



## Measure Information

This document contains the information submitted by measure developers/stewards, but is organized according to NQF's measure evaluation criteria and process. The item numbers refer to those in the submission form but may be in a slightly different order here. In general, the item numbers also reference the related criteria (e.g., item 1b.1 relates to sub criterion 1b).

### Brief Measure Information

**NQF #:** 2850

**Corresponding Measures:**

**De.2. Measure Title:** Family Experiences with Coordination of Care (FECC)-16: Child has shared care plan

**Co.1.1. Measure Steward:** Seattle Children's Research Institute

**De.3. Brief Description of Measure:** The Family Experiences with Coordination of Care (FECC) Survey was developed to gather information about the quality of care coordination being received by children with medical complexity (CMC) over the previous 12 months. The FECC Survey is completed by English- and Spanish-speaking caregivers of CMC aged 0-17 years with at least 4 medical visits in the previous year, and it includes all of the information needed to score 20 separate and independent quality measures, a sub-set of 8 of which are included in this submitted measure set. CMC are identified from administrative data using the Pediatric Medical Complexity Algorithm (PMCA)<sup>1</sup>, which uses up to 3 years' worth of International Classification of Diseases—9th Revision (ICD-9) codes to classify a child's illness with regard to chronicity and complexity. CMC are children identified by the PMCA as having complex, chronic disease.

The full NQF submission includes a set of 8 of the FECC quality measures; this submission relates to FECC 16, described below. The short descriptions of each quality measure follows; full details for FECC-16 are provided in the Detailed Measure Specifications (see S.2b):

2842: FECC-1: Has care coordinator

2843: FECC-3: Care coordinator helped to obtain community services

2844: FECC-5: Care coordinator asked about concerns and health changes

2845: FECC-7: Care coordinator assisted with specialist service referrals

2846: FECC-8: Care coordinator was knowledgeable, supportive and advocated for child's needs

2847: FECC-9: Appropriate written visit summary content

2849: FECC-15: Caregiver has access to medical interpreter when needed

2850: FECC-16: Child has shared care plan

Each of the quality measures is scored on a 0-100 scale, with higher scores indicating better care. For dichotomous measures, a score of 100 indicates the child received the recommended care; a score of 0 indicates that they did not. Please see Detailed Measure Specifications (see S.2b) for additional measure-specific scoring information.

**1b.1. Developer Rationale:** In March 2011, the Centers for Medicare and Medicaid Services (CMS) and the Agency for Healthcare Research and Quality (AHRQ) partnered to fund seven Centers of Excellence on Quality of Care Measures for Children (COEs). These Centers constitute the Pediatric Quality Measures Program mandated by the Child Health Insurance Program Reauthorization Act (CHIPRA) legislation passed in January of 2009. The charge to the seven COEs was to develop new quality of care measures and/or enhance existing measures for children's healthcare across the age spectrum. Our Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) was charged by CMS and AHRQ to develop measures assessing the quality of care coordination for children with medical complexity (CMC).

Increasing numbers of children in the United States are living with medical complexity.<sup>(2)</sup> Although these children with medical complexity (CMC) comprise only 13% of the pediatric population, they account for a disproportionately high 26-49% of hospital days<sup>(3,4)</sup> and 70% of overall health expenditures.<sup>(5)</sup> 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.

Comprehensive, well-coordinated care in a medical home improves patient and family experiences of care<sup>6-8</sup> and patient medical outcomes.<sup>(6,7,9,10)</sup> Care coordination interventions among CMC have also been associated with decreased unmet specialty care need<sup>11</sup> and improved utilization of health care services, decreasing hospitalizations and cost.<sup>8,9,12-14</sup> Improving care coordination for CMC is likely to improve many aspects of care received by these children and their families.

Little is known about the quality of care coordination received by CMC. Present assessments of care coordination are generally limited to whether care coordination was received or not, 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% of parents of children with special health care needs report not getting needed help with care coordination;<sup>(15,16)</sup> little is known about the quality of the help that is being received.

While limited information on quality of care coordination exists, 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.<sup>(16)</sup> 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.<sup>(15)</sup> These data suggest that there may also be disparities in quality of care coordination received by race/ethnicity and language. The FECC Survey can be collected with data on child and parent race, ethnicity and language, which will allow for tracking of disparities in care coordination quality over time.

references:

2. Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Matern Child Health J.* 2008;12(1):1-14.
3. Berry JG, Hall M, Hall DE, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatr.* 2013;167(2):170-177.
4. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics.* 2010;126(4):647-655.
5. Ireys HT, Anderson GF, Shaffer TJ, Neff JM. Expenditures for care of children with chronic illnesses enrolled in the Washington State Medicaid program, fiscal year 1993. *Pediatrics.* 1997;100(2 Pt 1):197-204.
6. Farmer JE, Clark MJ, Sherman A, Marien WE, Selva TJ. Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics.* 2005;116(3):649-656.
7. Farmer JE, Clark MJ, Drewel EH, Swenson TM, Ge B. Consultative care coordination through the medical home for CSHCN: a randomized controlled trial. *Matern Child Health J.* 2011;15(7):1110-1118.
8. Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. *Pediatrics.* 2004;113(5 Suppl):1507-1516.
9. Counsell SR, Callahan CM, Clark DO, et al. Geriatric care management for low-income seniors: a randomized controlled trial. *JAMA.* 2007;298(22):2623-2633.
10. Rocco N, Scher K, Basberg B, Yalamanchi S, Baker-Genaw K. Patient-centered plan-of-care tool for improving clinical outcomes. *Qual Manag Health Care.* 2011;20(2):89-97.
11. Boudreau AA, Perrin JM, Goodman E, Kurowski D, Cooley WC, Kuhlthau K. Care coordination and unmet specialty care among children with special health care needs. *Pediatrics.* 2014;133(6):1046-1053.
12. Casey PH, Lyle RE, Bird TM, et al. Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children. *Arch Pediatr Adolesc Med.* 2011;165(5):392-398.
13. Dorr DA, Wilcox AB, Brunner CP, Burdon RE, Donnelly SM. The effect of technology-supported, multidisease care management on the mortality and hospitalization of seniors. *J Am Geriatr Soc.* 2008;56(12):2195-2202.
14. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med.* 2007;161(10):937-944.
15. Zickafosse JS, Davis MM. Medical home disparities are not created equal: differences in the medical home for children from different vulnerable groups. *J Health Care Poor Underserved.* 2013;24(3):1331-1343.

**S.4. Numerator Statement:** The numerator for FECC-16 is specified in the Detailed Measure Specifications (see S.2b). A brief description of each numerator is laid out in Table 1 in section De.3, and a more detailed description of FECC-16 follows:

FECC-16: Caregivers of CMC should report that their child's primary care provider created a shared care plan for their child.

