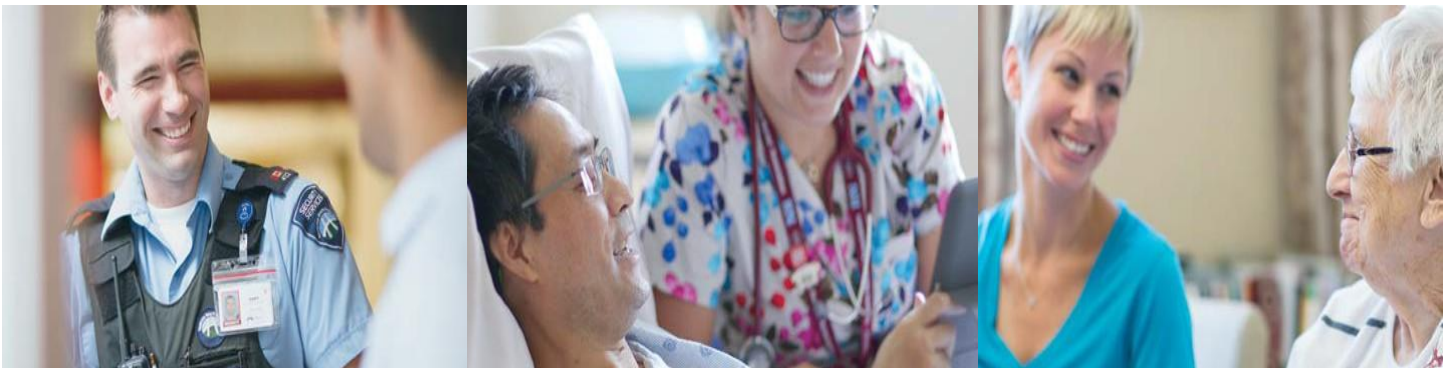




Patient and Family Advisor Handbook



About this handbook

This handbook was developed by Patient and Family Advisors (PFAs) for PFAs to prepare and support you in your new role. The information will:

- Provide an overview of Hamilton Health Sciences (HHS)
- Explain the responsibilities and expectations of PFAs
- Outline tips for being engaged in your role

Acknowledgements

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We appreciate the opportunity to have reviewed, adapted and adopted some of our content from the following handbooks:

- Agency for Healthcare Research and Quality. (n.d.). *Patient and family advisor orientation manual*. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Tool_9_AdvisorTrain_508.pdf
- Institute for Patient-and-Family-Centered Care. (2017, June). *How to be an effective patient & family advisor: Guide to partnering with your clinic*. Patient Centered Primary Care Collaborative. <https://www.pcpcc.org/sites/default/files/resources/Patient%20and%20Family%20Advisor%20Guide.pdf>
- St. Joseph's Care Group. (2020, March). Guide for client & family partners: Supporting you in your role.
- Trillium Health Partners. (2017, March 31). Patient and family advisor information booklet.
- Vancouver Coastal Health. (2017, September). *Community engagement advisory network CEAN members handbook*. <http://cean.vch.ca/wp-content/uploads/sites/26/2017/09/CEAN-Member-Handbook-FINAL-4.pdf>

TABLE OF CONTENTS

	Page
Welcome to Hamilton Health Sciences	4
Section 1: About Hamilton Health Sciences <ul style="list-style-type: none"> ○ Vision, Mission, Values ○ Strategic Plan ○ Our locations ○ What is Patient and Family Centered Care? ○ What are the benefits of Patient and Family Centered Care? ○ Organizational chart – Patient and Family Advisor (PFA) Program ○ What is the PFA Program? ○ Benefits of being a PFA ○ Key contacts and supports 	5
Section 2: Responsibilities and expectations <ul style="list-style-type: none"> ○ Training and orientation ○ Time commitments ○ What does a PFA do? ○ How PFAs become aware of opportunities ○ Finding the right fit ○ Staff liaison ○ What happens when the opportunity I am involved with ends? ○ Tracking your volunteer hours 	14
Section 3: Tips for being an engaged PFA <ul style="list-style-type: none"> ○ How can I effectively participate? Advice from one PFA to another ○ Guidelines on working together – preparing for opportunities ○ Virtual meeting guidelines ○ Sharing your healthcare experiences 	18
Section 4: Ways to learn more	23
Appendix A: Activity log template	24
Appendix B: Healthcare acronyms and terminology for PFAs	25



Welcome Letter

Welcome Patient and Family Advisors!

It is my pleasure to welcome you to the Patient and Family Advisor (PFA) Program at Hamilton Health Sciences (HHS). Thank you for volunteering your time to partner with staff, physicians and leaders across the organization to improve healthcare delivery, safety, and experiences. At HHS, we value patient and family-centered care and strive to provide an excellent patient and family experience every time by communicating, collaborating and responding with compassion.

As a PFA, you help to support a culture where we are continuously improving the hospital experience to support our vision of providing the Best Care for All. As an integral member of the HHS community, your voice of lived experiences and perspectives opens our eyes and ears to those we serve, and guides what, where, and how improvement efforts are best spent. Your work in partnership with a variety of stakeholders helps focus attention on what really matters to patients and families, and shapes safety and quality improvement changes to make the greatest impacts.

We are grateful you have chosen to volunteer at HHS and thank you for sharing your time, knowledge, lived experience and perspective to improve the care we deliver every day.

A handwritten signature in black ink that reads 'Tim Dietrich'.

Tim Dietrich

Interim Vice President, Quality and Performance

SECTION 1: ABOUT HAMILTON HEALTH SCIENCES

VISION

Best Care for All

MISSION

To provide excellent health care for the people and communities we serve and to advance healthcare through education and research

