



Quality Resource Brief

TRIPLE AIM ACHIEVEMENT • AUGUST 2016

The Missouri Hospital Association will periodically release tips and tools to assist hospitals in achieving the Triple Aim — better health, better care, lower costs. These resources, and many more, can be accessed at www.mhanet.com/quality-and-health-improvement

Developing a Patient Family Advisory Council: Actions for Success

Patient and family advisory councils serve as a powerful resource to promote the hospital's mission and the Triple Aim goals of better health, better care and lower costs. An advisory council establishes ongoing relationships with regular meeting times and seeks diverse perspectives representing the populations served. Innovative ideas that come from PFACs have shown great benefit to both the patient and health provider; however, these programs require resources — often scarce in today's health care settings. Despite this, engagement of patients and families in care is a call to action. Legislation, such as the Caregiver Advise, Record, Enable Act (enacted in 10 states to-date) and the proposed Discharge Planning Rule¹, calls for increased involvement of patients and families in their care, both during and after hospital stays and procedures. Development of a PFAC provides a venue for patients and families to share their voice and help providers understand and assess their care, resource and education needs. A PFAC is necessary in today's health care environment of shifting measures, changing payment models and maintaining market share. Health care providers who leverage the knowledge of consumers will be better positioned financially and play a significant role in the population health of the community they serve. MHA is pleased to have Sheryl Chadwick and DeeJo Miller, patient and family advisors from Children's Mercy, Kansas City, share practical information on creating a PFAC. Creating sound structure and using key member selection criteria are critical steps to ensure that a beneficial advisory council is achieved.

WHY START A PFAC

As end-users of the health care experience, patients and families have a unique perspective that isn't focused on reports and scientific evidence; it's about how their health care needs and experiences affect their daily lives and the lives of their loved ones. PFAs are patients or family members who are able to use their insight and health care experiences to contribute to, and improve, the patient experience during and after hospitalization.

The journey of patient and family engagement at Children's Mercy has been an evolution. Today's success is a result of many years of building trust and confidence in partnering with patients and families — this is not an overnight achievement. Senior leadership encourages engaging patients and families early in the care process and

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believes using their expertise — from the bedside to the boardroom — to be essential to the success of ongoing culture change. One of the most successful strategies in patient and family engagement was the creation of advisory boards.

The Agency for Healthcare Research and Quality states, “Working with patients and families as advisors at the organizational level is a critical part of patient and family engagement and patient- and family-centered approaches to improving quality and safety. PFAs are valuable partners in efforts to reduce medical errors and improve the safety and quality of health care. They help identify what the hospital is doing well and where opportunities for improvement exist. Advisors can help the hospital move beyond the problem-finding stage to developing effective solutions.”ⁱⁱ

The American Hospital Association’s Health Research and Educational Trust developed an actionable framework for leaders to follow to establish effective partnerships with patients and families on improvement initiatives (Figure 1).ⁱⁱⁱ

RECRUITING PFAs

There are endless opportunities for hospitals to collaborate with PFAs. Some organizations may engage members on standing hospital committees or short-term projects; others may utilize them as educators for families and staff, while many have created successful PFACs.

Potential Advisors – Key Selection Criteria

- ability to share insights and information about their experiences in ways in which others can learn
- ability to look beyond personal experiences or biases and speak for all patients or caregivers

Figure 1: Framework for Hospitals Partnering With PFAs



Source: Health Research & Educational Trust, 2015

“It is not enough to write a treatment plan. You have to make sure the patient and family are fully engaged and on the same page. You have to understand what the patients really care about and what their values and needs really are.”

Kay Swint, MD Anderson,
PFAC Co-chair

- have a genuine interest in improving health care and are committed to partnering and collaborating with staff while respecting the perspectives of others
- desire to represent the patients and families you serve

There are numerous places to find PFA candidates within your organization. One strategy is to survey staff who work directly with patients. They can identify patients who have expressed improvement ideas or dissatisfaction with current processes. Patient advocate and social work departments also can serve as a resource. Additionally, posting information on the hospital website, social media sites and in clinic waiting rooms are other avenues to recruit potential PFAs.

