

The Development of a Pediatric Inpatient Experience of Care Measure: Child HCAHPS[®]

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abstract

The Centers for Medicare and Medicaid Services (CMS) uses Adult Hospital Consumer Assessment of Healthcare Providers and Systems (Adult HCAHPS[®]) scores for public reporting and pay-for-performance for most US hospitals, but no publicly available standardized survey of inpatient experience of care exists for pediatrics. To fill the gap, CMS and the Agency for Healthcare Research and Quality commissioned the development of a pediatric version (Child HCAHPS), a survey of parents/guardians of pediatric patients (<18 years old) who were recently hospitalized. This article describes the development of Child HCAHPS, which included an extensive review of the literature and quality measures, expert interviews, focus groups, cognitive testing, pilot testing of the draft survey, a national field test with 69 hospitals in 34 states, psychometric analysis, and end-user testing of the final survey. We conducted extensive validity and reliability testing to determine which items would be included in the final survey instrument and develop composite measures. We analyzed national field test data of 17 727 surveys collected in November 2012 to January 2014 from parents of recently hospitalized children. The final Child HCAHPS instrument has 62 items, including 39 patient experience items, 10 screeners, 12 demographic/descriptive items, and 1 open-ended item. The 39 experience items are categorized based on testing into 18 composite and single-item measures. Our composite and single-item measures demonstrated good to excellent hospital-level reliability at 300 responses per hospital. Child HCAHPS was developed to be a publicly available standardized survey of pediatric inpatient experience of care. It can be used to benchmark pediatric inpatient experience across hospitals and assist in efforts to improve the quality of inpatient care.



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Patient-centeredness, a key component of healthcare quality, refers to the principle that care should be designed around patients' needs, preferences, circumstances, and well-being.¹ In pediatrics, the goal is family-centeredness, meaning care that addresses the needs of the family as well as the child.² The National Quality Forum lists assessment of

patient experience, often conducted using patient experience surveys, as a top priority.^{3,4} In hospitals caring for adults, patient experience is generally assessed using the Adult Hospital Consumer Assessment of Healthcare Providers and Systems (Adult HCAHPS[®]) Survey. The Centers for Medicare and Medicaid Services (CMS) uses results from Adult HCAHPS to

inform consumer choice through public reporting on the Hospital Compare website and calculate incentive payments for the CMS Hospital Value-Based Purchasing Program.^{5,6}

Whereas Adult HCAHPS has become the national standard for adult inpatients, an analogous pediatric inpatient survey has not been previously developed. In response to this gap, the Agency for Healthcare Research and Quality and CMS through the Pediatric Quality Measures Program funded the Center of Excellence for Pediatric Quality Measurement (CEPQM) to design the Child HCAHPS. In this article, we describe the development and national field test of the Child HCAHPS survey. Throughout the development of Child HCAHPS, we followed standard CAHPS development methods, which involve extensive validation and testing, and adhered to all CAHPS design principles.^{5,7,8}

SURVEY DEVELOPMENT PROCESS

Literature Review, Measures Review, and Expert Input

To inform the Child HCAHPS development process, we conducted a systematic literature search of the PubMed database on patient experience of care, reviewing >1500 abstracts and articles. We also examined existing adult and child experience-of-care surveys. We drew on Adult HCAHPS whenever appropriate so that Child HCAHPS could be harmonized with the adult survey.^{5,7,8} Our goals were to understand the value of patient experience as a measure of healthcare quality and to identify essential domains for potential incorporation into the Child HCAHPS survey. As part of this process, we reviewed 67 surveys and articles describing patient experience surveys. The literature

highlights the importance of measuring patient experience as a key element of quality and a target area for quality improvement efforts.^{9–18} The preponderance of the evidence shows positive correlations between patient-centeredness and a variety of quality measures, including performance on clinical processes of care and patient adherence to recommended treatment plans, as well as health outcomes.^{9–12,14,16,19–23} In pediatric studies, positive parent report of communication with providers is associated with positive parent perception of discharge preparedness and correlates with a lower readmission likelihood and higher overall quality ratings by parents.^{13,15,17} In addition, parents and patients have identified several domains of quality as important to patient- and family-centered care. These domains (eg, communication with providers, being kept informed, patient safety) encompass aspects of care with which patients are able to reliably report their experiences.^{18,24}

