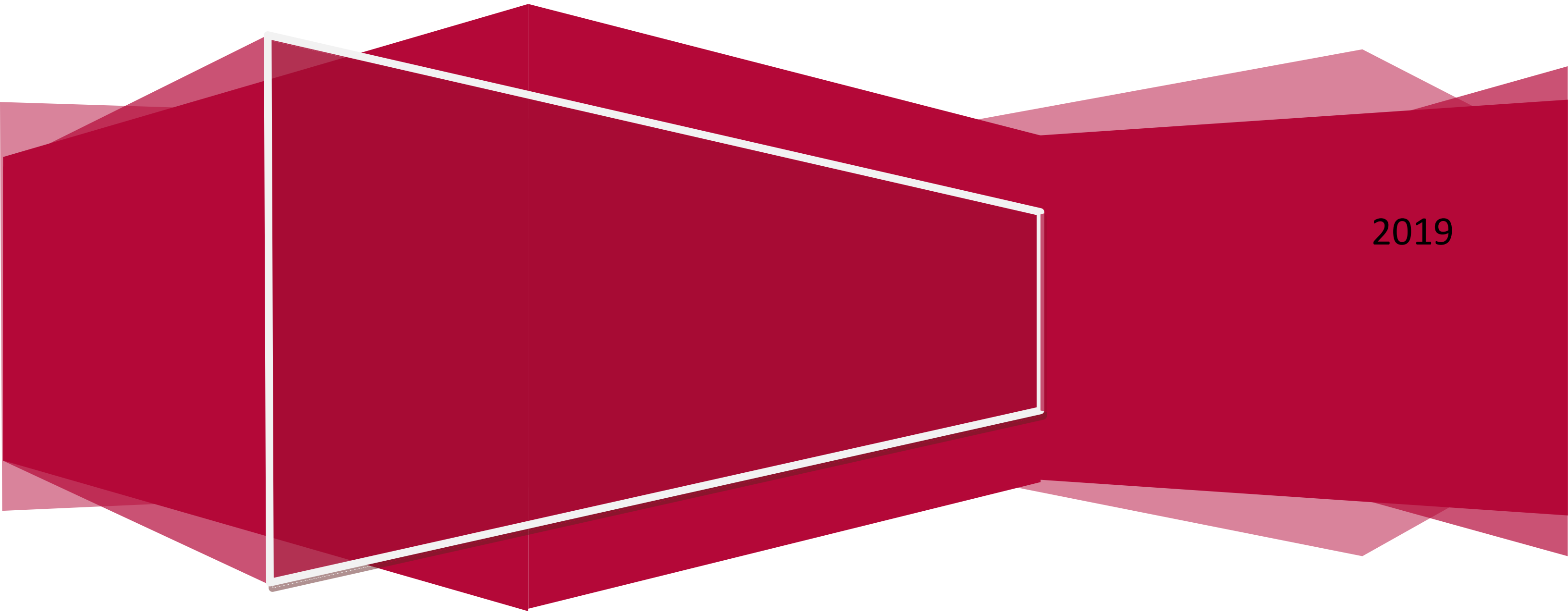
UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA

PATIENT ALUMNI
ASSOCIATION DES
ANCIENS PATIENTS

Patient Partner Guide

The University of Ottawa Heart Institute



2019

Welcome!

Thank you for agreeing to become a Patient Partner with the University of Ottawa Heart Institute (UOHI). We are excited to have you join our team of physicians, nurses, researchers, staff and volunteers.

As a Patient Partner, your lived experiences are a powerful tool for inspiring change in our care practices and/or in directing our research activities at UOHI. By sharing your perspective and working with our UOHI staff, researcher, and other patients and family members, you can make a real difference. The time and energy you invest will help us make important changes and improve the care experience for other patients and families!

