

## BRIEF REPORT

# Using Stakeholder Engagement to Develop a Hospital-Initiated, Patient-Centered Intervention to Improve Hospital-to-Home Transitions for Children With Asthma

Kavita Parikh, MD, MSHS, Pamela S. Hinds, PhD, RN, FAAN, Stephen J. Teach, MD, MPH

Stakeholder engagement is emerging as a tool for clinician investigators to learn from patients, families, and health professionals to better design and implement interventions that are responsive to patient and family needs and preferences. In this article, we demonstrate that multidisciplinary stakeholder engagement can meaningfully influence intervention design. We present a model of efficient yet substantive engagement of parents and health professionals in developing a hospital-to-home transition intervention for children hospitalized with asthma. We engaged parents during the acute hospitalization with one-on-one interviews, and we used one-on-one interviews and focus groups to engage key health professionals to facilitate meaningful engagement. We worked with a group of selected parent advisory council members (composed of parents of children with asthma) to refine the information gained from the parents and health professionals. We found that multidimensional stakeholder engagement can meaningfully shape intervention development, and we hope that these tools can be used or adapted to other hospital-based quality improvement, education, or research efforts.

## ABSTRACT

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Address correspondence to Kavita Parikh, MD, MSHS, Division of Hospital Medicine, Children's National Medical Center, 111 Michigan Ave NW, Suite 4800, Washington, DC 20010. E-mail: [kparikh@childrensnational.org](mailto:kparikh@childrensnational.org)

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*Children's National  
Medical Center,  
Washington, DC*

As part of the Affordable Care Act, the Patient-Centered Outcomes Research Institute was established in 2010 as an independent, nonprofit organization authorized by Congress to fund research that can help support patients and families to make well-informed decisions about their health care.<sup>1</sup> As health care providers, we know that our patients and their families face complex decisions, which are often confusing, and sometimes traditional research (despite remarkable advances) has not been able to answer many of the questions that patients and families want answered. Stakeholder engagement is emerging as a tool for clinician investigators to learn from patients and their families to better design and implement programs or interventions that are responsive to their needs and preferences.<sup>2,3</sup>

With funding from the Agency for Healthcare Research and Quality, we sought to develop and pilot an intervention to improve the hospital-to-home (H2H) transition for children hospitalized with asthma at Children's National Medical Center in Washington, DC. The prevalence of asthma among children <17 years of age is higher in Washington, DC (14%)<sup>4</sup> than nationwide (8.3%).<sup>5</sup> For patients hospitalized for an asthma exacerbation, admission and the transition from H2H are disruptive and stressful for the whole family; for example, patients miss school, and parents miss work.<sup>6</sup> In addition, the process of discharging a pediatric patient from an acute care facility is complex, and more than 20% of parents report problems in the transition from H2H.<sup>7</sup> Problems in discharge transition, stemming from poor communication or disjointed continuity of care, may culminate in adverse events, unscheduled emergency department visits, or readmissions.<sup>8</sup>

Reducing asthma-related hospitalizations hinges in part on improving care coordination.<sup>7</sup> History of asthma hospitalization in the past 12 months is the most significant independent predictor of early readmission.<sup>9</sup> Therefore, targeting patients who are hospitalized for an asthma

exacerbation can reduce future hospitalizations and reduce readmissions. Given the growing role of incorporating patient and family stakeholders in the development of scholarly questions, interventions, and outcomes,<sup>10-12</sup> we sought to engage families and other key health professional stakeholders in the development of an H2H transition intervention for children hospitalized with asthma at our hospital. In this Brief Report, using an example of asthma care coordination, we describe our process of stakeholder engagement as well as how this crucial and important input shaped our intervention. We found that multidimensional stakeholder engagement is feasible and can meaningfully shape intervention development, and we hope that these tools can be used or adapted to other hospital-based quality improvement, education, or research efforts.

## **METHODS: WHAT WE DID TO ENGAGE OUR STAKEHOLDERS**

Over a 6-month period (September 2016 to February 2017), our study team engaged families and health professionals involved in the care of children with asthma in the community we serve. In an earlier article, we detail the methods, interview tools, and analysis plans,<sup>13</sup> and in this current article, we highlight how we used this information to inform our intervention. Our engagement approach consisted of 3 approaches to provide input to the team regarding intervention design, which we outline below. Institutional review board approval was obtained by the committee at Children's National Medical Center.

