Attachment 6:

Moderator Guide & Respondent Materials for Providers (CNMC and CCHMC)

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ACTION SCD – Provider Focus Group Moderator Guide

Research Objective:

Gather qualitative data from health care providers of patients with sickle cell disease (SCD) regarding their experiences with transitioning patients: (1) between and among care sites, and (2) from pediatric to adult care; and to identify barriers and facilitators to providing high quality care during these transitions.

Goals:

- Understand provider experiences including facilitators and barriers transitioning patients between and among care settings (e.g., inpatient to outpatient)
- Understand provider experiences and barriers transitioning patients from pediatric to adult care
- Identify key barriers and information needs for providers of patients with SCD, including health data needs during transitions of care
- Receive feedback on the value and components of a possible tool that would support patients' care transitions

Participant Profile:

Each group will consist of 6-10 participants with a mix of the following characteristics. Based on recruitment success, criteria will be prioritized in partnership with AHRQ:

- Clinicians with experience treating SCD patients in diverse settings (including a mix of rural/urban/suburban geographic locations and pediatric/adult)
- Participants who are both men and women and represent racial/ethnic diversity
- Mix of providers serving as primary care providers, emergency physicians, hospitalists, nurses, hematologists and clinical social workers
- Varying lengths of tenure in current role as a provider (e.g. new faculty vs. senior faculty)
- Varying lengths of tenure within profession overall (e.g. recently trained clinicians vs. senior clinicians)
- Varying familiarity and comfort with HIT and technology-based healthcare tools such as Electronic Health Records

Public reporting burden for this collection of information is estimated to average 120 minutes per response, the estimated time required to complete the focus group. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

Logistics:

Two focus groups for providers will be conducted, one at Cincinnati Children's Hospital Medical Center focused on pediatric to adult care transitions and one at Children's National Medical Center focused on care transitions across care settings.

- 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: participants will be asked at sign-in to sign a sheet confirming their approval for recording the session and consenting to participate*.) We anticipate the session will last up to 2 hours. Participants should feel free to get up at any time for breaks.

Discussion:

Thank you for taking time to join us today. We are conducting a research study for the Agency for Healthcare Research and Quality (AHRQ) to inform the technical and design considerations for the development of a technology-enabled tool to support management of health care transitions for individuals with Sickle Cell Disease. I want to remind you that your participation in today's session is entirely voluntary. You were invited to participate based on your expertise in this field. Although we hope you will actively participate in the entire conversation, you may choose not to answer any question or questions and can stop at any time. Please ask for clarification or explanation if anything is difficult to understand, or if it is unclear what is being asked or discussed.

The purpose of this discussion is to gather input from providers like you about your experiences transitioning SCD patients: (1) between and among care sites such as from the emergency room and outpatient clinic, and (2) from pediatric to adult care, and to identify barriers and facilitators to high quality care during both of these transitions.

Questions:

Care Transitions from Pediatric to Adult Care

1. Let's talk about how patients with SCD make the transition from pediatric care settings to adult care.
    a. Describe a scenario where the transitions went very smoothly or happened in an ideal way.
    b. Describe a scenario where things did not go well.
    c. What kind of information is important for you as a provider to have during the transition process?
    d. What information do you expect your patients to know during the transition process from pediatric to adult care?
    e. Tell me about whether and how care is coordinated among different providers who have seen the patients?

f. Do you use any type of technology to help you share information with other providers treating your patient?
g. Do you use any paper-based tools such as a care plan or pain diary, etc.
h. What about sharing information and communicating with your patient themselves? Does that take place outside the visit and if so, how? Do you think there is a role for technology in coordinating care or communicating with patients?

Care Transitions Among Care Settings: Inpatient to Outpatient

2. Let's talk about how patients with SCD make transitions in care settings, specifically from inpatient to the outpatient setting.
   a. Describe a scenario where the transitions went very smoothly or happened in an ideal way.
   b. Describe a scenario where things did not go well.
   c. What kind information is or was important for you as a provider to have during the transition process?
   d. What information do you expect your patients to know or have during the transition process from the inpatient to outpatient setting?
   e. Tell me about whether and how care is coordinated among different providers who have seen the patients?
   f. Do you use any type of technology to help you share information with other providers treating your patient?

      Do you use any paper-based tools like a care plan, appointment card, etc.
   g. What about sharing information directly with your patient themselves outside of the visit (such as sending emails or text messages)?
      i. Does that take place and if so, how?
      ii. Do you think there is a role for technology in coordinating care or communicating with patients?

Care Transitions Between Care Settings: Outpatient to Inpatient

3. Let's talk about how patients with SCD make transitions in care settings, specifically from outpatient to the inpatient setting.
   a. Describe a scenario where the transitions went very smoothly or happened in an ideal way.
   b. Describe a scenario where things did not go well.
   c. What kind of information is important and helpful for you as a provider to have during the transition process?
   d. What information do you expect your patients to know or have during the transition process from the outpatient to inpatient setting?
   e. Tell me about whether and how care is coordinated among different providers who have seen the patients?

    f. Do you use any type of technology to help you share information with other providers treating your patient? Do you use any paper-based tools like a care plan, a note to the emergency room, etc.
    g. What about sharing information by communicating with your patient themselves outside of the visit? Does that take place and if so, how?   Do you think there is a role for technology in coordinating care or communicating with patients?

