Providence
Health Care
How you want to be treated.

Patient and Family Partner Handbook for Work with Research Teams

Use your experiences with the health care system to improve health care delivery for everyone served by Providence

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Thank you for your interest in partnering with Providence Health Care (PHC) as a Patient and Family Partner (PFP) on a research team. Your patient and family experience can help shape how health care is delivered at PHC. This guide will help you decide if being a PFP on research and quality improvement (QI) projects is right for you and explain what person- and family-centred care means at PHC.

What is a Patient and Family Partner (PFP)?

PFPs have received health care themselves, or have a family member who has received care. This care might be as a resident in a long-term care facility or as an inpatient or outpatient visiting a health centre. PFPs use their experiences with health care delivery to bring a patient- and family-focused lens to health care improvement and the research projects that drive this improvement.

A PFP on a research team is not a research subject. Rather, they are someone who draws on their unique experience to advise the research team. A PFP on a research team may or may not have past experience participating as a research study subject.

PFPs volunteer their time and receive a specialized orientation to initially support them to complete this work. PFPs cannot be employed by Providence Health Care, or any other health care institution while serving as a PFP. This includes but is not limited to Vancouver Coastal Health, Fraser Health, and the Provincial Health Services Authority.

Why is PHC partnering with patients and families?

At PHC we recognize the importance of patient and family voices in conducting research that creates a better health care system. Historically health care improvement has often focused on people who work in the system, such as doctors, nurses, technicians, investigators or physiotherapists. Evidence and day-to-day experience shows us that in fact everyone’s voice needs to be included – not just the people who provide the care and lead the research. This is why PHC is partnering with patients and families to provide effective person- and family-centred care.

Why is it important to involve patients in research?

Patient-oriented research aims to improve health outcomes (preventing death after a heart attack, or reducing injuries from falls in long term care homes, for example) and to enhance patients' experiences by using evidence to inform decisions at all levels in the health system. Patient-oriented research offers an important opportunity to make health research more responsive to the priorities of the patient and the health care system. For example, if patients are involved in a study evaluating the effectiveness of a particular treatment or health service, the evaluation questions would likely explore outcomes or elements that are important to the patients in reaching their health goals. In some cases, these questions may not have been identified as important by the clinicians or researchers. Patients are experts on their own conditions and have unique perspectives. Involving patients in priority-setting and decision-making related to research allows researchers and clinicians to develop a more comprehensive understanding of the patient experience of care and to collaboratively identify and explore gaps in evidence.

What is person and family centred care?

Person- and family-centred care is an approach to planning, delivering and evaluating health care. It is based on a partnership between healthcare providers, patients and residents, and their families. In person-centred care, patients and residents define their family and determine how family will be part of their care and decision making. Similarly, research that is conducted in partnership with patients and families answers research questions that matter to patients and aims to improve health care. By volunteering as a PFP, you can use your experiences with the health care system and your skills to improve health care delivery for everyone served by PHC.

Providence Health Care – who we are

Providence Health Care (PHC) is one of the largest Catholic health care organizations in Canada. We were founded in 1894 when the Sisters of Providence came to Vancouver and opened St. Paul's Hospital in Vancouver's West End. We currently operate 18 health care locations, including hospitals, long-term care homes, hospices and community clinics across the Lower Mainland.

Guided by the principle ***How You Want to Be Treated***, PHC delivers compassionate care to 600,000+ patients each year, and have 900+ residents living across Providence's seven long-term care homes and hosts a robust research program that informs our care. While large enough to support the most advanced medical technologies, PHC remains a person- and family-centred organization that values leadership, independent thinking and courageous choices.

What is research?

Research is the careful and detailed study into a specific problem or issue, using scientific methods, to reach new conclusions. Health research is vital to understanding human health, discovering better ways to prevent and treat disease and improving patient care.

What is Quality Improvement (QI)?

In health care, there are always opportunities to improve care and the patient experience. QI is a systematic approach, using specific techniques, to improve the quality of health care.

PHC Vision, Mission and Values

Vision:

Driven by compassion and social justice, we are at the forefront of exceptional care and innovation.

Mission:

Inspired by the healing ministry of Jesus Christ, Providence Health Care is a Catholic health care community dedicated to meeting the physical, emotional, social and spiritual needs of those served through compassionate care, teaching and research.

Values:

SPIRITUALITY:
We nurture the God-given creativity, love and compassion that dwells within us all.

