

BC Cancer

Patient and Family Experience Program

# Patient and Family Partner Handbook



Provincial Health Services Authority

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## OVERVIEW

At BC Cancer, we partner with patients, families, carers and community in care planning, design and delivery to enable a **people-centred approach** to care and to improve cancer care in BC.

We engage our patients and families in many ways, including:

- Through co-design, to plan and design services or improve experience with services
- Partnering with patients and families in the delivery of care and for all health decisions
- By ensuring patients and families are involved as they wish to be in care delivery
- Making sure patients and families have the information needed to make decisions about their care, including understanding treatments, side effects and options
- Seeking input from patients and families through surveys, advisory committees, focus groups and informal day-to-day feedback

**The Patient and Family Partner Network** (“Partner Network”) is what we call the group of people with cancer care experience and their loved ones who bring their lived experience to support specific BC Cancer activities and projects. Each partner is part of the Partner Network and this group is organized and supported by the Patient and Family Experience Program.

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## POSITION DESCRIPTION

### Who are Patient and Family Partners?

Patient and Family Partners are people who

- Have experienced cancer care as a patient or family member/caregiver/loved one
- Care about high quality cancer care for all patients and families
- Are willing to share their positive and/or negative experiences in a respectful manner, with the goal of strengthening health care services
- Join projects, committees, consultations and working groups to design, review and improve cancer care services. We call these “engagements”.
- Volunteer their time

### What skills do I need to be a Partner?

- You can think beyond personal experience to help shape care for all patients and families
- You are dependable, patient and honest
- You can and enjoy working with others
- You have respect for sensitive and private information

If you have experience in committees and working groups, this will be helpful for some engagements.

### How much time do I need to give?

- It’s up to you. Dependent on the engagement, it could be one to four hours per month
- Orientation (60 minutes)
  - One-time introductory call with the Leader, Patient and Family Experience (30 minutes)
  - One-time orientation video (30 minutes)
- Some of the engagements will include a selection process where you may need to answer some questions over email or meet with the project lead. This will help the Patient and Family Experience team and the project lead determine which partners are the best fit for the project.
- Most engagements will involve an “onboarding” call where you will meet with the project lead to hear more about the project specifics and ask questions, before you get started.

## Who will I work with?

- Partners are recruited and supported by the Patient and Family Experience Program
- Partners work with health care staff and physicians (“project leads”) for specific engagements (e.g. partners who are members of a Regional Patient Experience Committee work with the Cancer Centre leadership and clinical team members).

## What training and support will I get?

The Patient and Family Experience Program train and support partners.

Each partner will receive:

- A one-time orientation on being a patient and family partner
- A monthly or twice-monthly e-newsletter with invitations to join engagements and information updates from the Patient and Family Experience Program. Engagements are also advertised on our website <http://www.bccancer.bc.ca/about/accountability/patient-family-experience/get-involved>
- A check-in email or phone call during an engagement and at the end of it. For short engagements, we will usually just check-in with you at the end of the activity.
- A short engagement evaluation survey at the end of each engagement. We want to hear how it went and any areas for improvement.
- Opportunities to participate in program focus groups and Partner Network calls to stay connected and gather input from partners on specific projects and quality improvement activities.

**We want you to feel comfortable and supported. If you ever have any concerns or questions, please reach out to the Patient and Family Experience team on [patientexp@bccancer.bc.ca](mailto:patientexp@bccancer.bc.ca)**

## Screening

All Partners must be interviewed and registered with the Patient and Family Experience Program. We use a patient and family partner introductory call guide. We will ask things to learn more about your:

- Motivation and interest in being a partner
- Experience with cancer care
- Skills and experience
- Potential conflicts of interest
- Support needs

You can become a partner at any time, including during treatment. We know and understand that patient partners having treatment, and family partners who have recently experienced loss, may be emotional. If you are struggling in your role or need support please reach out to the Patient and Family Experience Program. We will also check-in with partners as part of engagements to hear how you are doing and provide help, if needed.

**To be a partner you must:**

- Fill out the online application form and consent to the Partner Agreement terms
- Have an introductory phone call with a member of the Patient and Family Experience Program
- Complete the online course (orientation module)
- Read this Handbook

**Staff as Partners**

BC Cancer staff who have experienced cancer care as a patient or family member/caregiver/ loved one may join the Partner Network. If you are a BC Cancer staff member, you must tell the Patient and Family Experience Program.

**Supervision and support**

The Patient Experience Program supervises and supports all Partners. The Provincial Lead – Patient and Family Engagement is the main person who will supervise and support you.

## POLICIES

Policies are rules you have to follow as a partner. Partners have to follow the same policies as doctors, staff and volunteers at BC Cancer. The Patient and Family Experience Program will help you understand and follow these policies. You can find the Core PHSA Policies in the link provided in the “References” section of this document.

### Advice about cancer treatment

You are not allowed to give information or advice about cancer drugs or treatments. If patients, family members or visitors ask you questions, you must tell them to “talk to their health care team”.

