



Provincial Health Services Authority

Patient & Family Experience Program

Patient and Family Engagement

Highlights 2021-2022

What is engagement? And why do we do it?

“Nothing about us without us”¹ A concept borrowed from disability empowerment. It means that no policy or practice should be put in place without the full involvement of all stakeholders. For BC Cancer, our stakeholders include people with cancer and their families and caregivers.

BC Cancer strives to build care tailored to the needs of our patients and families. We want to support partnerships between patients, families and health professionals. Our goal is to help patients make informed decisions about their care.

Many patients face barriers to cancer care: language, culture, finances, geography and many others. Systemic racism within the healthcare system, as well as distrust of the medical system, prevent many from accessing healthcare.

Although the healthcare system has a lot of work to do to remove these barriers, it cannot do so without engaging patients and families. We need to ask patients:

- what they need
- for their ideas and solutions
- to share their experiences so we can learn from them.

We cannot develop solutions to problems if we do not involve the people who are affected by those problems and solutions.

There are many ways to engage with patients and families. Sometimes, we want their input on a decision. Other times, we ask them to join a working group. We may even co-design a solution with them or give them the power to solve a problem.

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.

————— 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

The way we engage with patients and families is different for each project. The amount of power our patient and family partners have will also vary. It is critical that patients and families know their level of influence. This helps to set expectations and allows the partners to contribute to the project.

Overall, the most important thing is that we engage. We seek to understand patient needs so we can better serve them. This is critical to providing person-centred care.

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*

BC Cancer Network of Patient and Family Partners

Network of Patient and Family Partners

In 2017, we established the Network of Patient and Family Partners, under the governance of the Patient & Family Experience Program. We recognized the need to improve our understanding of how people navigate health services. We also needed to know the barriers to care experienced by our patients and families.

The Network is part of our strategic approach to give patients and families a voice in the design and delivery of health care. For the last 5 years, our patient and family partners have worked to improve cancer care for all people in B.C.

The information in this report is for the fiscal year April 1, 2021 – March 31, 2022.

Partners' profile

As at March 31, 2022, we have 132 patient and family partners in the Network. We enrolled 33 partners this year.

Almost 75% of the partners participated in at least one engagement initiative.

Geographic unit	Number	%
Large urban population centre (100,000 or greater)	74	56.06
Medium population centre (30,000 to 99,999)	43	32.58
Small population centre (1,000 to 29,999)	15	11.36

Most partners have received care in a BC Cancer regional centre. The remaining received care at their local hospital or community clinic. Over a third of the partners resided in the Vancouver Coastal Health region; about 27% were from the Fraser Health region. 18% of the partners lived in the Island Health region; 14% were from the Interior Health region. Close to 4% were from the Northern Health region.

Health authority	Number	%
Vancouver Coastal Health	49	37.12
Fraser Health	35	26.52
Island Health	24	18.18
Interior Health	19	14.39
Northern Health	5	3.79

Other demographic information on the partners is summarized in the following tables.

Education	Number	%
High school or less	3	2.27
Some post-secondary education	11	8.33
College or technical training	18	13.64
University	27	20.45
Advanced degree	34	25.76
Prefer not to answer	39	29.55

Age	Number	%
31-40	8	6.06
41-50	13	9.85
51-60	18	13.64
61-70	26	19.70
71-80	27	20.45
Prefer not to answer	40	30.30

Gender	Number	%
Female	66	50.00
Male	27	20.45
Prefer not to answer	39	29.55

The tumour types as stated by the patient and family partners are in the table below. Breast cancer was most commonly cited (32%), followed by cancers of the digestive system (20%) and pelvic (17%).

Tumour types (cited, include multiple sites)	Number	%
Blood & Lymphoid Cancer	17	9.14
Bone and soft tissue	6	3.23
Brain and central nervous system	4	2.15
Breast	60	32.26
Childhood	2	1.08
Digestive system	38	20.43
Head and neck	11	5.91
Lung	9	4.84
Pelvic	32	17.20
Skin	4	2.15
Urinary	3	1.61
Total	186	100.00

Engagement at BC Cancer

Engagement activity

This year, there were 39 new engagement initiatives. 33 were from BC Cancer and 6 were from the community.

