A Leadership Resource for Patient and Family Engagement Strategies

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This grant also includes resources to survey the patient and family engagement practices currently in place in America’s hospitals. That survey is being conducted in the summer of 2013 and results from it will be reported after it is complete. While HRET assumes full responsibility for all materials created through this grant, we gratefully acknowledge input from the project’s advisory panel and from the Gordon and Betty Moore Foundation. More information on the Foundation’s Patient Care Program is available at: http://www.moore.org/patient-care/.

Resources: For information related to patient and family engagement, visit www.hpoe.org.


Contact: hpoe@aha.org (877) 243-0027

Accessible at: www.hpoe.org/Patient-family-engagement

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Executive Summary

Introduction

Engaging patients and families is a critical strategy to improving care. The American Hospital Association (AHA) report *Engaging Health Care Users: A Framework for Healthy Individuals and Communities* and the Agency for Healthcare Research and Quality (AHRQ) resource *Guide to Patient and Family Engagement in Hospital Safety and Quality* include excellent summaries of the research supporting patient engagement and descriptions of proven methods and tools for engaging patients and families successfully. This leadership resource leverages those and other valuable resources and focuses on the most important steps that organizational leaders can take to effectively promote patient and family engagement. While others within your organization seek advice on which engagement strategies to use and how to implement them successfully, your leadership role is to focus on ensuring that engagement strategies are successfully implemented and sustained.

This resource gives hospital and health system leaders concrete, practical steps grounded on evidence-based research to improve patient and family engagement in their organizations by:

- assessing how well the organization is doing,
- identifying processes and systems to support patient engagement,
- ensuring staff obtain training for effectively using these systems and processes,
- intervening to overcome specific obstacles that may emerge, and
- monitoring progress toward achieving patient and family engagement goals.

Why Patient and Family Engagement Matters

Fundamentally, hospitals exist to meet the physical, social and emotional needs of patients and their families. None of these needs can be met without fully engaging patients and families in their own care and partnering with patients and families in redesigning, improving and evaluating health care services. From a business perspective, patient and family engagement is critical because it contributes to outcomes directly affecting hospital costs and reimbursement.

Five Ways Patient and Family Engagement Directly Impacts Your Hospital

- Contributes to better clinical outcomes
- Reduces institutional and individual costs of care
- Increases adherence to recommended treatment regimens, which can lead to fewer complications and re-hospitalizations
- Improves patient satisfaction with care coordination and other patient experience measures that impact the hospital’s reimbursement rates from Medicare and other payers
- Enables compliance with patient engagement requirements included in HITEC meaningful use and patient-centered medical home payment models
Leadership Action Steps

Hospitals have many systems and processes in place to ensure that patients receive safe, high-quality and efficient care. But unlike processes designed to manufacture products, which use standardized and inert raw materials, hospital processes must be adaptable to the needs of patients and families that differ with respect to what they know and have experienced in the past. Patients and families have different beliefs, preferences and values that can affect their choices for end-of-life care, communication with providers, diet and family presence. Creating an organization with systems and processes that can identify and adapt to diverse patient needs and with staff trained to effectively use these systems is a priority and responsibility of every hospital leader. Many hospitals do not fully engage patients and their families.

This resource describes five steps to move your hospital to full patient and family engagement. These steps will help you (1) develop the vision of what your hospital could look like when staff, physicians and leaders fully engage patients and families, (2) determine opportunities to improve your skills, knowledge and confidence, (3) develop a plan and prioritize it to achieve patient engagement goals, (4) monitor your progress, and (5) provide ongoing implementation support, including resources your staff, patients and families will need to be successful.
Developing a Clear Vision

Developing a clear vision for how your hospital can fully engage patients and families requires more than defining patient engagement. It encompasses defining what your organization would look like in order to consistently and effectively engage with patients and their families. The checklist at right notes the actions a hospital leader should take to support development of a clear organizational vision of successful patient and family engagement.

