Patient Enrollment Survey

Version 1.1 (11/28/2017)

Subject ID

We are interested in learning more about people who have sickle cell disease. As you complete this form, answer the questions as best as you can. If you don't know the answer or do not want to answer a question, you may leave it blank.

1. What is today's date? |__|__|/ |__|__|/ | 2 | 0 |___|___|
   Month Day Year

2. What is your year of birth? |___|___|___|___|
   Year

3. How old are you today? ______ years

4. How old were you when you were diagnosed with sickle cell disease? |___|___| years

5. What type of healthcare professional has been providing the majority of care for your sickle cell disease in the past 2 years?
   - ❒ Sickle cell specialist or hematologist (including all care providers in the SCD clinic)
   - ❒ Primary care or general practice
   - ❒ Emergency department
   - ❒ I don't currently receive care for my sickle cell disease

A. YOUR PAIN HISTORY

6. Do you take pain medicine every day for your sickle cell disease?
   - ❒ Yes
   - ❒ No

7. In the past 12 months, how many sickle cell pain attacks (crises) did you have?
   - ❒ I did not have a pain attack in the past 12 months
   - ❒ 1
   - ❒ 2
   - ❒ 3
   - ❒ 4 or more

8. When was your last pain attack (crisis)?
   - ❒ I've never had a pain attack (crisis)
   - ❒ More than 5 years ago
   - ❒ 1-5 years ago
   - ❒ 7-11 months ago
   - ❒ 1-6 months ago
   - ❒ 1-3 weeks ago
   - ❒ Less than a week ago
   - ❒ I have one right now

9. How severe was your pain during your last pain attack (crisis)? **Circle a number from 0 to 10 below**, where 0 is no pain and 10 is the worst pain imaginable.

0	1	2	3	4	5	6	7	8	9	10

No pain — Worst pain imaginable

10. How much did your last pain attack (crisis) interfere with your life?

- ❒ I've never had a pain attack (crisis)
- ❒ Not at all, I did everything I usually do
- ❒ I had to cut down on some things I usually do
- ❒ I could not do most things I usually do
- ❒ I could not take care of myself and needed some help from family or friends
- ❒ I could not take care of myself and needed constant care from family, friends, doctors, or nurses

11. About how long did your most recent pain attack (crisis) last?

- ❒ I've never had a pain attack (crisis)
- ❒ Less than 1 hour
- ❒ 1-12 hours
- ❒ 13-23 hours
- ❒ 1-3 days
- ❒ 4-6 days
- ❒ 1-2 weeks
- ❒ More than 2 weeks

12. Think about your pain in the **past 7 days**, and answer the following questions.

		Never	**Rarely**	**Sometimes**	**Often**	**Always**
a.	How often did you have very severe pain?	❒	❒	❒	❒	❒
b.	How often did you have pain so bad that it was hard to finish what you were doing?	❒	❒	❒	❒	❒

13. Now think about your pain in the **past 6 months**, and answer the following questions.

		Never	**Rarely**	**Sometimes**	**Often**	**Always**
a.	How often did you have very severe pain?	❒	❒	❒	❒	❒
b.	How often did you have pain so bad that it was hard to finish what you were doing?	❒	❒	❒	❒	❒

14. Think about how your pain felt in the **past 7 days**, and answer the following questions.

		Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
a.	Did your pain feel like pins and needles?	❒	❒	❒	❒	❒
b.	Did your pain feel sore?	❒	❒	❒	❒	❒

B. YOUR HISTORY OF HYDROXYUREA USE

15. Did a doctor **ever** suggest you take hydroxyurea?

❒ Yes
❒ No

16. What makes it difficult for you to take hydroxyurea or is there a reason why you do not take hydroxyurea? Please select one or more from the list below whether or not you have ever taken hydroxyurea.

