

**Attachment 9:  
Key Informant Interview Guides**

## Moderator Guides

### Attorney (Two Interviews)

- Open ended question – Our work is the first phase in AHRQ’s effort toward the development of a health information technology (HIT) enabled tool such as an app for a phone designed to aid adolescents and young adults with sickle cell disease (SCD) during transitions of care. What opportunities do you see for the development/use of such a tool? What overarching red flags arise?
- What privacy and security concerns might be encountered from a: patient-caregiver; patient/caregiver-provider; or provider-provider perspective? Or when using the tool when transitioning between care settings? What legal safeguards should be put in place to address privacy/security concerns?
- In the potential exchange of protected health information across state lines or other types of legal boundaries, are there additional privacy and security legal considerations?
- What malpractice implications or issues might arise from provider use of patient-reported data?
- What liability issues should we consider as we develop the tool or app? With patient-reported data, are there different or other liability concerns?
- If patient-reported data raises red flags regarding medical emergencies, errors or necessary follow-up, who is liable for that medical follow-up? Are there specific procedures or norms applicable to health tools?
- If data reported by another provider raises a red flag regarding errors, emergencies or need for follow-up, which provider is liable for that medical follow-up?
- What intellectual property or patent considerations should we consider in the design, development and release phases? Are there implications for leveraging functionality and design of tools already in the marketplace?

### Office of the National Coordinator for Health Information Technology (Two Interviews)

- Open ended question – Our work is the first phase in AHRQ’s effort toward the development of a health information technology (HIT) enabled tool designed to aid adolescents and young adults with sickle cell disease (SCD) during transitions of care. What are some of your initial thoughts or suggestions about our project? What opportunities do you see for the development/use of such a tool?

- From your perspective, are there privacy and security concerns that might be problematic from a: patient-caregiver; patient/caregiver-provider; or provider-provider perspective?
- In the potential exchange of protected health information across state lines or other legal boundaries, are there additional privacy, legal or policy considerations? Are there lessons learned from the State HIE or Beacon programs regarding sharing of data? What trends in state policy around privacy and security is ONC seeing?
- In what ways can meaningful use criteria impact a care transition tool like this? For example, current proposed Stage 3 criteria require EHRs accept patient-generated data from 10% of patients. Are there specific functionality or certification processes that will be required of tools to support these criteria? Is the Federal government planning to certify tools like this (such as is currently done for EHRs)?
- What innovations are ONC seeing in the marketplace with regards to patient engagement and patient-centeredness, patient reported data, and care coordination through HIT?
- What innovations is ONC seeing in the marketplace with regards to apps for underserved or minority populations?
- What are ONC’s plans for consumer engagement in the next 2-3 years? What would ONC like to see in the provider community where patient engagement is concerned? Are there relevant projects or initiatives that this project could be aligned with?
- What are some issues that we should be considering now to ensure that the tool would work well with national HIT initiatives (e.g., health information exchanges, personal health records, etc.)?”
- What recommendations does ONC have with regard to ongoing or future funding vehicles to support and fund the development and implementation phases for such a tool?

### **State Medicaid Director (Two Interviews)**

- Open ended question – Our work is the first phase in AHRQ’s effort toward the development of a health information technology (HIT) enabled tool designed to aid adolescents and young adults with sickle cell disease (SCD) during transitions of care. What opportunities do you see for the development/use of such a tool? What overarching red flags, concerns, or thoughts and suggestions arise?
- Does your state have an existing care transition, health home or medical home programs? Is there a way to link the use of this tool to any existing program such as supporting certain quality or performance metrics? If care coordination performance/incentive payments are being used within the state, are care transition tools applicable to support such payments and performance incentives?

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- What reimbursement implications might there be for providers who use care coordination HIT-enabled tools in the delivery of care to Medicaid enrollees? What about for patients who may want to purchase/use the tool? Are there any criteria the state uses to assess the qualification of such a tool for reimbursement?
- Are there existing state policies or laws around data sharing or patient-provided data that we should consider as we develop this app?
- What recommendations do you have with regard to future or ongoing funding vehicles to support and fund the development phases for such a tool?
- What outcomes would the state want to see to demonstrate value of such a tool for the state to consider funding the use or development of the tool?
- What state monitoring or oversight issues should be considered?
- Does the state have any special initiatives in place for patients with sickle cell disease?

### **Sickle Cell Disease Patient Advocate (One Interview)**

- Open ended question – Our work is the first phase in an effort by the Agency for Healthcare Research and Quality toward the development of a health information technology (HIT) enabled tool designed to aid adolescents and young adults with sickle cell disease (SCD) during transitions of care. What opportunities do you see for the development/use of such a tool? What are your initial thoughts and concerns about this project and why?
- What privacy and security concerns might be encountered from a patient or caregiver (or both) perspective? If patients were to use a web-based tool, are there privacy concerns that patients might have in this case? Which kinds of information would cause the most concern?
- What features of a tool might be important to include making a tool more useful to patients and families? Is there anything you think we should not do or watch out for that would not help you or other people with sickle cell disease?
- What key issues (current barriers and challenges) are SCD patients facing with regards to sharing health information and care transitions that a tool might support? What are the key issues that patients with SCD struggle with? Do you think this type of tool will help with those? Why or why not?
- What other barriers to use might there be from a patient perspective? Are there cultural and linguistic considerations that should be integrated into the design to support broad use of the tool?
- Is there anything else we should know about how hard or easy it is to get good care when you have sickle cell?
- We want to work with people who have sickle cell to make sure things get better. How might we best engage patients / consumers in the development stages of this tool?