**S.6. Denominator Statement:** 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 (PMCA) (see Simon TD, Cawthon ML et al. 2014)
3. Child had at least 4 visits to a healthcare provider over the previous year

While some of the FECC measures only apply to a subset of the overall eligible population for the survey (e.g., measures related to the quality of care coordination services provided are only scored for those caregivers who endorse having a care coordinator), eligibility for these quality measures can only be gleaned from responses to the FECC Survey itself. This is analogous to the situation with many H-CAHPS measures, where, for example, measures about blood draws and laboratory testing are scored only for those who had the relevant service performed during the time frame or hospitalization in question.

**S.8. Denominator Exclusions:** Denominator exclusions:

1. Child had died
2. Caregiver spoke a language other than English or Spanish

**De.1. Measure Type:** Process

**S.17. Data Source:** Claims, Instrument-Based Data

**S.20. Level of Analysis:** Health Plan, Population : Regional and State

**IF Endorsement Maintenance – Original Endorsement Date:** May 04, 2016 **Most Recent Endorsement Date:** May 04, 2016

**IF this measure is included in a composite, NQF Composite#/title:**

**IF this measure is paired/grouped, NQF#/title:**

**De.4. IF PAIRED/GROUPED, what is the reason this measure must be reported with other measures to appropriately interpret results?** not applicable

## 1. Evidence, Performance Gap, Priority – Importance to Measure and Report

Extent to which the specific measure focus is evidence-based, important to making significant gains in healthcare quality, and improving health outcomes for a specific high-priority (high-impact) aspect of healthcare where there is variation in or overall less-than-optimal performance. ***Measures must be judged to meet all sub criteria to pass this criterion and be evaluated against the remaining criteria.***

**1a. Evidence to Support the Measure Focus – See attached Evidence Submission Form**

[NQF\\_Evidence\\_FECC\\_16.docx](#)

**1a.1 For Maintenance of Endorsement: Is there new evidence about the measure since the last update/submission?**

Please update any changes in the evidence attachment in red. Do not remove any existing information. If there have been any changes to evidence, the Committee will consider the new evidence. If there is no new evidence, no updating of the evidence information is needed.

### 1b. Performance Gap

Demonstration of quality problems and opportunity for improvement, i.e., data demonstrating:

- considerable variation, or overall less-than-optimal performance, in the quality of care across providers; and/or
- Disparities in care across population groups.

**1b.1. Briefly explain the rationale for this measure (e.g., how the measure will improve the quality of care, the benefits or improvements in quality envisioned by use of this measure)**

***IF a PRO-PM (e.g. HRQoL/functional status, symptom/burden, experience with care, health-related behaviors), provide evidence that the target population values the measured PRO and finds it meaningful. (Describe how and from whom their input was obtained.)***

***IF a COMPOSITE (e.g., combination of component measure scores, all-or-none, any-or-none), SKIP this question and provide rationale***

*for composite in question 1c.3 on the composite tab.*

In March 2011, the Centers for Medicare and Medicaid Services (CMS) and the Agency for Healthcare Research and Quality (AHRQ) partnered to fund seven Centers of Excellence on Quality of Care Measures for Children (COEs). These Centers constitute the Pediatric Quality Measures Program mandated by the Child Health Insurance Program Reauthorization Act (CHIPRA) legislation passed in January of 2009. The charge to the seven COEs was to develop new quality of care measures and/or enhance existing measures for children's healthcare across the age spectrum. Our Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) was charged by CMS and AHRQ to develop measures assessing the quality of care coordination for children with medical complexity (CMC).

Increasing numbers of children in the United States are living with medical complexity.(2) Although these children with medical complexity (CMC) comprise only 13% of the pediatric population, they account for a disproportionately high 26-49% of hospital days(3,4) and 70% of overall health expenditures.(5) 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.

Comprehensive, well-coordinated care in a medical home improves patient and family experiences of care(6-8) and patient medical outcomes.(6,7,9,10) Care coordination interventions among CMC have also been associated with decreased unmet specialty care need(11) and improved utilization of health care services, decreasing hospitalizations and cost.(8,9,12-14) Improving care coordination for CMC is likely to improve many aspects of care received by these children and their families.

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While limited information on quality of care coordination exists, 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.(16) 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.(15) These data suggest that there may also be disparities in quality of care coordination received by race/ethnicity and language. The FECC Survey can be collected with data on child and parent race, ethnicity and language, which will allow for tracking of disparities in care coordination quality over time.

#### references:

2. Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Matern Child Health J.* 2008;12(1):1-14.
3. Berry JG, Hall M, Hall DE, et al. Inpatient growth and resource use in 28 children's hospitals: a longitudinal, multi-institutional study. *JAMA Pediatr.* 2013;167(2):170-177.
4. Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. *Pediatrics.* 2010;126(4):647-655.
5. Ireys HT, Anderson GF, Shaffer TJ, Neff JM. Expenditures for care of children with chronic illnesses enrolled in the Washington State Medicaid program, fiscal year 1993. *Pediatrics.* 1997;100(2 Pt 1):197-204.
6. Farmer JE, Clark MJ, Sherman A, Marien WE, Selva TJ. Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics.* 2005;116(3):649-656.
7. Farmer JE, Clark MJ, Drewel EH, Swenson TM, Ge B. Consultative care coordination through the medical home for CSHCN: a randomized controlled trial. *Matern Child Health J.* 2011;15(7):1110-1118.
8. Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. *Pediatrics.* 2004;113(5 Suppl):1507-1516.
9. Counsell SR, Callahan CM, Clark DO, et al. Geriatric care management for low-income seniors: a randomized controlled trial. *JAMA.* 2007;298(22):2623-2633.
10. Rocco N, Scher K, Basberg B, Yalamanchi S, Baker-Genaw K. Patient-centered plan-of-care tool for improving clinical outcomes. *Qual Manag Health Care.* 2011;20(2):89-97.
11. Boudreau AA, Perrin JM, Goodman E, Kurowski D, Cooley WC, Kuhlthau K. Care coordination and unmet specialty care

among children with special health care needs. *Pediatrics*. 2014;133(6):1046-1053.

12. Casey PH, Lyle RE, Bird TM, et al. Effect of hospital-based comprehensive care clinic on health costs for Medicaid-insured medically complex children. *Arch Pediatr Adolesc Med*. 2011;165(5):392-398.

13. Dorr DA, Wilcox AB, Brunker CP, Burdon RE, Donnelly SM. The effect of technology-supported, multidisease care management on the mortality and hospitalization of seniors. *J Am Geriatr Soc*. 2008;56(12):2195-2202.

14. Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML, Havens P. A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med*. 2007;161(10):937-944.

15. Zickafoose JS, Davis MM. Medical home disparities are not created equal: differences in the medical home for children from different vulnerable groups. *J Health Care Poor Underserved*. 2013;24(3):1331-1343.