To inform the development and use of Child HCAHPS, we interviewed experts in the fields of quality measurement, pediatric care, and patient experience. These experts, representing providers, payers, and professional organizations, provided technical and clinically relevant advice on quality measurement, quality improvement, health disparities, and information technology. Experts highlighted the importance of ensuring that items were age-appropriate and culturally sensitive. Throughout the development process, CEPQM's National Stakeholder Panel advised on Child HCAHPS content and item wording and its usefulness as a measure for future use in public reporting and quality improvement. National Stakeholder Panel participants supported the domains included in the survey and the use of Child HCAHPS for

measurement at the local level and for comparisons across hospitals. In addition, we received feedback from parent advocacy groups such as Family Voices and professional groups such as the Child Life Council.

On behalf of CEPQM, the Agency for Healthcare Research and Quality published a notice in the *Federal Register* in January 2012 requesting public input on measures and instruments to review and key domains to consider in developing the Child HCAHPS survey. Submissions included items on age-appropriateness of care, discharge efficiency, and patient comfort, as well as suggestions for domains such as emergency department care, comfort, and privacy.

Focus Groups

During November and December 2011, we conducted 6 focus groups with parents of recently hospitalized children and 2 with recently hospitalized adolescents in Boston, Los Angeles, and St. Louis. Two of these groups were conducted with parents of children with special health care needs. Focus groups were conducted in both English and Spanish. The focus groups covered several aspects of care important to patients and families. Table 1 provides examples of findings. The focus groups also commented on the domains identified by the literature review and experts and raised additional domains for potential inclusion in our instrument, including family involvement and child-appropriate care.

Cognitive Interviews

Throughout the survey development process, we conducted 94 full and 25 partial cognitive interviews with parents of recently hospitalized children during which candidate items were tested. Cognitive interviews took place in Boston, Los Angeles, Miami, and St. Louis in both English and Spanish. The English

TABLE 1 Key Findings From Child HCAHPS Focus Groups

Parents and adolescents described poor experiences with admissions via the emergency department, frequently citing excessive wait times and a lack of information and support throughout the process:
<ul style="list-style-type: none">• If you come in with your sick child through the ER, they can say, “you’re being admitted” and it can be 6 o’clock at night, but you don’t get your room until 2 in the morning. Now, I don’t know of anybody who gets discharged between 6 and 2, so I don’t know why there is such a gap there between “yes, you’re being admitted” and “okay, we’re finally bringing you to your room.” There’s a really big gap there.• I mean, we have some nurses who are really good that will come in, you know, “What do you need? What do you want? What can we get for you?” and there’s other times that I’m totally forgotten about, like, she hasn’t gotten any of her night meds and they all have to be switched over to IV because she can’t take anything [by mouth] because she’s throwing up everywhere and you remind the nurses, “she still needs her meds, she needs her seizure meds and she needs her GI meds, we need to get these on board.”
Parents were frustrated when doctors did not communicate, listen, or involve them in discussions during their child’s inpatient stay:
<ul style="list-style-type: none">• You get the residents that are coming in and rotating through, they’ve all got a chip on their shoulder like, “we know more than you because we’re doctors.” And I’m like, “Yeah, but I’m the parent and I know my kid better than you do.” I butt heads with the new residents that rotate through ... because they’re like, “I’m the doctor!” and I’m like, “Yeah, back off, I’m the mother.”• I think that some of the nurses, I don’t know, maybe because they have a lot going on, they tend to get mad when you ask questions. But before you do anything to my child, before you give him anything, I feel I need to know what it is.
Several parents conveyed the importance of doctors’ respecting both parents and patients:
<ul style="list-style-type: none">• I do have friends who have kids who might have some degree of developmental delay but they can understand but they’ve said that there’s been times where a doctor may come in and want to get some history about the child and so the parent is being asked questions like, “Tell me about what happened when he was born,” “What went wrong?” those kinds of things, where its like, the parent is like, I don’t want to talk about this in front of my child ... due to his understanding.• You do have to take the parent’s consideration when you are dealing with the kid. Even though the parent is not a doctor, there are some things that a parent knows about the child that a doctor or a nurse doesn’t.
Parents were concerned about clinicians making mistakes in their child’s care:
<ul style="list-style-type: none">• I had one doctor come in, daughter was intubated and a big sign at the foot of her bed, “Critical airways.” And she had pneumonia, so they had her on an [ventilator].... [T]he tube wasn’t down far enough and so if she coughed or moved it could have come out, so I guess the doctor heard that, came in the room and disregarded what the nurse said, disregarded what the sign said on the foot of her bed, and the nurse said, “Stop, don’t move her! She’s going to choke!” And he moved her.• My daughter, she has a feeding tube, so sometimes when she, you know when any kid is sick or anything is going on, they have to stop their feeds and hook them up to an IV and my daughter has an SIADH [syndrome of inappropriate antidiuretic hormone secretion] disorder, she’s fluid restricted, so if they give her too much fluid she’ll puff up. Sometimes you got to be very very clear with them because she’s on a lot of medication and they have to put that in IV form and then that’s just more volume that she’d be getting.... [S]o sometimes they don’t sit down and calculate and me and the wife would be constantly like, “Are you calculating this? Are you calculating this?” and then maybe like 24 hours later she’d be all puffed up, you know? And they weren’t taking some things into consideration.
Language barriers were associated with perceived increased wait times, lack of communication, and unequal treatment:
<ul style="list-style-type: none">• [Translated from Spanish] So that’s what I would say, that in my experience, those who cannot speak English are still cared for, but not in the same way that English speakers are. [English speakers] complain. One speaks and they listen. It’s like you do not have a voice if you do not speak English.• They profile us [as] Spanish.... We’re not Spanish, we’re Brazilian.... A month ago, I got [my daughter] in a room, and I say, “What time are they going to start [her therapy]?” “Oh, we’re waiting for an interpreter.” “I’ve been here for a half hour talking to you. Why are you waiting for an interpreter? For what?” “I just want to make sure that I understand everything.” “What do you mean you want to understand everything, what words in my mouth are you not understanding when I’m talking?”... And when they bring the interpreter, they bring a Spanish one. I don’t speak Spanish.

