

Appendix C
SCDTRCP Performance Measures Data Collection Documents

Includes:

SCDTRCP Provider Survey (pgs. 2–4)

Aggregate Performance Measures CoLab Data Entry Form for SCDTRCP Grantees (pgs. 5-47)

Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program

Provider Survey

From: [add name of organization with IRB approved survey distributor]

Hello,

You are being asked to participate in this survey to help us better understand variation among types of providers in the evaluation and treatment of patients with sickle cell disease. Completing this survey will provide valuable information, even if you only see a small number of patients with sickle cell disease. We know that your time is valuable and we greatly appreciate your assistance with this study.

Informed Consent: We have obtained permission to distribute this survey to health care providers from the [add name of IRB] Institutional Review Board.

Privacy: Your privacy will be maintained in all published and written data resulting from the survey. We will not use your name or address for any non-research purposes without your consent.

Rights of Participants: Your contribution is entirely voluntary and you have the right to discontinue the survey at any time. You also have the right to refuse to answer specific questions.

Eligibility: Licensed Prescribing Medical Providers (Physicians, Nurse Practitioners, Physician Assistants).

NOTE: You have been selected to participate in this survey because you are part of, or have participated in, a program run by the Sickle Cell Disease Treatment Demonstration Program. This program works with five regional teams from across the country to increase the number of providers treating persons for sickle cell disease or sickle cell related issues, increase the number of providers prescribing disease modifying therapies, such as hydroxyurea, and increase the number of patients receiving regular care from providers knowledgeable about treating sickle cell disease.

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 information collection is 0915-XXXX and it is valid until XX/XX/202X. This information collection is voluntary. Public reporting burden for this collection of information is estimated to average 1 hour 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 14N136B, Rockville, Maryland, 20857 or paperwork@hrsa.gov.

ABOUT YOU AND YOUR PRACTICE

Date survey completed: _____ (MM/DD/YYYY)

1. What type of licensed prescriber are you? [Please check one]

- Medical Doctor (MD, DO, MBBS, etc.)
- Nurse practitioner
- Physician assistant
- Other (Please specify) _____

2. Do you treat adults, children, or both?

- Adults (≥18 years old)
- Children (<18 years old)
- Both

3. What is your primary specialty/subspecialty? [Please check one]]

- Hematology
- Hematology/Oncology
- Primary care-Pediatrics
- Primary Care-Internal Medicine
- Primary Care-Family Medicine
- Primary Care-Med/Peds
- Hospitalist
- Emergency Medicine
- Other (Please specify) _____

4. Are you a regional or state lead for one of the Sickle Cell Disease Regional Demonstration Program regions? [Regions = Sickle Treatment & Outcomes Research in the Midwest (STORM), Pacific Sickle Cell Regional Collaborative, Sickle Cell Improvement Across the NorthEast ReGion (SiNERGe), Heartland Sickle Cell Disease Network, and the Education and Mentoring to Bring Access to CarE for SCD (EMBRACE) Network]

- Yes
- No

5. Please list the ZIP code(s) for all practice locations where you see patients

6. Which of the following best describes your primary practice location? [Check all that apply]

- Solo private practice
- Group private practice
- Practice affiliated with a university or medical school
- Practice affiliated with a non-profit hospital or hospital system
- Practice affiliated with a for profit hospital or hospital system
- Practice/clinic owned by a health maintenance organization or insurance company
- Federally Qualified Health Center or Community Health Center
- State or local government clinic
- Other (please specify) _____

ABOUT YOUR SICKLE CELL PATIENTS

7. IN THE PAST 12 MONTHS, did you personally see any patients with sickle cell disease?

- No (skip to QUESTION 12)
- Yes (continue with QUESTION 8)

8. IN THE PAST 12 MONTHS, how many unique patients with sickle cell disease did you personally see?

- a. Number of adults (age ≥ 18) _____
 - i. *OPTIONAL: Number of these adults with genotype Hb SS or Hb S β^0 -thalassemia* _____
- b. Number of children (age < 18) _____
 - i. *OPTIONAL: Number of these children with genotype Hb SS or Hb S β^0 -thalassemia* _____

9. IN THE PAST 12 MONTHS, for how many unique sickle cell patients did you prescribe hydroxyurea? (Note: we are interested in the number of patients to whom you gave a prescription, NOT how many went on to fill the prescription)

