



# Working With Patient and Families as Advisors

## Implementation Handbook



Agency for Healthcare Research and Quality  
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## Introduction

The *Guide to Patient and Family Engagement in Hospital Quality and Safety* is a resource to help hospitals develop effective partnerships with patients and family members with the ultimate goal of improving hospital quality and safety.\*

Working with patients and families as advisors at the organizational level is a critical part of patient and family engagement and patient- and family-centered approaches to improving quality and safety. Patient and family advisors are valuable partners in efforts to reduce medical errors and improve the safety and quality of health care.

The Working With Patients and Families as Advisors strategy and its tools help hospitals implement and develop effective partnerships with patients and family members at the organizational level.†

This handbook gives you an overview of and rationale for the strategy. It also outlines five steps for putting this strategy into place at your hospital and includes specific suggestions for how to work with patient and family advisors. Throughout this handbook, we have included examples and real-world experiences from three hospitals that implemented the *Guide* strategies in a year-long pilot project: Advocate Trinity Hospital in Chicago, IL; Anne Arundel Medical Center in Annapolis, MD; and Patewood Memorial Hospital in Greenville, SC. In addition, we have provided information and examples from other hospitals that have experience working with patient and family advisors.

### Overview of the Working With Patients and Families as Advisors Strategy

The goal of the Working With Patients and Families as Advisors strategy is to bring the perspectives of patients and families directly into the planning, delivery, and evaluation of care. The tools that accompany this handbook are intended to help hospitals recruit and orient patient and family advisors and prepare clinicians and hospital staff to work with patient and family advisors.



*"What's nice about the Guide is that it's not rigid. You can adapt the information about working with advisors to your culture and to your organization, but it's enough of a guide that you're going in the right direction."*

Anne Arundel Medical Center,  
Patient- and Family-Centered  
Care Committee Member

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\* The *Guide* was developed for the U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality by a collaboration of partners with experience in and commitment to patient and family engagement, hospital quality, and safety. Led by the American Institutes for Research, the team included the Institute for Patient and Family-Centered Care, Consumers Advancing Patient Safety, the Joint Commission, and the Health Research and Educational Trust. Other organizations contributing to the project included Planetree, the Maryland Patient Safety Center, Aurora Health Care, and Emory University Hospital.

† Materials in this handbook have been adapted from resources from the Institute for Patient- and Family-Centered Care, Bethesda, MD, and from Leonhardt K, Bonin D, Pagel P. Guide for developing a community-based patient safety advisory council. Rockville, MD: Agency for Healthcare Research and Quality; 2008. Available at: <http://www.ahrq.gov/qual/advisorycouncil>.

## What are the Working With Patients and Families as Advisors tools?

This section provides an overview of the tools included in this strategy.

	Use this tool to	Description and formatting
Recruit patient and family advisors		
<b>Tool 1</b> Help Improve Our Hospital: Become a Patient and Family Advisor	Recruit new patient and family advisors	<ul style="list-style-type: none"> <li>• This brochure provides information on who patient and family advisors are, how they help the hospital, and who can become an advisor.</li> <li>• Format: Tri-fold brochure. The electronic version of the document provides information about how to fold the brochure by indicating the front and back covers.</li> </ul>
<b>Tool 2</b> Personal Invitation for Patient and Family Advisors	Recruit new patient and family advisors	<ul style="list-style-type: none"> <li>• This postcard is for clinicians or hospital staff to give to potential patient and family advisors along with a verbal invitation to get involved. The postcard describes the role of an advisor and tells potential advisors how to get more information.</li> <li>• Format: Postcard</li> </ul>
<b>Tool 3</b> Patient and Family Advisor Application Form	Identify and screen potential patient and family advisors	<ul style="list-style-type: none"> <li>• Potential advisors complete this form that includes basic demographic information, questions on why the applicant wants to be an advisor, and questions on prior relevant experiences as an advisor or volunteer.</li> <li>• Format: 3-page handout</li> </ul>
<b>Tool 4</b> Sample Invitation and Regret Letters for Advisory Council Applicants	Notify advisory council applicants of their acceptance or rejection	<ul style="list-style-type: none"> <li>• These sample invitation and regret letters are for patients and family members who have applied to be advisory council members. Hospitals may wish to combine these with a personal phone call.</li> <li>• Format: 1-page letters</li> </ul>

	<b>Use this tool to</b>	<b>Description and formatting</b>
<b>Inform patient and family advisors</b>		
<b>Tool 5</b> Patient and Family Advisor Information Session	Conduct an information session for people who are interested in becoming advisors	<ul style="list-style-type: none"> <li>• This presentation gives information on who patient and family advisors are, what they do, and how they help the hospital and provides tips from other advisors.</li> <li>• Format: PowerPoint presentation with talking points</li> </ul>
<b>Tool 6</b> Am I Ready to Become an Advisor?	Help people who are interested in becoming advisors self-assess their readiness	<ul style="list-style-type: none"> <li>• This handout is to be given and completed during the advisor information session.</li> <li>• Format: 1-page handout</li> </ul>
<b>Tool 7</b> Sharing My Story: A Planning Worksheet	Help potential patient and family advisors plan how to talk about their experiences	<ul style="list-style-type: none"> <li>• This handout is distributed during the advisor information session.</li> <li>• Format: 1-page handout</li> </ul>
<b>Tool 8</b> My Participation Interests	Identify the specific interests of potential patient and family advisors	<ul style="list-style-type: none"> <li>• This form is completed at the end of the advisor information session.</li> <li>• Format: 1-page form</li> </ul>
<b>Train patient and family advisors</b>		
<b>Tool 9</b> Patient and Family Advisor Orientation Manual	Orient patients and family members who have been selected to serve as advisors	<ul style="list-style-type: none"> <li>• This manual provides information on hospital safety and quality and on what patient and family advisors do and how they help the hospital, and provides tips about being a patient and family advisor.</li> <li>• Format: Manual</li> </ul>

	<b>Use this tool to</b>	<b>Description and formatting</b>
<p><b>Tool 10</b> Sample Confidentiality Statement</p>	<p>Review confidentiality requirements with all patient and family advisors</p>	<ul style="list-style-type: none"> <li>• This is a sample confidentiality statement that hospitals can ask patient and family advisors or council members to sign before participating in advisory activities.</li> <li>• Format: 1-page handout</li> </ul>
<p>Train clinicians and hospital staff</p>		
<p><b>Tool 11</b> Working With Patient and Family Advisors (Presentation)</p>	<p>Introduce clinicians and hospital staff to the idea of working with patient and family advisors and to develop their skills for doing so</p>	<ul style="list-style-type: none"> <li>• This is a two-part training presentation. Part 1, Introduction and Overview, discusses who patient and family advisors are, the benefits of working with them, and opportunities for doing so. Part 2, Building Effective Partnerships, helps clinicians and hospital staff develop partnership skills.</li> <li>• Format: PowerPoint presentation and talking points</li> </ul>
<p><b>Tool 12</b> Working With Patient and Family Advisors (Handout)</p>	<p>Provide clinicians and hospital staff with an overview of working with patient and family advisors</p>	<ul style="list-style-type: none"> <li>• This handout is given at the clinician and staff training session that outlines the role of patient and family advisors and opportunities for working with them.</li> <li>• Format: 2-page handout</li> </ul>
<p><b>Tool 13</b> Working With Patient and Family Advisors on Short-Term Projects</p>	<p>Help clinicians and hospital staff identify opportunities for working with patient and family advisors</p>	<ul style="list-style-type: none"> <li>• This handout is distributed at the clinician and staff training session that contains suggestions for ways in which to incorporate advisors on short-term projects along with a form to request advisor participation.</li> <li>• Format: 4-page handout</li> </ul>
<p><b>Tool 14</b> Readiness to Partner with Patient and Family Advisors</p>	<p>Help clinicians and hospital staff identify attitudes and behaviors that help them partner effectively with advisors</p>	<ul style="list-style-type: none"> <li>• This handout is given at the clinician and staff training session that contains a checklist of behaviors and attitudes.</li> <li>• Format: 1-page handout</li> </ul>

## What are the resources needed?

Resources needed for the Working With Patients and Families as Advisors strategy will vary from hospital to hospital and depend on the size and scope of what you would like to accomplish.

- **Staffing.** Resources involved include time for a staff liaison, who is the point person responsible for overseeing and coordinating the work of patient and family advisors. The staff liaison helps recruit and train advisors, identifies opportunities to involve advisors in hospital activities, oversees the work of advisors, and reports to hospital leadership about the accomplishments of advisors. At some hospitals, this is a full-time position. At other hospitals, these responsibilities are folded into an existing position. The staff liaison is an important component of success in engaging patients and families.
- **Costs.** Material costs include printing of the patient and family tools for recruitment and orientation, printing of the health care professional training materials, or costs associated with making materials available online. As with other volunteers, hospitals may incur costs associated with background checks for advisors. Also, some hospitals choose to reimburse patients and families for expenses incurred during their work as advisors (e.g., parking, transportation, and child care) or offer stipends or honoraria for participation in meetings.



*"You have to get input from the end users — the patients and the families — as to what is going to make an impact on them, how much sense it makes to them, how readable it is to them."*

Implementation Coordinator,  
Patewood Memorial Hospital

## Rationale for Working With Patients and Families as Advisors

The goal of patient and family engagement is to create an environment where patients, families, clinicians, and hospital staff all work together as partners to improve the quality and safety of hospital care. Patient and family engagement encompasses **behaviors** by patients, family members, clinicians, and hospital staff, as well the **organizational policies and procedures** that support these behaviors.

## Why are patient and family advisors important?

Patient and family advisors are individuals who have received care at your hospital and who offer insights and input to help hospitals provide care and services that are based on patient- and family-identified needs rather than the assumptions of clinicians or other hospital staff about what patients and families want.



*"We envisage patients as essential and respected partners in their own care and in the design and execution of all aspects of health care.*

*In this new world of health care, organizations publicly and consistently affirm the centrality of patient- and family-centered care. They seek out patients, listen to them, hear their stories, are open and honest with them, and take action with them."*

Leape L, Berwick D, Clancy C, et al. Transforming healthcare: a safety imperative. *Qual Saf Health Care* 2009;18(6):424–8.

Patient and family advisors help identify what your hospital is doing well and also help pinpoint areas for improvement. Advisors can help your hospital move beyond the "what is wrong" stage to developing effective solutions.

Patient and family advisors can offer:

- Insights about a hospital's strengths and areas where changes may be needed
- Feedback on practices and policies that patients and families find meaningful and useful in helping them be active partners in their care
- Timely feedback and a fuller picture of the care experience than standard patient and family satisfaction surveys provide

The benefits of working with advisors include improvements in overall systems and processes of care. This can lead to longer-term benefits including:<sup>1</sup>

- Better health outcomes for patients
- Reduced errors and adverse events
- Increased patient loyalty
- Reduced risk of malpractice
- Increased employee satisfaction
- Improved financial performance

## Implementing Working With Patients and Families as Advisors

The Working With Patients and Families as Advisors strategy is designed to be flexible and adaptable to each hospital's environment and culture. The five steps outlined in this implementation handbook can help your hospital start the process of working with advisors or move further along with your current efforts.

### Step 1: Identify 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 supports advisors.

>> **Learn more:** [Step 1: Identify a staff liaison](#) (on page 8)

## **Step 2: Identify opportunities for involving patient and family advisors**

Hospitals that have little prior experience with advisors may want to start by working with advisors on short-term projects or consultations. Or, hospitals can create a more formal structure by forming a patient and family advisory council. Hospitals that have more extensive experience may be ready to incorporate advisors as members of quality and safety committees.

