

Subject ID



## **Provider Data Collection Form**

### **Baseline**

**Final Version 1.0, 1/17/2020**

Please answer the following questions to the best of your ability and return the completed form to the study coordinator when you are done.

**GENERAL INFORMATION**

Date form completed: |\_|\_| / |\_|\_| / |\_|\_|\_|\_|  
Month Day Year

Please select the clinic(s) in which you provide care for patients with SCD (sickle cell disease). (Check all that apply)

St. Jude Clinics:

- St. Jude Children's Research Hospital
- Methodist University Hospital
- Baptist Health Care

Duke Clinics:

- Duke Adult Sickle Cell Clinic
- Duke Pediatric Sickle Cell Clinic

Chicago Clinics:

- UI Hospital & Health Sciences System, Sickle Cell Center
- UI Hospital & Health Sciences System, Pediatric Department
- OSF Healthcare/Children's Hospital of Illinois
- Sinai Health System
- Lawndale Christian Health Center

UCSF Clinics:

- UCSF Benioff Children's Hospital Oakland
- UC Davis

Mount Sinai Clinics:

- Mount Sinai Hospital

Wash-U Clinics:

- St. Louis Children's Hospital Pediatric
- Barnes Jewish Hospital Hematology
- Christian Hospital Northeast-Hematology

Augusta Clinics:

- Augusta University Adult Center for Blood Disorders
- AU Pediatric Hem/Onc
- AU Macon Outreach Clinic
- AU Sylvester Outreach Clinic
- AU Savannah Outreach Clinic

MUSC Clinics:

- MUSC Adult Sickle Cell Clinic
- MUSC Pediatric Sickle Cell Clinic

Other clinic, specify: \_\_\_\_\_

**EXPERIENCES PROVIDING CARE TO PATIENTS WITH SICKLE CELL DISEASE (SCD)**

1. How many patients with SCD (all sickle genotypes) would you estimate currently receive regular care from you?

\_\_\_\_\_ # of patients

2. Do you have any specific training for SCD? (Check all that apply)

Fellowship training

Residency training

Attended special course

Attended online training

Learned "on the job"

Other, specify \_\_\_\_\_



8. What do you consider to be the best sources of information about SCD and SCD treatment, including hydroxyurea? Rank the items below in order of importance:

		Most important 1	2	3	4	5	Least important 6
a.	Textbooks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Peers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	Scientific articles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	Online videos (e.g., YouTube)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	NHLBI guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	Other society guidelines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### HYDROXYUREA SELF EFFICACY

9. 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
- I rely on recommendations from a specialist
- I do not prescribe hydroxyurea
- Other, specify \_\_\_\_\_

10. 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
- I don't know

11. How effective do you think hydroxyurea is for preventing painful events in people with SCD?

- Very effective
- Somewhat effective
- Effective
- Not effective
- I don't know

12. How many hours of CME have you completed related to hydroxyurea prescribing for patients with SCD in the past 3 years?

\_\_\_\_\_ # of hours or  I don't know

13. How often should hydroxyurea be taken by individuals with SCD?

- Once daily
- Twice daily
- Three times daily
- Every other day
- Once a week
- I don't know

14. What is the NHLBI recommended initial daily dosing of hydroxyurea for individuals with SCD?

- 0.5 mg/kg/day
- 1 mg/kg/day
- 20 mg/kg/day
- 50 mg/kg/day
- 100 mg/kg/day
- I don't know

