



Complete this form if the subject has had a cardiac ECHO, EKG or heart catheterization with results in the medical record since the last medical record abstraction. Leave measurements blank if they are not on the report.

DATE FORM COMPLETED: |_|_|-|_|_|-|_|_|_|_|

A. CARDIAC ECHO

- a) Date of most recent ECHO: |_|_|-|_|_|-|_|_|_|_| ECHO report not available
- b) Reason ECHO was done: _____
- c) Patient's Body Mass Index (BMI) _____ kg/m²
- d) Heart rate on date of ECHO _____ beats/min
- e) Pericardial effusion None Trivial Small Moderate Severe Large Unknown

QUALITATIVE AND QUANTITATIVE ECHO MEASUREMENTS

Left Atrium (LA)		
1.	LA Volume	<input type="checkbox"/> normal <input type="checkbox"/> moderate <input type="checkbox"/> mild <input type="checkbox"/> severe
		LAESVI in ml/sq.m _____ ml/m ²
2.	LA Diameter	_____ mm
Right Atrium (RA)		
3.	RA Volume	<input type="checkbox"/> normal <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe
Left Ventricle (LV)		
4.	LV Mass	_____ gm
5.	LV Volume	<input type="checkbox"/> normal <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe
		LV end systolic dimension LVESD = _____ mm LV end systolic volume LVESV = _____ ml/m ² LV end diastolic dimension LVEDD = _____ mm LV end diastolic volume LVEDV = _____ ml/m ² LV posterior wall thickness at end-diastole LVPwD= _____ mm
6.	LV Ejection Fraction	_____ %
7.	Fractional Shortening	_____ %
		PEDIATRICS ONLY
8.	Global Longitudinal Strain	Apical chamber average _____ %
9.	Septal e' Velocity	_____ cm/s
10.	Lateral e' Velocity	_____ cm/s
11.	E/A Ratio	_____

Right Ventricle (RV)			
12.	RV Size	<input type="checkbox"/> normal <input type="checkbox"/> mildly enlarged <input type="checkbox"/> moderately enlarged <input type="checkbox"/> severely enlarged <input type="checkbox"/> unknown	RV basal diameter _____mm RV end diastolic dimension RVIDd = _____mm
13.	RV Systolic Pressure, Estimated	_____mmHg	
14.	RV Systolic Excursion Velocity	_____cm/s	
15.	RV Hypertrophy	<input type="checkbox"/> normal <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe	
16.	RV Function	<input type="checkbox"/> normal <input type="checkbox"/> mildly reduced <input type="checkbox"/> moderately reduced <input type="checkbox"/> severely reduced <input type="checkbox"/> unknown	
17.	Interventricular Septum Diameter	_____mm	Mention of interventricular septal flattening? <input type="checkbox"/> Yes <input type="checkbox"/> No
Aortic Valve (AV)			
18.	Aortic Valve Regurgitation	<input type="checkbox"/> none <input type="checkbox"/> trivial <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe	
19.	AV Peak Velocity	_____m/s	
20.	Left Ventricular Outflow Tract (LVOT) Peak Velocity	_____m/s	
21.	LVOT Velocity Time Integral	_____cm	
22.	AV Mean Gradient	_____mmHg	
23.	LVOT Diameter	_____mm	
Mitral Valve			
24.	Mitral Valve Regurgitation	<input type="checkbox"/> none <input type="checkbox"/> trivial <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe	
25.	E wave Mitral Inflow Velocity	_____cm/sec	
26.	A wave Mitral Inflow Velocity	_____cm/sec	
Tricuspid Valve			
27.	Tricuspid Valve Regurgitation	<input type="checkbox"/> none <input type="checkbox"/> trivial <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe	
28.	TR Peak (Jet) Velocity	_____m/s	
29.	Tricuspid Annular Plane Systolic Excursion (TAPSE)	_____mm	
Pulmonic Valve			
30.	Pulmonic Valve Regurgitation	<input type="checkbox"/> none <input type="checkbox"/> trivial <input type="checkbox"/> mild <input type="checkbox"/> moderate <input type="checkbox"/> severe	
Inferior Vena Cava (IVC)			
31.	IVC Diameter	<input type="checkbox"/> Cat 1: <2.1 cm <input type="checkbox"/> Cat 2: >2.1 cm with > 50% collapse <input type="checkbox"/> Cat 3: >2.1 cm with <50% collapse <input type="checkbox"/> Unknown	

B. EKG

a. Date of most recent EKG: |__|__|_|-|__|__|_|-|__|__|__|__|

EKG not available

b. Reason EKG was done _____

Measurement from EKG		Diagnosed?
32.	Arrhythmia	<input type="checkbox"/> Yes → type _____ <input type="checkbox"/> No <input type="checkbox"/> Unknown
33.	Ventricular rate	_____ bpm <input type="checkbox"/> NA
34.	PR Interval	_____ ms <input type="checkbox"/> NA
35.	QRS duration	_____ ms <input type="checkbox"/> NA
36.	QT/QTc	____/____ ms <input type="checkbox"/> NA
37.	P-R-T axis	P: ____ R: ____ T: ____ <input type="checkbox"/> NA

C. RIGHT HEART CATHETERIZATION

a. Date of most recent right heart catheterization: |__|__|_|-|__|__|_|-|__|__|__|__|

Report not available

b. Reason right heart cath was done _____

Target		Measurement
38.	RA pressure (mean)	_____ mm/hg <input type="checkbox"/> NA
39.	RV pressure (mean)	_____ mm/hg <input type="checkbox"/> NA
40.	PA pressure (mean)	_____ mm/hg <input type="checkbox"/> NA
41.	Pulmonary artery saturation	_____ % <input type="checkbox"/> NA
42.	Pulmonary vascular resistance	_____ dynes-sec-cm ⁻⁵ <input type="checkbox"/> NA
43.	Pulmonary capillary wedge pressure (PCWP or PAWP)	_____ mm/hg <input type="checkbox"/> NA
44.	Cardiac output and index	_____ L/min <input type="checkbox"/> NA

This form should be completed using data abstracted from the medical record. This should be completed going back to the **date the last abstraction form was completed**.

