

Chartering your PFAC: Purpose and Structure

What do we hope the PFAC will do for our practice?

What kind of information are we looking for?

Do we hope that the PFAC will tell us what we don't know we should be asking about, or do we have specific questions that we want feedback on?

→ If you're not sure, [browse the accomplishments of other PFACs](#) to help you look for ideas.

Do patients and families need to have specific skills to participate or are we looking to engage as wide a range of families as possible?

What structure will be most appealing for our patients and families?

- If you don't have the answers to these questions, find out from your patients and families:
- Are they able to make a long-term commitment? Would they prefer one-time or short-term feedback opportunities? Which structure engages a wider range of families?
 - Are they more likely to come to a meeting if we offer a training session in addition to just asking for feedback?

PFAC Sustainability Worksheet

Identify all of the audiences you'd like to communicate with:

- Practice staff
- Practice leadership
- Organizational leadership
- Other practices in our organization
- Hospital board
- Hospital PFAC
- Patients and families
- Other affiliates
- Professional organizations
- Community organizations
- _____
- _____

Brainstorm on all the ways you can reach the audiences you want to communicate with. Here are some possibilities:

- Add a regular update to your practice website.
- Contribute a story to your hospital newsletter.
- Deliver a presentation to your hospital board, senior leadership, at staff meetings or retreats.
- Send out an email to all practice staff after each PFAC meeting describing the highlights.
- Devote a section of your practice's bulletin board to your PFAC.
- Include PFAC announcements and achievements on your closed circuit TV in your hospital.
- Create a face page of PFAC members and share with staff and leadership.
- Write articles or brief notices and submit them to your local paper.
- Include PFAC updates on social media, like your practice's Facebook page or Twitter account.
- Create a PFAC newsletter to highlight recent accomplishments, ongoing work and ways to get involved; share it in your waiting room and send it out to local community-based organizations.
- _____
- _____
- _____
- _____
- _____

Considering your audience, your budget and your time frame, check the publicity options you would like to use from the list you created above. Encourage PFAC members to collaborate or partner with you where possible on these activities. Model authentic family-professional partnership by co-presenting at meetings and co-authoring newsletter articles.

Measuring a Practice’s Perception of Feedback Opportunities

Adapted from “Essential Allies Checklist for Involving Families as Advisors and Consultants” by the Institute for Patient and Family-Centered Care. [\[source\]](#)

This assessment is a tool to help think about ways that families are participating as advisors and consultants at the policy and program level. Rate each item and then cite specific examples that illustrate how the program is involving families. Use this tool to initiate new opportunities to work in partnership with families or to expand on current activities. For example, you could identify all items that were indicated as not being done well, and develop an action plan to improve on one or two of them by the next time you collect data on this measure.

	We’re not doing well	We’re doing okay	We’re doing very well	Examples
We recognize and respect the expertise of families as policy and program advisors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We are vigilant about seeking opportunities to involve families in advisory activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We seek to involve families who reflect the racial, ethnic, cultural, and socioeconomic diversity of families <i>currently</i> served by the program.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We seek to involve families who reflect the racial, ethnic, cultural, and socioeconomic diversity of families in the broader community and region.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We use a variety of strategies to identify and recruit families to serve in advisory roles.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We demonstrate appreciation for the contributions that families make to policy and program development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	We're not doing well	We're doing okay	We're doing very well	Examples
We have developed both short term and long term advisory roles for families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We create opportunities for families to participate that are consistent with their cultural practices and individual personalities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<p>We have developed a range of ways for families to participate as advisors including:</p> <ul style="list-style-type: none"> • Participating as trainers in staff orientation and inservice programs • Reviewing written and audiovisual materials developed by our practice • Conducting evaluation activities • Participating in focus groups • Serving as members of committees, boards, and task forces • Reviewing grants • Developing educational and informational materials for other families • Conducting needs assessment 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
<p>We support families serving in advisory roles by:</p> <ul style="list-style-type: none"> • Reimbursing their travel and child care expenses • Offering a stipend or honorarium for their participation • Providing mentors • Offering training programs or workshops • Providing secretarial support • Facilitating their networking with other families • Being aware of parental burn out 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
We provide training to staff on working collaboratively with families at the policy and program level.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	We're not doing well	We're doing okay	We're doing very well	Examples
We have a PFAC or committee.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Membership on the advisory council reflects the diversity of families served by the program.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
The PFAC reports to top level administration.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Tips for Using a Focus Group Format in a PFAC Meeting

