Subject ID

Patient Follow-up Survey

Final Version 2.0, 11/25/2019

INSTRUCTION:
We are interested in learning how you have been doing since we were last in touch with you. 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.

What is today's date? |__|__|- |__|__|- |___|___|___|___|
Month Day Year

A. YOUR RECENT PAIN

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

2. What pain medicines do you currently take for your sickle cell disease? On the list below, check the box next to the name of the **pain medicines** you take (even if not everyday). Check here if you don't take pain medicines → ❒

PAIN MEDICATIONS	
❒ acetaminophen & codeine (Tylenol-Codeine #3 or #4)	❒ magnesium salicylic acid (Durasal)
❒ acetaminophen & oxycodone (Percocet, Endocet)	❒ meperidine (Demerol)
❒ acetaminophen & hydrocodone (Vicodin, Norco, Lortab)	❒ methadone (Dolophine)
❒ acetaminophen (Tylenol)	❒ morphine sulfate (MS Contin, Kadian)
❒ amitriptyline/Elavil	❒ morphine and naltrexone (Embeda, MS IR)
❒ aspirin (any brand)	❒ naproxen (Aleve, Naprosyn)
❒ buprenorphine/Belbuca/Butrans	❒ oxycodone (Oxycontin, Roxicodone)
❒ butalbital, acetaminophen, and caffeine (Fioricet)	❒ oxymorphone (Opana)
❒ butalbital, aspirin, caffeine, & codeine (Ascomp-Codeine)	❒ pentazocine/Talwin
❒ celecoxib (Celebrex)	❒ pregabalin (Lyrica)
❒ diclofenac/Voltaren/Cambia/Solaraze	❒ promethazine/Phenergan with codeine
❒ esomeprazole (Nexium)	❒ tapentadol/Nucynta
❒ Excedrin	❒ tramadol
❒ fentanyl (Duragesic)	❒ venlafaxine/Effexor
❒ gabapentin (Neurontin)	❒ medical marijuana/cannabis
❒ hydromorphone (Exalgo ER, Dilaudid)	❒ topical/skin cream for pain (all types)
❒ ibuprofen (Motrin, Advil)	❒ Other pain medication (specify below)
❒ ketorolac/Toradol	

3. 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

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

5. 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.

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Pain Imaginable

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

- ❒ 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

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

- ❒ Less than 1 hour
- ❒ 1-12 hours
- ❒ 13-23 hours
- ❒ 1-3 days
- ❒ 4-6 days
- ❒ 1-2 weeks
- ❒ More than 2 weeks

8. 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?	❒	❒	❒	❒	❒

9. 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?	❒	❒	❒	❒	❒

10. 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?	❒	❒	❒	❒	❒

11. Would you say that your pain management plan is…..

- ❒ Effective for managing your pain
- ❒ Somewhat effective for managing your pain
- ❒ Ineffective at managing your pain
- ❒ You don't have a pain management plan

B. YOUR MEDICAL CONDITIONS

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

- ❒ Yes
- ❒ No

13. In the past 12 months, how many units (pints) of blood have you received?

- ❒ None
- ❒ 1 – 2
- ❒ 3 – 5
- ❒ 6 – 10
- ❒ 11 – 15
- ❒ >15
- ❒ Don't Know

14. Are you **currently** on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy)?

- ❒ Yes
- ❒ No
- ❒ Don't Know

15. In the past 12 months, has your spleen been removed?

- ❒ Yes
- ❒ No

16. In the past 12 months, have you been **newly diagnosed** with any of the following conditions?

	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	❒	❒
k.	Liver problems such as hepatitis, iron overload, or cirrhosis	❒	❒
l.	Skin ulcers	❒	❒

C. HYDROXYUREA USE

17. In the past 12 months, have you taken hydroxyurea?

- ❒ Yes
- ❒ No → ***skip to Section D***

18. Are you **currently** taking hydroxyurea?

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

19. In the past 12 months, what is the reason you discontinued or stopped taking hydroxyurea? Please select one from the list below.

- ❒ Side effects
- ❒ Personal preference
- ❒ Provider decision
- ❒ Didn't work
- ❒ Pregnancy concerns
- ❒ Other reason not listed above, specify_____

20. 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

21. In the last 12 months, which of the following side effects did you experience while you were taking hydroxyurea? Select one or more from the list below.

