Medical Record Abstraction Form

Subject ID Label

If date or age is not available, enter '99'. Name of Abstractor: ________________

1. DATE OF ENROLLMENT: |___|___|-|___|___|-|___|___|___|___|

2. Location where person enrolled:

   - ☐ Routine visit--main SCDIC center
   - ☐ Routine visit--satellite SCDIC center
   - ☐ Emergency Department
   - ☐ Acute Pain Center
   - ☐ Hospital in-patient
   - ☐ Primary Care offices
   - ☐ Community event (e.g. SCD walk)
   - ☐ Other ______________________________

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

Diagnosis		Diagnosis	
a. Hb SS or sickle cell anemia	☐	e. Hb S hereditary persistence of fetal Hb (S/HPFH)	☐
b. Hb SC disease	☐	f. Hb SE	☐
c. Hb S beta^0 thalassemia	☐	g. Hb SD	☐
d. Hb S beta$^+$ thalassemia	☐	h. Hb SO	☐

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

4. Approximate age of first diagnosis (physician confirmed): ________ AGE In YEARS **OR** ☐ NEWBORN SCREENING **OR** ☐ UNKNOWN

For subjects age 15-25 at time of enrollment:

   a. Date of most recent visit to pediatric sickle cell provider. |__|__|-|__|__|-|__|__|__|__| ☐ DATE UNAVAILABLE
   Date of first visit to adult sickle cell provider. |__|__|-|__|__|-|__|__|__|__| ☐ DATE UNAVAILABLE
   ☐ HAS NOT SEEN ADULT PROVIDER

☐ FORM COMPLETE, MEDICAL RECORDS NOT AVAILABLE

5. Ever tested 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?
6. Height	☐	|___|___|___| CM		Y N
7. Weight	☐	|___|___|___|.|___| KG		Y N
8. Temperature	☐	|___|___|.|___| Celsius		Y N
9. Heart Rate	☐	|___|___|___| BEATS/MINUTE		Y N
10. Respiration Rate	☐	|___|___|___| BREATHS/MINUTE		Y N
11. Oxygen saturation (SpO_2)	☐	|___|___|___| %		Y N
12. Blood Pressure	☐	|___|___|___| / |___|___|___| ON ANTI-HYPERTENSIVE MEDS? ☐ Yes ☐ No		Y N

13. Has the subject ever used hydroxyurea? ☐ Yes ☐ No ➔ SKIP TO MEDICATION TABLE ON NEXT PAGE

   a. Start date (mm/yyyy) ______/__________
   b. Stop/last date (mm/yyyy) ______/__________
   c. Total duration of use _____ ☐ Months or ☐ Years ☐ Unknown
   d. Current dose _____ Mg/kg or _____ Mg

14. Please list all medications the subject is **currently** taking (at time of enrollment). ☐ NONE CURRENTLY BEING USED

Name of Medication	Name of Medication
a.	k.
b.	l.
c.	m.
d.	n.
e.	o.
f.	p.

Most recent visit to ….	Not in record	Visit/Admission Date (mm/yyyy)	Length of stay (in days)	Was visit for acute pain?	# of total visits in past year for acute pain/crisis
15. Acute Pain/Infusion Center (not admitted)	☐			☐ Yes ☐ No	
16. Emergency Department (not admitted)	☐			☐ Yes ☐ No	
17. Hospitalization	☐			☐ Yes ☐ No	

Most recent visit to…	Not in record	Visit Date (mm/yyyy)	Most recent visit to….	Not in record	Visit Date (mm/yyyy)
18. Primary care physician (i.e. family/internal medicine, pediatrician)	☐		19. Behavioral medicine/psychiatrist	☐	
20. Hematologist	☐		21. Orthopedic surgeon	☐	
22. Nephrologist	☐		23. Ophthalmologist	☐	
24. Cardiologist	☐		25. Neurologist	☐	
26. Pulmonologist	☐		27. OB/GYN	☐	

Transfusion History at Clinic Site

	None	# ever had	# total units	First time (mm/yyyy)	Last time (mm/yyyy)	Reason stopped	Frequency	Type
28. Episodic, simple	☐						☐ Less than once/year ☐ About once a year ☐ More than once/year ☐ Unknown	
29. Chronic, simple	☐					☐ Hemochromatosis ☐ Alloimmunization ☐ Other ☐ Unknown	☐ Once every 4 weeks ☐ Once every 6 weeks ☐ Once every 8 weeks ☐ Unknown	
30. Episodic, exchange	☐						☐ Less than once/year ☐ About once a year ☐ More than once/year ☐ Unknown	☐ Automated ☐ Manual ☐ Unknown
31. Chronic, exchange	☐					☐ Hemochromatosis ☐ Alloimmunization ☐ Other ☐ Unknown	☐ Once every 4 weeks ☐ Once every 6 weeks ☐ Once every 8 weeks ☐ Unknown	☐ Automated ☐ Manual ☐ Unknown

