How to Use the Guide to Patient and Family Engagement

The Guide to Patient and Family Engagement in Hospital Quality and Safety is an evidence-based resource that hospitals can use to develop effective partnerships with patients and family members, with the ultimate goal of improving hospital quality and safety. This document outlines four broad steps to help hospitals start the process of using the strategies and tools in the Guide.

- **Step 1**: Identify opportunities for patient and family engagement efforts at your hospital
- **Step 2**: Get commitment from and the support of hospital leadership
- **Step 3**: Form a multidisciplinary team that includes patients and families to plan implementation of the Guide strategies
- **Step 4**: Implement and evaluate the Guide strategies

Implementing the Guide strategies is similar to any type of quality improvement initiative in that it takes careful planning. There is no one correct pathway for implementing the strategies in the Guide. Hospitals should work within their individual environments and contexts to figure out what works best for them. If your hospital already has a strong process in place for implementing quality improvement initiatives, work within that existing process.

This document contains examples from hospitals that have experience with patient and family engagement, and information from Advocate Trinity Hospital in Chicago, IL, one of three hospitals that implemented the Guide strategies in a year-long pilot project.

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

† This document outlines broad steps to help hospitals get started. More specific implementation guidance is provided in the implementation handbooks for each of the four strategies in the Guide.
Step 1: Identify Opportunities for Patient and Family Engagement Efforts at Your Hospital

The Guide contains tools associated with four strategies. These strategies address critical opportunities to create partnerships between patients, families, and hospitals around the same goals. Before you select which Guide strategies to implement, think about how the strategies align with your hospital’s needs, priorities, and strengths.

Assess your hospital’s needs and capabilities

- **Review your hospital’s strategic plan.** Identify ways in which you can engage patients and families to help achieve your hospital’s short-, mid-, and long-term goals. This can help identify opportunities and priorities.

- **Assess the degree to which your hospital’s current policies and practices reflect best practices for patient and family engagement.** Conducting an initial assessment of your organization’s patient and family engagement and patient- and family-centered care policies helps you understand where your organization can make improvements. It also provides you with baseline data by which to assess improvements.

- **Review quality information and data related to core hospital processes.** Look at any quality information your hospital currently collects to identify areas for improvement. For example, many of the CAHPS® Hospital Survey measures reflect key elements of patient and family engagement — particularly those related to patient-provider communication, pain management, medications, and the provision of discharge information. It can also be helpful to examine patient feedback, such as phone calls or letters, or recent events at the hospital. Focus on both positive and negative feedback and events.

- **Get input from clinicians, hospital staff, patients, and families.** Gathering input from clinicians, hospital staff, patients, and families on experiences, ideas for changes and improvements, and questions or concerns can help define the care experience at your hospital and create a shared vision of what the ideal experience would look like. Getting input from these parties also can help you identify potential barriers to implementing patient and family engagement generally (and the Guide specifically) and begin to gather input about how to address these barriers. If your hospital is working with patient and family advisors, this is a great
time to reach out to them to help assess your hospital’s strengths, areas for improvement, and ways in which the Guide strategies can contribute to improvements.

Visitation policies and patient and family engagement

It is difficult for organizations to provide patient- and family-centered care if times for family presence are limited. Families should be “respected as part of the care team — never visitors — in every area of the hospital, including the emergency department and the intensive care unit.” Therefore, it is helpful for hospitals to review (and change if needed) policies related to visitation and family presence. The term “family” has many meanings and can include bonds created by marriage, ancestry, close friendships, shared child rearing, and romantic relationships. Patients should be allowed to define who their “family” is and how they want them involved.

In November 2010, the Centers for Medicare & Medicaid Services (CMS) and the U.S. Department of Health and Human Services announced a new rule granting patients the right to choose their own visitors during a hospital stay. Under this rule, hospitals are required to explain to all patients their rights to choose who may visit them during an inpatient stay and to note that “visitors” may include family members, friends, or any other type of visitor. For hospitals, the consequences of not adhering to this broad definition of visitors could include being barred from participating in the Medicare and Medicaid programs.

