

**Children's Hospitals'**  
**Solutions for**  
**Patient Safety**  
Every patient. Every day.

# The Road to Eliminating Pediatric Harm:

Partnering with and Engaging Patients and Families



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## HOW TO USE THIS CHANGE PACKAGE

The Patient and Family Engagement Change Package was created for leaders, managers, and clinicians at hospitals who care for pediatric Medicare beneficiaries, especially those who work at hospitals that predominantly serve an adult population. Because engaging pediatric patients and their families is different from engaging adult patients and their families, hospitals for whom pediatric patients represent a minority may not have acquired the experience needed to engage this unique patient population.

The purpose of this change package is to provide these health care professionals with a high-level roadmap for improving patient and family engagement when caring for pediatric patients and a toolkit of resources to support this work. It is based on the experience of hospitals in the Solutions for Patient Safety network that have demonstrated expertise in this area. This change package presents their guidance, best practices, practical tools, and “pearls of wisdom” in a condensed, easy-to-use format. It contains a variety of suggestions and tools that can be used by leaders, managers, and clinicians to improve patient and family engagement when caring for pediatric populations in the inpatient setting.

The change package is organized into three levels: strategies, change concepts, and action steps. These are presented in the tables that follow. Specific resources and tools are listed with the relevant action step, either as hyperlinked URLs or as hard copies that are included in the Appendix. Together, these elements will help teams who care for pediatric patients more effectively engage patients and families to improve patient safety.

## MAGNITUDE OF THE PROBLEM AND WHY IT MATTERS

Great strides have been made in reducing harm related to pediatric inpatient care. For example, a control-comparison study covering three years of the SPS collaborative found a significantly lower incidence in 8 of 9 hospital acquired conditions (HACs) among the SPS network hospitals, compared with control hospitals, with decreases ranging from 9 percent to 71 percent ( $P < 0.005$  for all). (Lyren 2017) However, substantial variation exists in the rate of harm across hospitals that care for children. Among the first 78 hospitals to join SPS, those that adopted all the elements of the pressure injury active surveillance and prevention bundle and achieved 80 percent compliance with the bundle had significantly lower rates than SPS hospitals as a whole. (Frank 2017) Reducing this variation is an important safety goal. Partnering with and engaging patients and families is essential for preventing harm, reducing the variation in use of best practices, reducing the variation in harm rates, and ultimately reducing the rate of pediatric harm across the country.

At their best, hospital physicians and staff form meaningful, working relationships with patients and their families to deliver the highest quality of patient care. Patient activation has been shown to correlate with positive health outcomes. (Greene 2011) Patients and family members provide important information about the patient's past history, medication allergies, current condition, and other topics that are germane to patient safety. For example, one study of patient and family centered rounds in a pediatric setting found that more than half of patients and families initiated conversations about medication concerns. (Benjamin 2015) In eight percent of cases, clinicians were able to make critical adjustments to the medications to avoid potentially significant medical errors.

While anecdotal experience and common sense strongly support the effectiveness of patient and family engagement (PFE) in improving patient safety and outcomes, little research has been conducted to confirm and quantify this effect. (Cene 2016; Berger 2013) The I-PASS tools (a bundle of multidisciplinary, family-centered interventions) have been shown to significantly reduce preventable adverse events (AEs) from 8.2 per 100 admissions to 5.3 per 100 admissions. (Khan 2017a) Interestingly, non-preventable adverse events also decreased significantly after the intervention. Another study used family safety interviews to assess whether patients and families would report adverse events not otherwise identified. (Khan 2017b) A total of 113 adverse events were identified from all sources. Family reports included 8 otherwise unidentified AEs, including 7 preventable AEs. The event rates for family reports were similar to those of staff members, yet almost 3-fold higher than the rates captured by hospital incident reports.

Certain principles of PFE, such as respect and honesty, apply regardless of the age of the patient. However, several aspects of PFE in the pediatric patient population require additional consideration.

First, pediatric patients require a unique level of advocacy in the hospital setting because they typically have neither the legal agency nor the developmental ability to understand health information well enough to provide informed consent or protect themselves from errors. In fact, the majority of hospitalized children are infants less than one year of age (Weiss 2014). For this reason, parents and other caregivers are essential as advocates and sources of information.

Furthermore, parents and other caregivers are often knowledgeable about their children's conditions, observers of how their children are responding to treatment, and champions for their children when there are possible gaps in care or unrecognized concerns. Time and again, these family members intercept potential errors by providing critical history, making careful observations, asking good questions, and double-checking the care that is being provided. By the same token, when patients, parents, and other caregivers are given a voice at executive and key committee meetings, they can provide valuable insights that can help improve patient safety, care quality, and the patient experience.

The challenges unique to children are exacerbated when health disparities exist. Strategies (Harris 2017) known to reduce or mitigate the effects of health disparities, such as those that acknowledge differences in health literacy and language proficiency, are of paramount importance.

