



PATIENT AND FAMILY ADVISORY COUNCILS BLUEPRINT

A START-UP MAP AND STRATEGY GUIDE

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AHA Physician Alliance
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OVERVIEW

Patient and Family Advisory councils (PFACs) are an excellent way to help health care institutions and providers better understand the perspective of patients and families while also helping caregivers better identify the needs of their patient population and bring patient and clinicians views closer together.^{1,2} As COVID-19 divided and devastated communities, many organizations worked with their PFACs to inform outreach, reduce barriers caused by COVID-19 and drive lasting improvements. To capture learnings and help the field build and sustain high performing PFACs, the AHA gathered a group of patient and family engagement leaders to share their insights. Participants included:

- Tom Bauer, MBA, John Hopkins Hospital and Health System, Baltimore, MD
- Jacqueline Beckerman, University of Rochester Medical Center, Rochester, NY
- Robyn Begley, DNP, RN, NEA-BC, FAAN, American Organization for Nursing Leadership, American Hospital Association, Chicago, IL
- Adrienne Boissy, MD, MA, Chief Medical Officer, Qualtrics, Cleveland, OH
- Nathan Cunningham, MPH, VCHU Health, Richmond, VA
- Micheal Daly, Levine Children's Hospital (Atrium Health), Charlotte, NC
- Caroline Delongchamps, MUSC Health, Charleston, SC
- Nicole Iarrobino, MS, John Hopkins Hospital and Health System, Baltimore, MD
- Pam Rudisill, DNP, RN, NEA-BC, FAAN, Community Health Systems
- Pam Ullman-Farris, CPXP, Bassett Healthcare Network, Cooperstown, NY

PATIENT AND FAMILY ADVISORY COUNCILS AND COVID-19

Through the COVID-19 pandemic, as many institutions paused elective committees due to social distancing requirements and increased patient care needs, many PFACs were just ramping up their work to help patients, providers and families navigate the new challenges presented by COVID-19.

The use of virtual meeting platforms has sustained PFAC access and connectivity during the pandemic and for some, it has encouraged PFAC member inclusion in broader hospital committees to provide perspectives. Tom Bauer, MBA, senior director of Patient Education and Engagement at John Hopkins Hospital and Health System shared “It is important to include the PFAC’s wisdom during times of rapid change. Virtual platforms allowed this to happen and the PFACs were instrumental in advising us.”

As the COVID-19 pandemic progressed it created new challenges for providers in how they interact with their patients and families. For example, the use of telehealth could limit patient interactions with nurses and patient care techs and reduce opportunities for supportive care. Further, the elimination or reduction of family members in the hospital for safety reasons has also reduced their ability to support care delivery, be present for all interactions with providers, and provide ongoing social support to their loved ones. These challenges have made patient and family engagement more difficult, including developing care

plans that include and are focused on the patient’s needs. In addition, health care professionals noted that the absence of family support for a patient leads to providers stepping in to play that role, only adding to the emotional toll.

Caroline DeLongchamps, manager of Patient and Family-Centered Care at MUSC Health shared the important role PFACs played leading to changes in visitation policy for parents. Within 24 hours of a community member bringing forward a concern, PFAC members were able to hear the problem and bring it to the attention of hospital leaders in a way that lead to immediate and meaningful change. [Learn more via the related podcast.](#)

Beyond the challenges of engaging with families and patients, the pandemic has continued to rapidly push new communication modes, procedures and protocols. As our teams work to familiarize themselves with these new modes and technologies, Patient and Family Advisory Councils can assist organizations in understanding how these changes impact patients and how to best communicate and deploy them.

KEY TAKEAWAY: In an era of distancing and reduced visitation, PFACs can serve as an even more important connection and lifeline to the voice of patients.² As COVID-19 has highlighted the social, economic and health inequities evident in our society, this connection to patients will be critical as health systems continue to address health equity and structural racism.³ Without including the patient’s perspective in these critical areas, we risk implementing solutions that will not address the problem.