>> **Learn more:** [Step 2: Identify opportunities for involving patient and family advisors](#) (on page 10)

## **Step 3: Prepare hospital leadership, clinicians, and staff to work with advisors**

The engagement of hospital leadership, clinicians, and staff helps develop and sustain meaningful partnerships with patient and family advisors.

>> **Learn more:** [Step 3: Prepare hospital leadership, clinicians, and staff to work with advisors](#) (on page 12)

## **Step 4: Recruit, select, and train patient and family advisors**

One of the best ways to ensure successful partnerships is to recruit advisors who are a good match with your organization's needs and then make sure they receive appropriate training.

>> **Learn more:** [Step 4: Recruit, select, and train patient and family advisors](#) (on page 15)

## **Step 5: Implement and coordinate advisor activities**

Successful staff liaisons identify advisor activities, match advisors with activities, provide coaching and mentoring, and track and communicate advisor accomplishments.

>> **Learn more:** [Step 5: Implement and coordinate advisor activities](#) (on page 22)

## Step 1: Identify a Staff Liaison

Hospitals that are most effective in engaging patient and family advisors designate a clinician or staff member to serve as a staff liaison. This individual 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 supports advisors.

The staff liaison's job is to facilitate partnerships, ensure that advisors are ready to participate, and ensure that staff are ready to engage in partnerships.



For the three hospitals that pilot tested the *Guide*, identifying a point person to serve as a staff liaison was an important part of successful implementation.

Effective liaisons were passionate about patient- and family-centered care, well respected by leadership and their peers, and well connected within the hospital. They also benefitted from having clinical backgrounds, which helped them anticipate challenges and directly address staff concerns.

### Who should be a staff liaison?

In hospitals that are just starting to work with patient and family advisors, the staff liaison is usually someone who is already on staff. This may be someone who already work in patient and family education, quality improvement, or administration. The staff liaison should be someone who has a passion for patient- and family-centered care and who has time to devote to the role of staff liaison.

Staff liaisons will work with a variety of people to build support for advisor engagement and participation. Because of this, it is helpful for the staff liaison to be someone who has or can build a strong rapport with hospital leadership, clinicians, staff, and patients and family members. It also is helpful for staff liaisons to have the following qualities:

- A passion for patient- and family-centered care
- The ability to listen and be open to new ideas
- The ability to work positively and proactively
- The willingness to both learn and educate
- Well respected by senior leadership and their peers
- Well connected within the hospital
- Patience and perseverance
- The ability to see strengths in all people in all situations and to build on these strengths
- Flexibility and a sense of humor

Although having a clinical background is not required, it may be helpful in anticipating challenges and directly addressing staff concerns.

## What are the staff liaison's responsibilities?

The staff liaison is a consultant, educator, guide, and mentor. As such, the staff liaison has responsibilities to hospital leadership, clinicians, staff, and advisors.<sup>2</sup>

Staff liaison responsibilities to **hospital leadership** include:

- Working with hospital administrators to get their buy-in and commitment for working with patient and family advisors (see Step 3: Prepare Hospital Leadership, Clinicians, and Staff to Work with Advisors for more information)
- Keeping leadership apprised of advisor activities and accomplishments

Staff liaison responsibilities to **hospital staff** (clinicians and other staff) include:

- Educating staff about the roles of advisors and opportunities for working with them
- Assisting staff with developing plans for involving advisors on specific projects or workgroups
- Helping staff understand how to act on and implement advisor suggestions or to provide feedback about why changes are not possible
- Problem solving in challenging situations

Staff liaison responsibilities to **patient and family advisors** include:

- Obtaining the necessary resources
- Cultivating opportunities for advisor involvement
- Overseeing the recruitment and selection of advisors
- Communicating with advisors in a timely manner about recruitment status and potential opportunities
- Training advisors and helping them understand how the organization works
- Overseeing advisor activities, providing mentoring and coaching, and facilitating the ongoing engagement of advisors
- Bringing concerns of advisors to hospital leaders or helping to create direct connections between advisors and leaders
- Tracking and communicating advisor accomplishments

## Step 2: Identify Opportunities for Working With Patient and Family Advisors

This section contains information and guidance to help staff liaisons think about opportunities for working with patient and family advisors. These opportunities are neither mutually exclusive nor do they represent the only ways of working with patient and family advisors. Plans for short-term activities should fit within a longer term vision of the role patient and family advisors will play in your organization. For more detailed information about implementing the opportunities in this section, refer to the appendixes of this handbook.

### Advisors on short-term projects

Hospitals that have little prior experience working with advisors may wish to start by working with advisors on short-term projects or one-time consultations (e.g., working with advisors to implement the other strategies included in this *Guide*). Other examples of ways to work with advisors include:

- Invite two or three patient and family advisors to a hospital staff or committee meeting to discuss their hospital stay. Advisors can share what went well, what could have been done better, and any ideas they have for changes and improvements.
- Work with advisors to develop or revise written and audiovisual materials, such as patient and family handbooks, informational videos, or care instructions. To get the most of advisor input, be sure to bring in patient and family advisors early in the project when their ideas and input can have the biggest impact.
- Invite advisors to present at staff orientations and in-service programs to share their perspectives of care and the impact of illness or hospitalization on patients and families.

>> **Learn more:** [Appendix A: Working With Patient and Family Advisors on Short-Term Projects](#) (on page 31)

Use advisors to help you plan and implement the other strategies in the *Guide* (**Communicating to Improve Quality, Nurse Bedside Shift Report, and the IDEAL Discharge Planning**).

Anne Arundel Medical Center worked with patient and family advisors in creating their own training video on bedside shift report. Advisors helped by playing patients in the video.

Watch the video they developed:

<http://www.youtube.com/watch?v=PllzlvXpSDY>

## Patient and family advisory councils

A patient and family advisory council is a formal group that meets regularly for active collaboration between clinicians, hospital staff, and patients and family members on policy and program decisions. It is not a support group, grievance committee, staff meeting, or presentation forum.

Advisory councils can identify opportunities for improving the patient and family experience, advise on policies and practices to support patient and family engagement, and recommend how to better measure, quantify, and evaluate patient and family engagement. Specific roles of council members may include serving as a sounding board for new initiatives; generating ideas; sharing best practices; planning and evaluating programs; and providing input on institutional policies, programs, and practices.<sup>3</sup>

Prior to implementing a patient and family advisory council, the staff liaison should specify eligibility criteria for membership, outline general roles and responsibilities, draft a general mission statement and bylaws, and identify general opportunities for council involvement.

>> **Learn more:** [Appendix B: Establishing and Working With Patient and Family Advisory Councils](#) (on page 38)

## Advisors as members of quality and safety committees

Hospitals that are new to working with patient and family advisors should not begin with this opportunity. However, hospitals that have more extensive experience working with patient and family advisors may be ready to take the next step and incorporate advisors as members of quality and safety committees. As members of quality and safety committees, patient and family advisors may be asked to participate in the following activities:

- Reviewing and interpreting the results of patient surveys and other data on hospital quality and safety and developing strategies for improvement
- Participating in quality improvement projects
- Co-presenting in training sessions for nurses, doctors, and other staff focused on improving communication, safety, and quality

>> **Learn more:** [Appendix C: Working With Advisors as Members of Hospital Quality and Safety Committees](#) (on page 50)

## Step 3: Prepare Hospital Leadership, Clinicians, and Staff To Work With Advisors



*"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."*

Essential Allies: Patients, Residents, and Families as Advisors. (In press). Institute for Patient- and Family-Centered Care.

The most important factor for ensuring the success of efforts to work with patient and family advisors is the belief that partnering with patients and families is absolutely essential to improving hospital quality and safety.

This section of the implementation handbook provides guidance for staff liaisons to help build partnerships and garner support for patient and family advisors among hospital leadership, clinicians, and staff. This support is critical to creating sustained and meaningful partnerships with advisors.

### Gathering information

One of the first things that staff liaisons can do to build support for working with advisors is to ensure a personal understanding of the hospital's culture, current policies, and decisionmaking processes.

Ways to do this include:

- **Identify and get to know the formal and informal leaders in the hospital.** The support and approval of both formal and informal leaders is needed to effect change. To identify informal leaders and talk to clinicians and staff to find out whom they listen to and respect. Think about ways to bring leaders into the process of working with patient and family advisors.
- **Learn how decisions are made.** Understanding established processes and protocols for making changes will help identify who and what influences decisions about advisor involvement.
- **Learn about the clinicians and staff in the hospital.** A key factor for success is clinician and staff willingness to be involved in a multidisciplinary, collaborative approach that includes patients and families. Gathering information about clinicians' and staff's experiences, ideas for changes and improvements, and questions or concerns about advisor participation can help prepare clinicians and staff to partner with advisors.



*"I think one of the things that has been really helpful for us is the strong leadership support. Our president talks about patient- and family-centered care. That's the expectation she sets out. But to sustain it, people have to see the value of it. And, after a committee has worked with an advisor and it's been a positive experience, then they get it. And that keeps it sustained."*

Anne Arundel Medical Center  
Patient- and Family-Centered  
Care Committee member



With leadership support from the president and vice president of nursing, Advocate Trinity Hospital developed plans for working with patient and family advisors. They used **Tool 11: Working With Patient and Family Advisors** to develop support among the executive team and departmental leaders.

- **Assess the hospital's experience** with including patient and family perspectives in previous change and improvement initiatives. Learning about the process and outcomes of these experiences will help identify lessons learned, potential barriers, and successes upon which to build.

## Building support

The next step is to build a broad base of support from key individuals and groups, including hospital administration, managers, task force leaders, patient advocates, support groups, and other patient groups. The process of obtaining buy-in will not be a one-time occurrence. Regular communication with leadership, clinicians, and staff is important to help them understand the process of working with patient and family advisors -and the opportunities for doing so.

Practical steps to take in building support include:

- **Talk to hospital leaders about the importance and value of patient and family advisors.**
- **Meet with clinicians and staff individually and in groups to discuss what it means to work with patient and family advisors.** These efforts should be discussed as deep-rooted, long-term commitments to evolve the system of care. Hospital staff and clinicians also need to know about the expected benefits of working with advisors along with what will be expected of them. Ask to be put on the agenda of a staff meeting or invite clinicians and staff to a brown bag lunch discussion.
- **Identify individuals on the staff who can help champion the idea of patient and family advisors.** Invite these individuals to participate in a training session to learn how to partner effectively with patient and family advisors.
- **Invite staff and leadership to conduct a walkabout** to explore how the hospital welcomes, engages, and supports patients and families. Begin at the first point of entry into the unit and include the patient room, treatment rooms, admitting area, family lounge, and other areas visible to patients and families. Focus feedback on what the project will be about or what the issue of concern is. Findings from the walkabout will give a new context for discussions about working with patient and family advisors to make improvements.

>> **Learn more about conducting a walkabout:** [Appendix A: Working With Patient and Family Advisors on Short-Term Projects](#) (on page 31)

### Guide Resources



The following *Guide* resources can help you train hospital staff on working with advisors.

**Tool 11: Working With Patient and Family Advisors: Part 1. Introduction and Overview** is a PowerPoint presentation with talking points that you can use to introduce clinicians and staff to the idea of working with advisors.

The session includes a handout titled **Tool 12: Working With Patient and Family Advisors** that provides an introduction to the topic. You may also want to ask a patient or family member to share his or her story during this presentation.

