PARTNERING TO IMPROVE QUALITY AND SAFETY: A FRAMEWORK FOR WORKING WITH PATIENT AND FAMILY ADVISORS

March 2015
ACKNOWLEDGMENTS

The Symposium for Leaders in Healthcare Quality would like to thank Tanya Lord, PhD, MPH, patient and family engagement consultant, for her assistance in creating this guide.


Accessible at: www.hpoe.org/pfaengagement

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EXECUTIVE SUMMARY

Patient and family engagement is no longer a buzzword or fad but rather a strategy that hospitals and care systems have embraced as an integral part of improving quality, safety and patient outcomes. Beyond involving patients in their own care while receiving treatment, health care organizations that are leaders in patient and family engagement are intentionally and systematically partnering with patients and family members and integrating them as advisors on improvement efforts. Health care leaders should use the insights and expertise of their patients to work to achieve the Triple Aim—better care, better health and lower cost.

This guide supplements the existing literature on patient and family engagement by focusing on partnering with patient and family advisors on advisory councils, hospital committees and collaborative projects to improve quality and safety. It provides an actionable framework for leaders who are considering partnering with patients and families on improvement initiatives. To establish effective partnerships, hospital leaders must successfully: 1) recruit patient and family advisors, 2) prepare the advisors for improvement work, 3) create a culture of engagement, 4) implement improvement initiatives and measure impact, and 5) sustain the relationships over the course of many projects. See Figure 1.

Field interviews, which feature both the patient and leadership perspectives of partnering with patient and family advisors for improvement, are included in this guide, along with additional resources for hospital leaders on increasing patient and family engagement, building patient and family advisory councils and working with patient and family advisors.

**Figure 1. Framework for Hospitals Partnering with Patient and Family Advisors**

- **RECRUIT**
  - Identify patient and family advisors with knowledge of or experience with the topic at hand.

- **PREPARE THE ADVISORS**
  - Provide education and training in the basics of quality improvement.
  - Offer coaching on how to use storytelling to promote change.

- **CREATE A CULTURE OF ENGAGEMENT**
  - Explain the role of patient and family advisors and how they will contribute to the project.
  - Model a culture of partnership.
  - Encourage questions and feedback from staff.

- **IMPLEMENT IMPROVEMENT INITIATIVES AND MEASURE IMPACT**
  - Engage patient and family advisors in improvement initiatives including PDSA cycles and projects facilitated by patient safety and quality committees.
  - Measure the impact on patient satisfaction, quality, safety, and health outcomes.

- **SUSTAIN THE RELATIONSHIPS**
  - Maintain open channels of communication.
  - Update patient and family advisors on new developments with the project.
  - Share information on additional opportunities to participate in improvement projects.

INTRODUCTION

Achieving the Triple Aim—better care, better health and lower cost—requires engaging patients and families in their own care as well as in organizational improvement initiatives. Engaging patients in the care process by using practices such as shared decision making, bedside shift change, teach-back and open visitation policies improves patient satisfaction and outcomes. As outlined in the 2013 American Hospital Association Committee on Research report “Engaging Health Care Users: A Framework for Healthy Individuals and Communities,” hospitals can find many ways to engage patients beyond the bedside, including involving them in projects to improve safety and quality.

Hospitals and care systems currently are expanding beyond singular bedside interventions and engaging patients and families through focus groups and in advisory roles to use stories of patient harm to initiate change. Through these channels, many health care organizations are consulting patient and family advisors on decisions related to facility planning, patient experience and educational resources. Fewer organizations, however, have taken the next step of inviting patient and family advisors to partner on projects related to quality and safety.

This is the next frontier of patient and family engagement—using the experience, expertise and insight of patients to improve care. This guide provides a framework for health care leaders to initiate and prepare for partnerships with patients and families as advisors on quality and patient safety improvement projects.

BEYOND THE BEDSIDE

Many national health care improvement organizations support the movement toward increased engagement of patients in their own care and in hospitalwide improvement projects. For example, the Institute for Patient- and Family-Centered Care promotes four concepts to use as the core of any policy change, system redesign or improvement strategy: 1) dignity and respect, 2) information sharing, 3) participation, and 4) collaboration. These guiding concepts reinforce the value of transparency and the inclusion of patients in their health care experience and in the design of that experience.

