

# Satisfaction with Care from the Hematologist for Children with Sickle Cell Disease

## Section 1. Basic Measure Information

### 1.A. Measure Name

Satisfaction with Care from the Hematologist for Children with Sickle Cell Disease

### 1.B. Measure Number

0219

### 1.C. Measure Description

**Please provide a non-technical description of the measure that conveys what it measures to a broad audience.**

This measure assesses the degree to which parents are satisfied with the care they receive for their child with sickle cell disease (SCD). Specifically, this measure reports the percentage of parents and guardians of children younger than 18 years of age identified as having SCD, who responded on a scale of 1 to 5, “Satisfied (4)” or “Very Satisfied (5)” to a survey question regarding satisfaction with care from their child’s hematologist. A higher proportion indicates better performance, as reflected by high parent/guardian satisfaction.

Approximately 2,000 infants are born with SCD in the United States each year, a condition that occurs predominantly in people of African and Hispanic descent. SCD is a chronic hematologic disorder, characterized by the presence of hemoglobin S. From infancy onward, this hemoglobin variant can lead to an array of serious medical conditions. For young children with SCD, a pediatric hematologist is a crucial member of their healthcare team, offering guidance about comprehensive care and expertise regarding treatment for acute illnesses. Based on these encounters, patients with SCD and their families have direct and relevant experience to offer regarding care received. Parent surveys provide a valuable mechanism by which to gather and reflect the patient/caregiver perspective back to providers. Providers, in turn, can use this information to improve practices and better support their pediatric patients as they face a challenging, complex disease. An example of possible practice adjustments includes increasing the length of appointment times for hematology visits. There are no existing quality measures for assessing satisfaction of care received from hematologists for children with SCD.

This measure uses survey responses to calculate the percentage of parents and guardians of children with SCD who responded to a survey question regarding satisfaction with care from their child’s hematologist.

## 1.D. Measure Owner

The Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC).

## 1.E. National Quality Forum (NQF) ID (if applicable)

Not applicable.

## 1.F. Measure Hierarchy

**Please note here if the measure is part of a measure hierarchy or is part of a measure group or composite measure. The following definitions are used by AHRQ:**

- 1. Please identify the name of the collection of measures to which the measure belongs (if applicable). A collection is the highest possible level of the measure hierarchy. A collection may contain one or more sets, subsets, composites, and/or individual measures.**

This measure is part of the Q-METRIC Sickle Cell Disease Measures collection.

- 2. Please identify the name of the measure set to which the measure belongs (if applicable). A set is the second level of the hierarchy. A set may include one or more subsets, composites, and/or individual measures.**

This measure is part of the Q-METRIC Sickle Cell Disease Parent/Guardian Satisfaction Survey set.

- 3. Please identify the name of the subset to which the measure belongs (if applicable). A subset is the third level of the hierarchy. A subset may include one or more composites, and/or individual measures.**

Not applicable.

- 4. Please identify the name of the composite measure to which the measure belongs (if applicable). A composite is a measure with a score that is an aggregate of scores from other measures. A composite may include one or more other composites and/or individual measures. Composites may comprise component measures that can or cannot be used on their own.**

Not applicable.

## 1.G. Numerator Statement

The eligible population for the numerator is parents or guardians of children younger than 18 years of age identified as having SCD who responded on a scale of 1 to 5 as “Satisfied (4)” or “Very Satisfied (5)” to survey questions (Table 1; see Supporting Documents) regarding satisfaction with care from their child’s hematologist, during the measurement year (January 1-December 31). Eligible parents or guardians are restricted to those with a child who has a

positive, confirmed newborn screening result of SCD in State newborn screening program records. Acceptable SCD hemoglobin variants for screening results are listed in Table 2 (see Supporting Documents), along with corresponding ICD-9 codes.

### **1.H. Numerator Exclusions**

Children with a result in the State newborn screening records indicating one of the SCD variants listed in Table 3 (see Supporting Documents), along with corresponding ICD-9 diagnosis codes, that should not be included in the eligible population unless there is also a positive, confirmed newborn screening result of SCD (Table 2, see Supporting Documents).

### **1.I. Denominator Statement**

The eligible population for the denominator is parents or guardians of children younger than 18 years of age identified as having SCD who responded to survey questions regarding satisfaction with care from their child’s hematologist during the measurement year (January 1-December 31). Eligible parents or guardians are restricted to those with a child who has a positive, confirmed newborn screening result of SCD in the State newborn screening program records; acceptable SCD hemoglobin variants for screening results are listed in Table 2 (see Supporting Documents), along with corresponding ICD-9 codes.

### **1.J. Denominator Exclusions**

Children with a result in the State newborn screening records indicating one of the SCD variants listed in Table 3 (see Supporting Documents), along with corresponding ICD-9 diagnosis codes, that should not be included in the eligible population unless there is also a positive, confirmed newborn screening result of SCD (Table 2, see Supporting Documents).

### **1.K. Data Sources**

**Check all the data sources for which the measure is specified and tested.**

Survey; parent/caregiver report.

**If other, please list all other data sources in the field below.**

Not applicable.

## **Section 2: Detailed Measure Specifications**

**Provide sufficient detail to describe how a measure would be calculated from the recommended data sources, uploading a separate document (+ Upload attachment) or a link to a URL. Examples of detailed measure specifications can be found in the CHIPRA Initial Core Set Technical Specifications Manual 2011 published by the Centers for Medicare & Medicaid Services. Although submission of formal programming code or algorithms that demonstrate how a measure would be calculated from a query of an appropriate electronic data source are not requested at this time, the availability of these resources may be a factor in determining whether a measure can be recommended for use.**

See the Supporting Documents for detailed measure specifications.