While the corporate world has long held focus groups to try out ideas for products and new concepts, practices have a shorter history of involvement as both participants and as conductors of focus groups. Getting a small group of people together to respond to questions relevant to their own experiences is a great way to get insights before planning a new program, policy change or even just to find out issues for families that are not being addressed anywhere. Families often appreciate being asked for their experience.

We recommend that a group or organization planning a family focus group have a good reason to do so. It is important to frame the questions that need to be answered and create a script that can be used for several groups which allows for response comparison. Each script has key questions along with sub questions to help probe for deeper meanings. Scripts also contain prompts to keep the discussion focused on the key questions. Open-ended questions help bring up ideas important to the families that can help direct next steps for a group.

Having an experienced family leader to conduct the discussion gives credibility to the process and protects the participants who might not speak freely with a professional even if guaranteed confidentiality. Best practice includes small groups (8-12 people), open discussion and a facilitator who can hear all opinions in a neutral fashion, remembering that each participant is an expert. Many experienced family leaders are accustomed to giving workshops, presentations and information to families, but in this case they are there to listen and help participants express their opinions without dominating the time. Topics can be very personal, such as dealing with a diagnosis of a child's disability. It is important for the facilitator to help each member feel their experiences are credible and valuable to the discussion.

Conducting the discussion in a professional manner will require several people: one to greet participants, one to record responses to questions, and one to facilitate and lead the group. Be sure to review the outcomes as soon as possible and decide if your script needs revision before holding any additional discussion groups.

Recruitment should identify the audience with most relevant experience to the questions. Your audience can be identified by age group or medical condition, and the audience can be general or specific to meet your needs. Offering a small gift and a meal helps families feel their time is valued. Choose a suitable location.

Additional Resources (From *Bright Futures for Families*)

- [Stock Phrases for Challenging Situations](#)
- *Facilitating Successful Family Focus Groups - Best Practices*
 - [Slides \[PDF\]](#)
 - [Archived Webinar Recording](#)
 - [Tips Sheet](#)

Exercise: Understanding Difficult Conversations

Difficult conversations are ones in which opinions differ; the stakes are high; and/or emotions run strong.

Most families and professionals say situations leading to difficult conversations happen to them daily. Situations that involve children often have high stakes. Parents and professionals have strong feelings about many topics, and opinions will differ in large and small ways.

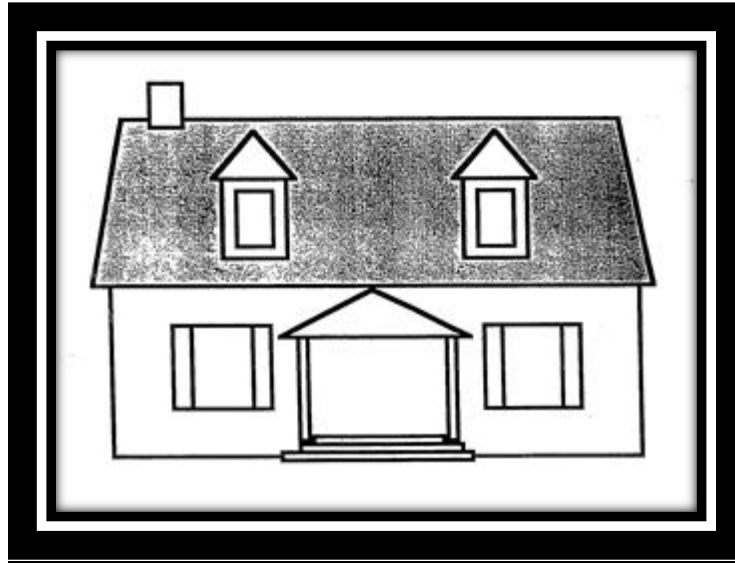
In the book *Crucial Conversations* authors Joseph Grenny and Kerry Patterson discovered that most challenging or difficult conversations have the same three ingredients.

