

# **Ohio Hospital Association**

## **Patient and Family Advisory Council (PFAC) Toolkit**

**Chrissie Nadzam Blackburn, MHA  
Patient and Family Engagement Sub-Contractor  
Ohio Hospital Association**

# Table of Contents

1. What are Patient and Family Advisory Councils and Patient and Family Advisors? (Page 3)
2. Planning Committee for developing a PFAC (Page 4)
  - a. Who should attend and items to discuss
3. Patient and Family Advisory Council Membership and Structure (Pages 5-10)
  - a. Ratio of staff and Patient and Family Advisors
  - b. The READI Patient and Family Advisor™
  - c. Responsibilities of the PFAC Staff Liaison
  - d. The READI Staff Liaison™
  - e. Responsibilities of the Patient and Family Advisor co-chair
  - f. The READI Patient and Family Advisor co-chair™
4. Roles and Responsibilities (Pages 11-12)
  - a. Roles of Patient and Family Advisors
  - b. What Patient and Family Advisors do
5. Application and Volunteer Services (pages 13-14)
  - a. PFAC applications and interview questions
  - b. Process for volunteer services
6. Recruitment Strategies (Page 15)
  - a. Examples and ideas
7. Time Commitments (Page 16)
  - a. Why term limits are important for Patient and Family Advisors and the PFAC
  - b. Annual meetings
  - c. PFA activity between meetings
8. Mission, vision, charter, and goals (Pages 17-18)
  - a. Examples to use in your PFAC's development
9. Budget Considerations (Page 19)
  - a. Incentives for Patient and Family Advisors
  - b. Recognition of volunteering and success
  - c. Average annual cost for running a PFAC
10. Successful meetings (Page 20-21)
  - a. Best practices for successful meetings
  - b. Senior leadership support and presence
  - c. Staff education of PFACs

## **What are Patient and Family Advisory Councils (PFACs)?**

A PFAC is a formal group that meets regularly for active collaboration between clinicians, hospital staff, and patient and family advisors on policy and program decisions.

Agency for Healthcare Research and Quality, (AHRQ, 2013).

## **What are Patient and Family Advisors (PFAs)?**

A PFA is a former or current patient and family member of the hospital, who is emotionally, physically, and mentally ready to volunteer and partner with the organization to make improvements. This is typically a patient who is interested in being actively involved in their care or the care of a family member and has offered constructive feedback in the past.

Agency for Healthcare Research and Quality , (AHRQ, 2013).

# Planning Committee

## Who Should Attend

### Suggested hospital staff should include:

- One executive sponsor (President, Chief Medical Officer, Chief Operating Officer, Chief Nursing Officer, Patient Safety Officer, or Chief Quality Officer). It is important for leadership to actively support the PFAC, staff members, PFAs, and the council's efforts.
- One staff physician
- One staff nurse
- One quality leader
- One nursing director or manager
- One volunteer services representative

### Patients and Families:

Identify 2-3 patient and family members in your organizations to partner and help in the development stage; although they may have not been through the interviewing process. Staff is usually able to identify patients and families that have the professionalism and patient experiences to participate in the structural development of the PFAC

### Items to Discuss (in this order):

1. Development of a work plan, bylaws, PFAC structure, and time line
2. Volunteer vetting process
3. Interview and application process for patients and families
4. Recruitment ideas and action
5. Possible goals and objectives for the PFAC
6. Resources for PFAC- dinners, parking, small gifts of appreciation, celebration, etc.
7. Identifying a PFAC Staff Liaison
8. Identifying a PFA co-chair
9. Assigning specific duties to staff and PFAs

Give the development and structural foundation time, it can take up to 3 months to get the PFAC structure developed and ready for hospital wide recruitment. It will move as quickly as the Planning Committee wants it to.

# Patient and Family Advisory Council Membership

## Ratio of staff and PFAs

Make up should be 30-40% staff and 60-70% PFAs.

## Identifying PFAs and staff

The READI Patient and Family Advisor™ is a good way to look at the characteristics of PFAs. It is important that the PFAs on the PFAC do not have their own agenda and have a global perspective for the care of all the patients and families that come through the organization. In addition, PFAs must have had current care at the organization (usually within the last 1-5 years, maximum). There are some situations, such as family member who cared for someone with cancer or chronic conditions that may go beyond the 5 years maximum. This experience and expertise should be considered.

