improvement in engaging patients and families at BC Cancer were identified. Partners highlighted the collaborative relationship between health professionals and Partners, and feeling included when health professional were intentional in seeking their input and were open to their feedback. Partners appreciated the opportunity to “give back”, share their stories on finding engagements that they were passionate about and delivering important messages to the community beyond BC Cancer. They also valued the learnings about health care delivery and system, and having the voice of the family caregivers in the design and delivery of care.

Partners concurred that it is important for them to connect with one another, in-person or virtually, for sharing information and rendering support. Partners reiterated the need for consistent communication with leaders of the engagement and for patience, particularly when the engagements are process-

oriented and when the engagement activities are on pause due to leadership and priority changes. Further, when Partners were able to see the tangible results of the engagement, they would be assured that they had contributed.

To improve on their engagement experience, the following learning opportunities were identified:

- Include diverse representation of the patient and family voice in research and engagement
- Reach out to Partners, prepare and engage them earlier on in the initiatives
- Clarify goals, roles and amount of influence Partners will have in the engagement
- Explain terminology used in the engagement meetings
- Communicating to Partners on the changes in the engagement plan (leadership, timeline)
- Report back to Partners on engagement outcomes
- (Partners) Be proactive by giving feedback to BC Cancer leaders in the engagement to improve communications in the partnership, and seeking clarification and updates from the leaders on the engagement outcomes
- (Initiative Leads) Give feedback to Partners and share responsibilities among project team members to engage the Partners in conversations that are relevant to the care recipients' experience.

Conclusions

Over the past year, the Network of Patient and Family Partners continued to enrol new members from across B.C. With the onset of the COVID-19 pandemic, engagement activities were reduced as priorities shifted to address emerging health care needs of patients and families. The Patient Experience Program's work in evaluating patient and family engagement at BC Cancer remains a priority, ensuring that Partners and health professionals are supported throughout their partnership.

An area of improvement noted in the 2020/2021 evaluation reporting is the higher response rate from health professionals, compared to the past 2 years of evaluation. The readiness to respond may be attributed to the email reminders, an approach introduced to strengthen response rate among Initiative Leads. At the same time, it reflected the commitment of the health professionals to engaging Partners, of which evaluation is a key component of engagement.

While attempts were 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 engaged patients and family caregivers that were not members of the Partners Network or when the engagements were not reported to the Patient Experience Program would not be included in this report. As participation in the evaluation is voluntary, Partners and Initiative Leads will continue to be encouraged to complete the questionnaires, in order to have more informative reporting of their engagement experience.

Despite the slower uptake of engagement activities in the reporting period, members of the Network of Patient and Family Partners at BC Cancer continues to be engaged through different means of communication. Partners also had further 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 will be pivotal to BC Cancer's continuous efforts to engage patients and families in their 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.

Engagements/Engagement initiatives/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 initiative.

P2P Connect: Partners to Partners Engagement 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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B.C. Ministry of Health (2018). Patient, Family, Caregiver and Public Engagement Framework. Retrieved from <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>

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:

- [!\[\]\(97faa0168e491544be255cfcab218e9b_img.jpg\) Best Practices for Successful Engagement](#)
- [!\[\]\(b2166b76608b8499cffc130bf1b1fe60_img.jpg\) Diversity in Patient Engagement](#)
- [!\[\]\(b29da0f81af7d31816596405aed0e378_img.jpg\) Engagement Methods](#)
- [!\[\]\(52b4a21f1e75ded8f9710f4114e70d28_img.jpg\) FAQ on Engagement](#)
- [!\[\]\(07221912d1bf206beb97cefd77af5f78_img.jpg\) How to Request Patient and Family Partners](#)
- [!\[\]\(c91d9fd9eb37f21f63405f290fd824c2_img.jpg\) Matching Partners](#)
- [!\[\]\(14a82b1cdd6b1489ba04a4334bdc8552_img.jpg\) Planning Engagement](#)
- [!\[\]\(d7e57fae97bcb08f452f04012143cb4c_img.jpg\) Presenting With Patient Partners](#)
- [!\[\]\(4b6a3d6d2e338eb31753f2fba4f530b7_img.jpg\) Reimbursing Partners](#)

D. Spectrum of engagement

INCREASING LEVEL OF INFLUENCE IN THE DECISION 

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Definition	To give information	To get feedback	To understand	To work together	To give power to
Example Techniques	Fact sheet Web site	Survey Focus group	Conversation Dialogue	Committee Working group	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.

E. Engagement techniques

Engagement techniques	Number of engagements	Explanation
Committee	24	Partner and health professional representatives meet in-person or by teleconference to provide input to planning process.
Consultation group	11	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	1	A group of Partners meet (in-person or phone) to participate in a planned discussion facilitated by a health professional.
Photo shoot	1	Partners participate in a session of photo taking and/or filming with health professionals for purpose of BC Cancer service promotion.
Review (website, material)	8	Partners review BC Cancer resources prior to publication/posting by attending in-person/phone meeting or by email.
Working group	15	An appointed group of Partners and health professionals working together on identified topics to achieve specific goals.

F. Partners midterm engagement questionnaire

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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G. Partners end-of-engagement questionnaire

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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H. Health professionals midterm engagement questionnaire

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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I. 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. 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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