

2022/23 Patient & Family Experience Annual Report



Working Together

"Nothing About Us Without Us"

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Executive Summary

At BC Cancer, we value the experience of cancer care for our patients and their families. The Patient and Family Experience (PFE) Program is reporting on work completed from April 1, 2022 until March 31, 2023.

Engagement in Action

The PFE Program strives to create a culture in BC Cancer where patients and their families are meaningfully engaged in designing cancer care. This year, we had 136 patient and family partners registered with our program and 64 different engagements were carried out including projects and ongoing committees. Partners were engaged in partnership 3 times, 44 engagements requested input from partners, and in 17 engagements a solution was co-designed.

Educating our Patients

In order for information to be useful for patients, it must be given at the right time, in the right way, and use language the patient and their family can understand. The PFE team applied health literacy principles to create clear, easy to read patient information. This improved the care experience for both the patient and care team.

Evaluating the Experience of Cancer Care

It is important to listen to patients and their families to understand their care experience care. In 2022/23, BC Cancer evaluated the cancer care experience during a change to the model of care. We are designing an evaluation to see how the experience of care changes as we prepare for a new electronic medical record.

Looking Ahead

In November 2022, the PFE Program hosted a forum for our patient and family partner network to co-design an action plan to guide our work in 2023/2024. Our partners want BC Cancer to continue working towards more meaningful, intentional, and person-centred engagement. Our Program has set priorities to continue supporting BC Cancer to hear and integrate the voices of our patients and their families. We are working on strategies to reach more British Columbians with different perspectives and experiences.

We are deeply grateful for the amazing patient and family partners that give their time and share their stories with us. We are excited for the year ahead!

- The Provincial Patient & Family Experience Team



“We ended up with a product that is real, honest and works.”

-D, Family Partner

Network of Patient & Family Partners

Working with Partners



136
Partners



94
Partners Actively Engaged



64
Total Engagements

Level of Engagements (IAP2)



24
Consult

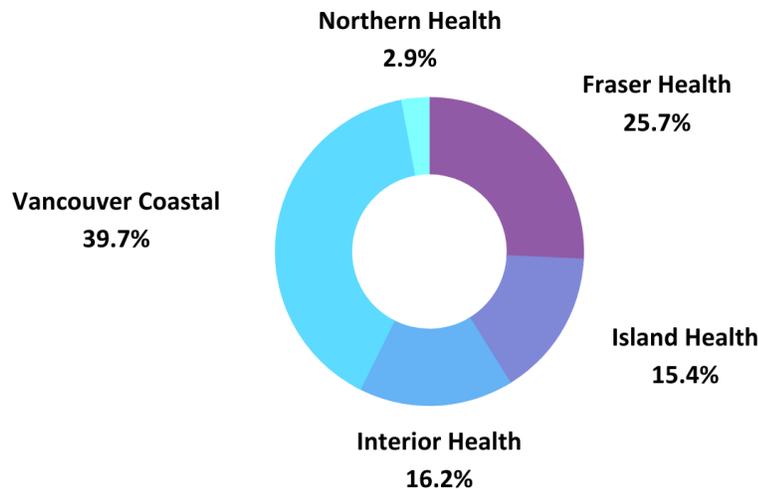


27
Involve



13
Collaborate

Partner Health Region Distribution



Engagement in Action Across BC Cancer

At BC Cancer, we strive to build our services around patients and families. By working with our passionate group of partners on projects and committees, we ensure lived experience and perspectives are woven into our care.

Patient and family partners are matched to various activities or engagements across BC Cancer. These engagements range in the level of partner involvement.¹

