

# Follow-Up Referral After Positive Developmental Screen

## Section 1. Basic Measure Information

### 1.A. Measure Name

Follow-up Referral after Positive Developmental Screen

### 1.B. Measure Number

0204

### 1.C. Measure Description

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

Percentage of patients aged 6 to 36 months who were referred for follow-up care within 7 calendar days of receiving a positive developmental screening result.

### 1.D. Measure Owner

Agency for Healthcare Research and Quality (AHRQ), Pediatric Measurement Center of Excellence (PMCoE)

### 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.**

Developmental Screening and Follow-up

- 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.**

Developmental Screening and Follow-up

- 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**

Patients who received a referral for follow-up care (see note 1) by the screening clinician within 7 calendar days of receiving a positive developmental screening result (see note 2).

Note 1: Referral for follow-up care is defined as the formal event by which the clinician provides a referral to the patient family (and does not include any further steps in the process, such as securing the appointment, confirming the appointment attendance, etc.) and refers for further evaluation or to any type of therapy, intervention, or education to mitigate developmental delays. A referral can be within the medical home or outside of the medical home. A referral can also include a form of watchful waiting by which the clinician offers practice-based intervention(s) and schedules a follow-up visit within 3 months. Some referral types are listed here, but the list is not exhaustive: Part C, Early Intervention Program, Referral for Follow-up Testing, Home Visiting for 0-5, Physical Therapist, Occupational Therapist, Speech/Language Pathologist, Medical Home Clinician Internal, Specialty Clinician External, Early Head Start, Network Care Manager, Family-to-Family Support, Hearing and Vision Specialists, and Mental Health Specialist.

Note 2: A positive developmental screening result refers to a result from a validated developmental screening tool that indicates the patient tests positive for risk of a developmental delay.

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

None.

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

All patients aged 6 months to 36 months who received a positive developmental screening result or an indication from the family that there is a developmental concern.

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

Patients who have already received or are receiving therapy, intervention, or education that would also be applicable for developmental delay follow-up care.

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

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

Paper Medical Record, Electronic Health Record.

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

## **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.**

Please refer to the attachments for measure specifications.

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

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

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

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

- **Addresses a known or suspected quality gap and/or disparity in quality (e.g., addresses a socioeconomic disparity, a racial/ethnic disparity, a disparity for Children with Special Health Care Needs (CSHCN), a disparity for limited English proficient (LEP) populations).**

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

Follow-up with a referral for either further evaluation or treatment following a concerning developmental screen is essential to early childhood pediatric care quality. However, in a cross-sectional study by Tang et al., high-risk infants who were seen at neonatal follow-up for at least two visits before their third birthday were studied in regards to developmental follow-up and referrals. The authors found that between 34 to 37 percent of high-risk infants who failed a developmental screen were not referred to either early intervention (EI) or other therapies (Tang, Feldman, Huffman, 2012).

Furthermore, in a study conducted by the American Academy of Pediatrics (AAP) (2006), 61 percent of children who failed a developmental screen were not referred for further evaluation. Additionally, in contrast to screening rates, referral rates did not increase between July 2006 and March 2007, in fact they were noticeably lower in the later months of the project. Subgroup analysis found that among practices using the PEDS, fewer than one in three children with a failing result was referred to any source (King, Tandon, Macias, et al., 2010). Further, 6 of the 17 participating practices successfully tracked their patient referrals and found that a large number of families never followed through with their recommended referrals and that many families did not understand the reason for their referral (King, et al., 2010).

Further, as described and documented in the American Academy of Pediatrics policy statement of 2006, Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening (AAP, 2006), early identification and treatment of children with neurodevelopmental and behavioral problems is critical to their well-being and development. This guidance provided the pediatric practitioner with a new paradigm and algorithm to direct screening within the medical home. This policy statement is being revised to “create a universal system of screening of all children in the primary care setting for the wide range of neurodevelopmental and behavioral conditions that affect the early and long term development and achievement of affected children.” Early identification of problems and referral for treatment are essential for children to achieve their full potential. The 2006 policy statement emphasizes the critical need to simultaneously pursue any indicated medical evaluation while also linking the family with EI or early childhood education.

This goal of universal surveillance and screening is encouraged and expected, not only in medical homes, but now with other health care professionals in numerous settings. For example, the Departments of Health and Human Services and Education have just recently launched their developmental and behavioral screening initiative: Birth to 5: Watch Me Thrive! This effort encourages all early childhood experts to work together to screen, identify developmental delays, and refer for more in-depth evaluation and treatment, as appropriate (Birth to 5, Web site). The Federal partners that are a part of this initiative speak to the need and importance of screening and referral and include: the Administration for Children and Families; the Centers for Disease Control and Prevention; the National Institute of Child Health and Human Development; the Substance Abuse and Mental Health Services Administration; the Centers for Medicare & Medicaid Services; the Health Resources and Services Administration; and the Office of Special Education and Rehabilitative Services at the Department of Education. There are existing developmental screening measure (National Committee for Quality Assurance [NCQA], 2011; NCQA, 2009a, 2009b; National Quality Measures Clearinghouse, 2007; Child and Adolescent Health Measurement Initiative, undated); however, at this time, these measures have not been adopted nationally for use in quality assessment and improvement.

Please see Attachment 3A.1, Existing Developmental Screening and Developmental Screening Follow-up Measures, for additional information on the existing measures. In addition, the current proposed set of measures on Developmental Screening Follow-up is recommended for use.

These and other initiatives are necessary because of the known quality gap in developmental screening and follow-up. As noted by the Centers for Disease Control and Prevention, 13 percent of children in the United States have developmental or behavioral disabilities (Goulet, Boyle, Schieve, 2009); however, according to the U.S. Department of Education, fewer than half of the children with developmental delays are identified before starting school (U.S. Department of Education, Website). Obviously, when a delay in diagnosis and treatment occurs, critical and often time-sensitive early brain and child development opportunities are missed. Over the last few years there has been an improvement in the number of primary care physicians who routinely perform developmental screening with a validated tool, but still only 50 percent do so, demonstrating the potential and need for quality improvement in this area. Even for those who perform the evaluation, the issues of documenting the results, discussing the results with the families, referring when appropriate, and following up on the referrals are daunting at best. The importance of the measures becomes even more critical with the addition of numerous organizations involved in the screening. The link back to the medical homes will be crucial—in order to not only assure that the screening is done and the families receive consistent messaging, but also to complete the evaluation and to confirm/document the referrals and follow the outcomes with partners.

These measures are applicable to changes across the developmental stages of infancy and early childhood. Their association with children's future health and education has been documented. The earlier the intervention, the less need for future, more extensive, intensive, and expensive interventions (Heckman website). The recent Robert Wood Johnson Foundation Commission to Build a Healthier America number one recommendation was to “make investing in America's youngest children a high priority” to “build a strong foundation in the early years for a lifetime of good health (Robert Wood Johnson Foundation).

## References

American Academy of Pediatrics. Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics* 2006; 118(1):405-20.

Birth to 5: Watch Me Thrive! Early Childhood Development Web site. Available at [www.acf.hhs.gov/programs/ecd/watch-me-thrive](http://www.acf.hhs.gov/programs/ecd/watch-me-thrive). Accessed July 19, 2016.

