Contract Final Report

Guide to Patient and Family Engagement: Environmental Scan Report

Prepared for:

Agency for Healthcare Research and Quality
Rockville, MD

Contract HHSA 290-200-600019

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American Institutes for Research

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AHRQ Publication No. 12-0042-EF
May 2012

Suggested citation:

Maurer M, Dardess P, Carman, KL, et al. Guide to Patient and Family Engagement: Environmental Scan Report. (Prepared by American Institutes for Research under contract HHSA 290-200-600019). AHRQ Publication No. 12-0042-EF. Rockville, MD: Agency for Healthcare Research and Quality; May 2012.

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Executive Summary

This goal of this project is to promote patient and family engagement in hospital settings by developing, implementing, and evaluating the *Guide to Patient and Family Engagement: Enhancing the Quality and Safety of Hospital Care* (hereafter referred to as the Guide). The Guide will comprise tools, materials, and/or training for patients, family members, health professionals (e.g., hospital clinicians, staff), hospital leaders, and those who will implement the materials in the Guide. Our preliminary vision of the Guide included four components, each with a series of "tools" (e.g., materials, resources, items for training): (1) Patient and Family Active Involvement Materials; (2) Patient and Family Organizational Partnership Materials; (3) Health Professional Materials; and (4) Leadership and Implementation Materials. The tools in the Guide are intended to:

- Support the involvement of patients and family members in the safety and quality of their care.
- Encourage the involvement of patients and family members in improving quality and safety within the hospital setting.
- Facilitate the creation of partnerships between health professionals and patients/family members.
- Outline the steps needed to implement changes.

Purpose and Methods

This report presents the results of the environmental scan that serves as an evidence-based foundation for the development of the Guide. In conducting this environmental scan, our intent was to: be comprehensive while targeting topics and questions that are directly relevant to the goals of the project; reflect the concepts of consumer engagement and patient- and family-centered care around the issues of patient safety and quality in the hospital setting; and incorporate diverse input and perspectives from multiple individuals and organizations representing patients, families, health professionals, and hospitals.

We developed a working definition of patient and family engagement and a guiding framework to organize and inform our search. From the framework, we identified five main topic areas for further investigation:

1. Individual characteristics, perspectives, and needs of the target audiences—patients, families, and health care professionals—with regard to patient and family engagement.
2. Organizational context within hospitals, including culture, and its influence on patient and family engagement.
3. Hospital-based interventions and materials that are designed to facilitate patient and family engagement, particularly around the topics of safety and quality.
4. Specific content areas for the Guide.
5. Best methods for dissemination of the Guide.

The environmental scan was conducted from November 2009 to February 2010 and gathered information through internal team input, key informant interviews, and a review of the peer-reviewed and grey literature, as well as by identifying and assessing relevant tools and interventions. The team scanned the medical and social science peer-reviewed literature—including both descriptive qualitative and quantitative studies—using PubMed, PsycInfo, CINAHL, and the Cochrane databases. To scan the grey literature, we gathered documents from the Agency for Healthcare Research and Quality (AHRQ), the project team, and external experts during the key informant interviews. In addition, we conducted a more targeted search of 110 Web sites recommended by our partners for non-peer-reviewed literature and potential tools. In total, 238 peer-reviewed and grey literature articles were reviewed and abstracted; we also assessed the content of 330 tools and assessed the usability of approximately 80 tools.

Findings

We have grouped our findings according to the main categories identified in the preliminary conceptual framework:

- Individual characteristics, perspectives, and needs of the target audiences—patients, families, and health care professionals—with regard to patient and family engagement.
- Organizational context within hospitals, including structures and processes that influence patient and family engagement.
- Hospital-based interventions and materials that are designed to facilitate patient and family engagement, particularly around the topics of safety and quality.

Here we briefly summarize what we learned from these three categories of information.

Individual Characteristics of the Target Audiences

Quality and safety. Both patients and providers tend to think that the quality of care they receive or give is generally good, despite evidence that suggests this is not always true. However, they do not always share the same views of what constitutes quality or safety. Providers tend to focus on the clinical aspects of care, while patients and family members focus on interpersonal interactions.

As with quality, patients and providers can differ in their perspectives on patient safety, and patients may not understand safety as researchers or other experts define it. Patients define patient safety more narrowly in terms of medical errors. In addition, providers may feel that errors are primarily under an individual's control and therefore place less emphasis on the importance of system-level changes.

Engagement. Conceptually, both patients and providers support patient and family involvement and participation in their own care and recognize that it can lead to better patient experiences and outcomes. Patient and provider support for participation becomes more uncertain when patient engagement includes a higher level of involvement—for example, making diagnosis or treatment decisions.

Most of the literature on patient and family engagement roles focuses on what patients could do (or what researchers and policymakers want patients to do) instead of discussing what behaviors patients and family members currently engage in or would be willing to engage in during clinical encounters.

In general, the literature suggests that patients are more likely to engage when the goal relates to obtaining specific information about their care (e.g., asking questions to get information about their condition, treatment, functional activities, or discharge). Patients are less likely to engage when faced with behaviors that seem new or confrontational (e.g., asking providers to wash their hands or mark surgical sites).

Barriers and facilitators. Barriers to engagement for patient and family members include fear, uncertainty, low health literacy, and provider reactions. Facilitators include self-efficacy, information, invitations to engage, and provider support. For providers, barriers to support patient and family engagement include professional norms and experiences, fear of litigation, and perceived level of effort. Facilitators for providers include those factors discussed in the organizational context section.

Organizational Context

Motivation. We examined potential external and internal motivators for organizations to encourage patient and family engagement in safety and quality. Key external motivators include the desire to imitate competitors, health care legislation or mandated policies, leadership from influential bodies, alignment of financial incentives; public reporting, and accreditation and awards. Key internal motivators included the occurrence of a sentinel event, the business case for patient and family engagement, the desire to improve quality and safety performance, stories from patients and families, and altruism.

Organizational structure. Structural aspects of a hospital that influence the ability to initiate and sustain change include the size of the hospital, profit or academic status, and medical staff organization. Although there is general recognition of the potential influence of structural factors on an organization's ability to adopt and sustain innovations, there is insufficient evidence about whether and how these structural factors act specifically as barriers to or facilitators of change.

Organizational processes. A number of processes affect an organization's ability to implement and sustain change. These include: the organization's understanding of and experience with patient and family engagement, the existing quality and safety culture, the strength of leadership at all levels, the hierarchy (whether rules, regulations, and reporting relationships are emphasized), the existence of slack resources (cushion of resources that can be used in a discretionary manner), absorptive capacity (ability to identify, capture, interpret, share, reframe, and recodify new knowledge to link it with its own knowledge base, and to put it to appropriate use), and internal alignment (consistency of plans, processes, information, resource decisions, actions, results, and analysis to support and/or change key organizational goals).

Implementation strategies. Organizational strategies to foster change within the hospital setting include pre-implementation strategies such as conducting an initial assessment of the proposed change, developing and fostering a shared vision, developing a clear plan for implementation, obtaining buy-in, providing an infrastructure, aligning internal incentives for participation, and considering sustainability from the beginning. Strategies during interventions include engaging staff at all levels, engaging an internal champion, communicating consistently throughout the process, using appropriate tools, and collecting data and feedback.

Interventions and Strategies

We found two broad types of strategies or interventions that promoted or facilitated patient and family engagement: hospital-level and individual-level strategies. Hospital-level interventions[a] are implemented by means of changes in hospital policies, processes, systems, procedures, or

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[a] We use the term "hospital level" interventions with the understanding that hospital level could imply hospital systems as well as individual hospitals.

structures. Individual-level interventions are designed to change individual knowledge, attitudes, or skills by means of tools for educating, informing, activating, and engaging individuals. The two types of interventions are not mutually exclusive. That is, individual-level tools may support hospital-level interventions and uptake of new individual behaviors may be facilitated by hospital-level support. With either type of strategy, there was a lack of evidence-based information associated with outcomes.

Hospital-level strategies. We grouped the hospital-level strategies into four main categories:

- *Health care team*. Interventions and strategies used to engage patients and families as members of their health care team include bedside rounds, bedside change of shift reports, patient- or family-activated rapid response teams, specific efforts to encourage family participation, and access to medical record information by patients and family members.
- *Facilitating communication*. Procedures and policies to assist patients and family members in communicating with providers include understanding which staff members are involved in the patient's care and strategies to guide clinician-patient encounters.
- *Increasing patient knowledge, skills, or abilities*. Hospital-level strategies to increase patient and family engagement include supporting patients and families in care coordination, establishing systems for patients and family members to track medications and health records post-discharge, communicating with physicians, and providing access to health information.
- *Input into management and processes*. Strategies for involving patients and family members in management and processes within the hospital include establishing patient and family advisory councils, introducing other opportunities for patients and families to be involved, and eliciting patient and family feedback.

Individual-level strategies. We reviewed publicly available tools, resources, and relevant literature. We discuss the tools according to the following components of the Guide:

- *Component 1 (Patient and family active involvement)*. The majority of tools fell into this component. The main topics addressed were patient safety, communication with providers, patient engagement and activation, care coordination, and infection prevention.
- *Component 2 (Organizational partnership)*. Tools were available to help hospitals implement Patient and Family Advisory Councils and provide other opportunities for engagement at this level. A smaller number of tools provided guidance for patients and family members about assuming these roles.
- *Component 3 (Health care professional)*. Most of the tools were targeted at clinicians instead of the broader "health professional" audience. However, the tools did not make distinctions between physicians and nurses. Main topics included communication with patients, infection control, teamwork and communication training, and provider training on implementation strategies.
- *Component 4 (Hospital leadership and implementation)*. Most tools related to this component focused on steps or tips for hospitals to promote and support organizational change and included assessment tools.

Format. Across all components, most tools reviewed were paper-based and included brochures, handouts, flyers, posters, checklists, booklets, and handbooks.

Implementation guidance. Most of the tools reviewed related to Component 1 (patient and family active involvement) and Component 3 (health care professional) but lacked detailed supporting guidance for how to implement them. Overall, more guidance and instructions were available for Component 2 (organizational partnership) materials.

***Usability*.** Overall, our usability assessment indicated that although several tools provide a strong base of information to build on, few can be used “as is” without additional testing or modification.

Overall Strength of Evidence

Reasonably strong evidence is available from related fields, but existing approaches to and resources and tools for patient and family engagement lack a strong evidence base to support evidence of efficacy or effectiveness. Because patient and family engagement in quality and safety is a newer field, we have drawn on fields with stronger evidence (e.g., systematic reviews of patient-provider communication or shared decisionmaking). Most studies reviewed tended to be single descriptive studies or case studies. Overall, evaluations of implementations lacked strong designs. Similarly, in our review of the tools, little information was available on whether the tools had been developed with input from the target audiences or whether they had been evaluated for efficacy, effectiveness, or feasibility.

Discussion

In addition to identifying literature and tools available to support patient and family engagement, the environmental scan sought to identify gaps in subject matter (i.e., content) and in the appropriateness (i.e., usability) of materials for the intended target audiences.

Gaps in Content and Topic Areas

- **Content gap 1: Strategies are not attuned to patient and family member experience of hospitalization.** One existing gap is the lack of tools that are based more equally on patient and family perspectives and that focus on the priorities of patients and families during hospital stays—as opposed to tools that are more reflective of health professional and hospital views and organization of their work.
- **Content gap 2: Lack of individual tools to support hospital-level strategies**. Many hospital-level interventions may not have tools at an individual level (for both patients/families and providers) to support their effectiveness.
- **Content gap 3: Lack of concrete, actionable support for individual users to engage in behaviors**. In evaluating the individual-level tools to support patient and family engagement efforts, we found that the tools often lack concrete, actionable support for individual users. We identified general information about patient safety topics, information that patients and families should generally know about the hospital, and many tools for patients and families to communicate with their providers, both generally (e.g., questions to ask about prescribed medications), and specifically (e.g., safety topics like hand washing). However, providing general information or instructing individuals to ask a series of questions in an encounter with providers does not necessarily provide sufficient support to help individuals take action.
- **Content gap 4: Complementary materials**. Hospitals and the health professionals who work in them will have an enormous impact on the ability of patients and families to engage in issues related to safety and quality. With the exception of infection control, we found few complementary or paired tools that support the Guide’s intended target audiences—patients, family members, and providers—around the same topics and issues. Having complementary materials will help facilitate uptake and sustainment of the intervention.

- **Content gap 5: Nurse-patient communication materials**. Nurses are often on the front line of quality improvement initiatives, and although physician buy-in will be needed to make the initiative successful, nurses may be responsible for much of the work. There seems to be a dearth of tools specifically for nurses on how to better communicate with patients and vice versa.

Gaps in Usability and Appropriateness of Tools

In cases where the content of the tools was applicable, the usability or appropriateness of the materials was not adequate. We did not find true turn-key options—those materials that could be included in the Guide without additional repackaging, content modification, and testing.

- **Usability gap 1: Lack of key usability criteria.** We assessed tools according to a pre-specified set of criteria that represented our "ideals" for tools to be included in the Guide. Often, materials had appropriate content but were difficult to read because of problems with plain language, format, or organization of information. Very few tools for patients and family members have accompanying information to indicate that the development process included input and feedback from the target audience. Without information about the development process, it was difficult to ascertain whether the materials have been tested with the target audience to ensure appropriate comprehension.
- **Usability gap 2: Implementation guidance.** There is limited implementation information on the specific tools and strategies used in the patient and family engagement efforts. In particular, most of the tools in Components 1 (active involvement) and 3 (health professionals) lack detailed supporting implementation guidance for how to implement them, including how materials should be distributed or by whom. Key pre-implementation and implementation steps are generally not addressed.

In sum, we have many resources and strategies to pull from, but considerable gaps remain about outcomes associated with those strategies, as well as gaps in tools and materials that can be included in the Guide without modification.

Implications for the Guide

Implications that must be considered during development of the Guide include:

- **Implication 1. Reflect an understanding of and incorporate target audiences' perspectives and individual and organization contexts.** Implementing a Guide for patient and family engagement often will require change—for individuals (patients, families, and health professionals) and organizations. To help facilitate change, the materials in the Guide should reflect what is important and most salient to each individual target audience and link the strategies to existing motivators and activities.
- **Implication 2. Provide tightly coupled materials and more individual support for engagement in hospital processes and decisionmaking.** To address the gaps, barriers, and challenges discussed here, the Guide should be organized so that it pairs support for individual- and hospital-level strategies around the same concepts. The hospitals and the health professionals who work in them will have an enormous impact on the ability of patients and families to engage in issues related to safety and quality. All three entities (hospitals, patients and families, and health care professionals) are important and should be considered together. The Guide should include complementary materials for patients and

families, health care professionals, and hospital leadership to ensure that a range of individuals can participate. Having “paired” materials will help facilitate uptake and sustainment of the intervention.

- **Implication 3. Be accessible to individuals and organizations at different stages of willingness, readiness, and confidence to support patient and family engagement.** Another consideration for the Guide is the need to provide guidance for hospitals at different stages in implementing strategies for patient and family engagement in safety and quality issues. Therefore, the Guide must be organized in a way that helps hospitals identify their stage of readiness and access the most appropriate information for their next steps, whether those steps are strategies that are easier or more difficult or have a smaller or greater impact.
- **Implication 4. Reflect additional key design principles**. The scan highlights core principles that must be followed in the development of the Guide. The materials in the Guide must focus on actions that can be taken and provide support to ensure those actions. Also, because many of the existing strategies and approaches to patient and family engagement lack clear evidence, we must rely on our own testing, piloting, and evaluation to provide this evidence.
- **Implication 5. Provide strong implementation guidance**. Although there was limited implementation information on the specific tools and strategies used in the patient and family engagement efforts, the literature on organizational context specifies key pre-implementation and implementation steps during quality improvement activities. The Guide will need to provide guidance on these key activities for each potential strategy to support hospital implementation. It will also need to supply information and tools to help senior [nursing] management understand why these strategies are important.
- **Implication 6. Assess the need for implementation assistance**. Given how new and challenging this engagement is likely to be for individuals and organizations, we anticipate that technical assistance may be an important factor in supporting patients, families, and organizations and the individuals in them to most effectively implement the Guide. The needs for technical assistance will be an ongoing focus of inquiry with organizations who participate in testing, piloting, evaluation, and dissemination.

Next Steps

Available information provides a valuable foundation to begin defining the content and tools for inclusion in the Guide. However, as the preceding review and implications suggest, important decisions about the focus, content, and approach of the Guide remain. Although there is much to build on, there are no turn-key solutions to rely on. Because of this, we anticipate the need for a longer, iterative process to define the final elements of the Guide and the key activities necessary to complete initial drafts for testing. The Task 3 Guide Development Plan will build on the information gathered in this scan and will discuss in more detail how to operationalize the implications discussed in this section. We will continue to collaborate with AHRQ, the Steering Group, and our partners to further refine the structure, content, and format of the Guide.

Introduction

Background

This project will promote patient and family engagement in hospital settings by developing, implementing, and evaluating the *Guide to Patient and Family Engagement: Enhancing the Quality and Safety of Hospital Care* (hereafter referred to as the Guide). The Guide will comprise tools, materials, and/or training for patients, family members, health professionals (e.g., hospital clinicians, staff), hospital leaders, and those who will implement the materials in the Guide. Our preliminary vision of the Guide included four components, each with a series of "tools" (e.g., materials, resources, items for training): (1) Patient and Family Active Involvement Materials; (2) Patient and Family Organizational Partnership Materials; (3) Health Professional Materials; and (4) Leadership and Implementation Materials. The tools to be included in the Guide are intended to support the involvement of patients and family members in their care, encourage the involvement of patients and family members in improving quality and safety within the hospital setting, facilitate the creation of partnerships between health professionals and patients/family members, and outline the steps needed to implement changes.

This report presents the results of the environmental scan that serves as an evidence-based foundation for the development of the Guide. The goals of environmental scan were to:

- Be comprehensive while targeting topics and questions that are directly relevant to the goals of the project.
- Reflect the concepts of consumer engagement and patient- and family-centered care around the issues of patient safety and quality in the hospital setting.
- Incorporate diverse input and perspectives from multiple individuals and organizations representing patients, families, health professionals, and hospitals.

In this report, we first describe the overall conceptual framework of patient and family engagement in hospital quality and safety that informed the literature review and scan. Then, we describe the methods for getting input from experts, reviewing published and unpublished literature, and identifying and reviewing existing tools and resources. Finally, we present our results by main theme and end with discussion and implications for the Guide.

Conceptualization of Patient and Family Engagement

Working Definition of Patient and Family Engagement

Because the Guide is intended to facilitate patient and family engagement in health care safety and quality in a hospital setting, the environmental scan is designed to clarify and refine exactly what we do and do not mean by patient and family engagement. Prior to beginning the environmental scan, we developed a working definition of patient and family engagement. We viewed this definition as fluid in that it not only would influence how we searched the literature, but it also would be informed by the results of our literature search. Our working definition was as follows:

> *A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations. For this project, the desired goals of patient and family engagement include improving the quality and safety of health care in a hospital setting.*

Based on the results of the literature scan, we will continue to use this definition of patient and family engagement as we move forward.

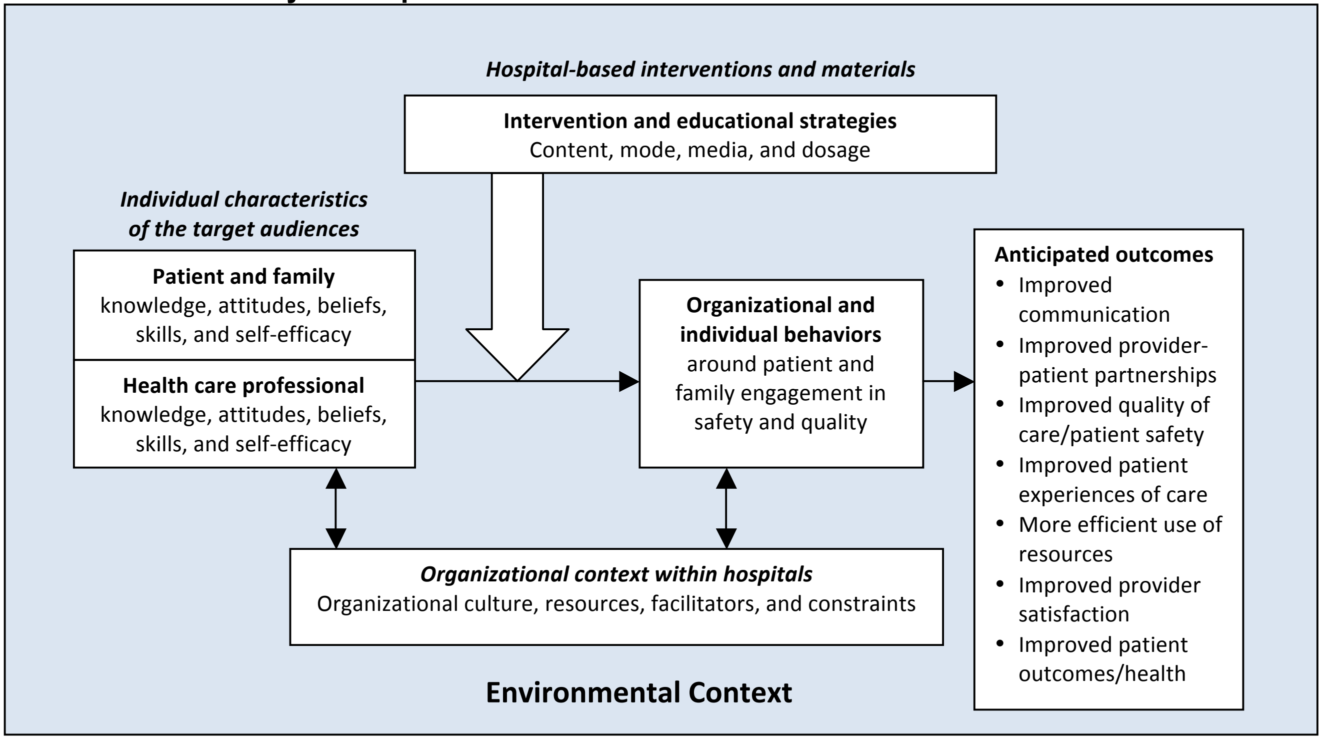
Conceptual Framework

To enable us to identify and assess the strategies and resources that are most relevant to the development of the Guide, we prepared a preliminary conceptual framework (Exhibit 1) that informed and refined search strategies for literature and resources. The conceptual framework highlights (1) the ultimate goals of improving quality and patient safety through patient and family engagement and (2) the external, organizational, and individual factors that are likely to affect these outcomes. Many different fields of inquiry (e.g., patient- and family-centered care, shared decisionmaking, general behavioral science) provide important concepts, approaches, and theoretical guidance for developing the Guide. Although this project is not tasked with developing an overarching conceptualization for patient and family engagement, the explication of a conceptual framework for how engagement is likely to occur, along with its anticipated outcomes, assisted with the selection and review of appropriate materials for the environmental scan.

The conceptual framework illustrates how hospital-based interventions and complementary resources and materials may influence patients, families, health care professionals, and organizations to engage in specific behaviors that facilitate and support patient and family engagement around safety and quality. The framework also highlights the existing individual, organizational, and environmental contexts in which a Guide to support patient and family engagement will be implemented. The overarching perspective of this project is that any intervention must be consistent with the principles of patient- and family-centered care, as opposed to disease- or clinician-centered care.

An intervention will have an impact on the individual characteristics of patients, families, and health care professionals (such as knowledge, beliefs, attitudes, skills, and self-efficacy); the partnership between providers, patients, and families; and the organizational context within hospitals (including culture, resources, facilitators, and constraints). Ultimately, engaging patients and families in patient safety and quality will likely lead to anticipated outcomes, such as improvements in health care delivery, patient-provider partnerships, care quality, safety, patient and staff satisfaction, and health outcomes. All these elements occur within an external environmental context that includes resources, constraints, and facilitators outside the hospital setting that affect the ability of individuals and organizations to engage. As a hospital-based intervention, the Guide will focus on organizational and individual behaviors that both patients and health care professionals will accept and that are feasible within the hospital setting.