DATE THIS FORM COMPLETED: |__|__|__| - |__|__|__| - |__|__|__|__|__|
 Month Day Year

1. Confirmed enrollment diagnosis: (CHECK ONLY ONE). DIAGNOSIS MUST BE SUPPORTED BY SOURCE DOCUMENTATION.

Diagnosis		Diagnosis	
a. Hb SS or sickle cell anemia	<input type="checkbox"/>	e. Hb S hereditary persistence of fetal Hb (S/HPFH)	<input type="checkbox"/>
b. Hb SC disease	<input type="checkbox"/>	f. Hb SE	<input type="checkbox"/>
c. Hb S beta ⁰ thalassemia	<input type="checkbox"/>	g. Hb SD	<input type="checkbox"/>
d. Hb S beta ⁺ thalassemia	<input type="checkbox"/>	h. Hb SO	<input type="checkbox"/>

- a. What was the basis for diagnosis? Newborn screening
 Hemoglobin fractionation
 Hemoglobin electrophoresis
 DNA sequencing

2. Approximate age of first diagnosis (physician confirmed): _____ AGE In YEARS **OR** NEWBORN SCREENING **OR** UNKNOWN

3. Has the subject ever been evaluated for curative gene therapy? Yes No

4. Most recent test results for alpha-thalassemia?
 Yes—single alpha globin gene deleted
 Yes—two alpha globin genes deleted
 Yes—negative
 No—not evaluated
 Unknown

Basic Measurements (most recent)	Not in Record	Measurements	Date (mm/yyyy)	Steady state?
5. Height	<input type="checkbox"/>	__ __ __ CM		Y N
6. Weight	<input type="checkbox"/>	__ __ __ . __ KG		Y N
7. Temperature	<input type="checkbox"/>	__ __ . __ Celsius		Y N
8. Heart Rate	<input type="checkbox"/>	__ __ __ BEATS/MINUTE		Y N
9. Respiration Rate	<input type="checkbox"/>	__ __ __ BREATHS/MINUTE		Y N
10. Oxygen saturation (SpO ₂)	<input type="checkbox"/>	__ __ __ %		Y N
11. Blood Pressure	<input type="checkbox"/>	__ __ __ / __ __ __ ON ANTI-HYPERTENSIVE MEDS? <input type="checkbox"/> Yes <input type="checkbox"/> No		Y N

12. Has the subject ever used hydroxyurea? YES NO (if NO skip to Endari question)

13. Is the subject currently taking hydroxyurea? Yes No
 a. Start date (mm/yyyy) |__|__| - |__|__|__|__|
 b. Stop/last date (mm/yyyy) |__|__| - |__|__|__|__| Currently using

14. Has the subject ever taken Endari Yes No → **GO TO Q16**

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ Mg/kg or _ Mg

15. Has the subject ever taken Adakveo? Yes No → **GO TO Q18**

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ _ Mg/kg or _ Mg

16. Has the subject ever taken Oxbryta? Yes No → **GO TO Q20**

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ Mg/kg or _ Mg

20. Please list all medications the subject is **currently** taking. NONE CURRENTLY BEING USED

Name of Medication	Name of Medication
a.	k.
b.	l.
c.	m.
d.	n.
e.	o.
f.	p.
g.	q.
h.	r.
i.	s.
j.	t.

SCD Complications Indicate whether the subject has ever had a diagnosis of each condition and the date of the most recently diagnosed episode	NO	YES	Most recent dx (age or date)		Condition currently under treatment
			Age	Date mm/yyyy	
Musculoskeletal					
24. Avascular necrosis (<i>check all that apply</i>)	<input type="checkbox"/>	<input type="checkbox"/>			
a. Hip	<input type="checkbox"/>	<input type="checkbox"/>			
b. Shoulder	<input type="checkbox"/>	<input type="checkbox"/>			
c. Knee	<input type="checkbox"/>	<input type="checkbox"/>			
d. Other location, specify _____	<input type="checkbox"/>	<input type="checkbox"/>			
Genitourinary					
25. Chronic kidney disease	<input type="checkbox"/>	<input type="checkbox"/>			
26. End stage renal disease (<i>if yes, complete Renal form</i>)	<input type="checkbox"/>	<input type="checkbox"/>			
a. Kidney transplant	<input type="checkbox"/>	<input type="checkbox"/>			
b. Kidney transplant rejection	<input type="checkbox"/>	<input type="checkbox"/>			
27. Priapism	<input type="checkbox"/>	<input type="checkbox"/>			
Nervous system					
28. Stroke (<i>check all that apply</i>)	<input type="checkbox"/>	<input type="checkbox"/>			
a. Ischemic	<input type="checkbox"/>	<input type="checkbox"/>			
b. Hemorrhagic	<input type="checkbox"/>	<input type="checkbox"/>			
c. Transient ischemic attack (TIA)	<input type="checkbox"/>	<input type="checkbox"/>			
d. Silent	<input type="checkbox"/>	<input type="checkbox"/>			
29. Intracranial bleeding	<input type="checkbox"/>	<input type="checkbox"/>			
Cardiovascular					
30. Pulmonary arterial hypertension	<input type="checkbox"/>	<input type="checkbox"/>			
a. Mean pulmonary artery pressure > or = to 25 mm Hg	<input type="checkbox"/>	<input type="checkbox"/>			
b. Tricuspid regurgitation velocity (TRV) > or = to 3.0 m/sec	<input type="checkbox"/>	<input type="checkbox"/>			
31. Left ventricular dysfunction	<input type="checkbox"/>	<input type="checkbox"/>			
Respiratory					
32. Acute chest syndrome	<input type="checkbox"/>	<input type="checkbox"/>			
33. Asthma	<input type="checkbox"/>	<input type="checkbox"/>			
Digestive					
34. Gallstones/cholelithiasis, cholecystitis	<input type="checkbox"/>	<input type="checkbox"/>			
35. Splenomegaly (<i>check all that apply</i>)	<input type="checkbox"/>	<input type="checkbox"/>			
a. PRBC transfusion given for splenomegaly? <input type="checkbox"/> Yes <input type="checkbox"/> No					
b. Splenic sequestration # sequestration episodes in past 12 months _____	<input type="checkbox"/>	<input type="checkbox"/>			
c. Splenic infarcts, symptomatic	<input type="checkbox"/>	<input type="checkbox"/>			
d. Hypersplenism	<input type="checkbox"/>	<input type="checkbox"/>			
e. Splenectomy	<input type="checkbox"/>	<input type="checkbox"/>			
Other Autoimmune/Inflammatory					
36. Deep vein thrombosis (DVT)	<input type="checkbox"/>	<input type="checkbox"/>			
a. Pulmonary embolism	<input type="checkbox"/>	<input type="checkbox"/>			
b. Venous thromboembolism (VTE)	<input type="checkbox"/>	<input type="checkbox"/>			

