Patient Survey

Please complete the survey below.

Thank you!

The patient has opted out of taking this survey ☐

INSTRUCTIONS:

To be done at months 4 and 8 between annual patient surveys

Thank you for taking the time to complete this survey and share your experiences. The information you provide is very valuable to the research and may be helpful for improving the care for people living with sickle cell disease. Some of the questions ask about things that happened during certain periods of time, for example the past 7 days, or the past 6 or 12 months, or something happening right now. Read the questions carefully to make sure you know what timeframe is being asked about.

Some questions may seem personal or you may not want to answer them-it's okay to skip these questions. The answers you provide are private, and the care you receive will stay the same, regardless of how you answer the questions. If the survey questions spark a need to talk further about some items, let your study coordinator know and they will direct you to the best place for help. Please feel free to let the study coordinator know if you need help with the survey itself or if you have other questions about the research.

What is today's date?

_____
(mm-dd-yyyy)

A. YOUR RECENT PAIN

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

2. 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?	◯	◯	◯	◯	◯

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

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. How much did pain interfere with your day to day activities?	◯	◯	◯	◯	◯
b. How much did pain interfere with work around the home?	◯	◯	◯	◯	◯
c. How much did pain interfere with your ability to participate in social activities?	◯	◯	◯	◯	◯
d. How much did pain interfere with your household chores?	◯	◯	◯	◯	◯

4. 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?	◯	◯	◯	◯	◯

5. 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?	◯	◯	◯	◯	◯

6. Have you had at least 15 days per month with pain for at least 6 months?

◯ Yes
◯ No

7. 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 SOCIAL AND MENTAL HEALTH

8. Think about the past 7 days, and respond to each question or statement.

In the past 7 days.....

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I feel fatigued.	◯	◯	◯	◯	◯
b. I have trouble starting things because I am tired.	◯	◯	◯	◯	◯
c. How run-down did you feel on average?	◯	◯	◯	◯	◯
d. How fatigued were you on average?	◯	◯	◯	◯	◯
e. I felt tired.	◯	◯	◯	◯	◯

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

In the past 7 days.....

	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.	○	○	○	○	○

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

In the past 30 days.....

	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?	○	○	○	○	○

In the past 30 days.....

	Never	Rarely	Sometimes	Often	Always
c. How often did your health slow you down?	○	○	○	○	○
d. How often did your health make it hard for you to do things?	○	○	○	○	○
e. How often did your health keep you from going out?	○	○	○	○	○

C. YOUR PHYSICAL AND OVERALL HEALTH

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

	Excellent	Very good	Good	Fair	Poor
a. In general, would you say your health is	○	○	○	○	○
b. In general, how would you rate your physical health?	○	○	○	○	○

	Completely	Mostly	Moderately	A little	Not at all
c. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	◯	◯	◯	◯	◯

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

In the past 7 days.....

	Never	Rarely	Sometimes	Usually	Always
a. How often were your joints very stiff when you woke up?	◯	◯	◯	◯	◯
b. How often were your joints very stiff during the day?	◯	◯	◯	◯	◯
c. How often were your joints so stiff during the day that you could not move?	◯	◯	◯	◯	◯
d. How often did you wake up so stiff that you could not move?	◯	◯	◯	◯	◯
e. How often did it take you a very long time to get out of bed because of stiffness?	◯	◯	◯	◯	◯

D. YOUR SLEEP

13. 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?	◯	◯	◯	◯	◯
c. How often was it very easy for you to fall asleep?	◯	◯	◯	◯	◯
d. How often did you stay up all night because you could not fall asleep?	◯	◯	◯	◯	◯
e. How often did you stay up half of the night because you could not fall asleep?	◯	◯	◯	◯	◯

Comments