## **Section 3. Importance of the Measure**

**In the following sections, provide brief descriptions of how the measure meets one or more of the following criteria for measure importance (general importance, importance to Medicaid and/or CHIP, complements or enhances an existing measure). Include references related to specific points made in your narrative (not a free-form listing of citations).**

### **3.A. Evidence for General Importance of the Measure**

**Provide evidence for all applicable aspects of general importance:**

- **Addresses a known or suspected quality gap and/or disparity in quality (e.g., addresses a socioeconomic disparity, a racial/ethnic disparity, a disparity for Children with Special Health Care Needs (CSHCN), a disparity for limited English proficient (LEP) populations).**
- **Potential for quality improvement (i.e., there are effective approaches to reducing the quality gap or disparity in quality).**
- **Prevalence of condition among children under age 21 and/or among pregnant women.**
- **Severity of condition and burden of condition on children, family, and society (unrelated to cost).**
- **Fiscal burden of measure focus (e.g., clinical condition) on patients, families, public and private payers, or society more generally, currently and over the life span of the child.**
- **Association of measure topic with children’s future health – for example, a measure addressing childhood obesity may have implications for the subsequent development of cardiovascular diseases.**
- **The extent to which the measure is applicable to changes across developmental stages (e.g., infancy, early childhood, middle childhood, adolescence, young adulthood).**

### **Sickle Cell Disease Prevalence and Incidence**

SCD is one of the most common genetic disorders in the United States (Kavanagh, Sprinz, Vinci, et al., 2011). The National Heart, Lung, and Blood Institute (NHLBI) estimates that 2,000 infants are born with SCD in the United States each year (NHLBI, 2002). SCD affects 70,000-100,000 children and adults in the United States, predominantly those of African and Hispanic descent (Hassell, 2010).

### **Sickle Cell Disease Pathology and Severity**

Vaso-occlusion (the sudden blockage of a blood vessel caused by the sickle shape of abnormal blood cells) is responsible for most complications of SCD, including pain episodes, sepsis, stroke, acute chest syndrome, priapism, leg ulcers, osteonecrosis, and renal insufficiency (Steinberg, 1999). In addition, SCD can have hemolytic and infectious complications that result in morbidity and mortality in children with SCD (Kavanagh, et al., 2011).

### **Sickle Cell Disease Burden in Daily Life**

The effect of SCD on children and families is significant; severe pain episodes and hospitalizations restrict daily activities and reflect negatively on school attendance and performance, as well as on sleep and social activities (Alvim, Viana, Pires, et al., 2005; Lemanek, Ranalli, Lukens, 2009). Although medical management of SCD has continued to improve over time, 196 U.S. children died from SCD-related causes between 1999 and 2002 (Yanni, Grosse, Yang, et al., 2009).

### **Sickle Cell Disease Cost**

In a study of healthcare utilization among low income children with SCD between 2004 and 2007, 27 percent of these children required inpatient hospitalization, and 39 percent used emergency care during a year. Of these children, 63 percent averaged one well-child visit per year, and 10 percent had at least one outpatient visit with a specialist (Raphael, Dietrich, Whitmire, et al., 2009). Patients with SCD use many parts of the healthcare system, incurring significant costs. In 2009, mean hospital charges for children with SCD and a hospital stay were \$23,000 for children with private insurance and \$18,200 for children enrolled in Medicaid (Agency for Healthcare Research and Quality [AHRQ], 2012). Kauf and colleagues estimate the lifetime cost of healthcare per patient with SCD to be approximately \$460,000 (Kauf, Coates, Huazhi, et al., 2009).

### **Outcomes Associated with Assessing Satisfaction with Care for Children with Sickle Cell Disease**

Patients – or, for children, their parents and family caregivers – are the main source for assessing satisfaction with personal aspects of care. And satisfaction is important because it can be essential to successful healthcare outcomes (Darby, 2002).

In general, healthcare quality assessment focuses on two different elements: (1) the technical aspect of care (use of the health sciences to manage a health problem), and (2) the interpersonal aspect (psychosocial interactions between patients [and their families] and providers). Satisfaction with the latter — the patient’s role in the process of treatment — involves such matters as whether the patient’s preferences are addressed and whether information is shared accurately. These aspects are essential for diagnosis, treatment, and outcomes, and can be especially relevant if the patient is not satisfied (Darby, 2002). Satisfaction is also known to be associated with patient adherence to treatment and use of preventive services (Halfon, Inkelas, Mistry, et al., 2004; Lewis, Scott, Pantell, et al., 1986). Patient satisfaction with care reflects the patient’s expectations of care and implies an opinion about the delivery of health services (Halfon, et al., 2004).

SCD is a complex and challenging condition. The damage done by the misshapen Hb S sickle cells affects many organs and systems, resulting for some patients in an ongoing sequence of medical issues, including infection, fever, risk of stroke, and pain. While many children with SCD receive their primary care from a general pediatrician or family physician, a pediatric hematologist guides the SCD-related aspects of their care (American Academy of Pediatrics [AAP], 2002; NHLBI, 2002). Results from existing surveys on provider visits offer examples of specific improvements to address patient satisfaction. Research shows that time spent in face-to-face contact with a clinician may have a strong influence on satisfaction, even when adjusting for a child's health status, demographics, insurance, healthcare setting, total well-child visits, and delayed/missed care. Longer visits are associated with an increase in satisfaction and an increased likelihood of discussing preventive health topics (Halfon, et al., 2004). Given the emphasis that clinical guidelines place on the partnership between general pediatricians and pediatric hematologists, visits with the latter are likely to be subject to the same effect: time spent in direct conversation about the day-to-day management of SCD will affect patient satisfaction.