Boulet SL, Boyle CA, Schieve LA. Health care use and health and functional impact of developmental disabilities among U.S. children, 1997-2005. *Arch Pediatr Adolesc Med* 2009; 163(1):19-26.

The Child and Adolescent Health Measurement Initiative (CAHMI). Measure of whether standardized development and behavioral screening using parent-completed tools occurred: Summary Report of CAHMI the Recommended Items, Development and Testing of the Items and Future Steps. Portland, OR: CAHMI.

Heckman Web site. The case for investing in disadvantaged young children. Available at [www.heckmanequation.org/content/resource/case-investing-disadvantaged-young-children](http://www.heckmanequation.org/content/resource/case-investing-disadvantaged-young-children). Accessed July 19, 2016.

King, TM, Tandon SD, Macias MM, et al. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 2012; 125(2):350-60.

National Committee for Quality Assurance (NCQA). Quality measures for child health care. Washington, DC: NCQA; 2009.

National Committee for Quality Assurance (NCQA). Well-Child Visits in the First 15 Months of Life. Washington, D.C.; 2009a.

National Committee for Quality Assurance (NCQA). Well-Child Visits in the Third, Fourth, Fifth and Sixth Years of Life. Washington, D.C.; 2009b.

National Quality Measures Clearing House (NQMC). Measure Summary: Follow-up for children at risk for delays: proportion of children who were determined to be at significant risk for development, behavioral, or social delays who received some level of follow-up care. Rockville (MD); 2007.

Robert Wood Johnson Foundation Commission to Build a Healthier America. Time to Act: Investing in the Health of Our Children and Communities. Updated January 2014. Available at [www.rwjf.org/content/dam/farm/reports/reports/2014/rwjf409002#page=44](http://www.rwjf.org/content/dam/farm/reports/reports/2014/rwjf409002#page=44). Accessed July 19, 2016.

Tang BG, Feldman HM, Huffman LC, et al. Missed opportunities in the referral of high-risk infants to early intervention. *Pediatrics* 2010; 129(6):1027-34.

U.S. Department of Education, Office of Special Education Programs [Internet], Data Analysis System (DANS), Part C Child Count, 1997–2006.

### **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, Diagnosis, and Treatment benefit in Medicaid (EPSDT).**
- **Any other specific relevance to Medicaid/CHIP (please specify).**

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) was established to meet the child health component of Medicaid (Medicaid Web site). EPSDT specifically addresses: Early—starting at birth; Periodic—checking at appropriate times and ages; Screening—developmental, hearing, vision, physical, mental and other tests to identify problems; Diagnosis—performing appropriate testing when a problem is identified; and Treatment—treating any problems found. In 1967, the program was developed to “discover, as early as possible, the ills that handicap our children” and to provide continuing follow-up and treatment “so that handicaps do not go neglected.” This program is exactly what is being facilitated with the proposed measures as defined. It is clear to see why CMS is involved in the Help Me Thrive initiative.

In addition, the prevention guidelines for children (Bright Futures and the Periodicity Schedule), as included in the Affordable Care Act (ACA), clearly define the times for pediatric preventive care visits in the first 5 years of life, at which time developmental surveillance and screening should take place (American Academy of Pediatrics, 2015). The screening evaluation, follow-up, and referral are the next necessary steps. Documentation and measurement of the provision of a follow-up referral for further evaluation or treatment are critical for appropriate interventions and outcomes.

Federal law requires that Medicaid cover a comprehensive set of benefits and services specifically for children. Since one in three U.S. children under age 6 is eligible for Medicaid, EPSDT offers a very important way to ensure that young children receive appropriate health, mental health, and developmental services (Maternal and Child Health Bureau, EPSDT Overview).

Both the Title V Maternal and Child Health Services Block Grant and the EPSDT component of Medicaid recognize social and emotional development as an integral aspect of children’s health care, and research demonstrates the value of early identification and intervention to address children’s needs. In Title V, the definition of children with special health care needs (CSHCN) includes social-emotional needs (Maternal and Child Health Bureau, Title V).



From screening, to diagnosis, to treatment, Medicaid and EPSDT are critical to financing evidence-based services for children (Howell, Teich, 2008). Federal law requires comprehensive well-child examinations with screening services through EPSDT, including screening for potential developmental, mental, behavioral, and/or substance use disorders. EPSDT also finances diagnostic and treatment services, if medically necessary, for these conditions (Maternal and Child Health Bureau, EPSDT).

However, studies have found that as few as 23 percent of low-income children enrolled in Medicaid receive the recommended preventive and developmental services considered a basic threshold for quality care (NCINQ, 2011). In addition, children insured by Medicaid had almost a two-fold higher prevalence of any developmental disorder compared to those with private insurance, and children from families below the Federal poverty level had a higher prevalence of developmental disabilities (Centers for Disease Control and Prevention, 2011). Given the higher prevalence of developmental delay and the low percentage of children receiving adequate developmental services, quality measures that evaluate whether a follow-up referral was provided could greatly improve the long-term health outcomes of children enrolled in Medicaid and CHIP.

## References

American Academy of Pediatrics (Web site). Periodicity schedule; 2015. Available at [www.aap.org/en-us/professional-resources/practice-support/Pages/PeriodicitySchedule.aspx](http://www.aap.org/en-us/professional-resources/practice-support/Pages/PeriodicitySchedule.aspx) Accessed May 9, 2016.

Centers for Disease Control and Prevention. (2011). Trends in the Prevalence of Developmental Disabilities in U.S. Children, 1997-2008. Available at [www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html](http://www.cdc.gov/ncbddd/developmentaldisabilities/features/birthdefects-dd-keyfindings.html). Accessed May 10, 2016.

Howell EM, Teich J. Variations in Medicaid mental health service use and cost for children. *Admin Policy Ment Health* 2008; 35(3):220-8.

Maternal and Child Health Bureau, Health Resources and Services Administration. EPSDT Program Background: Overview. Available at <http://mchb.hrsa.gov/epsdt/overview.html>. Accessed May 10, 2016.

Maternal and Child Health Bureau, Health Resources and Services Administration. Title V: Maternal and Child Health Services Block Grant Program. Available at <http://mchb.hrsa.gov/programs/titlevgrants/>. Accessed May 10, 2016.

Medicaid Web site. Early and Periodic Screening, Diagnostic, and Treatment. Available at [www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html). Accessed May 9, 2016.

Sand N, Silverstein M, Glascoe FP, et al. Pediatricians' reported practices regarding developmental screening: do guidelines work? Do they help? *Pediatrics* 2005; 116(1):174-9.

### **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).**

This measure enhances the developmental screening measure in the initial core set (Background Report, 2009) filling the critically important referral/follow-up component of screening. This measure will complement other existing measures and the others in this set through assessment of whether a follow-up referral occurred after a positive developmental screening result. This measure will give a better indication about the outcomes of the screening event, and whether the screening event was successful and fully utilized in directing the patient and the patient's parents or guardian towards the next appropriate step in diagnosing and treating their child's developmental health concerns when they exist.

#### ***Reference***

Background Report on Request for Public Comment on Initial, Recommended Core Set of Children's Health Care Quality Measures for Voluntary Use by Medicaid and CHIP Programs. Rockville, MD: Agency for Healthcare Research and Quality; 2009.

