<u>Improving Sickle Cell Transitions, Focus Group Moderator Guide: IT Developers</u>

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This is a focus group guide designed to be conducted with developers across a health care system. The tool includes questions to assess user's needs of electronic health records, health information exchange, personal digital assistants, and personal health records.

ACTION SCD – IT Developer Focus Group
Moderator Instructions and Discussion Guide

Research Objective:

The goal of the IT Developer focus group is to provide recommendations to inform the design and development of a technology enabled tool to support management of transitions across the health care system for individuals with Sickle Cell disease. The focus group will consider and discuss the following:

1. Identification of key functional specifications, including considerations in the development of information architecture;

2. Identification of factors promoting patient/parent/physician digital interactivity

3. Identification of key factors relevant to a positive user experience and interface design

4. Criteria for selecting an appropriate software development platform and design elements that consider integration with clinical workflows and existing HIT tools, including electronic health records, patient registries, pharmaceutical databases, and other health IT systems

5. Analysis of potential challenges relating to compatibility with existing electronic health record and other HIT systems, including Health Information Exchanges, pharmaceutical databases and claims information

6. Development of general technical framework for an SCD care transitions tool

7. Issues relating to security of a SCD care transitions tool

Goals:

- Understand how to translate the needs of tool users (young adult and adolescent patients, caregivers, providers) into tool specifications and user experience cases ("use cases") for actionable recommendations for tool design and functionality

- Assess adaptability/compatibility with near-future technological developments

Participant Profile:

We will seek experts in each of the following areas of expertise; where possible, given the breadth of expertise we are seeking, we will preferentially include individuals who fulfill more than one area. Specific technology platforms and areas of expertise:

- Smartphones and smartphone applications

- User interface design

- Electronic health record platforms, both institutional (e.g., Cerner, Epic) and cloud based (e.g., eClinicalWorks, AthenaHealth)

- Web portals, Personal Health Records and Personal Child Health Records

- Health information exchange

- Application of HIT solutions to transition –not necessarily specific to children

- Application of HIT to vulnerable populations, including low literacy, African American and Latino communities

We will seek a balance of individuals working in the academic and private sectors.

Logistics:

The focus group of IT developers will be conducted at the NICHQ office in downtown Boston. We anticipate the discussion will take place over four hours, including a twenty-minute break. Date and time TDB.

Discussion Guide

Moderator Script and Discussion Questions	Instructions & Probes
Welcome and Introduction	
Thank you for taking the time out of your day to meet with us. As we wrote in the invitation, we are conducting a research study for the Agency for Healthcare Research and Quality 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. Sickle cell disease (SCD) is an inherited red blood cell disorder that affects close to 100,000 people in U.S. This condition is characterized by chronic anemia, low blood count, and unpredictable episodes of severe pain and end-organ damage that begin in early childhood and lead to altered functioning, poor health-related quality of life, increased health care use, and early mortality. As recently as 30 years ago, children with SCD usually did not survive into adulthood. Now, as a result of advances in screening and treatment, more than 90 percent of individuals with SCD reach adulthood, and life expectancy is typically into the 40's. Times of transition--from pediatric to adult care, to and from primary care providers and specialists, and to and from outpatient and inpatient care--continue to be periods of high risk for both poor outcomes including death. In one study following a group of patients, all the recent deaths occurred in patients that were 18 years or older and all but one of these occurred shortly after the transition to adult care. The severity and symptoms of SCD can vary considerably for individuals; from pain	*Co-moderators introduce themselves and their roles. Participants will be told that their responses will be used to inform the design of a potential HIT tool for facilitate transition. We anticipate the session will last up to 4 hours.*

Moderator Script and Discussion Questions	Instructions & Probes
crises to a range of developmental variation, from normal or above average functioning to being moderately or severely disabled. In addition, differences between the health care culture in pediatrics and that of adult medicine can be challenging and confusing for any patient, but difficulties are exaggerated for those with disabilities or who are disadvantaged in other ways as many patients with SCD are. A critical concern is that patients are often unprepared for the level of responsibility needed to take care of themselves independently when they transition to an adult care facility. Furthermore, there are only a small number of adult providers who have the training and experience to take care of patients with SCD since it was only seen in pediatrics until recently which can also limit access to high quality care during the times of transition.

Moreover, currently few effective transition programs for SCD exist. Many clinics described involving families in transition planning and routinely providing information about adult providers, but a minority described seeing adolescents without their parents, having patients schedule their own visits, or having the patient meet the adult provider prior to transition. Reaching an adult age and pregnancy were cited as the most frequent triggers for transition events which may not allow for adequate preparation, assessment of readiness or accounting for the developmental differences typical in patients with SCD, many of whom have cognitive and neurological deficits as a result of strokes.

Transitions should ideally be a continuous process, rather than a discrete event that occurs when a patient reaches a certain age, with attention to early preparation and the ability to practice and subsequently master skills in self-management and independence. Ideally, transition support for the patient should be systematically and routinely integrated into care plans. Adult and pediatric providers should work collaboratively to share information.