Bassett’s network-wide PFAC was just hitting its stride when COVID-19 hit. Rather than pausing its work, Bassett decided to keep its PFAC going. This inspired fresh enthusiasm from PFAC members. Remote council meetings were a connection with others during months in quarantine. Meanwhile, projects gave patient and family advisors a way to support their health care network during a major crisis. The result was a burst of productivity in patient- and family-centered improvement projects. During a six months period alone, the PFAC completed or advanced three patient- and family-centered improvement projects and advised on eleven areas of interest.

PAM ULLMAN-FARRIS

CPXP, INTERIM DIRECTOR AND MANAGER OF PATIENT EXPERIENCE OPERATIONS, BASSETT HEALTHCARE NETWORK



PFAC SUCCESS: A HOW-TO FLOW CHART

As highlighted by the American Institutes for Research (AIR), at a fundamental level the benefit to working with patient advisors is better health outcomes for patients, including reductions in hospital-acquired infections and conditions, reductions in preventable readmissions and improved patient experiences.⁴ At an organizational level, The Agency for Healthcare Research and Quality identifies several benefits of PFACs including increased employee satisfaction and improved financial performance.⁵ Although so much has changed recently, the basics of creating and utilizing a PFAC haven't. Two key resources for PFAC creation include the [Agency for Healthcare Research and Quality's \(AHRQ\) Working With Patient and Families as Advisors: Implementation Handbook](#) and [IPFCCs A Patient and Family Advisory Council Work Plan: Getting Started](#). The following strategies highlight key learnings from these documents as well as advice from member leaders.

STEP 1: Determine Size

A PFAC should have a membership that allows for diverse viewpoint, but should be sized to allow the group to reach consensus.

Successful PFAC programs have between 12 and 25 advisors, depending on committee structure and community. Most importantly, PFACs should reflect the patient population served. Jacqueline Beckerman, chief patient experience officer and senior director at ICARE Commitment at the University of Rochester Medical Center, shared that at the University of Rochester Medical Center, they have a large central council and a smaller group of network advisory councils made up of underrepresented areas in their community. Examples of the network advisory councils include a behavioral health patient and family advisory council, a deaf patient and advisory council, a transgender and gender diverse patient advisory council, and more. Each of these network advisory groups has a representative on the larger central council. [Learn more via the related podcast.](#)

STEP 2: PFAC Structure

Like all committees the PFAC will need to establish guiding structures including a mission statement or charge, bylaws, time commitment and meeting frequency and budget among others. PFACs are not just about bringing people together in a room on an ad hoc basis, they require dedicated staff and resources to properly engage conversations with patients. It is important to make sure that PFAC work doesn't just happen in a monthly meeting, PFAC members should be a voice side by side with clinicians and those making decisions across the board.

Initial PFAC sessions will need to consider the following items:

- How will the PFAC accomplish its work?
- How does the PFAC charge align with the organizational strategies?
- What education and resources should be developed for guiding the PFAC on organizational efforts?
- How will PFAC activities be connected to the larger organization?
- How will the PFAC be engaged in ongoing projects?

Strategic planning needs to happen at conception but should be reviewed and reassessed on an annual basis. Understanding how PFACs will be engaged on organizational needs will allow for flexibility and agility.

STEP 3: Advisor Recruitment and Retention

It is important to have both internal and external advisors that represent the diverse group of patients that the hospital serves.

At Bassett Healthcare Network, they found that their biggest challenges in establishing a PFAC stemmed from being a rural network. Bassett provides care across 5,600 square miles and eight counties in Central New York. To properly represent the diverse communities across this area, Bassett needed an active recruitment strategy. Once it was running, it would need a sound operational structure. Thankfully, the effort received strong executive and board support. Using provider recommendations, community events, web pages and public service campaigns, Bassett created a council with advisors making up 50 percent of the council and representing all communities. It also developed an effective communication plan with a triad management model. The result has been a dynamic group that produces creative, team-based solutions to problems.

