

SC2 Patient Needs Assessment Survey

Thank you for giving your consent to take part in the MUSC SC2 Needs Assessment survey. We want to hear from you about what gaps you see in services for youth and adults with sickle cell disease in our region. We also want to hear from you about what you think could help improve sickle cell disease care. We will combine your responses with those of other youth and adults with sickle cell disease and their providers in order to plan ways to improve sickle cell disease care. Some of the same information is being collected in 7 other sites around the U.S., so that we can learn from each other as we develop these plans.

Your responses are confidential. That means that your survey will be assigned a number and only the researcher will be able to link your responses with your name. Your providers will NOT be able to link your responses with your name. You are free not to answer an item if you prefer. The study coordinator will be nearby if you have any questions.

Thank you again!

-- VISIT DATE --

Today's date:

Please click the 'Today' button:

-- SICKLE CELL DISEASE PHENOTYPE --

Please tell us your Sickle Cell Disease Phenotype:

- ☐ SS Disease
- ☐ S Beta 0 Thalassemia
- ☐ SC Disease
- ☐ S Beta + Thalassemia
- ☐ Don't know
- ☐ Other Variant

If 'Other' variant(s), please type the variant in the box:

-- FREQUENCY OF SICKLE CELL PAIN EPISODES (PhenX)--

PAINFUL EVENTS - Number of visits should include visits to BOTH your hospital AND outside hospitals.

1. In the last 6 months, how many times did you visit an emergency room because of a sickle cell painful event?

- ☐ 0
☐ 1
☐ 2
☐ 3
☐ 4 or more

2. In the last 12 months, how many times were you admitted to a hospital because of a sickle cell painful event?

- ☐ 0
☐ 1
☐ 2
☐ 3
☐ 4 or more

3. In the last 6 months, have you had a pain episode severe enough to keep you from doing your usual daily activities, but without being seen by a doctor or a nurse?

- ☐ Yes
☐ No

Number of pain episodes in the last 6 months?

- ☐ Less than 4
☐ At least 4

How many days did you miss doing your usual activities due to pain in the last 6 months?

- ☐ Less than 1 week
☐ At least 1 week

-- PAIN INTERFERENCE in the past 7 days -- (PROMIS 29)

	Not at all	A little bit	Somewhat	Quite a bit	Very much
1. How much did pain interfere with your day to day activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How much did pain interfere with work around the home?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How much did pain interfere with your ability to participate in social activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How much did pain interfere with your household chores?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

-- QUALITY OF CARE FOR SICKLE CELL DISEASE (ASCQ-Me) --

Answer all the questions by checking the box that best matches your experiences or how you feel.

1. In the past 12 months, did you try to make an appointment to see a doctor or nurse?

- ☐ Yes
☐ No

2. In the past 12 months, when you tried to make an appointment to see a doctor or nurse, how often were you able to get one as soon as you wanted?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

3. In the past 12 months, how often were you satisfied with the care you received during these scheduled appointments?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

4. Do you have a doctor or nurse who you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?

- ☐ Yes
☐ No

5. In the past 12 months, how many visits have you had with this doctor or nurse?

- ☐ 0 visits
☐ 1 visit
☐ 2 visits
☐ 3 visits
☐ 4 or more visits

6. In the past 12 months, how often did this doctor or nurse explain things in a way that is easy to understand?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

7. In the past 12 months, how often did this doctor or nurse listen carefully to you?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

8. In the past 12 months, how often did this doctor or nurse treat you with courtesy and respect?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

9. In the past 12 months, how often did this doctor or nurse spend enough time with you?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

10. In the past 12 months, how often were you satisfied with the care you received from this doctor or nurse?

- ☐ Never
☐ Sometimes
☐ Usually
☐ Always

11. How much does this doctor or nurse know how sickle cell affects you personally?

- ☐ Nothing
☐ A little bit
☐ Some
☐ Quite a bit
☐ Very much

12. Does this doctor or nurse treat a lot of patients with sickle cell disease?

- ☐ Yes
☐ No

13. In the past 12 months, did you go to an emergency room for any sickle cell care you needed right away?

- ☐ Yes
☐ No

Which ER was this?