VALUES

Respect

We will treat every person with dignity and courtesy

Caring

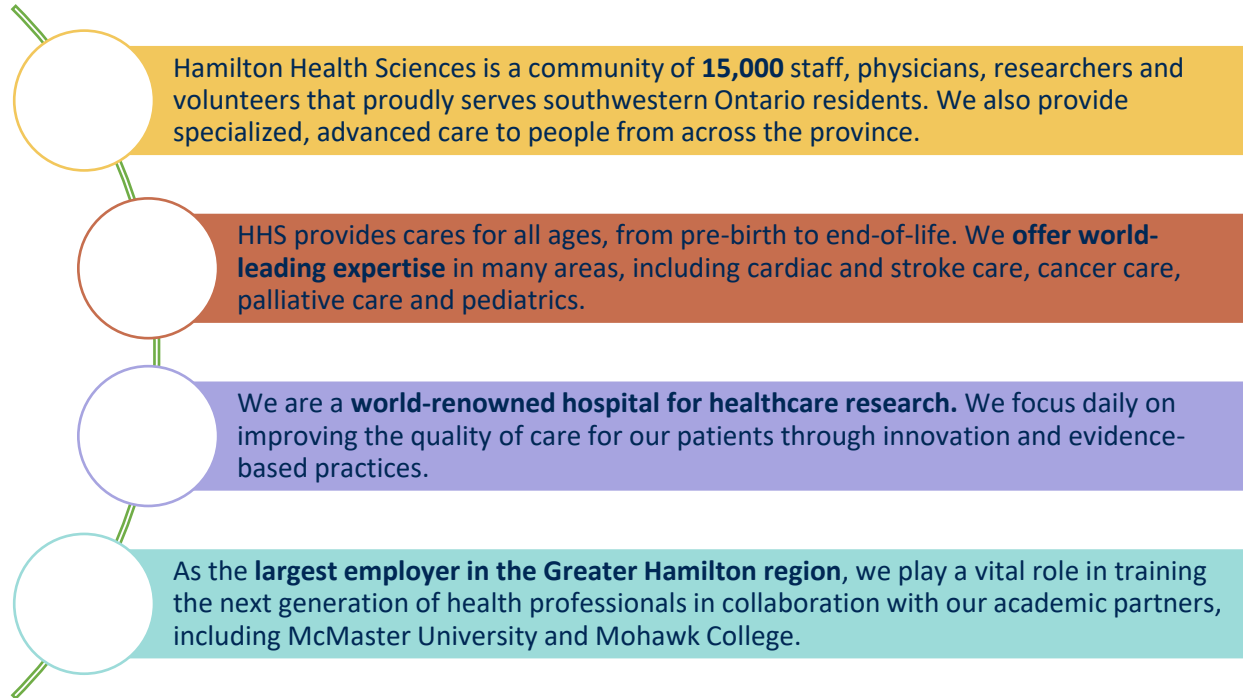
We will act with concern for the well-being of every person

Innovation

We will be creative and open to new ideas and opportunities

Accountability

We will create value and accept responsibility for our activities



STRATEGIC PLAN

North Star Objectives



Patients

- ▶ Be a top ranking hospital for the quality of our care and the excellence of our patient and family experience.



Sustainability

- ▶ Be responsible resource stewards.



People

- ▶ Create a safe work environment with highly engaged staff and physicians.



Research, Innovation & Learning

- ▶ Be one of Canada's top research hospitals.



TRANSFORMATION PROGRAM

- Our Healthy Future
- Epic Optimization
- Post-COVID Recovery
- Workforce Planning

CORPORATE PROJECTS

- Equity, Diversity and Inclusion Plan
- Staff Wellness
- Clinical Services Review
- Epic Stabilization
- Scheduling and KRONOS Renewal
- Environmental Management Plan
- Clinical Program Review - NICU
- 2023 Accreditation
- Physician Feedback Process
- Research Strategic Plan

IN-YEAR OBJECTIVES

- Sepsis
- Hospital deaths following major surgery
- Pressure injuries
- Lost time injury
- Bar Code Medication Administration
- Hand hygiene

OUR VISION:

Best Care For All

OUR MISSION:

To provide excellent health care for the people and communities we serve and to advance health care through education and research

OUR VALUES:

Respect | Caring | Innovation | Accountability

Last updated: May 2023

To learn more about Hamilton Health Sciences' Strategic Plan, please visit <https://www.hamiltonhealthsciences.ca/about-us/our-organization/>

HHS SITES AND DESCRIPTIONS

Hamilton General Hospital (HGH)



- The cardiac and vascular program performs more heart surgeries and procedures than any other facility in the province.
- The neurosciences and trauma program is a provincial leader in both volume and complexity of care provided.
- The stroke program has pioneered an integrated approach to care, and the burn treatment program is one of only two in Ontario.

Ron Joyce Children’s Health Centre (RJCHC)



- Ron Joyce Children’s Health Centre (RJCHC), a site of McMaster Children’s Hospital, is home to a range of outpatient services focused on child rehabilitation and developmental health.
- It hosts Canada’s largest prosthetics and orthotics program, which serves both children and adults across the country.

Juravinski Cancer Centre (JCC)



- Regional referral centre for central-west Ontario and serves more than 1.7 million people.
- JCC is where cancer treatments such as chemotherapy and radiation take place, as well ground breaking cancer research.
- The state-of-the-art CIBC Breast Assessment Centre at the JCC provides leading-edge care in the diagnosis of breast cancer.

St. Peter’s Hospital (SPH)



- St. Peter’s Hospital provides complex continuing care.
- It provides four inpatient programs: palliative care, restorative rehabilitation, complex medical and behavioral.
- Outpatient clinics for diseases related to aging and the GERAS Centre for Aging Research, affiliated with McMaster University, are also based at St. Peter’s.

Juravinski Hospital (JH)



- Best known as the host hospital for the Regional Cancer Program.
- In addition to dedicated wards for cancer patients, Juravinski Hospital is also a general medical/surgical hospital with a community Emergency Department. Joint replacement surgery, e.g. hip or knee, commonly takes place at Juravinski Hospital.

West End Clinic/Urgent Care Centre (UCC)



- Offers walk-in medical care for patients with urgent health concerns that can’t wait for a family doctor.
- Home to HHS preoperative clinic, which provides services to patients scheduled for surgery at HHS.
- Home to our special immunology clinic, which provides specialized care to children and adults who are living with HIV.

McMaster Children's Hospital (MCH)



- Patients ranging in age from infancy to 17 receive care through a family-centred approach that accounts for the child's emotional, mental and physical well-being.
- Home to the fastest-growing kids-only emergency department in Ontario, one of Canada's most advanced neonatal intensive care units, and a range of programs and clinics with unique expertise in a number of areas including children's cancer, digestive diseases, and mental health.

McMaster University Medical Centre (MUMC)



- Home to a range of adult specialty clinics and day surgery, as well as a nationally-recognized digestive diseases care and research program.
- MUMC also hosts one of Ontario's largest labour & delivery programs and shares its campus with McMaster Children's Hospital, providing seamless care for newborns who require additional hospital care after birth.

Regional Rehab Centre (RRC)



- Provides specialized care to help patients recovering from spinal cord injury, acquired brain injury, trauma, stroke and orthopedic surgery.
- The state-of-the-art facility provides both inpatient and outpatient services and clinics, a therapeutic pool and an outdoor therapeutic track.

West Lincoln Memorial Hospital (WLMH)



- As a community hospital, WLMH provides both inpatient services and outpatient services including emergency services, complex and palliative care, surgery and a maternal and newborn program

Satellite Health Facility (SHF)



- In 2020, Hamilton Health Sciences (HHS) and St. Joseph's Hospital Hamilton (SJHH) opened the Satellite Health Facility (SHF), a temporary facility in downtown Hamilton to increase local healthcare capacity in the midst of the COVID-19 pandemic.
- The space allows HHS and SJHH teams to support patients who are waiting for alternate care arrangements in the community, while reserving in-hospital space for those with the most urgent medical needs.