Level of Partner Involvement

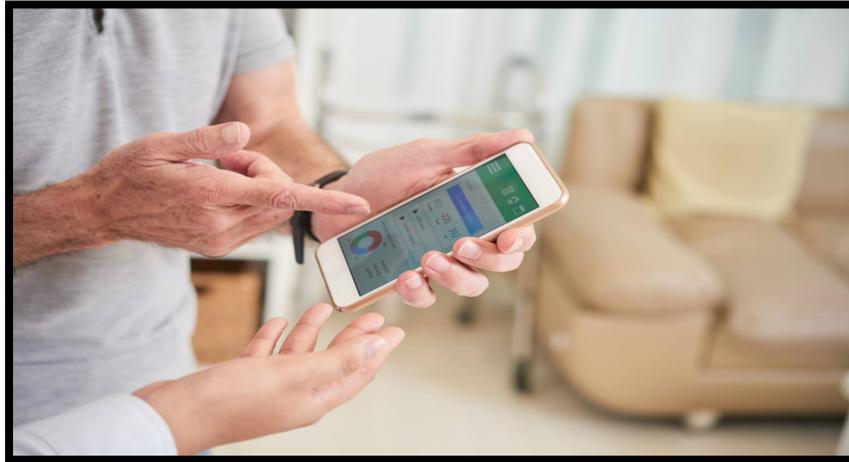
1. **Inform:** Provide partners with information
2. **Consult:** Partners provide feedback as needed
3. **Involve:** Partners are involved throughout the engagement to provide feedback
4. **Collaborate:** Partners collaborate with the project team in decision-making
5. **Empower:** Partners have final decision-making

The following provides a snapshot of engagements held in 2022-23.

Understanding the Needs of Our Patients for a Patient Portal

BC Cancer is committed to empowering patients with the information they need to feel prepared to make decisions and participate fully in their care. In order to understand what elements of a patient portal are most important to people living in different communities, with a variety of education levels, the patient and family experience team conducted one-to-one patient interviews with two patients. Both patients provided input about what marginalized populations would want from a patient portal. They recommended questions that asked about unique aspects of patient care. For example, one pointed out that income is less important than if a family is able to live off the money they make at their jobs.

¹ International Association of Public Participation (IAP2): IAP2 spectrum
[https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20\(1\).pdf](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf)



Survey questions were co-designed with the Provincial Lead of Patient Experience, an expert in health literacy, to gather preferences from patients across BC. The survey was piloted with the patient and family partner network. Hence, input and feedback informed the final survey. The survey was distributed to patients and their families at the 6 regional care centres and patients living in rural BC communities. Across BC, 241 patients provided their input about the most important features of a patient portal. This input was reported to the Provincial Digital Health and Information Services team within the Provincial Health Services Authority, ensuring that the voices of people who receive care at BC Cancer are captured in the planning of this service.

Nobody has ever asked me what I want. It feels good to know that my opinion matters. Thank you BC Cancer.”

– K, Patient and Family Partner

“We were able to hear from patients exactly what they want in terms of access to their own health information, and even how they wanted to be approached and asked questions. There is no replacement for the patient voice in work that connects patients to their care team and health information! We strive to create equity in digital and virtual health, highlighting further opportunities for us to partner with patient and family experience to explore together and achieve this.”

– Megan Courtney, Director, Clinical Informatics

Creation of Guide for People with Gynecologic Cancers

In response to patient requests for more comprehensive information on the gynecologic cancer journey, BC Cancer partnered with the Gynecologic Cancer Initiative (GCI) and a group of 19 patient partners to co-create a new resource: [Gynecologic Cancers: Your Journey](#). Patient partners shared their unique and personal perspectives about being diagnosed, receiving treatment, and living with gynecologic cancer, as well as what resources are available to help patients and their families.

To create the guide, gynecologic oncology specialists, palliative medicine specialists, supportive care staff, plain language specialists, library services, and others advised on best practices, language, and patient inclusivity. The result is a patient-centred resource that provides a tailored guide for people with gynecologic cancer, made by people with gynecologic cancer.

“Having a roadmap that has been traveled by others on their cancer journey helps. It shows you that although one’s personal journey is unique, there are people to help guide you and hopefully soften some of the hard bumps and life changes.”

- D, Patient and Family Partner

“Patients have such huge contributions. They all have different, individual stories but also many commonalities. Their stories were meaningful and I am so grateful that they were willing and able to share their personal experiences with the team.”

