

Family Engagement Breakout

Illinois Perinatal Quality Collaborative

Annual Conference

November 10, 2014

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Leading Efforts to Partner with Patients and Families



“Having a patient & family representative in the room changes the conversation in every way.”

-Jim Conway



The Role of Patients and Families...

Patient & Family Advisors work in a variety of healthcare settings sharing their personal stories to **represent** all patients & families in providing an educated perspective of care by bringing **authenticity**, empowerment, respect and **inspiration** to the design and delivery of healthcare systems. Patient & Family Advisor roles include partner, educator, speaker, listener, advocate, **collaborator** and leader, ensuring the focus of healthcare is centered on the patient & the family.*

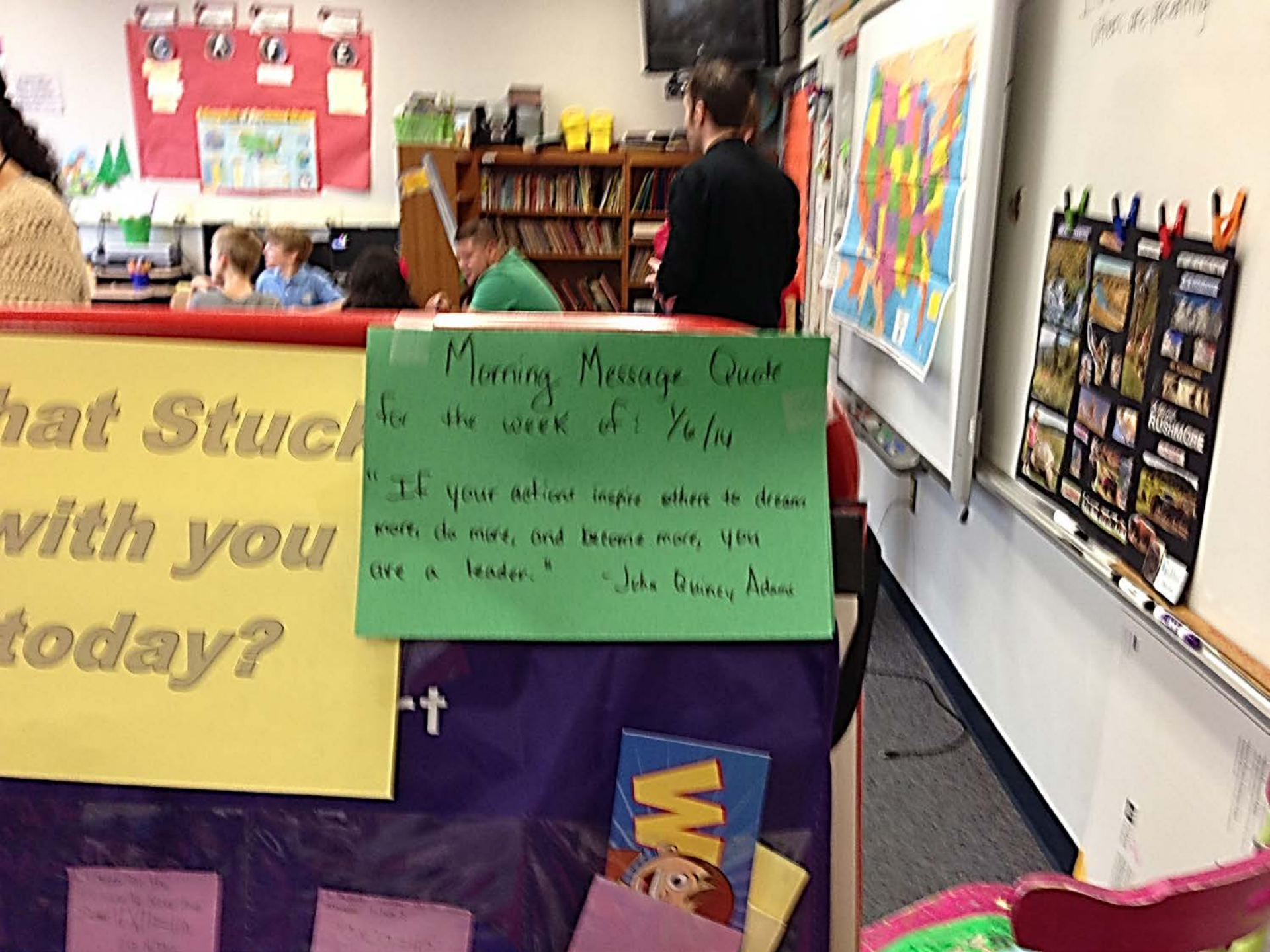
*Collaboratively written by the patient & family advisors in attendance at the IHI Forum, 2012