Second, hospitalized children are at higher risk of some types of medical errors than adults. This increased vulnerability is due to several factors. For example, the weights of children range from as little as a few hundred grams to over 100 kilograms, necessitating weight-based dosing, which is associated with a variety of potential errors. Infinite dosing possibilities mean that hospitals caring for pediatric patients must rely on individual dose preparation instead of using manufacturer-prepared unit doses, which is commonly the case in adult care. In addition, mathematical errors, such as factor of ten errors, are common, given the need to calculate the pediatric patient's dose for prescribing, verifying, dispensing, and administering medication. (Phillips SC)

Third, prevention of patient identification errors presents a unique challenge in children, and solutions may require engagement of parents and caregivers. Pediatric patients may also have unique risks for experiencing diagnostic error (Warrick 2014), and this risk appears to be higher in community hospitals than in children's hospitals (Matlow 2012). This increased risk of harm, as well as the need to robustly engage parents and other family members to assist in assuring their safety, are some of the reasons why hospitals must pay specific attention to pediatric PFE. (Singh 2009)

Health care providers must be skilled in forming effective partnerships with families at the bedside, and hospitals must have the resources to achieve reliable application of practices known to foster these partnerships (Dougherty 2014). Given the specific needs of pediatric patients—who may comprise a small proportion of the patients served at non-pediatric specialty hospitals—clinicians, staff, and leaders at these organizations are likely to benefit from additional tools and information to optimize bedside family partnerships for pediatric patients. This change package aims to provide the specialized tools and information needed to optimize PFE for pediatric patients.

#### **CURRENT DEFINITION:**

Patient and family engagement (PFE) has been defined as, "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care." (Carman 2013) PFE is an important part of patient- and family-centered care that enables patients, families, clinicians, and staff to work collaboratively to improve the quality and safety of care. (AHRQ 2013)

Hospitals that care for pediatric Medicare beneficiaries but predominantly serve an adult population may not have the experience or resources necessary to optimize patient and family engagement given the special needs of pediatric patients and their families. This change package focuses on improving patient and family engagement when caring for pediatric patients in inpatient settings. It includes best practices from pediatric-only hospitals with special attention to implementation at hospitals that primarily serve adult patients. Some changes require intensive resource allocation, but most are applicable in resource-limited settings.

#### **About the Solutions for Patient Safety Learning Network**

Ohio Children's Hospitals' Solutions for Patient Safety (SPS) is a true learning network. Through a commitment by SPS members to the principle of "All Teach, All Learn" and to sharing knowledge, skills, and data transparently within the network, all participants move toward improvement. SPS members have created the largest data collection ever assembled that connects process specific reliability to harm outcome rates for pediatric patients. The network identifies best practices and then uses data to continuously refine and improve the standard for pediatric patients.

## MEASUREMENT STRATEGY

In contrast with some other improvement initiatives, the optimal measurement strategy for PFE is not yet clear. Patient and family satisfaction can be evaluated via surveys, focus groups, and interviews, but satisfaction and engagement, though interrelated, are not the same. Organizations embarking on the journey to improve PFE should consider using a portfolio of measures to assess their progress over time. Patient and family satisfaction scores could be included in this package, but process measures should be included as well.

A suggested approach is to focus on the best practices that are highlighted in this change package and track the success or reliability of executing these practices. Such metrics might include yes/no “success” measures such as “Do we have patients and families represented on our board?” Others lend themselves to process reliability measurement. For example, “How often (what percentage of the time) do rounds occur at the bedside?”

When an organization begins to implement a specific practice, team members should set goals for implementation and explicitly measure their progress. The experience of many organizations engaged in quality and safety work has shown that measurement is a key factor in achieving improvement.

## EXISTING BUNDLES AND TOOLKITS

### Bundles and Toolkits for Improving PFE

- **National Center for Medical Home Implementation and American Academy of Pediatrics: Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnership in the Medical Home.**  
[https://medicalhomeinfo.aap.org/tools-resources/Documents/Positioning\\_FINAL\\_May24.pdf](https://medicalhomeinfo.aap.org/tools-resources/Documents/Positioning_FINAL_May24.pdf)
- **Agency for Healthcare Research and Quality (AHRQ): Patient and Family Engagement module of the Comprehensive Unit-based Safety Program (CUSP) Toolkit**  
<https://www.ahrq.gov/professionals/education/curriculum-tools/cusptoolkit/modules/patfamilyengagement/slpatfam.html>
- **Primary Care Collaborative: Patient Engagement Toolkit**  
<https://www.pcpcc.org/resource/patient-engagement-toolkit>
- **Patient and Family Advisory Council: Getting Started Toolkit**  
[https://c.ymcdn.com/sites/www.theberylinstitute.org/resource/resmgr/webinar\\_pdf/pfac\\_toolkit\\_shared\\_version.pdf](https://c.ymcdn.com/sites/www.theberylinstitute.org/resource/resmgr/webinar_pdf/pfac_toolkit_shared_version.pdf)
- **National Institute for Children's Health Quality: Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care**  
<https://www.nichq.org/resource/powerful-partnerships-handbook-families-and-providers-working-together-improve-care>
- **National Institute for Children's Health Quality: Creating a Patient and Family Advisory Council: A Toolkit for Pediatric Practices.**  
<https://www.nichq.org/resource/creating-patient-and-family-advisory-council-toolkit-pediatric-practices>

# PATIENT AND FAMILY ENGAGEMENT CHANGE PACKAGE

## Change package development

To begin, the change package development team conducted a literature review to identify the issues and national thought leaders in PFE. This information was used to identify selection criteria and to craft questions for the site visits. Next, the team used quantitative measures to select eight hospitals in the SPS network that were better performers in PFE and in reducing HACs; two that were relatively early in their efforts to improve PFE and six that were further along in the journey. The selection criteria included:

- **Transparency** – Hospitals must have agreed to transparently share outcomes data and information within the SPS network
- **Patient and Family Engagement** – Hospitals must meet the following:
  - Patient/family member participants on hospital-wide quality committee
  - Patient/family member participants on board committee
  - At least three HAC/harm area teams include patient/family member participants
- **Culture Training** - Hospital must complete all in-person SPS network culture wave trainings, which include training on error prevention, leadership methods, and root cause analysis.
- **Engaged Senior Leadership** - CEO or top pediatric leader must of attended one of the following learning opportunities within SPS in past year and must have signed the annual commitment with SPS:
  - CEO/Top Pediatric Leader Convening
  - CEO/Top Pediatric Leader Webinar
  - SPS Board Training
- **Highly Reliable Processes** - Hospital must implement and measure SPS Prevention Bundle standard elements house-wide. Hospital's centerline must meet or be less than the aggregate SPS centerline, and its process reliability must be near or greater than 90 percent for core harm areas.