To learn more about any of our sites and their locations, please visit <https://www.hamiltonhealthsciences.ca/about-us/our-organization/our-locations/>

WHAT IS PATIENT AND FAMILY CENTERED CARE?

Hamilton Health Sciences is committed to providing an excellent patient experience. The purpose of the Patient Experience Office is to promote patient- and family-centred care. We are here to partner with our patients, families and our fellow healthcare teams to influence systems, processes, behaviour and communication.

At Hamilton Health Sciences, patient- and family-centred care means:

- Recognizing patients as experts in their own experience and actively partnering with them to improve the quality, safety and experience of their care
- Partnering with patients and families to ensure their voice is part of the conversation at all levels of the organization, from the bedside to the boardroom

Our model of Patient and Family Centred Care includes three dimensions: **Communicating** with, **Collaborating** with, and **Responding** to our patients and their families **with compassion**. This model was developed by an interdisciplinary team with patient representatives. The team conducted focus groups and key informant interviews with patients and their families asking what mattered most during their visit to HHS. The themes from these interviews were translated into a series of attributes of patient-centered care, which we reference as our **Service Excellence Behaviours**.

WHAT ARE THE BENEFITS OF PATIENT AND FAMILY CENTERED CARE?

We understand that by listening to the people we serve and partnering with them on policy development, building processes and undertaking project work, we can improve the way we deliver care. By focusing on patient- and family-centred care as a strategic priority, we are building a culture where we are continuously improving the hospital experiences of patients, families, staff, physicians and learners.

This is what we heard from our patients and families:

As a patient I ask that you always...



Communicate with compassion

Introduce yourself and your role to me.

Make me feel welcome when I approach you. Smile. Look at me. Say "welcome to..." or "how can I help?" If I'm lost, please walk me to where I need to go, don't just point.

Inform me about my care plan and daily activities.

Stop. Look and listen to me.

Respond promptly and courteously to my questions or concerns. If you don't know the answer, please find someone who does.

Collaborate with compassion

Include me and those important to me in decisions about my care, in a way I can understand.

Get to know me and care about me as a person, by asking about my interests and preferences.

Say "here is what we can do for you..." instead of what you can't.

Speak positively about the people who work here.

Respond with compassion

Answer my call bell promptly. If you can't help me, please find someone who can.

Follow through on what you said you would do.

Initiate gestures of compassion to show me you care.

Apologize for problems or inconveniences.



An Integrated Perspective: The Beryl Institute

To learn more visit <https://www.theberylinstitute.org/>

AN INTEGRATED VIEW OF PATIENT EXPERIENCE

Traditional models of healthcare service often separate quality and safety from the patient experience. For patients, families and staff, the patient experience is integrated and includes: quality, safety, outcomes, service and cost.

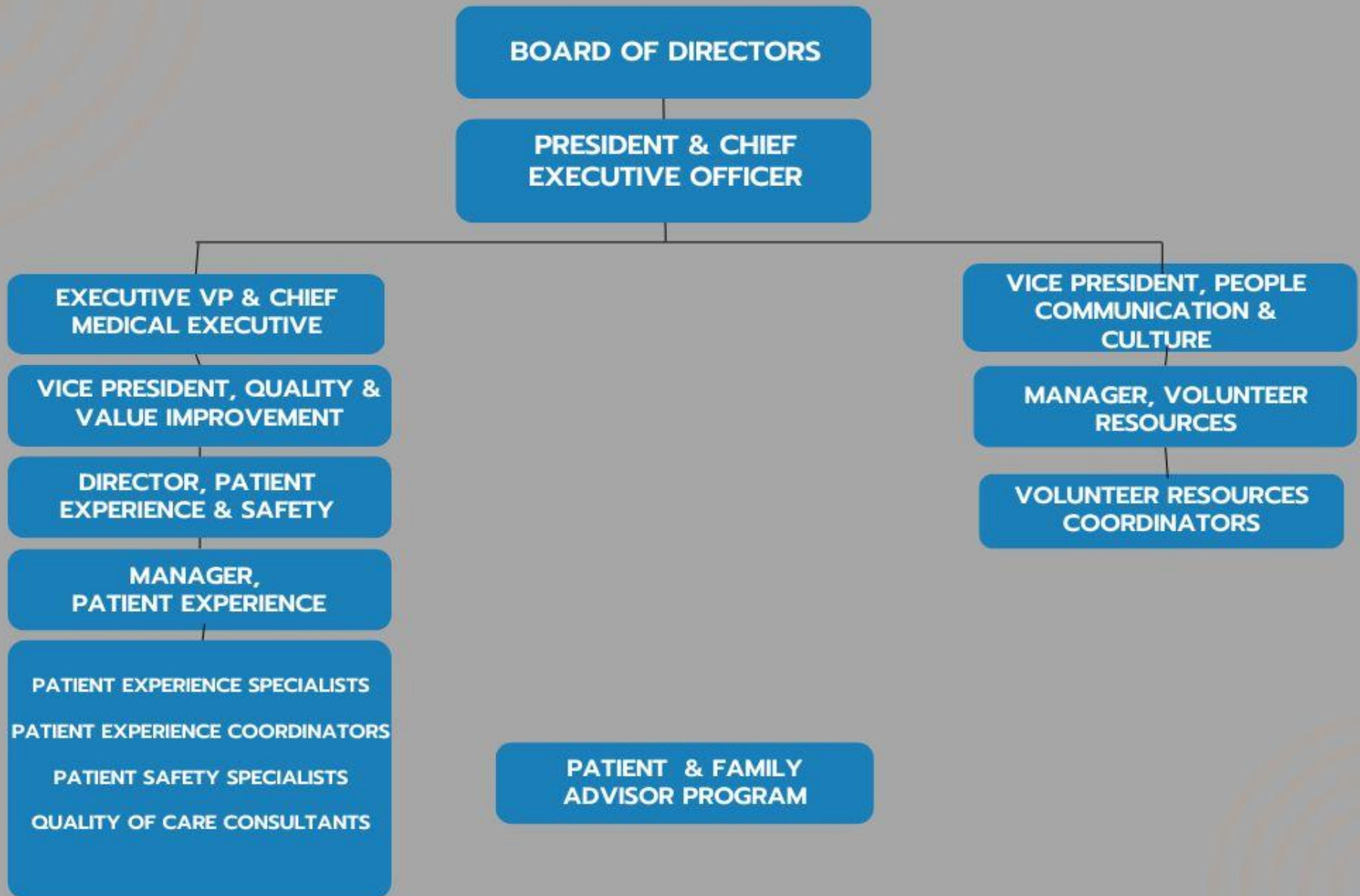
The Beryl Institute (2020) calls on healthcare providers to expand and integrate their perceptions and understandings of the patient experience to include quality and safety as key indicators of experience and also, to focus on the relational aspects of those providing healthcare. In other words, patient experience is made from many aspects of the lived experience itself and involves engagement between those receiving care, and those providing care.

