UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

Guide for Patient Partners

SHARING YOUR LIVED EXPERIENCE AT
THE UNIVERSITY OF OTTAWA HEART INSTITUTE

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This document is also available in French under the title | *Cette publication est aussi disponible en français sous le titre : Guide pour les patients partenaires*

Welcome!

Thank you for joining the University of Ottawa Heart Institute (UOHI) team of patient partners!

A patient partner is a patient, family member, or caregiver who shares valuable insight and experience to influence and transform clinical practices and research at the UOHI. The Patient Partnership Program is designed to be a positive and impactful experience for staff and patient partners alike. It is exciting to have you join our physicians, nurses, researchers, staff, and other volunteers. Patient partners are primarily volunteers. Some research projects budget to provide payment to patient partners.

Your lived experience is a powerful tool for inspiring change in our care practices and in influencing our research activities at the UOHI. By sharing your perspective and working with UOHI staff, researchers, other patients, and family members, you can make a real difference! The time and energy you invest will influence important changes and improve care for other patients and families.

This guide will help you understand what to expect in your role of patient partner and offer tips to help you get the most out of your partnering experience.

A note on diversity and inclusion in patient partnership:

The UOHI recognizes and respects the worth, dignity, and unique attributes of each person. Inclusion in patient partnership is achieved when we recruit and welcome the broadest possible range of people to the program.

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Section 1: About UOHI's patient engagement framework

At UOHI, patients are at the heart of everything we do.
Patient engagement means valuing the insight and lived experience of patients, their family members, and caregivers. The goal of patient engagement is to improve health outcomes and patient experiences.

Our guiding principles include:

We engage patients to enhance their personal care and health decisions. We also partner with patients and caregivers like you, to improve:

- Quality and delivery of patient care
- Design and delivery of research
- Knowledge and information exchange

As a patient partner, you may perform one or more of the following roles, depending on the project:

- Consult: Provide feedback on a health issue (for example, policy or decision)
- Deliberate: Discuss an issue and explore solutions together with healthcare staff
- Collaborate: Partner with healthcare staff to address an issue; develop, assess, and apply solutions

Examples of how this might look:

Quality and delivery of patient care	**Patient Partners can:** • Offer comments about their experience while receiving care • Share ideas and insights about their lived experience with cardiac disease and care to improve future care for all patients • Influence design, planning, and priorities for improvements in clinical services for patients
Design and delivery of research	**Patient Partners can:** • Influence research priorities based on patient needs and lived experiences • Contribute to research designs that reflect the services and outcomes important to patients • Participate in communicating research results
Knowledge and information exchange	**Patient Partners can:** • Help guide the design and content of educational material targeted to patients or family and caregivers • Help study teams translate results into patient-serving knowledge and actions • Facilitate information sessions for other patients

Please visit our website at ottawaheart.ca/patient-and-family-engagement for more information about patient and family engagement.

Section 2: Preparing for your patient partner role

There are two different ways that you may hear about a project:

1. The patient engagement coordinator will get in touch to present available partnership opportunities as they arise. If you express an interest in a partnership, the patient engagement coordinator will connect you with the project lead.
2. The project lead will contact you directly to discuss a patient partnership opportunity.

Regardless of how you are contacted, there should always be a conversation with the project lead where you can ask questions to make sure that you are comfortable with the duties, responsibilities, and time commitments. This discussion also helps ensure that the project lead understands what you are willing and able to give.

Some things to think about when considering a new partnership or project:

- Does the proposed work interest you?
- Is your experience of cardiac disease, care, or caregiving relevant to the topic?
- How involved do you want to be in the work?
- How much time and energy do you have to give?
- When are you available?
- Do you have any other time commitments or health considerations that may impact your participation?
- Are you comfortable participating virtually or in person, depending on the needs of the partnership or project?

Keep in mind that you can always contact the patient engagement coordinator or project lead if you have questions or concerns about whether a partnership or project is the right fit.