- Shaifa Nanji, Manager, Tumor Groups, Pathology & Medical Imaging

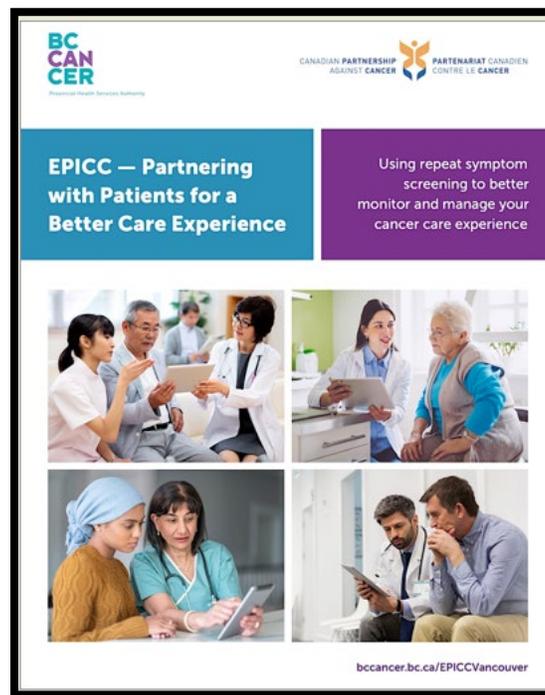
Early Symptom Indicators for Cancer Care Screening Program

The Early Symptom Indicators for Cancer Care Screening Program ([EPICC](#)) was a 5 year, \$1.2 million dollar Canadian Partnership Against Cancer sponsored quality improvement project. It developed a process to integrate repeat screening for physical symptoms and psychosocial issues throughout a patient’s cancer care journey. Each person experiences different symptoms and side effects during cancer care. Regular symptom screening improves care and gives patients a better quality of life by showing symptom patterns over time. The screening alerts the care team to symptoms and issues that are starting or getting worse. This gives the care team the information they need to help manage a patient’s mental, emotional, and spiritual distress.

“Thanks to [Pharmacist], I really feel heard for the first time. She listened when I explained my priorities, and made sure I understood that [they] would be at the forefront of [my care]”

-C, Patient and Family Partner

The EPICC project engaged 6 patient and family partners over 5 years. The partners were included in the Provincial Advisory Council, the Model of Care Working Group, the Education Working Group and the Evaluation Working Group. Their input helped develop and refine the screening questions, experience questionnaires, and patient education materials.



The EPICC project created a process to screen patients for symptoms before their appointment with their medical team. Training was developed to prepare the care team to discuss advance care planning and goals of care. The result is a care team that is prepared to help the patient when they arrive and that are responsive to the patient’s changing needs, which means a better overall experience of cancer care.

“Getting to know people impacted by my work, who are really cool, interesting, engaged and engaging, and who renew and refresh my passion to do what I do. “

– Antony Porcino, Project Manager, EPICC

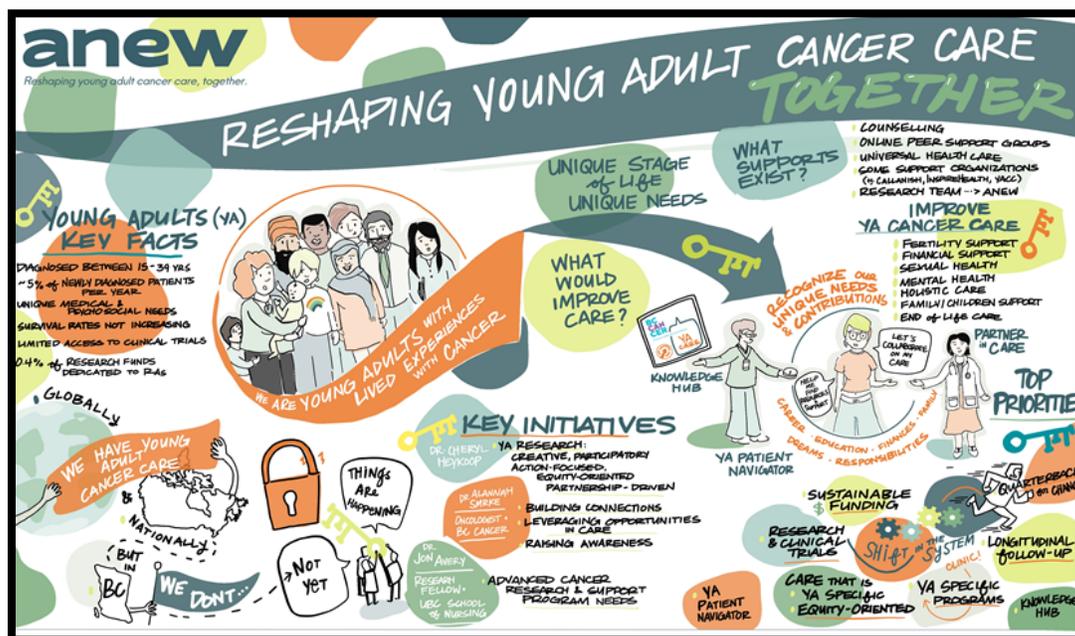
Reshaping Young Adult Cancer Care

During the 2022 BC Cancer Summit in November, BC Cancer collaborated with Cheryl Heykoop, Associate Professor, Royal Roads University, and the Anew Research Collaborative at Royal Roads University to host an engagement session entitled “Reshaping Young Adult Cancer Care.” A near equal mix of more than 70 care providers and young adults with lived experience with cancer took part in the interactive hybrid session (offered in-person and online).

