UCSF Focus Group / Interview Guiding Questions and Probes:

Individuals with Sickle Cell Disease

I. Research objectives

- Using a participatory engagement approach, engage stakeholders in Alameda, Contra Costa, Sacramento, San Francisco and Solano counties in a needs assessment to: (1) Identify facilitators and barriers to preventive and acute sickle cell disease (SCD) care and effective patient self-management; and (2) Determine facilitators and obstacles to enrolling patients in a SCD registry. Findings from the needs assessment, highlighting the unique characteristics and needs of our population and settings in Northern California will be used to inform the development of evidence-based strategies to improve SCD care in the region.

II. Participants

- Participants will be youth and adults ages 15 through 45 years with SCD living in the five counties (Sacramento, Solano, Contra Costa, Alameda, and San Francisco).

III. When/where will interviews take place

- The focus group interviews will begin in July of 2017. Group interviews will be conducted in clinical sites and community facilities within the five counties until saturation. Individual interviews will be conducted where it is difficult to gather a group together.

IV. Responsibilities of moderator, note taker and/or observer

- The interviews will be conducted with a moderator and a note taker and/or observer who will be trained prior to the interviews by Dr. Treadwell. The moderator will be responsible for facilitating the interview by using a structured interview guide to gain the maximum amount of information in the allotted time. The note taker and observer will be responsible for taking detailed notes of the interview, maintaining the voice recorder, and writing down participants' responses on the easel paper.
- All team members are responsible for reviewing consent forms with participants and obtaining signatures indicating consent. As participants enter the meeting space, team members work with participants privately to obtain consent
- Once consent forms are collected and reviewed for completeness, the interview can begin. The moderator uses the prepared script as follows to welcome the participants, remind them of the purpose of the interview, set ground rules and conduct the group/interview.
- Site Requirements:
    - Sites Must Have on Hand
        - Approval for the data collection from the local IRB
        - Honorariums for enrolled participants ([amount] per participant)
        - Healthy snacks for enrolled participants ([amount] per participant)
        - Name tags that will actually show participants' assigned numbers

- Forms Sites Must Complete
  - Per Participant – To be completed for each participating adult with sickle cell disease or parent of a child with sickle cell disease
    - Group interview Screener
    - Informed Consent
    - Demographic Information form
    - Participant Receipt
    - Unusual Occurrences Form (if applicable)
  - Per Site -- To update continually during study
    - Participant Enrollment Log
    - List of Problems & Suggestions
- Note: focus group facilitator comments are in **bold**

V. Timing of group

Topic	**Minutes**
Opening	3
Domain 1: Patient access to primary and specialty care	15
Domain 2: Emergency Department	15
Domain 3: Patient comfort level taking HU	10
Domain 4: Beliefs and practices related to pain control	15
Domain 5: Transition	10
Urgency of needs/availability of resources	10
Closing	2

VI. Focus group/interview

OPENING

Welcome! [Facilitator introduces him/herself] **Thank you for being a part of this focus group/interview. Your time and participation are greatly appreciated. I would also like to introduce** (note taker, any other assistant)**.**

The National Heart, Lung and Blood Institute has funded us to form the Sickle Cell Disease Implementation Consortium in eight states in the U.S. Our goal is to improve care provided to youth and adults with SCD ages 15-45 years, because it has been consistently found that they face numerous barriers to management of sickle cell-related complications. We want to find out what helps you get the care that you need and what might get in the way of that. We will use the information to develop strategies to improve SCD care in our region. Similar information is being collected in 7 other sites around the U.S., so that we can learn from each other as we develop those strategies.

For smooth flow of the discussion, I would like us all to consider some rules for the group:

1. **This is a recorder intended to capture our conversation so after the discussion we can put together your thoughts.** (Note-taker indicates recorder). **The note taker will also take notes just so we can be doubly sure of documenting the interaction. This way, we won't miss anything you say. Please be sure to speak up so that we can make sure that your voice is heard on the recorder when we listen to it later. Please**

set your mobile phones to silent. It will be helpful to avoid side conversations please, that means talking with your neighbor when someone else is talking.

2. **We'll need to move along. We have a lot to talk about and want to hear from everyone. There won't be enough time for long stories or full discussions of every topic. So please understand that when I ask that we move to a new topic or speaker, I don't mean to be rude. Our discussion will last about 1 1/2 to 2 hours. To make the most of the time that we have, there will not be any formal breaks. You may feel free to take a quick break if you need to.**

3. **We want YOU to do the talking. We want to hear from everyone, so I might call on you if I have not heard from you in a while.**

4. **There are no right or wrong answers. Every person's experiences and opinions are important. Please speak up whether you agree or disagree.**

5. **I want to let you know that we will do our best to keep your answers confidential. That means that we will not have your name connected with your answers once the discussion is over. If anything is said during the group that you do not want kept on the recording, let me know before you leave and we will delete it. Another part of this confidentiality is that you are all assigned a number, so that your name will not be associated with your responses either on the recording or in our notes. You can see each other's numbers on the label that you have attached to your shirts. You should refer to yourself by that number as should others. For example, you might say, "I agree with what Mr. One said" and so on. Finally, please do not share what has been discussed in the group with others outside of the group. We want you to speak as freely as possible so want you to feel that your privacy is being respected by us and by each other.**

6. **Is there anything else that you think might be important so that this group is as good of an experience as it can be for everyone? Is everyone in agreement? If there are no questions, we can begin.** (Note taker turns on recorder)

1. Domain: Patient access to primary and specialty care

Introductory statement for facilitator: **Many individuals living with SCD often see many different type of healthcare providers. These could include your hematologist, sickle cell specialist, primary care doctor, nurse practitioners, specialists to take care of your kidneys, lungs, hips, etc., social workers, pain specialists care coordinators, and psychologists or therapists. We would like to understand what kind of providers you see and any challenges you experience related to this, or things that work really well to help make sure you can get all the healthcare you need**.

Overarching question: **What kind of healthcare providers do you see? (or who do you see for your healthcare?)** (Facilitator note: try to guide responses specific to type of provider they are discussing)

Probes: [Facilitator note: if these probes are already mentioned by participants, do not ask these; also check off as participants are responding to keep track of which probes are mentioned]

☐ ***Tell me about your relationship with these providers***
☐ ***Are there any barriers you experience (to seeing these providers)?***
☐ ***Is insurance a barrier?***
☐ ***Is transportation a barrier?***
☐ ***Is the location of the clinic or health center a barrier? How about the hours/days the clinic is open?***
☐ ***What are some things that are helpful in allowing you to see these providers?***
☐ ***Do you work with a care coordinator?***
☐ ***Do you work with a social worker?***
☐ ***Do you work with a behavioral medicine specialist or psychologist?***
☐ ***What works/doesn't work?***
☐ ***If you could change one thing about the care you receive, what would it be?***
☐ ***Do any of you have children or other people that depend on you for care? If so, have you had to miss appointments because you had to take care of them?***

Overarching question: **Would a health coach or navigator be helpful to you in managing your appointments with providers, or in making your way through the healthcare system? They might also help you find resources in your community that might get in the way of your focus on your health, such as housing or transportation.**

2. Domain: Emergency Department
Introductory statement for facilitator: **Many persons living with SCD have had to go to the emergency department for treatment of either pain or other complications. We would like you to discuss those experiences.**

Overarching question: **Tell me about your experience in the emergency department** (ED).