Exhibit 1. Preliminary Conceptual Framework



Using this conceptual framework, we identified five main topic areas for further investigation in the environmental scan:

1. Individual characteristics, perspectives, and needs of the target audiences—patients, families, and health care professionals—with regard to patient and family engagement.
2. Organizational context within hospitals, including culture, and its influence on patient and family engagement.
3. Hospital-based interventions and materials that are designed to facilitate patient and family engagement, particularly around the topics of safety and quality.
4. Specific content area for the Guide.
5. Best methods for dissemination of the Guide.

As detailed in Exhibit 2, the information in the environmental scan sought to clarify questions in these five categories.

Exhibit 2. Categories and Questions in the Environmental Scan

Category	Questions
Individual characteristics, perspectives, and needs of the target audiences	• What are patients' and families' perspectives (knowledge, attitudes, and beliefs) on patient safety and quality of care? How can patients and families contribute to these areas? How do they want to contribute or feel capable of contributing to these areas? What is their current role in these areas? • What are providers' perspectives (knowledge, attitudes, and beliefs) on patient and family engagement in safety and quality of care? What is their role? How can providers encourage and support patient and family engagement? How do they want to encourage and support or feel capable of encouraging and supporting patient and family engagement? • What are the likely external and internal resources, facilitators, and constraints? • What behaviors from patients, families, and providers lead to improved patient safety and quality of care? What facilitates or challenges these behaviors? • What are the best ways to build partnerships among patients, families, and health care professionals to improve health care safety and quality? • Which educational and communication strategies are most appropriate for each audience?
Organizational context within hospitals	• How does organizational culture and infrastructure influence patient and family engagement in patient safety and quality, including partnerships among patients, families, and health professionals? What are the barriers and facilitators? • How can we motivate hospitals to undertake patient and family engagement efforts? What current hospital efforts and standards (e.g., HCAHPS, Joint Commission) can be linked with patient and family engagement? What economic models exist for the benefits of patient and family engagement? • How can hospital leaders motivate employees to undertake activities to further patient and family engagement? • What are the needs and resources of hospital leadership?
Hospital-based interventions and materials	• What strategies and interventions have been identified to engage patients and families in their care and decisionmaking? Who introduces these interventions in the hospital? What outcomes are associated with these interventions? • What tools and materials are currently available to support patients, families, and health care professionals in facilitating patient and family engagement and to facilitate partnerships among patients, families, and health care professionals to plan, implement, and evaluate patient and family engagement in quality and safety? • Who introduces these tools? What are the outcomes associated with these tools? How are AHRQ's current tools and resources being used? • Which points of hospital care and communication are most amenable to intervention or most likely to facilitate greater engagement (e.g., rounds, shift change, discharge)?
Content of the Guide	• Given the availability of and gaps in current resources, what topics should be included in the Guide? • What existing materials can be used in their current form? What existing materials can be adapted or modified? • What new materials need to be developed?
Dissemination of the Guide	• What are the most effective modes for disseminating the Guide? • What are the most effective sustainability models (e.g., centers of excellence, support centers) to ensure continued use and support of the Guide?

Methods

Below, we describe our methods for obtaining internal team input, conducting key informant interviews, reviewing the peer-reviewed and grey literature, and identifying and assessing relevant tools and interventions.

Internal Team Input

Because our project team represents the perspectives of patients, families, hospitals, health professionals, and health care organizations, we gathered input from internal team members to refine search strategies, identify tools and resources, and ensure equal input from all partners. We talked with representatives from each organization represented on the project Steering Group: Consumers Advancing Patient Safety (CAPS); the Institute for Family-Centered Care (IFCC); Carilion Clinic; the Joint Commission; the Health Research and Educational Trust (HRET); Aurora Health Care; Planetree; and the Maryland Patient Safety Center (MPSC). We also spoke with our two patient advisor Steering Group representatives. These informal conversations focused on the following topics: conceptualization of patient and family engagement around patient safety and quality; the perspectives and behaviors of patients, families, and health care professionals related to patient and family engagement; hospital interventions and strategies for patient and family engagement—what works and what does not work; recommendations for research (peer-reviewed and grey literature), tools, and resources to include in the scan; and recommendations for key informant interviews.

Key Informant Interviews

We conducted eight telephone interviews with key informants; one interview was still pending at the time this report was prepared, owing to scheduling conflicts. Based on conversations with our internal project team and in consultation with AHRQ, we developed a list of key informants who were knowledgeable about patient and family engagement and patient- and family-centered care and who could contribute a diverse and complementary set of perspectives. Our key informants were a patient, a patient and family educator, a hospital administrator, a physician, a nurse, a representative from the Veteran’s Health Administration, an expert in engagement and other initiatives, and an expert in safety and quality measurement.

For these key informant interviews, we developed a semi-structured interview protocol (Appendix A). The protocol focused on the following areas:

- Patient, family, and health care professional interventions to encourage engagement, along with barriers and facilitators to these interventions.
- Educational strategies that are most appropriate for each audience.
- Tools and resources that the interviewee uses or has used to engage patients and families and obtain feedback on their effectiveness.
- Priority areas in which the Guide could make a difference (i.e., where it can effect change and in what topic and content areas patients, families, and health professionals most need assistance).

All interviews were audiotaped, and detailed notes were taken. Analysis focused on major themes related to information needs, priorities, intervention strategies, and format preferences.

Search Methodology

Here, we describe the search strategies used for the peer-reviewed literature, grey literature, and tools.

Peer-Reviewed Literature

The team scanned the medical and social science peer-reviewed literature—including both descriptive qualitative and quantitative studies—using PubMed, PsycInfo, CINAHL, and Cochrane databases. We searched these databases using keyword search terms and MeSH headings (in PubMed) for each category of interest. The searches were limited to English-language articles published since 1999 and included resources developed domestically and internationally—especially in the United Kingdom, Australia, and Canada. We reviewed 6,315 abstracts that resulted from these searches. We retrieved 303 articles and reviewed and abstracted 188 of these. Detailed information about search terms is presented in Appendix B.

We conducted an initial review of all abstracts identified through searches of the databases listed above. Using the criteria noted in Exhibit 3, we determined which abstracts were of higher priority for review. Next, we retrieved the full text and reviewed each article. This review allowed us to further assess whether the article would be relevant in determining the content for the Guide, and if found to be relevant, we conducted an in-depth data abstraction of its content. We also reviewed reference lists in the articles that were retrieved and abstracted for relevant citations. In this review, we included significant (i.e., seminal) articles from prior to 1999, if appropriate. As we analyzed the literature, we conducted additional literature searches and reviewed articles to address possible gaps in knowledge. These additional articles were reviewed but not abstracted in the Access database.

Exhibit 3. Literature Review Inclusion and Exclusion Criteria

Higher priority	Lower priority or excluded
• Study target audience characteristics related to patient and family engagement around safety or quality • Describe elements of organizational culture and infrastructure related to patient and family engagement in safety or quality, including building partnerships among patients, families, and health care professionals • Describe interventions for patient and family engagement • Use qualitative and quantitative research methods, including meta-analyses and literature reviews • Describe theories related to patient and family engagement	• Focus on only history or value of patient and family engagement • Focus on only safety or quality without addressing patient or family engagement • Focus on only patient- and family-centered care without addressing safety or quality • Focus on only specific conditions, topics, issues, treatment decisions, or behaviors • Are opinion or editorial pieces

Grey Literature

We defined “grey literature” as any non-peer-reviewed literature that met the study’s inclusion criteria noted in Exhibit 3. This included presentations, articles, press releases, white papers, trade publications, issue briefs, and book anthologies. We did not include articles from magazines or newspapers.

To scan the grey literature, we gathered documents from AHRQ, the project team, and external experts during the key informant interviews. In addition, we conducted a more targeted search of 110 Web sites recommended by our partners for non-peer-reviewed literature and potential tools (Appendix C presents a list of Web sites reviewed). We also reviewed citation lists or bibliographies related to patient and family engagement found on these Web sites for additional peer-reviewed or grey literature.

Tools

The grey literature scan also included an inventory of tools that could be included in the Guide. Tools included handouts, flyers, brochures, posters, videos, and guides that addressed opportunities for patient and family engagement in safety and quality. We downloaded and reviewed tools that were available in the public domain and could be applied to the hospital setting. Tools were assessed on our ideal criteria for inclusion in the Guide: focusing on a hospital setting; reflecting target audience needs and priorities (user-centered); being actionable, that is, focusing on specific behaviors; having been developed with input from the target audience; and having been evaluated for effectiveness and feasibility in a hospital setting. However, we did not exclude tools that did not meet these criteria.

Data Abstraction and Analysis

Peer-Reviewed and Grey Literature

All documents were entered into a Reference Manager database. We exported the references from Reference Manager into an Access database to abstract key dimensions and identify key themes; the data abstraction protocol is shown in Appendix D. We developed an abstraction form in Microsoft Access for the peer-reviewed and grey literature. The main elements of the abstraction form were document information, purpose, methods, and main findings. Exhibit 4 shows the numbers and types of documents abstracted. We also noted the type of documents found in the literature (e.g., systematic reviews, single descriptive studies). Each findings section includes an exhibit that summarizes the strength of the evidence of documents reviewed in that section.

Once abstracted, the information was synthesized by main themes related to the conceptual framework: target audience perspectives, organizational context, and strategies and interventions.

Exhibit 4. Numbers of Documents Abstracted[b]

Theme	Peer-reviewed	Grey literature	Total
Target audience perspectives	83	18	101
Patient/family	42	6	48
Provider	41	12	53
Organizational context	37	6	43
Strategies and interventions	63	19	82
Combination	5	7	12
Total	188	50	238

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[b] Because we identified and reviewed additional articles during analysis, the numbers of articles abstracted in the database does not reflect the total number of articles reviewed and included in this report.

Tools

As with the literature review, we entered all tools and resources into a Reference Manager database and then exported these resources to the Access database. Once the tools were entered into the Access database, we classified them according to predefined dimensions. We developed a form in the Access database specifically for tools. The form included general information about the tool (e.g., content, target audience, mode of delivery) and also addressed the usability of the tool (e.g., literacy/use of plain language, organization of information, format, layout, cultural inclusivity, languages available, developed with input from target audiences, evaluated for effectiveness). We assessed the content and usability of approximately 80 tools. For the remaining tools, we assessed content but did not address usability. We will conduct a usability assessment on the remaining tools, depending on their correspondence to the priority topic areas identified for inclusion in Task 3. Exhibit 5 shows the numbers of tools abstracted.

Exhibit 5. Numbers of Tools Abstracted

Tools	Assessed content and usability	Assessed content only	Total
Patient and family active involvement	57	110	167
Patient and family organizational partnership	9	16	25
Health professional	12	77	89
Health leadership and implementation	0	45	45
Combination	0	4	4
Total	78	252	330

The analysis of the tools identified what existing materials can be adapted or modified and what new materials need to be developed. We reviewed materials to identify areas in which resources are limited or nonexistent and areas in which tools will need to be revised or updated if we want to focus on a particular substantive area or on a particular point in the care process.

Findings

Below, we discuss findings from the environmental scan. We have grouped findings according to the main categories identified in the preliminary conceptual framework (Exhibit 1):

- Individual Characteristics of the Target Audiences: Patients, Family Members, and Providers
- Organizational Context
- Strategies and Interventions
- Dissemination
- Key Informant Interview Recommendations for the Guide

Individual Characteristics of the Target Audiences

In this section, we sought to identify how the individual characteristics, perspectives, and experiences of the target audiences for the Guide—patients, families, and health care professionals—affect their willingness and ability to adopt behaviors related to patient and family engagement. We have grouped findings into three main categories:

- Patients, family members, and health professionals' **understanding and interpretation** of health care quality, safety, and patient and family engagement.
- Patients, family members, and health professionals' **experiences with and attitudes about** behaviors and roles associated with patient and family engagement to improve quality and safety
- Possible **facilitators and barriers** to those behaviors and roles

Exhibit 6 highlights the strength of evidence for articles reviewed in this section. Generally, this evidence represents lessons learned from the larger body of literature on patients' and providers' perceptions of and their willingness and ability to engage in behaviors related to quality, safety, patient- and family-centered care, and shared decisionmaking. The evidence comes primarily from qualitative and quantitative research studies and systematic literature reviews.

Exhibit 6. Strength of Evidence for Individual Characteristics of Target Audiences

Type of Document	Number
Systematic reviews	
Systematic review of randomized controlled trials	0
Systematic review of descriptive studies (quantitative / qualitative)	10
Single evaluative studies	
Randomized controlled trial	0
Nonrandomized controlled trial	0
Cohort / case-control study	1
Single site intervention (pre/post) / Case series study	2
Single descriptive studies	
Mixed methods study (qualitative / quantitative)	9
Quantitative study	20
Descriptive or qualitative study	26
Case study / description of implementation	10
Scholarly articles or reviews	17
Other (workshop overview, conference paper)	4

The focus of the studies reviewed in this section is evenly divided between patients and providers. The bulk of the literature on patients relates to patients or consumers more broadly; few articles specifically address family members. Similarly, the provider literature generally focuses on physicians and nurses, although several articles highlight the role that other health care professionals, such as social workers[1,2,3] or health educators,[4] can play to bridge the gap between patients and providers. There was a dearth of information related to nonclinical hospital staff, although we did review one article describing an intervention to train housekeepers in patient safety issues and include them as part of the health care team.[5]

Understanding and Interpretation of Quality, Safety, and Engagement

In this section, we discuss findings from the literature about how patients and providers understand and interpret the concepts of health care quality, safety, and engagement.

Health Care Quality

Both patients and providers tend to think that the quality of care they receive or give is generally good, despite evidence that suggests this is not always the case.[6,7,8,9,10,11,12] For example, in one qualitative study of consumers, participants could envision a health care provider making an occasional mistake, but they found it hard to believe that providers could deliver truly substandard care, particularly when it came to their own providers.[13] Likewise, in a survey conducted by the Kaiser Family Foundation (KFF), fewer than half of individuals surveyed reported perceiving “big” differences in quality among different health-related providers.[14]

Although patients and providers have a shared belief that health care quality is generally good, they do not always share the same views of what constitutes quality or safety. Below, we discuss differences in these perceptions.

Patients and family members. A systematic review of the literature found that patients consider quality primarily in terms of a provider’s ability to relieve their symptoms while keeping them safe from injuries.[15] Moreover, patients often feel that they, not outside “experts,” are in the best position to judge high-quality care. In a study that examined consumers’ reactions to quality information and clinical quality standards, participants felt that quality information was less significant than their own perceptions of quality. In addition, consumers in one study noted that “bad” care was something they would recognize when they saw it and therefore felt that they did not need to rely on external arbiters of quality.[13] When asked to identify poor-quality care, patients frequently pointed to lapses in service quality such as waits and delays, lack of sufficient information, and poor care coordination.[16,17,18,19]

Patients’ and family members’ perceptions of quality are also influenced to a large degree by their perceptions of a given provider. Because of this, patients often assess the quality of care primarily based on their interpersonal interactions with the provider, as opposed to the provider’s specific clinical skills in treatment and diagnosis.[13]Providers who are perceived to be responsive, empathetic, and attuned to patients’ needs are judged by patients as being of higher quality than providers who are perceived to be less responsive and empathetic, even if the clinical care delivered is the same.[13,15,20,21]

Providers. In evaluating quality of care, providers tend to emphasize the clinical aspects of quality in terms of skills in diagnosing, treating, and obtaining positive clinical outcomes.[21] Within a specific clinical encounter, a physician may focus more on biomedical aspects of the patient than other factors related to interpersonal communication, such as assessments of the patient’s emotions, mood, expectations, or personal life.[22] Providers do recognize the importance of communication as a component of quality, but they also tend to be overly positive in their perceptions of how effectively they communicate.[23]

Safety

As with quality, patients and providers differ at times in their understanding of patient safety. Moreover, they may not perceive safety in the same ways as researchers or other experts in the field.

Patients and family members. Consumers often have a narrow view of patient safety, seeing safety primarily in terms of medical errors. In one quantitative study where consumers ranked the importance of issues in health care, consumers did not equate the term "patient safety" with what they see as the more important issue: "medical errors."[24] Likewise, during cognitive testing of AHRQ's *Five Steps to Safer Health Care*,[c] Medicare beneficiaries equated the term "patient safety" specifically with falls and accidents instead of recognizing more general aspects of care safety.[25]

Although consumers may lack a complete picture of patient safety, they are aware that medical errors occur; one in three people says that he or she or a family member has experienced a preventable medical error and report that these errors often result in serious health consequences, such as severe pain or long-term disability.[26] However, while medical errors may be more salient than the general concept of patient safety, nearly half of consumers sampled in a 2006 Kaiser Family Foundation survey were still unfamiliar with the term.[26]

In general, patients and family members assume that most care is safe and that there are system checks to prevent errors.[25,27] When errors do occur, patients tend to think individual providers cause them, not the systems in which the providers work.[26,28] In addition, consumers tend to underestimate the number of medical errors that occur. For example, about half (49 percent) of consumers sampled in a KFF survey thought that 5,000 or fewer deaths occur in hospitals each year as a result of medical errors.[28] However, in 1999, the Institute of Medicine (IOM) estimated that this number is far greater—between 44,000 and 98,000 deaths each year.[8] Also of note is that studies have shown that patients with limited English proficiency are at higher risk of adverse events, although there is little research to assess specifically, the perspectives of culturally diverse patients on safety.[29]

Providers. In general, providers conceptualize safety more broadly than do patients, recognizing safety as an important component of quality. However, providers—like consumers and patients—may also view errors as individual deficiencies that are within the control of the individual provider, as opposed to system deficiencies.[30] Because providers (and particularly physicians) often think that errors are under their individual control and because they are worried about the level of effort required to address errors on a system level, they may not prioritize efforts to improve patient safety on a system level.[30] Physicians also are wary that focusing on and creating transparency about medical errors will lead to an increased risk of litigation.[30,31,32] For example, physicians in one study expressed concern that the term "medical errors" in AHRQ's "Five Steps to Safer Care" would signify liability and negligence.[32]

Within the general group of "providers," physicians and nurses may have different perspectives on patient safety. In a focus group study investigating perceptions of patient safety, nurses most frequently mentioned environmental, medical, and general safety issues as the main areas of

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[c] Five Steps to Safer Health Care. Rockville, MD: Agency for Healthcare Research and Quality; 2004. Available at http://www.ahrq.gov/consumer/5steps.pdf.

concern. Most comments described environmental safety, such as the use of bed rails, alarms, patient falls, or restraints. In addition, nurses most frequently mentioned self-initiated ‘‘double-checking’’ as their main safety task.[33] In the 2004–2005 Patient Safety Climate Survey administered to 92 U.S. hospitals, Singer and colleagues found that, compared with physicians, nurses perceived more problems with teamwork and were more negative toward their unit's support and recognition of safety efforts.[34] In addition, nurses expressed less personal embarrassment with regard to medical errors than did physicians.[34]

Patient and Family Engagement

Very few studies address patients' and providers' views on "engagement" specifically. However, findings from the broader literature on patient participation/involvement, patient- and family-centered care, and shared decisionmaking shed light on these perspectives. Although engagement is a broader concept than participation or shared decisionmaking, taken together, this literature facilitates our understanding of how patients and providers view engagement.

General perceptions of patient participation. Conceptually, both patients and providers support patient and family involvement and participation in their own care and recognize that it can lead to better patient experiences and outcomes. For example, in one survey of physicians and nurses, participants reported the perception that involving patients in their own care can lead to better outcomes.[35] Similarly, several studies of nursing staff and general practitioners have demonstrated positive feelings about ideas relating to patient involvement, to the degree that patients themselves feel comfortable.[36,37,38]

Shared decisionmaking—patient perceptions. Patient support for participation becomes more uncertain when patient involvement includes making diagnosis or treatment decisions. Analyses of multiple studies on shared decisionmaking indicates that most patient populations want to be involved in decisions about their health care but do not wish to make autonomous decisions or take on what they perceive as the provider's role.[39,40] Likewise, a long-term cohort survey found that consumers as a whole preferred to share information with and receive information from their health care providers, but that individuals differed in their preferences for involvement in decisionmaking.[41] However, patients also are amenable to increased involvement in the decisionmaking process. In one qualitative study of patients who were readmitted post-discharge, patients felt that readmission could have been prevented by enhanced patient education and involvement in the discharge decisionmaking process.[42]

Shared decisionmaking—provider perceptions. As with patients, most providers express general support for patient participation. For example, results from a systematic review of 38 studies examining health attitudes toward shared decisionmaking indicate that physicians perceive shared decisionmaking as leading to a positive impact on both patient outcomes and clinical practice.[43] However, providers also may have reservations about the reality of involving patients in the decisionmaking process. The same systematic review noted that a frequently mentioned barrier to implementing shared decisionmaking was a lack of applicability in individual situations because of patient characteristics and the clinical situation.[43] In addition, physicians most frequently cited time constraints as a barrier to implementing shared decisionmaking, suggesting that even if physicians support the idea in concept, there may be barriers to operationalizing it in practice.

Perceptions of the involvement of patient and family members on an organizational level. Few studies exist to provide information about whether patients and families want to participate in organization-level processes or decisionmaking with regard to quality or safety (e.g., as members of patient and family advisory councils). Information obtained from the key informant interviews conducted for this scan indicated that patients and family members are often motivated to get involved at an organizational level to "give back" because of positive experiences or to find ways to improve the system because of negative experiences.

Despite a willingness of certain patients to get involved at an organizational level, there are also significant perceived barriers to engaging in this way. In an Australian study of how consumers preferred to be involved in improving the quality of health care services in a medical center, participants identified the following barriers to participation: lack of time (44 percent); not interested (33 percent); costs involved and difficulty in transport (15 percent); poor health (14 percent); have no issues with medical center (6 percent); and lack of confidence (5 percent).[44] Likewise, patients may be intimidated or unsure about roles and expectations for engagement at this level, concerned that their participation will not lead to changes or results, fearful of dealing with conflict, or concerned about behaviors from health care professionals that are not respectful.[45]

On an organizational level, providers generally perceive benefits of patient and family involvement. For example, in one qualitative study, health professionals felt that including patients in health care planning could help provide accountability, balance priorities, identify patients' needs, increase recognition of the role of patients, and allow mutual learning. However, providers were most comfortable with patients in the role of consultant (i.e., providing advice and feedback) and less comfortable with patients being involved in the organizational decisionmaking process.[46]

Patient Experience and Attitudes About Behaviors/Roles

In this section, we discuss how patients and family members feel about specific roles and behaviors related to patient and family engagement (including their baseline level of experience with these behaviors). We conclude with a brief discussion of patients' and providers' attitudes toward the involvement of family members in ensuring safety and quality.

Patient and Family Roles

Most of the literature on patient and family engagement roles focuses on what patients could do (or what researchers and policymakers want patients to do) instead of discussing what behaviors patients and family members currently engage in or would be willing to engage in. From this broader perspective of how patients and family members could be engaged in safety and quality, the literature focuses on the following:

- ***Being informed, asking questions about, and participating in their care***. This includes making informed choices about providers, participating in reaching diagnoses, deciding on treatments, and participating in care coordination.[15,47,48]
- ***Helping prevent specific safety events/medical errors***. This includes medication safety, infection control, and, to a lesser degree, surgical safety. In addition, patients and family members can observe and assess care practices for consistency, accuracy, and safety.[48,49]

- ***Reporting on safety events after the fact***. This includes identifying adverse events that occur and reporting on these events.[15,16,18,19,48]

With regard to what patients themselves believe they can do, they generally believe that they have a role in health care safety, particularly with regard to the prevention of medical errors. For example, in one survey, 91 percent of patients agreed that patients could help prevent medical errors, and 98 percent agreed that the hospital should educate patients about error prevention.[15,47]

Patient and Family Experience in Quality and Safety

The literature on consumers' experience engaging in safety and quality generally reflects patients' and families' willingness to engage in potential behaviors, along with a few self-reports of actual behaviors. We found little observational research to provide evidence about behaviors that patients and families actively engage in within the hospital.