## Recognizing challenges

Challenges may arise during conversations about working with patient and family advisors, including:

- **Resources.** Training and supporting patient and family advisors and clinicians and hospital staff to engage in partnerships requires a commitment of personnel and financial resources. For example, the three pilot hospitals reported that planning, recruiting, and implementing advisor opportunities took more time than originally anticipated. Yet, all three hospitals reported that the investment was beneficial.
- **Administrative barriers.** With an eye on the bottom line, some administrators may see only the associated costs and not the long-term value of these partnerships. Administrators may also believe that privacy policies severely restrict the role for patients and families in discussions that occur when changes and improvements are being planned, implemented, and evaluated.
- **Planning and sequencing implementation activities.** Just as with other quality improvement initiative, it is important to lay out a long-term vision for working with advisors while planning smaller action steps. This will help maintain momentum and identify meaningful, immediate opportunities for advisor input.
- **Clinician and hospital staff attitudes.** Partnering with patient and family advisors is not something that most clinicians and hospital staff have been trained to do or learned about in their education. As such, they may have concerns about working with advisors and sharing ideas for change and improvement. They may feel that their expertise is not being validated, that advisors will disclose private information to others outside of the hospital, that advisors will make unreasonable or impractical suggestions, or that patients and families do not have the time to participate as advisors.

- **Patient and family attitudes.** When contemplating becoming an advisor, patients and family members may have doubts about how helpful they can be. Patients and families may see clinicians and hospital staff as having expertise that outweighs any ideas they may have. They also may not want to share concerns or negative experiences they had at the hospital directly with clinicians and hospital staff.

Listen carefully to the reasons for resistance and try to address them. One way to address resistance among leaders, clinicians, and staff is to find ways for them to see examples of collaboration with patients and family members in action. Try to create opportunities for interaction with patients and family members or with clinicians and staff who have worked with advisors.

It also is important to train clinical staff on how to work with patient and family advisors. Develop talking points that highlight the resources that will be available to support patient and family advisor engagement. For example:

- The staff liaison will be responsible for coordinating advisor recruitment, selection, orientation, placement, and supervision
- All advisors will be carefully screened to ensure that the role is a good fit
- All advisors will undergo training about their responsibilities and will sign confidentiality statements to affirm their commitment to keeping protected health information and data confidential
- The staff liaison will screen and train advisors to ensure readiness before invitations for placement on quality and safety committees are extended
- The staff liaison is available as a resource to clinicians and staff should concerns arise about the readiness, accountability, or skills of an advisor

## **Step 4: Recruit, Select, and Train Patient and Family Advisors**

This section of the implementation handbook provides guidance for staff liaisons to help identify, select, and train patient and family advisors. One of the best ways to ensure successful partnerships with patient and family advisors is to recruit patients and family members who are a good match with your organization's needs and make sure they receive appropriate training.

This section outlines the following steps for recruiting, selecting, and training patient and family advisors:

- Identify potential advisors
- Hold an information session for patients and family members who are interested in becoming advisors
- Interview and select advisors
- Train advisors

## Recruiting potential advisors

A patient or family advisor is a patient or family member of a patient who has experienced care in your hospital. It is best to recruit advisors who have received care at your hospital within the past 3 to 5 years. This helps ensure that their experiences and recommendations reflect the current patient and family experience. It is also helpful to recruit advisors who have diverse health care experiences and who reflect the diversity of the patients and families your hospital serves.

Throughout the process of recruitment, it is important to have personal, individual interactions with potential advisors. Many advisors report that personal interaction is the most influential factor in helping them decide to become an advisor.

### Advisor qualifications

No special qualifications or expertise are necessary to be a patient or family advisor. What is important is an individual's experience as a patient or family member at the hospital. However, it is helpful to look for individuals who:

- Are coping well with their hospital experiences
- Are willing to talk about their experiences and can effectively share insights and information
- Demonstrate a passion for improving health care for others
- Have the ability to listen well, respect the perspectives of others, interact with many different kinds of people, and work in partnership
- Enjoy working with others, show a positive outlook on life, and bring a sense of humor
- Represent a broad cross-section of your hospital's population



#### Guide Resources

Give the **Tool 2: Personal Invitation for Patient and Family Advisors** postcard to clinicians and staff. Ask them to distribute the postcard to individuals who they think would be good advisors.



### Guide Resources

**Tool 1: Help Improve Our Hospital: Become a Patient and Family Advisor** is a brochure you can customize and use to recruit patient and family advisors.



Anne Arundel Medical Center held a recruitment dinner to recognize existing advisors for their work and identify potential new advisors. They issued personal invitations and advertised the dinner in the local newspaper.

At the dinner, Anne Arundel used the advisor information session presentation (Tool 5), the advisor readiness checklist (Tool 6), and the story sharing planning worksheet (Tool 7).

## Finding potential advisors

To identify potential advisors or advisory council members, look for people who have demonstrated an interest in being actively involved in their care or the care of their family member. Also look for and consider individuals who have provided constructive feedback in the past. Other suggestions for identifying potential advisors or advisory council members include:

- **Enlist the support of clinicians and staff.** Patient and family advisors often say that a personal invitation from a clinician or other hospital staff member is the deciding factor in encouraging them to become an advisor. Ask clinicians and staff to provide you with the names of potential advisors. Some hospitals create competitions to recognize the clinical areas that identify the largest number of prospective patient and family advisors.
- **Distribute and verbally go over recruitment brochures.** Place advisor recruitment brochures in easily accessible locations on units for staff to distribute. These brochures can also be included in discharge packets, informational materials, welcome packets, or patient satisfaction survey mailings. Remember that the most effective method of recruiting advisors is with a personal invitation. When distributing brochures, make sure to also verbally describe what a patient and family advisor is and how to get involved.
- **Review letters or emails from patients and family members** to identify individuals who have provided constructive feedback to the hospital in the past.
- **Advertise opportunities at support groups or other patient meetings.** Distribute recruitment materials at patient education meetings and support groups within the hospital.
- **Work with patient representatives, ombudsmen, and other hospital staff,** such as social workers, to identify potential advisors.
- **Advertise opportunities on the hospital Web site.** Work with the hospital's marketing department to create a page on the hospital Web site that contains information on advisory opportunities. Include the recruitment brochures and advisor application form on the Web site.



### Guide Resources

#### **Tool 3: Application Form for Patient and Family Advisors**

is a form for advisors to complete to provide information about themselves and their interest in serving as a patient and family advisor.

#### **Tool 5: Become a Patient and Family Advisor: Information Session**

is a PowerPoint presentation with talking points. The session includes handouts called **Tool 6: Am I Ready to Become an Advisor?** and **Tool 7: Sharing My Story: A Planning Worksheet** to help patients and family members determine their readiness to be an advisor.

#### **Tool 8: My Participation Interests**

is a form for advisors to complete during the information session to indicate their interest in specific topic areas or initiatives.

## Recruiting advisors to be members of quality and safety committees

The strategies listed above are appropriate for identifying general advisors. However, candidates for becoming members of quality and improvement committees are typically individuals who are or have been advisors in other roles in your hospital. To identify these individuals, ask hospital staff who have worked with advisors for suggestions. The staff liaison or committee chair should contact potential advisors to inquire about their interest and ability to serve as a quality or safety committee member.

Be clear on participation term limits for committees with prospective patient and family advisors. Most often, a minimum of a 1-year commitment is desired because the projects often take at least a year to plan, implement, test, review, and reach their goal. Advisors should also receive a description of the committee's purpose or charge, information on meeting frequency and schedule, and a summary of recent projects the committee has completed. If advisors are being recruited to help with specific projects, they should receive a description of the project. All advisors for quality and safety committees should also receive a clear outline of their roles, responsibilities, and expectations. It may also be helpful to coordinate a meeting or conference call to introduce patient and family advisors to the leader of the committee and give them the opportunity to ask questions so they can make an informed decision about participation.

## Advisor information session

Before patients and family members can decide whether or not they want and are ready to serve as advisors, they need to understand the responsibilities associated with the role. The staff liaison can hold an information session for potential advisors to cover:

- The role of patient and family advisors, including responsibilities and the benefits of participation
- Logistic information, including time commitments, whether reimbursement or compensation is provided, what kind of training and support is available, and how the application process works
- Specific opportunities available for advisors at the hospital

The advisor information session should not take the place of an orientation session. The information session helps people understand what an advisor is. Once selected, the orientation session helps prepare advisors for their work.

## Selecting advisors: Applications and interviews

Patients and family members who are interested in serving as advisors should complete an application. For short-term projects, the hospital may want to consider allowing prospective advisors to simply complete an application instead of also undergoing a formal interview and selection process.

Selecting members of advisory councils requires a more formal structure because membership typically requires a 1- to 2-year commitment. All potential council members should be interviewed by the staff liaison and the council's key contact, if different from the staff liaison. Select additional interviewers as appropriate. Interviews can be conducted in person or by telephone.

During the interview, explore the applicant's responses to the open-ended questions included in his or her application form, including the reasons for wanting to become an advisor. Ask the applicant what he or she would like to do and explore with upcoming opportunities to assess his or her interests.

Additional questions to ask include:

- As an advisor, what strengths and skills would you bring?
- Tell us about a group situation where you were involved in a disagreement or had a different opinion than others. How did you attempt to resolve the situation? This can be in the hospital, school, at work, with family, or another setting. How did you feel about hearing differing opinions with which you disagree?
- How much time are you likely to have in your schedule to participate as an advisor?

Discuss with applicants where they would be best placed. Do not rely on a paper application or previous experiences with the applicant. Matching interests and skills with opportunities helps make sure advisors can contribute in substantive ways.

In making decisions about applicants, look for patients and family members who have diverse health care experiences in the hospital and who reflect the diversity of your patient and community population. If you are looking for advisors for a particular unit, select patient and family members who have care experiences

### Take It Further

If your hospital has been working with advisors for a while, ask experienced advisors to participate in interviews with advisor applicants. Experienced advisors can help answer questions, provide their perspectives, and assess whether an applicant would be a good fit.

### Guide Resources

The **Tool 4: Sample Letter of Invitation** can be customized by hospitals to invite selected advisor applicants to join an advisory council. This letter is accompanied by **Tool 4: Sample Letter of Regret** for applicants who are not selected.

within that unit. Work with your hospital's volunteer office as appropriate to ensure that any procedures are followed (e.g., background checks).

Inform patients and family members about selection in a timely manner. Not following up promptly with applicants may lead them to think they were not selected or needed. If there is not an appropriate match at the time, extend the invitation to explore future options for serving as an advisor.

## Orienting advisors

Advisors typically undergo general volunteer orientation as well as a specific orientation for advisor work. The volunteer orientation process typically includes information about confidentiality and other requirements, such as vaccinations.

After this general volunteer orientation, the staff liaison should meet with new advisors, either individually or as a group, to train them. Topics to cover in this meeting include:

- Background information on hospital quality and safety, patient and family engagement, and the principles of patient- and family-centered care
- Information on how patient and family advisors help improve hospital quality and safety, including where advisors are situated within the organizational structure
- An explanation of the responsibilities of and expectations for advisors, including expectations related to confidentiality and privacy (Health Insurance Portability and Accountability Act, or HIPAA)
- Tips for being an advisor and sharing personal stories of health care experiences
- Information on how the staff liaison will support the advisor

Allow time during this meeting for questions and a quick tour of the hospital. In addition, advisors who are preparing to help with a specific activity will benefit from having:

- A clear description of the activity, including the scope of work
- Administrative information, such as a list of people on the project or a list of committee members and a schedule of meeting times
- Information on related projects undertaken in the past
- Information on current projects or initiatives



### Guide Resources

**Tool 9: Patient and Family Advisor Orientation Manual** is a manual that hospitals can use and customize.

**Tool 10: Sample Confidentiality Statement** provides an example of the type of confidentiality forms that advisors should complete.

