Maximizing and Sustaining Patient and Family Engagement

Carrie Brady, JD, MA
Principal, CBrady Consulting
203-210-7484
cbradyconsulting@gmail.com
Congratulations!
We’ve Come a Long Way!
We Have Evidence . . .

• Summary of evidence from 55 studies
• Positive associations between patient experience and:
  – Health outcomes (objectively measured and self-rated)
  – Adherence to recommended medication and treatment
  – Preventative care
  – Health-care resource use
  – Quality and safety of care

BMJ Open 2013;3:e001570 (available online at no charge at http://bmjopen.bmj.com/content/3/1/e001570.full)
“[T]here was an inverse relationship between [patient] participation [in their care] and adverse events . . . [P]atients with high participation were half as likely to have at least one adverse event during the admission.”

We Have Reports and Frameworks
We Have CMS Metrics

Point of Care:
1. Discharge planning checklist discussed prior to admission
2. Shift change huddles/bedside shift reporting

Policy & Protocol:
3. Dedicated functional area for patient and family engagement
4. Active patient and family engagement committee or patient advisor

Governance:
5. Patient representative on governing board
Patients engaged in their own care report “higher quality care, experience fewer medical errors and have more positive views of the healthcare system.”
“Most of the literature on patient and family engagement 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.”

Maurer M et al., Guide to Patient and Family Engagement: Environmental Scan Report, AHRQ Publication No. 12-0042-EF, May 2012, p. 27
The Road Ahead

• Assessing Your Level of Engagement at the Front Lines
• Understanding and Overcoming the Barriers
• Taking the Next Steps: Opportunities to Expand Engagement
“An education isn’t how much you have committed to memory or even how much you know. It’s being able to differentiate between what you do know and what you don’t.”

Anatole France
Definitions of engagement include:

• an arrangement to meet or be present . . .
• a hostile encounter between military forces
• a job
• betrothal
Stages of Engagement

**Denial**
- Engagement as **Appointment**
  - We don’t need patients’ help or expertise but we are required to engage.

**Anger**
- Engagement as **Battle**
  - Patients are “noncompliant”

**Bargaining**
- Engagement as **Shared Responsibility**
  - What are our respective obligations to each other?

**Acceptance**
- Engagement as **Commitment**
  - We are in this together forever, across the lifespan and continuum.

*Elizabeth Kubler Ross*

Stages of Grief (minus depression)
Identifying Perceptions that Impede Progress

1. Patients, families (and non-clinical staff) don’t know anything – healthcare should be left to the clinical experts
2. Patient engagement is just feel-good “fluff”
3. Patients don’t want to engage
22% of 193 patients reported a “recent unsafe episode”

More than 80% of the reported experiences were classified by reviewers as “service quality incidents”

- 33% related to *waits and delays*
- 21% related to *poor communication and information for patients*
- 13% related to *poor coordination of care among staff*

Source: Weingart SN et al. “Patient-Reported Safety and Quality of Care in Outpatient Oncology” Joint Commission Journal on Quality and Patient Safety; 33:2, 2007
CONCLUSIONS:

“Patient-reported service quality deficiencies were associated with adverse events and medical errors. Patients who report service quality incidents may help to identify patient safety hazards.” (emphasis added)

Taylor BB et al. Medical Care 2008 Feb;46(2):224-228
The Need for a Different Perspective

Candy Sour Sugar Bitter Good Taste Tooth Nice Honey Soda Chocolate Heart Cake Tart Pie
The Quiz!
Were these words on the list?

