

# **Patient Experience Program**

Network of Patient and Family Partners

Your guide to being a Patient or  
Family Partner



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At BC Cancer we work hard to meet the needs of our patients and families. We want our patients and families to be actively engaged (very involved) in their cancer care.

We engage our patients by making sure

- They have the information they need to make good health decisions.
- They have control over their health decisions.
- We support them in their decisions.

When we engage patients and families and put their needs first, we are providing patient-centred care. Patient-centred care is one of the top goals for BC Cancer.

We work with our Patient and Family Partners to improve cancer care in BC. Partners work with BC Cancer staff members on many different engagements (projects). Patient and Family Partners help us design and provide patient-centred care.

Each Partner is part of the BC Cancer Network of Patient and Family Partners. This group is organized by the Patient 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 committees, consultations and working groups to design and review cancer care services.
- Volunteer their time (about one to four hours per month).

### **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 work 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?**

- About one to four hours per month. This can change depending on what engagement you are working on or what committee you are a part of.
- One time Partner phone interview (30 minutes).
- One time Partner orientation self-study online course (30 minutes).
- Partner matching phone meeting every time you are picked for an engagement (30 minutes).

### **Who will I work with?**

- Partners are recruited and supported by the Patient Experience Program.
- Partners work with health care leaders for specific engagements (e.g. Partners who are members of the Patient Experience Council work with the Manager of the Cancer Centre).

## **What training and support will I get?**

The Patient Experience Program will train and support Partners. Each Partner will get

- A one-time orientation on being a Patient or Family Partner.
- A monthly email with invitations to join engagements.
- A check-in email or phone call every six months, while partnering in an engagement, and at the end of the engagement.
- Opportunities to participate in education sessions and conferences that interest you.

There may be more frequent contacts during an engagement as needed.

## **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 Experience Program will help you understand and follow these policies.

### **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. You will listen to each person involved. You will aim 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.

If you are interested in being an advocate, you are invited to join a cancer patient advocacy organization. See the link in the References section of this handbook.

### **Code of ethics**

The Provincial Health Services Authority (PHSA) code of ethics must be followed by all BC Cancer and PHSA employees (including executives, doctors, contractors, medical staff, volunteers, university faculty, students and researchers working with or for PHSA).

If you do not follow the code of ethics, we may ask you to leave the Network of Patient and Family Partners or face legal action. The code includes

- Treating patients with respect, dignity, courtesy, compassion, kindness, fairness and optimism.
- Promoting equality, fairness, transparency (openness) and the use of good judgement.
- Giving health and social services to everyone, without judgement. We will not refuse treatment to someone based on their gender, gender identity, age, race, religion, ethnic origin, language, social status or sexual orientation.
- Promoting open communication and providing patients a way to give feedback about their care.
- Striving for professional excellence.

- Promoting a respectful work environment.

## **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. We will use your personal information when matching you to specific engagements.

The Patient Experience Program will collect the following information from you:

- Name and contact information (address, telephone number, email address).
- The reason you are interested in becoming a Patient or Family Partner.
- Work and volunteer experience related to being a Patient or Family Partner.
- Your cancer care experience, in your own words.
- Availability (days and times you can work on projects).
- Special diet needs.
- Health support needs (for in-person meetings).

We collect your personal information under section 26 (c) of the Freedom of Information and Protection of Privacy Act (FIPPA). We collect it to help us organize and run the Network of Partners.

## **Access to personal information**

When you are part of an engagement, you may learn personal information about other patients or families. This information is private. You are not allowed to share this information. The information can only be used for the reason it was shared. You can use this information in your role as a Partner. You cannot use this information for any other reason.

If you are not sure about what to do with personal information, talk to the Provincial Lead – Patient and Family Engagement, BC Cancer, Joyce Lee.

Phone: 604-877-6048

Email: [jlee2@bccancer.bc.ca](mailto:jlee2@bccancer.bc.ca)

## **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 choose the right Partner 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 locked cabinet and/or in a password-protected electronic file. When you stop being a Partner, your records will be kept for seven years.

If you have any questions about use of your personal information please contact Joyce Lee, Provincial Lead – Patient and Family Engagement.