- A description of the advisor’s role and responsibilities, including any expectations

Advisors serving on patient- and family-advisory councils may also benefit from having a one-on-one meeting with the committee chair prior to attending the first meeting. This provides an opportunity for introductions and for advisors to ask questions on the project. The staff liaison may wish to attend this meeting as well.

Advisors who will be serving as members of quality and safety committees will already be familiar with the general roles and responsibilities of advisors and the hospital environment. However, these individuals will need additional coaching and mentoring and specific orientation directed to the work they will be doing on quality and safety committees. Potential topics to address with these advisors will depend on your specific hospital system and needs but may include quality improvement models and methodologies used at the hospital, types of quality data collected, and a review of the importance of confidentiality and privacy.

## Feedback sessions and problem solving

Staff liaisons must provide feedback to and solicit feedback from patient and family advisors. Periodic check-ins to see how the work is going are helpful for advisors who are working on short-term projects. For advisors who are council members, staff liaisons may want to schedule a quarterly meeting to talk about how the experience is going and to identify whether there are any areas in which the advisor needs or wants to develop their skills.

Occasionally, despite careful recruitment, selection, and orientation, a patient and family advisor struggles with his or her duties. If this is the case, find out why. Perhaps the advisor needs additional training or would benefit from working closely with a mentor. Perhaps the advisor is not working on a project or in a situation that is a good match with his or her skills and interests. Or perhaps the advisor is not working in a supportive environment and is facing resistance from clinicians, staff, or other advisors. In this case, it may be helpful to work with clinicians and staff to help them develop more effective partnership skills.

Sometimes, a patient and family advisor is not a good match for a project. If this is the case, there may be other ways to work with that patient and family member. In very rare cases, the staff liaison may need to ask the patient or family advisor to step down from his or her position. In this case, staff liaisons should talk with the volunteer office about how to handle these situations. To be respectful, you need

to discuss the situation with the advisor, even if this is uncomfortable. As a followup for recordkeeping, provide the advisor with a letter asking the advisor to step down. Sample language for a letter is provided below.<sup>4</sup>

### Sample language for asking an advisor to step down

*Thank you for your commitment over the last year(s) in helping us provide a patient's (family's) perspective on the care that we provide to our community. We have really appreciated your honest and thoughtful comments and are hopeful that you also found the experience meaningful.*

*To get a broad understanding of what other patients (families) have experienced, we are going to be rotating the patient (family) membership of our quality (other) committee to a new person. We appreciate your help in this important work and want to continue to receive any thoughts and feedback that you think may be helpful to us. If you have additional ideas, please feel free to share them by contacting [name] at [contact information] so that we can make sure we catalog them and share them appropriately with the committee moving forward. Thank you again for your help.*

## Step 5: Implement and Coordinate Advisor Activities

This section of the implementation handbook provides guidance for staff liaisons to help track and communicate advisor activities.

### Tracking advisor opportunities

In working with patient and family advisory councils, the staff liaison should remain alert for strategic opportunities for advisor input. The staff liaison should encourage clinicians and staff to involve advisors in making changes and improvements and stay informed about upcoming initiatives in the hospital that might benefit from advisor input. They should also encourage staff to think about ways in which they can leverage advisor input. In the beginning, remind clinicians and staff frequently about the ways in which patient and family advisors are available to help.

#### Guide Resources



**Tool 13: Working With Patient and Family Advisors on Short-Term Projects** is a handout you can distribute to clinicians and staff to help them think about ways in which they can work with advisors.

If your hospital will be working with patient and family advisors on short-term or occasional projects, the staff liaison may want to keep a database that includes advisors' interests, availability, contact information, and participation history to identify which advisors are most suitable for a specific project.

If your hospital is working with advisors as members of hospital quality and safety committees, the staff liaison should keep a current list of the committees that are seeking patient and family advisors. The list of available opportunities can then be reviewed with advisors who might consider taking on this new role.

## Integrating patients and family advisors into your organization: Initial steps

The following tips can help expand your efforts to integrate patients and family advisors into the day-to-day work of your organization.

- During the hospital's annual planning process, encourage staff and administrators to incorporate specific patient and family engagement initiatives and strategies into their unit's or department's goals.
- Review current literature related to involving patient and family advisors. This is a way to build capacity for effective participation in quality improvement and other initiatives. Provide resources to help broaden the number of staff and faculty who are knowledgeable about the current literature.
- Create positive experiences for staff to understand the benefits of advisor perspectives and guidance by:
  - Supporting opportunities for advisors to share their stories at staff meetings, clinician trainings, and other hospital presentations.
  - Acknowledging advisor contributions to new materials, redesigned processes, or other projects.
  - Including displays and information about projects that have involved patient and family advisors at hospital staff educational programs. Ask for an advisor to be part of the presentation.



*"We tried to get across to [our advisors] that we really wanted their feedback. If it's something that we need to improve on, we need to change."*

Implementation Coordinator,  
Patewood Memorial Hospital

- Seek opportunities to improve communication and collaboration across disciplines. It is difficult to collaborate with patients and families if the organization does not strongly encourage interdisciplinary collaboration and consistently communicate the expectation that high-performing teams actively involve and build respect for all members.
- Explore how other hospitals have achieved successful partnerships with patient and family advisors. Hold a conference call or virtual meeting with other hospitals and include hospital administration, clinicians, staff, and patient and family advisors. The team may also wish to conduct a site visit if possible.

## Building a foundation for success: Tips for successful meetings and interactions

When patients and family members join committees or project workgroups, the first interactions and experiences are critical in establishing a foundation for success. Following are some tips to help promote positive experiences.

### Getting started

- Encourage existing committee or workgroup members to participate in the orientation of new patient and family advisor members. This helps patient and family advisors feel welcome and facilitates their understanding of the purpose of and goals for the committee or project.
- For the first few meetings that new patient and family advisors are present, include time on the agenda for introductions. It is also helpful to distribute rosters and use name tent cards to help with name recognition.
- Encourage the committee or workgroup to build in agenda time for sharing stories or ice-breaker activities that help members build trust and establish a good working relationship.
- Ask the committee or workgroup chair to recruit experienced members to mentor a new patient or family advisor. Mentors can contact the advisor after each meeting to answer questions and make sure the advisor remains confident with his or her participation. This commitment does not need to be longstanding. It is likely only needed for the first three to four meetings. The staff liaison can check in with each advisor at the end of the first 3 or 4 months to determine if he or she needs the mentorship to continue.

- Encourage the chair of the committee or workgroup to strategically analyze the tasks and goals to seek opportunities for involving advisors in both short- and long-term initiatives the committee or workgroup is addressing. As possible, encourage an initial focus on projects that have the potential to be small successes (i.e., short-term projects that are highly likely to succeed). Make sure that these successes are celebrated and communicated throughout the hospital (e.g., through employee newsletters or internal employee listservs).

### Sustaining involvement

- Ideally, when committees or workgroups engage patient and family advisor members, advisor involvement is throughout all phases of an initiative, from conception of the idea to planning, implementation, evaluation, and sustaining the effort over time. However, there will be times when advisor participation may be requested midstream in a project's design. In this case, ask the committee or workgroup chair to ensure that advisors are given sufficient information to help them understand the project background and which steps are already completed.
- As committee or workgroup chairs develop plans to involve patient and family advisors, encourage them to consider which aims and specific charges of the project are flexible. Keeping the focus on these aspects of the projects ensures that advisors' time is directed only at those features that are amenable to change. Likewise, committee chairs should also be encouraged to develop advisor members' understanding of standards of practice, regulatory standards, or other features of the care delivery system that cannot be changed or modified, including the reasons why.
- Encourage committee or workgroup chairs to model transparency and ownership of patient safety and quality-related issues, including acknowledging issues that are ongoing problems requiring attention. Frame discussions of safety issues in a way that embraces just culture and the view that errors represent systems breakdowns as opposed to an individual's mistake.
- The staff liaison should be accessible to and supportive of committees and workgroups as they work to embrace potential solutions that may create a new way of doing things. The staff liaison can work alongside the committee's chair if help is needed to gain cooperation from other departments and leadership.



#### Helpful Links

Just culture refers to a culture of shared accountability that encourages full disclosure of mistakes, sentinel events, and patient safety issues. The object is to promote learning from these types of events with the goal of identifying opportunities for system and process improvements.

For more information about just culture, see the Agency for Healthcare Research and Quality's CUSP Toolkit "Apply" module, which introduces the concept of just culture.

Available at:

<http://www.ahrq.gov/professionals/education/curriculum-tools/cusptoolkit/modules/apply/index.html>

- Acknowledge that there will be differing opinions, perceptions and, occasionally, tensions. When there are extreme differences in opinions or perceptions, the staff liaison should encourage the committee or workgroup chair to consider facilitation methods to navigate and bridge these differences. This may include:
  - Asking for assistance from a hospital staff member who is not part of the committee or workgroup and who is recognized as a skilled facilitator
  - Appointing a task force or subcommittee for further study of the issue
  - Asking the opinion of another group (e.g., another committee with experience involving patient and family advisors or a patient and family advisory council).
  - Delaying a decision and gathering additional information as needed, and developing a timeline for final decisionmaking
- Encourage the chair to periodically include time on meeting agendas to discuss how well the process of having patient and family advisors partnering with staff and clinicians is working. Ask for suggestions and incorporate strategies to improve the involvement of patient and family advisors.

### **Communication tips**

The following tips can help all members of committees and workgroups, including patient and family advisors, engage in meaningful conversations.

- Be wary of information overload. Do not try to communicate everything at once. When working with a complex issue, break it down into manageable pieces or elements. Find ways to make complex issues understandable (e.g., through logic models, cause-and-effect diagrams, or other schematic diagrams).
- Be prepared to provide more detailed materials that committee and workgroup members can review after the meeting.
- Leave a substantial amount of time for questions.
- Identify a feedback loop at the end of the meeting so that members can contact project leads or presenters between meetings, if needed.
- Develop and share plans for followup.

- Committee members should be prepared to talk openly. Know that both staff and advisors are prepared for honesty in these conversations.

In addition, during committee meetings, be mindful how communication style and language used can either create an inclusive or exclusive environment. For example, using acronyms or medical terms can create an atmosphere in which patients and family advisors feel like outsiders.

## Tracking and communicating advisor accomplishments

### Tracking advisor accomplishments

A critical part of sustaining and increasing advisor engagement is informing the entire hospital community about the work and accomplishments of advisors. This requires tracking involvement and collecting illustrative examples to share with the hospital community.

As staff liaison, you should devise a system for measuring and tracking advisor activities, the outcomes of projects in which advisors are involved, and the growth of advisor engagement over time. If possible, integrate these efforts into existing processes and monitoring efforts for volunteers at your hospital.