Similarly, the American Hospital Association has emphasized the value of including patients as stakeholders in their own health care as well as in the design and operation of the health care organization. The report from the 2013 AHA Committee on Research describes the potential benefits of engaging patients in care as a “game changer in the transformation of the health care system.” To facilitate transformational change, hospital leaders must begin by preparing themselves and their employees to embrace a culture that values and encourages active participation by patients.

ADVANTAGES OF WORKING WITH PATIENT AND FAMILY ADVISORS

Partnering with patient and family advisors on improvement initiatives offers many advantages. When patient and family advisors participate in quality improvement projects, health care professionals no longer need to make assumptions about what patients value or how patients and families can contribute to safer care—they have a representative on the team to ask. Patient and family advisors challenge what is possible by offering a fresh perspective and new ideas.

In the same way that patients and families offer a fresh perspective, they add value as quality improvement partners. Many hospitals are forming patient and family advisory councils to systematically engage patients in planning and improvement projects. A patient and family advisory council is a group of patients, family members and hospital employees that
Partnering to Improve Quality and Safety

is formed to provide ideas and insights on a variety of issues including patient experience, safety, quality, care processes and other areas in which the organization may be seeking change or improvement. Establishing a patient and family advisory council is an effective way to create a formal structure to seek and incorporate patient feedback on an ongoing basis.

The scope of patient and family advisory councils varies greatly. For example, a council at St. Joseph’s Hospital in New Hampshire helped revise the educational handbook that is given to each admitted patient. At University of Massachusetts Memorial Medical Center, a patient and family advisory council produced a training video for hospital employees on treating patients with respect and dignity. In some hospitals, council members interview prospective hospital leaders to ensure that patient centeredness is integral to the hiring process. Other councils have advised on the design of new departments or office spaces to optimize the experience for patients and families. At these and other hospitals, having the patient and family voice represented in the process was a key factor in the success of the projects. Additional resources on forming patient and family advisory councils are included at the end of this guide.

Given the effectiveness of engaging patient and family advisors, hospitals have many opportunities to capitalize on advisors’ insights and expertise to accelerate patient safety and quality improvement efforts. Patient and family advisors can attend standing patient safety or quality committee meetings; be involved in short- or long-term improvement projects; or serve as patient representatives at board meetings. (See Table 1.) Wherever and whenever improvements to patient care, safety and quality are being discussed, there is value in asking patient and family advisors to be part of the team.

“At the end of the day, [patient care] can only be made better if we work together as partners and sit at that table together and come up with strategies and solutions to work with one another.”
—Hala Durrah, Patient Advisor
Anne Arundel Medical Center
### Table 1. Examples of Patient and Family Advisor Roles in Quality and Safety Initiatives

<table>
<thead>
<tr>
<th>Quality and Safety Initiative</th>
<th>Patient and Family Advisor Role</th>
</tr>
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</table>
| Task force to develop patient educational materials, communication tools and signage            | • Contribute to the design and content of materials  
• Provide objective feedback from the patient’s perspective  
• Identify language or materials that are confusing or unhelpful, as well as identify which materials are particularly well formatted and helpful  
• Assist with piloting and testing the materials and follow up with other patients to gather their opinions |
| Root cause analysis                                                                            | • Share personal hospital story, leading to a more focused commitment by the RCA team  
• Identify pieces of the process that are confusing or missing from a patient’s perspective  
• Participate in information/data gathering  
• Discuss and analyze findings  
• Assist in developing action plans and recommendations |
| Discharge planning                                                                             | • Contribute to the design of new materials  
• Review the materials and process from the end user’s (patient’s) perspective  
• Participate in rounds  
• Assist in piloting new materials |
| Patient safety committee                                                                       | • Serve as a voice exclusively from the patient’s perspective in discussions  
• Question the assumptions of practitioners |
| Process improvement teams                                                                       | • Serve on teams to reduce patient harm, such as preventable readmissions, falls and infections  
• Review materials related to improvement initiatives  
• Pilot and test new hospital processes related to quality improvement |

GETTING STARTED
Hospital leaders may be apprehensive about exposing the hospital to risk by sharing stories of harm with external audiences and thus inclined to wait for the “perfect time” to launch patient engagement initiatives. There is no perfect time, however, and waiting will only hinder and delay opportunities to improve.