In general, the literature suggests that patients are more likely to engage when the goal relates to obtaining specific information about their care (e.g., asking questions to get information about their condition, treatment, functional activities, or discharge). However, patients are less likely to engage when faced with behaviors that seem new or confrontational (e.g., asking providers to wash their hands or mark surgical sites).[24] For example:

- One survey found that patients were very comfortable asking questions about a medication's purpose (91 percent) and general medical questions (89 percent), but they were less comfortable asking medical professionals about hand washing (46 percent).[47] This same survey found that when hospitalized, 85 percent of patients asked medical questions, and 75 percent asked about a medication's purpose, but only 17 percent marked their surgical site, and only 5 percent asked about hand washing.[47]
- In another survey, when asked about perceived likelihood or frequency of engaging in patient safety practices, more respondents were likely to ask for an explanation of something that they did not understand (91 percent); to question the reason for a procedure in the hospital (85 percent); or to question unfamiliar drugs in a hospital (84 percent). Fewer respondents were likely to ask for identity confirmation before a procedure (40 percent) or ask about hand washing (26 percent).[50]
- Finally, another study comprising 14 semi-structured patient interviews found that patients gathered information about the purpose of particular medications (i.e., information gathering) but did not confirm whether it was actually the right drug or correct dose, behaviors that are further outside the expected norm.[27]

The studies described above support what researchers found during the development of AHRQ's Five Steps to Safer Health Care: patients prefer messages that promote a collaborative patient-physician relationship as opposed to a confrontational one.[25]

Patient willingness to engage in perceived confrontational behaviors with providers may depend on the type of provider (i.e., physicians vs. nurses). For example, surgical patients were significantly more likely to ask physicians factual questions (e.g., When can I return to normal activities?) and were more likely to ask nurses challenging or confrontational questions (e.g., Did you wash your hands?).[51]

Patient and Provider Attitudes and Experiences with Family Involvement

The majority of the literature reviewed on family involvement focused on family involvement during rounds and invasive procedures. A brief discussion of findings related to family involvement follows.

Family member presence during rounds. Patients and family members indicate that the presence of family members during rounds can improve communication, facilitate information exchange and the provision of new information to medical staff, and generally improve care.[52] Recent studies have found that patients and family members prefer to have at least one family member present during rounds.[52,53,54] Results from a survey administered to staff, family members, and patients showed that family members believed that their presence would improve the medical staff's attitude toward the patient/family member and that it would improve communication with the medical staff.[54] Another observational study showed that patient perceptions about more effective communication may be accurate, demonstrating that new information was discovered from family members 46 percent of the time.[52]

Family presence during resuscitation and invasive procedures. In one survey assessing patient and family wishes for family presence during invasive procedures, both patients and family members responded that family member presence was important. Patients preferred family member presence because it would be comforting to have someone with them. Further, family members responded that it was their right to participate in a resuscitation or an invasive procedure and that participation would allow them to better understand the patient's condition.[55]

Provider perceptions of family involvement. Evidence suggests that providers have mixed attitudes toward family involvement. On the one hand, providers report that family presence can be beneficial to patients and family members[55] and useful in helping calm or comfort the patient.[37,56] On the other hand, providers may also place certain limits on family involvement. For example, one survey found that although health care providers thought that family participation in simple, hands-on care was acceptable, they expressed concern about family member presence, particularly during more invasive procedures.[37] Concerns associated with family member presence include potential interference with treatment, medical risk (e.g., exposure to infections), or the emotional response of the family member.[55,56,57] These same studies also suggest that providers are concerned that the presence of a family member could increase the anxiety of the health care providers in the treatment room, resulting in the decreased success of a procedure.[55,56,57]

Facilitators and Barriers to Patient and Family Engagement in Safety and Quality

In this section, we explore facilitators and barriers related to patient and family engagement behaviors, particularly around safety and quality. We first examine the characteristics (e.g., demographic information, experience) that affect the ability of individuals to engage in those behaviors. We then discuss what hinders patients' engagement (barriers) and what helps patients engage (facilitators). We also discuss barriers and facilitators to providers' support of patient and family engagement. Additional information about how hospitals as organizations can support patients and providers in engagement behaviors is discussed in the findings section on organizational context.

Influences on Patient and Family Engagement

In this section, we present findings about how demographic characteristics and prior experiences may influence patient participation, desire for shared decisionmaking, and engagement in safety behaviors.

Demographic characteristics. Individuals may differ in their desire for engagement based on demographic characteristics. For example, a systematic literature review and a study analyzing the data from six independent trials on shared decisionmaking found that patients who are younger, female, and more highly educated are more likely to want to be involved in health care decisions.[40,58] In addition, providers may be more likely to facilitate and reinforce engagement with certain types of patients. For example, one observational study found that specialists displayed more good communication behaviors with patients who were younger, more educated, and urban.[22] In contrast, patients who are at a power disadvantage (e.g., because of lower levels of education, language, or literacy difficulties) may be less likely to engage. For example, one mixed-methods study found that patients who spoke through an interpreter made significantly fewer comments during medical encounters than English-speaking patients.[59]

Although there is a dearth of literature in this area, race may also influence a patient's willingness or ability to engage in patient safety behaviors. A survey pilot test of elderly individuals found that African Americans were significantly less likely than whites to report participation in patient safety behaviors.[60] Another quantitative study with 2,765 respondents found that both Hispanics and African Americans were more likely than whites to prefer leaving decisions about medical care to the doctor.[61] Moreover, cognitive testing of the Spanish version of AHRQ's *Five Steps to Safer Care* revealed that many Spanish-speaking consumers were uncomfortable asking any questions of their physicians and did not know they could ask providers for test results.[25]

Experience. Experience may affect an individual's skills in navigating the health care system, desire for participation, or engagement in safety behaviors. One systematic literature review found that patients with more experience in the health care setting were better able to navigate the interpersonal interaction between patient/family and provider.[62] Similarly, experience over the course of a hospital stay may also affect the level of participation. In a mixed-methods study, family members were less likely to feel comfortable asking questions and more likely to find discussion confusing when interacting with providers during rounds on the first day of admission than before discharge.[52] Likewise, another mixed methods study found that patient preference for involvement in care was greater at discharge than at preadmission.[63]

Individuals who have experience with a particular condition or have chronic health issues also may be more willing to engage in patient safety behaviors, particularly those that may seem confrontational. A qualitative study found that patients with chronic conditions were particularly careful about medication administration and were more vocal about advocating for safety.[27] Likewise, in a small survey comparing patients who had a history of Methicillin-resistant *Staphylococcus aureus* (MRSA) with those who had no history of MRSA, those with a history of the infection were more likely to ask providers to wash their hands.[64] However, there may be limits to this willingness. One quantitative study of shared decisionmaking found that acutely ill patients preferred to leave all decisions to the doctor or to let the doctor make the final decision after having considered the options.[65]

Finally, patients and families may be more willing to take a proactive role in their health care if they are familiar with the procedure or treatment. For example, one study of patients receiving regular chemotherapy treatments in an outpatient clinic found that they reported engaging in behaviors such as detecting procedural errors (e.g., unexpected events that occurred outside of treatment procedures) and coordinating tasks across multiple providers (e.g., not to get adhesive on the skin by a provider administering chemotherapy when undergoing radiation).[49]

Barriers: What can hinder patient and family engagement?

Barriers at the patient/family level can affect engagement in health care more generally, and engagement related to quality and safety more specifically.

Fear and uncertainty. Patients and family members can be unsure how to be involved and may feel overwhelmed and intimidated by the health care system. One systematic review of the literature found that patients and family members reported being unsure of what to expect in a medical encounter and feeling intimidated by health professionals.[62] Beyond the individual encounter, a study based on focus groups and interviews with families and providers found that families felt overwhelmed by responsibilities for navigating the health care system and by the need to transmit highly technical information from one specialist to another.[66]

Health literacy. In one mixed-methods study, more than half (53 percent) of survey respondents agreed or strongly agreed with the statement “Most medical information is too hard for the average person to understand.”[67] The National Assessment of Adult Literacy reports that more than 90 million American adults have marginal literacy skills and are unable to read anything beyond very simple text. Additionally, more than 80 percent of American adults have less than “proficient” health literacy skills.[68] In one qualitative study of elderly women who were participating in discharge planning conferences, patients noted difficulties taking part in the discussion because providers used professional language or because they felt overwhelmed by too much information.[69]

Provider reaction. Lack of provider support for engagement also can pose barriers to patient and family involvement. For example, one survey found that patients who felt as though they were not being given the information they needed from their providers (e.g., getting a prescription without explanation) were less likely to participate in their health care.[70] In another study, patients reported significantly higher levels of satisfaction when they perceived physician facilitation of their involvement.[71]

Facilitators: What helps patients and family members engage?

Several factors can help patients and families engage in their health care.

Self-efficacy. In general, patients with higher self-efficacy are more likely to engage in patient safety behaviors. For example, a survey of patients found that patients who reported being “very comfortable” with specific behaviors were twice as likely as others to ask medical personnel about hand washing, mark their surgical location, have friends/family members watch for errors, ask general medical questions, report an error, and clarify a drug’s purpose.[47] In another study, patients with low self-efficacy and those who perceived their actions as less effective in preventing medical errors were 33 percent less likely than other patients to report a willingness to engage in preventive actions.[24]

Information. Providing patients with information may help them more fully engage in their care by increasing self-efficacy, confidence, and/or awareness. For example, one study found that patients who received less information about MRSA and hand hygiene upon hospital admission felt more anxious about asking providers to wash their hands.[64] In another study, patients reported feeling overwhelmed and unprepared to take on an active role in their health care at discharge, noting that more information from providers would help.[72] Information that patients indicated they needed to be able to assume an active role in their postoperative care included information about diet, postoperative functional activities, and care management. Interestingly, this study suggests that providers' perceptions of what information patients need may not match with patients' preferences. For example, nurses ranked wound care management as more important information to provide than the topics patients identified.[63]

Information is most helpful when it is tailored to patients' individual needs and concerns. For example, one study demonstrated that when patients received individualized care information, they were more likely to engage and participate in their health care.[73]

Invitation to participate. Extensive research has shown that although information is necessary, it is not sufficient to support behavioral change. Patients and families must also be motivated to participate in engagement behaviors through encouragement from others, such as providers, organizations, and systems and through positive feedback when they engage in these desired behaviors. One review of the literature in this area found that patient participation increased in interactions with those health care providers who responded positively to patients' needs and views.[58] Likewise, physicians' instructions to patients about asking questions significantly increased patients' willingness to ask challenging questions of both physicians and nurses.[51]

How can providers support patient and family engagement?

As noted above, reactions by providers can be a barrier to patient and family engagement, and their active invitation for patients and family members to participate can be a facilitator. In general, the bulk of the literature on what providers can do to support engagement focuses on communication. In one observational study, the authors found that patients contributed more to the visit when physicians displayed "facilitating behavior" such as nonverbal or verbal encouragement, summarizing patients' comments, educated guesses, emotional reflections, or attentive silence.1 In addition, a patient survey found that increased satisfaction with elements of physician-patient communication (e.g., overall communication, explanations, use of understandable words, listening, patient involvement in decisions) was related to an increased sense of empowerment.[74] Information from our key informant interviews noted that providers can make the "invitation" to participate more explicit by introducing themselves when entering the room, introducing all staff during rounds, sitting down, and asking about the patient's needs.

What hinders providers' ability to support engagement?

Even when providers see the need for better communication and patient-centered care, they may find it difficult to operationalize those skills in practice. For example, one survey found that even though providers recognized the importance of the elements of family-centered care, these elements were not always incorporated into care.[75] Barriers to providers' support included professional norms and experiences and perceived level of effort.

Professional culture and practice norms traditionally have been based on individual autonomy, which can be a barrier to the teamwork and patient-centered practices that a patient safety culture requires.[76] Also, providers lack experience with models that encourage collaboration with patients. Traditionally, professional schools have offered limited or no emphasis on patient/family engagement or patient- and family-centered care, and this applies not only to medical schools but also to academic programs that train health care leadership.[77]

Providers also may believe that patient and family engagement requires increased time and a greater level of effort. A systematic literature review and survey found that providers saw time constraints as a significant barrier to patient involvement.[35,43] In a mixed methods study, 82 percent of medical residents perceived that rounds took longer when families were present.[52] In fact, one article suggests that clinicians sometimes discourage patients from telling stories because they are afraid that it will take too much time.[78] In addition, providers may be concerned about the time that it takes to educate patients. In a qualitative pilot study, nurses expressed concern that they do not have the time to spend educating patients about their health status, health care, or medication.[38]

Despite these concerns, some data do not support these perceptions of increased time and level of effort. A literature review and a mixed mode study found that patient-centered interviews do not take significantly more time (only 1 to 2.5 minutes more) than traditional interviews.[52,79] Moreover, although a survey found that post-acute care unit (PACU) staff reported that a barrier to the new formal visitation policy was the staffing issues that arose, only 3 percent of PACU staff (not including physicians) reported that the presence of family members had hindered their performance.[57]

Individual Characteristics of the Target Audiences: Summary of Key Points

- ***Quality.*** Both patients and providers tend to think that the quality of care they receive or give is generally good, despite evidence that suggests this is not always true. However, they do not always share the same views of what constitutes quality or safety. Providers tend to focus on clinical aspects of care, while patients and family members focus on interpersonal interactions.
- ***Safety.*** As with quality, patients and providers can differ in their perspectives on patient safety, and patients may not understand safety as researchers or other experts define it. Patients define patient safety more narrowly in terms of medical errors. In addition, providers may feel that errors are primarily under an individual's control and therefore place less emphasis on the importance of system-level changes.
- ***Engagement.*** Conceptually, both patients and providers support patient and family engagement in their own care and recognize that it can lead to better patient experiences and outcomes. Patient and provider support for participation becomes more uncertain when patient engagement includes a higher level of involvement; for example, making a diagnosis or treatment decisions.

  Most of the literature on patient and family engagement roles focuses on what patients could do (or what researchers and policymakers want patients to do), instead of discussing what behaviors patients and family members currently engage in or would be willing to engage in.

  In general, the literature suggests that patients are more likely to engage when the goal relates to obtaining specific information about their care (e.g., asking questions to get information about their condition, treatment, functional activities, or discharge). Patients are less likely to engage when

Individual Characteristics of the Target Audiences: Summary of Key Points

faced with behaviors that seem new or confrontational (e.g., asking providers to wash their hands or mark surgical sites).

- ***Barriers and facilitators.*** Barriers to engagement for patient and family members include fear, uncertainty, health literacy, and provider reactions. Facilitators include self-efficacy, information, invitation to engage, and provider support. For providers, barriers to support patient and family engagement include professional norms and experiences, fear of litigation, and perceived level of effort. Facilitators for providers include those factors discussed in the organizational context section.

Organizational Context

In the preceding section, we discussed patient, family, and provider characteristics and factors that might affect the adoption, use, and success of hospital-based efforts to increase patient and family engagement and to inform the development of the Guide. As shown in the framework that guided this scan (Exhibit 1), individual-level factors, while crucial, are only part of the picture. Equally important to developing the Guide and to understanding potential barriers and facilitators to its implementation is the organizational context within which these individuals will be trying to operationalize the activities of the Guide.

Hospitals are complex systems in which many types of individuals—health professionals, patients, and families—work together within the context of specific organizational structures and processes. In addition, a clear implication from the previous section is that patient and family engagement in hospital safety and quality will require changes in knowledge, perspectives, behaviors, and roles for virtually everyone—patients, families, and health professionals. Given the relative lack of experience with strong patient engagement in general, and in hospitals specifically, we must address at least three strategic questions to create an effective Guide:

1. What will motivate hospitals to adopt patient and family engagement practices as an innovation? What are the key external and internal drivers to generate adoption of the Guide?
2. How do hospital structures and processes affect hospitals' ability to implement change and support individuals in desired behaviors?
3. What are the key factors to consider in determining how to successfully adopt, implement, and sustain change at the hospital organizational level?

In this section, we discuss the overarching question of how organizational context influences patient and family engagement in hospital safety and quality. We begin by discussing external and internal motivators of organizational change. We then discuss the organizational structures and processes that affect the ability of organizations to implement and sustain change and to support individuals, including patients, family members, and hospital staff, in engaging in new behaviors. We conclude with a discussion of organization-level strategies to facilitate successful and sustainable implementation.

The discussion in this section does not reflect a complete analysis of the literature related to organizational change and context; such a review is outside the scope of this scan. For this scan, we focused on key concepts from the literature on organizational change and quality improvement that are most applicable to understanding how organizations will adopt, implement, and sustain the types of interventions and activities we are likely to include in the Guide.

Generally, the evidence in this section represents lessons learned from literature on organizational learning, innovation, and change in health care—particularly as they relate to quality improvement. As such, the literature often reflects a broader perspective on organizational context and change instead of specific findings related to the organizational implementation of patient and family engagement. The majority of the evidence comes from case studies. Where specifically noted, the evidence in this section is supplemented with information from interviews with key informants, many of whom are organizational health care leaders. Exhibit 7 summarizes the strength of evidence with regard to organizational culture.

Exhibit 7. Strength of Evidence for Organizational Culture

Type of Document	Number
Systematic reviews	
Systematic review of randomized controlled trials	0
Systematic review of descriptive studies (quantitative / qualitative)	0
Single evaluative studies	
Randomized controlled trial	0
Nonrandomized controlled trial	0
Cohort / case-control study	0
Single site intervention (pre/post) / Case series study	0
Single descriptive studies	
Mixed methods study (qualitative / quantitative)	4
Quantitative study	3
Descriptive or qualitative study	5
Case study / description of implementation	16
Scholarly articles or reviews	15
Other (conference report)	2

Motivators of Organizational Change

Organizational motivators are systems, events, or environmental characteristics that create a "desire to make an effort toward a particular target."[80] They can occur either externally or internally to the organization and drive change by creating sufficient need and desire.

External Motivators

Here we highlight six key external motivators:

1. Desire to mimic competitors.
2. Health care legislation or mandated policies.
3. Leadership from influential bodies.

4. Alignment of financial incentives.
5. Public reporting.
6. Accreditation and awards.

Desire to mimic competitors. Health care organizations adopt initiatives, such as patient- and family-centered care or patient and family engagement, not only to achieve internally generated goals but also to keep up with competitors or imitate top performers. The motivators can be the desire to improve performance, increase market share, and the like.

Existing organizations whose actions have increased the visibility of patient and family engagement and provided a potential cadre of hospitals for others to mimic include the Dana Farber Cancer Institute, MCG Health, Children's Hospital of Philadelphia, Emory Health System, and Planetree hospitals, among others.

Legislation or state and national policies that mandate changes in care or the care experience. Motivation to adopt practices related to patient and family engagement may also come in the form of State- or national-level policy mandates. For example, in 2007 the State of Massachusetts enacted legislation (Senate Bill No. 1277) designed to promote health care transparency and facilitate consumer-provider partnerships.[81] One component of this legislation requires all hospitals in the State to establish Patient and Family Advisory Councils (PFACs) by October 2010 to provide meaningful input into hospital policy and management. Hospitals must also establish rapid response teams (RRTs) trained to assess and stabilize a patient's condition, educate and support medical staff, and assist with communication among the attending medical staff and the patient and family. Hospitals must allow a patient and/or the family to activate the RRT whenever they detect deterioration in the patient's condition.

Leadership and guidance from influential bodies. External motivation may also come from pressures or "pushes" from external organizations. Conway suggests several critical organizations that are promoting patient and family engagement, including consumer advocacy organizations (e.g., Consumers Advancing Patient Safety, the Institute for Family-Centered Care, the American Association of Retired Persons); quality organizations (e.g., Hospital Quality Alliance, Leapfrog Group); government entities (e.g., AHRQ, the Centers for Medicare & Medicaid Services); and other private and public entities (e.g., the Institute of Medicine, Institute for Healthcare Improvement).[82] Some of the most influential actions have come from the Institute of Medicine (IOM), which identified "patient centeredness" as one of six core attributes of high-quality care.9 The IOM has consistently placed patient centeredness as a fundamental focus of all efforts to reform and improve the U.S. health care system. Many other organizations have followed the IOM's lead. AARP advocates for quality initiatives, including the use of evidence-based, shared decisionmaking to improve care.[83] The World Health Organization (WHO) encourages partnerships among patients, their families, and health care workers to promote various quality initiatives in health care settings.[84] National Priorities Partners, a group representing 28 organizations with an interest in improving health care, also identified patient and family engagement as a national priority.[85] The advocacy and guidance these organizations provide help create an atmosphere in which doing anything less than accomplishing true patient-centered care is poor-quality health care.

Alignment of financial incentives. Health care purchasers continue to strive to become active purchasers of care by providing financial incentives for the provision of efficient, high-quality, and safe clinical care.[86,87,88] Payers are increasingly being offered models for value-based purchasing (VBP) or pay-for-performance, where incentives include payments based on factors such as attaining predetermined clinical and service targets, improvement toward target levels, or rankings against other specified benchmarks.[86,87] Negative incentives, such as penalties assessed to hospitals for not meeting targets, may also be included.[89]

Elements of VBP were incorporated into national policy in 2006 when Congress mandated that beginning in FY 2009, the Secretary of Health and Human Services (HHS) would develop a pay-for-performance program for hospitals that receive payments from the Medicare program.[86,90] Under this pay-for-performance program, "a hospital's ability to provide superior clinical outcomes and an exceptional patient experience will be directly linked to reimbursement."[91] Many experts also believe that this program will help solidify the economic incentives to providing patient- and family-centered care and enhancing service for the patient.

Changes in reimbursement that incorporate payment penalties for events or conditions that should not occur also can help facilitate changes in the hospital care experience for patients.[87,92] For example, the Centers for Medicare & Medicaid Services (CMS) has developed a list of 10 conditions that are preventable during the course of a hospital stay. If a patient develops one of these conditions, CMS will no longer pay an extra amount for the care related to the potentially avoidable condition.[92] Consequently, CMS's policy motivates hospitals to avoid financial losses by taking action to avoid the occurrence of avoidable conditions.

Public reporting of quality performance information. Public reporting of quality and safety information (one of the tenets of value-based purchasing) is another motivator for hospitals to improve performance on clinical or patient experience outcomes. A key objective of public reporting is to increase accountability of health care organizations by providing consumers and purchasers with the information they need to make more informed decisions about where they receive care or how they purchase care.

