

# Patients and Families Help Make Health Care Better

Did you know that many clinicians such as doctors, nurse practitioners and nurses invite patients and families to advise them on improving the health care services they provide? These individuals are called ***patient and family advisors (PFAs)***. PFAs volunteer their time to share their thoughts, experiences, and ideas. PFAs team up with the clinic to make health care experiences and health outcomes better.

***Your clinician and the health care team think you could be a strong partner and make a positive difference!***

## The topics covered in the guide will help you:

- ✧ **Learn** more about the patient and family advisor role
- ✧ **Decide** if this is something that you want to do
- ✧ **Understand** how to have a successful experience as a patient or family advisor
- ✧ **Find** other resources if you want to learn more!

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## Why Have I Been Asked?

### ***We believe patient and family voices matter!***

Your health care experience gives you knowledge and insight about what could improve the health care experience for others.

*We'd like you to consider becoming a Patient and Family Advisor (PFA).*

Patient- and Family-Centered Care (PFCC) is providing health care in partnership ***with*** patients and families rather than doing ***to*** and ***for*** them. In PFCC:

- ✧ Everyone is treated with dignity and respect.
- ✧ Information is shared in useful, timely, and understandable ways.
- ✧ People are encouraged and supported to be a part of their own care team – working with others in planning care, making decisions, and managing their health.
- ✧ The health care system collaborates with patients and families on program design, delivery, and evaluation ensuring their voices help inform changes.

When a PFA shares what has gone well and what can be improved, it helps:

- ✧ Keep the clinic grounded by sharing what's most important to patients and families
- ✧ Inspire and energize staff
- ✧ Highlight that health care is only one part of a person's life
- ✧ Make connections between clinicians, staff, and the community

# Is Becoming a PFA Right for Me?

Here are some reasons people choose to become advisors:

- ✧ I am interested in helping improve health care.
- ✧ I have a positive attitude and enjoy working with people.
- ✧ I have experiences as a patient, parent of a patient or caregiver that show how care could be improved for myself or others
- ✧ I have time in my schedule to be a PFA.
- ✧ I like to learn and want to learn more about patient- and family-centered care and how PFAs volunteer at my clinic.
- ✧ I am ready for this commitment and my family is ready for me to volunteer my time.



**Review the questions below. Your answers can help you decide if this is a role you think is important.**

- ✧ What is my goal for volunteering?
- ✧ What would meaningful participation look like for me?
- ✧ Experienced advisors enjoy solving problems, helping others, and making a positive difference in their communities. Are these activities that interest me?

*"If you want change, you have to be part of it – from the inside! 'The powers that be' at MetroHealth really listen but patients and families have to tell them what they need."*

**~ Brenda, Patient Advisor**

# What Do Advisors Do?

There are many ways for patient and family advisors to participate!

Common PFA Roles	Partnership Results	Time Commitment
<p><b>Advisory Council Member</b></p> <p><i>"I serve on the Patient and Family Advisory Council at Providence Medical Group in Oregon. We help identify projects to work on, provide input on how to increase the effectiveness of messages for patients and families related to the clinic."</i></p> <p>- Patient Advisor</p>	 <p>A brochure on the Medical Home and a 4-minute video were created.</p>	<p>The PFAC meets once a month in the evening for 2 hours. Dinner is provided.</p> <p>If I join a special workgroup, it might last for a couple months and involve up to another 5 hours of my time.</p>
<p><b>Facility Improvement Advisor</b></p> <p><i>"I was part of a group of parents that walked through the pediatric clinic and shared ideas on ways it could be more welcoming and healing."</i></p> <p>- Family Advisor</p>	 <p>Before</p> <p>Redesigned waiting area</p>	<p>It took 2 hours to complete the tour, provide ideas for improvement, and an additional hour to review design plans.</p>
<p><b>Clinic Board Member</b></p> <p><i>"I am very happy with the board (LFAB) because they allow us to contribute to projects happening at our child's clinic."</i></p> <p>- Parent Advisor</p>	 <p>Latino Family Advisory Board El Consejo de Familias Latinas</p>	<p>The monthly meeting can take 3 hours. This includes both time to review the agenda and to complete any follow-up activity.</p>

# Examples of Successful Partnerships with Patient and Family Advisors



**Partners in Safety:** Participate in quality improvement teams to increase use of best practices and improve outcomes.

Teams have helped improve patients' medication management and increased use of after visit summary reports by 40%.

**Patient Education:** Review patient information materials and edit for language choices, length of document, usefulness, and friendly formatting.



**Facility Design:** Share your ideas about clinic and waiting area spaces that feel welcoming and comfortable, efficient process flow patterns, and welcoming clinic signs.

**Staff Education:** Participate in a patient-family panel to share your experiences. For example you might discuss:

- ❖ Challenges and burdens of illness/injury and how you have overcome some of these.
- ❖ How your community supports or doesn't support healthy behaviors.
- ❖ Communication skills crucial to effective partnerships.