❒ 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
❒ No side effects

22. In the last 12 months, what makes it difficult for you to take hydroxyurea, or is there a reason why you do not take hydroxyurea? 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_____

D. OTHER MEDICATIONS YOU ARE TAKING

23. In the past 12 months, have you taken the drug called Endari (l-glutamine)?

❒ Yes
❒ No → ***skip to Question 28***

24. Are you **currently** taking Endari?

❒ Yes → ***skip to Question 26***
❒ No

25. In the past 12 months, what is the reason you discontinued or stopped taking Endari? Please select one from the list below.

❒ Side effects
❒ Personal preference
❒ Provider decision
❒ Didn't work
❒ Other reason <u>not listed above</u>, specify_____

26. How many days did you take Endari in the PAST WEEK?

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

27. In the last 12 months, what side effects have you experienced while you were taking Endari? Select one or more from the list below.

- ❒ No side effects
- ❒ Nausea/vomiting
- ❒ Stomach pain
- ❒ Cough
- ❒ Headaches or dizziness
- ❒ Other not listed above _____

28. We would like to know what other types of medications you are **currently** taking, ***excluding pain medications, iron chelators, hydroxyurea, and Endari*** which we already asked about.

Review the list in the table below and check the box next to the type of medications you are **currently** taking.

CATEGORIES OR TYPES OF DRUGS YOU MAY BE TAKING	
❒ Allergy drugs	❒ High cholesterol drugs
❒ Asthma or COPD inhalers (bronchodilators)	❒ Hypothyroid drugs
❒ Antibiotics	❒ Insomnia drugs & sleep aides
❒ ADD/ADHD drugs	❒ Nausea drugs
❒ Anti-seizure drugs	❒ Muscle relaxers
❒ Anti-anxiety drugs	❒ Stool softeners and laxatives
❒ Antidepressants	**TYPES OF VITAMINS**
❒ Birth control	❒ Iron supplements
❒ Blood thinning drugs (anticoagulants)	❒ Folic acid
❒ Diabetes drugs	❒ Vitamin D, all types
❒ Diuretics, fluid/water retention pills	❒ Multi-vitamins
❒ Heartburn, indigestion, acid reflux drugs	❒ Any other vitamins and supplements

29. Are you taking any medications for **high blood pressure** (hypertension) or for your **heart**? ❒ Yes ❒ No

If yes, what is the name of the high blood pressure or heart medication? _____

30. Are you taking any <u>other type</u> of medication that we did not already ask about? ❒ Yes ❒ No

If yes, what is the name of the other medication(s)? _____

31. Are you currently participating in a study where you are taking a medicine for sickle cell? ❒ Yes ❒ No

E. YOUR SLEEP

32. 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?	❒	❒	❒	❒	❒

F. YOUR SOCIAL AND MENTAL HEALTH

33. 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.	❒	❒	❒	❒	❒

34. 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.	❒	❒	❒	❒	❒

35. 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., therapy or doctor appointment, social gathering with friends/family)?	❒	❒	❒	❒	❒
c.	Managing your time to do most of your daily activities?	❒	❒	❒	❒	❒
d.	Learning new tasks or instructions?	❒	❒	❒	❒	❒

36. 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?	❒	❒	❒	❒	❒

G. YOUR PHYSICAL HEALTH

37. Please respond to each question or statement by marking one box per row.

		Excellent	Very good	Good	Fair	Poor
a.	In general, how would you rate your physical health?	❒	❒	❒	❒	❒
		Completely	**Mostly**	**Moderately**	**A little**	**Not at all**
b.	To what extent are you able to carry out your everday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	❒	❒	❒	❒	❒

H. YOUR ABILITY TO MANAGE YOUR SICKLE CELL DISEASE

38. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

- ❒ Never
- ❒ Rarely
- ❒ Sometimes
- ❒ Often
- ❒ Always

39. Please respond to each statement below by marking one box per row.

CURRENT Level of Confidence (confidence is how sure you are about each statement)		**I am not at all confident**	**I am a little confident**	**I am somewhat confident**	**I am quite confident**	**I am very confident**
a.	I can follow directions when my doctor changes my medications.	❒	❒	❒	❒	❒
b.	I can take my medication when there is a change in my usual day (unexpected things happen).	❒	❒	❒	❒	❒
c.	I can manage my medication without help.	❒	❒	❒	❒	❒
d.	I can list my medications, including the doses and schedule.	❒	❒	❒	❒	❒

I. BARRIERS TO YOUR MEDICAL CARE

40. 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 END***

41. In the past 12 months, did you not get the medical care you needed or have delays getting medical care you needed for any of the following reasons? Select one or more from the list below.

- ❒ 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 _____

This is the END of the survey. Please return it to the study coordinator. Thank you!