Subject ID

Patient Survey

Version 1.0, 06/1/2022

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 helfpul 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.

Please enter todays date |__|__|- |__|__|- |___|___|___|___|
Month Day Year

A. YOUR RECENT PAIN

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

2. 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

3. When was your last pain attack (crisis)?

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

4. 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

5. 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

6. 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

7. 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?	❒	❒	❒	❒	❒

8. 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?	❒	❒	❒	❒	❒

9. 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?	❒	❒	❒	❒	❒

10. 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?	❒	❒	❒	❒	❒

11. Have you had at least 15 days per month with pain for at least 6 months?
    - ❒ Yes
    - ❒ No

12. 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

13. Do you get regular blood transfusions for your sickle cell disease?
    - ❒ Yes
    - ❒ No

14. 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

15. Are you **currently** on iron chelation treatment (e.g., Desferal, Exjade, Jadenu, deferasirox, Ferriprox, deferiprone, phlebotomy)?
    - ❒ Yes
    - ❒ No
    - ❒ Don't Know

16. In the past 12 months, has your spleen been removed?
    - ❒ Yes
    - ❒ No

17. In the past 12 months, have you received an influenza (seasonal flu) vaccine?
    - ❒ Yes
    - ❒ No

18. In the past 12 months, have you had 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	❒	❒
m.	Cancer or myelodysplastic syndrome (MDS)	❒	❒
n.	Positive COVID test, with or without symptoms	❒	❒
o.	Chronic or ongoing COVID symptoms (also known as long COVID or PASC)	❒	❒

19. Have you **ever** received a COVID vaccine?
    - ❒ Yes
    - ❒ No → ***skip to Question 21***

20. Have you **ever** received a COVID vaccine booster shot?
    - ❒ Yes
    - ❒ No

21. Have you **ever** been hospitalized because of COVID?
    - ❒ Yes
    - ❒ No

C. HYDROXYUREA USE

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

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

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

    ❒ Yes → ***skip to Question 25***
    ❒ No

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

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

25. 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

26. 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

27. 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

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

    ❒ Yes
    ❒ No → ***skip to Question 33***

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

    ❒ Yes → ***skip to Question 31***
    ❒ No

30. 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 not listed above, specify_____

31. 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

32. 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 _____

33. In the past 12 months, have you taken the drug called **Adakveo (crizanlizumab)?**

    ❒ Yes
    ❒ No → ***skip to Question 38***

34. Are you **currently** taking Adakveo?

    ❒ Yes → ***skip to Question 36***
    ❒ No

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

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

36. How many infusions of Adakveo have you missed or rescheduled in the PAST 6 MONTHS?

❒ 0 infusions ❒ 1 infusion ❒ 2 infusions ❒ 3 infusions ❒ 4 infusions ❒ 5 infusions ❒ 6 infusions

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

❒ No side effects
❒ Fever
❒ Chills or shivering
❒ Nausea
❒ Vomiting
❒ Shortness of breath
❒ Muscle aches (myalgias)
❒ Other not listed above _____

38. In the past 12 months, have you taken the drug called **Oxbryta (voxelotor)**?

❒ Yes
❒ No → ***skip to Section E***

39. Are you **currently** taking Oxbryta?

❒ Yes → ***skip to Question 41***
❒ No

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

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

41. How many days did you take Oxbryta in the PAST WEEK?

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

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

❒ No side effects
❒ Rash or hives
❒ Headache
❒ Nausea
❒ Abdominal pain
❒ Loose stools
❒ Other not listed above _____

E. YOUR ABILITY TO MANAGE YOUR SICKLE CELL DISEASE

43. 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

44. 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.	❒	❒	❒	❒	❒

F. YOUR SOCIAL AND MENTAL HEALTH

45. 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 quality of life is…….	❒	❒	❒	❒	❒
b.	In general, how would you rate your mental health, including your mood and your ability to think?	❒	❒	❒	❒	❒

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

		Never	**Rarely**	**Sometimes**	**Usually**	**Always**
a.	I have someone who will listen to me when I need to talk.	❒	❒	❒	❒	❒
b.	I have someone to confide in or talk to about myself or my problems.	❒	❒	❒	❒	❒
c.	I have someone who makes me feel appreciated.	❒	❒	❒	❒	❒
d.	I have someone to talk with when I have a bad day	❒	❒	❒	❒	❒

47. 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?	❒	❒	❒	❒	❒

48. 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.	❒	❒	❒	❒	❒

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

	In the past 7 days…..	Never	Rarely	Sometimes	Usually	Always
a.	I felt fearful.	❒	❒	❒	❒	❒
b.	I found it hard to focus on anything other than my anxiety.	❒	❒	❒	❒	❒
c.	My worries overwhelmed me.	❒	❒	❒	❒	❒
d.	I felt uneasy.	❒	❒	❒	❒	❒

