

# **Attachment C**

## **Component 2:**

### **Organizational Partnership Materials**

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# **Organizational Partnership Materials**

## **Implementation Handbook**

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The *Guide to Patient and Family Engagement in Hospital Quality and Safety* (the *Guide*) is a resource to help hospitals develop effective partnerships with patients and family members, with the ultimate goal of improving hospital quality and safety.<sup>1</sup>

Working with patients and families at an organizational level (i.e., as advisors) 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 *Organizational Partnership Materials* component and its tools help hospitals implement and develop effective partnerships with patients and family members at the organizational level.<sup>2</sup>

This handbook gives you an overview of and rationale for the component. It also outlines five steps for putting this component into place at your hospital and includes specific suggestions for how to work with patient and family advisors.

## Overview of the Organizational Partnership Materials Component

The goal of the *Organizational Partnership Materials* component 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 train patient and family advisors, and prepare clinicians and hospital staff to work with patient and family advisors.

### What are the Organizational Partnership Materials tools?

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

Tool	Use this tool to...	Description and formatting
<b>Gain the support of hospital leadership</b>		
<b>Tool 1</b> <b>Organizational Partnership Materials: Leadership Support</b>	Build hospital leadership support for working with patient and family advisors.	<ul style="list-style-type: none"> <li>• A PowerPoint presentation and talking points for staff liaisons or others to use in speaking with hospital leadership about the benefits of working with advisors and the leadership resources needed.</li> <li>• Format: PowerPoint presentation slides with talking points</li> </ul>
<b>Recruit patient and family advisors</b>		

Tool	Use this tool to...	Description and formatting
<b>Tool 2</b> <b>Help Improve Our Hospital: Become a Patient and Family Advisor</b>	Recruit new patient and family advisors.	<ul style="list-style-type: none"> <li>• Brochure with information about who patient and family advisors are, how they help the hospital, and what it takes to be an effective patient and family advisor.</li> <li>• Format: Tri-fold brochure</li> </ul>
<b>Tool 3</b> <b>Personal Invitation for Patient and Family Advisors</b>	Recruit new patient and family advisors.	<ul style="list-style-type: none"> <li>• Postcard 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 4</b> <b>Become a Champion for Health Care Quality and Safety</b>	Recruit experienced patient and family advisors to become members of quality and safety committees.	<ul style="list-style-type: none"> <li>• Recruitment handout for patient and family advisors who may be interested in serving on hospital quality and safety committees of different types. Gives information about roles and responsibilities and tells how to get more information.</li> <li>• Format: 2-page handout</li> </ul>
<b>Tool 5</b> <b>Application Form for Patient and Family Advisors</b>	Identify and screen potential patient and family advisors.	<ul style="list-style-type: none"> <li>• Form for potential advisors to complete. Includes basic demographic information, questions about why the applicant wants to be an advisor, and questions about prior relevant experiences as advisors or volunteers.</li> <li>• Format: 2-page handout</li> </ul>
<b>Tool 6</b> <b>Sample Invitation and Regret Letters for Advisory Council Applicants</b>	Notify advisory council applicants of their acceptance or rejection.	<ul style="list-style-type: none"> <li>• Sample invitation and regret letters 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>Information session for patient and family advisors</b>		

Tool	Use this tool to...	Description and formatting
<b>Tool 7</b> <b>Patient and Family Advisor Information Session</b>	Conduct an information session for people who are interested in becoming advisors.	<ul style="list-style-type: none"> <li>• Gives information about who patient and family advisors are, what they do, how they help the hospital, and what it takes to be an effective patient and family advisor.</li> <li>• Format: PowerPoint presentation with talking points</li> </ul>
<b>Tool 8</b> <b>Am I Ready to Become an Advisor?</b>	Help people who are interested in becoming advisors self-assess their readiness.	<ul style="list-style-type: none"> <li>• Handout to be given at and completed during the advisor information session.</li> <li>• Format: 1-page handout</li> </ul>
<b>Tool 9</b> <b>Sharing My Story: A Planning Worksheet</b>	Help potential patient and family advisors begin to plan how to talk about their experiences.	<ul style="list-style-type: none"> <li>• Handout to be given at the advisor information session.</li> <li>• Format: 1-page handout</li> </ul>
<b>Tool 10</b> <b>My Participation Interests</b>	Identify the specific interests of potential patient and family advisors.	<ul style="list-style-type: none"> <li>• Form to be 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 11</b> <b>Patient and Family Advisor Training Manual</b>	Train patients and family members who have been selected to serve as advisors.	<ul style="list-style-type: none"> <li>• Gives information about hospital safety and quality, what patient and family advisors do, how they help the hospital, and provides tips about being an effective patient and family advisor.</li> <li>• Format: Manual</li> </ul>
<b>Tool 12</b> <b>Sample Confidentiality Statement</b>	Review confidentiality requirements with all patient and family advisors.	<ul style="list-style-type: none"> <li>• 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>
<b>Train clinicians and hospital staff</b>		



Tool	Use this tool to...	Description and formatting
<b>Tool 13</b> <b>Working With Patient and Family Advisors: Presentation</b>	Introduce clinicians and hospital staff to the idea of working with patient and family advisors and to develop their skills for doing so.	<ul style="list-style-type: none"> <li>• Two-part training presentation. Part 1 (Introduction and Overview) discusses who patient and family advisors are, the benefits of working with them, and the 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>
<b>Tool 14</b> <b>Working With Patient and Family Advisors: Handout</b>	Provide clinicians and hospital staff with an overview of working with patient and family advisors.	<ul style="list-style-type: none"> <li>• Outlines the role of patient and family advisors and the opportunities for their involvement.</li> <li>• Format: 2-page handout</li> </ul>
<b>Tool 15</b> <b>Working With Patient and Family Advisors on Short-Term Projects</b>	Help clinicians and hospital staff identify opportunities for working with patient and family advisors.	<ul style="list-style-type: none"> <li>• 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>
<b>Tool 16</b> <b>Readiness to Partner With Patient and Family Advisors</b>	Help clinicians and hospital staff identify attitudes and behaviors that may prevent them from partnering effectively with advisors.	<ul style="list-style-type: none"> <li>• Checklist of behaviors and attitudes.</li> <li>• Format: 1-page handout.</li> </ul>

# Rationale for Organizational Partnership Materials

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.

Patient and family advisors help identify those things 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:(1)

Better health outcomes for patients.

- Reduced errors and adverse events.
- Increased patient loyalty.
- Malpractice risk reduction.
- Increased employee satisfaction.
- Improved financial performance.

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

*In this new world of healthcare, 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, Conway J, Gluck P, Guest J, et al. Transforming healthcare: a safety imperative. *Qual Saf Health Care*. 2009;18(6):424-8.

# Implementing the Organizational Partnership Materials

The *Organizational Partnership Materials* component 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 or move farther 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.](#)

## 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.](#)

## 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 advisors.

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

## 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.](#)

## Step 5: Implement and coordinate advisor activities

Successful staff liaisons identify advisor activities and also track and communicate advisor accomplishments.

**Learn more:** [Step 5: Implement and coordinate advisor activities.](#)

## Step 1: Identify a Staff Liaison

Hospitals that are most effective in engaging patient and family advisors have a designated clinician or staff member who serves 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 and ensure that advisors are ready to participate.

### 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 does work with 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 is willing to devote time 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.
- 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.

### 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.(2)

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.
- Training advisors and helping them understand how the organization works.
- Overseeing advisor activities and facilitating the engagement of advisors.
- Bringing concerns of advisors to hospital leaders or helping create direct connections between advisors and leaders.
- Tracking 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 not mutually exclusive, nor do they represent the only ways of working with patient and family advisors. For more detailed information about implementing the opportunities in this section, refer to the appendices 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 (for example, 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 change and improvement.
- Work with advisors to obtain feedback on draft versions of written and audiovisual materials, such as patient and family handbooks, informational videos, or care instructions.
- 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 in [Appendix A: Working With Patient and Family Advisors on Short-Term Projects](#).

### 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.

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, program planning and evaluation, and providing input on institutional policies, programs, and practices.(3)

#### What is an advisory council?

An advisory council is an active partnership between patients and family members and hospital staff.

It is **not** a support group, grievance committee, staff meeting, or presentation forum.

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 in [Appendix B: Establishing and Working With Patient and Family Advisory Councils](#).

## **Advisors as members of quality and safety committees**

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:

- Review and interpret the results of patient surveys and other data about hospital quality and safety, and develop strategies for improvement.
- Participate in quality improvement projects.
- Reach out to patients and families in the hospital to identify ideas for improving quality and safety.
- Co-present in training sessions for nurses, doctors, and other staff focused on improving communication, safety, and quality.

Learn more in [Appendix C: Working with Advisors as Members of Hospital Quality and Safety Committees](#).

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

The most important factor for ensuring the success of patient and family advisory efforts 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. Without this support, sustained and meaningful partnerships with advisors cannot be realized.

*“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 and families as advisors. (In press). Institute for Patient- and Family-Centered Care.

### Gathering information

As a staff liaison, one of the first things you can do to build support for working with advisors is to ensure a strong understanding of your 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 affect change. To identify informal leaders, 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 you 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 you prepare clinicians and staff to partner with advisors.
- **Assess your 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.



- **Consider opportunities for patients and families** to serve as advisors. If your hospital is new to working with advisors, think about a short-term task or project that can benefit from patient and family advisor participation (see [Appendix A](#)). If your hospital already has experience working with patient and family advisors, you may want to consider moving to the next step and creating a patient and family advisory council (see [Appendix B](#)). If your hospital is more experienced, consider incorporating advisors as members of hospital quality and safety committees (see [Appendix C](#)).

## 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.**

<b>Guide Resource</b>	<i>Tool 1: Organizational Partnership Materials: Leadership Support</i> is a PowerPoint presentation with talking points that you can use to talk to hospital leadership about the benefits of working with advisors and the support that is needed.
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- **Meet with clinicians and staff individually and in groups about 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.

<b>Guide Resource</b>	<i>Tool 13: Working With Patient and Family Advisors: Part 1. Introduction and Overview</i> 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 <i>Working With Patient and Family Advisors</i> that provides an introduction to the topic. You may also want to ask a patient or family member to share their story during this presentation.
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- **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 work effectively with patient and family advisors.

<b>Guide Resource</b>	<i>Tool 13: Working With Patient and Family Advisors: Part 2. Building Effective Partnerships</i> is a PowerPoint presentation with talking points and exercises that you can use to help clinicians and staff develop skills for effective partnerships. The session includes a handout called <i>Readiness to Partner With Patient and Family Advisors</i> to help clinicians and staff assess their readiness.
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- **Inviting staff and leadership to do a “walk-about”** to explore how the hospital welcomes, engages, and supports patients and families. Begin at the first point of entry into the hospital (e.g., the parking lot), and continue to the inpatient unit and throughout the unit, including the patient room, treatment rooms, admitting area, family lounge, and other areas visible to patients and families. These findings will give a new context for your discussions about working with patient and family advisors to make improvements. Learn more about conducting a walk-about in [Appendix A: Working With Patient and Family Advisors on Short-Term Projects](#).

## Recognizing challenges

It helps to be aware of sources of resistance and challenges that you may encounter in your conversations about working with patient and family advisors. These challenges may include:

- **Administrative barriers:** Training and supporting patient and family advisors and clinicians and hospital staff to engage in partnerships requires a commitment of personnel and financial resources. 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.
- **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 you hear 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.

You also may want to 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, training, 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 HIPAA confidentiality statements to affirm their commitment to keeping protected health information private 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 then 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 an individual or family member 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.

#### *Advisor qualifications*

No special experience, qualifications, or expertise is necessary to be a patient or family advisor. 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 well 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.

## 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. You may also want to 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.

**Guide Resource** Give the *Tool 3: 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 effective advisors.

- **Distribute recruitment brochures.** Place advisor recruitment brochures in easily accessible locations on units for staff to distribute. You may also wish to include these brochures in discharge packets, informational materials, welcome packets, or patient satisfaction survey mailings.