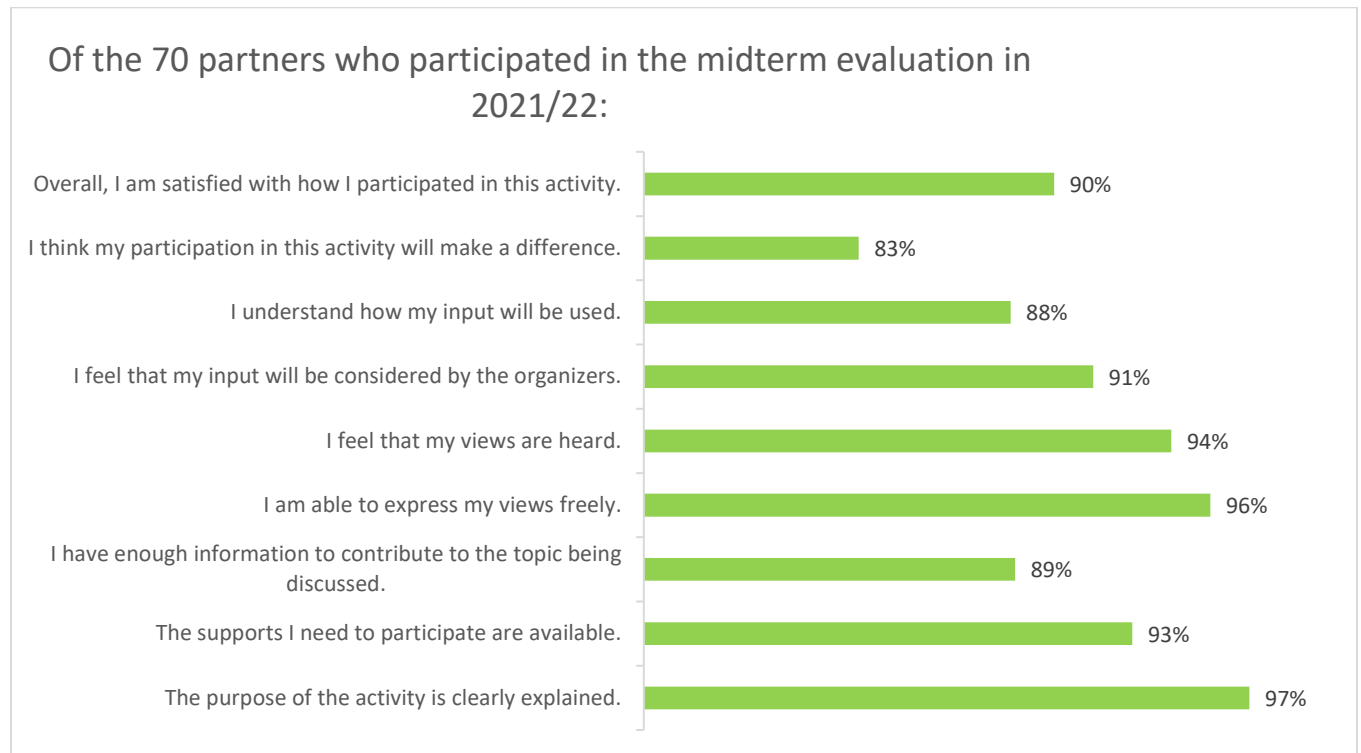
Twenty-nine initiatives carried forward from 2020/21. Of which, 17 remained active at the end of this year. Total initiatives for this year was 68.

This year, projects engaged partners on three levels: consult, involve and collaborate.

