

**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](mailto: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 ( $\geq 18$  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  $\geq 18$ ) \_\_\_\_\_
  - i. *OPTIONAL: Number of these adults with genotype Hb SS or Hb S $\beta$ <sup>0</sup>-thalassemia* \_\_\_\_\_
- b. Number of children (age  $< 18$ ) \_\_\_\_\_
  - i. *OPTIONAL: Number of these children with genotype Hb SS or Hb S $\beta$ <sup>0</sup>-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  $\geq 18$ ) prescribed hydroxyurea \_\_\_\_\_
  - (i) *OPTIONAL: Number of adults (age 18+) with genotype Hb SS or Hb S $\beta$ <sup>0</sup>-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 $\beta$ <sup>0</sup>-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

# Performance Measures (2020) · NICHQ

## 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

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### 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

**Percent****Annotation** No data

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

### Adults ( $\geq 18$ years of age)

---

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

### Children (<18 years of age)

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**Numerator****Denominator****Percent**

**Annotation**

Annotation

No data

**Both**

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**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**

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

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**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**

No data

## Urban Zip Codes

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### Numerator

### Denominator

### Percent

### Annotation

 No data

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

### Solo private practice

---

### Numerator

### Denominator

### Percent

### 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

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

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

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

## Federally qualified health center or community health center

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

## State or local government clinic

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

## Other practice type (please annotate)

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**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 >**

&lt;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**

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**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**

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**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**

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**Numerator**

Numerator

Denominator

**Denominator**

**Percent**

Percent

Annotation

**Annotation**

No data

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

### Hematology

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

### Hematology/Oncology

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

### Primary Care - Pediatrics

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**Numerator**



**Denominator**

Denominator
Percent

**Percent**

**Annotation**

Annotation
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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
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**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

**Denominator****Percent****Annotation** No data**Other**

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

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

### Rural Zip Codes

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**Numerator****Denominator**

**Percent**

Percent
Annotation

**Annotation**

No data

Urban Zip Codes

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**Numerator**

Numerator
Denominator

**Denominator**

**Percent**

Percent
Annotation

**Annotation**

No data

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

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**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
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**Denominator**

Denominator
Percent

**Percent**

**Annotation**

Annotation
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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
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**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

**Denominator****Percent****Annotation** No data**Other**

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

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

### Rural Zip Codes

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**Numerator****Denominator**

**Percent**

Percent
Annotation

**Annotation**

No data

Urban Zip Codes

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**Numerator**

Numerator
Denominator

**Denominator**

**Percent**

Percent
Annotation

**Annotation**

No data

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

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**Count**

Count
Annotation

**Annotation**

No data

PM-5a: (Hydroxyurea Use) Providers That Prescribed Hydroxyurea, 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**

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**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

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