**Guide Resource** *Tool 2: Help Improve Our Hospital: Become a Patient and Family Advisor* is a brochure you can customize and use to recruit patient and family advisors.

- **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 website.** Work with the hospital's marketing department to create a page on the hospital website that contains information about advisory opportunities. Include the recruitment brochures and advisor application form on the website.

## 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 individually to inquire about their interest and ability to serve as a quality or safety committee member.

<b>Guide Resource</b>	<i>Tool 4: Become a Champion for Health Care Quality and Safety</i> is a recruitment handout that you can distribute to potential quality and safety advisors.
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Be clear on participation term limits with prospective patient and family advisors for committee involvement. Most often, a minimum of a 1 year commitment is desired because the projects these committees are involved in often take at least a year to plan, implement, test, review, and reach their goal. Advisors should also be given a description of the committee's purpose or charge, information about committee meeting frequency and schedule, and a summary of recent projects the committee has completed. 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 people can make the decision about whether they want to serve as an advisor, they need to understand the responsibilities associated with the role. A good way to provide this information is to hold an information session for individuals who are interested in becoming advisors. The session is designed to help patients and family members determine whether they are interested in serving as advisors and to determine for themselves whether they are ready.

<b>Guide Resource</b>	<i>Tool 7: Become a Patient and Family Advisor: Information Session</i> is a PowerPoint presentation with talking points. The session includes handouts called <i>Tool 8: Am I Ready to Become an Advisor?</i> and <i>Tool 9: Sharing My Story: A Planning Worksheet</i> to help patients and family members determine their readiness to be an advisor.
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Information to provide during this session includes:

- 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.

<b>Guide Resource</b>	<i>Tool 10: My Participation Interests</i> is a form for advisors to complete during the information session to indicate their interest in specific topic areas or initiatives.
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## Selecting advisors: Applications and interviews

Patients and family members who are interested in serving as advisors should complete an application. For individuals who are interested in serving as advisors on short-term projects, having a completed application may be sufficient, meaning that advisors do not need to go through a formal interview and selection process.

<b>Guide Resource</b>	<i>Tool 5: Application Form for Patient and Family Advisors</i> is a form for advisors to complete to provide information about themselves and their interest in serving as a patient and family advisor.
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A more formal structure is recommended for selecting members of advisory councils, since membership on an advisory council typically requires a commitment of 1 to 2 years. All potential council members should be interviewed by the staff liaison and the council's key contact, if this person is different from the staff liaison. Select additional interviewers as appropriate. Once the council is well-established, the chair(s) of the council or other council members typically participate in interviewing potential members as well. Interviews can be conducted in-person or via telephone.

During the interview, explore the applicant's responses to the open-ended questions included in their application form, including their reasons for wanting to become an advisor. 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 within the hospital, school, at work, with family, or another setting. How did you feel about hearing opinions with which you disagree?

- How much time are you likely to have in your schedule to participate as an advisor?

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 within that unit.

Inform patients and family members about selection in a timely manner. If there is not an appropriate match at the time, extend the invitation to explore future options for serving as an advisor.

<b>Guide Resource</b>	The <i>Tool 6: Sample Letter of Invitation</i> can be customized by hospitals to invite selected advisor applicants to join an advisory council. This letter is accompanied by a <i>Tool 6: Sample Letter of Regret</i> for applicants who are not selected.
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## Training advisors

At most hospitals, advisors undergo general orientation with the training or volunteer office. This training typically includes information about confidentiality and other requirements, such as vaccinations.

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

- Background information about hospital quality and safety, patient and family engagement, and the principles of patient- and family-centered care.
- Information about how patient and family advisors help improve hospital quality and safety.
- An explanation of the responsibilities of and expectations for advisors.
- Tips for being an effective advisor and sharing personal stories about health care experiences.
- Information about how the staff liaison will support the advisor.

It is helpful to allow time during this meeting for questions, and also for a quick tour of the hospital.

<b>Guide Resource</b>	<p><i>Tool 11: Patient and Family Advisor Training Manual</i> is a manual that hospitals can use and customize.</p> <p><i>Tool 12: Sample Confidentiality Statement</i> provides an example of the type of confidentiality forms that advisors should complete.</p>
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## *Training for advisor members of quality and safety committees*

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 training 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, different types of quality data collected, and a review of the importance of confidentiality and privacy.

## **Feedback sessions and problem solving**

As staff liaison, one of your responsibilities is to provide feedback to and solicit feedback from patient and family advisors. If you have advisors who are working on short-term projects, check in with them periodically to see how the work is going. For advisors who are council members, you 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, you may find that despite careful recruitment, selection, and training, a patient and family advisor is struggling. 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 their 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.

### **Guide Resource**

*Tool 13: Working With Patient and Family Advisors: Part 2. Building Effective Partnerships* is a PowerPoint presentation with talking points and exercises that you can use to help clinicians and staff develop skills for effective partnerships. The session includes a handout called *Readiness to Partner With Patient and Family Advisors* to help clinicians and staff assess their readiness.

Sometimes, the role of a patient and family advisor is not a good match. You may be able to

Thank you for your commitment over the last year(s) in helping us to 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.

In order 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 further ideas, please feel free to share them by contacting [name] at [contact information] so that we can make sure we catalogue them and share them appropriately with the committee moving forward. Thank you again for your help.

identify other ways to work with that patient and family member. In very rare cases, you may need to ask an advisor to step down from their position. In this case, work with your volunteer office and talk with them about how they handle these types of situations with volunteers. Sample language for a letter asking an advisor to step down is provided below. (4)

## 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.

### Identifying advisor opportunities

In working with patient and family advisory councils, the staff liaison should remain alert for strategic opportunities for advisor input. 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 input. Encourage staff to think about ways in which they can leverage advisor input. In the beginning, you may need to remind clinicians and staff about the ways in which patient and family advisors are available to help.

<b>Guide Resource</b>	<i>Tool 15: Working With Patient and Family Advisors on Short-Term Projects</i> is a handout you can distribute to clinicians and staff to help them think about ways in which they can work with advisors.
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It is helpful to keep a database of all advisors that includes their interests, availability, contact information, and participation history. If your hospital will be working with patient and family advisors on short-term or occasional projects, when staff members have specific requests, you can use the database to identify which advisors are most suitable for the 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.

### Tracking and communicating advisor accomplishments

#### *Tracking advisor accomplishments*

A critical strategy for 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 were 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 or advisory council members.

- The number of distinct efforts in which advisors participated (e.g., councils, committees, training and orientation events, facility design planning, feedback sessions, workgroups).
- Total hours volunteered by advisors per year.
- Examples of work completed (e.g., minutes from council meetings; print, web, or video resources; 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, risk management).

### *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 an even 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, 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.

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.

## Appendix A: Strategy 1: Patients and families as hospital advisors

This appendix provides information about ways in which you can partner with patient and family advisors on short-term projects.(5)

One way in which you may want to work with patient and family advisors is in implementing other strategies from the *Guide to Patient and Family Engagement*. 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 1: Communicating to Improve Quality*, *Strategy 2: Nurse Bedside Change of Shift Report*, *Strategy 3: 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 to implement the strategies and in 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 endeavors.
- Hold brainstorming sessions with patients and families before developing patient education materials and involve them throughout 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 colead educational and support programs for other patients and family members.
- 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 or families to present at staff orientation and inservice 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.
- Convene focus groups of patients and families as specific issues arise. Ask a patient or family member to cofacilitate 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 Walk-About 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 and/or family member. It also offers an opportunity to reflect on what it is like to be actively engaged (or not) in care and decisionmaking. It can be conducted during a training and orientation session, committee meeting, or inservice session.

**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 (6)

#### **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 in order 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; in facility design; in patient safety and quality initiatives; and in professional education, as well as in the delivery of care.

Ask each person to share a personal or professional example of a direct care experience that illustrates partnerships. Encourage people to share examples that had a profound effect on them. The examples can either be positive or negative. Although clinicians and staff can describe a professional work experience, this activity is more meaningful when participants share a personal experience with the health care system. Remind all 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 2-3 minutes to tell their story. Encourage everyone to participate, but be prepared that some people might decline.

**During the exercise:** Be prepared to be a timekeeper and provide reminders of the 2-3 minute expectation. 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.

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

### *Activity 2: Patient and family stories*

Invite patients 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.

Following is a structure that it may be helpful to follow.

- [INTRODUCE PATIENT / FAMILY MEMBER.] Thank you for talking with us today. Stories provide a mechanism by which clinicians and hospital staff and patients can communicate and develop a shared understanding.
- [PATIENT OR FAMILY MEMBER] is here to share their 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.

You can either ask the patient or family member to recount their 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 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?

Potential additional 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 hospitalization experience:
  - How 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 if appropriate, did your family or trusted friend get information about your care in a way you could understand? Was the information 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 the positive connections you made with clinicians and staff here? What specifically did they do to build your comfort and/or trust and make that connection?
  - What did someone say or do or not say and do that failed to make a connection?
  - During your hospital stay, did you feel welcomed? Did people introduce themselves to you and your family members?
  - Did you know everyone's job title and function? Did clinicians and staff explain their roles in your care?
  - Did clinicians and staff tell you what to expect during your stay? Did they routinely explain procedures before they were carried out and in ways you could understand?



### *Activity 3: Conducting a “walk-about” from the patient and family perspective*

The walk-about 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 walk-about and related meetings can also be beneficial for patients and families. It builds their understanding of staff and clinician perspectives, and helps them understand care processes and the environment of care. It also allows them 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 walk-about**

For the walk-about, it is helpful to have two or three patient and family advisor participants. Invite hospital leaders, clinicians, and staff to participate. 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., 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 two hours or less.

Before starting, share the objective of the walk-about – to capture the processes, interactions, documents, and environment of the hospital from the perspectives of patients and families. Begin the walk-about at the first point of entry into the hospital (e.g., the parking lot), and continue to the inpatient unit and throughout the unit. Be sure to include all areas accessible to patients and families, including a patient room, treatment rooms, family lounge, communication center, and/or nursing station(s).

During the walk-about, 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, inpatient television programming).
- Process for transitions across care settings.
- Discharge information, packets, and processes.
- Characteristics of the physical environment (e.g., signage, wayfinding elements, artwork, arrangement of furnishings, and sleep spaces for families).

During the walk-about, the team should also collect “evidence.” Assign people to document the walk-about through:

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

Throughout the walk-about, 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 walk-about is holding a followup meeting to discuss what was discovered. Bring all the “evidence” to the meeting, including notes, photos or videos taken, and forms and materials collected. 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 decision-making? 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 walk-about 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 perspective and thoughts about the walk-about 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 walk-about 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 walk-about 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 walk-about.

## Appendix B: Strategy 2: Patients and families as advisory council members

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 about:

- Advisory council membership.
- Roles and responsibilities of advisory council members.
- Time commitments.
- Advisory council mission statement, bylaws, and goals.
- Budget considerations.
- Strategies for effective 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 representatives from hospital staff. Other councils find a closer balance between patients, families, clinicians, and hospital staff, although patients and families should still be the majority membership. At a minimum, the staff liaison attends council meetings to facilitate interactions and report feedback.

When looking for clinicians and other hospital staff to serve as council members, seek 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.

#### How many people should be on an advisory council?

Councils work best when they have between 12 to 25 members. Avoid creating a council that is too small to accomplish its goals, or a council that is so large it becomes difficult to manage and come to consensus.

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

## Roles and responsibilities of advisory council members

Most advisory councils include the following roles:

- **Chair or Co-chair.** The chair(s) 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 are actively participating in meetings, and that activities and outcomes of the council are communicated throughout the hospital and community. Successful patient and family advisory councils select a patient or family member to fill at least one of the chair positions.
- **Staff liaison.** 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.
- **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, annual training, and other requirements as indicated by the council. Some councils choose to rotate positions such as meeting facilitator, time keeper, and secretary.
- **Hospital staff or clinician members.** Members of the council who are from the hospital staff attend all council meetings and make the time to implement council initiatives in between meetings. Staff are expected to complete any orientation and training necessary for council members.