“Experience is something we have lived through. It is about something that happened and it is our lasting story. It is defined in all that is perceived, understood and remembered” (Christensen, 2020, pg.5, The Beryl Institute).

Quality and safety impact both the patient and family experience as well as the clinician and staff experience. As part of an integrated view, factors like the cost of healthcare and financial impact of safety affects both the experience of safety for healthcare providers and the perceptions of patients and families who are impacted by the overall experience.

Safety and experience are not distinct from one another but rather, integrated elements of patient and staff engagement in healthcare.

Organizational Chart



WHAT IS THE PATIENT AND FAMILY ADVISOR (PFA) PROGRAM?

The Corporate PFA Program was established in 2014 to begin having the patient, family and caregiver voice present across different levels of the organization. At HHS, we recognize that patients and their families can offer unique perspectives and valuable feedback. Through our PFA program, we partner with patients and their families who help us provide high quality, patient and family-centered care and services. Patient and Family Advisors are a group of volunteers who support various organizational initiatives. The PFA program is jointly supported by the Patient Experience Department and Volunteer Resources.

BENEFITS OF BEING A PFA

- Become meaningfully engaged in the system that supports you and your community's health
- Improve your understanding of the health care system
- Appreciate being involved, being listened to, and having your opinions valued
- Learn to advocate effectively for improved healthcare services
- Help to effect changes that will lead to healthcare quality improvement
- Gain new knowledge and skills
- Develop new relationships with staff, physicians and fellow Patient and Family Advisors
- Help to improve the delivery of safe and high-quality care
- Participate in education opportunities
- Receive recognition awards and invitations to recognition events
- Have access to complimentary parking

TITLE	NAME	CONTACT INFORMATION	ROLE IN SUPPORTING PFAS
Patient Experience Specialists	Julie Mills	Email: millsju@hhsc.ca Cell: 905-870-5749	<ul style="list-style-type: none"> • Assist with recruitment of PFAs through the Patient Experience feedback process and advertising efforts • Provide ongoing support to PFAs • Identify opportunities for PFA engagement and partnerships • Manage requests for PFAs from staff across HHS • Contact PFAs with new opportunities • Request and document PFA hours each month • Communicate pertinent information occurring in and around the organization as it impacts PFAs
	Carole Moss	Email: mosscc@hhsc.ca Cell: 905-870-0264	
	Nicole Rakowski	Email: rakowskin@hhsc.ca Phone: 905-521-2100 ext. 72074	
	Jane Hastie	Email: hastie@hhsc.ca Phone: 905-521-2100 ext. 74269	
Manager, Patient Experience	Dawn Sidenberg	Email: sidenberg@hhsc.ca Phone: 905-521-2100 ext. 74215	
Coordinator, Volunteer Resources	Samantha Chivers	Email: chiverssam@hhsc.ca Phone: 905-521-2100 ext. 75338	<ul style="list-style-type: none"> • Provide assistance and support with volunteer onboarding and orientation • Provide ongoing support to volunteers • Communicate pertinent information occurring in and around the organization as it impacts Volunteer Resources • Share the benefits of being a volunteer at HHS • Help arrange parking passes and applicable resources that contribute to conducting the PFA role safely and effectively • Share information about volunteer recognition awards and appreciation events
Coordinator, Volunteer Resources	Angie Ratzlaff-Lane	Email: ratzlafla@hhsc.ca Phone: 905-521-2100 ext. 46562	
Manager, Volunteer Resources	Morgan Richardson	Email: richardsonm@hhsc.ca Phone: 905-521-2100 ext. 44837	

SECTION 2: RESPONSIBILITIES AND EXPECTATIONS

INTERVIEW AND ONBOARDING

Following your application and interview, you will be asked to complete the Volunteer Resources onboarding documents listed below:

- ❖ Volunteer Profile
- ❖ Consent for Photography, Video/Audio Taping, Televising, Internet Imaging
- ❖ Terms of Engagement/Confidentiality
- ❖ Health Clearance (Pre-Placement Immunization Form)
- ❖ Two references
- ❖ Worker Health & Safety Training

TRAINING AND ORIENTATION

1. Volunteer Resources Orientation Video

- ❖ Topics Include:
 - Value Based Code of Conduct
 - Infection Control
 - Emergency Codes
 - Volunteer Association
 - Equity, Diversity and Inclusion and Resources
 - Confidentiality
 - Accessibility for Ontarians with Disabilities Act (AODA)
 - Violence in the Workplace
 - Volunteer Administration
 - Service Excellence Behaviors
 - Self- Monitoring & Reporting Illness

2. Patient and Family Advisor Handbook

3. Education Programs

- ❖ Hamilton Health Science's Centre for People Development offers select education programs that are available to you free of charge as a Volunteer at HHS. It can be found at www.centreforpeopledevelopment.ca
- ❖ Some of these programs include:
 - Introduction to A3 Problem Solving Thinking
 - Experience Based Co-Design in Healthcare: A Quality Tool
 - Ally in Action

TIME COMMITMENTS

As a Patient and Family Advisor, you can be involved at whatever level you choose. This means that the amount of time and level of involvement you contribute is up to you. Some PFAs volunteer eight to ten hours a month while others volunteer one hour every few months. Before committing to an opportunity, you will be provided information about the amount of time and commitment required to support you making a decision.

WHAT DOES A PFA DO?

Patient and Family Advisors bring the patient and family voice and experience to various hospital committees, project teams and opportunities. They provide input into projects and initiatives that improve the quality of care delivery, programs and services at HHS by participating in various ways.

Regular and ongoing opportunities

- ❖ **Patient & family advisor meetings**
 - Open to all PFAs to learn, collaborate, share and provide feedback on a variety of topics
 - Held once a month on the fourth Tuesday from 4:30pm – 5:30pm
 - Meeting invitations, agendas and minutes are distributed to all PFAs
- ❖ **Committee participation**
 - These are longer-term groups who review and make decisions on system issues
 - PFAs bring valuable insight and perspective to planning and decision making
 - Time commitment ranges from one to three hours per month for a term of 1 – 2 years
- ❖ **Quality improvement projects/working groups**
 - These are groups established to improve organizational, site or unit specific issues
 - Patient and Family Advisors partner with staff members, leaders and physicians, to share the patient and family lived experience
 - Time commitment ranges from one to four hours per month for approximately 6 - 12 months
- ❖ **Councils**
 - HHS has several site-specific Patient & Family Advisory Councils. The site-specific councils tend to provide input into site-specific operational issues
 - These groups make recommendations on programs, policies and practices at the site level
 - Time commitment ranges from one to six hours quarterly for a term of 1 – 2 years

ONE-TIME OPPORTUNITIES

- ❖ **Focus groups**
 - Individuals participate in a one-time meeting providing feedback and recommendations on a particular topic
 - Depending on the topic, there may be materials to review prior to the meeting to enable participation
- ❖ **Presentations/testimonials**
 - PFAs share stories about their experiences, both positive and areas for improvement, as an important way to better understand how the patient and family experience can be improved
 - A member of the Patient Experience Department would contact PFAs to discuss these type of opportunities, when applicable
- ❖ **Input/feedback on documents**

- Review documents and/or patient education materials, ensuring they are meaningful, easy to read and easy to understand
- Emails intermittently

❖ **Surveys or questionnaires**

- Complete a survey or questionnaire to provide your feedback on various topics
- Emails intermittently - often circulated to all PFAs

HOW PFAS BECOME AWARE OF OPPORTUNITIES

Staff, Physicians and Leaders from across the organization send a request form to the Patient Experience Department to find PFAs to support the work they are undertaking.