## PFAC Structure

The structure of the organization's PFAC is critical for success and sustainability. Some of the most important aspects for structure are:

- Ratio of staff to PFAs
- Having anywhere from 10-20 PFAs on the PFAC
- Identification of a PFA co-chair
- Identification of a staff liaison
- Meeting 10-12 times annually
- Bylaws/charter/guidelines
- Term limits for PFAs
- Senior leadership presence, support, and connection
- PFA leaders for membership and recruitment, speaking events, social events, and other activities to connect with the organization and community
- Training, education, and the Volunteer Services vetting process for the PFA
- The PFA understanding the organization's goals and priorities
- Staff's understanding of the PFAC structure and partnering with patients and families
- PFAs leading the PFAC projects and activities based on their experience and what they believe to be important for patients and families within the organization in collaboration with organizational goals and priorities.
- HIPAA training, health screening with vaccinations, and general safety training for all PFAs
- Keeping track of each PFA's start date on the PFAC

The **READI** Patient and Family Advisor™ is someone who:

- Is **R**ESPECTFUL, collaborates, speaks-up, and listens with hospital staff.
- Has **E**XPERIENCE of care at the hospital and is able to share their experiences to enhance care.
- Is **A**PPRECIATIVE of other patients and families and hospital staff.
- Is **D**EDICATED to enhance safety, quality, and experience for all patients and families.
- Is **I**NVOLVED in his/her own or a loved one's care, and creates opportunity to partner with the hospital and other patients and families based on his/her experiences.

University Hospitals Health System, Cleveland, Ohio, © 2014

Technical reasons and demographics for choosing Patient and Family Advisors:

- Positive and negative experiences while receiving care.
- Diversity of background (socioeconomic, culture, ethnicity, gender, Medicaid /Medicare recipients), disease or other medical care (surgeries, outpatient services, etc.)
- What PFAs are passionate about (quality, patient experience, safety, document review, etc.) to enhance the PFAC and organizational initiatives and programs.

**It is important that the PFAC reflects the community the organization serves.**

## Identifying a PFA co-chair

Another important aspect of the PFAC structure is identifying a PFA co-chair. PFA co-chairs help to guide the PFAC in sustainability, activities, communication, and structure. They partner directly with the Staff Liaison to ensure the goals of the PFAC are being met and what needs to be executed in order to meet those goals. They assist in the agenda for each PFAC meeting, co-lead PFAC meetings, oversee and provide direction in all PFAC activities, may put together ad hoc groups, help in interviewing new PFAs, are the official spokesperson for the PFAC, keep the PFAs informed of important information affecting the PFAC, and supervise preparation of reports coming from the PFAC.

The **READI** PFA co-chair™ is someone who:

- Is **R**ESPECTED by the other PFAC members and the organization's staff.
- Has the skills to **E**XECUTE the mission and vision of the PFAC.
- Is **A**CCOUNTABLE for the PFAC, PFAs, the structure, the activities, and leading, supporting, and assisting in the PFAC goals.
- Has **D**RIVE and is well connected, with the help of the Staff Liaison, to other hospital administrators and staff.
- Is **I**NSPIRATIONAL and sets by example the roles and responsibilities of a PFA.

## **Expectations and Responsibilities of Patient and Family Advisors**

Patient and Family Advisors believe in their hospitals and want to partner to enhance reaching an organizations mission and vision. In order to make the most of the organizations Patient and Family Advisory Councils and participation in activities and meetings we ask all Patient and Family Advisors to:

Respect our colleagues and other PFAs.

- Arrive to meetings on time.
- Silence cell phones.
- Come to meetings prepared and ready to get work done.
- Minimize sidebar conversations and keep on task.
- Don't interrupt.

Be responsible.

- If you are unable to attend a meeting, let the PFAC staff liaison or PFA co-chair know.
- Be proactive and take on a task if you have the skills and passion for the job.
- Meet deadlines to the best of your abilities. Ask for help if you need it.

Be a good communicator.

