

# How to Create and Sustain a Patient and Family Advisory Council (PFAC) to Improve Patient Safety



## **BOOT CAMP**

**New Jersey Hospital Association**

**October 4, 2018**

**Given by the Person and Family  
Engagement Contractor (PFEC)  
for  
Partnership for Patients (PfP)**



# Welcome

- Who is in the room?
- Tell us about yourself...
  - Name
  - Hospital
  - Location
  - What would help you most to start or sustain a PFAC is . . .



# Our Work Today

- Understand what PFAs and PFACs are and what they do
- Understand the steps to take to create a PFAC at your hospital
- Create a specific plan of action for your hospital's PFAC
- Discover and use the many tools and resources available to you

# Tools for PFAC Implementation

Strategy 1: Working With Patient and Families as Advisors (Implementation Handbook)



## Working With Patient and Families as Advisors Implementation Handbook

**Guide to Patient and Family  
Engagement in Hospital Quality and  
Safety**  
(Developed by AIR for AHRQ)

**A Patient and Family Advisory Council Workplan:  
Getting Started**



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# **OVERVIEW OF METRIC 4: UNDERSTANDING PFAS AND PFACS**

# PFE Metric 4

**PFAC or representative on hospital committee:** Hospital has an active Patient and Family Advisory Council (PFAC) **OR** at least one patient who serves on a patient safety or quality improvement committee or team

## **Intent:**

- Hospital has a formal relationship with PFAs who help guide hospital operations, policies, procedures, and quality improvement efforts
- PFAs have the same rights and privileges as all other committee members
- Ultimately, this metric confirms that a hospital systematically incorporates patients and care partners as advisors when addressing operations or quality improvement activities

# PFE Metric 4 in Perspective

## Point of Care

- **Metric 1: Preadmission Planning Checklist**
- **Metric 2: Shift Change Huddles OR Bedside Reporting**

## Policy & Procedure

- **Metric 3: Designated PFE Leader**
- **Metric 4: PFAC OR Representatives on Hospital Committee**

## Governance

- **Metric 5: Patient Representative on Board of Directors**



# Advisors: Who they are

## **Advisors are patients and family members who:**

- Received care at your hospital and want to help improve care experiences for others
- Serve as collaborative partners in developing and revising hospital policies, procedures, and practices
- Are selected from a rigorous application and screening process
- Are specifically trained for the role of an advisor



# Where can advisors help?

- Identify issues that would benefit from patient and family input and involvement
- Determine the most appropriate mechanisms for partnering with patients and families
  - Advisors on one-time efforts
  - Advisors on short-term projects
  - Patient and family advisory councils
  - Advisors as members of committees



# Patient Advisor's Perspective





# What is a PFAC?

- A committee comprised of 10 - 15 members
  - Patients and/or family caregivers from the community
  - Hospital staff and clinicians
- Works on hospital improvements as needed by incorporating the patient and family perspective
  - Identify and implement ways of improving the care experience for all patients and families
  - Discuss and plan changes to improve hospital quality and safety
  - Advising and problem solving from the patient/family perspective
- Formal group that meets regularly



# Where can PFACs help?

- **Group exercise:** Identify areas in which patient and family advisors could make a contribution
  - Quality improvement and safety initiatives
  - Facility design
  - Patient and family participation in care and decision making
  - Patient and family information and education
  - Health information technology
  - Clinician and staff training