Some resources that may help your organization assess family visitation policies are:

- **Are Families Considered Visitors in Our Hospital or Unit?** is a checklist from the Institute for Patient- and Family-Centered Care that is designed to help hospitals examine their practices and infrastructure to assess how well patient and family presence and participation is supported. Available at: [http://www.ipfcc.org/advance/arefamiliesvisitors.pdf](http://www.ipfcc.org/advance/arefamiliesvisitors.pdf)

- **Changing Hospital Visiting Policies and Practices: Supporting Family Presence and Participation: Executive Summary**, also from the Institute for Patient- and Family-Centered Care, provides guidelines with respect to changing hospital visitation policies and practices and includes examples of policies. Available at: [http://www.ipfcc.org/visiting.pdf](http://www.ipfcc.org/visiting.pdf)
Review the *Guide* Strategies

After assessing your hospital’s needs and capabilities, review the strategies in the *Guide* to see which ones help address identified needs, build on capabilities, and match with your hospital’s strategic priorities. The four strategies included in the *Guide* are:

- **Strategy 1: Working With Patients and Families as Advisors** shows how hospitals can work with patients and family members as organization-level advisors by providing a mechanism for involving patients and family members in policymaking; facility design; and the planning, delivery, and evaluation of care.

- **Strategy 2: Working With Patients and Families at the Bedside: Communicating to Improve Quality** helps improve communication between patients, family members, clinicians, and hospital staff from the point of admission, including giving patients a clearer understanding of how to ask questions, who to go to for information or help, and how to participate in their care.

- **Strategy 3: Working With Patients and Families at the Bedside: Nurse Bedside Shift Report** supports the safe handoff of care between nurses by involving the patient and family in the change-of-shift report for nurses.

- **Strategy 4: Working With Patients and Families at the Bedside: Care Transitions from Hospital to Home: IDEAL Discharge Planning** helps reduce preventable readmissions by engaging patients and family members in the transition from hospital to home.

Hospitals can implement as many or as few of the strategies as desired. However, Strategy 1 (Working With Patients and Families as Advisors) is a foundational strategy that can help lead to real organizational change. Hospitals that participated in the *Guide* pilot implementation project reported that working with patient and family advisors contributed to cultural change and a heightened awareness of the importance of patients and families in planning and delivering care. For the bedside strategies (Strategies 2 through 4), multiple strategies can be implemented together or in sequence.
Step 2: Get Commitment From and the Support of Hospital Leadership

Having leaders who can advocate for and participate in change initiatives significantly increases the likelihood of learning, innovation, and sustainability.\(^3\) Hospital leaders communicate the importance of partnering with patients and family members, provide resources, and set the tone for effective partnerships.

In some cases, the impetus for patient and family engagement originates from the top leadership level (e.g., the hospital board, the C-suite, or clinical leadership). In this case, hospital leaders may already be involved. In other cases, the impetus for patient and family engagement comes from unit leaders or other key individuals, and you will need to feed information upward.

Regardless of where the effort originates, organizational change for patient and family engagement requires strong leadership at multiple levels:

- **Boards of directors** play a critical role in setting the tone for the entire organization.\(^5\)
- **Senior leaders** (e.g., members of the C-suite) ensure that the organizational transformations required for patient and family engagement efforts occur.
- **Clinical leaders** assume responsibility for the ongoing program, set expectations for superior performance, model behaviors, and mobilize improvement efforts.\(^6\)\(^-\)\(^8\)
- **Other hospital leaders**, such as unit managers, ensure that engagement efforts occur daily.

How to bring senior leaders on board

Research conducted to evaluate the Guide found that having visible support from senior hospital leaders was one of the critical elements for successful implementation of the Guide strategies. “Visible support” included highlighting the hospital’s focus on providing patient- and family-centered care in communications with staff, ensuring necessary resources for implementation, and modeling desired behaviors via activities such as leadership rounds.