“I want to provide care that better acknowledges the unique experiences of young adults. We can do better for young adults.”

-Healthcare Provider

A [graphic recorder](#) captured key themes, actions, and recommendations. Recommendations included patient navigators skilled in guiding young adults through a cancer experience, comprehensive online access to resources and supports for young adults experiencing cancer, and program development, training, and research specific to the needs of young adults. Moving forward, our collaboration with Anew and young adults will continue to shape young adult programming at BC Cancer.

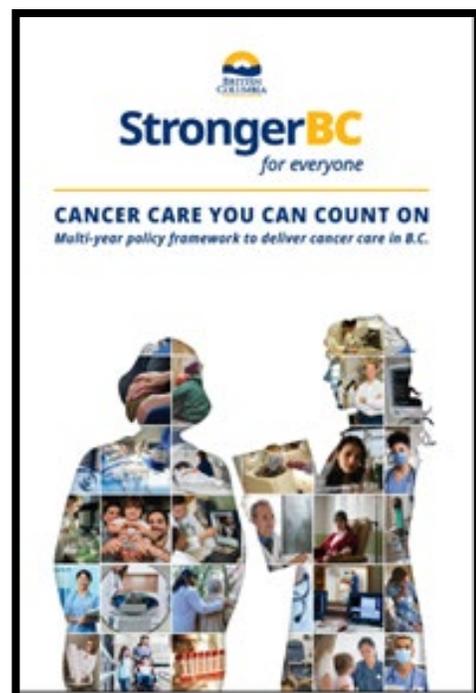


BC 10-Year Cancer Action Plan

The [BC 10-Year Cancer Action Plan](#) was announced on February 24, 2023. It reflects the BC government's commitment to immediate steps to better prevent, detect, and treat cancers, delivering improved care for people now while preparing for the growing needs of the future through an initial investment of \$440 million. As part of the announcement, Penelope (Penny) Hedges, a patient and family partner, joined BC Cancer leadership, Minister of Health Adrian Dix, BC Premier David Eby and other BC Cancer staff to share her thoughts. Penny spoke to why she chooses to spend her time contributing to bettering the cancer system.

“As a cancer survivor and a patient and family partner, I’ve seen first-hand the kindness, compassion, and commitment to putting patients first that’s shared by all of BC Cancer’s dedicated health professionals. With these new investments and BC Cancer’s commitment to keeping patient voices at the forefront, there’s no limit to what we can do to change the lives of British Columbians with cancer.”

-Penny



Regional Patient Experience Committees

Regional Patient Experience Committees, also known as RPECs, help integrate the patient and family voice in care planning and decision-making at BC Cancer regional centres. The RPECs advance best practices for patient experience, engagement, and education. BC Cancer – Kelowna and BC Cancer – Victoria each have a long-standing and successful RPEC. These RPECs have committed chairs, staff members, and patient and family partners working together to advance their goal of person-centred care.

“I want my voice and story to be heard to help make young adult cancer care better.”

-Young Adult

BC Cancer – Kelowna RPEC

The Kelowna RPEC is led by Michael Darud, Director, Operations in partnership with six patient and family partners. The group worked on a number of projects this past year including:

- **Entryway welcome wall:** Currently looking for artists to present artwork options. Patients, families and staff will vote for their favourite. The art will be a positive welcome message as people enter the centre.
- **Staff recognition stars:** Patients and families can fill out paper stars with appreciation for staff. Stars are put on posters in the lobby and on digital display in the staff room. The RPEC wants to add these recognition stars to all waiting rooms.
- **iGuide:** The RPEC is building a set of 360 degree images of areas in the centre. These images will go on the centres webpage and allow visitors to look at areas in the centre before they come into the building.