What Stuck
with you
today?

Morning Message Quote
for the week of: 1/6/14

"If your actions inspire others to dream
more, do more, and become more, you
are a leader." - John Quincy Adams



Preparing for Your Partnership Journey



“Set a nice table and good conversation will happen”

-Lydia Kent



Effective Partnerships

- ✓ Champion
- ✓ Shared outcomes
- ✓ Agreement on type of engagement
 - Networking
 - Coordination
 - Cooperation
 - Collaboration
- ✓ Recruit & Expect
- ✓ Evaluate

THE FIVE DEGREES OF PARTNERSHIP WORKING

- Co-existence

“You stay on your turf and I’ll stay on mine”

- Co-operation

“I’ll lend you a hand when my work is done”

- Co-ordination

“We need to adjust what we do to avoid overlap and confusion”

- Collaboration

“Let’s all work on this together”

- Co-ownership

“We all feel totally responsible”.



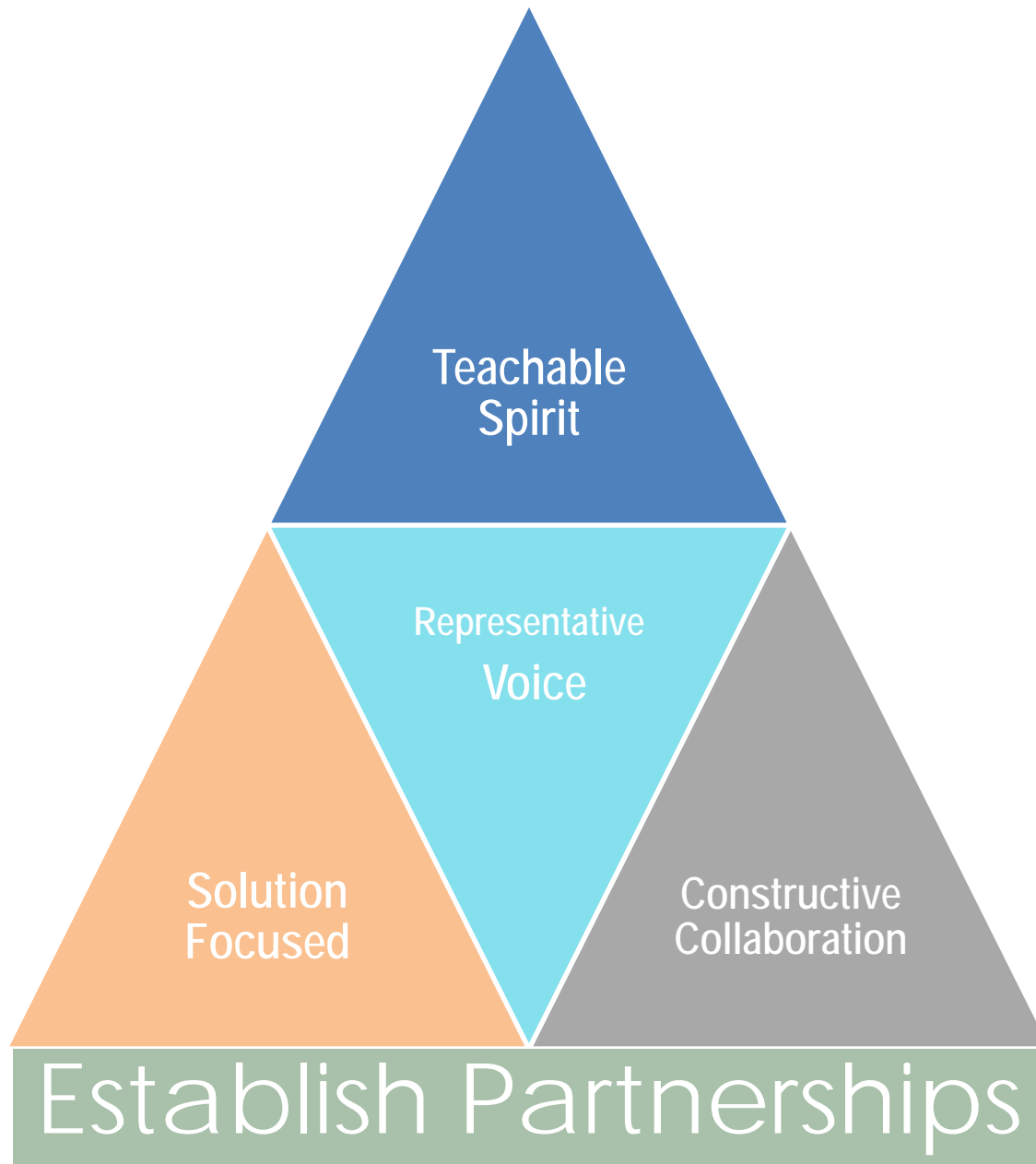
Selecting Patients and Family Members for the Team