To read some stories about how Patient Partners have made an important difference to the work of the UOHI, visit the Patient Engagement page at the UOHI website here: *https://www.ottawaheart.ca/patients-visitors/patient-engagement-framework*

About This Guide

This guide will help prepare you for your role as a Patient Partner. It is organized into the following sections:

- Section 1: What is patient engagement? Why do we want Patient Partners?
- Section 2: Expectations for Patient Partners
- Section 3: Six Tips for being an engaged Patient Partner
- Section 4: Sharing your story
- Section 5: Resources
- Appendix A: Sharing your story: A Planning Worksheet
- Appendix B: Volunteer Agreement
- Appendix C: Ground Rules for Dialogue
- Appendix D: Glossary of Terms

This guide is intended to accompany other training you may be required to undertake from the UOHI to help prepare you to be a Patient Partner.

Section 1: What is Patient Engagement? Why do we want Patient Partners?

At the University of Ottawa Heart Institute, we want to make sure that everyone who comes into the Institute has the best experience possible.

Patient engagement means involving patients in generating ideas and having discussions with health care providers about how to improve care. “Patient” could be the person who is getting the care or their caregiver (family member or other caring person). Care that puts the patient first is called “patient centered.” Our goal here at the University of Ottawa Heart Institute (UOHI) is to continue to give excellent patient-centered care. We know that we can reach this goal when we all work together.

We want patients to be engaged throughout their care journey: This includes during care, within the clinic or unit, within the UOHI, and within the community. This kind of engagement will improve care for individual patients, for patients in Ottawa, and for patients across health care systems. Here at the UOHI, we really want patient engagement to be part of daily life for our board members, leaders, researchers, staff, patients and caregivers.

The values that guide patient engagement at the UOHI include:

- Trust
- Inclusiveness
- Support
- Mutual respect
- Patient-centered care
- Partnership – a shared commitment

Becoming a Patient Partner provides you with an opportunity to share your point of view and work with hospital staff, researchers, and other patients and family members, to make a real difference. As a patient or family member, your lived experiences are a powerful tool for inspiring change in our care practices and/or directing research activities. The time and energy you invest will help us make important changes and improve the care experience for other patients and families.

Examples of specific ways in which Patient Partners have helped include:

- Participating in discussions about health care quality and safety with doctors, nurses, hospital staff, patients, families, and caregivers, including helping to identify places where errors might occur
- Sharing ideas about how patients and families can have meaningful opportunities to participate in their care and decisions about their care
- Revising or helping to create tools and resources for patients and families
- Sharing their story during training sessions for doctors, nurses, and other hospital staff
- Working with research teams to provide patient input into designing research studies, including choosing outcomes that are relevant to patients
- Reviewing and providing feedback on research proposals

The development and support for Patient Partners was created through a partnership between the UOHI and the UOHI Patient Alumni. Through a joint recognition of the opportunities and insight that could be generated by more fully integrating the patient experience in both patient care and research grew a mutual commitment for engaging our patients and caregivers in improving outcomes.

Section 2: Expectations for Patient Partners

As a Patient Partner, you may be assigned duties and/or responsibilities. Duties and responsibilities will be outlined by your program Director and will abide by hospital policies and procedures. The University is committed to ensuring a safe, secure and healthy work environment for all staff, volunteers and visitors. It is important to note that there are limitations and boundaries to your role, which must also be respected.

We commit to:

- Provide you with the training you need to be an engaged Patient Partner.
- Provide you with the resources and organizational support you need to do your tasks well.
- Identify a staff liaison that will help you prepare in advance for meetings; provide you with information; and be available if you have comments, questions, or concerns about your role.
- Be clear on the expectations related to the role we are asking you to take on: time needed for preparation and to attend meetings, how often you need to be at the UOHI in person, time for required training (if needed), etc.
- Listen and respond to your ideas and suggestions respectfully.
- Keep you informed about how your feedback and ideas contribute to changes and improvements.

You commit to:

- Support and contribute to the goals of the project, the mission and vision of the University of Ottawa Heart Institute (UOHI).
- Attend orientation and training, as needed.
- Prepare for meetings. This could include reviewing materials, reading a report, or completing a task before a meeting.
- Attend meetings as required. If for some reason, you cannot attend a meeting, please call your staff liaison. You can also ask if there is another way you can participate (for example, by phone).
- Actively participate in meetings by sharing your input and opinions while respecting the ideas and opinions of others
- Abide by the Policies, Procedures, and Guidelines of the UOHI.
- Maintain confidentiality. Read, understand and sign a Confidentiality Agreement.
- Read, understand and sign the Volunteer Agreement (Appendix B).