BC Cancer – Victoria RPEC

The Victoria RPEC is led by Heather Nash, Cancer Care Coordinator and Lawren Fischer, Dietitian, in partnership with four patient and family partners. The group completed a number of projects this past year including:

- **Framing origami cranes**
 - Staff, volunteers, patients and family members made 1000 origami cranes as part of a provincial project in 2019-2020.
 - This year, the RPEC had the cranes framed and they will be displayed in the centre.
- **Improved provision of information for patients**
 - Reinstated Life After Cancer Treatment package on last day of treatment.
 - During new patient calls, nurses now sign up patients to get the Supportive Care eBulletin.
 - Nurses tell patients about the library and Patient & Family Counselling services during the new patient call
- **New monitors to display digital signage in more patient waiting areas**



Patient Education Highlights

The patient education portfolio strives to follow health literacy best practices in all the work we do.

What is Health Literacy?

Health literacy is the ability to find, understand, and use information and services to inform health-related decisions and actions. More than half of Canadian adults, and over 80% of Canadian seniors, lack the necessary health literacy skills to navigate the health care system.

Low Health Literacy Leads to:

- Medication errors
- More hospital admissions
- More visits to the emergency room
- Poor adherence to treatment plans

Many factors affect health literacy including education level, socioeconomic status, and language barriers. Stress and lack of sleep also affect health literacy. Therefore, health literacy is a state, not a trait. It can change over time and day-to-day.

The following provides a snapshot of health literacy-focused projects in 2022/23

Revision of Emotional, Practical and Family Support Handouts

Over time, services change to meet the needs of patients. We need to review and update handouts regularly so they have the correct information. In 2022, we updated the [emotional](#), [practical](#), and [family](#) support handouts to meet clinical best practices and plain language guidelines.

Seventeen partners from our patient and family partner network were involved in this project. They added important information and suggested language changes to make the content easier to understand. These revised documents will better meet the needs of people with cancer and their families.

Updating Patient Education Procedure

The BC Cancer procedure for developing patient education material was designed to give staff enough information so that they could successfully develop materials on their own. Our clinical staff face increasing patient volume and demands. They are experts in cancer care, not plain language and health literacy. We revised the procedure to strengthen the language about contacting the provincial lead before starting a patient education project. In the past, staff were involving the provincial lead closer to the end of their project. The result of this was:

- No patient and family needs assessment was done at the start of the project
- The resource was written at a very high level and would require significant revisions
- Patients and families were not involved in the project or involved too late
- Extra time was needed for the project



The updated version of the procedure should be easier to follow, lead staff to involve the provincial lead much sooner, and result in patient resources that are easier to read and understand.

2022 Practice-Based Research Challenge

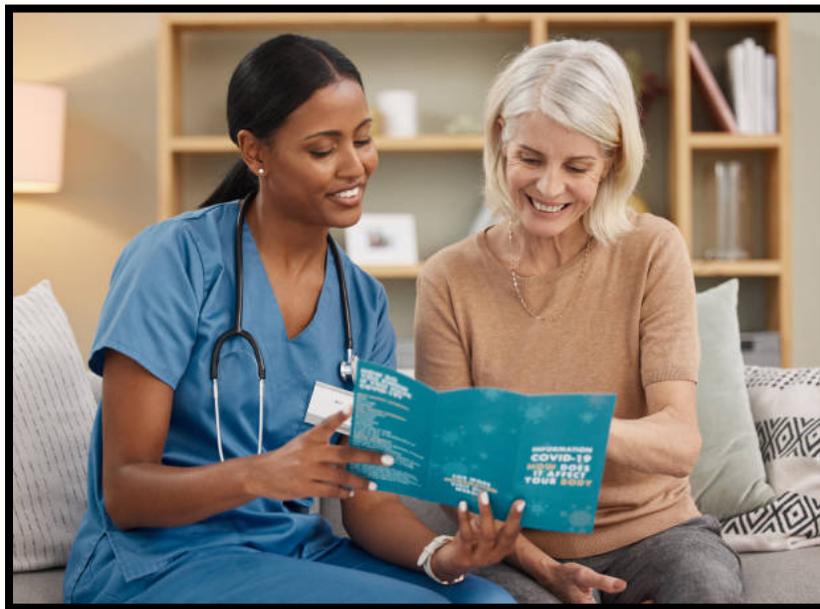
In 2021, we created four [radiation therapy patient education videos](#) with the Radiation Therapy Department. Our goal is to incorporate the videos into every day practice so that each person having radiation therapy watches the videos. This way, they know what to expect during their radiation planning and treatment.