## Time commitment

- Most advisory councils meet once a month for 9 to 10 months of the year (taking one or two summer months and December off).
- Council meetings typically last between 1 ½ to 2 hours. When there is work for members to complete in between council meetings, this work should not take more than 2 to 4 hours per month.

### Sustaining Involvement

Most hospitals offer ways for patient and family council members to continue to serve as advisors after their council term is completed.

You might ask these individuals to do things such as serve as faculty for clinician and staff orientation and in-service training or join a committee such as the patient safety committee.

- Patient and family advisory council members usually serve 1 to 2 year terms. It is helpful to stagger membership terms to ensure that you have a balance of new and experienced members. For example, as you are starting a council, 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.

## Advisory council mission statement

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

### **Mission Statement from the Dana-Farber Cancer Institute’s Adult Patient and Family Advisory Council**

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.

## Advisory council bylaws

Advisory councils may also establish bylaws to guide how the council functions and to outline the responsibilities of council members.

These bylaws typically include functional issues such as:

- Who is eligible for membership.
- Expectations for how long a member serves on the council.
- Council meeting schedule.
- Specific council member roles and responsibilities.

### **Find sample bylaws on the following hospitals’ websites:**

- Dana-Farber/Brigham and Women’s Center (Boston, MA) Adult Patient and Family Advisory Council Bylaws: Available at: [www.dana-farber.org/pat/pfac/establishing-patient-centered-care.html](http://www.dana-farber.org/pat/pfac/establishing-patient-centered-care.html)
- Eastern Maine Medical Center, (Bangor, ME) Advisory Council Bylaws: Available at: [www.emmc.org/family\\_centered\\_care.aspx?id=33368](http://www.emmc.org/family_centered_care.aspx?id=33368).

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.

For additional detail and information about developing advisory councils, see the *Guide for Developing Community-Based Patient Safety Advisory Council*, Available at: [www.ahrq.gov/qual/advisorycouncil](http://www.ahrq.gov/qual/advisorycouncil)

Bylaw development and approval can take time since the bylaws should be established in conjunction with all members of the council. A new advisory council may want to generate a few guiding principles or norms and then wait until a sub-committee can be formed to develop more formal bylaws.

## Advisory council goals

If the council is a new venture, 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, talk about, 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.

## Budget considerations

At a minimum, hospitals should reimburse patients and families for expenses incurred during their work on the advisory council (e.g., parking, transportation, child care). 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.

Download *A Patient and Family Advisory Council Workplan: Getting Started* to help organize the creation and maintenance of patient and family advisory councils. Available at: [www.ipfcc.org/tools/downloads.html](http://www.ipfcc.org/tools/downloads.html) under "Tools to Foster Collaboration with Patient and Family Advisors."

This tool is from the Institute for Patient- and Family-Centered Care.

Think creatively about 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 other hospitals write grants to community organizations or foundations.

## Strategies for effective 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 will help you prepare for and run effective meetings.

Prior to the meeting, make sure you know how members prefer to have materials sent to them (e.g., email, fax, or regular mail). At least one week before the meeting, mail out the agenda and any materials to give council members the chance to prepare. Many councils also find it helpful to have staff or a council member volunteer make a reminder phone call to council members two to three days before the meeting.

On the day of the meeting, place signs to let advisory council members know where to go. Plan to be in the meeting room at least 30 minutes ahead of start time to set up the room, distribute materials, set out name tags or tent cards, organize refreshments, and set up and test any audiovisual or computer equipment. This allows for you 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 you have advisors who have limited functionality, request a quick consult from an Occupational Therapist or other appropriate staff member at your hospital about how you might adapt the room to make it more comfortable and not draw attention to the different functional levels of advisors.

As members enter the meeting room, make sure that each person is 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 they 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 very 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). You may want to introduce yourself first to help model an introduction that keeps within the allotted time. Consider adding an icebreaker question to help people get to know each other on a more personal level. Let council



members know that there will be time on the agenda for the first several meetings to share more about themselves.

- **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. You may want 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(s) and/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 and/or chair have 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 within a few months. For example, you could ask council members to think about their experience of the admission process, and share one thing they would change. 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, advisory council co-chair) to reach 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 Meeting Agenda (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. (3) To help hospital staff carry out changes and improvements in the experience 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)**

### *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, be sure the agenda includes 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 guests or new members.

- Announcements from members.
- Evaluating the meeting and getting ideas for meeting improvement.
- Identifying follow-up 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 meeting 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 XX got a little off topic*” and not “*XX 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 – 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(s) 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(s) calls on the individual and asks if they have 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 with the group. Not everyone will have an idea or anything to add, but you want to ensure that 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(s) can offer to meet with this person to find out if there are ways they 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 liaison or chair(s) 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, an acute or chronic illness that limits their activity). If an advisor misses several meetings, the staff liaison should call them and find out if they need additional support to get to meetings or if they need to take time off from the council or resign their 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 them, and either let them know that you want to make sure that there is enough time in the agenda to let everyone have a chance to speak or that the topic they are 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(s) 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 the group 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 about 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 also 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, telling their own story, or hearing a story that triggers memories. The staff liaison and chair(s) should be mindful of these occurrences and make sure the council member receives support. After the member finishes sharing their 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*

In between meetings, it is important for the liaison and council chair(s) to be available to all council members for feedback and encouragement. For new council members, it is helpful to debrief regularly about their participation on the council. This is an opportunity to identify strengths that you see, solicit thoughts about how the council member wants to improve their involvement, and gently offer suggestions for improvement. If they desire, they can make a goal with you and you can set a future date to discuss progress.

### *Review annually*

All council members should go through an annual review process. This process can be tailored according to the review process you have for other hospital volunteers.

## Appendix C: Strategy 3: Patients and families as members of hospital quality and safety committees

Engaging patient and family advisors as members of quality and safety committees 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 for advisor engagement, modeling collaboration, and providing mentorship for these efforts.

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

The first step in the process is to assess the committees' 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; 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.
- Underlying fears and concerns about working with patient and family advisors.
- Committee members' perspectives on data transparency.
- Flexibility around general aims and specific improvement projects.
- Senior leadership support for patient and family involvement.
- Collaboration and teamwork.

**Advancing the Practice – Patient and Family Advisors and Leaders** contains information about and examples of how patient and family advisors have been involved with safety and quality programs. Available from the Institute for Patient- and Family-Centered Care at: [www.ipfcc.org/advance/pafam.html](http://www.ipfcc.org/advance/pafam.html)

The *Partnering With Patients and Families to Accelerate Improvement: Readiness Assessment* (7) shown on the next pages is a tool that can be used to guide the committee's discussion and identify planning steps for involving patient and family advisors on the committee.

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

Area	For each item, circle the box that best describes your team’s perspective and experience.		
<b>Data transparency</b>	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.
<b>Flexibility around aims and specific changes of improvement project</b>	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 patient and family members’ perspectives.
<b>Underlying fears and concerns</b>	We have identified several concerns about involving patient 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.
<b>Perceived value and purpose of patient and family involvement</b>	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.

Area	For each item, circle the box that best describes your team's perspective and experience.		
<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.
<p>1. What supports moving in the direction of involving patient and family advisors?</p> <p>2. What are your current challenges?</p> <p>3. How confident are you on 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)? _____</p>			



## Preparing advisors to participate on quality and safety committees

As members of quality and safety committees, 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 specific model for improvement used at the hospital. This will help advisors develop a more complete understanding of how changes are planned, implemented, evaluated, and disseminated.

#### **The Institute for Healthcare**

**Improvement** has information about quality improvement methods on their website that hospitals may wish to share with advisors. Available at:  
<http://www.ihl.org/IHI/Topics/Improvement/ImprovementMethods/>

### *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).

**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:  
[www.pickereurope.org/usingpatientfeedback/](http://www.pickereurope.org/usingpatientfeedback/)

### *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 up 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.

## 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.

**Guide Resource**     *Tool 12: Sample Confidentiality Statement* provides an example of a confidentiality agreement for advisors.

## Integrating patients and family advisors into quality and safety work: Initial steps

The following strategies and tips can help expand your efforts to integrate patients and family advisors into quality and safety work.

- During the hospital’s annual planning process, encourage staff and administrators to incorporate specific patient and family engagement initiative(s) and strategies into their unit’s or department’s goals.
- Review current literature related to involving patient and family advisors in quality improvement initiatives. This is a way to build capacity for effective participation in quality improvement and other initiatives. If the hospital has journal clubs, provide resources to help broaden the number of staff and faculty who are knowledgeable about the current literature.
- Create positive experiences for staff to experience 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.

Current bibliographies of quality and safety topics are available from:

The Institute for Patient- and Family-Centered Care, available at:  
[www.ipfcc.org/advance/supporting.html](http://www.ipfcc.org/advance/supporting.html)

The Picker Institute, available at:  
[www.investinengagement.info/SiteGuidetop](http://www.investinengagement.info/SiteGuidetop)

- 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 in quality and safety improvement initiatives. 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 quality and safety committees, 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 committee members to participate actively in the orientation of new patient and family advisor members. This helps patient and family advisors feel welcome and also facilitates their understanding of the purpose of and goals for the committee.
- 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 committee rosters and use tent cards to help with name recognition.
- Encourage the committee to build in agenda time for sharing of stories or ice-breaker activities that help all members build trust and establish a good working relationship.
- Ask the committee chair to recruit experienced members of the committee to mentor a new patient or family advisor on the committee. Mentors can contact the advisor after each meeting to answer questions and make sure the advisor remains confident with their participation. This commitment does not need to be long standing; 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 they need the mentorship to continue.

**The Quality Improvement Toolkit** is a resource from the Cystic Fibrosis (CF) Foundation designed to help patients with CF and their families become partners in improving care quality. Although it is written for CF patients and their families, the resource contains useful information about supporting patients and families as partners in quality improvement. Available at: [www.cff.org/LivingWithCF/QualityImprovement](http://www.cff.org/LivingWithCF/QualityImprovement).

- Encourage the chair of the committee to strategically analyze the tasks and goals of the committee to seek opportunities for involving advisors in both short and long-term initiatives the committee 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 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 mid-stream in the design of a project. In this case, ask the committee chair to ensure that advisors are given sufficient information to help them understand the background of the project and steps already completed.
- As committee 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 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 chairs to model transparency and ownership of patient safety and quality related issues, including acknowledging issues that are ongoing problems requiring attention. Encourage the chair to 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 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.
- Acknowledge that there will be differing opinions and perceptions, and occasionally tensions. When there are extreme differences in opinions or perceptions, the staff liaison should encourage the committee 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 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 place on meeting agendas time 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 the quality and safety committee, 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 with more detailed materials that the committee 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. The following guidelines can help promote an inclusive atmosphere and facilitate comprehension:

- 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 1000” 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.).
- Unfortunately, some jargon and acronyms are hard to avoid in quality and safety improvement projects. To avoid issues associated with jargon and acronyms, encourage advisors to ask for an explanation or definition if anyone on a committee uses a term 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 also find this list of acronyms and jargon to be helpful.

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/qual/pstools.htm>

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 to 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 that provide care to them or their family members. 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 methods for collecting patients' and families' views and experiences with the help of patient and family advisors. Options include asking 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 six 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, bedside change of 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 change of shift report) and provide them with training about 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 and encouraging patients and family members to complete **questionnaires** about 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/or 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 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/or 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 him/herself to the Charge Nurse or nurse lead for the day. The advisor should reconfirm that the time is still convenient for the advisor to be on the unit. Additionally, the advisor 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.
- Advisors should always visibly wear their name badge on the unit. Upon entering a patient's room, advisors should introduce themselves, explain their role to the patient and family, and ensure that it is a good time to speak with them.



- Advisors should 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 that advisors 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 for issues that may arise, including how to offer immediate communication to the unit or hospital staff about urgent problems. Advisors should have information about 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/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.