Three-in-One Conversation: Moving to a Learning Conversation		
	A Battle of Messages	A Learning Conversation
(1) The “What Happened?” Level	1A. Assumption: I know all I need to know to understand what happened.	1B. Assumption: Each of us is bringing different information and perceptions to the table; there are likely to be important things that each of us doesn’t know.
	Goal: Persuade them that I’m right.	Goal: Explore each other’s stories—how we understand the situation and why.
(2) The Feelings Level	2A. Assumption: I know what they intended.	2B. Assumption: I know what / intended, and the impact their actions had on me. I don’t and can’t know what’s in their head.
	Goal: Let them know what they did was wrong.	Goal: Share the impact on me, and find out what they were thinking. Also find out what impact I’m having on them.
(3) The Identity Level	3A. Assumption: It’s all their fault. (Or, it’s all my fault.)	3B. Assumption: We have probably <i>both</i> contributed to this mess.
	Goal: Get them to admit blame and take responsibility for making amends.	Goal: Understand the contribution system: how our actions interact to produce this result.
	Assumption: Feelings are irrelevant and wouldn’t be helpful to share. (Or, my feelings are their fault and they need to hear about them.)	Assumption: Feelings are the heart of the situation. Feelings are usually complex. I may have to dig a bit to understand my feelings.
	Goal: Avoid talking about feelings. (Or, let’em have it!)	Goal: Address feelings (mine and theirs) without judgments or attributions. Acknowledge feelings before problem-solving.
	Assumption: I’m competent or incompetent, good or bad, lovable or unlovable. There is no in-between.	Assumption: There may be a lot at stake psychologically for both of us. Each of us is complex, neither of us is perfect.
	Goal: Protect my all-or-nothing self-image.	Goal: Understand the identity issues on the line for each of us. Build a more complex self-image to maintain my balance better.

Source: Douglas Stone, Bruce Patton, & Sheila Heen. *Difficult Conversations*. Penguin Books, 1999.

Exercise: Storytelling to Make a Difference

In this exercise allow time for each person to contemplate the picture below and to write down or just think about responses to the questions. The group can then share their thoughts and see what different stories were told by the picture.



Facilitator Questions for Participants

We'd like to start by having you look at this picture and reflect on the following questions:

1. What do you see or notice? What stands out for you?
2. What memories, thoughts or associations does this bring to mind? Is it comfortable and warm? Or perhaps cause discomfort or negative associations?
3. What is your essential insight? Or lesson learned?
4. What story would you tell about this image?
5. How would you start? What would you say? How would you end?
6. What events might you describe?
7. How would you make it interesting? Make a point?

Long Ago and Far Away...Storytelling is Relevant Today: Tips for Family Storytelling

- Know your purpose
- Know your audience
- Pick a universal theme (e.g. family leadership, challenges you face, bonuses, humor, people who helped, what does or doesn't work)
- Create a structure: a beginning, middle and end
- Make it interesting
- Make it your own
- Choose what to share and keep it timed
- Be aware of memory, emotion and nerves

Exercise: ORID Conversation Technique

Use the ORID method (part of the Technology of Participation (TOP)[®] materials from the [Institute of Cultural Affairs](#)) to review discussions and meeting highlights and to reflect on information presented and learned.

This ORID method can be adapted by parents or professionals for any type of meeting. This technique is useful to generate a sense of accomplishment and excitement about what has been learned. It also promotes clarity among the participants and helps to avoid misunderstandings. The exercise can be done informally by posing even just one relevant question from each row. People often want to jump from R to D, skipping the I part, but that can lead to misunderstandings.