Section 3: Expectations of the Patient Partnership Program

While your project lead will discuss a lot of the details with you, there are some common commitments expected from all patient partners and all healthcare staff participating in the program:

As a patient partner, you commit to:

- Supporting and contributing to the goals of the project.
- Being clear about how much time you have to offer and what tasks you are comfortable taking on.
- Attending orientation and staying up to date on training, if needed.
- Preparing for meetings. This may include reviewing materials, reading a report, or completing a task before a meeting.
- Attending meetings. If, for any reason, you cannot attend a meeting, please let the project lead know.
- Sharing your input and opinions.
- Respecting the ideas and opinions of others.
- Understanding hospital policies that apply to your role.
- Reading, understanding, and signing the Volunteer Agreement.
- Maintaining confidentiality.
- Tracking your hours, especially if you are working onsite.

The patient engagement coordinator and the project lead commit to:

- Providing you with training so that you can be an engaged patient partner.
- Discussing the expectations (being clear about the time demands), limitations, and boundaries of your role.
- Providing you with support and helping prepare you in advance for meetings, if needed.
- Scheduling meetings based on availability of all team members, including yours, so that you can participate fully.
- Offering the option to attend meetings virtually or in person if that option is available.
- Treating your ideas and suggestions with respect and consideration.
- Informing you of hospital policies that apply to your role.
- Keeping you informed about how your feedback and ideas contribute to changes and improvements.

Confidentiality

As a patient partner, you may have access to health information about patients that must remain private. A federal law protects how health information can be used and disclosed. Health information cannot be shared outside the hospital or healthcare facility. It cannot be shared in any written, verbal, or email communications with friends, family, or anyone else unless specifically permitted. You must read and sign the confidentiality agreement to indicate your understanding of and cooperation with these requirements.

Conflict of interest

Are there any interests or commitments that could affect your ability to act in the best interest of your role as a patient partner? Conflicts may affect our judgment without us even realizing. You may be particularly interested in getting involved in projects that are related to conditions, treatments, or procedures you or your loved one have experienced. A commitment to improving things for others who are going through what you have experienced is not a conflict of interest. If you have any concerns about a perceived, potential, or actual conflict of interest, please speak to the patient engagement coordinator or project lead.

Section 4: Making a contribution

Here are some tips about how to be an engaged partner. As you read, make note of things that you think might be challenging for you. Discuss these with the patient engagement coordinator and ask for help if needed. Above all, have confidence in your participation, bring your positive attitude and sense of humour, and expect the best from your experience.

Tip 1: Share your views

You were asked to be a patient partner on a project because your ideas are valuable. You know what it is like to live day to day with your condition, or care for someone with a heart condition, and to receive care at a hospital—this is “lived experience.” As a patient partner, you are invited to draw on your lived experience to provide suggestions to improve the quality and safety of the care and research at the UOHI.

Focus on problem solving.	When sharing your thoughts, it is important to build on positive experiences. For example, “we found that things work well for our family when…” It is also helpful to share negative experiences. When you do, try to offer suggestions and solutions.
Respect people’s privacy.	If you share someone else’s experience, let people know that this experience did not happen to you personally and avoid using the person’s name. When speaking about experiences in the hospital, try not to use the names of staff members. If someone shares their personal story, do not use their name if you repeat a part of their story to support an idea or opinion with your team.
Keep an open mind.	Be willing to see past your own views and experiences. You will work with doctors, health professionals, nurses, hospital staff, and other patients and caregivers who bring their own views. Different perspectives can lead to better conversations and outcomes.

Tip 2: Draw on your communication and teamwork skills

As a patient partner, you will work with people from many backgrounds. You may work with healthcare providers, staff, hospital leaders, researchers, and other patients and family members who all bring their own views. Good communication and teamwork skills help you explain your ideas clearly and develop good working relationships.

- **Think carefully about the words you use.** If you want to tell a story that will bring up strong emotions, ask your patient engagement coordinator or another patient partner to help you think about what you want to say and how you want to say it. Think about the goal and think through how best to get your points across.
- **Focus on your key message.** It helps to choose a key message to decide what you want to focus on at a particular point in the discussion.
- **Be an active listener.** When someone is speaking, it is natural to think about what you are going to say in response. However, it is important to give all your attention to the person who is speaking and to hear them out before you respond.
- **Clarify when needed.** Make sure you understand what other people are saying. One way to make sure you understand someone's point is to say, "What I think I hear you saying is…" and then repeat what you believe you heard them say. This gives people a chance to clarify their points if needed.
- **Share the time.** Be aware of how you are sharing time with others when you are speaking. If needed, adjust to give others time to express their ideas.
- **Be accepting.** Others may interpret the same experience differently. Neither person is right or wrong. Experience is about you. Acknowledging that difference does not make your experience any less important.

