Subject ID

Sickle Cell Disease Implementation Consortium Needs Assessment: 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:
_____