

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
ED1	<b>Acute Care Visit Form:</b> (1) Date/time of registration (2) Date/time of triage (3) Time from registration to triage	Mean in minutes of the interval from registration to triage for SCD patients presenting at the ED during the measurement month.  NOTES: • If a patient presented more than once during the measurement month,	Average time from registration to triage for SCD patients presenting at the ED
ED2	<b>Acute Care Visit Form:</b> (1) Date/time of triage (2) Date/Time of initial pain assessment	Numerator: Count of SCD patients who presented with pain at the ED during the measurement month whose pain was assessed within 30 minutes of triage  Denominator: Count of SCD patients who presented with pain at the ED in the measurement month.  NOTES: • If a patient presented more than once during the measurement month, assess <i>the most recent</i> encounter. • Pain assessment must be performed using an age-appropriate pain scale	Percent of SCD patients presenting at the ED with acute pain who received an initial pain assessment within 30 minutes of triage
ED3	<b>Acute Care Visit Form:</b> (1) Date/time of triage (2) Date/time of first IV pain med administration (3) Minutes to first IV pain med dose	Numerator: Count of SCD patients presenting at the ED during the measurement month with an acute pain episode who received parenteral analgesic within 30 minutes of triage  Denominator: Count of SCD patients presenting at the ED during the measurement month with acute pain  NOTES: • If a patient presented more than once during the measurement month, assess the most recent encounter. • Registration refers to the time when the patient gave their name and other personal/insurance information to the registrar upon arrival to the ED or infusion center/day hospital; triage refers to the time when patient nurse provides brief, focused assessment of chief complaint and vital signs and assigns patient's acuity level	Percent of SCD patients presenting at the ED with acute pain who received parenteral analgesic within within 30 minutes of triage

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
ED4	<b>Acute Care Visit Form:</b> (1) Date/time of triage (2) Date/time of first IV pain med administration (3) Minutes to first IV pain med dose)	Mean in minutes of the interval from triage to administration of parenteral analgesic for SCD patients presenting at the ED with acute pain  NOTES: • If a patient presented more than once during the measurement month, assess the most recent encounter.	Average time from triage to administration of parenteral analgesic for SCD patients presenting at the ED with acute pain
ED5	<b>Acute Care Visit Form:</b> (1) Date/time of first IV pain med administration (2) What date/ time was the patient's pain re-assessed?	Numerator: Count of SCD patients presenting to the ED in the measurement month who presented with pain, who received parenteral analgesic, and had pain reassessed within 30 minutes of initial parenteral analgesic administration  Denominator: Count of SCD patients presenting to the ED in the measurement month who presented with pain and who received parenteral analgesic  NOTE: If a patient presented more than once during the measurement month, count the most recent encounter.	Percent of SCD patients presenting at the ED with acute pain who had pain reassessed within 30 minutes of administration of the first dose of parenteral analgesic
ED6	<b>Acute Care Form:</b> (1) Date/time of triage (2) Date/time of IV antibiotic administration (3) Minutes to first antibiotic dose:	Numerator: Count of SCD patients presenting to the ED in the measurement month who presented with temperature $\geq 38.5^{\circ}\text{C}$ or history of fever ( $\geq 38.5^{\circ}\text{C}$ ) within the previous 24 hours who received parenteral broad spectrum antibiotics within 60 minutes of triage  Denominator: Count of SCD patient presenting to the ED in the measurement month who presented with temperature $\geq 38.5^{\circ}\text{C}$  NOTES: • 'History of fever' requires that the patient's temperature was measured $\geq 38.5^{\circ}\text{C}$ within the previous 24 hrs. • If a patient presented more than once during the measurement month, count the most recent encounter.	Percent of SCD patients presenting at the ED with fever who had broad spectrum parenteral antibiotics administered within 60 minutes of triage