Tip 3: Ask questions

Sometimes, health workers use language that others may not understand. If this happens to you, feel confident to speak up and ask people to explain what they mean.

- **Ask clarifying questions**. For example, “Let me make sure I understand correctly. I think you are saying…”
- **Ask for definitions** of medical terms, abbreviations, or other terms. For example, “I’m not sure I know what ‘CABG’ means. Would you please explain it to me?”
- **Ask for more details**. For example, “Can you please walk me through this so I can picture it?”

Tip 4: Be prepared for different points of view

Disagreements are a natural part of working on a team. Expressing your views when they are different from those of other people can be challenging, especially in situations where your experience touches close to the heart. However, your honest opinion can lead to greater understanding.

- **Be considerate.** Describe your point of view in terms of your perception or opinion rather than as a fact or the truth for all patients and families. For example: “I see it differently,” “I have a different experience,” or “That doesn’t work so well for me.”
- **Respectfully challenge**. Ask for more background information when people say that a change is not possible. For example: “Help me understand why this change is not possible. What have you tried?” Sometimes hospital staff are so used to the way things have always been done that it is hard for them to imagine doing things in other ways. Sometimes, there are things that really cannot be changed, but you should ask to understand the reasons why.
- **Be receptive to team decisions.** Sometimes the decision taken may be different than the one you would have preferred. It is important that you are given more information about the reason for the decision and have an opportunity to ask questions.
- **Follow up.** If you find yourself upset after a meeting, talk to your patient engagement coordinator, who will make sure that your concerns are addressed and help you resolve them.

Tip 5: Take responsibility for your commitments

When you agree to become a patient partner, make sure you fully understand the commitment you are making. The project lead is relying on you to bring forward the patient/caregiver perspective. Without patient partner input, the results of the work will fall short. If something happens and you can no longer keep your commitment, please let the project lead know.

- **Prepare for meetings.** If there are tasks that you are asked to do between meetings, come to the meeting prepared to share information about your progress on these activities and projects. Do your best to be on time for meetings and stay until the end.
- **Be present and engaged.** During meetings and other exchanges with team members, focus on the discussion and contribute as the opportunity arises. If you need to step away for a few minutes, excuse yourself. This way, if a question arises that would benefit from your input, the team will know that you are momentarily distracted.
- **Provide feedback and input when asked, or when you feel you have value to add.** Take the time to review and respond to requests for feedback and input in a timely manner. This gives the project lead an opportunity to balance the multiple views from project team members at the same time.
- **Inform your project lead about your schedule.** If you cannot participate in a meeting, notify the project lead, and ask for an update before the next meeting. If you find that you are having difficulty balancing your other commitments with patient partner activities, talk to the patient engagement coordinator about cutting back on some of your duties or take a break.

Taking care of you

Please keep your health a priority! Your dedication and willingness to be a patient partner is greatly appreciated. Remember, your well-being is the reason for this important work.

If you cannot honour your commitments due to health reasons, this is never a problem.

Tip 6: Ask for feedback

One of the best ways to develop your skills as a patient partner is to ask for feedback. Getting feedback is especially important if you would like to expand your involvement and take on new roles and responsibilities.

- Ask for specific feedback after you have completed a task.
- Ask how you can learn more. If there is a topic you would like to learn more about or some skill you would like to work on, ask the patient engagement coordinator for resources, individuals to meet with, or time to discuss it further.

Tip 7: Build relationships with other patient partners

Ask them for support when you need it, and always be ready to support them as well.

Many projects include more than one patient partner. You may see familiar faces on multiple projects, or you may meet other patient partners in different forums. Feel free to collaborate and discuss your projects offline by email, phone, or in person. Discussing your thoughts between project meetings can help you brainstorm and get to know other patient partners.

- Introduce yourself to other patient partners at in-person and virtual meetings.
- If you notice that another patient partner is experiencing difficult emotions during a discussion, feel free to reach out to them to offer support. We all relate best to others who have had similar life experiences.
- Try to attend networking events for patient partners. This may be especially helpful if most of your volunteer work is virtual, and you don’t often meet other patient partners face-to-face.
- Patient partners volunteer at onsite and offsite events. Feel free to say hello if you see a fellow patient partner at an event!

