Using Patient and Family Advisors: Turning Concepts Into Action

November 13, 2013
Webinar Agenda

• Welcome & Introductions – Kathy Wallace
• Using Patient and Family Advisors: Turning Concepts into Action – Carrie Brady
  – Recognize your Barriers
  – Dip a Toe in the Water
  – Dive In!
• Patient & Family Advisor Response
  – Bob and Barb Malizzo
• Questions
The Evolution of Patient and Family Engagement

- We know best.
- This is the way we’ve always done it.
- Doesn’t always work so well.
- We’re all patients too. We can figure it out.
- What would our patients want?
- Let’s ask them.
We’ve Gotten Better at Listening

• Patient Experience Surveys
• Focus Groups
• Compliments and Complaints
• Rounding
• Post-discharge Phone Calls

“Hearing is one of the body’s five senses, but listening is an art.”

Frank Tyger
We Need to Move on to Partnering

• Patient and Family Advisors Change the Dynamic

• Patients and Families Don’t Just Identify the Problems, They Are Part of Developing Solutions
• P3—Hospital has a dedicated person or functional area that is proactively responsible for patient and family engagement and systematically evaluates patient and family engagement activities.
  – April - 47%
  – Oct. - 58%
Measuring Success

- P4—Hospital has an active Patient and Family Engagement Committee OR at least one former patient that serves on a patient safety or quality improvement committee or team.
  - April – 33%
  - Oct. - 46%
Moving from Concepts to Action

• Identify the Barriers
• Dip a Toe in the Water
• Dive in to an Effective Advisor Program
Identify the Perceived Barriers

- Resources (including Time)
- Diffusion of Responsibility
- Perception of Value
- Fear/Discomfort
- Operational Considerations (e.g. recruiting advisors)
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.

**Build Partnerships in Parallel**

**Tools for Professional Education**
- Working with Patient and Family Advisors (presentation and handout)
- Ideas for Working with Patient and Family Advisors on Short-term Projects
- Readiness Assessment

**Tools for Patients/Family Education**
- Patient/Family Advisor Information Session (presentation)
- Advisor Readiness Self-Assessment
- Sharing My Story Planning Worksheet
- Patient/Family Advisor Orientation Manual

All Tools Available in AHRQ Guide to Patient and Family Engagement in Hospital Safety (June 2013) Strategy 1: Working with Patients and Families As Advisors

Getting Started: Are You Ready?

“The single most important factor for ensuring the successful involvement of patients and families in policy and program activities is commitment to the idea. . .

Without a deeply held belief that patients and families have unique expertise and knowledge and that their participation is essential to improving services, true collaboration will not occur.”

Institute for Patient- and Family-Centered Care

*Essential Allies: Patients, Residents and Families As Advisors.*
## Assess Yourself

### Partnering With Patients and Families To Accelerate Improvement: Readiness Assessment

For each item, circle the box that best describes your team’s perspective and experience.

<table>
<thead>
<tr>
<th>Area</th>
<th>Description 1</th>
<th>Description 2</th>
<th>Description 3</th>
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</thead>
<tbody>
<tr>
<td>Data transparency</td>
<td>Our team is uncomfortable with the possibility of sharing performance data with patients and family members.</td>
<td>Our team is comfortable with sharing improvement data with patients and families related to current improvement projects.</td>
<td>This organization has experience with sharing performance data with patients and families.</td>
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<tr>
<td>Flexibility around aims and specific changes of improvement project</td>
<td>We have limited ability to refine the project’s aims or planned changes.</td>
<td>We have some flexibility to refine the project’s aims and the planned changes.</td>
<td>We are open to changing both the aims and specific changes that we test based on patients’ and family members’ perspectives.</td>
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<td>Underlying fears and concerns</td>
<td>We have identified several concerns about involving patients and families on improvement teams and would need assistance in creating a plan for addressing them.</td>
<td>We have identified several concerns related to involving patients and families on improvement teams but believe we can create a plan for how to address or manage them.</td>
<td>We have a plan to manage and/or mitigate issues that may arise due to patient and family member involvement on our team.</td>
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<tr>
<td>Perceived value and purpose of patient and family involvement</td>
<td>There is no clear agreement that patient and family involvement on improvement teams is necessary to achieve our current improvement aim.</td>
<td>A few of us believe patient and family involvement would be beneficial to our improvement work, but there is not universal consensus.</td>
<td>There is clear recognition that patient and family involvement is critical to achieving our current improvement aim.</td>
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<tr>
<td>Senior leadership support for patient and family involvement</td>
<td>Senior leaders do not consider patient and family involvement in improvement a top priority.</td>
<td>Senior leaders are aware of and communicate support for patient and family involvement in improvement.</td>
<td>Senior leaders provide resources necessary to involve patient and family advisors in improvement.</td>
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<tr>
<td>Experience with patient and family involvement</td>
<td>Beyond patient satisfaction surveys or focus groups, our organization does not have a formal method for patient and family feedback.</td>
<td>We have patient and family advisors and/or a patient and family advisory council.</td>
<td>Patient and families are members of standing committees and make decisions at the program and policy level.</td>
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<td>Collaboration and teamwork</td>
<td>Staff in this organization occasionally work in multidisciplinary teams to provide care.</td>
<td>Staff in this organization work effectively across disciplines to provide care to patients.</td>
<td>Staff are effective at working collaboratively in multidisciplinary teams that include patients and families as valued members of the care team.</td>
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Redefine Advisors as an Enormous Opportunity

• There are motivated people eager to help the hospital and they’ll do it at no charge!