INTEGRITY:
We build our relationships on honesty, justice and fairness.

STEWARDSHIP:
We share accountability for the well-being of our community.

TRUST:
We behave in ways that promote safety, inclusion and support.

EXCELLENCE:
We achieve excellence through learning and continuous improvement.

RESPECT:
We respect the diversity, dignity and inter-dependence of all persons.

What do PFPs do at PHC?

PFP participation helps to ensure that the research being conducted is relevant and valuable to the patients that it affects. Roles and tasks will differ from group to group and based on your personal interest and experience. Generally, the PFP role on research teams includes:

- Partnering with and advising research and QI teams, including survey development and sharing project findings
- Bringing patient and public experiences to the attention of the team
- Helping the team see how issues might be understood from a non- institutional perspective
- Helping the research team consider patient and family needs in their planning
- Sharing your knowledge, skills and experience with the research team
- Suggesting new areas or topics for future research
- Assisting with participant recruitment
- Assisting with data analysis
- Sharing project findings through reports, presentations, publications
- Learn from each other's perspectives in the team's discussions

PFPs should not be asked to bring the collective patient experience to a research team. We ask PFPs to bring personal experience as a patient, resident or family member. This means that PFPs do their best to bring their own journey with health care into the team's experience and offer reflections on what it means to be a patient. It's impossible to be the voice of all patients and family members.

How do I become a PFP?

If you want to volunteer to be a PFP on a research team, please contact the Research and Knowledge Translation (KT) group at researchtraining@providencehealth.bc.ca or the research team directly (or they may approach you), or the Patient Voices Network at https://patientvoicesbc.ca/patient-partners/sign-up-form/, or REACHBC, https://reachbc.ca to become a volunteer. They may contact you for a variety of volunteer opportunities, both at PHC and all over British Columbia.

The Patient Voices Network and PHC

Patient Voices Network (PVN) brings patients, family, and caregivers together to work towards improving the quality of health services in BC. PVN is administered by the Health Quality BC as part of its work to ensure person- and family-centred care throughout the health care system and funded by the BC Ministry of Health. Patient Partners are oriented to the patient partner role and supported to work alongside health care teams. While being a member of PVN is not mandatory, PHC and many of our current PFPs highly recommend it to support meaningful involvement and role clarity when working with health care teams. Please contact pvn@healthqualitybc.ca for more information.

Now that you know more about the role of PFPs at Providence, here is some information to help you prepare for the volunteer work you will do.

How do I prepare for meetings?

Preparing for the initial meeting

Prepare a brief verbal introduction of yourself, telling people:

☑ Your name
☑ That you are a PFP
☑ Any relevant experience (professional, voluntary, personal) that shows what you bring to the meeting or group
☑ What motivated you to join the committee or group
☑ Your expectations about the work and how much time you have to give to the group

Things you may want to bring to the meeting

☑ Paper or digital copies of any documents you were sent before the meeting, such as the agenda or items for discussion. You may want to create a binder or digital folder to keep all documents together.
☑ Note-taking materials – pen and paper, laptop, or tablet.

Preparing for subsequent meetings

To be an active and effective member of a meeting, you can:

- Go through the agenda in advance and review items.
- Get involved – participate at the level you feel comfortable, and understand that your voice is valued.
- For each agenda item, ask yourself:
    - How can I contribute to the discussion?
    - What could be some possible public concerns?
    - What is relevant information to bring to this discussion?

Guidelines on how we want to work together

- **Be respectful** and open to each person's ideas and opinions.
- **Listen to learn and understand**. One person speaks at a time without interruption. Please turn off cell phones and pagers.
- **Participate!** Share your ideas and experiences. Also, you can pass if you do not wish to contribute to any particular conversation.
- **Share air time**. Make sure everyone has a chance to speak.
- PFPs and staff should **avoid acronyms and abbreviations**, or define them if they can't be avoided.
- **Be respectful of privacy and confidentiality**. We must always keep private any personal information shared in the room.
- **Respect start and end times**. We will always try to start and end promptly. Do your part to respect times, session activities, breaks, etc.
- **Take care of yourself**. Do what you personally need to stay focused and involved: stand and stretch, use washrooms, etc.
- **Humour is welcome**. Remember to enjoy yourself.
- **Let us know what we can do to make the sessions work for you**.