As a Patient and Family Advisor, you will be kept informed about upcoming opportunities to be involved in different areas across the organization and you can choose which ones you want to be involved in.

Opportunities to get involved are circulated in two ways:

1. An email is distributed to all PFAs to determine who may be interested
2. Patient Experience Specialists will directly reach out to PFAs with an opportunity based on their identified experience and/or areas of interest

If you feel that you are not participating in opportunities that are of interest to you, or want to explore other ways to be involved, contact the Patient Experience Specialist. You may be asked for feedback about your experience as a Patient and Family Advisor. This information is helpful to continuously improve our Patient and Family Advisor Program.

FINDING THE RIGHT FIT

When you receive an email about a new opportunity, you should consider several factors to determine whether or not it is the right fit for you. Here are some questions to ask yourself when considering committing to a new opportunity.

- Does the date/time and location of the opportunity fit with my schedule?
- Can I commit to any additional work that may come out of the opportunity? i.e. follow-up meetings
- Am I interested in the topic/tasks? What can I contribute?
- Is there anything about participation in this opportunity that may be difficult for me to talk about/think about?

STAFF LIAISON

Once you are matched to a committee, you will be connected with a Staff Liaison who also sits on the committee/council/project you will be attending. Your Staff Liaison will be your main contact and will help to further orient you to the committee/council/project.

Staff liaisons:

1. Reach out to you prior to the first meeting to:
 - a. Introduce themselves
 - b. Provide context for key topics
 - c. Provide any additional details/information/resources that may be helpful in supporting your participation
 - d. Answer any questions you may have
2. Confirm meeting dates/times and your attendance
3. Orient you to the hospital/help you find meeting rooms
 - a. For virtual meetings they will be available via chat to answer questions, if possible
4. Introduce you to the committee chair and/or the committee
5. Be available to support you before, during and after meetings to enable participation
6. Communicate updates that happen between meetings to you and obtain your input, if needed
7. Obtain ongoing feedback from you on what is working well and what can be improved with the role

If you have questions or concerns related to the Committee, please contact the Staff Liaison to discuss. If you are not comfortable discussing concerns with the Staff Liaison, feel free to contact the Patient Experience Specialist and/or the Manager of Patient Experience.

WHAT HAPPENS WHEN THE OPPORTUNITY I AM INVOLVED WITH ENDS?

We strive to ensure that you receive communication about how your feedback/input was utilized for each engagement opportunity and share final materials and/or documents.

TRACKING YOUR VOLUNTEER HOURS

Recording the volunteer hours that you contribute in your role as a Patient and Family Advisor is important for both our volunteers and Hamilton Health Sciences. By keeping track of your volunteer hours, HHS can recognize the outstanding work contributed by our Patient and Family Advisors.

On the first of every month, a Patient Experience Specialist will contact you by email to request that you submit your total number of PFA hours for the previous month. It is recommended that you use the 'Activity Log' template (refer to Appendix A) to keep track of your hours.

If at any time you require assistance or have questions, please contact a Patient Experience Specialist.

SECTION 3: TIPS FOR BEING AN ENGAGED PATIENT AND FAMILY ADVISOR

HOW CAN I EFFECTIVELY PARTICIPATE? ADVICE FROM ONE PFA TO ANOTHER

Think broadly

- Be open-minded
- Give input based on both your own and the experience of others
- See past your personal experience
- Be understanding of why things happen / don't happen / can't happen – remember the bigger picture
- Think strategically
- Be curious – ask questions when you are uncertain of something or for clarification

Be prepared to actively participate

- Actively listen to what other people say
- Do not interrupt others; wait for them to finish speaking
- Speak comfortably and confidently

Be solution-oriented

- Reflect on what you think will work for yourself and others
- Share ideas in a positive manner and remain positive
- Do not use opportunities to advance your own agenda

Share experiences

- Share what worked and what could be improved from your own experience
- Share information based on what is being discussed – do not make discussion personal if it is irrelevant to the topic

Be respectful

- Respect meeting start and end times – be on time for meetings
- Keep meeting agreements
- Be reliable
- Be respectful of others' opinions
- Express thanks for being given the opportunity to share your experience and perspective

Respect confidentiality

- Do not share any information about what is discussed at the meeting – consider everything confidential

Honour commitments

- Follow through on what you agreed to do
- Don't be afraid to step down / away from an opportunity if it is not a good / comfortable fit

GUIDELINES ON WORKING TOGETHER – PREPARING FOR OPPORTUNITIES

- Meet with or speak to the lead person chairing the committee/council/project or your staff liaison prior to the first meeting
- Get any background information that may have been shared prior to you being on the committee
- Ask for a list of others on the committee and their role / position
- Ask for support / briefings after meetings, if required
- Make sure you understand the role and scope of work prior to committing (meeting times, duration, frequency, location; focus group, committee, materials review, presentation)
- Take time to prepare for the meeting or session by reviewing the agenda and any other related materials including the meeting location
- Share your views – focus on problem solving; if what you are sharing is negative, offer suggestions or possible solutions
- Do not feel pressure to say something if you have nothing to contribute (on a particular point / issue)
- Ask for clarification if you do not understand something
- Engage with all members of the group
- Be respectful of others and of others’ perspectives and ideas
- Be respectful of confidentiality
- Turn off cell phones and electronic devices during meetings
- Send regrets for any necessary absences from meetings
- Consider the things that you want to bring to the meeting, including:
 1. Paper copies of any documents you were sent before the meeting, such as the agenda or items for discussion. You may want to keep all documents in a folder or binder.
 2. Note-taking materials such as a pen and notebook or paper
- Be yourself. Your experience will be valued!

CODE OF CONDUCT

Hamilton Health Sciences will not tolerate racism, discrimination, oppression, harassment, or bullying in any form. All Patient and Family Advisors (PFAs) have the right to share their thoughts, experiences and perspectives in an environment that supports equity, diversity and inclusion. PFAs are expected to adhere to these principles, respect the rights of others, and act in alignment with Hamilton Health Sciences’ Values-Based Code of Conduct and other relevant policies and protocols.