This measure assesses the percentage of parents and guardians of children younger than 18 years of age identified as having SCD who responded "Satisfied" or "Very Satisfied" to a survey question regarding satisfaction with the overall care from their child's hematologist. The measure does not change across developmental stages.

### **Performance Gap**

There are several complexities involved in assessing patient satisfaction, given the subjective nature of the information involved. Expectations vary from one patient and family to another; therefore, patient satisfaction as a quality measurement has to account for differences in expectations (Darby, 2002). Likewise, satisfaction isn't static. As providers make improvements, patients may shift their expectations accordingly. As care improves patients may expect more; thus the level of satisfaction may remain the same even though the quality of the service provided is better (Darby, 2002). Evidence suggests, too, that physicians are often unable to accurately predict their patients' levels of satisfaction with medical care (Lewis, et al., 1986).

Regarding satisfaction with care from a provider, research shows a strong association among satisfaction measures with the amount of time spent in the last well-child visit. As reasoned above, because hematology care is an important component of comprehensive care for children with SCD, the concept of associating satisfaction with time spent may apply to these specialist visits as well. While an efficiently conducted 10-minute visit may cover the necessary topics, greater parent satisfaction is associated with visits that are 11 to 20 minutes long. Extra time spent is associated with cost, however; health plans must consider the tradeoff between cost and the quality perceived by parents (Halfon, et al., 2004). Families of children with poorer health status have reported lower satisfaction ratings. If adjustments are to be made in visit lengths, allocating more time for those in poorer health might address this greater need for time and information among the families of children with chronic health issues (Halfon, et al., 2004). Again, relating to the pediatrician/pediatric hematologist partnership, families of children with SCD might well report higher satisfaction with care from their hematologist if they feel sufficient time has been spent to convey key information about SCD care.

Another approach is to improve the efficiency of information exchanges during visits. For example, providing thorough written material for families to reference outside the visit could allow the clinician more time to be responsive to specific family needs while keeping the visit short (Halfon, et al., 2004).

### **3.B. Evidence for Importance of the Measure to Medicaid and/or CHIP**

**Comment on any specific features of this measure important to Medicaid and/or CHIP that are in addition to the evidence of importance described above, including the following:**

- **The extent to which the measure is understood to be sensitive to changes in Medicaid or CHIP (e.g., policy changes, quality improvement strategies).**
- **Relevance to the Early and Periodic Screening, Diagnostic and Treatment benefit in Medicaid (EPSDT).**
- **Any other specific relevance to Medicaid/CHIP (please specify).**

The majority of children with SCD are enrolled in Medicaid. In 2009, 67 percent of pediatric SCD patients discharged from the hospital were enrolled in Medicaid; only 25 percent had private insurance (AHRQ, 2012).

To characterize healthcare utilization in children with SCD, including care from a specialist, Raphael and colleagues (2009) studied administrative claims data from a managed care plan serving children with Medicaid and the State Children's Health Insurance Plan (CHIP) for 2007-2009. The researchers found that a substantial proportion of children with SCD did not meet minimum guidelines for hematology comprehensive care, and only 10 percent had a minimum of one outpatient visit per year with a hematologist. These findings are concerning, given that NHLBI guidelines recommend that pediatric patients with SCD should maintain a regular schedule of well-child visits, which include consultations with a pediatric hematologist (NHLBI, 2002). Earlier research by Kuhlthau and colleagues provided somewhat better results: at least 27 percent of children with SCD visited a relevant pediatric subspecialist annually (Kuhlthau, Ferris, Beal, et al., 2001). But even those numbers reflect insufficient care and suggest that children may use primary care for most healthcare needs, including those that arise from their chronic condition.

Medicaid enrollment often serves as a marker of poverty. The large number of children with SCD on Medicaid suggests some of these patients may be receiving suboptimum treatment because of unstable living situations. This may include delays in being taken for medical care if family situations are such that work responsibilities, school commitments for siblings, or lack of transportation make seeking prompt medical attention difficult (Tanabe, Dias, Gorman, 2013). Having consistent standards of care to treat children quickly and effectively when they present for care will help address disadvantages they face because of socioeconomic status.

### **3.C. Relationship to Other Measures (if any)**

**Describe, if known, how this measure complements or improves on an existing measure in this topic area for the child or adult population, or if it is intended to fill a specific gap in an existing measure category or topic. For example, the proposed measure may enhance an**

existing measure in the initial core set, it may lower the age range for an existing adult-focused measure, or it may fill a gap in measurement (e.g., for asthma care quality, inpatient care measures).

There currently are no quality measures for the diagnosis, assessment, or treatment of pediatric SCD.

## Section 4. Measure Categories

CHIPRA legislation requires that measures in the initial and improved core set, together, cover all settings, services, and topics of health care relevant to children. Moreover, the legislation requires the core set to address the needs of children across all ages, including services to promote healthy birth. Regardless of the eventual use of the measure, we are interested in knowing all settings, services, measure topics, and populations that this measure addresses. These categories are not exclusive of one another, so please indicate "Yes" to all that apply.

Does the measure address this category?