Of the eight hospitals selected, six care exclusively for children, and two treat both adults and children. One-day site visits were conducted between February 1, 2018 and April 10, 2018. Two or more members of the change package development team conducted each site visit. A standard set of questions was used to query interviewees. Questions specific to PFE included these, among others:

- Do you have a patient and family advisory council? If so, how does it affect bedside care?
- How are staff trained to engage patients and families?
- Does your organization conduct bedside rounds? Do patients and families participate?

The team also requested specific tools and resources that the site visit hospital had either developed or adapted from another sources. These tools and resources are listed within the change package, along with others identified by the change package development team.

## Key insights from site visits

The change package development team gleaned many important insights from site visits about the actions that high performing organizations take to engage patients and families, both at the individual patient level and at the organizational level. These hospitals prioritize PFE as an essential component of their organizational strategy. They made comments such as,

- “We invited [parents] to the table to help us get better.”
- “There are industries that have been engaging consumers for years to get their feedback on products and input on what can be improved. In health care we're behind, and there's a real need for [engagement] for us to be able to improve as a whole.”



- “When parents speak at our new hire orientation, it not only sends the message that the actual content of the story is important, but also that these people are on the agenda because we care about safety.”

Three features of PFE were especially prominent at these organizations. First, site visit participants described an authentic respect for families as having valuable insights and information about their child and their child’s care. One interviewee put it simply: “Sometimes parents are the experts.”

Second, site visit participants explained the ways in which they enabled effective and thoughtful communication with families at the bedside. While many parents and family members want to be deeply involved and have access to detailed information about their child’s care, there may be some information about risks or care that they do not want to know. Site visit participants emphasized the need to have explicit conversations with family members about how much information they wanted to have regarding potential harm. One interviewee said, “We asked families how much they want to know. Some said, ‘Don’t tell me I need to be a wingman responsible to report if something goes wrong.’” Another interviewee stated, “They don’t invite me into the cockpit to check their charts. I don’t want to be there. I want to trust that they’re doing their job. The idea that we’re going to build our parents into a system that helps us become highly reliable is outrageous.”

Finally, these organizations demonstrated meaningful engagement of families on committees, as advisors for projects, and in patient and family advisory councils (PFACs), not just “checking a box” to create a façade of PFE. They consider optimizing the entire patient experience as being essential and a prerequisite for engagement. One site visit participant stated, “Patient experience is everything the patient experiences from top to bottom. How do you open and close a phone conversation? How do you greet a customer? Do you put a smile on your face? Do you walk through the hallways looking at your cell phone? These are behaviors that would affect every single person that works in the organization, from the person who answers the phone in billing to the physician.” This attention to improving the entire patient experience, rather than focusing on the items reflected in patient surveys, was described by one interviewee: “It’s what’s in the meat of the comments in the HCAHPS surveys that gives us what we need to change and to work on.”

These organizations recognize the value of meaningful engagement, saying: “It’s been great to have a parent in the room during meetings. It’s been great to have [a parent’s] perspective because it makes us think differently.” And, “A parent being at the table, whether she speaks or not, whether she has an agenda or not, sends a powerful message and demonstrates what the patient’s team should look like on a regular basis.”

One parent, who was hired as a parent consultant at a site visit hospital, described the rewards of this level of engagement and her sense that her perspective as a parent was truly valued. “It so good to be able to put an eye on something, like the parking situation, and then be able to see the change accepted and valued. They really value my voice and a parent’s perspective on things.”

### **Strategies for improvement**

High-performing hospitals used four general strategies to develop meaningful PFE at the individual and organizational levels. These strategies, along with change concepts, action items, and relevant tools and resources are described in the tables that follow. For this change package, resources are materials that staff and leaders can read to gain further insights into a change concept or action item; tools are materials that staff and leaders can use to implement a change concept or action item.

Strategies for improving PFE:

1. Developing Meaningful Partnerships with Patients and Families for the Organization
2. Learning from Patients and Families
3. Partnering at the Bedside
4. Empowering Patients and Families to Voice Safety Concerns

## Strategy 1: Developing Meaningful Partnerships with Patients and Families for the Organization

**Please note:** Not all browsers support the links below. Try using Chrome or cut and paste the URL into your browser rather than clicking the link directly.