Probes: [Facilitator note: if these probes are already mentioned by participants, do not ask these; also check off as participants are responding to keep track of which probes are mentioned]

☐ ***Think about the last time that you went to the ED:***
- ☐ ***When and why did you decide to go?***
- ☐ ***How was your pain managed?***
- ☐ ***(if no problems cited) Some people with SCD have a lot of problems when they try to get ED care, including receiving poor care. Why do you think this might be***
- ☐ ***Was there any follow up recommended?***
- ☐ ***Was there any difficulty in getting the recommended follow-up?***

3. Domain: Patient comfort level taking HU
Introductory statement: **Hydroxyurea is a medicine that is taken by many persons with SCD to help prevent pain episodes and other complications. We would like to ask you some questions about taking HU, whether or not you currently take it, have taken it in the past, or have thoughts about taking it.**

Overarching question: **Tell us about HU, whether you use it, decided not to, or just what you have heard about?**

Probes: [Facilitator note: if these probes are already mentioned by participants, do not ask these; also check off as participants are responding to keep track of which probes are mentioned]

Do you take HU?
- If no
☐ ***Have you ever heard about HU or had it prescribed?***
☐ ***Do you know anyone who takes HU?***

- If yes, what did you hear about HU from them?
☐ ***Do you feel like you need education or more information on how to manage hydroxyurea dosing?***
☐ ***Why do you take HU? Or For what reasons was HU prescribed to you?***
☐ ***How long have you been taking it?***
☐ ***What made you decide to start taking it?***
☐ ***What other factors did you consider to decide to start taking it?***
☐ ***Whose advice did you seek before deciding to take it?***
☐ ***Do you use any apps, props, or phone features to help you manage your HU? If yes, which ones?***
☐ ***Do you use any websites to help you with taking HU? If yes, which ones?***
☐ ***Are there any barriers to taking it daily?***
☐ ***Is insurance a barrier to getting your prescription filled?***
☐ ***If not taking HU:***
☐ ***What made you decide not to take HU?***
☐ ***If your doctor recommended HU for you, what might change your mind to take it?***
☐ ***Was concern about side effects a factor in your deciding not to take HU?***
☐ ***What side effects are you concerned about?***
☐ ***From what source did you learn about HU?(e.g. internet, physicians, etc…)***

4: Domain: Beliefs and practices related to pain control
Introductory statement: **Many patients with sickle cell experience both acute pain, often referred to as vaso-occlusive crisis or severe pain episodes, and/or chronic pain at some point in their lives. We would like to talk about that now.**

Overarching question: **Tell me about the pain you experience and how you manage it.**

Probes: [Facilitator note: if these probes are already mentioned by participants, do not ask these; also check off as participants are responding to keep track of which probes are mentioned]

☐ ***Tell me about medicines you take to manage your pain.***
☐ ***Do you have problems with being given or picking up opiates? If yes, tell me more.***
☐ ***What else do you do to manage pain other than meds?***
☐ ***Do you have a pain plan? What is it?***
☐ ***Is insurance a barrier to getting your prescriptions filled?***

Overarching question: **Would a health coach or navigator be helpful to you in managing pain or your medicine? This would be someone who would help you make plans to remember to take your medicine or help you organize what is important to you so you can focus on your health.**

5. Domain: Transition from pediatric to adult care
- **If not transitioned: Do you have a plan for your healthcare for when you have to leave pediatric care?**
    - **Do you have any concerns or challenges about transitioning?**

    - **What are some of your fears and worries about transitioning?**
- **If transitioned: What was most helpful to you in planning for transition from pediatric to adult care? What were some of the difficulties that you faced while transitioning?**

6. Domain: Urgency of needs/availability of resource

- **What are the top three issues in SCD care in our region that we have talked about today?** (note taker/observer records on easel pad)
- **What are the top three solutions to those issues?** (note taker/observer records on easel pad)

CLOSING

I would like to thank you for taking the time to talk with us. Is there anything that you did not get to say that you think would be important for us to know, about any of the topics that we discussed? I would like to ask you to complete a brief survey and then we will be done. We are also providing you with reimbursement for your time and travel. We will ask you to sign a receipt to acknowledge that you received your reimbursement.

Thank you again for your help!

ED Provider Focus Group and Individual Interview Guide

Session Information

Interview date:
Interview team:
Participant ID number:

INTRODUCTION: PROVIDERS

Intro statement for facilitator to read: The purpose of this interview/focus group is to understand challenges to and resources available for caring for people with sickle cell disease in a five county region – Alameda, Contra Costa, Sacramento, San Francisco and Solano. We would also like to discuss the implementation of the NHLBI recommendations for treatment of sickle cell disease into routine practice. Please help us understand your practice so we can move forward with strategies to implement the recommendations and improve health for individuals living with sickle cell disease.

GROUND RULES:

For smooth flow of the discussion, I would like us to consider some ground rules typical for this type of interview:

1. *These are a tablet and a recorder intended to capture our conversation so after the discussion we can transcribe what was said. Please note that this is a microphone, not a camera. Please be sure to speak up so that we can make sure that your voice is heard on the recorder when we listen to it later. If anything is said during the interview that you do not want kept on the recording, let me know before you leave and we will delete it.*
2. *We have a lot to talk about and want to hear from everyone. So please understand that when I ask that we move to a new topic or speaker, I don't mean to be rude. Sometimes the notetaker and I will confer, as well, just to make sure every topic is covered thoroughly.*

INTRODUCTION: ED PROVIDERS

Intro statement for facilitator to read: The purpose of this interview/focus group, is to understand challenges to and resources supporting implementation of the NHLBI recommendations for treatment of SCD, specifically treatment of VOE, into routine practice. This information will help us move forward with strategies to implement the recommendations and improve health for individuals living with SCD.

Overarching question: **Please describe your practice and the population of individuals with sickle cell disease you see in practice.**

- For example, what are the approximate numbers of patients, age ranges, demographic and clinical characteristics, etc.?
- What is the most common reasons for patient visits?

INTERACTIONS WITH SCD SPECIALISTS AND PCPS

1. ***Overarching question:*** **Tell me about how you interact with SCD specialists or PCP's related to SCD patients.**

Probes:

- Do you have a provider you can refer patients to?
- Do you have other resources you can refer patients to?
- Can you refer patients to case management?

OPIOIDS IN THE ED

2. ***Overarching question:*** **Tell me about your treatment for sickle cell pain?**

Probes:

- Tell me about your comfort level administering opioids for treatment of VOC in the ED?
- How do you decide how to treat a patient with sickle cell pain?
- How do you decide which drugs and routes of treatment to use?
- Is there anything you would change about the care you provide patients during sickle cell pain episodes?
- Are you aware of the NHLBI recommendations for treatment of sickle cell pain?
- What are the barriers to providing good pain management in your ED?
- Are there specific challenges or barriers that adolescents face in your ED?
- What would you need to provide better care to sickle cell patients in your ED?
- Tell me how you advocate for patients right to appropriate pain management.
- Tell me how you ensure opioid safe prescribing practices.
- Tell me about how and when you prescribe opioids at discharge.
- What factors most influences the likelihood you would prescribe opioids at discharge?

Provider Focus Group and Individual Interview Guide

Session Information

Interview date:
Interview team:
Participant ID number (if applicable):

Participants Information

Gender (male/female/other):
Age:
Race (self-identify):
Ethnicity (self-identify):
Provider type (e.g., MD, RN, PA):
Years in clinical practice:
Medical specialty (e.g., Internal medicine, pediatrics, Hematologist):
Patient age range:
Practice setting:

INTRODUCTION: PROVIDERS

Intro statement for facilitator to read: The purpose of this interview/focus group, is to understand challenges to and resources available for caring for persons with SCD. We would also like to discuss the implementation of the NHLBI recommendations for treatment of SCD into routine practice. Please help us understand your practice so we can move forward with strategies to implement the recommendations and improve health for individuals living with SCD.

Overarching question: **Please describe your practice and the population of individuals with sickle cell disease you see in practice.**

- For example, what are the approximate numbers of patients, age ranges, demographic and clinical characteristics, etc.?
- What is the most common reasons for patient visits?

PRIMARY AND SPECIALTY CARE

Intro statement for facilitator to read: Persons with SCD suffer from a complex chronic disease associated with premature mortality. This care often requires care from SCD specialists, other specialist such as nephrologists, pulmonologists, pain specialists, primary care and emergency department providers. In this section of the interview we would like to explore your thoughts on how you work with these other disciplines and any barriers or facilitators to providing best practice.

1. ***Overarching question:*** **Tell me about the medical care you provide for persons with SCD. ****Note to interviewer, adjust questions to group being interviewed.***

   Probes:

   - Tell me about your access to primary/specialty providers for individuals with sickle cell disease.
   - Tell me what ideal co-management look like to you?