## **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: Yes. Other Community and Public Health Settings.**
- d. Service – preventive health, including services to promote healthy birth: Yes.**
- e. Service – care for acute conditions: No.**
- f. Service – care for children with acute conditions: Yes.**
- g. Service – other (please specify):**
- h. Measure Topic – duration of enrollment: No.**
- i. Measure Topic – clinical quality: Yes.**
- j. Measure Topic – patient safety: Yes.**

- k. **Measure Topic – family experience with care:** No.
- l. **Measure Topic – care in the most integrated setting:** Yes.
- m. **Measure Topic other (please specify):** No.
- n. **Population – pregnant women:** No.
- o. **Population – neonates (28 days after birth) (specify age range):** No.
- p. **Population – infants (29 days to 1 year) (specify age range):** Yes - 6 months to 36 months.
- q. **Population – pre-school age children (1 year through 5 years) (specify age range):** No.
- r. **Population – school-aged children (6 years through 10 years) (specify age range):** No.
- s. **Population – adolescents (11 years through 20 years) (specify age range):** No.
- t. **Population – other (specify age range):** No.
- u. **Other category (please specify):** No.

## **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.**

The intent of conducting a developmental screening is to assess the development of the child and to determine if there are developmental concerns in order to intervene to diminish the impact of the delay and address the developmental concern. A developmental delay can profoundly impact a child's ability to function in multiple settings; thus, it is imperative that children who have positive screens are referred to follow-up services as soon as possible. See Attachment 5A.1 for the Pediatric Developmental Screening Flowchart for appropriate evidence-based developmental screening follow-up.

It has been reported that physicians fail to identify and refer 60 to 90 percent of children with developmental delays in a timely manner (King, Tandon, Macias, et al., 2010). Similarly, among children classified as having delays at 9 months, only 9 percent received follow-up services; among children classified as having delays at 24 months, only 10-12 percent had received services (Medical Home Initiatives, 2008). Likewise, a study by Tang et al. found that 34-37 percent of high-risk infants who had a positive developmental screen were not referred to either early intervention (EI) or other therapies. A study cited in the report notes that the mean time between identification of a developmental delay and EI referral is more than 5 months (Tang, Feldman, Huffman, et al., 2012).

A study of standardized developmental screening found that when providers were instructed to score and respond to survey results with the parent at the visit during which the screen was interpreted, providers' confidence in their ability to screen and identify developmental delays increased. Similarly, discussing screening results with parents not only allowed providers to better refer children to follow-up services, it also provided an opportunity for parents to discuss general developmental concerns that might not have been identified with the screening tool (King, et al., 2010).

An implementation study of the AAP recommendations for developmental screening and referrals found that not only were referral rates among children with positive screens low (27-100 percent), but practices tended to deviate from the recommendation that children with positive screens be simultaneously scheduled for developmental/medical evaluations and referred for EI services. Providers tended to stratify their referrals by perceived severity of symptoms, age of child, and type of delay, and they occasionally failed to refer a child despite a positive screen (King, et al., 2010). A large longitudinal study found that it took about a year between first recognition of a concern about a child and the development of an individualized service plan (Macy, Marks, Towle, 2014). Further, the mean time between identification of a developmental delay and a referral to EI has been found to be greater than 5 months (Tang, et al., 2012). In addition, lack of coordination leads to delay in about half of referred children reaching EI agencies or alternative community resources. In addition, there is a need to supply a more advanced level of coordination and referral help for at-risk children, due to their greater and more complex needs for services (Macy, et al., 2014; Tang, et al., 2012).

There is consensus that EI programs have a positive moderate effect on eventual developmental attainment. Further, intervention programs have been shown to improve academic and intellectual achievement, along with improved scores on developmental outcome measures (Rydz, Shevell, Majnemer, et al., 2005). There is also evidence that prevention services have substantial effects that will last into adulthood. One study showed that children who took part in EI programs had lower odds of having failing grades or receiving assignments for special programs, attained higher achievement scores, and had greater chances of mentioning educational reasons as a source of pride (Rydz, et al., 2005). Children who participated in intervention studies and were referred to follow-up services had lower chances of being arrested or becoming pregnant as a teenager, and they had greater odds of earning higher wages, graduating high school, and seeking higher education. Further, \$100,000 per child was saved for each child who received follow-up services (Rydz, et al., 2005).

The American Academy of Pediatrics recommends that all children receive early identification services that include surveillance, screening, and developmental or medical diagnostic evaluation, if needed (Pizur-Barnekow, Erickson, Johnston, et al., 2010). The importance of early identification of developmental concerns and referral to EI services stems from the growing evidence indicating that early identification can bring about improved outcomes for children (Pizur-Barnekow, et al., 2010). Since early identification and treatment are beneficial to children with developmental delays, the access to follow-up care is a significant aspect of quality care (Jennings, Hanline, 2013).

### ***References***

Coker TR, Shaikh Y, Chung PJ. Parent-reported quality of preventive care for children at-risk for developmental delay. *Acad Pediatr*. 2012;12(5), 384-390.

King TM, Tandon SD, Macias MM, et al. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 2010; 125(2):350-60.

Macy M, Marks K, Towle A. Missed, misused, or mismanaged: improving early detection systems to optimize child outcomes. *Topics Early Child Spec Educ* 2014; 34(2):94-105.

Medical Home Initiatives for Children with Special Needs Project Advisory Committee. The medical home. *Pediatrics* 2008 (reaffirmed); 122(2).

Pizur-Barnekow K, Erickson S, Johnston M, et al. Early identification of developmental delays through surveillance, screening, and diagnostic evaluation. *Infants Young Child* 2010; 23(4):323-30.

Rydz D, Shevell MI, Majnemer A, Oskoui M. Developmental screening. *J Child Neurol*. 2005;20(1):4-21.

Tang BG, Feldman HM, Huffman LC, et al. Missed opportunities in the referral of high-risk infants to early intervention. *Pediatrics* 2012; 129(6):1027-34.

## **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.**

The Developmental Screening Follow-up Measure 2 – Follow-up Referral after a Positive Developmental Screen allows 7 calendar days for the pediatric clinician to provide a referral to the family. While most referrals will and should be provided on the same day as the visit, it was noted in the clinical experience of the Developmental Screening Follow-up Expert Workgroup that, at times, clinicians need to determine the most appropriate referral, which occasionally can take trial and error.

## 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.*

#### *Manual Chart Abstraction of the Measure*

The sites for testing reliability through manual chart abstraction of the measure elements included the primary care networks of the Chicago Pediatric Quality and Safety Consortium (CPQSC): Lurie Children’s Hospital, Advocate Children’s Hospital– Park Ridge, Advocate Children’s Hospital – Oak Lawn, and John H. Stroger, Jr. Hospital. See description of the CPQSC in Attachment 6A.1.

#### *Methods*

Each site identified two research nurses with previous experience conducting pediatric chart abstraction, who received additional, project-specific training on selection of charts for inclusion and how to conduct the manual chart abstraction. A chart abstraction tool and algorithm, (Attachment 6A.2) were used at each site to complete the manual chart abstractions, and the research nurses received formal training on how to use these tools.

Each site was instructed to identify up to 70 charts to review retrospectively in August, 2014 that matched the denominator criteria while taking into account any exclusions that existed.

Demographic information, numerator elements, and denominator elements were abstracted. This measure has one exclusion: patients who are already receiving services for developmental delay.