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>1. PFACs Are a Must Have</b></p> <p><i>Building standing, highly engaged patient and family advisory councils (PFACs).</i></p>	<ul style="list-style-type: none"> <li>• Seek potential members who have a passion for a particular topic and relevant experience (e.g., NICU)</li> <li>• Use specific criteria for selection and screening</li> <li>• Develop and provide training for patient and family volunteers on patient safety, how to collaborate, how to use their story to inform, and confidentiality</li> <li>• Seek diversity of PFAC members; consider partnering with a community group to solicit information from underrepresented populations</li> <li>• Consider developing multiple PFACs (e.g., an organization-wide PFAC or steering committee and one for each service line or department)</li> <li>• Convene an adolescent PFAC, facilitated by teen life specialist</li> <li>• Enable proactive engagement of PFAC (e.g., reviewing education materials before they are finalized)</li> <li>• Provide resources for PFACs to create or review bylaws, structure, strategic plan, and goals</li> <li>• Ensure that the outcome of agenda items are discussed in future PFAC meetings (i.e., closing the loop)</li> <li>• Consider term limits (e.g., 2 years). For PFAC members ending their term, identify ad-hoc committees, work groups, and other advisor roles to continue to harness their expertise and institutional knowledge</li> </ul>	<p><b>Tool:</b> Agency for Healthcare Research and Quality: Working with Patients and Families as Advisors <a href="https://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html">https://www.ahrq.gov/professionals/systems/hospital/engagingfamilies/strategy1/index.html</a> : includes a variety of downloadable tools such as sample orientation manual and sample confidentiality agreement</p> <p><b>Tool:</b> Description of specific selection and onboarding processes from a site visit</p> <p><b>Resource:</b> Patient Family Advisor Skills Exchange Preparation Program</p> <p><b>Resource:</b> Cook Children's. Parents as Partners Program <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Parents-as-Partners-Program_Cook.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Parents-as-Partners-Program_Cook.pdf</a></p> <p><b>Tool:</b> Position Description of a Family Advisory Council Advisor <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Advisory-Council-Member-Role-Description_Helen-DeVos.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Advisory-Council-Member-Role-Description_Helen-DeVos.pdf</a></p> <p><b>Tool:</b> Children's Hospital of New Orleans. PFAC Bylaws <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/PFAC-Bylaws_New-Orleans.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/PFAC-Bylaws_New-Orleans.pdf</a></p> <p><b>Resource:</b> Strategically Advancing Patient and Family Advisory Councils in New York State <a href="https://nyshealthfoundation.org/resource/strategically-advancing-patient-and-family-advisory-councils-in-new-york-state-hospitals/">https://nyshealthfoundation.org/resource/strategically-advancing-patient-and-family-advisory-councils-in-new-york-state-hospitals/</a></p> <p><b>Resource:</b> And Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils <a href="http://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf">http://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf</a></p> <p><b>Tool:</b> Rainbow Babies and Children's Hospital. Patient and Family Partnership Council (PFPC) Referral Form. <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/PF-Partnership-Council-Referral-Form_Rainbow.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/PF-Partnership-Council-Referral-Form_Rainbow.pdf</a></p> <p><b>Tool:</b> Rainbow Babies and Children's Hospital. Patient and Family Partner Family Service Description <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/PFP-Service-Description_Rainbow.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/PFP-Service-Description_Rainbow.pdf</a></p> <p><b>Tool:</b> Rainbow Babies and Children's Hospital. Patient and Family Partnership Council Toolkit <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/Patient-and-Family-Partnership-Council-Toolkit_Rainbow.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/Patient-and-Family-Partnership-Council-Toolkit_Rainbow.pdf</a></p> <p><b>Tool:</b> Rainbow Babies and Children's Hospital. Patient and Family Partnership Council Bylaws <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/PFP-Council-Bylaws_Rainbow.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/PFP-Council-Bylaws_Rainbow.pdf</a></p>

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>2. Partners Matter</b></p> <p><i>Prioritizing patient and family engagement.</i></p>	<ul style="list-style-type: none"> <li>• Ensure that patient and family engagement is a stated core value of the organization and that the care experience is considered a part of quality endeavors</li> <li>• Set clear expectations for all staff, interviewees, and new hires about behaviors related to patient and family engagement (i.e., “Be kind or work elsewhere.”)</li> <li>• Include stories showing the importance of patient and family engagement in executive meetings, staff orientation, and quality and safety training</li> <li>• During senior leader safety rounds, ensure that leaders ask:               <ul style="list-style-type: none"> <li>- “Do you have any safety concerns?”</li> <li>- “Do you know how to report a safety concern?”</li> </ul> </li> </ul>	<p><b>Tool:</b> People First framework (“<b>Know me, include me, empower me</b>”)</p> <p><b>Resource:</b> Agency for Healthcare Quality and Research: The Guide to Patient and Family Engagement: What Is It, and How Does It Benefit Our Hospital? <a href="https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/howtogetstarted/How_to_Use_Guide_Ldr_Slide_508.pptx">https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/howtogetstarted/How_to_Use_Guide_Ldr_Slide_508.pptx</a> Downloadable slide presentation for staff and leaders (<b>Please note: You must cut and paste this URL into your browser and the presentation will automatically download.</b>)</p> <p><b>Resource:</b> Health Research and Educational Trust: A Leadership Resource for Patient and Family Engagement Strategies <a href="http://www.hpoe.org/Reports-HPOE/Patient_Family_Engagement_2013.pdf">http://www.hpoe.org/Reports-HPOE/Patient_Family_Engagement_2013.pdf</a></p> <p><b>Tool:</b> Institute for Healthcare Improvement: Patient- and Family-Centered Care Organizational Self-Assessment Tool <a href="http://www.ihl.org/resources/Pages/Tools/PatientFamilyCenteredCareOrganizationalSelfAssessmentTool.aspx">http://www.ihl.org/resources/Pages/Tools/PatientFamilyCenteredCareOrganizationalSelfAssessmentTool.aspx</a></p> <p><b>Tool:</b> Solutions for Patient Safety. Bedside Toolkit <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Bedside-Toolkit_SPS.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Bedside-Toolkit_SPS.pdf</a></p> <p><b>Tool:</b> Solutions for Patient Safety. Organizational Toolkit <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Organizational-Toolkit_SPS.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Organizational-Toolkit_SPS.pdf</a></p>
<p><b>3. Set Expectations</b></p> <p><i>Ensuring clear alignment with frontline care</i></p>	<ul style="list-style-type: none"> <li>• Make explicit for frontline staff the connection between specific behaviors and patient and family engagement</li> <li>• To ensure consistency across the organization, develop standard work for engaging patients and families</li> <li>• Conduct leadership rounds for coaching staff on standard work</li> </ul>	