- Express your thoughts and ideas clearly, directly, honestly and respectfully.
- Be a good listener.
- Work cooperatively – **with** others – to get a job done.
- Expect occasional conflict - it is natural and to be expected. But if dealt with productively, conflict can lead to innovative problem solving.  
More viewpoints = more possibilities.

Actively participate and be flexible

- Every PFA has value and contributes to our collective successes. This does not just include meetings. It is critical that PFAs, pending on their availability, become active partners within the hospital.
- Consider different points of view and compromise when needed.

Ask questions if you need clarification.

Patient and Family Advisors are a reflection of the hospital. Having the ability and willingness to give back to the organization means a great deal to (hospital name) and can be a very rewarding experience to the PFA participating on a Patient and Family Advisory Council.

## Identifying a Staff Liaison

Staff is just as important as the PFA. Look for staff members that champion Patient and Family Centered Care and have the willingness to partner and keep the PFAC connected with the organization. It is also critically important that senior leadership participate with the PFAC, even if it is rotating meetings. The most successful PFACs have senior leadership participating in their efforts. In addition, identifying a staff liaison will be critical for the success of the PFAC. Please see the following to identify a staff liaison and their roles and responsibilities.

Hospitals that are most effective in engaging PFAs designate a clinician or staff member to serve as a Staff Liaison. The Staff Liaison works with hospital leaders to put in place the infrastructure necessary for advisor engagement; prepares staff and clinicians to work with Patient and Family advisors; and recruits, trains, and support advisors (AHRQ, 2013). The Staff Liaisons' job is to facilitate partnerships, ensure that advisors are ready to participate, and ensure that staff is ready to engage in partnerships (AHRQ, 2013).

The Staff Liaison is someone who has good rapport with leadership and clinicians. They also have the ability to work with many different departments and may already work in patient and family education, quality, safety, or administration (AHRQ, 2013). Clinical Staff Liaisons are also excellent because they can keep the PFAC closely tied to the hospital units and current unit projects, initiatives and programs. In addition the staff liaison should have refined facilitator experience

### The **READI** Staff Liaison™ is someone who:

- Is **R**ESPECTFUL of the patient and family perspective.
- Is well connected and **E**NGAGES and educates PFAs on how the hospital works, and staff and clinicians on partnering with patients and families.
- Leads, **A**PPRECIATES and champions Patient and Family Centered Care.
- Has patience and is **D**EDICATED to learn, persevere, and see strengths in all people in all situations.
- Looks for and **I**DENTIFIES opportunities for PFAs to be involved throughout the organization.

## What are the Staff Liaison's Responsibilities?

The Staff Liaison has a unique role in keeping closely connected to hospital leaders, clinicians, patient and family advisors, and other staff. They mentor, consult, and educate all those that they work with about the PFAC and Patient and Family Centered Care. According to AHRQ's Guide to Patient and Family Engagement (2013) there are several responsibilities for a staff liaison. Because of these responsibilities it is strongly suggested that the Staff Liaison have an Admin that is assigned to support the PFAC.

### Responsibilities to hospital leadership:

1. Working with administration to get their buy-in and commitment for working with PFAs.
2. Keeping leadership informed about the PFACs activities, accomplishments, and goals.

### Responsibilities to staff and clinicians:

1. Educating them about PFAs and opportunities to work with them
2. Helping staff with developing plans for involving advisors in specific projects and workgroups.
3. Helping staff understand how to interact with PFAs and how to implement their suggestions or to provide feedback about why changes may not be possible.
4. Problem solving in challenging situations.

### Responsibilities to PFAs:

1. Obtaining necessary resources.
2. Cultivating opportunities for PFA involvement.
3. Overseeing the recruitment and selection of PFAs.
4. Communicating with PFAs in a timely manner about recruitment status and potential opportunities.
5. Training PFAs and helping them to understand how the organization works
6. Overseeing PFA activities, providing mentoring and coaching, and facilitating the ongoing engagement of PFAs.
7. Bringing concerns of PFAs to leadership, or connecting PFAs with organizational leadership.
8. Tracking and communicating PFA accomplishments.

It is important that the Staff Liaison is well respected by his/her peers and is well connected with many areas of the organization. This will help to strengthen the Patient and Family Advisory Council and help to successfully engage PFAs in many initiatives and opportunities. **IMPORTANT:** The executive sponsor should support the staff liaison in their responsibilities.