In 2022, we successfully applied for the Practice-based Research challenge. Now, we have the funds to evaluate if the videos help patients prepare for radiation therapy. This project helps us move toward our goal of doing research and contributing to global knowledge about patient education.

Outreach to Adult Literacy Groups

When we develop patient resources, we often recruit partners from our patient and family partner network. Although the network improves the resources we produce, we recognize that many partners are very educated and literate.

The patient and family experience team has created a relationship with groups that support adults to learn reading and literacy skills. The goal of these relationships is to learn how to create educational resources that people with lower literacy can understand. We plan to work with these groups to develop more inclusive education materials that all people with cancer can use and understand.



Health Literacy & Cancer Module

BC Cancer Patient Experience Program collaborated with Princess Margaret Cancer Centre to create a course for BC Cancer staff. The Health Literacy & Cancer module is a short, 45-minute course divided into three separate activities. The course can be done all at once or in parts.

The Health Literacy & Cancer module will:

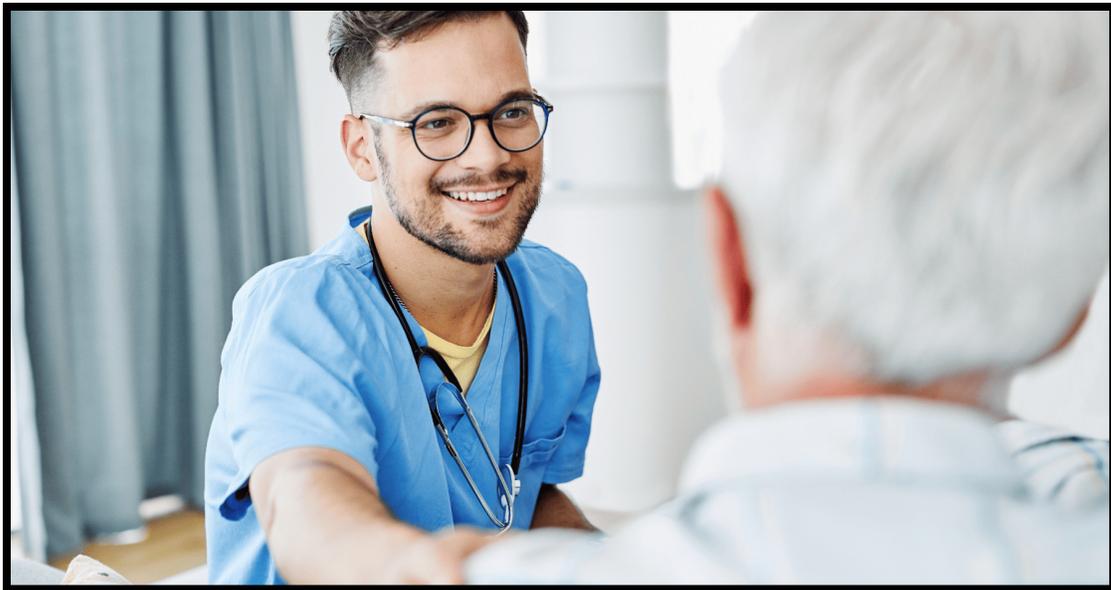
- Increase your understanding of low health literacy and its effects on patients
- Help you understand adult learning principles and how they impact communication
- Learn active listening techniques, teach-back, and how to check-in with your patients to ensure understanding

The course is hosted on [PM Cancer Campus](#) and is available to all BC Cancer staff. To take the course, users must create a login and enroll in the course. The enrollment key is **BCCancer**.

Evaluating the Experience of Cancer Care

Why Evaluate Patient Experience?

At BC Cancer, we want to know about the experience of people receiving cancer care. Evaluations help us understand what we are doing well and what areas need attention. Evaluating care experience is especially important when BC Cancer is making changes.



What Did We Do?

Team-Based Care Patient Experience Survey

BC Cancer has launched a new model of care called team-based care. This model wraps cancer care around the patient. The model intends to improve the patient experience.

In order to evaluate changes to the experience of cancer care, the Patient and Family Experience team created a survey using questions from the 2019 Ambulatory Oncology Outpatient Cancer Care survey. We added demographic questions to help the team understand if the care experience varies for different people served by BC Cancer. The team sent the survey to the network of patient and family partners for review.