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>4. Sensitive Sharing</b></p> <p><i>Balancing organizational accountability with sensitivity when communicating about safety events.</i></p>	<ul style="list-style-type: none"> <li>• Ensure that leaders carefully consider how they communicate the potential for adverse events to occur to avoid making patients and families feel overwhelmed, burdened or frightened</li> <li>• Develop a process by which patients and families are asked about the level of detail they would like to know about safety issues and prevention (i.e., a conversation first, then educate to the desired level)</li> </ul>	<p><b>Resource:</b> NYU Winthrop Hospital Children's Medical Center. CA-UIT Key Card <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/CAUTI-Key-Card_Winthrop.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/CAUTI-Key-Card_Winthrop.pdf</a></p>
<p><b>5. Active Partnership</b></p> <p><i>Involving patients and families on the board, on organizational committees, and as advisors.</i></p>	<ul style="list-style-type: none"> <li>• Maintain a roster of volunteers with relevant information on experience to allow for optimal matching of a volunteer to a particular committee</li> <li>• Engage patients and families to observe and provide feedback on work processes such as bedside shift reporting</li> <li>• Consider including at least two patients or family members on each committee to provide camaraderie and lower barriers to full participation</li> <li>• Educate staff on the availability and effective use of patients and families for consultation on specific projects (e.g., layout of new pediatric emergency department, process for bedside nursing shift report)</li> </ul>	<p><b>Resource:</b> Institute for Patient- and Family-Centered Care. Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees And Task Forces <a href="http://www.ipfcc.org/resources/tipsforgroupleaders.pdf">http://www.ipfcc.org/resources/tipsforgroupleaders.pdf</a></p>
<p><b>6. Partner Support</b></p> <p><i>Creating peer-to-peer outreach or mentoring programs.</i></p>	<ul style="list-style-type: none"> <li>• Train parent volunteers to visit and provide support to parents currently facing complex diagnostic or technology issues</li> </ul>	<p><b>Tool:</b> Slide set showing parent stories and impact of care experience</p> <p><b>Tool:</b> Position Description of a Parent Mentor <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Position-Description-of-a-Parent-Mentor.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Position-Description-of-a-Parent-Mentor.pdf</a></p> <p><b>Tool:</b> PFCC Best Practices - Peer Support <a href="http://www.ipfcc.org/bestpractices/peer-support.html">http://www.ipfcc.org/bestpractices/peer-support.html</a></p>
<p><b>7. Partnership Impact</b></p> <p><i>Tracking the impact of partnering with patients and families.</i></p>	<ul style="list-style-type: none"> <li>• Review comments on Press-Ganey survey responses</li> <li>• Assess involvement on committees</li> </ul>	<p><b>Resource:</b> Beryl Institute: PFACs: Where's the Money? The Financial Impact on Hospitals <a href="https://www.theberylinstitute.org/page/PFACResearchReport?">https://www.theberylinstitute.org/page/PFACResearchReport?</a></p>

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>8. Learn with Others</b></p> <p><i>Learning best practices for partnering with patients and families.</i></p>	<ul style="list-style-type: none"> <li>Join networks and access learning opportunities with peer organizations to identify and share best practices in engaging patients and families</li> </ul>	<p><b>Resource:</b> Institute for Healthcare Improvement: Open School: online courses on person-centered care and patient safety <a href="http://www.ihl.org/education/IHIOpenSchool/courses/Pages/default.aspx">http://www.ihl.org/education/IHIOpenSchool/courses/Pages/default.aspx</a></p> <p><b>Resource:</b> Institute for Patient- and Family-Centered Care: training for leaders, clinicians and patient and family advisors <a href="http://www.ipfcc.org/services/training.html">http://www.ipfcc.org/services/training.html</a></p> <p><b>Resource:</b> PFCC.Connect <a href="https://pfcc.connect.ipfcc.org/home">https://pfcc.connect.ipfcc.org/home</a></p> <p><b>Resource:</b> Solutions for Patient Safety webinar video: Strategy and Tactics: The Imperative of Patient and Family Engagement in Safety <a href="https://www.youtube.com/watch?v=Zk-5b969OCc&amp;feature=youtu.be">https://www.youtube.com/watch?v=Zk-5b969OCc&amp;feature=youtu.be</a></p>

## Strategy 2: Learning from Patients and Families

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>1. A Seat at the Board</b></p> <p><i>Ensuring patients and families have a permanent voice at the board level</i></p>	<ul style="list-style-type: none"> <li>Develop a paid position for a parent at the senior board level; look to philanthropic sources if needed for funding</li> </ul>	<p><b>Tool:</b> Institute for Patient- and Family-Centered Care. Patient and Family Leaders in Paid Positions: Common Challenges — Effective Solutions <a href="http://www.ipfcc.org/resources/Paid_Positions.pdf">http://www.ipfcc.org/resources/Paid_Positions.pdf</a></p>
<p><b>2. Simulation Training</b></p> <p><i>Teaching behaviors that create meaningful connections with patients and families.</i></p>	<ul style="list-style-type: none"> <li>Solicit input from patients and families to create curriculum (e.g., focus groups)</li> <li>Enlist trained parents or actors to run through scenarios with staff and assess on ability to engage with parents</li> </ul>	<p><b>Tool:</b> Children's National Medical Center. Sample Hourly Rounding Simulation <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/Sample-Hourly-Rounding-Simulation_National.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/Sample-Hourly-Rounding-Simulation_National.pdf</a></p>