### **Complaints and compliments**

As a Partner, you will share, listen, and work with your engagement team. The engagement is not the right place for making complaints.

If you have a complaint, 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 written comment card and put it in the collection boxes located throughout the 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, you may wish to 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 Partners monthly newsletter and information discussed in confidence at engagement initiative meetings.

If you recognize a patient or learn of a patient's medical condition, you must keep this information private. You cannot discuss this information with anyone unless they need to know it to do their job.

If you do not follow this policy, you may be removed as a Partner and may face disciplinary action. If you have concerns about confidentiality, talk to the Provincial Lead – Patient and Family Engagement.

### **Conflict of interest**

While you are acting as a BC Cancer Patient or Family Partner, you cannot

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

If you do not follow this policy, you may be removed as a Partner, and may face disciplinary action.

### **Discipline and dismissal**

The Provincial Lead – Patient and Family Engagement is responsible for making sure you follow the policies in this book.

If you do not follow these policies, the Patient Experience and Risk Management Teams will investigate. Each investigation will be different, depending on the situation. The Teams will decide if you should continue as a Partner or not.

The following situations may lead to your immediate removal from the Network of Patient and Family Partners:

- 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.
- Being under the influence of alcohol or drugs while acting as a Patient or Family Partner.
- Illegal, violent or unsafe acts.
- Unwillingness or inability to support the mission of BC Cancer and/or the goals of the Patient 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, talk to the Provincial Lead – Patient and Family Engagement.

## **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 Provincial Lead – Patient and Family Engagement. The Partner and Provincial Lead 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 the Cancer Centre when you are sick.

To reduce the spread of infection, you must follow these rules when at the Cancer Centre:

Hand Washing: Wash your hands before and after you come to the Cancer Centre. 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 Provincial Lead – Patient and Family Engagement. The Provincial Lead 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 the Provincial Lead – Patient and Family Engagement, 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.

## **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 our Communications department has said you can.

If the media contacts you, talk to the Provincial Lead – Patient and Family Engagement. The Provincial Lead will talk to Communications 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 and 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 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 have to talk to the Provincial Lead – Patient and Family Engagement about these costs before you pay for them. You need to give the Provincial Lead – Patient and Family Engagement all of your original receipts for these costs.

## **Patient contact outside the Centre**

In your role as a Partner you are not allowed 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 are allowed to bring animals to BC Cancer. Animals can spread germs and infections.

## **Recognition**

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

You may also get thank you cards, flowers, and gift certificates worth a small amount of money. If you present at events and conferences, you will be recognized in the same way as the other presenters. All Partners will also be invited to join Partner appreciation events, no matter where you live in BC.

## **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 Provincial Lead – Patient and Family Engagement. The Provincial Lead will give you instructions on how to track your activities.

## **Request for reference**

Partners who have participated in BC Cancer engagements can get a letter of reference from the Patient Experience Program. The Provincial Lead – Patient and Family Engagement 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 to be a Partner (that is, you need to resign), please let us know. We realize a lot of notice is not always possible.

Please send an email or write a resignation letter and send it to the Provincial Lead – Patient and Family Engagement.

## **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 dangerous and unpleasant for our patients and staff. Scents are not allowed in all areas of BC Cancer including elevators, hallways and the cafeteria.

## **Screening**

All Partners must be interviewed and registered with the BC Cancer Patient Experience Program. We use the Patient and Family Partner interview tool. This tool asks about your

- Motivation and interest in being a Partner.
- Experience with cancer care.
- Skills and experience.
- Potential conflict of interest.
- Support needs.

You can become a Patient or Family Partner at any time, including during treatment. We know that Patient Partners having treatment, and Family Partners who have recently experienced loss, may be very emotional. The Provincial Lead – Patient and Family Engagement will check-in to make sure you are not overwhelmed by your role as a Partner.

To be a Partner you must

- Fill out the online application form.
- Have a phone interview with the Provincial Lead – Patient and Family Engagement.
- Complete the online course (orientation module).
- Read this handbook.
- Sign the agreement at the end of this handbook.
- Have a Criminal Record Check (when you will be alone with children or vulnerable adults).