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
ED7	<b>Acute Care Visit Form:</b> (1) Date/time of triage (2) Date/time of IV antibiotic administration (3) Minutes to first antibiotic dose	<p>Mean in minutes of the interval from triage to administration of parenteral antibiotics for SCD patients presenting at the ED with temperature <math>\geq 38.5^{\circ}\text{C}</math> or history of fever (<math>\geq 38.5^{\circ}\text{C}</math>).</p> <p>NOTES:</p> <ul style="list-style-type: none"> <li>• 'History of fever' requires that the patient's temperature was measured <math>\geq 38.5^{\circ}\text{C}</math> within the previous 24 hrs.</li> <li>• If a patient presented more than once during the measurement month, count the most recent encounter.</li> </ul>	Average time from triage to administration of parenteral antibiotics for SCD patients presenting at the ED with fever
ED8	<b>Acute Care Visit Form:</b> (1) Did the patient have a CBC sent within 60 minutes of registration? (2) Did the patient have a reticulocyte count sent within 60 minutes of registration? (3) Did the patient have blood culture sent within 60 minutes of registration? (4) Did the patient have pulse oximetry performed within 60 minutes of registration?	<p>Numerators: Count of SCD patients presenting at ED in the measurement month with fever or history of fever (<math>\geq 38.5^{\circ}\text{C}</math>) who had 1) blood drawn for CBC, 2) reticulocyte count, 3) blood culture and 4) pulse oximetry obtained within 60 minutes of triage.</p> <p>Denominator: Count of SCD patients presenting at the ED in the measurement month with fever (<math>\geq 38.5^{\circ}\text{C}</math>) or history of fever</p> <p>NOTES:</p> <ul style="list-style-type: none"> <li>• 'History of fever' requires that the patient's temperature was measured (<math>\geq 38.5^{\circ}\text{C}</math>) within the previous 24 hrs.</li> <li>• If a patient presented more than once during the measurement month, count the most recent encounter.</li> </ul>	Percent of SCD patients presenting at ED with fever who had all indicated tests within 60 minutes of triage

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
Hemecare1	<p><b>Ambulatory Care Visit Form:</b> (1) On transfusion protocol? (2) Has the patient been assessed for iron overload in the past 12 months? Assessment date:</p>	<p>Numerator: Count of SCD patients <math>\geq 2</math> years as of the last day of the measurement period receiving a chronic transfusion program who had iron burden assessed within the past 12 months.</p> <p>Denominator: Count of patients <math>\geq 2</math> years as of the last day of the measurement period receiving a chronic transfusion program.</p> <p>NOTES:</p> <ul style="list-style-type: none"> <li>• Assessment for iron overload includes measurement of serum ferritin level. Iron overload is Serum ferritin level <math>&gt; 1000\text{ng/mL}</math></li> <li>• Chelation therapy is a treatment to remove excess iron. Medications used include Desferoxamine (Desferal), Deferasirox (Exjade); Deferiprone (Ferriprox)</li> <li>• Goal of therapy is to maintain ferritin <math>&lt; 1500</math> or liver iron <math>&lt; 7\text{mg / gm}</math> dry weight by biopsy or MRI [ferriscan]</li> </ul>	<p>Percent of patients with SCD receiving a chronic transfusion program who were assessed for iron burden in the past 12 months</p>
Hemecare2	<p><b>Ambulatory Care Visit Form:</b> (1) On transfusion protocol? (2) Has the patient been assessed for iron overload in the past 12 months? Assessment date: (3) Does the patient currently have iron overload? (4) Is the patient currently on chelation therapy? Chelation therapy start date:</p>	<p>Numerator: Count of SCD patients <math>\geq 2</math> years of age as of the last day of the measurement period receiving a chronic transfusion who have elevated ferritin or liver iron and are currently receiving chelation therapy.</p> <p>Denominator: Count of patients <math>\geq 2</math> years as of the last day of the measurement period receiving a chronic transfusion program and have elevated ferritin or liver iron.</p> <p>NOTES</p> <ul style="list-style-type: none"> <li>• Iron overload is Serum ferritin level <math>&gt; 1000\text{ng/mL}</math></li> <li>• Chelation therapy is a treatment to remove excess iron. Medications used include Desferoxamine (Desferal), Deferasirox (Exjade); Deferiprone (Ferriprox)</li> <li>• Chelation therapy is indicated if ferritin <math>&gt; 1000</math> or liver iron <math>&gt; 7\text{mg / gm}</math> dry weight by biopsy or MRI [ferriscan]</li> </ul>	<p>Percent of SCD patients who are at risk for iron overload who received chelation therapy</p>