**1b.2. Provide performance scores on the measure as specified (current and over time) at the specified level of analysis.** *(This is required for maintenance of endorsement. Include mean, std dev, min, max, interquartile range, scores by decile. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities include.) This information also will be used to address the sub-criterion on improvement (4b) under Usability and Use.*

The following performance scores were derived from our field-testing of the FECC measure set, in which we sampled 1500 caregivers from each of 2 states who had a child with medical complexity covered by Medicaid. We 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. Of caregiver respondents, 95% were female, 60% were non-Hispanic white, and 80% were English proficient (defined as speaking English “very well”). Thirty-six percent had completed high school as their highest education, and 53% had completed college. Please see Table T1, in section 1.6 of the testing attachment, for complete demographic characteristics of our sample.

Measure: FECC 16

Description: Child has shared care plan

Respondents (N): 1095

Mean (SD): 43.7 (49.6)

Min: 0

25th percentile: 0

Median: 0

75th percentile: 100

Max: 100

**1b.3. If no or limited performance data on the measure as specified is reported in 1b2, then provide a summary of data from the literature that indicates opportunity for improvement or overall less than optimal performance on the specific focus of measurement.**

not applicable

**1b.4. Provide disparities data from the measure as specified (current and over time) by population group, e.g., by race/ethnicity, gender, age, insurance status, socioeconomic status, and/or disability.** *(This is required for maintenance of endorsement. Describe the data source including number of measured entities; number of patients; dates of data; if a sample, characteristics of the entities included.) For measures that show high levels of performance, i.e., “topped out”, disparities data may demonstrate an opportunity for improvement/gap in care for certain sub-populations. This information also will be used to address the sub-criterion on improvement (4b) under Usability and Use.*

Disparities data are derived from the same field-testing data described above in section 1b.2, and in greater detail in section 2b2.2 of the testing attachment. Child and caregiver race/ethnicity, and caregiver languages are given below (see section 1.6 of the testing attachment for full demographic details of the respondents):

Caregiver race/ethnicity:

Non-Hispanic white: 722 (60%)

Hispanic: 250 (21%)

African American: 92 (8%)

Other: 119 (10%)

Missing: 26 (2%)

Caregiver English proficiency

Speaks very well: 972 (80%)

Speaks well: 78 (6%)

Does not speak well: 82 (7%)

Does not speak at all: 52 (4%)

Not answered: 25 (2%)

Language of survey completion

English: 1048 (87%)

Spanish: 161 (13%)

Child race/ethnicity

Non-Hispanic white: 585 (48%)

Hispanic: 308 (26%)

African American: 94 (8%)

Other: 195 (22%)

Missing: 27 (2%)

We evaluated differences in FECC quality measure scores by child race/ethnicity. Child race/ethnicity was categorized on the basis of 2 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. For full results stratified by race/ethnicity, please see Tables T10 (unadjusted) and T11 (adjusted) in the testing attachment (section 2b5.2). Results in which differences were found in adjusted analyses are presented here:

Measure: FECC 16

Description: Child has shared care plan

Non-Hispanic white (n=585): 38.3

Hispanic (n=308): 47.4\*

Black (n=94): 65.5\*\*\*

Other (n=222): 41.7

Compared to white reference group using linear or logistic regression: \*p<0.05 \*\*p<0.01 \*\*\*p<0.001

We also evaluated the FECC quality measures by caregiver English proficiency. We identified the LEP population using the methodology described by Karliner et al (2008), based on a combination of the US 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. 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 US 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.

Results for which a disparity was found in adjusted analyses are presented here:

Measure: FECC 16

Description: Child has shared care plan

English proficient (n=1094): 41.7

Limited English proficient (n=154): 55.1\*

Compared to English proficient reference group using linear or logistic regression: \*p<0.05 \*\*p<0.01 \*\*\*p<0.001

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. The quality measures in the FECC measure set 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.

**1b.5. If no or limited data on disparities from the measure as specified is reported in 1b.4, then provide a summary of data from the literature that addresses disparities in care on the specific focus of measurement. Include citations. Not necessary if performance data provided in 1b.4**

not applicable

## 2. Reliability and Validity—Scientific Acceptability of Measure Properties

Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. **Measures must be judged to meet the sub criteria for both reliability and validity to pass this criterion and be evaluated against the remaining criteria.**

**2a.1. Specifications** The measure is well defined and precisely specified so it can be implemented consistently within and across organizations and allows for comparability. eMeasures should be specified in the Health Quality Measures Format (HQMF) and the Quality Data Model (QDM).

**De.5. Subject/Topic Area** (check all the areas that apply):

**De.6. Non-Condition Specific**(check all the areas that apply):

Care Coordination

**De.7. Target Population Category** (Check all the populations for which the measure is specified and tested if any):

Children, Populations at Risk : Individuals with multiple chronic conditions

**S.1. Measure-specific Web Page** (Provide a URL link to a web page specific for this measure that contains current detailed specifications including code lists, risk model details, and supplemental materials. Do not enter a URL linking to a home page or to general information.)

<http://www.seattlechildrens.org/research/child-health-behavior-and-development/mangione-smith-lab/measurement-tools/>

**S.2a. If this is an eMeasure**, HQMF specifications must be attached. Attach the zipped output from the eMeasure authoring tool (MAT) - if the MAT was not used, contact staff. (Use the specification fields in this online form for the plain-language description of the specifications)

This is not an eMeasure Attachment:

**S.2b. Data Dictionary, Code Table, or Value Sets** (and risk model codes and coefficients when applicable) must be attached. (Excel or csv file in the suggested format preferred - if not, contact staff)

Attachment Attachment: NQF\_detailed\_specs\_FECC\_PMCA\_FECC\_16.xlsx

**S.3.1. For maintenance of endorsement:** Are there changes to the specifications since the last updates/submission. If yes, update the specifications for S1-2 and S4-22 and explain reasons for the changes in S3.2.

**S.3.2. For maintenance of endorsement**, please briefly describe any important changes to the measure specifications since last measure update and explain the reasons.

not applicable



**S.4. Numerator Statement** (Brief, narrative description of the measure focus or what is being measured about the target population, i.e., cases from the target population with the target process, condition, event, or outcome) DO NOT include the rationale for the measure.

IF an OUTCOME MEASURE, state the outcome being measured. Calculation of the risk-adjusted outcome should be described in the calculation algorithm (S.14).

The numerator for FECC-16 is specified in the Detailed Measure Specifications (see S.2b). A brief description of each numerator is laid out in Table 1 in section De.3, and a more detailed description of FECC-16 follows:

FECC-16: Caregivers of CMC should report that their child's primary care provider created a shared care plan for their child.

**S.5. Numerator Details** (All information required to identify and calculate the cases from the target population with the target process, condition, event, or outcome such as definitions, time period for data collection, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b)

IF an OUTCOME MEASURE, describe how the observed outcome is identified/counted. Calculation of the risk-adjusted outcome should be described in the calculation algorithm (S.14).