Many excellent definitions of patient and family engagement are included in the AHA report Engaging Health Care Users and Changing Behaviors: A Framework for Individuals,16 the AHRQ Guide to Patient and Family Engagement in Hospital Quality and Safety17 and other articles discussing the subject. One common definition adapted by the Gordon and Betty Moore Foundation from the AHRQ Guide to Patient and Family Engagement Environmental Scan Report is shown below, but there are many others.18, 19, 20, 21

A set of beliefs and behaviors by patients, family members, and health professionals and a set of organizational policies, procedures and interventions that ensure both the inclusion of patients and families as central members of the health care team and active partnerships with providers and provider organizations.22

Every definition has insights and limitations. The most important thing for your hospital is taking time to discuss what patient and family engagement is with your senior leadership, board, staff, patients and their families. With these discussions, you can choose an existing definition of engagement or create your own hybrid definition.

After agreeing on a definition, it is essential for senior leaders to develop and reinforce a vision for what patient and family engagement should be. Each organization’s vision will reflect its unique characteristics. An effective vision statement should encompass more than endorsing the importance of patient engagement. The statement should also include a vision for staff, processes, culture and other factors essential to achieving full patient and family engagement in the organization, including a vision for how patients and families will attain the skills, knowledge and confidence to be engaged.23
Facilitating discussions with the senior leadership team to develop a shared vision for how your organization can fully engage with patients and families is important. No one person can or should dictate this vision; instead, it might be reached through discussions and input from staff and patients and their families. Once there is agreement about the broad patient engagement goal, leadership should ensure that it is widely shared and regularly reviewed so everyone understands its importance to leadership and to the organization’s success. In addition, leadership should implement and use structures, resources and processes that support and reinforce the vision.

**Determine Improvement Opportunities**

Possessing a clear vision of how to engage patients and families needs to be coupled with a realistic assessment of where your hospital is now. Although many leaders are closely attuned to what is happening within their organization, it is also quite common for leaders to be unaware of significant organizational strengths and weaknesses related to patient and family engagement efforts. You need objective data to assess how your organization is doing and to set realistic improvement priorities and goals. The assessment checklist at right highlights important actions to consider.

Getting feedback from staff at all levels and from patients and families about the organization’s patient engagement efforts is key. Though simple and appealing, surveys are not a good substitute for facilitating forums for staff to candidly discuss what they see as challenges and opportunities in fully engaging patients and their families. To ensure accurate, realistic assessments, most such forums should not include members of senior leadership but should include patients and families whenever possible.

**Sample Patient and Family Engagement Vision Statement**

We aspire to be an organization in which:

- Patients and their families are fully engaged in their care and in our efforts to provide safe, high-quality care for every patient
- Every staff member is equipped and empowered to support the engagement of patients and their families
- We have systems and processes in place to engage patients and families at the bedside, in our training activities and in hospital planning and oversight
- Our culture continuously reinforces the necessity for fully engaging patients and their families

**Assessing Strengths and Gaps in Your Organization’s Patient Engagement Efforts: A Leader’s Checklist**

Have you:

- Elicited feedback from your senior leadership team, staff, patients and families about various patient engagement efforts
- Used one or more formal patient engagement assessments to identify strengths and gaps
- Inventoried policies, processes, position descriptions and training programs to determine whether patient and family engagement is appropriately included
- Discussed findings and conclusions with leadership, staff and patients to create awareness and lay the groundwork for improvement efforts
practical. Senior leadership should review summaries of these conversations and then discuss them as a key part of determining the organization’s current strengths, weaknesses and gaps. Participating staff and patients must be informed prior to the forum that the conversations will be disclosed to senior leadership.

Leadership might learn a great deal from these informal discussions about patient engagement. These insights can be enhanced by using one or more formal assessments of various aspects of patient engagement. Three useful tools are shown below and many others are cited in the recently released AHRQ Guide. An additional approach to better understand your organization’s progress toward fully engaging patients and families entails reviewing documents that your hospital creates and uses. At some hospitals, a thorough review of meeting agendas, incentive plans, employee evaluation processes, orientation materials, quality and patient safety teams and strategy documents would reveal that the important issue of patient and family engagement is not being addressed.