### Advocacy

- Your role as a partner is to act as an advisor, not an advocate. An advisor gives input to clarify a process. An advocate works towards a specific result.
- Your role as a partner is to work with people on the engagement. We ask every member of an engagement to listen to one another. We ask that each member aims to understand each other and find meaning and agreement.
- An advocate is a person who speaks or writes in support or defense of a person or cause. Advocates work to satisfy the interests of that person or cause. A partner is not an advocate.

### Standards of Conduct

The Provincial Health Services Authority (PHSA) expects Staff to adhere to the highest standards of conduct with respect to ethical, legal, and professional behaviour amongst themselves and with clients, patients, residents and others members of the public. Staff includes executives, doctors, contractors, medical staff, volunteers, university faculty, students and researchers working with or for PHSA.

#### **Please read and familiarize yourself with the Standards of Conduct**

<http://shop.healthcarebc.ca/phsa/PHSAPOD/Human%20Resources/C-99-11-20201.pdf>

If you do not follow the code of ethics, we may ask you to leave the Partner Network.

### Collection of your personal information

Your personal information will only be used for your role as a partner. We will collect this information when you become a partner through your application and a demographic questionnaire. We will use this information to better understand your unique experiences, help us organization and run the Partner Network and to better match you to engagements.

We collect your personal information under section 26 (c) of the Freedom of Information and Protection of Privacy Act (FIPPA).

### Access to personal information

When you are part of an engagement, you may learn personal information about other patients or family members. This information is private. You are not allowed to share this information. The information can only be used for the reason it was shared.

If you are not sure about what to do with personal information, talk to the Patient and Family Experience Team.

### Sharing your personal information

We share your personal information with BC Cancer staff or other partners when necessary.

When you tell us you are interested in an engagement, your response and your personal information may be shared with the BC Cancer staff who are leading the engagement. We share this information so we can match the right partner(s) for the engagement.

Also, if more than one partner is interested in an engagement, your contact information (email) may be shared with other partner(s). This allows you to email with other partners in the engagement.

Other situations where we would have to share your information are when:

- Required by law
- Required by a court order, subpoena or warrant
- The health or safety of an individual or group is at risk
- You have consented in writing to us sharing the information

### Storing your personal information

Your information will be stored in a password-protected electronic file. When you stop being a partner, your records will be kept for seven years.

### Complaints and compliments

As a partner, you commit to sharing, listening, and working with your engagement team. The engagement is not the right place for making complaints that are not related to the engagement.

If you have a complaint, we encourage you to please speak with the person who provided the service or to the manager of the area. It is best to talk about an issue at the time and place it happens.

You can also complete a comment card located throughout the Cancer Centres. Ask a BC Cancer staff member if you cannot find the collection boxes or comment cards.



If your complaint is not resolved after talking about the issue with the service area, or you are uncomfortable speaking with a staff person at the service area, you can contact the PHSA Patient Care Quality Office (PCQO). See the link in the References section of this Handbook.

## Confidentiality and privacy

PHSA and BC Cancer are responsible for protecting the confidentiality and privacy of all patients, doctors, employees, visitors, and volunteers.

The PHSA confidentiality and privacy policy applies to all employees, executives, volunteers, doctors, contractors, medical staff, university faculty, students and researchers affiliated with PHSA. Examples of confidential information are internal communication related to organizational initiatives (such as strategic plan), engagement information in the partner e-newsletter and information discussed in confidence at engagement meetings.

If you recognize a patient or learn of a patient's medical condition, you must keep this information private.

If you do not follow this policy, we may ask you to leave the Partner Network. If you have concerns about confidentiality, talk to the Patient and Family Experience team.

## Conflict of interest

While you are acting as a BC Cancer partner, you cannot

- Do any personal or financial business
- Influence others with your personal or religious beliefs

If you do not follow this policy, we may ask you to leave the Partner Network.

## Discipline and dismissal

The Patient & Family Experience Program is responsible for making sure you follow the policies in this book.

If you do not follow these policies, the Patient and Family Experience will investigate. Each investigation will be different, depending on the situation.

The following situations may lead to your immediate removal from the Partner Network:

- Not following PHSA/BC Cancer policies and procedures
- Lying, including false information on a form such as the Patient and Family Partner application form
- Stealing or misusing BC Cancer money, property or materials
- Abusing or mistreating patients, staff, volunteers or other partners

- Illegal, violent or unsafe acts
- Unwillingness or inability to support the mission of BC Cancer and/or the goals of the Patient and Family Experience Program

## Donations and gifts

You are not allowed to receive gifts, donations or favours from a person or business who works with BC Cancer.

You are not allowed to ask for gifts, donations or favours for friends or family from a person or business who works with BC Cancer.

Donations to BC Cancer must be done through the BC Cancer Foundation.

As a partner, you may be offered a gift. You can only accept a gift if it has nominal value, such as a meal or gift certificate. If you are unsure about what to do when you get a gift, reach out to the Patient and Family Experience Program.

## 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 Patient and Family Experience Program. The partner and Program will complete an incident report together. The report will be kept on file.

## Infection control

To keep our patients and staff healthy and safe, do not come to a Cancer Centre, BC Cancer site, or engagement location when you are sick.

