Measures: Family Experiences with Care Coordination measure set (FECC)

Measure Developer: Center of Excellence on Quality of Care Measures for Children With Complex Needs (COE4CCN)

Numerator	Denominator	Exclusions	Data Source(s)
The FECC Survey is composed of 20 separate and independent quality indicators related to care coordination for children with medical complexity. Each indicator's numerator is determined by caregiver response to specific questions, as described in the detailed measure specifications section of the candidate measure submission form (CPCF).	The denominators for each of the 20 FECC quality indicators are described in the detailed measure specifications. The population of caregivers eligible 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. Child classified as having a complex, chronic condition using the pediatric medical complexity algorithm (PMCA).[1] 2. Child had adequate data available for running the PMCA algorithm. For our validation study, this was defined as having at least 2 Medicaid eligibility months in the 3 months prior to obtaining the sample. 3. Parents speak English or Spanish.	Exclusions for individual indicators are listed in the detailed measure specifications. Overall exclusion criteria for survey participation were either of the following: 1. Child had died. 2. Listed household contact <18 years of age.	Administrative data including visit clinical classification software ICD-9 codes are used to run the PMCA and to identify children whose caregivers might be eligible for survey participation. Indicator numerators and denominators are constructed from caregiver responses to the FECC Survey.

Measure Importance

Increasing numbers of children in the United States are living with medical complexity.[2] Although these children with medical complexity comprise only 13 percent of the pediatric population, they account for a disproportionately high percentage (26–49 percent) of hospital days[3,4] and 70 percent of overall health care 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.

Evidence Base for Focus of the Measures

Comprehensive, well-coordinated care improves patient and family experiences of care[6-8] and patient medical outcomes.[6,7,9,10] Care coordination interventions among children with medical complexity have also been associated with decreased unmet specialty care needs,[11] improved utilization of health care services, decreased hospitalizations, and lower costs.[8,9,12-14] Improving care coordination for children with medical complexity is likely to improve many aspects of care received by these children and their families.

The little evidence that is currently available suggests that 29–41 percent of parents of children with special health care needs report not getting needed help with care coordination.[15,16] However, very little is known about the quality of the help that is being received.

Advantages of the Measures

- The quality indicators on the FECC Survey fill a gap in current approaches to pediatric quality assessment by measuring the quality of care coordination for children with medical complexity, rather than just whether care coordination was provided or not.

- These survey-based indicators measure care coordination in a family-centered way.

- Indicators function independently of one another, and so they may be used together, separately, or in any combination.

- Field testing showed that caregivers of children with medical complexity are willing to complete the survey.

- Both telephone-only and mail followed by telephone methods of survey administration were feasible.

- These measures are publicly available for noncommercial use.

Levels of Aggregation Applicable to the Measures

These measures are intended for aggregation and comparison at the State, regional, and health plan levels. They can also be used within provider groups to drive and monitor internal quality improvement interventions using repeated surveys over time; however, most provider groups will not have enough children with medical complexity to do so, and the low likelihood of multiple provider groups having large numbers of children with medical complexity makes between-group comparisons unlikely to be feasible.

Reliability and Validity of the Measures

- We tested the construct reliability of the six multi-item indicators included with the FECC survey using polychoric ordinal alphas.

  - In five out of six of the multi-item indicators, the alpha was > 0.7, indicating good inter-item reliability and therefore that the items all relate to the same underlying construct

  - The multi-item indicator with an alpha < 0.7 includes items that are independent attributes, so the lower alpha was not unexpected.

- Content validity was established through the indicator and survey development process by using the RAND-UCLA Modified Delphi Method[17] (described below) and cognitive interviews with caregivers of children with medical complexity.

- Construct validity was established by demonstrating convergent validity with previously validated measures of outpatient care experiences from the Clinician and Groups Consumer Assessment of Healthcare Providers and Systems (CG-CAHPS®) Child 12-month survey.[18] Most indicators were associated with better experience in terms of access to care and provider rating, both in unadjusted linear regression (not shown) and after adjusting for patient and caregiver characteristics (see Table).