- ☐ MUSC
☐ Beaufort
☐ Colleton
☐ Conway
☐ Grand Strand
☐ Lexington
☐ McLeod
☐ Orangeburg
☐ Palmetto Health Baptist
☐ Palmetto Health Park Ridge
☐ Palmetto Health Richland
☐ Providence
☐ Tidelands/Georgetown
☐ Tidelands/Waccamaw
☐ Tuomey Regional Medical Center
☐ Don't know
☐ Other _____

If "Other" ER, please specify:

14. In the past 12 months, when you went to the emergency room for this care, how often did you get it as soon as you wanted?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

15. In the past 12 months, when you went to the emergency room for this care, how often did the DOCTORS treating you seem to really care about you?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

16. In the past 12 months, when you went to the emergency room for this care, how often did the NURSES treating you seem to really care about you?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

17. In the past 12 months, when you went to the emergency room for this care, how often did the clerks and receptionists treat you with courtesy and respect?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

18. In the past 12 months, when you went to the emergency room for this care, how often were you satisfied with the care you received?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

19. In the past 12 months, how many times did you manage a pain attack (crisis) at home without going to a doctor, clinic, or hospital?

- ☐ I did not have a pain attack (crisis) in the past 12 months
- ☐ 0 times
- ☐ 1 time
- ☐ 2 times
- ☐ 3 times
- ☐ 4 or more times

20. In the past 12 months, did you ever delay or avoid going to an emergency room when you thought you needed care?

- ☐ Yes, I did not always go for care when I needed it
- ☐ No, I always went for care when I thought I needed it

21. How important were bad experiences in the emergency room in your decision to avoid going for care?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

22. How important were health insurance issues in your decision to avoid going for care?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

23. In the past 12 months, how many times did you go to the emergency room because of a pain attack (crisis)?

- ☐ 0 visits
- ☐ 1 visit
- ☐ 2 visits
- ☐ 3 visits
- ☐ 4 or more visits

24. In the past 12 months, how much were the emergency room doctors and nurses able to help your pain?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

25. In the past 12 months, how much did the emergency room doctors and nurses believe that you had very bad sickle cell pain?

- ☐ Not at all
- ☐ A little bit
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

26. In the past 12 months, what is the longest you had to wait in the emergency room before your sickle cell pain was treated?

- ☐ Less than 5 minutes
- ☐ 5 to 15 minutes
- ☐ 16 minutes to 1 hour
- ☐ More than 1 hour but less than 2 hours
- ☐ 2 hours or more

27. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate all of the care you received for your health in the last 12 months?

- ☐ 0 Worst care possible
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 Best care possible

-- SICKLE CELL DISEASE SELF-EFFICACY SCALE --

The following questions ask about HOW SURE YOU ARE about dealing day-to-day with sickle cell disease (SCD). So for each question tell us HOW SURE YOU ARE by putting a check in the box that best tells us how you feel.

There are no "right or wrong" answers, we just want to know what you think.

	Not at all	Not sure	Neither	Sure	Very Sure
1. How sure are you that you can do something to cut down on most of the pain you have when you have a pain episode?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. How sure are you that you can keep doing most of the things you do day-to-day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. How sure are you that you can keep sickle cell disease pain from interfering with your sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. How sure are you that you can reduce your sickle cell disease pain by using methods other than taking extra medications?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. How sure are you that you can control how often or when you get tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. How sure are you that you can deal with the frustration of having sickle cell disease?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

-- DEMOGRAPHICS SECTION --**Please tell us about yourself.**

--CURRENT AGE--

When were you born?

Enter MMDDYYYY

- ☐ Don't know
- ☐ Prefer Not to Respond

About how old are you?

Please use the arrow to select your age from the list

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
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- ☐ 97
- ☐ 98
- ☐ 99
- ☐ 100

-
- ☐ Don't know
 - ☐ Prefer Not to Respond

-- GENDER --

Are you male or female?

- ☐ Male
- ☐ Female
- ☐ Prefer not to respond
- ☐ Don't know

-- RACE --

What race or races do you consider yourself to be?
Please check all that apply.

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Black or African American
- ☐ White
- ☐ Other Race
- ☐ Prefer not to respond
- ☐ Don't know

-- ETHNICITY --

Do you consider yourself to be Hispanic, Latino, or of Spanish origin?

- ☐ Yes
- ☐ No
- ☐ Prefer not to respond
- ☐ Don't know

Select the group(s) that represents your Hispanic origin or ancestry.