37. Lupus	<input type="checkbox"/>	<input type="checkbox"/>			
38. Rheumatoid arthritis	<input type="checkbox"/>	<input type="checkbox"/>			
39. Gout	<input type="checkbox"/>	<input type="checkbox"/>			
40. Sarcoidosis	<input type="checkbox"/>	<input type="checkbox"/>			
Other Conditions					
41. Multi-organ failure (<i>check all that apply</i>)	<input type="checkbox"/>	<input type="checkbox"/>			
a. ICU	<input type="checkbox"/>	<input type="checkbox"/>			
b. Intubation	<input type="checkbox"/>	<input type="checkbox"/>			
c. Simple transfusion	<input type="checkbox"/>	<input type="checkbox"/>			
d. Exchange transfusion	<input type="checkbox"/>	<input type="checkbox"/>			
e. Hemodialysis	<input type="checkbox"/>	<input type="checkbox"/>			
f. Peritoneal dialysis	<input type="checkbox"/>	<input type="checkbox"/>			
42. Pneumococcal sepsis	<input type="checkbox"/>	<input type="checkbox"/>			
43. Skin ulcers	<input type="checkbox"/>	<input type="checkbox"/>			
44. Retinopathy	<input type="checkbox"/>	<input type="checkbox"/>			
45. Diabetes mellitus	<input type="checkbox"/>	<input type="checkbox"/>			
46. Iron overload (liver iron content > 3 mg/g of dry weight liver on MRI or serum ferritin above 1,000 ng/dL for >3 separate measurements or >18 PRBCs)	<input type="checkbox"/>	<input type="checkbox"/>			
47. Chronic refractory pain	<input type="checkbox"/>	<input type="checkbox"/>			
48. Seizure disorder	<input type="checkbox"/>	<input type="checkbox"/>			
49. Anxiety	<input type="checkbox"/>	<input type="checkbox"/>			
50. Depression	<input type="checkbox"/>	<input type="checkbox"/>			
51. Other psychiatric disorder, specify:	<input type="checkbox"/>	<input type="checkbox"/>			
52. Other major health condition, specify:	<input type="checkbox"/>	<input type="checkbox"/>			
Liver Conditions					
53. Liver cirrhosis	<input type="checkbox"/>	<input type="checkbox"/>			
54. Intrahepatic cholelithiasis	<input type="checkbox"/>	<input type="checkbox"/>			
55. Hepatitis B	<input type="checkbox"/>	<input type="checkbox"/>			
56. Hepatitis C	<input type="checkbox"/>	<input type="checkbox"/>			
57. Hepatic sequestration	<input type="checkbox"/>	<input type="checkbox"/>			
58. Hepatomegaly	<input type="checkbox"/>	<input type="checkbox"/>			
59. Bridging fibrosis	<input type="checkbox"/>	<input type="checkbox"/>			

60. Has the subject ever been diagnosed with a primary cancer?

- Yes
- No → GO TO Q61
- Don't know → GO TO Q61

a. CANCER TYPE AND LOCATION _____

b. CANCER STAGE _____

c. DATE OF DIAGNOSIS (MM/YYYY): |__|__| |__|__|__|__|

61. What kind of health insurance or health care coverage does the subject currently have? (Choose all that apply.)

- None
- Private health insurance
- Medicare
- Medicaid, Medical Assistance (MA), the Children's Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance
- TRICARE or other military health care, including VA health care
- Support from Charities or Donations
- Other type of health insurance, specify: _____

Name of Abstractor: _____

PI review and sign-off: _____



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.

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: _____

This form should be completed using data abstracted from the medical record. For people enrolled in the SCDIC-I, this should be completed going back to the **date the last abstraction form was completed (approximately 12 months)**.