and Spanish versions of the survey elicited similar responses. Overall, parents reported effectively on their own experiences of their child’s inpatient stay and were capable of distinguishing between their own

experiences and those of their child; Child HCAHPS contains both types of items. Parents of children of all ages with a broad range of reasons for hospitalization were able to answer most survey questions

appropriately and accurately. However, items for some domains were not included in Child HCAHPS because parents either lacked information to report on the experience or did not have a uniform understanding of the concept. For instance, parents were not able to report consistently on care coordination, which in the inpatient setting often occurs out of view of the parent. In addition, collecting data about experiences with shared decision-making was unsuccessful. For example, parents of children with planned hospital stays (eg, tonsillectomy) often felt that because the major decisions (eg, the decision to do the tonsillectomy) were made before the hospitalization, decisions made during the hospitalization seemed minor by comparison and were not sufficiently salient for parents to recall the decision-making process. Other times, when there was an emergent medical problem that led to hospitalization, parents felt that there were no “real” decisions to be made because the severity of the condition dictated the treatment course (eg, surgery for appendicitis).

Field Testing

Child HCAHPS Survey Administration

We followed the Adult HCAHPS survey administration processes whenever possible. The survey was conducted by CAHPS-approved vendors that routinely field proprietary patient experience surveys for the participating hospitals. Parents or guardians (henceforth referred to as parents) of eligible patients were randomly selected using standard sampling procedures and were contacted 48 hours to 6 weeks after the child was discharged. The survey was administered by mail or by telephone in English or Spanish. Spanish surveys were administered to parents whom the hospital’s records identified as preferring

Spanish. Exclusion criteria included patients ≥ 18 years of age, “no-publicity” patients (ie, parents who do not want to be contacted), court/law enforcement patients, wards of the state, observation patients, healthy newborns, obstetric patients, those with a foreign home address, those excluded because of state regulations, those admitted for a psychiatric diagnosis, those discharged to another health care facility, and deceased patients. Healthy newborns were excluded because their care is usually closely associated with a mother’s obstetric care and thus may not reflect a pediatric service’s quality of care. Patients admitted for obstetric care were excluded because care related to pregnancy does not generally fall within the purview of pediatric providers. Patients discharged with psychiatric diagnoses were excluded because these patients typically require specialized psychiatric care that is different from other care received in general acute-care hospitals and would be better assessed by a mental health-specific instrument. Emancipated minor patients and those with parents < 18 years old were also excluded in field testing.