## Patient and Family Advisory Council Impact



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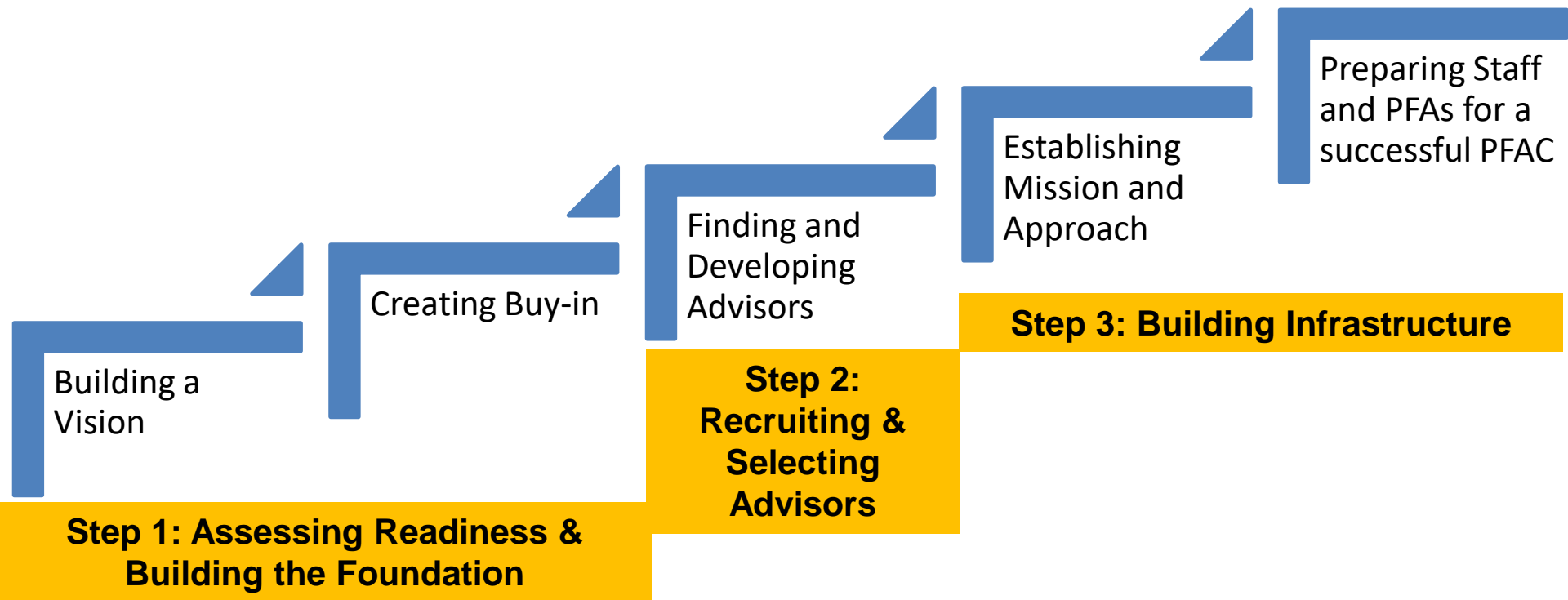


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# The Path for Implementing a PFAC





**STEP 1: ASSESSING READINESS &  
BUILDING THE FOUNDATION  
ARE WE READY FOR A PFAC?**



# Barriers to Buy-in

- Uncertainty by leadership about how PFE adds value
- Insufficient financial and personnel resources for PFE
- Finding patients and families who want to participate
- Staff resistance due to lack of information about or experience with PFE





# Four Common Myths about PFAs

- Patients and family members want to tell us everything we're doing wrong, especially if they've had a bad outcome.
- Patients and family members will have unreasonable demands for things we can't change if we wanted to.
- Patients and family members are unable to understand the complexities of issues related to hospital operations, procedures, or policies.
- Patients and family members will not be able to handle the confidential information about hospital operations and are likely to hurt our reputation in the community.



# **Activity #1: Leadership Readiness Assessment**



# Buy-in at all levels is critical

*“The single most important factor for ensuring the successful involvement of patients and families in policy and program activities is commitment to the idea. This point cannot be overstated. Without a deeply held belief that patients and families have unique expertise and knowledge and that their participation is essential to improving services, true collaboration will not occur.”*

Source: Institute for Patient- and Family-Centered Care. *Essential Allies: Patients, Residents, and Families as Advisors.*



# Leadership buy-in

- Identify and get to know the **formal and informal leaders**
- Talk with leaders about the importance and **benefits of a PFAC**
- Anticipate **questions** and be prepared to talk about potential risks
- Provide **written materials** on other PFACs
- Identify opportunities to **bring leaders into the process** of working with PFAs
- Present a **clear “ask”**

