BC CANCER

Provincial Health Services Authority

Your Guide to Being a Patient and Family Partner

Patient & Family Partnerships and Experience Program (PFPX)

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LAND ACKNOWLEDGEMENT

Provincial Health Services Authority (PHSA) provides specialized health care services to communities across British Columbia, on the territories of many distinct First Nations, who are the rights-holders with inherent authority, jurisdiction and self-determination. We are grateful to all the First Nations who have cared for and nurtured the lands and waters around us for all time, including the xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh Úxwumixw (Squamish Nation), and səl̓ílwətaʔ (Tsleil-Waututh Nation) on whose unceded and ancestral territory our head office is located.

COAST SALISH TEACHINGS

Thee eat

“Truth”

Eyhh slaxin

“Good Medicine”

Nuts a Maht

“We are one”

Whax hooks in shqwalowin

“open your hearts and your minds”

Kwum kwum stun shwalowin

“Make up your mind to be strong’

Tee ma thit

“Do your best”

At BC Cancer, we are guided by the Coast Salish Teachings, generously gifted by Siem Te’ta-in, Shane Pointe, and brought to life through the artwork of Nash’mene’ta’naht, Athena Picha. They offer guidance on how we can do our best as human beings and how we can show up meaningfully for our colleagues and the people we serve. To truly understand and integrate the Coast Salish teachings gifted by Siem Te’ta-in, we must take the time to sit with them and allow them to take root within us.

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OVERVIEW

BC Cancer is an agency of the Provincial Health Services Authority (PHSA). PHSA is responsible for governing, managing and funding BC Cancer, along with 10 other provincially mandated health care agencies. At BC Cancer, we collaborate with patients, caregivers, and communities to shape care planning, design, and delivery, ensuring a people-centred approach that enhances cancer care across BC. We engage our patients and families in many ways, including:

- **Through co-design** - we collaborate with patients and families to plan and design services or improve the experience with services. Co-design recognizes that the patient and family is part of the team, with expertise in their lived experience.
- **In partnership** - we partner with patients and families to actively involve them in initiatives that support people-centred care delivery.
- **With input from** - we gather insights from patients and families through advisory committees, surveys, focus groups, and day-to-day conversations. These contributions help shape service improvements and ensure care reflects what matters most to those we serve.

WHAT IS THE PATIENT AND FAMILY PARTNER NETWORK?

The Patient and Family Partner Network (“Partner Network”) is a group of individuals with firsthand experience at BC Cancer, either as a patient or caregiver (e.g. spouse, partner, children, aides, close friends). By sharing their perspectives, partners help enhance the quality of cancer care for all patients and families across the province. The Partner Network is supported by BC Cancer’s Patient & Family Partnerships and Experience (PFPX) Program.

ABOUT PATIENT AND FAMILY PARTNERS

Who are Patient and Family Partners?

Patient and Family Partners:

- Are current patients, former patients and caregivers (e.g. spouse, partner, children, aides, close friends) who have firsthand experience at BC Cancer.
- Participate in projects, committees, consultations and working groups to help design, review and improve cancer care services. We call these 'engagements'.
- Are willing to share their positive and/or negative experiences - in ways that feel right for them - with the goal of strengthening cancer care services.

Joining the Partner Network:

Interested individuals can fill out our 'Patient and Family Partner Expression of Interest (EOI) form' to express interest in becoming a patient and family partner. Once the PFPX team receives this request, we will schedule a 30-minute 'introductory call'. During this call, we'll discuss the individual's reasons for joining, experience with cancer care, interests, and support needs. We'll also share more about our program and what it means to be a patient and family partner.

Orientation Process:

After the introductory call, we will ask you to complete the orientation process, which includes:

- Watching a 30-minute orientation video
- Reviewing the following (approximately 1 hour):
  - 'Your Guide to Being a Patient and Family Partner' Guidebook
  - Patient and family partner honorariums: Information for partners
  - PHSA Vision, Values, and Coast Salish Teachings
  - Key Concepts: Cultural Safety, Equity and Inclusion
- Optional: Completing a demographic questionnaire so we can better understand

your unique experiences, match you to engagements, and use this information to continuously monitor and improve the diversity of our network.