<sup>1</sup>The Guide was developed for the Agency for Healthcare Research and Quality (AHRQ), in the U.S. Department of Health and Human Services, 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 (AIR), the team included the Institute for Patient and Family-Centered Care (IPFCC), Consumers Advancing Patient Safety (CAPS), the Joint Commission, and the Health Research and Educational Trust (HRET). Other organizations contributing to the project included Planetree, the Maryland Patient Safety Center (MPSC), and Aurora Health Care.

<sup>2</sup>Materials in this handbook have been adapted from resources from the Institute for Patient- and Family-Centered Care (IPFCC), Bethesda, MD, [www.ipfcc.org](http://www.ipfcc.org), 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>.

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# Organizational Partnership Materials: Leadership Support

**[Insert hospital name, presenter name and  
title, date of presentation]**

Organizational Partnership Tool 1: Leadership support presentation



# Today's presentation

- Who are patient and family advisors and what do they do?
- What are the benefits of working with patient and family advisors?
- What leadership support is needed for this effort?

# Patient and family advisors

---

Who are they?

What do they do?

# Advisors: Who they are

- Patients and family members who have received care at this hospital and who want to help improve care experiences for others
  - ◆ Undergo rigorous application screening process
  - ◆ Receive training

# Advisors: What they do

- Patient and family advisors help us improve the quality and safety of the care we provide
  - ◆ Provide input and feedback
  - ◆ Identify potential changes and improvements
  - ◆ Plan and implement changes that matter to patients and families

# The benefits of working with patient and family advisors

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# Benefits of working with advisors

- Insight to help translate actual care experiences to improvements in care for other patients and families
- Integrates patients and families into developing priorities for change
- Leads to improved practices and better use of resources - leading to higher quality, safer care

# Why should we do this?

- Consistency with our mission and vision
- Consistency with our strategic priorities
- Desire to demonstrate commitment to patient- and family-centered care
- Desire to be at the forefront of where health care is going

# What leadership support is needed?

---

# Importance of leadership support

- Commitment of senior leaders is one of the most critical determinants of success
- Leaders:
  - ◆ Set expectations
  - ◆ Model behaviors
  - ◆ Mobilize and help sustain the effort
  - ◆ Provide resources

# Leadership support needed

- Designate resources to support operational functions
- Develop and support “staff liaison” position:
  - ◆ Coordinates recruitment, selection, training, and placement of advisors
  - ◆ Mentors advisors and monitors progress
  - ◆ Updates leadership, clinicians, and hospital staff about accomplishments and outcomes

# Leadership support needed (cont.)

- Leadership participation to demonstrate support
  - ◆ Visible communications to spread and reinforce importance of patient and family advisors
  - ◆ Alignment of Volunteer Services or HR or Red Cross [*choose one*] to support advisor recruitment and training
  - ◆ Commitment to act on advisor guidance

- [Note: hospitals may wish to end the presentation in one of the following ways:
  - ◆ *Download and show the Best Practices - AHA Video: Patient- and Family-Centered Care: Partnerships for Quality and Safety*
  - ◆ Ask a patient or family advisor to speak to leadership about their experiences]

“In a growing number of instances where truly stunning levels of improvement have been achieved, organizations have asked patients and families to be directly involved in the process.

And those organizations’ leaders often cite this change—**putting patients in a position of real power and influence**, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.”

Reinertsen, J.L., Bisognano, M., & Pugh, M.D. (2008). Seven leadership leverage points for organizational-level improvement in health care (2<sup>nd</sup> ed.) Cambridge, MA: Institute for Healthcare Improvement.



# Thank you!

- For questions or more information:  
[Insert contact name and information]

[NOTE: Use this quote or include a quote from someone at your own hospital.] “Patient and family advisors have knowledge we don’t have...It is so humbling to realize that patients and families know more about [the hospital] than you do.”

Pat Sodomka, former hospital administrator

## Become an advisor!

When you or your family members were in the hospital, did you think there were things we could have done better?

Do you have ideas about how to make sure other patients and families get the best care possible?

**If so, please think about becoming a patient and family advisor!**

## Who can be a patient and family advisor?

You can be an advisor if you or a family member received care at [insert hospital name] in the last 5 years.

**You do not need any special qualifications to be an advisor.** We are looking for people who want to make a difference.

What’s most important is your experience as a patient or family member. We will provide you with any other training you need.

## What do patient and family advisors do?

[NOTE: Personalize this section for your hospital as appropriate.] As a patient and family advisor, you may be asked to:

- **Provide feedback on policies and care practices.** We may ask advisors about how to improve the things we do, such as discharging a patient from the hospital.
- **Review or help create informational materials.** As you know, we give a lot of materials to patients and families while they are in the hospital – forms, health information, medication lists, and discharge instructions. Patient and family advisors can help by giving input into and feedback on new and existing materials.
- **Serve on a patient and family advisory council.** The patient and family advisory council helps plan and discuss changes to improve hospital quality and safety. Most of the members are patients and family members. There are also a few hospital staff members on the council.
- **Serve on a quality improvement committee or work group.** We have committees and work groups made up of doctors, nurses, and other hospital staff that work to improve hospital quality and safety. Patient and family advisors may be invited to participate on these committees or workgroups.

## Why should you become a patient and family advisor?

At [insert hospital name], patient and family advisors help us improve the quality and safety of care we provide.

People who have been patient and family advisors say they get something out of it too:

- The chance to meet and work with other people.
- A sense of pride and accomplishment.
- New skills.
- Knowledge that they are helping to improve the care experience for other patients and families.

[NOTE: Insert picture or other graphic specific to your hospital.]

## Is being a patient and family advisor right for you?

Are you thinking about becoming an advisor?

Use the checklist below to help you figure out if you are ready.

### Effective advisors...

- Speak up and share suggestions and potential solutions to help improve hospital care for others.
- Are willing to talk about their experiences as a patient or family member.
- Are ready to move beyond any negative care experiences and respectfully share ideas about how things could have gone differently.
- Are willing to learn how to best serve as an advisor.
- Are able to work with people who may be different than themselves.
- Listen to and think about what others say, even when they disagree.
- Bring a positive attitude to discussions.
- Are willing to keep any information they may hear as an advisor private and confidential.
- Have the time to be an advisor (usually at least 1 hour and not more than 4 hours per month).

## How do I become an advisor?

To get more information about being an advisor at [hospital name] or to find out how to apply:

**Call:** Insert contact name and phone number

**Email:** Insert contact name and email address

**Mail:** Fill out the box below and mail to:

Contact name

Address

City, State, Zip Code

I would like to learn more about being a patient and family advisor. Please contact me.

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Email: \_\_\_\_\_

Phone number(s): \_\_\_\_\_

Best time to reach me: \_\_\_\_\_  
\_\_\_\_\_

**Come join us! Together we can work to make our hospital the best it can be!**

# Help Improve Our Hospital

## Become a Patient and Family Advisor



## Front of postcard:

**Do you have ideas to help improve our hospital?**

**Become a patient and family advisor.**

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

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

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

Sincerely,

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*[NOTE: Hospital staff member should sign and personally give this to patient or family member.]*

**Back of postcard:**

<p><b>There are many ways that patient and family advisors help us:</b></p> <ul style="list-style-type: none"><li>• Share your story about your hospital experience in training sessions for nurses, doctors, and other hospital staff.</li><li>• Help create materials and plans to improve health care quality and safety for all patients.</li><li>• Provide input about how to improve our policies and care practices.</li><li>• Give feedback about your hospital stay. Let us know what went well and what we can do better.</li></ul> <p>We are grateful to the patients and families who become advisors.</p> <p><b>Come join us!</b></p>	<p><b>What skills do advisors need?</b></p> <p>You do not need any special qualifications to be an advisor. We will provide any training that you need.</p> <p>Advisors...</p> <ul style="list-style-type: none"><li>• Listen and share their opinions respectfully.</li><li>• Think about ways to improve health care.</li><li>• Work well with others.</li></ul> <p><b>For more information about becoming an advisor, please contact:</b></p> <p>[Insert staff liaison name]</p> <p>[Insert telephone]</p> <p>[Insert email]</p>
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## Become a Champion for Health Care Quality and Safety

At **[insert hospital name]** we have been partnering with patient and family advisors to help us make changes and improvements.

**Now we are looking for patient and family advisors who are interested in working together with hospital staff on committees that are focused solely on hospital quality and safety.**

**[NOTE: Edit the list below as appropriate for your hospital's priorities]**

As an advisor for hospital safety and quality, you may be asked to do things like:

- Help us review and interpret the results of patient surveys and other data about hospital quality and safety.
- Help us develop strategies for improvement and plan changes to improve the quality and safety of care we provide.
- Have discussions with patients and families in the hospital to identify ideas for improving quality and safety.
- Participate in quality improvement projects that plan and test changes to make sure we are achieving the desired outcomes.
- Review materials we give to patients and families and help us change them to make them easier to understand and more helpful.
- Review how we partner with patients and families when they are in the hospital and help us improve the ways in which we encourage patients and families to be active participants in care and decisionmaking.
- Give presentations at training sessions for nurses, doctors, and other staff focused on improving communication, safety, and quality.

There are many ways to get involved in quality and safety initiatives. The following committees are looking for experienced patient and family advisors:

[NOTE: Insert the names and a brief description of committees that are interested in working with advisors].

- [Insert committee name and description]
- [Insert committee name and description]

## Am I ready to become an advisor for quality and safety?

Are you thinking about becoming an advisor for quality and safety but wonder whether you are ready? Complete the following checklist to see.

### I'm ready to become an advisor for patient safety when...

- I have served as a patient or family advisor at [insert hospital name].
- If I, or my family member, experienced a safety issue or medical error while in the hospital, I am coping well with the experience.
- I am ready to respectfully share my experiences and ideas about how to prevent errors and improve safety.
- I listen to and think about what others say, even when I disagree.
- I bring a positive attitude to discussions.
- I am willing to keep any information I may hear as an advisor private and confidential.
- I am willing to go through additional training to become an effective member of quality and safety teams.
- I have time in my schedule to be an advisor. Usually advisors for quality and safety volunteer between 2 to 4 hours per month.
- I can commit to serve on a committee for a minimum of 1 year.

## Please join us!

To get more information becoming an advisor for safety and quality at [insert hospital name], contact [insert contact name and information].

We are grateful to the patient and family advisors who volunteer their time and share their energy and knowledge with us. Thank you for helping [insert hospital name] be the best we can be!

# Application Form: Patient and Family Advisors



Return this form to: [Insert patient and family advisor liaison name and contact information]

## Your Contact Information

<b>Name (first and last):</b>			
<b>Street Address:</b>			
<b>City:</b>	<b>State:</b>	<b>Zip Code:</b>	
<b>Home phone:</b> (      )	-		
<b>Cell phone:</b> (      )	-		
<b>Email address:</b>			
<b>Preferred contact (circle one):</b>	<b>Home phone</b>	<b>Cell phone</b>	<b>Email</b>

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

1. **What language(s) do you speak?** \_\_\_\_\_
2. **Are you a...**
  - Patient
  - Family member of a patient
3. **The dates of my care experiences at this hospital are:** (check all that apply)
  - 2010 to current year
  - 2009
  - 2008
  - 2007
  - 2006 or before



4. **I (or my family member) received care on the following unit(s):** (check all that apply)

[Insert name of unit]

[Insert name of unit]

[Insert name of unit]

[Insert name of unit]

5. **We recognize that our patient and family advisors have busy lives. How much time do you have to commit to being a patient and family advisor?** (check one)

Less than 1 hour per month

1 to 2 hours per month

3 to 4 hours per month

More than 4 hours per month

6. **Are you available to serve as an advisor for at least 1 to 2 years?** (You can still be an advisor if you answer “no.”)

Yes

No

7. **I am interested in helping in the following ways:** (check all of your interest areas) **[NOTE: Edit the list below as appropriate for your hospital’s priorities]**

Serving as a member of the patient and family advisory council. Potential advisory council members should be ready to commit to serving on the council for at least 1 to 2 years. The advisory council meets once a month for 1 ½ to 2 hours.

Helping to develop or review informational materials for patients and family members.

Reviewing procedures and providing input to improve the hospital admission process.

