

**Appendix B**  
**SCDTDRCP Quality Improvement Measures Data Collection Documents**

Includes:

A Sample RedCap Quality Improvement Data Collection Form for a Local Site (pgs. 2–25)  
Aggregate Quality Improvement Measures CoLab Data Entry Form for SCDTDRCP Grantees (pgs. 26-35)

All Quality Improvement Data Collection Forms developed for respondents, using Excel, RedCap or another database form, will display the following 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 13 hours 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).

**QI Measure #1a. Hydroxyurea use among Children/Adolescents.**

**Patients  $\geq$  9 months and  $<$  18 years of age diagnosed with SS or S $\#$ 946-0 who were prescribed HU in the last 6 months**

Do you have data to report for this measure?  Yes  No

Please state reason for why data was not collected for this measure (more than 1 choice is acceptable)

We do not see any pediatric patients  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify \_\_\_\_\_

Numerator:  
 Number SS or S $\#$ 946-0 patients  $\geq$  9 months and  $<$  18 years of age as of last day of the measurement period who have a prescription for Hydroxyurea provided during the six months preceding the end of the measurement period.

\_\_\_\_\_

NOTE: EXCLUDE those on chronic transfusion

Denominator:  
 Number of SS or S $\#$ 946-0 patients  $\geq$  9 months and  $<$  18 years of age as of last day of the measurement period who are eligible candidates for Hydroxyurea.

\_\_\_\_\_

NOTE: EXCLUDE those on chronic transfusion

Additional notes

\_\_\_\_\_ (Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**QI Measure #1b. Hydroxyurea use among Adults.****Patients  $\geq$  18 years of age diagnosed with SS or S $\leq$ 946-0 who were prescribed HU in the last 6 months**

Do you have data to report for this measure?

- Yes  
 No

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any adult patients  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify

\_\_\_\_\_

Numerator:

Number of SS or S $\leq$ 946-0 patients  $\geq$  18 years of age as of last day of the measurement period who have a prescription for Hydroxyurea provided during the six months preceding the end of the measurement period

\_\_\_\_\_

NOTE: EXCLUDE those on chronic transfusion

Denominator:

Number of SS or S $\leq$ 946-0 patients  $\geq$  18 years as of last day of the measurement period who are eligible candidates for Hydroxyurea.

\_\_\_\_\_

NOTE: EXCLUDE those on chronic transfusion

Additional notes

\_\_\_\_\_  
(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**QI Measure #2a. Disease modifying therapy use other than HU among Children/Adolescents.****Patients  $\geq$  9 months and  $<$  18 years of age diagnosed with SS or S#946-0 who were prescribed disease-modifiers other than HU in the last 6 months**

Do you have data to report for this measure?

- Yes  
 No

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any pediatric patients  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify

Numerator:

Number of SS or S#946-0 patients  $\geq$  9 months and  $<$  18 years of age as of last day of the measurement period who received a disease modifying therapy other than Hydroxyurea during the six months preceding the end of the measurement period.

NOTE:

INCLUDE all those on chronic transfusion, L-glutamine/Endari, or other FDA approved drug.

EXCLUDE those on HU.

Denominator:

Number of SS or S#946-0 patients  $\geq$  9 months and  $<$  18 years of age as of last day of the measurement period

NOTE: EXCLUDE those on HU.

Please specify what other therapies were used

(more than 1 choice is acceptable)

- Chronic transfusion  
 L-glutamine  
 Other

Please specify

---

Additional notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**QI Measure #2b. Disease modifying therapy use other than HU among Adults.****Patients >18 years of age diagnosed with SS or S&#946-0 who were prescribed disease modifying therapy other than HU in the last 6 months**

Do you have data to report for this measure?

- Yes  
 No

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any adult patients  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify

Numerator:

Number of SS or S&#946-0 patients  $\geq$  18 years of age as of last day of the measurement period who received a disease modifying therapy other than Hydroxyurea during the six months preceding the end of the measurement period

NOTE:

INCLUDE all those on chronic transfusion, L-glutamine/Endari, or other FDA approved drug.