## How Can I Sign-up?

### To begin:

- ✧ Contact \_\_\_\_\_ at the clinic to say you are interested.
- ✧ Ask about the application process and what that may involve (for example, will you need training/orientation, a background check, immunizations, or identification badge?)
- ✧ Discuss any questions you may have about the PFA role in your clinic.

### Learn more by asking any of the questions below:

- ✧ What training will the clinic provide to me about my role as a PFA?
- ✧ What is the mission, vision, and goals of the clinic?
- ✧ What activities will PFAs be working on?
- ✧ Is there financial support to cover parking, transportation, and child care costs?
- ✧ Will I be oriented about confidentiality and be asked to sign a form agreeing to maintain the privacy of others?
- ✧ What are the different ways I could participate as a PFA, for example, in-person, by phone, or online?
- ✧ Who will provide me with all the important details about meeting times, locations, what to bring and review before meetings, and what to wear?

**Are You Ready to Say Yes?  
If so, CONGRATULATIONS!**

## How Can I Effectively Participate?

# 8 Ways To Be An Effective PFA

### *“Advice from Advisors, to Advisors”*

#### **Be Curious**

- Ask questions to better understand.
- Explore what’s possible.

#### **Listen Deeply**

- Actively listen to what other people think.
- Avoid interrupting others; wait for them to finish.

#### **Be Respectful**

- Be on time for meetings.
- Keep meeting agreements.

#### **Share Experiences**

- Share what worked and what could be improved from your own experience.

#### **Think Broadly**

- Be open-minded.
- Give input based on both your own and the experience of others.

#### **Respect Confidentiality**

- Do not share private information about other people or the clinic outside of meetings.

#### **Honor Commitments**

- Follow through on what you agreed to do.
- If you can’t attend a meeting as planned, let someone know.

#### **Be Solution-Oriented**

- Reflect on what you think will work for yourself and others.
- Share ideas in a positive manner.

## How Do I Share My Story, Opinions, and Ideas Well?

### Patient and Family Stories Raise Awareness of Issues and Impact Change

- ✧ Everyone has a story about receiving care or a loved one receiving care. Sharing relevant aspects of your story can help others understand care from the patient or family member viewpoint.
- ✧ When in meetings that discuss different parts of the health care experience, you will be asked what you think. Consider both what worked well and what could be improved as you share your thoughts.
- ✧ Share your ideas and opinions about how changes to care can be improved. Be brief and stay on the topic being discussed.

*“I work with practices to share my story, to work toward solutions that help both the staff and the patient and their family. Staff cannot know what it is like to be in our shoes and we cannot understand what it is like to be in theirs. But in working together in this forum, we can get a better idea and build better solutions that work for all.”*

*- Kathryn, Family Advisor*

### When you are asked to share your care experiences:

- ✧ Find out why you are being asked to share your story and who will be there to hear it.
- ✧ Consider what main ideas you want to emphasize about your experience and how it relates to the setting/discussions.
- ✧ Be brief, share highlights, and describe what are the most important lessons you want them to take away.

# Learn More

## Websites, Tools, and Resources for PFAs

Here are some website links you can use to find more information about being a patient and family advisor and the organizations that developed this guide. Talk to the clinic staff for information on how to look up information about other health care topics.

Websites	Link
PFAC Network – An online learning community for advisors and staff	<a href="http://pfacnetwork.ipfcc.org/main/summary">http://pfacnetwork.ipfcc.org/main/summary</a>
Institute for Patient- and Family-Centered Care – information for PFAs and clinics	<a href="http://www.ipfcc.org">www.ipfcc.org</a>
Patient-Centered Primary Care Collaborative – information for PFAs and clinics	<a href="https://www.pcpcc.org/tcpi/getting-started">https://www.pcpcc.org/tcpi/getting-started</a> <a href="http://www.pcpcc.org/tcpi">www.pcpcc.org/tcpi</a>
Planetree International – information to help clinics and hospitals improve	<a href="http://www.planetree.org">www.planetree.org</a>
The Agency for Healthcare Policy and Research – a government agency that has information on patient engagement	<a href="https://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/casestudies.html">https://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/casestudies.html</a>
National Patient Safety Foundation	<a href="http://www.npsf.org/">http://www.npsf.org/</a>

Tools and Resources	Link
Bob’s Story: What is PFCC? (video)	<a href="https://www.youtube.com/watch?v=fm7w36VpLIU">https://www.youtube.com/watch?v=fm7w36VpLIU</a>
The Power of Listening: Melissa’s Story (video)	<a href="https://www.advisory.com/Research/Nursing-Executive-Center/Multimedia/Video/2012/High-impact-storytelling">https://www.advisory.com/Research/Nursing-Executive-Center/Multimedia/Video/2012/High-impact-storytelling</a>
Patient and Family Partnership Councils and Beyond	<a href="http://planetree.org/patient-and-family-partnerships-councils-and-beyond-primer/">http://planetree.org/patient-and-family-partnerships-councils-and-beyond-primer/</a>

# Notes