Appendix I. Qualitative Interview Protocol

Time of interview: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Place: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Researcher: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Participant: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Introduction**:

(Participant name), I want to thank you for taking the time to talk with me today.

Everything we say is on the record unless you request otherwise during the interview.

As stated in the recruitment letter, I am conducting a study with four students for a research class project at U.A.B. The purpose of our study is to understand how you learn about sickle cell. During this interview, I will take notes and record the interview so I do not miss anything you say. To protect your privacy, please use a fake name and do not name your child.

**Questions:**

Icebreaker #1: Tell me a little about your child?

Icebreaker #2Who are the people taking care of your child?

Icebreaker #3: Do any of these people have sickle cell anemia?

Icebreaker#4: How many people do you know have sickle cell anemia?

**Main Questions**

1. How did you feel when your child was diagnosed with sickle cell anemia?

(probes: scared, nervous)

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2. How did you learn more about sickle cell anemia after you were told your child has it?

(probe: have you tried to learn about SCA, have people talked to you about SCA)

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 3. Describe your reaction to getting information about your child’s disease? (Based on above: Probe for difficulties with learning about SCA, trust of sources, comfort with talking with others, comfort with asking for information, experience with physicians, DESCRIBE the ease of finding sources)

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4. How easy or difficult was it for you to learn about SCA?

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(Probe: Find out what has made it difficult or easy for you to learn about SCA)

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5. At your appointment, what else do you want to learn about SCA? (Probe for questions you want answered)

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6. At your appointment, how do you want to learn about your child’s disease? (Probe for how you learn: video, one-on-one, doctor or nurse, role of physician mistrust)

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7. Is there anything else you would like to add about learning about SCA?

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Thank you for your participation. Please be assured that your confidentiality will be maintained throughout the study. May I call you after your appointment if I need to clarify anything?