Attachment 3:

Moderator Guide & Respondent Materials for Patients Ages 18+ (CNMC)

Table of Contents

ACTION SCD – Patient, 18 years & older, 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.

Goals:

The objective of this research is to develop an electronic transition tool or app for individuals with Sickle Cell Disease to help organize medical information to improve the safety of health care transitions. By care transitions we mean anytime you change doctors who are caring for you. 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. Specifically we will want to:

Understand your experience with different health care transitions

Understand how you and your medical providers communicate with one another

Understand how you have been organizing your medical information

Obtain feedback about the types of technology you use currently

Understand how you may find a medical sickle cell disease app helpful or not

Your ideas about what would make a good app for people 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, mixed hemoglobinopathy representation (Hb SS, S beta thalassemia, SC), 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

Logistics:

One focus group for youth age 18 years and older will be conducted at Children's National Medical Center.

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 cell phone, if you have one and to get your ideas for designing an electronic medical tool or app that might be able to help with changing 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 us 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 and healthy 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.

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

Discussion Topics and Possible Probes/Follow-up

Experience with Care Transitions and Barriers

1. Tell us about how things have gone when you've been to the hospital with a problem and needed to stay overnight.
    a. Do you feel you are able to tell the doctor or nurse in the hospital what brought you into the hospital? Why or why not?
    b. What happened after you left the hospital?

2. When you go to see a new doctor, either in a clinic or emergency room, how do the doctors and nurses get to know about you and your medical history/past?
    a. Are there differences depending on where you go for care? Can you give some examples?
    b. Compare how you were treated by providers who know you versus providers who don't. Which do you prefer and why?
    c. Who explained your medical history (including your allergies and medications) to the different doctor? –you or someone else—who?
    d. Was there medical information that the doctors didn't have that you think would have been useful for them to know?
    e. What could be done to make it better in the future?

3. If they have, how have your doctors discussed with you 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. How do you think your medical information will get from your pediatric to adult doctor?
    c. In your opinion, what is the best way for your medical information to be explained to your new doctor?
    d. What role do your parents/caregivers play in care transition situations?

Experience with Provider Communication

4. Do you see your SCD provider(s) or specialists alone without a parent/caregiver for all or 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?

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 medical and surgical history, or a list of medications.
    a. How or where do you keep this information now?
    b. How does this information get updated?
    c. If you don't carry your own information, who is responsible?

6. Is there any sensitive information about your health (e.g. birth control/ reproductive health or mental health) that you would not be comfortable sharing with your parents/caregivers?
    a. Can you tell us about if and how you discuss your sensitive information with your doctors?

Technology use

7. 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. Do you use a computer for anything related to your health? Checking web sites, looking up lab tests or reading your medical record? (if yes…could you tell us about that; if no, why not?)

    e.   Who pays for your devices?

    f.   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?

    g.   Do your parents check the text messages/Emails on your phone?

    h.   Do you ever communicate electronically with your health care providers (e.g., emails or text messaging?)
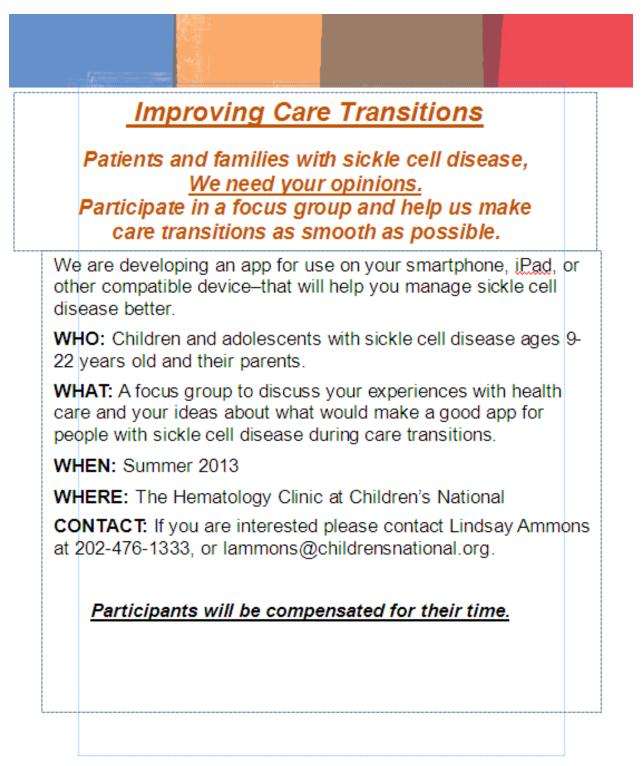
SCD tool

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 need to start going to an adult doctor now, or when you are being seen in the emergency room, or when you are being discharged from the hospital, for example.

8. Do you think such an app would be helpful to you (and why)?

9. Could you see yourself using an app to help manage your health information?

10. Ideally, what would that app do for you (and why)?

11. How would you want information to be entered? From the medical record directly? Input by parents? Caregivers? Themselves?

12. Who would you want to have access to this information?

13. Are there some types of information you would prefer not be shared, and if so why not and with whom?

14. How would you feel if your parent/caregiver could use it too? Do you think your parents could learn to use these types of tools? Is that important to you?

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.

Participants will be compensated for their time.

Children's National
Medical Center.

www.ChildrensNational.org