Agency for Health Research and Quality. *Guide to Patient and Family Engagement: Working with Patient and Families as Advisors*. AHRQ, 2013.

## Roles of Patient and Family Advisors

The Patient and Family Advisor serves as a very unique volunteer to health care organizations. The work of the PFAC must be purposeful and meaningful to the PFA. They typically have a beginner's to advanced understanding of the hospital system, have received care at the organization, and have a loyalty to the health care organization to see it succeed and be the best it can be. Patient and Family Advisors may have different tasks and activities once they join a PFAC and their roles within the organization can vary depending on the activities they may want to be trained, educated, involved in, and have the time to commit to.

Examples of different PFA roles:

- Trained and educated to serve on quality, safety, root cause analysis, or patient experience committees at varying levels (senior leadership committees, board of directors, etc.).
- Trained and educated to serve on hospital units and/or departments working with inpatient or outpatient patients and families.
- Document and literature review.
- Organize social events for hospitalized patients and families.
- Trained and educated to speak publicly and educate physicians, nurses, students, and other hospital staff about their own story as a patient or caregiver, PFACs, Patient and Family Centered Care, and Patient and Family Engagement.
- Recruitment of other potential Patient and Family Advisors.
- Public speaking at community events.
- Based on budget, PFAs may attend local, state, or national conferences to learn more about being a PFA, Patient and Family Centered Care, safety and quality, and more.
- Development of creative ideas and initiatives to help patients and families who may be hospitalized or in the outpatient setting.
- Assisting and partnering in hospital initiatives and programs.
- Some PFAs may get involved in other local, state, or national organizations also serving as a PFA.

The key is match a PFA with their passion, skill, and what they want to enhance or change in healthcare.

## What Patient and Family Advisors Do, and What They Mean to a Healthcare Organization

Patient and Family Advisors partner on PFACs and other organization committees to offer the patient or caregiver perspective based on their experiences within the organization. They typically have a sense of loyalty and want to give back whether they have had positive or negative experiences. In general, PFAs have a global perspective and want to help other patients and families who are in the hospital or outpatient setting to navigate, and teach about what they have learned going through the hospital or outpatient experience. There may be a desire to collaborate with clinicians and administration, and to learn more about how the organization works and how their perspective may assist and help other patients and families in making enhancements to care delivery, patient education, patient experience, safety and quality, and many other areas of health care.

Bringing patients and families to the organizational table, almost always, changes and enhances the conversation. They are able to provide and give insight to what it really means to be a patient or caregiver within the organization. Many may offer their insights based on what they have experienced or what they have learned to what may make care transitions smoother, enhance the patient's experience, processes in safety and quality, or important suggestions that should be added to patient education literature.

For organizations that have not had the experience of working with patients and families, they will find that it can be an enlightening experience. They will learn a great deal about how their organization is functioning and delivering care, and how they may approach different strategies or techniques to enhance care. It is important to keep PFAs and PFACs involved, *from the beginning*, in the development of new strategies, initiatives, and programs, to ensure they are patient and family centered and integrate the patient and family perspective. Following up with PFAs and PFACs during the development of programs and initiatives is important in maintaining the organizational/PFAC relationship. If there are suggestions from PFACs and it simply cannot be done, an explanation should be given along with the education for the PFAC to understand why.