After Completing the Orientation Process:

Congratulations! You are now a member of our Partner Network. Our team will add you to our mailing list and you will start receiving our newsletters with engagement opportunities that you can sign up for. Review this pathway for more information.

Time Commitment:

- We ask that partners aim to take part in, or show interest in, at least one engagement activity within 18 months.
- For each engagement opportunity, the time commitment will be communicated in advance (e.g., 1 hour total or 2 hours every month).
- You can withdraw your participation at any time by contacting the PFPX program.

Who will Partners Work With?

Partners will work closely with ‘Engagement Leads’, these are BC Cancer staff and physicians and/or external academic groups.

What it Means to be an ‘Active’ Member:

We use the following criteria to help understand when a member is actively engaged in the program, recognizing that involvement may look different for everyone:

- You have completed the orientation.
- You have participated in, or indicated interest in, an engagement activity within the last 18 months.

We recognize that our partners may experience fluctuating energy levels and availability. Our goal is to build long-term connections. If the participation outlined above isn’t met, we’ll first reach out to check in.

If we don’t hear back, we’ll assume you’ve decided not to participate or that circumstances have changed. To respect your preferences and privacy, we’ll then remove your contact information from our records and mark your status as inactive.

If you wish to become an active member again in the future, you are always welcome to rejoin the network by contacting the PFPX Program.

What You Can Expect as a Partner:

As a network member, you have the right to:

- Feel safe.
- Be treated with respect, dignity and fairness.
- Engage in culturally safe and trauma- and violence- informed engagements.
- Freely express your cultural, gender, and spiritual identity.
- Have your privacy and confidentiality protected.
- Be provided with information and support so you can take part in engagements.
- Have the option to receive honoraria for your time.
- Know the outcome of engagements you take part in.
- Leave an engagement at any time.
- Take a break from, or leave, the Partner Network anytime.

What We Ask of You:

As a network member, we ask that you:

- Share your experience and ideas in ways that feel right for you - your insights and life experiences matter.
- Ask questions when you need to - if something isn't clear, feel free to ask. The PFPX Coordinator can also ask questions on your behalf.
- Focus on opportunities - approach challenges with curiosity, cultural humility, and a willingness to explore solutions.
- Work collaboratively - use everyone's strengths to find impactful and practical ways forward.
- Listen with an open mind - let others share their thoughts without interrupting or judging.

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- Be kind, respectful, and thoughtful - help make a space where everyone feels welcome and heard.
- Respect privacy and confidentiality - keep engagement details private, don't speak to the media without our guidance, and let us know if confidentiality may have been breached.
- Take care of yourself - tell us how we can support you, whether that's flexible ways to participate, accessibility help, or other needs.
- Reflect PHSA's vision, values, and Coast Salish Teachings in your participation.

Learning and Support:

The PFPX Program coordinates the activities of the Partner Network. As a network member, you will receive:

- A one-time orientation on being a patient and family partner.
- If you so choose, honoraria and reimbursement.
- A monthly or bi-monthly e-newsletter that contains:
  - Information about new engagement opportunities.
  - Learning Opportunities.
  - Updates from the PFPX program.
- Support from the PFPX Team, throughout your engagement journey.

Partner Well-Being:

We know that sharing your personal experiences and taking part in engagement activities can sometimes be emotionally challenging.

Your wellbeing matters to us, and we want you to feel supported. If you experience emotional distress or discomfort during your participation, we encourage you to:

- Take a break.
- Step away from the engagement altogether—this won’t affect your future involvement as a Partner.
- Let us know what support would help. We will adjust the engagement approach to meet your needs, wherever possible.

We also welcome requests for culturally meaningful supports, such as time and space for reflection, the use of grounding or ceremonial practices, or other approaches that reflect your cultural identity and values. If there are practices or ways of engaging that differ from ours and would better support your participation, we invite you to share them with us so we can support you as best as possible.

The PFPX program and Engagement Leads are always available for a one-on-one chat to talk about how we can make your experience feel more comfortable and better suited to you.

Honoraria and Reimbursement:

Honorarium(s) are a one-time payment made to show appreciation and recognize knowledge, expertise, and lived experience. They are often given to volunteers, patient or family partners, and community members who work with PHSA to improve programs and services. One way the PFPX Program supports inclusive participation is by providing voluntary honorariums to partners in recognition of their time and expertise.