Instead of focusing on the possibility of exposing errors or harm events, hospitals should focus on the opportunity to demonstrate to patients and the community the organization’s commitment to improving safety, quality and outcomes. Patients already know what does not work well in health care, and they may have stories about negative experiences. What patients may not always realize is how many people inside the hospital are working diligently on improving care. Engaging patient and family advisors in quality and safety improvement projects not only bolsters the effectiveness of the projects but also contributes to a culture of transparency and connection between the hospital and the community it serves.

**Figure 2. Framework for Hospitals Partnering with Patient and Family Advisors**

**RECRUIT**
- Identify patient and family advisors with knowledge of or experience with the topic at hand.

**PREPARE THE ADVISORS**
- Provide education and training in the basics of quality improvement.
- Offer coaching on how to use storytelling to promote change.

**CREATE A CULTURE OF ENGAGEMENT**
- Explain the role of patient and family advisors and how they will contribute to the project.
- Model a culture of partnership.
- Encourage questions and feedback from staff.

**IMPLEMENT IMPROVEMENT INITIATIVES AND MEASURE IMPACT**
- Engage patient and family advisors in improvement initiatives including PDSA cycles and projects facilitated by patient safety and quality committees.
- Measure the impact on patient satisfaction, quality, safety, and health outcomes.

**SUSTAIN THE RELATIONSHIPS**
- Maintain open channels of communication.
- Update patient and family advisors on new developments with the project.
- Share information on additional opportunities to participate in improvement projects.


RECRUITING PATIENT AND FAMILY ADVISORS AS IMPROVEMENT PARTNERS
The place to begin recruiting patient and family advisors for quality improvement initiatives is from the hospital’s or care system’s existing patient and family advisory council, if it has one. Choosing a patient and family advisor requires first identifying specific criteria or experiences that may be essential to the role. A patient and family advisor who can truly identify with the improvement initiative will likely provide the most focused and effective insights. For example, if the committee is charged with reducing patient falls, it would be helpful to include a patient who fell during a recent hospital stay or the spouse of a patient who fell. Additionally, the committee should attempt to recruit more than one...
patient and family advisor to decrease the sense of tokenism and provide participants with colleagues to whom they can turn for questions and support throughout the project.

Some patient and family advisory councils will not have a patient and family advisor who fits the quality improvement committee’s needs, and other hospitals and care systems may not yet have established a patient and family advisory council. In this case, it is helpful to reach out to hospital- or community-sponsored groups to recruit advisors. For example, a diabetes support group that meets at the local community center or a forum for new mothers seeking advice on prenatal care may have participants who are eager to improve health care. External recruitment activities include placing advertisements in hospital newsletters or publicizing patient and family engagement opportunities on the hospital’s website with a “how to get involved” tab. With their outreach and recruitment efforts, organizations should include a questionnaire and checklist so interested patients can explore the benefits they might bring to the team; better understand the expectations and commitment; and further understand the hospital’s motivation for partnering with patients. On all outreach materials, it is important to include contact information.

**Preparing Patient and Family Advisors to Be Partners**

After recruitment, patient and family advisors should receive information and training to prepare for participating in the improvement project. Table 2 provides a checklist of information to be included in the orientation process. (Table 2. Orientation Checklist for Patient and Family Advisors)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Committee history</td>
<td>» Purpose</td>
</tr>
<tr>
<td></td>
<td>» Accomplishments</td>
</tr>
<tr>
<td></td>
<td>» Barriers</td>
</tr>
<tr>
<td></td>
<td>» Background</td>
</tr>
<tr>
<td>Goals and objectives</td>
<td>» Progress</td>
</tr>
<tr>
<td></td>
<td>» Measures for success</td>
</tr>
<tr>
<td></td>
<td>» Any priority shifts</td>
</tr>
<tr>
<td></td>
<td>» Strategic objectives</td>
</tr>
<tr>
<td>Committee composition</td>
<td>» Roster and background of members</td>
</tr>
<tr>
<td></td>
<td>» Roles and responsibilities</td>
</tr>
<tr>
<td>Medical background information</td>
<td>» Current research</td>
</tr>
<tr>
<td></td>
<td>» Relevant policies and protocols</td>
</tr>
</tbody>
</table>


As a committee delves into its work, hospital staff should be conscious of including patient and family advisors in ad hoc discussions that occur outside of formal meetings. To ensure this occurs on an ongoing and timely basis, it is good practice to assign a committee member to be a patient and family advisor’s contact. This person is responsible for communicating any updates, changes or decisions that are made outside of regularly scheduled meetings and for soliciting the patient and family advisor’s input on those changes.
The hospital also should be transparent with patient and family advisors about what makes a hospital improvement committee meeting different from other meetings. Some notable differences may include:

» **Health care jargon:** Committees should explain any jargon and acronyms and establish a culture where patient and family advisors are allowed and encouraged to speak up when they do not understand something.

