Pediatric Quality Measures Program
Transcranial Doppler Ultrasonography (TCD) Screening Among Children with Sickle Cell Anemia Toolkit
Acknowledgements

The Transcranial Doppler Ultrasonography (TCD) Screening among Children with Sickle Cell Anemia (SCA) toolkit is the product of collaboration among academic and research institutions, state and Federal agencies, and private sector stakeholders.

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Introduction

This toolkit presents a children’s health care quality measure from the AHRQ-CMS Pediatric Quality Measures Program (PQMP). The measure has been developed by PQMP Centers of Excellence (COE) grantee, Dr. Gary L. Freed, M.D., M.P.H.

The measure, Transcranial Doppler Ultrasonography (TCD) Screening among Children with Sickle Cell Anemia (SCA), calculates the percentage of children ages 2 through 15 years old with SCA who received at least one TCD screening within the measurement year. Children with SCA have over three hundred times the stroke risk than children with normal hemoglobin, and TCD screening is a reasonable method to assess stroke risk among children with SCA. A higher proportion of TCD screening indicates better performance as reflected by appropriate testing.

This toolkit includes materials to support users in:

- Utilizing a claims-based method for identifying receipt of TCD screening among populations of children with SCA,
- Defining the target population and calculating performance rate, and
- Implementing strategies to improve TCD screening among children with SCA.

The intended audience for this toolkit includes decision-makers at the state and health plan levels. The measure may be used at the state-level for public reporting, public health/disease surveillance, and quality improvement efforts within the state and among Medicaid and CHIP health plans. Health plans may use the measure for public reporting and quality improvement efforts within the organization.

This toolkit is organized into 6 sections:

1. Overview
2. About the Measure
3. Key Driver Diagrams
4. Quality Improvement Strategies
5. Improvement Data
6. Other Resources
Overview

This NQF-endorsed measure (NQF#2797), Transcranial Doppler Ultrasonography (TCD) Screening among Children with Sickle Cell Anemia (SCA), establishes a claims-based method for identifying receipt of TCD screening among populations of children with sickle cell anemia. The measure was created by the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (QMETRIC) operating through the University of Michigan, a Pediatric Quality Measures Program grantee. This measure was initially endorsed by the National Quality Forum in May 2016 and has maintained endorsement since that time. This measure was also recommended for inclusion in the 2016 and 2018 Medicaid and CHIP Child Core Set (Child Core Set) by the Measure Applications Partnership.

Specifically, the measure calculates the percentage of children ages 2 through 15 years old with SCA (Hemoglobin [Hb] SS or HbSβ0-thalassemia) who received at least one TCD screening within the measurement year. A higher proportion indicates better performance as reflected by appropriate testing. The measure specifications are reflective of the guidelines from the National Heart, Lung, and Blood Institute (NHLBI), as well as recent guidance from the American Society for Hematology (ASH) that was updated after development of this measure, and the performance scores calculated through this measure identify areas in need of improvement.

The following text was taken from the NQF Measure Submission (2016): Children with SCA have over three hundred times the stroke risk than children with normal hemoglobin (Verduzco and Nathan, 2009). Without intervention, approximately 11% of children with SCA will have a stroke by age 20 (Verduzco and Nathan, 2009; Ohene-Frempong et al., 1998). TCD ultrasonography measures the blood velocities within the cerebral vessels (Adams et al., 1997; Adams et al., 1992). Children over the age of 2 with a time-average mean maximum blood flow velocity of 200cm/sec or greater as measured by TCD ultrasonography have been shown to have 27 times the risk of stroke than children with velocities less than 200cm/sec. This corresponds to a 40% risk of stroke among those with high velocities within 3 years (Adams et al., 1997). Initiation of chronic blood transfusions reduces the risk of stroke by 92% among children at highest risk of stroke as identified through TCD screening (Adams et al., 1997; Adams et al., 1992). TCD screening is a reasonable method to assess stroke risk among children with SCA, as it is safe, non-invasive and low cost (Markus, 2000). Although other predictors of stroke have been examined, such as hematocrit levels and white blood cell count, TCD velocities have been shown to be the only independent predictor of stroke (Adams et al., 1992). Given the importance of TCD screening to stroke prevention among children with SCA, the National Heart, Lung, and Blood Institute (NHLBI) recommends each child receive one TCD screen per year from ages 2 through 15 years (National Heart, Lung, and Blood Institute, 2014). Although the benefits of TCD screening among children with SCA have been known since the late nineties, prior studies indicate that TCD screening rates are low. However, these reports are limited in their generalizability, as they are often focused on a single healthcare provider or registry. This measure establishes a claims-based method for identifying receipt of TCD screening among larger and broader populations.
of children with SCA. The measure specifications are reflective of the guidelines from the NHLBI, and the performance scores calculated through this measure will identify areas in need of improvement in receipt of TCD screening among children with SCA.

INTENDED END USERS

It is intended that this measure will be used at the state and health plan levels. Although the measure is valid at the health system level, some health systems may not be able to implement the measure as it may not be possible for them to determine if TCD screenings were obtained outside of their health system. The measure may be used at the state-level for public reporting, public health/disease surveillance, and quality improvement efforts within the state and among Medicaid health plans. Health plans may use the measure for public reporting and quality improvement efforts within the organization.

MEASURE IMPLEMENTATION FEASIBILITY AT STATE, HEALTH PLAN AND HEALTH SYSTEM LEVELS

This TCD measure may be implemented at the state, health plan and health system levels, although as noted above, health systems may find it more challenging to implement. To specifically address attribution within the context of implementing the measure at different levels, the QMETRIC team assessed the ability to fold the measure up and down using aggregated and disaggregated data. Identifying accurate denominator populations at the state, health plan, and health system levels was the focus of the team for folding down the measure. Efforts to fold the measure up required ensuring measure validity at each level.

METHODS

FOLDING DOWN FROM STATE LEVEL

To fold the measure down from the state to the health plan and from the state to the health system level, the QMETRIC team sought to determine which one health plan and one health system was accountable for the care of each child with SCA. The approaches the QMETRIC team explored are detailed below.

Health Plan Attribution

QMETRIC first identified all children who were enrolled in Michigan Medicaid for a calendar year, regardless of which Medicaid health plan (MHP) the child was enrolled in. A full year of enrollment (12 months continuous enrollment) is necessary to calculate this measure. Guidelines from the NHLBI strongly recommend each child with SCA should receive one TCD screen within a 12-month period; therefore, this time period is necessary to capture guideline-adherent quality of care. To attribute children to MHPs, the QMETRIC team attributed each person-month of enrollment to an MHP and summed months across the measurement year. They then assessed the number of children who were attributed to each MHP when requiring seven months, 11 months, and 12 months enrollment in
a calendar year. For each continuous enrollment requirement, the proportion of children with SCA who could be attributed to an MHP was calculated. Likewise, the proportion of children with SCA who were enrolled in Michigan Medicaid for a calendar year but not attributable to an MHP was calculated for each of the enrollment requirements. Performance scores were calculated for each MHP based on the enrollment requirements.

