Anticipatory Guidance Regarding School Attendance/Performance for Children with Sickle Cell Disease

Section 1. Basic Measure Information

1.A. Measure Name

Anticipatory Guidance Regarding School Attendance/Performance for Children with Sickle Cell Disease

1.B. Measure Number

0226

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 percentage of children 5 through 17 years of age identified as having sickle cell disease who received anticipatory guidance regarding school attendance/performance as part of outpatient care during the measurement year. A higher proportion indicates better performance as reflected by appropriate guidance.

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 blood disorder, characterized by the presence of hemoglobin S (HbS). From infancy onward, the presence of this hemoglobin variant can lead to an array of serious medical complications. Children who have chronic diseases are likely to miss significant amounts of school, and those with SCD are no exception.

Reasons for absence from school and school activities include pain episodes, recurring complications such as infections, and the significant number of healthcare appointments needed for comprehensive SCD care. With regard to school performance, a number of children with SCD suffer strokes and silent brain infarcts, both of which can affect their ability to manage schoolwork.

Anticipatory guidance on the subject of school attendance is helpful to better enable young patients with SCD and their families to proactively manage the many challenges associated with this important aspect of their lives. However, there are no existing quality measures regarding the provision of anticipatory guidance in the context of outpatient care for school attendance for children with SCD.

This measure uses medical record data and is calculated as the percentage of eligible children who received anticipatory guidance regarding school attendance and performance as part of outpatient care.

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 Medical Record Data 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 the number of children 5 through 17 years of age with SCD who received anticipatory guidance regarding school attendance and performance as part of outpatient care during the measurement year (January 1-December 31). Eligible children

are restricted to those with SCD variants identified in Table 1 (see Supporting Documents), based on appropriate ICD-9 codes as documented in the medical record. Evidence of anticipatory guidance is determined through medical record review of outpatient visits (Table 2; see Supporting Documents).

Anticipatory guidance is any written or face-to-face verbal communication regarding school attendance or school performance as part of outpatient care with the patient, parent, or family member. Evidence of anticipatory guidance is determined through medical record review. Documentation must include, at minimum, a note containing the date on which verbal or written anticipatory guidance was provided.

1.H. Numerator Exclusions

1. Inpatient stays, emergency department (ED) visits, and urgent care visits are excluded from the calculation.
2. Children with a diagnosis in the sampled medical record indicating one of the SCD variants listed in Table 3 (see Supporting Documents) should not be included in the eligible population unless there is also a diagnosis for a sickle cell variant listed in Table 1 (see Supporting Documents).

1.I. Denominator Statement

The eligible population for the denominator is the number of children ages 5 through 17 years with SCD who received outpatient care during the measurement year (January 1 – December 31). Eligible children are restricted to those with SCD variants identified in Table 1 (see Supporting Documents), based on appropriate ICD-9 codes as documented in the medical record.

1.J. Denominator Exclusions

1. Inpatient stays, ED visits, and urgent care visits are excluded from the calculation.
2. Children with a diagnosis in the sampled medical record indicating one of the SCD variants listed in Table 3 (see Supporting Documents) should not be included in the eligible population unless there is also a diagnosis for a sickle cell variant listed in Table 1 (see Supporting Documents).

1.K. Data Sources

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

Paper medical record; Electronic medical record.

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 measure specifications are provided; 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 of Anticipatory Guidance Regarding School Attendance and Performance

School is central to the lives of most children, both for learning and social development. Children with SCD, however, face several challenges when trying to have a normal experience at school. First, the myriad physical problems they experience as a consequence of SCD often substantially reduce the amount of time they feel well enough to attend class. Research by Shapiro and colleagues found that children with SCD missed school on approximately 21 percent of school days, with half of those absences due to pain episodes. The absences averaged only 3

days, however, not long enough to qualify for State-supported tutoring (Shapiro, Dinges, Orne, et al., 1995).