To complete the manual chart abstraction, the following algorithm was followed:

1. Select Charts: Patients with CPT code 96110; well-child visit codes 99381, 99382, 99391, and 99392; and between ages 6-42 months during 2011 and 2013; charts meeting these criteria were randomized for inclusion.
2. Scan charts for specific phrases using Natural Language Processing (NLP), if possible (Attachment 6A.3).

3. Collect demographics and elements for equity assessment: gender, race/ethnicity, language preference, insurance status/type, age.
4. Review and document measure elements in the chart abstraction tool.
5. Record summary of measure elements.
6. Note relevant comments.

### *Analysis*

The intent of the analysis was to test the construction of this measure through manual chart abstraction and to test the reliability and validity of the measure for use as a measure of performance for public reporting and quality improvement.

### *Results*

Across all testing sites, the medical charts for 141 pediatric patients aged 6 – 42 months were reviewed. See Patient Characteristics in Attachment 6A.5 Table 1. Of these, 15 (~11 percent) children had a positive developmental screen result.

Performance and reliability results for this measure are found in Attachment 6A.4, Table 2. For reliability, we report the overall agreement and kappa statistics based on two independent reviews of the medical charts. Agreement (93.6 percent) and kappa (kappa=0.87) for the use of a validated tool and agreement and kappa for the measure Follow-up Referral after a Positive Developmental Screen (73 percent), (kappa=0.67), were reasonably high.

For overall performance, only 39 percent of those children who had a positive developmental screen received a follow-up referral. See Attachment 6A.4, Table 3.

There was considerable cross-site variability for this measure. Performance ranged from approximately 30 percent to approximately 100 percent. See Attachment 6A.4, Tables 1-3.

### *eMeasure Testing*

Based on feasibility testing (See Section 8 for more detail), two sites, Children’s Hospital of Philadelphia (CHOP) and Ashe Pediatrics, were able to implement the Developmental Screening Follow-up Measure 2: Follow-up Referral after Positive Developmental Screen measure in their electronic health records (EHRs). CHOP performed feasibility testing in their fully electronic system by implementing the measure and assessing the reliability of the output through comparison of documentation within the measure’s fields in the EHR. Ashe Pediatrics participated in parallel forms reliability testing.

### *CHOP Testing*

CHOP started using a customized EHR system for developmental screening in 2011, and use extends across practices and early intervention programs in 13 counties in Pennsylvania and New Jersey, with approximately 42,000 developmental screens completed each year. Screenings at well-child visits can be completed by the patient's family, and the clinician is presented with a summary score and full responses to each item in the chart. When relevant, tailored decision support tools will appear. Follow-up referrals, when necessary, are also stored in the electronic system.

To test the ability to construct this eMeasure, CHOP randomly selected 20 patient records with a positive developmental screen between July 2011 and April 2014. The CHOP EHR system was able to construct this measure. Review of the results and reliability assessment through comparison with manual review of the documentation of the specific measure elements through chart review determined that documentation in relevant structured fields was missing for 25 percent of referrals, primarily due to clinician workflows. However, when a provider does use the provided drop-down menu, a wealth of information can be collected, including why a patient was not referred (already receiving services, etc.).

CHOP was able to identify patient-records with a failed screen result. Of the 20 patient records, 40 percent (N=8) met the eMeasure by having a discreetly identifiable referral letter or consult order on file. However, 15 percent of patient records (N=3) contained information regarding referrals in the progress note and required chart review for inclusion in the measure. Of the sampled charts, when a manual review was done, 55 percent (N=11) contained documentation that a referral to follow-up care was provided within 7 days, which is consistent with reported studies (King, Tandon, Macias, 2010). Referrals were most frequently provided to Early Intervention, Audiology, Ophthalmology, Speech, and Developmental Pediatrics. Overall 45 percent (N=9) did not meet the measure.

### *Ashe Pediatrics*

Ashe Pediatrics is a small private practice in North Carolina with a highly customized electronic medical record (EHR) based on eClinicalWorks.

As feasibility testing indicated that this measure was technically feasible in Ashe Pediatrics' EHR system, this site performed parallel forms reliability testing. The measure was constructed in the EHR, and manual chart abstraction was performed on the same charts. Ashe Pediatrics implemented the Developmental Screening Follow-up Measure 2: Follow-up Referral after Positive Developmental Screen measure in their EHR using an electronic algorithm, which constructed the measure automatically and generated a performance report on a sample of patients. At the same time, a trained chart abstracter performed manual chart reviews on the same patients' charts. Performance according to manual chart abstraction was then compared to the automated data eMeasure report to determine the reliability of the overall measure and individual measure elements.



A total of 224 developmental screens (117 unique patients) were identified in the time period of January 2013 – December 2013 and were abstracted both manually and electronically. While this eMeasure was considered technically feasible, parallel forms reliability testing indicated that the structured field for indicating that a developmental screening score is abnormal is not routinely used. The denominator elements of this eMeasure could not be identified; the eMeasure failed implementation feasibility but could be feasible with workflow changes.

### ***Reference***

King TN, Tandon SD, Macias MM, et al. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 2010; 125(2):350-60.

## **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).***

### ***Manual Chart Abstraction Data***

The data collected through the manual chart abstraction in the primary care networks of the CPQSC were also used to assess the accuracy of the performance score and the validity of the measure. Direct inspection of the data was performed to determine that each of the elements of the measure could be abstracted from the charts. The data were reviewed to assess for missing data or other irregularities in the data to assess the accuracy of the data and the validity of the resulting overall performance score.

### ***Results of Manual Chart Abstraction***

All the elements of the Follow-up Referral after Positive Developmental Screening measure are generally documented in the charts when done. Clinical performance on this measure is consistent with the literature reports of the results overall and across sites, given the sites' characteristics (Boulet, Boyle, Schieve, 2009; King, Tandon, Macias, et al., 2010). See Attachment 6A.4, Tables 1-3.

### ***Public Comment***

In fall of 2013, the three Developmental Screening Follow-up measures went through an online public comment process. Prior to the Public Comment Period, members of the PMCoE Developmental Screening Follow-up Expert Workgroup were asked to identify organizations and individuals who could provide valuable feedback on the measures. Materials were provided to these groups and they were asked in turn to pass along the materials as well in order to achieve a comprehensive and broad range of stakeholder views and comments. Stakeholders were notified and requested to participate through an email that included links to the measures and the online survey. Participants were provided with some background information on the AHRQ-CMS CHIPRA PMCoE and the Pediatric Quality Measurement Program and then were asked to review the descriptions of each of the measures. Comments were requested specifically on any or all of the following aspects of the measure: importance, feasibility, consistency with organizations' current practices, and additional evidence for consideration. One hundred and eighty-five stakeholders started the public comment survey, and 108 stakeholders reviewed and commented on the developmental screening follow-up measure set. See Attachment 6B.1 for a summary of participants.

Feedback received during public comment was then analyzed by the PMCoE Developmental Screening Follow-up Leadership Team. Results on a scale of 1 (not important) to 9 (extremely important) were aggregated for the domains of importance, feasibility, validity, and clinical relevance. See Attachment 6B.2 for histograms of the validity and clinical relevance domains.