• Advisors are extra sets of eyes and ears (and sometimes extra sets of hands too).


Dip Your Toe in the Water

• Use existing programs to begin seeking advice from patients and families
  • Diagnosis specific support group participants
  • Volunteers

• Ask patients and family members to improve hospital communication materials

• Designate a family meeting time on one unit and post signs inviting family to attend
Other First Steps

• Invite patients/family to serve as faculty:
  – Orientation
  – Patient experience “rallies”
  – Leadership retreats
  – Patient/family education (e.g. joint replacement)

• Review all upcoming or recently initiated hospital projects/committees, identify which are being led by champions for patient engagement, and invite patients/families to participate in the process
Dive In!

• Identify a staff liaison

• Build enthusiasm for an advisory program
  – Identify topics for discussion, documents for review, upcoming projects, operational challenges where patient and family partnership would be valuable
  – Seek opportunities to sit in on another hospital’s meeting with advisors
  – Begin to catalog informal advisor success stories (patient and family insights and suggestions that have improved care, saved money, avoided wasted resources, etc.)
  – Proactively address concerns (e.g. explain how advisors will be screened and trained)
Organizational Considerations for an Advisory Council

- Mission and Vision
- Recruiting Process
- Size
- Eligibility and Terms
- Leadership
- Meeting Frequency
- Resources
Finding Excellent Partners

• Identification of prospective advisors
  – Ask staff and clinicians for suggestions (including ombudsmen and patient representatives)
  – Distribute brochures, including at support group meetings
  – Review patient compliments/complaints
Choosing the Best Candidates

• Ask advisors to apply
  – Immediately screens out some candidates who aren’t able to invest the time in the program

• Consider offering an informational session
  – Helps people to understand the advisory role and to realistically assess their interest

• Interview advisor candidates
  – Match interests, experiences, and skills to needs
  – Assess ability to partner effectively
Support Advisors

• Orient new advisors
  – General hospital orientation and advisor specific information, including expectations
  – Turn lack of clinical expertise into an asset
  – Emphasize representative role, not just personal

• Provide advisors with contact information for hospital liaison and keep the lines of communication open

• Pair a new advisor with a committee mentor
Plan the First Meeting

• Welcome advisors and set the right tone
• Topics to address include:
  – Introductions
  – Purpose and goals of the committee
  – Meeting procedures
  – Improvement ideas (e.g. review of specific process)
  – Closing thoughts and evaluation (what went well/what could be improved)

Sample agenda available in AHRQ Guide
Recruit Staff Partners

• Give as much thought and attention to recruiting staff as to recruiting advisors
• Choose mentors and leaders and give them the tools and skills they need to work effectively with patients and families
• Ensure that the advisors are well positioned for meaningful organizational action, not just an interesting discussion
Learning to Swim: Avoid Common Pitfalls

- Lack of Organization
- Ineffective Communication
- Ambiguous or Unrealistic Goals
-Disconnected from Operations and Governance
- Confrontational v. Collaborative Attitude
“Don’t ask if you don’t want answers.”

Patient and Family Advisory Council Member
Maintaining Momentum

• Setting Realistic Goals
  – Obtaining Resources
  – Connection to Operations

• Meaningful Engagement of Council
  – Productive and significant meanings
  – Timely follow-up
  – Collaboration
  – Continuity
  – Mutual respect

• Celebration of Accomplishments

“We need to do more than just eat lunch.”

Advisory Council Member
A Tale of Two Programs

“It was the best of times, it was the worst of times . . .”

Get Involved in a Family-Centered Care Program

The concept of family-centered care is based on the idea that family members are actively involved as partners in the care of their children. However, some family members choose to be involved on a larger scale, by participating as Family Advisors in some of the family-centered care programs established at CHOP.

Family advisors are valued partners in our mission to advance family-centered care. Many have told us that having the opportunity to be involved in improving the care experience for future families is a valuable gift that they take with them.


Family consultants on 34 hospital committees at Children’s Hospital of Philadelphia!
AHRQ Tools are available for everything we discussed today.