*Working with Patient and Family Advisors Presentation (Tool 11)*



# Obtaining buy-in at all levels

- Gather information to better understand the hospital's culture, current policies, and decision-making processes
  - Learn how decisions are made
  - Learn about the clinicians and staff including their readiness to engage and any concerns/questions
  - Assess the hospital's experience with including patient and family perspectives in previous change and improvement initiatives

***Readiness to Partner With Patient and Family Advisors (Tool 14)***



# Obtaining buy-in at all levels (cont'd)

- Build support from key individuals and groups
  - Meet with clinicians and staff individually and in groups to discuss what it means to work with PFAs
  - Identify individuals on the staff who can help champion the PFAC
  - Invite staff and leadership to conduct a walkabout to explore how the hospital welcomes, engages, and supports patients and families
- Recognize and address challenges
  - Administrative barriers (e.g., budgetary restraints, privacy policies)
  - Clinician and staff attitudes
  - Other



# Benefits of working with advisors

- Patient and family advisors help improve care:
  - Offer insights about what your hospital does well and areas where changes may be needed
  - Help develop priorities and make improvements based on patient- and family-identified needs
  - Help inspire and generate new ideas and solutions
  - Serve as a link to the broader community



# Benefits of working with advisors (cont'd)

- Long-term benefits:
  - Improved quality and safety
  - Better health outcomes for patients
  - Better business outcomes for the hospital
  - Better experiences of care for patients, family members, clinicians, and staff





## Patient and Family Engagement: From the Boardroom to the Bedside

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# Hospital CEO Testimony

**Joel Seligman:** A key initiative has been to increase patient and family caregiver involvement in improvement efforts, through our Patient and Family Engagement Council (PFEC), which consults with us on a host of projects, as well as their participation on hospital committees and teams. Patients help us rethink the way we communicate with patients and families. For example, PFEC members worked directly with our ICU nurses and physicians to design an ICU family orientation, simplifying complicated medical jargon and encouraging family involvement in the plan of care. The PFEC also helped us rethink our patient discharge checklist to help assure that the patient and family feel prepared for their transition home.

Joel Seligman, President and CEO, Northern Westchester

Source: "Top Hospital CEOs Predict A Brave New World Of Patient Engagement"  
Forbes, February 27, 2017.



# **Activity #2: PFAC Workplan: Getting Started**

**Complete Section A, Question 1 a-g —  
Initial Steps**



## **STEP 2: RECRUITING AND SELECTING PATIENT AND FAMILY ADVISORS**



# Defining your target population

- Know your patient population and identify vulnerable populations
  - Who are the unheard voices that need to be amplified?
- For the council to be effective in helping the hospital to make meaningful changes, **it must be reflective of the patients served and the staff that care for them**
- Think baby steps, this takes time!



# Key qualities of effective advisors

- Listen to and respect the perspectives of others
- Work well with different kinds of people
- Speak comfortably and openly in group settings
- Share insights and information
- See beyond their own experiences
- Show concern for more than one issue or agenda

***Am I Ready to Become an Advisor? (Tool 6)***



# Recruiting advisors

- Ask clinicians and staff to provide names
- Look for individuals who have provided constructive feedback in the past
  - Ask patient relations office, patient representatives, ombudsmen, social workers for recommendations
  - Review letters or emails from patients and family members to identify candidates

Do you have ideas  
to help improve  
our hospital?

Become a patient  
and family advisor.

Dear \_\_\_\_\_,

I would like to invite you to find out more  
about becoming a patient and family advisor at [insert  
hospital name].

I think you may have great ideas about how we can  
improve the health care experience for patients and  
families.

I hope you are interested in learning more about  
serving as a patient and family advisor. Please see the  
back of this card for more information.

Sincerely,

\_\_\_\_\_

### Patient and family advisors help us by:

- Sharing stories about their hospital experience in training sessions for nurses, doctors, and other hospital staff.
- Helping to create materials and plans for improving health care quality and safety for all patients.
- Providing input on how to improve our policies and care practices.
- Giving feedback about their hospital stay.
- Letting us know what went well and what we can do better.