- a. Number of adults (age ≥ 18) prescribed hydroxyurea _____
 - (i) *OPTIONAL: Number of adults (age 18+) with genotype Hb SS or Hb S β^0 -thalassemia prescribed hydroxyurea* _____
- b. Number of children (age < 18) prescribed hydroxyurea _____
 - (i) *OPTIONAL: Number of children (age < 18) with genotype Hb SS or Hb S β^0 -thalassemia prescribed hydroxyurea* _____
 - i. _____

10. IN THE PAST 12 MONTHS, did any of your sickle cell patients use outpatient, billable telemedicine to receive sickle cell care?

- Yes
 - 1-5 patients
 - 6-10 patients
 - >10 patients
- No
- Don't know

11. Please tell us how you provided the patient data for Questions 8-10.

- Recall
- Chart review
- EHR data pull

ABOUT YOUR USE OF TELEMENTORING

12. Have you ever participated in TeleECHO related to sickle cell disease? [TeleECHO is a training model that uses multi-point teleconferencing with specialist mentors to engage clinicians in order to manage patients with complex conditions, such as sickle cell disease. TeleECHO sessions include education, virtual clinics, and/or case presentations.]

- Yes
 - a. If Yes, IN THE PAST 12 MONTHS, how many times did you participate in TeleECHO related to sickle cell disease? _____
- No

13. How would you rate your current level of comfort treating sickle cell patients?

- Very low
- Low
- Medium
- High
- Very high

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Surveys-Sent: (All Providers) Providers Sent the SCDTDP Provider Survey

Count

Count
Annotation

Annotation

No data

PM-1-Total: (Access to Care) Number of SCDTDP Network Providers

Count

Count
Annotation

Annotation

No data

PM-1a: (Access to Care) Providers by Provider Type >

Medical Doctor

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Nurse Practitioner

Numerator

Denominator

Percent

Annotation

 No data

Physician Assistant

Numerator

Denominator

Percent

Annotation

 No data

Other Provider

Numerator

Denominator

Percent**Annotation** No data

PM-1b: (Access to Care) Providers by Age Group >

Adults (≥ 18 years of age)

Numerator**Denominator****Percent****Annotation** No data

Children (< 18 years of age)

Numerator**Denominator****Percent**

Annotation

Annotation

No data

Both

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-1c: (Access to Care) Providers by Specialty/Subspecialty >
Hematology

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hematology/Oncology

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Pediatrics

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Internal Medicine

Numerator

Numerator
Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Family Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Med/Peds

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hospitalist

Numerator**Denominator****Percent****Annotation** No data

Emergency Medicine

Numerator**Denominator****Percent****Annotation** No data

Other

Numerator**Denominator****Percent**

Percent

Annotation

Annotation

No data

**PM-1d: (Access to Care) Regional or State Leads Providers >
Regional or State Leads**

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

**PM-1e: (Access to Care) Providers by Primary Practice Location >
Rural Zip Codes**

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Urban Zip Codes

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-1f: (Access to Care) Providers by Primary Practice Location/Type



Solo private practice

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Group private practice

Numerator

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation No data**Practice affiliated with a university or medical school****Numerator**

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation No data**Practice affiliated with a non-profit hospital or hospital system****Numerator**

Numerator

Denominator

Denominator**Percent**

Annotation No data

Practice affiliated with a for-profit hospital or hospital system

Numerator**Denominator****Percent****Annotation** No data

Practice/clinic owned by a health maintenance organization or insurance company

Numerator**Denominator****Percent****Annotation** No data

Federally qualified health center or community health center

Numerator**Denominator****Percent****Annotation** No data

State or local government clinic

Numerator**Denominator****Percent****Annotation** No data

Other practice type (please annotate)

Numerator**Denominator**

Percent

Percent

Annotation

Annotation No data**PM-2-Total: (Access to Care) Number of Sickle Cell Patients****Count**

Count

Annotation

Annotation No data**PM-2a: (Access to Care) Patients by Age Group >**

<18 years of age

Numerator

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation No data

≥18 years of age

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-2b: (Access to Care) Patients by Provider Specialty/Subspecialty > Hematology

