

Satisfaction with Care in the Emergency Department for Children with Sickle Cell Disease

Section 1. Basic Measure Information

1.A. Measure Name

Satisfaction with Care in the Emergency Department for Children with Sickle Cell Disease

1.B. Measure Number

0220

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 about satisfaction with care received in the emergency department (ED). 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. Because children with SCD are urged to seek care as soon as complications arise, many will visit an ED with time-sensitive issues such as infection, fever, and pain. 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. Examples of possible practice adjustments include providing patients and families in the ED with realistic time estimates and detailed discharge instructions. There are no existing quality measures for assessing satisfaction of care in the ED for children with SCD.

This measure uses survey responses to calculate 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 received in the ED.

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 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 “Satisfied (4)” or “Very Satisfied (5)” to a survey question (Table 1; see Supporting Documents) regarding satisfaction with the care received in the ED 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, 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 a survey question regarding satisfaction with the care received in the ED 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, 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.

Detailed technical specifications for this measure are available; please see the Supporting Documents.

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 Africa 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 the condition (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 continues to improve over time, 196 children in the United States 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. 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 health sciences to manage a health problem); and (2) the interpersonal aspect of care (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 positive 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 HbS 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. Given the speed with which children with SCD can become sick and the severity of the illnesses they face, such as stroke and sepsis, access to 24-hour care is essential. Many patients will need to be seen at an ED, where rapid, expert assessment is essential. In a study of the Healthcare Cost and Utilization Project inpatient and ED databases, Brousseau and colleagues found that for acute care encounters per year in children with SCD ages 1 to 9 years, 57.4 percent had one to two visits per year, and 8.6 percent had 3 to 10 encounters. For children with SCD ages 10 to 17, those numbers were 51.0 percent and 12.6 percent, respectively (Brousseau, Owens, Mosso, et al., 2010).

Results from existing surveys offer examples of specific improvements to address patient satisfaction regarding care in the ED. Research shows that steps to improve patient satisfaction include giving patients and families a clear sense of the likely waiting time, taking a caring approach to children and their families, and providing clear instructions for care following discharge (Darby, 2002).

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 survey questions regarding satisfaction with care received in the ED. 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' level of satisfaction with medical care (Lewis, et al., 1986).

Regarding satisfaction with care provided during ED visits, research shows that satisfaction correlates with aspects such as waiting time and a caring approach from providers (Darby, 2002). Underdeveloped quality standards for treating children with SCD presenting to the ED also pose a gap (Tanabe, Dias, Gorman, 2013). Caring for children in this setting is complex from both the medical and behavioral perspectives. Children vary developmentally, and their ability to communicate and degree of independence may vary widely. For children with SCD, physical challenges and neurocognitive deficits can make ED visits even more complicated. The quality measures developed by Q-METRIC are one approach to providing consistent standards of care, as are quality of care indicators, such as those proposed by Wang and colleagues (Wang, Kavanagh, Little, et al., 2011).

Adequate treatment of pain is a particular concern for children with SCD and their families when they seek care in the ED. Several barriers exist regarding the effective management of pain in children with SCD. Pain assessment poses many challenges in infants and preverbal children with SCD, given the subjective and complex nature of vaso-occlusive pain, as well as the development and language limitations that preclude comprehension and self-report (Stinson, Naser, 2003). Clinicians are sometimes suspicious about the truth or validity of the pain scores reported by children with SCD. These providers often believe that children who are watching TV, playing, or sleeping are not in as much pain as they report. But children may use these strategies as ways of coping with pain. The disparity between the patient's self-report and his or her affect and behavior leads to distrust on the part of healthcare providers. Further, unfamiliarity with the effective use of analgesics and fear of adverse effects, such as respiratory depression and addiction, may affect the clinician's use of analgesics, resulting in a cycle of under-treatment of pain (Stinson, Naser, 2003). Healthcare providers should be trained to assess and manage SCD pain so as not to unwittingly dismiss a patient's pain or cause an exacerbation of pain-related behaviors. Education is important because inconsistent or adversarial care given in these settings can cause mistrust or other problems that affect patients' relationships with other healthcare professionals (NHLBI, 2002).

Another common complaint among patients with SCD and their families involves receiving inappropriate care in the ED because staff members are unfamiliar with the individual presenting. Given the fast pace of most EDs and the needs of the young patient with SCD for rapid and efficient evaluation, quick access to individual care plans and patient records is essential. Electronic medical records, patient information cards, and phone calls to patient providers are all ways to transmit information quickly during an emergency (NHLBI, 2002).

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).