Comments were sorted initially by measure and by domain. Then, comments were analyzed thematically and sorted according to the newly identified themes. For this measure, themes included how to handle watchful waiting, referral quality, measure biases, exceptions, EHR use and configuration, definitional comments and changes, denominator exceptions, validity, numerator clarifications and additions, feasibility, clinical relevance, timeframe concerns, new information for consideration, appropriate funding and resources, validity of screening results, importance, and other. This allowed the Leadership Team and Expert Workgroup to identify key stakeholder concerns and then to address those concerns by updating and refining the measure as necessary.

#### *Results of Public Comment Process*

On a scale of 1 (not important) to 9 (extremely important), 68 percent of the stakeholders who commented on Developmental Screening Follow-up, Measure 2 – Follow-up Referral after Positive Developmental Screen responded that the measure was extremely important, with 91 percent of the participants providing an importance score of 7 or higher. Similarly, 75 percent of participants thought that the measure was very valid (score of 7 or higher), and 87 percent thought that the measure was very clinically relevant (score of 7 or higher), indicating that stakeholders think that this measure accurately represents the concept being evaluated and would be useful in a clinical context.

Participants were also provided with a free text comment box in which they could comment on the measure and suggest any changes. Some excerpts that speak to the validity of the measure include:

- “Considered a highly clinically relevant measure.”

- “This measure is important.”
- “We believe that providing follow-up referrals after positive developmental screening to a family is key in the process to ensure children have access to the care they need to appropriately reach their potential.”
- “I approve of these proposed quality measures.”
- “The measure is reasonable and important.”

The primary concern regarding the validity of this measure was regarding what to do when a screening test yields a false positive, and referral is not the correct response. The Leadership Team discussed this issue and decided that while a false positive may not necessitate a referral, a positive screening test should not be taken lightly and requires follow-up care with the primary care physician to ensure that a developmental delay is not present. As a result, the Leadership Team decided to change the definition of referral to include scheduling an appointment with the primary care clinician within 3 months, recognizing that scheduling a follow-up visit prior to the next scheduled well-child visit allows for additional evaluation and, if necessary, an earlier referral.

## References

Boulet SL, Boyle CA, Schieve LA. Health care use and health and functional impact of developmental disabilities among U.S. children, 1997-2005. *Arch Pediatr Adolesc Med* 2009; 163(1):19-26.

King TM, Tandon SD, Macias MM et al. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 2010; 125(2):350-60.

## 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 first developmental screening follow-up measure – follow-up with patient family after a developmental screen – was tested in four of the CPQSC sites by manual chart review. Across all sites, 32.14 percent of the population was white, 30.71 percent was black, 14.29 percent was Hispanic, 7.86 percent was other, and 15.00 percent was unknown. See Attachment 7A.1 for Table 1, Demographic Information.

In order to meet the denominator criteria of this measure, a validated screening tool must be administered during a developmental screening. Across all sites, over 90 percent of white patients were screened with a validated screening tool. In stark contrast, only approximately 17 percent of black patients and 52 percent of Hispanic patients were screened using a validated tool. This disparity is further pronounced when looking across the sites, as one site (Site D) has a predominantly black patient population and rarely uses a validated screening tool, reporting rates as low as 16.5 percent for white patients, 8.5 percent for black patients, and 20 percent for Hispanic patients. See Attachment 7A.1 for Table 2, Use of a Validated Tool by Race.

As for measure performance, sites were unable to easily identify patients with positive developmental screens prior to performing a chart review and very few patients met the denominator criteria for this measure. As such, we were unable to conduct enough chart reviews to evaluate the performance of this measure by race/ethnicity.

Our results are supported by AHRQ's National Health Care Disparities Report, 2013 that reports in 2011 and 2012, black children and Hispanic children had lower rates of well-child visits compared with their white counterparts (National Healthcare Disparities Report, 2014). If children are unable to attend well-child visits, they are unlikely to receive a developmental screening administered with a validated screening tool. Further, even with access to care, developmental screening in the pediatric setting with a standardized tool is only close to 50 percent, and the American Academy of Pediatrics in a Technical Report on racial and ethnic disparities concluded that racial/ethnic disparities in children's health and health care are extensive, pervasive, and persistent and occur across the spectrum of health and health care (Flores, 2010).

## **References**

Flores G. Technical report: racial and ethnic disparities in the health and health care of children. *Pediatrics* 2010; 124(4):e979-e1020.

National Healthcare Disparities Report, 2013. Rockville, MD: Agency for Healthcare Research and Quality; May 2014. Available at <http://www.ahrq.gov/research/findings/nhqrd/nhdr13/index.html>. Accessed May 12, 2016.

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

The performance of this measure was not assessed for children with special health care needs, as all children who qualify for this measure will have had a positive developmental screening result and would be considered children with special health care needs.

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

Across all testing sites, 64.29 percent of patients used Medicaid, 32.14 percent of patients used private insurance, and insurance data were missing for 3.57 percent of patients. Please see Attachment 7A.1 for Table 1 Demographic Information.

In order to meet the denominator criteria of this measure, a validated screening tool must be administered during a well-child visit. Across all testing sites, approximately, 41.76 percent of Medicaid users were screened using a validated tool, while nearly 98 percent of patients using private insurance were screened with a validated tool. The site-specific data are included in Attachment 7C.1 Table 1 Use of a Validated Tool by Insurance Status.

As for measure performance, sites were unable to easily identify patients with positive developmental screens prior to performing a chart review, and very few patients met the denominator criteria for this measure. As such, we were unable to conduct enough chart reviews to evaluate the performance of this measure by insurance status.

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

All testing sites are located in the Chicago area; therefore, the measure performance was not tested by rurality/urbanicity.

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

Across all testing sites, the majority of patients were English speaking (95.74 percent). Please see Attachment 7A.1 for Table 1 Demographic Information.

In order to meet the denominator criteria of this measure, a validated screening tool must be administered during a well-child visit. Across all sites, approximately 59 percent of English-speaking patients and 67 percent of non-English-speaking patients received a developmental screen using a validated screening tool. While it may appear that non-English-speaking patients were more likely to use a validated tool, this result is primarily driven by the low rates of validated tool use at Site D, as in all other sites, non-English speaking patients were as likely or less likely as English-speaking patients to receive a developmental screening using a validated screening tool. Please see Attachment 7E.1 for Table 1 Use of a Validated Tool by Language.

As for measure performance, sites were unable to easily identify patients with positive developmental screens prior to performing a chart review, and very few patients met the denominator criteria for this measure. As such, we were unable to conduct enough chart reviews to evaluate the performance of this measure by limited English proficient populations. Our results are supported by an AAP Periodic Survey of Fellows, which reported that while health literacy is not limited to immigrant families, developmental screening, referral, and follow-up can certainly be much more difficult in the context of language proficiency (American Academy of Pediatrics).

### ***Reference***

American Academy of Pediatrics. Periodic survey of fellows No.86. August 2013 – 2014. Accessed August 25, 2014. Available at <http://www.aap.org/en-us/professional-resources/Research/pediatrician-surveys/Pages/Periodic-Survey-of-Fellows.aspx>. Accessed May 16, 2016.

## **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?**

#### ***Manual Chart Abstraction***

Feasibility of construction of the Developmental Screening Follow-up Measure 2: Follow-up Referral after Positive Developmental Screen measure was tested in the primary care networks of the Chicago Pediatric Quality and Safety Consortium (CPQSC), including: Mount Sinai Children’s Hospital, Advocate Children’s Hospital – Park Ridge, Advocate Children’s Hospital-Oak Lawn, John H. Stroger Hospital, and Lurie Children’s Hospital.