Source: Patient Voices Network "Guidelines on how we want to work together"

Debate versus dialogue

Another aspect of being effective as a PFP is to look at your goal when meeting with others. There can be many different goals for committees, but one goal that is common to all groups is to have a culture of dialogue. Many think dialogue is just talking back and forth but it's more than that!

Dialogue is the art of a good conversation. Debate means stating your point of view without taking time to consider other options, or getting your point across while trying to make others back down. Dialogue is the process of putting two or more different opinions together to create a unified idea.

Debate	Dialogue
Assumes that there is a right answer and someone has it	Assumes that many people have pieces of the answer and together they can create a solution
Defending assumptions as truth	Revealing assumptions for re-evaluation
Combative: participants attempt to prove the other side wrong	Collaborative: participants work together toward common understanding
Defending one's own views against those of others	Reflecting on and re-evaluating one's own views
Listens to find flaws and make counterarguments	Listens to understand, find meaning and agreement
Searches for problems and weaknesses	Searches for strengths and value in others' ideas
Countering of the other position without consideration of feelings or relationship -- often belittles or deprecates the other person	Genuine concern for the other person and seeks to not alienate or offend
About winning	About discovering new options

Privacy and confidentiality in your role as a PFP

While you volunteer as a PFP, you may encounter information or circumstances that are confidential or private to individual people or to the health care organization. We ask that you respect privacy, as others in the room have been asked to respect your privacy.

All participants are asked to sign the “Confidentiality Undertaking for PHC Volunteers” on page 13. Please return the signed confidentiality form to your committee or research team leader. If you have questions about signing the pledge or want more information, please talk to the committee or research team leader. Additionally, some research teams may require the PFP to sign the “VCH & PHC Confidentiality Undertaking for Researchers”, which is an online consent form. Your research team will let you know if this is required.

Reimbursement while acting as a PFP

PFPs who are taking part in research teams may be reimbursed for approved expenses that they have incurred getting to these meetings.

In order to be financially responsible, we ask that you choose the most cost- effective option where possible. We also ask you to send in your expenses regularly throughout the year rather than waiting until the end of the year. This ensures you get reimbursed in a timely manner. Please discuss with the research team leader in advance the expenses you will incur as a volunteer on the team. The team leader will be able to direct you on how to get reimbursed for approved expenses.

The following items are eligible for reimbursement: travel expenses, including transit costs, plane or ferry costs, rental cars; hotel; conference registration; per diem for meals, etc. Parking and mileage reimbursement rates and limits may change. Mileage at $0.52/km to a maximum of 60 km (each way) for one meeting each day.

Individual committees may provide refreshments. It varies depending on the department and the committee. Unfortunately, PHC cannot guarantee that all meetings will have refreshments available.

Common challenges for Patient and Family Partners

“So, David, what do patients think?”

Staff members see you as ‘representing the public.’ It is not possible, of course, for you to represent all public opinion on the committee, as you are one person with one set of life experiences. Even if you have worked or volunteered with many people whose health is affected by the committee’s scope (e.g. diabetes or mental illness), you cannot ‘represent’ their opinions or experiences.

How to answer?

You could say: ***“I can’t speak to everyone’s experience, but here is my experience…”***

“This work is so slow! We’re not DOING anything!”

Research teams often work quite slowly. This can be frustrating for members of the public who may be used to concrete results and fast turn-around. Change takes time, and it can take a considerable length of time before research teams start to see the impact of their efforts.

The role of PFPs is vitally important to this work, but the work is very much a ‘long-term investment’. Please speak to the team leader if you become concerned. You may be raising a timely concern for the team to consider!

Remember, one of the biggest changes is simply having a patient and family voice present. You are instrumental to this change. You may not be able to see the impact of your role, but your presence is felt by other members of the team. Collaboration can be the first step in improving the overall care experience.

How much time will it take to be a PFP?

PFPs are involved at the level they choose. This means that the amount of time and level of involvement you wish to contribute is up to you. Some of our PFPs volunteer six to eight hours a month. Others volunteer one hour a month. Some of our volunteers give a few hours of their time for a one-time commitment – and others prefer to volunteer over a long period of time, perhaps even months or years.

Please advise the team or leader of the project you are involved in about how much time you have to give.

How do I find a project or committee that fits my goals as a PFP?

To get involved contact the PVN at patientvoicesbc.ca and they can connect with you with different projects at PHC. You can also contact the staff or leader of the program you or your family member is receiving care from and ask if you can participate as a PFP.

In addition to the Patient Voices Network and the unit leader, you can also contact the Research and KT group at researchtraining@providencehealth.bc.ca.