» **Medical terminology:** Some clinicians may speak about patients or disease progression in a manner that seems harsh or insensitive to a patient and family advisor. Those who are responsible for orienting patient and family advisors should be transparent about this and check in often to find out how advisors are reacting to what they are hearing.

In addition to this information and items on the orientation checklist, the hospital should provide some general training in the basics of improvement methodology as well as education on the organization’s specific approach to quality improvement. The patient and family advisors are not required to become performance improvement experts. However, having some background on how the organization approaches improvement work and about applicable tools and processes will help maximize an advisor’s effectiveness.

After orientation to the hospital and the advisory role, patient and family advisors should become familiar with the hospital’s improvement culture and strategies. Table 3 outlines considerations for designing improvement science orientation for patient and family advisors.

**Table 3. Orientation Topics for Patient and Family Advisors**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training in improvement science</td>
<td>» How is staff trained in improvement methodology?</td>
</tr>
<tr>
<td></td>
<td>» Is the existing training an option for patient and family advisors? If not, the organization should consider designing a brief training session or creating a collection of resources for new patient and family advisors.</td>
</tr>
<tr>
<td>Organization-specific improvement methods</td>
<td>» What methodology does the organization use for improvement (e.g., Lean, Six Sigma, PDSA)?</td>
</tr>
<tr>
<td></td>
<td>» Is there consistency in methodology across departments, or are different groups using different strategies and tools?</td>
</tr>
<tr>
<td>Mentorship</td>
<td>» Who can serve as a patient and family advisor mentor (e.g., other patient advisors or hospital employees)?</td>
</tr>
</tbody>
</table>

Patient and family advisors should receive an introduction to improvement theory, which will enable them to move beyond simply sharing their perspective and to become active members of the team. Additional training in the organization’s specific improvement methodology will help the advisors to become more comfortable and further increase their effectiveness.

Additionally, the complex nature of hospital processes may be difficult for many patient and family advisors to understand, so it may be helpful to provide advisors with an overview of how different departments and approval structures function. The better-informed and better-prepared patient and family advisors are, the more effective they will be.

**Figure 3. BEST PRACTICES FOR ENGAGING PATIENT AND FAMILY ADVISORS**

**Encourage patient and family advisors to:**

1. **Participate in a root cause analysis.** This is a specialized role, requiring effective preparation for the patient and family advisor and the committee, but the patient and family perspective can be valuable in identifying areas where things went wrong and opportunities to improve.

2. **Speak at new employee orientation.** This will set the tone for all new employees—that patients are seen as an important element of quality improvement.

3. **Interview or meet with candidates for leadership positions.** This will help to build and ensure a culture of patient centeredness.

4. **Review educational materials and signage** to improve communication, an important step in improving patient care overall.


**Maximizing Impact through Storytelling**

The most powerful tool of patient and family advisors may be their health care story. Many advisors are motivated to participate in quality and safety initiatives because of a personal experience during a hospital stay. Patient and provider stories have been the catalyst for many national patient safety and quality initiatives. Similarly, these stories can motivate and inspire action at individual organizations. By touching both minds and hearts, stories have the unique power to inspire change and improve health care. When beginning a project with new patient and family advisors, it is important to understand their stories and perspectives and how they motivate their participation in the project. It also can be helpful to coach advisors in how to tell their story in a way that maximizes the impact.

When a traumatic event occurs, individuals tell a story for three main reasons. First, they tell it to process, understand and internalize the event. Next, they tell the story to connect with others who share similar experiences. Finally, stories may be used to inspire change. Specifically, stories in health care may be used to inform, inspire and serve as a catalyst for improvement.

Before serving as an advisor, most patient or family members may have told their story for the first two purposes—for internalizing or for connecting with others. To use the story to inspire change, the advisor can learn several techniques to maximize the impact of the story.