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>3. Patients and Families as Teachers</b></p> <p><i>Building new platforms for learning from patients and families</i></p>	<ul style="list-style-type: none"> <li>• Invite PFAC volunteers to speak at every new hire orientation, emphasizing the impact (positive or negative) that every employee has on the care experience</li> <li>• Create a burning platform for change by inviting patients and families to speak at annual CEO grand rounds about their experience</li> <li>• Ask patients and families to create a checklist of the characteristics of ideal family-centered rounds, assess teams on these items, and interview a sample of patients and families for feedback on the quality of rounds</li> </ul>	<p><b>Resource:</b> PFCC Best Practices - Partnerships in Interprofessional Education <a href="http://www.ipfcc.org/bestpractices/interprofessional-education.html">http://www.ipfcc.org/bestpractices/interprofessional-education.html</a></p> <p><b>Tool:</b> Rainbow Babies and Children's Hospital. Standard Operating Procedures for Patient and Family Storytelling. <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/Storytelling-SOPs_Rainbow.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/Storytelling-SOPs_Rainbow.pdf</a></p> <p><b>Tool:</b> Rainbow Babies and Children's Hospital. Patient Family Partner Program: Participation Request Form <a href="https://www.solutionsforpatientsafety.org/wp-content/uploads/PPF-Participation-Request-Form_Rainbow.pdf">https://www.solutionsforpatientsafety.org/wp-content/uploads/PPF-Participation-Request-Form_Rainbow.pdf</a></p>
<p><b>4. Get Feedback</b></p> <p><i>Using patient and family satisfaction surveys effectively</i></p>	<ul style="list-style-type: none"> <li>• Review results from patient satisfaction surveys (e.g., Press-Ganey) monthly and share results with staff at the unit level</li> </ul>	<p><b>Tool:</b> Randall Children's Hospital. Tool for reviewing Press-Ganey results each month <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Randall-Childrens-Press-Ganey-Tool-for-Review.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Randall-Childrens-Press-Ganey-Tool-for-Review.pdf</a></p> <p><b>Tool:</b> MUSC Children's Hospital. Patient and Family-Centered Care Dashboard <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Patient-and-Family-Centered-Care-Dashboard_MUSC.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Patient-and-Family-Centered-Care-Dashboard_MUSC.pdf</a></p>

### Strategy 3: Partnering at the Bedside

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>1. Know the Family</b></p> <p><i>Gathering information to be aware family composition.</i></p>	<ul style="list-style-type: none"> <li>• Ask, "Who is defined as family? Who can participate in rounds and discussions with staff?"</li> </ul>	

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>2. Let's Talk</b></p> <p><i>Engaging in frequent, effective communication with patients and families.</i></p>	<ul style="list-style-type: none"> <li>• Provide contact information and identifying photographs for care team members near white board in patient rooms (i.e., face sheet)</li> <li>• Train staff in communication skills, including active listening</li> <li>• Ensure availability of interpreters, including during bedside rounds</li> <li>• Use whiteboard in patient's room to ensure timely information is easily accessible to patient and family; include on white board:               <ul style="list-style-type: none"> <li>- Daily goals for patient</li> <li>- List of current medications</li> <li>- Planned diagnostic tests and consults</li> </ul> </li> <li>• Develop scripts for staff to ensure limit-setting related to safety is clearly communicated; ensure that scripts are reviewed by PFAC volunteers prior to use</li> </ul>	<p><b>Tool:</b> Helen DeVos template of tool with photos and names of care team</p> <p><b>Tool:</b> Interpretation applications on digital tablet</p> <p><b>Tool:</b> Script for nurse to set limit during medication administration</p> <p><b>Resource:</b> Cincinnati Children's Hospital. Whiteboard Communication: Partnering with Patients and Families <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Whiteboard-Communication_Cincinnati.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Whiteboard-Communication_Cincinnati.pdf</a></p>
<p><b>3. Invite Us In</b></p> <p><i>Setting expectations for patients and families.</i></p>	<ul style="list-style-type: none"> <li>• Provide welcome packet and video</li> <li>• Set expectations about care processes and about communication</li> <li>• Explicitly invite patients and families to share information about care and safety concerns</li> <li>• Explain to patients and families how to communicate with the care team</li> </ul>	<p><b>Tool:</b> Cincinnati Children's Hospital. Journey Map. <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Journey-Maps_Cincinnati.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Journey-Maps_Cincinnati.pdf</a></p> <p><b>Tool:</b> Cincinnati Children's Hospital. Be the Voice video. <a href="https://www.youtube.com/watch?v=cZ-ptsFLLqQ&amp;feature=youtu.be">https://www.youtube.com/watch?v=cZ-ptsFLLqQ&amp;feature=youtu.be</a></p> <p><b>Tool:</b> Pact cards</p> <p><b>Tool:</b> Cook Children's Hospital. Top 10 Things I Wish I Knew <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Top-10-Things-I-Wish-I-Knew_Cook.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Top-10-Things-I-Wish-I-Knew_Cook.pdf</a></p> <p><b>Tool:</b> Institute for Patient- and Family-Centered Care. Changing Hospital "Visiting" Policies and Practices: Supporting Family Presence and Participation <a href="http://www.ipfcc.org/resources/visiting.pdf">http://www.ipfcc.org/resources/visiting.pdf</a></p> <p><b>Resource:</b> PFCC Best Practices: Better Together—Partnering with Families <a href="http://www.ipfcc.org/bestpractices/better-together.html">http://www.ipfcc.org/bestpractices/better-together.html</a></p> <p><b>Tool:</b> MUSC Children's Hospital. Patient Safety Handbook <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Patient-Safety-Handbook_MUSC.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Patient-Safety-Handbook_MUSC.pdf</a></p>