- Tell me about other healthcare providers you consult for persons with SCD? Care managers, social workers? Etc. Tell me about care coordination ie. care managers, social workers
- Tell me what factors influence your decision to make a referral?
- Tell me about the key challenges individuals with sickle cell disease face to receiving care from a primary/specialty care provider?
- Tell me what you experience as the key challenges individuals with sickle cell disease face to receiving care from a primary/specialty care provider?
- Tell me the greatest challenges you face as a provider in providing care to persons with SCD?
- What are the three most urgent needs for the SCD population?
- Tell me what longitudinal care looks like for sickle cell patients?
- Do you have an infusion center in your institution? Does it accept SCD patients?
- Tell me what policy-level factors influence the care you provide to individuals with sickle cell disease? For example, what challenges are there to reimbursement for services?
- How sure are you that you are providing evidence-based care for individuals with sickle cell disease?
- Tell me what tools / resources you use to help you make care decisions about your sickle cell patients. Include resources in the community.
- Tell me your preference regarding receiving clinical information on patients referred to you.
- Tell me about the adequacy of the information systems (EMR) and appointment scheduling systems you use and how they influence care that you provide.
- Tell me about how reimbursement and insurance affects your ability to provide care to persons with SCD.
- *Are you interested in in-services on SCD? Discussion by group.*
- PRIMARY AND SPECIALTY CARE

HYDROXYUREA TREATMENT

Intro statement for facilitator to read: Hydroxyurea is used to treat many individuals living with SCD. HU can prevent many complications but requires close monitoring and drug titration.

2. ***Overarching question:*** **Tell me about your experiences using HU with persons with SCD.**

Probes:

- Tell me about how well prepared you feel to prescribe HU.
- Do you feel like you need education or more information on how to manage hydroxyurea dosing?
- Tell me about any concerns you may have about prescribing HU?
- Tell me about any patients with SCD for whom you would not prescribe HU?
- Tell me about the local pharmacy ability to carry HU and in different (other than 500mg?)
- Tell me about why hydroxyurea is under-utilized.
- Tell me about your experience prescribing hydroxyurea?
- Tell me about your patients' experiences taking hydroxyurea?
- For which indications do you prescribe HU?
- If you prescribe HU, tell me about the evidence or guidelines you use to support the use of hydroxyurea?

OPIOIDS AND PAIN

Intro statement for facilitator to read: Many persons with SCD experience both acute and chronic pain that may require treatment with short and long acting opioids; some patients require long term opioid therapy.

3. ***Overarching question:*** **Tell me about your role in helping your patients with pain control.**

Probes:

- Tell me about your comfortable level in prescribing opioids.
- Tell me about your preference in who should prescribe opioids.
- How do you decide how to treat a patient with VOC?
- How do you decide which drugs and routes of treatment to use?
  - Tell me what strategies you use to facilitate opioid prescriptions for your patients.
- Tell me about how and when you prescribe opioids.
- Tell me what factors most influences the likelihood you would prescribe opioids?
- Tell me how you advocate for patients right to pain medication.
- Tell me how you ensure opioid safe prescribing practices?
- Are you aware of the NHLBI recommendations on chronic pain?
- Tell me about your comfort level in supporting self-management.
- Tell me about what resources you need to support self-management.

EMERGENCY DEPARTMENT (ED) MANAGEMENT

4. ***Overarching question:*** **Tell me how you work with the ED, both from a referral to the ED, and receiving follow up after an ED visit?**

Probes:

- Tell me what services are beneficial in the ED for patients experiencing sickle cell related pain.
- Tell me what prompts you to send a patient to the ED for care?
- Tell me how the care at your practice differs from the ED.
- Are there any things you would change about the way you and the ED work together?
- What special considerations are in place in your ED for youth and young adults with SCD?

REGISTRY

Intro statement for facilitator to read: The NHLBI SCDIC also is asking us to identify youth and adults with SCD ages 15 – 45 and ask them to enroll in a registry (describe what a registry is and the types of questionnaires that the person will fill out). They particularly want us to enroll those individuals facing the greatest challenges in accessing outpatient preventive care into the registry.

Overall Questions: **What do you think will be the biggest barriers that we will face in enrolling 300 of these vulnerable individuals into the registry? What do you think will be the biggest barriers that we will face in keeping all of these individuals enrolled in the registry, with annual follow up for six years?**

1. What organizations or resources exist in the community that can help us with the SCD registry enrollment? What do you think might be an effective solution to addressing any problems that we might face in enrollment and retention in the registry?

2. I have a list here of potential measures that will allow us to track improvements in SCD care as we implement interventions that we develop from this needs assessment [**INSERT LIST FROM REGISTRY**]. Please look through the measures and let me know what you think are the absolute top three measures that we should prioritize, that would show that our interventions to improve care have been effective.

Subject ID

Patient Survey

Thank you for giving your consent to take part in the [name of SCDIC site] Needs Assessment survey. We want to hear from you about what gaps you see in services for youth and adults with sickle cell disease ages 15-45 years, in our region. We also want to hear from you about what you think could help improve sickle cell disease care. We will combine your responses with those of other youth and adults with sickle cell disease and their providers in order to plan ways to improve sickle cell disease care. Some of the same information is being collected in 7 other sites around the U.S., so that we can learn from each other as we develop these plans. Your responses are confidential. That means that your survey will be assigned a number and only the researcher will be able to link your responses with your name. Your providers will NOT be able to link your responses with your name. You are free not to answer an item if you prefer. The study coordinator will be nearby if you have any questions. Thank you again!

A. VISIT DATE

Today's date: _____

B. SICKLE CELL DISEASE PHENOTYPE

Please tell us your Sickle Cell Disease Phenotype:

- ❑ SS Disease
- ❑ S Beta 0 Thal
- ❑ SC Disease
- ❑ S Beta + Thalassemia
- ❑ Other Variant

If 'Other' variant(s), please type the variant here: _____

- ❑ Not sure

C. Barriers to Sickle Cell Disease Care Checklist

Please take a look at this list of things that can get in the way of getting the sickle cell disease care that you need. Please check off all of these barriers that apply to you. If there are no barriers, please check "no barriers."

1. Transportation Barriers
    - ❑ I can't get transportation
    - ❑ Public transit is not easy to get to
    - ❑ Transportation costs too much for me
    - ❑ I do not have a vehicle
    - ❑ I do not have access to a vehicle
    - ❑ No barriers

2. Access to services
    - ❑ I don't know where to get care
    - ❑ I can't get care because the health care provider's office is too far away
    - ❑ No barriers
3. Insurance barriers
    - ❑ I don't have insurance
    - ❑ My insurance does not cover the services I need
    - ❑ My insurance will not let me go where I want to get services
    - ❑ My insurance does not cover services that will keep me well
    - ❑ My insurance does not cover medicines or my co-pay are too high
    - ❑ My insurance does not cover services that allow different health care providers to talk with each other so they are on the same page about the health care that I need
    - ❑ Health care services are too expensive because of the co-pay or share of cost
    - ❑ It takes too long to get approval for the care that I need
    - ❑ My insurance paperwork is too hard to fill out
    - ❑ Getting reimbursement for some treatments or services is hard
    - ❑ My insurance will not cover needed services if I have to go to a different county
    - ❑ No barriers
4. Provider knowledge and attitudes
    - ❑ Providers don't believe that I have genuine pain and need help
    - ❑ I am not seen quickly enough when I am in pain
    - ❑ Providers accuse me of drug-seeking
    - ❑ Providers let me know that they do not appreciate how knowledgeable I am about my disease
    - ❑ It is hard for me to find a provider who has enough experiences with or knowledge about sickle cell disease
    - ❑ I am treated differently from other patients
    - ❑ Communication between me and the providers has been difficult
    - ❑ No barriers
5. Access and accommodation within places where you get health care
    - ❑ Places for me to go to learn how to stay well are not close by or easy to get to
    - ❑ The health care providers' hours are not convenient for me
    - ❑ The wait in the health care office is too long for me
    - ❑ The paperwork I have to fill out is too much
    - ❑ I could not get an appointment
    - ❑ No barriers
6. Social, family, and caregiver support
    - ❑ I do not have enough support
    - ❑ The people who take care of me or give me support are burned out
    - ❑ I am burned out by taking care of others or by giving support to them
    - ❑ I need help with daily chores/ just doing daily activities
    - ❑ I am socially isolated
    - ❑ There are other things going on in my family that are more important than my health care
    - ❑ It is hard to make appointments because it is hard for me to find childcare
    - ❑ No barriers