SHARING YOUR STORY TO SHAPE HEALTHCARE

Sharing your healthcare experiences can be a powerful way to bring the patient and family voice and lived experience to various hospital committees and project teams that work to improve the quality of care delivery, programs and services at HHS. It can help others understand care from the patient or family member perspective and how these experiences have affected you and your family.

Sharing patient stories is an important process, and we want to ensure that you feel supported throughout the process and knowledgeable about the risks and benefits before you commit.

Why

We want to include patient stories because they provide qualitative insights and grounded data in real life experiences that are foundational to understanding and transforming healthcare.

What

We are asking you to share positive, inspirational and difficult experiences within the healthcare system to help create awareness and invite others to consider new ways of thinking, being and doing.

Tone

While it is important to share the difficult experiences within healthcare, it is important that all of our messages offer hope and point the way to a better outcome. Difficult experiences need to be shared in a way that is not re-triggering for you or the person reading/hearing the story, and invites rather than calls out providers and patients to be part of the solution.

We are not asking you to reduce or sugar coat your experience but consider how it could be used to inspire learning, unlearning and relearning.

Risks & Benefits

As you know there are many benefits to sharing your story but it is important to consider the risks too.

When Retelling Your Story

- It may trigger you to re-experience the situation you went through (emotions)
- Consider how sharing your story could affect those around you (loved ones, care partners)
- Not everyone may respond positively to what you share
- Your personal information will be available to others
- Be sure to debrief after your story is shared and have a support system in place ahead of time

Please see the “Sharing your story safely” PDF from the Mental Health Commission of Canada
https://mentalhealthcommission.ca/wp-content/uploads/2021/06/covid_19_tip_sheet_sharing_your_story_safely_eng.pdf

Ownership

This is your story and you own it; if you change your mind at any time and no longer want to share your story please let HHS staff know and we will support you and make the necessary changes.

Preparing to Share

Story should be up to 3 – 5 minutes in length

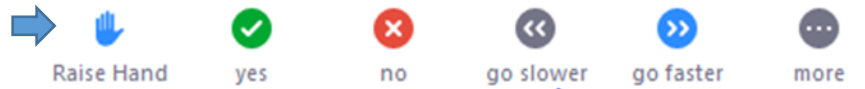
- **Outline**
 - Topic – what are you sharing
 - Purpose – why are you sharing this?
 - What happened
 - Remember we aren't here to place blame, or call people out
 - We want to create awareness, invite people in and leave them with new knowledge and a desire to put it into action
 - Inspiration – what was done well, what is the opportunity
 - This is the opportunity to bring people in and create awareness, the teachable moment
 - Resources
 - Are there resources available you want to share?
 - If it is a case study
 - What are the questions you want to ask to inspire learning and unlearning?

After You Share Your Story

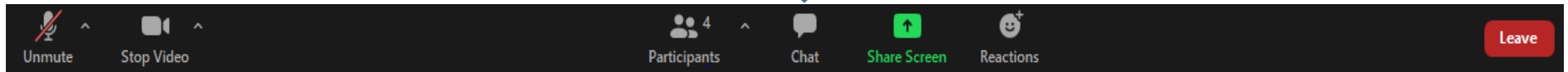
An HHS staff member will be available to debrief the experience and ensure you feel heard and supported.

VIRTUAL MEETING GUIDELINES

- Mute your microphone/phone when you are not speaking
- If you are calling into a Zoom meeting, use *6 to mute when you are not speaking
- Use the raise your hand feature to contribute the conversation



- Use the chat to ask questions and/or contribute to conversation



SECTION 4: WAYS TO LEARN MORE

To learn more about the broader Hamilton Health Sciences services, you can visit us our website <https://www.hamiltonhealthsciences.ca/> or check us out on social media at:

Facebook

<https://www.facebook.com/HamHealthSci/>

YouTube

<https://www.youtube.com/user/HamHealthSciences>

Twitter

<https://twitter.com/hamhealthsci>

Consider registering for a free membership with The Beryl Institute: a global community of healthcare professions and experience champions (like you!), committed to transforming the human experience in healthcare. Get access to videos, newsletters, training and more: <https://www.theberylinstitute.org/>. If you are interested in signing up, please contact Dawn Sidenberg at sidenberg@hhsc.ca.

To learn more about health care quality, patient safety, and being a patient and family advisor, please visit the websites below:

Agency for Healthcare Research and Quality (AHRQ)

<http://www.ahrq.gov>

Institute for Healthcare Improvement

<http://www.ihl.org/>

Beryl Institute

<https://www.theberylinstitute.org/>

Institute for Patient and Family-Centered Care

<http://www.ipfcc.org>

Healthcare Excellence Canada

<https://www.healthcareexcellence.ca/>

Ontario Health

<https://www.ontariohealth.ca/>

Acronym / Key Term	Meaning	Additional Details
A3		A problem solving tool commonly associated with Toyota Production System Named “A3” after the size of paper (11x17) Incorporates PDSA (Plan-Do-Study-Act) cycles
A3 Problem Solving Thinking		The value of the A3 is the process and thinking used to work through the tool (A3 thinking) Follows the A3 structure of solving a problem to root cause and sustaining improvements Can be used for problems of any size
Acute Care		Usually delivered in a hospital-like setting, acute care is the type of care that your healthcare team will provide if you are sick or injured, or recovering from a treatment such as surgery. When you are admitted to an acute care hospital to receive care, you are usually called an “inpatient”.
AFHTO	Association of Family Health Teams of Ontario	An advocate, network and resource for team-based primary care clinics in Ontario. Primary care is most peoples’ first line of healthcare (like family doctors).
ALC	Alternate Level of Care	Used in hospitals to describe patients who occupy a bed but do not require the intensity of services provided in that care setting.
Allied Health		Health care professions distinct from nursing, medicine and pharmacy. Allied health professionals work in health care teams to make the health care system function by providing a range of diagnostic, technical, therapeutic and direct patient care and support services that are critical to the other health professionals they work with and the patients they serve (for example, Social Work, Occupational Therapy, Physical Therapy, Respiratory Therapy)
Ambulatory Care		All types of health services that are provided on an outpatient basis, in contrast to services provided in the home or to persons who are inpatients. While many inpatients may be ambulatory, the term ambulatory care usually implies that the patient must travel to a location to receive services that do not require an overnight stay.

