# Attachment 5:

# Moderator Guide for Parents/Caregivers (CCHMC, Nemours, and CNMC)

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Form Approved
OMB No. 0935-XXXX
Exp. Date XX/XX/20XX

# ACTION SCD – Parent/Caregiver Focus Group Moderator Guide

## Research Objective:

Gather qualitative data from parents/caregivers of patients with sickle cell disease (SCD) regarding their previous experiences and perceived needs with transitioning their son or daughter between healthcare sites and from pediatric to adult care, to identify barriers and facilitators to high quality care during these transitions from the perspectives of parents and caregivers, and understand their current use of technology and how it could be used to improve transitional care.

## Goals:

- Understand parents/caregivers of pediatric patients with SCD previous experiences and barriers transitioning between care settings (e.g., inpatient to outpatient, clinic to ER)
- Understand parents'/caregivers' previous experiences and barriers transitioning pediatric to adult care
- Identify key information needs for parents/caregivers of patients with SCD during transition of healthcare
- Understand current use of technology by parents/caregivers and gain perspective on how they think technology could aid with health transitions
- Receive input on the value and components of a possible tool that would support healthcare management and transitions

## Participant Profile:

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

- Parents/caregivers of patients with sickle cell disease of mixed genders and age and including children with varying sickle cell disease severity (High acuity will be defined by the following criteria: a.>3 hospital admissions/year b. history of stroke c. history of acute chest syndrome d. receiving chronic transfusion therapy)
- Mixed hemoglobinopathy representation (Hb SS, S beta thalassemia, SC) of patients

- As possible, participants with:
  - Mixed immigration status, ethnicities and household makeup (single parent versus nuclear family versus extended family versus other family types eg. caregivers such as grandparents or other extended family member, foster parents)
  - Varying consistent lengths of stay at current pediatric hematology practice (defined as patient/family followed at pediatric hematology center
    a) Under 1 year
    b) 1-5 years
    c) 5-10 years
    d) >10 years
  - Varying technology device usage (defined as patient having prior experience with any or all of the following IT devices: cell phones, computers, tablets)

### Logistics:

Three focus groups for parents of SCD patients will be conducted, one at Cincinnati Children's Hospital Medical Center (CCHMC), one at Nemours Children's Clinic-Jacksonville (NCC-J) and one at Children's National Medical Center –Washington, D.C. ( CNMC )

- Dates 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: participants will be asked at sign-in to sign a sheet confirming their approval for recording the session*). We anticipate the session will last 2 hours. Participants will be given at least 1 break during the 2 hour focus group to be determined by co-moderators.

### Discussion:

Tell respondents what they will be doing – participating in a discussion, expressing their views honestly and openly, and that they do not have to answer any particular question or group of questions they do not wish to answer, and that they may ask for clarification or explanation if anything is difficult to understand, or if it is unclear what is being asked or discussed.

As a parent/caregiver of a child with sickle cell disease, you know that kids with sickle cell disease can receive poorer quality healthcare and end up getting sick when they have to obtain this care from an unfamiliar doctor or hospital. And, we are here today to try to figure out why this happens and how to make these situations better. We are very interesting in learning more about health care transitions specific to your sickle cell disease. Care transitions included such situations as being admitted to a hospital or switching from seeing a doctor who takes care of children to a doctor for adults. We believe that there might be a way for a technology-based tool, like a smart phone app, to make these transitions of care easier for your son or daughter and other patients with sickle cell disease. Such a tool might store useful information about your child's health or care plan.

For this first half of our focus group discussion, we will be talking about how you and your child with sickle cell disease currently use technology such as computers, smart phones, and tablets.

This will be followed by a discussion on how your child with sickle cell disease personal health information is currently tracked.

The second half of our focus group discussion will begin with you sharing your feelings, needs and challenges surrounding transitions of healthcare. When we use the word "Transition" it means a change in setting or doctor. This could refer to a change from the outpatient clinic to the hospital or a change from pediatric care to adult care or a change from your primary care doctor to a specialty doctor such as a sickle cell doctor.