To reduce the spread of infection, you must follow these rules when at a BC Cancer location or engagement location:

Hand Washing: Wash your hands before and after you come to the location. Hand washing is the most important thing you can do to stop spreading germs.

Contact with Fluids: You should not have contact with patient blood, body fluids or any products which could be harmful. If you do come into contact with any of these things, tell a BC Cancer staff member immediately. Once you are safe and the incident is over, please tell the Patient and Family Experience Program. The Program will make sure to follow-up on the incident.

Influenza vaccination: During flu season between November and March, you must have a flu shot or wear a mask in any patient care area. This will protect our patients and staff from getting the flu. The flu can be very dangerous and even lead to death.

Partners can get the flu shot for free. Ask a staff member or Patient and Family Experience Program for details.

If you do not get the flu shot, you can get a mask from any nursing station or reception desk at the Cancer Centre.

#### COVID-19 vaccination:

The Provincial Health Officer (PHO) has ordered that all health-care workers must be vaccinated against COVID-19. Mandatory vaccination includes all those employed by PHSA, staff and physicians employed by B.C. health authorities, as well as all students, researchers, fee-for-service/contract physicians, medical staff and all individuals and contractors who work, study or volunteer at our sites.

### **Media and social media**

In your role as a partner, you are not allowed to speak with the media on behalf of BC Cancer unless the Patient and Family Experience Program and the BC Cancer Communications department has said you can.

If the media contacts you, talk to the Patient and Family Experience Program. The Program will talk to the Communications department and they will let you know what you should do.

The term “social media” applies to social media platforms, including online forums, blogs, and micro blogging sites such as Twitter and wikis. It also includes social networking sites such as Facebook, Instagram, LinkedIn, photo/video sharing sites such as YouTube and Pinterest, as well as any other applicable social media.

In your role as a partner, you are not allowed to represent BC Cancer on social media unless our Patient and Family Experience Program and Communications department has said you can. When using social media in relation to 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, even in general terms
- Never post a photo of someone without their permission. If you post a photo, make sure the photo does not include private information such as patient/chart info, patient address, and any other items that may identify a person who did not provide permission
- Remember, what you say on social media cannot be deleted and becomes a permanent part of the public record

For more information, see the References section of this Handbook.

## Reimbursement of costs

BC Cancer will pay you back for any costs you have that are related to your engagement. We will pay you back for

- Parking or transit costs
- Travel, accommodation and meal costs if you need to travel outside of your community

You need to talk to the Patient and Family Experience Program about these costs before you pay for them. You need to give the Program all of your original receipts for these costs.

## Patient contact outside the Centre

In your role as a partner you are not allowed to become involved in the personal affairs of patients and their families. This includes legal, financial or property matters.

You are not allowed to sign any legal documents or forms on behalf of patients or their families.

You are not allowed to give your personal information to patients or families. You are not allowed to ask patients and families for their personal information.

You are not allowed to drive patients or families in your car.

## Pets at BC Cancer

You are not allowed to bring an animal to any BC Cancer building. Only certified and approved pet visiting volunteers and programs are allowed to bring animals to BC Cancer (e.g. Pet Therapy Program).

## Recognition

Partners are recognized by BC Cancer for your meaningful contributions to improving cancer care. This can be as simple as a “thank you.”

You may also get thank you cards, flowers, gift certificates worth a small amount of money or honoraria. If you present at events and conferences, you will be recognized in the same way as the other presenters.

## Record of activity

You do not have to keep track of your engagement activities or hours. If you need to track your hours, talk to the Patient and Family Experience Program.

## Request for reference

Partners who have participated in BC Cancer engagements can get a letter of reference from the Patient and Family Experience Program. The Program will write the letter of reference for you. The request for a reference and the letter of reference will be noted in your file.

## Resignations

If you are no longer able or would like to be a partner (that is, you resign), please let us know.

Please send the Patient and Family Experience Program an email on [patientexp@bccancer.bc.ca](mailto:patientexp@bccancer.bc.ca)

## Scent

BC Cancer is a scent-free place. This means that you cannot wear anything that smells. Perfumes, creams, soaps and other products with a scent cannot be worn while you are at BC Cancer or participating in an engagement. Scents can be harmful and unpleasant for our patients and staff. Scents are not allowed in all areas of BC Cancer including elevators, hallways and the cafeteria.

## Shoes

You may spend time in patient care areas where there are wheelchairs, beds on wheels and other equipment. This equipment could run over or hurt bare feet. When you are in patient care areas, you must wear shoes that protect your full foot. Sandals, open-toe shoes, and flip-flops are not allowed.

## Visits and tours

You are not allowed to arrange visits or tours of the Cancer Centres for your family members or friends.

## Work experience

The Patient Experience Program does not make arrangements for people who want work experience including internships, observations, or job shadowing.

## REFERENCES

- [Freedom of Information and Protection of Privacy Act \(FIPPA\) \[RSBC\] Chapter 165](#)
- [Core PHSA Policies](#)
- [PHSA Patient Care Quality Office \(PCQO\)](#)