Priorities for Pediatric Patient Safety Research

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BACKGROUND: Developing a research agenda that is focused on the priorities of key stakeholders may expedite implementation and dissemination. Our objective was to identify the highest-priority patient-safety research topics among pediatric clinicians, health care leaders, and families.

METHODS: The Children’s Hospitals Solutions for Patient Safety Network is a network of >100 children’s hospitals working together to eliminate harm due to health care. Parents and site leaders responded to an open-ended, anonymous e-mail survey used to elicit research topics. A key stakeholder panel winnowed related topics and prioritized topics using Likert scale ratings. Site leaders and parents responded to a second anonymous e-mail survey and rated the importance of each topic. Health system executive interviews were used to elicit their opinions regarding top priorities for patient-safety research.

RESULTS: The elicitation survey had 107 respondents who produced 49 unique research topics. The key stakeholder panel developed a final list of 24 topics. The prioritization survey had 74 respondents. Top-priority research topics concerned high reliability, safety culture, open communication, and early detection of patient deterioration and sepsis. During 7 qualitative interviews, health system executives highlighted diagnostic error, medication safety, deterioration, and ambulatory patient safety as priority areas.

CONCLUSIONS: With this study, we take a first step toward a stakeholder-driven research agenda on the basis of the assumption that stakeholders are best positioned to determine what research will be used to address the problems of most concern to them.

WHAT’S KNOWN ON THIS SUBJECT: Focusing on the priorities of key stakeholders may expedite research implementation and dissemination. An expert panel of physicians, researchers, and policy makers defined World Health Organization priorities for patient safety. Patients and clinicians participated in research prioritization in other fields.

WHAT THIS STUDY ADDS: Parents, clinicians, and health system leaders from a network of >100 health systems proposed and prioritized pediatric patient-safety research topics. Top-priority topics included high reliability, safety culture, open communication, and early detection of patient deterioration and sepsis.

Over the last several decades, multiple factors, including policy changes, new regulations, and societal pressures have converged to increase attention on patient safety. The results of these efforts are decidedly mixed, yet clear examples of defined success exist.\textsuperscript{1–3} For example, the Agency for Healthcare Research and Quality (AHRQ) scorecard on hospital-acquired conditions (HACs) reveals a 17% decrease in HACs when 2014 rates are compared with 2010 rates, and HACs further decreased by 8% when 2016 data were compared with 2014 data.\textsuperscript{4} The Children’s Hospitals Solutions for Patient Safety Network (SPS) is a network of >130 children’s hospitals, grounded in learning health system concepts, working together to eliminate harm due to health care.\textsuperscript{5–7} Despite the SPS demonstrating a clear reduction in HACs for children who are hospitalized, other data sources have revealed no significant change in the rate of harm from medical error in hospitals.\textsuperscript{8,9} However, our ability to identify and quantify adverse events and preventable adverse events continues to improve.\textsuperscript{10–12}

The current state of patient-safety efforts and opportunities to accelerate improvement was recently reviewed by the National Patient Safety Foundation. In the report, the authors noted the importance of a total systems safety approach as compared with the current approach that is focused on improvements centered on eliminating a specific harm. In addition, the need for additional funding for patient-safety research and implementation science was noted.\textsuperscript{13} Given the limited resources available to further advance patient safety, prioritization of research efforts is essential to maximize reduction in harm across the largest possible population. More than 10 years ago, the World Health Organization sponsored the development of international priorities in patient-safety research for developed, transitional, and developing countries using an expert consensus process, and more recently, the World Health Organization completed a prioritization effort focused on primary care.\textsuperscript{14} Research priorities are also indicated by the major funders of patient-safety research. In recent years, the AHRQ has focused on topics such as patient safety in ambulatory care settings and the safety of health information technology.\textsuperscript{15}

Research priorities for patient safety in pediatrics have not been studied. Children have different needs to ensure that their health care is safe (eg, weight-based medication dosing).\textsuperscript{16,17} There may be unique priorities for patient-safety research in pediatrics that differ from broader priorities. As an example of a learning health system that deliberately integrates quality improvement and research within a community of engaged patients, clinicians, and health system executives, SPS is uniquely positioned to identify patient-safety research priorities.\textsuperscript{18} Our objective was to identify the highest-priority patient-safety research topics among clinicians, health care system leaders, and families of pediatric patients.