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>4. Include Us</b></p> <p><i>Encouraging active involvement in care.</i></p>	<ul style="list-style-type: none"> <li>• Explicitly invite patients and families to participate in rounding</li> <li>• Ensure that all members of the immediate care team are present (e.g., bedside nurse); ideally invite others to attend (e.g., personnel from pharmacy, respiratory, and dietary)</li> <li>• Ensure presence of interpreter, if needed</li> <li>• Use technology to support rounding (e.g., calls on speaker phone, videocalling)</li> <li>• Whenever possible, schedule rounds within a narrow window (e.g., one hour rather than four) to accommodate parents</li> <li>• Set the expectation that nurses will round once an hour to check in and engage with patients and families</li> <li>• Assess for variations in the degree of engagement of nursing staff in rounds</li> <li>• Enable bedside reporting by nurses at change of shift</li> <li>• Train staff to use motivational interviewing – a collaborative, person-centered communication strategy that strengthens the client's own motivation to change – especially at discharge, and assess competency in using the technique</li> </ul>	<p><b>Tool:</b> Institute for Patient- and Family-Centered Care. Applying Patient- and Family-Centered Concepts to Bedside Pediatric Rounds <a href="http://www.ipfcc.org/resources/PH_RD_Applying_PFCC_Rounds_Pediatric.pdf">http://www.ipfcc.org/resources/PH_RD_Applying_PFCC_Rounds_Pediatric.pdf</a></p> <p><b>Tool:</b> Example for sign on door if parents want to join am rounds</p> <p><b>Tool:</b> Medical City Children's Hospital. Hourly Rounding Expectation and Required Elements <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Hourly-Rounding-Expectations_Medical-City.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Hourly-Rounding-Expectations_Medical-City.pdf</a></p> <p><b>Resource:</b> The Joint Commission Journal on Quality and Patient Safety. Making the Transition to Nursing Bedside Shift Reports <a href="http://www.jcrinc.com/assets/1/14/S1-JQPS-0612_wakefield.pdf">http://www.jcrinc.com/assets/1/14/S1-JQPS-0612_wakefield.pdf</a></p>



CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>5. Teach Us</b></p> <p><i>Educating patients and families about topics meaningful to them.</i></p>	<ul style="list-style-type: none"> <li>• Ensure that all patients and families receive education on hospital basics by patient services or a similar department or service line</li> <li>• Provide information in preferred language and at appropriate literacy level</li> <li>• Consider the health literacy level of patients and families when developing and providing education</li> <li>• Ensure consistency in education across the organization</li> <li>• Ensure that translation and interpreter services are easily accessible</li> <li>• Solicit input from patients and families when developing education tools and signage</li> <li>• Provide education on specific hospital acquired conditions</li> <li>• Educate patients and families about current medications and any medication changes</li> <li>• Facilitate consistent educational resources across the organization, through a shared online resource</li> <li>• Use Kamishibai cards (lean tool: K-cards) in rounding to assess staff performance</li> </ul>	<p><b>Tool:</b> Knowing Notes: specific family education on paper and video <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Knowing-Notes-Preoperative-Showering-Instructions.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Knowing-Notes-Preoperative-Showering-Instructions.pdf</a></p> <p><b>Tool:</b> Library referral to provide disease-specific information</p> <p><b>Tool:</b> Cook Children's. Medical notebook to organize information created for families by PFAC <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Medical-Notebook-by-PFAC_Cook.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Medical-Notebook-by-PFAC_Cook.pdf</a></p> <p><b>Tool:</b> Cook Children's. Use of pictures and color coding to help with medication administration after discharge <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Help-with-Medication-Administration_Cook.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Help-with-Medication-Administration_Cook.pdf</a></p> <p><b>Tool:</b> Brightly colored card listing medication list, purpose, and top side effects for use at the bedside and at home after discharge</p> <p><b>Tool:</b> Teach Back Toolkit <a href="http://www.ihl.org/resources/Pages/Tools/AlwaysUseTeachBack!.aspx">http://www.ihl.org/resources/Pages/Tools/AlwaysUseTeachBack!.aspx</a></p> <p><b>Tool:</b> Ask Me 3 <a href="http://www.npsf.org/?page=askme3">http://www.npsf.org/?page=askme3</a></p> <p><b>Tool:</b> Article on use of K cards at Helen DeVos Children's Hospital <a href="http://www.solutionsforpatientsafety.org/how-helen-devos-childrens-hospital-created-a-fantastic-and-influential-approach-for-the-clabsi-prevention-bundle-using-a-lean-tool/">http://www.solutionsforpatientsafety.org/how-helen-devos-childrens-hospital-created-a-fantastic-and-influential-approach-for-the-clabsi-prevention-bundle-using-a-lean-tool/</a></p>
<p><b>6. Be Aware</b></p> <p><i>Addressing unconscious biases.</i></p>	<ul style="list-style-type: none"> <li>• Provide diversity sensitivity training for staff to raise awareness of unconscious biases to avoid negative impact on patient and family engagement</li> </ul>	<p><b>Tool:</b> Nationwide Children's. The Cost of Poverty. <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Cost-of-Poverty-Experience_Nationwide.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Cost-of-Poverty-Experience_Nationwide.pdf</a></p>
<p><b>7. Home Safe</b></p> <p><i>Using an effective discharge planning process.</i></p>	<ul style="list-style-type: none"> <li>• Review discharge instructions in detail</li> <li>• Start planning for discharge as soon as appropriate by teaching during hospitalization</li> <li>• Develop system by which there is a direct connection between the discharging clinician and the primary care provider (i.e., a "warm handoff")</li> </ul>	<p><b>Tool:</b> Agency for Healthcare Quality and Research: RED (Re-Engineered Discharge) toolkit <a href="http://www.ahrq.gov/professionals/systems/hospital/red/toolkit/index.html">http://www.ahrq.gov/professionals/systems/hospital/red/toolkit/index.html</a></p>