DATE THIS FORM COMPLETED: |_|_|-|_|_|-|_|_|_|_|_|

DATE LAST ABSTRACTION FORM COMPLETED: |_|_|-|_|_|-|_|_|_|_|_|

DATE PATIENT LAST KNOWN TO BE ALIVE: |_|_|-|_|_|-|_|_|_|_|_|

MEDICAL RECORDS NOT AVAILABLE, FORM COMPLETE

1. Has the subject received a bone marrow transplant (BMT) since the date of the last abstraction?
 - Yes → Date of BMT: |_|_|-|_|_|-|_|_|_|_|_| (report data only up to BMT date. Complete Off-Study Form.)
 - No
2. Has the subject been evaluated for curative gene therapy since the date of the last abstraction? Yes No
3. Test results for alpha-thalassemia since the date of last abstraction?
 - Yes—single alpha globin gene deleted
 - Yes—two alpha globin genes deleted
 - Yes—negative
 - No—not evaluated
 - Unknown

Basic Measurements (most recent)	Not in Record	Measurements	Date (mm/yyyy)	Steady state?
4. Height	<input type="checkbox"/>	_ _ _ _ CM		Y N
5. Weight	<input type="checkbox"/>	_ _ _ _ . _ _ KG		Y N
6. Temperature	<input type="checkbox"/>	_ _ _ _ Celsius		Y N
7. Heart Rate	<input type="checkbox"/>	_ _ _ _ BEATS/MINUTE		Y N
8. Respiration Rate	<input type="checkbox"/>	_ _ _ _ BREATHS/MINUTE		Y N
9. Oxygen saturation (SpO ₂)	<input type="checkbox"/>	_ _ _ _ %		Y N
10. Blood Pressure	<input type="checkbox"/>	_ _ _ _ / _ _ _ _ ON ANTI-HYPERTENSIVE MEDS? <input type="checkbox"/> Yes <input type="checkbox"/> No		Y N

12. Is the subject currently taking hydroxyurea? Yes No
13. Has the subject started or stopped hydroxyurea since the date of last abstraction? Yes No → **GO TO Q14**
 - a. Start date (mm/yyyy) |_|_|-|_|_|_|_|_|
 - b. Stop/last date (mm/yyyy) |_|_|-|_|_|_|_|_| Currently using
 - c. Total duration of use _____ Months or Years Unknown
 - d. Current dose _____ Mg/kg or _ Mg

14. Is the subject currently taking Endari? Yes No

15. Has the subject started or stopped Endari since the date of last abstraction? Yes No → GO TO Q16

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ Mg/kg or _ Mg

16. Is the subject currently taking Adakveo? Yes No

17. Has the subject started or stopped Adakveo since the date of last abstraction? Yes No → GO TO Q18

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ _ Mg/kg or __ Mg

18. Is the subject currently taking Oxbryta? Yes No

19. Has the subject started or stopped Oxbryta since the date of last abstraction? Yes No → GO TO Q20

- a. Start date (mm/yyyy) |__|__|-|__|__|__|__|
- b. Stop/last date (mm/yyyy) |__|__|-|__|__|__|__| Currently using
- c. Total duration of use ____ Months or Years Unknown
- d. Current dose ____ Mg/kg or _ Mg

20. Please list all medications the subject is **currently** taking. NONE CURRENTLY BEING USED

Name of Medication	Name of Medication
a.	k.
b.	l.
c.	m.
d.	n.
e.	o.
f.	p.
g.	q.
h.	r.
i.	s.
j.	t.

Health Care Encounters

21. Transfusions

Complete the table below for all transfusions the subject had since the last abstraction.

	Date of transfusion MM/DD/YYYY	# units
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

	Date of transfusion MM/DD/YYYY	# units
11.		
12.		
13.		
14.		
15.		
16.		
17.		
18.		
19.		
20.		

22. Outpatient Visits

Complete the table below for all Outpatient Visits the subject had since the last abstraction. *If the person had multiple visits to the same provider in the same month, enter 99 for DAY and record the number of visits in the month in the last column.*

	Date of Outpatient Visit MM/DD/YYYY	Provider Type (from code list)	Total number of visits to same provider in same month
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
15.			
16.			
17.			
18.			
19.			
20.			

PROVIDER TYPE CODES	
1.	Primary care physician
2.	Hematologist
3.	Nephrologist
4.	Cardiologist
5.	Pulmonologist
6.	Behavioral medicine/psychiatrist
7.	Orthopedic surgeon
8.	Ophthalmologist
9.	Neurologist
10.	OB/GYN
11.	Other specialist

23. Acute Care Visits (hospital admissions, ED, acute or urgent care)

Complete the table below for all admissions or visits the subject had to the hospital, ED/EDTR, or acute or urgent care since the last abstraction.

	Date of admission MM/DD/YYYY	Date of Discharge MM/DD/YYYY	Visit Type (see code list)	Primary Reason for Visit/Admission (from code list)
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				
11.				
12.				
13.				
14.				
15.				
16.				
17.				
18.				
19.				
20.				
21.				
22.				
23.				
24.				
25.				
26.				
27.				
28.				
29.				
30.				

VISIT TYPE CODES
1. Hospital admission
2. ED or EDTR
3. Acute or urgent care

PRIMARY REASON FOR VISIT/ADMISSION CODES
1. Pain crisis
2. Pneumonia
3. Acute chest syndrome
4. Stroke
5. Non-SCD related condition/symptom
6. Pregnancy-related
7. Labor and delivery
8. Procedure
9. Surgery
10. Other, specify