To fully engage patients and families, health care organizations must change at multiple levels:  

► **At the individual level**, change is needed to ensure individuals and families are encouraged and supported to be active participants in care and decision making  
► **At the health care team level**, change is needed to ensure that the health care team is prepared and supported for collaboration with patients, families and other members of the care team  
► **At the organizational level**, change is needed to assign accountability, encourage partnerships and integrate the patient and family perspective into all aspects of hospital planning, implementation and evaluation of programs and services
Health care organizations can learn much about their culture, operations and their patient engagement efforts by reviewing materials to see if any changes are evident. Examples of materials you can review include:

<table>
<thead>
<tr>
<th>Policies and Procedures</th>
<th>Personnel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policies in place related to key patient and family engagement efforts</td>
<td>Commitment to patient and family engagement in position descriptions</td>
</tr>
<tr>
<td>Mechanisms for employees, patients and families to report concerns about failures to engage patients or families</td>
<td>Patient engagement embedded in new employee orientation and other staff and physician training, with patients and family as faculty</td>
</tr>
<tr>
<td>Processes for acknowledging and correcting engagement failures</td>
<td>Support for patient and family engagement evaluated in employee reviews</td>
</tr>
<tr>
<td>Defined ways to review and improve patient and family engagement processes over time</td>
<td>Incentives linked to meeting patient and family engagement goals</td>
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<table>
<thead>
<tr>
<th>Meetings and Committees</th>
<th>Data Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine inclusion of patients and families as advisors</td>
<td>Patient experience data collected and reviewed</td>
</tr>
<tr>
<td>Agendas with topics directly related to patient and family engagement</td>
<td>Evaluation data collected about patient engagement efforts and training</td>
</tr>
<tr>
<td>Minutes reflect substantive discussions of patient and family engagement</td>
<td>Monitoring targeted outcomes for improvement linked to engagement initiatives</td>
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</table>

Leaders should discuss the organization’s relevant policies and procedures that encourage or create barriers for patient and family engagement. Reviewing all these materials may expose specific gaps where improvements are needed. In some hospitals, this review will unearth little that reflects a substantive commitment to meaningful patient and family engagement. Though that may be discouraging, the review also creates opportunities for making rapid improvements.

**Prioritize and Plan**

Developing a clear vision of how your hospital will fully engage patients and assessing your progress toward achieving this vision are important preliminary steps. A third step that is equally critical for hospital leaders is setting priorities and ensuring viable plans are created and executed to achieve the vision. The checklist below is for guiding activities in the implementation phase.

Although hospital leaders need not fully understand details about specific engagement strategies, it is important to know the general categories of patient and family engagement strategies and to lead efforts to set priorities for implementing these strategies. The AHA report *Engaging Health Care Users and Changing Behaviors: A Framework for Individuals* identifies engagement strategies at four distinct levels within the health care system: community, organization, health care team and individual. The table on the next page summarizes engagement strategies being used by hospitals at each of these four levels.
Examples of Engagement Strategies

