Attachment 1:

Moderator Guide & Respondent Materials for Patients Ages 9-13 (CCHMC)

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ACTION SCD – Patient, 9-13 years old, Focus Group
Moderator Guide

Research Objective:

Gather qualitative data from patients ages 9-13 years old with sickle cell disease (SCD) to better understand how young adolescents: (1) contextualize their disease, (2) define experiences and perceived needs around care transitions, and (3) use technology currently and understand how they think technology could aid health care transitions.

Goals:

- Understand how young adolescents live with and think about SCD

- Understand young adolescents experiences and barriers transitioning between care settings (e.g., ED to inpatient; discharge to home)

- Understand young adolescents current use of technology

- Receive feedback on the value and components of a possible tool that would support SCD care transitions

Participant Profile:

The group will consist of 6-10 participants with a mix of the following characteristics:

- Participants with a mix of ages 9-13 years old

- Mixed hemoglobinopathy representation (Hb SS, S beta thalassemia, SC) if possible

- Participants with a mix of genders and ethnicities

- SCD patients with varying care transitions experiences

- Varying familiarity with technology and its use

Logistics:

One focus group for adolescents 9-13 years old will be conducted at Cincinnati Children's Hospital Medical Center.

- Date and times TBD

Introduction:

Co-moderators introduce themselves and their roles. Note the discussion will be recorded, however, participant responses will be used for research, remain confidential, and will be reported

anonymously. (*Note: signed parental permission will be attained for all minor participants and adolescents ≥11 years old will provide signed adolescent assent prior to participation*) We anticipate the session will last 2 hours. Participants should feel free to get up at any time for breaks.

Discussion:

We are here today because the Agency for Healthcare Research and Quality, part of the US government, is interested in developing a technology-based tool, like an app or computer program, that could help people who have sickle cell disease manage their health. We are interested in learning more about sickle cell disease, and especially about care transitions. Care transitions are things like being admitted to a hospital and then taking care of your sickle cell condition at home, or switching from seeing a doctor for kids to a doctor for adults. We think there might be a way for a cell phone app or computer program to make these care transitions easier. . Such a tool might also have useful information about your health or care plan.

First, we would like to hear about your experience living with sickle cell disease and what it is like for you when you go to the doctor and/or the hospital. We would also like to learn about how you currently use technology, like cell phones and computers, and whether you think technology might be able to help you live better with sickle cell disease. What you share will help us design a technology-based tool. Everything you say will be kept private. Does anyone have any questions?

Questions:

Experience with SCD

1. Please tell me what it is like to be a kid or teen with sickle cell?
   a. What is hard about having sickle cell?
   b. What is the worst thing about having sickle cell?
   c. What are you afraid of?
   d. What if anything would help make living with sickle cell better?
   e. Do you have friends with sickle cell? Do you talk about sickle cell with your friends? Why or why not?

Thank you for sharing. Now we are going to talk more about your experiences when you go to the hospital or doctor.

Experiences with Care Transitions

2. How have things gone when you were sick and had to be admitted to the hospital and needed to stay overnight?
   a. What went well?
   b. What didn't go well or could have gone better?
   c. How did the doctors that took care of you learn about you and that you had sickle cell? Who was with you?

3. Think about the last time you were in the hospital. What happened after you left the hospital?

a. What things did you do—such as medications you took and when you had to go back to the doctor

b. What things does your parent/caregiver do to help take care of you and your illness?

c. How does your regular doctor find out you were in the hospital?

d. Do you know if the hospital gets in touch with your regular doctor and tells them what happened? How do you know?

4. When you go to see a new doctor/nurse, either in a clinic or in the emergency room, how do they get to know about you and your illness? Do you or your parents do most of the talking? Why?

a. What happens when you go to the sickle cell doctor?

b. What happens when you go to the emergency room and see whoever is there?

5. When you go to the doctor or hospital, would you like to be more in charge of your health? (be the one making the decisions about medicine or other things)? Why or why not?

a. What about when you are older?

b. Would you like to see the doctor without your parent being in the room? Why or why not?

6. What is your biggest worry about seeing a new doctor or going to a new hospital?

Thank you. Now we are going to talk about technology – cell phones, apps, and computers – and how you might use this for sickle cell.

Opinions about Technology Use and Sickle Cell

7. Which do you use the most: cell phone, computer, tablet, laptop?

a. When and where do you use it?

b. Do you have rules around when/how you can use your cell phone?

c. Do you have rules around when/how you can use the computer/internet?

d. Do your parents check the text messages/e-mails on your phone or computer?

8. Do you think having information about your sickle cell disease on your phone or computer would be helpful or a good thing? Why or why not?

a. Would having information about your sickle cell disease on your phone or computer be helpful to keep track of your doctors or medications? Why or why not?

b. What about learning about sickle cell or playing games that might be about sickle cell?

9. Think about something like an app on a phone or computer program that might help with your sickle cell.

a. What information about your sickle cell should the app or program have?

b. What types of information would you not want the app or program to have?

c. Who should be able to look at the information? (may need prompts—parents, teachers, doctors others)

d. Who should be able to change the information?

e. If information about your sickle cell was on a cell phone or computer, would you be worried about keeping that information private?

f. Would you want your parent/guardian to be able to use the app or computer program? What things might they use it for?

g. How do you think your parents/guardians would feel about your having an app to help with your SCD? (Prompt—things they would like? Things they wouldn't like)

h. What problems might your parents/guardians have with you using an app or program for your SCD? What would they be worried about?

Close:

Before closing and thanking participants for their time and input, ask the following question:

10. Is there anything else we should know about your thoughts or feelings about going from the hospital to home or going to a new doctor that would help us? Anything else about apps, computers or pictures/videos and how you use them or would like to use them to help manage your SCD that we should know?

Recruitment Flyer for Patients (CCHMC)

Cincinnati Children's

DISCUSSION GROUP FOR CHILDREN 9-13 YEARS WITH SICKLE CELL DISEASE

As child with sickle cell disease, we want to learn more from you. Come and share what it is like to live with and think about sickle cell disease. We also want to understand your current use of cell phones, computers, and tablets and how these could be used to improve care. The information you provide will be used to help develop a technology based health data management tool.

All participants will receive $50 for their time and travel

Your participation is appreciated!

Date and Time: TBD
Cincinnati Children's
Location: TBD

To participate or to ask questions, please call 513-xxx-xxxx or email xxx@cchmc.org