The numerator for FECC-16 is specified in the Detailed Measure Specifications (S.2b).

**S.6. Denominator Statement** (Brief, narrative description of the target population being measured)

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 (PMCA) (see Simon TD, Cawthon ML et al. 2014)
3. Child had at least 4 visits to a healthcare provider over the previous year

While some of the FECC measures only apply to a subset of the overall eligible population for the survey (e.g., measures related to the quality of care coordination services provided are only scored for those caregivers who endorse having a care coordinator), eligibility for these quality measures can only be gleaned from responses to the FECC Survey itself. This is analogous to the situation with many H-CAHPS measures, where, for example, measures about blood draws and laboratory testing are scored only for those who had the relevant service performed during the time frame or hospitalization in question.

**S.7. Denominator Details** (All information required to identify and calculate the target population/denominator such as definitions, time period for data collection, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b.)

IF an OUTCOME MEASURE, describe how the target population is identified. Calculation of the risk-adjusted outcome should be described in the calculation algorithm (S.14).

The details for denominator identification are provided in S.2b, including the ICD-9 codes used for determining the PMCA. The PMCA SAS programming code is available at:

<http://www.seattlechildrens.org/research/child-health-behavior-and-development/mangione-smith-lab/measurement-tools/>

The process of converting the ICD-9 codes to ICD-10 codes for calculating the PMCA is underway, and should be complete and available within 6-9 months. However, because the PMCA uses up to 3 years' worth of retrospective administrative data, the ICD-10 code version is not expected to be needed for widespread use immediately.

**S.8. Denominator Exclusions** (Brief narrative description of exclusions from the target population)

Denominator exclusions:

1. Child had died
2. Caregiver spoke a language other than English or Spanish

**S.9. Denominator Exclusion Details** (All information required to identify and calculate exclusions from the denominator such as definitions, time period for data collection, specific data collection items/responses, code/value sets – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format at S.2b.)



Please see S2.b.

**S.10. Stratification Information** *(Provide all information required to stratify the measure results, if necessary, including the stratification variables, definitions, specific data collection items/responses, code/value sets, and the risk-model covariates and coefficients for the clinically-adjusted version of the measure when appropriate – Note: lists of individual codes with descriptors that exceed 1 page should be provided in an Excel or csv file in required format with at S.2b.)*

Please see the response to S.14, below, for details about producing a clinically-adjusted model that could be stratified by caregiver education (the sociodemographic factor we recommend adjustment for). The specifications for those models are also included in S.2b.

**S.11. Risk Adjustment Type** (Select type. Provide specifications for risk stratification in measure testing attachment)

Other

If other: case mix adjustment

**S.12. Type of score:**

Other (specify):

If other: Each of the quality measures is scored on a 0-100 scale, with higher scores indicating better care. For dichotomous measures, a score of 100 indicates the child received the recommended care; a score of 0 indicates that they did not. Please see Detailed Measure Specifications (see S.2b) for additional measure-specific scoring information.

**S.13. Interpretation of Score** *(Classifies interpretation of score according to whether better quality is associated with a higher score, a lower score, a score falling within a defined interval, or a passing score)*

Better quality = Higher score

**S.14. Calculation Algorithm/Measure Logic** *(Diagram or describe the calculation of the measure score as an ordered sequence of steps including identifying the target population; exclusions; cases meeting the target process, condition, event, or outcome; time period for data, aggregating data; risk adjustment; etc.)*

To produce scores for the FECC quality measure set, the following steps were taken, in order:

1. Identify children 0-17 years of age
2. Include only those with parent or legal guardian contact information
3. Run the PMCA algorithm, and retain only those children classified as having complex chronic disease
4. Retain children with at least 4 health care provider visits in the past year
5. Exclude caregivers who speak only a language other than English or Spanish
6. Exclude caregivers if child had died
7. Administer FECC Survey to remaining sample, over the telephone or via mail
8. Score each measure according to detailed measure specifications in S.2b
9. For comparisons between health plans, states, or by demographic groups, adjust scores for caregiver education level (and assigned survey mode, if applicable) using linear or logistic regression.

**S.15. Sampling** *(If measure is based on a sample, provide instructions for obtaining the sample and guidance on minimum sample size.)*

IF a PRO-PM, identify whether (and how) proxy responses are allowed.

We recommend sending the FECC survey to a simple random sample of eligible caregivers. Depending on the size of the population of CMC in question, in some cases it may be appropriate to send the survey to all eligible caregivers.

Regarding minimum sample size recommended, we provide guidance below based on the level of measurement.

State or other geographic level: For comparing state or other entity 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 or other entities to one another, 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.

Medicaid or CHIP payment model: Recommended minimum sample sizes are the same as those listed for the state level.

Health plan: Recommended minimum sample sizes are the same as those listed for the state level.

Individual provider: These 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.

Hospital: Not recommended. Care coordination is generally provided within the context of an outpatient primary care or subspecialty medical practice, so it would not make sense for hospitals to measure the quality of care coordination being provided to CMC.

Practice, group, or facility: 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. To compare between groups, the sample sizes listed above for state apply. 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.

**S.16. Survey/Patient-reported data** (*If measure is based on a survey or instrument, provide instructions for data collection and guidance on minimum response rate.*)

IF a PRO-PM, specify calculation of response rates to be reported with performance measure results.

The FECC survey can be administered over the telephone or via a mailed version, although we recommend a mixed-mode approach (mailing followed by telephone interview for mail non-responders). A copy of the survey is attached with this submission.

In the mixed-mode approach, two mailings were sent to participants prior to transferring to telephone mode, at which time a maximum of 10 attempts were made to complete the survey by telephone. The telephone survey was administered by trained research assistants using a computer-assisted telephone interview script. Both the mailed and telephone surveys were offered in English and Spanish.

Regarding minimum response rate, we suggest a target of 40% (achieved in our field testing) and a minimum of 25%, primarily on the basis of face validity.

**S.17. Data Source** (*Check ONLY the sources for which the measure is SPECIFIED AND TESTED*).

*If other, please describe in S.18.*

Claims, Instrument-Based Data

**S.18. Data Source or Collection Instrument** (*Identify the specific data source/data collection instrument (e.g. name of database, clinical registry, collection instrument, etc., and describe how data is collected.)*)

IF a PRO-PM, identify the specific PROM(s); and standard methods, modes, and languages of administration.

The overall FECC-eligible population is identified using ICD-9 codes and administrative data. Data for the measure numerators and some denominator elements come from caregiver responses to the FECC Survey (attached). The survey was administered via mail and telephone, in English and Spanish.