Look for people who are:

- interested in the topic being addressed by the committee or task force;
- comfortable speaking in a group with candor;
- able to use their personal experience constructively; and
- able to listen and hear differing opinions.





Preparing Patients and Family Members for the Team



Information to Provide New Team Members

- Name of committee, its members and their roles/titles, time of meeting and location.
- The purpose of the group is there a document that outlines its charter or by-laws?
- Previous minutes or documents generated by the group.
- Summary of data that is reviewed regularly in the meeting and its purpose.
- Special words or terminology used in the committee.
- Length of service required.



Additional Questions New Team Members May Have

- May I meet with the committee chair prior to my first meeting?
- Would it be helpful if I provide to the committee, before my first meeting, a short written bio, a recent picture of me and a statement of why I would like to be involved in the committee?
- Are there any special skills or background I will need to work on this group?
- Are there other advisors who serve on the committee? If so, may I meet them before my first meeting?
- What kinds of recommendations or work does this group produce?
- How have advisors been involved with this group in the past?



Once Oriented, Team Members Should Be Able to Answer...

- What is quality improvement and what tools or methods are used to improve services in the organization?
- What are key safety concerns, terms, tools, and methods for improvement?
- What is the team trying to accomplish?
- What is my role on the team?
- How will we know that change is an improvement?
- Who is my main contact for ongoing support and assistance?



Supporting Meaningful Engagement of Patients and Family Members on the Team



During the Meeting

- Spend extra time on introductions at the beginning of a meeting, especially for new committees or new members.
- As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.
- Avoid using jargon. Explain technical terms when used.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- Acknowledge that there will be tensions and differing opinions and perceptions.



During the Meeting, cont'd

- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- If a personal story becomes very prolonged, acknowledge the power and importance of the story, suggest that some policy implications can be learned from the story and that there may be other appropriate forums where this story should be shared. *Tips for Group Leaders and Facilitators on*



Supporting Staff to Partner with Patients and Family Members on the Team



Changing Culture

“We are professionals with a license to practice. We don't need families to let us know if we do it wrong.”



“Collaboration means that no one interest group is always right. It means taking what you think and what I think, and what someone else thinks, and coming up with something that works for everyone.”


-B. Crider

From: *Essential Allies,
Families as Advisors*



“Patient engagement is a skill, not a trait.”