15. In which scenario below should hydroxyurea be held due to drug toxicity?

- Hb 5 mg/dL, Absolute neutrophil count 4500/mm<sup>3</sup>, Absolute reticulocyte count 20 x10<sup>6</sup>/mm<sup>3</sup>, and platelets 250 x10<sup>3</sup>/mm<sup>3</sup>
- Hb 7 mg/dL, Absolute neutrophil count 4500/mm<sup>3</sup>, Absolute reticulocyte count 200 x10<sup>6</sup>/mm<sup>3</sup>, and platelets 250 x10<sup>3</sup>/mm<sup>3</sup>
- Hb 9 mg/dL, Absolute neutrophil count 4000/mm<sup>3</sup>, Absolute reticulocyte count 130 x10<sup>6</sup>/mm<sup>3</sup>, and platelets 250 x10<sup>3</sup>/mm<sup>3</sup>
- Hb 9 mg/dL, Absolute neutrophil count 4500/mm<sup>3</sup>, Absolute reticulocyte count 120 x10<sup>6</sup>/mm<sup>3</sup>, and platelets 250 x10<sup>3</sup>/mm<sup>3</sup>
- Hb 9 mg/dL, Absolute neutrophil count 4500/mm<sup>3</sup>, Absolute reticulocyte count 120 x10<sup>6</sup>/mm<sup>3</sup>, and platelets 150 x10<sup>3</sup>/mm<sup>3</sup>
- I don't know

16. In which scenario below should hydroxyurea be held due to drug toxicity?

- Platelets 70 x10<sup>3</sup>/mm<sup>3</sup>
- Platelets 150 x10<sup>3</sup>/mm<sup>3</sup>
- Platelets 250 x10<sup>3</sup>/mm<sup>3</sup>
- Platelets 350 x10<sup>3</sup>/mm<sup>3</sup>
- Platelets 450 x10<sup>3</sup>/mm<sup>3</sup>
- I don't know

17. In which scenario below should hydroxyurea be held due to toxicity?

- Absolute neutrophil count 800/mm<sup>3</sup>
- Absolute neutrophil count 3000/mm<sup>3</sup>
- Absolute neutrophil count 3500/mm<sup>3</sup>
- Absolute neutrophil count 4000/mm<sup>3</sup>
- Absolute neutrophil count 4500/mm<sup>3</sup>
- I don't know

## DEMOGRAPHICS

Please tell us about yourself.

1. What is your age? \_\_\_\_\_
2. Do you consider yourself Hispanic or Latino?
  - Yes
  - No

3. What race do you consider yourself to be? You can pick more than one.
- American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or Pacific Islander
  - White
4. What is your current gender identity? (Check all that apply)
- Male
  - Female
  - Female-to-male (FTM)/transgender male/trans man
  - Male-to-female (MTF)/transgender female/trans woman
  - Genderqueer, neither exclusively male nor female
  - Additional gender category/(or other), please specify: \_\_\_\_\_
  - Prefer not to respond
5. What sex were you assigned at birth on your original birth certificate? (Check one)
- Male
  - Female
  - Prefer not to respond
6. Please mark the role/profession you play related to the treatment of sickle cell patients:
- Physician (MD, DO, etc.)
  - Physician's Assistant
  - Nurse Practitioner
  - Licensed Practical Nurse
  - Other professional training, specify \_\_\_\_\_
7. How many years have you been in clinical practice? \_\_\_\_\_ (years)
8. Which of the following descriptions best characterizes your comfort and expertise in caring for patients with SCD?
- I am a primary care provider or hematologist/oncologist; I do not seek SCD patients in my practice; I do not prescribe hydroxyurea for SCD patients; I do not feel comfortable with SCD management.
  - I am a PCP or hematologist/oncologist willing to care for SCD patients; I am willing to learn to prescribe hydroxyurea; I am unfamiliar or unaware of evidence-based prescribing for SCD; I frequently refer to our consult SCD experts.

- I am a PCP or hematologist/oncologist; I accept and try to attract SCD patients in my practice; I feel comfortable prescribing hydroxyurea; I am aware of evidence-based prescribing for SCD; I care for 25 or fewer SCD patients.
- I am a PCP or hematologist/oncologist; I accept and try to attract SCD patients; I prescribe and care for greater than 25 SCD patients; I am often sought for SCD management decisions by other providers; I am usually at an academic medical center.

9. What is your specialty area of practice? (Check all that apply)

- Internal Medicine
- Pediatrics
- Family Medicine
- Med-Peds
- OB/GYN
- Hematology/Including SCD
- Hematology/Not including SCD
- Emergency Medicine
- Other specialty area (specify): \_\_\_\_\_

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

- Birth to 18 years
- 19 to 24 years
- 25 years and older

***This is the END of the survey. Please return it to the study coordinator.***

***Thank you for your participation.***