Information to consider collecting and reporting includes:

- The number of advisors recruited or total number of advisors
- The number of advisors or advisory council members
- The number of distinct efforts in which advisors participate (e.g., councils, committees, training and orientation events, facility design planning, feedback sessions, and workgroups)
- Total hours volunteered by advisors per year
- Examples of work completed (e.g., minutes from council meetings; print, web, or video resources; or revisions to hospital policies or procedures)

If advisors consult on quality and safety initiatives, work with your quality improvement department to identify and monitor measures tied to these initiatives (e.g., outcomes, experiences of care, and risk management).



*"At our nurses' fair, we had a table about patient- and family-centered care, and we had seven advisors staff this table throughout the day. I think we can talk about the importance of having an advisor, but when staff can actually talk to an advisor, it makes a difference."*

Anne Arundel Medical Center,  
Patient- and Family-Centered  
Care Committee Member

## Communicating advisor accomplishments

Communicating accomplishments and achievements to clinicians, staff, hospital leadership, advisors, and the community provides incentives for sustaining initiatives and can help create a broader base of support. Ways to celebrate and communicate accomplishments include the following:

- **Publicize information about activities that involved patient and family advisors in a variety of venues.** These venues may include the hospital's annual report, employee newsletters, community newsletters, the hospital Web site, hospital patient television education station, staff skills days, staff meetings, and hospital display boards. Make sure the information you provide includes examples of ways that advisors had an impact.
- **Create opportunities to share accomplishments with leadership,** for example through the use of monthly leadership email bulletins or a summary of accomplishments. Another idea is to develop a brief presentation for the leadership team or governing board and to co-present with an advisor. You can also invite members of the hospital leadership team to meet with patient and family advisors or observe activities in which they are involved.
- **Share improvements and lessons learned with others at local, regional, and national meetings.** Look for opportunities to present at conferences or to share your experiences with workgroups or other hospitals. One of the most important things you can do is to model patient and family engagement by co-presenting with a patient or family advisor.
- **Followup with advisors about project status and how their input helped to improve care.** Make sure to communicate with advisors about the status of the project and let them know how their input made a difference.

Regardless of the mechanism for publicizing accomplishments, it is important to provide ongoing and positive feedback to patient and family advisors and to the leaders, staff, and clinicians who partner with them. This reinforces the message that the hospital is committed to the meaningful involvement of patients and families and to engaging in effective, long-term partnerships.

## Additional Resources

### IPFCC Resources

#### **Institute for Patient- and Family-Centered Care**

This organization provides leadership to advance the understanding and practice of patient- and family-centered care. It offers guidance, information, and resources related to multiple aspects of patient- and family-centered care and involving patients and family advisors in the planning, delivery, and evaluation of care.

Web site: <http://www.ipfcc.org>

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

This workplan from the Institute for Patient- and Family-Centered Care helps hospitals initiate and organize a patient and family advisory council.

Available at: [http://www.ipfcc.org/advance/IFCC\\_Advisoryworkplan.pdf](http://www.ipfcc.org/advance/IFCC_Advisoryworkplan.pdf)

#### **The Patient and Family Advisory Council Network**

This Web site provides a way for people to ask questions and share information and ideas as they work to build or sustain efforts to work with patient and family advisors.

Available at: <http://pfacnetwork.ipfcc.org/main/summary>

### Examples of Patient and Family Advisory Councils in Action

**Georgia Health Sciences Health System** in Augusta, GA, has more than 225 trained patient and family advisors who are members of patient and family advisory councils, sit on quality and safety teams, and contribute to facility design processes.

Available at: <http://www.mcghealth.org/patient-family-centered-care/McgContentPage.aspx?nd=2546>

**Memorial Regional Hospital** in Hollywood, FL, has Patient and Family Resource Centers that provide useful health information to patients and the community. The hospital's patient and family advisory councils provide direct input on many organizational policy and engagement efforts.

Available at: <http://www.mhs.net/patients/pfcc/>

**Dana-Farber Cancer Institute** in Boston, MA, established the Adult Patient and Family Council to help patients and their families collaborate with hospital staff, become involved in overall patient care, and participate in cancer programs and services.

Available at: <http://www.dana-farber.org/Adult-Care/New-Patient-Guide/Adult-Patient-and-Family-Advisory-Council.aspx>

**The Wilmot Cancer Center** in Rochester, NY, has a 19-member Patient and Family Advisory Council that strengthens coordination between patients, families, and their health care and promotes patient and family advocacy in their health care environment.

Available at: <http://www.urmc.rochester.edu/cancer-center/patients-families/support/advisory-council.aspx>

**Cincinnati Children’s Hospital Medical Center** in Ohio has a 38-member Family Advisory Council that empowers families to take part in their loved ones’ health care experiences.

Available at: <http://www.cincinnatichildrens.org/patients/care/family-centered/fac/>

**The Children’s Hospital of Philadelphia** established The Family Advisory Council to represent patient and family perspectives during the development of organizational programs, projects, and policies.

Available at: <http://www.chop.edu/service/family-centered-care/family-centered-care-programs-at-chop.html>

## Appendix A. Working With Patient and Family Advisors on Short-Term Projects<sup>‡</sup>

Hospitals that piloted the *Guide* used or planned to use advisors to revise way-finding signage in the hospital, develop and review educational materials, share their discharge stories at a unit-based council meeting, and involve advisors in the construction of a new Gastrointestinal lab.

This appendix provides information on ways in which you can partner with patient and family advisors on short-term projects.<sup>5</sup> One way in which you may want to work with patient and family advisors is in implementing other strategies from the *Guide*. For example:

- Solicit input from patient and family advisors about which of the Working With Patients and Family at the Bedside strategies to pursue (e.g., Strategy 2: Communicating to Improve Quality, Strategy 3: Nurse Bedside Shift Report, or Strategy 4: IDEAL Discharge Planning)
- Ask patient and family advisors to help you tailor and customize the *Guide* materials to best meet the needs of your hospital
- Involve patient and family advisors in planning and implementing the strategies, including training sessions for clinicians and hospital staff
- Ask patient and family advisors to participate in evaluation and feedback activities to assess how well the strategy is received and what improvements can be made

Other examples of ways to work with patient and family advisors on short-term projects include:

- Appoint patients and families to task forces and work groups related to facility design, registration procedures, documentation systems, patient safety, and other quality improvement initiatives
- Hold brainstorming sessions with patients and families before developing patient education materials and involve them in the development process
- Ask patients and families to assist in adapting patient information materials to meet the literacy and language needs of patients and families
- Offer opportunities for patients and families to lead or co-lead educational and support programs for other patients and family members

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<sup>‡</sup> This appendix includes information adapted from resources developed by the Institute for Patient- and Family-Centered Care.

- Solicit patient and family involvement in building relationships with community programs and resources
- Ask patients and families to join staff when they meet with funders and community groups
- Invite patients and families to present at staff orientation and in-service programs
- Ask patients or families to offer a clinician trainee the opportunity to spend a day with them to observe how patients manage their care in their daily life
- Invite patients and families to assist in creating or revising a patient and family satisfaction survey and involve them in developing strategies to respond to concerns and problems reported via the survey
- Convene focus groups of patients and families as specific issues arise, and ask a patient or family member to co-facilitate the group

## Three initial activities to conduct with patient and family advisors

The following activities — sharing personal and professional experiences, patient and family stories, and conducting a walkabout from the patient and family perspective — are activities that health care organizations have found effective in the early stages of partnering with patient and family advisors.

### **Activity 1: Sharing personal and professional experiences**

This activity increases staff awareness of how care is experienced as a patient or family member. It can be conducted during a training and orientation session, committee meeting, or in-service program.

**Purpose.** This exercise is intended to help clinicians, hospital staff, and patient and family advisors share experiences about developing and working in partnerships with each other.

**Introduce the exercise.** The facilitator should spend 5 to 10 minutes reviewing the core concepts of patient- and family-centered care.<sup>6</sup> Ask each participant (patients, families, hospital staff, and clinicians) to share a personal or professional example of a direct care experience that illustrates partnership. Encourage participants to share examples — positive or negative — that had a profound effect on them. Although clinicians and staff can describe a professional work experience, the activity is more meaningful when participants share a personal experience with the health care system. Remind participants that all experiences shared are considered private and confidential.

Sometimes it is helpful for the facilitator to share a story to serve as a model. Suggest that people be fairly brief and take no more than 2 to 3 minutes to tell their story. Encourage everyone to participate but be prepared that some might decline.

**During the exercise.** Be prepared to be a timekeeper and provide reminders of the 2- to 3-minute time limit. Listen to the stories and include your observations of how the stories illustrate one or more of the core concepts of patient- and family-centered care and, as appropriate, point out how these stories illustrate important qualities of the partnership between patients and their families and staff.

### Core Concepts of Patient- and Family-Centered Care

**Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

**Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information to effectively participate in care and decisionmaking.

**Participation.** Patients and families are encouraged and supported in participating in care and decisionmaking at the level they choose.

**Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation, facility design, patient safety and quality initiatives, professional education, and delivery of care.

From the Institute for Patient- and Family-Centered Care

**Conclusion.** Thank participants for sharing their experiences. As possible, note commonalities that emerged during the storytelling process and summarize how they illustrate partnerships.

### Activity 2: Patient and family stories

Invite patient and family advisors to share their stories with clinicians and other hospital staff (e.g., during meetings, workshops, or training sessions). Work with advisors prior to the meeting or training to prepare them to tell their story.

During the meeting, workshop, or training, set up the activity in the following way:

*[Introduce the patient or family member.] "Thank you for talking with us today. Stories provide a mechanism by which clinicians, hospital staff, and patients can communicate and develop a shared understanding.*

*[Patient or family member] is here to share [his or her] experiences at our hospital, including what went well, what did not go well, and what we might have done or can do differently to improve the experiences of care."*

Then, ask the patient or family member to recount his or her story or use a guided technique where you ask patients and family members to address specific questions. For example:

- "Please share with us a little bit about who you are, and, if you are comfortable, what condition or diagnosis brought you to the hospital. Also tell us a little bit about your family, if you don't mind."
- "Please tell us about a care experience that went particularly well."
- "Please share with us a care experience that did not go so well. If you could make a change in the care you received, what would it be?"
- "Thank you for sharing these powerful personal experiences. Your courage and generosity will benefit all future patients and their families. Do you have anything else that you want to share with us?"

Additional potential questions include:

- "Please tell us about your first encounter with the hospital as a patient:"
  - "What were your feelings when you arrived at the hospital? Were you frightened? Overwhelmed? Confident? Relieved? Prepared?"
- "We would welcome some insights about your hospital experience:"
  - "Were you given the opportunity to communicate whether you wanted a family member or close friend with you during your care? Was your family's presence and participation in your care supported in the way you wished?"
  - "Did you and your family get information about your care in a way you could understand? Was the information you received what you needed and wanted?"
  - "Were your observations and concerns about your care respected and addressed by clinicians and staff members? Was there time available for you to ask questions?"

- “Can you tell us about any positive connections you made with clinicians and staff here? What specifically did they do to build your comfort or trust and make that connection?”
- “What did someone say or do or not say or do that failed to make a connection?”
- “During your hospital stay, did you feel welcomed? Did people introduce themselves to you and your family?”
- “Did you know everyone’s job title and function? Did clinicians and hospital staff explain their roles in your care?”
- “Did clinicians and staff tell you what to expect during your stay? Did they routinely explain procedures in ways you could understand before they were carried out?”

### **Activity 3: Conducting a walkabout from the patient and family perspective**

The walkabout focuses attention on the expertise that patient and family advisors bring to the table and helps build trust in and comfort with the collaborative process. The walkabout and related meetings can also be beneficial for patients and families to build their understanding of staff and clinician perspectives and to help them understand care processes and the environment of care. The walkabout process also allows patient and family advisors to begin to get a broader view of the positive elements of the system of care as well as areas for quality and safety improvement.