Currently, tools like flash drives and paper-based pain management plans are being used by some patients, but these have obvious problems (e.g., damaging or losing the paper) and limitations (e.g., they are not interactive nor easily customizable to the dynamics of changing conditions and preferences.) We would like to consider ways in which technology might improve/facilitate the transition processes.

The purpose of this discussion is thus to gather input from all of you (IT developers) about experiences with mobile health care information technology, chronic disease management, care transition applications and HIT application development and to help us understand the questions that need to be posed to other focus group participants who will be users of this technology so that once we understand their needs, we will be able to translate those needs into a tool that can serve them. | |

Moderator Script and Discussion Questions	Instructions & Probes
Review of Permissions/Conditions of Participation	
Before we get started, I want to review the permissions you have provided and the conditions around your participation in today's session. Our session today will take place over the course of four hours with one twenty-minute break in the middle. 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. The participant check-in sheet you just completed includes your agreement to participate in this session. Although we hope all of you will actively participate in the conversation, you may choose not to answer any particular 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. Your responses will be compiled in a written summary that that will be shared with AHRQ. We will not identify your name, your organization, or any other identifying information in our meeting minutes, but the context of comments may make it possible for readers, including the public, to infer who was present in the group and provided them. I would also like to record our session today so we can check our notes after our conversation to ensure that your input is accurately recorded, but we will be deleting the recording immediately after we are finished with it. Are you okay with me recording our discussion? Do you have any questions before we begin? Let's get started with the panel.	*Address any concerns or questions as needed.* *Collect check-in sheet.* *Collect informed consent forms.*
Ground Rules/Housekeeping	
Great, I'd like to start by setting some ground rules for our discussion to ensure everyone is comfortable in the group and everyone is able to add to the discussion. • Please talk one at a time and speak up as much as much as possible so everyone can hear each other. • Please respect one another's opinions. There will be a range of opinions and experiences shared as we work through the questions, and we do not expect everyone to agree with one another. • Feel free to respond to each other about these topics, not just answer my questions. This will help us have a good discussion about each topic as well as to make sure all the important questions are asked and answered. • Are there any other ground rules we should set to help guide our discussion today? Great, let's break the ice with introductions. If we could go around the room, please say your first name and your area of expertise. (Participants share their first name and area of expertise to break the ice.) Please feel free to get up at any time for breaks as you need them, and there will be a scheduled 20 minute break half way through the session.	*Ensure all participants are aware of the location of restrooms, access to water, etc.*

Moderator Script and Discussion Questions	Instructions & Probes
Presentation of Workflows by the Moderator	

Thank you everyone for introducing yourselves and sharing your background. I'd like to start our conversation by sharing with you some key workflows related to transition from pediatrics to adult care for individuals with SCD, copies of which were included in your advance materials packet. We will be presenting two workflows that are exemplars of two types of transition processes, in order to establish a framework for our discussion and ensure that we are all on the same page about the key processes in transitions for individuals with Sickle Cell Disease. Keep in mind that these workflows are presented from the provider-focused perspective, but the primary end user for this tool will likely be the patient. One challenge we would like you to think through as you consider these workflows is how providing a patient tool can simplify the process and engage the patient and family more actively and pro-actively throughout.

(Moderator reviews workflows)

Provider Workflows Related to Pediatric to Adult Transition

1. **Identification of transition age youth**
   a. Identification of transitioning (current/ future) SCD youth (ages 12 years and older) in pediatric practice
   b. Practice enrolls these patients in a registry/database to facilitate tracking of these patients
   c. Pediatric provider discusses practice's transition policy with patient/family and transition preparation process.

2. **Transition Preparation**
   a. Determine if patient has history of significant school problems, overt strokes, or silent infarcts. If patient has a positive history, refer for cognitive battery of tests.
   b. Assess patient's current insurance status, and plan for obtaining insurance as an adult
   c. If patient deemed not likely to be independent by 18 years of age, recommend parents make arrangements for power of attorney before patients' 18th birthday
   d. Pediatric health care team initiates a jointly developed transition plan with youth and their parents
   e. Pediatric health care team conducts Annual Transition Readiness Assessments of youth/family to address gaps in preparation, knowledge and skills
   f. Pediatric health care team uses checklists to assess self-management skills in key domains (e.g., health care skills, education/vocation; insurance)
   g. Pediatric health care team reviews results of assessments/checklists with patient/family and develops with patient and family strategy to complete the necessary tasks for transition

Instructions & Probes:

Explain that this panel will provide input on tools that can address two distinct types of transition…one from hospital to home, and the other from pediatric care (that is, care by a provider or health care delivery system with primary expertise in caring for children) to adult care. For each type, the moderator will first outline the workflows that the tool is intended to facilitate, and then ask you to discuss specific questions related to that workflow.