If senior leadership is not already involved, it is helpful to develop a succinct explanation of what you want to do, why you want to do it, and what resources you will need. When talking to hospital leaders, keep your rationale short and sweet. Talk about how patient and family engagement:
• Relates to and can help achieve your hospital’s strategic goals or key areas outlined in the mission statement, vision statement, and strategic plan

• Can help your hospital realize quality and safety improvements (e.g., improvements in CAHPS Hospital Survey scores, decreases in length of stay, and reductions in preventable readmissions)

• Can lead to improved staff satisfaction

• Can lead to improved financial performance due to decreased litigation and malpractice claims, fewer complications, and shorter lengths of stay

• Can help differentiate your hospital from other competitors by establishing a brand identity around patient and family engagement

• Relates to issues of local or regional importance (e.g., any high-profile stories about hospital quality; safety issues; existing or proposed legislative mandates, such as Massachusetts’ mandate that hospitals create patient and family advisory councils; or any issues that have occurred recently at your hospital)

Having a face-to-face conversation can be helpful in identifying and allaying concerns, as shown by the experiences of one of three hospitals that implemented the Guide in a year-long pilot project. At Advocate Trinity Hospital in Chicago, IL, the clinical manager of a medical-surgical unit was responsible for overseeing implementation of the Guide strategies. The clinical manager met with Trinity’s patient safety committee chair to discuss bringing patient and family advisors into the committee. Although the patient safety committee chair was initially hesitant about liability and legal ramifications, the clinical manager was able to allay these fears by walking the committee chair through the Guide materials on working with patient and family advisors.

During conversations with senior leaders, discuss any data you have collected during Step 1, such as information from patient experience of care surveys, CMS quality care measures, or informal feedback from patients and families. Think about your leadership audience and what issues are likely to be most compelling (e.g., financial or personal stories) to help you make the argument.

It is also important to outline the overall aim and scope of your effort, either in the initial conversation or subsequent conversations. This includes providing specific information about which Guide strategies you want to implement, what resources will be involved, and what baseline data you are trying to improve.

Once you have reached out to hospital leaders, it is important to promote and sustain their interest. Even if senior leadership is already engaged, the tactics below may help reinforce or sustain their commitment to patient and family engagement. Also remember that building a base of support and obtaining buy-in is not a one-
time occurrence. Regular communication emphasizes the ongoing opportunities for and benefits of patient and family engagement.°

**Check in with hospital leaders at meetings**
Throughout the process of identifying areas for improvement, selecting the Guide strategies to implement, and implementing and evaluating the strategies, it is important to ensure the continued engagement of hospital leadership. One way to do this is to ask for time on the agenda at regular senior leadership and board meetings, at clinical leader meetings, or at clinician staff meetings to provide updates on your efforts. If possible, ask a patient or family member who has received care at your hospital to attend the meeting with you. One of the most powerful ways to convince senior leaders of the merits of patient and family engagement is to create connections with patients and family members.°,°° If a patient or family member cannot attend in person, solicit and share a few stories.

**Have leaders conduct rounds with patients and families**
Another way to promote patient and family engagement is to have leaders conduct rounds with patients and families. Leadership rounds are regular announced or unannounced visits in which leaders interact directly with patients and families, either by visiting current patients on specific units or by inviting patients and family members to scheduled chat sessions. Leadership rounds offer the opportunity for leaders to observe staff, clinicians, patients, and family members and talk with them in a nonthreatening way about quality, safety, and other related issues. Rounds often include personal discussions with patients and staff that allow leaders to hear firsthand what is happening on the front lines of care and solicit suggestions for improvement.°°°°° These conversations can give leaders a good sense of the potential value of patient and family engagement and help inform dialogue in the board room.°°° A good way to get board members involved is to hold leadership rounds before regularly scheduled board meetings.

