

Attachment D
Intensive Interview Protocol
Child HCAHPS Narrative Elicitation Pilot Test

1. Tracking Information [*Not* read to respondent, but to be noted on paper and at beginning of audio recording for purposes of tracking, record-keeping and analysis]
 - a. Name of interviewer_____
 - b. Date of interview_____
 - c. Date of elicitation _____
 - d. ID number of interviewee_____
 - e. Name interviewee would like to be called during interview
 - f. How interviewee would like us to refer the child who was hospitalized_____
 - g. Age of child who was hospitalized_____

2. **Introduction**– points to cover with the respondent before the interview begins.
 - i. Thank respondent for agreeing to do this interview, and make sure it is still a good time for them to participate.
 - ii. Note that -- as she or he may recall from agreement to do this interview – the interview will last up to 60 minutes, and focus on the child’s most recent hospital stay.
 - iii. Note that some of these questions may sound similar to the ones he or she answered on the earlier survey and that “in this interview we again would like to talk to them about their child’s most recent hospital stay and the experiences that they and their child had during that stay.”
 - iv. Reassure the respondent not to worry about repeating anything from the earlier survey. “Although this may repeat some of the information from the earlier survey you completed, we want to start here from the ground-up, to be sure that we have the full and complete picture of this hospitalization for your child”.
 - v. Reassure respondent that we simply want to hear how the hospital experience felt to them and was seen through their eyes. “There are absolutely no right or wrong answers here; what we want is to hear from you in your own words.”
 - vi. Before beginning, see if the respondent has any questions.

3. **WARM UP QUESTION(s):** So before we begin, I'd love to get a sense from you about how much exposure you have had to hospitals. Prior to your child's recent hospitalization, how much experience would you say you have had, if any, with immediate family members going to the hospital?

IF SOME → Then it sounds like you have already had some experience with hospitals and/or with being a caregiver for someone in the hospital.

IF NONE → Then it sounds like this was a really new experience for you and your family; thank you for being willing to talk with me about this today.

DRILL-DOWN ON THE ELICITATION QUESTIONS

NOTE: *In addition to the general probes suggested under each question, be sure to offer probes throughout the interview that are customized to the particular experiences being recounted (and referencing earlier information the respondent provided where appropriate). In particular, for this set of questions, be sure to ask “was there anything else?” after respondent has replied to each question. Also, be sure to balance positive and neutral probes to prevent bias. To get the detail and texture we want, probes throughout the interview have to be contextual and cannot be captured in a static protocol.*

A. So let’s start off by thinking back on the time you and your child spent in the hospital. How would you say things went?

PROBES: What other aspects of your child’s hospital stay felt important to you?

How well did things go with this aspect of care?
[Repeat as needed]

B. Now, we’d like to focus on experiences during your child’s hospital stay that went particularly well (if any). Please explain what happened, how it happened, and how it felt.

PROBES: *[If the respondent is reporting an event not yet mentioned]*
Please explain what happened, how it happened, and how it felt to you.

[If the respondent is reporting an event already mentioned earlier]
Can you explain a bit more about what happened, how it happened, and how it felt to you?

[If the respondent is reporting an aspect of their relationship to a hospital provider or staff, rather than a specific event or episode]
Can you give me some examples of this? *[reflect back reported aspect]?*

and/or

How did this come through in your interactions with *[reflect back provider or staff respondent referenced]?*

B.1 *[Repeat as needed]*

Is there anything else that went particularly well? Can you tell me more about that? (what happened, how it happened, how it felt, what behaviors the staff/named provider exhibited that supported it going well)

C. Next, we'd like to focus on any experiences during your child's hospital stay that you wish had gone differently. Please explain what happened, how it happened, and how it felt.

PROBES: *[If the respondent is reporting an event not yet mentioned]*
Please explain what happened, how it happened, and how it felt to you.

[If the respondent is reporting an event already mentioned earlier]
Can you explain a bit more about what happened, how it happened, and how it felt to you?

[If the respondent is reporting an aspect of their relationship to the provider or staff, rather than a specific event or episode]

Can you give me some examples of this? *[reflect back reported aspect]*?
and/or

How did this come through in your interactions with *[reflect back provider or staff respondent referenced]*?

C. 1 *[Repeat as needed]*

Is there anything else that you wish had gone differently?

D. Please describe how the doctors, nurses, and others who cared for your child related to and interacted **with you**.

PROBES: Can you give me some examples of this? *[reflect back reported aspect]*?
and/or

How did this come through in your interactions with *[reflect back provider or staff respondent referenced]*?

E. Please describe how the doctors, nurses, and others who cared for your child related to and interacted **with your child**.

PROBES: Can you give me some examples of this? *[reflect back reported aspect]*?
and/or

How did this come through in your child's interactions with *[reflect back provider Or Staff respondent referenced]*?

ELABORATION OF THE EXISTING CHILD HCAHPS DOMAINS

NOTE: Before proceeding to the next set of open-ended questions, please thoroughly review the following short list of substantive questions about hospital experiences. Please ask each of the questions that follow in ways that adapt to respondent's previous answers; the prompts below are structured to facilitate this adaptation. Not all probes will be asked in every interview (if the topics were already introduced in the responses above).

The following text should be used to orient the respondent to this part of the interview.

For this next part of the interview, I want to ask about aspects of being in the hospital that we've heard about from other people we have interviewed, just to see if they might remind you of something similar that may or may not have happened during your child's last hospital stay.

F. Many people whose children have been in the hospital talk specifically about their interactions with nurses.

In addition to what you have already described, is there anything else about your interactions with nurses that was important to you during your child's hospital stay? For example:

- **Ask only about those aspects which have not already been discussed.**

- **F.1** How did you feel about the ways in which the nurses communicated with you about your child's care?
- **F.2** How well did the nurses help you or your child feel comfortable during the hospital stay?
- **F.3** To what extent did you feel like the nurses were warm, compassionate, and caring?