We are grateful to the patients and families who  
become advisors.

Join us!

### What skills do advisors need?

Advisors need to:

- Listen and share their opinions respectfully.
- Think about ways to improve health care.
- Work well with others.

You do not need any special qualifications to be an  
advisor. We will provide any training that you need.

For more information about becoming an advisor,  
please contact:

[Insert staff liaison name]

[Insert telephone]

[Insert email]

[Insert Web site]

***Help Improve Our Hospital: Become a Patient and Family Advisor (brochure, Tool 1)  
Personal Invitation for Patient and Family Advisors (postcard, Tool 2)***





# Recruiting advisors (cont'd)

- Post advertisements in your facility, distribute recruitment brochures
  - Public locations, admission or welcome packets, discharge packets, care instructions, include with survey mailings
- Advertise at support groups or other patient and family meetings
- Advertise opportunities on your website
- Work with local community groups or hold a public event / information session

***Patient and Family Advisor Information Session (Tool 5)***

## UW MEDICAL CENTER

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# Patient and Family as Advisors



*ICU Advisory Council Group*

## What is an Advisor?

Advisors are patient and family volunteers who work with UWMC care providers and staff to improve the healthcare experience for everyone. This partnership fosters the philosophy of patient and family centered care that is central to our services at UWMC.

As part of a continuing process to include patients and families in everything from creating guidebooks to interviewing residents, UWMC has seven advisory councils. These councils cover inpatient, intensive care, neonatal intensive care, outpatient, pregnancy and childbirth, rehabilitation services and transplant units.

## How do I become an Advisor?

- [Complete an application form](#) and mail it to Andrea Dotson at the address below.
- Or, send an email to [pfcc@uw.edu](mailto:pfcc@uw.edu).
- Or, call 206.598.7448. If you receive a recording, please include your name, interest in becoming an advisor, and a way to contact you.



# **Activity #3: PFAC Workplan: Getting Started**

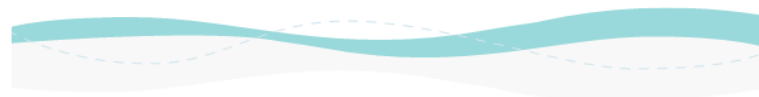
**Complete Section B, Question 7b –  
Sources for Recruitment**



# Selecting advisors - application

- Ask potential advisors to complete an application
  - Contact information
  - Demographic information
  - Dates of care experience, units on which they received care (if at hospital)
  - Interest areas
  - Open-ended questions:
    - Why they want to become an advisor
    - Previous volunteer or speaking experience
    - Brief information about care experiences

# Sample application form



## Patient and Family Advisor Application Form

Name (First and Last): \_\_\_\_\_  
Street Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ ZIP Code: \_\_\_\_\_  
Home phone: \_\_\_\_\_ Cell phone: \_\_\_\_\_ Email address: \_\_\_\_\_  
Preferred contact (circle one):    Home phone    Cell phone    Email

### The following questions will help us get to know you better.

1. Are you a...
  - Patient
  - Family member of a patient
2. When was your care experience at this hospital? (Check all that apply.)
  - 2013 to current year
  - 2012
  - 2011
  - 2010
  - 2009 or before
3. What language(s) do you speak? \_\_\_\_\_



4. Which unit(s) provided care for you or your family member: (check all that apply)
  - [insert name of unit]
  - [insert name of unit]
  - [insert name of unit]
  - [insert name of unit]
5. We recognize that our patient and family advisors have busy lives. How much time are you able to commit to being a patient and family advisor? (Check one)
  - Less than 1 hour per month
  - 1 to 2 hours per month
  - 3 to 4 hours per month
  - More than 4 hours per month
6. Are you available to serve as an advisor for at least 1 to 2 years? (You can still be an advisor if you answer "no.")
  - Yes
  - No
7. How do you want to help? I want to: (Check all of your interest areas) **[NOTE: Edit the list below as appropriate for your hospital's priorities]**
  - Serve as a member of the patient and family advisory council. Potential advisory council members should be ready to commit to serving on the council for at least 1 to 2 years. The advisory council meets once a month for 1 ½ to 2 hours.
  - Review procedures and provide input to improve the hospital admission process.
  - Help develop or review informational materials for patients and family members.
  - Provide input as we implement bedside shift report, where nurses who are going off duty share information with nurses coming on duty at the patient's bedside.
  - Help improve patient safety and the prevention of medical errors.
  - Review procedures and provide input to improve transitions in care (for example, between hospital units or discharge from hospital to home).
  - Help improve the patient and family role in care decisionmaking.
  - Other issues (please describe): \_\_\_\_\_
  - Help improve the hospital facilities (for example, patient care areas, or family resource room). \_\_\_\_\_
  - Help educate or train hospital staff and clinicians. \_\_\_\_\_