7. Barriers for individuals

   - ❑ I don't really know what to do to stay healthy
   - ❑ I don't know enough about the sickle cell disease care that I need I don't understand the system or find it too hard to work through
   - ❑ It is hard to follow up on care, by going to the pharmacy, taking medicines at the right time, or making follow up appointments
   - ❑ I miss appointments because of memory problems
   - ❑ The medical instructions are hard to follow
   - ❑ Staff are hard to talk to
   - ❑ Staff are hard to understand
   - ❑ The medical system is very confusing to me
   - ❑ I am not interested in getting sickle cell disease care
   - ❑ I have too many different health problems so it is hard for me to make sickle cell disease care a priority
   - ❑ It is hard for the staff to get a hold of me (for example, I move a lot or don't have a phone)
   - ❑ No barriers

8. Barriers related to sickle cell disease

   - ❑ Worry or fear
   - ❑ Frustration or anger
   - ❑ Lack of confidence
   - ❑ It is hard to be assertive
   - ❑ It is embarrassing
   - ❑ I am concerned about the costs
   - ❑ I am tired
   - ❑ I am in pain
   - ❑ No barriers

9. Please list below any 'other barriers' you may have getting sickle cell disease care that we did not cover.

   _____

   _____

   _____

D. Barriers to Hydroxyurea Use

Select one or more things that make it hard for you to take hydroxyurea. If there are none, check "no barriers."

1. Select one or more things that make it hard for you to take hydroxyurea. If there are none, please check "No barriers."
    - ❑ Doctor does not recommend it.
    - ❑ There are other things going on in my life that are more important than taking this medicine.
    - ❑ I don't know enough about the medicine.
    - ❑ I am not interested in taking another medicine.
    - ❑ It is hard to take the medicine at the right time.
    - ❑ I forget to take the medicine.
    - ❑ I am worried about side effects (list them below).
    - ❑ I don't like the frequent blood tests.
    - ❑ I don't like the frequent clinic visits.
    - ❑ I don't like to think about having sickle cell disease when I am feeling well.
    - ❑ I tried it and it did not work.
    - ❑ I have heard some scary things about this medicine (list them below).
    - ❑ Other barrier (specify below).
    - ❑ No barriers.
2. List side effects you are worried about:

    _____

    _____

    _____
3. List any scary things you have heard about hydroxyurea:

    _____

    _____

    _____
4. List the 'other' barriers than make it hard for you to take hydroxyurea

    _____

    _____

    _____

E. FREQUENCY OF SICKLE CELL PAIN EPISODES

PAINFUL EVENTS - Number of visits should include visits to BOTH your hospital AND outside hospitals.

1. In the last 6 months, how many times did you visit an emergency room because of a sickle cell painful event?
   - ❑ 0
   - ❑ 1
   - ❑ 2
   - ❑ 3
   - ❑ 4 or more
2. In the last 12 months, how many times were you admitted to a hospital because of a sickle cell painful event?
   - ❑ 0
   - ❑ 1
   - ❑ 2
   - ❑ 3
   - ❑ 4 or more
3. In the last 6 months, have you had a pain episode severe enough to keep you from doing your usual daily activities, but without being seen by a doctor or a nurse?
   - ❑ Yes
   - ❑ No

   a. Number of pain episodes in the last 6 months?
      - ❑ Less than 4
      - ❑ At least 4

   b. How many days did you miss doing your usual activities due to pain in the last 6 months?
      - ❑ Less than 1 week
      - ❑ At least 1 week

F. PAIN INTERFERENCE in the past 7 days

1. In the past 7 days how would you rate your pain on average?
   - ❑ 0 (No pain)
   - ❑ 1
   - ❑ 2
   - ❑ 3
   - ❑ 4
   - ❑ 5
   - ❑ 6
   - ❑ 7
   - ❑ 8
   - ❑ 9
   - ❑ 10 (worst imaginable pain)

		Not at all	A little bit	Somewhat	Quite a bit	Very much
1.	How much did pain interfere with your day to day activities?	❑	❑	❑	❑	❑
2.	How much did pain interfere with work around the home?	❑	❑	❑	❑	❑
3.	How much did pain interfere with your ability to participate in social activities?	❑	❑	❑	❑	❑
4.	How much did pain interfere with your household chores?	❑	❑	❑	❑	❑

G. QUALITY OF CARE FOR SICKLE CELL DISEASE

Answer all the questions by checking the box to the left of your answer. You are sometimes told to skip over some questions in this survey. When this happens you will see a note that tells you what question to answer next, like this:

❑ Yes → *(If Yes, Go to Question 1)*
❑ No

1. In the past 12 months, did you try to make an appointment to see a doctor or nurse?
   - ❑ Yes
   - ❑ No → *(If No, Go to Question 4)*
2. In the past 12 months, when you tried to make an appointment to see a doctor or nurse, how often were you able to get one as soon as you wanted?
   - ❑ Never
   - ❑ Sometimes
   - ❑ Usually
   - ❑ Always
3. In the past 12 months, how often were you satisfied with the care you received during these scheduled appointments?
   - ❑ Never
   - ❑ Sometimes
   - ❑ Usually
   - ❑ Always
4. Do you have a doctor or nurse who you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?
   - ❑ Yes
   - ❑ No → *(If No, Go to Question 13)*
5. In the past 12 months, how many visits have you had with this doctor or nurse?
   - ❑ 0 visits → *(If 0 visits, Go to Question 13)*
   - ❑ visit
   - ❑ visits
   - ❑ visits
   - ❑ or more visits

6. In the past 12 months, how often did this doctor or nurse explain things in a way that is easy to understand?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

7. In the past 12 months, how often did this doctor or nurse listen carefully to you?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

8. In the past 12 months, how often did this doctor or nurse treat you with courtesy and respect?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

9. In the past 12 months, how often did this doctor or nurse spend enough time with you?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

10. In the past 12 months, how often were you satisfied with the care you received from this doctor or nurse?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

11. How much does this doctor or nurse know how sickle cell affects you personally?
    - ❑ Nothing
    - ❑ A little bit
    - ❑ Some
    - ❑ Quite a bit
    - ❑ Very much

12. Does this doctor or nurse treat a lot of patients with sickle cell disease?
    - ❑ Yes
    - ❑ No

13. In the past 12 months, did you go to an emergency room for any sickle cell care you needed right away?
    - ❑ Yes
    - ❑ No → *(If No, Go to Question 19)*

14. In the past 12 months, when you went to the emergency room for this care, how often did you get it as soon as you wanted?
    - ❑ Never

- ❑ Sometimes
- ❑ Usually
- ❑ Always

15. In the past 12 months, when you went to the emergency room for this care, how often did the DOCTORS treating you seem to really care about you?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

16. In the past 12 months, when you went to the emergency room for this care, how often did the NURSES treating you seem to really care about you?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

17. In the past 12 months, when you went to the emergency room for this care, how often did the clerks and receptionists treat you with courtesy and respect?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

18. In the past 12 months, when you went to the emergency room for this care, how often were you satisfied with the care you received?
    - ❑ Never
    - ❑ Sometimes
    - ❑ Usually
    - ❑ Always

19. In the past 12 months, how many times did you manage a pain attack (crisis) at home without going to a doctor, clinic, or hospital?
    - ❑ I did not have a pain attack (crisis) in the past 12 months → *(If you did not have a pain attack in the last 12 months, Go to Question 27)*
    - ❑ 0 times
    - ❑ 1 time
    - ❑ 2 times
    - ❑ 3 times
    - ❑ 4 or more times