When preparing or coaching someone in storytelling, consider emphasizing the following:
Use descriptions versus judgments: “The nurse did not answer my question” instead of “The nurse was cold hearted and left without answering my question.”

Consider impact versus intent: “I didn’t understand what the doctor said” instead of “The doctor didn’t care if I understood.”

Focus on teaching versus chastising: Stories should be told with a teaching spirit. The goal is not to chastise or punish the players in the story but rather to inspire change.

Be conscious of describing versus defending: Particularly for providers telling stories of harm, the intent is not to defend any particular action but rather for others to learn from the experience.

Emphasize information versus repetition: Focus on sharing new information, not simply reiterating the same themes.

Additional strategies to maximize the effectiveness of storytelling for improvement include:

Know the audience. Points of emphasis may change based on the audience. Understanding the audience is important for delivering the content in the most relevant and meaningful way for them.

Lead to conclusions. Instead of explicitly stating an opinion or what may be perceived as an emotionally charged opinion, present the facts that will lead the audience to draw their own conclusions. When storytellers lead with facts, they are more likely to make others agree with their conclusions.

Speak in a spirit of contribution. Storytellers should be conscious of their goal—to inform, inspire or improve. Understanding their own intention will help deliver the story most effectively to others.

Make it relatable. Particularly for stories of patient harm, it is easy for the audience to dismiss a story as something that would never happen in their organization. Emphasize parallels and similarities so that the audience relates with the story and is compelled to take action.

Emphasize key takeaways. Remind the audience of key points from the story, which will help create a path for action.

Keep details focused on a key theme. Do not be distracted by the desire to give too many details. Remember who the audience is and the story’s key takeaways and include only details that reinforce that theme.

Stories of harm include many different stakeholders, from the patient to providers to family members and friends, and it is important to consider the potential impact on all of these stakeholders. If a provider is sharing his or her version of the story, consider the potential impact on the individual as well as on the organization. The intent is not to hide or diminish the facts, but rather to avoid additional emotional trauma to the individuals involved in the incident.

The final component to telling a story effectively is for storytellers to understand the desired outcome. Patient and family advisors and the hospital should understand this perspective to help build the most productive partnerships for improvement. It is easy to sympathize with a sad story, but sympathy does not promote change. A story should touch hearts and also include a call to action. Patient and family advisors should be coached to tie their story to an action, which will help inspire, motivate and empower the audience to promote change.
Creating a Culture of Engagement

Working alongside patient and family advisors as improvement partners may be a new concept for some hospital staff. Preparing staff to work with the new advisors will help them become comfortable having patient and family advisors as team members. See Table 4.

Table 4. Preparing Hospital Staff to Work with Patient and Family Advisors

<table>
<thead>
<tr>
<th>Consideration</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link patient and family advisor involvement to specific goals and objectives</td>
<td>Identify how patient and family advisors have contributed to achieving the team’s objectives, showing that the advisors are valued as integral members of the team</td>
</tr>
</tbody>
</table>
| Provide opportunities for staff members to ask questions, express concerns and give feedback | Areas to address may include:  
  » HIPAA and other concerns related to confidentiality  
  » Concerns related to fit and culture  
  » Concerns related to disruption in existing workflows  
  Keep communication channels open, which will help alleviate any concerns early in the process and build a culture of transparency and acceptance |
| Provide a mechanism for ongoing feedback          | Periodically check in with staff members to evaluate how the partnership is working and address any barriers as necessary (typically done by committee chair) |


The goal of including patient and family advisors on a hospital improvement committee and in improvement initiatives is to engage them as equal members of the project team. Committee members may be inclined to treat patient and family advisors as “honored guests” and give them special standing or leeway on the committee. However, the patient and family advisors should receive the same professional treatment and expectations as any other committee member. Remembering that a patient and family advisor is a full member of the team and treating him or her as such will lead to a more successful partnership.