Across all testing sites, the medical charts for 141 pediatric patients, aged 6 – 42 months were reviewed. See Patient Characteristics in Attachment 6A.4 Table 1. Of these, 4 children (~24 percent) received a referral.

Results for this measure are found in Attachment 6A.4 Table 2. There was considerable drop-off in charts meeting the denominator criteria, leading to a small N for analysis.

#### ***eMeasure Feasibility Testing – CPQSC***

Feasibility testing of the eMeasure was conducted in the primary care networks of the CPQSC. The EHR vendor systems assessed included Epic, Cerner, and Allscripts TouchWorks. See the Data Element Table (DET) tool used for data collection (Attachment 8A.1, DET Example).

Test site capabilities to calculate the measure are summarized in Table 8.1-8.2. Demographic data elements including race, gender, ethnicity, preferred language, and payer are currently captured in structured data fields at all sites. Some important data elements required to calculate this measure do not exist in structured fields in CPQSC EHRs at this time. Therefore, it is not possible to calculate this measure electronically using only structured data fields from the EHRs of these test sites.

### *eMeasure Feasibility Testing – National Search*

The PMCoE Team conducted a national search through the networks and suggestions of the PMCoE Developmental Screening Follow-up (DSF) Expert Workgroup for practices with EHRs that may have the measure elements in structured fields to test this eMeasure for public use.

Twelve networks comprising 52 sites overall were recommended. Of these, seven networks could feasibly or nearly feasibly construct the measures in the Developmental Screening Follow-up measure. Systems that had the necessary elements for the measures were either eClinicalWorks or individually customized EHR systems. The Children’s Hospital of Philadelphia (CHOP) and Ashe Pediatrics performed feasibility testing.

### *eMeasure Testing – CHOP*

CHOP started using an electronic system for developmental screening in 2011, and coverage now extends across practices in 13 counties and EI programs. Screenings at well-visits can be completed by the patient’s family. The clinician is presented with a summary score as well as full responses to each item in the chart. Follow-up referrals are also stored in the electronic system.

To test the feasibility to construct this eMeasure in the CHOP EHR, CHOP randomly selected 20 patient records with a positive developmental screening, between July 2011 and April 2014. The CHOP EHR system was able to construct this measure. Through detailed review of the results and reliability testing through comparison with manual chart review, it was determined that documentation in relevant structured fields was missing in 25 percent of all referrals.

### *eMeasure Testing – Ashe Pediatrics*

Ashe Pediatrics, a private practice in North Carolina with a customized EHR system based on eClinicalWorks, also completed feasibility testing. All required structured, queryable fields exist in the Ashe Pediatrics EHR and therefore, it is technically possible to calculate this measure electronically using only structured data fields. See Attachment 8A.1 and Table 8.2 for the DET and feasibility testing results.

**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?**

Important data elements required to calculate this measure do not currently exist in structured data fields in CPQSC site EHRs at this time. For example, the denominator element “positive developmental screening result” and the corresponding date are not captured as a structured variable at any of the test sites. While developmental screening can be identified with CPT code 96110 at each test site, none of the sites have structured fields to indicate administration of an acceptable developmental screening tool for this measure. If a developmental screening tool is administered at a site, the results are scanned into the EHR systems and there is no structured data field indicating whether or not the screen was positive. The numerator element “Referral for follow-up care” is captured as an HL7 coded value at two sites for internal referrals only (paper requests are sent to outside providers). At three of the five test sites, both internal and external referrals were paper-based.

Recommendations for changes to future EHR systems include the following:

1. All sites should administer a developmental screening tool to patients, preferably electronically rather than paper-based so that the results could be more easily incorporated into the EHR.
2. Each site should have a structured data field within the EHR that stores a dichotomous variable (e.g., “positive” or “negative”), indicating the results of the screen and the corresponding date.
3. Each site should have a structured data field within the EHR that stores a dichotomous variable (e.g., “true” or “false”) indicating whether or not a patient received a referral for follow-up care and include a drop-down menu of referral types.
4. A structured field for the date of the referral is provided.
5. As was done in CHOP’s customized EHR, a structured field with a drop-down menu should be included to assess the reasons a referral was not made.
6. Clinician workflows affected referral documentation in structured fields. However, when a provider does use the drop-down menu, a wealth of information can be collected including why a patient was not referred (already receiving services, did not want services, etc.).
7. Sites capable of free text searches using natural language processing (NLP), such as Lurie Children’s Hospital, may be capable of extracting the necessary data elements with NLP. Sites for which NLP techniques cannot be implemented will require workflow modifications or changes to the EHRs. See the Recommendations to Vendors Table Attachment 8A.2.

## **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.**

The Developmental Screening Follow-up Measure – Follow-up Referral after Positive Developmental Screen, as specified by the PMCoE Developmental Screening Leadership Team and Expert Technical Panel, is in use in the American Board of Pediatrics (ABP) Maintenance of Certification (MOC) – Part 4 Performance Improvement Module (PIM) for use by physicians in the process of Re-Certification.



**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?**

Pediatric physicians must conduct a PIM in the process of Re-Certification and can select to conduct 100 chart reviews using the Developmental Screening Follow-up Referral after Positive Developmental Screen measure specifications, assess their own performance, implement improvement, and conduct 100 chart reviews afterwards to assess improvement. This is then entered into the ABP MOC PIM electronic system.

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

The ABP found this measure to be an effective and usable measure within the structure of the MOC PIM for physician Re-Certification.

## **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?**

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 available at this time.

**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?**

There are no unintended consequences for reporting this measure if the data are accurate. For State programs that do not reimburse for CPT code 96110, which indicates that a validated developmental screening tool was used, it may be difficult to identify the accurate denominator population if physicians use this code to indicate that an appropriate screening tool was used.

**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)

Yes.

**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 available at this time.

**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?**

There are no unintended consequences for reporting this measure if the data are accurate.

**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)

Yes.

**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 available at this time.

***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?**

There are no unintended consequences for reporting this measure if the data are accurate. For State programs that do not reimburse for CPT code 96110, which indicates that a validated developmental screening tool was used, it may be difficult to identify the accurate denominator population if physicians use this code to indicate that an appropriate screening tool was used.

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

***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?**

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 available at this time.

***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?**

There are no unintended consequences for reporting this measure if the data are accurate.

***Provider Level***

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

***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?

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 available at this time.

**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?

There are no unintended consequences for reporting this measure if the data are accurate.

#### **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 available at this time.

**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)**

Yes.

**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 available at this time.

**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?**

There are no unintended consequences for reporting this measure if the data are accurate.

## **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).**

*For Public Reporting*

This measure is based on guideline-recommended practice (AAP, Developmental Screening in Early Childhood Systems; AAP, Developmental/Behavioral Screening) and modeled on the elements of the well-respected AAP Bright Futures national initiative and the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program (AAP, Bright Futures; HRSA, EPSDT). In addition, the measures in the Developmental Screening Follow-up measure set are currently in the process of being developed for use in two State Medicaid/CHIP Programs (North Carolina and Pennsylvania). Developmental screening follow-up, and particularly the follow-up referral after a developmental screening, is a fundamental aspect of pediatric practice and is essential to early childhood/pediatric care quality. It is easy for both clinicians and families to understand the rationale and importance for patients to receive further evaluation or treatment to assess a concern following a concerning developmental screening. This is an important measure for assessment of care quality because there are known gaps in care in this domain. In a study conducted by the AAP, 61 percent of children who had a positive developmental screening result were not referred for further evaluation, and in a subgroup analysis, among practices using the PEDS, fewer than one in three children with a failing result were referred to any source (King, Tandon, Macias, 2010). It is easy to understand that this represents suboptimal quality of care.