We would like to end our discussion with each of you giving us your thoughts and ideas about how to develop a technology tool that could help your son or daughter in the future with tracking their personal health information, managing their sickle cell disease, and assisting their doctors with healthcare transitions. What you share in this focus group will help us design a technology-based tool. Everything you say will be kept private. Does anyone have any questions before we start?

The purpose of this discussion is to gather input from parents/caregivers about their previous experiences, perceived needs and concerns regarding transitioning their child between healthcare sites and from pediatric to adult care and to identify barriers and facilitators to high quality care during these transitions. An additional goal is to gain information on parents/caregivers current use of technology and views on how use of technology could improve the transition process for their child.

### *Familiarity with Use of Technology*

For the first part of this focus group, we are going to talk about technology and how it might be used in helping your child manage his/her sickle cell disease. But first, we would like to talk with you about how you and your child with sickle cell disease are currently use technology such as computers, smart phones, tablets.

1. Please describe your current familiarity with technology such cell phones, computers, and tablets?
    a. Which devices and apps do you own or use most and feel most comfortable using?
    b. Do you use technology to communicate with your friends and family? If so how?
    c. Have you ever used technology to communicate with other patients/families affected by SCD? If so,how?
    d. Who pays for your family's devices and upgrades, and is this a hardship?
    e. Have you ever used technology including cell phone and text message or emails to communicate with healthcare providers? If so, with whom and how?
    f. Have you ever used the internet or other technology such as health apps to obtain medical information? If so, how? What health related websites or mobile apps, if any, do you use or have?
    g. Do you use technology to schedule healthcare appointments or request medication refills or review lab results? If so how?
    h. Do you currently use health information technology to store/access personal health information?

If so, what types of information have you stored and what type of device or software was used?

i. What, if any, concerns do you have about health information technology, such as concerns about privacy?

2. Next, please describe your son or daughter with sickle cell disease current familiarity with technology such cell phones, computers, and tablets?
    a. Which devices and apps does your child own or use most and feel most comfortable using?
    b. Does he or she use technology to communicate with their friends and family? If so how?
    c. Has he or she ever used technology to communicate with other patients/families affected by SCD? If so, how?
    d. Who pays for your family's devices and upgrades, and is this a hardship?
    e. Has your child ever used technology including cell phone and text message or emails to communicate with healthcare providers? If so, with whom and how?
    f. Does your child ever use the internet or other technology such as health apps to obtain medical information? If so, how? What health related websites or mobile apps, if any, does he or she use or have?
    g. Has your child ever used technology to schedule healthcare appointments or request medication refills or review lab results? If so how?
    h. Does your child currently use health information technology to store/access their personal health information?

        If so, what types of information have been stored and what type of device or software was used?

    i. What, if any, concerns do you have about health information technology, such as concerns about privacy?

### *Previous Experiences with Healthcare Transitions*

Navigating your way around different hospital departments, outpatient clinics or even the emergency room can at times be somewhat challenging even for the most seasoned of parents.

For the next part of our discussion, we would like you to share with us your feelings, needs and challenges surrounding transitions of healthcare for your son or daughter with sickle cell disease. When we use the word "Transition" it means a change, particularly a change in settings or doctors. This could refer to a change from the outpatient clinic to the hospital or a change from pediatric care to adult care or a change from your child's primary care doctor to a specialty doctor such as a sickle cell doctor.

To begin, we would first like you to think about an experience that you and your child have had in a ***familiar*** hospital, emergency room or outpatient clinic setting that required a transition of care such as from your home to the emergency room or from your outpatient hematology clinic to an inpatient hospitalization or perhaps from the emergency room to an inpatient hospitalization.

3. Can you first briefly describe the setting and your child's healthcare transition experience that in your opinion went well?
4. Can you also briefly describe a healthcare experience that you felt did not go well?
    a. How were you able to communicate with the doctors about your child's current medical condition, their personal health information such as their sickle cell disease history and their current medications and allergies?
    b. Did you just talk about your son or daughter's medical information or did you have any written or electronically stored information that you were able to show the doctor(s)?
    c. Do you know if the doctors were able to obtain all the necessary medical information they needed from you in order to care of your child?