**S.19. Data Source or Collection Instrument** (*available at measure-specific Web page URL identified in S.1 OR in attached appendix at A.1*)

Available in attached appendix at A.1

**S.20. Level of Analysis** (*Check ONLY the levels of analysis for which the measure is SPECIFIED AND TESTED*)

Health Plan, Population : Regional and State

**S.21. Care Setting** (Check *ONLY* the settings for which the measure is SPECIFIED AND TESTED)

Other

If other: The FECC quality measures concern care coordination that occurs across the spectrum of health care settings, from inpatient to outpatient to home health. However, the majority of care coordination services assessed were provided by the outpatient clinics

**S.22. COMPOSITE Performance Measure** - Additional Specifications (Use this section as needed for aggregation and weighting rules, or calculation of individual performance measures if not individually endorsed.)

## 2. Validity – See attached Measure Testing Submission Form

[NQF\\_FECC\\_testing\\_FECC\\_16.docx](#)

### 2.1 For maintenance of endorsement

*Reliability testing: If testing of reliability of the measure score was not presented in prior submission(s), has reliability testing of the measure score been conducted? If yes, please provide results in the Testing attachment. (Do not remove prior testing information – include date of new information in red.)*

### 2.2 For maintenance of endorsement

*Has additional empirical validity testing of the measure score been conducted? If yes, please provide results in the Testing attachment. (Do not remove prior testing information – include date of new information in red.)*

### 2.3 For maintenance of endorsement

*Risk adjustment: For outcome, resource use, cost, and some process measures, risk-adjustment that includes SDS factors is no longer prohibited during the SDS Trial Period (2015-2016). Please update sections 1.8, 2a2, 2b2, 2b4, and 2b6 in the Testing attachment and S.14 and S.15 in the online submission form in accordance with the requirements for the SDS Trial Period. NOTE: These sections must be updated even if SDS factors are not included in the risk-adjustment strategy. If yes, and your testing attachment does not have the additional questions for the SDS Trial please add these questions to your testing attachment:*

*What were the patient-level sociodemographic (SDS) variables that were available and analyzed in the data or sample used? For example, patient-reported data (e.g., income, education, language), proxy variables when SDS data are not collected from each patient (e.g. census tract), or patient community characteristics (e.g. percent vacant housing, crime rate).*

*Describe the conceptual/clinical and statistical methods and criteria used to select patient factors (clinical factors or sociodemographic factors) used in the statistical risk model or for stratification by risk (e.g., potential factors identified in the literature and/or expert panel; regression analysis; statistical significance of  $p < 0.10$ ; correlation of  $x$  or higher; patient factors should be present at the start of care)*

*What were the statistical results of the analyses used to select risk factors?*

*Describe the analyses and interpretation resulting in the decision to select SDS factors (e.g. prevalence of the factor across measured entities, empirical association with the outcome, contribution of unique variation in the outcome, assessment of between-unit effects and within-unit effects)*

## 3. Feasibility

Extent to which the specifications including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement.

### 3a. Byproduct of Care Processes

For clinical measures, the required data elements are routinely generated and used during care delivery (e.g., blood pressure,

lab test, diagnosis, medication order).

**3a.1. Data Elements Generated as Byproduct of Care Processes.**

Coded by someone other than person obtaining original information (e.g., DRG, ICD-9 codes on claims), Other

If other: Caregiver report via survey

**3b. Electronic Sources**

The required data elements are available in electronic health records or other electronic sources. If the required data are not in electronic health records or existing electronic sources, a credible, near-term path to electronic collection is specified.

**3b.1. To what extent are the specified data elements available electronically in defined fields (i.e., data elements that are needed to compute the performance measure score are in defined, computer-readable fields)** Update this field for **maintenance of endorsement**.

Some data elements are in defined fields in electronic sources

**3b.2. If ALL the data elements needed to compute the performance measure score are not from electronic sources, specify a credible, near-term path to electronic capture, OR provide a rationale for using other than electronic sources.** For **maintenance of endorsement**, if this measure is not an eMeasure (eCQM), please describe any efforts to develop an eMeasure (eCQM).

Administrative data are used to identify children eligible for the FECC Survey, using billing data (ICD-9 codes) for the Pediatric Medical Complexity Algorithm. Such billing data are readily available to practices, hospitals, and insurers. However, the caregiver-reported measures on 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% (1209 out of 3000), which was quite good given that 632 of the original 3000 (21%) were unable to be contacted (bad phone number or undeliverable mail); only 285 (9.5%) actively refused participation, and another 525 (17.5%) passively refused by non-response. Caregivers are currently the best source of information for assessing the quality of care coordination services being provided to CMC. We attempted to compare caregiver report to medical records data for a subset of the FECC quality measures for which such comparison would be relevant. We found that very few medical records (paper or electronic) contained the necessary information to assess eligibility and scoring for this subset of FECC care coordination quality measures. For example, among respondents with medical records data available, 39% of parents reported having a shared care plan, while such a plan was identified in 2% of their children's medical charts.

**3b.3. If this is an eMeasure, provide a summary of the feasibility assessment in an attached file or make available at a measure-specific URL. Please also complete and attach the NQF Feasibility Score Card.**

Attachment:

**3c. Data Collection Strategy**

Demonstration that the data collection strategy (e.g., source, timing, frequency, sampling, patient confidentiality, costs associated with fees/licensing of proprietary measures) can be implemented (e.g., already in operational use, or testing demonstrates that it is ready to put into operational use). For eMeasures, a feasibility assessment addresses the data elements and measure logic and demonstrates the eMeasure can be implemented or feasibility concerns can be adequately addressed.

**3c.1. Required for maintenance of endorsement.** Describe difficulties (as a result of testing and/or operational use of the measure) regarding data collection, availability of data, missing data, timing and frequency of data collection, sampling, patient confidentiality, time and cost of data collection, other feasibility/implementation issues.

**IF a PRO-PM, consider implications for both individuals providing PRO data (patients, service recipients, respondents) and those whose performance is being measured.**

The FECC Survey was completed by 1209 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. Given the low average and median number of eligible CMC per provider, we determined that it would be nearly impossible to make meaningful comparisons on the FECC measures at the provider level, and only possible to do so at the practice level for practices meeting the minimum sample sizes discussed above in S.20.

We achieved an overall survey response rate of 40% (1209 out of 3000), which was quite good given that 632 of the original 3000 (21%) were unable to be contacted (bad phone number or undeliverable mail); only 285 (9.5%) actively refused participation, and another 525 (17.5%) passively refused by non-response. In our field-testing, we randomized participants to either mixed mode (mailings followed by telephone contact) or telephone only arms. The response rate among those assigned to the mixed mode was 45.5% (7.3% refusal rate) and was 35.9% (10.3% refusal rate) among those assigned to telephone only mode. Compared to respondents randomized to telephone mode, mixed mode mail respondents (and their children) were significantly more likely to be non-Hispanic white and English proficient, while mixed mode telephone respondents (and their children) were more likely to be of a minority race/ethnicity and limited English proficient. We therefore recommend a mixed mode approach, given the higher overall response rate and the different approaches to maximize participation of a range of demographic groups.