<table>
<thead>
<tr>
<th>Health Care System</th>
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<tbody>
<tr>
<td>Community</td>
<td>► Providing health education and health literacy classes</td>
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<tr>
<td></td>
<td>► Providing healthy cooking and physical education classes</td>
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<tr>
<td></td>
<td>► Using patient navigators and peers to provide support</td>
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<tr>
<td></td>
<td>► Making local policy changes that promote healthier lifestyles (e.g., eliminating sugary drinks from school cafeterias)</td>
</tr>
<tr>
<td>Organization</td>
<td>► Using volunteers or patient advocates to support care</td>
</tr>
<tr>
<td></td>
<td>► Involving patients and families in patient and family advisory councils, governance and other committees</td>
</tr>
<tr>
<td></td>
<td>► Removing restrictions on visiting policies for families</td>
</tr>
<tr>
<td></td>
<td>► Opening access to medical records</td>
</tr>
<tr>
<td></td>
<td>► Using email and social media technology (e.g., Facebook, Twitter)</td>
</tr>
<tr>
<td>Health Care Team</td>
<td>► Using bedside change-of-shift reports</td>
</tr>
<tr>
<td></td>
<td>► Involving patients and families in multidisciplinary rounds</td>
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<tr>
<td></td>
<td>► Using patient- and family-activated rapid response</td>
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<tr>
<td></td>
<td>► Providing shared decision-making tools</td>
</tr>
<tr>
<td></td>
<td>► Using patient teach-back</td>
</tr>
<tr>
<td></td>
<td>► Using clinic-based multidisciplinary care teams</td>
</tr>
<tr>
<td>Individual</td>
<td>► Seeking health information and knowledge</td>
</tr>
<tr>
<td></td>
<td>► Adhering to treatment plans and medication regimens</td>
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<tr>
<td></td>
<td>► Participating in shared decision making</td>
</tr>
<tr>
<td></td>
<td>► Using online personal health records</td>
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<td></td>
<td>► Engaging in wellness activities</td>
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AHRQ’s *Guide to Patient and Family Engagement in Hospital Safety and Quality* focuses on four specific engagement strategies for which strong evidence of impact exists: working with patients and families as advisors, improving communication at the bedside with patients and families, using nurse bedside shift reporting to engage patients and families and engaging patients and families transitioning to home using the IDEAL discharge planning process. Reviews of published articles related to patient engagement include other engagement approaches, though evidence supporting the impact of some approaches is limited.

Based on the patient engagement vision you have created for your organization, the areas you have identified as the most significant weaknesses and a review of available options for engaging patients and families, your hospital’s leadership team should set implementation priorities. Hospital leaders are familiar with priority-setting processes since they are used regularly. The table below highlights specific considerations related to implementing patient engagement strategies.

**A Leader’s Checklist**

- Assess the options for strengthening patient and family engagement in your hospital
- Set priorities based on needs, opportunities and input from key stakeholders
- Equip and empower your staff to support the engagement strategies you are implementing
- Anticipate barriers and proactively intervene to overcome them
Factors in Setting Implementation Priorities

<table>
<thead>
<tr>
<th>Areas</th>
<th>Need for early successes to show impact</th>
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<tbody>
<tr>
<td>Passion of staff and key stakeholders</td>
<td>Presence of champions to support effective rollout</td>
</tr>
<tr>
<td>Presence of champions to support</td>
<td>Ability to fully train and equip staff</td>
</tr>
<tr>
<td>Implementation</td>
<td>Ability to spread across units and facilities</td>
</tr>
</tbody>
</table>

In general, taking into account patients, families and staff needs, opportunities for rapid positive impact and the resources required for successful implementation all might be primary considerations in setting your priorities.\(^{33}\)

As you set priorities and empower organizational leaders to begin putting patient and family engagement strategies in place, several recommendations can increase your ability to succeed:

► Conduct small and rapid tests of change in particular hospital units to help pave the way for broader rollouts of engagement strategies
► Avoid implementing too many engagement strategies in the same place at the same time to increase the likelihood of success and lower the likelihood of staff burnout and frustration
► Align implementation efforts with related improvement activities to help use resources efficiently and avoid dividing the attention of key staff supporting your implementation efforts
► Prioritize, which requires allocating the resources and time needed for implementation to succeed
► Include patient and family representatives in the teams that plan and implement engagement strategies to reduce staff objections and increase your ability to make changes of maximum benefit to patients

Staff training is a frequently overlooked dimension in many efforts to strengthen patient engagement.\(^{34},^{35}\) The best systems and processes for patient engagement will be of little benefit unless staff is well equipped to use them. Effective communication with patients and families is central to most engagement. Most staff will need training in several areas, as noted below.