- a. Care Setting – ambulatory: Yes.
- b. Care Setting – inpatient: No.
- c. Care Setting – other – please specify: No.
- d. Service – preventive health, including services to promote healthy birth: Yes.
- e. Service – care for acute conditions: No.
- f. Service – care for children with special health care needs/chronic conditions: Yes.
- g. Service – other (please specify): No.
- h. Measure Topic – duration of enrollment: No.
- i. Measure Topic – clinical quality: Yes.
- j. Measure Topic – patient safety: No.
- k. Measure Topic – family experience with care: Yes.
- l. Measure Topic – care in the most integrated setting: No.
- m. Measure Topic other (please specify): No.
- n. Population – pregnant women: No.
- o. Population – neonates (28 days after birth) (specify age range): Yes; all ages in this range.
- p. Population – infants (29 days to 1 year) (specify age range): Yes; all ages in this range.
- q. Population – pre-school age children (1 year through 5 years) (specify age range): Yes; all ages in this range.
- r. Population – school-aged children (6 years through 10 years) (specify age range): Yes; all ages in this range.
- s. Population – adolescents (11 years through 20 years) (specify age range): Yes; adolescents 11 through 17 years (i.e., younger than 18 years of age).
- t. Population – other (specify age range): Not applicable.
- u. Other category (please specify): Not applicable.



## **Section 5. Evidence or Other Justification for the Focus of the Measure**

The evidence base for the focus of the measures will be made explicit and transparent as part of the public release of CHIPRA deliberations; thus, it is critical for submitters to specify the scientific evidence or other basis for the focus of the measure in the following sections.

### **5.A. Research Evidence**

Research evidence should include a brief description of the evidence base for valid relationship(s) among the structure, process, and/or outcome of health care that is the focus of the measure. For example, evidence exists for the relationship between immunizing a child or adolescent (process of care) and improved outcomes for the child and the public. If sufficient evidence existed for the use of immunization registries in practice or at the State level and the provision of immunizations to children and adolescents, such evidence would support the focus of a measure on immunization registries (a structural measure).

**Describe the nature of the evidence, including study design, and provide relevant citations for statements made. Evidence may include rigorous systematic reviews of research literature and high-quality research studies.**

This measure focuses on care for children with SCD, specifically satisfaction with care from a child's hematologist that, if received, results in desirable clinical outcomes (appropriate comprehensive care for children with SCD). The measure highlights where healthcare providers are falling short in offering quality healthcare from hematologists for children with SCD.

Patient satisfaction is an important aspect of care and can affect individual elements of a patient's experience with a chronic condition, including adherence to treatment and outcomes. For children, their parents and caregivers often serve as the main source of information about the patient's experience with care. For children with SCD, therefore, gathering feedback from families can inform the care their children receive and perhaps influence the course of their treatment. Clinical guidelines indicate that comprehensive care for children with SCD should include oversight from pediatric hematologists regarding disease-related aspects of care. Table 4 (see Supporting Documents) summarizes several key sources of evidence for this measure, using the U.S. Preventive Services Task Force (USPSTF) rankings (criteria denoted in Table 4).

### **5.B. Clinical or Other Rationale Supporting the Focus of the Measure (optional)**

**Provide documentation of the clinical or other rationale for the focus of this measure, including citations as appropriate and available.**

Not applicable.

## **Section 6. Scientific Soundness of the Measure**

**Explain the methods used to determine the scientific soundness of the measure itself. Include results of all tests of validity and reliability, including description(s) of the study sample(s) and methods used to arrive at the results. Note how characteristics of other data systems, data sources, or eligible populations may affect reliability and validity.**

### **6.A. Reliability**

**Reliability of the measure is the extent to which the measure results are reproducible when conditions remain the same. The method for establishing the reliability of a measure will depend on the type of measure, data source, and other factors.**

**Explain your rationale for selecting the methods you have chosen, show how you used the methods chosen, and provide information on the results (e.g., the Kappa statistic). Provide appropriate citations to justify methods.**

This measure is based on survey results, with eligibility determined using newborn screening results obtained from the Michigan Department of Community Health (MDCH).

#### **Data and Methods**

Our testing data consisted of survey results from an SCD health status assessment given to Michigan residents with SCD by the Michigan chapter of the SCDA, in conjunction with MDCH in an effort to document unmet needs. While the SCDA ultimately will complete these surveys from among all individuals with SCD in Michigan, the results presented here are based on a convenience sample of the SCD population.

### **6.B. Validity**

**Validity of the measure is the extent to which the measure meaningfully represents the concept being evaluated. The method for establishing the validity of a measure will depend on the type of measure, data source, and other factors.**

**Explain your rationale for selecting the methods you have chosen, show how you used the methods chosen, and provide information on the results (e.g., R<sup>2</sup> for concurrent validity).**

The validity of this measure was determined from two perspectives: face validity and concurrent validity of the survey data, with health services utilization determined from administrative claims.

#### **Face Validity**

Face validity is the degree to which the measure construct characterizes the concept being assessed. The face validity of this measure was established by a national panel of experts and advocates for families of children with SCD convened by Q-METRIC. This expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, measure validity was considered by experts in State Medicaid program operations, health plan quality measurement, health informatics, and healthcare quality.

measurement. In total, the Q-METRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for States and health plans.

The Q-METRIC expert panel concluded that this measure has a 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: satisfaction with care from the hematologist received an average score of 7.2; a score of 9 represented the highest possible ranking.

### **Validity of Survey Data**

This measure was tested using parent survey response data linked to Medicaid administrative claims to gauge the degree to which respondents had office visits during the measurement year. Overall, 182 parents or responsible parties completed the health status assessment survey; of those, a total of n=144 (79 percent) could be matched with Michigan Medicaid administrative claims. Among the n=144 of Medicaid beneficiaries, 93 percent had one or more claims for an office or outpatient visit during the measurement period.