**METHODS**

We used consensus development methods to elicit and prioritize pediatric patient-safety research topics. Specifically, we conducted a survey to elicit topics, convened a stakeholder panel to winnow and prioritize the elicited topics, and conducted a second survey to obtain importance ratings for each topic. The process concluded with a set of health system executive interviews that were done to receive feedback on the final list of research topics. The project was approved by Cincinnati Children’s Hospital Medical Center’s Institutional Review Board (protocol 2015-3522; waiver of consent granted).

**Setting and Participants**

As a group, SPS hospitals care for 50% of all children who are hospitalized annually. To realize the shared vision of eliminating harm to children caused by health care, each participating institution in SPS is committed to the guiding principles of the Institute for Healthcare Improvement’s Breakthrough Series approach: (1) transparency of outcomes, (2) data sharing, (3) an “all teach, all learn” culture of open sharing of successes and failures in implementing recommended strategies, (4) agreement not to compete on safety, and (5) commitment from senior leadership to the work. By using these methods, SPS has seen a significant decline in stage 3 and 4 pressure injuries and a reduction in surgical site infection rates.\textsuperscript{19,20} Similar outcomes have been seen in several other forms of preventable harm,\textsuperscript{9} with significant harm reduction occurring in central-line–associated bloodstream infections, adverse drug events, falls, and ventilator-associated pneumonia. With the participation of many US pediatric health-system leaders, SPS is in a unique position to elicit and prioritize pediatric patient-safety research priorities.

Using SPS e-mail listservs, we sent invitations to site leads at each participating SPS hospital. To invite parents, we e-mailed 20 invitations using listservs that included parent advisory groups and parents. These were used by parents to communicate about research and clinical care of children with chronic conditions. We employed snowball sampling, asking participants (parents and SPS leaders) to forward our invitational e-mail and survey link to interested colleagues, friends, and parents. Efforts to improve response rates...
Elicitation Survey

Parent and health system leader surveys were developed to elicit safety research topics. We piloted questionnaires with parents and health system leaders to ensure clarity of topics and refined them on the basis of feedback. In response to parent feedback, we added a definition of patient safety (preventing harm to patients caused by medical care) and examples to the parent survey. This process generated a final 4-item questionnaire (Supplemental Information).

The SPS questionnaire included demographic questions about sex, age, and hospital role. The parent survey did not include any demographic questions. The elicitation questions were all open ended and worded as follows: “For children in the hospital, what is the most important and urgent learning opportunity for hospital staff regarding patient safety? What information do you think is needed to make healthcare safer for patients in the hospital?” Two additional questions were asked, replacing the word “hospital” with (1) “emergency department” and (2) “outpatient clinic” or “doctor’s office.” In the final question, participants were asked, “Are there any additional urgent learnings that you would like clinical staff to have in order to improve patient safety for children?”

The elicitation survey was first sent in July 2015, with 2 reminder e-mails sent before data collection ended in August 2015.

Research Topic Review Process

Two members of the research team, a physician safety researcher (K.E.W.) and a quality improvement coordinator (S.W.), grouped identical topics. To do this, we used card sorting, in which each response was placed on an index card, and K.E.W. and S.W. independently grouped responses that were considered identical. K.E.W. and S.W. then met and came to a consensus through discussion. In cases in which K.E.W. and S.W. were unable to come to a consensus, a panel of 6 individuals (see below) made the final decision about whether these responses were independent or grouped responses. For example: “high reliability” and “identify methods to develop a highly reliable healthcare system” were grouped into a single “high reliability healthcare” topic. Longer stories or comments included by respondents were left as is for the stakeholder panel to discuss during a teleconference (eg, “Direct room vitals and checking in insurance in the ER. NO TRAUMA BAY. Keep CF kids on CF floor and let other specialty come to them.”)

A panel of 6 individuals (the parent of a child with a chronic disease [E.M.], a physician health system leader [E.S.], a nurse leader and safety researcher [H.L.T.-C.], a pharmacist patient-safety leader [J.M.H.], and a quality improvement consultant [E.O.]), met to clarify the wording of each topic elicited by the survey. Each member of the panel also rated the topics using a Likert-type item from 1 (no direct impact on patient-safety outcomes) to 10 (extremely high impact on patient-safety outcomes). This was done to narrow the list of elicited topics to a manageable number that could be prioritized by a large and diverse sample of patient-safety stakeholders. The Likert scores were averaged to create a rank order. The panel used this ranking to narrow the list by leaving only the top 24 ranked items (3-way tie for the 25th spot).