**Health System Attribution**

To attribute children to a health system, the QMETRIC team conducted a comprehensive assessment of other attribution models. A series of standards to determine health system attribution for children with SCA based on patterns of care was developed. First, all children with SCA enrolled in Michigan Medicaid for a 12-month period were identified. Secondly, each child's health services encounters, including inpatient admissions, outpatient visits, and emergency department visits, were characterized and summed. Then the QMETRIC team identified the health system that provided care during each encounter, using the billing provider information (i.e., the National Provider Identifier (NPI)) and a manual review to match the NPI to the correct health system. Next, for each child, the percentage of their encounters at each health system was calculated. The QMETRIC team then applied a series of “cut-offs” for attribution to a health system. Specifically, a child was attributed to a health system if 90 percent, 75 percent, or 51 percent of the child’s encounters occurred within that hospital system. Based on the above encounter requirements, the proportion of children with SCA that could be attributed to a specific health system was calculated.

**FOLDING UP FROM HEALTH PLAN LEVEL**

To assess if a measure could be folded up from the health plan to the state level, it was necessary to determine if the measure was valid at the health plan level. To validate the measure at the health plan level, the QMETRIC team compared two sets of performance scores: (1) rates calculated through attributing children using state-level Medicaid data to specific MHPs (process described above), and (2) rates calculated directly by each of the three partner MHPs using their in-house data.

**RESULTS**

**FOLDING DOWN FROM STATE LEVEL**

**Health Plan Attribution**

The following results used 2018 Michigan Medicaid data to illustrate the impact of the varying eligibility requirements within a single MHP (seven months, 11 months, and 12 months). Among children continuously enrolled in Michigan Medicaid for the calendar year, the proportion of children that could not be attributed to a specific MHP varied significantly across the years 2010-2018. Across the entire study period, the number of children enrolled in fee-for-service for the entire year decreased substantially. The QMETRIC team was able to calculate performance scores for both the attributed and the non-attributed children, providing data to illustrate opportunities for improvement across all children enrolled in Michigan Medicaid.
Health System Attribution

The following results used 2017 Michigan Medicaid data to illustrate the impact of varying encounter requirements for a health system. To assess the validity of each approach, QMETRIC expanded the age ranges to children with SCA from one year to 17 years specifically for understanding the tradeoffs of health system attribution cutoffs; no changes were made to age criteria for calculation of the TCD measure. During this time, there were 402 children with 7,131 encounters. Among these children, 280 children (70 percent) received at least 90 percent of their care at the same health system. An additional 44 children (total of 81 percent) received at least 75 or 51 percent of their care at the same health system.

FOLDING UP FROM HEALTH PLAN LEVEL

There were no significant differences in performance scores for MHPs when comparing 2017 and 2018 performance scores obtained by attributing children from the state level to three MHPs and performance scores obtained directly from these MHPs.

CONCLUSIONS

The QMETRIC findings regarding the attribution of children to one MHP have implications for all pediatric quality measures. Other measures will face similar challenges, i.e., there will be children who cannot be attributed to a single MHP for the measure but are enrolled within a state Medicaid plan for the enrollment period. This impacts the targets of QI initiatives to improve the performance scores of the measure. Development of sustainable strategies at the state Medicaid level that incentivize MHPs to retain pediatric members may be one such opportunity. This would allow MHPs to identify members to target for improvement in performance scores. Otherwise, mechanisms to assign responsibility for the quality of care of these children should be in place. Care should be taken to ensure that children who enroll in different health plans across one year do not fall through the cracks.

The findings regarding the attribution of children to one health system also have implications for quality measurement. As discussed above, there are no validated methods for health system attribution. The QMETRIC method, which assessed several cutoffs and assessed the attribution tradeoffs at each cutoff, provided evidence to support the decision to use the 75 percent of encounters at one health system as the attribution method. Other chronic conditions may have different patterns of care. Therefore, health system attribution models should be based on both a conceptual framework of how children access the healthcare system, as well as an evidence-based approach as described above, to perform the most appropriate attribution.

Based on the PQMP QMETRIC findings, this measure can be folded down from the state level to the health plan level and from the state level to the health system level. Folding down the measures from the state to health system level allowed the QMETRIC team to identify performance gaps, enabling quality improvement initiatives to be implemented at the health system level.
This measure can be **folded up** from the health plan to the state level. However, all measures must be assessed for validity at each level prior to attempting to fold up. Further, it is important to consider which children may not be included when folding up. For example, as described above, there is a significant proportion of children who would not be included in the measure when folding up from the health plan to the health system, as these children may not have been enrolled in the same MHP for the year.

**REFERENCES**


About the Measure

The Transcranial Doppler Ultrasonography (TCD) Screening among Children with Sickle Cell Anemia (SCA) establishes a claims-based method for identifying receipt of TCD screening among children with SCA. The measure was created by the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (QMERIC) operating through the University of Michigan, a Pediatric Quality Measures Program grantee. This measure was initially endorsed by the National Quality Forum in May 2016 and has maintained endorsement since that time. This measure was also recommended for inclusion in the 2016, 2017, 2018 and 2019 Child Core Set by the Measure Applications Partnership. The measure was not adopted for inclusion in the Child Core Set.

Specifically, the measure calculates the percentage of children ages 2 through 15 years old with SCA (Hemoglobin Hb SS or HbSβ0-thalassemia) who received at least one TCD screening within the measurement year. A higher proportion indicates better performance as reflected by appropriate testing. The measure specifications are reflective of the guidelines from the National Heart, Lung, and Blood Institute (NHLBI), and the performance scores calculated through this measure identify areas in need of improvement.

MEASURE SPECIFICATIONS

The QMERIC technical measure specification has been validated at the health system, health plan, and state levels and can be downloaded at https://www.ahrq.gov/pqmp/implementation-gi/toolkit/tcd/index.html. A change to ICD-10-CM from ICD-9-CM coding required re-specification of the measure and extensive testing to ensure reliability and validity at the health plan and state level. It also required the development of a valid claims-based case definition. Ultimately, a definition with >90% sensitivity and specificity, was validated. This definition ensured the feasibility of using only administrative claims for this measure.

AVAILABILITY OF DATA

This measure exclusively uses administrative claims data, so accurate and complete data is generally available. A lag in claims availability at the state level may create a delay in use of Medicaid claims. QMERIC found that health plans have more ready access to their own claims and can obtain measure performance data on a more rapid basis.

SPECIFICATION VARIATION AT MULTIPLE LEVELS

This measure is endorsed by the National Quality Forum and has been rigorously assessed for reliability and validity at all levels. The detailed measure specification may be used on administrative claims in any context. This measure can be easily aligned across state Medicaid programs, health plans, and health systems, and as it is claims-based, there is very little cost or effort required to collect measure performance data.
There was no difficulty in having QMETRIC’s state or health plan partners implement the measure and obtain performance scores. The unmet challenge was to get some health plans and health systems to act on the poor performance identified by the measure and engage in meaningful quality improvement (QI) activities to address this. QMETRIC found for some health plans, available QI and case management resources are directed at other conditions which (1) have an extrinsic force prompting action (e.g., Core Set, HEDIS) or (2) are high cost to the plan. Health systems had significant difficulty locating some of the patients attributed to them, due to the limited case management resources.