## **Section 7. Identification of Disparities**

**CHIPRA requires that quality measures be able to identify disparities by race, ethnicity, socioeconomic status, and special health care needs. Thus, we strongly encourage nominators to have tested measures in diverse populations. Such testing provides evidence for assessing measure's performance for disparities identification. In the sections below, describe the results of efforts to demonstrate the capacity of this measure to produce results that can be stratified by the characteristics noted and retain the scientific soundness (reliability and validity) within and across the relevant subgroups.**

### **7.A. Race/Ethnicity**

Race and ethnicity data from the State of Michigan are presented in Table 5 (see Supporting Documents); the data represent the State's entire population of births from 2004 to 2008 with an initial newborn screening result indicating SCD. The table summarizes the distribution across race and ethnicity groups for all SCD births in Michigan during the specified time period. This information was not gathered as part of the parent satisfaction survey.

### **7.B. Special Health Care Needs**

The survey data collected for this study did not include indicators of special healthcare needs.

### **7.C. Socioeconomic Status**

The survey data collected for this study did not include indicators of socioeconomic status.

### **7.D. Rurality/Urbanicity**

The survey data collected for this study did not include indicators of rural/urban residence.

## 7.E. Limited English Proficiency (LEP) Populations

The survey data collected for this study did not include indicators of LEP.

## Section 8. Feasibility

**Feasibility is the extent to which the data required for the measure are readily available, retrievable without undue burden, and can be implemented for performance measurement. Using the following sections, explain the methods used to determine the feasibility of implementing the measure.**

### 8.A. Data Availability

#### 1. What is the availability of data in existing data systems? How readily are the data available?

Our testing data consisted of survey results from an SCD health status assessment given to Michigan residents with SCD by the Michigan chapter of the SCDA, in conjunction with the MDCH, in an effort to document unmet needs. SCDA maintains a roster of people living with SCD in Michigan. The majority of those on the list were identified by Michigan's newborn screening program as having SCD, but the roster also includes people living with the disease who may have moved into the State. SCDA maintains different levels of contact with people on the roster, depending on age, for center activities such as monitoring penicillin prophylaxis, assessing psychosocial needs and linking with services, and offering education and support groups. Contact is maintained by five patient advocates with social work training located in the communities where the majority of people with SCD reside (Saginaw/Flint, Grand Rapids/Muskegon, Kalamazoo/Benton Harbor, Lansing/Jackson, Detroit/Ann Arbor/Pontiac).

Part of the ongoing contact that SCDA maintains with its clients includes collection of the health status assessment survey, which has been collected periodically over the past 5 years. The survey is conducted through in-person interviews for many participants; it also may be conducted over the phone, if a participant prefers. Patient advocates began with their existing rosters for their area and contacted participants based on usual work schedule to avoid surveying participants who had just participated in the psychosocial assessment survey.

These are intensive interviews, as there is often discussion about needs beyond the survey questions themselves. This is important information for the patient advocate to have to guide activities for individual clients. There are multiple tasks that occur out of the interview, and patient advocates follow up with participants for referrals or education after the survey is completed.

Each month, the patient advocates gather in the Detroit offices of the SCDA. Part of that monthly meeting includes education around the survey tool, resolution of issues/problems with the tool or with logistics of reporting the results to SCDA, and most importantly for

participants, discussion of the needs of the individual participants and the overall population identified on the survey.

Results for this measure indicate a high degree of satisfaction among parents for the care provided by their child's hematologist. Overall, n=182 parents or guardians of children with SCD responded to the survey question. The vast majority (92 percent) of these respondents indicated a high degree of satisfaction (rated 4 or 5) with hematologist care (Figure 1; see Supporting Documents); few (5 percent) indicated a lower satisfaction rating (3 or lower), while 4 percent indicated that the question was not applicable (N/A).

**2. If data are not available in existing data systems or would be better collected from future data systems, what is the potential for modifying current data systems or creating new data systems to enhance the feasibility of the measure and facilitate implementation?**

Not applicable. See section 11.D in this report regarding opportunities for future data systems to facilitate implementation of this measure.

## **8.B. Lessons from Use of the Measure**

**1. Describe the extent to which the measure has been used or is in use, including the types of settings in which it has been used, and purposes for which it has been used.**

To our knowledge, this measure is not currently in use anywhere in the United States.

**2. If the measure has been used or is in use, what methods, if any, have already been used to collect data for this measure?**

Not applicable.

**3. What lessons are available from the current or prior use of the measure?**

Not applicable.

## **Section 9. Levels of Aggregation**

**CHIPRA states that data used in quality measures must be collected and reported in a standard format that permits comparison (at minimum) at State, health plan, and provider levels. Use the following table to provide information about this measure's use for reporting at the levels of aggregation in the table.**

**For the purpose of this section, please refer to the definitions for provider, practice site, medical group, and network in the Glossary of Terms.**

**If there is no information about whether the measure could be meaningfully reported at a specific level of aggregation, please write "Not available" in the text field before progressing to the next section.**

***Level of aggregation (Unit) for reporting on the quality of care for children covered by Medicaid/ CHIP†:***

***State level\* Can compare States***

***Intended use: Is measure intended to support meaningful comparisons at this level? (Yes/No)***

Yes.

***Data Sources: Are data sources available to support reporting at this level?***

Yes.

***Sample Size: What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?***

This sample would include parent/guardian responses for eligible children with SCD identified in their respective State (see Table 2 in the Supporting Documents).

***In Use: Have measure results been reported at this level previously?***

No.

***Reliability & Validity: Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?***

No.

***Unintended consequences: What are the potential unintended consequences of reporting at this level of aggregation?***

None identified.