### **Parent Engagement**

Parent engagement consisted of one-on-one interviews of parents during the inpatient stay for their child who was admitted with an asthma exacerbation. Interviews were done at the bedside on the inpatient unit. In previous work from our study team, we had shown an attrition of interested parents if they were asked to come back to the hospital after discharge for an interview or focus group.<sup>14</sup> Interviews were conducted with a semistructured interview guide, and the

interviews were recorded and transcribed and subsequently analyzed by using content analysis approach.

### **Health Professional Engagement**

Health professional engagement consisted of both one-on-one interviews as well as focus groups. On the basis of convenience, certain health professional groups, asthma educators, physicians (inpatient, outpatient, and specialist), and health payer interviews were conducted one-on-one. Payer interview was conducted over the phone, and all other health professional interviews or focus groups were done face-to-face. School nurses were interviewed in focus groups because this was preferred by them for convenience, and these focus groups were conducted at a local school. Again, interviews and focus groups were conducted with a semistructured interview guide that was adapted with learnings from previous interactions, and the interviews were recorded and transcribed and subsequently analyzed by using content analysis or descriptive thematic analysis.

### **Asthma Parent Advisory Council Meeting**

A single face-to-face meeting was conducted in the hospital during the evening to share our findings with an established asthma parent advisory council (PAC) and invite their feedback. This stakeholder engagement was used to provide further parent perspective and validation on the findings we had previously gathered from the early parent and health professional engagement. After this meeting, we continued to engage the parents through e-mail.

In our engagement plan, we used 2 key strategies that supported success: purposeful inclusion of diverse health care professionals and method flexibility. As a team, we identified the key stakeholders in the H2H transition for a child with asthma. Engaging parents was central to our effort, but we also sought to engage other key stakeholders, including physicians, nurses, educators, and insurance payers. To successfully gather feedback from these groups, we had to be flexible in our

research approach. For this reason, some interviews were conducted one-on-one, whereas others were focus groups.

### Key Findings

Although the specific results from our stakeholder engagement have been recently published,<sup>13</sup> we want to highlight the key findings in this Brief Report that directly supported our intervention development. We found that focused engagement strategies can provide invaluable insight into program design and execution, and we highlight 2 aspects of this work.

#### *Engagement of Families During the Hospitalization Is Feasible and Informative*

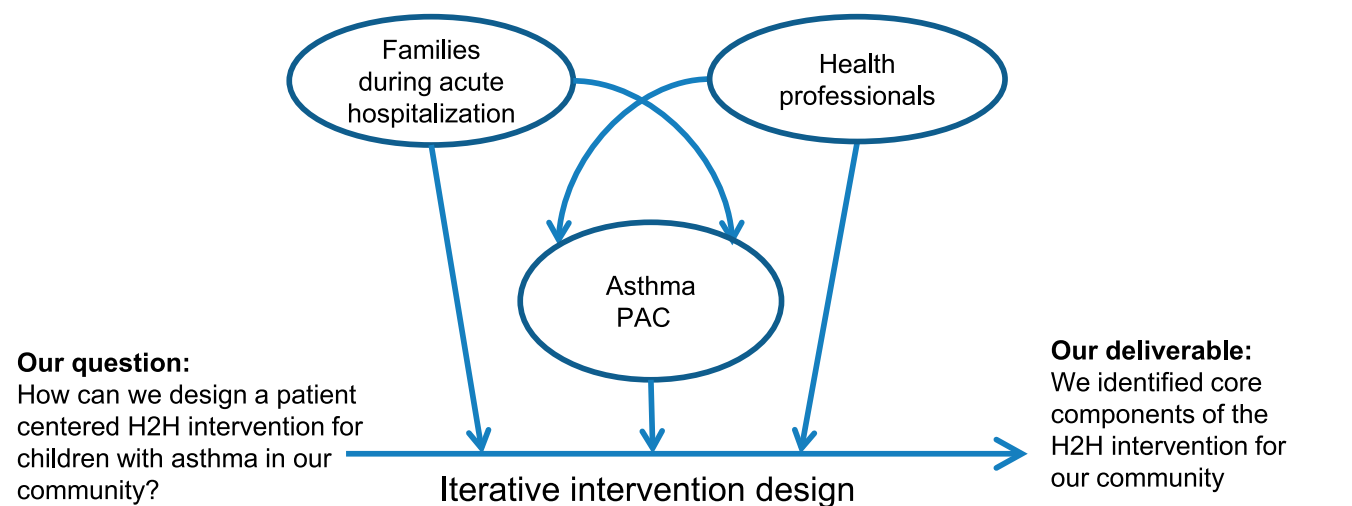
Although there are different approaches to family engagement, we found that approaching families while they are in the

