

**Attachment 4:**  
**Moderator Guide & Respondent Materials for**  
**Patients – Mixed Ages (CNMC)**

## **Table of Contents**

<b>Moderator Guide.....</b>	<b>4-3</b>
<b>Recruitment Flyer for Patients and Adults (CNMC).....</b>	<b>4-7</b>

## **ACTION SCD – Patient, 9-18 years old, Focus Group Moderator Guide**

### **Research Objective:**

To better understand how adolescent and young adult sickle cell patients: (1) contextualize their disease, (2) define experiences and perceived needs around care transitions, and (3) use technology currently. The focus groups will also serve to gather adolescent and young adult sickle cell patients' perspectives about how technology could aid with health care transitions. Additionally, older participants will have the opportunity to reflect on discussion topics prompted by both younger participant opinions as well as relate their experiences with transitions throughout their adolescence.

### **Goals:**

- Understand patient experience with different health care transitions
- Understand how patients and their medical providers communicate with one another
- Understand if and how patients have been organizing their medical information and how it has changed over time
- Obtain feedback about the types of technology patients use currently for health and non-health purposes
- Understand how patients may find a medical sickle cell disease app helpful or not
- Obtain ideas about what would make a good app for individuals with sickle cell disease during care transitions

### **Participant Profile:**

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

- SCD patients with varying disease severity, hemoglobinopathies, and care transitions experiences
- Participants with a mix of genders and ethnicities (African, Hispanic, Caribbean, and African American)
- Participants aged 18 years old and older
- Varying familiarity with technology and its use

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## **Introduction – Explanation of Project:**

First, I would like to thank all of you for participating in this focus group. The goal of this session is to better understand how it's gone for you when you've seen new doctors (we're interested in both the positive and negative things), how you use the internet and a computer and, if you have one, a cell phone, and to get your ideas for designing an electronic medical tool or app that might be able to help with some of the problems related to changes between doctors and settings such as clinics and hospitals. We call these changes between doctors and medical settings health care transitions. Examples include being admitted to the hospital from the Emergency Department, or visiting a clinic or doctor where you haven't been seen before, or when you are discharged from the hospital and go back to see your primary care doctor.

We are interested in your opinions which will help design an electronic transition tool or app for young people with Sickle Cell Disease. We want this app to help organize your personal medical information so that health care transitions are as safe as possible. We are going to ask you a series of open-ended questions. You are not required to answer any particular question and please ask for clarification if anything is unclear.

We would like to give the younger participants a chance to speak first for each topic, then hear from the older participants.

Are there any questions before we begin? Thanks again everyone, let's get started.

## **Discussion Topics and Possible Probes/Follow-up**

For each probe, moderators give the younger participants a chance to speak first. Ask the older participants if this was their experience when they were younger and how their experience has, or has not, changed over time.

### ***Experiences with Care Transitions***

1. How have things gone when you were sick and had to come 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 disease? Who was with you?
  - d. How did it go when you left the hospital?

Do you know if the hospital gets in touch with your regular doctors and tells them what happens? How do you know?
2. 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 and what's happened to you? ? Do you or your parents do most of the talking? Why?
  - a. Follow up for older participants:
    - i. Was your experience similar when you were younger?

- ii. How has your experience with speaking with doctors changed as you have gotten older?
- 3. Have any of your doctors discussed having to leave pediatrics for an adult doctor?
  - a. What, if anything, are you and your doctor doing to make sure you are ready?
  - b. Do you know how your medical information will get from your pediatric to adult doctor? If yes, how?
  - c. In your opinion, what is the best way for your medical information to be explained to your new doctor?

### ***Experience with Provider Communication***

- 4. Do you see your doctors (such as your primary care or SCD doctor) alone without a parent/caregiver for some part of the visit?
  - a. Do you see your regular doctor alone without a parent/caregiver for some part of a visit?
  - b. Give some examples of when you would or wouldn't have your parent in the room with you.
  - c. Do your parents ever speak to doctors without you in the room?  
Are you ok with that? Or would you be ok with that?  
Why or why not?
  - d. Follow up for older participants:
    - i. Was your experience similar when you were younger?
    - ii. How has your experience with speaking with doctors changed as you have gotten older?

### ***Relationship with Parent/ Caregiver***

- 5. At what age do you think it is necessary for young people with sickle cell disease to be responsible for (or have handy/carry with them) their medical information? For example their insurance card, their history/surgeries, their medications, etc.
  - a. Do you keep information about your medical history? Like a list of medications, doctors you see, allergies, or surgeries and hospitalizations?
  - b. How or where do you keep this information?
  - c. How does this information get updated?
  - d. If you don't carry your own insurance information, who is responsible?
  - e. Follow up for older participants:  
What advice would you give younger people with SCD to help with keeping track of their medical information?

### ***Technology Use***

- 6. Which device do you use the most (cell phone, computer, tablet, laptop, other) and why?
  - a. When and where do you use the device?
  - b. What kind of information, if any, do you have on your phone or computer?

- c. What rules do you have around how you can use your cell phone or the internet?
- d. Who pays for your devices?
- e. What apps do you use the most?
  - i. What do you like best about them?
  - ii. Are there apps you don't like to use?  
Can you give some examples and explain why you don't like them?
- f. Do your parents check the text messages/Emails on your phone?

### **SCD Tool**

We are thinking of developing an app – something you can use on your phone, on your iPad, or some other device that hasn't even been invented yet – that will help you live with sickle cell disease better. In particular, we are thinking the app might be most useful when you are changing doctors because you are changing to an adult doctor, when you are being seen in the emergency room, or when you are being discharged from the hospital, for example.

- 7. Do you think such an app would be helpful to you (and why)?
- 8. Could you see yourself using an app to help manage your health information?
- 9. What would that app do for you (and why)?
- 10. How would you want information to be entered? From the medical record directly? Input by parents? Caregivers? Patients themselves?
- 11. Who would you want to have access to this information?
- 12. As you get older, there may be things that you would like to keep private, just between you and your doctor. Are there some types of information you would prefer not be shared, and if so why not and with whom?  
Follow up for older participants: Can you tell us about a situation where you were not comfortable sharing private information?
- 13. How would you feel if your parent/caregiver could use it too?

### **Close:**

Before closing and thanking participants for their time and input, ask the following question: Is there anything we missed about this topic that you would want to talk about?

## Recruitment Flyer for Patients and Adults (CNMC)

### *Improving Care Transitions*

*Patients and families with sickle cell disease,  
We need your opinions.  
Participate in a focus group and help us make  
care transitions as smooth as possible.*

We are developing an app for use on your smartphone, iPad, or other compatible device—that will help you manage sickle cell disease better.

**WHO:** Children and adolescents with sickle cell disease ages 9-22 years old and their parents.

**WHAT:** A focus group to discuss your experiences with health care and your ideas about what would make a good app for people with sickle cell disease during care transitions.

**WHEN:** Summer 2013

**WHERE:** The Hematology Clinic at Children's National

**CONTACT:** If you are interested please contact Lindsay Ammons at 202-476-1333, or [lammons@childrensnational.org](mailto:lammons@childrensnational.org).

*Participants will be compensated for their time.*