Education and Training on How to Communicate With Patients and Families

► Develop approaches for eliciting the values, goals and needs of patients and families
► Create opportunities to hear patients and family members describe their perspective of the hospital care experience
► Get help for families in different situations that might arise
► Learn strategies to involve patients and families in process improvement, redesign work and/or committees
► Develop skills in the teach-back method
► Work with patients and families in difficult situations
Most hospitals have developed processes and assigned staff focused on staff orientation and training. While delegating training responsibilities to these staff members is appropriate, stress the importance of including patients and families in these training sessions whenever possible. Specific options to suggest include:

- Invite patients or families to attend staff orientation and in-service programs and share stories about their care experiences
- Involve patient and family advisors in training activities for staff and physicians that focus on collaborating with patients and families to improve safety and quality
- Train patient and family advisors to participate as “actors” in simulation-based training for clinicians and staff
- Involve patient and family advisors in teaching medical students, residents, fellows, other physicians and faculty and nurses about medical errors

Regardless of how well you have set priorities, planned and invested in staff training staff to support your patient and family engagement strategies, barriers are inevitable. Common barriers can be grouped into three general categories: provider barriers, organizational barriers and patient and family barriers.
Supporting your implementation leaders’ efforts to overcome these barriers is essential. Overcoming each barrier may require a different response from you and your senior leadership team, but several approaches may prove useful and reassuring to staff responsible for leading the hospital’s efforts to strengthen patient and family engagement. These include:

- Barriers, challenges and setbacks are inevitable. Leadership sets the expectation for success in overcoming obstacles
- The staff members directly involved in patient engagement implementation efforts are best situated to identify solutions to barriers. Leadership works to remove obstacles and facilitate effective patient engagement strategies
- Staff should be actively working with patients and families to understand and solve barriers; patients are key to helping develop solutions to many challenges
- Leadership communicates the importance of patient engagement as an organizational goal and affirms the organization’s ability to be creative and flexible in meeting that goal

Monitor Progress

The only way to know if you are moving toward greater patient engagement is to measure results. Measurement must strike the right balance between being detailed enough to gauge meaningful engagement and simple enough to avoid undue reporting burdens. The checklist at right highlights four key leadership responsibilities related to monitoring progress. You may ask the staff leading these improvement efforts to select the measures they believe are most important. You also need to be certain that the measures selected include ones that will allow you, senior leadership and your board to be confident your efforts are achieving results.

Once measures are chosen, collect the required data collected easily, accurately and quickly. Even if imprecise, most data are accurate enough to give you a general sense if progress is being made. Appendix A provides examples of process and outcome measures to recommend to your staff.

Most hospitals possess far more data than anyone looks at or uses to guide decision making. For your patient engagement efforts to succeed, verify that the measures are easy to understand and regularly shared and discussed with key decision makers in your organization. The process of reviewing progress will allow you to see when implementation efforts are struggling—so you can intervene and see when progress is being made—so you can celebrate your successes. Investing leadership time in reviewing your selected measures shows staff that strengthening patient and family engagement is an organizational priority.
Provide Ongoing Implementation Support

With hundreds of journals, dozens of conferences, and scores of white papers and other tools, it is impossible for you or most of your staff to remain fully informed about the growing body of information related to patient and family engagement. Several resources do an exceptional job of summarizing the literature and offering practical guidance to hospitals seeking to fully engage with patients and their families.


► Changing the Concept of Families as Visitors: Supporting Family Presence and Participation Institute For for Patient- and Family-Centered Care. (http://resources.ipfcc.org/product_p/32084-1.htm?1=1&CartID=0)

► Developing Patient and Family-Centered Vision, Mission, and Philosophy of Care Statements. Institute for Patient- and Family-Centered Care. (http://resources.ipfcc.org/product_p/32098-1.htm?1=1&CartID=0)


► Institute for Patient- and Family-Centered Care: assessment tools, literature reviews, etc. (http://www.ipfcc.org)

► Institute for Healthcare Improvement: white papers, improvement stories, case studies, etc. (http://www.ihi.org)

► Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities. Institute for Patient- and Family-Centered Care. (http://resources.ipfcc.org/product_p/3215-1.htm?1=1&CartID=0)


► Patients as Partners: How to Involve Patients and Families in Their Own Care. Institute for Healthcare Improvement. (http://www.ihi.org/knowledge/Pages/Publications/PatientsasPartnersHowtoInvolvePatientsandFamiliesinTheirOwnCare.aspx)

► Putting Patients First: Best Practices in Patient-Centered Care (by Susan B Frampton)