A further note on Confidentiality

As a Patient Partner, you may have access to health information about patients that MUST remain private. It is important to know that a federal law protects how health information can be used and disclosed. Health information cannot be shared outside the hospital or health care facility. It cannot be shared in any written, verbal, or e-mail communications with friends, family, or anyone else unless specifically permitted.

What you see or hear in your role as a Patient Partner must remain here. We will ask you to read and sign a 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 the Patient Partner activity that you are involved with? Conflicts may affect our judgment without us even realizing it. You may be particularly interested in getting involved in projects that are related to conditions you have experienced. Your commitment to improve things for others who are going through what you have experienced is not a conflict of interest. If you have any concerns about having a perceived, potential or actual conflict of interest, please speak to your liaison about it.

Section 3: Six Tips for being an engaged Patient Partner

This section contains tips for Patient Partners 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 your staff liaison and ask for more help if needed. Above all, have confidence in your participation as a partner and keep at it. Bring your positive attitude, sense of humor and expect the best from your experience.

Tip 1: Share your views

You have been asked to be a Patient Partner because your ideas are valuable. You know what it is like to live day to day with your condition and to receive care at a hospital -- what we often call “lived experience”. As opportunities for improvement arise, the committee selects Patient Partners based off their “lived experiences” to join in on discussions. By hand selecting members, we are able to hear your suggestions for improving the quality and safety of the care we provide, and your ideas for the research we undertake. This helps ensure the best possible experience for our patients and families.

- **Focus on problem solving.** When sharing your story, 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 possible solutions. More ideas on how you can prepare to share your story are in the next section of this Guide.
- **Respect people’s privacy.** If you share someone else’s story, let people know that this experience did not happen to you 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 attribute names if you share their story outside the room.
- **Keep an open mind.** Be willing to see past your own views and experiences. You will be working 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 skills

As a Patient Partner, you will work with many types of people from many different backgrounds. You may work with health care providers, staff, hospital leaders, researchers and other patients and family members – who all bring their own views. Good communication skills will 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 staff liaison or another Patient Partner to help you think about what you want to say and how you want to say it. Try to remember that anger usually does not produce good results.
- **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 as you in a different way. Neither person is right or wrong. Experience is about you. Acknowledging that difference in no way makes your experience less important.

Tip 3: Ask questions

Through your care experience, there may have been times when health workers used language that you did not understand. That can happen when you are working as a Patient Partner too. If it does, 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 ready for different points of view

Disagreements are a natural part of working on a team. Expressing your views when they are different from the views of others 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 doctors, nurses, and other hospital staff are so used to the way things have always been done that it is hard for them to see doing things in other ways. Sometimes, there are things that really cannot be changed, for very appropriate reasons. In this case, you should ask about the reasons why.
- **Be receptive to decisions.** Sometimes the decision taken may be different than the one you would like. Know that your experience has been heard and respected. The decision needs to be accepted for the work of the team to move forward together. Sometimes, we can agree to disagree.
- **Follow- up.** If you find yourself upset after a meeting, talk to your staff liaison. Your staff liaison can make sure that your concerns are addressed and help you resolve them.

Tip 5: Honor your commitments

When you agree to become a Patient Partner, make sure you fully understand the commitment you are making, and then keep that commitment.

Taking Care of You

Please be sure to keep your health a priority! You are first and foremost our patient. We greatly appreciate your dedication and willingness to be a Patient Partner. Remember, you are the reason we do the work we do.

If you are not able to honor your commitments due to health reasons, this is never a problem.

- **Prepare for meetings.** If there are responsibilities that you are asked to fulfill between meetings, come to the meeting prepared to share information about your progress on these activities and projects. Be on time for meetings and stay until the end.
- **Inform your staff liaison about your schedule.** If you are not able to attend a meeting in person, ask if you can call in (through conference call or speaker phone). If you cannot participate in a meeting, notify your key contact or staff liaison; ask if you can get an update before the next meeting. If you find that you are having difficulty balancing your personal and family life with Patient Partner activities, talk to your staff liaison about whether you can cut back on some of your duties or take a short-term break.