# Selecting advisors - interviews

- Interviews can be conducted in-person or over the phone
- Staff liaison should interview candidates and bring in other interviewers as needed (staff, other advisors)
- Ask about:
  - What they would like to do as an advisor
  - Perceived strengths and skills
  - Ability to handle differences of opinion
  - Time commitment



# Selecting advisors – making decisions

- Don't select advisors just to have them!
- Look at individuals and the pool of advisors as a whole – select diverse and complementary skills, interests, backgrounds and be sure they reflect your patient population
- Inform candidates of decision in a timely manner – via phone, email, or mail
- If an applicant is not selected, let them know you will keep their information on file for future opportunities

***Sample Invitation and Regret Letters (Tool 4)***



# Mentoring Potential Patient and Family Advisors

- Moving beyond the experience: helping patients and family continue to heal
- Coaching patients and family to tell their story
- Helping patients and families realize a larger vision for their role
- Helping patients and family members identify their goals and grow their qualifications

*Am I Ready to Become an Advisor? (Tool 6)*  
*Sharing My Story: A Planning Worksheet (Tool 7)*  
*My Participation Interests (Tool 8)*





# Moving from the Patient Story to the Hospital Story

- Relating your story to the larger quality or safety issue
- Connecting your story to other patient or caregiver stories
- Focusing on broad solutions beyond personal circumstances
- Offering hospitals ideas on how to make changes or improvements from lessons learned in your experience



# **STEP 3: BUILDING THE INFRASTRUCTURE**



# Developing a Mission Statement

- Helps guide and focus the work of the PFAC
- Includes council's purpose, major goals, and key stakeholders

## ***Sample Mission Statement***

“The Adult Patient and Family Advisory Council is dedicated to assuring the delivery of the highest standards of comprehensive and compassionate health care by Dana-Farber/Brigham and Women's Cancer Center. We do this by working in active partnership with our health care providers to:

- Strengthen communication and collaboration among patients, families, caregivers and staff
- Promote patient and family advocacy and involvement
- Propose and participate in oncology programs, services, and policies.”



# **Activity #4: PFAC Workplan: Getting Started**

**Complete Section A, Question 2 -  
Purpose of your PFAC**



# Onboarding Patient Advisors

- Responsibilities and Expectations
- Tips on Becoming an Effective Advisor/PFAC Member
- How Advisors Help Improve Quality and Safety
- How Things Work at Our Hospital

***Patient and Family Advisor Orientation Manual (Tool 9)***



# A word on confidentiality

- Advisors may have access to protected health information (PHI)
- Ask advisors to sign confidentiality agreement
  - Explanation of PHI and HIPAA
  - PHI can only be used and disclosed as permitted by law – can't be shared outside of healthcare facility, can't be shared in written, verbal, email communications unless permitted
- Let people know that “what you see or hear here must remain here”

***Sample Confidentiality Statement (Tool 10)***



# Tips for the first meeting

- Introductions - leave plenty of time (3-4 minutes per person)
- Welcome from hospital leadership
- Review purpose and goals of the PFAC
- Discuss procedures and roles
- Discuss potential projects, upcoming activities
- Wrap up, action items, and next steps