EXCLUDE those on HU.

Denominator:

Number of SS or S&#946-0 patients  $\geq$  18 years of age as of last day of the measurement period

NOTE: EXCLUDE those on HU

Please specify what other therapies were used

(more than 1 choice is acceptable)

- Chronic transfusion  
 L-glutamine  
 Other

Please specify

Additional notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

### QI Measure #3. Patients between ages 2-16 diagnosed with SS or S&#946-0 that had a Transcranial Doppler (TCD) screening within the last 15 months

Do you have data to report for this measure?

- Yes  
 No

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any patients in this age range  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify

\_\_\_\_\_

Numerator:

Number of SS or S&#946-0 patients  $\geq 2$  years of age at the start of the measurement period and  $< 17$  at the end of the measurement period who received a TCD within the past 15 months (12 months plus 3-month grace period).

\_\_\_\_\_

Denominator:

Number of SS or S&#946-0 patients  $\geq 2$  years of age at the start of the measurement period and  $< 17$  at the end of the measurement period

\_\_\_\_\_

Additional notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**QI Measure #4a. SCD patients < 18 years old who are up to date with vaccinations by vaccination series (PCV, PPSV, MenACYW, Hib, Flu, MenB) and/or who are up to date on ALL vaccinations.**

Refer to this immunization schedule

[Attachment: "ImmunizationSchedule\_12.23.19.pdf"]

Do you have data to report for this measure?

- Yes  
 No  
 Only for some vaccinations

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any pediatric patients  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify

Which vaccinations do you have data to report on?

(more than 1 choice is acceptable)

- PCV  
 PPSV  
 MenACYW  
 Hib  
 Flu  
 MenB  
 All (number of patients who are up to date with ALL of the above vaccinations)



**PCV for patients < 18 years**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with their PCV vaccinations

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**PPSV for patients < 18 years**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with their PPSV vaccinations

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**MenACYW for patients < 18 years**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with their MenACYW vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**Hib for patients < 18 years**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with their Hib vaccinations

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**Flu for patients < 18 years**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with their flu vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**MenB for patients < 18 years**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with their MenB vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**Patients < 18 years who are up to date on ALL (PCV, PPSV, MenACYW, Hib, Flu, MenB)**

Numerator:

Number of eligible SCD patients < 18 years old as of the last day of the measurement period who are up to date with all (PCV, PPSV, MenACYW, Hib, flu and MenB) of their vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

---

Denominator:

Number of SCD patients < 18 years old as of the last day of the measurement period.

---

Additional Notes

---

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**QI Measure #4b. SCD patients  $\geq$  18 years old who are up to date with vaccinations by vaccination series (PCV, PPSV, MenACYW, Hib, Flu, MenB) and/or who are up to date on ALL vaccinations.**

Refer to this immunization schedule

[Attachment: "ImmunizationSchedule\_12.23.19.pdf"]

Do you have data to report for this measure?

- Yes  
 No  
 Only for some vaccinations

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any adult patients  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 Other

Please specify

Which vaccinations do you have data to report on?

(more than 1 choice is acceptable)

- PCV  
 PPSV  
 MenACYW  
 Hib  
 Flu  
 MenB  
 All (number of patients who are up to date with ALL of the above vaccinations)



**PCV for patients  $\geq$  18 years**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with their PCV vaccinations

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients  $\geq$  18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**PPSV for patients  $\geq$  18 years**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with their PPSV vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients  $\geq$  18 years old as of the last day of the measurement period.

Additional notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**MenACYW for patients  $\geq$  18 years**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with their MenACYW vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients  $\geq$  18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**Hib for patients  $\geq$  18 years**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with their Hib vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients  $\geq$  18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**Flu for patients  $\geq$  18 years**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with their flu vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

---

Denominator:

Number of SCD patients  $\geq$  18 years old as of the last day of the measurement period.