A highly influential comparative quality reporting effort that can motivate hospitals to focus on patient and family engagement is Hospital CAHPS (HCAHPS; https://www.cahps.ahrq.gov/Surveys-Guidance/Hospital.aspx), the first national standardized publicly reported survey of patients' perspectives of hospital care. Many of the measures captured in the HCAHPS survey, including communication with providers, hospital environment, and discharge information, reflect critical elements of patient and family engagement. CMS has put in place a financial incentive for hospitals to participate in the HCAHPS program—a 2 percent reduction in the annual payment update for inpatient hospital services if they do not provide HCAHPS data.[93]

To date, the greatest impact of public reporting initiatives has been on quality improvement. A 2008 review of the literature evaluated results from 45 articles to examine the effects of public reporting on quality of care. The authors found that the strongest effect of public reporting on hospital quality has been to increase quality improvement activity.[94] Studies examining the effects of HCAHPS public reporting have shown that HCAHPS is creating the incentive for hospitals to engage in quality improvement and is having a resulting impact on clinical care and patient satisfaction outcomes.[93] Other studies have found that States that publicly report morbidity and mortality rates after cardiac surgery have experienced more rapid declines in mortality rates than States that do not publicly report such measures.[95] However, studies have not demonstrated a strong and consistent association between the public reporting of quality information and the resulting effect on consumer choices.[94]

Public reporting of safety information is still in a nascent stage. Although reporting of hospital infection rates is currently occurring and soon will be the practice in 27 States, only 16 of these States make reports publicly available.[96] Because this reporting is new, evidence on its impact is still emerging. However, in Pennsylvania, an early leader in public reporting of hospital infections, infection rates dropped 8 percent between the first and second years of reporting.[97]

Accreditation and awards. Prestigious awards such as the Malcolm Baldrige National Quality Award engender organizational change.[98] The Joint Commission (JC), the national accrediting body for many health care institutions (including hospitals), is also highly influential. The JC has developed national patient safety goals for hospitals that support patient and family involvement and improved patient and provider communication. Specifically, the JC has identified goals for hospitals that include improving the effectiveness of communication among caregivers, improving medication accuracy, reducing hospital-associated infections, reducing risk of harm from patient falls, and preventing hospital-associated pressure ulcers.[99,100]

Internal Motivators

Empirical work on quality improvement suggests that although external motivators are important, unless they reflect mandates to change (e.g., in the form of legislation), they are typically insufficient—"internal" organizational motivation to change or improve is also required.[101]

In this section, we discuss five key internal motivators:

1. The occurrence of a sentinel event.
2. The business case for patient and family engagement.
3. The desire to improve quality and safety performance.
4. Stories from patients and families.
5. Altruism.

Sentinel event. One of the most powerful internal motivators for change unfortunately can be the occurrence of a sentinel event, defined by the JC as "any unanticipated event in a health care setting resulting in death or serious physical or psychological injury to a person or persons, not related to the natural course of the patient's illness."[102] Sentinel events create a sense of urgency within the institution and highlight system deficiencies; and, they can be used as an opportunity to begin addressing these deficiencies.[15] For example, during a 3-year period at the Dana Farber Cancer Institute (DFCI), one woman died and another was severely injured due to an overdose of chemotherapeutic drugs.[103,104] The errors were a result of protocol breakdowns, inefficient error reporting, and lack of quality assurance leadership, supervision, and oversight. Because of these tragic occurrences, DFCI enacted many substantial changes to improve safety and quality, including establishing mechanisms for partnering with patients on an organizational level (e.g., on PFACs and decision-making committees). [103, 104]

Sentinel events also lead to external pressures to change. In the example discussed above, DFCI received both regional and national media attention after its sentinel events.[104] Additionally, accreditation may require an active response to a sentinel event.[102]

Business case. Another change motivator is the desire to improve financial performance, which requires recognition of the "business case" for a specific initiative or change. A business case for change requires the alignment of costs and benefits within the same entity (i.e., a positive financial return that accrues to the same organization that makes the program investment).[105] The benefits must also occur within a period that is short enough to be valued by that entity. In the case of patient and family engagement or patient- and family-centered care (PFCC), the "business case" argument is that PFCC can lead to outcomes that improve financial performance, including shorter length of stay, decreased emergency department visits, statistically significant lower costs per cases, decreased malpractice claims, and improved patient adherence.[82] Nonfinancial measures contributing to the business case for patient engagement/PFCC include the enhanced reputation of the organization, increased satisfaction among employees (which in turn leads to greater retention and opportunities for recruitment), brand identity, and increased market share and performance relative to competitors.[91]

Desire to improve quality and safety performance. The desire to improve performance on quality and safety also may result from perceived or real poor organizational performance—or may simply reflect dissatisfaction with the status quo.[15] For example, MCG Health System in Augusta, GA, performed an internal assessment that revealed that the care being delivered addressed primarily the needs of providers and did not adequately respond to patients' and families' needs and concerns. Although there was no external mandate to change the care experience, it was important to MCG to deliver care consistent with the tenets of patient- and family-centeredness. Thus, in 1993, the organization began a transformative process that ultimately resulted in PFCC becoming the core business model for the organization.[106]

Stories from patients and families. For many organizations, understanding how patients and family members experience their hospital stay can highlight opportunities for change and improvement.[107] Surveys such as HCAHPS allow hospitals to capture information about patient experiences of care, but this quantitative data can lack the richness and contextual detail of more qualitative information. As a way to augment more quantitative data, the Planetree Patient-Centered Care Improvement Guide highlights the importance of routinely sharing with staff patient and family stories and their suggestions for change.[108] Selected hospitals in the United Kingdom have embraced this idea and are currently using narratives from patients and their families to inform service improvements through a process known as the Discovery Interview Process. Proponents suggest that this method is a potentially powerful approach for informing quality improvement.[109]

Sharing patient stories was a particular motivator for many of the organizations represented in our own key informant interviews—the organizations found that these stories were invaluable in understanding how the experience an organization intends to provide matches the reality of how patients actually live through it.

Altruism: It's the right thing to do. Finally, individuals' (and organizations') inherent desires to do the right thing and provide high-quality care are powerful motivators.[80] Many health professionals note that their personal motivation for entering the health care profession was to help others.[82] Conway argues that increasing the focus on the patient and increasing PFCC is "just the right thing to do," and that the desire to do the right thing is crucial to change.[82] In interviews with 15 primary care practices in Ohio, Litaker and colleagues noted common motivators for change included the desire to "serve the needs of a vulnerable population" and "provide high-quality care."[80]

Factors that Influence the Ability to Implement and Sustain Change

In this section, we discuss organizational context, or those factors that affect the ability of a hospital to promote, support, and sustain patient and family engagement.[110] These factors, discussed below, include the hospital's structure (e.g., size, profit and teaching status, medical staff organization, nursing staff organization) and processes (e.g., experience with patient and family engagement, existing quality/safety culture, leadership, hierarchy, slack resources, absorptive capacity, internal alignment).

Organizational Structure

Here, we discuss structural factors of hospitals that affect the initiation, implementation, and sustainability of change initiatives. The structure of a health care organization comprises the internal environment in which any intervention is implemented. Building on the work of Donabedian[111] and the Institute of Medicine's *Crossing the Quality Chasm*,*9* it has long been understood that organizational structure has an impact on care processes and, ultimately, on both organizational outcomes (e.g., efficiency, effectiveness) and patient outcomes (e.g., mortality, morbidity, patient experiences).

Structural aspects of a hospital that can influence the ability to initiate and sustain change include the size of the hospital, profit or academic status, and medical staff organization. Larger organizations often have better access to resources (e.g., money, expertise, skills) than smaller organizations. However, as organizational size increases, coordination and communication become more difficult. Thus, larger health care organizations may have resource advantages but also a greater challenge in implementing, integrating, and sustaining an intervention.[112,113]

With regard to profit status, if there is a perceived positive business or strategic case for change, for-profit hospitals may be more likely to aggressively pursue an initiative than not-for-profit hospitals. Because of this, for-profit hospitals often are able to more quickly adopt innovations and practices that positively affect their financial performance.[113] Similarly, academic medical centers may be more likely to adopt an innovation, in part because they may have more resources but also because the implementation of innovation is consistent with their mission to learn.[114, 115]

The organization of medical staff also can affect leverage of the hospital in initiating and sustaining change. One factor is the relationships between various units or levels of the organization. The few empirical studies that exist on this topic suggest that some types of organized delivery systems that are centralized or moderately centralized may have advantages relative to freestanding hospitals with respect to quality improvement and patient outcomes.[116] Another factor is whether the hospital employs a staff model, in which financial incentives are aligned and under the control of the hospital, or a community practice model. In staff models, hospitals pay the salaries of physicians who are part of the organization—meaning that everyone shares the same incentives for hospital performance and goals.[117] In contrast, community-practicing physicians may work with multiple hospitals and therefore competing incentives.

Hospitals that employ a staff model often have more levers for change. For example, hospitals have the ability to include items related to quality improvement initiatives in job descriptions.[117]

Unfortunately, although there is general recognition of the potential influence of structural factors such as size, teaching and profit status, nursing staff organization, and medical staff organization on an organization's ability to adopt and sustain innovations, there is insufficient evidence about whether and how these structural factors act specifically as barriers to or facilitators of change.

Organizational Processes

Many other factors affect an organization's ability to implement and sustain change, discussed in this section as organizational processes. These processes include the organization's understanding of and experience with patient and family engagement, the existing quality and safety culture, leadership, hierarchy, the existence of slack resources, absorptive capacity, and internal alignment.

Understanding of and experience with patient and family engagement. An organization's baseline understanding of concepts related to patient and family engagement, along with previous experience, affects its ability to initiate, expand upon, or improve engagement initiatives. For health care organizations to understand how to succeed with patient and family engagement, they need to have a clear understanding of what engagement is and what success would look like. This may be more complicated than it seems, particularly for organizations with less experience. Although there are accepted definitions of patient- and family-centered care and patient and family engagement,[118] the concepts of patient and family engagement may be construed and operationalized in different ways by different organizations. Developing an organizational understanding of patient and family engagement therefore involves understanding what behaviors are required, who is involved, why it should be implemented, and when and where changes must take place. The development of this understanding reflects both experiences and future capacities for change.

Existing culture, including quality and safety culture. Culture refers to the norms, values, beliefs, and behaviors of an organization that reflect and shape how things are done within the organization.[110] Evidence from the patient safety and quality improvement literature suggests that organizational culture greatly influences the ability to engage in quality and safety improvement initiatives.[119,120] In general, organizations that embrace continual learning and evaluation by emphasizing accountability and responsibility in a nonpunitive way will find it easier to implement and sustain new interventions.[121]

Value for quality and continual improvement. One important aspect of organizational culture in facilitating the uptake of new initiatives is the value placed on quality and continual improvement. Successful health care organizations recognize that change is a given, and that true quality improvement is proactive, not reactive.[122, 123] A culture conducive to quality improvement will encourage, if not require, continual evaluation of how the organization is performing, learning, and making efforts to improve on current practices.[120] Generally speaking, hospitals with a more developed and mature quality improvement perspective report better implementation of strategies to improve patient centeredness.[124]

Experience. Past efforts at and experience with undertaking change are important resources, with evidence suggesting that the success of past efforts shapes the willingness of individuals to act on future opportunities for change.[80]

Positive safety culture. Within an organization, a "positive" patient safety culture can also improve patient safety, decrease medical errors, and facilitate greater buy-in from staff for patient safety initiatives.[123] This culture of safety involves embracing the viewpoint that errors point to failings of systems rather than individuals—and that errors are an opportunity to correct these systemic failings.[125] In addition, a culture of safety demands accountability of all individuals at all levels,[121] effective communications between hospital team members,[121, 126,127] active patient participation,[126] and a proactive stance of looking toward the future rather than reacting to past failures.[123] Another critical aspect of a positive patient safety culture is a transparent and nonpunitive approach to patient safety, whereby medical errors are discussed openly and viewed as learning and change opportunities—as opposed to opportunities for individual punishment.[125]

Leadership. The organizational change literature suggests that strong leadership, specifically the presence of individuals who advocate for and participate in initiatives, increases the likelihood of learning, innovation, and sustained change.[82,128] The leadership exhibited within an organization may be formal—leaders who lead by virtue of a title—or informal—individuals who do not have titles but who are nonetheless regarded as thought leaders.[80] It also may come at a variety of levels, including from senior management/executives, the board of directors, and physicians, nurses, and other staff.[82]

Senior management. The literature suggests that the engagement of and leadership by formal senior management directly affect the success of quality improvement activities generally[129,130] and patient- and family-centered care specifically.[131] To establish a culture of supportive change, senior management should serve as models for staff by taking a personal interest in the quality improvement initiative, advocate for improvement, have relationships with clinical staff, disseminate data from the initiative, and procure resources to support improvement.[132]

The patient safety literature shows that senior management advocacy for learning, combined with support in the form of organizational structures and infrastructure, can establish an environment in which patient safety initiatives flourish.[133] Moreover, as mentioned above, aligning the organization with the change is an important function of senior management.[134,135] Senior management needs to lead staff by setting expectations and resolving conflicts and tension between organizational units and departments.[123] A further tenet of positive leadership is direct interaction with staff, patients, and their families.[117]

To lead patient safety improvement, senior management must be visible and must take an active role in quality improvement.[136] The importance of top management to effecting change cannot be overemphasized—a nationwide survey of 162 Veteran's Health Administration hospitals found that hospitals in the top quartile of quality improvement implementation had significantly higher commitment from top management, along with managers who had a clear vision for quality improvement and an orientation toward change.[137] Other studies have shown that committed hospital leadership—which means leaders who provide clarity about goals and expectations, establish infrastructure, provide resources, and institutionalize a quality improvement culture—is a key motivating factor for physicians.[117]

Board of directors. The engagement of hospital boards and trustees in quality and safety initiatives is another critical element of change.[138,139] Conway suggests that involvement of the board of directors in organizational change and quality improvement should include setting goals and aims, creating infrastructure, gathering data, establishing measures, changing the environment with policies and culture, and establishing accountability.[117, 138] In short, the board of directors helps "set the tone" for the entire organization.

Clinical leadership. A third type of leader—the clinical leader—also plays a crucial role in championing organizational change and quality improvement. Physician involvement in quality improvement and other initiatives can be critical to their success.[140] As a side benefit, leadership engagement by physicians may lead to increased professional satisfaction.[141] Mastal specifically argues that the role of the Chief Nursing Officer is also pivotal in ensuring the success and sustainability of quality and safety efforts.[142]

Hierarchy. In almost all cases, an overly hierarchical culture emphasizing rules, regulations, and reporting relationships is negatively associated with the implementation of quality improvement and related practices.[143] Models of change, such as the Studer Group's three-stage journey to creating a culture of excellence, suggest that breaking down vertical thinking and hierarchy is an important step toward increasing service excellence and patient satisfaction.[144] These ideas are supported by research findings. For example, an investigation by Litaker and colleagues demonstrated that at primary care practice sites in which the allocation of power was perceived as being shared, potential avenues for change were openly sought and discussed.[80] In addition, an investigation by Keroack and colleagues found that high performance in academic medical centers was associated with a structure that blended central control (i.e., centralized goals) and decentralized responsibility (i.e., the ability to implement tactics as desired).[145] In addition to being a barrier to change initiation, hierarchy also can affect professional communication and team collaboration, thus acting as a barrier to effective implementation.[146]

Slack resources. Slack resources refer to a cushion of excess resources that the organization can use in a discretionary manner.[147] Three types of slack resources are: available, resources not yet committed; recoverable, resources that can be recovered and made available through redesign; and potential, future resources that can be generated. The presence of slack resources may be a facilitator for innovation in that they lessen organizational risk associated with change.[147] Likewise, when financial resources are limited, the lack of resources may be used as a justification for avoiding change opportunities or maintaining the status quo.[148] For example, Litaker and colleagues conducted an ethnographic study of 15 primary care practices in Ohio and discovered that in practices where finances were perceived as scarce or constrained, opportunities for change were viewed as a potential drain on already tenuous finances and subsequently were avoided or resisted.[80]

Internal alignment. Internal alignment refers to consistency of plans, processes, information, resource decisions, actions, results, and analysis to support key organizational and change-specific goals.[101] Alignment throughout all levels and facets of the organization increases the likelihood of learning, innovation, and change, in addition to providing greater potential for rapid implementation and movement.[101,134] In Litaker's study of 15 primary care practices, the alignment of incentives and motivations led to more efficient use of resources and a greater openness to creating and exploring change.[80] In practices with aligned incentives, this alignment created the ability to spend time working in a coordinated fashion to attain similar goals.

Absorptive capacity. Greenlaugh and colleagues define an organization's absorptive capacity as the ability to identify, capture, interpret, share, reframe, and recodify new knowledge; to link it with its own knowledge base; and to put it to appropriate use.[149] It also includes the qualities and characteristics that enable an organization to "modify both its technical aspects and its values and/or beliefs regarding how it operates," along with the ability of an organization to recognize, understand, and evaluate the possibilities for learning and change that are available to them.[80] Precursors of absorptive capacity include the knowledge and skills of key staff and the organization overall.

Implementation of Organizational Change

The literature on organizational learning, innovation, and change also provides insights on successful implementation strategies to be used when trying to foster change. These tactics are important when considering the sustainability of the change. We conclude this section with a discussion of organization-level strategies to facilitate successful and sustainable implementation, separating our discussion into two parts: (1) pre-implementation strategies to foster change and (2) implementation and sustainability strategies to foster change.

Pre-implementation Strategies to Foster Change

Conduct an initial assessment. In addition to capturing a picture of where the organization stands in relation to the proposed change, the process of conducting an initial organizational assessment itself can help inform participants about the core concepts and strategies being assessed.[150,151] Several self-assessment tools relate to patient and family engagement, including the following:

- Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory. Developed by the Institute for Family-Centered Care (IFCC), this assessment inventory is designed to help hospital and health system leaders, trustees, medical staff, and employees determine priorities for change and improvement by assessing how the institution operationalizes patient- and family-centered care.[152]
- Patient- and Family-Centered Care: Organizational Self-Assessment Tool. Developed by the Institute for Healthcare Improvement (IHI) in conjunction with the National Initiative for Children's Healthcare Quality (NICHQ), this assessment tool helps organizations assess their current practices in relation to elements of hospital-based PFCC.[151]
- Checklist for Attitudes about Patients and Families as Advisors. This IFCC-developed tool is intended for organizations to explore staff and physicians' attitudes about partnering with patients and family members on an organizational level (e.g., as members of advisory councils and other hospital committees).[153]

In addition, AHRQ's *A Decisionmaker's Guide to Adopting Innovations* is a more general tool designed to help health care organizations determine whether an innovation will be a good fit by raising questions to consider (e.g., should the innovation be done, can it be done, how will it be done).[154]

Develop and foster a shared vision. Organizational literature widely recognizes the importance of having a clear vision and mission associated with proposed change.[150,155] A clear vision comes from top leadership, but ideally it should reflect the perspectives and input of all involved parties (e.g., clinicians, staff, patients, family members).[152] A strong vision can facilitate growth and improvement by creating a pathway for change and fostering a shared sense of purpose. In an analysis of six health care organizations, leaders at top-performing hospitals all reported creating a shared sense of purpose by prioritizing critical elements of patient care in their mission.[145]

Develop a clear plan for implementation. Developing a clear plan for implementation involves building on the organization's vision by enacting an overarching strategy on patient-centered care and engagement and creating specific measurable goals.[156,157] The implementation plan should consider which projects meet organizational feasibility criteria;[157] take into account challenges, constraints, and potential barriers to implementation and sustainability;[150] and consider how to build on past successes.[158] An environmental scan may be a helpful activity in identifying these challenges.[157]

Obtain buy-in. Buy-in, or support, at all levels, including top leadership and administration to frontline staff, is critical to successful implementation.[157] If the change vision does not come from top leadership, these individuals must be educated, motivated, and brought on board. If change does come from the top levels, it is still important to have buy-in from all parties, including staff at all levels, patients, and family members. The process of obtaining buy-in can be facilitated by a clear articulation of the vision, desired goals, and implementation plan.[157]

Provide infrastructure and resources. Prior to implementing change, it is crucial to set up an infrastructure to minimize conflicting priorities, provide clear lines of authority, and establish accountability.[159] Adequate resources must also be identified and made available for all planning and implementation activities. These resources may include funding, time for staff training, opportunities for staff participation, and physical space.[160]

Align internal incentives for participation. As noted above, incentives (financial and otherwise) play a significant role in motivating entities to change and obtaining buy-in. Creating internal incentives for participation or aligning the new initiative with existing incentives fosters change. For example, performance reviews or bonuses for meeting patient engagement goals or conducting activities can be tied to implementation goals and objectives.[134]

Establish partnerships. Establishing partnerships both within and external to the organization can help new initiatives gain a foothold. Hospitals can benefit from forming partnerships and strategic alliances with key stakeholders (i.e., those individuals or groups who have an investment in the success of the organization along with the capacity to influence how the organization acts). This may include individuals and groups internal and external to the organization.[80]

Consider sustainability. The consideration of long-term needs, plans, and intervention sustainability should be taken into account early in the planning process. Early consideration of these issues allows the organization of data collection, leadership support, infrastructure, and incentives to support sustainment.[134,157]

Implementation Process Activities to Foster and Sustain Changes

Engage staff at all levels. Staff members should be engaged during both the planning and the implementation processes. During the development phase, using inter- or multidisciplinary teams may help obtain needed buy-in, while helping change be more sustainable. In addition, staff may be engaged by opening the doors to two-way communication and providing staff with mechanisms to provide input and feedback. Another way to engage staff is to create short-term wins—i.e., opportunities for positive results and successes at an early stage.[72] In general, staff are more likely to be engaged if they feel as though the work is meaningful and that positive outcomes or impacts are likely to result from the change.[43,161] Actual positive experiences in turn help to further motivate staff in a reinforcing cycle.[43]

Demonstrate executive commitment. Executive Level Walkarounds are an intervention developed in the patient- and family-centered care arena to demonstrate senior management commitment and leadership.[136] During these walkarounds, leaders make announced or unannounced visits to facilities (or departments or units within these facilities) to observe and talk with staff and physicians in a nonthreatening environment about quality and safety issues. The overarching objectives of walkarounds are to connect top executives with frontline staff and to demonstrate to clinicians and staff that leadership is committed to patient safety.[136,162] Walkarounds also provide opportunities for leadership to articulate these commitments and to identify opportunities for improvement. Moreover, they can improve the safety climate and safety culture while engaging frontline staff and patients and their families.[136,163]

Engage an internal champion. Just as important as strong leadership from the top levels is the presence of physician or other clinical champions. Champions, particularly among physicians, are critically important in creating forward movement on quality improvement initiatives.[117,164] Champions are respected by their peers within their area of expertise and can help achieve buy-in among staff by engaging with them on a different level than top management.

Communicate clearly and consistently throughout the process. Although it is important to communicate goals and priorities prior to implementation, it is equally important to continue communicating clearly throughout the life cycle of the intervention. Staff members are more likely to sustain their engagement with an initiative if they are kept apprised of what the organization is doing and informed about the status of progress toward initial goals.[150] With regard to clinical staff, one effective message to emphasize throughout the process is that the initiative is not merely administrative in nature—rather, the purpose of the intervention and the larger goal should be framed in terms of improved patient outcomes.[117]

Collect data (feedback and measurement). Data also should be collected to assess progress toward improvement and implications for sustainability. Studies show that top performers in areas such as quality and safety or patient- and family-centered care set goals and measure progress toward them,[145,165] and that hospitals that provide timely feedback to staff are more likely to foster quality improvement.[164] The data collected during the initiative should help to show whether goals and objectives are being met and should be reported so that the data help implementers, leadership, and stakeholders understand the improvement.[157] In addition, to make the numbers meaningful and important, staff must see how their specific actions feed into the data.[164] Finally, accountability for performance and change should be built into the data collection and reporting process.[150]

Integrate and sustain. Although many factors affect the sustainability of an intervention, the literature suggests that integration into an organization is the best way to sustain a change or its outcomes, processes, or practices.[134] The ability to achieve integration results from many of the factors discussed above, including internal alignment of goals, rewards, performance measures, and the creation of organizational policies. Moreover, leadership support is essential in sustaining the change.[134]

Organizational Context: Summary of Key Points

- ***Motivation***. We examined potential external and internal motivators for organizations to encourage patient and family engagement in safety and quality.
    - Key external motivators included the desire to mimic competitors; health care legislation or mandated policies; leadership from influential bodies; alignment of financial incentives; public reporting; and accreditation and awards.
    - Key internal motivators included the occurrence of a sentinel event; the business case for patient and family engagement; the desire to improve quality and safety performance; stories from patients and families; and altruism.
- ***Organization structure***. Structural aspects of a hospital that influence the ability to initiate and sustain change include the size of the hospital, profit or academic status, and medical staff organization. Unfortunately, although there is general recognition of the potential influence of structural factors on an organization's ability to adopt and sustain innovations, there is insufficient evidence about whether and how these structural factors act specifically as barriers to or facilitators of change.
- ***Organization processes***. Processes that affect an organization's ability to implement and sustain change include the organization's understanding of and experience with patient and family engagement; the existing quality and safety culture; the strength of leadership at all levels; the hierarchy (whether rules, regulations, and reporting relationships are emphasized); the existence of slack resources (cushion of resources that can be used in a discretionary manner); absorptive capacity, or the ability to identify, capture, interpret, share, reframe, and recodify new knowledge, to link it with its own knowledge base, and to put it to appropriate use; and internal alignment (consistency of plans, processes, information, resource decisions, actions, results, and analysis to support key organizational goals and change specific goals).
- ***Implementation strategies***. Organizational strategies to foster change include pre-implementation strategies such as conducting an initial assessment; developing and fostering a shared vision; developing a clear plan for implementation; obtaining buy-in; providing infrastructure; aligning internal incentives for participation; and considering sustainability. Strategies during interventions include engaging staff at all levels; engaging an internal champion; communicating consistently throughout the process; using appropriate tools; and collecting data and feedback.