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
Hemecare3	<b>Ambulatory Care Visit Form:</b> (1) Transcranial doppler screen in past 12 months? Date of last TCD: (2) Did the patient have at least 1 abnormal TCD in the past 12 months? (3) Did the patient have a repeat TCD within 2 months of the abnormal TCD study? (4) Did the patient have 2 consecutive abnormal TCDs in the past 12 months? (5) On transfusion protocol?	Numerator: Count of SCD patients with two abnormal TCDs in the past 12 months who were placed on chronic transfusion therapy  Denominator: Count of SCD patients with two abnormal TCD results in the past 12 months  <ul style="list-style-type: none"> <li>• An abnormal TCD showing increased or abnormal time-averaged maximal mean velocity (TAMMv <math>\geq 200</math>cm / s)</li> <li>• Second TCD should occur within 30 days of the first abnormal test</li> <li>• Transfusion should be started within 60 days of the second abnormal TCD</li> <li>• A chronic transfusion program includes transfusions more than 3 times in 90 days</li> <li>• Transfusions are normally preceded by measurement of Hgb S levels</li> </ul>	Percent of SCD patients with two abnormal TCDs in past 12 months who are on chronic transfusion therapy
Hemecare4	<b>Ambulatory Care Visit Form:</b> Transcranial doppler screen in past 12 months?	Numerator: Count of SCD patients $\geq 24$ months and $\leq 16$ yrs who received transcranial doppler screening within the past 12 months.  Denominator: Count of SCD patients 2-16 yrs as of the last day of the measurement period.	Percent of SCD patients between ages 2-16 years who received a transcranial doppler within the past 12 months
Hemecare5	<b>Ambulatory Care Visit Form:</b> Is the patient currently on hydroxyurea?	Numerator: Count of SCD patients $\geq 24$ months of age as of the last day of the measurement period who are currently on hydroxyurea  Denominator: Count of SCD patients $\geq 24$ months of age as of the last day of the measurement period who are candidates for hydroxyurea  NOTE: Candidates for hydroxyurea include individuals with $\geq 3$ pain crisis in 12 months, pain that interferes with daily activities or quality of life, history of severe and/or recurrent chest syndrome, symptomatic chronic anemia with interferes with daily activities or quality of life.	Percent of SCD patients $\geq 24$ months of age currently taking hydroxyurea therapy