When a potential PFA has been identified, contact them either by phone, email or letter, and clearly explain their role as a PFA, the projects or committees in which they may participate and the expected time commitment. An example of a PFA service description used by Children’s Mercy is located in Appendix A.

In addition to serving on hospital committees, PFAs at Children’s Mercy also are trained as family educators — parents and guardians of children with complex medical needs who use their story to educate physicians and hospital staff. Family educators also are included in new employee training.

SAMPLE LETTER OUTLINING THE FAMILY EDUCATOR ROLE

You have been recommended as a candidate to be a Family Educator in the Resident Education Program at Children’s Mercy. As the parent of a child with special health care needs, you have a unique perspective and a wealth of knowledge to help future pediatricians learn about patient- and family-centered care.

During the three-year residency program, the stories that family educators share about their life experiences will become part of the educational process for the pediatric residents. Residents will now learn patient- and family-centered care directly from families.

Family educators will be required to commit to the following.

- Teach residents about your experience in a productive and educational manner with an emphasis on lessons learned.
- Attend a two-hour training session.
- Participate in a one-hour lunch with the residents following training where you will be matched with two residents.
- Host residents during a two-hour visit in your home. This will provide them a small glimpse into what life is like for families whose children have unique health care needs.
- Complete an evaluation about the content of the program, the engagement of the residents you are teaching and a self-evaluation for your role as an educator.
- Be willing to have residents evaluate you as an educator.



Sample PFA Interview Questions

- Briefly tell us about you and your family.
- What types of health care services have you used at our hospital?
- Please describe a positive experience you have had at our hospital.
- Have you had an experience that was not helpful? How could it have been changed or improved?
- What would you do if someone had a difference of opinion as a result of their culture or values?
- If you could change one thing at our hospital, what would it be?
- Why do you want to be a patient family advisor at our hospital?

Once a promising candidate has been identified, training and orientation to the hospital and specifically-assigned committees or projects should be provided. Setting the individual up for success through adequate training gains buy-in, cooperation and a strong improvement champion for the patients and hospital.

Suggested Training Topics

- hospital history and mission statement
- staff directory
- benefits for PFAs
- benefits for staff
- characteristics of a successful advisor
- tips for serving on a hospital committee or project
- role boundaries
- confidentiality and HIPAA policies
- tracking volunteer hours

ENGAGING IN THE PFAC

Once a PFA has been assigned to a committee, it is imperative to share the history of the committee including its purpose, accomplishments, barriers and background. A roster of committee members including roles and responsibilities, as well as the goals and objectives of the committee, should be provided to the PFA prior to the first meeting.

To ensure the stability and sustainability of engaging patients and families as advisors, it is good practice to have a dedicated staff member who is responsible for the administration and supervision of the PFA program. This person will serve as the liaison between the advisor and committee chair. The committee chair will be accountable for integrating the PFA into the work and is responsible for communicating with them regarding meeting times and locations, soliciting input, and debriefing following meetings.

One way that many hospitals effectively use PFAs is by creating diagnosis-specific PFACs. A PFAC doesn't have to be organizationwide; it can be a smaller council within an organization that is dedicated to collaborating with patients and families. Examples would be an advisory council representing a cancer or birth center.



“As we continue to focus our efforts on transforming our care model, having our patients at the table is not just a luxury, it’s a necessity.”

Kurt Knoth, Vice President,
Performance Improvement

Children’s Mercy currently has nine active PFACs. The Family Advisory Board and el Consejo de Familias Latinas/Hispanas are hospitalwide councils with members representing a variety of diagnoses. The meetings are conducted in English and Spanish respectively. There are four PFACs representing specific populations, including the intensive care nursery, inflammatory bowel disease, cystic fibrosis and food allergy. In addition, there are three teenage patient councils including the Teen Advisory Board, Hematology Oncology Teens, and Kids and Families Impacting Disease through Science (KIDS KC). Accomplishments for these PFACs can be found at www.childrensmercy.org.

The engagement of PFAs isn’t designed just for pediatrics. This program can, and should be, duplicated in all types of medical settings — adult, psychiatric, ambulatory and clinic-based are examples. The end-users have a vested interest in the quality and safety of care for themselves and their loved ones.

Think about the committees you currently have at your hospital. How many of them have patients and families represented at the table? In your organization, where would a good place be to invite a PFA to participate?

