

## APPENDIX:

### Sample Questions from Semi-Structured Interview Guide

1. First, can you tell me about your child and why they are on a monitor?
  - a. What goals, if any, did your doctor set for your child in relation to monitoring? (Specific numbers or length of time?)
2. What medical devices does your child use at home – can you tell me a little bit about each of them?
  - a. What training or education did you receive about your child's medical device? From whom did you receive the information?
3. What is it like living with that medical technology at home?
  - a. What do you feel are the positive or good parts?
  - b. What do you feel are the negative or bad parts?
  - c. Can you tell me a little about what it's like during the day? What about in the evening or at night?
4. We are interested in how families deal with alarms from their in-home medical devices, particularly those that are used for monitoring like pulse oximeters. Tell me about your experience with alarms.
  - a. Who typically responds to alarms?
  - b. How have alarms impacted your daily life? (i.e. work, school, taking care of other children in the home, etc.)
    - i. [If they're having trouble answering, probe with "On a scale from 'not at all' to 'all the time'..."]
    - ii. How do you plan for trips outside of the home with the monitoring device? What, if any, logistical issues do you run into during this process?
  - c. How often do they wake you up at nighttime?
  - d. Can you tell me about a time you were so tired that you slept through alarms?
  - e. Does your child ever spend any time off of the monitoring devices? Can you tell me more about how you decide when (or not) to remove them and why?
    - i. How do you feel when your child is off of or away from the device?
5. Alarms can indicate a few different scenarios.
  - a. If there was an alarm, what steps would you take to resolve or troubleshoot?
    - i. What are the guidelines or reference materials you might use to help?
  - b. How often are the alarms that occur emergencies? Can you tell me about a time that the alarm indicated an emergency?
  - c. Are there ever alarms that occur and are not emergencies? If so, could you tell us about them?
    - i. Was there a time when the alarm did not go off when it should have? If so, could you tell me about that?
  - d. Can you tell me about a time you got so many false alarms that you ended up turning the monitors off, or ignoring alarms?
6. We are also interested in how you monitor alarms.
  - a. How do you keep track of how often alarms occur, when they occur, and what caused them?
  - b. How do you communicate that alarm information to the doctors and nurses who are in charge of the care your child is receiving?
  - c. Who makes up the medical team you communicate with? If there is an emergency who on the team do you contact?

7. Sometimes families come up with ways to more effectively manage alarms for themselves.
  - a. What are the changes, adaptations, adjustments, or “hacks” that you have developed to make life with monitoring easier, especially to make dealing with alarms easier?
  - b. Have you had to make changes to the way you use your child’s monitor to a way that is different than how it was originally prescribed to be used?
  - c. What advice would you give to other families to make life with medical devices easier? What about for dealing with alarms?
8. Alarms can be fatiguing. What part of the home monitoring system would you most like to change, and why?
9. Is there anything I didn’t ask about that is important for us to know about how you or your family interacts with home monitoring and alarms?