Research has shown that increases in stress and negative mood related to pain in children with SCD were associated with reduced school attendance. Positive mood was associated with better participation, even when there was pain (Gil, Carson, Porter, et al., 2003). Understanding the way pain and psychological factors relate to activity and participation is important, as frequent school absences may lead to poor academic progress and other consequences, such as depression. Since pain usually precedes stress and mood changes that are associated with decreases in school attendance, clinicians might consider treating SCD pain more aggressively to preserve school involvement and minimize impact on daily mood (Gil, et al., 2003).

The large number of healthcare appointments associated with comprehensive care for those with SCD – for example, participation in a chronic transfusion program to help prevent first or recurrent stroke – can also interfere with school attendance. Some medical facilities treating children with SCD offer evening and weekend transfusion appointments to help make school participation easier (NHLBI, 2002).

In addition to school absences because of physical illness and healthcare appointments, families may perceive their children as vulnerable and keep them out of school for problems that would not interfere with school attendance for most children (Shapiro, et al., 1995). Likewise, pediatric healthcare professionals, in their desire to protect children with chronic illness, often inadvertently erect barriers to normal childhood behaviors and accomplishments (NHLBI, 2002). Falling behind in school work may lead to a pattern of school avoidance (Shapiro, et al., 1995). Further, socioeconomic factors may also play a role in lack of success in school for children with SCD (NHLBI, 2002).

One very serious impediment to school performance is ischemic injury of the central nervous system. As such, failure to do well in school could be a function of neurological complications of SCD. In many young children with SCD, MRIs will show evidence of silent brain infarcts. These are symptomless strokes that nevertheless cause brain damage. School-age children with compromised neuropsychologic function show a decline in cognitive performance upon testing. Therapeutic interventions before children begin school may well prevent or lessen cognitive impairment (Wang, Langston, Steen, et al., 2001).

Performance Gap

Routine comprehensive care for children with SCD is essential to support their optimal health. Outpatient visits often provide the setting for healthcare providers to make sure parents and other primary caregivers receive anticipatory guidance about a range of important issues specific to managing this challenging condition. It is important, therefore, that all affected children receive dependable outpatient care. To characterize healthcare utilization in children with SCD, Raphael and colleagues (2009) studied administrative claims data for 2007-2009 from a managed care plan serving children with Medicaid and the State Children's Health Insurance Plan (SCHIP). The researchers found that a substantial proportion of children with SCD did not meet minimum guidelines for outpatient primary care and hematology comprehensive care. During the study period, only 63 percent of patients had one routine outpatient visit with a primary care provider,

and only 10 percent had a minimum of one outpatient visit per year with a hematologist. These findings are concerning, as missed visits could mean lost opportunities for assessing health risks and providing anticipatory guidance and education about SCD and associated medical conditions.

Another potential performance gap regarding the provision of anticipatory guidance involves the manner in which guidance is presented. It is important that providers take the time to listen to concerns voiced by the families of children with SCD so that information is presented in a way that is sensitive to medical and psychosocial needs and that families have assistance in assessing available resources. Failure to consider and appreciate ethnic and cultural differences that may exist among providers, patients, and families contributes to misunderstanding and lack of trust. Education should be provided in an open, non-judgmental, mutually respectful environment. Providers should recognize that personal and cultural beliefs about illness, stress, and support systems affect the way that families respond to the challenge of raising a child with this chronic illness (Lane, Buchanan, Hutter, et al., 2001).

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 children with SCD discharged from the hospital were covered by Medicaid, while 25 percent had private insurance (AHRQ, 2012). 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, despite the provision of anticipatory guidance. These children may also experience 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).

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).

Currently, there 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:** 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:** No.
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):** No.
p. **Population – infants (29 days to 1 year) (specify age range):** No.
q. **Population – pre-school age children (1 year through 5 years) (specify age range):** Yes; children ages 5 and older.
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.
t. **Population – other (specify age range):** No.
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 a clinical process (anticipatory guidance regarding school attendance and performance for children with SCD), that, if followed, results in a desirable clinical outcome (regular school attendance and increased likelihood of successful school performance). The measure highlights where providers or health systems are falling short in providing maintenance healthcare for children with SCD.

