



Care Redesign Patient Registration Form

Version 1.0 (2/3/2020)

Subject ID Label

By entering this form into the DMS, you are entering this patient subject into the SCDIC Care Redesign database. The REDCap patient reported outcome survey is accessible after the consent date has been entered. Demographics should be completed for confirmed subjects only.

Registration Checklist:

1. The subject provided signed consent to participate in the Care Redesign study on:

|_|_|_|/|_|_|_|/|_|_|_|_|_|_|
(mm/dd/yyyy)

1a. Assent form signed (minors only)

2. The subject completed the patient reported outcome survey via the following mode (check one):

- Self-administered; hard copy Self-administered; online entry
- Interview; hard copy Interview; online entry
- Interview; phone

3. Clinic Location:

St. Jude Clinics:

- St. Jude Children's Research Hospital
- Methodist University Hospital
- Baptist Health Care

Duke Clinics:

- Duke Adult Sickle Cell Clinic
- Duke Pediatric Sickle Cell Clinic

Chicago Clinics:

- UI Hospital & Health Sciences System, Sickle Cell Center
- UI Hospital & Health Sciences System, Pediatric Department
- Sinai Health System
- Lawndale Christian Health Center

UCSF Clinics:

- UCSF Benioff Children's Hospital Oakland
- UC Davis

Mount Sinai Clinics:

- Mount Sinai Hospital

Wash-U Clinics:

- St. Louis Children's Hospital Pediatric
- Barnes Jewish Hospital Hematology
- Christian Hospital Northeast-Hematology

Augusta Clinics:

- Augusta University Adult Center for Blood Disorders
- AU Pediatric Hem/Onc
- AU Macon Outreach Clinic
- AU Sylvester Outreach Clinic
- AU Savannah Outreach Clinic

MUSC Clinics:

- MUSC Adult Sickle Cell Clinic
- MUSC Pediatric Sickle Cell Clinic

Other clinic, specify:

*****PATIENT REPORTED OUTCOME SURVEY IS NOW ACCESSIBLE IN REDCAP*****

Patient Demographics for Consented Subjects 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. Biological Sex Male
 Female

5. Zip code of primary residence |__|__|__|__|__|

6. Is this patient enrolled in the Registry?(If patient is not enrolled in the Registry at the time of Care Redesign enrollment, enroll patient at Week 12 visit)

6a. Yes, provide Registry Subject ID: |__|__|__|__|__|__|__|

No