**Invite staff and leadership to do a walkabout**
Walkabouts help hospital leaders explore the hospital experience through the eyes of patients and family members. If possible, invite several patients or family members to participate in this activity. 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 rooms, treatment rooms, admitting area, family lounge, and other areas visible to patients and families. At each point, observe how the hospital welcomes, engages, and supports patients and families. These findings will give a different context for meetings and discussions.

Both leadership rounds and walkabouts are additional ways to gather data and identify potential areas for improvement.

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**Guide Resources**

**Strategy 1, Implementation Handbook: Working With Patients and Families as Advisors** has detailed information about how to conduct a walkabout.
Step 3: Form a Multidisciplinary Team that Includes Patients and Families to Plan Implementation of the Guide Strategies

Patient and family engagement creates an environment in which hospital leaders, clinicians, hospital staff, patients, and families work together as partners to promote improvements in care. Therefore, all of these groups, including patients and families, should be represented on a multidisciplinary team that has responsibility for planning and implementing your patient and family engagement efforts.

In cases where your hospital is starting from a blank slate in identifying areas for improvement, task the multidisciplinary team with gathering and reviewing a variety of information to help identify needs (as described in Step 1). In cases where your hospital already has identified key improvement areas, ask the multidisciplinary team to weigh in on and prioritize these areas. The multidisciplinary team can help clarify these ideas and ensure that everyone’s perspectives are reflected.

Recruit team members

The composition of the multidisciplinary team will vary depending on what works best for your hospital. Ideally, the team will include clinician and hospital staff champions, other key staff, and patient and family advisors. Also think about ways to ensure that hospital leaders either sit on the team or are informed about your efforts.

- **Clinician and staff champions.** Respected by their peers within their area of expertise, champions help achieve buy-in by engaging their peers on a different level than top management. Over time, champions can help convince their peers of the quality and safety benefits of patient and family engagement and also model best practices and behaviors. Recruit individuals who have an interest in working with patients and family members, are respected by both senior leaders and their peers, and have the passion and skill set necessary for planning patient and family engagement efforts.

- **Other key staff.** To broaden the multidisciplinary team’s reach, include other staff members who can help promote and support patient and family engagement. These additional staff members will depend on your organization but may include child and family life specialists; social workers; heads of quality and safety committees; and staff from patient affairs, family services, patient- and family-centered care, or quality improvement departments.
• **Patient and family advisors.** Patient and family members are critical members of the team. They should not be token members and should have the same voice and presence on the committee as hospital clinicians and staff. If your hospital already works with patient and family advisors, ask several of them to sit on the multidisciplinary team. If your hospital does not have experience working with patient and family advisors, look for several patients or family members who have had recent care experiences at your hospital and who are interested in helping to make improvements.

• **Hospital leaders.** To be effective, patient and family engagement must be integrated into the organizational culture. Therefore, involving hospital leadership is critical to promoting and supporting change. Hospital leaders (e.g., board members, the chief executive officer, the chief medical officer, the chief nursing officer) may not need to be involved on an everyday basis, but consider ways that the team can report to and engage senior leadership on an ongoing basis. Also think about other leaders to involve (e.g., unit directors and nurse managers).

### Plan implementation

If priorities for patient and family engagement have not yet been identified, the multidisciplinary team can help clarify them and identify which Guide strategies are the best fit for your hospital (as in Step 1). In selecting strategies, think about providing opportunities for success as a pathway to wider scale change.

Three hospitals that participated in a year-long pilot implementation of the Guide found that a key to success was beginning with implementation of the Guide bedside strategies (Strategies 2 through 4) on a single, higher performing unit. This allowed hospitals to target their resources and focus attention on achieving small-scale success before large-scale implementation. An added benefit of beginning implementation on a single unit was that it fostered a sense of unit pride and enabled staff to serve as champions for the large-scale roll out.

The multidisciplinary team also can help set time-specific goals, establish measures of improvement, use a standardized process for implementation, measure progress toward goals, and provide timely feedback about that process. These are all things done by hospitals that are top performers in quality, safety, and patient and family engagement. Use your multidisciplinary team for input about how to adapt the strategies and tools in the Guide for your hospital.
Step 4: Implement and Evaluate the Guide Strategies

Implementation

An implementation handbook accompanies each of the four strategies included in the Guide. These handbooks contain information, guidance, and specific instructions to help your organization plan and implement each strategy.