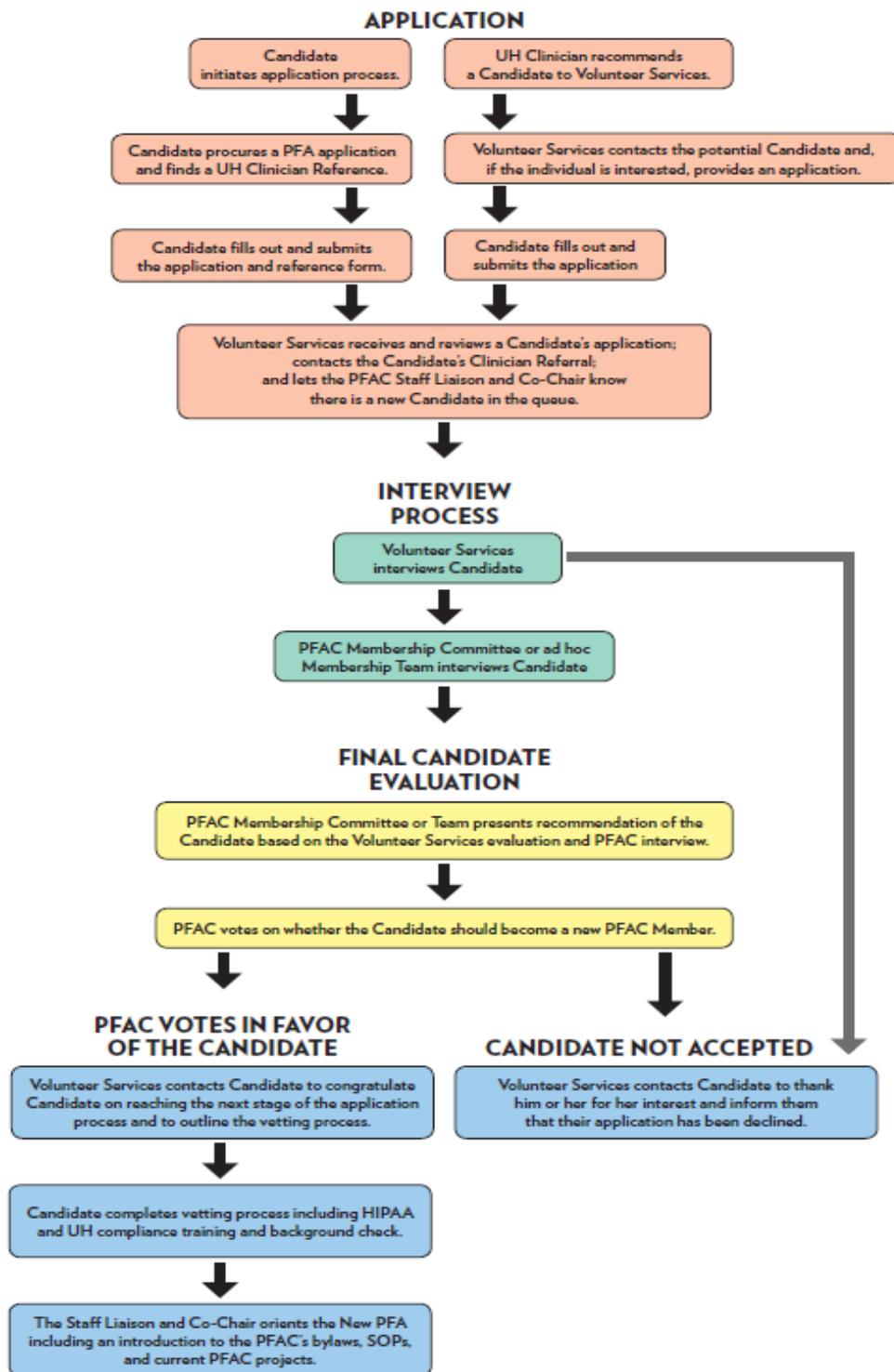
Just like working with any new colleague, it can take some time to get “used to” working with patients and families. It is possible the organization may hear things that they don't want to hear, so keeping an open mind is critical while starting to work with PFAs. Over time, the organization will be able to recognize the value of having PFAs partnering with them for success, and that incorporating them as a team member will become second nature. The experience is rewarding, not only for the organization, but also for the Patient and Family Advisor.

## **Application, Interviewing, and Volunteer Services**

Like any job role it is important to have potentially interested patient and families apply, go through interviewing, and the vetting process with volunteer services. It is also important to have a process like this in place to screen for potential personal agendas, recent care experience, the passion and desire to give back of the patient or family member, to hear the story of the patient and family member, availability to be involved, time commitments, and much more.