        If not, in what other ways were the doctors able to obtain this information? Did they have to take care of your child without information that they needed or wanted?
    d. At the time of leaving the appointment or visit, did you receive any instructions from doctors about changes or additions to your child's medications, treatment plans, things to watch for and/or necessary follow-up appointments, etc? How was this information given to you (verbally, paper document such as discharge instruction sheet or electronically through email)?
    e. Following your child's appointment or visit, do you know if any of your child's other doctors such as his or her primary care physician or regular sickle cell doctor received any information about this healthcare encounter?

        If so, what information did they receive and how did they receive this information (doctor-doctor (in person or on the phone) discharge instruction sheet, accessing information via an electronic medical record?)

Next, we would like to get some information from anyone who has ever had to take their child to an *unfamiliar* hospital, clinic or emergency room in order to receive sickle cell care by doctors who did not know your child.

5. Can you briefly describe the setting and your child's healthcare experience in this unfamiliar setting? What went well? What did not go well?
    a. How were you able to communicate with the doctors about your child's current medical condition, their personal health information such as their sickle cell disease history and their current medications and allergies?
    b. Did you talk about everything or did you have any written or electronically stored information that you were able to show to the doctor(s)?
    c. Do you think your child's doctor(s) were able to get all the medical information they needed from you in order to care of your child?

        If not, in what other ways were the doctors able to obtain this information? Did they have to take care of your child without information they wanted or needed? What happened then?

d. At the time of leaving the appointment or visit, did you receive any instructions from doctors about changes or additions to your child's medications, treatment plans, things to watch for and/or necessary follow-up appointments, etc?

   How was this information given to you (verbally, paper document such discharge instruction sheet, electronically through email?)

e. Following the appointment or visit, do you know if any of your child's other doctors such as his or her primary care doctor, regular sickle cell doctor received any information about this healthcare encounter?

   i. If so, what information did they receive and how did they receive this information (doctor-doctor- face to face versus phone call, discharge instruction sheet, accessing information via an electronic medical record?)

   ii. What strikes you as different between these experiences—in places that are familiar versus places that are not?

### *Opinions/Needs/Challenges Surrounding Pediatric to Adult Focused SCD Transitions*

An important upcoming transition in your child's future will be transitioning his/her sickle cell care from a child-focused to an adult focused healthcare system.

6. Do you have any personal experience transitioning yourself or a family member with sickle cell disease or any other chronic illness from pediatric to adult care? If so, what went well? What could have been improved?

7. Next we want to hear from you about how transitions from pediatric to adult care occur within your child's current pediatric hematology practice. Now tell us how you really WANT it to work? What do you hope will take place for your child when they are ready to make the transition to adult sickle cell care?

8. In your opinion, during a sickle cell disease healthcare transition, what is the role of the following people:

   a. You, the patient with sickle cell disease
   b. Your parent(s)/guardians(s)
   c. Your (handing off care) pediatric healthcare team
   d. Your (receiving care) adult healthcare team

   (Who should be in charge? Who should make the appointments? Who could help your child the most during this transition of care? )

### *Health Information Management*

Next, let's talk about how your child's personal health information should be transitioned over to the adult sickle cell healthcare team. Personal health information generally refers to protected health information such as your medical history, laboratory and other testing results, medications, demographic data, immunization record and insurance information.

9. How would you prefer your child's personal health information be communicated to your new adult hematologist (through verbal conversation face to face versus phone

conversation, written documentation such as a transition summary and/or access to your pediatric medical chart or electronic medical record)?

10. Is there any part of your child's current personal health information that you would have concerns about having his or her new adult hematologist or other members of the adult health care team have access to?

We will end our discussion with each of you giving us your thoughts and ideas about how we could develop a technology tool that in the future could help your son or daughter with tracking their personal health information, managing their sickle cell disease, and assisting with healthcare transitions.

