Attachment 2:

Moderator Guide & Respondent Materials for Patients Ages 14-17 (Nemours)

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Form Approved
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ACTION SCD – Patient, 14-17 years old, Focus Group Moderator Guide

Research Objective:

Gather qualitative data from patients with sickle cell disease (SCD) ages 14-17 regarding their previous experience with healthcare transitions, perceived needs with upcoming transitions from pediatric to adult healthcare, and finally to understand their current use of technology and how it could be used to improve their healthcare management and transitional care.

Goals:

- Understand patients' with SCD ages 14-17 previous experiences and barriers transitioning between care settings (e.g., inpatient to outpatient, clinic to ER)
- Identify key informational needs and concerns for SCD patients ages 14-17 transitioning from pediatric to adult care
- Understand current use of technology by patients with SCD ages 14-17 and gain perspective on how they think technology could aid with their healthcare management and transitions
- Receive input on the value and components of a possible tool that would support sickle cell disease healthcare management and transitions

Participant Profile:

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

- Patients with SCD age 14-17 mixed genders, age and varying disease severity. (High acuity will be defined by the following criteria: a. >3 admission/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)
- As possible, participants with:
    - Mixed immigration status, ethnicities and household makeup (single parent versus nuclear family versus extended family versus other family types eg. legal guardians such as grandparents or other extended family member or foster parents)
    - Varying patient length of consistent treatment 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 of the following IT devices: cell phones, computers, tablets)

Logistics:

One focus group for SCD patients ages 14-17 will be conducted at Nemours Children's Clinic in Jacksonville, Florida

- Date and time TBD.

Introduction:

Co-moderators introduce themselves and their roles. Notes will be taken during the focus group discussion. However participant responses will be used for research, remain confidential and will be reported anonymously. (*Note: signed parental permission will be obtained as well as patient assent prior to participation.*). 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 informing them 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.

Sometimes kids with sickle cell disease get sick when they have to obtain care from an unfamiliar doctor or hospital and we are trying 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 care these transitions of care easier for you and other sickle cell patients. Such a tool might store useful information about your health or care plan.

Today, we would like to talk about your experience living with sickle cell disease and your thoughts about getting ready to see a new doctor who works with older kids and young adults. We would also like to learn about how your currently use technology and how you think technology might be able to help you live with sickle cell disease. 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 patients with SCD age's 14-17 about:

a. Their current use of technology
b. How they keep track of their personal healthcare information
c. Their previous experiences and perceived needs with seeking sickle cell related care in unfamiliar healthcare settings (eg. ER, inpatient, etc) and how their care was coordinated
d. Their concerns about transitioning from pediatric to adult healthcare providers
e. Their thoughts and views about the development of a technology based sickle cell disease health management and transition tool.

Overview of the Focus Group:

For this first half of our focus group discussion, we will be talking about how you currently use technology such as computers, smart phones, tablets. This will be followed by a discussion on how you currently keep track of your personal health information.

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 you in the future with tracking your personal health information, managing your sickle cell disease, and assisting you and your doctors with healthcare transitions. Does anyone have any questions?

Questions:

Familiarity with Use of Technology

So, let us start with how you currently use technology such as cell phones, computers or tablets like iPads.

1. Do you currently use any of these devices to communicate with your family and friends? If so, which type of devices and can you briefly describe where, when and how you use them.
2. What apps do you and your friends currently enjoy using?
3. If you have a device, who paid for your device(s) and who pays to maintain your device (monthly fees, upgrades, etc.)?
4. Do your parents have any rules about how and when you can use these devices?
5. What concerns do you currently have about using technology in today's world (cost, privacy issues, loss of information, etc.)?
6. Do you currently use technology to communicate with your healthcare providers? If so, how?

Health Information Management

Now, let us switch gears just a bit and explore how you currently keep track of your own personal health information. Personal health information generally refers to private health information such as your medical history, the fact that you have sickle cell for example, and laboratory and other testing results, medications you've taken, demographic data, immunization records and insurance information. It also includes basic information like your name date of birth, address, age, etc.

7. Do you keep track of this information, or do you rely on someone else like a parent to keep track of this information?
8. What types of health or personal information do you keep track of?
9. Where do you currently store or keep this information? Are you good at remembering and storing this information in your head? Or, is this information written down on a paper document? Or do you use a computer, smart phone or tablet to store this information?