Please check all that apply

- ☐ Puerto Rican
- ☐ Dominican (Republic)
- ☐ Mexican/ Mexicano
- ☐ Mexican American
- ☐ Chicano
- ☐ Cuban
- ☐ Cuban American
- ☐ Central or South American
- ☐ Other Latin American
- ☐ Other Hispanic
- ☐ Don't know

-- CURRENT EDUCATION LEVEL --

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

- ☐ Never attended / Kindergarten only
- ☐ 1st grade
- ☐ 2nd grade
- ☐ 3rd grade
- ☐ 4th grade
- ☐ 5th grade
- ☐ 6th grade
- ☐ 7th grade
- ☐ 8th grade
- ☐ 9th grade
- ☐ 10th grade
- ☐ 11th grade
- ☐ 12th grade, No Diploma
- ☐ High School Graduate
- ☐ GED or equivalent
- ☐ Some college, no degree
- ☐ Associate degree: Occupation, Technical, or Vocational program
- ☐ Associate degree: Academic program
- ☐ Bachelor's degree (Ex. BA, AB, BS, BBA)
- ☐ Master's degree (Ex. MA, MS, MEng, MEd, MBA)
- ☐ Professional School Degree (Ex. MD, DDS, DVM, JD)
- ☐ Doctoral degree (Ex. PhD, EdD)
- ☐ Prefer not to respond
- ☐ Don't know

What is the highest grade or level of school the head of your household has completed or the highest degree they have received?

- ☐ Never attended / Kindergarten only
- ☐ 1st grade
- ☐ 2nd grade
- ☐ 3rd grade
- ☐ 4th grade
- ☐ 5th grade
- ☐ 6th grade
- ☐ 7th grade
- ☐ 8th grade
- ☐ 9th grade
- ☐ 10th grade
- ☐ 11th grade
- ☐ 12th grade, No Diploma
- ☐ High School Graduate
- ☐ GED or equivalent
- ☐ Some college, no degree
- ☐ Associate degree: Occupation, Technical, or Vocational program
- ☐ Associate degree: Academic program
- ☐ Bachelor's degree (Ex. BA, AB, BS, BBA)
- ☐ Master's degree (Ex. MA, MS, MEng, MEd, MBA)
- ☐ Professional School Degree (Ex. MD, DDS, DVM, JD)
- ☐ Doctoral degree (Ex. PhD, EdD)
- ☐ Prefer not to respond
- ☐ Don't know

-- CURRENT EMPLOYMENT STATUS --

We would like to know about what you do for a living.

Are you working now, looking for work, retired, keeping house, a student, or what?

- ☐ Working now
- ☐ Only temporarily laid off, sick leave or maternity leave
- ☐ Looking for work, unemployed
- ☐ Retired
- ☐ Disabled, permanent or temporary
- ☐ Keeping house
- ☐ Student
- ☐ Other _____

Please type your 'Other employment' status in the box:

-- CURRENT MARITAL STATUS --

Now we would like to ask about marital status and living together.

What is your current marital or living together status?

- ☐ Married
- ☐ Not married but living together
- ☐ Widowed
- ☐ Divorced or annulled
- ☐ Separated, not living together
- ☐ Never been married

-- ANNUAL HOUSEHOLD INCOME --

Please pick the number showing your yearly income for your household.

Please include all income sources:

- ☐ Less than \$5,000
- ☐ \$5,000-\$9,999
- ☐ \$10,000-\$14,999
- ☐ \$15,000-\$19,999
- ☐ \$20,000 to \$29,999
- ☐ \$30,000-\$39,999
- ☐ \$40,000-\$49,999
- ☐ \$50,000-\$59,999
- ☐ \$60,000 to \$79,999
- ☐ \$80,000-\$94,999
- ☐ \$95,000 and over

-- CURRENT HEALTH INSURANCE COVERAGE --

What type of Health Insurance Coverage do you have?