Strategies and Interventions

In conducting this environmental scan, we sought to identify strategies and interventions that have been used to engage patients and families in their care and at an organizational level with regard to safety and quality. Overall, we found two broad types of strategies or interventions that promoted or facilitated patient and family engagement:

1. Hospital-level interventions[d] that are implemented by means of changes in hospital policies, processes, systems, procedures, or structures.
2. Individual-level interventions that are implemented to change individual knowledge, attitudes, or skills by means of tools for educating, informing, activating, and engaging individuals.

The two types of interventions are not mutually exclusive. That is, hospital-level interventions may be supported by individual-level tools, and uptake of new individual behaviors may be facilitated by hospital-level support.

Next, we discuss the types of hospital-level and individual-level interventions identified in the scan, addressing what strategies have been used, who is involved, and what outcomes have been assessed.

Exhibit 8 highlights the strength of evidence for articles reviewed in this section. Most evidence in this section is from case studies or empirical articles about interventions, strategies, or tools used in a single hospital. In general, these articles did not discuss sustainability of the interventions.

Exhibit 8. Strength of Evidence for Strategies and Interventions

Type of Document	Number
Systematic reviews	
Systematic review of randomized controlled trials	1
Systematic review of descriptive studies (quantitative / qualitative)	5
Single evaluative studies	
Randomized controlled trial	3
Nonrandomized controlled trial	3
Cohort / case-control study	0
Single site intervention (pre/post) / Case series study	8
Single site intervention (post only)	8
Single descriptive studies	
Mixed methods study (qualitative / quantitative)	2
Quantitative study	3
Descriptive or qualitative study	6
Case study / description of implementation	39
Scholarly articles or reviews	10
Other (workshop summary, PowerPoint presentation)	4

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[d] We use the term "hospital-level" interventions with the understanding that hospital level could imply hospital systems as well as individual hospitals.

Hospital-level strategies

We grouped the hospital-level strategies into four main categories:

1. Engaging patients and families as members of their care team
2. Facilitating communication among patients, family members, and the care team
3. Supporting increases in patient or family member knowledge, skills, or abilities
4. Involving patients and families at a hospital level

At the outset, it is important to note that some of the strategies and interventions described here fall short of truly engaging patients and families in safety and quality issues. As noted in our discussion of the characteristics of the target audiences, information by itself is typically insufficient to motivate true behavior change. In our discussions, we note where the intervention serves as a first step (such as providing information) but may need to be accompanied by additional materials or strategies to help individuals take action.

Engaging Patients and Families as Members of Their Care Team

Interventions and strategies used to engage patients and families as members of their health care team include bedside rounds, bedside change of shift reports, patient/family-activated rapid response teams, access of medical record information by patients and family members, and other specific efforts to encourage family participation,. Exhibit 9 briefly summarizes these interventions along with outcomes that have been measured for each strategy.

Exhibit 9. Strategies to Engage Patients and Families as Part of the Health Care Team

Description	Who is involved	Outcomes measured
Bedside rounds2’3,[52,107,166,167,168,169,170,171]		
Patients and families participate in rounds. Orders and discharge paperwork clarified, patients/ families involved in decisions	Patients, families, usually multidisciplinary teams	Process measures • 85% of families participate in rounds [107,170] • New information discovered from family 46% of time[52] • Family member added 1 minute to rounding time[52] vs. family-centered rounds take 20% longer[170] Outcome measures • Improved patient satisfaction2’3,[166,170,171] • Improved staff satisfaction2’3 • Length of stay decreased[166]
Bedside change of shift[172,173,174]		
Nurses conduct bedside report for change of shift	Patients, families, incoming/ outgoing nurses	• Nurses reported better ability to prioritize work[172] • Decrease in staff time.[172,174] One study noted a decrease in time over shift by 100 hours in first two pay periods[172] • Increased nursing staff and physician satisfaction[172,173,174]
Patient/family–activated rapid response teams[175,176]		
Patients encouraged to use internal phone line if notable changes in patient’s health or patient’s concerns	Team response includes nursing supervisor; others	• Patients and families were favorable toward programs[175,176] • Most calls were related to communication

are not being addressed. Team responds within minutes. Patients told at admission with verbal review of guidelines.	such as physician, unit nurse, or patient relations coordinator	issues between patients and clinicians[176]
Specific efforts to increase family participation[57,158,177]		
Open visitation policy[57]; Presence during invasive procedures[158]; Patient given VIP button for family member/ friend and is considered part of care team[177]	Family, patient, nurses, and other providers	- Only 3% of employees surveyed 6-month post-implementation reported that "performance had been hampered by family members"[57]
Access to medical records by patients and families[169]		
Allow patients and families to access medical records or online portals for information	Patients, family, provider, online access	*More in-depth information about electronic medical records or online portals was not included in this review*

Bedside rounds. Bedside rounding is one strategy used in both pediatric and adult hospitals to facilitate patient and family participation as part of the health care team. Bedside rounds include, at a minimum, the attending physician and patient or family member, but can also include multi-disciplinary team members such as nursing staff, social workers, pharmacists, resident physicians, and others as needed. In some cases, patients and family members are given the choice about whether to participate in rounds. However, studies have noted that when given the choice, almost all patients and family members choose to participate. [107,170,178]

There is evidence to support the idea that bedside rounding facilitates patient and family engagement. For example, studies suggest that bedside rounds facilitate not only patient and family involvement in treatment decisions but also clarification of orders and discharge instructions.2’3’[52,107,166,167,168,169,170,171,179] Moreover, one observational study reported that family members’ participation in rounds resulted in the discovery of new information 46 percent of the time.[52] Several studies also noted improved patient satisfaction2’[3,166,170,171] and improved staff satisfaction2’3 after the implementation of bedside rounds. Finally, one study noted that the length of stay decreased after implementation.[166] In the pediatric realm, the Committee on Hospital Care of the American Academy of Pediatrics (AAP) issued a policy statement in 2003 that attending physician rounds in patient rooms with families present should be standard practice.3

A commonly lodged criticism of bedside rounds is that they require extra time on the part of the care team. However, the available evidence on this issue is conflicting. Although one study found that family-centered rounds take 20 percent longer,[170] another noted that family member presence during rounds added only one minute to the process.[52]

Bedside shift reports. Conducting bedside change of shift reports is another strategy used to encourage patient and family involvement as part of the health care team. Conducting change of shift reports at the bedside, instead of at the nurses’ station or in the hallway, allows family members to participate more fully,[172,173,174] facilitates the sharing of information, and also allows outgoing staff to introduce incoming staff to patients and family member.[173] Strategies for conducting bedside shift reports include issuing nurses a pocket guide to ensure that all issues are covered during the report, such as identifying patient priorities and team priorities.[172] Other strategies include having staff encourage patients to ask questions and using appropriate language so that patients do not feel “talked over.”[173]

Hospitals that have implemented bedside change of shift reports have seen positive effects on nursing staff and physician satisfaction, as well as decreases in staff time.[172,173,174] One study noted a decrease in time over shift by 100 hours in the first two pay periods.[172] Nurses also have reported better ability to prioritize work/cases during their shift and a positive impact on patient outcomes through improved discharge planning.[173]

Patient family-activated rapid response teams. Rapid Response Teams (RRTs) address situations of acute deterioration of a patient while under hospital care. RRTs bring critical care expertise to the bedside (or wherever care is needed) to address the effects of early warning signs of health trauma affecting a patient. Teams typically comprise a wide array of health care professionals from various departments.

The Condition H (Condition Help) program at the University of Pittsburgh Medical Center (UPMC) provides an example of how RRTs have been implemented to encourage patient and family engagement. The Condition H program allows patients or family members to activate RRTs.[175,176] Patients or family members are encouraged to use an internal telephone line if there is a noticeable change in a patient's condition and the health care team is not responsive to the change or to patient and family concerns. All patients and families receive the telephone number and information about Condition H upon admission, and the admitting nurse reviews this information. The Condition H team is led by an administrative nursing coordinator and includes a physician, unit nursing staff, and a patient relations coordinator. Similar RRT programs have been implemented in other hospitals, and they may have different types of staff and processes associated with them.[175]

Within 9 months of implementing Condition H at UPMC, there were 21 Condition H calls.[176] Interviews with the patients and family members who initiated these calls generated positive responses to the program. Specifically, patients reported feeling safe, respected, and empowered. One concern associated with the implementation of Condition H is that patients or family members will activate the RRT for noncritical "complaints." However, UMPC found that the majority of Condition H calls met the criteria established for emergency needs and that the impetus for most calls was related to communication issues between patients and clinicians.[176]

Efforts to increase family participation. Hospitals also may implement other specific efforts to increase family participation during the hospital stay. Efforts include changes in organizational policies to allow open visitation or family presence during invasive procedures; provider and patient reactions to these policies were discussed in more detail in the findings about individual characteristics of the target audiences.[57,158] Another study described a VIP program in which patients designate a family member or friend as a VIP who participates as part of the health care team. VIPs share patient "likes" and "dislikes" with health care workers and participate in direct patient care to better assist the patient upon discharge. For their part, providers cannot argue with VIP perceptions of care and are responsible for determining how best to resolve the situation when there are different perceptions between the VIP and health care workers.[177]

Access to medical records by patients and families. Several hospitals have implemented strategies to allow patients and families to access medical records or online portals for information.[e] For example, The Children's Hospital of Philadelphia provides patients with online access to shared care plans, allowing patients to collect information about providers and medicines in one place that they can share with their physicians. As another example, Planetree hospitals have an open chart policy that allows patients to read and write in their medical records.[169] The literature reviewed did not provide information about the effects or reactions to these types of programs.

Facilitating Communication Among Patients, Family Members, and the Care Team

The second main group of hospital-level strategies to increase patient and family engagement involves the implementation of procedures and policies to assist patients and family members in understanding which staff members are involved in the patient's care or facilitating communication between patients and providers. Exhibit 10 briefly summarizes these interventions along with outcomes that have been measured for each strategy.

Exhibit 10. Facilitating Communication Among Patients, Family Members, and the Care Team

Description	Who is involved	Outcomes measured
Understanding which staff members are involved in the patient's care[180,181,182]		
Structural changes, such as using whiteboards in patient rooms to identify nursing staff or provide written information on who is on the patient's health care team	Nurses, patients, families	• Use of whiteboard found positive impacts on patient's perceptions of nursing behaviors[180]
Facilitating communication with physicians[183,184,185]		
Pre-visit coaching of patients to help them generate concerns or questions to ask physician	Coach, patient	• Compared with controls, intervention physicians received higher ratings of their communication style and exhibited more patient-centered communication behaviors.[183] • Intervention patients obtained more information per question and exhibited greater involvement during the visit than controls.[183] • Intervention intensity had a clear relationship to improvements in physicians' behaviors; the relationship was less pronounced with patients.[183]
Using shared care plans / daily goals sheets [186,187]		
Shared care and daily care plans—engaging patients and family members in plans typically used by providers	Patient, nurse, physician	• *This literature review did not find outcomes assessed with this strategy*

Understanding which staff members are involved in patients' care. As noted in the section on individual characteristics, patients and family members may find it difficult and intimidating to

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[e] Because the implementation of electronic medical records (EMRs) is beyond the scope of this project, we did not specifically search for articles focusing on patient involvement in the development or use of EMRs or in outcomes associated with these online tools.

understand the unfamiliar environment of the hospital and who in the hospital is providing care. As one member of this project's Steering Group noted, each hospital is like a continent, with each hospital unit like a country. Each unit has its own culture, language, and traditions, and it is difficult for an outsider (the patient) to understand this environment without some introduction or education. Although the interventions noted in this section can help inform patients about the staff providing care, this may not lead to true engagement and communication with providers without additional support.

One strategy involves the use of whiteboards in each patient's room to convey and share information among patients, family members, and members of the care team. In one study, nursing staff used whiteboards in each patient's room to help patients and family members identify who did what among nursing staff, including names, roles, and education level. Family members used whiteboards to enter their own phone numbers and leave messages for nursing staff about the patient's needs. Post-implementation evaluation results demonstrated positive increases in patients' ratings of nurses' promptness in responding to call light requests, making periodic checks without a request, and the positive manner of nursing care provided. The authors hypothesized that prominently posting staff names may have increased staff members' sense of accountability, leading to these changes in nursing behaviors.[180]

Other strategies include providing written materials or posting information for patients and family members about staff names, telephone numbers, and other information about the hospital (such as visiting times, meal times, round times). For example, one hospital developed a ''deck'' of staff name cards, bound with binder rings, that was hung in the patient's room.[181] Another hospital developed a business card to give to patients and relatives with information about the patient's location.[182] Articles about these interventions did not report outcomes.

Facilitating communication with physicians. A systematic review of randomized controlled trials conducted by Rao and colleagues[183] examined interventions to enhance the communication behaviors of physicians and patients, rating the intensity of the intervention (e.g., number of times delivered, additional personnel required) and examining associated outcomes. Of the 36 studies reviewed, 18 studies targeted physicians, 15 targeted patients, and 3 targeted both physicians and patients.

Overall, the review found that the interventions improved physician communication behaviors on patient ratings of their communication style and demonstration of patient-centered communication behaviors (e.g., asking open-ended questions). Patient interventions showed similar effects; interventions increased information obtained per question and involvement in the visit.[183]

Intensity of the intervention had a clear relationship to improvements in physician behaviors. Almost all interventions targeting physicians were rated as moderately or highly intense. Three-quarters (76 percent) of the interventions included three or four intervention types (e.g., information, modeling, feedback, practice), and nearly all (95 percent) required additional personnel. The relationship between intensity and improvements was less clear for patients. However, interventions targeting patients were mostly low intensity. A third included one intervention type, and less than half (44 percent) involved additional staff to implement the intervention.[183]

We looked at two studies that evaluated the impact of coaching—either by a consultation planner or a clinic assistant—on the patient's ability to ask questions or raise concerns during pre- or post-hospitalization visits with physicians. The coaching usually used a structured protocol to help patients generate their questions and concerns about the upcoming meeting with their physicians.[184,185] In one study, patients attended a 20-minute session before a regular office visit, during which a clinic assistant reviewed their most recent record and helped them identify relevant medical decisions in their care and questions for their physician.[185] Although patients in the experimental and control groups asked similar numbers of questions during the physician visits, patients in the experimental group were more likely to control the flow of the conversation by using alternative strategies such as joking about uncertainty or introducing topics attributed to others (such as "my friend had this treatment...").[185] Despite initial poorer health, patients in the experimental group reported better role and physical functioning after the intervention than did patients in the control group, indicating a positive impact on patients' health outcomes.[185] In the other study, a pre-hospitalization intervention, a consultation planner (employee, volunteer, nurse, or non-nurse) used a structured interview to help patients generate questions and concerns for an upcoming meeting with their physician.[184] In an evaluation of the intervention's impact on patient satisfaction, 60 percent of patients reported maximum satisfaction with how the intervention helped them prepare for the medical visit.[184] Satisfaction was not correlated with whether the planner was an employee or a volunteer, or a nurse or a non-nurse. Although this intervention was effective in increasing satisfaction, the evaluation focused only on this outcome. Therefore, it is unclear whether the session with the consultation planner was similarly effective in increasing the patient's ability to ask questions or get the information needed during the visit.

Using shared care plans and daily goal plans/sheets. Another strategy designed to facilitate communication with care providers is the use of shared care plans or daily goal/care plans. The shared care plan was developed largely as a self-management tool to help individuals keep track of their health, including managing chronic conditions.[187] Some hospitals are now implementing the systemic use of shared care plans to improve communication among all members of the care team. For example, St. Joseph's Hospital (Washington) has implemented a program where electronic shared care plans are used to ensure that all care team members (including family members) share up-to-date, accurate, and complete information. The shared care plan also helps create a platform by which patients, family members, and providers can work together to identify problems, priorities, treatment plans, and goals. At St. Joseph's, the electronic shared care plans are linked to patients' online medical records so that information from the medical records is automatically imported.[186] Patients, family members, and clinicians all share the same ability to access and write in the shared care plan, which contains information on personal and family health history, medications, allergies, health indicators such as cholesterol and blood pressure, personal health goals, and the patient's preferences (e.g., religious and dietary preferences). The literature review did not find outcomes assessed with the use of a shared care plan as a strategy for engaging patients and family members in quality and safety.

A similar strategy is the use of daily care/goal plans and sheets. The daily care plan is a patient information sheet that lists allergies, current medications, and any tests and procedures scheduled for the day. The daily care plans are given to patients and families each day to help providers communicate with patients and families about plans for care. However, the extent to which patients and family members are allowed to be involved in the creation of these daily care plans is unclear.

Supporting Increases in Patient Knowledge, Skills, and Abilities

The third main group of hospital-level strategies to increase patient and family engagement includes interventions that involve structural changes to support increases in patient knowledge, skills, or abilities. This includes implementing structural changes to engage and support patients and families in care coordination, establishing systems for patients and family members to track medications and health records after discharge, providing support for asking questions or raising concerns during communication with physicians, and providing access to general health information. Exhibit 11 briefly summarizes these interventions along with the outcomes that have been measured for each strategy.

Exhibit 11. Supporting Increases in Patient Knowledge, Skills, and Abilities

Description	Who is involved	Outcomes measured
Engaging and supporting patients and families in transition planning[32,188,189,190,191,192,193,194]		
Designating a person to ensure patient and family involvement in care from admission to post-discharge	Care coordinator, patient, family	• Care coordinators typically spent from 1 to 2½ hours per discharge[32,194] • Patient satisfaction with the discharge process increased[193,194] • Patients receiving the intervention were half as likely to be readmitted to hospitals as those who did not receive the intervention[190]
Establishing systems for patients and family members to track medications and health records[190,191,192,195,196]		
Providing patients with daily medication lists, post-discharge medication lists, or post-discharge medical records; participating in medication reconciliation	Patient, family	• Increases in number of medication lists reconciled[196]
Accessing health information[182]		
Establishing an information resource center for patients and families within the hospital or providing access to education videos through the hospital's television system	Patient, family	• *This literature review did not find outcomes assessed with this strategy*

Engaging and supporting patients and families in transition planning. After discharge, one in five hospital patients will experience an adverse event (with adverse drug events being the most common).[87,197,198,199] These adverse events lead to emergency department visits or hospital readmission; often, readmissions result from a lack of continuity of care at discharge.[200,201] Several of the articles we reviewed discussed hospital-level strategies to support patients' and family members' transition from admission to post-discharge[32,188,189,190,191,192,202] and specifically noted the need for patients' and family members' engagement in discharge planning throughout the hospital stay.[32,194,203] In general, many discharge and transition interventions reflect hospital processes and procedures without accompanying strategies to increase patient or family member knowledge and skills related to engaging in the health care encounter.

Most of the discharge strategies involved establishing procedures or systems to ensure that a designated person engages patients in their care from admission to post-discharge. Depending on the study or intervention, this person was called a discharge planner,[193] transition coach,[190,203] or patient navigator.[189] Most often, the care coordinator was a nurse or nurse practitioner, but it also could be another staff person or a patient or family member volunteer. In the studies reviewed, care coordinators were responsible for the following:

- Making sure that patients and family members were involved in discharge planning and assessing patients' understanding of discharge instructions.[32,194,203]
- Ensuring that followup appointments with ambulatory care physicians were made before discharge, at a time convenient to the patients/family members.[32,192,203]
- Ensuring that hospital records or discharge summaries were sent to the ambulatory care physicians before the followup appointment[32,203] or that patients or family members took these records to the appointment.[32,190,191]
- Making post-discharge phone calls and/or home visits to assess discharge issues and any patient or family member concerns.[32,192]
- Helping patients reconcile pre- and post-hospitalization medications.[32,190]
- Providing coaching to patients and family members to prepare questions or concerns to ask physicians during followup visits.[190]

Evaluations have shown that care coordinators typically spent from 1 to 2½ hours per discharge,[32, 194] and that they are effective in increasing patient satisfaction with the discharge process.[193,194] In one evaluation, hospitalized patients who received a patient-centered intervention designed to encourage patients to take a more active role in managing the transition from hospital to community were half as likely to be readmitted to hospitals as those who did not receive the intervention. The intervention included a transition coach (nurse practitioner) who helped patients reconcile medications and prepare for post-hospitalization physician visits as well as identify "red flags" of worsening condition through a series of telephone and home visits.[190]

In a guide for hospital leaders on how to reduce preventable hospital readmissions, Osei-Anto and colleagues discussed several hospital-level strategies that hospitals could implement.[204] Although most of these strategies are not focused on patient and family engagement, elements of the strategies encourage patient and family involvement.[139] One strategy, the Re-Engineered Discharge (RED) program, has been adopted by the National Quality Forum as one of its "Safe Practices." This hospital-level program uses an After Hospital Care Plan (AHCP) for patients, which is generated electronically by providers at a dedicated workstation. The AHCP is a spiral-bound, color booklet with information needed by patients for the days between discharge and their first visit with their ambulatory care physician.[32] Although adverse event data are still being assessed from a randomized controlled trial in a single hospital, intervention group participants had a significantly lower rate of emergency department visits and hospitalizations within 30 days of discharge.[205]

Establishing systems for patients and family members to track medications and health records. Another structural change to support increases in patients' and family members' knowledge, skills, and abilities is the establishment of mechanisms for patients and family members to track medications and health records post-discharge. For example, some hospitals provide patients with a post-discharge personalized medication list[195] or forms for patients to maintain their own medication lists.[192] Similarly, the shared care or daily plans discussed above can be updated to reflect the most recent hospitalization and communicate a shared understanding of post-discharge plans. This plan can help patients plan for discharge and facilitate their continued involvement in their own care management.

Other strategies include providing forms or patient-held medical records with information about procedures, test results, and other clinical data that can be taken by the patient or family member to the followup appointment.[190,191] Because these tools are designed for use on an individual basis (and may benefit from, but not require, hospital-level implementation), we discuss these tools in more detail below, in the section on individual-level strategies, topics of Component 1.

Another strategy to help patients track their own health information is the establishment of procedures to help patients and families do their own medication reconciliation. For example, one ambulatory care center implemented a program in which clinic assistants printed copies of patients' medical records and asked the patients to update their own records while waiting for their visits. This intervention resulted in a 400 percent increase in the number of medication lists reconciled, with specific changes including deleting medications no longer used, adding medications that were not previously on the list, and correcting dose or frequency errors.[196]

Accessing health education materials. Hospitals also have the opportunity to provide patients and families with access to health education materials or information. Examples of these strategies include establishing an information resource center for patients and families within the hospital or providing access to education videos through the hospital's television system.[182] Our literature search uncovered scant research on the outcomes or effectiveness of these strategies. Although providing information about conditions or treatments is a first step in engagement, other supports would need to be in place to help patients and family members use the information to communicate with providers.