The OHA Living Document PFAC Toolkit will contain examples of PFAC applications, interviewing questions, referral forms, bylaws, and membership procedures. It is important, just like with any other type of interview, to ask behavioral questions, to rule out any grievances with the organization, and to ensure the patient or family member has not been through a recent traumatic life event. In addition, as the interviewer you will want to listen for many of the attributes in the READI Patient and Family Advisor acronym. Ask about professional experience, as well as other councils or committees they may have participated on in the community. Ask how they deal with conflict and if they are open to learning from others. Make sure the PFAC candidate uses phrases that speak globally to the organization's patients and families, listen for their passion in healthcare, and how their experiences could benefit the safety, quality, or experience for other patients and families and help to enhance the programs or initiatives at the organization. Make sure the candidate understands and has the availability to make a commitment to the PFAC; however, that if they or their loved one becomes ill, it is understandable to take a respite. Last, and most important, listen to their story, this will tell the interviewer a great deal about the candidate.

## PFAC Volunteer Selection Process



## Recruitment Strategies

There are many different ways to recruit patients and families to serve on Patient and Family Advisory Councils. Much of their availability will depend on whether or not they are well, have the time to volunteer, and are able and willing to make a commitment to the PFAC.

Examples of recruitment strategies:

- Educate and speak to nursing, physicians, social workers, and other members of the care team in department meetings about the PFAC, the group's goals, the necessity of diversity, and recruitment
- Hold an open house to discuss exploration of a PFAC with potential patients and families. This can be done via telephone or US mail
- Design an internal brochure that could be placed in multiple places within the organization. Some patient and family members may self refer.
- Discuss the PFAC often, in various meetings, and the need to identify members. This will also start to integrate the utilization of the PFAC in the organization's culture
- Talk with your patient advocates within the organization. They have many insights with many patients and families and may be able and willing to identify potential PFAs for the PFAC
- More advanced recruitment would be marketing on the organization's website
- Review returned Press Ganey and HCAHPS survey comments, and recruit if a patient left their name
- Place an ad in the local community newspaper that the organization is looking for current or former patients and families to volunteer on a PFAC
- Discharge follow up phone calls
- Patient Experience rounding
- Educating and working with Primary Care Physicians for referral and recruitment
- Personal letter of invitation from doctors, nurses, and other members of the care team

## Time Commitments

Like any council or committee it is important to have different insights and perspectives to bring depth to the conversation. Term limits for PFAs on PFACs is important for the following reasons:

- Health care delivery is constantly changing, therefore patient and family experiences and perspectives may change.
- Other patients and families may be interested and should be given the chance to participate.
- New members bring new perspectives and new energy to the PFAC.
- Naturally, PFAs may want or need to come off the PFAC.
- To keep the patient and family perspective current.

Although term limits put a time line on a PFA's participation on a PFAC, it does not mean the PFA needs to stop sharing the patient perspective or volunteering. PFAs may graduate and find other opportunities on many different committees within the organization after they have reached their term limit on a PFAC. In addition, they may also still participate of the PFAC, but the PFAC may choose to have no voting privileges for those members.

In addition, the PFAC should meet at least 10-12 per year; this keeps the momentum of the group moving forward, and decreases the likelihood of PFAs not returning to the group.

Last, there can be "homework" in between meetings. It is important to remember that what the PFACs do in between meetings is just as important to what they do during the meetings. On average, the time allotted for other work really depends on how involved the PFA and PFAC is. If a PFA just wants to do document review it may be anywhere from 1-3 hours, whereas another PFA who wants to be at the organization interacting with staff, patients, and families, it could be 10-25 hours. It all depends on the availability and interest of the PFA.

## **Mission, Vision, Charter, and Goals**

Every PFAC should have a mission and vision that illustrates how they would like to be seen and heard by the organization. In addition, by creating a charter, it will help the PFAC to stay structured, create healthy turn over of PFAs, and maintain focus on the PFACs goals. The charter should be reviewed once annually or as a topic is brought up by the PFAC. It is important when developing PFAC goals to encourage the group to drive what those goals might be. Although the group should be educated on the goals of the organization, patients and families may see other opportunities from the patient perspective that need enhancement or improvement.

Breakdown of Bylaws (what should be included):

- Eligibility of membership
- Term limits
- Meeting schedule
- Roles and responsibilities
- Required training and orientation
- PFA expectations
- PFA leadership role descriptions
- Current PFAC roster (PFAs and staff)
- Annual bylaw and other review process
- Processes/steps if PFA is struggling with commitment to the PFAC

## **Patient and Family Advisory Council Goals**

Aligning the goals of the organization and the PFAC will help in addressing what activities, projects, and development of initiatives should be started and executed. It is important for the PFAs to understand the goals of the organization, but also very important for the organization and its leaders to understand the goals of the PFAC. By aligning, much can be accomplished and the PFAC can be more integrated on to working teams within the organization.