O Objective Facts: <i>What</i>	What topic or phrase stood out to you today?	What did you see on the wall or flip chart that sticks with you?	What info do you remember most?	What statements or comments that you heard stand out for you?	What new tools or ways to proceed were presented?
R Reflective: <i>Gut</i>	What was your favorite part of today's training or meeting?	What was valuable to you?	What wasn't helpful?		
I Interpretive: <i>So What? What difference will it make?</i>	What information is important to your group?	What difference could this make once we apply it?	What would you be most confident in replicating or trying out on another group?	What types of trainings, workshops and leadership activities should be included?	
D Decisional: <i>Now What? What will we do differently?</i>	What is the one idea you will take back and begin to act on?	How will you use this information when you get back home?	What steps can we take to ensure that the things we value are reflected in our work?	What skills learned would you like to share back home?	

Sample questions for use at the end of a PFAC meeting

Ask the group to take a minute to summarize by responding to a few questions.

O: What have we said today that is new information or most remarkable?

R: What was troubling for the group about today's conversation and what was most valuable?

I: What information or part of the discussion will make a difference in planning for my child?

D: What have we all agreed should be incorporated into the IEP and carried out?

Further Resource

Block, P. *Community: The Structure of Belonging*. San Francisco: Berret-Koehler, 2008.

Exercise: Focus On What You Really Want

Source: Patterson, Grenny, McMillan, Switzler. *Crucial Conversations*. McGraw-Hill, 2002.

These deceptively simple questions that will help you re-focus your energies on a productive approach to your conversation.

1A. What do I *really* want for myself?

1B. What do I *really* want for others?

1C. What do I *really* want for the relationship?

2A. How did my actions and/or words match with what I said I wanted?

2B. How did my actions and/or words *not* match with what I said I wanted?

2C. How might I behave in the future if I *really* wanted these results?

Exercise: The Feelings Conversation

Source: *Nonviolent Communication: A Language of Compassion* by Marshall B. Rosenberg, Ph.D. © 1999.
keepcomingback.com

We all have feelings and they are neither right nor wrong, they just are. Now, that could sound like we don't have any choice and that we're victims of our feelings but that's not exactly true. We always have a choice about how and when we express our feelings.

This assumes, however, that we know what our feelings are—which is not always the case. There are people who dread the question, “How do you feel about that?,” because they don't have easy access to feeling language. Many people when expressing themselves tend to use words that are related to feelings but aren't really feelings.

Take a minute to look at the Feelings List handout (from *Nonviolent Communication* by [Marshall Rosenberg](#)) and circle a few of the words in each category that you either use pretty often or have used in the past. See which ones are actually feeling words, and which ones aren't. Being clear about our feelings isn't always easy, especially because when we're having strong feelings blood leaves our brains and rushes to our extremities as part of the body's natural fight or flight response. This response is hard wired, so it takes conscious, concerted effort to remain calm during emotional times.

When Our Needs Are Being Met

affectionate	enlivened	moved
alert	enthusiastic	optimistic
alive	excited	overjoyed
amazed	exhilarated	overwhelmed
amused	expansive	peaceful
animated	fascinated	pleasant
appreciative	free	pleased
astonished	friendly	proud
blissful	fulfilled	quiet
breathless	glad	refreshed
buoyant	glowing	relaxed
calm	good-humored	relieved
carefree	grateful	satisfied
cheerful	gratified	secure
comfortable	happy	sensitive
complacent	helpful	serene
composed	hopeful	spellbound
confident	inquisitive	surprised
contented	inspired	thankful
curious	intense	thrilled
dazzled	interested	touched
delighted	intrigued	tranquil
eager	invigorated	trusting
elated	joyous, joyful	upbeat
enchanted	jubilant	warm
encouraged	loving	wide-awake
energetic	mellow	wonderful