Prioritization Survey

Using the final list of topics from the stakeholder panel, we developed a second consensus survey. Respondents answered 4 questions about their sex, their age, their role in their organization, and whether they answered the previous survey. Respondents used 5-point Likert-type items (very important [5], between very and somewhat important [4], somewhat important [3], between somewhat and not important [2], or not important [1]) to rate each topic. The topics were treated as interval-level data and then ordered from highest to lowest average Likert score. The prioritization survey was first sent in March 2016, with 2 reminder e-mails sent before the survey was closed in July 2016.

Health System Executive Interviews

We interviewed health system executives who were stakeholders for patient-safety research (eg, vice president for safety or chief medical officer) for their perspectives on the priorities identified through the surveys. We selected a purposive sample of pediatric health system leaders to include both female and male nurse and physician leaders from throughout the country and larger and smaller health systems. An introductory e-mail from a member of the SPS research and publications committee (K.E.W.) was used to facilitate the selection of appropriate hospital executives. The semistructured interview guide was used to ask for their reflections on the importance and usefulness of the prioritized topics for their institution and for children’s hospitals in general. A copy of the topics was e-mailed to the participants for review before the interview. Executives were also asked to elaborate on research priorities.
beyond those listed in the top 24 that were used in the elicitation survey. This might include topics considered important by participants or those currently being worked on at the participants’ institutions that were missing from the list. Interviews took place between September 2016 and December 2016.

A single pediatric safety researcher (K.E.W.) conducted interviews by telephone. A total of 7 senior administrators in 7 unique hospitals were interviewed, including nurse executive leaders, physician executive leaders, and nonclinician executive leaders. The diversity of this group represented a suitable convenience sample for this study. Interviews lasted ~30 minutes; participants were not offered any honorarium. Interviews were recorded and transcribed for analysis; field notes were also used. Two authors (J.M.H. and N.J.K.) performed an inductive content analysis of the transcripts using techniques from the constant comparative method.

RESULTS

There were 107 respondents to the elicitation survey; almost half were parents (46%), 18% were nonclinical quality improvement experts, 15% were physicians, 14% were nurses, 5% were patient-safety researchers, and 2% were pharmacists. Respondents came from 22 states and 48 different health systems (Fig 1). Respondents suggested a total of 167 research topics. Removal of duplicates yielded 49 unique topics. The key stakeholder panel further grouped and reduced the number of topics, and the top 24 topics were chosen for inclusion in the prioritization survey. There were 74 respondents to the prioritization survey, with at least 51 respondents rating all top 24 research priorities. Thirty percent responded to the first survey as well. The sex and age breakdown of the respondents was similar between the first and second survey (Table 1). A larger proportion (81% total) of respondents to the second survey were health system employees.

Respondents (both health system employees and parents) to the prioritization survey rated safety

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**TABLE 1** SPS Pediatric Safety Research Prioritization Survey Respondent Demographics

<table>
<thead>
<tr>
<th>Role</th>
<th>Elicitation Survey, N = 107</th>
<th>Prioritization Survey, N = 74</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse leader</td>
<td>14 (14)</td>
<td>12 (16)</td>
</tr>
<tr>
<td>Physician leader</td>
<td>16 (15)</td>
<td>30 (22)</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2 (2)</td>
<td>2 (3)</td>
</tr>
<tr>
<td>Patient-safety researcher</td>
<td>5 (5)</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Parent</td>
<td>48 (46)</td>
<td>14 (19)</td>
</tr>
<tr>
<td>Nonclinical QI leader</td>
<td>18 (18)</td>
<td>25 (34)</td>
</tr>
<tr>
<td>Female sex</td>
<td>38 (68% of 58 who reported sex)</td>
<td>55 (79% of 70 who reported sex)</td>
</tr>
<tr>
<td>Age, y, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–30</td>
<td>4 (13)</td>
<td>5 (7)</td>
</tr>
<tr>
<td>31–64</td>
<td>50 (89)</td>
<td>61 (88)</td>
</tr>
<tr>
<td>≥65</td>
<td>2 (9)</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Responded to open ended survey?</td>
<td>Not applicable</td>
<td>22 (30%)</td>
</tr>
</tbody>
</table>

QI, quality improvement.