To ensure the PFAC includes a diverse group of advisors, creative recruiting can help, such as:

- Reach out to staff to get friends and family engaged
- Hold recruiting fairs in the hospital to encourage patients to join
- Ask patients who have worked with your patient representative department

Inclusive approaches can help ensure a diversity of thought. Consider the following approaches:

- Involving interpretation services in the PFAC
- Scheduling meetings at varying times, including nights and weekends to accommodate all schedules
- Utilizing virtual platforms to eliminate transportation barriers

STEP 4: Orientation

Hospitals and health systems are complex organizations and a thorough orientation, informed by current PFAC members or patient advisors will be critical to strong communication and input.

New PFAC members need to understand the goals and structure of their committee, as well as the culture and connection points throughout the organization. Adrienne Boissy, MD, MA, neurologist and former Chief Experience Officer of the Cleveland Clinic shared “PFAC members go through a very structured orientation program where they learn the mission, vision, and principles of the organization. We also provide resources to members with position descriptions as well as opportunities for them to engage and ask questions with other members and hospital staff.” [Learn more via a PowerPoint presentation.](#)



There isn't just one approach, its many approaches at the same time. This year at John Hopkins, we have had success with indirect outreach. Our marketing team placed a blurb about PFACs in our general marketing email that went to almost all of our patients, we had many people click on this and received some applications. We also had some success with putting up a banner on our website. While these have been great, we also need to get to those individuals who might not have found us on the internet. This year, we created a video of our PFAC members sharing their stories of why they joined. We plan to use this among our staff for internal recruitment. Additionally, we have added PFAC advertisement to our pharmacy hold message. Recruitment is an ongoing part of our strategic plan.”

NICOLE IARROBINO

SENIOR PROJECT ADMINISTRATOR OF PATIENT AND FAMILY ADVISORY COUNCILS, AND PATIENT AND FAMILY-CENTERED CARE AT JOHN HOPKINS HOSPITAL AND HEALTH SYSTEM



STEP 5: Determine Staff Support Members

Staff should “ensure that council activities are meaningfully integrated into changes and improvements within the hospital” by facilitating discussions, advocating for inclusion and reporting on the PFAC’s achievements” - AHRQ.

Success factors:

- Limit staff involvement to 3 to 4 per group
- Select engaged and interested team members who are regularly able to attend
- Look for active listening skills and those open to hearing feedback
- Where possible, involve informal leaders from across the organization
- Include front line nurses to enhance connection to the bedside

The Journal of Critical Care Nurse highlights that “nurses benefit from advisory councils by having a better understanding of the needs of patients and patients’ families from the perspective of the patients and the patients’ family members and integrating this information into systems and processes that improve the quality, safety and efficiency of care.” Our patient family engagement leaders also enforce this importance in connecting the PFAC’s work to bedside providers.⁶ To establish a direct connection to the bedside consider including front line nurses in the PFAC.



It seemed like a perfect marriage to get nurses involved in PFACs. Patients and families have responded well to their ability to explain the inner workings of health care and both parties came away with a richer picture of what it takes to provide superior care with quality and safety as key components. At the national level, we at AONL believe that all nurses have the potential to be leaders and PFACs are a prime area for nurses to get involved.”

ROBYN BEGLEY, RN,

CHIEF NURSING OFFICER AND SENIOR VICE PRESIDENT
OF WORKFORCE AT THE AMERICAN HOSPITAL
ASSOCIATION



Approaches to consider:

- Creating PFAC champions among bedside nurses in each unit
- Involving PFAC champions in hospital orientation
- Utilizing PFAC participation as career growth opportunity by explicitly highlighting the value as part of internal career development resources
- Engaging nursing students with PFAC work and involving patient advisors in nursing education

STEP 6: Goals and Ongoing Engagement

As with any committee, outlining measurable goals is key to demonstrating performance.