If you are curious about how to raise or respond to a certain situation, making connections with other patient partners is an opportunity for you to touch base with someone familiar with this work.

Section 5: Sharing your story

There will be times when sharing your story can help others understand your healthcare experiences and how they have affected you and your family or caregivers. It can also be a powerful way to show the need for specific changes and improvement at the UOHI.

As a patient partner, you may be asked to share your story with a variety of people. For example, you may be asked to help inform doctors, health professionals, nurses, and other hospital staff about why it is important to conduct bedside shift reports or how involving patients and families in the discharge process improves outcomes. Or you may be asked to speak to a group of patients and family members about becoming patient partners. The patient engagement coordinator will provide you with training and support for each of these opportunities. You should only accept invitations to speak if you are comfortable with the request.

Before you agree to share your story

Ask what is expected of you and what you can expect:

- When, where, and for how long do you want me to speak?
- What part of my story is relevant to the topic being discussed in the session?
- What do you hope will happen as a result of me sharing my story?
- Who is the audience? How many people will be there?
- Who else will be speaking?
- Will I be answering audience questions?
- Will the session be broadcast or recorded?

Preparing to share your story

If you have decided to share your story, think about what you want to say and how you want to say it. Some people write down their main points to keep them focused. You can use the worksheet below called Sharing Your Story to help you organize your thoughts.

Before you speak in a meeting or to a group, take the time to practice. Time yourself and see if you are staying within the requested time frame.

Also keep in mind:

- **Focus on making a difference:** What do you want people to learn from your story? How do you think it can help influence change?
- **Share to move the discussion forward.** If you have had a poor healthcare experience, sharing it may be a way to contribute as a patient partner in order to improve the experience of future patients. If you feel very angry or sad about a situation or an event, pause and think about whether you can share it without those strong emotions taking over. Staff are very interested in learning from your experience, and it would be unfortunate to unintentionally derail the discussion. To consider ways to share your suggestions for improvement in a way that helps you manage the emotions, talk to the project lead, the patient engagement coordinator, or someone else you trust.
- **Focus on experiences rather than individuals.** Try to avoid using the names of doctors, nurses, and other staff. If you talk about another facility where you received care, please do not mention it by name.
- **Be prepared for emotional reactions.** Expect that some people who hear your story may be deeply moved. Also remember that you may feel emotional when you tell your story.
- **Remember that you are in control.** If people ask you questions and you do not know the answer or are uncomfortable sharing the answer, it is okay to say so. If you do not want to answer a question, it is okay to say that as well.

See ***Appendix A – Sharing Your Story: A planning worksheet***

Section 6: Resources

University of Ottawa Heart Institute

For more information about the University of Ottawa Heart Institute, its mission, vision, values, structure, and more, please visit:

- About UOHI: ottawaheart.ca/who-we-are
- UOHI Strategic Plan: ottawaheart.ca/our-strategic-plan
- Research goals and priorities: ottawaheart.ca/research-goals-priorities

Patient Engagement Framework

Foundations for patient engagement at the UOHI:

- Patient Engagement Framework: ottawaheart.ca/media/18802
- Health Quality Ontario Patient Partnering Framework: hqontario.ca/Patient-Partnering/Patient-Partnering-Framework
- Canadian Institutes of Health Research Strategy for Patient Oriented Research (SPOR): cihr-irsc.gc.ca/e/48413.html

To read some stories about how patient partners have made an important difference to the work of the UOHI, visit: ottawaheart.ca/be-patient-partner.

Appendix A – Sharing Your Story: A planning worksheet

Use this worksheet to help plan what you want to share about your experience.

Why were you asked to share your story? What aspect of your story is relevant to this audience?

What are the key messages you want to share?

What are the two or three specific points that you want the audience to remember?

1.

2.

3.

Key points about your lived experience; keep in mind what you are willing to share and comfortable talking about.

What went well during your lived experience? What things did people say or do that were helpful?

What did not go well during your lived experience? What things did people say or do that were not helpful?

Is there anything else about your lived experience that you would like to share?