Goals of the PFAC should visible during every meeting. It helps to keep the PFAC on track and to remain focused on what they would like to achieve. In addition, a review of these goals at every meeting, and current status, is beneficial. The goals should also be shared with many different departments within the organization, this keeps the PFAC aligned and other staff aware of what they would like to achieve in partnership and collaboration.

## Budget Considerations

Sustaining and running a PFAC takes effort and resources. It is important to consider the PFAs volunteering their time, the PFACs successes, and whether the organization may decide to send PFAs to conference or other educational sessions.

### Incentives and Awards for Patient and Family Advisors:

Although PFAs are aware they are volunteering time, it is always an appropriate gesture to offer lunch or dinner (depending on when the organization holds PFAC meetings) and parking. Other ideas for incentives are:

- Giving back to patients and families, and helping others
- Giving back to the hospital
- Hospital based tote bags, pens, or lanyards when a PFA joins the PFAC
- Small honorariums for time spent on activities (this would be optional for the PFA to take)
- Letters of thanks and appreciation from the organization's president
- Annual meeting with organization's president to work on goals
- Annual celebratory dinner with recognition of goals and work accomplished
- Making a difference in the hospital and the lives of the patients and families we care for

### Annual Resources for a PFAC:

PFAC budgets can vary greatly depending on the operating budget from which the resources are coming from (nursing, quality, auxiliary, operations, foundation boards, grants, etc.), and whether or not the PFAC may send PFAs to conferences or educational sessions. An average annual budget for a PFAC can range from \$1k-\$10k, pending on where the resources are coming from. PFAC activities, conference participation, honorarium for speaking, research, and educational participation on various committees, and just some example of why a resources are necessary.

Monetary compensation is not required, but may be a consideration for the hospital for PFAC members.

Resources also depend on materials, brochures, food, activities (such as Be Our Guest lunches and dinners), travel (if any), or incentives or gifts of recognition for PFAs. The annual cost also depends on what the organization is willing to spend to maintain the group, provide further education, and other opportunities for the PFAs.

## Best Practices for Successful Meetings

There are many ways to have successful meetings. Typically a PFAC's agenda is quite full, so pacing the group is important.

- Tents with each PFA and staff's name and role
- Introduction of every member and guests
- Visible PFAC goals at every meeting for review and assessment
- Senior leadership presence (can be rotating) to actively support and educate the group
- Staff Liaison and PFA co-chair co-leading the meeting
- PFA secretary to record meeting minutes
- Agenda put together with PFAC input, by PFA co-chair and Staff Liaison
- Dinner provided
- Visible mission and vision
- Open discussion on ways to improve and other ideas
- Close every meeting with time for questions, staff contact information, comments, etc.
- Time keeper to stay on track
- Annual visit (or more if time allows) from organization's president
- Visible annual PFAC goals at the meeting, on the agenda, or on a flip chart

## Support and Sustainability

Senior leadership support, presence, follow up, and execution of feasible feedback from Patient and Family Advisory Councils are critical for the successful utilization and sustainability of the groups. Some of the most successful PFACs across our nation's hospitals have at least one senior leader present at each PFAC meeting. By modeling the involvement and interest of the PFAC leaders can, like many other behaviors in an organization, show what the expectation is for PFACs and staff's involvement. It can also connect the PFAC to many other organizational initiatives and programs. In addition, PFAs can help to promote and publically speak about the organization in the community. This will help to grow loyalty of patients and families to the organization and shows that University Hospitals cares about and listens to the patient and family voice.

### Staff Education:

All staff should be educated on what a Patient and Family Advisory Council is, how it is structured, the goals, and the mission and vision of the group. It is also important to educate about the roles of the Patient and Family Advisors, how they are selected, and their desire to give back to the organization and patients and families. By providing education it gives staff the opportunity to learn about the PFAC, what it can do for their ideas, programs, and initiatives, and how to effectively partner with PFAs.

This toolkit can help you design appropriate staff education.