Connected Care Study Guide – Family Caregiver Experience

Part 1: Pre-hospital preparedness

1. Let's talk about when you were in the hospital – can you tell me about the technology that your child was started on?

2. Can you tell me about your experience learning to care for your child's new medical technology?
   a. [Can prompt]: Can you elaborate on what you learned?
   b. [Can prompt]: Did you receive teaching in the hospital, or at bedside, or in a classroom?
   c. [Can prompt]: Was the teaching in one session or split across sessions?
   d. [Can prompt]: What was most helpful about the training that you received?
   e. IF VIRTUALLY:
      i. [Can prompt]: What was it like to receive the training through zoom?
      ii. [Can prompt]: Do you think it would have been different to have the training in person?
      iii. [Can prompt]: Were you watching or were you able to practice with a mannequin?
   f. [Can prompt]: Was there anyone else in your household that received the training?

3. Before you left the hospital, did you feel like you had enough training before you went home?
   a. Did you feel like you had enough practice and had the tools to succeed?
   b. Now that you've gone home, do you feel like there was anything missing from the training you received?

4. What didn't go well in preparing for your child's care at home?
   a. Do you think there was anything else that could have made you more confident?

Part 2: Home readiness experience

5. Let's talk about after you were discharged from the hospital - Can you tell me about an average day in your life caring for your child using a medical technology at home?
   a. How does your new medical new technology fit into your day?
   b. How do you stay organized with all that you have to handle?
   c. How are you managing or coping?

6. Which aspects of your CCP training are you using on an average day?
   a. Is there any extra training or preparation you could have had in the hospital that would make a day like this a bit easier?

Part 3: Access and supports

7. Now let's talk about your supports at home – how is it going with your home care nurses?
   a. Do you think they feel comfortable caring for your child?
   b. Are you confident in their skills as they care for your child's technologies?
   c. Have you had any issues with your homecare support, such as cancelled shifts or nurses falling asleep during their night shift?

8. Connected Care offers home care nurses access to call them 24/7. Do you know if your home care team used this service?
   a. Can you tell me about any of your nurse's experiences communicating post-discharge with the 24/7 hotline or by e-mail or over the phone? Are you aware of any?
   b. Have you spoken with your homecare nurses about their experience? Were you aware of the program (prompt Connected Care live)?

9. Let's talk about your life at home. Often children recently discharged from hospital with new medical technologies may experience trouble or complications with the technology. Can you tell me if you have experienced this and what happened?
   a. [*Can prompt*] Did you need to go to the hospital?
   b. [*Can prompt*] What was your experience finding education and resources? Did you feel that your needs were identified and met?
   c. Which materials or resources were especially helpful for you?
   d. Which of the connected care materials did you make use of? If any, do you have any feedback to share about these?
   e. Is there anything that would have been helpful that you didn't have?
   f. Do you feel prepared for handling emergencies?

10. Apart from the complications we discussed, have you experienced any other 'bad days' with the technology? Perhaps where your child had a medical emergency or an equipment failure or just a day that went sideways.
    a. Is there anything that would have helped you get through this day?
    b. Help us understand how we can better support families who are caring for a child with a new medical technology at home?

11. We are coming to the end of the interview, do you have any additional questions or thoughts?