Providing input to help implement bedside change of shift report, where nurses give their shift change report at the patient’s bedside.

Reviewing procedures and providing input to improve transitions in care (for example, between hospital units, or discharge from hospital to home).

Improving patient safety and the prevention of medical errors.

Improving the patient and family role in care decisionmaking.

Improving the hospital facilities (for example, patient care areas).

Helping to educate or train hospital staff and clinicians.

Other issues (please describe)\_\_\_\_\_

**Please tell us a bit about yourself by answering the following questions.**

**8. Why do you want to become a patient and family advisor?**

**9. If you have served as an advisor, been an active volunteer, or done public speaking, please briefly describe this experience.**

**10. Please describe any specific things that doctors and hospital staff did or said that were helpful to you or your family.**

**11. Please describe any specific things that you think doctors and hospital staff could have done *differently* in order to be more helpful.**

**12. We believe that our patient and family advisors should reflect the diversity of the patients and families we serve. Please share anything about yourself that you think would add to the diversity of our advisors.**

## Sample Letter of Invitation for Advisory Council Applicants

Dear [insert name],

I am pleased to invite you to join the [patient and family advisory council or name of the council if it has been chosen].

**Our first meeting will be held on [insert day and date] from [insert times] in the [insert room number or name and building number or name].**

[NOTE: Insert information about whether refreshments will be provided. Also insert logistical information about where to park, parking reimbursement and procedures, child care arrangements, stipends, or any other reimbursements provided]

At this first meeting, we will take time for introductions, review the purpose and general goals of the advisory council, discuss initial steps, answer any questions you have, and decide on the best times for future meetings.

If you cannot attend this important meeting, please let me know as soon as possible.

We are looking forward to working with you to improve our care and services at [insert hospital name]. If you have any questions before the first meeting, please feel free to contact me.

Sincerely,

[Staff liaison or key contact name, position title, and contact information]

# Sample Letter of Regret for Advisory Council Applicants

Dear [insert name],

Thank you for your interest in joining the [insert patient and family advisory council or the name of council if it has been chosen] at [insert name of hospital]. At this time, due to the limited number of positions, we will not be able to offer you a position as an advisory council member.

I would be pleased to speak with you about other opportunities for advisors or other volunteer roles that you might be interested in. If you are interested, please contact me.

We also will keep your name and contact information in our database. Please let us know if you do not want to be considered for another position in the future.

Again, thank you for your interest in serving as an advisor at [insert name of hospital]. We appreciate your desire to improve the care experience for our patients and families.

Sincerely,

[Insert staff liaison or key contact name, position title, and contact information]

# Become a Patient and Family Advisor: Information Session

**[Insert hospital name, presenter name and title,  
date of presentation]**

Organizational Partnership Tool 7: Patient and Family Advisor Information Session



# Today's session

- How do patient and family advisors help improve hospital quality and safety?
- Who are patient and family advisors? What do they do?
- What opportunities are available for patient and family advisors at our hospital?
- What is the application process?
- Questions?

# Working with patients and families as partners

---

Improving the quality and safety of hospital care

# Hospital quality

- Patients get care that is safe
- Patients get the right care for their condition
- Patients get care they need when they need it
- Patients get care that makes wise use of resources
- No differences in treatment based on race, ethnicity, income, education, or social status
- Care is patient- and family-centered



# Patient- and family-centered care

- Mutually beneficial **partnerships** among clinicians and hospital staff, patients, and families
- Core concepts:
  - ◆ Dignity and respect
  - ◆ Information sharing
  - ◆ Participation
  - ◆ Collaboration

# Patient and family engagement

- Critical component of patient- and family-centered care
- Patients and family members as:
  - ◆ Members of the health care team
  - ◆ Advisors working with staff, clinicians, and leaders to improve policies and procedures

# Goal of patient and family engagement

- 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 advisors

---

Who are advisors?

What do they do?

# Advisors: Who they are

- Patients and family members who have experienced care at our hospital
- Your experiences qualify you for the role
- We provide any additional training needed

# Advisors: What they do

- Provide input into or feedback about:
  - ◆ Policies and care practices
  - ◆ Informational materials we give to patients and families
  - ◆ Facility design
  - ◆ Your care experiences
- Your experiences are a powerful tool for inspiring change!

# Patient and family advisor opportunities at **[Insert hospital name]**

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How can I get involved?

- Note: This presentation discusses several ways of working with advisors:
  1. Patients and families as advisors on individual projects, typically on an as-needed basis
  2. Patients and families as advisory council members
  3. Patient and family advisors as members of hospital quality and safety committees
- Not all hospitals will choose to work with advisors in all 3 ways. Select and adapt the slides that are appropriate to the opportunities available within your organization, and delete the others.



# Advisors for short-term projects

- Participate in a discussion group to provide input into proposed changes in care practices or policies
- Serve as a member of a workgroup or committee
- Review, revise, or help create informational materials for patients and families
- Share your story with hospital clinicians and other staff

# Example projects

- [Insert examples of opportunities for advisors at your hospital to participate in specific projects, or include examples of past projects— e.g., review materials, participate in discussion groups, tell your story]
- [Insert photo or illustrative example]

# Advisor commitments

- [Insert info on typical time commitment for short-term advisors per month]
- [Insert info on procedures – how do advisors know when you need their assistance?]
- [Insert any information on stipends or reimbursement]

- [Note: The following slides are about patient and family advisory councils. If your hospital does not offer this opportunity, delete these slides.]

# Advisors as council members

- Patient and family advisory councils are a more formal way to create partnerships
  - ◆ Membership: Patients, families, hospital staff, clinicians
- Our advisory council
  - ◆ [Insert purpose statement or goals for patient and family advisory councils at your hospital (either in existence or planned)]

# Example advisory council projects

- [Insert examples of advisory council projects and efforts at your hospital (either based on past experiences or anticipated needs)]
- [Insert photo or illustrative example]

# Advisory council commitments

- [Insert information about how often the council meets and for how long]
- [Insert information about time commitment, term length, compensation, and training]

- [Note: The following slides are about patient and family advisors as members of hospital quality and safety committees. If your hospital will not offer this opportunity, delete these slides.]



# Quality and safety advisor opportunities

- Patient and family advisors as members of hospital quality and safety committees
- [Insert information about specific opportunities at your hospital (either in existence or planned)]
  - Names of committees

# Example quality and safety committee projects

- [Insert examples of how patient and family advisors have served or could serve as members to facilitate the work of different committees]
- [Insert photo or illustrative example]

# Quality and safety advisor commitments

- Your responsibilities as a committee member
  - ◆ [Insert info about how often the committee(s) meet and for how long]
  - ◆ [Insert information about time commitment, term lengths, compensation, training]

# Preparing to become an advisor

---

Am I ready to become an advisor?

Tips for being an effective advisor

How we will help you prepare

# The importance of your experiences

- While you were in the hospital, did you ever think there were things we could have done better or differently?

**OR**

- While you were in the hospital was there a time when you felt encouraged by us to participate actively in your care or decisionmaking?

# What does it take to be a good advisor?

- Listen to and respect the perspectives of others
- Partner with different kinds of people
- Speak comfortably and candidly in group settings
- Share insights and information in ways that help others learn
- See beyond your own experiences
- Show concern for more than one issue or agenda

# Am I ready to become an advisor?

- Patients and family members are ready to become advisors when:
  - ◆ They are willing to talk about their experience in a constructive manner
  - ◆ They are ready to work with people from different backgrounds who may have differing viewpoints
  - ◆ They are willing to keep information they hear private and confidential

# What are some tips for being an effective advisor?

- Listen well
- Ask questions
- Share your views
- Keep an open mind
- Be willing to cope with disagreement
- Ask for feedback
- Keep commitments
- Think about your story



# How will we help you prepare to be an advisor?

- Our staff liaison, [**insert liaison name**] is here to support advisors
  - ◆ Recruitment
  - ◆ Orientation
  - ◆ Coaching and training

# Questions?

- Questions from you?

# Final thoughts

- Your perspectives and experiences provide the rich data we need to improve our services
- Your participation allows us to work together to improve care experiences
- Continuous improvement is a journey, not a destination – your stories make the journey worthwhile

# Thank you!

- For questions or more information:  
[Insert name and contact information of patient  
and family advisor liaison]

## Am I Ready to Become an Advisor?

Are you thinking about becoming an advisor? Complete the checklist below to see if you are ready.

### I am ready to be an advisor when...

- I am willing to talk about my experiences as a patient or family member.
- I am coping well with the experiences I had when my family member or I was hospitalized.
- I am ready to move beyond any negative experiences I had in the hospital and respectfully share my ideas about how things could have gone differently.
- I am ready to speak up and share suggestions and potential solutions to help improve hospital care for others.
- I enjoy working with people who are different than me.
- I can listen to and think about what others say, even when I disagree.
- I can bring a positive attitude to discussions.
- I am willing to keep any information I may hear as an advisor private and confidential.
- I am willing to learn how to best serve as an advisor.
- I have time in my schedule to be an advisor. Usually advisors spend at least 1 hour a month and not more than 4 hours per month on advisor work.

Adapted from resources from the Institute for Patient- and Family-Centered Care, Bethesda, MD, [www.ipfcc.org](http://www.ipfcc.org).

## Sharing My Story: A Planning Worksheet

Use this worksheet to help plan what you want to share about your hospital experience.

<b>Key Points About Your Hospital Experiences</b>
What went well during your hospital experience? What things did people say or do that were helpful?
What did not go well during your hospital experience? What things did people say or do that were not helpful?
What improvements would you suggest?

Adapted from University of Washington Medical Center, Patient and Family Centered Care and Education Services, 1959 N.E. Pacific Street, Box 358126 Seattle, WA 98195.

## My Participation Interests

### Contact information

<b>Name (first and last):</b>			
<b>Street Address:</b>			
<b>City:</b>	<b>State:</b>	<b>Zip Code:</b>	
<b>Home phone:</b> (      )	-		
<b>Cell phone:</b> (      )	-		
<b>Email address:</b>			
<b>Preferred contact (circle one):</b>	<b>Home phone</b>	<b>Cell phone</b>	<b>Email</b>

I am interested in more information about the following activities (please check all that apply):

[NOTE: Edit the list below as appropriate for your hospital's priorities.]

- Helping to develop or review informational materials for patients and family members.
- Providing feedback on and helping to improve hospital policies, staff and clinician practices, programs, or the design of facilities.
- Helping to educate or train hospital staff, clinicians, and trainees in the health professions.
- Sharing my story with health care providers or others.
- Serving as a member of the patient and family advisory council.
- Serving on [insert name of committee].
- Other: \_\_\_\_\_.

**Thank you for your interest! Please return this form to:**

[Insert hospital name, staff liaison name, and email and phone contact information]

Component 2, Tool 11:

## **Patient and Family Advisor Training Manual**



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## About This Training Manual

This training manual is for all patient and family advisors. This manual covers:

- **Section 1.** What you should know about the responsibilities of and expectations for patient and family advisors.
- **Section 2.** Tips for being an effective patient and family advisor.
- **Section 3.** Information about hospital quality and safety and how patient and family advisors help us improve hospital quality and safety.
- **Section 4.** How things work at [insert hospital name].
- **Section 5.** Ways to learn more about health care quality, patient safety, and being a patient and family advisor.

## Section 1. Responsibilities and Expectations

As a patient and family advisor, your experiences are a powerful tool for inspiring change at our hospital. By sharing your perspectives and working with hospital staff and other patient and family advisors, you can make a real difference. The time and energy you invest helps us make important changes and improve the care experience for other patients and families.

As an advisor, there are things that we will ask you to do. There also are things we will do to make sure we are doing our best to build a strong partnership with you.

### We promise to:

- Provide you with the training you need to be an effective advisor.
- Identify a staff liaison who will help you prepare for meetings, provide you with information, and be available if you have comments, questions, or concerns about your role.
- Listen and respond to your ideas and suggestions.
- Keep you informed about how your feedback and ideas contribute to changes and improvements.
- Provide you with reimbursement for expenses related directly to your attendance at advisory meetings. [NOTE: Revise this bullet as needed based on your reimbursement policies.]