When Our Needs Are *Not* Being Met

afraid	disgruntled	impatient	scared
aggravated	disgusted	indifferent	sensitive
agitated	disheartened	intense	shocked
alarmed	dismayed	irate	skeptical
angry	displeased	irked	sorrowful
annoyed	distressed	irritated	sorry
anxious	disturbed	jealous	spiritless
apathetic	downhearted	jittery	surprised
apprehensive	embarrassed	lethargic	startled
ashamed	exasperated	listless	suspicious
bewildered	exhausted	lonely	terrified
bitter	fatigued	mad	tired
blah	fearful	miserable	troubled
blue	fidgety	mournful	uncomfortable
bored	frightened	nervous	unconcerned
brokenhearted	frustrated	numb	uneasy
concerned	furious	overwhelmed	unglued
confused	gloomy	panicky	unhappy
cross	guilty	passive	unnerved
dejected	harried	perplexed	unsteady
depressed	heavy	pessimistic	upset
despairing	helpless	puzzled	uptight
detached	hesitant	reluctant	vexed
disenchanted	horrified	repelled	weary
disappointed	horrible	resentful	withdrawn
discouraged	hostile	restless	worried
	hurt	sad	

Interpretation Words We Substitute for Feeling Words

abandoned	misunderstood
abused	neglected
attacked	overworked
betrayed	patronized
boxed-in	pressured
bullied	provoked
cheated	put down
coerced	rejected
co-opted	taken for granted
cornered	threatened
diminished	unappreciated
distrusted	unheard
interrupted	unseen
intimidated	unsupported
let down	unwanted
manipulated	used

Exercise: Early Memories

In this exercise the facilitator asks the group to think about their earliest memory of difference. The difference can be of any type as long as it is an early memory. Participants are encouraged to think back as far as they can.

Choose a partner and take two-to-three minutes to describe this experience to your partner. Then reverse roles for two-to-three minutes. While one is speaking the partner remains silent and just listens.

Discussion

The facilitator will then ask the group members to share with everyone their early memory saying that for many of us this is a first time to discuss these experiences and that many may be familiar. Anyone can pass if they wish, and if a new memory has come to them that is different from the one they shared with their partner they can choose which to tell the group.

As this can be very emotional for participants to remember and share, the facilitator may want to take a moment after hearing a story to thank the speaker for their willingness to share their experiences.

Questions the Facilitator Might Ask Include:

1. What was it like to participate in this exercise?
2. Was it comfortable or uncomfortable for you to think about these early memories?
3. What was it like to hear other people's memories?
4. Do some of the same situations come up more than once in the group?
5. Do we see some parallels in what the differences are and how we learn that they are differences?
6. What did you notice about the age the person was when he/she remembers learning about differences?
7. How do we help other people learn and accept our children with special needs as more than just being different?

Material in this module is based on the work of:

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Exercise: Deep Listening

Deep listening helps us to lower our fear and discomfort level by establishing a sense of safety and trust. It is an explicit practice of bypassing stereotypes and bias by focusing on listening to another person without responding or judging. It sets the tone for building on commonalities and generates energy for change.

When we participate in deep listening exercises or practice deep listening in daily life, deep listening has the ability to remind us to:

- “Show up” or be present
- Model the value of focused attention
- Practice reciprocity
- Experience non-judgment and sense of equality
- Enjoy mutual discovery of differences and commonalities

The deep listening exercise described below is a variation created by Roberto Chene for use by families of children with special needs.

Facilitator Instructions

Ask the question: What questions are you struggling with around intercultural diversity?

Record all the answers on a flip chart for everyone to see. Then, introduce the activity. The activity is set-up with the following script.

Facilitator Script

“This is an activity about relationship. It’s about being intentional and not leaving it to chance. How do I, as a leader, create, facilitate and nourish an inclusive environment?”

Find a partner and sit face to face with them. You can pick someone sitting near you or anyone you’d like to get to know better. You’ll be taking turns and you will always be giving them your total, undivided attention – without talking, making no comments and asking no questions. The speaker will have seven minutes to tell his or her life’s story.

Here are some guidelines:

- As the speaker, if you run out of life story before your seven minutes are up, it’s still your seven minutes. The other person will continue to listen to whatever you decide to share.
- No note taking. This is not an introductions activity where you’ll be asked to introduce the person you just listened to.
- Decide who will go first. Person A will have seven minutes to tell their life story. Person B will only listen. No talking, no asking questions. Just listen and demonstrate that you are completely interested in what the person is telling you. Head nodding and non-verbal communication, e.g., facial expressions, are okay.