The PFPX program follows the rates and guidelines outlined in this document when providing honoraria. Reimbursement is the process of repaying partners for pre-approved out-of-pocket expenses incurred for local travel costs.

The PFPX program will reimburse you for:

- Parking, transit and mileage costs
- Travel, accommodation and meal costs for out-of-town travel.

Partners are required to provide original receipts for these costs.

Updating Your Participation Status:

Your participation in the network is entirely voluntary. If you'd like to take a break or step away, please reach out to the PFPX program.

Supporting Positive Participation:

The PFPX Program is committed to creating a respectful and welcoming space for all Partners. We ask that Partners follow the shared agreements and policies outlined in this guidebook (see 'Policies' on Page 12).

If concerns come up about a Partner's participation, we'll take time to talk about the situation together and the best way to move forward. In some cases, we may need to ask a Partner to leave the Network. These situations may include:

- Not following PHSA policies and procedures.
- Choosing not to support the goals of the PFPX program.
- Giving false information on a program form, such as the Patient and Family Partner Expression of Interest (EOI) form.
- Stealing or misusing BC Cancer money, property or materials.
- Abusing or mistreating patients, staff, volunteers or other partners.
- Taking part in illegal, violent or unsafe acts.

Staff as Partners:

PHSA staff who have experience with cancer care as a patient or a caregiver are welcome to join the Partner Network. If you are a staff member, please let the PFPX team know during the introductory call.

Media and Social Media:

If you are approached by the media, please inform the PFPX program. Please don't speak with the media on behalf of BC Cancer unless approved by the PFPX program and BC Cancer Communications team.

The term "social media" refers to all platforms, including X (formerly Twitter), Facebook, Instagram, LinkedIn, YouTube, Pinterest, and other relevant photo, video, or content-sharing sites. When using social media about your role as a partner:

- Only post information about BC Cancer/PHSA that is a fact and available to everyone.
- Never write or talk about patient information or discuss a patient's health status.
- Never post a photo of someone without their permission. If you post a photo, make sure that the image does not contain private information, such as patient records, addresses, or any details that could identify someone without their consent.
- When in doubt, speak to the PFPX program first.

COMMITMENT TO INDIGENOUS CULTURAL SAFETY AND ANTI-RACISM PRACTICES

Indigenous Cultural Safety:

We recognize that First Nations, Inuit, and Métis peoples have faced historical and current harm within healthcare systems. These harms are rooted in the ongoing impacts of colonization, systemic racism, intergenerational trauma and covert (subtle) and overt (obvious) acts of racism. These experiences have contributed to a deep mistrust of institutions, including research and health-related initiatives. Guided by the Coast Salish teachings, the PFPX program is committed to creating spaces that feel safe, respectful, and welcoming of all Indigenous persons.

These are spaces where relationships are built on trust, care, reciprocity, and a genuine willingness to listen and learn. We understand that meaningful engagement must go beyond inclusion, and it requires acknowledging past and present harms and actively working together to foster healing and accountability.

Indigenous partners are welcome to request culturally appropriate supports, such as involvement of Elders, use of traditional protocols, or alternative approaches to participation (such as a smaller sharing circle) that align with Indigenous ways of knowing.

Anti-Racism:

At PFPX, we all share the responsibility to create a space that is free from racism and discrimination. If harmful behavior happens, we will address it and work together to prevent it.

Harmful behavior can include both subtle and obvious actions. This may be:

- **Subtle actions** - such as microaggressions. These are verbal, physical, or written comments or actions that may be intentional or unintentional and can harm people from marginalized groups (for example, people from racial or ethnic minorities).
- **Obvious actions** - such as stereotyping or discrimination. This involves making unfair generalizations or assumptions about a group of people.

These harmful behaviors can be based on a person's race, ethnicity, gender identity,

POLICIES

Partners follow the same policies as BC Cancer physicians, staff and volunteers. You can find the Core PHSA Policies in the link provided in the “References” (page 17) section of this document.

Standards of Conduct:

It is mandatory for Partners to adhere to PHSA's 'Standards of Conduct'. Please read and familiarize yourself with the Standards of Conduct by clicking here.

