

Appendix 1. Parent and Child Interview Guides

PARENT

Preamble Statement

The goal of this study is to **improve the care** that children with complex medical care needs and their families receive in the pediatric intensive care unit (PICU). You have a great deal of knowledge and experience that we can learn from.

For this part of the study, we would like to better understand your thoughts and feelings about the care [child's name] and your family received in the PICU. I will ask you some questions about [that/those] care experience[s]. There are no right or wrong answers; we are trying to understand and learn from **your experiences**. (Please try to speak to me, and not to the camera.)

Interview Questions:

1. Tell me about [child's name]. What are his/her care needs at home. (Probes: Who provides [child's] care at home? What is [child's] typical care routine?)
2. Can you describe for me why [child] was last admitted to the PICU? (Probes: What was it like when she/he was in the PICU?)
3. As a parent, you are used to providing your child's care at home. In the PICU, the staff provides some of that care. How were you involved in [child's] care in the PICU? How would you like to have been involved? (Probes: Do you think that being involved/more involved in [child's] care is/would be helpful for you? For [child]?)
4. How are decisions made about your child's care when in the PICU? (These can be small decisions, such as who does what, or more significant goals of care decisions.) (Probes: Who is involved in decision-making? How do you feel about your role in the decision-making process?)
5. How would you describe your interactions/communication with staff in the PICU? (Probes: With nurses, with doctors, with other health care professionals working in the PICU? How have communication and relationships evolved over time?)

6. Can you tell me about a time when partnership with staff went well? (Probes: What made the situation feel positive? What was it that worked well?)
7. What could PICU staff do to better to support you and [child]? (Probes: How can staff work together with you to care for [child]? Were there things staff did during a previous admission that you found helpful?)
8. If you could change something about the care your child and family received while in the PICU, what would it be? Why?
9. If a parent of a child with similar care needs was preparing for a PICU admission and asked you what to expect, and how to prepare – what would you tell that parent?

Did you expect me to ask questions that I did not ask today? What would those be?

THANK YOU for accepting to meet with me. Your participation is very valuable to our research and will contribute to improving patient and family care in the PICU.

CHILD

Toolkit

- **Role play with puppets** (if the child has a favorite toy/toys that this could be acted out with – a toy that was also ‘in the hospital’ with them)

We will pretend that 'toy 1' is a nurse, and that 'toy 2' wakes up in intensive care after a surgery he/she had.

Toy 1 (interviewer), Toy 2 (interviewee)

Interviewer: Hello 'toy 2', I'm going to come and check your vital signs and bandage from your surgery. Today I would like you to get out of bed and sit in your chair. I know it might hurt a little bit, but I could give you some medicine to make it hurt less before you get in the chair. What do you think about that?

- **Photo elicitation**

We're going to pretend that this is an intensive care hospital room.

1. If you were in the hospital room here in Intensive Care, where would you be? What would you be doing?
2. Who is there with you? What are they doing? (use specific term/language she uses to describe people who would be present).
3. What are they saying?
4. Who would be in the room with you? Who would you like to have in the room with you? Who wouldn't you like to have in the room with you? Why wouldn't you like to be in the room with you?
5. What kinds of things does your mommy do for you when you are in the hospital that make you feel better? Does the nurse/RT/doctor do these things? Would you like them to do them?
6. How would you feel if the staff did 'things' the way your mom does them? (Fill in the blank of whatever she replies for the above question)

- **Vignette**

I would like to tell you a story about Charlotte. This is Charlotte in the picture here. She is 9 years old, and she has [medical condition], just like you. Charlotte is in the hospital in the intensive care unit after a surgery she had, and she is resting. Her nurse goes into the room and wakes Charlotte up to take her vital signs and check her dressing from her surgery.

1. What do you think Charlotte is going to tell the nurse when she goes into her room?
2. How do you think Charlotte will feel when the nurse enters the room?
3. How do you think Charlotte will communicate with the nurse if she needs something? (Prompts: As if she has a dry mouth, or needs to be sucked on, or change positions)
4. Do you have a story like Charlotte's?