As a result of the ongoing relationships and trust that were built by the PFA program, there has been a continuous increase in the use of advisors at Children’s Mercy. Figure 2 displays the success of implementing a formal PFA program. The first growth occurred when parents were hired to serve as full-time, paid PFAs in 2008. The second increase came after the patient- and family-centered care policy was implemented in 2012. There has been a tenfold increase in the use of PFAs on committees since parents were hired to manage the program.

EXAMPLES OF CHILDREN’S MERCY PFA COMMITTEES AND PROJECTS

- nine hospital-acquired conditions committees
- readmissions committee
- ethics committee
- health literacy
- council on violence prevention
- quality and safety council
- quality and safety committee of the board of directors
- National Patient Safety goals
- financial assistance
- website redesign
- plus many more standing committees and short-term projects

PFAs report many benefits of collaborating with hospital staff. Some benefits include the following.

- Improves services for their loved one and other patients. PFAs report satisfaction when they see processes being improved as a result of their input.
- Provides an opportunity to bring about meaningful change. Advisors appreciate being invited as an equal member of the team to make beneficial changes to the system.



“The members feel that using their insight will really benefit other patients and caregivers. That helping others by serving on the council is one of the most important ways to make a difference. I am humbled by the dedication of these individuals.”

PFAC Co-chair, Annette Mercurio

- Increases opportunities to share information with others. As end-users of care, PFAs are able to see things through a different lens and value the opportunity to share their thoughts and ideas.
- Makes them feel good to make a contribution and give back to the system that provides care for them or their loved one.
- Patients and families with health care needs often feel isolated in their lives, and serving on a committee or project provides them an opportunity to network with others.
- Expands their knowledge and skills, which ultimately results in better care for their family member.

The organization directly benefits by collaborating with PFAs. Some benefits include the following.

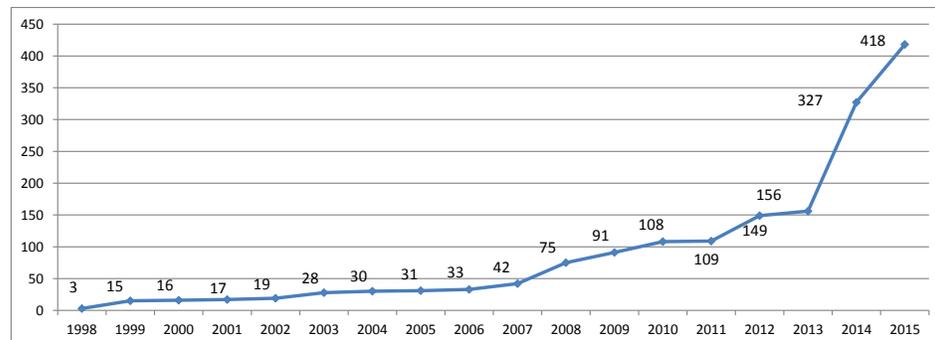
- Advisors have a unique perspective and see things differently than health care employees and ask, “Why?” They also challenge the status quo and don’t accept an explanation of, “That’s the way it’s always been done.”
- Staff make fewer assumptions about what patients and families want because they are at the table to answer questions. This results in an improved planning process, greater efficiency and achievement of the organization’s mission.
- Advisors add fresh perspectives and provide solutions to problems that are shared.
- PFAs are advocates for better services, while increasing the empathy for, and understanding of, patient and family needs.

LESSONS LEARNED

As program managers for the PFA program, there have been many lessons learned.

- First and foremost, it is vital to have support from hospital leadership.
- It is important to designate a staff member to coordinate patient and family engagement. It needs to be a dedicated responsibility to communicate with PFAs. These volunteers will need a single point of contact.
- When recruiting PFAs, ask staff for suggestions. They know patients and families best and can help identify good candidates.
- Set meeting times that will work for both PFAs and staff. Ask patients and families what time works best for them to ensure good attendance, and then commit staff to attend those monthly meetings.

Figure 2: Children’s Mercy, Kansas City, PFAC Involvement, 1998-2015



Source: Children’s Mercy



One physician at Children’s Mercy sent the following email after working with a PFA.