Institute of Medicine (IOM) 2013 Report, *Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement*

MEETING SUMMARY  AUGUST 2013

INSTITUTE OF MEDICINE
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For more information, visit iom.edu/partneringwithpatients

Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

In February 2013, the Institute of Medicine's Roundtable on Value & Science-Driven Health Care convened a workshop, gathering patients and experts in areas such as decision science, evidence generation, communication strategies, and health economics to consider the central roles for patients in bringing about progress in all aspects of the U.S. health care system. This Meeting Summary is being released in conjunction with a complete transcript of the event, the Workshop Proceedings. Over the course of 2 days, 31 speakers commented on the importance of patient and caregiver engagement in achieving the best care at lower cost.

The discussions highlighted the critical role and capacity for patients and families to be leaders in informed care decisions, knowledge generation, and value improvement.

Individual workshop participants identified a few overarching themes and messages.

Overarching themes and messages:

- **Culture dominates.** “Culture eats strategy for lunch every time,” as mom-turned-advocate Cristin Lind noted. Thus, improving the quality of the care experience and using limited resources wisely will require significant culture shifts.
- **“Listen first, listen fully.”** That’s what Ekene Obi-Okoye, a premedical intern at the University of California, San Francisco, learned as she supported patients with breast cancer. By listening first and listening fully, patient and caregiver voices are integrated fully into every possible level of decision making—care, system design, and policy making—and the quality of care improves.
- **Patient engagement is a skill, not a trait.** Being an engaged patient and actively engaging patients are not intuitive skills. Patients and clinicians learn these skills over time and through partnership with a supportive care team.
- **Trust matters.** Effectively delivering cost and quality information requires trusted translators who convey information in ways that are easy to understand.
- **Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.** Achieving and exceeding these three basic aims of health and health care policy calls for partnering with patients as leaders and drivers of care improvement.

INFORMED, SHARED CARE DECISIONS
A meaningful care experience is when the patient is fully informed and the provider has elicited the patient's preferences and goals.

Evidence strongly indicates that when patients are fully informed and engaged in making decisions about their care, patient satisfaction goes up, results improve, and health care costs go down, stated Gary Langer of Langer Research Associates and a number of other workshop participants. In pursuit of more- and higher-quality shared decision making, the first workshop session explored how to increase demand for shared decisions, as well as the changes in infrastructure, culture, and training that would be necessary.



Assist Staff in Understanding the Roles of Patients and Families

- Develop clear guidelines for the participation of patients and families and what can be asked of them.
- Help staff realize appropriate boundaries for patients, families, and staff.
- Offer suggestions and assist staff, patients, and families in dealing with conflicts.
- Be prepared to support staff who have been confronted by angry patients/families and are unprepared to deal with their angry feelings.
- Challenge them to identify opportunities to include patients and families in policy and program planning, implementation, and evaluation.



What Does Success Look Like?





Measuring Patient and Family Engagement and Its Impact



Elements of Partnerships

- Attitudes and beliefs (personal, unit, system)
- Behaviors (actions, words)
- Enablers and barriers (why we do it and why we don't)

**Perinatal Quality Collaborative
of
North Carolina**

**Patient and Family Engagement 2
Draft Outcome Measures**

Aim:

Create a multidisciplinary, hospital-based community that is focused on providing a standardized approach to, and building of support for, the recruitment, training, and engagement of patients and families with diverse perspectives as members of quality improvement teams by September 30, 2014.