After seven minutes, I will give you a signal and then you will switch roles with your partner. I’ll signal you when the second seven minutes is up and we’ll debrief it together.”

Part 2:

“Take one minute to say what you like about yourself. Then after one minute, switch and the second person tells what they like about him or herself. Same guidelines apply. Start with the last listener speaking first.”

Part 3:

“Then, for one minute tell your partner what you like or admire about him or her. Reverse so the partner can tell you in one minute what he or she likes or admires about you.”

Discussion

The Facilitator then asks a series of questions of the group:

1. What was the experience like for you?
2. What was it like to tell someone your life story?
3. How did it feel to you as the listener?
4. What does this tell us about how we usually listen?
5. What was it like to talk about what you like about yourself?
6. What was it like to hear someone say what they liked about you?
7. Do you feel you know the other person better now than before?
8. What might you do differently or be aware of as a result of this exercise?

Exercise: The Brick Wall and The Gateway

This exercise is intended to help individuals reflect on the experience of respectful conversations and identify best practices. It may also result in a set of meeting guidelines.

Materials Needed:

- Have about 8 feet of wall space to post 3-4 half sheets of paper in a row from left to right and 3 or 4 rows down, too for display when completed
- 12-15 white half sheets of paper, create red and black borders on them with a marker (to represent bricks)
- 12-15 bright green half sheets;
- A white half sheet with red & black border with the words “Brick Wall” printed on it; a green half sheet with the word “Gateway” printed on it
- Stop watch
- Three flip chart pages that have been sprayed with 3M Spray Mount, a repositioning spray

Script for Facilitator:

- Ask **people to pair up for three minutes** and each one takes a turn sharing one thing that *doesn't* contribute to having a respectful conversation (based on past experiences).
- After the three minutes, **ask for one response from each pair** and print them on the white half-sheets under the “Brick Wall” sign and create a brick wall. Can do 3 rows of 4 or 4 rows of 3, whatever simulates a brick wall best.
- Now ask people to **pair up with someone different** and this time take **three minutes** to come up with the kinds of behaviors and actions that contribute to respectful conversations.
- After three minutes, **ask for one response from each pair**, print those ideas on the green 1/2 sheets and put them under the green “Gateway” sign and create an archway.
- Reinforce the imagery of the brick wall and the gateway and **ask how it feels to be on the receiving end of each cluster of ideas**. For example, “What does it feel like to have someone interrupt before you’re finished talking?” Then, the gateway: “How does it feel when someone sustains eye contact and is attentive while you’re talking?”

Characteristics of Effective Family Advisors

Effective family advisors:

- Have credibility with both parents and professionals
- Have their “ears to the ground,” make an effort to reach out to other parents in their community and find out their concerns
- Meet regularly with the organizational leaders to pass along parent concerns, especially those shared by several or many parents
- Have good relationships with the staff in their practice and speak at PFAC meetings at least once each year to voice parent concerns.
- Are able to connect parents with other parents who have shared experiences so they can provide guidance and support
- Provide multiple ways for parents to access information they need and to connect with other parents (for example, a listserv, in-person meetings, or a referral network of parents to talk to)
- Are good at asking for and getting help from other parents, especially in areas where other parents have more expertise
- Encourage initiative and leadership in others, not insisting on being in charge of every area
- Are good at mentoring parents of younger children to help them and bring them into the process of advocating for their child
- Know when to quit and turn their successful participation over to the next energetic group of parent leaders who will maintain the PFAC as a resource for parents and administrators and make it even better

Recruitment Plan Worksheet

Begin by listing all of the possible ways you can recruit patients and families. Enlist the help of as many people in your organization as you can to develop this list.