20. In the past 12 months, did you ever delay or avoid going to an emergency room when you thought you needed care?
    - ❑ Yes, I did not always go for care when I needed it
    - ❑ No, I always went for care when I thought I needed it → *(If No, Go to Question 23)*

21. How important were bad experiences in the emergency room in your decision to avoid going for care?

- ❑ Not at all
- ❑ A little bit
- ❑ Somewhat
- ❑ Quite a bit
- ❑ Very much

22. How important were health insurance issues in your decision to avoid going for care?

- ❑ Not at all
- ❑ A little bit
- ❑ Somewhat
- ❑ Quite a bit
- ❑ Very much

23. In the past 12 months, how many times did you go to the emergency room because of a pain attack (crisis)?

- ❑ 0 visits → *(If 0 times, Go to Question 27)*
- ❑ 1 visit
- ❑ 2 visits
- ❑ 3 visits
- ❑ 4 or more visits

24. In the past 12 months, how much were the emergency room doctors and nurses able to help your pain?

- ❑ Not at all
- ❑ A little bit
- ❑ Somewhat
- ❑ Quite a bit
- ❑ Very much

25. In the past 12 months, how much did the emergency room doctors and nurses believe that you had very bad sickle cell pain?

- ❑ Not at all
- ❑ A little bit
- ❑ Somewhat
- ❑ Quite a bit
- ❑ Very much

26. In the past 12 months, what is the longest you had to wait in the emergency room before your sickle cell pain was treated?

- ❑ Less than 5 minutes
- ❑ 5 to 15 minutes
- ❑ 16 minutes to 1 hour
- ❑ More than 1 hour but less than 2 hours
- ❑ 2 hours or more

27. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate all of the care you received for your health in the last 12 months?

- ❑ 0 Worst care possible
- ❑ 1
- ❑ 2
- ❑ 3
- ❑ 4
- ❑ 5
- ❑ 6
- ❑ 7
- ❑ 8
- ❑ 9
- ❑ 10 Best care possible

H. SICKLE CELL DISEASE SELF-EFFICACY SCALE

The following questions ask about HOW SURE YOU ARE about dealing day-to-day with sickle cell disease (SCD). So for each question tell us HOW SURE YOU ARE by putting a check in the box that best tells us how you feel.

There are no "right or wrong" answers, we just want to know what you think.

		Not at all	Not sure	Neither	Sure	Very sure
1.	How sure are you that you can do something to cut down on most of the pain you have when you have a pain episode?	❑	❑	❑	❑	❑
2.	How sure are you that you can keep doing most of the things you do day-to-day?	❑	❑	❑	❑	❑
3.	How sure are you that you can keep sickle cell disease pain from interfering with your sleep?	❑	❑	❑	❑	❑
4.	How sure are you that you can reduce your sickle cell disease pain by using methods other than taking extra medications?	❑	❑	❑	❑	❑
5.	How sure are you that you can control how often or when you get tired?	❑	❑	❑	❑	❑
6.	How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?	❑	❑	❑	❑	❑
7.	As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?	❑	❑	❑	❑	❑
8.	How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?	❑	❑	❑	❑	❑
9.	How sure are you that you can deal with the frustration of having sickle cell disease?	❑	❑	❑	❑	❑

I. DEMOGRAPHICS SECTION

Please tell us about yourself.

1. Current Age

When were you born?	❑ Enter _____ / _____ / _____ MM / DD / YYYY ❑ Don't know ❑ Prefer Not to Respond
About how old are you?	❑ _____ Years ❑ Don't know ❑ Prefer Not to Respond

J. GENDER

1. Are you male or female?
   - ❑ Male
   - ❑ Female
   - ❑ Prefer not to respond
   - ❑ Don't know

K. RACE

1. What race or races do you consider yourself to be? Please check all that apply.
   - ❑ Black/ African American
   - ❑ White
   - ❑ Asian
   - ❑ Pacific Islander
   - ❑ Other Race
   - ❑ Don't know

   Asian:
   Please type which country _____

   Pacific Islander:
   Please type which country _____

   Other Race:
   Please type your race in the box: _____

L. ETHNICITY

a. Do you consider yourself to be Hispanic, Latino, or of Spanish origin?
   - ❑ Yes
   - ❑ No
   - ❑ Prefer not to respond
   - ❑ Don't know

b. Select the group(s) that represents your Hispanic origin or ancestry. Please check all that apply.

- ❑ Puerto Rican
- ❑ Dominican (Republic)
- ❑ Mexican/Mexicano
- ❑ Mexican American
- ❑ Chicano
- ❑ Cuban
- ❑ Cuban American
- ❑ Central or South American
- ❑ Other Latin American
- ❑ Other Hispanic
- ❑ Don't know

M. CURRENT EDUCATION LEVEL

1. What is the highest grade or level of school you have completed or the highest degree you have received?

- ❑ Never attended / Kindergarten only 1st grade
- ❑ 2nd grade 3rd grade
- ❑ 4th grade
- ❑ 5th grade
- ❑ 6th grade
- ❑ 7th grade
- ❑ 8th grade
- ❑ 9th grade
- ❑ 10th grade
- ❑ 11th grade
- ❑ 12th grade, No Diploma
- ❑ High School Graduate
- ❑ GED or equivalent
- ❑ Some college, no degree
- ❑ Associate degree: Occupation, Technical, or Vocational program
- ❑ Associate degree: Academic program
- ❑ Bachelor's degree (Ex. BA, AB, BS, BBA)
- ❑ Master's degree (Ex. MA, MS, MEng, MEd, MBA)
- ❑ Professional School Degree (Ex. MD, DDS, DVM, JD)
- ❑ Doctoral degree (Ex. PhD, EdD)
- ❑ Prefer not to respond
- ❑ Don't know

2. What is the highest grade or level of school the head of your household has completed or the highest degree they have received?

- ❑ Never attended / Kindergarten only 1st grade
- ❑ 2nd grade 3rd grade
- ❑ 4th grade
- ❑ 5th grade
- ❑ 6th grade
- ❑ 7th grade
- ❑ 8th grade
- ❑ 9th grade
- ❑ 10th grade
- ❑ 11th grade
- ❑ 12th grade, No Diploma
- ❑ High School Graduate
- ❑ GED or equivalent
- ❑ Some college, no degree
- ❑ Associate degree: Occupation, Technical, or Vocational program
- ❑ Associate degree: Academic program
- ❑ Bachelor's degree (Ex. BA, AB, BS, BBA)
- ❑ Master's degree (Ex. MA, MS, MEng, MEd, MBA)
- ❑ Professional School Degree (Ex. MD, DDS, DVM, JD)
- ❑ Doctoral degree (Ex. PhD, EdD)
- ❑ Prefer not to respond
- ❑ Don't know

N. CURRENT EMPLOYMENT STATUS

We would like to know about what you do for a living.

1. Are you working now, looking for work, retired, keeping house, a student, or what?

   - ❑ Working now
   - ❑ Only temporarily laid off, sick leave or maternity leave
   - ❑ Looking for work, unemployed
   - ❑ Retired
   - ❑ Disabled, permanent or temporary
   - ❑ Keeping house
   - ❑ Student
   - ❑ Other _____

   Please type your 'Other employment' status: _____

O. CURRENT MARITAL STATUS

Now we would like to ask about marital status and living together.