   If you use a technology device, do you use a password and are you comfortable at selecting a password that you believe is secure? Have you ever shared your password(s) with anyone else such (family member or friend)?
10. Do you think it is important for you to keep track of your personal health information? Why or why not?
11. If you were able to have access to your personal health information through a quick and easy technology based tool, do you believe that such a tool would make any difference in your overall health and/or the quality of healthcare you receive? Why or why not?

Needs/Concerns about Healthcare Transitions

We are now half way through our discussion today, and the next topic we would like to talk with you about is transitioning your healthcare. The word "Transition" means a change. Transitions in healthcare 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 specialty doctor such as a sickle cell doctor. A very important transition in your future will be moving from child to adult focused healthcare for your sickle cell disease.

Transitioning to an Unknown Provider: First, we would like to get some information from anyone who has ever had to receive sickle cell care at an *unfamiliar* hospital, clinic or emergency room by doctors who did not know you and your medical history.

12. How was that experience? What went well? What didn't go well?
13. How were you able to communicate with the doctors about your current medical condition, your medical history or your current medications ?
14. Did you just talk about this medical information or did you have anything written down in an electronic format that you were able to show to the doctor(s)?
15. Do you think the doctors received all the medical information they needed from you in order to care for you?
    a. If not, in what other ways was the doctor able to obtain your personal health information or did they have to take care of you without important information?
16. At the end of your visit or appointment
    b. Did you receive any instructions from doctors about changes or additions to your medications, treatment plans, things to watch for and/or necessary follow-up appointments?
    c. And how was this information given to you (verbally, via a paper document such as a discharge instruction sheet or electronically through email)?
    d. And, do you know if your regular doctor received any information about your healthcare encounter?

       If they did, do you know what information they received and how they received this information (verbally doctor-doctor in person or on the phone, paper documentation via discharge instruction sheet, accessing information via an electronic medical record?)

Transitioning to an Adult Provider: Now, let us talk a bit about transitioning or moving your sickle cell care from a children's doctor and hospital to an adult doctor and hospital**.**

17. We want to first hear from you about how you think it currently works within your pediatric. hematology practice followed by a discussion of how you really WANT it to work?
18. 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?)

19. Who could help you the most during this transition of care and why?

20. Can you identify three things that might help you to better manage your sickle cell disease as you move from the pediatric healthcare system to adult care?

Next, let's talk about how your personal health information should be transitioned over to the adult sickle cell healthcare team. Personal health information generally refers to private information such as your medical history, the fact that you have sickle cell for example, and laboratory and other testing results, medications you've taken demographic data, immunization records and insurance information.

21. How would you like your new doctor to find out about you? From talking to your pediatric doctor, from talking to you or from receiving a written summer, by looking up your records that are electronic?

22. Are there any parts of your information that you wouldn't want your new doctor to know? What would these be and why?

23. What information would you like to have yourself to help with your sickle cell disease and getting good care and staying healthier?

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 a place where you keep track of your personal health information. Second, it could be something your doctor uses to communicate with you or keep track of information about you. Also, it could be something that is used to remind you about appointments or help you schedule visits to the doctor. What do you think about some of these ideas? Helpful or not helpful? Why or why not?

24. Can you tell us what you would like this tool to look like?
    a. What information should it contain?
    b. What parts of your personal health information would you not want to be included in the tool and why?
    c. What type of tool do you think would be easiest for you to keep track of and use?
    d. What type of technological tool would be easiest for you to pay for or for your family to pay for?
    e. Who should be able to look at or change the information in the tool and how would they gain access to this information? (Doctors, parents?)
    f. Should this tool also have the ability to access email and/or Face book ? Should it also contain other apps that could also help you to better manage your sickle cell disease such as an app that lists of all the adult sickle cell centers in the U.S., direct access to websites such as The Sickle Cell Information Center, listing of local Sickle Cell Disease Associations, etc.)

Close:

Before closing, is there anything else you want to bring up about 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 Patients (Nemours)

Nemours.

DISCUSSION GROUP FOR CHILDREN 14-17 YEARS WITH SICKLE CELL DISEASE

As a teenager 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.

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

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