During initial field testing, one measure (of the original 21) and 11 sub-parts were dropped from analysis and removed from the FECC Survey due to low eligibility and/or ceiling effects. For example, the initial shared care plan 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 last 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 survey.

We also determined that caregiver survey is 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 subset of the FECC measures for which such comparison would be relevant. We found that very few medical records (paper or electronic) contained the necessary information to assess eligibility and scoring for this subset of FECC care coordination quality measures. For example, among respondents with medical record data available, 39% of parents reported having a shared care plan, while such a plan was identified in 2% of their children's medical charts.

Survey administration is expensive and time consuming; while it is currently the most valid approach for assessing care coordination quality for CMC, further work should investigate alternate modes of administration, including electronic survey data collection at the point of care using portable devices such as tablet computers.

The FECC survey quality measures are currently being used by a number of groups across the country (see below), but so far additional data related to feasibility and implementation are not available.

**3c.2. Describe any fees, licensing, or other requirements to use any aspect of the measure as specified (e.g., value/code set, risk model, programming code, algorithm).**

Not applicable

## 4. Usability and Use

Extent to which potential audiences (e.g., consumers, purchasers, providers, policy makers) are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations.

### 4a. Accountability and Transparency

Performance results are used in at least one accountability application within three years after initial endorsement and are publicly reported within six years after initial endorsement (or the data on performance results are available). If not in use at the time of initial endorsement, then a credible plan for implementation within the specified timeframes is provided.

### 4.1. Current and Planned Use

NQF-endorsed measures are expected to be used in at least one accountability application within 3 years and publicly reported within 6 years of initial endorsement in addition to performance improvement.

Specific Plan for Use	Current Use (for current use provide URL)
Public Reporting	Quality Improvement (Internal to the specific organization) Children's Healthcare of Atlanta unknown Boston Children's Hospital

	<p>unknown  Children's Hospital of Wisconsin  unknown  School of Nursing, University of Minnesota, Minneapolis, MN  unknown  Department of Pediatric and Communicable Diseases, University of Michigan Hospital and Health Systems, Ann Arbor, MI  unknown  Oregon Health &amp; Science University, Portland, OR  unknown  Meridian Health Plan  unknown  Health Resources and Services Administration, Maternal and Child Health Bureau, Washington, DC  unknown  James B. Fahner MD Pediatric Hospice Program, Hospice of Michigan, Ada, MI  unknown  Mathematica Policy Research, Inc., Ann Arbor, MI  unknown  National Research Corporation, Lincoln, NE  unknown  Cleveland Clinic Children's Hospital, Cleveland, OH  unknown</p>
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**4a.1. For each CURRENT use, checked above (update for maintenance of endorsement), provide:**

- Name of program and sponsor
- Purpose
- Geographic area and number and percentage of accountable entities and patients included
- Level of measurement and setting

Below is a list of requested user and uses of the FECC Survey, along with date of request. We do not have information beyond the information presented here, including about the number of patients or accountable entities included

1. Javier Tejedor-Sojo, MD; Children's Healthcare of Atlanta, Atlanta, GA; 4/25/15; Tracking work with medically complex patients.

2. Eli Sprecher, MD, MPP, General Academic Pediatric Fellow; Boston Children's Hospital, Boston, MA; 5/1/15; Improving their internal process measures and patient experience measurement for their population of children with medical complexity.

3. John Gordon, MD, Medical Director, Special Need Program; Children's Hospital of Wisconsin Milwaukee, WI; 5/11/15; Adding FECC care coordination survey questions to current parent report questionnaires for medically complex patients.

4. Wendy Looman, PhD, APRN, CNP, Associate Professor; School of Nursing, University of Minnesota, Minneapolis, MN; 5/12/15; Tracking quality of care coordination for their newly developed complex care program

5. Katie Freundlich, MD, Clinical Instructor; Department of Pediatric and Communicable Diseases, University of Michigan Hospital and Health Systems, Ann Arbor, MI; 5/12/15; Currently conceptualizing a hospital-based complex care program.

6. Colleen Peck Reuland, MS, Director – Oregon Pediatric Improvement Partnership; Oregon Health & Science University, Portland, OR; 5/12/15; Assessing care coordination for medically complex children in their network of practices

7. Elzbieta Rozmiej, MD, Medical Director; Meridian Health Plan, Michigan; 5/12/15; Assessing quality of care coordination services for their pediatric clients with medical complexity

8. Marie Mann, MD, MPH; Division of Services for Children with Special Needs, Health Resources and Services Administration, Maternal and Child Health Bureau, Washington, DC; 5/12/15; Sharing with state integration/care coordination grantees for implementation into their work.



9. Mary Spicketts, MSN, RN, CHPN, CHPPN, Director, Pediatric Program; James B. Fahner MD Pediatric Hospice Program, Hospice of Michigan, Ada, MI; 5/12/15; Potential use as grant-writing/Research opportunity within pediatric hospice/palliative care and CMC patient populations.

10. Joe Zickafoose, MD, MS, Health Researcher; Mathematica Policy Research, Inc., Ann Arbor, MI; 5/12/15; No reason given.

11. Sarah Fryda, MS, Senior Research Associate; National Research Corporation, Lincoln, NE; 5/15/15; Interested in amending their current child HCAHPS survey to incorporate FECC.

12. Skyler Kalady, MD, Medical Director, Pediatric Complex Care Clinic; Cleveland Clinic Children's Hospital, Cleveland, OH; 5/18/15; Currently crafting metrics for the Pediatric Complex Care Clinic.

**4a.2. If not currently publicly reported OR used in at least one other accountability application (e.g., payment program, certification, licensing) what are the reasons?** (e.g., Do policies or actions of the developer/steward or accountable entities restrict access to performance results or impede implementation?)

The FECC quality measure set is not currently used in public reporting due to its relatively recent development. There are no policies or other restrictions in place preventing more wide-spread use.

**4a.3. If not currently publicly reported OR used in at least one other accountability application, provide a credible plan for implementation within the expected timeframes -- any accountability application within 3 years and publicly reported within 6 years of initial endorsement.** (Credible plan includes the specific program, purpose, intended audience, and timeline for implementing the measure within the specified timeframes. A plan for accountability applications addresses mechanisms for data aggregation and reporting.)

The FECC Survey measures are being widely distributed to complex care programs across the country, with rapid uptake and application to program evaluation and quality improvement efforts. We expect some of these efforts to be publicly reported in the future. We also know of at least one Centers for Medicare and Medicaid Innovation (CMMI) grant that is using the FECC Survey measures to evaluate the impact of different approaches to care coordination for children with medical complexity; we expect the results of this Pediatric Partners in Care program to be publicly reported within the next 5 years. In addition, the Advancing Care for Exceptional Kids Act (ACE Kids Act; Senate bill 298; House bill 546), if it is approved, may use the FECC Survey measures to document current state and track improvements in care coordination for children with medical complexity, which would also lead to public reporting on a large scale.