In a study looking at acute care encounters (ED and hospitalization combined), Brousseau and colleagues (2010) found that for patients with SCD, children ages 1-9 years with public insurance had 1.6 visits per year compared with 1.4 visits for those with private insurance and 1.1 visits for the uninsured. Research looking at patients with SCD enrolled in TennCare, Tennessee's Medicaid managed healthcare program, from January 1995 to December 2002, showed much

higher rates of ED use compared with similar patients in TennCare without SCD. For children younger than 5 years of age, the rate ratio (RR) of ED visits per 1,000 person years was 1.8 for boys (95 percent confidence interval [CI] = 1.7 to 1.9) and 2.0 for girls (1.9 -2.2). For those ages 5 to 9 years, the RR for boys was 2.7 (2.5-2.9) and for girls was 3.0 (2.8-3.2). For those ages 10 to 19 years, the RR for boys was 3.7 (3.5-3.9) and for girls was 3.7 (3.4-3.7) (Shankar, Arbogast, Mitchel, et al., 2005).

Medicaid enrollment often serves as a marker of poverty. The large number of children with SCD on Medicaid suggests that 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, et al., 2013). Having consistent standards of care to treat children quickly and effectively when they present in the ED will help address the 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, taken 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: No.**
- e. Service – care for acute conditions: Yes.**
- 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):** Not applicable.
- n. **Population – pregnant women:** Not applicable.
- 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 received in the ED) that, if received, results in desirable clinical outcomes (appropriate acute care for children with SCD). The measure highlights where healthcare providers are falling short in offering quality healthcare in the ED 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 children with SCD should receive sensitive, prompt, and thorough care when presenting to an ED. 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).

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 Sickle Cell Disease Association of America (SCDAA), in conjunction with the MDCH in an effort to document unmet needs. While the SCDAA 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., R2 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. The Q-METRIC 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 in the ED received an average score of 7.7; 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 ED visits during the measurement year. Overall, 183 parents/responsible parties completed the health status assessment survey; of those, a total of 143 (78 percent) could be matched with Michigan Medicaid administrative claims. Among the 143 Medicaid beneficiaries, 60 percent had one or more claims for an ED 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 for its entire population of births from 2004 to 2008 with an initial newborn screening result indicating SCD are shown in Table 5 (see Supporting Documents); the distribution across race and ethnicity groups is summarized. This information was not gathered as part of the parent satisfaction survey.

7.B. Special Health Care Needs

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

7.C. Socioeconomic Status

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

7.D. Rurality/Urbanicity

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

7.E. Limited English Proficiency (LEP) Populations

The survey data gathered 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, and Detroit/Ann Arbor/Pontiac).

Part of the ongoing contact that SCDAAs maintains with its clients includes administration 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 may also 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 SCDAAs. 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 SCDAAs, 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 received in the ED. Overall, 182 parents of children with SCD responded to the survey question. The majority (85 percent) of these respondents indicated a high degree of satisfaction (rated 4 or 5) with ED care (Figure, see Supporting Documents); 15 percent indicated a lower satisfaction rating (3 or lower), while 38 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 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?

The sample would include parent/guardian responses from eligible children with SCD identified in their respective State (Table 2; see 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 satisfaction with care provided to children with SCD in the ED. 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 treatment in the ED, is managed in children with SCD.

This measure has not been assessed for comprehension. The primary information 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.

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 ED visit recorded in an EHR could trigger a parent survey request to be delivered via a patient portal. 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 ED 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)?

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. Visit type (emergency department).
4. Survey responses.
5. 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. Integrating the results of this measure into a health IT system may enable providers to directly make changes in care delivery that affect these measures. For example, how might ED staff change procedures after a patient expresses dissatisfaction? This record gives a more complete picture of care and allows providers to offer a more complete service to the patient.

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 SCD who responded, on a scale of 1 to 5, “Satisfied (4)” or “Very Satisfied (5)” to survey questions regarding satisfaction with the care received in the ED. 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), parent or guardian survey responses, visit type, and dates of administration. These data may be available from State community health/public health departments and from local/State-level nonprofit organizations supporting individuals diagnosed with SCD. As noted in section 11.C, continuing advances in the development and implementation of EHRs 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 in the Emergency Department for Children with Sickle Cell Disease, assesses the percentage of parents and guardians of children younger than 18 years of age identified as having SCD who responded to a survey question regarding satisfaction with

care received in the ED. 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 ED care for children with SCD.

Because children with SCD are urged to seek care as soon as complications arise, many will visit an ED with time-sensitive issues such as infection, fever, and pain. Based on these encounters with ED staff, 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. Survey results have shown that taking time in a busy ED to keep patients informed about matters such as realistic waiting times and providing them with clear, comprehensive instructions at discharge improves satisfaction.

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 85 percent of parents or guardians indicated a high degree of satisfaction (rated 4 or 5) with care provided in the ED.

This measure provides a straightforward means of assessing how well basic levels of comprehensive care are being provided for children with SCD, including satisfaction with ED care. The primary information needed for this measure includes birth dates, newborn screening results (hemoglobin variants), survey responses, type of visit, 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.

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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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