What are the limits to my role as a PFP?

Volunteering as a PFP on a research team is a great way to share experiences you have had in a hospital, clinic, or long-term care setting and collaborate on research projects that may improve patient care and safety. Volunteering as a PFP is not an opportunity to "vent." Personal stories about care can provide very meaningful reasons why care needs to be improved. Being a PFP may not provide a "fix" to an issue, but it can provide an opportunity for discussion.

What if I want to stop volunteering as a PFP?

You can choose to stop volunteering as a PFP at any time. If you encounter a conflict or problem on your team, discuss your situation with your team leader or PVN leader, and let them know if you wish to stop volunteering.

Questions?

To learn more about PFPs in general and their work at PHC, contact the Person and Family-Centred Care team at pfcc@providencehealth.bc.ca or call 604 682 2344 ext. 63725. If you want to know more about your specific role on a research team, contact the leader of the committee or project you are working with. If you are registered with the Patient Voices Network, they can also provide assistance for issues resulting from your experience as a PFP.

Recommendations from Previous PFPs

A research project led by PHC staff in 2018 explored the perspectives of PFPs who had participated as advisors to research teams. Findings and recommendations from this study are summarised in the table below.

Table 1: Recommendations for Leaders, Researchers, Patient Research Partners (PRPs)

Themes	Recommendations
Research Environment	• Promote a welcoming atmosphere for PRPs joining project team. • Ensure at least two PRPs on the team. • Invite the perspectives of PRPs during team meetings. • Avoid the use of undefined acronyms.
Expectations	• Clarify the roles and expectations for PRPs and all members of the team. • Provide closure through interim and end-of-project reports.
Support	• Cover the expenses (parking, travel, meals) of PRPs to engage and consider giving PRPs compensation or honoraria. • Offer preparation/training about working together on health care research project teams to PRPs and to researchers. • Designate a coordinator position to liaise with PRPs regarding project work. • Offer support for PRPs to participate in presentations on the project findings.
Value	• Facilitate the use of the PRPs' skill sets. • Utilize the perspectives PRPs bring from their experiences with illnesses or health conditions. • Acknowledge the contributions of PRPs to the research.

Used with permission of authors: Black, A, Strain, K, Wallsworth, C, Charlton, S, Chang, W, McNamee, K, Hamilton, C. (2018). What Constitutes Meaningful Engagement for Patients and Families as Partners on Research Teams? Journal of Health Services Research and Policy. Vol. 23(3) 158–167.