- Set annual goals and report out on progress and completion
- Communicate PFAC goals and accomplishments across the organization
- Provide ongoing education to staff on the value of the PFAC
- Measure impact and share feedback and results with the PFAC
- Ensure follow up when PFAC input is requested

To facilitate ongoing engagement from both team members and the PFAC members, successful PFACs use the following approaches:

- Use term limits to encourage a diversity of participation from both staff and advisors.
- Outline a clear communication strategy
- Recognize and celebrate PFAC members and their accomplishments
- Include PFAC at the initiation of the project instead of post-production review
- Schedule regular and ongoing education to the broader team through formal and informal methods including
 - Office Hours
 - Weekly Coffee Talks
 - Unit Rounding
- Have a plan for staff to get involved with the PFAC
- If possible, network with other PFAC leaders to share ideas and learnings

Jackie Beckerman from the University of Rochester shared that they have recorded videos of their council members discussing why the council is so important to them. These videos help energize members and reaffirm the importance of this work. [Learn more via the related podcast.](#)

STEP 7: Create a Culture

Leadership buy-in is a major component of creating a culture of patient and family centered care.

At an organizational level creating a culture that supports PFAC feedback includes:

- Incorporating PFAC advisors in your organization's strategy planning process
- Leadership role modeling inclusion of the PFAC, including inviting advisors to meetings and proactively consulting advisors on challenges
- Including advisors at orientation, include information about your PFAC in yearly competency assessments



Leadership has made this a priority and had led by modeling. Leaders will sit in meetings and any time a new initiative comes up they make sure there is a PFAC involved, everything is done with the patient in mind.

NICOLE IARROBINO,
JOHNS HOPKINS

[Learn more via the related podcast.](#)



Expanding upon this, we also need to ensure we are building a culture at a unit level by providing opportunities for PFAC members to connect with frontline staff. Ways to accomplish this could include:

- Ask PFAC members to join unit-based committee meetings
- Have PFAC members round on units
- Involve PFAC members in interviews for senior-level positions

To expand and sustain your PFAC it is critical to advocate for routine and proactive inclusion in organizational activities and sharing of appropriate data, scorecards and dashboards. A high performing PFAC is welcome at all levels of the organization, from the board room to the patient's room.

CONCLUSION

PFACs at their foundation are about relationships.⁷ While effective structures can support their functioning, commitment to developing those connections will sustain these programs. To create a successful PFAC, organizations must be sensitive to the local factors and changing culture, and most of all recognize the PFAC as a key part of the health care team.

PFACs have supported their organizations and communities throughout the COVID-19 pandemic, providing a sounding board on patient-facing COVID resources, input on resources to support families and patients as COVID-19 restrictions kept them apart and supports for helping alleviate the additional tasks clinicians at the bedside were taking on as a result of the pandemic. As a trusted voice of the community and a resource that knows health care, the PFACs helped bridge the isolation and physical distancing needed to keep patients safe.

Pam Rudisill, DNP, RN, NEA-BC, FAAN, senior vice president and chief nursing officer at Community Health Systems shared, “The COVID-19 pandemic has put forth no question that PFACs are an important entity. First, COVID-19 was uncharted territory and the urgent need to focus on the impact to the patient and family cannot be underestimated. Second, the work of caring for these extremely high acuity patients by the dedicated staff across the country was challenged by the use of protective measures and PPE that made communication and the human connectedness needed very difficult. As we looked at the ever changing emotional, social, mental, and certainly physical needs of the patients, we knew we needed the support of more than just our front-line care team. Our PFACs were there to support us and were listening to what our patients and families were telling us every single day, helping to change policies on a day-to-day basis.” [Learn more via the related podcast.](#)

PFACs will continue to play an important role in creating an organization that is patient-centered and an active member in the communities they serve.

TOOLS TO GET STARTED:

- [The Institute for Patient- and Family-Centered Care](#)
- [The Beryl Institute](#)
- [Cleveland Clinic Healthcare Partner Program PowerPoint \(PDF\)](#)
- [Podcast: Nursing Leadership in PFACs](#)
- [Podcast: Establishing a PFAC in your Organization, Councils truly reflect the patients they serve](#)
- [Podcast: PFACs creating partnerships between providers, patients, and families](#)
- [Podcast: PFACs supporting hospitals through COVID-19](#)
- [Podcast: Joining Hands: PFACs and COVID-19](#)
- [Every Patient Deserves a Voice: Deaf, Behavioral Health and Transgender PFACs](#)
 - [Video: Behavioral Health](#)
 - [Video: Transgender](#)
 - [Video: Deaf](#)

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