Illness, healthcare appointments, overprotective caregivers, neurocognitive disabilities, and even patterns of avoidance can all result in difficulties in terms of successful schooling. It is important that patients, families, and healthcare providers spend time discussing the challenges involved in school attendance for children with SCD. Helping these children develop positive, realistic expectations for class work and activities will contribute to making school a meaningful aspect of their lives.

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 medical record data. A description of reliability testing follows.

Data and Methods

Our testing data consisted of an audit of medical records from the three largest centers serving SCD patients in Michigan during 2012: Children's Hospital of Michigan (CHM, Detroit), Hurley Medical Center (Hurley, Flint), and the University of Michigan Health System (UMHS, Ann Arbor). Combined, these sites treat the majority of children with SCD in Michigan. Medical records for all children with SCD meeting the measure specification criteria during the measurement year were abstracted at each site. Abstracting was conducted in two phases; during Phase 1, 435 records were abstracted among the three sites. In Phase 2, an additional 237 cases were abstracted at one site. In total, 672 unique records were reviewed for children with SCD to test this measure.

Reliability of medical record data was determined through re-abstraction of patient record data to calculate the inter-rater reliability (IRR) between abstractors. Broadly, IRR is the extent to which the abstracted information is collected in a consistent manner. Low IRR may be a sign of poorly executed abstraction procedures, such as ambiguous wording in the data collection tool, inadequate abstractor training, or abstractor fatigue. For this project, the medical record data collected by two nurse abstractors were compared.

Measuring IRR at the beginning of the abstraction is imperative to identify any misinterpretations early on. It is also important to assess IRR throughout the abstraction process to ensure that the collected data maintain high reliability standards. Therefore, the IRR was evaluated during Phase 1 at each site to address any reliability issues before beginning data abstraction at the next site.

IRR was determined by calculating both percent agreement and Kappa statistics. While abstraction was still being conducted at each site, IRR assessments were conducted for 5 percent of the total set of unique patient records that were abstracted during Phase 1 of data collection. Two abstractors reviewed the same medical records; findings from these abstractions were then compared, and a list of discrepancies was created.

Three separate IRR meetings were conducted, all of which included a review of multiple SCD measures that were being evaluated. Because of eligibility criteria, not all patients were eligible for all measures. Therefore, records for IRR were not chosen completely at random; rather, records were selected to maximize the number of measures assessed for IRR at each site.

Results

For this measure, 11 of 435 unique patient records (3 percent) from Phase 1 of the abstraction process were assessed for IRR across the three testing sites.

Table 5 (see Supporting Documents) shows the percent agreement and Kappa statistic for the measure numerator for each site and across all sites. The agreement for this measure is 100 percent, and the Kappa is 1.00, indicating that a perfect IRR level was achieved.

Discrepancies

There was perfect agreement among the sample of records selected for IRR, and no discrepancies were noted.

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 validity of medical record data.

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, receiving an average score of 7.2 (with 9 as the highest possible score).

Validity of Abstracted Data

This measure was tested using medical record data, which is considered the gold standard for clinical information. Our findings indicate that these data have a high degree of face validity and reliability. This measure was tested among a total of 342 children ages 5 through 17 years with SCD (Table 6; see Supporting Documents). Overall, 74 percent of children with SCD received

anticipatory guidance regarding school attendance/performance as part of outpatient care (range: 44-83 percent).

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

The measure was tested using medical records from the three largest centers serving SCD patients in Michigan during 2012: CHM, Detroit; Hurley, Flint; and UMHS, Ann Arbor. Combined, these centers serve the vast majority of SCD patients in Michigan. While race and ethnicity data were not abstracted as part of the medical record review process, information is available from the State of Michigan for its entire population of births from 2004 to 2008 with an initial newborn screening result indicating SCD. Table 7 (see Supporting Documents) summarizes the distribution across race and ethnicity groups for all SCD births in Michigan during that time period.

7.B. Special Health Care Needs

The medical records abstracted for this study did not include indicators of special healthcare needs.

7.C. Socioeconomic Status

The medical records abstracted for this study did not include indicators of socioeconomic status.