hospital with a child with an acute illness is practical once the child is stabilized and improving. We found that as the child was recovering from his or her asthma exacerbation, parents were amenable to discussing barriers and facilitators for discharge. Despite the stressful and disruptive nature of hospitalization, they were receptive to speaking with us, with few disruptions or competing responsibilities, perhaps because they had often adjusted their schedule to be with their sick child. In addition, during the acute episode of hospitalization, families were eager to share with us how to improve the H2H transition and to avoid future asthma exacerbations, possibly because of the stress of experiencing their child's difficulty in breathing. Previous work at our institution has had varying success when parents were asked to return to the hospital for a focus

group,<sup>14</sup> even when compensation was provided, so this approach of engagement is encouraging.

#### *Multidimensional Stakeholder Engagement Can Meaningfully Support Program and Intervention Development. Engagement of Families During the Hospitalization Is Feasible and Informative*

Stakeholder engagement shaped our intervention in several ways (Fig 1). Through our parent engagement, we were able to uncover educational gaps in knowledge about asthma in terms of chronicity, activity limitation, and management of asthma.<sup>13</sup> After engaging with the school nurses, we identified clear gaps in communication between the school nurses and the care team and the negative impact of this communication void on the care of the child



Group	Description of Engagement	Core Component of the H2H Pilot Intervention
Parents	<ul style="list-style-type: none"> <li>One-on-one interviews with parents during the acute hospitalization</li> </ul>	<ul style="list-style-type: none"> <li>Addressing knowledge gaps or misconceptions</li> </ul>
	<ul style="list-style-type: none"> <li>Single meeting and continued communication with the asthma PAC</li> </ul>	<ul style="list-style-type: none"> <li>Facilitating medications in hand at time of discharge</li> </ul>
Health professionals	<ul style="list-style-type: none"> <li>One-on-one interviews with the clinicians, asthma educators, payers</li> </ul>	<ul style="list-style-type: none"> <li>Improving communication between inpatient care and primary care</li> <li>Facilitating home visits to address triggers</li> </ul>
	<ul style="list-style-type: none"> <li>Focus groups with the school nurses</li> </ul>	<ul style="list-style-type: none"> <li>Improving communication with school nurses</li> <li>Facilitating school-based asthma therapy</li> </ul>

**FIGURE 1** Stakeholder engagement process to support intervention design. Adapted from Shelef DQ, Rand C, Streisand R, et al. Using stakeholder engagement to develop a patient-centered pediatric asthma intervention. *J Allergy Clin Immunol.* 2016;138(6):1512–1517.

in school. With clinician engagement, we appreciated some of the challenges with education during the actual hospitalization because the hospital visit is often an unexpected event, and families are often overwhelmed. And lastly, our discussions with an existing asthma PAC highlighted the need to improve medication access at the time of discharge, so we established processes to improve medications in hand at the time of discharge. Through different avenues of engagement with key stakeholders, we were able to improve the content, coordination, and processes of our intervention.

## CONCLUSIONS

The currently presented findings are the foundational work for our ongoing pilot randomized control trial aimed to improve the H2H transition for children hospitalized with asthma through stakeholder engagement to design a support program. In this model, engagement with patients and families is central to the development of our study program and intervention. Building on a framework published by Shelef et al,<sup>10</sup> in this article, we want to provide an example to engage patients and families alongside other key stakeholders, including clinicians, educators, school nurses, and payers, in the development of patient-centered programs and interventions for children who are hospitalized. Too often research, education, and quality improvement teams overlook this source of crucial and valuable information, and we encourage study teams to consider this opportunity.

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