Pilot Test

After revising some survey items based on input from cognitive interviews, we conducted a pilot field test of the draft survey with parents of recently hospitalized children in 8 hospitals across the United States. The pilot instrument was administered by mail and contained 78 items: 55 items that asked respondents about whether or how often they had had a particular experience and overall rating of the hospital stay, 14 screeners (ie, gateway items that ensure that respondents are answering only items that are relevant to their child’s experience), 8 demographic or descriptive items, and 1 open-ended item. We

received 2092 responses for an average hospital response rate of 22.5%, which we analyzed for item nonresponse, inter-item correlation, and response variation. In addition, we administered 60 telephone surveys and coded the respondent–interviewer interaction to identify any additional difficulties for participants completing the survey by telephone (eg, confusion about items, need for an item to be repeated, hang-ups, substantial delays in answering). Based on the analyses of the pilot test and behavioral coding, the survey was revised before the national field test.

National Field Test

From December 2012 to January 2014, we tested the revised draft survey in 69 hospitals across 34 states. Hospitals that participated included free-standing children’s hospitals (36%), children’s hospitals within an adult hospital (41%), and pediatric wards (23%). The sampling frame for the national field test included medical and surgical patients who were discharged between November 2012 and February 2014 after a stay of ≥ 1 night at a participating hospital. The total number of patients whose parents were contacted by mail or phone was 103 565. Of the 69 hospitals, 59 hospitals administered Child HCAHPS by mail and 10 by phone. We received 17 727 completed surveys, for an overall response rate of 17.1%, which is comparable to that attained by proprietary, pediatric patient-experience surveys. There was an average of 257 responses per hospital, with broad representation with respect to child and respondent characteristics (Table 2).

Statistical Analyses

To determine which items would be included in the final Child HCAHPS survey instrument and develop composite measures, we conducted

TABLE 2 Child and Respondent Descriptive Characteristics

Variable	%
Child age, years (<i>N</i> = 17 727)	
0	20.9
1 to 4	25.9
5 to 8	16.0
9 to 12	14.7
13 to 17	22.5
Child gender (<i>N</i> = 17 725)	
Female	45.9
Male	54.1
Child race/ethnicity (<i>N</i> = 17 168)	
American Indian or Alaskan Native	0.5
Asian/Pacific Islander	3.6
Black, non-Hispanic	10.4
Hispanic	17.8
Multiracial	3.9
White, non-Hispanic	63.8
Child global health status (<i>N</i> = 17 253)	
Excellent	40.7
Very Good	32.4
Good	18.2
Fair	7.2
Poor	1.5
Respondent age, years (<i>N</i> = 17 261)	
< 25	8.3
25 to 34	33.7
35 to 44	37.0
≥ 45	21.0
Respondent education (<i>N</i> = 16 857)	
8th grade or less	3.0
Some high school	4.8
High school graduate or GED	17.9
Some college or 2-y degree	32.1
4-y college graduate	22.6
More than 4-y college degree	19.6
Respondent relationship to child (<i>N</i> = 17 128)	
Father	11.0
Mother	85.1
Other	3.9
Respondent language preference (<i>N</i> = 16 915)	
English	91.7
Spanish	7.0
Other/missing	1.3

extensive validity and reliability testing. Quantitative methods included exploratory factor analysis, correlations of items and composites with overall ratings, estimation of hospital-level and internal consistency reliability, and case-mix models to adjust comparisons of hospitals for effects of measured patient and respondent characteristics. Each of the measures within the Child HCAHPS survey was conceived of as a hospital-level

measure of hospital performance, and therefore, validity and reliability testing of each measure focused on hospital-level analyses.

