

Statewide Patient and Family Advisory Council Orientation Manual



Welcome to MHA's Statewide PFAC

Patient and family advisory councils foster collaboration between patients, families and members of the health care team to provide guidance toward improving the health care experience, while working to improve the health of the patient. At the state level, a PFAC serves to inform health care initiatives and policy, while applying the unique feedback and insight of the patient and family to improve care delivery. It is widely accepted in health care today that the consumer voice is critical to achieving the Quadruple Aim of better health, better care, lower costs and joy in work.

Patients and families — two often untapped resources — have the power to partner with the health care team to reduce harm and adverse events, improve the patient experience across the care continuum, drive down health care costs, and address health-related issues within their communities. These individuals are well-positioned to inform health care providers in understanding how to best meet patients' and families' needs. MHA promotes greater value of this voice through the PFAC with the shared vision to build a statewide culture of health.

As a member of MHA's PFAC, your experiences, knowledge and ideas are powerful tools for improving Missouri's health care system. By sharing your perspective and working with hospital staff and other patient and family advisors, you can help make important changes and improve the care experience for patients and families across the state.

We appreciate your dedication to this important endeavor and your commitment of time, ideas and support.

Structure

MHA's statewide PFAC will be comprised of hospital staff, patients, family members and community leaders from across the state, with the goal of having representation reflective of the diverse health care communities served in Missouri.

Mission Statement

We will provide leadership and support to advocate for the sustainable integration of patient and family engagement across the care continuum in Missouri to achieve the Quadruple Aim.

Vision

To build a statewide culture of health. The following visual represents what a statewide culture of health means to the PFAC.



PFE Definition

Patient and family engagement is defined as “patients, families, their representatives and health professionals working in active partnership at various levels across the health care system — direct care, organizational design and governance and policy making — to improve health, *health equity* and health care” (Carman et al, 2013).

PFAC Responsibilities and Expectations

Eligible representatives include employed or volunteer patient advocates or patient advisors, a patient or family member who would represent health care organizations at the state level, or a hospital staff member otherwise responsible for patient and family engagement activities. This is a voluntary position serving a two-year term.

As a member of the statewide PFAC, you agree to:

- support the PFAC’s mission and vision,
- attend two in-person meetings and at least one webinar/conference call annually, and be available for ongoing feedback requests,

- listen and respond to ideas and suggestions, and participate with a high level of engagement, bringing experiences and insight to improve health care across the care continuum for all populations,
- assist MHA staff with content expertise and feedback on publications and projects,
- engage, as needed, in advocacy efforts to inform policy development as opportunities arise, and
- maintain confidentiality as required by HIPAA, the Health Insurance Portability and Accountability Act.

To build a strong partnership, MHA agrees to:

- support the PFAC’s mission and vision,
- provide resources and information needed to be an engaged advisor,
- provide structure and facilitation for council meetings and activities,
- keep the council informed about how their feedback and ideas contribute to changes and improvements, and
- facilitate and fund selected education, resources and tools relevant to advancing the PFE agenda across the state.

How to Be an Engaged Advisor

Share your views – your ideas are valuable.

- Focus on problem solving. It is important to build on positive experiences (e.g., “We found that things worked well for our family when...”). It also is helpful to share negative experiences. When you do, try to offer suggestions and possible solutions.
- Consider word choice when discussing highly emotional information. If you want to tell a story that will bring up strong emotions, write out your main points in advance to help you focus. Remember to tell your story with the intent of improvement. See the “Sharing Your Story” section of this document for additional strategies.
- Respect patient privacy. Feel free to share your experiences and the experiences of patients and family members. If sharing 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, avoid use of hospital, provider, staff member or patient name.

Draw on your communication skills.

As an advisor, you will work with many types of people from different backgrounds. You may work with health care providers, hospital staff, hospital leaders, other patients and family members. Good communication skills will help you explain your ideas clearly and develop positive working relationships.

- Keep an open mind. Different perspectives can lead to better conversations and outcomes.
- Practice active listening. 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 of your attention to the person who is speaking and to hear them out before you respond.
- Make sure you understand what other people are saying. One way to make sure you understand someone's point is to say, "What I hear you saying is..." and then repeat what you heard them say. This gives an opportunity to clarify their points if needed.
- Be aware of how you are sharing time with others when you are speaking. If needed, make adjustments to give others time to express their ideas.
- Mind those acronyms and medical jargon. Health care is full of acronyms, which can be confusing for nonclinical members or those not familiar with a particular subject area. Try not to use acronyms, and if it is necessary, be sure to clarify its meaning.

Ask questions.

- Ask clarifying questions (e.g., "Let me make sure I understand correctly. I heard you say...").
- Ask for definitions of medical terms, abbreviations or other terms (e.g., "I'm not sure I know what CAHPS means. Would you please explain it to me?").
- Ask for more details (e.g., "Can you walk me through this so I can picture it?").

Be ready for disagreements.

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. However, your honest opinion can lead to greater understanding.