AODA	Accessibility for Ontarians with Disabilities Act	Provincial legislation that ensures the accessibility of individuals related to goods, services, facilities, employment, accommodation and buildings.
BSR	Behaviour Safety Risk	The Behaviour Safety Risk program helps ensure the safety of staff, doctors and comfort of patients when a behaviour safety risk is identified. The program is in place to identify and communicate potential safety risks for patients and to develop care planning actions to keep everyone safe and calm. The program is part of a larger strategy at HHS to ensure we're providing a safe and respectful environment, while fostering a culture of safety.
CAUTI	Catheter Associated Urinary Tract Infection	An infection of the urinary tract caused by a tube (urinary catheter) that has been placed to drain urine from the bladder.
CCO	Cancer Care Ontario	The Ontario government's main advisor on health care for cancer and renal systems.
CHC	Community Health Centre	A non-profit organization funded by the Ontario Ministry of Health that employs inter-professional teams of staff to provide primary health care, illness prevention and health promotion programs and services that promote wellness in the community.
CIHR	Canadian Institute for Health Research	A Canadian health agency that collects and reports on clinical and non-clinical data.
CLS	Child Life Specialist	Certified Child Life Specialists are educated and clinically trained in the developmental impact of illness and injury. Their role helps improve patient and family care, satisfaction, and overall experience.
CMHA	Canadian Mental Health Association	An organization that promotes the mental health of all and supports the resilience and recovery of people experiencing mental illness.
CPSO	College of Family Physicians and Surgeons of Ontario	The body that regulates the practice of medicine to protect and serve the public interest.
CQI	Continuous Quality Improvement	The Continuous Quality Improvement (CQI) management system is a set of tools and behaviours that focus on setting up our people and our processes for success in providing quality care to patients.
DI	Diagnostic Imaging	A department in a hospital that uses medical technology to diagnose and consult on medical illnesses. Also called MI for Medical Imaging.

ECFAA	Excellent Care for ALL Act	Provincial legislation that focuses on enhancing every hospital's quality agenda.
ECP	Essential Care Partner	Identified and designated by the patient or by their Substitute Decision Maker to partner in their care. Most often they are family members, caregivers, or close friends who typically know the patient's health history, lived experience and personal values. They directly impact the physical, emotional and psychological well-being and safety of patients.
EDI	Equity, Diversity and Inclusion	Three closely linked values held by many organizations that are working to be supportive of different groups of individuals, including people of different races, ethnicities, religions, abilities, genders and sexual orientations.
EPIC		Hamilton Health Sciences' new Health Information System (HIS).
ELT	Executive Leadership Team	A group of health administrators consisting of the organization's CEO and VPs.
EMR	Electronic Medical Record	A centralized computer system that collects patient clinical and demographic information.
FER	Family Engagement in Research	Patients and/or family members work together with health researchers and professionals to improve the quality of health research and services.
FHT	Family Health Teams	Primary health organizations that include a team of family physicians, nurse practitioners, registered nurses, social workers, dietitians, and other professionals who work together to provide primary health care for their community.
FY	Fiscal Year	Used for accounting and performance management. The time period from April 1st to March 31 st .
GP	General Practitioner	A term used for a family doctor, or a physician in the community focused on family medicine.
HCCSS	Home and Community Care Support Services	Ontario's 14 Home and Community Care Support Service organizations coordinate in-home and community based care for patients across Ontario include the management of Ontario's long term care home placement process
HHT	<i>Hamilton Health Team</i>	The Hamilton Health Team is a collaboration of Hamilton health and social service partners and includes representation from more than 20 organizations, reflecting primary care, home care, hospitals, community agencies, long-term care, mental health,

Indigenous health, post-secondary education, and the City of Hamilton (Healthy and Safe Communities Department, Public Health and Paramedic Services).

HEC	Healthcare Excellence Canada	An independent, not for profit organization that works with partners to spread innovations, building capability and catalyze policy changes so everyone in Canada has safe and high quality healthcare.
Health Links		Health Links is an integrated patient-centered approach to care that focuses on enhancing and coordinating the care for patients living with multiple chronic conditions and complex needs.
HGH	Hamilton General Hospital	Hamilton Health Sciences Site
HHS	Hamilton Health Sciences	A hospital system of 10 sites and 15,000 staff, physicians, researchers and volunteers that proudly serves southwestern Ontario residents. We also provide specialized, advanced care to people from across the province. We're the only hospital in Ontario that cares for all ages from pre-birth to end-of-life.
HIRESB	Hamilton Integrated Research Ethics Board	HiREB is responsible, on behalf of the institutions, for ensuring that all research involving human subjects under the auspices of its institutions meet current ethical standards. The HiREB reviews and approves research projects that meet acceptable ethical and scientific standards and for which adequate facilities and resources are available. The HIREB also provides advice on the ethical, scientific and technical aspects of planning research projects.
HIROC	Healthcare Insurance Reciprocal of Canada	HIROC is a trusted healthcare safety advisor, committed to offering a full spectrum of insurance products and support throughout a claim.
HITS	Health Information Technology Services	A department focused on clinical and non-clinical information systems and technology.
HR	<ol style="list-style-type: none"> Human Resources Health Records 	<ol style="list-style-type: none"> A department in the hospital Specific documents within a patient chart. Also, a department in the hospital.
ICES	Institute for Clinical Evaluative Sciences	An independent not-for-profit corporation funded by the government that leads studies that evaluate health care delivery and outcomes.

IDEAS	Improving and Driving Excellence Across Sectors	A province-wide initiative to enhance Ontario's health system performance by increasing quality improvement, leadership and change management capacity across all health care sectors.
IHI	Institute for Healthcare Improvement	The institute for Healthcare Improvement (IHI), founded in 1991, is a non-profit organization located in the U.S. that focuses on improvement science and patient safety to advance and sustain better outcomes in health and health care outcomes across the world.
IPC	Inter-professional Care	A principle where multiple healthcare professionals work collaboratively to deliver care.
JH	Juravinski Hospital	Hamilton Health Sciences Site
JCC	Juravinski Cancer Centre	Hamilton Health Sciences Site
LTC	Long-Term Care	<p>Long- term care homes in Ontario are regulated and funded by the government and must have a license or minister's approval to operate. Long term care homes provide care including:</p> <ul style="list-style-type: none"> • help with most or all daily activities • access to 24-hour nursing and personal care <p>The Ontario government will pay for the resident's personal and nursing care in a long-terms care home. The resident must pay for accommodation such as room and board.</p>
MAiD	Medical Assistance in Dying	Medical Assistance in Dying (MAiD) is a process through which a doctor or nurse practitioner assists an individual at their request, to intentionally end their life. MAiD is administered with the aid of drugs that can be taken orally or administered intravenously. No matter which option is chosen, a physician or nurse practitioner is always present during the process.
MCH	McMaster Children's Hospital	Hamilton Health Sciences Site
MOHLTC	Ministry of Health and Long Term Care	The portion of the provincial government that governs healthcare, long-term care and health promotion/prevention.
MRP	Most Responsible Physician	Refers to the physician, or other regulated healthcare professional, who has overall responsibility for directing and coordinating the care and management of a patient at a specific point in time.