#### Improvement

Progress toward achieving the goal of high-quality, efficient healthcare for individuals or populations is demonstrated. If not in use for performance improvement at the time of initial endorsement, then a credible rationale describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.

**4b. Refer to data provided in 1b but do not repeat here. Discuss any progress on improvement (trends in performance results, number and percentage of people receiving high-quality healthcare; Geographic area and number and percentage of accountable entities and patients included.)**

**If no improvement was demonstrated, what are the reasons? If not in use for performance improvement at the time of initial endorsement, provide a credible rationale that describes how the performance results could be used to further the goal of high-quality, efficient healthcare for individuals or populations.**

Measurement and reporting on processes related to care coordination for children with medical complexity would be expected to drive improvements in those processes, which, based on our evidence reviews, would in turn be expected to improve patient outcomes. While the population of CMC is small compared to the population of children overall, they consume a great deal of resources and require more services than most children, putting them at increased risk for failing to receive all needed care.

#### 4c. Unintended Consequences

The benefits of the performance measure in facilitating progress toward achieving high-quality, efficient healthcare for individuals or populations outweigh evidence of unintended negative consequences to individuals or populations (if such evidence exists).

**4c.1. Please explain any unexpected findings (positive or negative) during implementation of this measure including unintended impacts on patients.**



No negative consequences or unintended effects have occurred to our knowledge as a result of FECC quality measure implementation.

**4c.2. Please explain any unexpected benefits from implementation of this measure.**

**4d1.1. Describe how performance results, data, and assistance with interpretation have been provided to those being measured or other users during development or implementation.**

**How many and which types of measured entities and/or others were included? If only a sample of measured entities were included, describe the full population and how the sample was selected.**

**4d1.2. Describe the process(es) involved, including when/how often results were provided, what data were provided, what educational/explanatory efforts were made, etc.**

**4d2.1. Summarize the feedback on measure performance and implementation from the measured entities and others described in 4d.1.**

**Describe how feedback was obtained.**

**4d2.2. Summarize the feedback obtained from those being measured.**

**4d2.3. Summarize the feedback obtained from other users**

**4d.3. Describe how the feedback described in 4d.2 has been considered when developing or revising the measure specifications or implementation, including whether the measure was modified and why or why not.**

## 5. Comparison to Related or Competing Measures

If a measure meets the above criteria and there are endorsed or new related measures (either the same measure focus or the same target population) or competing measures (both the same measure focus and the same target population), the measures are compared to address harmonization and/or selection of the best measure.

### 5. Relation to Other NQF-endorsed Measures

Are there related measures (conceptually, either same measure focus or target population) or competing measures (conceptually both the same measure focus and same target population)? If yes, list the NQF # and title of all related and/or competing measures.

Yes

#### 5.1a. List of related or competing measures (selected from NQF-endorsed measures)

0009 : CAHPS Health Plan Survey v 3.0 children with chronic conditions supplement

0718 : Children Who Had Problems Obtaining Referrals When Needed

0719 : Children Who Receive Effective Care Coordination of Healthcare Services When Needed

**5.1b. If related or competing measures are not NQF endorsed please indicate measure title and steward.**

### 5a. Harmonization of Related Measures

The measure specifications are harmonized with related measures;

**OR**

The differences in specifications are justified

**5a.1. If this measure conceptually addresses EITHER the same measure focus OR the same target population as NQF-endorsed**

measure(s):

Are the measure specifications harmonized to the extent possible?

No

**5a.2. If the measure specifications are not completely harmonized, identify the differences, rationale, and impact on interpretability and data collection burden.**

The currently available NQF-endorsed measures related to care coordination and care for children with chronic conditions are related to, but fundamentally different from, the quality measures addressed in the FECC measure set. To begin with, the measures differ with regard to target population. The currently-endorsed measures address children with chronic conditions (0009), children who have received a referral to specialty services (0718), and children who received care from at least 2 types of health care services (0719), while the FECC measures address children with medical complexity. While the other measures likely apply to CMC (in addition to many other children), the FECC measures are specific to CMC. In addition, the FECC measure set differs from currently-endorsed measures with regard to focus. The currently-available measures mostly focus on whether families who needed specialized services for their child found it easy or difficult to obtain them and whether anyone in their health plan or child's doctor's office/clinic helped them to get that service. In contrast, the FECC measure set focuses more on the quality of services provided by a family's self-identified care coordinator, delving into the specific care coordination attributes and processes that have been associated with better outcomes in the literature. For example, the measures regarding care coordination for children with chronic conditions (0009) ask about whether a particular child needed a given type of services, how difficult they were for the family to obtain, and if anyone helped them, which provides valuable information about the family experience and whether they received help. While there is some overlap between those types of measures and some of the measures within the FECC measure set (for example, FECC 3: care coordinator helped to obtain needed community services), those questions within the FECC measure set are predicated upon having a designated care coordinator (a care structure we found to be important for CMC based on the literature), and are assessing the functioning of that care coordinator, rather than just whether a service was provided to the family. The remaining measures within the FECC measure set are similarly focused on specific actions and attributes of the care coordinator and/or main medical provider, and would be expected to provide clearly actionable items for quality improvement intervention. For example, identifying that families are not receiving help with accessing recommended community services is important, but leaves open to interpretation why that may be; using the FECC measure set would help to separate out whether the problem was due to not having a care coordinator, or whether it was due to having a care coordinator not adequately doing their job. In addition, the FECC measure set addresses other aspects of care coordination beyond the quality of services provided by the care coordinator, as they also assess quality of written communication between providers and families, and between providers and the child's school, along with the quality of care planning with the family. Therefore, the FECC measure set should be seen as complementary to, and enhancing the currently available measures.

**5b. Competing Measures**

The measure is superior to competing measures (e.g., is a more valid or efficient way to measure);

**OR**

Multiple measures are justified.

**5b.1. If this measure conceptually addresses both the same measure focus and the same target population as NQF-endorsed measure(s):**

**Describe why this measure is superior to competing measures (e.g., a more valid or efficient way to measure quality); OR provide a rationale for the additive value of endorsing an additional measure. (Provide analyses when possible.)**

Please see discussion above (5a.2) for a description of how the FECC measures complement, focus, and extend the information provided by the currently-endorsed measures.

## Appendix

**A.1 Supplemental materials may be provided in an appendix.** All supplemental materials (such as data collection instrument or methodology reports) should be organized in one file with a table of contents or bookmarks. If material pertains to a specific submission form number, that should be indicated. Requested information should be provided in the submission form and required attachments. There is no guarantee that supplemental materials will be reviewed.