#### **Instructions for the walkabout**

For the walkabout, it is helpful to have two or three patient and family advisor participants. Invite hospital leaders, clinicians, and staff to participate as well. One option is to tour the facility or unit as a group. Another option is to split up into smaller groups and explore different elements of the hospital (e.g., the registration and admission process; engaging patients and families in care, decisionmaking, and safety; and discharge process). Each of the smaller groups should contain at least one patient and family advisor. The group should be able to complete this activity in 2 hours or less.

Before starting, share the objective of the walkabout, which is to capture the processes, interactions, documents, and environment of the hospital from the perspectives of patients and families. Begin the walkabout at the first point of entry into the hospital (i.e., the parking lot) and continue to and throughout the inpatient unit. Be sure to include all areas accessible to patients and families,

including patient rooms, treatment rooms, family lounge, communication center, and nursing stations.

During the walkabout, the group should explore how well the following elements support patients and families and encourage their active engagement in care, decisionmaking, and quality and safety:

- Registration and admission
- Exchange of information among patients, their families, staff, and physicians (e.g., nurse change-of-shift report, rounds, or discharge planning meetings)
- Information about family presence during procedures
- Patient and family informational and educational materials or programs (e.g., support groups, videos, and inpatient television programming)
- Process for transitions across care settings
- Discharge information, packets, and processes
- Characteristics of the physical environment (e.g., signage, way finding elements, artwork, arrangement of furnishings, and sleep spaces for families)

During the walkabout, the team should also collect evidence. Assign people to document the walkabout through:

- Digital photos or videos
- Notes of observations (one individual should be designated as notetaker)
- Blank samples of documents (e.g., admission forms, informed consent documents, and discharge materials) used throughout a patient's hospitalization
- Samples of informational and educational materials for patients and families
- Specific quotes or messages on posters or other public announcements

Throughout the walkabout, encourage patient and family advisors to share their perceptions. All team members should be given the opportunity to identify elements and processes that contribute to the patient and family experience of care.

### Hold a meeting to discuss findings

An important part of the walkabout is holding a followup meeting to discuss what was discovered. Bring all the evidence collected to the meeting, including notes, photos or videos, forms, and materials. The group can use a root-cause analysis model for questions and discussion. Example questions include:

- What do you see here?
- What is really happening here?
- How does this relate to the experience of care? Does it encourage and support patient and family engagement in care and decisionmaking? Does it encourage and support the engagement of patients and families?
- Why does this current practice, situation, or concern exist?
- How can we use the walkabout information to reinforce current best practices and guide change and improvement in partnering with patients and families?

A facilitator should lead the meeting to ensure that all members have the opportunity to offer their perspectives and thoughts about the walkabout findings. Record all observations and suggestions. Before the meeting ends, ask each participant to identify one change they believe could improve quality and safety. These ideas should be documented to help foster discussion in future meetings about planning improvements. Save and archive all of the evidence collected so that it can serve as a resource for the planning committee. This will also provide the committee with a historical reference to use when communicating changes and outcomes to hospital leaders, clinicians, and other staff.

### Planning changes

After the initial meeting to discuss the walkabout findings, form a committee of patient and family advisors and hospital staff to begin prioritizing items for change and develop action plans. The list of changes generated during the walkabout should be shared with all committee members at least 1 week prior to the meeting. The leader of the committee should ask members to review the list and think about what one to three changes they view as high priority. The group can then propose one or two projects based on the results of the walkabout.

## Appendix B. Establishing and Working With Patient and Family Advisory Councils

An advisory council is a formal group that meets regularly for active collaboration between clinicians, hospital staff, and patient and family advisors on policy and program decisions. This appendix provides information on:

- Advisory council membership
- Roles and responsibilities of advisory council members
- Time commitments
- Advisory council mission statement, bylaws, and goals
- Budget considerations
- Strategies for successful advisory council meetings
- Ongoing support of advisory council members

### Advisory council membership

Eligibility requirements for advisory councils vary among hospitals. Some advisory councils are made up of mostly patients and families with a few clinician and hospital staff representatives. Other councils find a closer balance between patients, families, clinicians, and hospital staff, although patients and families should always be the majority membership.

Councils vary in size, but typically work best when they have between 12 and 25 members. Councils that are too small may find it difficult to accomplish goals. On the other hand, when councils are too large, it can be challenging to manage and come to consensus.

When looking for clinicians and other hospital staff to serve as council members, try to identify individuals who can help build relationships between the advisory council and the hospital or unit. Look for individuals who are enthusiastic about partnering with patients and families and who model these behaviors in their everyday practice. Hospital staff council members should be comfortable speaking about their experiences with patient and family members and demonstrate commitment to improving quality and safety. For a hospital-wide advisory council, it is helpful to recruit staff and clinicians from a variety of units and disciplines.

For information about recruiting patients and family members for advisory council membership, see Step 4: Recruit, Select, and Train Patient and Family Advisors.

#### Helpful Links

For additional information about developing advisory councils:

***Developing a Community-Based Patient Safety Advisory Council.*** Available at: <http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/patient-safety-advisory-council/>

***A Patient and Family Advisory Council Workplan: Getting Started.*** Available at: <http://www.ipfcc.org/tools/downloads.html> under “Tools to Foster Collaboration With Patient and Family Advisors”



## Roles and responsibilities of advisory council members

Most advisory councils include the following roles:

- **Staff liaison.** The staff liaison is a hospital staff member who is responsible for overseeing and working with patient and family advisors. In addition to general advisor management duties, the staff liaison supports the council and its members and helps ensure that council activities are meaningfully integrated into changes and improvements within the hospital. The staff liaison typically is the lead contact for other hospital members seeking to be included on the council's agenda. At a minimum, the staff liaison attends council meetings to facilitate interactions and report feedback to hospital leadership or management.
- **Chair or co-chairs.** Successful patient and family advisory councils select a patient or family member to fill at least one of the chair positions. The chair works closely with the staff liaison to keep the council running smoothly. This includes ensuring that the council is on track to meet its goals, that all members actively participate in meetings, and that activities and outcomes of the council are communicated throughout the hospital and community.
- **Patient and family members.** Patient and family council members attend meetings and actively participate by sharing their perspectives, ideas, and feedback. They are expected to complete orientation and other requirements as indicated by the hospital or council. Some councils rotate positions, such as meeting facilitator, timekeeper, and secretary.
- **Hospital staff or clinician members.** Hospital staff and clinician members of the council attend all council meetings and make the time to implement council initiatives in between meetings. Staff members are expected to complete any orientation and training necessary for council members.

At Anne Arundel Medical Center, the staff liaison for the patient and family advisory council was responsible for logistical activities, such as scheduling the council meetings. The co-chairs were responsible for establishing the council's vision.

## Time commitment

- Most advisory councils meet once a month for 9 to 10 months of the year, taking off one or two summer months and December.

Council meetings typically last between 1 ½ to 2 hours. When there is work for members to complete in between council meetings, it typically should not take more than 2 to 4 hours per month.

- Patient and family advisory council members usually serve 1- to 2-year terms, although membership may continue longer on a case-by-case basis. It is helpful to stagger membership terms to ensure a balance of new and experienced members. For example, as the council is starting, you can accept 12 to 15 members in the first year. For the second year, recruit 10 to 12 additional members. In this way, you have the benefit of new advisors who bring fresh perspectives coupled with veteran members who can mentor and support the new members.
- Most hospitals offer ways for patient and family council members to continue to serve as advisors after their council term is completed. For example, these individuals can serve as faculty for clinician and staff orientation and in-service training or join hospital safety and quality committees.

### Take It Further ■ ■ ■

Once the advisory council is up and running, you may wish to create a buddy system in which more experienced patient and family advisors mentor new advisors on the council. Mentors can help orient new members to their roles and responsibilities and serve as a general source of support.

## Advisory council mission statement

Creating a mission statement helps guide and focus the work of the advisory council. Mission statements typically indicate the council's purpose, outline major goals, and identify the key stakeholders.

Below is a sample mission statement from the Dana-Farber Cancer Institute's Adult Patient and Family Advisory Council.

### *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"



### Helpful Link

#### Sample by-laws:

Dana-Farber/Brigham and Women's Center Adult Patient and Family Advisory Council Bylaws: Available at:

<http://www.dana-farber.org/uploadedFiles/Library/adult-care/new-patient-guide/patient-safety-and-advocacy/advisory-council/patient-and-family-care/adult-patient-and-family-advisory-council-bylaws.pdf>

Eastern Maine Medical Center, (Bangor, ME) Advisory Council Bylaws: Available at:

[http://www.emmc.org/family-centered\\_care.aspx?id=33368](http://www.emmc.org/family-centered_care.aspx?id=33368)

(Click on EEMC's Pediatric Advisory Council.)

#### Descriptions of other councils' goals:

East Tennessee Children's Hospital Family Advisory Council priority goals:

Available at:

[http://www.etch.com/family\\_advisory\\_council.aspx](http://www.etch.com/family_advisory_council.aspx)

UMass Memorial Medical Center Pediatrics Family Advisory Committee goals:

Available at:

<http://www.umassmemorial.org/FamilyAdvisoryCommittee>

## Advisory council bylaws

Advisory councils may also establish bylaws to guide how the council functions and outline council members' responsibilities. Bylaw development and approval can take time because the bylaws should be established with agreement from all members of the council. A new advisory council may want to generate a few guiding principles or norms and then wait until a subcommittee can be formed to develop more formal bylaws.

Advisory council bylaws typically address functional issues such as:

- Eligibility for membership
- Expectations for how long a member serves on the council
- Meeting schedule
- Specific council member roles and responsibilities

Optional issues that may be addressed include:

- Required training and orientation for new council members
- Expectations for attendance at meetings
- Reimbursement for expenses
- Annual or other review processes

## Advisory council goals and activities

For newly formed advisory councils, all members should be actively involved in the development of the council structure and processes. During the first few months that the advisory council meets, all members of the council will have the chance to suggest, discuss, and choose specific goals and activities to work on over the year.

Until more formal goals are established, general goals can be to:

- Provide feedback and advice for changes to hospital policies, care practices, and materials
- Help create materials and strategies for improving health care quality and safety for all patients
- Help hospital staff carry out changes to improve hospital safety and quality

As an initial step, advisory councils may wish to undertake the activities described in Appendix A: Working With Patient and Family Advisors on Short-Term Projects. These activities include conducting walkabouts and sharing personal and professional experiences and stories.

## Budget considerations

Hospitals may want to reimburse patients and families for expenses (e.g., parking, transportation, child care) incurred during their work on the advisory council. Some programs also offer stipends or honoraria for participation in meetings. Many councils celebrate accomplishments or a membership term with small acknowledgements, such as gift cards.

Other budget line items for the advisory council may include: refreshments or meals for council meetings, printing expenses, communication expenses (mail and phone), and expenses for supplies.

Think creatively about whether and how you will secure funding for these expenses. Some hospitals use an administration discretionary fund, some use general operating funds, some have guilds or service leagues that provide earmarked dollars specifically for this support, and some write grants to community organizations or foundations.

## Strategies for successful advisory council meetings

The first few patient and family advisory council meetings are critical for setting the tone and establishing an appropriate meeting structure. The strategies in this section can help the staff liaison prepare for and run effective meetings.

Prior to the meeting, find out how members prefer to have materials sent to them (e.g., email, fax, or regular mail). At least 1 week before the meeting, send out the agenda and any materials (e.g., orientation materials, contact lists, and meeting minutes) to give council members the chance to prepare. Include directions to the meeting site and room. Many councils also find it helpful to have staff or a council member volunteer make a reminder phone call or send an email to council members 2 to 3 days before the meeting.

On the day of the meeting, place signs to let advisory council members know where to go. The staff liaison should plan to be in the meeting room at least 30 minutes before the meeting to set up the room, distribute materials, set out name tags or table tent cards, organize refreshments, and set up and test any audiovisual or computer equipment. Once members begin to arrive, the staff liaison's goal is to be fully present to welcome and help council members settle in before the meeting starts.

Consider how the room is set up to ensure that all members can see one another and that there is room for wheelchairs or other adaptive equipment, as appropriate. If the council membership includes individuals with physical impairments or functional limitations, request a quick consult from an occupational therapist or other appropriate staff member on adapting the room to make it more comfortable and functional.

As members enter the meeting room, each person should be personally welcomed by the staff liaison and the chair of the council (if one has been identified in the council member selection process). Make sure council members know where refreshments are and where the nearest restroom is located. Find out if council members have any logistical questions, such as parking reimbursement, if there is time before the meeting begins.

### **Topics to cover at the initial advisory council meeting**

At the first advisory council meeting, much of the agenda will be devoted to introductions and reviewing the purpose, goals, and structure of the advisory council.

- **Introductions.** Allow enough time for all advisory council members to introduce themselves (2 to 3 minutes per person). Consider adding an icebreaker question to help people get to know each other on a more personal level. Although these types of introductions do not need to occur at every meeting, it is helpful to include time on the agenda for the first several meetings to allow council members to share more about themselves. If they are comfortable, ask advisors to share information about who is in their family, where and how they learned about the advisory council, and why they want to serve on the council. It may be helpful to send these types of questions in advance of the meetings to give members a chance to prepare.
- **Purpose and goals of the council.** The purpose and general goals of the council will likely have been communicated to all council members, but it is helpful to review them. It may be helpful to type the purpose and goals on the bottom of the agenda or post them on a flip chart for everyone to see throughout the meeting. Let the council know that at the next several meetings they will be asked to suggest, discuss, and prioritize specific goals and activities for the council to work on. Mention that the group also may decide to develop a mission statement after a few meetings.

- **Meeting procedures.** The chair or staff liaison will lead and facilitate the meetings, but councils may want to identify additional roles to ensure the effectiveness of the meetings. For example, it is helpful to have a secretary who is responsible for taking notes during the meeting and developing minutes to distribute to council members. For a new advisory council, this role is best assigned to a hospital staff member. It is also useful to have a timekeeper to ensure that meetings are productive and stay on track. This person should monitor times allotted for specific agenda items and give members a warning a few minutes before time is up. Another decision to be made in the first meeting is about the best times for future meetings. If consensus cannot be reached about the best time to meet, the group may wish to rotate meeting times.
- **Ideas for improvement.** During the first council meeting, there may not be time to discuss specific activities. However, if the staff liaison or chair has identified an initial activity for the council to begin working on, the council members can provide early input and feedback. It is best to select an initial activity that will be relatively easy for the council to accomplish successfully within a few months. For example, council members could review the materials for one of the strategies in the *Guide* (e.g., nurse bedside shift report) and provide suggestions about how the strategy might be implemented at your hospital. If there is not time on the agenda, this could be planned as an activity to think about and discuss at the next meeting.
- **Closing.** The staff liaison or chair should ask if there are any questions or comments before the meeting ends. Let all council members know the appropriate person (e.g., staff liaison or advisory council chair) to contact if they have questions before the next meeting and make sure they have accurate contact information. Also let them know that the staff liaison will contact each council member to have a short discussion about their reactions to the first council meeting.

A sample agenda for the initial advisory council meeting is shown on the next page.



### 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)**



During early meetings of Anne Arundel Medical Center's Patient and Family Advisory Council, various hospital committees made presentations on issues or projects for which they wanted advisors' input (e.g., having visitors in the recovery room after an operation on the post-anesthesia care unit). Later meetings focused on developing council bylaws, gathering input on fiscal year goals, and creating orientation materials for future advisors.

## Topics to cover during subsequent meetings

For future meetings, the council chair(s) should develop an agenda with council member input. Because a key goal of the council is to elicit multiple points of view and allow time for discussion, the agenda should include ample time for these discussions. In the beginning, it may be helpful to schedule time for small group breakout discussions to allow members to become comfortable working with each other. As the council matures, most of the agenda will be devoted to the work and less time will be needed for relationship building.

Agendas should also include time for:

- Introducing any new members or guests (e.g., as the council gets established and new members are recruited, you may want to offer potential members the opportunity to sit in and observe a meeting before they formally join the council)
- Announcements from members
- Evaluating the meeting and getting ideas for meeting improvement
- Identifying followup items, including due dates and the names of members who are responsible for them
- Soliciting suggestions for the next council meeting agenda

## Evaluating the meeting

Quick written or verbal debriefs at the end of council meetings can help in making adjustments to council operations and functions. Spend a few minutes asking questions such as *"What went well during this meeting?"* and *"How can we improve future meetings?"* Keep people focused on the process and not individual behaviors. For example, *"I noticed the discussion around 'X' got a little off topic"* and not *"X' spent too much time talking about an unrelated issue."* Be sure to take time at each meeting and at least once a year to celebrate accomplishments, both big and small.

## Ongoing support of council members

One of the most critical roles of the staff liaison is to provide ongoing support and guidance to council members.

## Encourage participation

During advisory council meetings, the staff liaison should work closely with the council chair to support active participation of all members. If someone has not

had a chance to share an idea or give feedback, the staff liaison can make sure that the chair calls on the individual and asks if he or she has something to share.

Other more spontaneous methods to encourage and support participation are one-on-one discussions on select topics with followup reporting or asking everyone to write their ideas related to a specific topic and then share them with the group. Not everyone will have an idea or something to add, but this ensures anyone who wants to participate in discussions has a chance to do so. If a member is routinely not participating in advisory council meetings, the staff liaison and council chair can offer to meet with this person to find out if there are ways he or she can be supported to be more active.

### **Establish norms and ground rules**

Advisory council members need to know what is expected of them. An obvious expectation is that council members will show up for and participate in meetings or inform the staff liaison or chair if they are going to be absent. When patients and families serve as advisors, there may be events or circumstances that prevent them from coming to a meeting (e.g., a hospitalization or an acute or chronic illness that limits their activity). If an advisor misses several meetings, the staff liaison should call him or her and find out if he or she needs additional support to get to meetings or if he or she needs to take time off from the council or resign his or her position.

During meetings, remind council members of the importance of sticking to the time limits for each agenda item. If a council member is going on too long or getting off topic, politely stop him or her, and either let him or her know that you want to make sure that there is enough time in the agenda to let everyone have a chance to speak or suggest that the topic he or she is bringing up may be appropriate for a future meeting. You can say, *“I wonder if we can stop here and ask others for ideas...”* or *“It sounds like this is an important issue for you, so we may want to allocate time in a future meeting for discussion or I can discuss it with you after the meeting...”*

### **Manage conflict**

There may be times when challenging situations arise during an advisory council meeting. One of the most important roles for the staff liaison and chair will be to identify and manage conflicts constructively as they arise. Here are some helpful strategies:

- Acknowledge that, at times, there will be tensions and differing opinions.

- If you become aware of a conflict during a meeting, take the time to stop and reflect back to the group what you are hearing. Listen to each side. Remind everyone of the topic of discussion and ask for ideas for resolving the disagreement.
- If the conflict cannot be managed effectively within the council meeting, offer the opportunity to hold a discussion before the next meeting.
- Make sure that everyone who wants to participate is invited to discuss the conflict and work on resolution.
- During the conflict resolution meeting, ensure that everyone has a chance to voice their perspective. Clarify perspectives and how each is connected to the goals of the council. Keep the focus on the goal and purpose of the original task and not the conflict or individuals involved.
- Be available to debrief with all meeting participants.
- On the rare occasion that you are not able to manage the conflict, you may want to consider asking a hospital staff member with experience in facilitation to lead the discussion.

### **Acknowledge difficult emotions**

There may be times when council members experience strong emotions, for example, when telling their own stories or hearing stories that trigger memories. The staff liaison and chair should be mindful of these occurrences and make sure the council member receives support. After the member finishes sharing his or her experience, it may be helpful to step back from the agenda item and acknowledge the emotions the story brought up and ask if anyone wants to reflect. Ask if the council needs a short break before coming back to the agenda. After the meeting, the liaison can check in with any members that may need an individual reflection.

### **Debrief regularly**

Between meetings, it is important for the liaison and council chair to be available to all council members for feedback and encouragement. For new council members, it is helpful to debrief regularly about participation on the council. This is an opportunity to identify strengths, solicit thoughts on how council members want to improve their involvement, and offer suggestions for improvement.

It can also be helpful for patient and family advisors to participate in periodic coaching sessions where the staff liaison and advisor discuss and address progress toward specific goals. At some hospitals, council members go through an annual review process. This is typically done in accordance with the review process for other hospital volunteers.

## Appendix C. Advisors as Members of Quality and Safety Committees

As your hospital gains experience working with advisors, a potential next step is to engage patient and family advisors as members of quality and safety committees. This activity requires close collaboration between the hospital leadership team, existing members of hospital quality and safety committees, patient and family advisors, and the staff liaison for patient and family advisors. In particular, the staff liaison has a critical role in supporting operational processes.

### Preparing quality or safety committees for advisors' participation

The first step in the process is to assess the committee's readiness to partner with patient and family advisors. The staff liaison can schedule an initial meeting to discuss advisor participation. During the meeting, allow time for committee members to raise challenges and concerns and explore how confident each member is about involving patients and families on the committee.

As needed throughout the meeting, address concerns and ask members to generate possible solutions. Also recognize that not all concerns may be addressed in one meeting, and plan to follow up as needed. Specific topics to discuss during the meeting include:

- Benefits of patient and family involvement
- Previous experiences with patient and family advisors
- Concerns about working with patient and family advisors
- Perspectives on data transparency
- Flexibility around general aims and specific improvement projects
- Support from senior leadership for patient and family involvement
- Collaboration and teamwork

It may also be helpful to suggest a trial period for advisor involvement accompanied by predetermined indicators of success for the involvement of advisors. At the end of the trial period (e.g., 3 to 4 months), work with the committee to evaluate the inclusion of advisors. Hospitals that have used this strategy typically report that by the end of the trial period, the committee has realized the value of including patient and family advisor members.

#### Helpful Link

##### *Advancing the*

##### *Practice — Patient and Family Advisors and Leaders*

contains information on and examples about working with patient and family advisors, including working with advisors on quality and safety programs. Available from the Institute for Patient- and Family-Centered Care at:

<http://www.ipfcc.org/profiles/index.html>



The *Partnering With Patients and Families to Accelerate Improvement: Readiness Assessment* from the Institute for Healthcare Improvement<sup>7</sup> shown here and on the next page is a tool that can be used to guide the quality and safety committee’s discussion and identify planning steps for involving patient and family advisors.

## Partnering With Patients and Families To Accelerate Improvement: Readiness Assessment

For each item, circle the box that best describes your team’s perspective and experience.