1. What is your current marital or living together status?

   - ❑ Married
   - ❑ Not married but living together
   - ❑ Widowed
   - ❑ Divorced or annulled
   - ❑ Separated, not living together
   - ❑ Never been married

P. ANNUAL HOUSEHOLD INCOME

1. Please pick the number showing your yearly income for your household. Please include all income sources:

   - ❑ Less than $5,000
   - ❑ $5,000-$9,999
   - ❑ $10,000-$14,999
   - ❑ $15,000-$19,999
   - ❑ $20,000 to $29,999
   - ❑ $30,000-$39,999
   - ❑ $40,000-$49,999
   - ❑ $50,000-$59,999
   - ❑ $60,000 to $79,999
   - ❑ $80,000-$94,999
   - ❑ $95,000 and over

Q. CURRENT HEALTH INSURANCE COVERAGE

1. What type of Health Insurance Coverage do you have? Please check all that apply

- ❑ Private Health Insurance
- ❑ Medicare
- ❑ Medicaid/ [insert State specific Medicaid] _____
- ❑ SCHIP (CHIP/Children Health Insurance Program)
- ❑ Military Health Care (TRICARE/VA/CHAMP-VA)
- ❑ Indian Health Service
- ❑ State Sponsored Health Plan
- ❑ Other - Government program
- ❑ No Coverage of any type
- ❑ Don't know

R. LANGUAGE PREFERENCE

1. What language do you feel most comfortable speaking with your doctor or nurse?

- ❑ English
- ❑ Spanish
- ❑ Arabic
- ❑ Bengali
- ❑ Burmese
- ❑ French
- ❑ German
- ❑ Gujarati
- ❑ Hindi
- ❑ Italian
- ❑ Japanese
- ❑ Javanese
- ❑ Kannada
- ❑ Korean
- ❑ Malayalam
- ❑ Mandarin Chinese
- ❑ Marathi
- ❑ Oriya
- ❑ Panjabi
- ❑ Persian
- ❑ Polish
- ❑ Portuguese
- ❑ Russian
- ❑ Tamil
- ❑ Telugu
- ❑ Thai
- ❑ Turkish
- ❑ Ukrainian
- ❑ Urdu
- ❑ Vietnamese

2. In what language do you prefer to read health-related English materials?

- ❑ English
- ❑ Spanish
- ❑ Arabic
- ❑ Bengali
- ❑ Burmese
- ❑ French
- ❑ German
- ❑ Gujarati
- ❑ Hindi
- ❑ Italian
- ❑ Japanese
- ❑ Javanese
- ❑ Kannada
- ❑ Korean
- ❑ Malayalam
- ❑ Mandarin Chinese
- ❑ Marathi
- ❑ Oriya
- ❑ Panjabi
- ❑ Persian
- ❑ Polish
- ❑ Portuguese
- ❑ Russian
- ❑ Tamil
- ❑ Telugu
- ❑ Thai
- ❑ Turkish
- ❑ Ukrainian
- ❑ Urdu
- ❑ Vietnamese

Subject ID

ED Provider Survey

Before we get started with the survey, please tell us whether you primarily provide care through an Emergency Department (ED), and how this survey is being administered.

1. Do you primarily provide care through ED?
   - ❑ Yes
   - ❑ No
2. How is this survey being administered?
   - ❑ Electronically
   - ❑ In-person interview
   - ❑ By phone

A. Emergency Department (ED) Care

1. Does your ED have protocols for treating Sickle Cell pain?
   - ❑ Yes
   - ❑ No
   - ❑ Don't know
   - ❑ Prefer not to respond
2. Does your ED use individualized dosing protocols to treat Sickle Cell pain?
   - ❑ Yes
   - ❑ No
   - ❑ Don't know
   - ❑ Prefer not to respond
3. Are you aware of the NHLBI recommendations for the treatment of Vaso-Occlusive Crisis (VOC)?
   - ❑ Yes
   - ❑ No
   - ❑ Prefer not to respond

B. Please indicate your level of agreement with the following statements regarding taking care of persons with Sickle Cell Disease (SCD) in the ED.

		Strongly disagree	Disagree	Agree	Strongly agree	Don't know	Rather not provide
1.	I have the knowledge to provide care to person with SCD.	❑	❑	❑	❑	❑	❑
2.	I have the training to deliver care to the person with SCD.	❑	❑	❑	❑	❑	❑
3.	I have the administrative support I need to treat patients with SCD.	❑	❑	❑	❑	❑	❑
4.	I have access to medications I need to treat pain in individuals with SCD.	❑	❑	❑	❑	❑	❑
5.	I am able to make a follow-up appointment with a sickle cell specialist following discharge.	❑	❑	❑	❑	❑	❑
6.	I am able to make a follow-up appointment with a primary care provider following discharge.	❑	❑	❑	❑	❑	❑
7.	I am able to refer patients to a case management program upon discharge.	❑	❑	❑	❑	❑	❑
8.	I work in an ED with sufficient nurse staffing to provide good pain management to persons with SCD.	❑	❑	❑	❑	❑	❑
9.	I work in an ED with sufficient physician/provider staffing to provide good pain management to persons with SCD.	❑	❑	❑	❑	❑	❑
10.	Nursing staff ratios allow our ED to provide safe care.	❑	❑	❑	❑	❑	❑
11.	Our nursing staffing allows our ED to provide high-quality care.	❑	❑	❑	❑	❑	❑
12.	A lack of insurance, or being under insured does not affect my ability to provide good care.	❑	❑	❑	❑	❑	❑
13.	The workflow in our ED is conducive to proving high quality care for sickle cell pain crises.	❑	❑	❑	❑	❑	❑

14. Upon discharge from the ED for sickle cell pain, do you prescribe Scheduled-II medications (i.e. opioid analgesics) to patients who request them?

- ❑ Yes
- ❑ No
- ❑ I have never taken care of a SCD patient
- ❑ I have never been asked by an SCD patient for opioid analgesics for their pain management
- ❑ Prefer not to respond

If no, what are the barriers to prescribing Scheduled-II medications (i.e. opioid analgesics) to patients who request them? _____

C. Barrier to care for individuals with SCD

1. Please check all barriers to caring for individuals with sickle cell disease in your ED. *(Please check all that apply.)*

   - ❑ Overcrowding
   - ❑ Implicit bias
   - ❑ Lack of medical equipment (i.e. monitors)
   - ❑ Comfort with level of doses ordered
   - ❑ Opioid epidemic
   - ❑ Lack of care pathway/protocol
   - ❑ Administrative support
   - ❑ Stigma around sickle cell
   - ❑ Social work support
   - ❑ Psychiatric support
   - ❑ Concern about addiction
   - ❑ Provider attitudes
   - ❑ High patient ratios
   - ❑ Patient behavior
   - ❑ Other
   - ❑ Don't know
   - ❑ Prefer not to respond

   If "Other" please specify: _____

D. Demographics Section

2. What is your age?

   - ❑ _____ Years
   - ❑ Prefer not to provide

3. What is your gender?

   - ❑ Female
   - ❑ Male
   - ❑ Prefer not to provide

4. What ethnicity do you self-identify with?

   - ❑ Non Hispanic or Latino
   - ❑ Hispanic or Latino
   - ❑ Prefer not to provide

5. What race do you self-identify with?

- ❑ American Indian or Alaskan Native
- ❑ Asian
- ❑ Native Hawaiian or Other Pacific Islander
- ❑ Black or African American
- ❑ White
- ❑ Prefer not to provide

6. What is your provider type?

- ❑ Medical Doctor
- ❑ Physician's Assistant
- ❑ Nurse Practitioner
- ❑ Licensed Practical Nurse
- ❑ Registered Nurse
- ❑ Social Worker / Therapist
- ❑ Other
- ❑ Prefer not to provide

If "Other" professional training, please specify: _____

7. How many years have you been in clinical practice?

- ❑ _____ Years
- ❑ Prefer not to provide

8. What is your practice setting?

- ❑ Rural
- ❑ Urban
- ❑ Suburban
- ❑ Prefer not to provide

Subject ID

Primary Care and Sickle Cell Specialist Provider Survey

Before we get started with the survey, please tell us whether you primarily provide care through an Emergency Department (ED), and how this survey is being administered.

1. How is this survey being administered?
   - ❑ Electronically
   - ❑ In-person interview
   - ❑ By phone
2. Do you primarily provide care through an ED?
   - ❑ Yes
   - ❑ No

A. Experiences providing care to patients with Sickle Cell Disease (SCD)

1. Have you ever provided primary care for patients with SCD?
   - ❑ Yes
   - ❑ No
   - ❑ Prefer not to respond
2. How many patients with SCD (includes SS, SC, sickle beta thalassemia) would you estimate that you provided primary care to in the past year?
   - ❑ 0
   - ❑ 1
   - ❑ 2-3
   - ❑ 4-9
   - ❑ 10-30
   - ❑ 31-100
   - ❑ >100
   - ❑ Don't know
   - ❑ Not applicable - It was not my role to provide primary care to patients with SCD over the past year
   - ❑ Prefer not to respond
3. How many patients with SCD (includes SS, SC, sickle beta thalassemia) would you estimate are in your panel and currently receiving regular care from you?
   - ❑ 0
   - ❑ 1
   - ❑ 2-3
   - ❑ 4-9
   - ❑ 10-30
   - ❑ 31-100
   - ❑ >100
   - ❑ Don't know

- ❑ Prefer not to respond

4. What resources do you currently use if you have questions about the management of patients with SCD? *(Please check all that apply.)*
   - ❑ What I learned in residency
   - ❑ What I learned from CME
   - ❑ Textbook
   - ❑ Internet
   - ❑ Colleague
   - ❑ Specialist
   - ❑ National Heart Lung and Blood Institute Management Guide
   - ❑ I do not know where to find resources
   - ❑ Other
   - ❑ Prefer not to respond

   If "Other" please specify: _____

5. How often do you typically see your patients with SCD for preventive care?
   - ❑ Every month
   - ❑ Every 3 months
   - ❑ Every 6 months
   - ❑ Once a year
   - ❑ As needed
   - ❑ Not applicable
   - ❑ Prefer not to respond

6. Do you routinely screen your SCD patients, when appropriate, for the following? *(Please check all that apply.)*
   - ❑ Renal Disease
   - ❑ Pulmonary Hypertension
   - ❑ Hepatitis
   - ❑ HIV
   - ❑ Iron Overload
   - ❑ Cancer
   - ❑ Elevated Cholesterol
   - ❑ Diabetes
   - ❑ Tobacco use
   - ❑ Substance Use Issues
   - ❑ Retinopathy
   - ❑ Depression
   - ❑ Health related quality of life
   - ❑ Not applicable
   - ❑ Prefer not to respond

7. Do the other physicians of your patients with SCD communicate about their medical issues with you?
   - ❑ Yes
   - ❑ No
   - ❑ Don't know
   - ❑ Not applicable

- ❑ Prefer not to respond

8. Do you feel that the medical needs of your patients with SCD are being met?
   - ❑ Yes
   - ❑ No
   - ❑ Don't know
   - ❑ Not applicable
   - ❑ Prefer not to respond

9. Do you feel that the behavioral health or mental health needs of your patients with SCD are being met?
   - ❑ Yes
   - ❑ No
   - ❑ Don't know
   - ❑ Not applicable
   - ❑ Prefer not to respond

10. How comfortable are you with your ability to provide preventive ambulatory care to a patient with SCD?
    - ❑ Very Uncomfortable
    - ❑ Somewhat Uncomfortable
    - ❑ Neither Comfortable or Uncomfortable
    - ❑ Somewhat Comfortable
    - ❑ Very Comfortable
    - ❑ Don't know
    - ❑ Not applicable
    - ❑ Prefer not to respond

11. How comfortable are you with your ability to manage co-morbidities (e.g. pulmonary hypertension, diabetes, renal disease) experienced by individuals with SCD?
    - ❑ Very Uncomfortable
    - ❑ Somewhat Uncomfortable
    - ❑ Neither Comfortable or Uncomfortable
    - ❑ Somewhat Comfortable
    - ❑ Very Comfortable
    - ❑ Don't know
    - ❑ Not applicable
    - ❑ Prefer not to respond

12. Comorbidities I am least comfortable managing are: _____

13. Comorbidities I am most comfortable managing are: _____

14. How comfortable are you with your ability to manage acute pain episodes experienced by patients with SCD?
    - ❑ Very Uncomfortable
    - ❑ Somewhat Uncomfortable
    - ❑ Neither Comfortable or Uncomfortable
    - ❑ Somewhat Comfortable
    - ❑ Very Comfortable
    - ❑ Don't know
    - ❑ Not applicable

- ❑ Prefer not to respond

15. How comfortable are you in managing chronic pain in individuals with SCD?

- ❑ Very Uncomfortable
- ❑ Somewhat Uncomfortable
- ❑ Neither Comfortable or Uncomfortable
- ❑ Somewhat Comfortable
- ❑ Very Comfortable
- ❑ Don't know
- ❑ Not applicable
- ❑ Prefer not to respond

16. Do you prescribe opioids to patients with SCD?

- ❑ Yes
- ❑ No
- ❑ Prefer not to respond

17. Please indicate your impression of how much each of the following concerns is a barrier to using opioids in the management of chronic nonmalignant pain (e.g., SCD) to you:

	Not a barrier	Minimal barrier	Somewhat a barrier	Moderate barrier	Complete barrier	Don't know	Rather not provide
Lack of efficacy	❑	❑	❑	❑	❑	❑	❑
Respiratory effects	❑	❑	❑	❑	❑	❑	❑
Cognitive effects	❑	❑	❑	❑	❑	❑	❑
Psychomotor effects	❑	❑	❑	❑	❑	❑	❑
Tolerance	❑	❑	❑	❑	❑	❑	❑
Dependence	❑	❑	❑	❑	❑	❑	❑
Addiction	❑	❑	❑	❑	❑	❑	❑
Community perception	❑	❑	❑	❑	❑	❑	❑
Regulatory	❑	❑	❑	❑	❑	❑	❑
Overview	❑	❑	❑	❑	❑	❑	❑
Cost	❑	❑	❑	❑	❑	❑	❑
Availability	❑	❑	❑	❑	❑	❑	❑
Diversion	❑	❑	❑	❑	❑	❑	❑
Provider restrictions	❑	❑	❑	❑	❑	❑	❑
Training in prescribing opioids	❑	❑	❑	❑	❑	❑	❑
Time (prior authorization, dose adjustments and/or State database assessment)	❑	❑	❑	❑	❑	❑	❑
Other	If "Other" please specify: _____						

18. Please estimate the percentage of your patients with SCD that you are currently managing with hydroxyurea?

- ❑ 0
- ❑ 1 - 10%
- ❑ 11 - 20%
- ❑ 21 - 30%
- ❑ 31 - 40%
- ❑ 41 - 50%
- ❑ More than 50%
- ❑ I do not manage hydroxyurea therapy for SCD
- ❑ Don't know
- ❑ Not applicable
- ❑ Prefer not to respond

19. Which of the following CRITERIA do you use to place patients with SCD on hydroxyurea therapy? *(Check all that apply.)*

- ❑ Episodes of acute chest syndrome
- ❑ At least three painful episodes/year requiring hospitalization
- ❑ At least three painful episodes/year at home
- ❑ Chronic pain requiring excessive or frequent opioid use
- ❑ Stroke history
- ❑ Renal failure
- ❑ Priapism
- ❑ Low hemoglobin F levels
- ❑ Pulmonary hypertension
- ❑ Symptomatic severe anemia
- ❑ Elevated white cell count without evidence of infection
- ❑ Leg ulcers
- ❑ Patient or family request
- ❑ Presence of hypoxemia
- ❑ Other
- ❑ Prefer not to respond

If "Other" please specify: _____

20. Indicate the number of episodes of acute chest syndrome required to initiate treatment with hydroxyurea:

- ❑ 0
- ❑ 1
- ❑ 2
- ❑ 3
- ❑ 4
- ❑ 5+
- ❑ Prefer not to respond

21. Please estimate the proportion of patients with SCD or their families that you offer hydroxyurea to refuse it?

- ❑ 0
- ❑ 1 - 10%
- ❑ 11 - 20%
- ❑ 21 - 30%
- ❑ 31 - 40%
- ❑ 41 - 50%
- ❑ More than 50%
- ❑ I do not prescribe hydroxyurea
- ❑ Don't know
- ❑ Prefer not to respond

22. What are the most common reasons patients/families refuse hydroxyurea?

- ❑ Worry about carcinogenic potential
- ❑ Worry about side effects
- ❑ Don't think it will work
- ❑ Don't want to take another medicine
- ❑ Don't want the additional laboratory monitoring
- ❑ Don't want the additional clinic visits
- ❑ Other
- ❑ Don't know
- ❑ Not applicable
- ❑ Prefer not to respond

If "Other" please specify: _____

23. Sometimes providers do not initiate hydroxyurea use even though its use might be indicated. In your experience, how important has each of the following reasons influenced YOUR prescribing of hydroxyurea?