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
Hemecare6	<b>Ambulatory Care Visit Form:</b> How many times was the patient admitted to the hospital in the past 12 months for sickle cell related illnesses? How many times was the patient seen in Day Hospital or Infusion Center in past 12 months?	Numerator: Count of SCD-related hospital admissions by sampled SCD patients Denominator: Count of sampled SCD patients	Average number of hospital stays per SCD patient in the past 12 months
Hemecare7	<b>Acute Care Visit Form:</b> How many times was the patient seen in an Emergency Room in past 12 months?	Numerator: Count of SCD-related ED visits by sampled SCD patients in the past 12 months Denominator: Count of sampled SCD patients	Average number of ED visits per SCD patient in the past 12 months
Medhome1	<b>Ambulatory Care Visit Form:</b> In the past 12 months, has the patient had evaluation with a hematologist or sickle cell specialist? Date of evaluation?	Numerator: Count of SCD patients with documented evaluation within 12 months of the last day of the measurement month.  Denominator: Count of SCD patients.  NOTES: •Sickle cell specialists include hematologist, nurse practitioner or physician assistant specializing in sickle cell care • An evaluation' should include (1) review of medical history, (2) physical examination, (3) complete blood cell count and pulse oximetry • Patients without a visit in the past 12 months, or lacking documentation are not included. • The hematology or specialist visit must have been completed - referral alone is not sufficient for inclusion • Telemedicine encounters are included	Percent of SCD patients with an evaluation with a hematologist or sickle cell specialist documented within the past 12 months.
Medhome2	<b>Ambulatory Care Visit Form:</b> (1) Did the patient have BP screening in the past 12 months? BP screening date: (2) Did patient have depression screening in past 12months? Depression screening date (3) Did patient have ophthalmologic (dilated retinal) exam in the past 12 months? Ophthalmologic exam date:	Numerator: Count of SCD patients ≥18 yrs who had all of the following elements of care documented within 12 months of the last day of the measurement period: 1) screening for high blood pressure, 2) screening for depression, 3) ophthalmologic exam  Denominator: Count of SCD patients 18 yrs and older as of the last day of the measurement period.	Percent of adults with SCD 18 yrs and older who had all recommended elements of care within the past 12 months

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
Medhome3	<b>Ambulatory Care Visit Form:</b> Does the patient have a written transition plan?	<p>Numerator: Count of patients <math>\geq 16</math> years at the time of their most recent SCD visit who had a current transition plan. Include patients whose plan was completed during the visit.</p> <p>Denominator: Count of patients <math>\geq 16</math> years with SCD visits in the measurement month</p> <p>NOTE: Transition plan must include the following documented elements:</p> <ul style="list-style-type: none"> <li>• A written transfer summary of the medical history (history of complications, preventive measures, current medications, treatments)</li> <li>• Patient's readiness to self-manage his or her health care</li> <li>• Steps needed for a successful transition</li> </ul>	Percent of SCD sampled patients 16 years and older seen in the past month with a transition plan to adult care
Medhome4	<b>Ambulatory Care Visit Form:</b> (1) Does the SCD patient have a documented primary care provider?	<p>Numerator: Count of patients with a documented primary care provider with whom the patient has completed at least 1 primary care visit within the past 12 months</p> <p>Denominator: Count of SCD patients</p> <p>NOTE: 'documented pcp' means that the patient is assigned to an individual provider panel</p>	Proportion of SCD patients with a documented primary care provider with whom the patient has completed at least 1 primary care visit within the past 12 months
Medhome5	<b>Ambulatory Care Visit Form:</b> Does the patient have a care manager?	<p>Numerator: Count of patients with a documented care manager within the past 12 months</p> <p>Denominator: Count of SCD patients</p> <p>NOTE: care managers include nurse case managers; care coordinator; patient navigator; community health workers that help to coordinate care of SCD patients</p>	Proportion of SCD patients with an assigned care manager to coordinate and improve their quality of care