# Sample Advisory Council Agenda – Initial Meeting

## Sample Advisory Council Agenda—Initial Meeting (2 hours)

- **Introductions (60 minutes).** Each member takes 2 to 3 minutes to tell a bit about themselves.
  - My name is...
  - For patient and family advisors: I choose this hospital for my care because ...
  - For staff members: I choose to work at this hospital because ...
  - I wanted to join the advisory council because ...
  - Optional icebreaker question: One thing about me you would not guess is ...
- **Review agenda (5 minutes)**
- **Purpose and goals of the patient and family advisory council (15 minutes)**
  - **Purpose:** *[Edit as necessary.]* The purpose of the advisory council is to bring together, on a regular basis, patient and family advisors with hospital staff to plan and discuss changes that will help improve the safety and quality of care at this hospital.
  - **Goals:** *[Edit as necessary.]* The general goals are: (1) To provide feedback and advice for changes to hospital policies, care practices, and materials that will help patients and families be actively involved in their own health care; (2) To help create materials and strategies for improving health care quality and safety for all patients; and (3) To help hospital staff carry out changes and improvements in the experiences of care.
- **Meeting procedures and roles (10 minutes)**
  - Secretary
  - Timekeeper
  - Meeting dates and times
- **Ideas for improvement and potential initial activities (20 minutes)**
- **Closing (10 minutes)**





# Tips for all meetings

- Before meetings
  - Send materials well ahead of time (agenda, materials to review, directions)
  - Reminder phone calls or emails
- Day of meeting
  - Signage!!
  - Name tags or name tents
  - Ensure access for individuals with disabilities, impairments, functional limitations



# Tips for successful interactions

- Establish norms and ground rules
  - Start and end on time, policies about absence, importance of sharing the floor
- Don't try to tackle too much at once
  - Be wary of information overload
- Communicate complex information clearly
  - Plain language, explain clinical terms, explain QI processes, visual depiction of data
- Provide ongoing support of advisors
  - Follow up after meetings to encourage participation, ask about experiences



# Developing bylaws

- Guide how the council functions and outline council members' responsibilities.
- Address functional issues such as:
  - Eligibility for membership
  - Expectations for how long a member serves
  - Meeting schedule
  - Specific council member roles and responsibilities

**The *Implementation Handbook* includes links to sample bylaws (p. 41).**



# Sustaining relationships

- Advisors want to know that they are making a difference!
  - Track and communicate activities
  - Share outcomes of projects
  - Communicate their work and impact to hospital leadership
  - Thank advisors for their work
- Invite leadership to meet with advisors
- Look for opportunities to present at conferences with advisors
- Provide ongoing, transparent feedback and communication



# Sustaining the council

- Invest in building leadership skills of the members
- Select advisors wisely—and be sure they are representative of those served
- Devote time to planning and evaluation
- Maintain balance between new members and committed members longevity of service
- Set priorities and focus on meaningful collaborative projects

Source: Institute for Patient and Family-Centered Care (2010). *Creating a Patient and Family Advisory Council*.



# Problem solving

- Careful selection and training helps minimize, not eliminate, later difficulties
- Debrief regularly, address any problems quickly
- Look for ways to make the situation work
  - Provide additional training, coaching, or mentoring
  - Examine match between advisor skills and situation, personalities
  - Think about whether advisors have been set up for success
- If all else fails, ask the advisor to step down – position this as wanting to bring in new advisors and new perspectives



# **Activity #5: PFAC Workplan: Getting Started**

**Complete Section C, Question 2 -  
Barriers and How to Overcome Them**



# **Activity #6:**

## **Developing Your Action Steps and Identifying Tools**



# Resources

- Guide to Patient and Family Engagement in Hospital Quality and Safety (AHRQ):  
<http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/guide.html>
- Diverse Voices Matter: Improving Diversity in PFACs (IPFCC): <http://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf>
- A PFAC Workplan: Getting Started (IPFCC):  
[http://www.ipfcc.org/resources/A Patient and Family Advisory Council Workplan Getting Started.pdf](http://www.ipfcc.org/resources/A_Patient_and_Family_Advisory_Council_Workplan_Getting_Started.pdf)

# Contact information

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***Thank you for your time and  
participation!***