---

Additional Notes

---

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**MenB for patients  $\geq$  18 years**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with their MenB vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients  $\geq$  18 years old as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**Patients  $\geq$  18 years who are up to date on ALL (PCV, PPSV, MenACYW, Hib, flu and MenB) of their vaccinations.**

Numerator:

Number of eligible SCD patients  $\geq$  18 years old as of the last day of the measurement period who are up to date with all (PCV, PPSV, MenACYW, Hib, flu and MenB) of their vaccinations.

NOTE: Individuals should be counted as "up to date" if they are not age eligible for this vaccine

NOTE: Individuals who were offered the vaccine and refused should be counted as NOT "up to date"

Denominator:

Number of SCD patients  $\geq$  18 years old (adult) as of the last day of the measurement period.

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )

**QI Measure #5. Transition to Adult Care. Number of SCD patients  $\geq 14$  and  $< 17$  that have a documented transition education plan.**

Do you have data to report for this measure?

- Yes  
 No

Please state reason for why data was not collected for this measure

(more than 1 choice is acceptable)

- We do not see any patients within the age range ( $\geq 14$  years, less than 17)  
 We do not have a system in place to collect this data  
 We do not have sufficient staff to collect this data  
 We do not transition our patients to other providers (i.e. pediatric provider keeps seeing adult patients)  
 Other

Please specify

\_\_\_\_\_

Numerator:

Number of SCD patients  $\geq 14$  years of age at the start of the measurement period and  $< 17$  at the end of the measurement period with a documented transition education

\_\_\_\_\_

Denominator:

Number of SCD patients  $\geq 14$  years of age at the start of the measurement period and less than 17 at the end of the measurement period.

\_\_\_\_\_

Additional Notes

(Please report any details regarding data collection difficulty, delay, inaccuracy, etc. )



**QI Measure #6. ECHO Count**

Count of providers participating in project ECHO meetings or Tele-mentoring calls

(broad definition of providers from physicians to social workers, nurses, health workers, etc.)

What type of providers have participated?

- physician
- nurse practitioner
- nurse
- therapist
- social worker
- community based organization
- other

Please specify

\_\_\_\_\_

# QI Measures

## QI-1: Hydroxyurea Prescription, by Age Group

≥9 months and <18 years of age, as of last day of the measurement period

---

### Numerator

Numerator

### Denominator

Denominator

### Percent

Percent

### Annotation

Annotation

No data

≥18 years of age, as of last day of the measurement period

---

### Numerator

Numerator

### Denominator

Denominator

### Percent

Percent

### Annotation

Annotation

No data

Overall (auto-calculated)

---

**Numerator**

0

**Denominator**

0

**Percent**

Percent

**QI-2: Other Disease Modifying Therapies Prescription, by Age Group**



≥9 months and <18 years of age, as of last day of the measurement period

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

≥18 years of age, as of last day of the measurement period

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**Overall (auto-calculated)**

---

**Numerator**

0

**Denominator**

0

**Percent**

Percent

**QI-3: Transcranial Doppler Screening**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**QI-4a: Immunization <18 Years Old, by Vaccination Series** **PCV**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**PPSV**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**Men ACYW**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

## Hib

---

### **Numerator**

Numerator

### **Denominator**

Denominator

### **Percent**

Percent

### **Annotation**

Annotation

No data

## Flu

---

### **Numerator**

Numerator

### **Denominator**

Denominator

### **Percent**

Percent

### **Annotation**

Annotation

No data

## MenB

---

### **Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**All**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**QI-4b: Immunization  $\geq$ 18 Years Old, by Vaccination Series **

**PCV**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**PPSV**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**Men ACYW**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data



## Hib

---

### Numerator

Numerator

### Denominator

Denominator

### Percent

Percent

### Annotation

Annotation

No data

## Flu

---

### Numerator

Numerator

### Denominator

Denominator

### Percent

Percent

### Annotation

Annotation

No data

## MenB

---

### Numerator

Numerator

### Denominator

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**All**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

**QI-5: Transitions to Adult Care**

---

**Numerator**

Numerator

**Denominator**

Denominator

**Percent**

Percent

**Annotation**

Annotation

No data

## QI-6: ECHO

---

### Count

Count

### Annotation

Annotation

No data

---