The checklist below summarizes critical steps to be completed in planning for implementation. Regardless of the order in which these steps are conducted, completing all of these activities will help you get the most out of the Guide strategies and resources.

Implementation Checklist

- Assess your hospital’s needs and capabilities
  - Review the hospital’s strategic plan and short- and long-term goals
  - Assess the hospital’s current policies and practices for patient and family engagement, including family visitation policies
  - Review quality information and data related to core hospital processes
  - Get input from clinicians, hospital staff, patients, and families
- Identify which strategies are the best fit for your hospital’s needs and capabilities
  - Review the Guide strategies and materials
  - Identify strategies that reflect the hospital’s priorities
- Get commitment from and support of hospital leadership
  - Develop a succinct explanation for senior leadership of what you want to do, why you want to do it, and what resources you will need
  - Reach out to hospital leaders via regular meetings, rounds with patients and families, or walkabouts
- Identify the overall scope and aims for the Guide strategy — either initially with senior leadership or with the multidisciplinary team
- Form a multidisciplinary team to plan implementation
  - Recruit team members, including clinician and staff champions, key hospital staff, patient and family advisors, and hospital leaders
  - Review data and information collected in Step 1 and prioritize or clarify areas for improvement
Finalize which strategies will be selected for implementation
Identify which unit or units will implement the Guide strategy or strategies
Adapt the Guide tools for your hospital

Identify ways to evaluate implementation (see more information below)
Identify potential data sources
Identify ways to collect and analyze information
Identify ways to provide feedback to staff and senior leadership

Evaluation

Organizations engaging in patient and family engagement initiatives need to create structures and metrics to evaluate their impact. Evaluating patient and family engagement efforts and attributing the results of engagement efforts can be challenging. The implementation handbooks for each of the Guide strategies provide guidance on ways to assess the success of your efforts. Ongoing evaluation:

- Assesses the effectiveness of interventions and whether they should be continued, expanded, or made permanent
- Identifies and addresses any problems to stimulate ongoing improvement
- Keeps key stakeholders apprised of progress in meeting key priorities related to patient and family engagement
- Keeps individuals engaged and enthusiastic by demonstrating whether goals and objectives are being met

Evaluation of patient and family engagement efforts can also inform the annual performance review, compensation, and determination of awards and recognition for both individuals and departments. Hospitals can incorporate patient and family engagement measures into existing performance dashboards that include metrics related to key strategic areas outlined in the mission statement, vision statement, and strategic plan. Initially, such measures may relate to processes, such as having a patient or family advisor on a short-term project. Over time, metrics included on dashboards may evolve into more outcomes-oriented measures, such as CAHPS Hospital Survey scores, including overall scores and scores on questions that relate more directly to the patient and family experience and level of patient and family engagement.
Hospital Examples:
Adding Questions to Patient Experience of Care Surveys to Assess Patient and Family Engagement Strategies

Valley View Hospital in Glenwood Springs, CO, added survey questions to its experiences of care survey to address five issues related to patient and family engagement.¹⁵

- Staff effort to include patients in decisions about treatment
- Extent to which patient and family are educated on how to report concerns related to care, treatment, services, and patient safety
- Extent to which patient and family are educated on how to request additional assistance if an urgent response is needed
- Extent to which staff checks two forms of identification before giving medications, drawing blood, or transporting for a test
- Extent to which staff cleaned/sanitized their hands before examining the patient

The University of Washington Medical Center added these questions to its survey:¹⁵

- Degree to which patient and family could participate in care decisions
- How well staff explained their roles in care
- Degree to which staff supported family members throughout the health care experience
- Degree to which the patient’s choices were respected to have family and friends present during care
- Degree to which staff respected the family's cultural and spiritual needs
References