7.D. Rurality/Urbanicity

The medical records abstracted for this study did not include indicators of rural/urban residence.

7.E. Limited English Proficiency (LEP) Populations

The medical records abstracted 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?

This measure is based on review of medical record data. The medical chart audit included records from the three largest centers serving SCD patients in Michigan during 2012: CHM, Detroit; Hurley, Flint; and UMHS, Ann Arbor. Data were abstracted from medical record systems at two sites that use EHRs (both Epic systems) and from one site using paper charts.

Medical records for 100 percent of children with SCD meeting the measure specification criteria during the measurement year were abstracted from each hospital. In total, 672 unique records were reviewed; 342 records (51 percent) met denominator criteria for this measure.

Based on the abstracted chart data, the rate was calculated as the percentage of children 5 through 17 years of age identified as having SCD who received anticipatory guidance regarding school attendance/performance as part of outpatient care (74 percent); measure numerator (253) divided by denominator (342); see Table 6 in the Supporting Documents.

Medical record abstraction for this measure was accomplished with a data-collection tool developed using LimeSurvey software (version 1.92, formerly PHPSurveyor). LimeSurvey is an open-source online application based in MySQL that enables users to develop and publish surveys, as well as collect responses. The tool was piloted to determine its usability and revised as necessary. The measure specification for this measure also underwent revisions following pilot testing.

Data abstraction was completed by experienced nurse abstractors who had undergone training for each medical record system used, electronic and paper. Abstractors participated in onsite training during which the measure was discussed at length to include the description, calculation, definitions, eligible population specification, and exclusions. Following training, abstractors were provided with a coded list of potentially eligible cases from each of the sites. To abstract all pertinent data, two nurse abstractors reviewed the electronic and paper medical records. In addition to the specific data values required for this measure, key patient characteristics, such as date of birth and hemoglobin variant type, were also collected.

Abstraction Times

In addition to calculating IRR, the study team assessed how burdensome it was to locate and record the information used to test this measure by having abstractors note the time it took to complete each record. During Phase 1, on average, the abstractors spent 13 minutes per eligible SCD case abstracting the data for this measure, with times ranging from 1-30 minutes.

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?

The proposed measure was determined to be feasible by Q-METRIC using medical record data from the three largest centers serving SCD patients in Michigan during 2012. Although paper charts were used at one of the sites, this was not found to be a barrier. In fact, the average time

spent abstracting records from paper charts (12 minutes) was only slightly more than the 11-minute average reported at one center using electronic medical records and much less than the 19-minute average reported for the other site with electronic medical records.

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)**
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.

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)**
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 all children ages 5 through 17 with clinical documentation of sickle cell disease.

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.

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 how well basic levels of comprehensive care are being provided for children with SCD. Low rates for the provision of anticipatory guidance are easily understood to be unsatisfactory. Likewise, the simplicity of the measure makes it a straightforward guide for providers and purchasers to assess how well comprehensive care, including anticipatory guidance, is managed for children with SCD.

This measure has not been assessed for comprehension. The primary information needed for this measure comes from medical records data and includes basic demographics, diagnostic codes,

and procedure codes, all of which are widely available. The nurse abstractors testing the measure provided feedback to refine the abstraction tool and thus the specifications. These changes are reflected in the final documentation.

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.

In the short term, the predominant role of health IT for this measure is through displaying documentation templates and aggregating provider-captured anticipatory guidance information. Because most of this information is in one section of the EHR, it will be relatively easy to find and to use data mining techniques to extract data for the purposes of this measure. Over time, two phenomena may improve the use of the measure. First, it should be possible, given standards regarding ages and stages for providing this guidance, to develop patient-specific templates for documentation. These templates have been shown to improve compliance with recommended care practices, which will result in improved anticipatory guidance discussion. Second, the role of the patient and of patient portals is only beginning to emerge. It will likely be the case that these issues, as well as tools to help patients manage their illness, will be available through applications (apps) or personal health records that then communicate back to EHRs (or care coordinators) to improve the behaviors that these measures address.