***Other geographic level: Can compare other geographic regions (e.g., MSA, HRR)***

***Intended use: Is measure intended to support meaningful comparisons at this level? (Yes/No)***

No.

***Data Sources: Are data sources available to support reporting at this level?***

No.

***Sample Size: What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?***

Not applicable.

***In Use: Have measure results been reported at this level previously?***

No.

***Reliability & Validity: Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?***

No.

***Unintended consequences:*** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

***Medicaid or CHIP Payment model:*** Can compare payment models (e.g., managed care, primary care case management, FFS, and other models)

***Intended use:*** Is measure intended to support meaningful comparisons at this level? (Yes/No)

No.

***Data Sources:*** Are data sources available to support reporting at this level?

No.

***Sample Size:*** What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?

Not applicable.

***In Use:*** Have measure results been reported at this level previously?

No.

***Reliability & Validity:*** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

***Unintended consequences:*** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

***Health plan\*:*** Can compare quality of care among health plans.

***Intended use:*** Is measure intended to support meaningful comparisons at this level? (Yes/No)

No.

***Data Sources:*** Are data sources available to support reporting at this level?

No.

***Sample Size:*** What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?

Not applicable.

***In Use:*** Have measure results been reported at this level previously?

No.

**Reliability & Validity:** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

**Unintended consequences:** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

**Provider Level**

**Individual practitioner:** Can compare individual health care professionals

**Intended use:** Is measure intended to support meaningful comparisons at this level?  
(Yes/No)

No.

**Data Sources:** Are data sources available to support reporting at this level?

No.

**Sample Size:** What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?

Not applicable.

**In Use:** Have measure results been reported at this level previously?

No.

**Reliability & Validity:** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

**Unintended consequences:** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

**Provider Level**

**Hospital:** Can compare hospitals

**Intended use:** Is measure intended to support meaningful comparisons at this level?  
(Yes/No)

No.

**Data Sources:** Are data sources available to support reporting at this level?

No.

**Sample Size:** What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?



Not applicable.

***In Use:*** Have measure results been reported at this level previously?

No.

***Reliability & Validity:*** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

***Unintended consequences:*** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

***Provider Level***

***Practice, group, or facility:\*\* Can compare:*** (i) practice sites; (ii) medical or other professional groups; or (iii) integrated or other delivery networks

***Intended use:*** Is measure intended to support meaningful comparisons at this level?  
(Yes/No)

No.

***Data Sources:*** Are data sources available to support reporting at this level?

No.

***Sample Size:*** What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?

Not applicable.

***In Use:*** Have measure results been reported at this level previously?

No.

***Reliability & Validity:*** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

***Unintended consequences:*** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

## **Section 10. Understandability**

**CHIPRA states that the core set should allow purchasers, families, and health care providers to understand the quality of care for children. Please describe the usefulness of this measure toward achieving this goal. Describe efforts to assess the understandability of this measure (e.g., focus group testing with stakeholders).**

This measure provides a straightforward means to assess levels of family satisfaction with care provided to children with SCD by their hematologist. Low rates of satisfaction are easily understood to be unacceptable. The simplicity of the measure likewise makes it a straightforward guide for providers and purchasers to assess how well comprehensive care, including pediatric hematology care, is managed in children with SCD.

This measure has not been assessed for comprehension. The primary information needed for this measure comes from survey data.

## **Section 11. Health Information Technology**

**Please respond to the following questions in terms of any health information technology (health IT) that has been or could be incorporated into the measure calculation.**

### **11.A. Health IT Enhancement**

**Please describe how health IT may enhance the use of this measure.**

Electronic health records (EHRs) provide mechanisms for improving all aspects of care before, during, and after the visit, while personal health records and applications are able to target patients.

Satisfaction with care is information that could be fed back to providers and healthcare systems, who can then explore, using data from the EHR, specific parameters that affect satisfaction. For example, a hematologist might provide less satisfactory care related to delays in scheduling appointments, long visit times, and/or errors of omission (forgetting to prescribe and having to be reminded) or commission (ordering a blood test multiple times.) Each of these reasons for lowered satisfaction may be addressed using health IT.

### **11.B. Health IT Testing**

**Has the measure been tested as part of an electronic health record (EHR) or other health IT system?**

No.

**If so, in what health IT system was it tested and what were the results of testing?**

Not applicable.

### **11.C. Health IT Workflow**

**Please describe how the information needed to calculate the measure may be captured as part of routine clinical or administrative workflow.**

Satisfaction with any visit is most accurately captured immediately after the visit, and those results are recorded by people uninvolved with the visit. The information for this measure might be captured easily using text messaging, a check-out kiosk in locations away from the provider, or

via a phone call within hours of the visit (as is common practice in many settings already.) Other options, such as secure patient portals, may offer alternatives to capturing patient (parent/guardian) satisfaction information in a timely manner. Portals currently use secure messaging in a “content-agnostic” method to deliver messages to patients (parents/guardians of patients). It is possible that completion of an office visit recorded in an EHR could trigger a parent survey request to be delivered via patient portals. As these patient portal technologies improve their interfaces to support small form-factor screens (e.g., smart phones), the timeliness of patient satisfaction feedback following an office visit will be improved. In all cases, these results then need to be placed in a standard setting. One potential enhancement to the EHR data model would be to add a field corresponding to whether a satisfaction survey was requested and received. The satisfaction information itself could be stored with a visit ID from the encounter (mapping back to provider, clinic, and date of visit) to facilitate combining EHR data with these data.

#### **11.D. Health IT Standards**

**Are the data elements in this measure supported explicitly by the Office of the National Coordinator for Health IT Standards and Certification (ONC) criteria (see [healthit.hhs.gov/portal/server.pt/community/healthit\\_hhs\\_gov\\_\\_standards\\_ifr/1195](http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__standards_ifr/1195))?**

Yes.