MUMC	McMaster University Medical Centre	Hamilton Health Sciences Site
Never Events		Never events are patient safety occurrences that result in serious patient harm or death and that can be prevented by using organizational checks and balances.
NP	Nurse Practitioner	Nurse Practitioners (NPs) are registered nurses who have additional education and nursing experience which enables them to autonomously diagnose and treat illness, order and interpret tests, prescribe medication, perform medical procedures.
OHA	Ontario Hospital Association	Supports hospitals across the province by providing hospital staff and leadership with high-quality products and services, education opportunities, and championing health system innovation and policy.
OMA	Ontario Medical Association	Represents the political, clinical and economic interests of the province's medical profession.
ONA	Ontario Nurses Association	A proactive union committed to improving the economic welfare and quality of work-life for its members, to enable them to provide high-quality health care.
OH	Ontario Health	An agency created by the Government of Ontario with a mandate to connect and co-ordinate our province's health care system to help ensure Ontarians receive the best possible care.
OPSEU	Ontario Public Service Employee Union	A trade union that represents about 120,000 employees in the broader public service of the Province of Ontario, Canada.
OP	Outpatient	When a person is not admitted to the hospital for an overnight stay, but still comes to a physician's office, clinic, hospital, day surgery office or other healthcare facility for diagnosis, treatment or to receive care, that patient is considered an "outpatient".
PDSA	Plan-Do-Study-Act	An approach used to test change ideas and build confidence in the change by making small, incremental changes.
PE	Patient Experience	At HHS, we have adopted the definition of Patient Experience as developed by The Beryl Institute – the sum of all interactions shaped by an organization's culture that influence patient perceptions across the continuum of care. As such, the Office of Patient

Experience provides leadership and support to promote an excellent patient/ family experience. Our office also works with patients and families who may have compliments, questions or concerns about the care or service received in hospital.

PFA	Patient & Family Advisor	A person who has been a patient, the family member of a patient or the caregiver of a patient, and is partnering with staff at a health care organization to provide input into policies, programs and practices that affect patient care and services. PFAs ensure that the voice of the patient is heard and influences planning and decision making on issues that affect patient care.
PFAC	Patient & Family Advisory Council	A Patient & Family Advisory Council (PFAC) is a committee of patients and family members from across the corporation or hospital site, who volunteer their time and experience to improve the quality, safety and experience of health care services. Together, with senior and executive leaders, physicians, clinicians and clinical support teams, the Advisors work ensure the voices of patients and family are included in the design and planning of policies and services within the corporation/site. More specifically, it provides a mechanism to: <ul style="list-style-type: none"> • See and learn from the patient and family perspective • Promote a culture of patient-and family-centered care (PFCC) within an organization • Guide PFCC implementation through collaboration to improve programs, services, and policies • Enhance the delivery of high quality and safe care
PFCC	Patient-&-Family-Centered Care	An approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families and health care.
PHI	Personal Health Information	A term used to generalize all health information related to a patient.
PHIPA	Personal Health Information Protection Act	PHIPA provides a set of rules for the collection, use and disclosure of personal health information.
POA	Power of Attorney	A legal document in which a person gives someone they trust (called their “attorney”) the right to make decisions for them about their health care, housing and other aspects of personal life if they become mentally incapable of making these decisions on their own.

POGO	Pediatric Oncology Group of Ontario	A non-profit organization with charitable status that works to ensure that everyone affected by childhood cancer has access to the best care and support. Partner to achieve an excellent childhood cancer care system for children, youth, their families, survivors and healthcare teams in Ontario and beyond.
PPE	Personal Protective Equipment	Specialized equipment worn by an individual for protection against infectious materials.
QBP	Quality Based Procedure	Quality-Based Procedures (QBPs) are health care services for which evidence-based best practices have been defined, and health care providers receive funding for those services based on an established price. For each QBP, a clinical handbook is developed by a multi-disciplinary clinical expert advisory panel that includes leading clinicians, scientists and patients. The clinical handbook outlines evidence-based care pathways, recommended practices and performance indicators to monitor for ongoing quality improvement. In this patient-based funding model, health care providers receive funding for health care services based on an established price, adjusted for the level of acuity of the patients they serve, and a volume target based on historical activity and population growth needs.
QCIPA	Quality of Care Information Protection Act	Under the legislation, information provided to hospital quality of care committees and other designated quality of care committees that deal with quality improvement would be shielded from disclosure in legal proceedings.
QI	Quality Improvement	A principle involving all stakeholders in planned changes to improve patient outcomes, better system performance, and better professional development.
QIP	Quality Improvement Plan	A Quality Improvement Plan (QIP) is a public commitment to meet quality improvement goals. By developing a Quality Improvement Plan, a health care organization outlines how it will improve the quality of care provided to their patients in the coming year.
RJCHC	Ron Joyce Children’s Health Centre	Hamilton Health Sciences Site
ROP	Required Organizational Practice	An essential practice that organizations must have in place to enhance patient/client safety and minimize risk. Part of the Accreditation process.
RPN	Registered Practical Nurse	Registered Practical Nurses (RPN)s complete a post-secondary nursing program at the college level that is usually takes two years. RPNs provide and coordinate care for individuals, families, and groups in a variety of settings and with a variety of health

		professionals. They can work with clients of varying complexity, recognizing when consultation and collaboration with other health professionals is required.
RN	Registered Nurse	Registered Nurses (RNs) usually complete a four year post-secondary university nursing program to become a nurse. The program prepares the RN to give direct care and to take on the role of coordinating care for individuals, families, groups, communities and populations in a variety of health care setting and with a variety of health professionals. Clinical instruction prepares the RN to take a leadership role when the care requirements become more complex.
SDM	Substitute Decision Maker	An individual that is designated to make personal care decisions on behalf of a patient who is deemed incapable of making a decision.
SHF	Satellite Health Facility	Hamilton Health Sciences Site.
SOR	Safety Occurrence Report	A documented report of an occurrence that is prepared in sufficient detail to enable the reader to access its significance, consequences, or implications and to evaluate the actions being proposed or employed to correct the condition or to avoid recurrence.
SPH	St. Peter's Hospital	Hamilton Health Sciences Site.
SSI	Surgical Site Infections	An infection that occurs after surgery in the part of the body where the surgery took place
TBD	To Be Determined	A term used when further planning is needed.
TOA	Transfer of Accountability	An interactive process of transferring patient specific information from one caregiver to another or from one team of caregivers to another for the purpose of ensuring the continuity of care and the safety of the patient
UCC	Urgent Care Centre	Hamilton Health Sciences Site
UTI	Urinary Tract Infection	An infection in any part of the urinary system. The urinary system includes the kidneys, ureters, bladder and urethra.
Visitor		Plays an important social role for patients however, does not engage as an active partner in care. May be family member, a friend, or someone from the community who brings cheer and support.

VR	Volunteer Resources	Hospital department that recruits, on-boards, supports and recognizes volunteers
WLMH	West Lincoln Memorial Hospital	Hamilton Health Sciences Site
WOW/ COW	Workstation on Wheels	Staff physicians, and learners use convenient workstations or computers on wheels to access the health information system. These devices can be brought to the bedside to share information with patients. With ever growing use of computerized systems, there will also be more hand held devices used such as smart phones and tablets.