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
Medhome6	<b>Ambulatory Care Visit Form:</b> (1) In the past 12 months, did the patient have a written individual care plan?	Numerator: Count of SCD patients with documented individual care plan within the past 12 months  Denominator: Count of SCD patients  NOTE: Individual care plan must include: 1) Current medications, 2) pain management plan, 3) fever management plan, 4) current blood counts (HGb, HCT)	Percent of sampled SCD patients who have had a written individual care plan in past 12 months
Medhome7	<b>Ambulatory Care Visit Form:</b> (1) In the past 12 months, did the patient have a written individual care plan? (2) Was the care plan reviewed with the patient during the current visit?	Numerator: Count of SCD patients with SCD visit during the measurement month with documented Individual care plan that was reviewed with the patient  Denominator: Count of SCD patients with SCD visit in the measurement month  NOTES: <ul style="list-style-type: none"> <li>• Individual care plan must include: Current medications, pain management plan, fever management plan, current blood counts (HGb, HCT)</li> <li>• If the patient had more than one SCD visit during the measurement month, include the most recent visit</li> <li>• Include patients whose plan was completed at the time of the visit.</li> </ul>	Percent of sampled SCD patients who have a written individual care plan that was reviewed with the patient during the current visit.
Medhome8	<b>Ambulatory Care Visit Form:</b> (1) Is the patient up to date for PCV7 / PCV13 vaccination? (2) Is the patient up to date for PPV23/Pneumovax vaccination? (3) Is the patient up to date for meningococcal (MCV4 or MPSV4) vaccination? (4) Is the patient up to date for haemophilus influenza (HIB) vaccination? (5) Did the patient receive a flu vaccine during the past flu season?	Numerator: Count of SCD patients less than 18 yrs as of the last day of the measurement period who are up to date with the following vaccinations: 1) PCV7 / PCV13, 2) PPV23/Pneumovax, 3) Meningococcal (MCV4 or MPSV4), 4) Haemophilus influenza (HIB), 5) annual influenza  Denominator: Count of SCD patients less than 18 yrs as of the last day of the measurement period.  NOTE: Please refer to the CDC immunization schedule and the catch-up immunization schedule for details <a href="http://www.cdc.gov/vaccines/recs/schedules/">http://www.cdc.gov/vaccines/recs/schedules/</a>	Percent of SCD patients <18 years who are up to date with all recommended vaccinations



## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
Medhome9	<p><b>Ambulatory Care Visit Form:</b> Is the patient up to date for PCV7 / PCV13 vaccination? Is the patient up to date for PPV23/Pneumovax vaccination? Is the patient up to date for meningococcal (MCV4 or MPSV4) vaccination? Is the patient up to date for haemophilus influenza (HIB) vaccination? Did the patient receive a flu vaccine during the past flu season? When was the most recent flu vaccine administered? Is the patient up to date for hepatitis B, vaccination?</p>	<p>Numerator: Count of SCD patients ≥18 yrs who are up to date with the following vaccinations: 1) PCV7 / PCV13, 2) PPV23/Pneumovax, 3) Meningococcal (MCV4 or MPSV4), 4) Haemophilus influenza (HIB), 5) annual influenza 6) Hepatitis B</p> <p>Denominator: Count of sampled SCD patients ≥18 yrs as of the last day of the measurement period.</p>	Percent of SCD patients ≥18 years who are up to date with all recommended vaccinations
Profile1		Count of SCD patients in your network. A sampled patient is one who has had contact with a network provider within the 24 months prior to the last day of the current measurement period.	Count of sampled SCD patients in catchment area
Profile2	<p><b>Participant Profile:</b> Genotype -Hemoglobin SS, Hemoglobin SC, Hemoglobin Sbeta zero thalassemia, Hemoglobin Sbeta plus thalassemia, Hemoglobin S variant, Hemoglobin Variant (AV/ FAV, FAO/E, FAD/G), Sickle cell trait ( AS/FAS), Hemoglobin C trait (AC/FAC), Beta thalassemia trait, Other trait, Not available</p>	<p>Numerators: Count of SCD patients with each of the following types of sickle cell disease documented: Sickle Cell Disease (SS) / Sickle-Hemoglobin C Disease (SC) / Sickle Beta-Plus Thalassemia / Sickle Beta-Zero Thalassemia / Other-specify / Don't Know</p> <p>Denominator: Count of sampled SCD patients</p>	Distribution of SCD genotypes.
Profile3	<p><b>Participant Profile:</b> Born in U.S.? Country of birth:</p>	The country where the patient was born.	Distribution of country of origin