In addition to these resources, the Gordon and Betty Moore Foundation is funding a survey of hospitals’ patient and family engagement strategies. This survey, developed with input from a panel of experts, is being sent to the leaders of 2,000 hospitals in the summer of 2013. Findings from this survey will be shared in the fall of 2013. They will allow hospital leaders to compare their progress implementing patient and family engagement strategies with those of comparable hospitals across the U.S. The survey also may add to what is known about which engagement strategies are linked to patient satisfaction and other relevant outcomes such as hospital acquired conditions, quality of care, and financial viability. If your hospital is selected to participate in this survey, we encourage you to respond to it and contribute to efforts to strengthen patient and family engagement in every American hospital.
Appendix A:

Patient Engagement Process and Outcome Measures

<table>
<thead>
<tr>
<th>Description</th>
<th>Measurement</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Access To Medical Records By Patients And Families</td>
<td>Number of times the portals are used</td>
<td>Increase in patient satisfaction scores</td>
</tr>
<tr>
<td></td>
<td>Surveys of patients’ use of portals</td>
<td>Increased medication compliance</td>
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</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>Measurement</th>
<th>Outcome</th>
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</thead>
<tbody>
<tr>
<td>Bedside Change-of-Shift Report</td>
<td>Nursing staff and physician satisfaction scores</td>
<td>Increase in staff satisfaction scores</td>
</tr>
<tr>
<td></td>
<td>Patient satisfaction scores</td>
<td>Increase in patient satisfaction scores</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Improved ability of nurses to prioritize work</td>
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<tr>
<td></td>
<td></td>
<td>Decrease in staff time</td>
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<tr>
<td></td>
<td></td>
<td>Decrease in handoff errors</td>
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</table>

Metrics for Measuring Engagement

- Number of patient and family advisors involved with the hospital
- Number of patient and family advisors serving on committees or quality improvement teams
- Number of staff trained in partnering with patients and families
- Number of staff trained in communicating to support patient and family engagement
- Changes in patients’ ratings of hospital care as patient and family engagement strategies are implemented
- Changes in clinical process and outcomes as patient and family engagement strategies are implemented
- Changes in market or financial performance as patient and family engagement strategies are implemented
- Number of patient and family members oriented to serve on improvement projects

The table below lists several engagement strategies and provides suggestions on measuring the progress that hospitals have made in engaging their patients. Measuring hospitals’ patient and family engagement efforts also requires collecting data to document and link effective patient and family engagement to improved patient outcomes and patient satisfaction, among other outcomes.
<table>
<thead>
<tr>
<th>Description</th>
<th>Measurement</th>
<th>Outcome</th>
</tr>
</thead>
</table>
| **Multidisciplinary Rounds** | ▶ Percentage of families that participate in rounds  
▶ Number of stories in which new information is discovered from family  
▶ Length of time for rounds  
▶ Patient satisfaction scores  
▶ Staff satisfaction scores  
▶ Length of stay | ▶ Length of stay decreased  
▶ Increase in satisfaction scores  
▶ Decrease in readmissions rate, safety outcomes  
▶ Change in percentage of near misses versus errors |
| Patients and families participate in rounds  
Orders and discharge paperwork are clarified; patients and families are involved in decisions | | |
| **Rapid Response Teams (RRT)** | ▶ Patient knowledge of RRT process  
▶ Number of RRT calls  
▶ Response time | ▶ Incidence of cardiac arrests outside the intensive care unit  
▶ Total hospital mortality rate  
▶ Error or near-miss discovery |
| Patients and families are encouraged to call for RRT if patient’s health changes notably or patient’s concerns are not being addressed  
Team responds within minutes. Patients are informed at admission with verbal review of guidelines | | |
| **Decision Aids** | ▶ Number of eligible patients who receive a decision aid  
▶ Record of when clinician gives patients personalized materials  
▶ Survey of patients to find out how informed they were about the decision, how actively they were involved in the decision-making process and whether the decision made was consistent with the patient’s preference | ▶ Increase in patient knowledge  
▶ Reduction in discretionary surgery  
▶ Increase in written advance directives |
| Patients receive decision aids to improve patient-provider communication | | |
Endnotes


19. Ibid.