## Strategy 4: Empowering Patients and Families to Voice Safety Concerns in Real Time

CHANGE CONCEPTS	ACTION ITEMS	TOOLS AND RESOURCES
<p><b>1. When We Are Worried</b></p> <p><i>Delivering clear information on communication processes for concerns.</i></p>	<ul style="list-style-type: none"> <li>At admission, provide verbal information and video on the composition of the care team and who to contact for various levels of concern</li> </ul>	<p><b>Tool:</b> Videos on Get Well Network <a href="https://www.getwellnetwork.com/">https://www.getwellnetwork.com/</a></p> <p><b>Resource:</b> Batz Guides <a href="http://www.louisebatz.org/">http://www.louisebatz.org/</a></p>
<p><b>2. Rapid Response Team</b></p> <p><i>Empowering patients and families to voice and escalate safety concerns in real time.</i></p>	<ul style="list-style-type: none"> <li>Explain how to contact the medical response team for help and concerns</li> </ul>	<p><b>Resource and tools:</b> Josie King Foundation. Condition H (Condition Help) <a href="http://josieking.org/programs/condition-help-condition-h/">http://josieking.org/programs/condition-help-condition-h/</a></p> <p><b>Resource:</b> Institute for Healthcare Improvement: How-to guide for deploying rapid response teams <a href="http://www.ihl.org/knowledge/Pages/Tools/">http://www.ihl.org/knowledge/Pages/Tools/</a></p> <p><b>Tool:</b> The Hospital for Sick Children. Pamphlet of Keeping Your Child Safe <a href="http://www.solutionsforpatientsafety.org/wp-content/uploads/Sick_Kids_Safety_Pamphlet.pdf">http://www.solutionsforpatientsafety.org/wp-content/uploads/Sick_Kids_Safety_Pamphlet.pdf</a></p>
<p><b>3. Help Us Speak Up</b></p> <p><i>Making it easy to share concerns</i></p>	<ul style="list-style-type: none"> <li>Invite patients and families to share concerns during bedside rounds</li> <li>Clearly explain use of the call light</li> <li>Develop a mechanism by which patients and families can call a number to access a supervisor if they have concerns that are not being addressed</li> </ul>	

## ACTION PLANNING

Take action. Effectively implementing the strategies in this change package requires a basic capability in improvement science. If your organization or team does not yet have the relevant knowledge and skills, take the time to acquire them or collaborate with others in your organization that have this expertise.

There are many ways to approach implementing this change package and the one most likely to be effective will depend on the existing organizational culture, the size and components of the organization, the degree of engagement of executive and board leaders, and past experience with PFE. However, these basic steps should be part of any initiative to improve PFE:

- Ensure leadership engagement
- Assemble a multidisciplinary team
- Support staff through efforts to improve staff satisfaction and increase their capacity to engage patients and families
- Review metrics regularly to monitor progress
- Communicate effectively across the organization

**Address barriers.** Effectively engaging patients and families to improve patient safety requires that health care leaders and staff recognize potential barriers and proactively address them.

According to the Lucian Leape Institute, some of the barriers to PFE include: (LLI 2014)

- Health literacy issues
- Fear of retribution from health care professionals
- Inefficient workflow design
- Lack of effective tools and training
- Lack of executive and board leadership for safety
- Lack of a safety culture

Likely the most potent barrier to improving PFE is leadership that is not engaged or does not prioritize a focus on PFE, because it affects every item on the list of potential barriers. Leaders are critical in creating and maintaining a safety culture, prioritizing workflow re-design, and allocating resources toward staff training on PFE, including how to effectively engage patients and families with limited health literacy.

Supporting the importance of leadership in improving PFE, a report published by the Canadian Foundation for Healthcare Improvement stated, "In the face of growing pressures to increase productivity and improve safety and quality of care, many health care managers and clinicians do not see efforts to change practice toward patient-centered approaches as a priority. Patient engagement to improve patient-centered care at clinical, organizational and system levels appears less pressing than other system goals." (Baker 2014) Only when leaders make visible the high priority of PFE will managers and clinicians adopt the attitudes and behaviors that enable full engagement of patients and families in their care.

## CONCLUSION

Patient and family engagement is an essential lever for advancing patient safety. PFE requires a different approach when working with pediatric rather than adult patients, in part because of the dependence of children on their parents or caregivers for advocacy and decision-making. Pediatric populations are at higher risk for certain harms, such as medication errors because of the need for weight-based calculation of dosage, and the engagement of patients and families is especially important to reduce the risk of harm.

This change package offers to hospitals that treat pediatric patients strategies and best practices to optimize PFE. Because the steps in the change package are gleaned from high performing institutions, they offer real-world suggestions for better engaging patients and families to improve patient safety. While the change package includes many specific suggestions from these hospitals, four overarching principles emerged as extremely important: ensure patients and families are engaged in meaningful ways within the organization (not just “paying lip service” to the idea of engagement); build processes that allow clinicians, managers, and leaders to learn from the experience of patients and families; develop ways to actively partner with patients and families at the bedside; and create mechanisms that enable patients and families to readily voice any safety concerns.

These strategies—and the associated action steps—take time, resources, focus, and commitment to implement effectively. Top leadership must be engaged in this work and must set optimizing PFE as an organizational priority. The experience of hospitals within the SPS network is that such efforts are achievable and are well worth the required effort. This change package offers a roadmap for hospitals that care for pediatric patients to optimize PFE and improve patient safety.

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## APPENDIX