This measure can be used to provide transparency regarding comparative best, evidence-based pediatric practice for the patient's family and provide a measure of accountability for payers, purchasers, and States. Because this measure and the two other measures in the Developmental Screening Follow-up measure set are focused on such a fundamental aspect of primary care pediatrics, these may represent a proxy for general pediatric primary care quality. This measure is meant to be used to calculate performance and/or reporting at the practice, institution, health plan, State, regional, and national levels.

The results from a broad range of stakeholders (N=108) through Public Comment regarding this measure indicate that the measure is Important, Valid, and Clinically Relevant. See Attachment 6B.2.

### ***For Performance Improvement***

Performance measurement serves as an important component of a quality improvement strategy. This measure can be used appropriately for performance measurement directed at improving the frequency of evidence-based follow-up with the patient's family after a developmental screening. These measures can provide critical information to direct improvement, as they are linked directly to specific guideline-recommended processes for developmental screening follow-up and operational steps that clinicians can apply in pediatric primary care practice to improve care.

### ***References***

American Academy of Pediatrics. Bright Futures: Practice Guides and Other Resources. Available at <https://brightfutures.aap.org/Pages/default.aspx>. Accessed May 16, 2016.

American Academy of Pediatrics. Developmental screening in early childhood systems: summary report. Available at <http://www.healthychildcare.org/pdf/DSECSreport.pdf>. Accessed May 16, 2016.

American Academy of Pediatrics. National Center for Medical Home Implementation: Developmental/Behavioral Screening. Available at [http://www.medicalhomeinfo.org/how/clinical\\_care/developmental\\_screening/](http://www.medicalhomeinfo.org/how/clinical_care/developmental_screening/). Accessed May 16, 2016.

Health Resources and Services Administration. EPSDT & Title V Collaboration to Improve Child Health. Available at <http://mchb.hrsa.gov/epsdt/>. Accessed May 16, 2016.

King TM, Tandon SD, Macias MM, et al. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 2010; 125(2):350-60.

## **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.**

Health IT could be helpful in resolving two main issues with construction of the measure in the EHR. The issues are related to denominator element “positive developmental screening result” and the numerator element “referral for follow-up care” after a positive screening result. First, positive developmental screening results could be more clearly identified and stratified within the EHR if two pieces of information were encoded: one, a dichotomous variable in a structured field indicating whether or not a developmental screen result was positive (i.e., yes/no or true/false) and the corresponding date the positive screening result was identified; and two, including one or more ICD-9-CM codes that further describe a positive developmental screen. Some possibilities include 783.42 (Delayed milestones), 315.31 (Language disorder, developmental), 315.9 (Learning disorder, NOS), 348.3 (Static encephalopathy), and 781.3 (Lack of coordination). See Attachment 11A.1 for additional codes.

Second, a referral for follow-up care would be more effectively documented by coding three pieces of information in the EHR: one, a dichotomous variable in a structured field indicating if a referral for a positive developmental screen was ordered, along with the corresponding date; two, the type of referral given, possibly from a drop-down list, including, but not necessarily limited to Part C, Early Intervention Program, Referral for Follow-up Testing, Home Visiting for 0-5, Physical Therapist, Occupational Therapist, Speech/Language Pathologist, Medical Home Clinician Internal, Specialty Clinician External, Early Head Start, Network Care Manager, Family-to-family Support, Hearing and Vision Specialists, and Mental Health Specialist; and three, one or more CPT and/or ICD-9-CM codes for the referral (CPT 99241-99245, 99201-99205, 99211-99215, 90806, 97001, 97002, 97039, 97110, 97116, 97530, 92506, 92507, 92610, ICD-9-CM V68.81).

### **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?**

Feasibility testing for construction of this measure was conducted using four EHR vendor systems (Cerner, EPIC, Allscripts TouchWorks, and eClinicalWorks) and a self-developed system. It was determined that of these systems, only eClinicalWorks has the necessary elements for the construction of Developmental Screening Follow-up Measure 2 – Follow-up Referral after Positive Developmental Screen. Further detail is given in Section 8 and Table 8.1.

### **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.**

The Health IT workflow for this measure could be enhanced in two ways (see Attachment 8A.2 for a summary). For example:

- A structured data field could be created for the EHR to identify if the score from a screening result that is entered into the record lies below the cutoff according to the particular scoring tool's logic. In addition, a prompt function could be activated if the score falls below the cutoff. This would help to flag the record and remind the provider that the patient should be referred to an appropriate specialist to address the issue(s).
- In order to keep track of and summarize a patient's developmental progress over time, a report function could be created that allows grouping positive screens by time interval, individual primary care provider, domain, or child age.
- Another way to improve workflow and prevent oversight would be to create a structured data field for referral categories, allowing the provider to choose the category from a drop-down list. In the case that a patient received a positive developmental screening result and no referral was ordered, a prompt function reminding the provider to indicate the screening type would be helpful.
- Finally, by providing a report function that is capable of returning a list of children with a positive screening result by date and type of referral would help with comparative analysis and to identify trends in the patient population.

Of course, to be effective these workflow modifications should fit well with current practices and not significantly increase the time the provider takes to enter information into the EHR, since complicating information entry would tend to decrease the amount of time the provider spends conversing with the patient, parent, or caregiver.

### **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 criteria (see [healthit.hhs.gov/portal/server.pt/community/healthit\\_hhs\\_gov\\_\\_standards\\_ifr/1195](http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__standards_ifr/1195))?**



No.

**If Yes., please describe.**

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

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

Two of the elements for this measure (“birth date” and “encounter”) were identifiable and encoded as structured data in the EHR systems of each of our test sites. We are confident that these two elements will exist as structured data in the majority of EHR systems. The biggest concerns regarding the calculation of this measure is that the two remaining denominator elements (“positive developmental screening result” and “positive developmental screening result, date”) and the two numerator elements (“referral for follow-up care” and “referral for follow-up care, date”) will not be captured in structured data fields.

There are four potential issues. The first is the ability to determine whether a developmental screen was positive. This element will most likely not exist in many EHR systems. The second issue is whether or not it is possible to determine that, if a screening result was positive, a referral for follow-up care was provided. The third issue is that, if a referral was made, was the category or type of referral identifiable in the EHR. We have identified a list of possible referrals (Part C, Early Intervention Program, Referral for Follow-up Testing, Home Visiting for 0-5, Physical Therapist, Occupational Therapist, Speech/Language Pathologist, Medical Home Clinician Internal, Specialty Clinician External, Early Head Start, Network Care Manager, Family-to-family Support, Hearing and Vision Specialists, and Mental Health Specialist) that could be ordered. A possible fourth issue that we identified during feasibility testing is that the EHRs at some facilities (both Advocate sites in our test) have the capability to record internal (i.e., within-network) but not external referrals, which will lead to inconsistent results in measure calculation. For this measure to work correctly, all referrals would need to be tracked electronically and have all relevant information stored within the patient’s record.

