



New Patient Survey

Version 1.0, 05/4/2023

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.

Please enter today's date |__|__| - |__|__| - |__|__|__|__|
Month Day Year

TELL US ABOUT YOURSELF

1. What is your year of birth? |__|__|__|__|
Year
2. How old are you today? _____ years
3. Do you consider yourself Hispanic/Latine or not Hispanic/Latine?
 - Hispanic or Latine
 - Not Hispanic or Latine
4. 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
5. 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
6. 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
7. 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
8. 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): _____
9. How old were you when you were diagnosed with sickle cell disease? |__|__| years

10. 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 RECENT PAIN

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

12. 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

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

- I've never had a pain attack (crisis) → **skip to Question 17**
- More than a year ago → **skip to Question 17**
- 7-11 months ago
- 1-6 months ago
- 1-3 weeks ago
- Less than a week ago
- I have one right now

14. 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

15. 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

16. 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

17. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Did your pain feel sore?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How much did pain interfere with work around the home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	How much did pain interfere with your ability to participate in social activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	How much did pain interfere with your household chores?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How often did you have pain so bad that it was hard to finish what you were doing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How often did you have pain so bad that it was hard to finish what you were doing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

- Yes
- No

22. 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

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

- Yes
- No

24. 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

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

- Yes
- No
- Don't Know

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

- Yes
- No

27. In the past 12 months, have you received an influenza (seasonal flu) vaccine?

- Yes
- No

28. Has a doctor or nurse ever told you that you have or had any of the following conditions?

	Condition	YES	NO
a.	Lung problems such as pneumonia or acute chest syndrome	<input type="checkbox"/>	<input type="checkbox"/>
b.	Kidney damage	<input type="checkbox"/>	<input type="checkbox"/>
c.	Eye damage called retinopathy	<input type="checkbox"/>	<input type="checkbox"/>
d.	Damage to your hip or shoulder due to sickle cell disease	<input type="checkbox"/>	<input type="checkbox"/>
e.	High blood pressure in your lungs (also called pulmonary hypertension)	<input type="checkbox"/>	<input type="checkbox"/>
f.	Heart failure	<input type="checkbox"/>	<input type="checkbox"/>
g.	Blood clots in your legs or arms or that went to your lung	<input type="checkbox"/>	<input type="checkbox"/>
h.	A stroke	<input type="checkbox"/>	<input type="checkbox"/>
i.	Asthma	<input type="checkbox"/>	<input type="checkbox"/>
j.	Diabetes	<input type="checkbox"/>	<input type="checkbox"/>
k.	Liver problems such as hepatitis, iron overload, or cirrhosis	<input type="checkbox"/>	<input type="checkbox"/>
l.	Skin ulcers	<input type="checkbox"/>	<input type="checkbox"/>
m.	Cancer or myelodysplastic syndrome (MDS)	<input type="checkbox"/>	<input type="checkbox"/>
n.	Positive COVID test, with or without symptoms	<input type="checkbox"/>	<input type="checkbox"/>
o.	Chronic or ongoing COVID symptoms (also known as long COVID or PASC)	<input type="checkbox"/>	<input type="checkbox"/>

29. Have you **ever** received a COVID vaccine?

- Yes
- No → **skip to Question 31**

30. Have you **ever** received a COVID vaccine booster shot?

- Yes
- No

31. Have you **ever** been hospitalized because of COVID?

- Yes
- No

C. HYDROXYUREA USE

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

- Yes
- No

33. 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 _____

34. Have you ever taken hydroxyurea?

- Yes
- No → **skip to Section D**

35. 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 _____
- No side effects

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

- Yes → **skip to Question 38**
- No

37. 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 _____

38. 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

D. OTHER MEDICATIONS YOU ARE TAKING

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

- Yes
- No → **skip to Question 44**

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

- Yes → **skip to Question 42**
- No

41. 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 _____

42. 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

43. 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 _____

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

- Yes
- No → **skip to Question 49**

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

- Yes → **skip to Question 47**
- No

46. 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 _____

47. 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

48. 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 _____

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

- Yes
 No → **skip to Section E**

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

- Yes → **skip to Question 52**
 No

51. 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 _____

52. 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

53. 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

54. 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

55. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I can take my medication when there is a change in my usual day (unexpected things happen).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I can manage my medication without help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I can list my medications, including the doses and schedule.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

F. YOUR SOCIAL AND MENTAL HEALTH

56. 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.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	In general, how would you rate your mental health, including your mood and your ability to think?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

57. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I have someone to confide in or talk to about myself or my problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I have someone who makes me feel appreciated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I have someone to talk with when I have a bad day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

58. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I felt helpless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I felt hopeless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	How often did you feel completely hopeless because of your health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	How often were you very worried about needing to go to the hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

59. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I have trouble <u>starting</u> things because I am tired.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	How run-down did you feel on average?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	How fatigued were you on average?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	I felt tired.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

60. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I found it hard to focus on anything other than my anxiety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	My worries overwhelmed me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I felt uneasy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

61. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	My thinking was slow.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I had to work really hard to pay attention or I would make a mistake.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I had trouble concentrating.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

62. 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)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	Managing your time to do most of your daily activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	Learning new tasks or instructions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

63. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How much did your health make it hard for you to do things with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In the past 30 days		Never	Rarely	Sometimes	Often	Always
c.	How often did your health slow you down?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	How often did your health make it hard for you to do things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	How often did your health keep you from going out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

64. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I feel left out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	I feel that I am no longer close to anyone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	I feel alone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	I feel lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	I feel isolated from others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

65. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	I have a hard time making it through stressful events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	It does not take me long to recover from a stressful event.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	It is hard for me to snap back when something bad happens.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	I usually come through difficult times with little trouble.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	I tend to take a long time to get over setbacks in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

G. YOUR PHYSICAL AND OVERALL HEALTH

66. 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.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	In general, how would you rate your physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

67. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How often were your joints very stiff during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	How often were your joints so stiff during the day that you could not move?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	How often did you wake up so stiff that you could not move?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	How often did it take you a very long time to get out of bed because of stiffness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

H. YOUR SLEEP

68. 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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	How often did you have a lot of trouble falling asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	How often was it very easy for you to fall asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	How often did you stay up all night because you could not fall asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	How often did you stay up half of the night because you could not fall asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I. BARRIERS

69. 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 71**

70. 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 _____

71. 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

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

- Yes
- No

73. 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?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
b.	Getting hired or getting a job?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
c.	At work?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
d.	Getting housing?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
e.	Getting medical care?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
f.	Getting service in a store or restaurant?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
g.	Getting credit, bank loans, or a mortgage?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
h.	On the street or in a public setting?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more
i.	From the police or in the courts?	<input type="checkbox"/>	<input type="checkbox"/> →	<input type="checkbox"/> 1-2 times	<input type="checkbox"/> 3 or more

J. ALCOHOL AND SMOKING HISTORY

74. Have you consumed at least one alcoholic drink in the past 12 months?

- Yes
- No

75. 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

76. 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

77. Have you ever used one or more tobacco products (such as cigarettes, cigars, pipe, chewing tobacco)?

- Yes
- No → **SURVEY IS COMPLETE, THANK YOU**

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

_____ years

79. Have you used tobacco products in the past 12 months?

- Yes → **skip to Question 81**
- No

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

81. 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: _____