Table: Validation of developed indicators using access composite and overall provider rating from CG-CAHPS as validation metrics

	Access Composite (0-100)		Overall Provider Rating (0-100)	
	N	β (95%CI)[a]	N	β (95%CI)[a]
Care Coordination Services				
Has care coordinator	771	0.07 (0.04, 0.1)***	768	0.06 (0.03, 0.08)***
Access to care coordinator	557	0.11 (0.03, 0.19)**	556	0.08 (0.02, 0.14)*
Care coordinator helped to obtain community services	250	0.06 (0.01, 0.11)*	250	0.05 (0.02, 0.09)**
Care coordinator contact in the last 3 months	551	0.07 (0.03, 0.1)***	550	0.05 (0.03, 0.07)***
Care coordinator asked about concerns and health changes	244	0.29 (0.2, 0.38)***	244	0.14 (0.08, 0.2)***
Care coordinator asked about progress towards goals	99	0.06 (-0.03, 0.16)	99	0.1 (0.03, 0.16)**
Care coordinator assisted with specialist service referrals	417	0.05 (0.01, 0.09)*	416	0.08 (0.05, 0.11)***
Care coordinator was knowledgeable, supportive, and advocated for child's needs	513	0.21 (0.12, 0.3)***	513	0.28 (0.22, 0.35)***
Caregiver has access to medical interpreter when needed	113	0.27 (0.08, 0.46)**	114	0.04 (-0.04, 0.12)
Messaging				
Appropriate written visit summary content	649	0.26 (0.18, 0.34)***	648	0.15 (0.09, 0.2)***
Written visit summary was useful and easy to understand	726	0.32 (0.24, 0.39)***	724	0.22 (0.17, 0.27)***
Invited to join hospital rounds	238	0.01 (-0.04, 0.06)	236	-0.01 (-0.05, 0.03)
Appropriate written hospitalization summary content	220	0.21 (0.05, 0.36)*	219	0.2 (0.06, 0.33)**
Written hospitalization summary was easy to understand	221	0.09 (-0.03, 0.22)	220	0.2 (0.09, 0.31)***
Caregiver has access to electronic health record	1084	0.03 (0, 0.06)*	1084	0.03 (0.01, 0.05)**
Electronic health record has immunization and medication information	321	0.05 (0, 0.11)	321	0.07 (0.03, 0.11)**
Health care provider communicated with school staff about child's condition	601	0.07 (0.03, 0.1)***	601	0.05 (0.02, 0.08)***
Protocols/Plans				
Child has shared care plan	998	0.07 (0.04, 0.09)***	996	0.07 (0.05, 0.09)***
Child has written transition plan	162	0.2 (0.08, 0.31)***	162	0.1 (0, 0.19)
Child has emergency care plan	1042	0.07 (0.04, 0.1)***	1040	0.06 (0.03, 0.08)***

*p<0.05; **p<0.01, ***p<0.001

[a]Adjusted for State, mode of survey administration (mixed mode or phone only mode), child age, child race/ethnicity, caregiver gender, caregiver age, caregiver race/ethnicity, caregiver education, caregiver relationship to child, caregiver English language proficiency, and language of survey used (English or Spanish).

Measure Development and Testing

The development of the FECC Survey included creation of a conceptual framework, extensive literature reviews, a modified Delphi panel for indicator selection, cognitive interviews, and multi-modal field testing in two States.

Based on potential gaps in care identified through development of the conceptual framework, the process began with literature reviews across six domains to identify care coordination processes associated with improved outcomes for children with medical complexity. Measure developers then created draft indicators based on the literature reviews and expert consensus.

Following the RAND-UCLA Modified Delphi Method, a panel of nine experts, nominated by relevant professional organizations, was convened to review the literature reviews and evaluate the draft indicators. Panelists independently scored the indicators on validity and feasibility twice, with group discussion in between. For a quality indicator to be retained for the survey, it had to have a median validity score of seven or greater (scale 1-9).

Indicators retained by the Delphi panel were then operationalized into survey items, which then underwent structured cognitive interviews with nine caregivers of children with medical complexity, in both English and Spanish. Changes to problematic items were made as needed. This process ensured understandability of survey items by families.