Types of engagement	Number	%
Consult	29	43
Involve	13	19
Collaborate	26	38
Total	68	100

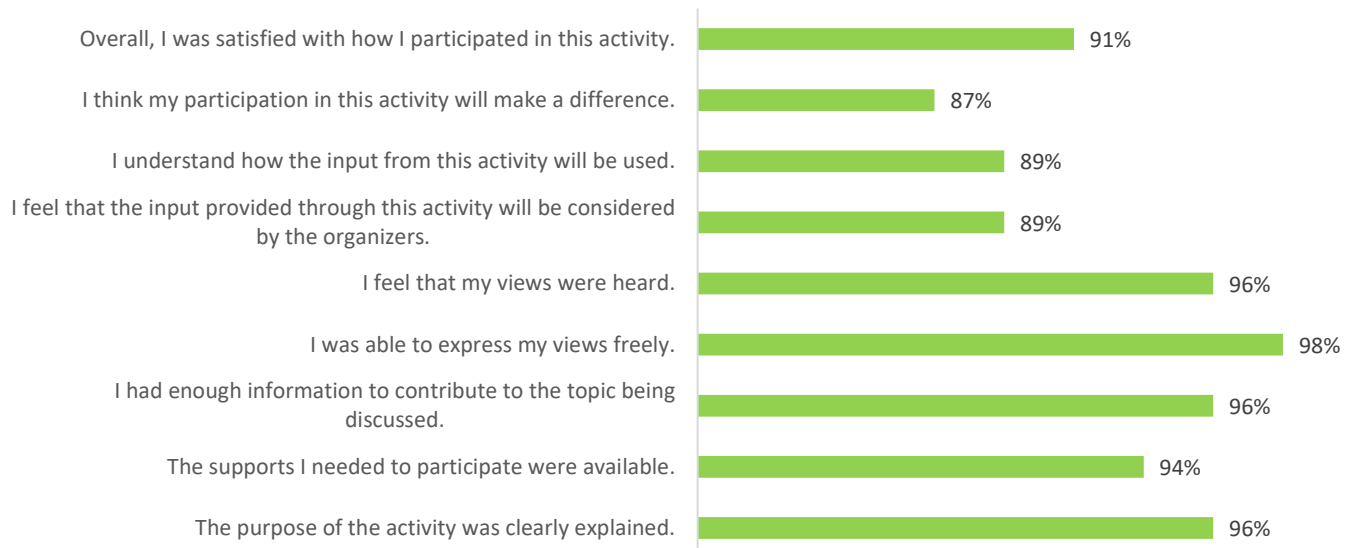
Evaluation results

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. We evaluate engagements at two time points: midterm (6 months after engagement start date) and end-of-engagement. Both w partners and initiative leads complete the evaluations.



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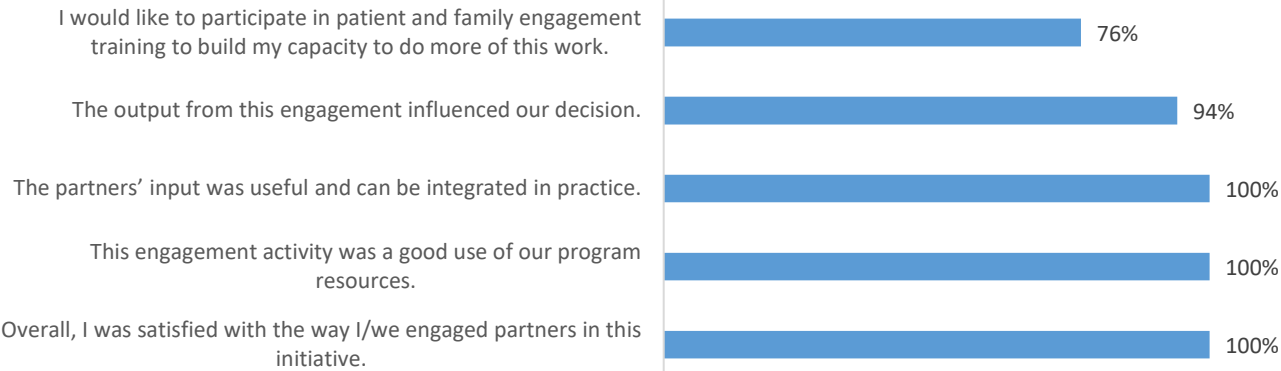
Of the 47 partners who participated in the end-of-engagement evaluation in 2021/22:



Of the 30 initiative leads who participated in the midterm engagement evaluation in 2021/22:



Of the 17 initiative leads who participated in the end-of-engagement evaluation in 2021/22:



Engagement Success Stories

Partners help develop BC Cancer's Personalized OncoGenomics (POG) video

BC Cancer's Personalized OncoGenomics (POG) program is a patient-centred cancer research initiative studying the impact of embedding genomic sequencing into clinical care of advanced cancers. The overarching goal of POG is to use the genomic information to direct patients toward targeted therapy clinical trials.

To help people understand POG, the program wanted to develop a short animated video. To do this, they consulted with patient and family partners.

The POG team engaged eight patient and family partners at the “consult” level of engagement. They asked partners for feedback on the video script and the video. They listened to and acknowledged the partners’ feedback and concerns. Partners gave feedback through surveys, email and by phone.

There were multiple rounds of review and revision. Throughout, the initiative leads kept in contact with the partners. They explained how they used their feedback and when they could not make certain changes, they explained why.

The engagement result was a 5-minute video that “communicates the science in plain vocabulary with engaging graphics in six languages”. The video makes cancer genomics easier to understand and shows the benefits of using genomic data for precision cancer treatment. This video will improve cancer care for patients.



The video debuted on February 17, 2022, at the POG Program seminar [Creative Knowledge Translation to Support BC Cancer’s POG Program: An Animation](#). Read more and watch the video on the [Genome Sciences Centre](#) website.

“I found all steps of this engagement were clearly explained and I had a clear understanding of my role. Thank you for allowing me to participate!” – Patient/Family Partner

“Really was outstanding-no issues at all. Feedback well received and great communications from the initiative lead. Think the video will help many understand this (POG) and so glad I was involved with it.” – Patient/Family Partner

The POG initiative leads were also satisfied with the way they have engaged partners in the project. They agreed that it was a good use of their program resources and that the partners' input was useful and can be integrated in practice.

“Engagement from the patient partners was highly impactful Without the feedback and suggestions from the engaged patient partners, our final video script would not have come to fruition in the way that it did, nor to the quality it did. The program (engagement) was run seamlessly from initiation/request for engagement to closure of the engagement. I am so very grateful for a program like this within the BC Cancer networks. It truly is a valuable initiative, and one that our project team intends on tapping into in the immediate future and for years to come.” – Initiative lead

“The engagement had a significant influence in the development of the script, the storyboard, including images and text, as well as final edits made to rough cut of the animation, including adding and removing information or images to make concepts more clearly understood, as well as to enhance the sense of diversity and inclusivity of all potential demographics. I feel that this engagement was very successful and would seek to replicate it in the future.” – Initiative lead

Dr. Janessa Laskin, co-lead of POG Program, added ““Education and community engagement is a fundamental component of POG and we look forward to sharing this new resource.”

Digital agent learns from patient and family partners

Over the course of the pandemic, there was a surge in call volume from patients and families receiving care at BC Cancer. BC Cancer deployed the digital agent (chatbot) for the website to meet this critical need. The chatbot pulls information from web pages and uses machine learning to create appropriate responses.

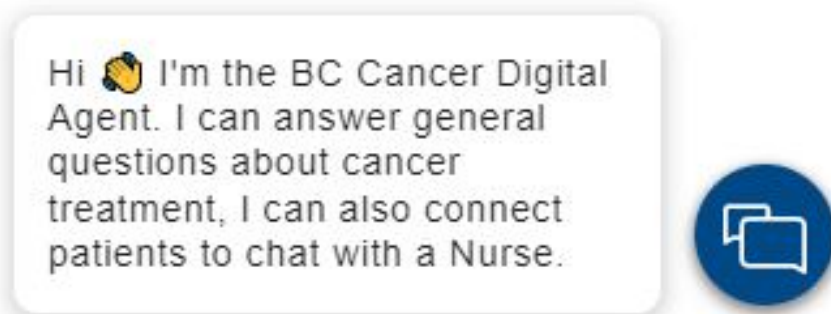
In November 2021, a team from BC Cancer Clinical Informatics & Digital Health led a project to explore the opportunity of expanding the chatbot functions. They wanted the chatbot to answer simple questions and then transfer complicated questions to a live agent. .