SCD Complications since the last abstraction			
Ever present in timeframe: previously reported condition still being actively monitored or treated or a new diagnosis within the timeframe of abstraction			
Date of new diagnosis: chronic condition not previously diagnosed or a new episode of an acute condition within the timeframe of abstraction			
Received treatment: received an intervention within the timeframe of abstraction (i.e. surgery, procedure, medication)			
	Ever present in timeframe	Date of new diagnosis only (mm/yyyy)	Received treatment in timeframe
Musculoskeletal			
24. Avascular necrosis (<i>check all that apply</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. Hip	<input type="checkbox"/>		<input type="checkbox"/>
b. Shoulder	<input type="checkbox"/>		<input type="checkbox"/>
c. Knee	<input type="checkbox"/>		<input type="checkbox"/>
d. Other location, specify _____	<input type="checkbox"/>		<input type="checkbox"/>
Genitourinary			
25. Chronic kidney disease	<input type="checkbox"/>		<input type="checkbox"/>
26. End stage renal disease (<i>if yes, complete Renal form</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. Kidney transplant	<input type="checkbox"/>		
b. Kidney transplant rejection	<input type="checkbox"/>		
27. Priapism	<input type="checkbox"/>		<input type="checkbox"/>
Nervous system			
28. Stroke (<i>check all that apply</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. Ischemic	<input type="checkbox"/>		<input type="checkbox"/>
b. Hemorrhagic	<input type="checkbox"/>		<input type="checkbox"/>
c. Transient ischemic attack (TIA)	<input type="checkbox"/>		<input type="checkbox"/>
d. Silent	<input type="checkbox"/>		<input type="checkbox"/>
29. Intracranial bleeding	<input type="checkbox"/>		<input type="checkbox"/>
Cardiovascular			
30. Pulmonary arterial hypertension	<input type="checkbox"/>		<input type="checkbox"/>
a. Mean pulmonary artery pressure > or = to 25 mm Hg	<input type="checkbox"/>		<input type="checkbox"/>
b. Tricuspid regurgitation velocity (TRV) > or = to 3.0 m/sec	<input type="checkbox"/>		<input type="checkbox"/>
31. Left ventricular dysfunction	<input type="checkbox"/>		<input type="checkbox"/>
Respiratory			
32. Acute chest syndrome	<input type="checkbox"/>		<input type="checkbox"/>
33. Asthma	<input type="checkbox"/>		<input type="checkbox"/>
Digestive			
34. Gallstones/cholelithiasis, cholecystitis	<input type="checkbox"/>		<input type="checkbox"/>
35. Splenomegaly (<i>check all that apply</i>)	<input type="checkbox"/>		<input type="checkbox"/>
a. PRBC transfusion given for splenomegaly? <input type="checkbox"/> Yes <input type="checkbox"/> No			
b. Splenic sequestration	<input type="checkbox"/>		<input type="checkbox"/>
# sequestration episodes in past 12 months _____			
c. Splenic infarcts, symptomatic	<input type="checkbox"/>		<input type="checkbox"/>
d. Hypersplenism	<input type="checkbox"/>		<input type="checkbox"/>
e. Splenectomy	<input type="checkbox"/>		
Other Autoimmune/Inflammatory			
36. Deep vein thrombosis (DVT)	<input type="checkbox"/>		<input type="checkbox"/>
a. Pulmonary embolism	<input type="checkbox"/>		<input type="checkbox"/>
b. Venous thromboembolism (VTE)	<input type="checkbox"/>		<input type="checkbox"/>
37. Lupus	<input type="checkbox"/>		<input type="checkbox"/>
38. Rheumatoid arthritis	<input type="checkbox"/>		<input type="checkbox"/>
39. Gout	<input type="checkbox"/>		<input type="checkbox"/>

SCD Complications since the last abstraction			
<u>Ever present in timeframe</u> : previously reported condition still being actively monitored or treated or a new diagnosis within the timeframe of abstraction			
<u>Date of new diagnosis</u> : chronic condition not previously diagnosed or a new episode of an acute condition within the timeframe of abstraction			
<u>Received treatment</u> : received an intervention within the timeframe of abstraction (i.e. surgery, procedure, medication)			
Ever present in timeframe	Date of new diagnosis only (mm/yyyy)	Received treatment in timeframe	
40. Sarcoidosis	<input type="checkbox"/>		<input type="checkbox"/>
Other Conditions			
41. Multi-organ failure (<i>check all that apply</i>)	<input type="checkbox"/>		
a. ICU			<input type="checkbox"/>
b. Intubation			<input type="checkbox"/>
c. Simple transfusion			<input type="checkbox"/>
d. Exchange transfusion			<input type="checkbox"/>
e. Hemodialysis			<input type="checkbox"/>
f. Peritoneal dialysis			<input type="checkbox"/>
42. Pneumococcal sepsis	<input type="checkbox"/>		<input type="checkbox"/>
43. Skin ulcers	<input type="checkbox"/>		<input type="checkbox"/>
44. Retinopathy	<input type="checkbox"/>		<input type="checkbox"/>
45. Diabetes mellitus	<input type="checkbox"/>		<input type="checkbox"/>
46. Iron overload (liver iron content > 3 mg/g of dry weight liver on MRI or serum ferritin above 1,000 ng/dL for >3 separate measurements or >18 PRBCs)	<input type="checkbox"/>		<input type="checkbox"/>
47. Chronic refractory pain	<input type="checkbox"/>		<input type="checkbox"/>
48. Seizure disorder	<input type="checkbox"/>		<input type="checkbox"/>
49. Anxiety	<input type="checkbox"/>		<input type="checkbox"/>
50. Depression	<input type="checkbox"/>		<input type="checkbox"/>
51. Other psychiatric disorder, specify:	<input type="checkbox"/>		<input type="checkbox"/>
52. Other major health condition, specify:	<input type="checkbox"/>		<input type="checkbox"/>
Liver Conditions			
53. Liver cirrhosis	<input type="checkbox"/>		<input type="checkbox"/>
54. Intrahepatic cholelithiasis	<input type="checkbox"/>		<input type="checkbox"/>
55. Hepatitis B	<input type="checkbox"/>		<input type="checkbox"/>
56. Hepatitis C	<input type="checkbox"/>		<input type="checkbox"/>
57. Hepatic sequestration	<input type="checkbox"/>		<input type="checkbox"/>
58. Hepatomegaly	<input type="checkbox"/>		<input type="checkbox"/>
59. Bridging fibrosis	<input type="checkbox"/>		<input type="checkbox"/>

60. Has the subject been diagnosed with a primary cancer since the last abstraction?

- Yes
- No → GO TO Q61
- Don't know → GO TO Q61

a. CANCER TYPE AND LOCATION _____

b. CANCER STAGE _____

c. DATE OF DIAGNOSIS (MM/YYYY): |__|_|_| |__|_|_|_|_|_|

61. What kind of health insurance or health care coverage does the subject currently have? (Choose all that apply.)

- None
- Private health insurance
- Medicare
- Medicaid, Medical Assistance (MA), the Children's Health Insurance Program (CHIP), or any kind of state or government-sponsored assistance
- TRICARE or other military health care, including VA health care
- Support from Charities or Donations
- Other type of health insurance, specify: _____

Name of Abstractor: _____

PI review and sign-off: _____



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 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.

