Participant Profile

Participant ID _____
((do not change this value))

OMB Number (0915-XXXX) Expiration date (XX/XX/20XX)

Public Burden Statement: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0915-XXXX. Public reporting burden for this collection of information is estimated to average ____ hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 10-29, Rockville, Maryland, 20857.

Legacy Participant ID _____

Most recent reviewer's initials: _____

Most recent chart review date: _____

Status: ☐ Active ☐ Inactive

Demographics

Gender ☐ Male ☐ Female ☐ Unknown

Year of birth: _____

State of Residence:

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

Born in U.S.? ☐ Yes ☐ No ☐ Not available

Country of birth: _____
(if unknown enter "Not available")

Primary care site: _____

Primary Care Phone: _____

Hematology Care Site: _____

Hematology Care Phone: _____

Sickle Cell Status

Genotype:
- ☐ Hemoglobin SS
- ☐ Hemoglobin SC
- ☐ Hemoglobin Sbeta zero thalassemia
- ☐ Hemoglobin Sbeta plus thalassemia
- ☐ Hemoglobin S variant
- ☐ Hemoglobin Variant (AV/ FAV, FAO/E, FAD/G)
- ☐ Sickle cell trait (AS/FAS)
- ☐ Hemoglobin C trait (AC/FAC)
- ☐ Beta thalassemia trait
- ☐ Other trait
- ☐ Not available

Was the diagnosis of sickle cell disease/sickle cell trait made in the past 12 months?
- ☐ Yes, SCD diagnosed in the past 12 months
- ☐ Yes, SCT diagnosed in the past 12 months
- ☐ No

Was the diagnosis of SCD made in the newborn period?
- ☐ Yes, diagnosis made through newborn screening.
- ☐ No, diagnosis not made in the newborn period. Diagnosis made through testing after 1 month of age.

Date of screening: _____

Date of testing: _____

Was the diagnosis of SCT made in the newborn period?
- ☐ Yes, diagnosis made through newborn screening.
- ☐ No, diagnosis not made in the newborn period. Diagnosis made through testing after 1 month of age.

Date of screening: _____

Date of testing: _____

Was confirmatory testing performed? ☐ Yes ☐ No ☐ Not available

Date of confirmatory testing: _____

Time difference between SCD screening and confirmatory test dates. _____ (not for data entry)

Were results given/discussed with parents/caregiver? ☐ Yes ☐ No ☐ Not available

Results discussed/given date: _____

Were the results given/discussed with patient/parents/caregivers? ☐ Yes ☐ No ☐ Not available

Results discussed/given date: _____

Was genetic counseling provided? ☐ Yes ☐ No ☐ Not available

Counseling date: _____

Time Difference between confirmatory testing and genetic education dates: _____ (not for data entry)

Did the newborn have an initial follow-up appointment with the hematologist? ☐ Yes ☐ No ☐ Not available

Follow-up date: _____

Time difference between screening and follow-up dates _____
(not for data entry)

Did the patient have an initial follow-up appointment with a hematologist? ☐ Yes ☐ No ☐ Not available

Follow-up date: _____

Time difference between confirmatory testing and follow-up dates _____
(not for data entry)