❒ I have no difficulties or concerns using hydroxyurea
❒ I don't know enough about the medicine
❒ Sometimes I forget to take the medicine
❒ I am worried about side effects
❒ I don't like the frequent blood tests or clinic visits
❒ I'm feeling well and I don't think I need it
❒ The cost is more than I can afford
❒ I have heard that hydroxyurea may cause cancer
❒ I have heard that hydroxyurea may cause problems with having healthy children
❒ Other difficulty, specify___________________________

17. Have you **ever** taken hydroxyurea?

❒ Yes
❒ No → ***skip to Question 23***

18. Have you experienced any side effects related to hydroxyurea?

❒ Yes
❒ No → ***skip to Question 20***

19. What side effects have you experienced while you were taking hydroxyurea?

❒ Hair loss/thinning
❒ Nail blackening or discoloration
❒ Lowered blood counts (e.g., platelets, white count, hemoglobin)
❒ Low sperm count or other fertility problems
❒ Nausea/vomiting
❒ Skin ulcers
❒ Weight gain
❒ Headaches or dizziness
❒ Fatigue/drowsiness
❒ Other, specify________________________________

20. Are you **currently** on hydroxyurea?

❒ Yes
❒ No → ***skip to Question 22***

21. How many days did you take hydroxyurea in the PAST WEEK?

❒ 0 days
❒ 1 day
❒ 2 days
❒ 3 days
❒ 4 days
❒ 5 days
❒ 6 days
❒ 7 days

Skip to Section C, Question 23 after answering this question

22. What is the reason you discontinued or stopped taking hydroxyurea?

- ❒ Side effects
- ❒ Yours/your family's preference
- ❒ Other reason, specify_______________________________

C. YOUR HISTORY OF BLOOD TRANSFUSIONS

23. Do you get regular blood transfusions for your sickle cell disease?

- ❒ Yes
- ❒ No

24. Estimate the number of units (pints) of blood that you have **ever** received.

- ❒ none
- ❒ 1 to 10
- ❒ 11 to 20
- ❒ 21 to 50
- ❒ 50-100
- ❒ more than 100
- ❒ Don't Know

25. Are you on iron chelation treatment **at this time**?

- ❒ Yes
- ❒ No

26. Have you **ever** been told that it is difficult to find blood for you (i.e., you have antibodies or react to other people's blood red blood cells)?

- ❒ Yes
- ❒ No
- ❒ Don't Know

27. Have you **ever** been referred for a bone marrow transplant?

- ❒ Yes
- ❒ No

D. YOUR MEDICAL HISTORY

28. Has a doctor or nurse ever told you that you have or had any of the following conditions? Please check YES or NO for each condition.

	Condition	YES	NO
a.	Lung problems such as pneumonia or acute chest syndrome	❒	❒
b.	Kidney damage	❒	❒
c.	Eye damage called retinopathy	❒	❒
d.	Damage to your hip or shoulder due to sickle cell disease	❒	❒
e.	High blood pressure in your lungs (also called pulmonary hypertension)	❒	❒
f.	Heart failure	❒	❒
g.	Blood clots in your legs or arms or that went to your lung	❒	❒
h.	A stroke	❒	❒
i.	Asthma	❒	❒
j.	Diabetes	❒	❒

29. Have you ever had open sores on your legs or feet (leg ulcers)?

- ❐ Yes
- ❐ No

30. Has your spleen either been removed or seriously damaged due to sickle cell disease?

- ❐ Yes
- ❐ No

E. MEDICATIONS YOU ARE TAKING AT THE PRESENT TIME

31. Please list all medications you are **currently** taking.

Name of Medication	Name of Medication
1.	6.
2.	7.
3.	8.
4.	9.
5.	10.

F. BARRIERS TO YOUR MEDICAL CARE

32. During the past 12 months, was there any time when you didn't get the medical care you needed or had delays in getting the care you needed?

- ❐ Yes
- ❐ No → ***skip to Question 34***

33. Did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons?

- ❐ Worry about the cost
- ❐ The doctor or hospital wouldn't accept your health insurance
- ❐ Your health plan wouldn't pay for the treatment
- ❐ You couldn't get an appointment soon enough
- ❐ You couldn't get there when the doctor's office or clinic was open
- ❐ It takes too long to get to the doctor's office or clinic from your house or work
- ❐ You couldn't get through on the telephone
- ❐ You were too busy with work or other commitments to take the time
- ❐ You didn't think the problem was serious enough
- ❐ You had previous bad experiences with the health care system
- ❐ People at the doctor's office or clinic don't speak the same language I do
- ❐ Some other reason not listed above, please specify _______________________________