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?	<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"/>

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?	<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"/>

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?	<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"/>

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?	<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"/>

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	<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"/>

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.	<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

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.....	<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"/>

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.	<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"/>

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.	<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"/>

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.	<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"/>

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.	<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"/>

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.	<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"/>

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)?	<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"/>

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?	<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"/>

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.	<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"/>

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.	<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

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.....	<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?					
		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"/>

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?	<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

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?	<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

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?	<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

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: _____

	Type of Procedure	Response	Date of Most Recent Procedure
1.	Was a liver biopsy ever done? 1a. If yes, what was the reason for the procedure? _____ 1b. What was the result/diagnosis? <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal, specify _____	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
2.	Was an MRI of the liver ever done? 2a. If yes, what was the reason for the procedure? _____ 2b. If yes, what was the MRI method? <input type="checkbox"/> R2* <input type="checkbox"/> T2* 2c. What was the liver iron content (LIC)? _____ mg Fe/g dry weight	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
3.	Was a cardiac MRI ever done? 3a. If yes, what was the reason for the procedure? _____ 3b. What was the result/diagnosis? <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal, specify _____	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
4.	Was a cardiac ECHO ever done? <i>If yes, complete the Supplemental Cardiac Form</i>	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
5.	Was a cardiac EKG ever done? <i>If yes, complete the Supplemental Cardiac Form</i>	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
6.	Was a cardiac catheterization ever done? <i>If yes, complete the Supplemental Cardiac Form</i>	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
7.	Was an MRI of the brain ever done? 7a. If yes, what was the reason for the procedure? _____ 7b. What was the result/diagnosis? <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal, specify _____	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
8.	Was a transcranial doppler (TCD) ever done? 8a. If yes, what was the reason for the procedure? _____ 8b. What was the result/diagnosis? <input type="checkbox"/> Normal <input type="checkbox"/> Conditional <input type="checkbox"/> Abnormal, specify _____	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
9.	Was imaging of the spleen ever done? 9a. If yes, what was the reason for the procedure? _____ 9b. What type of imaging was done? <input type="checkbox"/> CT <input type="checkbox"/> MRI <input type="checkbox"/> ECHO 9c. What was the result/diagnosis? <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal, specify _____	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year
10.	Was a pulmonary function test (PFT) ever done? 10a. If yes, what was the reason for the procedure? _____ 10b. What was the result/diagnosis? <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal, specify _____	<input type="checkbox"/> Yes → <input type="checkbox"/> No	_____/_____/_____ Month Day Year



Laboratory Reporting Form

Subject ID Label

Complete using medical records with values from the subject in steady state.

Abstractor: _____

Test Name	Units	Date of Most Recent	NA
1. Nucleated RBC	_ _ _ . _ _ 10 ³ /mm ³	___/___/___	<input type="checkbox"/>
2. White Blood Cells	_ _ _ . _ _ 10 ³ /mm ³	___/___/___	<input type="checkbox"/>
3. RBC	_ _ _ . _ _ 10 ⁶ /mm ³	___/___/___	<input type="checkbox"/>
4. Hemoglobin	_ _ _ . _ _ g/dL	___/___/___	<input type="checkbox"/>
5. Hematocrit	_ _ _ . _ _ %	___/___/___	<input type="checkbox"/>
6. MCV	_ _ _ micrometer ³	___/___/___	<input type="checkbox"/>
7. MCH	_ _ _ . _ _ pg	___/___/___	<input type="checkbox"/>
8. MCHC	_ _ _ . _ _ g/dL	___/___/___	<input type="checkbox"/>
9. Platelets	_ _ _ _ 10 ³ /mm ³	___/___/___	<input type="checkbox"/>
10. Neutrophils (segmented and band together)	_ _ _ %	___/___/___	<input type="checkbox"/>
11. Lymphocytes	_ _ _ %	___/___/___	<input type="checkbox"/>
12. Monocytes	_ _ _ %	___/___/___	<input type="checkbox"/>
13. Eosinophils	_ _ _ . _ _ %	___/___/___	<input type="checkbox"/>
14. Reticulocytes	_ _ _ . _ _ % AND/OR _ _ _ 10 ³ /microliter	___/___/___	<input type="checkbox"/>
15. Serum BUN	_ _ _ . _ _ mg/dL	___/___/___	<input type="checkbox"/>
16. Serum Creatinine	_ _ . _ _ mg/dL	___/___/___	<input type="checkbox"/>
17. Estimated creatinine clearance	_ _ _ _ mL/min	___/___/___	<input type="checkbox"/>
18. Total Cholesterol	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
19. Non-Fasting HDL	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
20. Fasting HDL	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
21. Non-Fasting LDL	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
22. Fasting LDL	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
23. Triglyceride	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
24. Non-Fasting Blood Glucose	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
25. Fasting Blood Glucose	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
26. CRP	_ _ _ . _ _ mg/dL	___/___/___	<input type="checkbox"/>
27. Bilirubin serum, total	_ _ _ . _ _ mg/dL	___/___/___	<input type="checkbox"/>
28. Bilirubin, serum, direct	_ _ _ . _ _ mg/dL	___/___/___	<input type="checkbox"/>