Each facility will have a process in place for identifying patients/family members to assist with their improvement teams who represent their patient population

- Percentage of teams with an action plan for identifying patients/family members
- Number of patients/family members identified

Each facility will contact 3 patients/family members about assisting with their improvement efforts

- Number of patients/family members approached
- Demographic characteristics of patients/family members approached
- Number of patients/family members who agreed to participate
- Perceived barriers to participation

Each facility will have 1 patient/family member attend and meaningfully engage in each improvement team meeting

- Number of improvement team meetings held
- Number of patients/family members present at each meeting
- Percentage of attendees who felt the patient/family perspective was respected
- Percentage of attendees who believe patients/family members felt comfortable asking questions
- Percentage of attendees who felt patients/family members were properly prepared to participate
- Percentage of attendees who felt patient/family engagement was supported by team
- Percentage of PDSA cycles that were a product of patient/family feedback
- Percentage of PDSA cycles that included a task to be completed by patients/family members

Each facility will have a process in place for educating providers/staff regarding the importance of the patient/family perspective

- Percentage of teams with an action plan for educating providers/staff
- Mode of education
- Number of providers/staff members receiving education
- Percentage of teams using patients/family members as presenters
- Percentage of providers/staff reporting that the information received was useful
- Percentage of providers/staff reporting that they are likely to change their practice based on the education received



PFE2 Outcomes

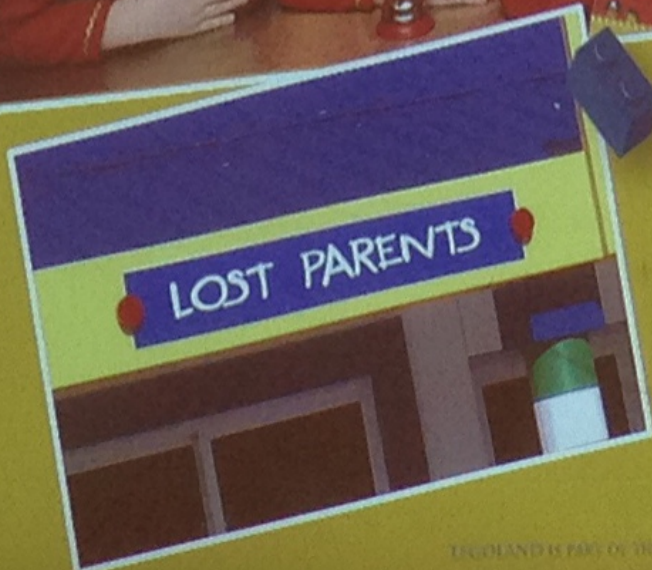
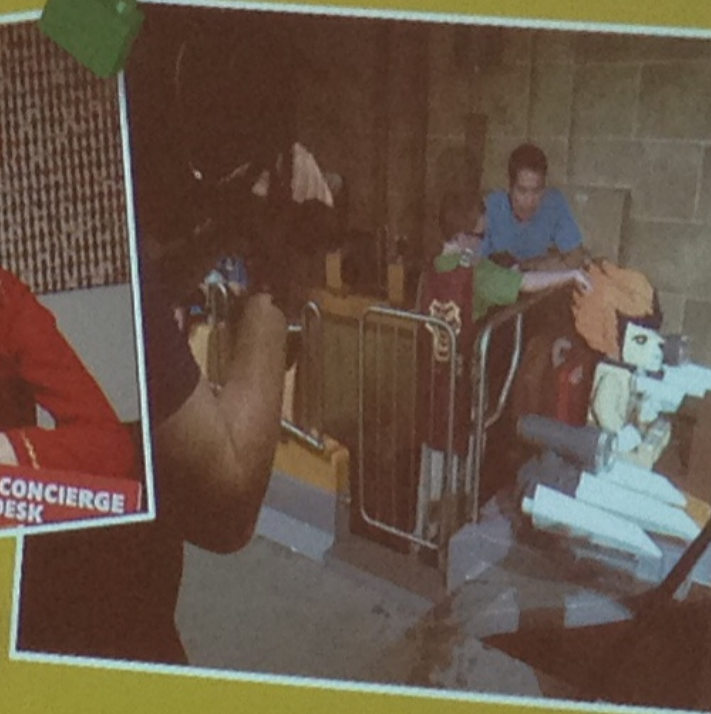


Reporting the Impact of Patient and Family Engagement





Involving Children...



- Junior Concierge's
- Child News Reporters
- Child signage

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