- Taste
- Point
- Sweet
“Give it to me straight, Doc. How long do I have to ignore your advice?”
Rethinking “Noncompliance”

• Are we giving patients any other option?
  – Are patients engaged in shared decisionmaking? Is the provider aware of each patient’s values, goals, and preferences?
  – Do patients have the opportunity to raise concerns about the treatment plan, discharge instructions etc.?
  – Is the plan realistic and understandable?
For engagement to be effective, we need to stop actively disengaging our patients and families.
THANK YOU FOR NOT MENTIONING DR. OZ.
But Many Organizational Process Factors Impair Our Ability to Engage

- Understanding of/experience with patient and family engagement
- Formal and informal leadership
- Hierarchy
- “Slack” resources
- Internal alignment
- Absorptive capacity
- Culture

AHRQ Environmental Scan
Provider Attitudes Matter

**Patient Barriers**
- Fear and uncertainty
- Low health literacy*
- Provider reactions

**Patient Facilitators**
- Self-efficacy
- Information
- Invitations to engage
- Provider support

*In a recent study, 53% of survey respondents agreed or strongly agreed that “most medical information is too hard for the average person to understand” - Environmental scan, p.25
Build Provider Communication Skills

• Redesign provider education to build necessary skills such as teachback, motivational interviewing
  – E.g. Iowa Health System Teach Back Toolkit www.teachbacktraining.com/

• Keep the lines of communication open and make information accessible
  – Follow-up phone calls/point of contact
  – Patient portal
  – Take advantage of technology

• Reflect and Connect
  – Every interaction counts
When we call patients and families “good,” or at least spare them the “difficult” label, we are noting and rewarding acquiescence. . . . “good” means you agree with me and you don’t bother me and you let me be in charge of what happens and when. Such a definition runs counter to what we know about truly good care as a collaborative process. From the history that so often generates the diagnosis to the treatment that is the basis of care or cure, active participation of patients and families is essential to optimal outcomes.
Explore Reverse Teachback

• Providers frequently use teachback to verify patient understanding of what they have said.
• Why not use teachback to verify what patients have communicated to providers?
  – Respects patient/family expertise
  – Sets expectation of partnership
Taking The Next Steps
Operate on Multiple Levels Simultaneously

Patient with known non-Hodgkin’s lymphoma presents in ED with shingles and is admitted. A large neutropenic precautions sign placed on door. Family mentions to oncology office staff that sign is not being consistently followed.

Oncology Nurse Instructs Family: “It is your job to tell the staff they must use appropriate precautions. Physically block them at the door if you have to, but don’t let them near the patient.”
Recognize the Patient As the Control Tower

- Commercial planes will not take off or land without guidance from the control tower.
- Without the control tower, the pilot can’t get a complete picture of the route ahead.
- Healthcare can’t take off without permission from the patient, but in healthcare we often stop using the control tower after takeoff.
Simple (But Underutilized) Strategies

Observe
(Shadowing)

Invite
(Care Processes)

Review
(Patient Communications)

Expand
(include family)
Guide to Patient and Family Engagement in Hospital Quality and Safety

Research shows that when patients are engaged in their health care, it can lead to measurable improvements in safety and quality. To promote stronger engagement, the Agency for Healthcare Research and Quality (AHRQ) developed a guide to help patients, families, and health professionals work together as partners to promote improvements in care.

The Guide to Patient and Family Engagement in Hospital Quality and Safety focuses on four primary strategies for promoting patient/family engagement in hospital safety and quality of care:

- Encourage patients and family members to participate as advisors.
- Promote better communication among patients, family members, and health care professionals from the point of admission.
- Implement safe continuity of care by keeping the patient and family informed through nurse bedside change-of-shift reports.
- Engage patients and families in discharge planning throughout the hospital stay.

http://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/
Get to Know Your Health Care Team

You and your family or friends

You are part of your health care team. Doctors and nurses may know more about medicine, but you are the expert on you.

Your family and friends can be a part of your health care team, if you like. At [insert hospital name], families and friends are not visitors but are part of your health care team. They can give you comfort and support. They also can tell your doctors and nurses about your needs and concerns.
**Unleash Patients’ and Family Members’ Expertise**

- Recognize patients’ expertise about their bodies
- Integrate patient and family in care
  - Clinical processes (e.g. huddles, bedside shift reporting, rounding)
  - Access to medical records/health information
- Orient patients to processes, including safety
  - E.g. family activated rapid response teams
Build on Patient/Family Expertise with Education and Information

• Change the timing
  – Engage the public, not just patients
  – Advance education for scheduled procedures

• Provide tools and resources
  – Shared decision-making
  – Self-management of condition
  – Patient/family roles
  – Mentors

• Create consistency across the continuum

Danish Society for Patient Safety
Use the Information You Already Have More Wisely

- Existing programs can provide essential information to support quality improvement (e.g. follow-up phone call process, rounding)
- Use the information gained to guide your improvement activities, not just to identify and address individual patient needs
- Recognize that post-discharge information is important for improvement - discharge isn’t the end of care
What are the Communicating to Improve Quality tools?