- 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 (e.g., "I see it differently," "I have a different priority," or "That doesn't work so well for me.>").
- Ask for more background information when people say that a change is not possible (e.g., "Help me understand why this change is not possible.>"). Sometimes when we are used to the way things have always been done, it is hard to see other ways of doing things. Recognize that sometimes there are things that cannot be changed. In this case, you should ask about the reasons why to provide understanding.

- If you find yourself upset after a meeting, talk to the council chair who can make sure that your concerns are addressed and help resolve them.

Be prepared.

There is a time and energy commitment as a member of the statewide PFAC. It is important to understand that commitment and to allow time in your schedule for the meetings, including any work outside the meetings.

- 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.
- Keep the council chair informed about your schedule relative to council activities. If you cannot participate in a meeting, notify your council chair. Ask if you can get an update before the next meeting. If you find that you are having difficulty balancing your advisory activities with your other responsibilities, talk to your council chair.
- Ask how you can learn more. If there is a topic you would like to learn more about or a skill you would like to work on, ask for resources, individuals to meet with or time to discuss it further.
- Ask for support from other members when you need it, and always be ready to provide support to them.

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 also can be a powerful way to show the need for specific changes and improvements in care delivery.

Preparing to share your story.

If you 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. Before you speak in a meeting or to a group, it also helps to practice.

As you are preparing what you want to say, think about the following questions.

- 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 to the audience to remember?
- What am I willing to share? What is too private to share?
- What examples can I give of when things went well?

- What examples can I give of things that could have gone better?
- What ideas do I have about how my experience could have been improved?

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.
- Focus on experiences rather than individuals. Try to avoid using the names of doctors, nurses and other staff. If you talk about a 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. Silence following your story is okay; it shows listeners are processing the story and their own emotions.
- Remember that you may feel emotional when you tell your story. It may be helpful to practice in advance or to write out 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.

Council Member Expense Management

MHA will reimburse council members for mileage, lodging (for those traveling more than 150 miles one-way) and reasonable meal costs incurred for travel related to attending in-person meetings, except for those meals provided as part of the meeting agenda. Expense forms will be disbursed at the opening of each meeting and need to be turned in, along with all itemized receipts, by close of the meeting. *Please ensure all receipts include the itemized purchase detail.*

Learn More

The websites listed below have information on health care quality, patient safety and the role of a patient and family advisor.

Agency for Healthcare Research and Quality

The Agency for Healthcare Research and Quality is a U.S. government agency that is part of the Department of Health and Human Services. AHRQ funds, conducts and disseminates research to improve the quality, safety, efficiency and effectiveness of health care. The website has information to help patients, families, clinicians, leaders and others make informed decisions about health care.

Website: <http://www.ahrq.gov>

Consumers Advancing Patient Safety

Consumers Advancing Patient Safety believes that consumers and health care providers should work together as partners to create health care systems that are safe, compassionate and just. The website has information and resources for patients and health care providers.

Website: <http://www.patientsafety.org/>

Institute for Healthcare Improvement

The Institute for Healthcare Improvement is a nonprofit organization dedicated to improving health care. The website has resources and improvement tools to promote health care quality and safety.

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

Institute for Patient- and Family-Centered Care

The Institute for Patient- and Family-Centered Care provides guidance, information and resources related to multiple aspects of patient- and family-centered care, including how to involve patients and family advisors in the planning, delivery and evaluation of care.

Website: <http://www.ipfcc.org>

Josie King Foundation

The Josie King Foundation offers information and resources on patient safety, the prevention of medical errors, and how health care providers and consumers can work together.

Website: <http://www.josieking.org/>

Medically Induced Trauma Support Services

Medically Induced Trauma Support Services is a nonprofit organization that creates awareness, promotes open and honest communication, and provides services to patients, families and clinicians affected by medically induced trauma.

Website: <http://www.mitss.org/>

Medline Plus

Medline Plus is the website for the National Institutes of Health. It serves patients and families by providing information about diseases, conditions and wellness issues in plain language and includes a medical dictionary.

Website: <http://www.nlm.nih.gov/medlineplus>

National Family Caregivers Association

The National Family Caregivers Association provides information and support for individuals who care for others who are aged, disabled or chronically ill. The website has tools and stories to educate and empower caregivers.

Website: <http://www.nfcares.org/>

National Patient Safety Foundation

The National Patient Safety Foundation is dedicated to improving the safety of patients through education and raising public awareness. The website offers information on patient safety issues and has a variety of resource links.

Website: <http://www.npsf.org/>

References

Carman, K. L., Dardess, P., Maureer, M., Sofaer, S., Adams, K., Betchel, C., & Sweeney, J. (2013). Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Affairs*, 32(2). Retrieved from <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2012.1133>

Adapted from:

Agency for Healthcare Research and Quality (2017). Guide To Patient And Family Engagement: Patient And Family Advisor Orientation Manual. Retrieved from <https://innovations.ahrq.gov/learning-communities/patient-and-family-centered-care/resourceguide/patient-and-family-advisor-manual>

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