“I have had the opportunity to be on committees when PFAs were present and they offer all of the clinicians around the table a point-of-view very important for us to hear as we try so hard to improve the product we provide for all our patients. So, thank you for letting us have access to them. PFAs are wonderful to work with and are not intimidated by “the profession,” so they provide us with honest and forthright insights into care from the patient and parent’s perspective. They are invaluable to our mission.”

- When establishing a PFAC, create a partnership between the PFAC chair and staff to co-lead meetings. There needs to be regular communication to set agendas and discuss needs and ideas from patients, families and staff.
- Use plain language and avoid acronyms and clinical lingo. Remember that most patients and families do not have a medical background.
- Don’t set your expectations too high for the first year; go for the “low hanging fruit.” Find projects that will have a quick turnaround, but still have a positive impact on the patient experience.
- Report back to PFAs on changes made as a result of their input. As volunteers, patients and families don’t always recognize the changes that have been made as a result of their efforts, so be specific and provide feedback often.
- Celebrate accomplishments with staff and advisors.
- And finally, remember culture change doesn’t happen overnight, but it is worth the investment.

CONCLUSION

Incorporating PFAs into the hospital’s quality improvement practice is the right thing to do for many reasons. For hospitals that have not yet embarked on this journey, it is important to get started. If creating an organizationwide council is daunting, start small. Engage a volunteer PFA around one issue, use the tools provided by Children’s Mercy as examples for recruiting and training, and debrief with them often to gain feedback. For hospitals that are currently engaging PFAs, identify opportunities to increase the degree of involvement and collaboration.

Creating a functional, integrated PFAC is worth the effort and has been shown to decrease patient grievances, improve care transitions and mitigate issues of potential patient harm.

Spectrum Health, another health care organization leveraging patient and family engagement to achieve their mission, produces an annual impact [statement](#) on the work of their multiple PFACs — one of the many resources available to showcase the value of engaging patients and families in the health care experience. Keeping the lines of communication open between providers, patients and families is pivotal to maximizing the return on investment and achieving the Triple Aim of better health, better care and lower costs.

ⁱ Centers for Medicare & Medicaid Services. (2015, November). Medicare and Medicaid Programs; Revisions to Requirements for Discharge Planning for Hospitals, Critical Access Hospitals, and Home Health Agencies. *The Federal Register*. Retrieved from <https://www.federalregister.gov/articles/2015/11/03/2015-27840/medicare-and-medicaid-programs-revisions-to-requirements-for-discharge-planning-for-hospitals>

ⁱⁱ Agency for Healthcare Research and Quality. *Working with patients and families as advisors implementation toolkit*. Retrieved from <http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html>

ⁱⁱⁱ Health Research & Educational Trust. (2015, March.) *Partnering to improve quality and safety: A framework for working with patient and family advisors*. Chicago, IL: Health Research & Educational Trust. Retrieved from www.hpoe.org



Nationally, the inclusion of patients and families on committees and projects has become increasingly common, and hospitals are embracing their input. Patients and families have a role in the redesign of the health care systems in which they receive care. Many organizations are hesitant or resistant to invite patients and families into meetings where confidential or negative information about the hospital's care may be discussed; however, it is a mistake to believe that patients and families do not already see opportunities for improvement and have insightful ideas and solutions to offer.

Children's Mercy actively welcomes patients and families into work efforts. To ensure strong collaborative relationships, staff and PFAs are provided the following information during training.

WHAT WE WANT CHILDREN'S MERCY STAFF TO KNOW

- We can be honest in our discussions. Parents who have been invited to join us understand our goal and the need for confidentiality about what is discussed. This is a safe environment for these discussions.
- You may feel awkward discussing certain things; that is normal and expected. We will work through this area together.
- There may be times when the parents challenge us. *That is a good thing.* We want their perspective to be included, being open to change and not accepting the status quo. It is important to remember that the family's goals are *exactly* aligned with our own — to have a safe, effective, patient- and family-centered course of care for their child.
- This is somewhat of an unknown for the parents who are joining us. They are committed to, and passionate about, partnering with us. They want us to know that they too are learning and want to be sure they are being helpful.