## **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.

## **Staff as Partners**

BC Cancer staff who have experienced cancer care as a patient or family member/caregiver/loved one may join the Network of Partners. If you are a BC Cancer staff member, you must tell the Provincial Lead – Patient and Family Engagement.

## **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.

## **Visits and tours**

You are not allowed to arrange visits or tours of the 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**

Advocacy organizations: a list of advocacy organizations is available on the BC Cancer website: <http://www.bccancer.bc.ca/our-services/services/library/recommended-websites/advocacy-websites>

BC Cancer Volunteer Services Provincial Policies

Freedom of Information and Protection of Privacy Act (FIPPA) [RSBC] Chapter 165

Patient Voices Network Volunteer Agreement

PHSA Code of Ethics: <http://www.phsa.ca/about-site/Documents/code-of-ethics.pdf>

PHSA Confidentiality and Privacy Policy: <http://www.phsa.ca/about-site/Documents/code-of-ethics.pdf>

PHSA Patient Care Quality Office (PCQO): <http://www.phsa.ca/about/accountability/patient-experience/compliments-complaints>

PHSA Personal Use of Social Media: Procedures

## **Patient and Family Partner Agreement**

We want our Patient and Family Partners to have high quality, safe and meaningful engagements. Please read the information in this handbook and the information below. Please sign the Agreement to show that you agree to follow the rules listed in this handbook.

Our commitment to you as a Partner is to make sure that

- You are treated with fairness, courtesy, dignity and respect.
- Your personal information is protected and kept confidential. We will only use it for the reasons listed in this handbook.
- You are offered opportunities for engagement that meet your skills and interests.
- You get guidance, orientation, and skills development.
- You are recognized for your time.
- You feel safe and supported.

Your commitment to BC Cancer as a Partner is to

- Work with others.
- Respect the rights and views of others.
- Treat others with fairness, courtesy, dignity and respect.
- Volunteer for engagements that meet your skills and interests.
- Speak with the Provincial Lead – Patient and Family Engagement about any conflicts of interest you might have. This includes any benefits to your work or business.
- Direct questions from the media to the Patient Experience Program.
- Tell the Provincial Lead – Patient and Family Engagement any information that can help support your involvement.

As a Partner, you will not

- Harass or discriminate against any person or group.
- Give medical advice and refer people with medical questions to their doctor.

Your commitment to confidentiality:

- I understand that all personal information about staff and patients/family who receive services is confidential. This information includes patient medical records. I may not communicate this information to anyone in any way unless told to do so by PHSA or BC Cancer.
- I understand that all non-public information about PHSA and BC Cancer is confidential. This information includes administrative, corporate or financial information. I may not communicate this information to anyone in any way unless told to do so by PHSA or BC Cancer.
- If I take confidential information outside of BC Cancer, I must protect it from theft or loss. I will keep the information with me at all times or store it in a locked and secure area. For electronic information, I will make sure electronic devices, like a computer, are password-protected.
- Unless told to do so by PHSA or BC Cancer, I will not copy, change, destroy or remove any confidential information or records.
- I understand that, in my role as a Partner, I am not allowed to access my health record or the records of family, friends or others. If I have access to patient records, I can only use them for what I need in my role as a Partner.
- If I think I have accidentally broken the confidentiality rules, I will immediately tell the Provincial Lead – Patient and Family Engagement.
- I understand that my own personal information is protected by this agreement and by the PHSA Policy on privacy and confidentiality. This includes information about my experience with cancer care and information collected to register me as a Patient or Family Partner.

As a Patient or Family Partner with BC Cancer, I understand and agree to

- The Partner role description.
- The collection of my personal information.
- How my personal information will be used.
- The use of my name and email address for subscription to the Partners e-newsletter.
- The BC Cancer policy about privacy and confidentiality.
- Ask any questions I have about confidentiality.
- Follow all of the rules in this handbook. If I do not follow the rules, I may be removed from the Network of Patient and Family Partners. I may also face disciplinary actions.

This agreement is in place during and after my role as a Partner. This means that even when I am no longer a Partner, I must follow the confidentiality rules for the information I learned as a Partner.

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Name (print)

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Signature of Patient or Family Partner

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Date (day/month/year)

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Signature, Patient Experience Program Representative

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Date (day/month/year)