Please check all that apply

- ☐ Private Health Insurance
- ☐ Medicare
- ☐ Medicaid
- ☐ SCHIP (CHIP/Children's Health Insurance Program)
- ☐ Military Health Care (TRICARE/VA/CHAMP-VA)
- ☐ Indian Health Service
- ☐ State Sponsored Health Plan
- ☐ Other - Government program
- ☐ No Coverage of any type
- ☐ Don't know

MEDICAID State

Please use the arrow to select your state from the list

- ☐ Alabama ☐ Alaska
- ☐ Arizona ☐ Arkansas
- ☐ California ☐ Colorado
- ☐ Connecticut ☐ Delaware
- ☐ Florida ☐ Georgia
- ☐ Hawaii ☐ Idaho ☐ Illinois
- ☐ Indiana ☐ Iowa ☐ Kansas
- ☐ Kentucky ☐ Louisiana
- ☐ Maine ☐ Maryland
- ☐ Massachusetts ☐ Michigan
- ☐ Minnesota ☐ Mississippi
- ☐ Missouri ☐ Montana
- ☐ Nebraska ☐ Nevada
- ☐ New Hampshire ☐ New Jersey
- ☐ New Mexico ☐ New York
- ☐ North Carolina ☐ North Dakota
- ☐ Ohio ☐ Oklahoma
- ☐ Oregon ☐ Pennsylvania
- ☐ Rhode Island ☐ South Carolina
- ☐ South Dakota ☐ Tennessee
- ☐ Texas ☐ Utah ☐ Vermont
- ☐ Virginia ☐ Washington
- ☐ West Virginia ☐ Wisconsin
- ☐ Wyoming

State of Sponsored Plan:

Please use the arrow to select your state from the list

- ☐ Alabama ☐ Alaska
- ☐ Arizona ☐ Arkansas
- ☐ California ☐ Colorado
- ☐ Connecticut ☐ Delaware
- ☐ Florida ☐ Georgia
- ☐ Hawaii ☐ Idaho ☐ Illinois
- ☐ Indiana ☐ Iowa ☐ Kansas
- ☐ Kentucky ☐ Louisiana
- ☐ Maine ☐ Maryland
- ☐ Massachusetts ☐ Michigan
- ☐ Minnesota ☐ Mississippi
- ☐ Missouri ☐ Montana
- ☐ Nebraska ☐ Nevada
- ☐ New Hampshire ☐ New Jersey
- ☐ New Mexico ☐ New York
- ☐ North Carolina ☐ North Dakota
- ☐ Ohio ☐ Oklahoma
- ☐ Oregon ☐ Pennsylvania
- ☐ Rhode Island ☐ South Carolina
- ☐ South Dakota ☐ Tennessee
- ☐ Texas ☐ Utah ☐ Vermont
- ☐ Virginia ☐ Washington
- ☐ West Virginia ☐ Wisconsin
- ☐ Wyoming

State Plan name:

Please type the name of your plan in the box

-- LANGUAGE PREFERENCE --

What language do you feel most comfortable speaking with your doctor or nurse?

Use the arrow to select a language from the dropdown list

- ☐ English
- ☐ Spanish
- ☐ Arabic
- ☐ Bengali
- ☐ Burmese
- ☐ French
- ☐ German
- ☐ Gujarati
- ☐ Hindi
- ☐ Italian
- ☐ Japanese
- ☐ Javanese
- ☐ Kannada
- ☐ Korean
- ☐ Malayalam
- ☐ Mandarin Chinese
- ☐ Marathi
- ☐ Oriya
- ☐ Panjabi
- ☐ Persian
- ☐ Polish
- ☐ Portuguese
- ☐ Russian
- ☐ Tamil
- ☐ Telugu
- ☐ Thai
- ☐ Turkish
- ☐ Ukrainian
- ☐ Urdu
- ☐ Vietnamese

In what language do you prefer to read health-related materials?

Use the arrow to select a language from the dropdown list

- ☐ English
- ☐ Spanish
- ☐ Arabic
- ☐ Bengali
- ☐ Burmese
- ☐ French
- ☐ German
- ☐ Gujarati
- ☐ Hindi
- ☐ Italian
- ☐ Japanese
- ☐ Javanese
- ☐ Kannada
- ☐ Korean
- ☐ Malayalam
- ☐ Mandarin Chinese
- ☐ Marathi
- ☐ Oriya
- ☐ Panjabi
- ☐ Persian
- ☐ Polish
- ☐ Portuguese
- ☐ Russian
- ☐ Tamil
- ☐ Telugu
- ☐ Thai
- ☐ Turkish
- ☐ Ukrainian
- ☐ Urdu
- ☐ Vietnamese