* Some respondents selected >1 role.
events that impacted all types of harm the highest, including how to achieve high reliability (mean: 4.57; \( n = 53 \)), how to achieve a culture of safety (mean: 4.44; \( n = 54 \)), and developing processes and methods to ensure open communication between families, doctors, and other health care workers (mean: 4.40; \( n = 54 \); Table 2). Early warning systems to improve the speed and accuracy of detection of sepsis (mean: 4.38; \( n = 52 \)) and patient deterioration (mean: 4.43; \( n = 52 \)) were also highly ranked. Medication safety topics and diagnostic errors and delays also fell in the top 10 research topics. When examining parent responses separately, early detection of patient deterioration, open communication, medication reconciliation, and recognition of sepsis were highlighted as important topics.

Four topics were mentioned by at least 3 health system executives as particularly important. These included patient deterioration and early warning, diagnostic errors and delays, medication safety and medication reconciliation, and outpatient safety (Table 3). A few respondents felt that the list included some topics that had already been addressed at their institution and had become opportunities for broader implementation and dissemination rather than new discovery.

Communication was specifically mentioned in several items on the prioritization topic list, and respondents found that other priorities revealed the implicit importance of communication. For example, 1 respondent stated, “I felt like there was a theme of communication and using different communication strategies…we’d have to figure [out] actually what are those strategies that we would test, or what the researchers would want to hone that down to. We talk about it all the time.” Related to high reliability, some interviewees discussed a change in focus from ensuring that as little as possible goes wrong
(“Safety I”) to ensuring that as much as possible goes right ("Safety II"). Health system executives referred to the emerging concept of Safety II to extend and clarify differences by respondents on the basis of the maturity of their patient-safety work. Those health systems that are early on in efforts to improve patient safety should focus on Safety I whereas those that have succeeded in beginning to improve safety may need to shift to Safety II to further reduce harm.

**DISCUSSION**

Within the nation’s largest network devoted to improving the safety of pediatric health care, we used consensus development methods that involved parents, clinicians, quality improvement leaders, and health system executives to identify top priorities for patient-safety research in children. Our methods involved participants from 25 states, with respondents from 48 health systems participating. Priority topics included high-reliability health care, a patient-safety culture, early warning systems for patient deterioration, and open communication between clinicians.
High reliability, the top-rated priority, is garnering significant attention within the patient-safety community. Embracing the techniques of high-reliability organizations (HROs) requires deep leadership commitment and often a culture change to embed practices, such as preoccupation with failure, sensitivity to operations, and commitment to resilience, into the organization. As high-reliability concepts emerge in health care, researchers can advance these efforts by determining the specific actions needed and developing validated measurement tools to evaluate progress. Some experiences implementing and evaluating practices that support high reliability are emerging. One tool to measure progress toward HRO practices was recently evaluated in US Department of Veteran’s Affairs hospitals, but no similar studies have been done in pediatric settings. Creating a culture of safety is connected to establishing HRO principles. It also fell into the top 5 research topics from the final survey. Creating a culture of safety is an essential priority for health care leaders and can have many benefits because research indicates a relationship between teamwork, engagement, burnout, willingness to report patient-safety events, and other aspects of patient safety. Additionally, parents and patients indicate that if communication and teamwork with families are poor, they are less likely to report unsafe care to their providers or health care system. A variety of measurement tools for a safety culture are well established and used widely. However, using these data to improve care can be complex. Experiences in which patient-safety culture data are used to guide improvements, including reduction in patient harm, are emerging in pediatric health care settings.

Other highly rated topics include predicting clinical deterioration and early detection of sepsis. Evidence for the value of early warning systems in children who are hospitalized is accumulating, but substantial variation exists in the performance of these systems. Two recent systematic reviews revealed the need for additional research. One challenge is defining a meaningful outcome measure because mortality outside of the PICU is a rare event in children who are hospitalized. More easily measured and frequently occurring events may not be clinically important or clearly related to the early warning scoring system. Measures that provide a meaningful aggregate associated with mortality, such as critical deterioration, will be used to facilitate useful research in this area.