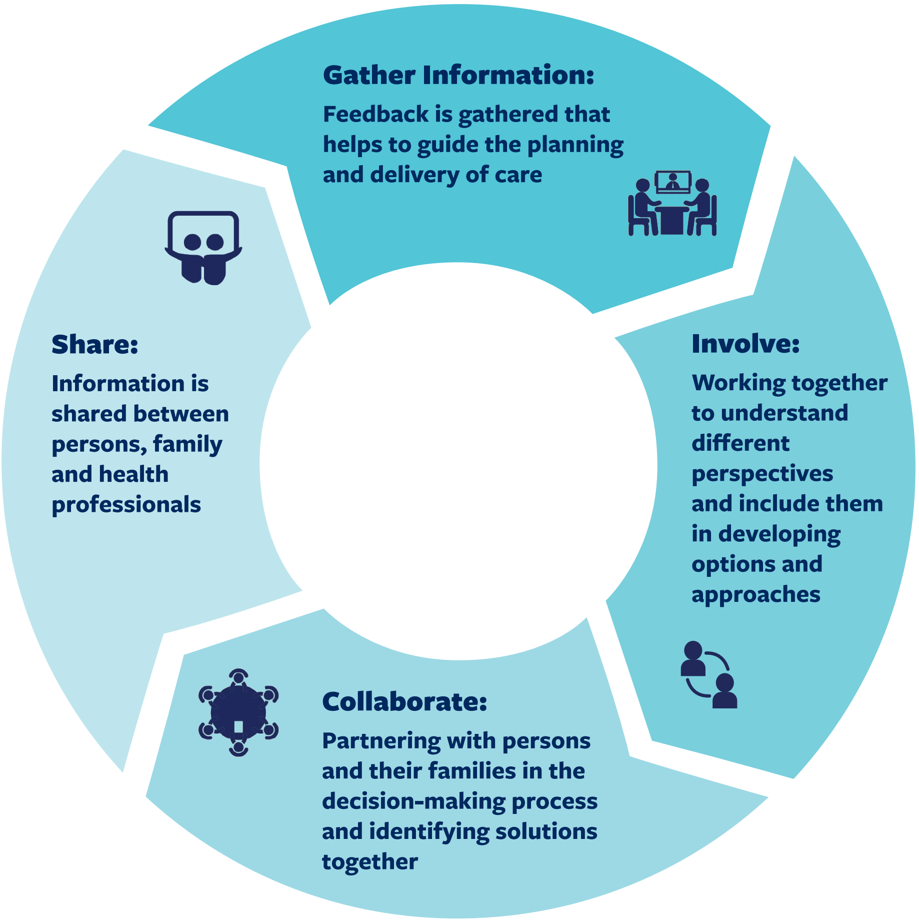
Resources and references

- The Patient Voices Network website at patientvoicesbc.ca
- REACH BC is a new online platform that aims to improve how British Columbians can connect with opportunities to volunteer in health research: reachbc.ca
- The BC Support Unit (Support for People and Patient-Oriented Research and Trials): bcsupportunit.ca
- The Institute for Patient and Family Centred Care: ipfcc.org
- CPH 1500: Travel & Business Expense Reimbursement Policy
- CPH 0400: Signing Authority
- Patient & Public Advisors Handbook – a VCH Community Engagement/Patient Voices Network collaboration
- Yankelovich, Daniel. The Magic of Dialogue: Transforming Conflict into Cooperation. New York: Simon & Schuster, 1999.

Principles of Patient and Family Centred Care

Respect and Dignity	Information Sharing	Participation	Collaboration
Patients and families are treated with respect and dignity throughout PHC	Patients and families have open access to their own information throughout PHC	Patients and families are invited to participate in clinical decision making at the level they choose	Patients and families are invited to partner with us as advisors

Ways of Engaging



Gather Information:
Feedback is gathered that helps to guide the planning and delivery of care

Involve:
Working together to understand different perspectives and include them in developing options and approaches

Collaborate:
Partnering with persons and their families in the decision-making process and identifying solutions together

Share:
Information is shared between persons, family and health professionals

Providence Health Care
How you want to be treated.

Confidentiality Undertaking
For PHC Volunteers (General)

In consideration of my volunteer service at Providence Health Care (“PHC”), I acknowledge and agree as follows:

- I have read, understand and will comply with the PHC Information Privacy & Confidentiality policy and related policies as amended from time to time, concerning the collection, use and disclosure of “Personal Information”, as defined in the BC *Freedom of Information and Protection of Privacy Act*, in the course of providing volunteer services to PHC;
- I understand that all Personal Information concerning staff, volunteers and clients who receive services (including medical records relating to patients and residents) is confidential and may not be communicated to anyone in any manner, except as required to perform my work duties and done in accordance with applicable policies;
- I understand and acknowledge that all information regarding PHC, including corporate, financial and administrative records, is confidential and may not be communicated or released to anyone in any manner except as authorized by PHC, or applicable policies;
- I understand I must protect all confidential information taken outside the office from theft or loss. This includes keeping the information with me at all times, storing it in a locked and secured area when unattended, and encrypting and password protecting it when stored on electronic mobile devices (e.g. USB drives, laptops, etc.);
- I will not copy, alter, destroy or remove any confidential information or records except as authorized by PHC in accordance with established policies;
- I understand that access to patient care information systems and other records is only for the purpose of and limited to what is required to perform my role. I will not access my record or those of family, friends or others, unless I am directly involved in providing care or other services to the individual the information is about.
- I will immediately report to the PHC Information Access & Privacy Office the potential or actual unauthorized disclosure or loss of any Personal Information as per policy;
- I understand that compliance with this Undertaking is a condition of my volunteer service with PHC and that failure to comply may result in immediate termination of my services, in addition to legal action by PHC and/or others.
- I agree that my confidentiality obligations in this Confidentiality Undertaking continue even after my relationship with PHC ends.

By accepting these terms, I am confirming that I acknowledge, understand and agree to the above.

☐ **I accept these terms.** *(please tick the box)*

Name (please print)	Signature	Volunteer Employee No.	Date

CPF0300: PHC Information Privacy & Confidentiality Policy

Direct questions to the PHC Information Access & Privacy Office: 604.806.8336 or privacy@providencehealth.bc.ca

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providencehealthcare.org