### We ask you to:

- Support and commit to the mission and vision of our hospital.
- Attend orientation and training.
- Prepare for meetings as needed – for example, by reviewing materials, reading a report, or completing a task before a meeting.
- Attend meetings as required. If for some reason, you cannot attend a meeting, please call your staff liaison. You can also ask if there is another way you can participate (for example, by phone).
- Actively participate in meetings by sharing your input and opinions.
- Maintain confidentiality. As a patient and family advisor, you may have access to protected health information about other patients. We ask that you follow the rule, “What you see or hear here, must remain here.”

## Key contacts for the patient and family advisor program

[NOTE: Insert information about who is in charge of the patient and family advisor program (e.g., the staff liaison). Include contact information and summarize the liaison's role and responsibilities. Sample text is provided below. If your hospital has an advisory council, insert contact information for the council chair or other key council contacts.]

[NOTE: insert name and correct title here] coordinates all the activities of patient and family advisors. [NOTE: She or He] will make sure you get the training you need and that you complete all the necessary requirements. [NOTE: Insert name] also works with hospital staff to prepare them to work together with patient and family advisors.

[NOTE: She or He] is always available to you by phone, email, or in-person to answer any questions you have or to discuss your participation as an advisor.

## Training and orientation

We are committed to making sure that you have the training you need to feel confident in your role as a patient and family advisor. This manual is only one part of your training. Other parts of your training will include:

- [NOTE: Insert information about other training. This may include the hospital volunteer orientation, HIPAA training, and advisor orientation. Be specific about the topics that will be covered in each part of training / orientation and the time commitment associated with each.]

## Other requirements

[NOTE: List any other requirements. For instance, will advisors have to complete a background check? Do they need any tests for TB or are they eligible for a waiver? ]

## Time commitments

The amount of time you spend on advisor activities depends on your specific role. [NOTE: Tailor this information depending on the advisory opportunities offered by your hospital.]

- [NOTE: Insert information about meetings: How often advisors meet, when meetings are held, how long the meetings are, whether there is a minimum attendance expectation.]
- [NOTE: Insert information about other time commitments outside of meetings: Time spent reviewing documents or materials, preparing for meetings, or completing other tasks.] You may be asked to review materials to prepare for a meeting. We will make

sure you have enough time to review materials. We will send these materials to you either by mail or by email, depending on your preference.

[NOTE: If your hospital will be working with advisors on a short-term basis, insert information about how advisors will be informed about opportunities.]

## Reimbursements and stipends

[NOTE: Describe any reimbursements for parking, transportation, or child care. Note any stipends. Delete this section if you will not provide any reimbursements or stipends.]

## Confidentiality agreements

As a patient and family advisor, you may have access to protected health information about other patients. It is important for you to know that any protected health information can only be used and disclosed as permitted by law. This means that protected health information cannot be shared outside the hospital or health care facility. It cannot be shared in any written, verbal, or email communications with friends, family, or anyone else unless specifically permitted. **The easiest way to remember what this means is the saying, “What you see or hear here must remain here.”** We will ask you to read and sign a confidentiality agreement to indicate your cooperation with these requirements.

## Feedback and review process

Your feedback helps us better understand how we can support you and your advisor work. The staff liaison will meet with you on a regular basis to get your feedback about how things are going. These meetings are also a chance for you to let the staff liaison know how we can improve and expand our advisory activities. During these meetings, the staff liaison will also ask you about your goals, and whether there are any areas in which you would like to strengthen or expand your skills.

[NOTE: Insert a brief narrative describing the specific feedback or review process the hospital volunteer office or unit may ask advisors to participate in (e.g., feedback survey). Also describe any process that the hospital has for working with patient and family advisors (e.g., meetings to review advisor’s work and to get their feedback about how things are going).]

## Section 2. Tips for Being an Effective Advisor

Read this section for tips from other patient and family advisors about how to be an effective advisor. As you read, make note of things that you think might be difficult for you. Discuss these with your staff liaison and ask for more help if needed.

### Six tips for being a successful advisor

#### *Tip 1. Share your views*

You have been asked to be an advisor because your ideas are valuable. You know what it is like to get care in our hospital. We want to hear your ideas about how we can help other patients and families have a good experience. We also want to hear your ideas about how we can improve the quality and safety of the care we provide.

- **Build on positive experiences whenever possible.** For example: “*We found that things worked well for our family when...*” It can be helpful to share negative experiences, but when you do, try to offer positive suggestions and possible solutions. Problem-solving is always appreciated!
- **Think carefully about the words you use.** If you want to tell a story that will bring up strong emotions, ask your staff liaison or another advisor to help you think about what you want to say and how you want to say it. Try to remember that anger usually does not produce good results.
- **Respect people’s privacy.** Feel free to share your experiences and the experiences of patients and family members other than yourself. If you do share someone else’s story, let people know that this experience did not happen to you and avoid using the person’s name. When speaking about experiences in the hospital, try not to use the names of individual staff members.

#### *Tip 2. Communicate clearly*

As an advisor, you will work with many types of people from different backgrounds. You may work with health care providers, hospital staff, hospital leaders, and other patients and family members. Good communication skills will help you explain your ideas clearly. They can also help you develop good working relationships.

- **Listen well.** When someone is speaking, it is natural to think about what you are going to say in response. However, it is important to give all of your attention to the person who is speaking and to hear them out before you respond.

- **Keep an open mind.** Keep an open mind and be willing to see past your own views and experiences. You will be working with doctors, nurses, hospital staff, and other patient and family advisors who bring their own views. These different perspectives lead to better conversations and outcomes.
- **Try not to jump to a response or conclusion about what other people are saying.** One way to make sure you understand someone’s point is to reflect back to them by saying, “*What I hear you saying is...*” and then repeating what you heard them say. This gives people a chance to clarify their points if needed.
- **Be aware of how you are sharing time with others** when you are speaking. If needed, make adjustments to give others time to express their ideas.

### Tip 3. Ask questions

When you or your family members were in the hospital, there may have been times when hospital staff used terms or language that you did not understand. That can happen when you are working as an advisor too. If it does, speak up and ask people to explain what they mean.

- **Ask clarifying questions.** For example: “*Let me make sure I understand correctly. I heard you say...*”
- **Ask for definitions of medical terms, abbreviations, or other terms.** For example: “*I’m not sure I know what Hospital CAHPS means. Would you please explain it to me?*”(See the Health Care Quality and Safety section of this training manual for information about the CAHPS® Hospital Survey.)
- **Ask for more details.** For example: “*Can you walk me through this so I can picture it?*”

### Tip 4. Be ready to cope with disagreements

Disagreements are a natural part of working on a team, even when everyone is doing their best to communicate effectively. Learning how to express your views when they are different from the views of others can be challenging. However, your honest opinion can lead to greater understanding.

- **Describe your point of view in terms of your perception or opinion** rather than as a fact or the truth for all families. For example: “*I see it differently,*” “*I have a different priority,*” or “*That doesn’t work so well for us.*”
- **Ask for more background information when people say that a change is not possible.** For example: “*Help me understand why this change is not possible. What have you tried?*” Sometimes doctors, nurses, and other hospital staff are so used to the “way

things have always been done” that it is hard for them to see other ways of doing things. Sometimes, there are things that really cannot be changed. In this case, it is important for you to understand the reasons why.

- If you find yourself upset after a meeting, talk to your staff liaison at the hospital. Your staff liaison can make sure that your concerns are addressed and help you resolve them.

### ***Tip 5. Keep your commitments***

When you agree to become an advisor, make sure you fully understand the commitment you are making, and then keep these commitments.

- If there are responsibilities that you are asked to fulfill in between meetings, come to the meeting prepared to share information about your progress on these activities and projects.
- Be on time for meetings and stay until the meetings are completed.
- If you are not able to attend a meeting in person, ask if you can call in (through conference call or speaker phone) as an option.
- If you cannot participate in a meeting at all, notify your key contact or staff liaison. Ask if you can get an update before the next meeting.
- If you find that you are having difficulty balancing your personal and family life with advisory activities, talk to your staff liaison about whether you can cut back on some of your advisor duties or take a short-term break.

### ***Tip 6. Ask for feedback***

One of the best ways to develop your skills as an advisor is to ask for feedback. Talk to your staff liaison about your participation, including what is going well, and what skills you would like to work on. Getting feedback is especially important if you would like to expand your involvement and take on new roles and responsibilities.

- If you are participating in a one-time discussion group or very short-term work group, ask your staff liaison if you can talk to them about your participation after you have completed the task.
- If you will be serving as an advisor for several months or more, ask your staff liaison to meet with you on a regular basis so that you can become aware of your strengths and areas for improvement.



- If there is a topic you would like to learn more about or some skill you would like to work on, ask your staff liaison for resources, individuals to meet with, or time to discuss it further.
- Ask for support from other advisors when you need it. And always be ready to provide support to them.
- **[NOTE: Revise this bullet according to your hospital’s review process for advisors/volunteers and according to the level of involvement of the advisor.]** The hospital’s volunteer office will have your staff liaison complete an annual review with you to identify how to continue to best support you as an advisor and to help you improve your participation as an advisor.

Above all, have faith in your participation as an advisor and keep at it! Bring your sense of humor, and expect the best from your participation.

## Sharing your story

Sharing your story can help others understand your health care experiences and how these experiences have affected you and your family.

For example, you may be asked to share your story with hospital leaders to help them understand why it is important for our hospital to work with patient and family advisors. You may be asked to help educate doctors, nurses, and other hospital staff about why it is important to conduct bedside shift report or to involve patients and families in the discharge process. Or you may be asked to speak to a group of patients and family members about becoming advisors.

Sharing your experiences as a patient or family member is a powerful way to help implement specific changes and improvements at the hospital.

We will provide you with training and support for each of these opportunities. For any invitations, you should accept only if you are comfortable with the request.

### *Before you agree to share your story*

Before you agree to share your story in a training, meeting, or presentation, get information about what is expected of you and what you can expect. Ask the following questions:

- When and where do you want me to speak? How long do you want me to speak?
- Why do you want me to speak? What do you hope will happen as a result of me sharing my story?

- Who is the audience or group? How many people will be there?
- Who else will be speaking? Will there be other patients and families? Will doctors, nurses, or other hospital staff be speaking?
- Will I be answering questions from the audience?
- Will the session be audio- or videotaped?
- Is there reimbursement for child-care or transportation?
- When do you need an answer?

### *Preparing to share your story*

If you have decided to share your story, sit down and think about what you want to say and how you want to say it. Some people write down their main points to keep them focused. You can use the worksheet below called *Sharing Your Story* to help you organize your thoughts.

Before you speak in a meeting or to a group, it also helps to practice. Time yourself and see if you are staying within the requested time frame.

As you are preparing what you want to say, think about the following questions:

- Why was I asked to share my story? What is the desired outcome?
- What am I willing to share? What do I feel is too private to share? What does my family not want me to talk about?
- What are the key messages I want to share? What are the two or three specific points that I want to the audience to remember?
- What examples can I give of when things went well? What examples can I give of things that could have gone better? What ideas do I have about how my experience could have been improved?

Also keep in mind the following tips:

- If you still feel very angry about a certain situation or event and do not think you can talk about it in a helpful manner, it may best not to share that part. You can also talk about it with someone you trust. Ask for ideas about how to share that part of the story in a way in which people will listen.
- Avoid using the names of doctors, nurses, and other staff. If you talk about another facility where you have received care, please do not mention it by name.

- Expect that some people who hear your story may be deeply moved. Also remember that you may feel emotional when you tell your story.
- If people ask you questions and you do not know the answer, say so. If you do not want to answer a question, say so.

# Sharing Your Story – A Planning Worksheet<sup>1</sup>

Use this worksheet to help plan what you want to share about your hospital experience.

<b>Key Points About Your Hospital Experiences</b>
What went well during your hospital experience? What things did people say or do that were helpful?
What did not go well during your hospital experience? What things did people say or do that were not helpful?
What improvements would you suggest?

