Novel Coronavirus and COVID-19 Patient Impact Survey

(version date: 7/29/2020)

DATE FORM COMPLETED: |___|___|-|___|___|-|___|___|___|___|
MONTH DAY YEAR

INSTRUCTIONS:
To help us understand the health of SCDIC Registry participants during and after the novel coronavirus pandemic, we would like to ask you some questions to find out how the Coronavirus may have changed things for you or changed your activities, including your use of healthcare services. When we ask about **COVID-19**, we specifically mean **the disease that is caused by the novel coronavirus (from here on referred to as just coronavirus)**.

1. Have you been exposed to someone known to have coronavirus or COVID-19?
   - ❒ Yes
   - ❒ No

2. Have you been tested for the novel coronavirus?
   - ❒ Yes
   - ❒ No → *skip to Question 5*
   - ❒ No, but I wanted to be tested and was not able to → *skip to Question 5*

3. What kind of test was it? *(Check all that apply.)*
   - ❒ Saliva test
   - ❒ Nasal swab
   - ❒ Blood test

4. What was the result of your coronavirus test?
   - ❒ Positive
   - ❒ Negative
   - ❒ Result is pending
   - ❒ Don't know

5. Has a healthcare provider ever told you that you had COVID-19 (the disease caused by coronavirus)?
   - ❒ Yes, definitely → *skip to Question 7*
   - ❒ Yes, probably or suspected → *skip to Question 7*
   - ❒ No

6. Do you think you had/have COVID-19?
   - ❒ Yes
   - ❒ No → *skip to Question 16*
   - ❒ Don't know → *skip to Question 16*

7. What symptoms of COVID-19 did you have at the time you tested positive? *(Check all that apply.)*

Symptom	✓ **YES**	**Symptom**	✓ **YES**		✓ **YES**
Fever		Abdominal pain		Swollen lymph nodes	
Chills		Severe fatigue		Swollen hands or feet	
Cough		Muscle or body aches		Red or purple toes	
Chest pain		Runny nose		Rash	
Shortness of breath		Nasal congestion		Conjunctivitis (pink eye)	
Nausea/vomiting		Sore throat		Confusion	
Diarrhea		Headache		I had no symptoms	
Pain crisis		Loss of taste or smell			

8. What month and year did you first start having symptoms of COVID-19? _____/_____ ❒ I had no symptoms
   Month Year

9. Did you go to the Emergency Room because of your COVID-19 symptoms? ❒ Yes ❒ No

10. Were you admitted to the hospital because of your COVID-19 symptoms? ❒ Yes ❒ No → *skip to Question 13*

11. Please indicate which things you recall happening to you in the hospital. Check all the things you can remember.

	✓ **YES**		✓ **YES**
Presented with a pain crisis		Received oxygen by pressure mask (CPAP/BIPAP)	
Admitted to ICU		Put on a breathing machine or ventilator	
Received simple blood transfusion		Was put in a medically-induced coma	
Received exchange transfusion		Had a chest X-ray	
Had a blood clot		Had a CT scan of your lungs	
Had irregular heartbeat (arrythmia)		Had an MRI of your brain	
Had kidney failure		Received a blood thinner	
Had a stroke		Received Remdesivir	
Had acute chest syndrome		Received hydroxychloroquine (NOT hydroxyurea)	
Received oxygen by nasal canula or face mask		I do not remember everything that happened	

12. How long were you in the hospital because of COVID-19?

    _____ # weeks OR _____# days

    ❒ Don't Know

13. How long were you sick with COVID-19?

    _____ # weeks OR _____ # days

    ❒ Still sick

    ❒ Don't Know

14. How would you rate the severity of your COVID-19 at its worst?

    ❒ Mild
    ❒ Moderate
    ❒ Severe

15. Do you feel like you have made a full recovery from your COVID-19?

    ❒ Yes
    ❒ No → Please explain your ongoing symptoms or complications_____

16. During the coronavirus pandemic, what types of healthcare visits did you have with your sickle cell doctor? *(Check all that apply.)*

    ❒ On video → *skip to Question 18*
    ❒ Over the phone (no video)
    ❒ In person
    ❒ Written communication (for example, sending an email, text, or messaging through a patient portal)
    ❒ None of the above

17. Why didn't you have a video visit with your sickle cell doctor? *(Check all that apply.)*

    ❒ I did not have internet access
    ❒ I did not have the needed technology/device, for example a smartphone or computer
    ❒ I was concerned about privacy
    ❒ I was uncomfortable with video
    ❒ The doctor did not suggest a video visit
    ❒ None of the above

18. <u>*During the first few months*</u> of the coronavirus pandemic, how often did the following things happen*? (Check an answer in each row.)*

	Never	Once (one time)	More than once
I avoided going to the Emergency Room	❒	❒	❒
I avoided going to the doctor for an in-person visit	❒	❒	❒
My in-person appointments were cancelled by my doctor/doctor's office	❒	❒	❒
I was unable to get medications that I needed	❒	❒	❒
I was unable to get medical tests or procedures that I needed	❒	❒	❒
I was unable to get the mental health services that I needed	❒	❒	❒
I was unable to see a doctor, even though I needed to	❒	❒	❒

19. How often did the following things happen during the *past month*? *(Check an answer in each row.)*

	Never	Once (one time)	More than once
I avoided going to the Emergency Room	❒	❒	❒
I avoided going to the doctor for an in-person visit	❒	❒	❒
My in-person appointments were cancelled by my doctor/doctor's office	❒	❒	❒
I was unable to get medications that I needed	❒	❒	❒
I was unable to get medical tests or procedures that I needed	❒	❒	❒
I was unable to get the mental health services that I needed	❒	❒	❒
I was unable to see a doctor, even though I needed to	❒	❒	❒

20. During the first few months of the Coronavirus pandemic, how often did you do the following things? *(Check an answer in each row.)*

	Never	Rarely	Sometimes	Usually	Always
Avoided grocery stores or other essential businesses (e.g. pharmacies)	❒	❒	❒	❒	❒
Used delivery or curbside pickup for groceries or other essential items	❒	❒	❒	❒	❒
Avoided gatherings or crowds	❒	❒	❒	❒	❒
Avoided leaving the house	❒	❒	❒	❒	❒
Avoided eating at restaurants	❒	❒	❒	❒	❒
Worn a mask or other face covering when not at home	❒	❒	❒	❒	❒

21. How has the COVID-19 pandemic changed the following things for you? Please respond to each statement by marking one box per row.

	Much better	Somewhat better	About the same	Somewhat worse	Much worse
Your mood	❒	❒	❒	❒	❒
Your sleep	❒	❒	❒	❒	❒
Your stress level	❒	❒	❒	❒	❒
Your appetite or interest in eating	❒	❒	❒	❒	❒
Your financial situation	❒	❒	❒	❒	❒
Your job-related income	❒	❒	❒	❒	❒
Your relationship with your family	❒	❒	❒	❒	❒
Your relationship with your friends	❒	❒	❒	❒	❒
Your interest in going out to restaurants	❒	❒	❒	❒	❒

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