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hematology/Oncology

Numerator

Numerator

Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Pediatrics

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Internal Medicine

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Family Medicine

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Med/Peds

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Hospitalist

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Emergency Medicine

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Other

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

PM-3-Total: (Provider Education) Number of Providers Participating in Tele-mentoring

Count

Count
Annotation

Annotation

No data

PM-3a: (Provider Education) Providers Participating in Tele-mentoring by Provider Type >

Medical Doctor

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Nurse Practitioner

Numerator

Numerator
Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Physician Assistant

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Other Provider

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-3b: (Provider Education) Providers Participating in Tele-mentoring by Specialty/Subspecialty >

Hematology

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Hematology/Oncology

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Pediatrics

Numerator

Numerator

Denominator

Denominator

Percent

Percent**Annotation**

Annotation

 No data**Primary Care - Internal Medicine**

Numerator

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation No data**Primary Care - Family Medicine**

Numerator

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation

No data

Primary Care - Med/Peds

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hospitalist

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Emergency Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Other

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-3c: (Provider Education) Providers Participating in Tele-mentoring by Primary Practice Location >

Rural Zip Codes

Numerator

Numerator

Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Urban Zip Codes

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

PM-3d: (Provider Education) Regional or State Leads Providers Participating in Tele-mentoring

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

PM-4-Total: (Provider Education) Number of Providers Reporting Feeling Comfortable Treating Patients

Count

Count
Annotation

Annotation

No data

PM-4a: (Provider Education) Providers Reporting Feeling Comfortable Treating Patients, by Provider Type >

Medical Doctor

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Nurse Practitioner

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Physician Assistant

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Other Provider

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

PM-4b: (Provider Education) Providers Reporting Feeling Comfortable Treating Patients, by Specialty/Subspecialty >

Hematology

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Hematology/Oncology

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Pediatrics

Numerator

Numerator

Denominator

Denominator

Percent

Percent**Annotation**

Annotation

 No data**Primary Care - Internal Medicine**

Numerator

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation No data**Primary Care - Family Medicine**

Numerator

Numerator

Denominator

Denominator**Percent**

Percent

Annotation

Annotation

No data

Primary Care - Med/Peds

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hospitalist

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Emergency Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Other

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-4c: (Provider Education) Providers Reporting Feeling Comfortable Treating Patients, by Primary Practice Location >

Rural Zip Codes

Numerator

Numerator

Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Urban Zip Codes

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

PM-5-Total: (Hydroxyurea Use) Number of Providers That Prescribed Hydroxyurea,

Count

Count
Annotation

Annotation

No data

PM-5a: (Hydroxyurea Use) Providers That Prescribed Hydroxyurea, by Provider Type >

Medical Doctor

Numerator**Denominator****Percent****Annotation** No data**Nurse Practitioner****Numerator****Denominator****Percent****Annotation** No data**Physician Assistant****Numerator****Denominator****Percent**

Percent

Annotation

Annotation

No data

Other Provider

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-5b: (Hydroxyurea Use) Providers That Prescribed Hydroxyurea, by Specialty/Subspecialty >

Hematology

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hematology/Oncology

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Pediatrics

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Internal Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Family Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Med/Peds

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Hospitalist

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Emergency Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Other

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-5c: (Hydroxyurea Use) Providers That Prescribed Hydroxyurea, by Primary Practice Location >
Rural Zip Codes

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Urban Zip Codes

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

PM-6-Total: (Hydroxyurea Use) Number of Patients That Saw Providers That Prescribed Hydroxyurea

Count

Count

Annotation

Annotation

No data

PM-6a: (Hydroxyurea Use) Patients Seen by Provider That Prescribed Hydroxyurea, by Age Group >

<18 years of age

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

≥18 years of age

Numerator

Numerator

Denominator

Denominator
Percent

Percent

Annotation

Annotation

No data

PM-6b: (Hydroxyurea Use) Patients Seen by Provider That Prescribed Hydroxyurea, by Specialty/Subspecialty >

Hematology

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Hematology/Oncology

Numerator

Numerator
Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Pediatrics

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Internal Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Primary Care - Family Medicine

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Primary Care - Med/Peds

Numerator

Numerator
Denominator

Denominator

Percent

Percent
Annotation

Annotation

No data

Hospitalist

Numerator

Numerator
Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Emergency Medicine

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data

Other

Numerator

Numerator

Denominator

Denominator

Percent

Percent

Annotation

Annotation

No data