**MEASURE REPORTING**

**VALIDITY AND RELIABILITY TESTING**

This measure was originally tested for validity and reliability during the first PQMP grant to QMETRIC using ICD-9-CM codes. Children with sickle cell anemia (SCA) were identified through the presence of at least three separate healthcare encounters related to SCA (defined as hemoglobin [Hb]SS) within the measurement year. SCA-related healthcare encounters were identified through the following ICD-9-CM codes: 282.61 (Hb-SS disease w/o crisis) and 282.62 (Hb-SS disease with crisis). Children ages 2 through 15 years are included within the target population (i.e., must not have a 2nd or 16th birthday within the measurement year).

It is important to note that accurate calculation of this measure requires that the target population be selected from among children who have all of their health services for the measurement year included in the administrative claims data set. For children who have dual enrollment in other health plans, their claims may not be complete since some of their health services may have been paid for by another health plan. Inclusion of children with other health insurance would potentially cause this measure to be understated. As a consequence, this measure requires that children must not only be continuously enrolled within the health plan from which claims are available, the enrollment files must also be assessed to determine whether other forms of health insurance existed during the measurement year. Children with evidence of other insurance during the measurement year (i.e., coordination of benefits) must be excluded from the target population.

**Performance Rate Calculation**

1. Identify the denominator: Determine the eligible population using administrative claims. The eligible population is all individuals who satisfy all specified criteria, including age, continuous enrollment, and diagnosis requirements within the measurement year.

2. Identify the numerator: Identify numerator events using administrative claims for all individuals in the eligible population (denominator) within the measurement year.

3. Calculate the rate (numerator / denominator).

**Data Sets and Data Elements**

This measure was tested by QMETRIC using the following data sets:
• Michigan Medicaid administrative claims data provided by the Michigan Department of Health and Human Services (MDHHS): Consisted of all Medicaid claims for Medicaid enrollees within the state of Michigan.

• Medicaid Analytic eXtract (MAX) administrative claims data for 6 state Medicaid programs provided by the Centers for Medicare & Medicaid Services (CMS): Consisted of Medicaid claims reported to CMS for Medicaid enrollees within 6 state Medicaid programs with moderate to high prevalence of SCA: Florida, Illinois, Louisiana, Michigan, South Carolina, and Texas.

• Medical record data from three Michigan medical centers: Children’s Hospital of Michigan (CHM), Detroit, Michigan; Hurley Medical Center (HMC), Flint, Michigan; and University of Michigan Health Services (UMHS), Ann Arbor, Michigan. These three large medical centers are located in urban areas which are reflective of the residence of the vast majority of children with SCA living in Michigan.

• Michigan Newborn Screening (NBS) Results: Consisted of all births within Michigan.

The primary information needed for this measure includes a unique member identifier, health plan enrollment information, date of birth, dates of service, diagnosis codes, and procedure codes. These data are widely available, although obtaining them may require a restricted-use data agreement. For multiple-state comparisons, national Medicaid data are available from CMS. When the measure is used at the single-state level, state health departments can use their own Medicaid data.

Feasibility
QMETRIC testing determined that this measure is feasible using existing data from administrative claims systems. While QMETRIC testing efforts support the feasibility of implementing this measure, the testing process demonstrated the technical challenges that may exist when identifying SCA cases from very large administrative claims files, such as MAX data. This measure was also tested using Medicaid administrative claims data acquired directly from the state of Michigan. Acquisition of data directly from state Medicaid programs requires the cooperation of those jurisdictions, as well as modification of the statistical programming code developed for use with MAX files. Such modifications are necessary given the unique structure of the data files obtained directly from state Medicaid programs.

Reliability of MAX Data
MAX data from Florida, Illinois, Louisiana, Michigan, South Carolina, and Texas were used to test the reliability of this measure. The reliability of MAX data to evaluate TCD screening is of high importance since this is the only national source of state Medicaid data available upon which state-to-state comparisons may be conducted. The reliability of this measure was calculated using a signal-to-noise analysis. The signal-to-noise analysis was focused on assessing the reliability to confidently distinguish the performance of one state’s Medicaid program from that of another state. For this
approach, reliability was estimated with a beta-binomial model (RAND Corporation, TR-653-NCQA, 2009).

State-specific reliability was very good; observed reliability was consistently greater than 0.95. In general, reliability scores can range from 0.0 (all variation is attributable to measurement error) to 1.0 (all variation is caused by real differences). While there is not a clear cut-off for minimum reliability level, values above 0.7 are considered sufficient to distinguish differences between some states and the mean; reliability values above 0.9 are considered sufficient to see differences between states (RAND Corporation, TR-653-NCQA, 2009). The median reliability observed across states was 0.98 (range: 0.96-0.99), which is consistent with a high degree of reliability.

**Abstractor Reliability**
In addition, the reliability of the data element abstracted from the medical chart was assessed by identifying a subset of the charts to be re-abstracted by another trained medical record abstractor; the results of the two abstractors were compared using percent agreement and kappa. Ten charts were chosen for evaluation of inter-rater reliability; the two trained abstractors had 100% agreement with each other for abstracting receipt of TCD screening from the medical records, resulting in a kappa of 1.00. A kappa of greater than .81 is considered almost perfect agreement (Landis and Koch, 1997).

**Validity of Critical Data Elements**

**Numerator:** The accuracy of administrative claims in identifying receipt of TCD screening was assessed through comparison to the gold standard of medical charts. An audit was conducted by trained medical record abstractors to compare administrative claims data with corresponding medical records data. Medical records were abstracted for all children meeting the TCD screening measure specification criteria; agreement between the medical records and the administrative claims was assessed using kappa. Furthermore, the sensitivity, specificity, negative predictive value (NPV) and positive predictive value (PPV) of administrative claims for receipt of TCD screening were calculated; the medical charts were the gold standard for comparison.

For this comparison, children with SCA who were enrolled within Michigan Medicaid were successfully matched with their Michigan Medicaid administrative claims data. Among these children, by comparing administrative claims data with medical records QMETRIC determined that TCD screening was identified in both for approximately 50% of cases. Similarly, approximately 45% of cases were classified as not having a TCD in both data sources, yielding an overall agreement of 96.7% (kappa = 0.93, 95% confidence interval (CI): 0.86, 1).

Using administrative claims to identify receipt of TCD screening resulted in a sensitivity of 94% (95% CI: 83%-99%), a specificity of 100% (95% CI: 91%-100%), a NPV of 93% (95% CI: 81%-99%), and a PPV of 93% (95% CI: 92%-100%) compared with the gold standard of medical records.

**Denominator:** The accuracy of the case definition using ICD-9-CM codes (at least 3 claims for SCA (Hemoglobin SS) within the measurement year) to identify children with SCA was assessed through comparison to the gold standard of newborn screening results for the state of Michigan for children
enrolled in Michigan Medicaid in 2010 and 2011 with at least one SCD-related healthcare claim within their enrollment year(s). The area under the receiver operating characteristic (ROC) curve, sensitivity, specificity, PPV, and NPV were calculated for the case definition. As a comparison, these values were also calculated for those with a minimum of at least 1 or 2 HbSS claims within each year.