Test Name	Units	Date of Most Recent	NA
29. AST	_ _ _ . _ _ U/L	___/___/___	<input type="checkbox"/>
30. ALT	_ _ _ . _ _ U/L	___/___/___	<input type="checkbox"/>
31. Alkaline Phosphatase	_ _ _ _ . _ _ U/L	___/___/___	<input type="checkbox"/>
32. Total Protein (plasma)	_ _ _ . _ _ g/dL	___/___/___	<input type="checkbox"/>
33. Albumin	_ _ _ . _ _ g/dL	___/___/___	<input type="checkbox"/>
34. LDH (serum)	_ _ _ _ U/L	___/___/___	<input type="checkbox"/>
Reference range	_____ -- _____		
35. Direct antiglobulin test-Anti-IgG*	_ 0/negative _ positive	___/___/___	<input type="checkbox"/>
36. Direct antiglobulin test-Anti-C3d*	_ 0/negative _ positive	___/___/___	<input type="checkbox"/>
37. NT-pro-BNP	_ _ _ _ _ pg/mL	___/___/___	<input type="checkbox"/>
38. BNP	_ _ _ _ _ pg/mL	___/___/___	<input type="checkbox"/>
39. Serum iron	_ _ _ _ ug/dL	___/___/___	<input type="checkbox"/>
40. Total iron binding capacity (TIBC)	_ _ _ _ ug/dL	___/___/___	<input type="checkbox"/>
41. Serum transferrin	_ _ _ _ mg/dL	___/___/___	<input type="checkbox"/>
42. Ferritin	_ _ _ _ ng/mL	___/___/___	<input type="checkbox"/>
43. 25-Hydroxy Vitamin D	_ _ _ ng/mL	___/___/___	<input type="checkbox"/>
44. Erythropoietin (EPO)	_ _ _ mU/ml	___/___/___	<input type="checkbox"/>
45. Urine albumin	_ _ _ _ . _ _ mg/g	___/___/___	<input type="checkbox"/>
46. Urine albumin / creatinine	_ _ . _ _ _ _ mcg/mg	___/___/___	<input type="checkbox"/>
47. Urine protein (dipstick)	_ 0/negative _ trace _ 1+ _ 2+ _ 3+ _ 4+ _ positive	___/___/___	<input type="checkbox"/>
48. Urine protein / creatinine	_ _ . _ _ _ _ mg/g	___/___/___	<input type="checkbox"/>
49. Urine dipstick heme	_ 0/negative _ trace _ 1+ _ 2+ _ 3+ _ 4+ _ positive	___/___/___	<input type="checkbox"/>
50. Urine microscopic RBCs	_ _ _ . _ _ 10 ³ /mm ³ (if < 100, enter exact value) OR _ ≥ 100 10 ³ /mm ³	___/___/___	<input type="checkbox"/>
51. Urine microscopic WBCs	_ _ _ . _ _ 10 ³ /mm ³ (if < 100, enter exact value) OR _ ≥ 100 10 ³ /mm ³	___/___/___	<input type="checkbox"/>
52. Hemoglobin fractionation, most recent	Hb A _ _ _ % Hb A2 _ _ _ % Hb C _ _ _ % Hb D _ _ _ % Hb E _ _ _ % Hb F _ _ _ % Hb O _ _ _ % Hb S _ _ _ % Genetic modified A variant _ _ _ % * Other, _____ _ _ _ %	___/___/___	<input type="checkbox"/>



Off Study Form

Subject ID _____

Complete this form to document off-study events that have occurred to enrolled subjects. By completing this form, the subject will be not be considered for any additional follow-up activities.

1. Event Duplicate → **Form Complete**
 Withdrew from study, Reason: _____
 Loss to follow-up, Reason: _____
 Death → **GO TO Q3**

2. Date last known alive: |__|_|-|__|_|-|__|_|_|_| → **STOP, complete Follow-up Form up to this date**
 Month Day Year

3. Date of death: |__|_|-|__|_|-|__|_|_|_| → **CONTINUE and complete Follow-up Form up to this date**
 Month Day Year

4. Cause of death from death certificate
 Primary cause: _____
 Secondary cause(s): _____
 Death certificate Not Available

5. Other sources of Cause of Death (check **all** that apply)
 No Other Sources Family Member Medical Record Autopsy Report

a. Cause of Death from other sources (identify in consultation with site PI)

	Primary/ Immediate Cause (check one)	Secondary/ Underlying or Comorbid Causes (check all that apply)
Acute Chest Syndrome	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory Failure	<input type="checkbox"/>	<input type="checkbox"/>
Sudden Death	<input type="checkbox"/>	<input type="checkbox"/>
Infection	<input type="checkbox"/>	<input type="checkbox"/>
Stroke, Ischemic	<input type="checkbox"/>	<input type="checkbox"/>
Stroke, Hemorrhagic	<input type="checkbox"/>	<input type="checkbox"/>
Cardiac Arrest	<input type="checkbox"/>	<input type="checkbox"/>
Sickle Cell Disease Multiorgan Failure Syndrome	<input type="checkbox"/>	<input type="checkbox"/>
Kidney Failure	<input type="checkbox"/>	<input type="checkbox"/>
Liver Failure	<input type="checkbox"/>	<input type="checkbox"/>
Pulmonary Embolism	<input type="checkbox"/>	<input type="checkbox"/>
Trauma	<input type="checkbox"/>	<input type="checkbox"/>
Cancer (specify type, location): _____	<input type="checkbox"/>	<input type="checkbox"/>
Other primary (specify): _____	<input type="checkbox"/>	<input type="checkbox"/>
Other secondary (specify): _____	<input type="checkbox"/>	<input type="checkbox"/>

6. Is an autopsy report available? (copies of autopsy reports should be maintained locally) Yes No



Patient Registration Form

Version 1 (6/1/2022)

Subject ID _____

Coordinator: By entering this form into the DMS, you are entering this subject into the SCDIC-II Registry. The REDCap survey is accessible after the date of consent and confirmation of available medical records has been entered. Demographics should be completed only for subjects that were not in SCDIC-I.

- The subject has provided signed consent to participate in the Registry.
- The subject has an available medical record for abstraction.

