Registration

Clinic ID
{[clinic_id] text}

_____

1. Clinic Name:
{[clinic_name] dropdown}

- ◯ {1} St. Jude Children's Research Hospital
- ◯ {2} Methodist University Hospital
- ◯ {3} Baptist Health Care
- ◯ {4} Duke Adult Sickle Cell Clinic
- ◯ {5} UI Hospital & Health Sciences System, Sickle Cell Center
- ◯ {6} UI Hospital & Health Sciences System, Pediatric Department
- ◯ {7} OSF Healthcare/Children's Hospital of Illinois
- ◯ {8} Sinai Health System
- ◯ {9} Lawndale Christian Health Center
- ◯ {10} UCSF Benioff Children's Hospital Oakland
- ◯ {11} UC Davis
- ◯ {12} Mount Sinai Hospital
- ◯ {13} St. Louis Children's Hospital Pediatric
- ◯ {14} Barnes Jewish Hospital Hematology
- ◯ {15} Christian Hospital Northeast-Hematology
- ◯ {16} Augusta University Adult Center for Blood Disorders
- ◯ {17} AU Pediatric Hem/Onc
- ◯ {18} AU Macon Outreach Clinic
- ◯ {19} AU Sylvester Outreach Clinic
- ◯ {20} AU Savannah Outreach Clinic
- ◯ {21} Adult Sickle Cell Clinic
- ◯ {22} Pediatric Sickle Cell Clinic
- ◯ {23} Duke Pediatric Sickle Cell Clinic

Clinic Data Collection Form

Please complete the survey below.

Thank you!

A. Clinic Contact Name and Address

Primary Clinic Contact: (Division Chief, Medical Director, or Clinical Lead):

1. Name
{[s1f4qa01] text}

_____

2. Address

a. Number and street
{[s1f4qa02_a] text}

_____

b. City
{[s1f4qa02_b] text}

_____

c. State
{[s1f4qa02_c] text}

_____

d. Zipcode
{[s1f4qa02_d] text zipcode}

_____

3. Phone number
{[s1f4qa03] text phone}

_____

4. Email address
{[s1f4qa04] text email}

_____

5. Date of Assessment
{[s1f4qa05] text date_mdy}

_____

B. Patients Population

Total number of SCD patients(n)
Total SCD patients, by genotype(n)
 Total SCD patients, by sex (n)
 Total SCD patients, by age (n)

s1f4qb04
SS Disease: s1f4qb01a
S Beta zero Thalassemia s1f4qb01b
SC Disease s1f4qb01c
S Beta plus Thalassemia s1f4qb01d
Other Variant s1f4qb01e

Males s1f4qb02a
Femaless1f4qb02b

15 to 18 years s1f4qb03a
19 to 25 years s1f4qb03b
26 and older s1f4qb03c

1. Total SCD patients, by genotype (n):

a. SS Disease
{[s1f4qb01a] text integer}

_____

b. S Beta zero Thalassemia
{[s1f4qb01b] text integer}

_____

c. SC Disease
{[s1f4qb01c] text integer}

_____

d. S Beta plus Thalassemia
{[s1f4qb01d] text integer}

_____

e. Other Variant
{[s1f4qb01e] text integer}

_____

2. Total SCD patients, by sex (n)

a. Males
{[s1f4qb02a] text integer}

_____

b. Females
{[s1f4qb02b] text integer}

_____

3. Total SCD patients, by age (n)

a. 15 to 18 years
{[s1f4qb03a] text integer}

_____

b. 19 to 25 years
{[s1f4qb03b] text integer}

_____

c. 26 and older
{[s1f4qb03c] text integer}

_____

4. Total number of SCD patients (n)
{[s1f4qb04] text integer}

_____

C. Patients who meet NHLBI criteria* to receive hydroxyurea (if known)

Total number of SCD patients eligible for hydroxyurea(n)
Total SCD patients eligible for hydroxyurea, by genotype (n)
 Total SCD patients eligible for hydroxyurea, by sex (n)
 Total SCD patients eligible for hydroxyurea, by age (n)

s1f4qc04
SS Disease: s1f4qc01a
S Beta zero Thalassemia s1f4qc01b
SC Disease s1f4qc01c
S Beta plus Thalassemia s1f4qc01d
Other Variant s1f4qc01e

Males s1f4qc02a
Femaless1f4qc02b

15 to 18 years s1f4qc03a
19 to 25 years s1f4qc03b

*The NHLBI criteria to receive hydroxyurea is defined as:

Adults: HbSS or HbS beta zero with 2 or more VOC in the past 12 months

Children: all HbSS and HbS beta zero

1. Total SCD patients eligible for hydroxyurea, by genotype (n)

a. SS Disease
{[s1f4qc01a] text integer}   _____

b. S Beta zero Thalassemia
{[s1f4qc01b] text integer}   _____

c. SC Disease
{[s1f4qc01c] text integer}   _____

d. S Beta plus Thalassemia
{[s1f4qc01d] text integer}   _____

e. Other Variant
{[s1f4qc01e] text integer}   _____

2. Total SCD patients eligible for hydroxyurea, by sex (n)

a. Males
{[s1f4qc02a] text integer}   _____

b. Females
{[s1f4qc02b] text integer}   _____

3. Total SCD patients eligible for hydroxyurea, by age (n)

a. 15 to 18 years
{[s1f4qc03a] text integer}   _____

b. 19 to 25 years
{[s1f4qc03b] text integer}   _____

c. 26 and older
{[s1f4qc03c] text integer}   _____

4. Total number of SCD patients eligible for
hydroxyurea(n)   _____
{[s1f4qc04] text integer}

D. Patients who are prescribed hydroxyurea

Total number of SCD patients prescribed hydroxyurea(n)
Total SCD patients prescribed hydroxyurea, by genotype (n)
Total SCD patients prescribed hydroxyurea, by sex (n)
Total SCD patients prescribed hydroxyurea, by age (n)

s1f4qd04
SS Disease: s1f4qd01a
S Beta zero Thalassemia s1f4qd01b
SC Disease s1f4qd01c
S Beta plus Thalassemia s1f4qd01d
Other Variant s1f4qd01e

Males s1f4qd02a
Femaless1f4qd02b

15 to 18 years s1f4qd03a
19 to 25 years s1f4qd03b
26 and older s1f4qd03c

---

1. Total SCD patients prescribed hydroxyurea, by genotype (n)

---

a. SS Disease
{[s1f4qd01a] text integer}   _____

---

b. S Beta zero Thalassemia
{[s1f4qd01b] text integer}   _____

---

c. SC Disease
{[s1f4qd01c] text integer}   _____

---

d. S Beta plus Thalassemia
{[s1f4qd01d] text integer}   _____

---

e. Other Variant
{[s1f4qd01e] text integer}   _____

---

2. Total SCD patients prescribed hydroxyurea, by sex (n)

---

a. Males
{[s1f4qd02a] text integer}   _____

---

b. Females
{[s1f4qd02b] text integer}   _____

---

3. Total SCD patients prescribed hydroxyurea, by age (n)

---

a. 15 to 18 years
{[s1f4qd03a] text integer}   _____

---

b. 19 to 25 years
{[s1f4qd03b] text integer}   _____

c. 26 and older
{[s1f4qd03c] text integer}

_____

4. Total number of SCD patients prescribed Hydroxyurea
(n)
{[s1f4qd04] text integer}

_____

E. Case-mix of clinic. Please report the distribution of insurance carriers for the population

Total patients insured by Medicaid (n)
 Total patients insured by Medicare (n)
 Total patients with private insurance (n)
Total of uninsured patients (n)
 Total patients with unknown insurance type

s1f4qe01
s1f4qe02
s1f4qe03
s1f4qe04
s1f4qe05

1. Total patients insured by Medicaid (n)
{[s1f4qe01] text integer}

_____

2. Total patients insured by Medicare (n)
{[s1f4qe02] text integer}

_____

3. Total patients with private insurance (n)
{[s1f4qe03] text integer}

_____

4. Total of uninsured patients (n)
{[s1f4qe04] text integer}

_____

5. Total patients with unknown insurance type (n)
{[s1f4qe05] text integer}

_____

F. Provider and Clinic Setting Description

Total physicians (n), MD or DO
List specialty of each provider, and indicate (n) of each type
 Total NPs, DNPs and PAs (n)
List specialty of each provider, and indicate (n) of each type
  Type of practice
 Type of clinic setting

Total number : s1f4qf01
Specialties: s1f4qf01_a

Total number : s1f4qf02
Specialties: s1f4qf02_a

s1f4qf03
 s1f4qf04
Please specify other s1f4qf04_a

1. Total physicians (n), MD or DO
{[s1f4qf01] text integer}

_____

List specialties of providers
{[s1f4qf01_a] textarea}

_____

2. Total NPs, DNPs and PAs (n) - List specialty of
each provider
{[s1f4qf02] text integer}

_____

List specialties of providers
{[s1f4qf02_a] textarea}

_____

3. Type of practice
{[s1f4qf03] radio}

◯ {1} Urban
◯ {2} Suburban
◯ {3} Rural

4. Type of clinic setting
{[s1f4qf04] radio}

◯ {1} Tertiary academic
◯ {2} Community
◯ {3} Both academic and community
◯ {4} Research institute
◯ {5} Other

Specify other
{[s1f4qf04_a] text}
{Branching logic (show if): [s1f4qf04] = 5}

_____