A sensitivity of over 90% and a specificity of approximately 80%, as well as the reliability across years, allow QMETRIC to conclude that the denominator, using ICD-9-CM codes, is valid for accurately identifying children with SCA within administrative claims. These results indicate that the case definition used has a very high ability to correctly identify true cases and a somewhat lower ability to distinguish false positives. However, other less stringent case definitions resulted in substantially more misclassification than the chosen definition of at least 3 HbSS claims within the measurement year.

**Empirical Validity Testing of Performance Measure**

Although a state would typically have direct access to its own Medicaid data, it is unlikely that a state would have similar access to other states' data for comparison. However, CMS develops and maintains standardized MAX data for public use using administrative claims submitted by each state Medicaid program. The MAX data are the only national, person-level administrative claims dataset available for the Medicaid program. As a consequence, MAX data, rather than data acquired directly from individual Medicaid programs, are likely to be used to perform cross-state comparisons of TCD screening among children with SCA. Since states submit their Medicaid data to CMS for conversion into the MAX datasets, a state's own Medicaid data can be considered the authoritative source for administrative claims.

QMETRIC’s empirical validity testing of this performance measure compared the MAX data for the state of Michigan (obtained from CMS) to the gold standard of Michigan Medicaid data (obtained directly from Michigan’s claims data warehouse) for the same time period (2007-2009). Note that the testing time period was constraint to align with the most recent MAX data available from CMS at the time of this analysis. Rates of TCD screening using each source of data were calculated and compared using z-tests for two proportions; for these tests, the null hypothesis was that the rate in each year would be the same in both Michigan Medicaid data and MAX data. Additionally, the correlation coefficient and squared correlation coefficient were calculated to identify the extent of the linear relationship between the two data sources.

The comparison of rates of TCD screening from the Michigan Medicaid data as compared to MAX data showed that the number of TCD cases among children with SCA ranged from 45 to 114 screenings in the claims acquired directly from the Medicaid data warehouse, versus a range of 26 to 93 screenings from MAX data for the same time period.

These results suggest that, compared with the Michigan Medicaid data, MAX data has a very high degree of validity. When TCD screening was assessed for the same state (Michigan) from these two data sources for the same time period (2007-2009), no differences in rates were observed (all p-
values >0.20). Additionally, the high values of the correlation coefficient and the squared correlation coefficient indicate a high level of reliability. Correlation coefficients of greater than 0.70 indicate a strong positive linear relationship; therefore, these results suggest that compared with Michigan Medicaid data, MAX data is highly valid. The squared correlation coefficient value of 0.96 indicates that nearly 96% of the variability in the MAX data from CMS for the state of Michigan can be explained by variation in the data received directly from the Michigan Medicaid program. This finding indicates that the strength of the relationship between the two data sources is extremely strong.

**Face Validity of Performance Measure Score**
The face validity of this measure was established by a panel of national experts and advocates for families of children with sickle cell disease (SCD) convened by QMETRIC. This expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, this measure’s validity was considered by experts in state Medicaid program operations, health plan quality measurement, health informatics, and health care quality measurement. In total, the QMETRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for states and health plans. The expert panel assessed whether the performance of the measure would result in improved quality of care for children with SCD. Specifically, in respect to TCD screening, the panel weighed evidence to determine if the performance of TCD as outlined in the measure would improve the quality of care provided to patients. The voting process to prioritize the measure was based on the ability of the measure to distinguish good from poor quality.

The expert panel concluded that this measure has a very high degree of face validity through a detailed review of concepts and metrics considered to be essential to effective SCD management and treatment. Concepts and draft measures were rated by this group for their relative importance. This measure was highly rated, receiving an average score of 8.5 (with 9 as the highest possible score) by both expert panels. In addition, the expert panel concluded that the performance of TCD as outlined in this measure would improve the quality of care provided to patients, and the measure would be able to distinguish good from poor quality.

**Demographic, Clinical and Social Risk Adjustment**
This measure was not risk adjusted.

**Disparities**
During testing using ICD-9-CM codes, there were no identified gender disparities in TCD screening among children with SCA (chi-square=1.2, p-value=0.28). The data used for performance scores was state Medicaid programs; therefore, there were no disparities identified by insurance or socioeconomic status. Younger children (ages 2-6) were more likely to receive TCD screening than older children (chi-square=99.01, p-value<0.0001). For those 2 to 6 years old, 36% received a TCD screen; for those ages 7 to 11 years, 31% received a TCD screen; and for those ages 12-15 years, 25% were screened.
**Benchmarking**

A benchmark was not established for this measure for two primary reasons: (1) a lack of any real variation among the different measured stakeholders and (2) there were no high performers among the measured entities. The QMETRIC team was not able to establish a standard for groups to aspire to with regard to performance. Due to the lack of variation and poor performance, any benchmark would have been arbitrary.

**TRANSITION FROM ICD-9-CM TO ICD-10-CM CODES**

Because the measure had been validated and endorsed by NQF using ICD-9-CM codes, it was necessary to revalidate the measure using ICD-10-CM codes. The re-specification of the measure had to be completed manually due to the failure of the "automated" conversion tools to perform in a valid manner. As such, this was a very laborious and time-consuming endeavor. However, it was an essential process to result in a valid and reliable claims-based measure using ICD-10-CM codes.

As a first step in re-specifying the measure using ICD-10-CM codes, it was necessary to develop a valid claims-based case definition for identifying children with SCA. A manuscript has been published by the QMETRIC team that provides a complete description of the process used to develop, test, and validate a new case definition (Reeves, et al., 2020).

A summary of this process is provided in the following excerpt from Reeves SL, et al. manuscript.

> Using specific SCA-related (D5700, D5701, and D5702) and nonspecific (D571) diagnosis codes, 23 SCA case definitions were applied to Michigan Medicaid claims (2016) to identify children with SCA. Measures of performance (sensitivity, specificity, area under the ROC curve) were calculated using newborn screening results as the gold standard. A parallel analysis was conducted using New York State Medicaid claims and newborn screening data. In Michigan Medicaid, 1597 children had ≥1 D57x claim; 280 (18%) were diagnosed with SCA. Measures of performance varied, with sensitivities from 0.02 to 0.97 and specificities from 0.88 to 1.0. The case definition of ≥1 outpatient visit with a SCA-related or D571 code had the highest area under the ROC curve, with a sensitivity of 95 percent and specificity of 92 percent. The same definition also had the highest performance in New York Medicaid (n = 2454), with a sensitivity of 94% and specificity of 86%. Children with SCA can be accurately identified in administrative claims using this straightforward case definition. This methodology can be used to monitor trends and use of health services after transition to ICD-10-CM.

The development of this new valid case definition ensured the feasibility of the use of this claims-only measure.

The re-specification continued with a translation of all other codes required for measure implementation which included a manual review to ensure the accuracy of this process. The new ICD-10-CM measure specification was then provided to each of three partner Medicaid health plans who were asked to determine their performance scores using their claims data. The new specification
was also provided to the New York Medicaid program so that they could also determine the performance scores for their state. This was done for both 2018 and 2019 measurement years.

Using Michigan Medicaid administrative claims (available with permission via a data use agreement), the overall performance score for the state of Michigan was calculated. State Medicaid claims were then sorted by health plan and a performance score for each partner health plan was determined. QMETRIC then developed an algorithm to assign sickle cell patients to specific health systems within the State of Michigan. Again, using the Michigan Medicaid claims, patients were sorted to each partner health system and a performance score for the patients assigned to each health system was determined.