Model a Culture of Partnership

Hospital leaders have a significant impact on how patient and family advisors are received and integrated into the hospital’s operating and decision-making processes. Leaders who demonstrate an active commitment to listening and responding to patient and family advisors and who actively incorporate or address their feedback will be more successful in promoting a culture of partnership. If patient concerns are not respected or considered in meetings with the advisor and in other meetings that do not involve them, other staff in the organization will treat the patients’ contributions as unimportant. Leaders must set the expectation that patient feedback is to be considered seriously and acted upon.
Committee members should be reminded that this is a new environment and experience for patients. Patient and family advisors may be hesitant at first to speak up or contribute. Alternatively, they may be very animated and attempt to dominate the conversation. It is important for committee members to understand the patients’ experiences (i.e., harm event or other bad experience) and to have patience in incorporating advisors as effective members of the committee. Leaders must keep lines of communication open and encourage patient and family advisors and also employees to express their hesitations or concerns on an ongoing basis so they can be addressed. Building relationships and encouraging all parties to understand the perspective of others will help increase the effectiveness of patient and family advisors.

Another common concern and perceived barrier to including patient and family advisors on improvement teams relates to HIPAA privacy and security rules. Though these concerns should be taken seriously, HIPAA should not be viewed as a barrier to partnering with patients and families. The hospital should conduct HIPAA trainings for patient and family advisors, as they would for employees or other volunteers. The hospital can create guidelines on information sharing and confidentiality and may take steps to de-identify sensitive data when appropriate. The Institute for Patient- and Family-Centered Care, Agency for Healthcare Research & Quality and other organizations have created many resources to assist in this area. See the Additional Resources section.

**Implementing Improvement Initiatives and Measuring Impact**

Improvement teams must measure the success of their efforts through monitoring processes and outcomes. Measurement is an essential part of any improvement effort, whether the team aims to increase patient satisfaction scores or reduce infection rates. In addition to measuring outcomes, teams should measure the impact and effectiveness of patient and family advisors.

Hospital leaders can measure the effectiveness and success of a patient and family advisor program by examining process metrics, such as project development and team cohesion, and outcome metrics, such as patient satisfaction and safety. It is important that hospital leaders align the correct metric to each quality improvement group that has patient and family advisors. See Table 5.

**Table 5. Suggested Metrics to Track the Effectiveness of Patient and Family Advisors**

<table>
<thead>
<tr>
<th>Focus</th>
<th>Metrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Committee/project effectiveness</td>
<td>» Productivity metrics such as number of ideas generated and diversity of ideas</td>
</tr>
<tr>
<td></td>
<td>» Length of time for implementation of projects</td>
</tr>
<tr>
<td></td>
<td>» Number of successful projects</td>
</tr>
<tr>
<td></td>
<td>» Costs of projects</td>
</tr>
<tr>
<td>Patient satisfaction</td>
<td>» HCAHPS scores</td>
</tr>
<tr>
<td>Patient safety and quality</td>
<td>» Reduction in hospital-acquired conditions such as falls, pressure ulcers, infections, adverse drug events</td>
</tr>
</tbody>
</table>

Ultimately, the measure of success of a patient and family advisor program is the impact on quality, safety and health outcomes. Patient and family advisors add to the robustness of discussions, projects and interventions that are working to improve these outcomes. As contributors to project teams, advisors broaden the group’s perspective to consider new interventions to test.

One way to track activity and success is to prepare an annual report that details the project team’s activities and accomplishments to help leadership understand both the breadth and depth of patient and family advisors’ work. These reports should specifically tie the activities of patient and family advisors to the outcomes of an improvement initiative. For example, it is not sufficient to say “the organization had four patient advisors who participated in monthly safety committee meetings.” Instead, the report should include details related to the outcomes of those meetings (e.g., reduced surgical site infections by 35 percent, reduced readmissions by 10 percent) and how the patient and family advisors contributed to those goals (e.g., through providing new ideas, implementing tests of change). The Institute for Patient- and Family-Centered Care has many examples of patient and family advisory council annual reports available. See the Additional Resources section.

At MedStar Health, a health system in the Baltimore-Washington, DC, area, all patient and family advisory councils—specifically those related to quality and safety—create S.M.A.R.T. goals. S.M.A.R.T.—specific, measurable, attainable, relevant and time-bound—goals enable the organization to track progress objectively, like other committees, teams and task forces, and create a structure for accountability. These measures track results related to quality, safety and health outcomes. To further quantify the specific contributions of patient and family advisors, MedStar is developing a questionnaire to assess the participation value for its patient and family advisors, hospital employees and senior leaders.