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
SCDscreen1	<p><b>Participant Profile:</b> (1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period (a) Yes, diagnosis made through newborn screening. Date of screening:(3) Was confirmatory testing performed? Yes, Date of confirmatory testing:</p>	<p>Numerator: Count of newborns screened for SCD 2 months prior to the measurement month who had a positive result and documented confirmatory test completed within 60 days of birthdate Denominator: Count of newborns screened for SCD 2 months prior to the measurement month with positive result NOTES: • Confirmatory test hemoglobin electrophoresis, not solubility test (sickle dex) • For premature infants, clinicians should use best clinical judgment about date of initial screening, • For premature infants who were transfused in the NICU repeat screen should be sent at least 4 months post transfusion</p>	<p>Percent of newborns with a positive newborn screening test for SCD who received confirmatory testing within 2 months of initial screen</p>
SCDscreen2	<p>(1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period (a) Yes, diagnosis made through newborn screening. Date of screening: (3) Was confirmatory testing performed? Yes, Date of confirmatory testing: (4) Were results given/discussed with parents/caregiver? Yes, Date:</p>	<p>Numerator: Count of newborns with positive confirmatory test for SCD in the measurement month whose results were discussed with parents/patient Denominator: Count of newborns with positive confirmatory test for SCD in the measurement month NOTE: • Confirmatory test hemoglobin electrophoresis, not solubility test (sickle dex) • For premature infants, clinicians should use best clinical judgment about date of initial screening, • For premature infants who were transfused in the NICU repeat screen should be sent at least 4 months post transfusion</p>	<p>Percent of parents/caregivers of newborns with a positive confirmatory test for SCD who had a discussion about the results</p>

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
SCDscreen3	(1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period (a) Yes, diagnosis made through newborn screening. Date of screening: (3) Was confirmatory testing performed? Yes, Date of confirmatory testing: (5) Was genetic counseling provided? Yes, Date:	Numerator: Count of parents/caregivers of newborns with a positive confirmatory test for SCD 2 months prior to the measurement month who received genetic education within 2 months of diagnosis Denominator: Count of newborns with positive confirmatory test for SCD 2 months prior to the measurement month NOTE: • Confirmatory test hemoglobin electrophoresis, not solubility test (sickle dex) • For premature infants, clinicians should use best clinical judgement about date of initial screening, • For premature infants who were transfused in the NICU repeat screen should be sent at least 4 months post transfusion	Proportion of parents/caregivers of newborns with a positive confirmatory test for SCD who received genetic education about SCD within 2 months of diagnosis
SCDscreen4	(1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period (a) Yes, diagnosis made through newborn screening. Date of screening: (3) Was confirmatory testing performed? Yes, Date of confirmatory testing: (6) Did the newborn have a follow-up appointment with the hematologist? Yes, Date: No	Numerator: Count of newborns with a positive confirmatory test for SCD 2 months prior to the measurement month with hematology visit within 60 days of birthdate Denominator: Count of infants with positive confirmatory test 2 months prior to the measurement month NOTES: • Sickle cell specialists include hematologist, nurse practitioner or physician assistant specializing in sickle cell care • The hematology or specialist visit must have been completed - referral alone is not sufficient for inclusion	Proportion of newborns with positive confirmatory test who completed follow-up appointment with hematologist within 60 days of birth

