Family Experiences with Coordination of Care (FECC) Measure Set

Section 1. Basic Measure Information

1.A. Measure Name

Family Experiences with Coordination of Care (FECC) Measure Set

1.B. Measure Number

0166 FECC Survey/Measure Set

1.C. Measure Description

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

The FECC Survey was developed to gather information needed to score 20 separate and independent quality measures that assess the quality of care coordination services received by children with medical complexity (CMC) over the preceding 12 months.

1.D. Measure Owner

Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN).

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

Eight of the FECC measures have been endorsed by NQF:
2842 – Family Experiences with Coordination of Care (FECC)-1: Has Care Coordinator.
2843 – Family Experiences with Coordination of Care (FECC)-3: Care Coordinator Helped to Obtain Community Services.
2844 – Family Experiences with Coordination of Care (FECC)-5: Care Coordinator Asked About Concerns and Health.
2845 – Family Experiences with Coordination of Care (FECC)-7: Care Coordinator Assisted with Specialist Service Referrals.
2846 – Family Experiences with Coordination of Care (FECC)-8: Care Coordinator Was Knowledgeable, Supportive, and Advocated for Child's Needs.
2847 – Family Experiences with Coordination of Care (FECC)-9: Appropriate Written Visit Summary Content.
2849 – Family Experiences with Coordination of Care (FECC)-15: Caregiver Has Access to Medical Interpreter When Needed.
2850 – Family Experiences with Coordination of Care (FECC)-16: Child Has Shared Care Plan.

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.**

   The FECC Survey comprises a set of 20 independent Family Experiences with Coordination of Care (FECC) measures.

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.**

   Family Experiences with Coordination of Care (FECC) Measure Set.

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

   Not applicable.

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

   Not applicable.

1.G. Numerator Statement

The numerators for each of the 20 care coordination quality measures included within the FECC survey are specified in the detailed measure specifications (see Supporting Documents).

1.H. Numerator Exclusions

All numerator exclusions are provided in the detailed measure specifications (see Supporting Documents).

1.I. Denominator Statement

The denominators for each of the 20 care coordination quality measures included within the FECC survey are specified in the detailed measure specifications (see Supporting Documents). The eligible population of caregivers for the FECC survey overall is composed of those who meet the following criteria:

1. Parents or legal guardians of children 0-17 years of age.
2. Child classified as having a complex, chronic condition using the Pediatric Medical Complexity Algorithm (Simon, Cawthon, Stanford, 2014).
3. Child had adequate data available for running the pediatric medical complexity algorithm (PMCA). For our validation study, this was defined as having at least two Medicaid eligibility months in the 3 months prior to obtaining the sample.
4. Parents speak English or Spanish.

1.J. Denominator Exclusions

1. Child had died.
2. Listed household contact <18 years of age.

1.K. Data Sources

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

Administrative data (e.g, claims data), Survey – Parent/caregiver report.

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

See Supporting Documents for the mail and telephone interview versions of the FECC Survey.

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.

We have provided detailed measure specifications for the 20 care coordination quality measures included in the FECC Survey in the Supporting Documents (see Table 1).

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).**

Importance of Children with Medically Complex Illness to the U.S. Health Care System

Increasing numbers of children in the United States are living with medical complexity (Bethell, Read, Blumberg, et al., 2008). Although these CMC comprise only 13 percent of the pediatric population, they account for a disproportionately high 26-49 percent of hospital days (Berry, Hall M, Hall DE, 2013; Simon, Berry Feudtner, et al., 2010) and 70 percent of overall health care expenditures (Ireys, Anderson, Shaffer, et al., 1997). Given the cost and complexity of caring for these children, optimizing the quality of their care is likely to yield significant health and economic benefits.

Impact of Care Coordination on Other Aspects of Care

Comprehensive, well-coordinated care in a medical home improves patient and family experiences of care (Farmer, Clark, Drewel, et al., 2011; Farmer, Clark Sherman, et al., 2005; Palfrey, Sofis, Davidson, et al., 2004) and patient medical outcomes (Counsell, Callahan, Clark, et al., 2007; Farmer, et al., 2005; Farmer, et al., 2011; Rocco, Scher, Basberg, et al., 2011). Care coordination interventions among CMC have also been associated with decreased unmet need for specialty care (Boudreau, Perrin, Goodman, et al., 2014), as well as improved utilization of health care services and decreasing hospitalizations and costs (Casey, Lyle, Bird, et al., 2011; Counsell, et al., 2007; Door, Wilcox, Brunker, et al., 2008; Gordon, Colby, Bartelt, et al., 2007;

Palfrey, et al., 2004). Improving care coordination for CMC is likely to improve many aspects of care received by these children and their families.