Consent information

1. Date consent form signed |__|__|/|__|__|/|__|__|__|__|
(mm/dd/yyyy)
2. Subject agrees to be contacted for future research studies Yes No
- Check if subject is a minor and provided signed Assent

Subject Demographics for Subjects Not in SCDIC-I:

3. Date of birth |__|__|/|__|__|/|__|__|__|__|
(mm/dd/yyyy)
4. Race (check all that apply) American Indian or Alaska Native
 Asian
 Black or African American
 Native Hawaiian or Pacific Islander
 White
5. Ethnicity (check one) Hispanic or Latino
 Not Hispanic or Latino
6. Sex Male
 Female
7. Zip code of primary residence |__|__|__|__|__|

Patient-Reported Outcome Scales on the SCDIC-II Patient Surveys

<i>Measurement and Domain</i>	<i>Completeness of Measure</i>	<i>Enrollment Survey Questions</i>	<i>FU Survey Questions</i>	<i>Variable Names</i>
ASCQ-ME v2.0				
Pain Episode Frequency and Severity	5/5	A12 – A16	A2 – A6	p3f1q03_v3v4 p3f1q04_v3v4 p3f1q05_v3v4 p3f1q06_v3v4 p3f1q07_v3v4
Pain Impact Short Form (SF)	2/5	A19a, A19b	A9a, A9b	p3f1q08a_v3v4 p3f1q08b_v3v4
Pain Impact (time frame 6 mo)	2/5	A20a, A20b	A10a, A10b	p3f1q09a_v3v4 p3f1q09b_v3v4
SCD Medical History Checklist (time frame last 12 mo instead of ever)	9/9	A11, B23, B26, B28a, B28b, B28c, B28d, B28h, B28i	A1, B13, B16, B18a, B18b, B18c, B18d, B18h, B18i	p3f1q01_v3v4 p3f1q12_v3v4 p3f1q17b_v3v4 p3f1q16a_v3v4 p3f1q16b_v3v4 p3f1q16c_v3v4 p3f1q16d_v3v4 p3f1q16h_v3v4 p3f1q16i_v3v4
Stiffness Impact SF	5/5	G67a-e	G56a-e	p3f1q65a_v3v4 p3f1q65b_v3v4 p3f1q65c_v3v4 p3f1q65d_v3v4 p3f1q65e_v3v4
Emotional Impact SF	2/5	F58e-f	F47e-f	p3f1q34e_v3v4 p3f1q34f_v3v4
Sleep Impact SF	5/5	H68a-e	H57a-e	p3f1q32a_v3v4 p3f1q32b_v3v4 p3f1q32c_v3v4 p3f1q32d_v3v4 p3f1q32e_v3v4
Social Functioning SF	5/5	F63a-e	F52a-e	p3f1q38a_v3v4 p3f1q38b_v3v4 p3f1q38c_v3v4 p3f1q38d_v3v4 p3f1q38e_v3v4
PROMIS				
Pain Interference SF 4a	4/4	A18a-d	A8a-d	p3f1q09a2_v3v4 p3f1q09b2_v3v4 p3f1q09c2_v3v4 p3f1q09d2_v3v4
Neuropathic Pain Quality 5a	1/5	A17a	A7a	p3f1q10a_v3v4
Nociceptive Pain Quality 5a	1/5	A17b	A7b	p3f1q10b_v3v4
Fatigue SF4a	4/4	F59a-d	F48a-d	p3f1q57a_v3v4 p3f1q57b_v3v4 p3f1q57c_v3v4 p3f1q57d_v3v4

Fatigue – one extra from bank	1/1	F59e	F48e	p3f1q48e_v3v4
Emotional Distress – Anxiety SF 4a	4/4	F60a-d	F49a-d	p3f1q35a_v3v4 p3f1q35b_v3v4 p3f1q35c_v3v4 p3f1q35d_v3v4
Emotional Distress – Depression SF 4a	4/4	F58a-d	F47a-d	p3f1q34a_v3v4 p3f1q34b_v3v4 p3f1q34c_v3v4 p3f1q34d_v3v4
Emotional Support SF 4a	4/4	F57a-d	F46a-d	p3f1q33a_v3v4 p3f1q33b_v3v4 p3f1q33c_v3v4 p3f1q33d_v3v4
Social Isolation SF 4a	1/4	F64f	F53f	p3f1q39f_v3v4
Global Health 10	5/10	F56a-b, G66a-c	F45a-b, G55a-c	p3f1q54b_v3v4 p3f1q53d_v3v4 p3f1q41_1a_v3v4 p3f1q41_1b_v3v4 p3f1q41_2b_v3v4
Self-Efficacy for Managing Medications and Treatments SF 4a	4/4	E55a-d	E44a-d	p3f1q53a_v3v4 p3f1q53b_v3v4 p3f1q53c_v3v4 p3f1q54a_v3v4
Neuro-QoL				
Cognition Function SF	8/8	F61a-d, F62a-d	F50a-d, F51a-d	p3f1q36a_v3v4 p3f1q36b_v3v4 p3f1q36c_v3v4 p3f1q36d_v3v4 p3f1q37a_v3v4 p3f1q37b_v3v4 p3f1q37c_v3v4 p3f1q37d_v3v4
NIH Toolbox				
Loneliness (ages 18+) Fixed Form	5/5	F64a-e	F53a-e	p3f1q39a_v3v4 p3f1q39b_v3v4 p3f1q39c_v3v4 p3f1q39d_v3v4 p3f1q39e_v3v4
Other				
Brief Resilience Scale	6/6	F65a-f	F54a-f	p3f1q40a_v3v4 p3f1q40b_v3v4 p3f1q40c_v3v4 p3f1q40d_v3v4 p3f1q40e_v3v4 p3f1q40f_v3v4
Chronic Pain	1/1	A21	A11	p3f1q12_2_v3v4