50. 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.	❒	❒	❒	❒	❒

51. 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?	❒	❒	❒	❒	❒

52. 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?	❒	❒	❒	❒	❒

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

In the past month, please describe how often...		Never	Rarely	Sometimes	Usually	Always
a.	I feel alone and apart from others.	❒	❒	❒	❒	❒
b.	I feel left out.	❒	❒	❒	❒	❒
c.	I feel that I am no longer close to anyone.	❒	❒	❒	❒	❒
d.	I feel alone.	❒	❒	❒	❒	❒
e.	I feel lonely.	❒	❒	❒	❒	❒
f.	I feel isolated from others.	❒	❒	❒	❒	❒

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

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a.	I tend to bounce back quickly after hard times.	❒	❒	❒	❒	❒
b.	I have a hard time making it through stressful events.	❒	❒	❒	❒	❒
c.	It does not take me long to recover from a stressful event.	❒	❒	❒	❒	❒
d.	It is hard for me to snap back when something bad happens.	❒	❒	❒	❒	❒
e.	I usually come through difficult times with little trouble.	❒	❒	❒	❒	❒
f.	I tend to take a long time to get over set-backs in my life.	❒	❒	❒	❒	❒

G. YOUR PHYSICAL AND OVERALL HEALTH

55. 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?	❒	❒	❒	❒	❒

56. 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?	❒	❒	❒	❒	❒

H. YOUR SLEEP

57. 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?	❒	❒	❒	❒	❒

I. BARRIERS

58. 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 60***

59. 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
❒ The Coronavirus/COVID-19 pandemic
❒ Some other reason not listed above, please specify _____

60. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?

❒ Not hard at all
❒ Not very hard
❒ Somewhat hard
❒ Hard
❒ Very hard

61. Did you lose your health insurance in the past year?

❒ Yes
❒ No

62. In the past 12 months, have you experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in any of the following situations because of your race, ethnicity, or color?

If yes, please indicate whether it happened 1-2 times or 3 or more times in the past 12 months.

		No	Yes →	How many times did this happen in the past 12 months?	
a.	At school?	❒	❒ →	❒ 1-2 times	❒ 3 or more
b.	Getting hired or getting a job?	❒	❒ →	❒ 1-2 times	❒ 3 or more
c.	At work?	❒	❒ →	❒ 1-2 times	❒ 3 or more
d.	Getting housing?	❒	❒ →	❒ 1-2 times	❒ 3 or more
e.	Getting medical care?	❒	❒ →	❒ 1-2 times	❒ 3 or more
f.	Getting service in a store or restaurant?	❒	❒ →	❒ 1-2 times	❒ 3 or more
g.	Getting credit, bank loans, or a mortgage?	❒	❒ →	❒ 1-2 times	❒ 3 or more
h.	On the street or in a public setting?	❒	❒ →	❒ 1-2 times	❒ 3 or more
i.	From the police or in the courts?	❒	❒ →	❒ 1-2 times	❒ 3 or more

J. ALCOHOL AND SMOKING HISTORY

63. Have you consumed at least one alcoholic drink in the past 12 months?
    - ❒ Yes
    - ❒ No

64. How often do you have a drink containing alcohol?
    - ❒ Never
    - ❒ Monthly or less
    - ❒ 2 to 4 times per month
    - ❒ 2-3 times per week
    - ❒ 4 or more times per week

65. During the last 30 days, on how many days (if any) have you used marijuana?
    - ❒ Never used marijuana
    - ❒ None in past 30 days
    - ❒ 1 or 2 days
    - ❒ 3-5 days
    - ❒ 6-9 days
    - ❒ 10-19 days
    - ❒ 20-30 days

66. Have you ever used one or more tobacco products (such as cigarettes, cigars, pipe, chewing tobacco)?
    - ❒ Yes
    - ❒ No → **SURVEY IS COMPLETE, THANK YOU**

67. What was your age when you first started using tobacco products?

    _____ years

68. Have you used tobacco products in the past 12 months?
    - ❒ Yes → ***skip to Question 70***
    - ❒ No

69. What was your age when you stopped using tobacco products? _____ years

70. In the past 30 days, what is the average number of cigarettes you smoked per day?
    - ❒ 0 cigarettes
    - ❒ 1-2 cigarettes
    - ❒ 3-5 cigarettes
    - ❒ 6-15 cigarettes (about a half a pack)
    - ❒ 16-25 cigarettes (about a pack)
    - ❒ About 1 ½ packs per day
    - ❒ More than 1 ½ packs per day

SURVEY IS COMPLETE, THANK YOU.

Comments:_____

_____

_____

_____

_____