



# Patient Registration Form

Version 2 (7/2/2018)

Subject ID Label

By entering this form into the DMS, you are entering this subject into the SCDIC Registry database. The REDCap survey is accessible after the SCD diagnosis status is entered. Demographics should be completed for eligible subjects only.

## Registration Checklist:

- The subject provided signed consent to participate in the Registry on \_\_\_\_\_.  
(DATE)
  - Assent form signed (minors only)
- The subject completed the patient survey via the following mode (check one):
  - Interview; hard copy
  - Interview; online entry
  - Interview: phone
  - Self-administered; hard copy
  - Self-administered; online entry

## Diagnosis Status:

- Confirmed (with documentation) by newborn screening, hemoglobin fractionation, hemoglobin electrophoresis or DNA sequencing
- Pending – DO NOT ENTER DEMOGRAPHICS INTO DMS UNTIL CONFIRMED
- Unable to Confirm, subject not eligible – FORM COMPLETE

**\*\*\*\*\*PATIENT SURVEY IS NOW ACCESSIBLE IN REDCap\*\*\*\*\***

## Subject Demographics for Confirmed Diagnoses Only:

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

Unaffiliated patients have NOT been seen by a sickle cell provider (non-acute setting) as an outpatient in the past 2 years [for new patients, this excludes the visit during which they were enrolled].

6. Is this patient unaffiliated?
  - Yes
  - No