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
SCDscreen5	<p>(1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period? (b) No, diagnosis not made in the newborn period. Diagnosis made through testing after 1 month of age. Date of testing: (3) Was confirmatory testing performed? Yes, Date of confirmatory testing: (4) Were the results given/discussed with patient/parents/caregivers? Yes, Date:</p>	<p>Numerator: Count of adult patients or parents/caregivers of patients &gt;30 days of age with a positive test for SCD in the measurement month who had a discussion of the results Denominator: Count of adult patients or parents/caregivers of patients &gt;30 days of age with a positive test for SCD in the measurement month NOTE: •Test: hemoglobin electrophoresis, not solubility test (sickle dex)</p>	<p>Percent of adult patients or parents/caregivers of patients &gt;30 days of age with a positive test for SCD (not identified through newborn screening) who had a discussion about the results</p>
SCDscreen6	<p>(1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period? (b) No, diagnosis not made in the newborn period. Diagnosis made through testing after 1 month of age. Date of testing: (3) Was confirmatory testing performed? Yes, Date of confirmatory testing: (5) Was genetic counseling provided? Yes, Date:</p>	<p>Numerator: Count of adult patients or parents/caregivers of patients &gt;30 days with a positive test for SCD in the month 2 months prior to measurement month who received genetic education within 2 months of diagnosis Denominator: Count of adult patients or parents/caregivers of patients &gt;30 days with positive test for SCD in the month 2 months prior to measurement month NOTE: • Tests hemoglobin electrophoresis, not solubility test (sickle dex)</p>	<p>Proportion of adult patients or parents/caregivers of patients &gt;30 days of age with a positive test for SCD (not identified through newborn screening) who received genetic education about SCD within 2 months of diagnosis</p>
SCDscreen7	<p>(1) Was the diagnosis of SCD/SCT made in the past 12 months? (a) Yes, SCD diagnosed in the past 12 months (2) Was the diagnosis of SCD made in the newborn period? (b) No, diagnosis not made in the newborn period. Diagnosis made through testing after 1 month of age. Date of testing: (3) Was confirmatory testing performed? Yes, Date of confirmatory testing: (6) Did the patient have a follow-up appointment with a hematologist? Yes, Date:</p>	<p>Numerator: Count of adult patients or patients &gt;30 days with a positive test for SCD who completed a visit with a hematologist within 6 months of diagnosis. Denominator: Count of adult patients or patients &gt;30 days with positive test for SCD</p>	<p>Proportion of adult patients or patients &gt;30 days of age with positive test for SCD (not identified through newborn screening) who had a follow-up visit with a hematologist after initial diagnosis.</p>

## Hemoglobinopathy Learning Collaborative QI Measurement Bank

Measure Label	Question/s on REDCap	Operational Definition (Numerator & Denominator or other)	Measure
SCDscreen8		Count of patients with positive test for SCT during the current measurement period	Count of individuals with positive test for SCT
SCDscreen9	(1) Was the diagnosis of SCD/SCT made in the past 12 months? (b) Yes, SCT diagnosed in the past 12 months (2) Was the diagnosis of SCT made in the newborn period? (a) Yes, diagnosis made through newborn screening. Date of screening: (5) Was genetic counseling provided? Yes, date:	Numerator: Count of parents/caregivers of newborns with a positive test for sickle cell trait 2 months prior to the measurement month who received genetic education within 2 months of diagnosis Denominator: Count of newborns with positive test for sickle cell trait 2 months prior to the measurement month NOTE: 1) Test: hemoglobin electrophoresis, not solubility test (sickle dex) 2) This education could occur at hematology, primary care, Community Based Organization or geneticist office	Proportion of parents/caregivers of newborns with a positive screen for sickle cell trait who received genetic education about sickle cell trait within 2 months of diagnosis
SCDscreen10	(1) Was the diagnosis of SCD/SCT made in the past 12 months? (b) Yes, SCT diagnosed in the past 12 months (2) Was the diagnosis of SCT made in the newborn period? (b) No, diagnosis not made in the newborn period. Diagnosis made through testing after 1 month of age. Date of testing: (5) Was genetic counseling provided? Yes, Date:	Numerator: Count of adult patients or parents/caregivers of patients >30 days with a positive test for SCT 2 months prior to the measurement month who received genetic education within 2 months of diagnosis Denominator: Count of adult patients or patients >30 days with positive test for SCT 2 months prior to the measurement month NOTE: this counseling could occur at hematology, primary care, Community Based Organization or geneticist	Proportion of adult patients or parents/caregivers of patients >30 days of age with positive test for sickle cell trait (SCT) (not identified through newborn screening) who received genetic education about Sickle Cell Trait within 2 months of diagnosis