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

<table>
<thead>
<tr>
<th>Tool 1</th>
<th>Be a Partner in Your Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use this tool to</td>
<td>Inform the patient and family of scheduled opportunities where they can interact with the health care team</td>
</tr>
<tr>
<td>Description and formatting</td>
<td>This handout gives information on routine events and highlights tools (e.g., white boards) the hospital uses to talk with the patient and family. Format: 1-page handout</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tool 2</th>
<th>Tips for Being a Partner in Your Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use this tool to</td>
<td>Help the patient and family know how to interact with the health care team</td>
</tr>
<tr>
<td>Description and formatting</td>
<td>This handout describes four tips for patients to be partner in their care: (1) tell doctors and nurses about their health, (2) check to see if they understand what doctors and nurses say, (3) ask questions until they understand the answers, and (4) let health care staff know which friends and family members should be involved in their care. Format: Tri-fold brochure. The electronic version of the tri-fold checklist provides information about how to fold the brochure by indicating the front and back covers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tool 3</th>
<th>Get to Know Your Health Care Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use this tool to</td>
<td>Help the patient and family understand the roles of different members of the health care team</td>
</tr>
<tr>
<td>Description and formatting</td>
<td>This handout gives information on the different members of the health care team: The patient, family, clinicians, and hospital staff. Format: 2-page handout</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tool 4</th>
<th>We Are Partners in Your Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use this tool to</td>
<td>Remind the patient, family, and clinicians of the importance of being partners and what they can do</td>
</tr>
<tr>
<td>Description and formatting</td>
<td>Designed to be posted in patient rooms or elsewhere in the hospital, this flyer summarizes the main action items from the other handouts for the patient, family, and clinicians. Format: Poster to be printed on 11x17 tabloid-size paper</td>
</tr>
</tbody>
</table>

Reinforce partnership through immediate orientation and education
Welcome Patient/Family Partnership

• Invite family to share ideas on a regular basis
  – E.g., set aside time on a weekly basis for an informal meeting with any family members who would like to give feedback

• Identify who are your best eyes and ears and use them for quality improvement
  – E.g. mine your data for the most critical group on a particular topic such as cleanliness and round on all patients in that group to ask what they observed
Observe: Shadow Patients/Families

- Hospitals can gain invaluable perspectives through shadowing.
- Shadowing involves following a patient/family through a particular process and recording observations.
Tips for Shadowing

• Identify a specific process to shadow
  – e.g. admission, ED, outpatient surgery

• Define the starting and ending points of the shadowing experience
  – e.g. duration, event

• Preferably assign shadowers to a process they are less familiar with, such as a different unit

• Convene shadowers to discuss what they have learned
Who Can Shadow? Anyone!

- Provide guidelines to shadowers
  - Role is to observe, not to intervene
  - Identify specific areas of interest (if any)
  - Annotate exemplary processes, as well as opportunities for improvement
“Tune In” to Patient Comments (for innovation and safety)

University of Pittsburgh Medical Center’s Guardian Angels Program
Based on a patient comment that the person shadowing her was a “guardian angel”, every transplant patient is assigned a guardian angel.

Northern Westchester Hospital’s Program for Patient/Family Infection Prevention Education at Meals
Inspired by a parent comment about wanting to wash her child’s hands before a hospital meal.