Measurement is essential for any improvement initiative. Organizations should tie the activities and contributions of patient and family advisors to quality, safety and health outcomes. Through this intentional tracking, hospitals will be able to monitor both the substantive and financial impact of advisors and quantify the return on investment.

**SUSTAINING THE RELATIONSHIPS**

Once an improvement project ends, patient and family advisors will not have the same ability as other project team members to stay informed of the intervention’s progress. To continue building a culture of partnership with patients, families and the community, acknowledge the contributions of patient and family advisors, thank them for their commitment and keep communication channels open regarding project developments and future initiatives.

- Keep patient and family advisors on all distribution lists for emails regarding the project and future meetings. Patients will have an external email address, so remember to be mindful when sending any sensitive or confidential information.
- Invite patient and family advisors to meetings within the hospital that will address the project’s outcome.
- Invite patient and family advisors to participate in Grand Rounds or other presentations about the project, within the hospital or at outside conferences.

Engaging patients and families and striving for quality improvement can extend beyond the four walls of the hospital. Community engagement can include:

- Highlighting the success of the project in hospital newsletters, local news media and other communication venues.
» Hosting community events co-led by patient and family advisors to highlight achievements of the partnership

» Including patient and family advisors in community education forums

Take every opportunity to discuss and publicize new patient and family partnerships, not only to enhance the hospital’s reputation in the community but also to build interest among patients and recruit more volunteers. Consider promoting patient and family engagement initiatives and opportunities on the hospital’s website.

CONCLUSION

Preparation is the key for hospitals to successfully partner with patient and family advisors for quality improvement. Working with patients and families will involve a culture change that may be met with some initial resistance. To alleviate concerns and ensure success, hospital leaders must prepare patient and family advisors through orientation to the hospital as well as education on basic quality improvement principles. Leaders also must prepare hospital employees and committee members, explaining the purpose of engaging patient and family advisors and establishing metrics to track the impact of working with the advisors. The benefits and insights that hospital teams can gain by partnering with patient and family advisors will outweigh any initial challenges.

In the era of health care transformation, hospitals and health care systems cannot afford to ignore the preferences and expectations of patients. Nor can they ignore the experience, knowledge and insights of patients. Health care organizations that do not use the expertise of patients and their families risk missing a huge opportunity to drive improvement and innovation within their facility. Partnering with patients to improve care leads to improved outcomes and creates trusting relationships within the community. Hospital leaders who move quickly and systematically to create partnerships with patients will be well positioned to successfully navigate health care transformation and achieve the Triple Aim: better care, better health and lower costs for everyone in the community.

When the hospitals take that step, I have not heard one hospital say, “I wish we hadn’t brought those patients and families in.” Every single hospital is so thankful that they took that step, and they are seeing benefits to it immediately. And as it gets further down the line, they are seeing that it is saving them money, saving them time and they are getting better results.
—Lisa Juliar, Patient/Family Consultant Minnesota Hospital Association
**What is your role as a patient and family advisor?**

As a member of Baystate Medical Center’s Adult Patient/Family Advisory Council and its current chair, I have attended many of the hospital’s safety committee meetings. Before becoming a member of the safety committee and since joining, I have heard from patient advisors at other hospitals that their leadership is often reluctant to have patients serve on safety committees. As such, I expected my membership on this committee to be awkward and our interactions to be tense and uncomfortable for the hospital employees and myself. However, I have found the safety committee meetings to have the same tenor and nature as all of the others I attend. The sensitive and important information that is shared is a perfect match for the presence of patient advisors.

**Describe your experience attending meetings and working with hospital staff.**

It is apparent at every meeting how steeped the hospital is in gathering and evaluating statistics. The hospital scrutinizes every aspect of treatment to ensure the safety of the people in its care. At times, I struggle to remember the meanings of the abbreviations and language that are used, as this is a vocabulary I hear primarily at monthly meetings, not every day. However, any requests for clarification are met with a willingness to explain, and in an interesting way these responses bring the focus right back to exactly what happened with a patient. The questions I ask mimic those that patients and families would have asked. The conclusions staff makes and the actions they choose do save lives or prevent harm to people every day. However, the presence of patient advisors in the room where these events or near misses are discussed humanizes the work that they do.

**How have you and other patient and family advisors participated in meetings and discussions?**

At a recent meeting, there was a discussion about whether or not it was always appropriate to call a family member when a patient suffers a fall, with or without injury. Many factors were taken into consideration, such as the patient’s cognitive level or ability to share with his family himself what happened.