**If yes, please describe.**

The ONC’s Health IT Standards explicitly address the receipt of laboratory results and other diagnostic tests into EHRs, which are directly relevant to this measure. In addition, these standards indicate the requirement for EHRs to track specific patient conditions, such as SCD. The ONC standards include the following specific requirements in the Certification criteria (ONC, 2010) pertaining to Stage 2 Meaningful Use requirements:

Stage 2 (beginning in 2013): CMS has proposed that its goals for the Stage 2 meaningful use criteria expand upon the Stage 1 criteria to encourage the use of health IT for continuous quality improvement at the point of care. In addition, the exchange of information in the most structured format possible is encouraged. This can be accomplished through mechanisms such as the electronic transmission of orders entered using computerized provider order entry (CPOE) and the electronic transmission of diagnostic test results. Electronic transmission of diagnostic test results includes a broad array of data important to quality measurement, such as blood tests, microbiology, urinalysis, pathology tests, radiology, cardiac imaging, nuclear medicine tests, and pulmonary function tests.

Incorporate clinical lab-test results into EHR as structured data:

1. Electronically receive clinical laboratory test results in a structured format and display such results in human readable format.
2. Electronically display in human readable format any clinical laboratory tests that have been received with LOINC® codes.
3. Electronically display all the information for a test report specified at 42 CFR 493.1291(c)(1)

through (7).

Generate lists of patients by specific conditions to use for quality improvement reduction of disparities outreach:

4. Enable a user to electronically update a patient's record based upon received laboratory test results. Enable a user to electronically select, sort, retrieve, and output a list of patients and patients' clinical information, based on user-defined demographic data, medication list, and specific conditions.

As a consequence, EHRs would be enabled to identify patients with SCD to conduct patient (parent/guardian of patient) satisfaction surveys using technologies linked to the EHR, such as short message service text messaging, auto-dialer phone calls, or secure patient portals.

## **11.E. Health IT Calculation**

**Please assess the likelihood that missing or ambiguous information will lead to calculation errors.**

Missing or ambiguous information in the following areas could lead to missing cases or calculation errors:

1. Child's date of birth.
2. Hemoglobin variants used to identify SCD.
3. Specialist (hematologist) visit.
4. Visit type (office visit).
5. Survey responses.
6. Survey dates.

## **11.F. Health IT Other Functions**

**If the measure is implemented in an EHR or other health IT system, how might implementation of other health IT functions (e.g., computerized decision support systems in an EHR) enhance performance characteristics on the measure?**

Health IT has been demonstrated to improve provider completeness, communication legibility, transmission turnaround times, safety (especially related to medication and procedural errors), and care quality in many settings. This measure may be an indirect gauge of a number of things. By integrating the results of this measure into a health IT system, it may enable providers to directly make changes in care delivery that affect these measures. For example, how might a hematologist change visits after a patient expresses dissatisfaction? This record gives the provider a more complete picture of care and allows the provider to offer a more complete service to the patient. A special visit, a home visit, or other interventions may be appropriate; these, in turn, likely affect at least one of these measures.

## Section 12. Limitations of the Measure

**Describe any limitations of the measure related to the attributes included in this CPCF (i.e., availability of measure specifications, importance of the measure, evidence for the focus of the measure, scientific soundness of the measure, identification of disparities, feasibility, levels of aggregation, understandability, health information technology).**

This measure assesses the percentage of parents and guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded, on a scale of 1 to 5, “Satisfied (4)” or “Very Satisfied (5)” to a survey question regarding satisfaction with care from their child’s hematologist. A higher proportion indicates better performance, as reflected by high parent/guardian satisfaction.

This measure is implemented and tested with parent/guardian survey data. The primary information needed for this measure includes date of birth, newborn screening results (hemoglobin variants), specialist (hematologist) visits, type of visit (office), parent or guardian survey responses, and dates of administration. These data may be available from State community health/public health departments and from local/State-level nonprofits supporting individuals diagnosed with SCD. As noted in section 11.C, continuing advances in the development and implementation of electronic health records may allow for the integration of survey results in ways that enable providers to be responsive to issues of satisfaction.

## Section 13. Summary Statement

**Provide a summary rationale for why the measure should be selected for use, taking into account a balance among desirable attributes and limitations of the measure. Highlight specific advantages that this measure has over alternative measures on the same topic that were considered by the measure developer or specific advantages that this measure has over existing measures. If there is any information about this measure that is important for the review process but has not been addressed above, include it here.**

This measure, Satisfaction with Care from the Hematologist for Children with Sickle Cell Disease, assesses the percentage of parents and guardians of children younger than 18 years of age identified as having sickle cell disease (SCD) who responded to a survey question regarding satisfaction with care from their child’s hematologist. A higher proportion indicates better performance, as reflected by high parent/guardian satisfaction. This measure was tested using survey data. There are no existing quality measures assessing satisfaction with hematology care for children with SCD.

For young children with SCD, a pediatric hematologist is a crucial member of their healthcare team, offering guidance about comprehensive care and expertise regarding treatment for acute illnesses. Based on these encounters, patients with SCD and their families have direct and relevant experience to offer regarding care received. Parent surveys provide a valuable mechanism by which to gather and reflect the patient/caregiver perspective back to providers. Providers, in turn, can use this information to improve practices and better support their pediatric patients as they face this challenging disease. However, assessing patient satisfaction is a complex task, given the subjective nature of the information involved. Expectations vary from

one patient and family to another; patient satisfaction as a quality measurement has to account for differences in expectations.