### *Views about a Technology Based Transition Tool*

Finally, we would like you now to think about a technology tool, such as an app for a smart phone or a tablet or a computer software program that could serve several purposes. First, it might be able to better help your children to self-manage their sickle cell disease by allowing them to have access to their personal health information and/or to receive messages and reminders from their doctors and nurses. Secondly, by allowing doctors and nurses to have quicker and easier access to some or all of your child's personal health information, a tool might help doctors to better manage your child's sickle cell disease especially during times of transition. These are some examples but we want to hear about your ideas rather than ours.

11. Now, try to envision a technology-based tool that might assist you and/or your child with management of their sickle cell disease especially during times of healthcare transitions.
    a. What would this tool be able to do?
    b. What information would it have?
    c. Who could use the tool and how?
    d. What kind of technology do you think would be easiest for your child to keep track of and use?
    e. Are your worried about who might see the information? If so, who should have access to this tool? And, what kinds of information should they be able to access and what types of information should they not be able to access?

## Close:

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

*Is there anything else you want to bring up about your child moving between different doctors or hospitals, transitioning to adult healthcare, or how technology based apps or computer programs might be able to help with this?*

As we now come to the close to our discussion, we want to thank you for participating in this focus group. Your thoughts, ideas and comments that you have shared with use today were truly wonderful and will be extremely helpful to us in the future development of our technology tool. Know that everything that was discussed in this focus group today has been recorded anonymously and will remain confidential. We hope you have a wonderful rest of your day!

**Recruitment Flyer for Parents/Caregivers (CCHMC)**

# Improving Sickle Cell Care Transitions
# Parent Focus Groups

As parent/caregiver for a child with sickle cell disease, we value your input. Come and share your experiences of transitioning your child and/or young adult between healthcare sites and from pediatric to adult care. We also want to understand your current use of technology and how it could be used to improve transitional 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**

Cincinnati Children's

## Recruitment Flyer for Parents/Caregivers (Nemours)


# Improving Sickle Cell Care Transitions Parent Focus Groups

As parent/caregiver for a child with sickle cell disease, we value your input. Come and share your experiences of transitioning your child and/or young adult between healthcare sites and from pediatric to adult care. We also want to understand your current use of technology and how it could be used to improve transitional 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*