Area	Description 1	Description 2	Description 3
Data transparency	Our team is uncomfortable with the possibility of sharing performance data with patients and family members.	Our team is comfortable with sharing improvement data with patients and families related to current improvement projects.	This organization has experience with sharing performance data with patients and families.
Flexibility around aims and specific changes of improvement project	We have limited ability to refine the project’s aims or planned changes.	We have some flexibility to refine the project’s aims and the planned changes.	We are open to changing both the aims and specific changes that we test based on patients’ and family members’ perspectives.
Underlying fears and concerns	We have identified several concerns about involving patients and families on improvement teams and would need assistance in creating a plan for addressing them.	We have identified several concerns related to involving patients and families on improvement teams but believe we can create a plan for how to address or manage them.	We have a plan to manage and/or mitigate issues that may arise due to patient and family member involvement on our team.
Perceived value and purpose of patient and family involvement	There is no clear agreement that patient and family involvement on improvement teams is necessary to achieve our current improvement aim.	A few of us believe patient and family involvement would be beneficial to our improvement work, but there is not universal consensus.	There is clear recognition that patient and family involvement is critical to achieving our current improvement aim.

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

Area	Description 1	Description 2	Description 3
<b>Senior leadership support for patient and family involvement</b>	Senior leaders do not consider patient and family involvement in improvement a top priority.	Senior leaders are aware of and communicate support for patient and family involvement in improvement.	Senior leaders provide resources necessary to involve patient and family advisors in improvement.
<b>Experience with patient and family involvement</b>	Beyond patient satisfaction surveys or focus groups, our organization does not have a formal method for patient and family feedback.	We have patient and family advisors and/or a patient and family advisory council.	Patient and families are members of standing committees and make decisions at the program and policy level.
<b>Collaboration and teamwork</b>	Staff in this organization occasionally work in multidisciplinary teams to provide care.	Staff in this organization work effectively across disciplines to provide care to patients.	Staff are effective at working collaboratively in multidisciplinary teams that include patients and families as valued members of the care team.

- 1) What supports the idea of involving patient and family advisors?
  
- 2) What are your current challenges?
  
- 3) How confident are you about successfully involving patient and family advisors in your improvement work (on a 1–10 scale with 1 = not confident at all and 10 = extremely confident)?

## Preparing advisors to participate on quality and safety committees

As members of quality and safety committees, patient and family advisors will need additional information and training to help them perform effectively in their role. Depending on the committee and tasks, this may include training on quality improvement methodology, quality data, problem-solving methodology, and privacy and confidentiality.

### Quality improvement methodology

To better understand the quality improvement process, it is helpful for advisors to become familiar with the hospital's specific model for improvement. This will help advisors develop a more complete understanding of how changes are planned, implemented, evaluated, and disseminated.

### Exploring quality data

Quality and safety committees frequently work with quality and safety data, including data from patient and family experience of care surveys. Patient and family advisors will benefit from a basic understanding of how to interpret and apply quality data to generate solutions or improvement processes.

Staff liaisons may wish to provide advisors with the following:

- An orientation to survey instruments that are used to collect quality data
- A high-level overview of implementation methodology
- Training to strengthen numerical literacy (i.e., help them interpret numbers and statistics)

### Problem solving methodology

A common activity for safety committees is examining specific errors that occur in the hospital and identifying changes that can prevent the error from being repeated. Many hospitals use a process called root-cause analysis to illuminate the events and decisions that led to the error. Patient and family advisors who serve on a safety committee may need information and training on the specific process your hospital uses to investigate safety events and errors. It also may be helpful to review several case studies with advisors to walk them through the analysis process.

#### Helpful Link

For information about quality improvement methods that hospitals can share with advisors, see the Institute for Healthcare Improvement's materials.

Available at:

<http://www.ihl.org/knowledge/Pages/HowtoImprove/default.aspx>

#### Helpful Link

***Using Patient Feedback: A Practical Guide to Improving Patient Experience***

is a resource developed by the Picker Institute to help people understand how to use information from patient experience of care surveys.

Available at:

[http://www.improvement.nhs.uk/documents/CR\\_resources\\_by\\_type/patient\\_experience/PickerI\\_UsingPatientFeedback\\_2009.pdf](http://www.improvement.nhs.uk/documents/CR_resources_by_type/patient_experience/PickerI_UsingPatientFeedback_2009.pdf)



### Guide Resources

**Tool 10: Sample Confidentiality Statement** provides a sample confidentiality agreement for advisors.



### Helpful Link

Current bibliographies of quality and safety topics are available from:

The Institute for Patient- and Family-Centered Care  
Available at:  
<http://www.ipfcc.org/advance/supporting.html>

## Importance of privacy and confidentiality

During orientation to become an advisor or a member of an advisory committee, advisors signed a confidentiality agreement. Because committees focused on quality and safety often share data about the hospital and conduct individual case reviews, it is important to routinely review this statement and remind all committee members of their commitment to maintain privacy and confidentiality.

## Communicating quality and safety information

The following guidelines can help promote an inclusive atmosphere and facilitate comprehension for all members of the quality and safety committees:

- When reviewing or sharing data, present the information in a way that individuals without a clinical or statistical background can understand. Explain data using plain language and discuss what the data mean and why they are important.
  - Bring data and figures alive by including patient and family quotes or by asking a patient and family advisor to share a care experience that brings life to the numbers.
  - When presenting data, graphs often provide a better visual depiction than tables.
  - When presenting data, use whole numbers, for example “about 1 out of 1,000” instead of “less than 0.08.” Also, use natural frequencies instead of percentages, for example “3 out of 100” instead of “3 percent.” When possible, use a common denominator and report the time frame.
  - Help people understand the direction of an effect or the significance of results by using evaluative labels with numbers or other anchors (e.g., better than, worse than, the same as, common, rare, etc.).

Some jargon and acronyms are hard to avoid in quality and safety improvement projects. Encourage advisors to ask for an explanation or definition of any terms they do not understand. It may be helpful to encourage committee members who are beginning to work with patient and family advisors to develop a list of any acronyms and jargon associated with safety and quality improvement. Advisors and staff members can collaboratively develop and add on to this list as necessary. Hospital staff who are new to quality and safety improvement may also find this list to be helpful.



**Helpful Link**

The Agency for Healthcare Research and Quality provides a variety of patient safety resources for health systems, providers, and consumers. Available at: <http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/pstools.html>

Safety and quality committees that are new to having patient and family advisors as members should consider selecting initial projects that are most likely to be successful. For example, focus on projects that:

- Are identified as high priority by the majority of committee members, including patient and family advisors
- Are not prohibitively complex (i.e., the effort can be broken down into small achievable steps or designed as individual projects)
- Can be measured
- Require minimal resources for changing
- Have a high likelihood of support from administrators, clinicians, and staff

**Patient and family advisors: Reaching out to current patients and families**

Hospitals may also wish to involve patient and family advisors who serve on quality and safety committees in obtaining real-time feedback on hospital practices. Because patient and family advisors do not provide direct care, patients and families may be more candid with them than they are likely to be with clinicians or hospital staff. For this reason, providing opportunities for patient and family advisors to communicate directly with patients and families can help hospitals obtain a more complete picture of patients' and families' experiences of care. In addition, these opportunities can increase the visibility of patient and family advisors, resulting in greater awareness of the role of patients and family members as collaborators in system improvements.

There are multiple ways of working with patient and family advisors to collect information about patients' and families' views and experiences. You may want to ask advisors to:

- **Facilitate a small group discussion** with recent patients and family members to obtain information about how to improve specific processes. The group should contain between 6 and 10 people and last about 2 hours. Small group discussions are a good opportunity to obtain a range of perspectives on a specific topic or issue (e.g., getting feedback on the admissions process, nurse bedside shift report, or discharge).
- **Conduct one-on-one interviews** with patients or family members to collect more detailed information about experiences of care. These interviews can be conducted with recent patients and family members or even with current patients and family members. (See information below about having patient and family advisors visit units.)

- **Conduct an observation** to obtain information about care processes. When implementing a new patient safety or quality practice, it can be helpful to involve experienced patient and family advisors as observers to collect information on new practices from a patient and family perspective. Provide advisors with a checklist of things to assess (e.g., whether certain things happen during the bedside shift report) and provide them with training on being an objective observer.

Advisors also can be helpful in soliciting real-time feedback from patients and families on the unit where changes have been implemented, for example, by coupling the observation with real-time interviews.

- **Assist with distributing questionnaires and encouraging patients and family members to complete them** to provide feedback on their experiences in the hospital. Another option for obtaining real-time feedback is to create a brief survey with open-ended questions about the general experience of care, environment of care, respectful communication experience, and specific workflow issues. Hospitals may also wish to add questions to obtain feedback on experiences related to a new process design (e.g., the patient and family perspective of bedside change-of-shift report). Getting patients and families to complete this type of brief survey is not always easy; however, experienced patient and family advisors can be trained to help increase the rate of response while still being respectful of the patient's and family's stress, mindset, and situation while in the hospital.

### **Guidance for having patient and family advisors interact with current patients and family members**

In planning for advisors to interact with current patients and family members, advisors will need concrete information about roles and responsibilities, time commitments, and training activities. On-the-unit roles also make it critically important that advisor training include background checks, compliance with institutional training requirements for confidentiality and privacy (e.g., HIPAA), and required immunizations and health screenings. Advisors also need to understand that respecting the personal priorities of the patient and family is essential. The stress and exhaustion of a hospital stay may lead to patients and families not wanting to speak with advisors.

In working with advisors in this capacity, the staff liaison or staff lead of the quality and safety committee should:

- Schedule advisor presence on the unit and make sure it is approved by the nurse manager and charge nurse. Often, there are days of the week and times of day that are better in terms of unit workflow and process.

- Request that the advisor, upon entering the unit, locate and introduce himself or herself to the charge nurse or nurse lead for the day. The advisor should confirm that the time is still convenient for the advisor to be on the unit. Additionally, advisors should be prepared to do the following:
  - Confirm that the manager or charge nurse has informed the floor staff that the advisor will be on the unit that day
  - Go over the list of patients and families on the floor with the charge nurse to identify patients and families not to approach (e.g., due to health issues, infection control constraints, or other staff concerns)
  - Confirm the name and contact information for the person on the unit who is the appropriate point of contact for the advisor if an issue needing immediate attention is raised
  - Ask if an interpreter is needed to communicate with any of the patients and families currently on the unit and determine if this resource is available
- Wear their name badge on the unit and, upon entering a patient's room, introduce themselves, explain their role to the patient and family, and ensure that it is a good time to speak with them
- Be coached to return to a patient's room at a later time if a clinician or staff member is in the patient room, the patient is having their meal, or the patient is actively undergoing treatment or testing
- Ensure they thank the patient and family member they speak with, regardless of the result of the encounter

In speaking with hospitalized patients and families, advisors need to be prepared with strategies to handle issues that may arise, including how to offer immediate communication to the unit or hospital staff about urgent problems. Advisors should have contact information for the person who patients and families can call if they want to initiate working with a staff member for resolution or clarification. However, it is always important to distinguish between a concern or issue that needs immediate attention and notification of a doctor, nurse, or patient advocate or patient relations representative and concerns or issues that build awareness of the patient and family experience.

After the observation, it is important to work with advisors to ensure clear followup and debriefing. Results of the observation and written reports should be communicated to both the unit and the quality and safety committee. Results should be considered in terms of their ability to inform potential quality improvement projects and to identify areas in which patient and family advisors can help improve systems and processes.

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