11.B. Health IT Testing

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

Yes.

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

This measure was tested using electronic medical record review conducted at two major SCD treatment facilities in Michigan using the Epic electronic health records (EHRs) system. The third facility used paper medical records for outpatient visits.

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.

Anticipatory guidance in general comes in two forms: (1) check box lists or "standardized" text created using documentation templates and (2) unstructured text arising from dictation or potentially scanned documents in an EHR. This will be the primary way these data are captured in routine clinical workflow. Another, though less common, approach is to ask patients to complete forms before a visit. These forms, created by groups such as the American Academy of

Pediatrics (Bright Futures; see https://brightfutures.aap.org/Pages/default.aspx) and customized for specialty-specific conditions, could be captured in any of the methods described above, and would be available to calculate the measure after neuro-linguistic programming techniques or data extraction in some other form took place.

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 ability to create patient-specific reminders for preventive services, broadly defined. While such reminders may be aimed at future appointments for services, they can also include prompts for patients to engage in activities to properly manage chronic conditions (CMS, 2012). In addition, these standards indicate the requirement for EHRs to track specific patient conditions, such as SCD. Consequently, patient reminders for activities to appropriately manage SCD could be achieved through these mechanisms, meeting the goals of anticipatory guidance preventive care. The ONC standards include the following specific requirements in the Certification criteria (ONC, 2010) pertaining to Stage 2 Meaningful Use requirements include:

> (h) Generate patient lists. 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.

11.E. Health IT Calculation

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

1. Child's date of birth.

2. ICD-9 codes selected to indicate sickle cell disease.

3. Date and time of anticipatory guidance.

4. Care setting.

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?

Performance on this measure could benefit from a number of health IT integration steps, including:

a. Documentation templates filled out by providers (or potentially scribes, in communication with providers during the visit) could improve provider behavior with respect to these issues during the visit.

b. Documentation templates created in specialty clinics could help with missed opportunities to provide this counseling in EDs, other clinic visits, home visits, or through patient-initiated contact with the health system via a patient portal or personal health application.

c. Active decision support before, during, or after the visit could prompt providers or patients about these issues.

d. EHRs could generate triggers to providers to provide this guidance (again) based on events that suggest a need to re-teach (such as after an ED visit for pain).

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 children 5 through 17 years of age identified as having SCD who received anticipatory guidance regarding school attendance and performance as part of outpatient care during the measurement year.

This measure is implemented with medical record data and was tested with electronic and paper medical records. The primary information needed for this measure includes date of birth, diagnosis codes, and procedure codes and dates. These data are available, although obtaining them may require a restricted-use data agreement. It also requires the development of an abstraction tool and the use of qualified nurse abstractors. Continuing advances in the development and implementation of electronic medical records may establish the feasibility of regularly implementing this measure with data supplied by electronic medical records.

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.

School is central to the lives of most children, both for learning and social development. It is very important for children with SCD to have a productive and supportive school experience, despite the many challenges of their health status. Clinical guidelines suggest that comprehensive healthcare evaluations provide an ideal setting to offer age-appropriate guidance about school; these visits also provide an opportunity to evaluate and address psychosocial issues and school performance.

Nevertheless, illness, healthcare appointments, overprotective caregivers, neurocognitive disabilities, and even patterns of avoidance can all result in difficulties in terms of successful schooling. Anticipatory guidance on the subject of school attendance helps enable young patients with SCD and their families to proactively manage the many challenges associated with school attendance and to set realistic goals for appropriate academic achievement.

This measure was tested among a total of 342 children ages 5 through 17 years identified as having SCD. Overall, 74 percent of children received anticipatory guidance regarding school attendance/performance as part of outpatient care (range: 44-83 percent).

This measure provides a straightforward means of assessing how well basic levels of comprehensive care, including anticipatory guidance, are being provided for children with SCD. The primary information needed for this measure includes basic demographics, dates, diagnostic codes, and procedure codes, all of which are widely available. Continuing advances in the development and implementation of health IT may establish the feasibility of regularly implementing this measure with data supplied by electronic medical records.

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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.