Considering your audience, your budget and your timeframe, check off the publicity options you would like to use:

- Post flyers in the waiting room, throughout your facility or at special events like flu clinics.
- Run announcements or short videos on your organization's TV monitors.
- Mail flyers or postcards directly to all patients or a subset of patients and families.
- Ask staff to personally invite patients and families. People feel more engaged when they are personally asked.
- Include a message on your organization or practice's website.
- Send an email or message through your patient portal.
- Post flyers on local bulletin boards.
- Create a YouTube channel for your practice and post a short video invitation.
- Use social media like Facebook, listservs and Twitter. Ask your patients and families to spread the word in their electronic communities, like emailing their informal listservs for schools, sports leagues, recreation centers and faith-based organizations.
- Include a flyer in new patient materials.
- Write an article for your organization's newsletter.
- Add a page about the PFAC to your practice website.
- Collaborate with community-based organizations to get the word out.
- Be creative! Ask your patients where they get their news from.

Sample Membership Agreement Letter

January 3, 2013

Dear Mr. Ramirez:

We are so delighted that you will be joining Maplewood Pediatric Practice's Patient/Family Advisory Council. We know that collaborating with you and others families is the best way to improve our practice.

Before our first meeting there is some paperwork to complete. Cassandra Smith of our Volunteer Program will call you with more information.

Our meetings will be held on the 3rd Wednesday of each month. Here are the details for our first meeting:

What: Maplewood Pediatric Practice PFAC

When: February 21, 2013

Time: 7-9pm

Where: Maplewood Pediatric Practice Conference Room

Details: Child care, parking vouchers and food will be provided.

RSVP: Please RSVP to Judy Silver by Monday, February 11, 2013.

I will be your contact person if you have any questions. Thank you again for your interest in our Patient and Family Advisory Council!

Regards,

Judy Silver

555-555-5555

jsilver@maplewood.org

Invitation Checklist

What?

Describe the meeting and the focus of the meeting. If you're only going to be asking questions about a specific aspect of your practice, it's important to let people know ahead of time. See [Step 3 of the PFAC Toolkit](#) for more details on how to create a framing question.

When?

Pick a date and time that is convenient for the greatest number of families. Weeknights are usually best.

Where?

Let people know where you'll be meeting. If the practice has different security/parking procedures during the time you're meeting, let everyone know.

How?

Include details on what you'll be offering, such as child care, interpreting, food, parking vouchers, stipends for time and transportation.

Why?

Explain what your practice will do with the feedback.

Other Information

Include contact details if people have questions or to RSVP. Encourage them to bring a friend who is also a patient or family member of the practice if that is appropriate. Invite people to be in touch if they're interested in participating in the future but can't make this meeting.



LOGO

**Maplewood Pediatric Practice
Patient and Family Advisory Council (PFAC)
Kick-Off Meeting**

February 21, 2013

7:00pm-9:00pm

Maplewood Pediatric Practice Conference Room

Child care, parking vouchers and food will be provided.

What is This Meeting About?

Families have an important role in guiding our work at Maplewood Pediatric Practice. Although we try to provide what our patients need, we cannot do this without input from the families! The Patient and Family Advisory Council (PFAC) will advise the administration and medical leadership on patient needs and clinic priorities from a family perspective.

Who Should Attend?

Any adult family member of a current Maplewood Pediatric Practice patient can apply to join the Patient and Family Advisory Council. Come to our first meeting to learn more about how you can help make appropriate resources available for all Maplewood Pediatric Practice families!

Please RSVP by Monday, February 11, 2013!

Judy Silver

555-555-5555

jsilver@maplewood.org

Discovery Shopping

The goal of *Discovery Shopping* is to deeply understand the patient experience and to identify areas for improvement within your practice.

You can recruit a child or adolescent and replicate an office visit. The Discovery Shopping should be conducted by a practice staff member (acting as family), the child's parent (acting as parent or self), and the child or adolescent acting as the patient.

- The designated Discovery Shoppers should begin the visit by driving up to the clinic and then go through all the steps of an appointment.
- Take photos and make notes of what you see, hear, and smell.
- Record what your experience is like: Where are there delays, bottlenecks, waiting? What makes sense, what does not?

Your Practice PFAC and Bylaws

Use this document in conjunction with [Creating Patient and Family Advisory Councils](#) (Institute for Patient- and Family-Centered Care) to select some sample bylaws to amend for your practice.