Other concerns were related to privacy. At one point, a staff member turned to my co-patient advisor and me and said, “I want to hear what they have to say.” That remark in itself captures the willingness of the group to turn from their employee perspectives to those of the patient advisors in attendance. He fully realized that a patient’s perspective is a new set of eyes, an angle to look at things not previously available during the analyses the safety committee is charged with practicing.

At another recent meeting, the report-out came in a different form than at previous meetings. Listed next to the nature of the event was the first name and age of the person affected, which helped to further humanize the event. That change was well received by all in attendance. I have come to learn just how seriously hospitals like Baystate take patient safety and the enormous effort that goes into preventing harm. Having patient advisors on a safety committee is similar to listing the names of patients harmed next to the numbers. We speak to an important truth about statistics—these numbers are actually people.
WHAT CONTRIBUTIONS HAVE PATIENT AND FAMILY ADVISORS MADE TO IMPROVE QUALITY AND PATIENT SAFETY?

At Baystate, our leadership recognized early on the contributions to patient safety that patient and family advisors can make. We have been informed and involved in safety endeavors in many contexts beyond the safety committee itself, including root cause analyses and a falls committee membership. We are there to offer our unique perspectives, to learn and pass on to others the necessity for looking out for oneself and family members when they receive care.

CONTACT

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WHAT IS THE ROLE OF PATIENT AND FAMILY ADVISORS?

Patients and family members provide significant insight and learning regarding the delivery of care, especially in critical areas of care such as safety, quality and experience. At MedStar Health, we escalated our partnership with patients and families by recruiting a team of national experts to create the MedStar Corporate Patient and Family Advisory Council for Quality and Safety with the goal of achieving zero preventable harm. MedStar Health's longstanding “Patient First” philosophy made the acceptance of such a council an easy transition in the movement toward meaningful patient engagement. The guiding principle of each corporate patient and family advisory committee meeting is open and honest discussion that stretches the health system’s idea of what transparency in the delivery of care truly means.

Council members from the systemwide patient and family advisory committee mentor each MedStar entity in the formation of local patient and family advisory committees. All 10 MedStar hospitals are well into the process of forming their own patient and family advisory committee, with most hospitals already having hosted multiple patient and family advisory committee meetings. One MedStar Health hospital has set up multiple patient and family advisory committees, each focused on quality and safety challenges related to a specific service line such as the ICU, cardiology, perinatology and the NICU.

Council members from the corporate patient and family advisory committee assist local hospitals and ambulatory care leadership in creating charters for their committees. Additionally, they created marketing materials for community recruitment, reviewed applications of community members and associates, educated community advisors on the roles they would be providing and helped lead the initial meetings until the councils felt comfortable moving forward on their own.

WHAT CONTRIBUTIONS HAVE ADVISORS MADE TO IMPROVE QUALITY AND PATIENT SAFETY?

One of the unique aspects of MedStar Health’s corporate patient and family advisory committee that sets it apart from previous council work is its focus on specific quality and safety programs across the system. Examples of committee-led programs:

» Creating a model for engaging family members to help clinical teams manage delirium in ICUs, a common condition affecting critically ill patients
» Inspiring health care professionals at the front lines by becoming the inaugural health care organization for the Josie King Hero Award, monthly recognition for MedStar caregivers who stand up for quality and safety and inspire colleagues
» Holding MedStar’s quality and safety leaders accountable to ensure that patient engagement remains a priority across the health care system

In addition, local hospital patient and family advisory committee members attend quarterly corporate patient and family advisory committee meetings so learning at the system level can be shared with local councils. Similarly, best-practice projects being conducted at the hospitals and in the community can be shared at the system level. At MedStar, we have seen firsthand the growing benefit of partnering with patients and families in our goal to provide the safest, highest quality care.

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**ADDITIONAL RESOURCES**


11. Institute for Healthcare Improvement. “Profiles in improvement: Martha Hayward, IHI lead, public and patient engagement.” Improvement Stories. [http://www.ihi.org/resources/Pages/ImprovementStories/ProfilesInImprovementMarthaHayward.aspx](http://www.ihi.org/resources/Pages/ImprovementStories/ProfilesInImprovementMarthaHayward.aspx)