Involving Patients and Family Members at the Hospital Level

Next, we describe the fourth and final main group of hospital-level strategies to increase patient and family engagement: strategies for involving patients and family members at an organizational level. These strategies include establishing patient and family advisory councils, introducing other opportunities for patients and families to be involved, and eliciting patient and family feedback. In this section, we discuss the creation of these opportunities at a hospital level; in our discussion of Component 2 individual-level strategies, we will focus on strategies to help patients become involved once the opportunities exist. Exhibit 12 briefly summarizes these interventions along with outcomes that have been measured for each strategy.

In a summary for the Institute for Healthcare Improvement,[206] Reinertsen and colleagues described how involving patients and family members at an organizational level is an example of a small change that can bring about big results in performance.

> *We have observed that 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. Clearly, this is a leverage point where a small change can make a huge difference.[206]

Exhibit 12. Involving Patients and Family Members at the Hospital Level

Description	Who is involved	Outcomes measured
Establishing patient and family advisory councils[107,131,169,207,208,209,210,211,212,213,214,215,216]		
Councils enable patients and family members to be involved in key organizational decisions and to participate in safety policies, facility planning, and hiring of new staff or management	Patients, family members, hospital staff	Case studies provide some evidence of positive outcomes: • Improving satisfaction among patients, families, and staff • More efficiently using redesign resources • Improving the public image of the hospital • Enhancing hospital reputation and market share
Introducing other opportunities for patients and families to participate at a hospital level[107,169,213,215, 217]		
Participating on committees (e.g., patient safety, quality improvement teams) or serving as "faculty" for hospital orientation or training medical and nursing students	Patients, family members	• Patient satisfaction scores increased from the 40th to the 90th percentile after patient and family advisors participated in the redesign of the mammography program77
Eliciting patient and family member feedback [167,218]		
Patient satisfaction surveys or patient focus groups	Patients, families, moderator	• *This literature review did not find outcomes assessed with this strategy*

Establishing patient and family advisory councils. Establishing patient and family advisory councils (PFACs) is one mechanism for ensuring the participation of patients and family members at a broader organization level.[107,131,169,207,208,209,210,211,212,213,214,215,216] PFACs enable patients and family members to partner with hospitals to make key organizational decisions[207] and to participate in safety policies, facility planning,[213] organizational assessments,[212] training and education of hospital staff,[212] development of materials, and hiring of new staff or management.[215] The presence of PFACs also benefits hospital staff and administration by enabling them to learn about quality and safety from the perspectives of patients and family members.[207]

Although many benefits of PFACs have been cited, most of the available evidence to support these benefits comes from descriptive case studies of organizations that have implemented PFACs. For example, at John Nasseff Heart Hospital in St. Paul, Minnesota, perceived benefits associated with the implementation of the PFAC included enhancing the ability of nurses to better understand and meet patients' and family members' needs and subsequently improving satisfaction among patients, families, and staff; providing a sounding board for staff to use when designing or planning initiatives, allowing more efficient use of redesign resources; improving the public image of the hospital; and enhancing hospital reputation and market share.[212] The Medical College of Georgia (MCG) Health System experienced a steady drop in lawsuits over a 5-year period, along with improvements in cost efficiency, which MCG attributed in part to efforts to partner more closely with patients and family members at an organizational partnership level.[213] Also, case study descriptions have indicated that PFACs help to develop or improve patient information materials and may facilitate earlier detection of potential problems in quality and safety (i.e., before an adverse event).[208]

It is important to note that hospitals may adopt different models for the use of PFACs. At some institutions, PFACs have the authority to participate in the decisionmaking process, which reflects a higher level of patient engagement. At others, the PFAC has the authority to collect information, provide input and feedback, and make recommendations to leadership. However, the authority to make decisions remains in the control of leadership.[212]

In general, the materials we reviewed demonstrated that there is relatively strong guidance available on the process for establishing PFACs. Broadly speaking, the steps to form a PFAC include defining the purpose of the council, allocating resources, identifying and recruiting members, and providing training.[219] Membership should reflect the ethnic diversity of patient populations, and members should participate in an orientation or training that addresses HIPAA, confidentiality, working with professionals, team building, and quality improvement. PFACs may also accommodate family schedules and reimburse out-of-pocket expenses such as travel and child care.[107]

Examples of a small selection of PFACs, including who is involved and their roles and responsibilities, are highlighted in Exhibit 13. We also discuss PFACs further in our review of tools for Component 2, focusing there on individual-level information to support patients' and family members' involvement in PFACs.

Exhibit 13. Examples of Patient and Family Advisory Councils

Hospital	Participants	Roles/Responsibilities
Dana Farber Cancer Institute and Brigham & Women's Hospital[131,208,210,216]	15 patients and family members, nurses, and physician staff members	• Has an office in the hospital • Involved with three committees • Involved in conducting patient rounds and an educational program for first-year oncology fellows
John Nasseff Hear Hospital, St. Paul, MN[212]	Membership includes previous patients and family members	• Primary focus is to improve the access and availability of education materials for patients covering a wide variety of health problems within the critical care and heart hospital units • Offered input in comfort carts, orientation program for new critical care nurses; provided family journals in waiting areas • Can collect information and make recommendations to hospital leadership, but leadership makes decisions
Medical College of Georgia Hospital and Clinics—"Patient/Family-Centered Care Committee"/"Family Forum Advisory Council"/ "Children's Advisory Group"[213]	Parents and interdisciplinary sample of staff	• Redirect the philosophy of care • Input in issues affecting patient's values, preferences, and expressed needs and families' experiences of care • Ongoing input and insights from patients' and/or family members' perspectives • Elicits information from and builds relationships with patients and families for many design and planning processes throughout the hospital
Children's Hospitals and Clinics of Minnesota[214]	Parent s of children who have had inpatient or outpatient experiences at facilities	• Developing, implementing, and evaluating services and facilities • Input into hospital policies and initiatives • Interact with other patients and families by fielding concerns and suggestions
Children's Hospital of Philadelphia—"Youth Advisory Council"[220]	Group of frequently hospitalized adolescents and their siblings	• Provide feedback to staff on a "range of care issues"

Introducing other opportunities for patient and family involvement at a hospital level. In addition to PFACs, hospitals can provide other opportunities for patients and family members to participate at an organizational level. Potential ways for patients and family members to contribute their expertise include serving as "faculty" for hospital staff orientation, participating in staff training, and helping train and educate medical or nursing students.[107,169,213,215] Patients and family members also may participate on such committees as patient safety, patient and family education, or customer service and satisfaction.[169,217] Patients and family members may also participate in safety rounds or "on the spot" satisfaction surveys, where patient volunteers can interview other patients and families about their concerns.[169,215] Although the literature reviewed did not identify specific outcomes associated with these strategies, several of our key informant interview (KII) participants noted that there is a general perception that these are effective ways for the hospital and providers to understand the patient's perspective and incorporate it into their daily practice.

Eliciting patient and family member feedback. Eliciting feedback from patients and families is another hospital-level strategy to ensure that patient perspectives are incorporated into hospital policy and procedures. As noted in our discussion of organizational context above, patient satisfaction surveys such as HCAHPS can be important motivators for change at an organizational level and can also provide the opportunity for patients and family members to contribute feedback at the organizational level. Likewise, conducting patient and family focus groups can highlight important areas for improvement or change related to quality or safety.[167,218]

Individual-Level Strategies and Tools

As described earlier, individual-level interventions target changes in individuals' (patients, families, providers, leadership) knowledge, attitudes, or skills. Here, we present findings on individual-level interventions as they relate to each of the Guide components in terms of the topics covered, modes of distribution, overall usability issues of the tools, and implementation guidance provided.

The information in this section draws mainly on our review of publicly available tools and resources for educating individuals on the concepts of patient and family engagement in quality and safety. Occasionally and where noted, this information is supplemented by findings from our review of relevant literature.

Topics Covered

In this section, we discuss individual-level tools, grouped according to Guide components:

- **Component 1: Patient and family "active involvement"** tools provide information, encouragement, and support for patients and families to become actively involved in their hospital care as key members of the health care team.
- **Component 2: Patient and family "organizational partnership"** tools provide patients and families with information to prepare them for partnering with organizational leaders, opinion leaders, and other consumer and patient advocates to improve the safety and quality of hospital care at a systems level.
- **Component 3: Health professional** tools provide health professionals with information and strategies to prepare them for partnering with patients and families to improve health care safety and quality at two levels—in direct care and in policy and program development, quality improvement, and health care redesign.
- **Component 4: Leadership and implementation** tools provide systemic support to administrative leaders, departmental managers, opinion leaders in hospital cultures, and hospital staff members who will be responsible for implementing the Guide.

The main topics of the tools classified in each component are shown in Exhibit 14.[f] Because the format of available tools was consistent across all components, we discuss format in a separate section below.

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[f] A list of all tools reviewed for this report is available from Pam Dardess, MPH, Senior Research Analyst, American Institutes for Research, Health Program, 100 Europa drive, Suite 315, Chapel Hill, NC 27517; phone 919-918-2311; fax 919-960-6983.

Exhibit 14. Topics Addressed by the Tools, Organized by Component

Guide component	Main topics covered
Component 1: Patient and family "active involvement"	• Safety (general issues, medication, surgery) • Communicating with providers • Be informed/active patient • Care coordination • Infection prevention
Component 2: Patient and family "organizational partnership"	• Information about programs • Descriptions of patient/family members' roles
Component 3: Health professional	• Communicating with patients • Infection control • Partnering with patients at an organizational level • Team work and communication with other providers
Component 4: Leadership and implementation	• Organizational change • Guidance specific to patient safety or patient-centered care

Component 1: Patient and family active involvement. The majority of tools reviewed (136 of 213) related to Component 1 of the Guide. These tools focus on engaging patients in their individual care experiences and emphasize safety and quality issues. The main topics addressed were patient safety, communication with providers, patient engagement/activation, care coordination, and infection prevention. Each of these topics is discussed separately below.

In terms of the intended audience, the majority of the tools targeted patients as a discrete audience, rather than targeting patients and family members or family members only. However, a few tools were directed at caregivers or parents, and in many cases, the information in the patient-only tools could be applicable or useful to family members as well.

Safety. About one-third of the tools reviewed provided general education or specific information to patients about issues related to health care safety.

Some tools provided general information on patient safety specific to a particular topic (e.g., medications) or a particular setting (e.g., hospitals). These tools included high-level information discussed in more detail in other tools (e.g., speaking up, medication safety, preventing falls, communicating with providers, clean hands).

One frequently addressed topic was medication safety. Tools on medication safety focused on questions to ask providers about medications across settings (i.e., not just in the hospital but also in ambulatory care and pharmacy settings), how to take medications safely (e.g., follow dose and timing instructions, take the full course as prescribed, alert providers to any reactions), and tips for preventing errors (e.g., check to ensure the medication is the one you expected to have prescribed).

The information gathered from our review of the medication safety tools was complemented by several peer-reviewed articles that discussed techniques for educating patients about medication errors or methods for reconciling medication lists.[192,195,196,221,222] For example, in one randomized controlled trial (RCT), patients received a copy of their current medication list and an updated list every 3 days (experimental group only), as well as a one-page consumer education guide to medication safety (experimental and control group). There were no significant differences between the experimental and control groups in the rates of adverse drug events, close calls, or self-reported experience of care. In a post-implementation survey of nurses working with these patients, 29 percent reported that at least one medication error was prevented because a patient or a family member identified a drug-related problem.[222]

Another safety topic addressed by the tools was how to ensure safety when entering the hospital for surgical procedures. Tools of this type provided guidance related to surgical safety and focused mostly on marking surgical sites. However, one evaluation of an intervention to encourage surgical site markings suggests that this type of seemingly simple intervention may not be as effective as anticipated. In this study, DiGiovanni and colleagues found that after receiving a preoperative instruction sheet on which extremity needed surgery, 59 percent of patients were fully and 4 percent were partially compliant with instructions, but 37 percent made no mark.[223] As discussed in the earlier section on individual characteristics of the target audience, surgical site marking may feel to patients as though they are challenging their surgeon's expertise or authority, meaning it may be a more difficult behavior for them to adopt.

Overall, few of the tools related to patient safety provided information for patients on what providers and hospitals are doing to ensure safety. In one review of five major campaigns encouraging patients to engage in patient safety behaviors, the authors found that all campaigns emphasized steps patients could take to ensure their own safety, but none specified current standards or what providers were doing or could be doing to ensure safety. The reviewers of these campaigns expressed concern that the communications suggested a shifting of responsibility for safety from professionals to patients, as opposed to portraying safety as an issue in which both patients and providers play a role.[224]

Communicating with providers. A second major category of the tools related to Component 1 dealt with communicating with providers. The broad purpose of these tools (~30) was to facilitate successful interactions with providers. The tools tended to focus on helping patients obtain information from providers by providing guidance about questions to ask, mostly related to specific procedures (e.g., before surgery, after diagnosis) or topics (e.g., pain management). In short, these tools tended to address highly specific communication situations instead of providing patients with broader guidance about how to engage in successful interactions or encounters with their providers. The tools also provided virtually no guidance about how to engage in difficult conversations with providers or how to feel comfortable initiating conversations with providers—behaviors that often can be difficult for patients.[67,225]

Be an active patient/be involved. The third category of tools related to Component 1 provided general guidance to patients about the need to speak up, understand, and be active in their own health care. For example, the widely known National Patient Safety Foundation's "Ask Me 3" and Joint Commission's "Speak Up" materials both address these topics, encouraging patients to ask questions and seek information, arguing that developing a greater understanding of one's own health care leads to empowerment and better health outcomes. Tools in this category also often included information about patient roles and rights or explained what patients had a right to expect during their hospital stay.

As described earlier in the findings on individual characteristics, many factors affect patients' willingness and ability to become active participants in their own health care. Three articles that we reviewed evaluated specific interventions or strategies designed to promote patient involvement and participation.[226,227,228,229] Overall, the strategies discussed seemed to improve patient self-efficacy but did not seem to have a significant effect on actual behaviors. For example, in one randomized controlled trial, patients were assigned to one of five intervention groups (written encouragement to ask questions, question identification, question identification and rehearsal, or two control groups). Although the interventions increased the patient's self-efficacy related to asking questions, there was no difference in the numbers of questions asked between intervention and control groups. There also were no notable differences among the intervention groups in terms of self-efficacy or question asking.[226] Similarly, Weingart and colleagues[228] conducted an evaluation of an awareness campaign that trained patients and family members to use teamwork techniques to partner more effectively with health care providers. In addition to print materials and lobby displays, volunteer "rounders" gauged the interest of patients and then provided supporting written materials and used role-playing techniques to model an assertive but respectful way that patients can ask seemingly confrontational questions of providers. Although patients endorsed the impact of the campaign on their behavior, the evaluation did not show a change in patients' teamwork attitudes or experiences.[228] In another evaluation, the use of a tool to determine patient preferences for involvement and decisionmaking was perceived by doctors and patients as valuable for initiating dialogue; however, further research was needed to determine its impact on patient satisfaction and other outcomes.[227] Finally, in an uncontrolled evaluation of a program designed to enhance the involvement of older patients in their care, primary care physicians were invited to attend a 2-hour workshop or receive a 30-minute practice visit where they were instructed on how to use a leaflet distributed to patients and motivated to involve the patient. Patient involvement and satisfaction did not improve as a result, but half of patients and two-thirds of physicians found the intervention useful.[229]

Care coordination. Other tools related to Component 1 that we reviewed focused on aspects of coordination of care, either by helping patients keep track of health information (e.g., through health history logs or medication tracking tools) or by providing support for discharge planning (e.g., understanding discharge instructions).

Above, we discussed organizational procedures to help patients and family members keep track of health information such as hospital-level policies that involved printing out records or medication lists for patients. In our review of tools, we also found several individual-level tools for patients and families to track this health information, including health history logs and tools to organize and track medications. Although these tools seemed to be encouraged in the literature,[192,221] there has been little research on their effectiveness.

Likewise, in the previous section on hospital-level procedures, we also discussed hospital-level strategies for coordination of care from admission to discharge. Several individual-level tools have been designed for patients to support hospital admission and discharge planning. These mostly included checklists or lists of questions to ask before admission or discharge.

Infection prevention. A smaller number of materials, mostly from the Veteran's Health Administration, focused on encouraging patients to ask providers whether they have washed their hands. Literature shows variable results associated with these types of evaluations. For example, the "Partners in Care" intervention provides patients with brochures and supportive materials to encourage providers to wash their hands; evaluations of this program are included in three studies with slightly different designs and settings. The results indicate a wide range, anywhere from 38 percent to 79 percent, of patients who after receiving the intervention materials actually asked staff whether they had washed their hands.[230]

Component 2: Patient and family organizational partnership. In the previous section (hospital-level strategies), we discussed the creation of Patient and Family Advisory Councils (PFACs) or the development of other opportunities for patients and family members as hospital-level strategies to facilitate patient and family engagement. Clearly, these structural mechanisms need to be in place before individual-level information and guidance can be provided to patients and family members about what organizational partnership roles are available to them and how they can become involved. However, even when these opportunities exist, patients and family members need support and information about the benefits of becoming involved and what will be required of them.

In general, we reviewed fewer tools related to Component 2 than Component 1 (19 of 213). Most of the more comprehensive tools were targeted mainly toward hospitals and provided guidance about how to establish PFACs or other opportunities, as discussed above. We reviewed a small number of tools related to Component 2 that provided direct guidance for patients and family members about assuming roles as PFAC members, patient experience advisors (on committees, teams), or family advisors. In general, the majority of available tools do not provide support or specific instructions for people who may be more tentative about how to participate at an organizational level. With the exception of a guide developed by the Institute for Family-Centered Care (IFCC), the majority of these tools were hospital-specific and in the form of letters, application forms, or other correspondence to patients and families about the programs, roles, and responsibilities.

Component 3: Health professionals. Health professional tools accounted for 31 of 213 tools reviewed. Most of the tools were targeted to clinicians (physicians and nurses) instead of to the broader "health professional" audience. However, the tools did not make any distinctions between clinicians.

Communicating with patients. In general, few tools for health professionals focused specifically on facilitating increased patient and family engagement. Reviewing tools to support shared decisionmaking or facilitate patient-provider communication for specific treatments was not within the scope of this study; however, we summarize relevant findings to support patient engagement in the findings section on individual characteristics of the target audiences. The materials we did review focused mostly on engaging patients through improved communication, which included providing clinicians with information about the effects of poor patient-provider communication and low health literacy and outlining specific techniques to guide the patient encounter or ensure patient understanding (e.g., assessing patients' understanding of discharge instructions through the "Teach-Back" method).[203] Many of the tools in this arena seemed to discuss the need to improve communication as a way to correct inherent "deficiencies" in patients (e.g., low literacy, low health literacy) rather than as a way to encourage patients as partners.

As noted in the section on facilitating provider communication under hospital-level strategies, Rao and colleagues found that intense efforts appear to be necessary to change physicians' communication behaviors (i.e., intervention delivered multiple times in multiple modes and requiring the involvement of personnel in the delivery).[183]

The literature describes several tips for effective communication with patients, such as speaking simply, directly, and slowly using plain English;[79,231,232] providing specific information and detailed instructions and only a few pieces of new information at a time;[231,233,234] repeating information;[79,231,232] and using active listening and "teach-back" techniques.

The literature also describes techniques for allowing patients to contribute to the interaction, such as allowing patients to tell their story without being interrupted[78,79]; creating an environment where patients are comfortable asking questions[231,234]; and asking open-ended questions and prompting for full answers.[79,231,234] In addition, the literature describes the importance of affirming the patient by showing empathy, legitimizing the patient's feelings, and affirming the patient's efforts.[79] Moreover, a literature review found that physicians who were able to judge a patient's nonverbal behavior tended to have more satisfied patients and that a physician's nonverbal behavior can improve a patient's functioning.[235,236]

Infection control. In only one area—hand cleanliness—did we find materials designed to educate both patients and providers about the same topic. For Component 3, we reviewed hand cleanliness tools from the Veteran's Health Administration that promoted hand cleaning practices among providers and that were designed to complement Component 1 tools encouraging patients to ask providers about hand cleanliness. Specifically, the tools for providers (in the form of flyers) prepared them for patients asking whether providers have washed their hands and encouraged health care professionals to respond appropriately.

Partnering with patients at an organizational level. In looking for Component 3 materials, one of our original goals was to find materials designed to assist health professionals in partnering with patients—both in their direct care and at an organizational level in policy and program development or quality improvement activities. Although one article on a PFAC noted that they selected providers to work with patients and family members at an organizational level who could assess a situation from multiple perspectives and who would value patients' perspectives, [207] our review did not uncover tools to help health professionals partner with patients at an organizational level. Instead, the materials we found centered almost exclusively on direct care. The Component 2 materials on organizational partnership provided guidance for health leaders or patients, but were not necessarily targeted directly at front-line professionals.

Team work and communication with other providers. We also reviewed tools and strategies that focused on improving communication and teamwork between health care providers (e.g., TeamSTEPPS^{TM}, Situation-Background-Assessment-Recommendation).[237] Although these tools neither specifically addressed patient and family engagement nor included techniques for communicating with patients, we felt that lessons learned could potentially be extrapolated to patient-provider communications. For example, hospitals have made efforts to improve handoffs using standardized communication exchanges.[238]

The Situation-Background-Assessment-Recommendation (SBAR) is a mnemonic device that provides a framework for communication between members of the health care team about a patient's condition. Studies on SBAR have shown positive outcomes in perceived effectiveness of communications by providers on a pre- and post-survey,[239] increases in employee satisfaction,[127,240] decreases in nursing turnover,[127] and reductions in adverse events.[241] However, in a literature review of handoff mnemonics, Riesenberg and colleagues concluded that the literature on handoff mnemonics identified is not of sufficient quality and quantity to synthesize into evidence-based recommendations.[242]

TeamSTEPPS™ is a teamwork system developed by the Department of Defense and AHRQ to improve quality and safety through better collaboration and communication within institutions.[g] TeamSTEPPS™ has been shown to have a substantial impact on patient safety culture, teamwork, and communication.[243] Although suggestions have been made to expand the definition of the care team in TeamSTEPPS™ to include the patient and family,[244] no efforts have been made to operationalize these recommendations.

TeamSTEPPS and SBAR are just two examples of techniques designed to standardize and improve communication among providers. As yet, few efforts have built on these tools to expand them to patients and families.

Provider training. Only a few articles reviewed discussed the training involved for providers in supporting the use of tools, including:

- Developing a video that highlights different scenarios that staff might encounter and provides tips for how to resolve difficult situations.[158]
- Training physicians in a 2-hour workshop or a 30-minute practice session on motivating them to involve patients.[229]
- Training nurses using mnemonic devices to remember key actions to support patient engagement (e.g., KIDS CARE program: Knock, Introduce, Determine, Safety, Clean hands, Advocate, Respond, Explain).[220]
- Using a prompt sheet/script that requires minimal training and no technical assistance.[184]
- Employing train-the-trainer models, including developing a handbook for participants and trainers. In one example, adult learning methods employed included interactive lectures, small-group learning, and role play.[245]

Also, several program descriptions noted that patient education materials and programs helped educate and, in practice, train providers. For example, because providers knew that a patient education video was being shown to all patients, the video helped normalize some practices that initially were not particularly comfortable for staff (e.g., the video showed that it was normal for staff to repeatedly ask an inpatient for his/her name and date of birth).[246] Likewise, letters and flyers sent to physicians and nursing staff about an intervention to encourage patients to ask providers about hand washing actually increased compliance with hand washing before the start of the intervention; the intervention then provided continuous support.[247]

Component 4: Health Leadership and Implementation Materials. Finally, we reviewed tools that focused on hospital leadership and implementation (26 out of 213 tools). Most tools related to this component focused on steps or tips for hospitals to promote and support organizational change as it relates to patient safety or patient-centered care. Also, we reviewed some organization assessment tools on such topics as readiness for change and assessment of patient- and family-centered care.