Exploratory Factor Analysis

We investigated the structure underlying the covariance matrices of case mix-adjusted hospital-level item scores to identify groups of items that were empirically related at the hospital level. We estimated a Bayesian hierarchical model for hospital-level correlation structure after removing sampling variation due to individual variability in responses²⁵; this estimate was used for the factor analysis and all of the following correlational analyses. We explored analyses with different numbers of factors and with both varimax and promax rotations, with generally consistent results regarding item groupings. This analysis generally confirmed that items that we would group together on conceptual grounds were also empirically related, such as the discharge items (Supplemental Figure 1). We found that doctor and nurse communication items were substantially related to other

communication items such as “providers talked and acted age-appropriately” and “kept parent informed.” On conceptual grounds and for consistency with the Adult HCAHPS composites, we organized items into several composites for reporting purposes (see Table 3 for list of composite and single-item measures).

Hospital-Level Unit Reliability

Hospital-level unit reliability reflects measure variation between hospitals relative to random variation in the mean response within hospitals. CMS recommends collecting ≥ 300 responses per hospital to provide hospital-level unit reliabilities for the Adult HCAHPS item composites.²⁶ We used the Spearman-Brown formula to calculate the reliability at 300 completed surveys per hospital, aiming for a hospital-level reliability of ≥ 0.7 for most composite and single-item measures. Our composite and single-item measures demonstrated good to excellent hospital-level reliability (Table 3). Only 1 measure, “involving teens in their care,” had a hospital-level

reliability < 0.7 at 300 responses per hospital. The lower reliability reflects the fact that the constituent items were asked only of parents with teenage patients, which were only 22.5% of completed surveys. Six measures had reliabilities of 0.7 to < 0.8 , 6 had reliabilities of 0.8 to < 0.9 , and 5 had reliabilities of ≥ 0.9 , indicating excellent ability of the survey to distinguish high and low performers on the corresponding dimensions of patient experience.

Composite and Single-Item Correlations With Overall Rating

Criterion validity is the extent to which a measure relates to other measures as predicted by theory. We evaluated criterion validity by examining hospital-level correlations of composites and single-item measures with overall hospital performance, as reflected in the “overall rating” item. Of the 17 composite or single-item measures considered, 14 had significant positive correlations with the overall hospital rating, with a correlation of 0.90 for “would recommend this

TABLE 3 Child HCAHPS Measures: Quantitative Reliability and Validity Testing

Composite and Single-Item Measures	Items, <i>n</i>	Hospital-Level Unit Reliability at <i>n</i> = 300	Correlation of Hospital-Level Measure Score With Overall Rating
Communication with parent			
Communication between you and your child's nurses	3	0.73	0.69
Communication between you and your child's doctors	3	0.73	0.71
Communication about your child's medicines	4	0.86	0.66
Keeping you informed about your child's care	2	0.78	0.67
Privacy when talking with doctors, nurses, and other providers	1	0.83	0.51
Preparing you and your child to leave hospital	5	0.87	0.69
Keeping you informed about your child's care in the emergency department	1	0.71	0.16
Communication with child			
How well nurses communicate with your child	3	0.75	0.51
How well doctors communicate with your child	3	0.78	0.50
Involving teens in their care	3	0.62	0.53
Attention to safety and comfort			
Preventing mistakes and helping you report concerns	2	0.90	0.49
Responsiveness to the call button	1	0.77	0.19
Helping your child feel comfortable	3	0.90	0.56
Paying attention to your child's pain	1	0.73	0.57
Hospital environment			
Cleanliness of hospital room	1	0.86	−0.07
Quietness of hospital room	1	0.89	0.02
Global rating			
Overall rating	1	0.90	Not applicable
Recommend hospital	1	0.93	0.90

hospital” and correlations ranging from 0.49 to 0.71 for other measures (Table 3).

Additional Statistical Testing

Internal consistency reliability, commonly assessed with the Cronbach coefficient (α), quantifies how well a scale calculated from a set of items measures a single underlying construct. Internal consistency reliabilities for our composite measures were good to excellent. Although 3 composites had an internal consistency reliability <0.7 , the others ranged from 0.75 to 0.94 (Supplemental Table 5). Item-to-composite correlations indicate how each item within a composite correlates with the overall composite. The item-to-composite correlations ranged from -0.23 to 0.91 (Supplemental Table 5). The “mistakes and concerns,” “communication about your child’s medicines,” and “helping your child feel comfortable” composites had low item-to-composite correlations, probably because each consists of items that are conceptually related but deal with fairly distinct processes of care. Composite-to-composite correlations are used to determine whether composites are measuring distinct aspects of patient experience. These ranged from 0.33 to 0.88 ; the higher correlations reflected the strong associations at the hospital level among measures of communication (Supplemental Table 6).