### What are the Working With Patients and Families as Advisors tools?

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

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<tr>
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<td>Recruit patient and family advisors</td>
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| **Tool 1**  
Help Improve Our Hospital: Become a Patient and Family Advisor | Recruit new patient and family advisors  
- This brochure provides information on who patient and family advisors are, how they help the hospital, and who can become an advisor.  
- Format: Tri-fold brochure. The electronic version of the document provides information about how to fold the brochure by indicating the front and back covers. |
| **Tool 2**  
Personal Invitation for Patient and Family Advisors | Recruit new patient and family advisors  
- This postcard is for clinicians or hospital staff to give to potential patient and family advisors along with a verbal invitation to get involved. The postcard describes the role of an advisor and tells potential advisors how to get more information.  
- Format: Postcard |
| **Tool 3**  
Patient and Family Advisor Application Form | Identify and screen potential patient and family advisors  
- Potential advisors complete this form that includes basic demographic information, questions on why the applicant wants to be an advisor, and questions on prior relevant experiences as an advisor or volunteer.  
- Format: 3-page handout |
| **Tool 4**  
Sample Invitation and Regret Letters for Advisory Council Applicants | Notify advisory council applicants of their acceptance or rejection  
- These sample invitation and regret letters are for patients and family members who have applied to be advisory council members. Hospitals may wish to combine these with a personal phone call.  
- Format: 1-page letters |

*All Tools Available in AHRQ Guide to Patient and Family Engagement in Hospital Safety (June 2013)*

Strategy 1: Working with Patients and Families As Advisors

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<td><strong>Inform patient and family advisors</strong></td>
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| **Tool 5** Patient and Family Advisor Information Session | Conduct an information session for people who are interested in becoming advisors  
- This presentation gives information on who patient and family advisors are, what they do, and how they help the hospital and provides tips from other advisors.  
- Format: PowerPoint presentation with talking points |
| **Tool 6** Am I Ready to Become an Advisor? | Help people who are interested in becoming advisors self-assess their readiness  
- This handout is to be given and completed during the advisor information session.  
- Format: 1-page handout |
| **Tool 7** Sharing My Story: A Planning Worksheet | Help potential patient and family advisors plan how to talk about their experiences  
- This handout is distributed during the advisor information session.  
- Format: 1-page handout |
| **Tool 8** My Participation Interests | Identify the specific interests of potential patient and family advisors  
- This form is completed at the end of the advisor information session.  
- Format: 1-page form |

**Train patient and family advisors**

| **Tool 9** Patient and Family Advisor Orientation Manual | Orient patients and family members who have been selected to serve as advisors  
- This manual provides information on hospital safety and quality and on what patient and family advisors do and how they help the hospital, and provides tips about being a patient and family advisor.  
- Format: Manual |

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<td><strong>Train clinicians and hospital staff</strong></td>
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| **Tool 10** Sample Confidentiality Statement | Review confidentiality requirements with all patient and family advisors  
- This is a sample confidentiality statement that hospitals can ask patient and family advisors or council members to sign before participating in advisory activities.  
- Format: 1-page handout |
| **Tool 11** Working With Patient and Family Advisors (Presentation) | Introduce clinicians and hospital staff to the idea of working with patient and family advisors and to develop their skills for doing so  
- This is a two-part training presentation. Part 1, Introduction and Overview, discusses who patient and family advisors are, the benefits of working with them, and opportunities for doing so. Part 2, Building Effective Partnerships, helps clinicians and hospital staff develop partnership skills.  
- Format: PowerPoint presentation and talking points |
| **Tool 12** Working With Patient and Family Advisors (Handout) | Provide clinicians and hospital staff with an overview of working with patient and family advisors  
- This handout is given at the clinician and staff training session that outlines the role of patient and family advisors and opportunities for working with them.  
- Format: 2-page handout |
| **Tool 13** Working With Patient and Family Advisors on Short-Term Projects | Help clinicians and hospital staff identify opportunities for working with patient and family advisors  
- This handout is distributed at the clinician and staff training session that contains suggestions for ways in which to incorporate advisors on short-term projects along with a form to request advisor participation.  
- Format: 4-page handout |
| **Tool 14** Readiness to Partner with Patient and Family Advisors | Help clinicians and hospital staff identify attitudes and behaviors that help them partner effectively with advisors  
- This handout is given at the clinician and staff training session that contains a checklist of behaviors and attitudes.  
- Format: 1-page handout |
Other Great Resources

Both available for purchase through the Institute for Patient- and Family-Centered Care at http://www.ipfcc.org/resources/index.html

Includes a thumb drive with 200+ healthcare organization resources
Patient and Family Perspective

Bob and Barbara Malizzo
Call to Action

• In the next 30 days:
  – Identify advisor candidates
  – Build momentum among staff for advisors (e.g. make a list of documents to be reviewed, upcoming projects)
  – Identify staff champions
Evaluation

• Please remember to complete the simple three question evaluation by Nov. 20, 2013!
• Survey will also be distributed along with link to the recording before the end of the day on Friday
Final 2013 PFE Webinar

• Dec. 4, 11 a.m. – 12 p.m.

• Harborview Medical Center will discuss their Open Notes program. This program allows patients access to their doctors’ notes via a secure Internet portal.

• IHA will also be revealing our Patient & Family Engagement Resource Guide.

• Finally, we will be reviewing our progress since our initiation and discuss potential plans for 2014.
Thank you