WHAT WE WANT PARENTS TO KNOW

- You are welcome members of our team.
- Please understand that this is new for us too. It is hard to admit that we don't always do things as well as we would want. We are continually working to improve and are asking you to be active participants in that journey.
- We value your experiences and perspective, and welcome your input. We invite you to share your experiences with us. Don't hesitate to ask tough questions or raise issues of any concern.
- It is important that the things we discuss remain confidential. The general nature of the discussions and issues we are addressing are things that we would not want to share publicly.
- Some of the language or terms we use may be new to you, so ask us if you don't understand what we are talking about.

DEFINING SUCCESS

- All participants were open and honest in discussing topics and issues.
- All participants gained a new perspective about how our organization performs.
- Everyone felt the experience facilitates further integration of families into quality work.
- Parents who participated have a better understanding about improving quality, patient safety and the challenges the hospital faces.
- We all feel it was a success having parents join our committee *and*, we would not hesitate to consider involving families in any future quality or performance improvement efforts.



APPENDIX A



FAMILY CENTERED CARE SERVICE DESCRIPTION **PATIENT-FAMILY ADVISOR**

Supervisor: DeeJo Miller
Sheryl Chadwick

Telephone: 816-983-6957

Location: Family Centered Care Services
Children's Mercy Hospital

Purpose:

This volunteer actively partners with hospital staff in understanding the family perspective by offering advice, consultation, guidance and direction on projects and hospital committees.

Qualifications:

- Patient-Family Advisor volunteers must have a child that has been or is currently receiving treatment from CMH.
- Ability to listen to concerns of hospital staff and other partners.
- Be emotionally stable and have the ability to act professionally, calling on their own experience while "separating out" their own issues.
- Willing to accept training and supervision.
- Ability to maintain confidentiality.
- Possess level of maturity to deal with hospital systems.

Training Requirements:

Volunteer will receive Family Centered Care Services training.

Description of Duties:

- Ability to commit to committee/project expectations (time, meetings, assignments, other tasks)
- Share insights and information about their experiences in ways that others can learn from them
- See beyond their personal experiences
- Demonstrate concern for various issues
- Listen effectively
- Treat the perspective of others with dignity and respect
- Interact with diverse populations
- Speak comfortably with candor
- Work in partnership with others
- Demonstrate effective communication skills, the ability to collaborate with others, knowledge of the topic/issue at hand
- Provide feedback to hospital personnel to improve hospital services

SUGGESTED CITATION

Chadwick, S., Miller, D., & Shackelford, M. (2016, August).

Developing a patient family advisory council: actions for success. Missouri Hospital Association.

APPENDIX B

| | | | |
|--|------------------|--------------------|---|
| Patient / Family Advisor (PFA) Application | | |  Children's Mercy |
| Name: | _____ | | |
| | (Last) | (First) | (M.I.) |
| Address: | _____ | | |
| | (Street) | | |
| | _____ | | |
| | (City/State/Zip) | | |
| Home Phone: | (____) _____ | Cell Phone: | (____) _____ |
| Email Address: | _____ | | |
| Please briefly describe your experiences with Children's Mercy: | | | |
| _____ | | | |
| _____ | | | |
| _____ | | | |
| _____ | | | |
| Please list the areas of interest that you would like to volunteer as an advisor: | | | |
| _____ | | | |
| _____ | | | |
| What are the names of your children who were cared for at Children's Mercy Hospital? What clinics, units, and/or physicians did they receive care from? | | | |
| _____ | _____ | _____ | _____ |
| (Last) | (First) | (M.I.) | (Clinic/unit/physician) |
| _____ | _____ | _____ | _____ |
| (Last) | (First) | (M.I.) | (Clinic/unit/physician) |
| May we contact the clinics, units and/or physicians who have cared for your child(ren)? (**Please circle one) YES or NO | | | |
| Please return this completed application to the Family Centered Care Department, Children's Mercy Hospital, 2401 Gillham Road, Kansas City, MO 64108. | | | |
| If you have any questions, please contact Sheryl Chadwick or DeeJo Miller at 816-983-6957. | | | |
| Please note that the information you enter into this form will be held in the strictest of confidence and will not be used or disseminated for any purpose other than as a tool to determine your volunteer assignment. Thank you for your interest. | | | |
| _____ | _____ | | |
| Signature | Date | | |



MISSOURI HOSPITAL ASSOCIATION

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