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[g] For more information about TeamSTEPPS, go to http://teamstepps.ahrq.gov/.

Modes of Distribution and Implementation

In our review of tools, we assessed modes of distribution and guidance available for implementation.

Modes of distribution. Across all components, most tools reviewed were paper-based and included brochures, handouts, flyers, posters, checklists, booklets, and handbooks. These materials were publicly available online.

The majority of tools related to Components 1 and 3 were handouts (e.g., brochures, flyers, pamphlets), with the exception of materials from the Veterans Health Administration on infection control, which were primarily posters. In addition, we identified 15 videos to review, most related to Component 1. These videos generally addressed the following topics:

- *Hospital-specific orientation*. Hospital-specific orientations often provided an introduction to the hospital, including a tour of the units and information about how to use the call button, bed, or TV. These videos are usually produced by or for a specific institution. In general, the videos presented factual information related to the logistics of the hospital stay instead of promoting patient and family engagement.
- *Patient safety*. These videos provided an overview of safety issues in the hospital and what patients can expect and do (e.g., EMMI patient safety video). Most are not hospital-specific. In one post-intervention evaluation, patients reported feeling more comfortable talking with their health care workers about questions or concerns after watching a pre-admission video that covered topics related to engagement and safety, including the treatment plan, medication safety, falls, surgical site identification, hand washing, and discharge planning. The video also educated staff and physicians through increased awareness of what the hospital was encouraging patients to do and expectations for staff behavior.[246]
- *Proprietary educational materials*. Several companies offer videos that patients and families can view either before entering the hospital or during their hospital stay about their specific condition, treatment, or procedure. Because most of these tools are proprietary or focused on a specific condition, they were not included in our review.

Tools that were reviewed related to Components 2 and 4, particularly those focusing on institution-level strategies, were more likely to be guides than brief handouts and were longer than Components 1 and 3 materials. However, as noted earlier, Component 4 tools included checklists and readiness tools for organizations.

Implementation. Most of the tools in Components 1 (active involvement) and 3 (health professionals) lack detailed guidance for how to implement them, including how materials should be distributed or by whom. Only two articles that described evaluations of safety or quality described the actual campaigns or educational initiatives related to engaging patients and family members in safety and quality. For example, one hospital system educated patients on safety issues during a National Patient Safety Week fair that focused on fall prevention, security, infection control, advance directives and living wills, prevention of medical errors, and medication safety (including providing a universal medication form to patients). Awareness of the fair was conducted through radio/TV stations, newspaper articles, and announcements in local churches and civic organizations. Although no formal evaluation was conducted, there was positive feedback from hospital staff and the community, a decrease in the number of patient complaints, and an increase in the numbers of patients carrying the universal medication forms.[248] In an evaluation of a patient safety campaign at an Ontario hospital, only 17 percent of discharged patients surveyed had heard about the campaign; of those, a third had heard about the campaign through a brochure on patient safety tips and 14 percent used a summary form for discharge that was part of the campaign.[249]

Overall, more guidance and instructions were available related to the organizational partnership materials (Component 2). This guidance included assistance with how to create opportunities for patient and family involvement at an organizational level, the timeline for creating patient and family advisory councils, and ways to recruit and support patients and families on these councils.

Uptake and use. When implementing the hospital-level strategies discussed above, articles discussed ways to gain buy-in from clinicians or patients and family members before implementation. Several descriptions of implementation of intervention-level strategies reported including clinicians in the development process, either in terms of identifying goals and objectives related to front-line clinician needs[172,181] or soliciting feedback through surveys and focus groups about proposed programs or policy changes.[57,158,215] Another method for front-line staff included holding a poster contest illustrating how departments incorporated patient safety into daily business.[248] As noted in the section on engaging patients at the hospital level, organizations have used patient and family advisory councils as one way to test or develop materials and tools to ensure that they meet the needs of patients and family members.

Overall Usability

As a component of our review of available tools, we conducted a usability assessment of 78 tools. We assessed these tools according to a pre-specified set of criteria that represented our "ideals" for tools to be included in the Guide. For example, these criteria included focusing on a hospital setting; reflecting target audience needs and priorities (user-centered); being actionable, (i.e., focusing on specific behaviors); having been developed with input from the target audience; and having been evaluated for effectiveness and feasibility in a hospital setting.

Overall, our usability assessment indicated that although several tools provide a strong base of information to build on, few can be used "as is" without additional testing or modification. Specific findings relating to our evaluation criteria are discussed below.

Developed with input from users. Very few tools for patients and family members (e.g., AHRQ's *Five Steps to Safer Health Care,* Ontario Hospital Association's *Your Health Care—Be Involved* campaign) had accompanying information to indicate that the development process included input and feedback from the target audience; for example, using focus groups or cognitive testing.[25,249] Some literature indicated that some organizations may have been included in the development process, especially for hospital-level changes; however, this review did not uncover information about clinician input into the specific tools reviewed. Although the development process for other tools may have included this type of research for patients, family members, and providers, the information was not published or easily available for this review.

Support for user. Often, materials suggested doing a task (e.g., be involved in decisions) but provided little support or information about exactly how to do it (e.g., what steps to take, how to get started). Simply educating individuals about the need to do something does not give them the information they need to understand how to take action, particularly in areas where they already are reluctant or uncertain about how to engage. Similarly, some information by itself may feel overwhelming if it is not accompanied by appropriate supportive messages. For example, providing patients with descriptions of medical errors and what they need to do may feel overwhelming if not coupled with information about what providers and hospitals are also doing to ensure that mistakes do not happen.

Motivation of user. Most of the tools reviewed seemed to rely on the assumption that the nature and topic of the information being addressed would be inherently motivating to users. These tools were based on an assumption that patients, families, and providers would find the information relevant and the benefits clear and that the requested actions would be aligned or consistent with their wishes. However, in a time when patients, family members, and health care professionals all are overwhelmed with information, materials need to "speak" to the intended user to be viewed as salient or relevant. Several tools used questions and answers as a strategy to motivate or engage the reader. Another motivational strategy suggested as effective by most of our key informant interviewees and many of our Steering Group members was the use of patient stories to illustrate or highlight key points. However, almost none of the tools reviewed employed this strategy.

Format, organization, and flow of information. Often, materials had well-organized content but were difficult to read because the text was too small, the font was difficult to read, or there was too much content on the page without headings to break up the text. Several of the tools reviewed had text without much white space or visuals to add interest.

Plain language. Tools for patients and family members varied in their use of plain language. Most tried to simplify language, but some seemingly "basic" terms used in the materials (e.g., patient safety, quality care, medical errors) may not be understood as intended by the target audience.[13] Without information about the development process, it was difficult to ascertain whether the language was tested with the target audience to ensure appropriate comprehension.

Cultural inclusivity and languages available. Several tools for patients were available in other languages (mostly Spanish, but also Arabic, Chinese, and Russian). However, there was little or no information about how the materials were developed—whether in English and translated to other languages, or how the translations were done. Several tools stressed the importance of sharing different religious and cultural beliefs with providers. For the most part, tools with pictures tried to be culturally inclusive, representing people of different racial backgrounds.

Evaluation with target audience. This review found virtually no tools that had been evaluated for effectiveness or feasibility, either inside or outside a hospital setting.

Strategies and Interventions: Summary of Key Points

- ***Overall findings.*** We found two broad types of strategies or interventions that promoted or facilitated patient and family engagement: hospital-level and individual-level strategies. The two types of interventions are not mutually exclusive. That is, individual-level tools may support hospital-level interventions and uptake of new individual behaviors may be facilitated by hospital-level support. With either type of strategy, there was a lack of evidence-based information associated with outcomes.
- ***Hospital-level strategies.*** We grouped the hospital-levels strategies into four main categories:
  - Health care team. Interventions and strategies used to engage patients and families as members of their health care team include bedside rounds, bedside change of shift reports, patient- or family-activated rapid response teams, specific efforts to encourage family participation, and access to medical record information by patients and family members.
  - Facilitating communication. Implementation of procedures and policies to help patients and family members communicate with providers include understanding which staff members are involved in the patient's care and strategies to guide clinician-patient encounters.
  - Increasing patient knowledge, skills, or abilities. Hospital-level strategies to increase patient and family engagement include supporting patients and families in care coordination, establishing systems for patients and family members to track medications and health records post-discharge, communicating with physicians, and providing access to health information.
  - Input into management and processes. Strategies for involving patients and family members in management and processes include establishing patient and family advisory councils, eliciting patient and family feedback, and introducing other opportunities to be involved.
- ***Individual-level strategies.*** We reviewed publicly available tools and resources and relevant literature and discussed the tools according to the following components of the Guide:
  - Component 1. The majority of tools fell into this component. The main topics addressed were patient safety, communication with providers, patient engagement/ activation, care coordination, and infection prevention.
  - Component 2. Tools were available to help hospitals implement Patient and Family Advisory Councils and provide other opportunities for engagement at this level. A smaller number of tools provided guidance for patients and family members about assuming these roles.
  - Component 3. Most of the tools were targeted at clinicians instead of the broader "health professional" audience. However, the tools did not make distinctions between physicians and nurses. Main topics included communication with patients, infection control, team work and communication training, and provider training on implementation strategies.
  - Component 4. Most tools related to this component focused on steps or tips for hospitals to promote and support organizational change and included assessment tools.
- ***Format.*** Across all components, most tools reviewed were paper-based and included brochures, handouts, flyers, posters, checklists, booklets, and handbooks.
- ***Implementation guidance.*** Most of the tools related to Components 1 (active involvement) and 3 (health professionals) lacked detailed supporting implementation guidance for how to implement them. Overall, more guidance and instructions were available for Component 2 materials.
- ***Usability.*** Overall, our usability assessment indicated that although several tools provide a strong base of information to build on, few can be used "as is" without additional testing or modification.

Dissemination

In general, literature and research studies focus on developing, implementing or evaluating interventions to improve quality and safety, and less attention is paid in the literature to developing effective methods for their dissemination or diffusion and sustainability. In fact, little research has been conducted that addresses hospital health care managers' information behaviors, their decisionmaking processes, or their use of information to support decisionmaking.[250]

Much of the diffusion literature on hospitals focuses on dissemination of quality improvement strategies within a hospital, rather than strategies to disseminate to hospitals. Berwick[251] notes that dissemination of innovations studies generally focus on three categories of information:

1. Perceptions of the innovation.
2. Characteristics of those who adopt or fail to adopt the innovation.
3. Contextual factors that influence diffusion.

Conducting this environmental scan is the first step in understanding these clusters of information that affect dissemination.

AHRQ's Development of a Planning Tool to Guide Research Dissemination[h] is intended to help researchers disseminate research findings and products to potential users in the health care system. Our project builds on the best practices identified in this tool through:

- Seeking input from end users of the Guide during development via our Steering Group members: conducting testing of materials with patients, family members, providers, and hospital leadership; and responding and talking with those who request information about the Guide.
- Building on facilitators identified for patients, family members, and providers, as well as internal and external organizational motivators related to engaging patients and families in safety and quality.
- Using our respected partners to disseminate this information to hospitals (e.g., Joint Commission, Institute for Family Centered Care).
- Using appropriate strategies to communicate messages about the Guide (e.g., verbal presentations at conferences or email distribution).
- Developing a dissemination plan.

Strategies for reaching audiences are changing rapidly because of new technology and advances in social and digital media. We will track these trends during the project to inform and develop dissemination strategies. For example, we will ensure that key search terms are "built into" the Guide so that potential users can easily find the Guide during a Google search.

Information from our key informant interviews emphasized best practices. Participants noted that the Guide should be "validated" through publication in a peer-reviewed journal article and should be presented at conferences. Several noted that endorsement and promotion by the Joint Commission, the Institute for Family-Centered Care, or AHRQ would be important. In addition, when deciding how to implement change at their hospital, one key informant noted that they

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[h] Available at http://www.ahrq.gov/downloads/pub/advances/vol4/Carpenter.pdf.

spent 6 months researching available strategies; this research included conducting Google searches to identify hospitals in similar situations, interviewing administrators at those hospitals, and selecting four hospitals at which to conduct site visits.

Recommendations from Key Informant Interviews

During the key informant interviews, we asked about recommendations for the content and format of the Guide. Below, we present topline findings from these interviews on priority topics, the format of the Guide, and ways to gain buy-in from hospitals.

Priority Topics, Content Areas, and Points of Communication

Almost all key informants recommended that the Guide focus on ways to encourage patients to speak up or ask questions. One noted that the focus should be "a lot lower than where smart people would like to go." Strategies to speak up include tips on how to communicate most effectively, not only with providers but also through the "chain of command." Participants noted that patients and family members would need an invitation to ask questions of providers and the hospital system as well as a positive response from providers—both nurses and physicians—when they do speak up.

Interview participants suggested that nurses should be the priority target audience with regard to providers; however, several noted that nurses could not effect much change without support from physicians and senior leadership. Participants noted that the focus of health professional materials should be related to communication with patients and family members and should give specifics on how to include patients and family members as part of the health care team. Also, several participants noted the importance of demonstrating to providers the benefits of patient-centered care.

Other interviewees noted specific topics that should be addressed, such as hand washing, medication safety, bedside change of shift, and risks and benefits of specific procedures. In terms of points of communication, reactions were mixed about focusing on admission or discharge. Although getting patients and families information at admission was perceived as important, patients receive so much information (particularly in written format) that some participants thought it would be difficult to include more. Likewise, the discharge process was perceived as important; and at least one participant related the importance of discharge to the poor performance of hospitals on HCAHPS discharge scores. However, another participant noted that discharge often is rushed for the patient and that it may be difficult to convey information during this time.

Format

In terms of overall organization, one participant suggested organizing the Guide into individual toolkits by topic (e.g., including all components for medication safety or bedside rounds), so that hospital leadership could prioritize where to focus their efforts.

Most participants noted that the format of the Guide should be a combination of print and online materials. Participants assumed that health care organizations would access the Guide electronically. This Web site would include materials that could be used as is, such as downloadable materials or videos for patients and family members or assessment tools for hospital leadership. At least one participant noted that hospitals would want to brand patient and family materials with their logo.

Also, participants recommended that the Guide include materials that could be tailored, such as examples of letters sent to patients and family members asking them to participate in Patient and Family Advisory Councils or PowerPoint presentations for employee orientations or for convincing senior leadership of the importance of engaging patients and family members in safety and quality issues. One participant suggested that training for providers should include continuing education credits.

Gaining Acceptance from Hospitals

Almost every participant noted that engaging patients and family members in safety and quality issues is an organizational culture change that requires effective leadership and buy-in from the board, senior leadership, and front-line caregivers. In particular, participants noted that hospital leadership will need a compelling reason to institute changes, not only for changes in organizational policies and procedures, but also for individual-level changes in behavior in terms of improving patient-provider communication. Several participants discussed motivators tied to patient satisfaction (e.g., HCAHPS) because these scores have an impact on reimbursement by the Centers for Medicare & Medicaid Services (CMS), as well as market factors important to the bottom line for hospitals. One participant noted that those hospital leaders who focus only on the bottom line will be the most difficult to convince:

> *But one of the lessons that I learned early on was that so much follows. I didn't set out to fix the financial bottom line; I set out to fix the hospital. We did, and it was not an "I" it was a "we." And when we began fixing all the component parts and pieces of the hospital, the bottom line started following in place.*

Also, participants noted the importance of "storytelling" for all levels of the organization. Stories about experiences from patients and family members have a large impact at all levels—from the board to senior leadership to providers.

Summary and Discussion

Information about engaging patients and family members in health care quality and safety is becoming more available. We gathered information from several sources to obtain a broad and diverse perspective: the literature, both published and grey literature; publicly available tools and materials; and input from key informants as well as our partners who represent patients, families, health professionals, and hospitals.

This scan provides a foundation for the remaining tasks and has helped inform key issues for the content, format, and general structure of the Guide. Below, we briefly summarize what we learned, the main gaps identified in terms of content and appropriateness of materials, and limitations of the scan.

Knowledge Gained from the Process

As noted in our preliminary conceptual framework (Exhibit 1), we sought to understand factors that influence behaviors and actions at an individual and an organizational level that can lead to improved patient and family engagement in quality and safety. In identifying these factors, this scan summarizes major themes around three main categories of information:

- Individual characteristics, perspectives, and needs of the target audiences—patients, families, and health care professionals—with regard to patient and family engagement.
- Organizational context within hospitals, including structures and processes that influence patient and family engagement.
- Hospital-based interventions and materials that are designed to facilitate patient and family engagement, particularly around the topics of safety and quality.

Here we briefly summarize what we learned from the three categories of information.

Individual Characteristics of the Target Audiences: Patients, Family Members, and Providers

Quality and Safety

Both patients and providers tend to think that the quality of care they receive or give is generally good, despite evidence that suggests this is not always true. However, they do not always share the same views of what constitutes quality or safety. Providers tend to focus on the clinical aspects of care, while patients and family members focus on interpersonal interactions.

As with quality, patients and providers can differ in their perspectives on patient safety, and patients may not understand safety as researchers or other experts define it. Patients define patient safety more narrowly in terms of medical errors. In addition, providers may feel that errors are primarily under an individual's control and therefore place less emphasis on the importance of system-level changes.

Engagement

Conceptually, both patients and providers support patient and family involvement and participation in their own care and recognize that it can lead to better patient experiences and outcomes. Patient and provider support for participation becomes more uncertain when patient engagement includes a higher level of involvement; for example, making diagnosis or treatment decisions.

Most of the literature on patient and family engagement roles focuses on what patients could do (or what researchers and policymakers want patients to do), instead of discussing what behaviors patients and family members currently engage in or would be willing to engage in.

In general, the literature suggests that patients are more likely to engage when the goal relates to obtaining specific information about their care (e.g., asking questions to get information about their condition, treatment, functional activities, or discharge). Patients are less likely to engage when faced with behaviors that seem new or confrontational (e.g., asking providers to wash their hands or mark surgical sites).

Barriers and Facilitators

Barriers to engagement for patients and family members include fear, uncertainty, health literacy, and provider reactions. Facilitators include self-efficacy, information, an invitation to engage, and provider support. For providers, barriers to support patient and family engagement include professional norms and experiences, fear of litigation, and perceived level of effort. Facilitators for providers include those factors discussed in the organizational context section.

Organizational Context

Motivation

We examined potential external and internal motivators for organizations to encourage patient and family engagement in safety and quality. Key external motivators included the desire to imitate competitors, health care legislation or mandated policies, leadership from influential bodies, alignment of financial incentives, public reporting, and accreditation and awards. Key internal motivators included the occurrence of a sentinel event, the business case for patient and family engagement, the desire to improve quality and safety performance, stories from patients and families, and altruism.

Organizational Structure

Structural aspects of a hospital that influence the ability to initiate and sustain change include the size of the hospital, profit or academic status, and medical staff organization. Unfortunately, although there is general recognition of the potential influence of structural factors on an organization's ability to adopt and sustain innovations, there is insufficient evidence about whether and how these structural factors act specifically as barriers to or facilitators of change.

Organizational Processes

Processes that affect an organization's ability to implement and sustain change include the organization's understanding of and experience with patient and family engagement, the existing quality and safety culture, the strength of leadership at all levels, the hierarchy (whether rules, regulations, and reporting relationships are emphasized), the existence of slack resources (cushion of resources that can be used in a discretionary manner), absorptive capacity (ability to identify, capture, interpret, share, reframe, and recodify new knowledge, to link it with its own knowledge base, and to put it to appropriate use), and internal alignment (consistency of plans, processes, information, resource decisions, actions, results, and analysis to support key organizational goals and change specific goals).

Implementation Strategies

Organizational strategies to foster change include pre-implementation strategies, such as conducting an initial assessment, developing and fostering a shared vision, developing a clear plan for implementation, obtaining buy-in, providing an infrastructure, aligning internal incentives for participation, and considering sustainability. Strategies during interventions include engaging staff at all levels, engaging an internal champion, communicating consistently throughout the process, using appropriate tools, and collecting data and feedback.

Interventions and Strategies

Overall Findings

We found two broad types of strategies or interventions that promoted or facilitated patient and family engagement: hospital-level and individual-level strategies. The two types of interventions are not mutually exclusive. That is, individual-level tools may support hospital-level interventions, and uptake of new individual behaviors may be facilitated by hospital-level support. With either type of strategy, there was a lack of evidence-based information associated with outcomes.

Hospital-Level Strategies

We grouped the hospital-levels strategies into four main categories:

- ***Health care team***. Interventions and strategies used to engage patients and families as members of their health care team include bedside rounds, bedside change of shift reports, patient- or family-activated rapid response teams, specific efforts to encourage family participation, and access to medical record information by patients and family members.
- ***Facilitating communication***. Procedures and policies to assist patients and family members in communicating with providers include understanding which staff members are involved in the patient's care and strategies to guide clinician-patient encounters.
- ***Increasing patient knowledge, skills, or abilities***. Hospital-level strategies to increase patient and family engagement include supporting patients and families in care coordination, establishing systems for patients and family members to track medications and health records post-discharge, communicating with physicians, and providing access to health information.
- ***Input into management and processes***. Strategies for involving patients and family members in management and processes include establishing patient and family advisory councils, introducing other opportunities for patients and families to be involved, and eliciting patient and family feedback.

Individual-Level Strategies

We reviewed publicly available tools and resources and relevant literature and discussed the tools according to the following components of the Guide:

- ***Component 1***. The majority of tools fell into this component. The main topics addressed were patient safety, communication with providers, patient engagement and activation, care coordination, and infection prevention.

- ***Component 2***. Tools were available to help hospitals implement Patient and Family Advisory Councils and provide other opportunities for engagement at this level. A smaller number of tools provided guidance for patients and family members about assuming these roles.

- ***Component 3***. Most of the tools were targeted at clinicians instead of the broader "health professional" audience. However, the tools did not make distinctions between physicians and nurses. Main topics included communication with patients, infection control, teamwork and communication training, and provider training on implementation strategies.

- ***Component 4***. Most tools related to this component focused on steps or tips for hospitals to promote and support organizational change and included assessment tools.

Format

Across all components, most tools reviewed were paper-based and included brochures, handouts, flyers, posters, checklists, booklets, and handbooks.

Implementation Guidance

Most of the tools reviewed related to Components 1 (active involvement) and 3 (health professionals) and lacked detailed guidance for how to implement them. Overall, more guidance and instructions were available for Component 2 materials.

Usability

Overall, our usability assessment indicated that although several tools provide a strong base of information to build on, few can be used "as is" without additional testing or modification.

Overall Strength of Evidence

Reasonably strong evidence is available from related fields, but existing approaches to and resources and tools for patient and family engagement lack a strong evidence base to support their efficacy or effectiveness. Exhibit 15 shows the strength of evidence across the findings sections in this scan. Because patient and family engagement in quality and safety is a newer field, we have drawn on fields with stronger evidence (e.g., systematic reviews of patient-provider communication or shared decisionmaking). Most studies reviewed tended to be single descriptive studies or case studies. Overall, evaluations of implementations lacked a strong design. Similarly, in our review of the tools, little information was available on whether the tools were developed with input from the target audiences or whether they had been evaluated for efficacy, effectiveness, or feasibility.

Exhibit 15. Strength of Evidence for All Literature Reviewed

Type of Document	Number
Systematic reviews	
Systematic review of randomized controlled trials	1
Systematic review of descriptive studies (quantitative/qualitative)	15
Single evaluative studies	
Randomized controlled trial	3
Nonrandomized controlled trial	3
Cohort/case-control study	1
Single site intervention (pre/post)/case series study	10
Single site intervention (post only)	8
Single descriptive studies	
Mixed methods study (qualitative/quantitative)	15
Quantitative study	26
Descriptive or qualitative study	37
Case study / description of implementation	65
Scholarly articles or reviews	42
Other (e.g., PowerPoint presentations, workshop summaries)	10

Gaps Identified

In addition to identifying literature and tools available to support patient and family engagement, we also sought to identify "gaps between existing tools/materials and those that need to be developed." Specifically, we wanted to identify gaps in subject matter and in the appropriateness (i.e., usability) of materials for the intended target audiences. Below, we summarize our findings with regard to these gaps.

Gaps in Content and Topic Areas

Content gap 1: Strategies are not attuned to patient and family member experiences of hospitalization.

One existing gap is the lack of tools that are more equally based on patient and family perspectives and that focus on their priorities during their hospital stay—as opposed to tools that are more reflective of health professional and hospital views and the organization of their work.

We found relatively less research on strategies or opportunities to engage that adequately considered the perspectives of patients and family members. The structure of the strategies tended to coincide with the workflow from the perspective of health professionals and hospitals. The tools and explicit delineation of when patients and families can be involved tend to be built on hospitals' schedules and definitions of patient flow and on hospital staff's scheduled interactions with patients (e.g., bedside rounds), not on how patients might view their own flow or time in the hospitals. One possible exception is patient- and family-activated rapid response teams (Condition H), where the patient and family members, as the experts in the patient's condition, identify when providers need to be called and involved in the patient's care.

Because opportunities are generally defined from these provider perspectives, the initiation of patient and family engagement efforts depend on the opportunities that the hospital makes available (e.g., bedside rounds), instead of allowing patients and families to engage when and how they would prefer.

Content gap 2: There is a lack of individual tools to support system-level strategies.

The second gap identified is that many system-level interventions may not have tools at an individual level (for both patients/families and providers) to support their effectiveness.

Our scan has shown that there are important opportunities to engage patients and family members in processes that traditionally have been conducted out of sight (e.g., shift change reporting and handoffs). These "invisible" activities could be made much more visible to patients and families and include their perspective and engagement. However, this would require that such discussion occur in view of families, be organized to ensure their participation, and have supporting materials for both patients/families and providers to partner around these opportunities.

Likewise, there is a lack of individual tools to support patient and family engagement in hospital processes and decisions at an organizational level. Information is more readily available for hospitals on how to establish a Patient and Family Advisory Council from an organizational perspective. There is more limited information for patients and family members about how to develop organizational partnership skills (particularly for those individuals who may not have these abilities naturally but who still want to be involved).

Content gap 3: There is a lack of concrete, actionable support for individual users to engage in behaviors.

In evaluating the individual-level tools to support patient and family engagement efforts, we found that the tools often lack concrete actionable support for individual users. We identified general information about patient safety topics, information that patients and families should generally know about the hospital, and many tools for patients and families to communicate with their providers, both generally (e.g., questions to ask about prescribed medications), and specifically (e.g., safety topics like hand washing). However, providing general information or instructing individuals to ask a series of questions in an encounter with providers does not necessarily provide sufficient support to help individuals take action.

Content gap 4: There are few complementary materials.

Hospitals and the health professionals who work in them will have an enormous impact on the ability of patients and families to engage in issues related to safety and quality. With the exception of infection control, we found few complementary or paired tools that support the Guide's intended target audiences—patients, family members, and providers. For example, if tools ask patients to adopt a behavior (e.g., asking nurses to wash their hands), there must be accompanying training for nurses because their level of support and reaction will be a facilitator, or conversely a barrier, to the continued adoption of this behavior. Further, if hospital leaders do not ensure organizational supports and alignment of incentives for nurses to be supportive, the intervention will not succeed. Having these complementary materials will help facilitate uptake and sustainment of the intervention.

Content gap 5: More nurse-patient communication materials are needed.

Nurses are often on the front line of quality improvement initiatives, and although physician buy-in will be needed to make the initiative successful, nurses may be responsible for much of the work. There seems to be a dearth of tools specifically for nurses on how to better communicate with patients, and vice versa. Several strategies provide opportunities to facilitate communication between nurses and patients (e.g., use of whiteboards, bedside change of shift), but they do not provide the individual-level support for that communication.

Gaps in Usability and Appropriateness of Tools

In cases where the content of the tools was applicable, the usability or appropriateness of the materials was not adequate. We did not find true turn-key options—those materials that could be included in the Guide without additional repackaging, content modification, and testing.

Usability gap 1: Key usability criteria are lacking.

As noted earlier, we assessed tools according to a pre-specified set of criteria that represented our "ideals" for tools to be included in the Guide. These criteria included focusing on a hospital setting, reflecting target audience needs and priorities (user-centered), being actionable, having been developed with input from the target audience, and having been evaluated for effectiveness and feasibility in a hospital setting. Often, materials have appropriate content but are difficult to read because of problems with plain language, format, or organization of information. Very few tools for patients and family members have accompanying information to indicate that the development process included input and feedback from the target audience. Without information about the development process, it was difficult to ascertain whether the materials were tested with the target audience to ensure appropriate comprehension.

Usability gap 2: Implementation guidance is limited.

There is limited implementation information on the specific tools and strategies used in the patient and family engagement efforts. In particular, most of the tools in Components 1 (active involvement) and 3 (health professionals) lack detailed supporting guidance for how to implement them, including how materials should be distributed or by whom. Key pre-implementation and implementation steps generally are not addressed.

In sum, we have many resources and strategies to pull from, but considerable gaps remain about outcomes associated with those strategies, as well as gaps in tools and materials to be included in the Guide without modification. These gaps will require additional discussion among members of the project team and with AHRQ about which strategies are most desirable to employ, which tools will be most effective, and what organizational supports are needed to have a positive impact on quality, safety, and other important outcomes (e.g., patient satisfaction, patient health outcomes). Implications of these gaps are considered in the next section.

Limitations of the Scan

In conducting the environmental scan, we sought to be comprehensive while simultaneously targeting points of interest for the project. This broad but selective scope means that we have not conducted a full review of all the literature in all relevant areas. For example, in areas with large bodies of evidence (patient-provider communication, shared decisionmaking) we primarily sought to identify review articles. In addition, in at least one area (dissemination), our search terms and strategies did not yield the desired information and highlighted the need to obtain this information in other ways (e.g., in conversations with hospital leaders and engagement advocates).

Similarly, in our review of organizations and Web sites, we may not have identified all publicly available tools that could inform the Guide. Owing to the large numbers of tools identified, we were not able to conduct a full usability assessment on all tools. Further, we continue to receive additional tools and resources from interested parties and from responses to a request for best practices on patient and family engagement from the Joint Commission. We will continue to review these tools and materials and incorporate key concepts and findings in the development of the Guide.

Implications for the Guide

Implication 1. Reflect and Incorporate Target Audiences' Perspectives and Individual and Organizational Contexts

Implementing a Guide for patient and family engagement will often require change—for individuals (patients, families, and health professionals) and organizations. While seemingly a cliché, change can be hard for individuals and organizations, even when they are willing and highly motivated. The actions, behaviors, and roles that our Guide is likely to suggest may be new and challenging and may require support. Although important facilitators exist for patient and family engagement, so do barriers that must be adequately addressed in the conceptualization, focus, development, dissemination, and support for the Guide.

Build On and Reflect Priorities

The materials in the Guide should reflect what is important and most salient to each individual target audience. For instance, patients care about having a good experience; providers care about clinical and financial outcomes; and hospital leaders care about the former but also must address broader financial outcomes.

Link To and Build On Existing External and Internal Motivators

It will be easier for users to adopt the strategies in the Guide if they link the strategies to existing motivators and activities. Take medication safety as an example. At an individual level, the literature suggests that patients feel comfortable asking about a medication's purpose. Tools could build on their existing comfort levels but also encourage them to check the medication's dose and timing. At the hospital level, the Guide should link to existing mandates and efforts, such as HCAHPS.

Implication 2. Provide Tightly Coupled Materials and More Individual Supports for Engagement in Hospital Processes and Decisionmaking

To address the gaps, barriers, and challenges discussed in previous sections, the Guide should be organized so that it pairs support for individual- and hospital-level strategies around the same concepts. The hospitals and the health professionals who work in them will have an enormous impact on the ability of patients and families to engage in issues related to safety and quality. All three entities are important and must be considered together. For example, if we develop a tool to help hospitals implement bedside rounds, there must be accompanying information and tools to help patients and families understand and participate in these actions. We will also need supporting materials for health professionals because their support and reaction will be a facilitator, or conversely a barrier, to the continued adoption of this behavior.

Likewise, for strategies to support patient and family partnering in hospital processes and decisionmaking, the Guide should provide information and supports to help patients and families develop the skills they need to participate with hospital staff and management. The Guide should identify the supports patients and families might need to fully participate. This will help ensure that a range of individuals can participate, including those who do might not be sure they have the skills or abilities but could participate with appropriate support.

This “paired” approach will make the process of developing Guide components more efficient and, more importantly, it will provide a much stronger intervention. If hospital leaders do not ensure organizational supports and alignment of incentives for health professionals to be supportive, the intervention will not succeed. Having these matched pairs of materials will help facilitate uptake and sustainment of the intervention.

Implication 3. Be Accessible to Individuals and Organizations at Different Stages of Willingness, Readiness, and Confidence to Support Patient and Family Engagement

Another consideration is the need to provide guidance for hospitals at different stages in implementing strategies for patient and family engagement in safety and quality issues. We found some hospitals that are considered industry leaders in patient- and family-centered care and engagement. However, others have much less (or even no) experience. In addition, even the top-tier hospitals will need support for implementing and sustaining interventions.

In the same way, there are challenges in asking organizations to adopt strategies that are not currently part of their organizational norms. For instance, with Patient and Family Advisory Councils, patients and family members can participate simply as advisors or they can have input into organizational decisionmaking. Although true engagement may include patients and family members as partners in decisionmaking, not all organizations will feel comfortable allowing this. Creating the council may be a first step; with continued success, later steps could allow patients and family members to have more power at the organizational level. The materials in the Guide will need to balance what hospitals should be doing with the feasibility of and ability to implement the strategies.

Therefore, the Guide must be organized in a way that helps hospitals identify their stage of readiness and access the most appropriate information for those next steps, whether those steps are strategies that are easier or more difficult or strategies that have a smaller or greater impact. The Guide must also include elements that can be implemented for individuals and organizations at different stages. In other words, the Guide should have a sufficient range of tools so that interested and motivated organizations can find something they can implement from the Guide.

Finally, at an individual level, the literature indicates that there are challenges in asking patients to engage in behaviors that feel confrontational (e.g., asking providers to wash their hands). In developing the content of the Guide, we should consider whether to target these behaviors or others that seem less confrontational (e.g., communicating about patients' needs during change of shift). It is possible that if patients and family members are invited into one opportunity (e.g., change of shift), the impact of the intervention may spill over into other areas. However, no matter which strategies are targeted, we will need to ensure that the Guide includes the necessary supports for all parties.

Implication 4. Reflect additional key design principles

The scan and gap analysis highlight core principles that must be followed in the development of the Guide.

Focus on Actions

The Guide must be actionable. Many strategies and opportunities identified for engaging patients and family members in quality and safety simply provide information, which might be necessary for action but is not sufficient. In developing and refining strategies and interventions, the materials in the Guide must focus on actions that can be taken, present clear steps to take those actions, and provide support to do so to ensure that patients and family members are full partners, not just recipients of information or recipients of an intervention.

Include Testing and Evaluation of the Guide and Involve the Target Audiences in Its Development, Testing, and Evaluation

Supporting patient and family engagement in hospital quality and safety is in a nascent stage of development. While this field builds on findings and lessons learned from more substantially developed fields, such as shared decisionmaking and patient-provider communication, relatively less strong, empirical research exists to guide ideal approaches in this area. Existing strategies and approaches to patient and family engagement lack clear evidence; thus, we must rely on our own testing, piloting, and evaluation to provide this evidence.

Implication 5. Provide Strong Implementation Guidance

Although there was limited implementation information on the specific tools and strategies used in the patient and family engagement efforts, the literature on organizational context specifies key pre-implementation and implementation steps during quality improvement activities. The Guide will need to provide guidance on these key activities for each potential strategy to support hospital implementation. It also should supply information and tools to help senior management understand why these strategies are important.

In addition, a key component of the implementation materials must be guidance about why it is important and beneficial to undertake the interventions in the Guide. The supporting materials must clearly identify the benefits to patients, family members, health professionals, and hospitals. These benefits also must be conveyed through the dissemination of the Guide. Although many organizations and individuals have expressed an interest in the Guide, we also cannot assume that people and organizations will value and understand how to use the Guide just because we create it. We must provide the appropriate motivation to make this effort a priority for hospitals.

Implication 6. Assess the Need for Implementation Support

Given how new and challenging this engagement is likely to be for individuals and organizations, we anticipate that technical assistance will be necessary to support patients, families, and organizations to most effectively implement the Guide. In addition, and just as importantly, even though many organizations and individuals may be able to initiate change, it may be difficult for them to sustain the change over the long term. Technical assistance activities can help assess possible challenges in sustaining true patient and family partnering and engagement with hospitals on quality and safety and support long-term progress on these goals.

The need for technical assistance will be an ongoing focus of inquiry with organizations that participate in testing, piloting, evaluation, and dissemination.

Next Steps

The information available provides a valuable foundation to begin defining the content and tools to be included in the Guide. However, as the preceding review, gap analysis, and implications suggest, important decisions about the focus, content, and approach of the Guide remain. Although there is much to build on, there are no turn-key solutions to rely on. To restate previous findings, few, if any, materials meet all criteria: (1) usability, including some previous testing; (2) inclusion of "paired" guidance for patients and families and hospitals and health professionals; and (3) inclusion of clear implementation guidance.

The materials that come closest to meeting all criteria are those related to Component 2, the patient and family partnership in health care organization processes and decisionmaking material. However, even here, work remains to further outline support and guidance on an individual level to help people understand how to become involved and to build the skills and self-efficacy they need to participate at this level, and to conduct in-depth testing with end-users.

This, along with our findings and implications, suggests that to be effective in our approach to creating Guide components, we will have to be selective in what we develop and include in the Guide. Some level of testing, development of paired materials, or tailoring and adaptation must occur to complete the Guide Components.

In addition, because of the lack of turn-key materials and the need to make some key decisions about the content and focus of the Guide, we anticipate the need for a longer, iterative process to define the final elements of the Guide and the key activities necessary to complete initial drafts for testing. The timeline for these activities will be outlined in the Task 3 Guide Development Plan. We also expect that subsequent development of materials and testing of preliminary tools will uncover additional facilitators or barriers to engaging patients and family members not revealed by this review. By incorporating input from key stakeholders at multiple points in time, our process for Guide development ensures that the Guide ultimately will meet the needs of end users.

We will continue to work with AHRQ, the Steering Group, and our partners to further refine the structure, content, and format of the Guide.

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Appendix A. Draft Key Informant Interview Protocol

Topic Guide for Key Informant Interviews

November 24, 2009

Testing materials

- Audio recording equipment.
- Speaker phone.
- Email or fax consent form and brief survey (attachment 1) to participant before interview.
- Interviewer clock.

Procedures for obtaining informed consent

FOR TELEPHONE: Participant will be sent an informed consent form before the interview. At start of interview, interviewer will ask if participant has any questions about the consent form and if he or she agrees to be interviewed and audiotaped. A waiver of signed informed consent will be obtained from AIR's IRB.

Key informant interviews (60 minutes total)

Time in minutes for each section	Topic	Elapsed time at end of section
5	Introduction (welcome, ground rules) and background (roles, responsibilities)	5
15	Conceptualization of patient and family engagement	20
10	Experience engaging patient and families	30
10	Best practices and implementation	40
15	Recommendations for the Guide	55
5	Closing	60

Introduction (start at _____ – 2 min – end at _____)

Welcome—Explain purpose of the interview

- Thank you for agreeing to do this interview. My name is [NAME], and I'll be talking with you today.
- As you know, this project is being funded by the Agency for Healthcare Research and Quality, which is 1 of 12 agencies within the U.S Department of Health and Human Services. The Agency's mission is to improve the quality, safety, efficiency and effectiveness of health care for all Americans.
- The purpose of this interview today is to learn more about your experiences with and recommendations related to patient and family engagement in patient safety and quality.
- The interview will last about 1 hour.
- Did you read the consent form that was sent to you? Do you have any questions?

Ground rules

- Everything you tell us will be confidential. To protect your privacy, we won't connect your name with anything that you say.
- At any time during our conversation, please feel free to let me know if you have any questions or if you would rather not answer any specific question. You can also stop the interview at any time for any reason.
- Please remember that we want to know what you think and feel and that there are no right or wrong answers.
- Is it OK if I audiotape this interview today?

[Turn on recording equipment.]

Background (start at _____ – 3 min – end at _____)

I'd like to begin by asking you some questions about your current job.

1. What is your position at [organization]? What are your major responsibilities in your current position?
2. How long have you been with [organization]?
3. Can you tell me a bit about your work and experience as it relates to patient and family engagement? (Probe particularly for aspects of current job that relate to patient and family engagement.)
4. [FOR PATIENTS] How did you come to be involved in patient safety and quality issues?

Conceptualization of Patient and Family Engagement (start at _____ – 15 min – end at _____)

A key goal of our project is to help promote patient and family engagement in patient safety and quality in a hospital setting.

5. I'd like to get your opinions about the concept of "patient and family engagement." What do you think is meant by patient and family engagement? How would you describe it in your own words? What are the most critical components of patient and family engagement?
   - How, if at all, does patient and family engagement relate to patient- and family-centered care? Is it the same? Different?
   - What about shared decision-making? How does that relate to patient and family engagement?
   - In your opinion, what is the ultimate goal of patient and family engagement? From your perspective, what are the expected or hoped for outcomes of patient and family engagement?
6. How would you describe the state of patient and family engagement in hospitals? Where is it now and where does it need to go? What do we need to do to make this happen?
7. How do you think patients and families think about patient safety? What about quality? What does it mean for them? Do you think patients and families view themselves as having a role in patient safety and quality?
8. How can patients and families contribute to patient safety and quality at an individual level (i.e., related to their own health care experience)
   - What can patients do to contribute to improved safety and quality in a hospital?
   - What can family members do? (Probe for specific behaviors and actions)
   - What facilitates or challenges those behaviors?
9. How can patients and families contribute to patient safety and quality at a larger hospital policy level?
   - What can patients and family members do? (Probe for specific behaviors and actions)
   - What facilitates or challenges those behaviors?
10. How can health care professionals contribute to patient and family engagement?
    - Which health care professionals have the most to contribute?
    - Which health care professionals currently contribute the most? Is this the way it should be?
    - What behaviors do health care professionals need to do to support patient and family engagement in safety and quality?
    - What facilitates or challenges those behaviors?
11. What elements of organizational culture facilitate or challenge patient and family engagement in safety and quality?
    - Hospital leadership? Policies or procedures? Team work?
    - How would you define organizational culture?

Experience Engaging Patients and Families (start at _____ – 10 min – end at _____)

Now, let's talk about your organization.

12. What is your organization's experience with engaging patients and families in safety and quality? (Get details—with whom, what they know, what have they tried, how they assessed, etc.)
    - What staff, or who, from your organization have been involved in this effort?
    - What prompted your organization to get involved in this issue?
    - What was the goal of your effort? What did you hope to accomplish?
    - What resources does your organization have that are available for this effort (e.g., financial, staff expertise, etc.)?
    - How did you assess or evaluate these efforts?
13. Specifically, what activities have you undertaken, and what did you expect patients and families to do? Which health care professionals were involved? What did you expect them to do?
14. What have your experiences been? What did you do?
    - Tell me about the planning of this effort.
    - What tools or resources did you use? How effective were they?
    - Did you use tools or resources from the Agency for Healthcare Research and Quality? If so, what did you think of them?
    - Where did you go to look for information?
    - How did you engage patients, families, health care professionals?
15. How did you disseminate information to patients and families? Health care professionals?
    - What types of messages have you created and/or delivered?
    - What medium(s) or mode of delivering information did you use? (e.g., flyers, posters, workshops, trainings, handouts, brochures, videos, and so forth)
    - What was the frequency of communication?
    - At what point in the hospital stay?
16. What was the reaction to your efforts?
    - Did this differ for different types of patients, family members, or providers?
    - If so, what are the different types, and how do their information needs differ?
17. Was there anything you did that you thought worked well? What, if anything, would you do differently next time?
    - Among the topics that you have addressed or considered addressing, what aspects of patient and family engagement seem to resonate most with patients and families?
    - What aspects resonate least?
    - What about with health care professionals?
18. Can you please share any materials that you used?

Best Practices and Implementation (start at _____ – 10 min – end at _____)

Now, let's talk about best practices in engaging patients and families in patient safety and quality.

19. What are the best ways to engage patients and families in patient safety and quality?
    - Who is the best person/organization to deliver the information?
    - At what point in the hospital stay?
    - How should it be delivered?
    - How feasible is this?
    - When is the best time to begin to engage patients and families?
20. What are the best ways to educate and change the behaviors of health care professionals? How feasible is this?
    - Which attitudes facilitate involvement in patient and family engagement?
    - Which attitudes hinder patient and family engagement?
    - What are the best ways to build on positive attitude? Address or neutralize negative ones?
21. What are the best ways to bring patients, families, and health care professionals together around a common goal?
22. To your knowledge, what organizations have engaged patients and families in patient safety and quality? Have any been ***successful*** in engaging patients and families?
    - What particular strategies have they used (or what factors were present) that were successful?
    - What strategies were not so successful?
    - Can you recommend any particular print documents or Web resources that these organizations have produced that we should review?
23. What do you consider to be the best practices in patient and family engagement in safety and quality in a hospital setting?
    - What facilitates those best practices?
    - What are some challenges to those best practices?

Recommendations for the Guide (start at _____ – 15 min – end at _____)

As you know, we are developing a Guide to help hospitals engage patients and families in patient safety and quality. We'd like to get your input on the content and format of the Guide. The Guide will contain tools, materials, and/or training for patients, families, hospital clinicians and staff, hospital leaders, and those who will implement the materials in the Guide.

24. What do you think are the priority topics and content areas for the Guide?
    - With what topics do consumers and health care professionals need the most assistance?
    - Where can the Guide affect the most change?
    - What opportunities for engagement have not traditionally been used?
    - Are there target audiences that have been ignored?
25. Which types of hospitals would be most important to reach?
    - Settings (urban versus rural)
    - Size
    - Readiness to change (those whom are interested but haven't done this before or those whom are already doing it)
26. What is needed to get different participants to "buy in" to the Guide? Hospital leadership? Health care professionals? Patients? Families?
    - Is there anything that can be done during the development process?
    - What information or guidance should be included in the Guide?
27. What points of communication in a hospital setting are most amenable to intervention, especially in medical–surgery units? (e.g., bedside rounds, change of shift, rapid response)

For the next few questions, we are interested in learning about the best ways to ensure that the Guide gets used.

28. How would you foresee using the Guide? What format would be most useful? [*If needed, for example, web-based, video, written materials, Power Point presentation.*]

29. What are the best ways to disseminate the Guide?

30. What assistance would be needed to implement the tools and resources? What are the best ways to sustain those efforts?

Closing (start at _____ – 5 min – end at _____)

31. What is the most important message that you want us to take away from this interview?
32. Is there anything else that you would like to add about any of the topics that we’ve discussed or other areas that we didn’t discuss but you think are important?

If you know of any research, tools, or resources that may be useful to include or adapt for the Guide, please send them to me.

Thank you for your time and participation in this interview. The information that you provided to us will be very helpful in this project.