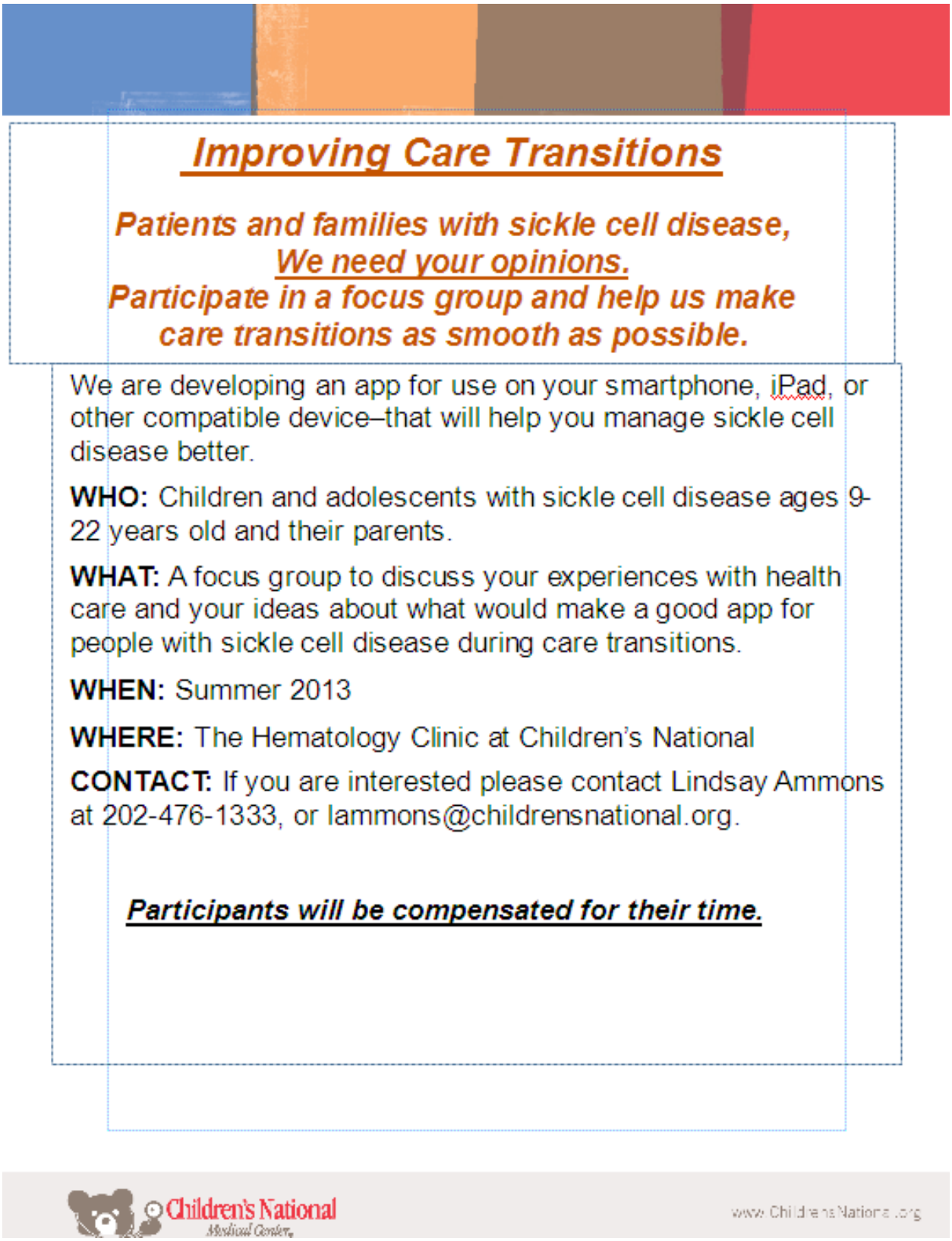
*Your participation is appreciated!*

**Date and Time: TBD**
**Nemours Children's Clinic**
**Location: TBD**

**To participate or to ask questions, please call 904-xxx-xxxx or email xxx@nemours.org**

Nemours.

**Recruitment Flyer for Patients and Adults (CNMC)**



# Parent/Caregiver Recruitment E-mail (CNMC)

Dear (parent):

The Sickle Cell Program at Children's National Medical Center (CNMC) is working with the Agency for Healthcare Research and Quality (AHRQ) to learn more about how an electronic medical tool or app can help people with sickle cell disease (SCD) when they change doctors or are seen in different parts of the hospital (like the emergency room (ER) or outpatient clinic). We call these changes between doctors and medical settings health care transitions. We want this app to help organize your personal medical information so that health care transitions are as safe as possible.

As part of this, AHRQ would like to hear from children and adolescents with SCD and their parents like you about their ideas for designing an app that might be able to help with some of the problems related to changes between doctors and settings such as clinics and hospitals. AHRQ has asked us to hold several group meetings for parents as well as children and adolescents to come and talk about SCD, their experiences with doctors who work in the ER, sickle cell clinic, and how they use technology (like cell phones and the internet).

The goals of each meeting are to:

- Understand patient experience with different health care transitions
- Understand how patients and their medical providers communicate with one another
- Understand 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
- 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

These group discussions are open to children and adolescents with SCD who receive their sickle cell care at CNMC as well as their parents. The discussions will be held in the early evening during the summer of 2013. You may get a call from us asking if you would like to be in one of these groups. We will also ask you a few questions at that time. If you do not want to participate, please just let us know when we call.

Each group session will last for two hours and will include 6-10 adolescents with SCD. We will have a separate group for 6-10 parents of adolescents with SCD at the same time. Someone will be there to lead the sessions and to take notes.

**Adolescents and parents who attend a group will receive $50 gift card as a thank you for participating. Refreshments will be served at the session.**

If you want to be in a group, you may also call or e-mail Lindsay Ammons, LGSW. When you call or e-mail, please tell us your name, your current phone number, and the best time to reach you, in case we need to call you back.

- E-mail: lammons@childrensnational.org
- Call: (202)476-1333

Thank you for your help with this important study.

Sincerely,