<sup>1</sup> Adapted from University of Washington Medical Center, Patient and Family Centered Care and Education Services, 1959 N.E. Pacific Street, Box 358126, Seattle, WA, 98195

## Section 3. Health Care Quality and Safety

As an advisor, you will hear people talk about the importance of health care quality and safety. You probably have your own ideas about what it means to get good quality health care. You may be able to think of some times when you or your family member got “good” quality care in the hospital. And you also may be able to think of some times when you or your family member did not get good quality care.

One of your jobs as a patient and family advisor is to help us improve the quality and safety of the care we provide in the hospital. But what does this really mean?

### What is health care quality?

If patients are getting high quality health care, it means that:

- **Patients get care that is safe.** Patients get care that is free from medical errors. The tests and treatments they get do not cause any harm.
- **Patients get the right care for their condition.** Patients get the tests and treatments that are recommended for their condition. The tests and treatments they get are based on what research has shown works best.
- **Patients get the care they need when they need it.** There are no delays in care. Patients get the tests and treatments they need at the time when they will do the most good.
- **Patients get care that makes wise use of resources.** Patients get as much care as they need, but no unnecessary care.
- **Patients are not treated differently based on their race, ethnicity, income, level of education, or social status.** Everyone is entitled to high quality healthcare. This includes people of all cultures and backgrounds.
- **Patients get care that is patient- and family-centered.** Health care providers ask about and respect each patient's and family's values, preferences, and goals. The patient's care represents a partnership between the patient, family, and health care providers. The four core concepts of patient- and family-centered care include:<sup>2</sup>
  - **Dignity and respect:** Health care providers ask about, listen to, and respect patient and family perspectives and preferences. Patients get care that reflects the patient's and family's knowledge, values, beliefs and cultural backgrounds.

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<sup>2</sup> Advancing the Practice of Patient- and Family-Centered Care: How To Get Started. The Institute for Patient- and Family-Centered Care. Available at [http://www.ipfcc.org/pdf/getting\\_started.pdf](http://www.ipfcc.org/pdf/getting_started.pdf)

- **Information sharing:** Health care providers communicate clearly. They share complete and unbiased information with patients and families in ways that are easy to understand and act on. Patients and families receive timely and accurate information so they can participate in care and decisionmaking.
- **Participation:** Health care providers encourage patients and families to participate in care and decisionmaking to the extent they choose. Patients and families are supported in whatever way they choose to participate.
- **Collaboration:** Health care leaders work with patients and families to develop, implement, and evaluate policies and programs; partner with them to design health care facilities; work with them to educate clinicians and hospital staff; and seek their feedback about how care is provided.

## How do we know whether patients are getting quality care?

One way to tell if patients are getting high quality care is to look at whether the “right” things happen as part of the patient’s treatment. For example, do patients get the medicines they need when they are supposed to? Do they get the correct tests and treatments?

Another important way to tell if patients are getting high quality care is to **ask them about their experiences**. For example, many hospitals ask patients to fill out surveys about their experiences in the hospital.

One survey that you may hear about as an advisor is called the CAHPS® Hospital Survey. Most hospitals in the United States give this survey to patients.

The CAHPS® Hospital Survey asks patients to answer questions about how well health care providers did at sharing information and listening. The survey also asks patients to rate how well their care was coordinated, how well their pain was managed, and whether they had the information they needed to take care of themselves after going home.

### Learn more

You can see how well hospitals did on the CAHPS® Hospital Survey on the “Hospital Compare” website.

The Hospital Compare Web site also lets you compare the quality of care provided by different hospitals.

Web site:

[www.hospitalcompare.hhs.gov](http://www.hospitalcompare.hhs.gov)

Results from the CAHPS® Hospital Survey help hospitals learn where we could be doing a better job. One of the ways we may ask advisors to help is by identifying things we could do to improve patients’ experiences in specific areas measured by the CAHPS® Hospital Survey.

## Patient and family advisors working to improve hospital quality and safety

Improving health care quality and safety is a challenging task. Health care is a lot better when everyone—patients, families, doctors, nurses, and other hospital staff—works together to ensure the quality and safety of the care we provide.

Because health care quality and safety have a direct effect on patients and families, it is particularly important for patients and families to participate in changes and improvements. As a patient or family advisor, you will be asked to share your ideas about ways to improve the quality and safety of care that patients get in our hospital. This helps make sure the care and services we provide are based on “patient- and family-identified” needs rather than the assumptions of clinicians and hospital staff about what patients and families want.

*...Leaders often cite this change—putting patients in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.*

Reinertsen J. L., Bisognano, M., & Pugh, M. D. (2008). Seven leadership leverage points for organization-level improvement in health care (2nd ed.). Cambridge, MA: Institute for Healthcare Improvement.

Specific ways in which we may ask patient and family advisors to help include:

- [NOTE: Edit bullets as appropriate for the opportunities available at your hospital.]
- Participating in discussions about health care quality and safety with doctors, nurses, hospital staff, and other patients and families, including helping to identify places where errors might occur.
- Sharing ideas about how to make sure that patients and families have meaningful opportunities to participate in their care and decisions about their care.
- Revising or helping to create informational and educational materials for patients and families.
- Participating in training sessions for doctors, nurses, and other hospital staff.

## Section 4. How Things Work at [insert hospital name]

Customize this section with information to help patient and family advisors understand how things work at your hospital. Consider including the following:

- Organizational chart for the unit, hospital, and / or system.
- Mission statement.
- Who's who? A list of hospital leaders and key personnel.
- Information about who patient and family advisors report to.
- Hospital strategic plans.



## Section 5. Ways to Learn More

The Web sites listed below have information about health care quality, patient safety, and being a patient and family advisor.

### Agency for Healthcare Research and Quality (AHRQ)

AHRQ is a U.S. government agency that is part of the Department of Health and Human Services. AHRQ funds, conducts, and disseminates research to improve the quality, safety, efficiency, and effectiveness of health care. Their Web site has information to help patients, families, clinicians, leaders, and others make informed decisions about health care.

Web site: [www.ahrq.gov](http://www.ahrq.gov)

### Consumers Advancing Patient Safety (CAPS)

CAPS believes that consumers and health care providers should work together as partners to create healthcare systems that are safe, compassionate, and just. Their Web site has information and resources for patients and health care providers.

Web site: [www.patientsafety.org](http://www.patientsafety.org)

### Institute for Healthcare Improvement (IHI)

IHI is a non-profit organization dedicated to improving health care. Their Web site has resources and improvement tools to promote health care quality and safety.

Web site: [www.ihl.org](http://www.ihl.org)

### Institute for Patient- and Family-Centered Care (IPFCC)

IPFCC provides leadership to advance the understanding and practice of patient- and family-centered care. Their Web site has guidance, information, and resources related to patient- and family-centered care and how to involve patients and family advisors in the planning, delivery, and evaluation of care.

Web site: [www.ipfcc.org](http://www.ipfcc.org)

### Josie King Foundation

This Web site provides information and resources about patient safety, preventing medical errors, and how health care providers and consumers can work together.

Web site: [www.josieking.org](http://www.josieking.org)

### **Medically Induced Trauma Support Services (MITSS)**

MITSS is a non-profit organization that was founded to create awareness, promote open and honest communication, and to provide services to patients, families, and clinicians affected by medically induced trauma.

Web site: [www.mitss.org](http://www.mitss.org)

### **Medline Plus**

Medline Plus is the National Institutes of Health's website for patients and families. The Web site has information about diseases, conditions, and wellness issues in plain language. The Web site also includes a medical dictionary.

Web site: [www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus)

### **National Family Caregivers Association (NFCA)**

NFCA provides information and support for individuals who care for others who are aged, disabled, or chronically ill. Their Web site has tools and stories to educate and empower caregivers.

Web site: [www.nfcacares.org](http://www.nfcacares.org)

### **National Patient Safety Foundation (NPSF)**

NPSF is dedicated to improving the safety of patients through education and raising public awareness. Their Web site has information about patient safety issues and a variety of resource links.

Web site: [www.npsf.org](http://www.npsf.org)



## Sample Confidentiality Statement for Advisors

As a patient and family advisor here at [insert hospital name], you will be trusted with information about our hospital and patients. This may include information about patient care experiences, diagnoses, hospital quality and safety, and other sensitive information. It may also include **protected health information** about patients.

**Protected health information** includes any information about a patient's visit at [insert hospital name]. This information includes, but is not limited to, a patient's name, address, phone number, date of birth, financial information, diagnosis, and treatment.

A federal law called "HIPAA" (pronounced "hip-uh") explains what health care providers must do to safeguard protected health information. HIPAA stands for Health Insurance Portability and Accountability Act. HIPAA requires us to define the minimum necessary information to which employees, volunteers, contracted agencies, and other individuals can have access.

As a patient and family advisor, you may have access to protected health information about other patients. It is important for you to know that any protected health information can only be used and disclosed as permitted by law. This means that protected health information cannot be shared outside the hospital or health care facility, and it cannot be shared in any written, verbal, or email communications with friends or family unless specifically permitted by law.

**The easiest way to remember what this law means is the saying, "What you see or hear here must remain here."** We require your cooperation in following these rules.

**Please sign below to let us know that you have reviewed this information, understand it, and agree to it.** Signing your name means that you have read and understood the information, that you have had a chance to ask questions, and that you agree to follow these guidelines.

**Name (please print)** \_\_\_\_\_

**Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

Adapted from Leonhardt K, Bonin K, Pagel P. *Guide for Developing a Community-Based Patient Safety Advisory Council*. Prepared by Aurora Health Care, Wisconsin. AHRQ Publication No. 08-0048. Rockville, MD: Agency for Healthcare Research and Quality. April 2008.

# Working with Patient and Family Advisors: Part 1. Introduction and Overview

**[Insert hospital name, presenter name and title, date  
of presentation]**

Organizational Partnership Tool 13: Working With Advisors Health Care Professional Training  
Presentation



# Today's session

- What is patient and family engagement?
- Who are patient and family advisors? What do they do?
- What are the benefits of working with patient and family advisors?
- What are the opportunities for working with patient and family advisors?
- What are we asking you to do?

# What is patient and family engagement?

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# Hospital quality

- Patients get care that is safe
- Patients get the right care for their condition
- Patients get care they need when they need it
- Patients get care that makes wise use of resources
- No differences in treatment based on race, ethnicity, income, education, or social status
- Care is patient- and family-centered



# Patient- and family-centered care

- Mutually beneficial **partnerships** among clinicians, hospital staff, patients, and families
- Core concepts:
  - ◆ Dignity and respect
  - ◆ Information sharing
  - ◆ Participation
  - ◆ Collaboration

# What is patient and family engagement?

- Critical component of patient- and family-centered care
- Patient and family engagement means involving patients and family members as:
  - ◆ Members of the health care team
  - ◆ Advisors working with clinicians and leaders to improve policies and procedures

# Goal of patient and family engagement

- To create an environment where clinicians, hospital staff, patients, and families all work together as partners to improve the quality and safety of hospital care

# Patient and family advisors

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Who are they?

What do they do?

# Advisors: Who they are

- Patients and family members who have received care at this hospital and who want to help improve care experiences for others
  - ◆ Rigorous application and screening process
  - ◆ Training provided

# Advisors: What they do

- Help us improve the quality and safety of the care we provide
  - ◆ Provide input and feedback
  - ◆ Identify potential changes and improvements
  - ◆ Plan and implement changes that matter to patients and families

# The benefits of working with patient and family advisors

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# Benefits of working with advisors

- Engaging patients and family members as:
  - ◆ Essential members of the health care team
  - ◆ Collaborative partners in hospital policies, procedures, practices



# Benefits of working with advisors

- Help translate patient care experiences to improvements in care for others
  - ◆ Areas where things went well
  - ◆ Areas where things could have gone better (e.g., near misses, failures in handoffs, communication breakdowns)

# Benefits of working with advisors

- Long term benefits:
  - ◆ Better health outcomes for patients
  - ◆ Better business outcomes for the hospital
  - ◆ Better experiences of care – for patients, family members, clinicians, and staffs

# Why are we doing this?

- Consistency with our mission and vision
- Consistency with our strategic priorities
- Desire to demonstrate commitment to patient- and family-centered care
- Desire to be at the forefront of where health care is going

# Video

American Hospital Association / Institute for  
Patient- and Family-Centered Care Video

Patient- and Family-Centered Care:  
Partnerships for Quality and Safety

# Why are we doing this?

“In a growing number of instances where truly stunning levels of improvement have been achieved, organizations have asked patients and families to be directly involved in the process.