## **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?**

Developmental screening follow-up is a critical and fundamental aspect of pediatric care with demonstrated performance gaps. To improve and enhance follow-up referrals for children with a positive developmental screen and to prevent oversight, a structured data field for a positive developmental screen could be created. In the case that a patient received a positive developmental screening result and no referral was ordered, a prompt function reminding the provider to order the referral would be helpful. A decision support tool could prompt the clinician to make a referral in a structured field with referral categories, allowing the provider to choose the category from a drop-down list.

## 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).**

### *Chart Review Measure Limitations*

There are two primary limitations of this measure: one, most State Medicaid and CHIP programs find chart review as a method for quality assessment to be challenging and burdensome, and therefore they do not use measures specified for manual chart abstraction; and two, because most EHRs do not include a structured field with a code to indicate a positive screen, manual review is required to identify records that fit the denominator criteria, making it burdensome to identify appropriate charts and leading to small numbers for assessment.

Developmental screening follow-up is a critical and fundamental aspect of pediatric care that, if not performed appropriately, can lead to considerable morbidity and costs. Because there are no appropriate administrative codes by which to assess developmental screening follow-up and only a few EHR systems can construct the measure as an eMeasure, manual chart review is the only current option for most practices. This will change quickly over the next few years, particularly if assessment of developmental screening follow-up becomes used for public reporting of pediatric care quality.

### *eMeasure Limitations*

The slow diffusion of EHRs in pediatrics provides a current limitation for the implementation of eMeasures. EHRs were not designed with pediatric patients in mind, as they were modified from records designed for billing in adult medicine, and therefore, they were not designed to prioritize pediatric-focused care. As more pediatric practices are using EHRs, these practices are beginning to customize their EHR systems in order to collect and report on fundamental aspects of pediatric care such as developmental screening and developmental screening follow-up.

Cerner and Epic, which have large proportions of the EHR market share, did not have structured fields for indicating a positive screen or indicating that a referral was made. In the EHR system used at Children's Hospital of Philadelphia (CHOP) that was customized for the purpose of collecting information about developmental screening and follow-up was able to determine that a referral was made in 75 percent of the cases in which a referral was provided. The CHOP system also had a structured field with a drop-down list of reasons that a referral was not provided.

This measure can be constructed in the eClinicalWorks EHR system and in several practices in Pennsylvania and North Carolina based on EHR systems customized through a CHIPRA State demonstration grant. The construction of this measure was tested as an eMeasure in the EHR system of Ashe Pediatrics and while there are structured queryable fields (technically feasible) in the EHR, the fields are not used by clinicians. Therefore, this eMeasure did not pass implementation feasibility and cannot be constructed at this time. Other large progressive practices with EHR systems are customizing their systems to make this measure constructible. We have also provided feedback to the pediatric EHR developers on elements for inclusion that are needed to construct this measure.

A limitation of this measure is that it cannot assess the quality or appropriateness of the referral provided and does not include information about whether the family scheduled and attended an appointment.

State Medicaid and Chip programs currently do not have repositories built to receive and store this type of measure information; however, quality representatives at several State Medicaid and CHIP programs have told us that having eMeasures specified for important quality measures that cannot be assessed through administrative claims is very important in order to inform the development of such repositories.

## **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.**

### ***Background***

In 2009, Congress passed the Children's Health Insurance Program Reauthorization Act (CHIPRA, Public Law 111-3), which presented an unprecedented opportunity to measure and improve health care quality and outcomes for children, particularly those enrolled in Medicaid and/or CHIP. As part of the law, the CHIPRA Pediatric Quality Measures Program (PQMP) was developed to establish a set of measures to effectively assess the quality of pediatric care. An Initial Core set of 25 pediatric measures was developed, and the measures were recommended for use. The Pediatric Measurement Center of Excellence (PMCoE) was funded by AHRQ and assigned to develop Developmental Screening Follow-up (DSF) quality measures.

### **Importance**

The intent of conducting a developmental screen is to assess the child's development, identify developmental concerns, and intervene when warranted to diminish the impact of the delay. A developmental delay can profoundly affect a child's ability to function in multiple settings. It is imperative that children who have a positive screen be referred to follow-up services as soon as possible (Centers for Disease Control and Prevention, 2014).

In a study conducted by the AAP, 61 percent of children with a positive developmental screen were not referred for further evaluation. Subgroup analysis found that in practices using the PEDS, less than one child of every three with a positive result was referred to any source (King, Tandon, Macias, et al., 2012).

Another study reported that physicians fail to identify and refer 60-90 percent of children with developmental delays in a timely manner (King, et al., 2012). Among children classified as having delays at 9 months, only 9 percent received follow-up services, and among children classified as having delays at 24 months, only 10-12 percent received services (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2008). Another study noted the mean time between developmental delay identification and referral for early intervention is greater than 5 months (Tang, Feldman, Huffman, 2012).

### ***Measure Development***

A quality measure to assess whether a practice regularly provides a referral after a positive developmental screen is a critical and fundamental aspect of pediatric care quality and should be publically assessed, monitored, and improved.

A framework for DSF quality measurement was proposed by PMCoE, modeled on Bright Futures and pediatric quality measurement work done in North Carolina and Pennsylvania. This framework included three measures: one, Follow-up with Patient's Family after Developmental Screen; two, Follow-up Referral after Positive Developmental Screen; and three, Follow-up Referral Tracking. This measure framework was reviewed, enhanced, and refined by the DSF Expert Workgroup (Attachment 13.1: Expert Workgroup Materials). A broad range of stakeholders (N=108) reviewed and commented on the measures across a public comment period. The measures were considered important, valid, and clinically relevant. Based on comments, the measures were refined and finalized for testing (Attachment 13.2: Finalized DSF Measure Worksheets).

### ***Measure Testing***

#### ***Feasibility***

Feasibility testing for construction as an eMeasure was performed in the CPQSC, and it was determined that the measures could not be constructed as eMeasures in any of the five sites. A national search was performed to identify sites that could test the measures as eMeasures. It was determined feasible to construct the measures in the EHRs of CHOP and in Ashe Pediatrics, one practice in a statewide network of practices that had customized their eClinicalWorks system with an electronic DSF module.

#### ***Reliability***

Manual chart abstraction was used to assess the reliability of the measure. Across four sites where reliability testing was performed, the agreement was 73 percent, Kappa was 0.67. Agreement was reasonable, but the Kappa was low do to the challenge of identifying appropriate charts.

## ***References***

Centers for Disease Control and Prevention. Developmental monitoring and screening for health professionals, 2014. Available at <http://www.cdc.gov/ncbddd/childdevelopment/screening-hcp.html>. Accessed May 17, 2016.

King TM, Tandon SD, Macias MM, et al. Implementing developmental screening and referrals: lessons learned from a national project. *Pediatrics* 2010; 125(2):350-60.

Medical Home Initiatives for Children with Special Needs Project Advisory Committee. The medical home. *Pediatrics* 2008 (reaffirmed);122(2).

Tang BG, Feldman HM, Huffman LC, et al. Missed opportunities in the referral of high risk infants to early intervention. *Pediatrics* 2012; 129(6):1027-34.

## **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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