Very high reliability was found in the performance scores that were calculated using Michigan Medicaid claims for each partner health plan as compared with the scores they calculated using their own claims data.

The re-specified measure has been proved to be valid at all levels for which it was used. The lag in claims availability at the state level creates a delay in use of Medicaid claims. Health plans have more ready access to their own claims and can use the measure on a more rapid basis.

REFERENCES


The following three Key Driver Diagrams are designed to help guide states, health plans and health systems in implementing strategies to improve TCD screening among children with sickle cell anemia (SCA). These Key Driver Diagrams can be adapted and tailored for use by other organizations at each level. Regardless of the organization using these diagrams, the strategies must be accompanied by a more comprehensive understanding of the many barriers faced by families and the broader activities and resources necessary to facilitate improved delivery of comprehensive preventive care for children with SCA.

- The State Key Driver Diagram
- The Health Plan Key Driver Diagram
- The Health System Key Driver Diagram

The three diagrams provided in this toolkit focus on TCD screening and reflect a subset of the 35 potential interventions at all levels of the health care system and six key drivers of high-quality preventive care for children with SCA identified during multi-stakeholder meetings convened by QMETRIC beginning in December of 2017 and continuing through May of 2020. Read more details about this effort and the accompanying comprehensive driver diagram. To refer only to the accompanying comprehensive drive diagram, go to https://www.ahrq.gov/pqmp/implementation-qgi/toolkit/tcd/key-driver.html.

LESSONS LEARNED IN USING TCD MEASURE AT MULTIPLE LEVELS

As part of the PQMP grant, QMETRIC sought to implement the sickle cell measures at the state, health plan and provider levels. It became quickly apparent that the resources to implement the TCD measure varied markedly both across and within levels. Provider groups had very limited resources to devote to quality improvement efforts in general, and to this measure specifically. Health plans had systems in place for using care management to improve care for chronic diseases, but these resources were rarely devoted to children and only to those areas for which their performance was contractually required or to those that created a large financial burden for the plan. The states control financial incentives for Medicaid health plans, but this has historically been reserved for those measures in either the Child Core Set, HEDIS or the annual PIPS. With these challenges in mind, specific insights at each level are provided below.

HEALTH SYSTEM INSIGHTS

QMETRIC’s partner sickle cell clinics that implemented the TCD measure are not in freestanding children’s hospitals but are part of larger hospital systems. As such, fewer resources tended to be made available for issues affecting pediatric populations relative to those affecting adults. All of the sickle cell clinics with which QMETRIC worked were underfunded and under-resourced, and therefore
had limited capacity to devote to quality improvement. In fact, one of the initial three collaborating
health systems (sickle cell center) withdrew from the project as they reported they had “absolutely no
resources” to devote to quality improvement (QI) because they could barely keep up with the clinical
demand for those who presented for care.

QMETRIC met individually with the two remaining partner healthcare providers and staff on multiple
occasions to review clinic processes, identify barriers to care for patients, and assess capacity to
implement QI strategies. Clinic performance data was shared and improvement plans were
developed. Examples of this activity are provided in the Improvement Data section of this toolkit.
While both centers were able to adopt some improvement strategies, they were still limited by staff
changes and shortages. As outlined in the Health System Key Driver Diagram and Health System
Strategic Road Map, a significant amount of clinic staff time is required to implement most suggested
improvement strategies. The Health System Key Driver Diagram is available for download at
https://www.ahrq.gov/pqmp/implementation-q/0olkit/tcd/key-driver.html. The Health System Strategic
Road Map can be found in the Quality Improvement Strategies section. In order to successfully
implement the Strategic Road Map, an institutional commitment to invest in these centers in general,
and specifically in QI, for this population is required.

HEALTH PLAN INSIGHTS
Health plans have many competing priorities. These are generally focused either on improvement in
the areas for which financial incentives have been created or for which they are required to report
(HEDIS measures). Other priorities are in high cost areas that are almost exclusively in the adult
population.

The QMETRIC team met repeatedly with the collaborating health plans to assist in moving forward a
quality agenda for the sickle cell disease patient population. Individual meetings with QI teams from
each health plan partner focused on developing an understanding of each of their approaches to QI in
general and any previous activity they may have conducted for the sickle cell disease population.
QMETRIC also shared health plan performance data and discussed improvement strategies. It was
determined that health plan care managers are best positioned to address gaps in care for these
members. Care managers are able to assist members by identifying barriers to accessing healthcare
and resolving the issues that create these. Care management is critical to the success of the
QMETRIC Health Plan Strategic Road Map.

Health plan levels of engagement with the QMETRIC team varied depending both on competing
priorities and on staff turnover. Successes in this area required intensive effort on the part of the
QMETRIC team and extraordinary personal commitments by specific individuals at the health plans.

STATE-LEVEL INSIGHTS
State Medicaid programs set contracts with health plans for Medicaid beneficiaries. These contracts
contain expectations for reporting and performance for specific conditions. These conditions are
uniformly contained in HEDIS measures or those on the Child Core Set of Quality Measures.
Conditions which are not a part of either of those systems are unlikely to become priorities of any State Medicaid Program. Because states report their performance on measures in the Child Core Set as well as HEDIS measures, their priority is to devote resources to improving performance on those measures. This means incentives are provided to the health plans to focus improvement efforts on those specific areas. *Measures which are not a part of the Child Core Set or of any other extrinsic imperative may struggle to gain attention or traction.*

QMETRIC met with the Quality Improvement & Program Development Section at the Michigan Department of Health and Human Services Managed Care Plan Division to understand the mechanisms behind the financial incentives they had in place to drive health plan performance and their methods of communication of priorities to the plans. QMETRIC also shared state-wide performance data and discussed strategies for how they might attempt to improve care. The Director of Quality, who was greatly moved by the personal stories of parents and patients with sickle cell disease at the expert design meeting, was also concerned by the very low measure performance rates for these patients. Additionally, there was a strong sense of a social justice imperative for these children among the staff in that office. The group was clearly committed to improving care and acting on that commitment. *Other states trying to implement similar QI initiatives, especially without financial incentives, will face significant challenges but will improve their chances of success by having a dedicated champion of the initiative in a leadership position at the state level.*

QMETRIC assisted the state in the development of a regionalized improvement collaborative for health plans. The state will use financial incentives to create an environment for plans within a specific Medicaid region to work collaboratively to improve measure performance for all children in that region, regardless of their plan affiliation. This “first in the nation” health plan collaborative for the care of children with sickle cell disease launched in Summer 2021. The fact that the state is willing to devote a portion of the financial incentive pool to this and other measures is unique and has great potential to substantially improve the health and lives of these children.
Quality Improvement Strategies

STRATEGIC ROAD MAPS

Each of the three key driver diagrams provided to be used at the state, health plan and health system levels is accompanied by a Strategic Road Map that identifies tools, workbooks, resources, and suggested actions for the respective strategies presented. The Strategic Road Maps were developed by QMETRIC based on learnings throughout the PQMP project, which included multi-stakeholder design meetings. The Strategic Road Maps are available in the tables below and for download as PDFs at https://www.ahrq.gov/pqmp/implementation-qii/toolkit/tcd/1qi-strategies.html.