And those organizations’ leaders often cite this change—**putting patients in a position of real power and influence**, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.”

Reinertsen, J.L., Bisognano, M., & Pugh, M.D. (2008). Seven leadership leverage points for organizational-level improvement in health care (2<sup>nd</sup> ed.) Cambridge, MA: Institute for Healthcare Improvement.

# Opportunities for working with patient and family advisors

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- [Note: This presentation discusses three different ways of working with advisors:
  1. As advisors on short-term projects
  2. As advisory council members
  3. As members of hospital quality and safety committees
- Not all hospitals are ready to offer all three opportunities. Select the slides that are appropriate to the opportunities available within your organization, and delete the others.]

# Patient and family advisors on short-term projects

- [Insert examples of opportunities for advisors to work on short-term projects at your hospital – e.g., review materials, participate in discussion groups, tell your story]
- [Insert photo or illustrative example]



- [Note: The following slides are about patient and family advisory councils. If your hospital does not offer this opportunity at this time, delete these slides.]

# Patient and family advisory councils

- Formal group that meets regularly
  - ◆ Membership: Majority patients and families, small number of hospital staff and clinicians
- Helps hospital leadership and staff integrate and apply patient and family insights

- [Note: The following slides are about patient and family advisors as members of hospital quality and safety committees. If your hospital does not offer this opportunity at this time, delete these slides.]

# Quality and safety advisor opportunities

- Experienced advisors who have membership on quality and safety committees
- [Insert information about specific opportunities at your hospital (either in existence or planned)]
  - Names of committees

# Patient and family stories

- “Facts bring us to knowledge, but stories bring us to wisdom.”

Rachel Naomi Remen, M.D.  
Kitchen Table Wisdom

# **Working with patient and family advisors: What we are asking you to do**

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# What we are asking you to do

- Help identify prospective patient and family advisors
- Look for opportunities to involve patient and family advisors
- Create settings where planning and decisionmaking is shared
- Help create teamwork and trust between advisors, staff, and clinicians

# Identify potential advisors

- Think about patients or family members who:
  - ◆ Share insights and experiences in productive ways
  - ◆ Listen well and speak comfortably
  - ◆ Express an interest in improving health care for others
- Distribute recruitment materials
  - ◆ Brochure
  - ◆ Personal invitation and postcard



# For more information

- For questions or more information
  - ◆ [Insert name and contact information of staff liaison]
  - ◆ Attend Part 2 of this presentation: Building effective partnerships

# Working with Patient and Family Advisors

## Part 2. Building Effective Partnerships

**[Insert hospital name, presenter name and title, date  
of presentation]**

# Today's session

- What does it mean to work with patient and family advisors in “true” partnerships?
- What are some principles for effective partnerships?
- What are the opportunities for working with patient and family advisors?

# Working with patient and family advisors

- Patients and family members as:
  - ◆ Essential members of the health care team
  - ◆ Collaborative partners in hospital policies, procedures, practices

# Principles of effective partnerships

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# Principles of effective partnerships

- Practice exercise: Patient and family engagement or not?

# Scenario 1

- Three patient and family advisors are invited to join a patient safety team that is beginning an initiative to improve medication reconciliation

# Scenario 2

- An administrator invites patients and families to comment on the final plans for the facility's upcoming renovation



# Scenario 3

- A multidisciplinary committee develops new educational materials about diabetes management and treatment for patients and their families

# Scenario 4

- A surgeon asks family members, who experienced a complicated surgical procedure with their adult son, to join the surgical residents' noon conference to discuss what communication from physicians was helpful and what was not

# Principles for effective partnership

- Define a clear role for advisor participation
  - ◆ Provide opportunities to contribute where they can make a tangible difference
- Give information about purpose, goals, and intended outcomes of the effort
- Clearly define expectations, including timelines, deadlines, and responsibilities

# Principles for effective partnership

- Designate a staff member or key contact for working with patient and family advisors
- Provide background information about the project
  - ◆ Avoid acronyms and jargon whenever possible
- Actively invite participation
- Listen with an open mind

# Principles of effective partnership

- Practice exercise: Readiness to collaborate with patients and family members

# Identifying opportunities

- Practice exercise: Identify areas in which patient and family advisors could make a contribution
  - ◆ Quality improvement and safety initiatives?
  - ◆ Facility design?
  - ◆ Patient and family participation in care and decisionmaking?
  - ◆ Patient and family information and education?
  - ◆ Health information technology?
  - ◆ Clinician and staff training?

# Taking action

- Patient and family advisor request form
- Committee membership

# Thank you!

- For questions or more information  
[Insert name and contact information of patient  
and family advisor liaison]



## Working With Patient and Family Advisors

*Patient and family advisors have knowledge we don't have...It is so humbling to realize that patients and families know more about [the hospital] than you do.* Pat Sodomka, Former Vice President for Patient and Family Centered Care, MCGHealth, Augusta, GA.

### The benefits of working with patient and family advisors

Working with patient and family advisors helps us improve the quality and safety of the care we provide. Patient and family advisors:

- Offer insights that illustrate what we do well and highlight where changes may be needed.
- Help us develop priorities and make improvements based on patient- and family-identified needs rather than on our own professional assumptions.
- Bring a fresh perspective and help us come up with solutions that clinicians and staff have not thought about.

Working with patient and family advisors helps build a shared agreement around safety and quality priorities. This shared sense of priorities fosters partnerships in care, enhances the care experience, and improves outcomes.

### Working with advisors is part of patient- and family-centered care

Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of care is a key component of **patient and family engagement** and **patient- and family-centered** approaches to improve safety and quality.

As defined by the Institute for Patient- and Family-Centered Care (IPFCC), patient- and family-centered care emphasizes collaboration with patients and families at all levels of care and in all health care settings. In patient- and family-centered care, patients and families are allies for quality and safety within the health care system.

The core concepts of patient- and family-centered care are:

- **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.** Clinicians and hospital staff 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 in order to effectively participate in care and decisionmaking.
- **Participation.** Patients and families are encouraged and supported to participate in care and decisionmaking at the level they choose.
- **Collaboration.** Patients, families, clinicians, hospital staff, and health care leaders collaborate in policy and program development, in implementation and evaluation; in facility design; and in professional education, as well as in the delivery of care.

## Ways to get started

There are countless ways that you can partner with patient and family advisors. Getting started involves small steps, often working with advisors on one specific issue or project. Below are examples of some initial strategies to begin working with patient and family advisors.

- Invite two or three patient and family members to a team meeting to discuss their hospital stay. Ask them to share with the team what went well, what could have been done better, and any ideas they have for change and improvement.
- Ask patients and families to give feedback on educational materials such as patient and family handbooks, a video script of instructions for home care after a hospital stay, or care transition instructions.
- Invite patients and families 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.
- Explore your hospital and unit through the eyes of patients and their families by doing a “walk-about” to explore how your unit welcomes, supports, and comforts patients and families and encourages their active participation in care and decisionmaking. These findings will give a different kind of context for your staff discussions. Begin at the first point of entry into the hospital (e.g., the parking lot), and continue to the inpatient unit and throughout the unit, including the patient room, treatment rooms, admitting area, family lounge, and other areas visible to patients and families.

Adapted from resources from the Institute for Patient- and Family-Centered Care, Bethesda, MD, [www.ipfcc.org](http://www.ipfcc.org).

## Working With Patient and Family Advisors on Short-Term Projects

Are you (or is your unit) planning to work on a short-term project to revise or create materials or to improve quality and safety? This document can help you identify how you may be able to partner with patient and family advisors to gain valuable insight and improve the work you do.

### Examples of how advisors can participate in short-term projects

Patient and family advisors are invaluable in providing their perspective of the experience of care in our hospital. Ways in which they can contribute include:

- **Participating in a discussion group.** We can call a group of patient and family advisors together for a meeting to get feedback on a specific resource for patients and families or a specific process.
- **Revising or helping create educational or informational materials for patients and families.** Patient and family advisors can help create new materials or revise existing materials (e.g., forms, letters, handouts, and instructions). Advisors can work with you over a few months to complete the work on the materials.
- **Serving on a committee or work group.** Hospital and unit committees and work groups can invite patient and family advisors to participate for a short time period (e.g., one or two meetings) to get feedback and ideas on a specific topic.

### How are advisors selected for a project?

The staff liaison for patient and family advisors coordinates advisor participation. We have a database of all patient and family advisors that we use to identify which advisors are most suitable for your project based on available time, areas of interest, and experience.

## Steps for working with patient and family advisors

Use the checklist below to ensure effective collaboration in working with patient and family advisors.

### Prior to the first meeting with patient and family advisors:

- Prepare a brief written introduction to what you are planning to work on.
- Provide a copy of any current materials or tools you are looking to revise.
- Identify specific issues on which you would like input or feedback.
- Identify questions you would like to have answered by advisors.
- Specify the number of meetings and length of meetings you anticipate this project will require.
- Provide a list of the anticipated start date, end date, and meeting times.
- Submit the *Request for Patient and Family Advisors* form to the staff liaison (see next page).

The staff liaison will review your request and assist you in scheduling meetings and sending materials to advisors for review.

### During meetings with patient and family advisors:

- Actively listen to feedback and ideas from advisors.
- Make sure that everyone in the group – staff and patient and family advisors – is encouraged to participate in the discussion.
- Stay focused on the current project.
- Identify a feedback loop at the end of the meeting. Provide e-mail or other contact information to accept additional comments or feedback.
- Develop and share ideas about how best to follow up once you have completed the project (such as followup meeting, conference call, or timeline for a progress report.)

## Request form for patient and family advisors

Complete the following form if you are interested in working with patient and family advisors.

**Requestor's name:**

**Date:**

**Unit:**

**Contact Information:**

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**Provide a brief introduction (or context) about what you are planning to work on.**

**What specific issues would you like input or feedback on?**

**What specific questions would you like patient and family advisors to answer?**

**1.**

**2.**

**Is there anything else you would like potential advisors to know about your project?**

**Information about schedule and time commitment:**

- **What is the anticipated start date for advisor involvement?**
- **How long will advisor participation last?**
- **Will the project require a one-time meeting or multiple meetings?**
- **If multiple meetings, how frequently will you meet?**
- **How long will the meetings run?**
- **What preferences do you have for meeting days? Meeting times?**

**What activities do you anticipate advisors may have to do between meetings (include how much time activities will require)?**

**If you are revising a current tool or materials, please attach a copy.**

**Please submit this form to:**

**[NOTE: Insert staff liaison name and contact information]**

## Readiness to Partner With Patient and Family Advisors

**As a clinician or staff member, I am ready to work with patient and family advisors when...**

- I am willing to talk about my experiences as a clinician or staff member with patient and family advisors and share suggestions, ideas, and potential solutions that will help improve hospital care.
- I feel comfortable listening and respectfully responding to both positive and negative care experiences that patient and family advisors may share.
- I enjoy working with people who are different than me.
- I can listen to and think about what others say, even when I disagree.
- I can bring a positive attitude to discussions about improving hospital care.
- I consistently let colleagues know that I value the insights of patient and family advisors.
- I believe in the importance of patient and family participation in planning and decisionmaking at the program and policy level.
- I believe that patients and family members bring a perspective to a project that no one else can provide.
- I believe that the perspectives and opinions of patient and family advisors, staff, and clinicians are equally valid in planning and decisionmaking at the program and policy level.
- I believe that patients, family members, staff, and clinicians can look beyond their own experiences and issues to come up with practical ideas and solutions.
- I am comfortable requesting that patient and family advisors be invited to participate in improvement initiatives in which I am involved.