Your Personal Information:

PHSA and BC Cancer are responsible for protecting the confidentiality and privacy of all Partners.

Collection:

We collect your personal information under section 26 (c) of the Freedom of Information and Protection of Privacy Act (FIPPA). It is collected as part of your onboarding process through the Expression of Interest (EOI) form and a voluntary demographic questionnaire. We use this information to better understand your unique experiences and help match you to engagements.

We recognize that for many Indigenous Peoples, sharing personal or demographic information may raise concerns due to past and ongoing harms in health and research systems. Sharing this information is always voluntary. We are committed to being transparent about how your information is used and stored, and we will work with you to support your comfort and understanding around any data-sharing processes.

Access:

As a Partner, you may have access to confidential information. This information must not be shared and should only be used for its intended purpose.

Sharing:

If you express interest in an engagement, your information will be shared with BC Cancer staff or Engagement Leads. If multiple partners are interested, your email address may be shared with other Partners.

Storage:

Your information is securely stored in a password-protected file. If you leave the program, your records will be retained for seven years before being deleted.

Incidents:

An ‘Incident’ is any unexpected or unwanted event that harms or places a person at risk of harm. It is also an event that results in loss, damage or theft of property or items. All incidents involving Partners must be reported to the PFPX program.
The Partner and program will complete an incident report together. The report will be kept on file.

Request for Reference:

Partners who have participated in BC Cancer engagements can request a letter of reference from the PFPX Program. The program will provide a letter and retain a copy for its records.

CONSIDERATIONS FOR IN-PERSON ENGAGEMENTS

Most of our engagement activities take place virtually. However, partners may occasionally participate in in-person engagements, such as speaking at conferences or conducting walk-through assessments of BC Cancer patient care spaces. If you are participating in an in-person engagement, please follow these guidelines:

Infection Control:

To keep our patients and staff healthy and safe, do not visit a BC Cancer site or engagement location if you are sick. All Partners must follow these rules when they are participating in in-person engagements:

- Hand Hygiene: Wash your hands before and after your visit to prevent the spread of germs.

- Contact with Fluids: Avoid contact with patient blood, body fluids, or harmful substances. If exposed, inform a BC Cancer staff member immediately and report the incident to the PFPX Program for follow-up.
- COVID-19 vaccination: We recommend that all partners receive COVID-19 vaccinations.
- Influenza vaccination: During flu season between November and March, we recommend that all partners get a flu shot or wear a mask in patient care areas. Masks are available at nursing stations and reception desks.

Pets at BC Cancer:

Please do not bring pets to any BC Cancer building. Only certified pet therapy volunteers and approved programs are permitted to bring animals on-site (e.g. Pet Therapy Program).

DEFINITIONS

Anti-Racism:

The practice of actively identifying, challenging, preventing, eliminating and changing the values, structures, policies, programs, practices and behaviours that perpetuate racism.

Cultural Humility:

A life-long process of self-reflection and self-critique. It is foundational to achieving a culturally safe environment. Cultural humility begins with an in-depth examination of our own assumptions, beliefs and privilege embedded in our own understanding and practice.

Cultural Safety:

Creating a respectful and inclusive environment where diverse cultural identities, values, and experiences are recognized, valued, and supported. It involves addressing power imbalances, racism, and discrimination to ensure that all participants feel safe, heard, and respected throughout the engagement process.

Indigenous Cultural Safety:

The process of making spaces, services and organizations safer and more equitable for Indigenous people by considering colonial history and seeking to eliminate structural Racism and Discrimination. Cultural safety is also an ‘outcome’ based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system; it is when Indigenous people feel safe when receiving Health Care.

Trauma and Violence- Informed:

Recognizes approaches that focus on minimizing the potential for harm and re-traumatization and enhancing safety, control, and resilience for those involved with systems or programs. t is more than just being “not racist” and involves taking action to create conditions of greater inclusion, equality and justice.

REFERENCES

- Core PHSA Policies
- PHSA Vision, Values and Coast Salish Teachings
- PHSA Patient and Family Engagement Framework
- Honorarium Guidelines
- Freedom of Information and Protection of Privacy Act (FIPPA) [RSBC] Chapter 165
- PHSA Patient Care Quality Office (PCQO)
- Coast Salish teachings
- In Plain Sight Report