- State Medicaid Program Strategic Roadmap
- Health Plan Strategic Roadmap
- Health System Strategic Roadmap

Table 1. State Medicaid Program – Strategic Road Map

<table>
<thead>
<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Plan Incentives to Promote TCD</td>
<td>Financially incentivize Medicaid health plans to increase the percentage of children with sickle cell anemia that receive an annual TCD screen by XX% over baseline in 12 months</td>
<td>Michigan Department of Health and Human Services Managed Care Plan Division, Quality Improvement &amp; Program Development Section: Medicaid health plan financial incentive program under development</td>
</tr>
<tr>
<td>Screening &amp; Follow Up</td>
<td></td>
<td>Refer to Measure Specification and Code Tables.</td>
</tr>
<tr>
<td>Engage &amp; Monitor TCD Screening QI</td>
<td>Identify health plan baseline performance rates and processes aimed at improving care for children with sickle cell disease, including increasing TCD screening rates</td>
<td>Michigan Department of Health and Human Services Managed Care Plan Division, Quality Improvement &amp; Program Development Section: Medicaid health plan financial incentive program under development</td>
</tr>
<tr>
<td>Efforts</td>
<td>Develop process for health plans to report new processes/activities aimed at improving care, including increasing TCD screening rates</td>
<td>Refer to Measure Specification and Code Tables.</td>
</tr>
<tr>
<td></td>
<td>Provide measure performance feedback to Medicaid and CHIP health plans on regularly scheduled basis</td>
<td></td>
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<tr>
<td></td>
<td>Establish processes for health plans to share best practices for improving care, including</td>
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<tr>
<td>Key Drivers</td>
<td>Strategies - Change Ideas</td>
<td>Tools, Resources, Suggested Actions</td>
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<tr>
<td></td>
<td>increasing TCD screening rates, with one another</td>
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*Table 2. Health Plan – Strategic Road Map*

<table>
<thead>
<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activate Care Management Strategies</strong></td>
<td>Pediatric members with SCD are assigned a health plan care manager</td>
<td>• Send introductory letter to each member with contact information and list of services that care management can provide</td>
</tr>
</tbody>
</table>
|                      | Communication process is established between clinic staff and health plan care managers to ensure care coordination (e.g., pre-approvals, transportation, no-shows, unable to reach) | • Follow communication process provided in Health Plan and Sickle Cell Clinic Communication Process flow diagram and meeting planning form.  
• Identify PCP and hematologist for each member  
• Send introductory letter to each member’s provider with contact information and list of services that care management can provide  
• Assist any member without a PCP and hematologist in obtaining each |
|                      | Care managers receive education regarding sickle cell disease and necessity of preventive care including TCD screening for children with sickle cell anemia | Educational resources from the NIH, Sickle Cell Disease News, NYU Langone Health, Michigan DHHS, and the Sickle Cell Disease Association of America are available at the following webpages:  
• [https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease](https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease)  
<p>|                      | Health plan staff develop a registry of pediatric members with SCD which tracks PCP/ hematologist visits, | • Refer to sample Health Plan Database for Members with SCD.  |</p>
<table>
<thead>
<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>medications, ED visits, and other healthcare related activities including TCD screening</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Registry is used to identify members who require annual TCD screen</td>
<td>• Refer to sample Health Plan Database for Members with SCD.</td>
</tr>
</tbody>
</table>
|             | Care manager contacts member (text, email, postal mail, phone call) to discuss scheduling a clinic visit | • Per standard practice  
• Text, email, post card, letter, phone call reminders  
• Contact includes list of services that care management can provide |
|             | Care manager provides educational materials which explain reasons for/value of preventive care including TCD screening for children with sickle cell anemia | Educational resources from Sickle Cell Disease News, NYU Langone Health, Michigan DHHS, and the Sickle Cell Disease Association of America are available at the following webpages:  
• [http://sicklecelldisease.net/resources-educational-materials/](http://sicklecelldisease.net/resources-educational-materials/) |
| Facilitate Patient Clinic Visits | Care manager assists in scheduling appointment, as necessary | • Per standard practice |
|             | Care manager identifies and note patient's preferred method and frequency for appointment reminders | • Identify during introductory contact |
|             | Care manager sends patient appointment reminders (text, email, postal mail, phone | • Post card, portal, email, phone call reminders  
• Reminders include option for patients to seek assistance with transportation, other needs |
<table>
<thead>
<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
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<tr>
<td>call) depending on patient preference</td>
<td></td>
<td></td>
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<tr>
<td>Care manager assesses potential barriers to care and provides assistance with transportation, other needs</td>
<td>• Per standard practice</td>
<td></td>
</tr>
<tr>
<td>Care manager contacts member to assist in rescheduling missed/cancelled appointments, identify barriers to attending appointments/obtaining care</td>
<td>• Per standard practice</td>
<td></td>
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<tr>
<td>Care manager implements “unable to reach” protocol for members who are not reached within a specified number of attempts</td>
<td>• Per standard practice</td>
<td></td>
</tr>
<tr>
<td>“Unable to reach” protocol includes home visit to identify barriers to obtaining care</td>
<td>• Per standard practice • If practice does not exist, establish procedures for in-home visit to discuss barriers to obtaining care</td>
<td></td>
</tr>
<tr>
<td>Key Drivers</td>
<td>Strategies - Change Ideas</td>
<td>Tools, Resources, Suggested Actions</td>
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</tr>
<tr>
<td>Health plan staff provide clinic staff with feedback on rates of children who received TCD screening (quality measure performance)</td>
<td>• Refer to Measure Specification and Code Tables.</td>
<td></td>
</tr>
<tr>
<td>Care manager sends patient reminders (text, email, postal mail, phone call) to schedule TCD screening</td>
<td>• Text, email, post card, letter, phone call reminders&lt;br&gt;• Reminders include option for patients to seek assistance with transportation, other needs</td>
<td></td>
</tr>
<tr>
<td>Care manager assists with scheduling appointment, as necessary</td>
<td>• Per standard practice</td>
<td></td>
</tr>
<tr>
<td>Care manager assesses potential barriers to care and provides assistance with transportation, other needs</td>
<td>• Per standard practice</td>
<td></td>
</tr>
<tr>
<td>Care manager follows up after specified time period following provider order to determine if TCD screen was obtained</td>
<td>• Administrative claims may be used to determine if TCD screen was obtained&lt;br&gt;• Refer to Measure Specification and Code Tables.</td>
<td></td>
</tr>
<tr>
<td>Key Drivers</td>
<td>Strategies - Change Ideas</td>
<td>Tools, Resources, Suggested Actions</td>
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<tr>
<td>Follow-Up</td>
<td>Care manager contacts member (text, email, postal mail, phone call) to schedule/reschedule TCD screening if not received within specified time period following date of provider order and identify barriers to attending appointments/obtaining care</td>
<td>• Per standard practice</td>
</tr>
</tbody>
</table>
|             | Care manager contacts member/clinic staff to obtain results                                                                                                                                                                                                                             | • Per standard practice  
• Per established communication route                                                                                                                                               |
|             | Care manager contacts member to assist with next steps in care, as necessary                                                                                                                                                                                                             | • Per standard practice                                                                                                                                                                    |