	Important	Very important	Somewhat important	Not important	Not applicable	Rather not provide
Cost issues	❑	❑	❑	❑	❑	❑
Age of patient (Patient is too young)	❑	❑	❑	❑	❑	❑
Patient/family adherence with hydroxyurea	❑	❑	❑	❑	❑	❑
Patient/family adherence with required blood tests	❑	❑	❑	❑	❑	❑
Patient anticipation of side effects	❑	❑	❑	❑	❑	❑
My discomfort with carcinogenesis potential	❑	❑	❑	❑	❑	❑
Doubt the effectiveness of the drug	❑	❑	❑	❑	❑	❑
Patients lack of contraception/ possible pregnancy	❑	❑	❑	❑	❑	❑
Provider lacks time/resources to adequately explain risks/benefits	❑	❑	❑	❑	❑	❑
Hydroxyurea is not FDA approved for use in children	❑	❑	❑	❑	❑	❑
There are a lack of formal guidelines for use in children	❑	❑	❑	❑	❑	❑
Concerns for hydroxyurea causing infertility in male patients	❑	❑	❑	❑	❑	❑
Other	If "Other" please specify: _____					

24. What is your comfort level in managing hydroxyurea as a disease modifying therapy for SCD?

- ❑ Very Uncomfortable
- ❑ Somewhat Uncomfortable
- ❑ Neither Comfortable or Uncomfortable
- ❑ Somewhat Comfortable
- ❑ Very Comfortable
- ❑ Don't know
- ❑ Not applicable
- ❑ Prefer not to respond

25. How effective do you think hydroxyurea is for preventing painful events in people with sickle cell disease?

- ❑ Very effective
- ❑ Somewhat effective
- ❑ Effective
- ❑ Not effective
- ❑ Don't know
- ❑ Prefer not to respond

26. Are you aware that the National Heart Lung and Blood Institute published guidelines on Primary Care Management for SCD?

- ❑ Yes
- ❑ No
- ❑ Prefer not to respond

27. What would prompt you to see patients (or to see more patients) with SCD? (Please check all that apply.)

- ❑ Higher reimbursement or Relative Value Units
- ❑ Accessible community health worker who you can consult to understand the social situation of your patients better
- ❑ Accessible case management services available without charge
- ❑ Pertinent sickle cell specific continuing medical education
- ❑ An easily accessible comprehensive sickle center
- ❑ An easily accessible day hospital
- ❑ Access to a SCD specialist (hematologist) on call to answer questions 24/7
- ❑ A pain management specialist on call to answer questions
- ❑ Access to pain management specialist who will manage my patients with chronic pain
- ❑ Better communication with hematologists about shared patients
- ❑ A formal agreement with a local emergency room that will treat my patients with an acute pain episode promptly and professionally
- ❑ Access to brief electronic medical records that includes specialty clinic and information on emergency department visits and hospitalizations
- ❑ Access to transportation for my patients to clinic
- ❑ Better understanding of your role in the patient's care vs. the hematologist's role
- ❑ No role in managing hydroxyurea
- ❑ Other
- ❑ I do not want to see any more patients with SCD than I do now
- ❑ I would prefer not to see patients with SCD
- ❑ Clinical decision support software
- ❑ Prefer not to respond

If "Other" please specify: _____

28. In the past 7 days... for which aspects of managing SCD patients would a clinical decision support tool be particularly useful (1 not useful at all, 4 very useful):

	Not useful at all	Somewhat useful	Useful	Very useful	Not applicable	Rather not provide
Diagnosis	❑	❑	❑	❑	❑	❑
Treatments	❑	❑	❑	❑	❑	❑
Avoiding complications	❑	❑	❑	❑	❑	❑

29. Are there any other factors that would prompt you to see patients, or see more patients, with SCD?

- ❑ Yes
- ❑ No
- ❑ Not applicable
- ❑ Prefer not to respond

If "Yes" please specify: _____

B. Other Comments

1. Please provide any other comment(s) that you have about the care and management of patients with SCD that were not addressed in this survey.

_____

_____

_____

_____

C. Demographics Section

1. What is your age?

- ❑ _____ Years
- ❑ Prefer not to provide

2. What is your gender?

- ❑ Female
- ❑ Male
- ❑ Prefer not to provide

3. What ethnicity do you self-identify with?

- ❑ Non Hispanic or Latino
- ❑ Hispanic or Latino
- ❑ Prefer not to provide

4. What race do you self-identify with?

   - ❑ American Indian or Alaskan Native
   - ❑ Asian
   - ❑ Native Hawaiian or Other Pacific Islander
   - ❑ Black or African American
   - ❑ White
   - ❑ Prefer not to provide

5. What is your provider type?

   - ❑ Medical Doctor
   - ❑ Physician's Assistant
   - ❑ Nurse Practitioner
   - ❑ Licensed Practical Nurse
   - ❑ Registered Nurse
   - ❑ Social Worker / Therapist
   - ❑ Other
   - ❑ Prefer not to provide

   If "Other" professional training, please specify: _____

6. How many years have you been in clinical practice?

   - ❑ _____ Years
   - ❑ Prefer not to provide

7. What is your area of practice?

   - ❑ Internal Medicine
   - ❑ Pediatrics
   - ❑ Family Medicine
   - ❑ Med-Peds
   - ❑ OB/GYN
   - ❑ Hematologist/SCD Specific
   - ❑ Emergency Medicine
   - ❑ Sub-specialist
   - ❑ Other
   - ❑ Prefer not to provide

   If "Sub-specialist", please specify the type: _____

   If "Other", please specify the practice area: _____

8. What is the age range of the patients you care for? *(Check all that apply)*

   - ❑ Infancy Through Young Adult
   - ❑ Adults
   - ❑ Prefer not to provide

9. What is your practice setting?

- ❑ Rural
- ❑ Urban
- ❑ Suburban
- ❑ Prefer not to provide

D. Continuing Medical Education (CME)

1. Would you be interested in free SCD CMEs?

- ❑ Yes
- ❑ No

2. What format would you prefer?

- ❑ Webinar
- ❑ Telephone
- ❑ Newsletter
- ❑ In-Person Lecture in your office
- ❑ Dinner forum
- ❑ Full-day retreat
- ❑ Other

If other, please specify: _____

3. What specific areas of SCD management would you be interested in learning about? *(Check all that apply.)*

- ❑ Acute Chest Syndrome and Other Pulmonary Complications
- ❑ Adolescent Health Care and Transitions
- ❑ Adult Health Care Maintenance
- ❑ Anesthesia and Surgery
- ❑ Bones and Joints
- ❑ Cardiovascular Manifestations
- ❑ Child Health Care Maintenance
- ❑ Contraception and Pregnancy
- ❑ Coordination of Care: Role of Mid-Level Practitioners
- ❑ Fetal Hemoglobin Induction
- ❑ Gall Bladder and Liver
- ❑ Genetic Counseling
- ❑ Genetic Modulation of Phenotype by Epistatic Genes
- ❑ Hematopoietic Cell Transplantation
- ❑ Infection
- ❑ Leg Ulcers
- ❑ Neonatal Screening
- ❑ Pain
- ❑ Priapism
- ❑ Psychosocial Management
- ❑ Renal Abnormalities in SCD
- ❑ Sickle Cell Eye Disease
- ❑ Sickle Cell Trait
- ❑ Splenic Sequestration
- ❑ Stroke and Central Nervous System Disease
- ❑ Iron Overload, and Chelation
- ❑ Transient Red Cell Aplasia
- ❑ Other

If other area, please specify:
_____