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 for regular feedback meetings** with your staff liaison. If you will be serving as a Patient Partner for several months or more, ask your staff liaison to meet with you on a regular basis so that you can become aware of your strengths and areas for improvement.
- **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 your staff liaison for resources, individuals to meet with, or time to discuss it further.
- **Ask for support** from other Patient Partners when you need it and always be ready to provide support to them.

Section 4: Sharing your story

Sharing your story can help others understand your health care experiences and how these experiences have affected you and your family. 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 share your story with hospital leaders to help them understand why it is important for our hospital to work with patients and family members. You may be asked to help inform doctors, health professionals, nurses, and other hospital staff about, for example, why it is important to conduct bedside shift reports or involve patients and families in the discharge process. Or you may be asked to speak to a group of patients and family members about becoming Patient Partners.

We will provide you with training and support for each of these opportunities. You should accept invitations to speak only if you are comfortable with the request.

Before you agree to share your story

Before you agree to share your story in a training session, meeting, or presentation, get information about what is expected of you and what you can expect. Ask the following questions:

- When, where, and for how long do you want me to speak?
- 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, audio or videotaped?

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, it helps to practice. Time yourself and see if you are staying within the requested time frame.

Also keep in mind the following tips:

- **Only share what you want to share.** If you still feel angry about a certain situation or event and do not think you can talk about it in a helpful manner, it may be best not to share that part. You can also talk about it with someone you trust. You may wish to ask for ideas about how to share that part of the story in a way in which people will listen.

- **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 have 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, 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 5: Resources

Understanding the University of Ottawa Heart Institute

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

- ✓ *About UOHI*
- ✓ *UOHI strategy*
- ✓ *ORACLE strategy*

Concerns, complaints and compliments

The UOHI Quality Department supports and manages concerns, complaints and compliments. The quality department can be reached at quality@ottawaheart.ca or by phone 613-696-7000 ext. 19305.

We want to make sure that patients and families have good experiences and feel supported while they are in the hospital. We welcome your thoughts and ideas about how to make sure this happens.

The UOHI Patient Alumni

The Patient Alumni is passionate and committed to supporting patient engagement at the UOHI and has been actively involved in integrating the patient experience in clinical and research work. All patients who have received care at the UOHI and their caregivers are members of the Patient Alumni. We seek opportunities to improve the patient experience at the UOHI through our work on patient engagement, as well as through events, community building, and funding support for other initiatives. The Patient Alumni offers other ways to get involved in the UOHI community to support patients and caregivers. Find out more here: http://ottawaheartalumni.ca

Interested in continuing to be a Patient Partner?

If you are participating in a one-time discussion group or very short-term work group, and would like to continue as a Patient Partner in Care, in another capacity, ask your staff liaison about your participation after you have completed the task. Not all Patient Partners will be asked to participate in every group or project. You may or may not be contacted to participate in future projects based on your specific complement. Please know that your contribution has been valuable.

If you are interested in continuing as a Patient Partner for Research, you may register on-line by completing a questionnaire on the UOHI website: https://www.ottawaheart.ca/patients-visitors/engage-clinical-research/be-patient-partner

If you are interested in continuing as a Patient Partner for Quality of Care, you may do so by sending an email to quality@ottawaheart.ca

Appendix A

Sharing Your Story: A planning worksheet

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

Why was I asked to share my story?

What are the key messages I want to share?

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

1.
2.
3.

Key points about your hospital experiences – keep in mind what you are willing to share and what is too private to share.

What went well during your hospital experiences?
What things did people say or do that were helpful?

What did not go well during your hospital experiences?
What things did people say or do that were not helpful?
(Reminder that this is not the official complaint mechanism)

What improvement would you suggest? What would you rather have happened?