Two patient and family partners joined the project group at the “collaborate” level of engagement. Over eight months, the partners met with the team bi-weekly over Zoom. They shared their experiences to help the team design the new function. Partners tested the live agent feature and gave feedback on the projects’ communicate strategy.

Initiative leads kept in touch with the partners through the meetings as well as through email. The leads made sure to communicate exactly how the partners’ involvement shaped the project.

BC Cancer launched the [live agent pilot project](#) in March 2022. To start, BC Cancer – Victoria is the only centre with this functionality. If this pilot project is successful, BC Cancer will roll it out to patients across the province.

There was also a [story](#) on the engagement posted on BC Cancer website, to acknowledge the partners’ contribution and to demonstrate the impact of their participation.



Both partners and the initiative lead agreed that they were satisfied with this engagement. Partners felt heard and think their participation will make a difference.

“There are times when someone doesn’t want to talk to a live person. The digital agent is assisted learning but it makes you feel like you are actually talking to someone. It can also easily direct patients to a nurse if needed.” – Patient/Family Partner

“During my personal cancer journey, looking for resources helped me a lot during a time of uncertainty. I wanted to be part of an initiative to help other patients in any way that I can.” – Patient/Family Partner

“We are very fortunate for the opportunity to collaborate and co-design on this solution with our patient partners and nurses across the province. This is a great example of how BC Cancer is leveraging digital technology to enhance patient experience.” – Initiative lead.

Revising BC Cancer advance care planning webpages

Advance care planning involves thinking about and writing down your wishes and instructions for your health. It includes choosing the people you want to make decisions for you, if you cannot speak for yourself.

Advance care planning may sound simple. However, it can be confusing and complex. When dealing with a serious illness, the process can be burdensome.

It is important for people with cancer to make an advance care plan. There are many resources available to make a plan and it is hard to know where to start.

BC Cancer's ACP webpages recommended many websites and resources from different organizations. The webpage was vague and lacked clear guidance for users.

Devon Poznanski, provincial lead, patient education, worked with Drs. Pippa Hawley, Michael McKenzie, and Stacy Miller to determine which ACP resources best served our patients. They chose the resources from the B.C. Center for Palliative Care (BCCPC).

As a first step, Devon drafted a new version of the ACP webpages, based on the BCCPC resources. Next, The group reached out to patient and family partners who are members of the Early Symptom Indicators for Cancer Care Screening group (EPICC). Five partners joined the project.

Partners reviewed the new version of the ACP webpages. They gave feedback through email. There were many reviews and revisions. Devon acknowledged the partners feedback, incorporated most changes and explained why they could not make some suggested changes.

The partners were instrumental in shaping the content of the ACP webpages. The partners:

- Recommended resources to include from BCCPC, as well as resources from other organizations.
- Suggested including examples of advance care plans to help those new to the process.
- Gave a framework for how to structure the web content.
- Revised language to ensure it was person-centred and accessible.
- Ensured there were clear definitions for all terms.

The final webpages give clear recommendations on how to write an advance care plan. Without collaborating with the partners, the webpages would have been complicated and less person-centred. The team hopes the new webpages will help all people with cancer more easily plan for their future health.

<http://www.bccancer.bc.ca/health-info/coping-with-cancer/advance-care-planning>

References

1. Charlton, James, *Nothing About Us Without Us: Disability Oppression and Empowerment* (Oakland, CA, 1998; online edn, California Scholarship Online, 24 May 2012), <https://doi.org/10.1525/california/9780520207950.001.0001>, accessed 28 July 2022.