Communication failure, one of the root causes of many different types of serious safety events, was mentioned in several of the top-priority research topics and also as an underlying theme by health system executives in interviews. Robust evidence for specific methods to enhance communication, such as the use of the I-PASS (illness severity, patient summary, action list, situational awareness, synthesis by receiver) approach to improve handoffs, is emerging, but additional techniques could be developed, or I-PASS may be adapted across other communication contexts. Communication between health care workers and caregivers in the inpatient setting is beginning to be explored. In the outpatient setting, unsafe care can result from failures in communication between caregivers (such as 2 parents) at home or in other settings (such as school), between caregivers and clinicians and nurses, and between different health care workers in fragmented settings. Limited data are available on the diffusion of these safety practices across children’s hospitals. Some of the research priorities we identified may be opportunities to improve implementation and dissemination of existing evidence rather than a need to generate new evidence. On the basis of the interviews we conducted, some health system executives believed that topics on the list have already been solved at their own institutions, indicating that the focus for these topics should be on optimal approaches for dissemination. However, there is novelty to these findings because few of the 24 priorities are listed in an AHRQ evidence review of patient safety interventions that should be implemented immediately. Because this research was completed in the context of an established network, we can reengage the network in the future to evaluate how frequently these practices are in place in network hospitals and if they remain research priorities.

Parent respondents highlighted early detection of deterioration, improved communication, and medication reconciliation as important areas for research on patient safety. In each of these areas, parents may be the first or only members of the care team to identify an unsafe situation. There have been a few early studies used to harness parent insights regarding the detection of deterioration and caregiver medication use. Although parents were responsive to the elicitation survey, there were fewer parent respondents to the prioritization survey. We used the same procedures in both surveys to reach out to parents, using e-mails with a link to the survey to the same parent advisory groups and listservs for both surveys. When using an anonymous survey, it is not possible to know why response is lower for the second survey. Two possibilities we have considered are as follows: (1) parents thought they already responded to the survey the first time, so they didn’t open the second survey or (2) parents found
the shorter, 4-item, open-ended elicitation more palatable than the 24-item Likert-type questions in the second survey. Although parent responses to the prioritization survey were low, response to the elicitation survey by parents was excellent. Of the 24 topics on the final list, 8 were originally generated by parents.

Health system executives highlighted areas of safety research as being important to inform further reductions in harm due to health care. Diagnostic error and ambulatory patient safety are 2 emerging areas of patient safety in which executives believed research would be especially informative. In Patient Safety in Ambulatory Settings, the AHRQ highlighted 28 important areas in ambulatory safety, most of which were understudied.57 In a recent report on diagnostic error, the Institute of Medicine called for the development and deployment of methods to identify, learn from, and reduce diagnostic error.58

Health system leader interviews reveal the importance of patient safety in the outpatient setting as an emerging topic for research. The prioritized list produced by key stakeholders includes some topics that are the focus of ambulatory care, including medication reconciliation, reduction of vaccination errors, and reduced transmission of disease in waiting rooms. Other areas of research on the list are more relevant to inpatient safety, such as detection of clinical deterioration. In our study, we did not specifically seek input from outpatient or inpatient safety experts per se. However, the prioritized list may reflect the current field of patient safety, in which the vast majority of current epidemiological studies, intervention testing, and patient safety improvement work are focused on the inpatient setting.53

Some newer areas of health care with emerging patient-safety risks did not make the top research priorities. For example, the safety risks of genomic medicine, which is a rapidly developing field, were not mentioned in the consensus process. A recent exploratory study revealed that risks for error exist across the entire process.59 Genomics also presents an opportunity to improve safety, such as through the implementation of pharmacogenomics, which has evidence comparable with that of other safety interventions.60,61

Although we sampled a large number of key stakeholders using a variety of methods in this prioritization study, there are some limitations. Only 30% of respondents to the prioritization survey answered the elicitation survey; both sets of respondents were sampled by using identical methods from the same population. There was a noted drop between those respondents who started and those who completed the prioritization survey. The fact that this was not a forced response survey is a likely explanation.

We interviewed 7 health system executives; although this is a small number of executives, it did allow us to reach saturation. Finally, although using the existing SPS network allowed us access to a sample of health systems that cared for >50% of the nation’s children who were hospitalized, it might impact generalizability to other settings. For example, the SPS network has focused on patient safety in the inpatient setting, which may explain the relative paucity of prioritized topics related to ambulatory patient safety. This method was not used to identify all research topics, but this is a study specific to children’s health care.

Key stakeholders identified and prioritized research topics for pediatric patient safety. Stakeholders identified a need for research on specific topics, such as early warning systems and diagnostic error, but broad areas, such as communication and culture, were also identified. Research grounded in this stakeholder-driven agenda is needed to improve pediatric patient safety, which should ensure the success of new interventions implemented to reduce patient harm.

ABBREVIATIONS

AHRQ: Agency for Healthcare Research and Quality
HAC: hospital-acquired condition
HRO: high-reliability organization
SPS: Children’s Hospitals Solutions for Patient Safety Network
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