

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.

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 Sβ-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 Sβ-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 Sβ-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 Sβ-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 Sβ-0 patients ≥ 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 Sβ-0 patients ≥ 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 ≥ 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 (≥ 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 ≥ 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 ≥ 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