Case-Mix Adjustment

When comparing hospitals, it is desirable to adjust for case-mix differences to estimate how different hospitals would score if they all provided care to comparable groups of patients. Case-mix adjustment estimates and removes the predictable effects of patient and respondent characteristics, such as age and health status, that are not under the control of the hospital and may affect scores on

performance measures. We tested the effects of variables available from the survey and hospitals’ administrative data and identified those that were predictive of responses and also had unequal distributions at different hospitals.²⁷ Our final model adjusted for the following variables, entered categorically: child age, child global health status, respondent age, respondent education, respondent relationship to child, and language preference. Of these, the 2 variables that had the largest effects were child global health status and parent education.

End-User Testing

After analyzing the national field test and proposing draft composite measures, we conducted an additional 23 cognitive interviews with parents to evaluate the understandability and validity of measure concepts and of measure labels used to describe each measure (eg, “privacy with providers”). End-user testing occurred in 2 rounds in Atlanta and Washington, DC. Based on this testing, measure labels were modified to improve their understandability. As a result of feedback from end-user testing, 3 measures—communication, patient safety, and pain—were prioritized as most important to a majority of parents.

We considered options for combining areas of communication (eg, combining nurse and doctor communication with children or combining child and parent communication with nurses) because of psychometric testing, stakeholder input, and the desire to simplify the survey results. However, end-user testing revealed that parents instead preferred to see each of the aspects of communication reported as separate measures (eg, nurse–parent communication, doctor–child communication). They

perceived communication with doctors as different from communication with nurses and distinguished communication with the parent from communication with the child. End-user testing also indicated that organizing measures into categories for reporting helped ease the cognitive burden of examining a long list of measures. Participants overwhelmingly expressed a preference for the use of categories, which enabled them to focus on the grouping that was most important to each of them.

Based on the quantitative analyses and end-user testing, the final Child HCAHPS instrument has 62 items, including 39 patient experience items, 10 screeners, 12 demographic/descriptive items, and 1 open-ended item. The 18 composite and single-item measures are categorized into 5 overarching groups: communication with parent, communication with child, attention to safety and comfort, hospital environment, and hospital rating. Table 4 shows the finalized wording for the Child HCAHPS items, including the response scales and any screener questions that precede the item.

CONCLUSIONS

Child HCAHPS is a publicly available, validated instrument of pediatric inpatient family experience of care. Patient experience is linked to other quality measures and health outcomes including mortality, readmission rates, and clinical processes of care. Child HCAHPS was developed according to standardized methodology and national testing in accordance with CAHPS development principles, and the Child HCAHPS measures have recently been endorsed by the National Quality Forum.²⁸ Adult HCAHPS has become the national standard of how hospitals measure and publicly report adult patient experience. Child HCAHPS provides