Operating guidelines/bylaws need to be developed by the council. Bylaws are important because they provide the framework for perceived goals and objectives. Bylaws also legitimize the group and help promote a feeling of an established, well-organized group. Developing bylaws can be time consuming, however, reviewing bylaws from existing advisory boards can save you time. They can be adapted and amended to suit your group's specific needs.

Select a small core group to develop the bylaws. Among the issues that should be addressed in the bylaws are:

- Purpose of the group
- Goals and responsibilities
- Structure of the group
- Size of the group
- Membership qualifications
- Nominations and elections of members and officers
- Duties of members and officers
- Committees and task forces
- Voting procedures
- Quorum
- Meetings
- Agendas
- Reporting mechanisms
- Guidelines of authority
- Confidentiality
- Amendment procedures

After developing your group's bylaws, present them to the administration for approval. The total membership should review, discuss and amend if necessary and give final approval.

Here are some sample bylaws:

- [Massachusetts General Hospital](#)
- [Franciscan Hospital](#)

Staff Readiness Assessment

Adapted from "Essential Allies: Families as Advisors." Institute for Patient- and Family-Centered Care. [\[source\]](#)

	1 Strongly agree	2 Somewhat agree	3 Neutral	4 Somewhat disagree	5 Strongly disagree
1. Do I believe that parents bring unique expertise to our relationship?					
2. Do I believe in the importance of family participation in decision making at the program and policy level?					
3. Do I believe that parents' perspectives and opinions are as important as those of professionals?					
4. Do I believe that families bring a critical element to the team that no one else can provide?					
5. Do I consistently let others know that I value the insights of families?					
6. Do I work to create an environment in which families feel supported and comfortable enough to speak freely?					
7. Do I listen respectfully to the opinions of family members?					
8. Do I believe that family members can look beyond their own child's and family's experiences?					
9. Will I be able clearly state what is required and expected of families in their advisory roles?					
10. Will I be able to help parents set clear goals for their role?					
11. Do I understand that a child's illness or other family demands may require parents to take time off from advisory responsibilities?					
12. Do I feel comfortable delegating responsibility to families?					

Pre-Planning Checklist

Activity	Owner	Target Date	Completion Date
Determine leader who will ensure the initiation and continued success of the PFAC.			
Form a steering committee composed of leadership, physicians and front-line staff.			
Select a coordinator/liason for the PFAC.			
Identify key stakeholders.			
Conduct research on patient and family advisory councils and patient and family-centered care.			
Gather and distribute informational articles about PFAC.			
Create a Business Case/Charter for PFAC.			
Contact peers who have been involved in creating a PFAC (see contact list in Resources).			
Select patients, families and staff to be part of the planning committee (utilize current hospital volunteers, ask for names of potential candidates from staff).			
Recruit patients, families and staff for the planning committee, inform them of dates/times of meeting.			
Perform readiness assessment with hospital staff.			
Recruit members for steering committee and meet at least 1 time with steering committee during pre-planning phase.			
Obtain commitment of funds for supplies, copying, manuals and refreshments for meetings.			
Obtain a commitment for meeting space for weekly planning committee meetings.			
Start recruitment of patients and families to the PFAC.			
Prepare for acceptance planning.			

Patient and Family Engagement Assessment

Adapted from the “Consumer Involvement Toolkit,” University of Massachusetts Medical School Office of Long-Term Support Studies. [\[source\]](#)

What are you asking the patient and families to do?

What are you offering in exchange for the consumer’s participation (e.g., stipend, gift certificate)?

How much of a time commitment are you asking for (e.g., one hour a month for three months)?

What are the patient and family’s options for participating (e.g., attend meetings, respond to emails, review draft materials)?

What is the extent of this group’s decision-making power?

What do you expect to accomplish as a result of this activity?

How long do you expect the process will last and will there be a product at the end?

When and how will you communicate to patient and families involved regarding what happens with the work and the result of recommendations made?

Who will be the contact person if the patient and families has questions or concerns?

Are there other resources in our organization that can help us with this?

Do we belong to a larger organization (health center, hospital or consortium) that can guide us and link us to patients and families who may already be active in our organization at another level?

What capacity and resources can our practice devote to this? What structure will maximize those resources?