Appendix B

Volunteer Agreement

1. **SALARY AND BENEFITS:** I understand that the work performed is on a volunteer basis and that there is no employment relationship with the University of Ottawa Heart Institute (UOHI). I am not entitled to a salary or to benefits.

2. **APPOINTMENT RESPONSIBILITIES:** I understand that my responsibilities are outlined by my program director and I endeavour to perform my duties to the best of my ability. This includes, supporting the Mission and Vision of the UOHI, and meeting the commitments of orientation, training, attendance and active and respectful participation.

3. **POLICIES:** I understand that, the conditions of my appointment are subject to all applicable laws and that I am expected to comply with all hospital policies, procedures and guidelines.

4. **CONFIDENTIALITY:** I understand that in my appointment I will have access to personal, financial or other information that is strictly confidential. I agree not to reveal this information to other persons or organizations. I agree to sign the more detailed Confidentiality Agreement.

5. **OWNERSHIP OF WORK:** I understand that, in accordance with the policies of the Institute, that the Institute owns all discoveries, inventions, research and development, formulas and technology (collectively the “Work”) that may be developed by my during the course of my appointment with the Institute in the scope of my work at the Institute and/or using facilities owned or operated by the Institute, and/or using funds administered by the Institute. I agree to waive all moral rights (requiring your name to be credited when your work is used) to any such Work (including, but not limited to, the right to the integrity of the Work, the right to be associated with the Work as its author by name or under a pseudonym and the right to remain anonymous).

6. **TERMINATION:** I understand that UOHI or I may terminate this agreement at any time, for any reason, with or without cause, and without notice. Upon termination, I hereby agree to return all Heart Institute property including, but not limited to: keys, identification badge, work related documents, equipment belonging to the Institute, etc.

I have read, understood and agree with the terms and conditions of this agreement. I accept the opportunity with the terms and conditions above.

______________________________	______________________________
Volunteer Name (Print)	**Date**
______________________________	______________________________
Volunteer Signature	**Witness**

Appendix C

Ground Rules for Dialogue

GROUND RULES FOR DIALOGUE

THE CHANGE FOUNDATION

- Express disagreement with ideas not personalities
- Share airtime
- Stay on topic–connect to what others have said
- Understand & learn from each other
- We are all equal. Leave rank at the door
- Listen respectfully especially when you disagree. Acknowledge you have heard the others
- Look for common ground
- Identify & test assumptions

changefoundation.ca

Glossary of Terms

Conditions

ACS = Acute Coronary Syndrome
AF = Atrial Fibrillation
DM = Diabetes
HF = Heart Failure
MI = Myocardial Infarction
NSTEMI = Non ST-Segment Elevation Myocardial Infarction
STEMI = ST-Segment Elevation Myocardial Infarction

Procedures

AVR = Aortic Valve Repair/Replacement
CABG = Coronary Artery Bypass Graft (Bypass surgery)
CATH = Cardiac catheterization
EP = Cardiac Electrophysiology
MVR = Mitral Valve Repair/Replacement
MVST = Multi Vessel Small Thoracotomy
PCI = Percutaneous Coronary Intervention
PTE = Pulmonary Thrombo Embellectomy
SVST = Single Vessel Small Thoracotomy

Infection Control

CDiff/CDAD = Clostridium Difficile Associated Disease
CLI = Central Line Infection
HH = Hand Hygiene (Handwashing)
MRSA = Methicillin-Resistant Staphylococcus Aureus
SSI = Surgical Site Infection
VAP = Ventilator Associated Pneumonia
VRE = Vancomycin Resistant Enterococci

Miscellaneous Terms

ALC = Alternate Level of Care
APN = Advanced Practice Nurse
BPG = Best Practice Guidelines
CQI = Continuous Quality Improvement
GAP = Guidelines Applied in Practice
IVR = Integrated Voice Response (automated calling)
M&M rounds = Morbidity & Mortality rounds
NP = Nurse Practitioner
PDSA = Plan, Do, Study, Act
PHIPA = Personal Health Information Protection Act

QCIPA = Quality of Care Information Protection Act
QIP= Quality Improvement Plan
THM = TeleHome Monitoring
Tx = Treatment