G. YOUR SOCIAL AND MENTAL HEALTH

34. Think about your sleep in the **past 7 days**, and answer the following questions.

		Never	Rarely	Sometimes	Often	Always
a.	How often did you stay up most of the night because you could not fall asleep?	❒	❒	❒	❒	❒
b.	How often did you have a lot of trouble falling asleep?	❒	❒	❒	❒	❒

35. In the **past 7 days**, how often did the following happen?

		Never	Rarely (Once)	Sometimes (2-3 times)	Often (once a day)	Very often (several times a day)
a.	I had to read something several times to understand it.	❒	❒	❒	❒	❒
b.	My thinking was slow.	❒	❒	❒	❒	❒
c.	I had to work really hard to pay attention or I would make a mistake.	❒	❒	❒	❒	❒
d.	I had trouble concentrating.	❒	❒	❒	❒	❒

36. How much DIFFICULTY do you **currently** have doing the following things?

		None	A little	Somewhat	A lot	Cannot do
a.	Reading and following complex instructions (e.g., directions for a new medication)?	❒	❒	❒	❒	❒
b.	Planning for and keeping appointments that are not part of your weekly routine (e.g, a therapy or doctor appointment, a social gathering with friends or family)?	❒	❒	❒	❒	❒
c.	Managing your time to do most of your daily activities?	❒	❒	❒	❒	❒
d.	Learning new tasks or instructions?	❒	❒	❒	❒	❒

37. Think about how you felt in the **past 7 days**, and respond to each question or statement.

		Never	Rarely	Sometimes	Often	Always
a.	I felt worthless.	❒	❒	❒	❒	❒
b.	I felt helpless.	❒	❒	❒	❒	❒
c.	I felt depressed.	❒	❒	❒	❒	❒
d.	I felt hopeless.	❒	❒	❒	❒	❒
e.	How often did you feel completely hopeless because of your health?	❒	❒	❒	❒	❒
f.	How often were you very worried about needing to go to the hospital?	❒	❒	❒	❒	❒
		Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
g.	I felt tired.	❒	❒	❒	❒	❒

38. Have you ever been treated for depression?

- ❒ Yes, currently receiving treatment
- ❒ Yes, treated in the past but not now
- ❒ No, never received treatment

39. In the **past 30 days**, how much did the following happen?

		Not at all	A little bit	Somewhat	Quite a bit	Very much
a.	How much did you rely on others to take care of you because of your health?	❒	❒	❒	❒	❒
b.	How much did your health make it hard for you to do things with your friends?	❒	❒	❒	❒	❒

H. TELL US ABOUT YOURSELF

40. Are you male or female?

❒ Male
❒ Female

41. Do you consider yourself Hispanic/Latino or not Hispanic/Latino?

❒ Hispanic or Latino
❒ Not Hispanic or Latino

42. Which of the following five racial designations best describes you? More than one choice is acceptable.

❒ American Indian or Alaska Native
❒ Asian
❒ Black or African American
❒ Native Hawaiian or Pacific Islander
❒ White

43. In what language do you feel most comfortable speaking with your doctor or nurse?

❒ English
❒ Spanish
❒ Another language

44. What is your current marital status?

❒ Not Applicable (subject is a child)
❒ Married
❒ Living as married (including living with a partner)
❒ Divorced or separated
❒ Widowed
❒ Never married

45. How many children and adults, including yourself, live in your household at least 4 nights a week?

_______ # of children _______ # of adults

46. What is your approximate yearly household income? Include income from all sources.

❒ $25,000 and under
❒ $25,001 - $50,000
❒ $50,001 - $75,000
❒ $75,001 - $100,000
❒ >$100,000

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

- ❒ Less than High School
- ❒ Some high school
- ❒ High school graduate or GED equivalent
- ❒ Some college or vocational training
- ❒ College graduate
- ❒ Some graduate school or professional school
- ❒ Graduate or professional degree

48. We would like to know about what you do -- are you working, looking for work, retired, keeping house, or what?

- ❒ Working now
- ❒ Only temporarily laid off, sick leave, or maternity leave
- ❒ Looking for work, unemployed
- ❒ Retired
- ❒ Disabled, permanently or temporarily
- ❒ Keeping house
- ❒ Student
- ❒ Other (Specify):______________________

This is the END of the survey. Please return it to the study coordinator.
Thank you for your participation.