Moderator Script and Discussion Questions	Instructions & Probes

3. Planning for Transition
 	
  a. Prepare portable medical summary and review with youth and parents; update summary at least twice a year
 	
  b. Prepare and review with youth and parents written pain action plan AND emergency care plan
 	
  c. Identify network of adult care providers (primary care and hematologist) that SCD patients can be transitioned to in local area
 	
  d. Patient/family in collaboration with pediatric team selects adult care providers
 	
  e. Notify adult provider of youth's pending transfer of care at least 1 year prior to transition
 	
  f. Arrange for individualized introduction between adult provider and patient/family
 	
4. Communication between Pediatric and Adult Care Providers in advance of Transition
 	
  a. Pediatric team to contact adult care providers to discuss pending transfer of care (e.g. email, phone or in person)
 	
  b. Review medical assessments that should be scheduled prior to transfer of care (e.g. cardiac evaluation; dental evaluation, ophthalmology evaluation, immunizations)
 	
  c. Send transfer letter to adult care provider including medical summary, pain action plan, and emergency care plan.
 	
5. Transfer of Care/ Transition Completion
 	
  a. Have patient/family schedule initial appointment with adult care provider
 	
  b. Pediatric and adult provider should communicate post transfer to ensure successful transition and patient integrated into adult care
 	
  c. Transition to adult care complete	

Workflows Related to Hospital to Home Transition
 	
1. Medication management
 	
  a. Identify medications that patient will take after discharge
 	
  b. Clarify any new medication, if prior medications discontinued or changed, or if continuation of prior regime
 	
  c. Provide appropriate education concerning medication management
 	
  d. Assure access to medication
 	
2. Appointment management
 	
  a. Identify who primary care provider is, and need for follow up appointments; schedule follow up appointments; convey information from hospital to PCP required for follow up.
 	
  b. Identify need for specialty follow up, which specialists are currently engaged with patient, which new specialists need to be engaged, schedule appointments and convey information from hospital to specialists required for follow up care.	

Moderator Script and Discussion Questions	Instructions & Probes

3. **SCD Contingency Plan Development/Modification (including pain management)**
 	
   a. Clarify signs and symptoms that patient/parent should monitor related to disease and to medications and other therapies
 	
   b. Develop (patient and provider together) specific plans for actions to be taken based on development of symptoms (e.g., if "mild" pain, take X; if "moderate," take Y and call Dr. X; etc.
 	
   c. Clarify mechanisms to communicate whether monitoring taking place, whether actions occurring and whether actions are achieving desired results.
 	
4. **Health Maintenance Plan Development/Modification**
 	
   a. Development of personal goals
 	
   b. Reminder mechanisms for general (e.g., flu shot) and condition-specific monitoring or interventions	

Discussion Questions	

- Information Architecture:
   o What are the existing tools that you could use as a base for a more generic application? Could you customize it/them for this specific need or use without further customization?
   o What are the key questions you would consider in building the information architecture of this tool?
   o What process would you use to develop the architecture to accommodate these workflows?
   o Should the tool be developed just for mobile deployment or should it be available via web browser?
- User Experience:
   o Are there elements that would make this particularly attractive to adolescents? What elements would best integrate into patient/caregiver/provider experiences in a way that would make these users most likely to utilize the tool?
   o How would you go about designing an application with broad appeal to both children and adults? Would you build two versions? How would this relate to a provider version?
   o How would you design a tool/application to facilitate an adolescent accomplishing some of the key processes and skill sets needed to facilitate transition and managing adult care listed below?
      o keeping track of their health summary (medical history, surgical history and medications);
      o managing their health insurance and other needed services
      o scheduling appointments and keeping them (e.g. appointment reminders);
      o identifying and meeting with an adult provider;
      o preparing for medical visits (i.e., a way to keep track of questions in between appointments);
	These questions apply to both workflow scenarios reviewed above.

Moderator Script and Discussion Questions	Instructions & Probes

o keeping track of PCP and specialty provider information and ensuring that these are connected;
      o managing lab tests and follow-up appointments;
      o finding community resources
 • Software Development:
      o What software framework would you select for development of this tool or application?
 • Interoperability:
      o What do you see as the benefits of a stand-alone tool versus one integrated with existing systems?
      o Would you develop an API for the purpose of integrating data with existing databases? Why or why not? What would be the challenges of doing that?
      o What would you do so that a patient could have access to the information at different health care sites (i.e., different hospitals)? So that a provider could transfer information across delivery systems? How would providers connect with a state health information exchange?
 • Security:
      o How would you make the tool HIPAA compliant (e.g., validation of patient/ caregiver identity)??
      o How could you address privacy/permissions with respect to different state laws concerning parental notification about care?
 • Feasibility:
      o What business models might sustain such applications? How does one keep costs low?
      o How would patients ensure that their health status (e.g., prescriptions, allergies, complications, etc.) is kept current?
      o How does one assure such systems are kept updated and maintained?
      o How could this tool tie in to providers' meaningful use requirements?
      o What about liability concerns?
      o How do you see the HIT and personal health app market changing in the next five years, and how would those changes affect the way you would approach developing such a tool?
      o What models or tools addressing health conditions could be applied to this scenario?	

Wrap-Up	
Our time is almost up, and I would like to give you the chance to say a final word or ask anything else you feel is important to the development of this tool. Does anyone have anything else to add? • Great, thank you everyone. I appreciate everyone sharing their expertise today.	*Answer questions as necessary.*