G. You've already mentioned a number of things about the interactions that you and your child had with doctors in the hospital.

In addition to what you have already described, can you talk a bit about:

- **Ask only about those aspects which have not already been discussed:**

- **G.1** Whether and how your child's doctors (including specialists, surgeons, hospitalists, etc.) kept you adequately informed about your child's care?
- **G.2** To what extent did you feel like the doctors were warm, compassionate, and caring?

NEW. How were the interactions with other people who cared for your child when in the hospital?

- **Ask only about those aspects which have not already been discussed.**

- **NEW.1** How did you feel about how these other people communicated with you and your child?
- **NEW.2** How well did these others help you or your child feel comfortable during the hospital stay?
- **NEW.3** To what extent were these others warm, compassionate, and caring?

H. We would like to learn a bit more about your experience with places where your child spent time while in the hospital – for example, his or her room [*substitute NICU bay if someone who had NICU experience*] or the emergency department. To what extent and in what ways did these settings feel like places where your child could heal and be cared for in an age-appropriate way?

I. What about the preparation for your child leaving the hospital? How well did doctors, nurses and others caring for your child prepare you for this transition and involve you in the process of deciding when the time was right?

CHILD HCAHPS DOMAINS IMPLEMENTED WITH SCREENING QUESTIONS

NOTE: *To make the survey more efficient and avoid priming responses that are not of high salience to the parent, questions for the following Child HCAHPS domains were constructed with a built-in screening item to skip respondents past low-salience aspects of the hospital stay.*

J. Was your child old enough at the time of this most recent hospitalization to be involved in discussions and choices about his or her medical care?

IF NO → SKIP to Question K

IF YES →

J.1 How good a job would you say doctors, nurses and others caring for your child did at involving your child in discussions about care in the hospital? What about preparing to leave the hospital?

K. While your child was in the hospital, did you ever think about their safety? We are referring to safety broadly – by safety we mean things the doctors, nurses and others caring for your child do to keep patients safe, as well as any mistakes or errors.

IF NO → SKIP to Question L

IF YES →

K.1 How well were these issues identified? How well were they discussed with you – did you feel like you fully understood any risks that your child was facing?

K.2 To what extent and in what ways did doctors, nurses and others caring for your child appear to be taking care to reduce any medical risks and errors?

L. Over the course of your child’s hospitalizations, was anything notable about the way doctors, nurses and others caring for your child handled situations that might be painful, scary or uncomfortable for your child?

IF NO → SKIP to Question M

IF YES →

L.1 What positive experiences (if any) were most notable?

L.2 What about negative ones (if any)?

M. Was privacy on your mind at any point during your child's hospitalization?.

IF NO → SKIP to Question N

IF YES →

M.1 What were the positive or negative experiences that caused you to think about privacy?

N. Did anything stand out to you about your child's experience with admission to the hospital?

IF NO → SKIP to Question P

IF YES →

N.1 What were the positive or negative experiences that were most notable?

EXPANSION TO INCLUDE DOMAINS DISTAL TO CHILD HCAHPS

*NOTE: The following questions are asked of everyone.
The “caring and compassion” domain was integrated into the question sequence above*

O. Compassion/emotional support of doctors and nurses when communicating with children and parents

O1. How compassionate were doctors and nurses towards you and your child?

P. Systemic practices affecting patient experience

P.1. How well would you say the doctors, nurses and others caring for your child balanced their attention to necessary routines with the personal needs of your child and your family?

Q. Technical quality and thoroughness

Q.1 How thorough would you say the doctors, nurses, and others caring for your child were in dealing with your child’s health needs? By thorough we could mean making a diagnosis, making sure treatments are working, and paying attention to your child’s overall well-being.

Q.2. What was your impression of the skill of the medical team providing your child’s care?

R. Coordination of care

R.1 To what extent did all your child’s doctors and nurses seem informed and up-to-date about your child’s well-being and care?

R.2 Were there any times when one or more of your child’s doctors and nurses seemed unaware of the actions that other doctors or nurses had taken regarding your child’s hospitalization?

INCORPORATING PROTOTYPE SHARED DECISION-MAKING QUESTIONS

S.a How well, if at all, did the doctors, nurses and others caring for your child take into account you or your child’s perspectives and preferences when talking about your child’s care?

Probe: How did they incorporate yours or your child’s perspectives and preferences? Can you tell me more about that?

S.b. To what degree did you feel like you and/or your child were involved in decisions about your child's care?

Probe: Can you provide an example of a decision that you felt you were involved in?

Could you also provide an example of a decision that you would have like to have been involved in or more involved in but that the doctors or nurses or staff did not seem open to it?

S.c. How did you feel about the way doctors, nurses and others caring for your child involved you and your child in making decisions?

Probe: Did they ask you at any point about your preferences for involvement?
Did they try and include you in decision making? If so, how did you know?

CLOSING QUESTIONS

NOTE: *The following questions are asked of everyone.*

T.1 Is there anything else about your and your child's most recent hospital experiences that you want to describe before we end this interview?

PROBES: Was there anything surprising about your and your child's experiences in the hospital?

Are there questions about your and your child's experiences at the hospital that I should have asked, but did not?

T.2 We are grateful to you for describing your experiences. Now, we would like to know how all these experiences in the hospital add up for you. Overall, would you say your responses taken as a whole could be most accurately described as:

- ¹ Almost entirely negative
- ² Mostly negative, but some positive
- ³ An even mix of negative and positive
- ⁴ Mostly positive, but some negative
- ⁵ Almost entirely positive