SCD Complications Indicate whether the subject has <u>ever</u> had each condition and the date it was most recently diagnosed.	**No**	**Not in record**	**Yes**	**Most recent dx** (record age OR date) **Age**	**Date (mm/yyyy)**
Musculoskeletal					
32. Avascular necrosis *(check all that apply)*	☐	☐	☐		
a. Hip	☐	☐	☐		
b. Shoulder	☐	☐	☐		
c. Knee	☐	☐	☐		
33. Dactylitis	☐	☐	☐		
34. Osteomyelitis	☐	☐	☐		
Genitourinary					
35. Chronic kidney disease	☐	☐	☐		
36. End stage renal disease	☐	☐	☐		
a. Kidney transplant	☐	☐	☐		
37. Priapism	☐	☐	☐		
Nervous system					
38. Stroke (*check all that apply*)	☐	☐	☐		
a. Ischemic	☐	☐	☐		
b. Hemorrhagic	☐	☐	☐		
c. Transient ischemic attack (TIA)	☐	☐	☐		
d. Silent	☐	☐	☐		
39. Intracranial bleeding	☐	☐	☐		
Cardiovascular					
40. Pulmonary arterial hypertension	☐	☐	☐		
a. Mean pulmonary artery pressure > or = to 25 mm Hg	☐	☐	☐		
b. Tricuspid regurgitation velocity (TRV) > or = to 3.0 m/sec	☐	☐	☐		
41. Left ventricular dysfunction	☐	☐	☐		
Respiratory					
42. Acute chest syndrome	☐	☐	☐		
43. Asthma	☐	☐	☐		
Digestive					
44. Gallstones/cholelithiasis, cholecystitis	☐	☐	☐		
45. Splenomegaly *(check all that apply)*	☐	☐	☐		
a. Splenic sequestration	☐	☐	☐		
b. Splenic infarcts	☐	☐	☐		
c. Hypersplenism	☐	☐	☐		
d. Splenectomy	☐	☐	☐		
Other Autoimmune/Inflammatory					
46. Deep vein thrombosis (DVT)	☐	☐	☐		
a. Pulmonary embolism	☐	☐	☐		
b. Venous thromboembolism (VTE)	☐	☐	☐		
47. Lupus	☐	☐	☐		
48. Rheumatoid arthritis	☐	☐	☐		
49. Gout	☐	☐	☐		
50. Sarcoidosis	☐	☐	☐		
51. Other autoimmune or inflammatory, specify:	☐	☐	☐		

Other Conditions	No	Not in record	Yes	Most recent dx (record age OR date) Age	Date (mm/yyyy)
52. Multi-organ failure *(check all that apply)*	☐	☐	☐		
a. ICU	☐	☐	☐		
b. Intubation	☐	☐	☐		
c. Simple transfusion	☐	☐	☐		
d. Exchange transfusion	☐	☐	☐		
e. Hemodialysis	☐	☐	☐		
f. Peritoneal dialysis	☐	☐	☐		
53. Pneumococcal sepsis (Pulmonary)	☐	☐	☐		
54. Skin ulcers (Integumentary)	☐	☐	☐		
55. Retinopathy (Ocular)	☐	☐	☐		
56. Diabetes mellitus (other systemic)	☐	☐	☐		
57. Iron overload (Other)	☐	☐	☐		
58. Chronic refractory pain (Other)	☐	☐	☐		
59. Anxiety (Mental health)	☐	☐	☐		
60. Depression (Mental health)	☐	☐	☐		
61. Other psychiatric disorder (Mental health) Specify:	☐	☐	☐		

62. Has the subject ever been diagnosed with cancer?

- ☐ Yes
- ☐ No ➔ GO TO Q 63
- ☐ Don't know ➔ GO TO Q 63

IF YES: For each primary cancer, complete a row in the table:

	Cancer Type & Location	Stage	When diagnosed? (record age or date) Age	Date (mm/yyyy)
a.				
b.				

63. What kind of health insurance or health care coverage does the subject have at the time of enrollment? (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
- ☐ Other type of health insurance, specify:______________________

64. Year of first visit in medical record: |___|___|___|___| ☐ Subject not seen at this institution

PI review and sign-off: ________________________________