**Table 3. Health System – Strategic Road Map**

<table>
<thead>
<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
</tr>
</thead>
</table>
| Identify Patient and Conduct Outreach | Clinic staff create and maintain sickle cell disease (SCD) patient registry to identify gaps in care (e.g., past due screenings) and enable QI processes                                                                                                                         | • Create existing patient list from electronic health record system. Refer to sample Master Patient List  
• Identify steps in the TCD screening process using the TCD Screening and Communication flow diagram  
• Utilize the Sample Sickle Cell Clinic Follow-Up Care Process flow diagram                                                                                                      |
<table>
<thead>
<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
</tr>
</thead>
</table>
| Clinic staff identify patients without a provider visit within 1 year | • Use patient list to identify those requiring clinic visit  
• Use EHR alerts for patients requiring clinic visit | |
| Clinic staff send patient reminders (text, portal reminder, email, postal mail, phone call) to schedule clinic appointment | • Per standard practice  
• Annual post card, portal, email, phone call reminders  
• Reminders include option for patients to seek assistance with transportation, other needs – health plan care manager number provided | |
| Reminders include educational materials that explain reasons for/value of preventive care including TCD screening for children with sickle cell anemia | Educational resources from Sickle Cell Disease News, NYU Langone Health, Michigan DHHS, and the Sickle Cell Disease Association of America are available at the following webpages:  
• [http://sicklecelldisease.net/resources-educational-materials/](http://sicklecelldisease.net/resources-educational-materials/) | |
| Communication process is established between clinic staff and health plan care managers to ensure care coordination (e.g., pre-approvals, transportation, no-shows, unable to reach) | • Obtain/create contact list of health plan care management departments to facilitate direct access to care managers  
• Follow communication process provided in the Health Plan and Sickle Cell Clinic Communication Process flow diagram and meeting planning form.  
• List of state Medicaid health plans may be obtained from state Department of Health and Human Services. An [example from Michigan](https://example.com) is available (PDF). | |
| Clinic staff hold weekly team meeting for pre-visit planning for patients being seen during week – review date of | • Refer to sample Master Patient List.  
• Review EHR alerts for scheduled patients  
• Create checklist for pre-visit planning | |
<table>
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<tr>
<th>Key Drivers</th>
<th>Strategies - Change Ideas</th>
<th>Tools, Resources, Suggested Actions</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>last TCD screening to determine if TCD screen is due</td>
<td></td>
</tr>
<tr>
<td></td>
<td>EHR reminders are created that prompt the provider to review date of last TCD screening and order TCD screening, if necessary</td>
<td>• Use EHR alerts for TCD screen date, TCD screen order</td>
</tr>
</tbody>
</table>
|             | Standardized order set that includes annual TCD screening is established | • Include standard order set in clinic visit checklist  
• Use EHR standard order set, smart phrases |
| Conduct Patient Clinic Visit & Education | Clinic staff identify and note patient’s preferred method and frequency for appointment reminders | • Per standard clinic practice  
• Question added to intake |
|             | Patient attends clinic visit - Provider reviews last TCD screening date, orders TCD screen | • Use clinic visit checklist that includes review of TCD screen date, TCD screen order  
• Information about TCD screening is available from Sickle Cell Disease News. |
|             | Patient preventive care education, including rationale for TCD screening, is provided during visit | Educational resources from Sickle Cell Disease News, NYU Langone Health, Michigan DHHS, and the Sickle Cell Disease Association of America are available at the following webpages:  
• https://sicklecellanemianews.com/transcranial-doppler-ultrasound-screening/  
• https://nyulangone.org/conditions/sickle-cell-disease-in-children/diagnosis  
• http://sicklecelldisease.net/resources-educational-materials/ |
<table>
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<tr>
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<th>Tools, Resources, Suggested Actions</th>
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</thead>
</table>
| Clinic staff provide health plan care manager contact information, share information regarding care management services | • Maintain contact list of health plan care management departments to facilitate direct access to care managers  
• Develop brief information sheet of health plan care management services (e.g., assistance with transportation, other needs)  
• Obtain information sheets from health plan care managers | |
| Clinic staff provide instruction for using patient portal to schedule appointments, ask questions, review test results | • Materials regarding patient portal provided per standard practice/per patient’s preferred method of contact  
• Clinic staff provide in-person instruction during clinic visit, assist with registration, log-in | |
<p>| Clinic staff schedule next clinic appointment at end of visit | • Per standard clinic practice | |
| Clinic staff implement process to reschedule missed/cancelled appointments | • Per standard clinic practice | |
| Support TCD Scheduling &amp; Screening | Clinic staff assist patient with scheduling TCD screening appointment at end of clinic visit | • Clinic staff schedule visit while patient present to coordinate schedules, identify transportation, child care needs, etc. |
| | Clinic staff send patient reminders to schedule TCD screening (text, portal reminder, email, postal mail, phone call) depending on | • Health plan care manager contacted as needed to assist with appointment barriers |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>patient preference</td>
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MULTI-STAKEHOLDER APPROACH TO SCA QUALITY IMPROVEMENT

QMETRIC hosted two in-person and multiple virtual expert design meetings to identify potential quality improvement (QI) interventions to deliver high-quality preventive care for children with sickle cell anemia (SCA). This group, known as the Sickle Cell Trailblazers, consisted of representatives from all partner health systems, health plans and the State Medicaid program, as well as parents of children with sickle cell disease and patients themselves. Through planned discussions during these meetings, participants laid out a common vision for an ideal future state of SCA preventive care, identified gaps in knowledge across stakeholders, and brainstormed dozens of potential interventions. These discussions identified multiple gaps in knowledge about the many barriers faced by families and resources available across stakeholder groups, which in itself represents a significant barrier to the delivery of coordinated, efficient, appropriate preventive care. The vision of ideal care that emerged from the design meetings is noteworthy as it calls for personalized, individual care for people with SCA and their families.

In terms of learning across stakeholders and brainstorming potential interventions, each participant contributed an important perspective to the design meetings, emphasizing the need for community approaches to improve care for children with SCA. First and foremost, SCA patients and parents provided unique insights into the challenges of obtaining high-quality preventive care. The participants were greatly moved by the parent stories as most (other than the clinicians) had never met a parent of a child with sickle cell disease nor an actual sickle cell patient. Importantly, the families who had the interest, time, and resources to join the design meetings recognized that they are empowered to advocate for their children. This may be in contrast to many families affected by SCA who may not have the knowledge and resources to advocate for themselves in the same way, a message echoed by community leaders.