TABLE 4 Child HCAHPS Items in Domain-Level Composite and Single-Item Measures

Items Grouped by Categories	Response Options
Communication with parent	
Communication between you and your child's nurses	
During this hospital stay, how often did your child's nurses listen carefully to you?	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's nurses explain things to you in a way that was easy to understand?	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's nurses treat you with courtesy and respect?	Never/Sometimes/Usually/Always
Communication between you and your child's doctors	
During this hospital stay, how often did your child's doctors listen carefully to you?	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's doctors explain things to you in a way that was easy to understand?	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's doctors treat you with courtesy and respect?	Never/Sometimes/Usually/Always
Communication about your child's medicines	
During the first day of this hospital stay, were you asked to list or review all of the prescription medicines your child was taking at home? ^a	Yes, definitely/Yes, somewhat/No
During the first day of this hospital stay, were you asked to list or review all of the vitamins, herbal medicines, and over-the-counter medicines your child was taking at home? ^a	Yes, definitely/Yes, somewhat/No
Before your child left the hospital, did a provider or hospital pharmacist explain in a way that was easy to understand how your child should take these new medicines after leaving the hospital? ^a	Yes, definitely/Yes, somewhat/No
Before your child left the hospital, did a provider or hospital pharmacist explain in a way that was easy to understand about possible side effects of these new medicines? ^a	Yes, definitely/Yes, somewhat/No
Keeping you informed about your child's care	
During this hospital stay, how often did providers keep you informed about what was being done for your child?	Never/Sometimes/Usually/Always
How often did providers give you as much information as you wanted about the results of these tests? ^a	Never/Sometimes/Usually/Always
Privacy when talking with doctors, nurses, and other providers	
During this hospital stay, how often were you given as much privacy as you wanted when discussing your child's care with providers?	Never/Sometimes/Usually/Always
Preparing you and your child to leave the hospital	
Before your child left the hospital, did a provider ask if you had any concerns about whether your child was ready to leave?	Yes, definitely/Yes, somewhat/No
Before your child left the hospital, did a provider talk with you as much as you wanted about how to care for your child's health after leaving the hospital?	Yes, definitely/Yes, somewhat/No
A child's regular activities can include things like eating, bathing, going to school, or playing sports. Before your child left the hospital, did a provider explain in a way that was easy to understand when your child could return to his or her regular activities?	Yes, definitely/Yes, somewhat/No
Before your child left the hospital, did a provider explain in a way that was easy to understand what symptoms or health problems to look out for after your child left the hospital?	Yes, definitely/Yes, somewhat/No
Before your child left the hospital, did you get information in writing about what symptoms or health problems to look out for after your child left the hospital?	Yes, definitely/Yes, somewhat/No
Keeping you informed about your child's care in the emergency department	
While your child was in this hospital's emergency department, were you kept informed about what was being done for your child? ^a	Yes, definitely/Yes, somewhat/No
Communication with child	
How well nurses communicate with your child	
During this hospital stay, how often did your child's nurses listen carefully to your child? ^a	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's nurses explain things in a way that was easy for your child to understand? ^a	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's nurses encourage your child to ask questions? ^a	Never/Sometimes/Usually/Always
How well doctors communicate with your child	
During this hospital stay, how often did your child's doctors listen carefully to your child? ^a	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's doctors explain things in a way that was easy for your child to understand? ^a	Never/Sometimes/Usually/Always
During this hospital stay, how often did your child's doctors encourage your child to ask questions? ^a	Never/Sometimes/Usually/Always
Involving teens in their care	
During this hospital stay, how often did providers involve your child in discussions about his or her health care? ^a	Never/Sometimes/Usually/Always
Before your child left the hospital, did a provider ask your child if he or she had any concerns about whether he or she was ready to leave? ^a	Yes, definitely/Yes, somewhat/No
Before your child left the hospital, did a provider talk with your child about how to take care of his or her health after leaving the hospital? ^a	Yes, definitely/Yes, somewhat/No
Attention to safety and comfort	
Preventing mistakes and helping you report concerns	
Before giving your child any medicine, how often did providers or other hospital staff check your child's wristband or confirm his or her identity in some other way? ^a	Never/Sometimes/Usually/Always
Mistakes in your child's health care can include things like giving the wrong medicine or doing the wrong surgery. During this hospital stay, did providers or other hospital staff tell you how to report if you had any concerns about mistakes in your child's health care?	Yes, definitely/Yes, somewhat/No