Likewise, satisfaction isn't static. As providers make improvements, patients may shift their expectations accordingly. Surveys have shown satisfaction can be improved with simple changes. Extra time spent by providers—in this case, hematologists—with patients has been shown in the literature to improve satisfaction. However, it is associated with expense; health plans must consider the tradeoff between cost and the quality perceived by families.

This measure was tested using responses from 182 parents or guardians of children younger than 18 years of age with SCD. Overall, results showed that 92 percent of parents or guardians indicated a high degree of satisfaction (rated 4 or 5) with care provided by their child's hematologist.

This measure provides families, providers, and purchasers with a straightforward means of assessing how well basic levels of comprehensive care are being provided for children with SCD, including satisfaction with hematology care or satisfaction. The primary information needed for this measure includes birth dates, newborn screening results (hemoglobin variants), specialist (hematologist) visits, visit type (office), survey responses, and dates of survey administration. Continuing advances in the development and implementation of health IT may support improvements in care by feeding satisfaction results back to providers and healthcare systems, who can then explore specific parameters that affect satisfaction, using data from the EHR.

## References

Agency for Healthcare Research and Quality. Welcome to HCUPnet: Healthcare Cost and Utilization Project (HCUP). Web site; 2012. Available at <http://hcupnet.ahrq.gov/>. Accessed January 22, 2019.

American Academy of Pediatrics (AAP) Section on Hematology/Oncology and Committee on Genetics. Health supervision for children with sickle cell disease. *Pediatrics* 2002; 109(3):526-35.

Alvim RC, Viana MB, Pires MA, et al. Inefficacy of piracetam in the prevention of painful crises in children and adolescents with sickle cell disease. *Acta Haematol* 2005; 113(4):228-33.

Darby C. Patient/parent assessment of the quality of care. *Ambul Pediatr* 2002; 2(4 Suppl):345-8.

Halfon N, Inkelas M, Mistry R, et al. Satisfaction with health care for young children. *Pediatrics* 2004; 113:1965-72.

Hassell KL. Population estimates of sickle cell disease in the U.S. *Am J Prev Med* 2010; 38(4 Suppl):S512-21.

Kauf TL, Coates TD, Huazhi L, et al. The cost of health care for children and adults with sickle cell disease. *Am J Hematol* 2009; 84(6):323-7.

Kavanagh PL, Sprinz PG, Vinci SR, et al. Management of children with sickle cell disease: A comprehensive review of the literature. *Pediatrics* 2011; 128(6):e1552-74.

Kuhlthau K, Ferris TGG, Beal AC, et al. Who cares for Medicaid-enrolled children with chronic conditions? *Pediatrics* 2001; 108(4):906-12.

Lemanek KL, Ranalli M, Lukens C. A randomized controlled trial of massage therapy in children with sickle cell disease. *J Pediatr Psychol* 2009; 34(10):1091-6.

Lewis CC, Scott DE, Pantell RH, et al. Parent satisfaction with children's medical care. *Med Care* 1986; 24(3):209-15.

National Heart, Lung and Blood Institute. *The Management of Sickle Cell Disease*. (4<sup>th</sup> ed). Bethesda, MD: National Institutes of Health; 2002.

Office of the National Coordinator for Health IT Standards and Certification (ONC). *Health information technology: Initial set of standards, implementation specifications, and certification criteria for electronic health record technology.* *Fed Regist* 2010; 75(8):2013-47.

Raphael JL, Dietrich CL, Whitmire D, et al. Healthcare utilization and expenditures for low income children with sickle cell disease. *Pediatr Blood Cancer* 2009; 52(2):263-7.

Steinberg MH. Management of sickle cell disease. *N Engl J Med* 1999; 340(13):1021-30.

Tanabe P, Dias N, Gorman L. Care of children with sickle cell disease in the emergency department: Parent and provider perspectives inform quality improvement efforts. *J Pediatr Oncol Nurs* 2013; 30(4):205-17.

Yanni E, Grosse SD, Yang Q, et al. Trends in pediatric sickle cell disease-related mortality in the United States, 1983-2002. *J Pediatr* 2009; 154(4):541-5.

## **Section 14: Identifying Information for the Measure Submitter**

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**The CHIPRA Pediatric Quality Measures Program (PQMP) Candidate Measure Submission Form (CPCF) was approved by the Office of Management and Budget (OMB) in accordance with the Paperwork Reduction Act.**

**The OMB Control Number is 0935-0205 and the Expiration Date is December 31, 2015.**

### **Public Disclosure Requirements**

**Each submission must include a written statement agreeing that, should U.S. Department of Health and Human Services accept the measure for the 2014 and/or 2015 Improved Core Measure Sets, full measure specifications for the accepted measure will be subject to public disclosure (e.g., on the Agency for Healthcare Research and Quality [AHRQ] and/or Centers for Medicare & Medicaid Services [CMS] websites), except that potential measure users will not be permitted to use the measure for commercial use. In addition, AHRQ expects that measures and full measure specifications will be made reasonably available to all interested parties. "Full measure specifications" is defined as all information that any potential measure implementer will need to use and analyze the measure, including use and analysis within an electronic health record or other health information technology. As used herein, "commercial use" refers to any sale, license or distribution of a measure for commercial gain, or incorporation of a measure into any product or service that is sold, licensed or distributed for commercial gain, even if there is no actual charge for inclusion of the measure. This statement must be signed by an individual authorized to act for any holder of copyright on each submitted measure or instrument. The authority of the signatory to provide such authorization should be described in the letter.**

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