Each regional centre implemented the survey resulting in 434 survey responses. There was one open-ended question in the survey: “Is there anything BC Cancer could do to improve your overall experience of care?” The team reviewed the answers to this question and separated them into themes. BC Cancer leadership received a summary of all survey responses.

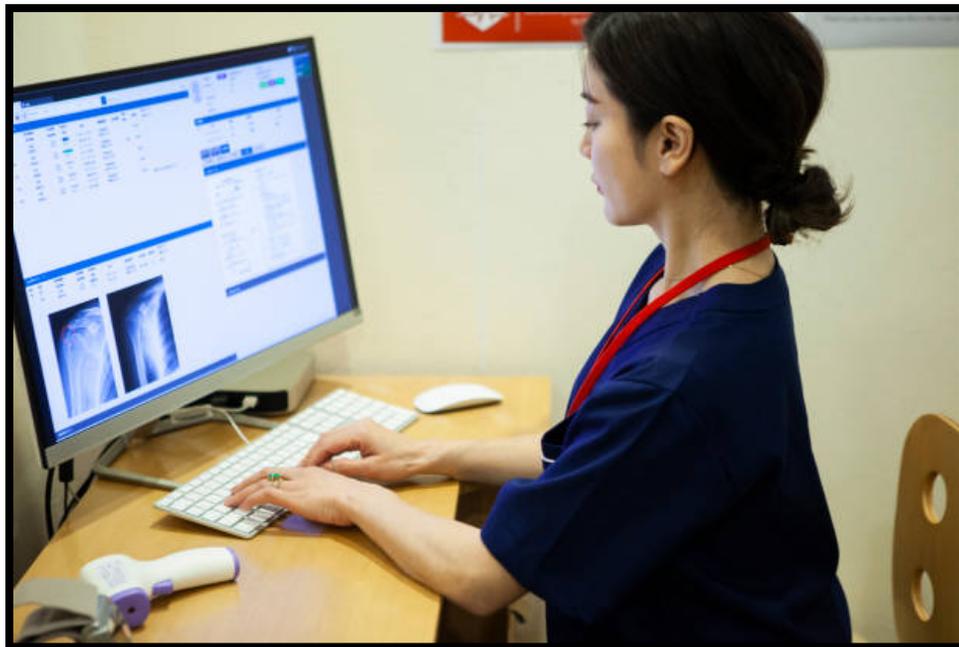
CST Go Live in Prince George

All six BC Cancer regional centres are transitioning to a new electronic medical record called CST Cerner. As staff learn the new system, the care experience may change for patients.

The Patient and Family Experience team worked with three patient and family partners. Two partners who received cancer care at BC Cancer - Vancouver during CST go live and one who received care at Centre for the North. The partners shared their perspectives on what parts of their care changed with the go live in Vancouver. The partner from Centre for the North gave regionally specific ideas about cancer care at their site and some of the ways they think care might change.

The partner’s perspectives and input helped create the questions for a patient experience survey. The team sent the survey to the patient and family partner network for review. The three patient and family partners helped draft the distribution plan for the survey and the messaging to patients.

CST Cerner is scheduled to go live at Centre for the North in 2023. The survey will be implemented three times to measure the patient experience: prior to go live (baseline), 3 months after go live, and 6 months after go live.



2023/24 Priorities

In November 2022, the patient and family experience team hosted a partner forum. Patient and family partners joined in-person and over zoom for this hybrid event. The partners co-designed an action plan to guide 2023/24 priorities.

Action Plan

1. Understand partner preferences
2. Create partner-specific communication
3. Ensure meaningful and intentional engagements
4. Close the loop

Objectives

Support the inclusion of the patient and family experience in the continuum of care at BC Cancer. Put the patient and their family at the centre of every decision, plan, and process about their care.

Overarching Priorities

1. Increase equity, diversity, and inclusion of the patient voice in engagements
2. Co-create culturally safe and appropriate ways of engaging Indigenous people with cancer and their families
3. Increase health literacy practices within patient and family experience processes
4. Use research to add to the global knowledge about successful methods to evaluate the experience of cancer care

More Information

At BC Cancer, we strive to build our services around our patients and families.

Want to become a patient or family partner?

START HERE

Want to work with a patient and family partner?

START HERE

This report was created by the BC Cancer Provincial Patient and Family Experience team in April 2023.

For more information, visit [Patient and Family Experience](#).