TABLE 4 Continued

Items Grouped by Categories	Response Options
Responsiveness to the call button After pressing the call button, how often was help given as soon as you or your child wanted it? ^a	Never/Sometimes/Usually/Always
Helping your child feel comfortable Things that a family might know best about a child include how the child usually acts, what makes the child comfortable, and how to calm the child's fears. During this hospital stay, did providers ask you about these types of things?	Yes, definitely/Yes, somewhat/No
During this hospital stay, how often did providers talk with and act toward your child in a way that was right for your child's age?	Yes, definitely/Yes, somewhat/No
Hospitals can have things like toys, books, mobiles, and games for children from newborns to teenagers. During this hospital stay, did the hospital have things available for your child that were right for your child's age?	Never/Sometimes/Usually/Always
Paying attention to your child's pain During this hospital stay, did providers or other hospital staff ask about your child's pain as often as your child needed? ^a	Yes, definitely/Yes, somewhat/No
Hospital environment Cleanliness of hospital room During this hospital stay, how often were your child's room and bathroom kept clean?	Never/Sometimes/Usually/Always
Quietness of hospital room During this hospital stay, how often was the area around your child's room quiet at night?	Never/Sometimes/Usually/Always
Global rating Overall rating Using any number from 0 to 10, where 0 is the worst hospital possible and 10 is the best hospital possible, what number would you use to rate this hospital during your child's stay?	0 through 10
Recommend hospital Would you recommend this hospital to your family and friends?	Definitely no/Probably no/Probably yes/Definitely yes
Other During your child's hospital stay, how much of the time were you at the hospital?	None of the time/A little of the time/Some of the time/Most of the time/All or nearly all of the time
How did that person help you? Mark one or more. ^a	Read the questions to me/Wrote down the answers I gave/Answered the questions for me/Translated the questions into my language/Helped in some other way (please print)
Is there anything else you would like to say about the care your child received during this hospital stay?	Write-in
Screeners Was your child born during this hospital stay?	Yes/No
For this hospital stay, was your child admitted through this hospital's emergency department?	Yes/No
Were you in this hospital's emergency department with your child?	Yes/No
Is your child able to talk with nurses and doctors about his or her health care?	Yes/No
Tests in the hospital can include things like blood tests and x-rays. During this hospital stay, did your child have any tests?	Yes/No
During this hospital stay, did you or your child ever press the call button?	Yes/No
During this hospital stay was your child given any medicine?	Yes/No
During this hospital stay, did your child have pain that needed medicine or other treatment?	Yes/No
Before your child left the hospital, did a provider tell you that your child should take any new medicine that he or she had not been taking when this hospital stay began?	Yes/No
During this hospital stay, was your child 13 years old or older?	Yes/No
Did someone help you complete this survey?	Yes/No
Demographics In general, how would you rate your child's overall health?	
What is your child's age?	
Is your child male or female?	
Is your child of Hispanic or Latino origin or descent? Mark one or more.	
What is your child's race? Mark one or more.	
How are you related to the child?	
What is your age?	
What is the highest grade or level of school that you have completed?	
What is your preferred language?	

^a Item requires a screener.

a new tool to assess and benchmark hospital performance, both within and across hospitals, and has the potential to become a national standard.

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ABBREVIATIONS

CEPQM: Center for Excellence for Pediatric Quality Measurement
CMS: Centers for Medicare and Medicaid Services
HCAHPS: Hospital Consumer Assessment of Healthcare Providers and Systems

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WHAT IS IN A NAME?: *We are in the midst of another season of tropical storms, all of which carry various male and female names. The United States did not begin naming storms until 1953. At first, only female names were used, but by 1979 both male and female names were used for Atlantic and Pacific storms. The World Meteorological Organization has established a strict procedure for naming storms. The names are used on a six-year rotation and remain in rotation unless a name is associated with a particularly deadly storm.*

Naming new human infectious diseases, however, is not so straightforward. Disease names can be associated with a place (e.g. Lyme disease), animals (mad cow, swine flu, etc.), or people (Lou Gehrig's disease). Such names can inspire fear, hurt local economies, or spur national debate. After the mad cow epidemic in England, tourists had to be coaxed back. The Indian Health Ministry waged a vigorous campaign to change the name given to a broad spectrum beta-lactamase described in a patient in India from "New Delhi Metallo-beta-lactamase-1" to something else, as the name implied the enzyme was unique to India and scared people from using Indian hospitals.

As reported by CNN (Health: May 11, 2015), the World Health Organization recently issued best practices for how to name a new human infectious disease. The organization recommends that names not include mention of animals, type of food, cultural or occupational references, geographic location, or names of people. The goal is to reduce fear of specific animals or locations. The name can be specific but should not be sensational. This is likely to be challenging. We know that the first Atlantic storm of 2017 will be named Adrian. We have no such nomenclature for human diseases. Furthermore, it takes a bit of time to identify the causal organism. By the time the organism is identified, the public may already have embraced a totally different name. Finally, "swine flu" is simply easier to say than the proposed A(H1N1)pdm09. I agree that we need to avoid demonizing a person, place, or animal. The trick will be how to ensure that local and national public health officials, as well as the media, use responsible naming practices.

Noted by WVR, MD