Extensive UPMC Shadowing resources available at (www pfcc.org/go-shadow/)

Use Patients/Family To Observe Us

Patient and families can:

• Gather observational quality improvement data
  – Responsiveness
  – Hand hygiene
  – Safety culture

• Serve as educators
  – Professional education programs
  – Orientation
  – Simulations
Set the Right Tone: Invite the Patient and Family onto the Team

• Determine what is most important to the patient and who should be engaged in their care
  – E.g. Twin Rivers Regional Medical Center Sacred Moment http://alwaysevents.pickleinstitute.org/?p=1789

• Proactively educate patients, family members, and healthcare professionals about their roles

“For the longest time I didn’t know the staff was doing this (bedside shift report) for me. They came into the room and had their conversation but it wasn’t until someone told me that I was welcome to participate that I started listening.”
Inform patients and families about care processes and invite them to participate

- e.g. remind patients before bedside shift reporting or interdisciplinary rounding that they are encouraged to participate in the process

- Help patients to record questions in advance

You are invited

You are invited to take part in nurse bedside shift report. You can also invite a family member or friend to take part with you.

Nurse bedside shift report happens every day between [7 and 7:30 a.m.] and [7 and 7:30 p.m.].

Let us know if you have any questions. We are partners in your care.
What are the Nurse Bedside Shift Report tools?

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

<table>
<thead>
<tr>
<th>Tool 1</th>
<th>Nurse Bedside Shift Report: What is it? How can you get involved?</th>
<th>Use this tool to</th>
<th>Description and formatting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Inform the patient and family about what bedside shift report is and how they can take part</td>
<td>• Given to patients on the day of admission, this handout explains what bedside shift report is, what patients and family or friends should expect, and what they need to do. It should accompany a verbal explanation by bedside nurse.</td>
</tr>
<tr>
<td>Tool 2</td>
<td>Bedside Shift Report Checklist</td>
<td>Train and remind nurses of the critical elements of bedside shift report</td>
<td>• Made available at training and all shift changes, this checklist highlights the six elements required to complete bedside shift report. As they would like, nurses can write on the form during bedside shift report.</td>
</tr>
<tr>
<td>Tool 3</td>
<td>Nurse Bedside Shift Report Training</td>
<td>Prepare nurses to conduct bedside shift report</td>
<td>• Slides and talking points to train nurses to conduct a bedside shift report and to help them understand how to engage patients and family members in the process.</td>
</tr>
</tbody>
</table>

Format: 
- Tool 1: Tri-fold brochure. The electronic version of the tri-fold checklist provides information about how to fold the brochure by indicating the front and back covers.
- Tool 2: 1-page handout
- Tool 3: PowerPoint presentation with embedded video
Review All Patient Materials

• **Always** involve patients in the development and review of patient communication materials

• This is an easy to implement starting point for patient/family advisors
  – Scalable: can start with one diagnosis (e.g. have heart failure patients review discharge instructions) or with broader informational materials (e.g. admission packets)
  – Can use existing patient groups (e.g. cancer support group)
Partner with Me
Always Event® Program
UCSF Medical Center

Improves hospital care for patients with dementia

- Patient/family preparation
  - Educational video
  - Education packet

- Targeted Care
  - Focused screening assessment
  - Dementia specific care plan

- Staff training
  - Alzheimer’s Association Training
  - Volunteer Team

http://alwaysevents.pickerinstitute.org/?p=1402
Use Patient/Family Mentors

• Former patients can be excellent resources for current patients (e.g. transplant patients) and for families
  – St. Jude Children’s Hospital Parent Mentor Program
    http://alwaysevents-pickerinstitute.org/?p=1706

• Programs are beneficial for staff, as well as patients/families
Incorporate Key Features of AHRQ Guide

• Includes paired tools, so providers and patients are receiving the same information
• Promotes concurrent skill development of providers and patients/family
• Implementation guides explain why, as well as what and how

Build these features into every engagement initiative
Never Lose Sight of the Goal

Mutual respect

Life-long commitment

Continuous partnership across the continuum
Engage Staff in Engagement

A simple and effective model to engage staff

Thank you for supporting NHS Change Day!
Present pledges stand at: 189034.
Click here to tell your story.
The best time to plant a tree is twenty years ago. The second best time is now.

Proverb