The output of the design meetings was a framework for idealized care of the sickle cell disease population and ultimately, a series of key driver diagrams at each level to improve care. A complete description of the design of the two in-person meetings may be found in the published manuscript “Designing a Multistakeholder Collaboration to Improve Preventive Care for Children with Sickle Cell Anemia.” (Bates KE, et al., 2019).
The Director of the Michigan Department of Health and Human Services Managed Care Plan Division, Quality Improvement & Program Development Section was greatly moved by the personal stories of parents and patients at the design meetings. There was also a strong sense of a social justice imperative for these children among the staff in that office. Recognizing the need to improve care for these children, the Director and his staff have taken the action and are developing an incentive program for Michigan Medicaid health plans to improve the care of their members with sickle cell disease. The state plans to use its financial incentives “lever” to encourage an environment for plans within a specific Medicaid region to work collaboratively to improve measure performance for all children in that region, regardless of their plan affiliation. QMETRIC is helping the State develop this “first in the nation” health plan collaborative for the care of children with sickle cell disease. The fact that the State is willing to devote a portion of the financial incentive pool to sickle cell quality measures is unique and has great potential to improve care.

REFERENCES


**Improvement Data**

Measure performance rates for all levels were calculated using state Medicaid administrative claims data. QMETRIC collaborators at the New York Department of Health provided measure performance rates using their own Medicaid administrative claims data.

One difficulty with using state administrative claims is the delay in data availability. Michigan Medicaid claims data become available approximately 6 months following the end of the year. As such, 2020 data was not available at the time of this writing.

**MICHIGAN AND NEW YORK MEDICAID PROGRAM**

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**Percent of Children with Sickle Cell Anemia Receiving Annual TCD screen - State Medicaid Rates**

<table>
<thead>
<tr>
<th></th>
<th>Michigan</th>
<th>New York</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016</td>
<td>37</td>
<td>44</td>
</tr>
<tr>
<td>2017</td>
<td>35</td>
<td>44</td>
</tr>
<tr>
<td>2018</td>
<td>36</td>
<td>45</td>
</tr>
<tr>
<td>2019</td>
<td>39</td>
<td>44</td>
</tr>
</tbody>
</table>

**STATE MEDICAID RATES**

Both Michigan Medicaid and New York Medicaid performance rates improved slightly from 2016 through 2018, then decreased in 2019. Of note is the similarity in rates between the states over the four-year period.
**ACTIONS**
The Michigan Medicaid Quality Improvement & Program Development Director and his team, in collaboration with the QMETRIC team, is establishing a pilot SCD Quality Improvement program. Through this unique and novel program, all Medicaid health plans with members having SCD within a specified region will be financially incentivized to improve measure performance for all SCD patients in the region. Incentives will be paid for improvement on a population-based (not plan-based) level. As such, plans will have to work together to achieve overall improvement in the region to receive the incentive payments. An SCD narrative report for health plans to use to report baseline SCA measure rates as well as current and future plans for improving care has been developed and is ready for implementation.

The State of New York is working separately from QMETRIC to address identified gaps in care.

**BARRIERS**
Baseline information was to be collected by the State from Michigan Medicaid health plans in the Spring, 2020. However, the COVID-19 pandemic necessarily created a reprioritization of this program. It is anticipated that the program will be piloted in the Summer, 2021.
Similar to rates obtained at the State level, from 2016 through 2018, increases were seen in the performance rates for two collaborating health plans, Plan A and Plan B. Rates for all health plans decreased in 2019.

A primary goal for this meeting was to increase the understanding among QMETRIC partners for the need for collaboration between care providers, health plans, and community organizations to ensure that each performs an effective role in the care for people living with SCD and their families. A Trailblazer small group call for care coordination and health plan relationship building took place in December 2017.
March 2018. In May 2018, regularly scheduled health plan huddles with the Q-METRIC QI team were established. QMETRIC then hosted another in-person Trailblazer meeting and follow-up call in June and July that focused specifically on health plan care management services. It is possible that the establishment of the Trailblazer group with in-person and virtual meetings were instrumental in improving rates in 2018 by encouraging health plans to focus some resources on children with SCD. It is also possible that Health Plan B had a greater proportion of its members in health system B (see below) and this could have accounted for its greater increase in performance.

In Oct. 2018, Health Plan A established an enhanced database for tracking its members with sickle cell disease and increased care management outreach services for these individuals. In early 2019, Health Plan B developed a sickle cell training program for members and providers. Other specific health plan activities included strengthening the outreach process, including additional calls to parents/providers, incorporating community health workers for door to door visits, educating health plan staff on SCD, and educate providers through provider network newsletters/meetings.

The QMETRIC team had hoped that with the focused efforts, 2019 rates for these two plans would further increase. However, as noted in the data, rates decreased in 2019.

**BARRIERS**

Health Plan C experienced staffing changes during 2018 which may have hampered an increased focus on this population and may have contributed to the lack of improvement. However, in 2019, this health plan hired an individual to specifically manage efforts for improving the care of its members with SCD.

Other barriers noted by collaborating health plans included high unable to reach rates and high member decline rate for care management services.
RATES
Over the four-year period, one of the two collaborating health systems demonstrated a significant increase in their performance rate, while the second health system rate declined. Again, one of the two collaborating health systems demonstrated a significant increase in their performance rate from 2016 through 2018, with a decline in 2019, while the second health system’s rate only declined during this period.

ACTIONS
Health System B improved by 42% from 2016 through 2018. A likely contributing factor was that a new hematologist started working at this health system in November 2017. This individual was very committed to improving the care for individuals with SCD. In April 2018, baseline data for tracking TCDs on a master patient list was collected for a PDSA cycle. The PDSA ended in May, and the master patient list and tracking process was adopted. These two events likely are responsible for the significant increase in TCD screening in 2018. Reasons for the decline noted in 2019 are unknown.
BARRIERS
Health System A experienced staffing changes and shortages, specifically losing a key nursing position, which may have contributed to the lack of improvement at that site. Other identified barriers include difficulty in identifying patients that may be lost to follow-up and that are in need of an annual TCD screen, since it is possible that any given patient may have obtained care at another health system.
Other Resources

TOOLS
The QMETRIC team created multiple resources that can be leveraged and adapted for use at other organizations and institutions. Links to these resources are available throughout the earlier sections of the toolkit. The majority are listed and include associated links in the three Strategic Road Maps.

MANUSCRIPTS
Multiple manuscripts provide detailed information regarding measure development and quality improvement activities related to improving preventive care for children with sickle cell anemia.

The following literature provides more detailed information regarding measure development, quality measurement and quality improvement activities.


- Carroll AE. Sickle Cell Disease Still Tends to be Overlooked. The New York Times, August 5, 2019, Appeared in Print on August 19, 2019 in Section B, Page 5 entitled “Sickle Cell Anemia Lacks the Attention it Deserves”


DESIGN MEETING MATERIALS - UNDERSTANDING QUALITY IMPROVEMENT
The following materials were used for the QMETRIC SCD Expert Design meetings to provide a general understanding of quality improvement principles.


Additional healthcare quality improvement materials may be obtained from the Institute for Healthcare Improvement (IHI) at www.ihi.org, and the Agency for Healthcare Research and Quality at www.ahrq.gov.

VIDEOS
The following videos provide information on strategies for quality improvement in healthcare.
- IHI Open School, “Don Goldmann: How do you use a driver diagram?” can be found at the following URL: https://www.youtube.com/watch?v=yfcE_Q-IRFg.

- Dr. Mike Evans, “Quality Improvement in Healthcare” can be found at the following URL: https://www.youtube.com/watch?v=jq52ZjMzqyl.