Opinions about transitions and their challenges (applicable to different types of transitions)

4. What are the biggest barriers or challenges to optimal health transitions for patients with SCD in your view?
    a. The main reasons they (transitions) don't go well
    b. What would make an ideal or successful transition?   Please describe.
    c. What do you think patients and families could do better or differently to help transitions work better? What could you do differently or better? What would help you to achieve this?

Familiarity and use of health information technology

5. Please describe your current familiarity or comfort with health information technology such as electronic health records or any mobile apps you use to help you do your job as a provider.
    a. Do you use HIT to communicate with other providers? If so, how? If not, why not?
    b. Do you use HIT to communicate with patients and caregivers directly such as clinical messaging services? If so, how? If not, why not?
    c. What, if any, concerns about HIT do you have (i.e. privacy, malpractice, etc.)?
    d. Do you use HIT tools differently when it comes to patients with SCD?
6. Do patients in your clinical practice/setting usually have electronic access to their medical records or health information such as lab test results? If yes, …
    a. How do patients access this information? (Through a portal, via email, other?)
    b. Do your typically patients access their health information? (Take advantage of the fact that they have access to it?)
    c. Do your patients seem to like having electronic access to this information? What do they like or not like about it?
    d. Are patients able to schedule their own appointments electronically?
    e. What about sensitive information such as information about adolescent issues. Does your organization limit electronic patient access to some types of sensitive information? Who can and cannot see it?

Views about a technology based transition tool

7. Please envision a technology based tool that might help with transitions (from pediatric to adult or across care settings) for patients with SCD. What would this tool be able to do? Who would use this tool and how?

8. Do you currently use any paper-based tools to support the transitions process such as discharge plans when moving patients from the inpatient to outpatient setting? Or pain management plans in paper form for patients to use overall or to transition from outpatient to inpatient setting? What about care plans for patients moving from pediatric to adult care?
    1. What are your experiences using paper-based tools to share health information with your patients?
    2. Do your patients appear to like the paper-based tools you use?
    3. Do you think a technology enabled tool could replace or improve any of the paper-based tools you currently use? Which ones and why or why not?

Close:

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

Is there anything else we should know about this topic that you would like to talk about?

Provider Recruitment Letter (CNMC)

Name
Address
City/State/Zip Code

Dear ( ):

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) during various health care transitions (ie from the outpatient clinic to the Emergency Department or from pediatric to adult care). We want this app to help organize personal medical information so that health care transitions are as safe as possible.

As part of this, AHRQ would like to hear from SCD health care providers about their ideas for designing an app that might be able to help with some of the problems related to health care transitions. In addition to the health care provider focus group, we will hold several group meetings for parents as well as children and adolescents with SCD, to share their experiences with health care providers from different specialties, and how they use technology.

The goals of each meeting are to:

- Understand provider experiences including facilitators and barriers transitioning patients between care settings (e.g., inpatient to outpatient)
- Understand provider experiences and barriers transitioning patients from pediatric to adult care
- Identify key barriers and information needs for providers of patients with SCD, including health data needs during transitions of care
- Receive feedback on the value and components of a possible tool that would support patients' care transitions

This focus group discussion is for SCD health care providers. The discussion 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. 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 SCD health care providers. Each focus group will have a facilitator who will lead the group and take notes.

Adolescents and parents who attend a group will receive a $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,

Provider Recruitment E-mail (CCHMC)

Dear <SCD provider>,

As part of an Agency for Healthcare Research and Quality (AHRQ) Award, we are conducting focus groups with pediatric and adult sickle cell disease providers to discuss your experiences with transitioning patients from pediatric to adult care and to identify barriers and facilitators to providing high quality care during these transitions. The information you provide will be used to help develop a technology based health data management tool designed to assist health care providers as well as adolescent and young adult sickle cell patients and their parents/caregivers during transitions of care.

The focus group is taking place **<Day>, <Date> at <Time>** at Cincinnati Children's**.**

To participate, please contact <insert name> (study coordinator, cc'd on this email) if you are interested. She will also be contacting you individually to ask if you are interested. After informed consent, you will fill out a short demographic questionnaire, and then participate in the focus group. The focus group will take approximately 2 hours. You will receive $50 cash for your time and effort.

Thanks in advance for you important contribution to this project!

Thanks,

Provider Recruitment E-mail (CNMC)

Dear <provider>,

As part of an Agency for Healthcare Research and Quality (AHRQ) Award, we are conducting focus groups with pediatric and adult sickle cell disease providers to discuss your experiences with transitioning patients from pediatric to adult care and to identify barriers and facilitators to providing high quality care during these transitions. The information you provide will be used to help develop a technology based health data management tool designed to assist health care providers as well as adolescent and young adult sickle cell patients and their parents/caregivers during transitions of care.

The focus group is taking place **<Day>,<Date> at <Time>**at Children's National Medical Center**.**

To participate, please contact <insert name> (study coordinator, cc'd on this email) if you are interested. She will also be contacting you individually to ask if you are interested. After informed consent, you will fill out a short demographic questionnaire, and then participate in the focus group. The focus group will take approximately 2 hours. You will receive a $50 gift card for your time and effort.

Thanks in advance for you important contribution to this project!

Thanks,