Limited Evidence for Quality of Care Coordination

Little is known about the quality of care coordination received by CMC. Present assessments of care coordination are generally limited to whether or not care coordination was received, without any attempt to identify potentially beneficial components of care coordination or the manner in which they were delivered. The evidence that is available suggests that 29-41 percent of parents of children with special health care needs report not getting needed help with care coordination (Toomey, Chien, Elliott, et al., 2013; Zickafoose, Davis, 2013); little is known about the quality of help that is being received.

Evidence Suggests Disparities in Services Provided

Although only limited information on quality of care coordination is available, data do demonstrate disparities in receipt of care coordination. Latino and black children have been found to be more likely to have unmet care coordination needs compared to non-Hispanic white children (Toomey, et al, 2013). In addition, children from families with limited English proficiency have reported higher unmet care coordination needs and greater difficulty getting needed referrals compared to English-proficient families (Zickafoose, et al., 2013). These data suggest that there also may be disparities according to race/ethnicity and language in quality of care coordination received. The FECC Survey can be collected with data on child and parent race and on ethnicity and language, which will allow for tracking of disparities in care coordination quality over time.

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

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

- **The extent to which the measure is understood to be sensitive to changes in Medicaid or CHIP (e.g., policy changes, quality improvement strategies).**

- **Relevance to the Early and Periodic Screening, Diagnostic and Treatment benefit in Medicaid (EPSDT).**

- **Any other specific relevance to Medicaid/CHIP (please specify).**

Understanding the quality of care coordination being received by CMC is of special importance to Medicaid and CHIP, as these children are disproportionately covered by public insurance (Berry, et al., 2013). In addition, given the costs incurred by CMC, the ability to identify and track the quality of care coordination they receive is likely to drive improvement efforts in a way that may be cost-saving.

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).

The 20 quality measures included in the FECC survey will fill a gap, as currently there are no measures assessing the quality of care coordination for CMC. All measures developed to date have focused on whether or not care coordination was provided, rather than on the quality of the services provided.

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:** Yes.
c. **Care Setting – other – please specify:** Yes; other community and public health settings.
d. **Service – preventive health, including services to promote healthy birth:** No.
e. **Service – care for acute conditions:** Yes.
f. **Service – care for children with acute conditions:** Yes.
g. **Service – other (please specify):** Yes; care for children with chronic conditions.
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:** Yes.
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; 90-364 days.
q. **Population – pre-school age children (1 year through 5 years) (specify age range):** Yes; 1-5 years.
r. **Population – school-aged children (6 years through 10 years) (specify age range):** Yes; 6-10 years.
s. **Population – adolescents (11 years through 20 years) (specify age range):** Yes; 11-17 years.
t. **Population – other (specify age range):** No.
u. **Other category (please specify):** Not applicable.

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

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

5.A. Research Evidence

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

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

We began development of the 20 quality measures included in the FECC Survey by first developing a conceptual framework for care coordination for children with medical complexity (see Supporting Documents, Figure 1). The framework indicates events that may lead to fragmented care, such as interpersonal discontinuity, where providers lack familiarity with the child's health issues, or informational discontinuity, where information needed to care adequately for the child is missing. The framework also illuminates how care coordination relates to both short- and long-term outcomes, such as emergency department utilization and health-related quality of life.

Based on the conceptual framework, we identified six topics for evidence review: shared care plans, goal setting, information exchange, care coordination, continuity of care, and the patient-centered medical home. We then conducted a systematic review of the relevant literature in each topic area, summarizing the evidence assessing links between care coordination structures, processes, and outcomes for children with medical complexity. From the reviews, we developed 45 quality measures that were supported by the identified evidence.

The group next convened a multi-stakeholder panel that used the RAND-UCLA modified Delphi method (Brook, 1994) to prioritize the quality measures for field testing. In brief, panelists evaluated and scored each measure on (1) validity, meaning the concept was supported by adequate levels of evidence and/or expert consensus, and that entities adhering to it would be considered higher quality, and (2) feasibility, meaning the data needed to assess the concept were obtainable at reasonable cost and burden. The panelists then discussed the measures in person and were able to privately re-score them after discussion and seeing median scores. Thirty-five of the 45 proposed quality measures progressed to the next development phase, of which 20 were caregiver survey-based measures. We then developed a caregiver survey to collect the specific

data elements necessary to identify eligibility and scoring for each quality measure. See the Supporting Documents for tables laying out the measures that were retained by the Delphi panel and the corresponding evidence to support them. They are arranged according to the topic areas identified in the conceptual model, although these should not be construed as composite domains: each quality measure is meant to assess a distinct aspect of care coordination.

On the basis of the field test results (described later), we retained all 20 of the field-tested quality measures for the final FECC Survey. See Supporting Documents for the evidence supporting the links between these aspects of care coordination process or structure and patient outcomes.

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

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

Not applicable.

Section 6. Scientific Soundness of the Measure

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

6.A. Reliability

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

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

We examined several aspects of the reliability of the FECC survey measures. While measure development was informed by domains identified in the conceptual model, measures within each domain were not meant to function as a scale, as they do not measure a single underlying construct but instead measure separate aspects of care coordination quality. We therefore do not present any measurement of the reliability within domains, and quality measures included in the FECC Survey may be used independently of one another.

Some of the measures include stems and sub-parts that were intended to function together as a scale and are scored together as a single measure. For those measures, we used a variation on Cronbach's alpha to establish the reliability of the construct measurement. Given the ordinal nature of the indicators, we used polychoric ordinal alphas rather than Pearson correlations. Results were calculated only for participants who were eligible for and answered all measure sub-parts. These results are presented in Table 6 (see Supporting Documents). In five out of six

of the multi-item measures, the alpha was > 0.7, indicating good inter-item reliability among the measure sub-parts. The multi-item measure found to have an alpha <0.7 specifies that a written visit summary should be both easy to understand and useful. While a written visit summary should ideally feature both attributes, they are independent of one another, and any given summary could easily be one without being the other. Therefore, the lower alpha value of 0.57 for the multi-item measure is not unexpected.

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).

Unlike with some quality measures, no gold standard exists for family experiences with care coordination, which the FECC measures aim to capture. Therefore, true criterion validity cannot be established. However, during the process of quality measure development and specification, survey development, cognitive interviewing, and field-testing, many efforts were made to demonstrate the content and construct validity of the 20 quality measures included in the FECC Survey, detailed below.

The RAND-UCLA Modified Delphi Method

The content validity of the quality measures assessed by the FECC Survey was established using the RAND-UCLA Modified Delphi Method (Brook, 1994). The process began with the nomination of nine panelists with expertise related to care coordination for CMC by relevant national stakeholder groups (see Supporting Documents, Table 7). The panel read the literature reviews written by project staff and reviewed and scored each proposed quality measure on validity. This method is a well-established, structured approach to measure evaluation that involves two rounds of independent panel member scoring, with group discussion in between (Brook, 1994). After reviewing literature reviews and draft quality measures, panel members were asked to rate the validity of each measure on a scale from 1 (low) to 9 (high). Validity was assessed by considering whether there was adequate scientific evidence or expert consensus to support its link to better outcomes; whether there would be health benefits associated with receiving measure-specified care; whether they would consider providers who adhere more consistently to the quality measure to be providing higher quality care; and whether adherence to the measure is under the control of health care providers and/or systems. The Delphi method has been found to be reliable and to have content, construct, and predictive validity (Hemingway, Crook, Feder, et al., 2001; Kravitz, Park, Kahan, 1997; Selby, Fireman, Lundstrom, et al., 1996; Shekelle, Chassin, Park, 1998; Shekelle, Kahan, Bernstein, 1998). For a quality measure to move to the next stage of measure development, it had to have a median validity score >7 (1-9 scale) and be scored without disagreement based on the mean absolute deviation from the median after the second round of scoring. This process ensures that only measures widely judged to be valid are moved forward into measure specification.

Cognitive Interviews

Twenty of the 31 quality measures that were endorsed by the Delphi panel were operationalized into survey items. Survey items were developed to specify (1) the eligible population for each measure (the denominator) and (2) whether the indicated care was received among those eligible (the numerator). Survey items underwent cognitive interviews with nine parents, in Spanish and English, to establish understandability by families. By using cognitive interviews prior to field testing, team members identified questions that required revision that might otherwise have impacted survey validity. The cognitive interviews are described in greater detail in Section 10 of this report.

Field Testing

The construct validity of the 20 quality measures in the FECC Survey was established by demonstrating convergent validity with previously validated measures of outpatient care experiences from the Clinician and Group (CG) Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Child 12-month Survey (CAHPS, 2017).

For the field test, we surveyed caregivers of CMC insured by Medicaid in Washington and Minnesota. To identify these children, we applied the Pediatric Medical Complexity Algorithm, based on International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes, to classify children with chronic disease according to level of medical complexity (Simon, et al., 2014). CMC were eligible for inclusion if they were (1) aged 0-17 years; (2) had at least 2 months of Medicaid eligibility during the 3 months prior to obtaining the sample; (3) had at least four visits to a health care provider during the prior 12 months; and (4) had a health care provider who participated in Medicaid. Children were excluded if (1) the child had died; (2) the listed household contact was < 18 years of age; or (3) the caregiver spoke a language other than English or Spanish. We sampled 1,500 caregivers in each State and administered the survey from July to November 2013 via both mixed mode (mail with phone follow-up) and phone only; the survey was available in English and Spanish. We obtained 600 completed surveys in Washington and 609 in Minnesota (see Table 1 in Gidengil, Parast, Burkhart, et al., 2017, for demographic characteristics of participating caregivers and their children).

FECC Survey Questions

The FECC Survey comprised 45 questions, including 6 questions related to care coordination outcomes. Of these outcome measures, two were newly developed, two were adapted from the National Survey of Children with Special Health Care Needs (Blumberg, Welch, Chowdhury, et al., 2008), and two were adapted from CAHPS measures (Hays, Martino, Brown, et al., 2014). The 20 quality measures were categorized into three groups: Care Coordination Services, Messaging, and Protocols/Plans. These groups were for organizational purposes and do not represent measure composite domains. All quality measures were scored on a 0-100 scale such that higher scores indicate better care. For binary measures, 100 indicated receipt of the recommended care, 0 indicated non-receipt. One quality measure and 11 measure were removed from the FECC measure set due to low eligibility and/or ceiling effects. For example, the initial shared care plan quality measure included four sub-parts, specifying that (a) a shared care plan was created; (b) the caregiver participated in creating it; (c) the caregiver participated in updating

it within the previous year, if it was first created >1 year ago; and (d) the caregiver received a copy of it.

Given that less than half of respondents endorsed having a shared care plan, and that measure sub-parts (b), (c), and (d) exhibited both low eligibility and ceiling effects, only measure sub-part (a) was retained in the final FECC measure set and survey.

CG CAHPS Experience Measures

Caregiver experience was measured using the overall provider rating and four questions concerning access to care (the Access Composite) from the CG-CAHPS Child 12-month Survey (CAHPS, 2017). Responses to the access questions were scored on a 0-100 scale (Never = 0, Sometimes = 33.3, Usually = 66.7, Always = 100); caregivers that answered at least one of the four questions received an Access Composite score calculated as the mean of the non-missing responses.

Analyses

We used linear regression to examine the association between quality measure scores and the two CAHPS measures, unadjusted and adjusted for child and caregiver characteristics. This analysis was carried out for each quality measure.

Table 3 in Gidengil, et al., shows the results of these validation analyses using the Access Composite and Overall Provider Rating. Since not all children were eligible for all quality measures, the sample size for each model varied and is shown (see detailed measure specifications in the Supporting Documents for more information). Most of the FECC quality measures were associated with better experience in terms of access to care and provider rating. The regression coefficients and significance levels changed only slightly after adjusting for caregiver and child characteristics. These results demonstrate convergent validity between the 20 quality measures included in the FECC Survey and the CG CAHPS items that we would also expect to be influenced by the quality and degree of care coordination assistance a parent receives for a CMC. This suggests that the quality measures included in the FECC Survey are indeed measuring what they purport to measure.

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

We evaluated differences in FECC quality measure scores by child race/ethnicity. Child race/ethnicity was categorized on the basis of two questions: "Is your child of Hispanic or Latino origin or descent?" and "What is your child's race? Please choose one or more from this list: white; black or African American; Asian; Native Hawaiian or other Pacific Islander; American Indian or Alaska Native; Other." Based on these questions, children were categorized as one of the following: non-Hispanic white, Hispanic, black, or other (including multiple races). Individual groups within the "other" category were too small to evaluate separately.

FECC quality measure scores were evaluated by race/ethnicity, both in unadjusted and adjusted analyses. In unadjusted analyses (see Table 11 in the Supporting Documents), some variability was seen on the basis of race/ethnicity. Compared to caregivers of non-Hispanic white children, caregivers of black children reported better scores on six quality measures; caregivers of Hispanic children reported better scores on four quality measures and worse scores on three measures.

In analyses adjusting for State, caregiver age, and child age, the majority of the differences for black children were no longer statistically significant (see Supporting Documents, Table 12). This may be due in part to a medical home initiative that was underway during FECC survey data collection in Minnesota, where the majority of the black participants lived. The findings for Hispanic children remained largely unchanged after adjustment. Black and Hispanic children remained significantly more likely than non-Hispanic white children to have a shared care plan or an emergency care plan, and black children remained more likely to have a transition plan.

7.B. Special Health Care Needs

The quality measures included in the FECC Survey apply exclusively to children with medical complexity and so are not intended to identify disparities between those who do and do not have special health care needs.

7.C. Socioeconomic Status

Because the field test was restricted to children receiving Medicaid, there was limited variability in socioeconomic status. We are therefore unable to comment on the FECC quality measures' ability to identify disparities based on socioeconomic status.

7.D. Rurality/Urbanicity

We assessed differences in FECC quality measure scores by residence in a metropolitan statistical area (MSA). We had access to MSA categorization for the entire sample from Minnesota (n=609). However, for Washington state, we had access to MSA data only for the subgroup of participants who both completed the FECC Survey and provided written consent for use of the child's administrative data (n=233).

In unadjusted analyses, we found that children living in an MSA were more likely to have both a shared care plan and an emergency care plan compared to those living outside an MSA (see

Supporting Documents, Table 13). After adjusting for State, caregiver age, and child age, the only difference we found was for emergency care plans, with children in MSAs most likely to have one (see Table 14 in the Supporting Documents). In our adjusted analysis, we did not control for child race/ethnicity, as race/ethnicity was colinear with living in an MSA.

7.E. Limited English Proficiency (LEP) Populations

We evaluated the FECC quality measures by caregiver English proficiency. We identified the LEP population using the methodology described by Karliner and colleagues based on a combination of the U.S. Census question regarding self-reported English proficiency (How well do you Speak English? Very well; Well; Not well; Not at all) and preferred language for health care conversations (Karliner Napoles-springer, Schillinger, et al., 2008). Those who report speaking English very well are considered English proficient. Those who report speaking English not well or not at all are considered LEP. Those who report speaking English well are classified as English-proficient if their preferred language for medical care is English, and LEP if it is another language. Compared to using the U.S. Census question alone, this methodology better identifies families who are likely to benefit from interpretation in the medical setting or, conversely, those most likely to suffer harm from lack of professional interpretation. The vast majority (147 out of 154) of the LEP respondents were Spanish-speaking, as the FECC Survey was available during field-testing in English and Spanish only.

Unadjusted analyses (see Table 15 in the Supporting Documents) and analyses adjusting for State, child age, and caregiver age (see Table 16 in the Supporting Documents) were similar. While LEP was positively associated with having a shared care plan, having a care coordinator, and receiving help with access-related aspects of care coordination, it was negatively associated with communication-related care coordinator attributes. The pattern of findings was similar to those observed for Hispanic ethnicity but with stronger associations, suggesting that language barriers may account for some of the ethnicity findings previously presented in Section 7.A.

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?

Administrative data are used to identify children eligible for the FECC quality measures, using billing data (ICD-9-CM codes) for the Pediatric Medical Complexity Algorithm. Such billing data are readily available to practices, hospitals, and insurers. However, the parent-reported quality measures included in the FECC Survey must be collected prospectively.

In our field test, we determined that it was feasible to collect information on care coordination quality from parents and caregivers of CMC. We achieved an overall survey response rate of 40 percent (1,209 out of 3,000), which was quite good given that 632 of the original 3,000 (21 percent) were unable to be contacted (bad phone number or undeliverable mail); only 285 (9.5 percent) actively refused participation, and another 525 (17.5 percent) passively refused by non-response. Caregiver survey is the only way to obtain information from caregivers on their experiences of care, and we found that it may also be the only way to identify the use of tools like shared care plans at the present time. We attempted to compare caregiver report to medical record abstraction for a selection of FECC quality measures for which such comparison would be relevant. We found that very few medical records contained information regarding care coordination in a place that was identifiable by trained medical record abstractors. For example, among respondents with medical record data available, 39 percent of parents reported having a shared care plan, while such a plan was identified in just 2 percent of the records.

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

Not applicable.

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 FECC Survey was completed by 1,209 parents of CMC in the States of Washington and Minnesota during field testing in 2013. In the context of the field testing and validation study, patients and families were identified from Medicaid enrollment data. The surveys were administered by the RAND Corporation Survey Research Group (RAND SRG), Santa Monica, CA, and included children served by a range of pediatric practice types, including small group, multi-specialty, urban, and rural practices. The average number of participating families per identified provider was 2.5, while the median was 1. The maximum number of participating families per provider was 26.

The FECC survey quality measures are currently being used by the Vermont Child Healthcare Improvement Partnership (V-CHIP) to assess the effectiveness of a medical home care coordination quality improvement intervention for children with medical complexity in the State of Vermont.

Under funding from PCORI (Patient-Centered Outcomes Research Initiative, principal investigator Paula Song), the FECC survey measures will also be used in the evaluation of the effectiveness of a care coordination intervention being implemented in an accountable care organization for children on SSI in the State of Ohio.

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?

The survey administration was coordinated through RAND SRG. Families were randomized within a State to either mail or telephone-only survey collection. In the mail group, two survey

mailings were sent out. Families that did not respond after the two mailings were then contacted by telephone, with up to eight telephone calls made. In the telephone-only group, up to 10 calls were made to each family.

For the V-CHIP project, the survey will be administered in primary care clinics using paper surveys. For the PCORI-funded project, the survey will be offered as a Web-based survey and as a telephone interview.

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

Our pilot testing allowed us to identify measures and measure sub-parts with very low eligibility and/or ceiling effects, which were dropped from the survey. This led to dropping one quality measure and 11 measure sub-parts from the final version of the FECC measure set and survey. We also discovered, when we sought to compare parent-reported measures on the FECC quality measures to medical-record-based versions of the same measures (e.g., having a shared care plan) that many of these care coordination quality measures cannot feasibly be ascertained from current state-of-the-art electronic health records or paper medical records. For the time being, these quality measures are only ascertainable from parent report.

Section 9. Levels of Aggregation

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

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

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

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

State level* Can compare States

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

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

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

For comparing State performance to a national benchmark, we recommend collecting a minimum of 199 responses to detect a small effect size (Cohen's d of 0.2), 34 responses to detect a medium effect size (Cohen's d of 0.5), and 15 responses to detect a large effect size (Cohen's d of 0.8). Cohen's d is calculated as the difference in the State mean and the national mean, divided by the standard deviation of the error. It can be calculated separately for each quality measure in order to determine the sample size needed to detect a specific difference in scores in the particular measure. For comparing the performances of two States, we recommend collecting a minimum of 394 responses per State to detect a small effect size (Cohen's d of 0.2), 64 responses per State to detect a medium effect size (Cohen's d of 0.5), and 26 responses per State to detect a large effect size (Cohen's d of 0.8). In this case, Cohen's d is calculated as the difference in the two States' means, divided by the standard deviation of the common error.

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

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?**
If incentives are tied to reporting on FECC quality measures, providers could choose to carve out populations of children with medical complexity that they will not care for.

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?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Recommended minimum sample sizes are the same as those listed for the State level.

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?**
If incentives are tied to reporting on FECC measures, providers could choose to carve out populations of children with medical complexity that they will not care for.

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?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Recommended minimum sample sizes are the same as those listed for the State level.

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?**
Information on validation is in press as of February 2018.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
If incentives are tied to reporting on FECC quality measures, providers could choose to carve out populations of children with medical complexity that they will not care for.

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?**
Yes.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Recommended sample sizes are the same as those listed for the State level.

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?**
Information on validation is in press as of February 2018.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
If incentives are tied to reporting on FECC quality measures, providers could choose to carve out populations of children with medical complexity that they will not care for.

Provider Level
Individual practitioner: Can compare individual health care professionals

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

Data Sources: **Are data sources available to support reporting at this level?**
No.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
These quality measures cannot be used to compare individual providers because most individual providers will not have sufficient numbers of children with medical complexity within their patient panels to make meaningful comparisons. In our field testing, the average number of participating patient families per provider was 2.5, and the median was 1.

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

Provider Level
Hospital: Can compare hospitals

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

Data Sources: **Are data sources available to support reporting at this level?**
No.

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
Care coordination is generally provided within the context of the outpatient primary care office, so it would not make sense for hospitals to measure the quality of care coordination being provided to CMC

In Use: **Have measure results been reported at this level previously?**
No.

Reliability & Validity: **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**
No.

Unintended consequences: **What are the potential unintended consequences of reporting at this level of aggregation?**
Not applicable.

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

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

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

Sample Size: **What is the typical sample size available for each unit at this level? What proportion of units at this level of aggregation can achieve an acceptable minimum sample size?**
These measures will likely not be useful for most groups or facilities because most groups will not have sufficient numbers of children with medical complexity within their patient panels to make meaningful comparisons. However, these measures could potentially be used by a group or facility over time to drive QI efforts, given a large enough population of CMC. We recommend obtaining a minimum of 199 responses per time period from the same group of caregivers to detect a small effect size (Cohen's d of 0.2), 34 responses per time period to detect a medium effect size (Cohen's d of 0.5), and 15 responses per time period to detect a large effect size (Cohen's d of 0.8). In this case, Cohen's d is calculated as the difference in the mean value at the two measurement time points, divided by the standard deviation of the common error. These calculations assume a correlation between time points of 0.5; with higher correlation (as one might expect when surveying the same caregivers at multiple time points), a larger effect size is detectable for any given sample size.

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?**
If incentives are tied to reporting on FECC quality measures, providers could choose to carve out populations of children with medical complexity that they will not care for.

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).

The FECC Survey explicitly aims to capture information that can only be obtained from parents and caregivers; therefore, understandability is of paramount importance. All of the FECC quality measures were pre-reviewed, prior to the Delphi process, by a family advisory committee made up of 10 parents of CMC from Family Voices (www.familyvoices.org). This initial step ensured that only measures that were understandable and important to parents even made it to the Delphi panel. A parent representative from Family Voices also participated in the Delphi process, during which time the initial measures were selected for operationalization. The Delphi process was used to establish content validity of the quality measures that were ultimately included in the FECC survey, and parent participation in that step helped to ensure that only measures that were understandable and had content validity moved forward, and that the measures were framed in a way that made sense to parents.

The quality measures were then operationalized as draft survey items that were used in cognitive interviews with parents of children with medical complexity prior to being included in the FECC Survey. Nine cognitive interviews were conducted in April, 2013. Five interviews were with English-speaking parents of CMC in Minnesota, and four were with Spanish-speaking parents of CMC in the Los Angeles area of California. Spanish-language interviews were conducted in-person in the home, and English-language interviews were conducted by telephone.

Participants in telephone interviews received written materials (e.g., show cards, comparison questions) in advance that they could reference during the interview. Average interview time was 70 minutes. Based on the results of these interviews, draft survey items were refined to improve understandability and reliability. The final survey reflects the questions that parents found to be understandable and relevant to their experiences regarding care coordination for their child with medical complexity.

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.

The FECC measures rely on parent report and therefore does not require any health IT functionality. The eligible population is identified using administrative data, so improved health IT systems could potentially make identification of the eligible population easier by automatically calculating the PMCA on an ongoing basis for all patients within a practice or health plan.

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?

The PMCA, used to identify the eligible population, has been tested in a number of health IT systems. Please see the Supporting Documents for further details.

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 billing diagnosis codes used for the PMCA are captured in some format on a routine basis by most health care systems.

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)?

Not applicable.

If yes, please describe.

Not applicable.

11.E. Health IT Calculation

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

The PMCA has been tested in several settings and compared to a gold standard population, based on medical record review. On the basis of this work, PMCA's sensitivity for correctly classifying children with medical complexity (complex chronic disease) was 84-89 percent, and the specificity was 85-92 percent, indicating that misclassification is infrequent (Simon, et al., 2014). However, missing or incomplete data are most likely to lead to children not being classified as having medical complexity, which could incorrectly exclude their caregivers from participation in the FECC Survey.

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?

Not applicable.

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).

The FECC quality measures have several limitations. The intent of the FECC quality measures is to assess aspects of care coordination for CMC for which the parent is the best source of information. These tend to be the more visible aspects of care coordination and the parents' experiences with them, such as having a shared care plan or having a care coordinator who is knowledgeable and supportive. The FECC quality measures are not designed to measure aspects of care coordination for which the parent is not the best source of information, such as whether a specialist communicated directly with the primary care provider. Such additional metrics evaluating care coordination quality will need to be obtained from alternate sources.

While a survey-based quality measure allows for ascertainment of care aspects best reported by the parent, it does introduce the possibility of recall bias. Specifically, the survey asks parents to report on events occurring over the previous 12 months. Parents with a particularly positive or negative experience may be more likely to recall a given occurrence or condition. In addition, parents may recall things that occurred more than 12 months prior and report them as having occurred in the previous 12 months.

There also were some limitations to the study validating the FECC quality measures. Specifically, the short study timeframe did not allow for prospective data collection following survey administration. Therefore, all findings are based on concurrent or retrospective data, so we were unable to ascertain whether aspects of care coordination reported in one year were associated with health care utilization or health outcomes in the subsequent year or whether the constructs measured by the FECC quality measures change over time.

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.

Children with medical complexity are a large and growing population in the United States. The care for these medically fragile children involves an increasing number of providers and services, all set within a health care system that is increasingly fragmented and complex. Effective care coordination has been found to improve care experiences and health outcomes for these children. Currently, however, only very gross measures exist of whether or not care coordination has been provided. No standards or metrics related to the quality of care coordination provided have been developed or studied. The 20 quality measures included in the FECC Survey address this gap.

Understanding the quality of care coordination provided to CMC is important for informing improvement efforts. Understanding parents' experiences with care coordination is of particular import, given the association between experiences of care and health outcomes, the central role family-centeredness plays in health care quality, and the unique needs and requirements of individual families caring for a child with medical complexity.

The quality measures included in the FECC Survey were developed based on a conceptual model and systematic literature reviews. The validity and feasibility of the quality measures were evaluated by a multi-stakeholder panel using the RAND-UCLA modified Delphi method. Measures that were endorsed by the Delphi panel were operationalized as survey items and underwent cognitive interviewing and revision to ensure understandability prior to use in the field test.

The field testing of the quality measures included in the FECC Survey was conducted in two States with a total of 1,209 parents of children with medical complexity. On the basis of field test results, one quality measure and 11 measure sub-parts were eliminated from the survey due to low eligibility and or ceiling effects. The 20 quality measures included in the FECC Survey demonstrated excellent correlation with other validated measures of family experience, specifically, the CG CAHPS Child 12-month Survey. The FECC survey was feasible to administer to families by mail with telephone follow-up and telephone alone with response rates of 46 percent and 36 percent, respectively.

Use of all or some of the FECC quality measures will allow for measuring family experiences related to an important aspect of care for a vulnerable population in a family-centered way. The 20 FECC measures can be administered as a stand-alone survey, or sub-sets of the survey items can be added to surveys already being administered for other quality monitoring purposes, allowing assessment of individual FECC measures, as the items are not intended to function as a scale. It will allow States, practices, and insurance plans to track the quality of care coordination being experienced by parents of CMC. It will also allow for targeted quality improvement

efforts, and ultimately, it will motivate improvement in the quality of care received by these fragile children.

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Section 14: Identifying Information for the Measure Submitter

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

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

Public Disclosure Requirements

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