The resulting survey items were field tested among caregivers of Medicaid-eligible children with medical complexity in Washington and Minnesota. Children with medical complexity were identified using the Pediatric Medical Complexity Algorithm (PMCA),[1] which uses administrative ICD-9 codes to classify children according to disease chronicity and complexity. One thousand five hundred caregivers in each State were administered the survey from July to November 2013 via both mixed mode (mail with telephone followup) and telephone only; the survey was available in English and Spanish. There were 600 completed surveys in Washington and 609 in Minnesota. Following testing, one indicator and 11 sub-parts were removed from the FECC survey due to low eligibility and/or ceiling effects.

Selected Results from Tests of the Measures

- The final FECC Survey has 20 separate indicators; each scored from 0 to 100.

- Average scores on individual indicators ranged from 9.7 to 95.9 out of 100.

- Differences in individual indicators were found on the basis of child race/ethnicity, caregiver English proficiency, and rurality.

Issues to Consider

- The FECC Survey only addresses elements of care coordination for which the caregiver is the best source of information (e.g., caregivers are not asked about whether subspecialists verbally communicated recommendations to the primary care provider).

- The quality indicators included in the FECC Survey ask about care coordination over the previous 12 months. While for most of the indicators, asking caregivers to reflect back over a shorter time period would not be relevant (e.g., shared care plans only need to be updated annually), it does introduce the possibility of recall bias.

More Information

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For more information about the PQMP, visit www.ahrq.gov/CHIPRA

The Children's Health Insurance Health Insurance Program Authorization Act (CHIPRA) called for establishment of a Pediatric Quality Measures Program (PQMP) as a followup to identifying the initial core set of children's health care quality measures. This fact sheet was produced by the Agency for Healthcare Research and Quality (AHRQ), based on information provided by the AHRQ-CMS Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) at the University of Washington-Seattle and Seattle Children's Research Institute. A listing of all submitted PQMP Centers of Excellence can be found at www.ahrq.gov/CHIPRA. All measures are publicly available for noncommercial use.

References

[1] Simon TD, Cawthon ML, Stanford S, et al. Pediatric medical complexity algorithm: a new method to stratify children by medical complexity. Pediatrics 2014;133:e1647-54.

[2] Bethell CD, Read D, Blumberg SJ, et al. 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;12:1-14.

[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;167:170-7.

[4] Simon TD, Berry J, Feudtner C, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. Pediatrics 2010;126:647-55.

[5] Ireys HT, Anderson GF, Shaffer TJ, et al. Expenditures for care of children with chronic illnesses enrolled in the Washington State Medicaid program, fiscal year 1993. Pediatrics 1997;100:197-204.

[6] Farmer JE, Clark MJ, Sherman A, et al. Comprehensive primary care for children with special health care needs in rural areas. Pediatrics 2005;116:649-56.

[7] Farmer JE, Clark MJ, Drewel EH, et al. Consultative care coordination through the medical home for CSHCN: a randomized controlled trial. Matern Child Health J 2011;15:1110-8.

[8] Palfrey JS, Sofis LA, Davidson EJ, et al. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. Pediatrics 2004;113:1507-16.

[9] Counsell SR, Callahan CM, Clark DO, et al. Geriatric care management for low-income seniors: a randomized controlled trial. JAMA 2007;298:2623-33.

[10] Rocco N, Scher K, Basberg B, et al. Patient-centered plan-of-care tool for improving clinical outcomes. Qual Manag Health Care 2011;20:89-97.

[11] Boudreau AA, Perrin JM, Goodman E, et al. Care coordination and unmet specialty care among children with special health care needs. Pediatrics 2014;133:1046-53.

[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;165:392-8.

[13] Dorr DA, Wilcox AB, Brunker CP, et al. The effect of technology-supported, multidisease care management on the mortality and hospitalization of seniors. J Am Geriatr Soc 2008;56:2195-202.

[14] Gordon JB, Colby HH, Bartelt T, et al. 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;161:937-44.

[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;24:1331-43.

[16] Toomey SL, Chien AT, Elliott MN, et al. Disparities in unmet need for care coordination: the national survey of children's health. Pediatrics 2013;131:217-24.

[17] Brook RH. The RAND/UCLA appropriateness method. In: McCormick KA, Moore SR, Siegel RA, eds. Clinical practice guidelines development:methodology perspectives. Rockville, MD: Agency for Health Care Policy and Research; 1994.

[18] Clinician and Group Surveys. (Accessed at https://cahps.ahrq.gov/surveys-guidance/cg/instructions/index.html.)