**Attachment** **Attachment:** [FECC\\_SURVEY\\_Telephone\\_Interview\\_Version-635848208218939300.docx](#)

## Contact Information

**Co.1 Measure Steward (Intellectual Property Owner):** [Seattle Children's Research Institute](#)  
**Co.2 Point of Contact:** [Rita, Mangione-Smith, rita.mangione-smith@seattlechildrens.org](#), 206-884-8242-  
**Co.3 Measure Developer if different from Measure Steward:** [Seattle Children's Research Institute](#)  
**Co.4 Point of Contact:** [Rita, Mangione-Smith, rita.mangione-smith@seattlechildrens.org](#), 206-884-8242-

## Additional Information

### Ad.1 Workgroup/Expert Panel involved in measure development

**Provide a list of sponsoring organizations and workgroup/panel members' names and organizations. Describe the members' role in measure development.**

#### WORK GROUP MEMBERS:

1. Rita Mangione-Smith, MD, MPH; Seattle Children's Research Institute/ University of Washington, Seattle, WA; Oversaw entire project (study PI), including literature reviews, measure development, Delphi panel, measure specification, field testing, and analysis.
2. K. Casey Lion, MD, MPH; Seattle Children's Research Institute/ University of Washington, Seattle, WA; Literature review, measure development, analytic team
3. Courtney Gidengil, MD, MPH; Boston Children's Hospital/ Harvard Medical School/ RAND Corporation, Boston, MA; Literature review, measure development, analytic team
4. Eric Schneider, MD, MSc; RAND Corporation, Boston, MA (now Commonwealth Fund); Provided oversight and participated in all aspects of measure development and testing
5. Elizabeth McGlynn, PhD; Center for Effectiveness and Safety Research, Kaiser Permanente, Pasadena, CA; Provided oversight and participated in all aspects of measure development and testing
6. Layla Parast, PhD; RAND Corporation, Santa Monica, CA; Biostatistician and analytic team lead
7. Q Burkhart, MS; RAND Corporation, Santa Monica, CA; Data analyst, analytic team
8. Marc Elliott, PhD; RAND Corporation, Santa Monica, CA; Biostatistician and analytic team
9. Kimberly Arthur, MPH; Seattle Children's Research Institute, Seattle, WA; Literature review and measure development
10. Julie A. Brown; RAND Corporation, Santa Monica, CA; Survey design and data collection
11. Adam Carle, MA, PhD; Cincinnati Children's Hospital Medical Center, Cincinnati, OH; Measure development
12. Laurie Cawthon, MD, MPH; WA State Department of Social and Health Services, Olympia, WA; Field testing, data acquisition and analysis
13. Carol Roth, RN, MPH; RAND Corporation, Santa Monica, CA; Quality measure operationalization and survey development
14. Justine Nelson, PhD; Minnesota State Medicaid, Minneapolis, MN; Field testing, data acquisition and analysis
15. Laura Richardson, MD, MPH; Seattle Children's Research Institute/ University of Washington, Seattle, WA; Literature review, measure development
16. Trina Colburn, PhD; Seattle Children's Research Institute, Seattle, WA; Literature review, measure development
17. Jean Popalisky, DNP, RN; Seattle Children's Research Institute, Seattle, WA; Literature review, measure development
18. Maria Britto, MD, MPH; Cincinnati Children's Hospital Medical Center, Cincinnati, OH; Literature review, measure development

#### DELPHI PANEL MEMBERS:

1. Richard Antonelli, MD, MS  
 Medical Director of Integrated Care and Strategic Partnerships  
 Medical Director Physician Relations and Outreach  
 Boston Children's Hospital  
 Assistant Professor of Pediatrics  
 Harvard Medical School  
 Nominated by American Academy of Pediatrics (AAP)
2. Allison Ballantine, MD, MEd  
 Assistant Professor of Pediatrics  
 University of Pennsylvania School of Medicine  
 Section Chief of Education  
 Medical Director, Integrated Care Services  
 Division of General Pediatrics

Attending Physician Palliative Care Team  
Attending Physician Inpatient General Pediatrics  
The Children's Hospital of Philadelphia  
Nominated by Society of Hospital Medicine (SHM)

3. Jennifer Bolden-Pitre, MA, JD  
Director of Integrated Systems,  
Statewide Parent Advocacy Network  
Family Fellow, Leadership Education in Neurodevelopmental Disabilities  
Children's Hospital of Philadelphia  
Nominated by Family Voices

4. Carol A. Ford, MD  
Professor of Pediatrics  
Orton Jackson Endowed Chair in Adolescent Medicine  
University of Pennsylvania  
Chief, Craig Dalsimer Division of Adolescent Medicine  
The Children's Hospital of Philadelphia  
Nominated by Society for Adolescent Health & Medicine (SAHM)

5. Jason Kessler, MD, FAAP, CHBE  
Medical Director  
Iowa Medicaid Enterprise  
Nominated by Medicaid Medical Directors Learning Network (MMDLN)

6. Karen Kuhlthau, PhD  
Associate Professor, Pediatrics  
Harvard Medical School  
Associate Sociologist, Pediatrics  
Center for Child and Adolescent Health Policy  
Massachusetts General Hospital for Children  
Nominated by Academic Pediatric Association (APA)

7. Dennis Kuo, MD, MHS  
Assistant Professor of Health Policy and Management  
Fay W. Boozman College of Public Health,  
University of Arkansas for Medical Sciences  
Assistant Professor of Pediatrics  
Section on General Pediatrics  
Center for Applied Research and Evaluation,  
University of Arkansas for Medical Sciences  
Pediatrician  
Medical Home Program for Children with Special Needs,  
Arkansas Children's Hospital  
Nominated by Children's Hospital Association (CHA)

8. Wendy Sue Looman, PhD, RN, CNP  
Pediatric Nurse Practitioner  
Cleft Palate and Craniofacial Clinic  
School of Dentistry, University of Minnesota  
Associate Professor  
School of Nursing, University of Minnesota  
Nominated by National Association of Pediatric Nurse Practitioners (NAPNAP)

9. Karen Pierce, MD, FAPA, FAACAP

Attending Physician  
Department of Child and Adolescent Psychiatry  
Children's Memorial Hospital, Chicago, Illinois  
Clinical Associate Professor  
Feinberg School of Medicine, Northwestern University Medical School  
Department of Psychiatry and Behavioral Sciences  
Nominated by American Academy of Child & Adolescent Psychiatry (AACAP)

**Measure Developer/Steward Updates and Ongoing Maintenance**

**Ad.2** Year the measure was first released: 2015

**Ad.3** Month and Year of most recent revision: 12, 2014

**Ad.4** What is your frequency for review/update of this measure? every 6 months

**Ad.5** When is the next scheduled review/update for this measure? 03, 2016

**Ad.6** Copyright statement:

**Ad.7** Disclaimers:

**Ad.8** Additional Information/Comments: