



JULY 2022

Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)

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Care coordination is a core component of federal and state efforts to improve health outcomes, reduce caregiver and patient burden, and decrease health care costs for children and adults with chronic and complex conditions.¹ Care coordination quality measurement can support states, health plans, and other stakeholders to create and sustain robust care coordination systems for children and youth with special health care needs (CYSHCN). It is especially important for stakeholders to consider the role of care coordination quality measurement as payment models shift towards value-based payments through which providers are incentivized for the quality rather than the volume of care they provide.² Quality measurement is also an important aspect of service delivery for CYSHCN enrolled in Medicaid managed care organizations (MCOs), since MCOs often include specific quality evaluation and reporting guidelines within their contractual agreements.³ This resource describes key considerations and challenges in care coordination quality measurement, and identifies sample metrics that could be leveraged to evaluate the quality of care coordination systems as outlined in the [National Care Coordination Standards for CYSHCN](#).



Comprehensive quality measurement of care coordination services is essential to evaluate and guide care coordination efforts, yet little agreement exists among stakeholders about how to best measure the provision and quality of care coordination services.⁴ Current measurable outcomes of care coordination include: patient experience with coordination of care, patient report of unnecessary care, quality of life of the patient and family, equity in care delivery, and patient-centeredness of care coordination services.⁵ Since CYSHCN, particularly children of color, face systemic and societal barriers to accessing robust care coordination services, it is important for stakeholders to understand where gaps in quality care coordination delivery exist for these populations.^{6,7} Targeted data collection and evaluation of specific areas of care coordination can equip stakeholders with an understanding of gaps experienced by children and their families, and help support the creation of robust and equitable delivery systems.

Measuring care coordination quality requires data from a range of stakeholders involved in care coordination activities, a defined goal of care coordination outcomes, and specific measurements for activities of care coordination. The National Care Coordination Standards for CYSHCN, released by the National Academy for State Health Policy in October 2020, describe the importance of focusing care coordination quality measurement for pediatric populations on the extent to which patients' and families' goals and needs are met and burdens reduced.⁸ The National Care Coordination Standards are designed to help state officials and other stakeholders develop and strengthen high-quality care coordination for children with the goal of identifying and assessing the need for care coordination, engaging families in the care coordination process to create a shared plan of care, building a strong and supportive care coordination workforce, and developing team-based communication processes to better serve children and families.⁹ The Care Coordination Standards were informed by a national work group comprised of state and federal Medicaid, public health, and mental health agency representatives, families of CYSHCN, health plans and insurers, and health care providers with expertise in CYSHCN. The Standards can be leveraged as a guiding resource for creating and evaluating existing care coordination systems.

Gaps and Challenges in Care Coordination Quality Measurement

Measuring the quality of care coordination and the outcomes of care coordination services is an important component of developing and sustaining high-quality care coordination systems for CYSHCN. The following challenges are important for states to consider as they implement quality metrics for care coordination systems:

- **Lack of Alignment of Metrics and Definitions of Care Coordination Quality.** Due to the relative novelty of care coordination system design for children, and CYSHCN, a consensus of care coordination has yet to emerge.¹⁰ The National Care Coordination Standards for CYSHCN defines care coordination as “patient-and family-centered, assessment-driven, team-based activities designed to meet the needs of children and youth. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes, and efficient delivery of health-related services and resources within and across systems.”^{11,12,13} Though the National Care Coordination Standards include a definition of care coordination, little agreement exists among stakeholders about how to best measure it.¹⁴
- **Barriers to Measuring Care Coordination Activities Across Health IT Systems.** It is difficult to capture the range of care coordination activities as many electronic medical records lack inclusion of social care received through community organizations, long-term care providers, or informal caregivers. These difficulties are heightened by underutilization of health information technology system capabilities and gaps in interoperability between health information systems.^{15,16,17}

- **Lack of Approaches for Measuring the Quality of Behavioral Health-Centered Care Coordination Activities.** There are significant gaps in care coordination measures that evaluate activities and outcomes related to behavioral health.¹⁸ As behavioral health concerns among pediatric populations grow as a result of isolation and the impact of COVID-19, it will be important to strengthen this area of measurement and improve quality of behavioral health focused care coordination services and supports.¹⁹



Existing Care Coordination for CYSHCN Quality Measurement Tools

The following evidence-based measurement tools are included for consideration due to their relative familiarity and widespread use in the child health field, their validation for use with CYSHCN populations, and their consideration of health equity. These tools may be used by states and other stakeholders to evaluate and improve their care coordination systems for CYSHCN.

- **National Survey of Children’s Health:** The National Survey of Children’s Health, which is funded and directed by the Health Resources and Services Administration, Maternal and Child Health Bureau, evaluates the prevalence and impact of special health care needs among children in the US, with specific focuses on access to medical homes, adequate health insurance, access to needed services, and adequate care coordination.²⁰
- **Family Experiences with Coordination of Care (AHRQ):** The Family Experiences with Coordination of Care survey was designed to specifically measure care coordination quality for children with medical complexity (CMC).²¹
- **Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey, Item Set for Children with Chronic Conditions:** The Children with Chronic Conditions set includes a five-item screener that classifies children with chronic conditions and a set of questions regarding the health care experiences of children with chronic conditions.²²
- **Patient-Centered Medical Home Assessment (PCMH-A):** The patient-centered medical home assessment is designed to help sites understand their current level of “medical homeness,” identify opportunities for improvement, and track progress toward practice transformation.²³

Quality Measures to Support Implementation of the National Care Coordination Standards for CYSHCN

The following tables feature specific quality measures that are related to and aligned with the National Care Coordination Standards for CYSHCN. States and other stakeholders can consider use of the following measures in use or adaptation of the National Care Coordination Standards. Measures are yes/no questions and outcomes unless otherwise noted.



Screening, Identification, and Assessment

Measurement Tool	Measure
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey, Item Set for Children with Chronic Conditions	<p>Does your child’s personal doctor understand how your child’s medical, behavioral, or other health conditions affect your child’s day-to-day life?</p> <p>Does your child’s personal doctor understand how your child’s medical, behavioral, or other health conditions affect your family’s day-to-day life?</p>
National Survey of Children’s Health	<p>Does this child have special health care needs based on the CSHCN Screener?</p> <p>Is this young child flourishing, age 6 months-5 years; 6 years – 17 years?</p> <p>Does this child have a mental, emotional, developmental or behavioral problem?</p> <p>Indicators 6.1 – 6.27 (focus on family health and activities, covering multiple topics relating to SDOH, family relational health and parental mental and physical health).</p>
Family Experiences with Coordination of Care (AHRQ)	Care coordinator has asked about concerns and health changes.
Patient-Centered Medical Home Assessment	Assessing patient and family values and preferences is systematically done and incorporated in planning and organizing care. (Score 1 -12)



Shared Plan of Care

Measurement Tool	Measure
National Survey of Children's Health	Has this child's doctors or other health care providers worked with you and this child to create a plan of care to meet his or her health goals and needs?
Family Experiences with Coordination of Care (AHRQ)	<p>Caretaker has access to electronic health record.</p> <p>Caregivers report that main provider created a shared care plan.</p> <p>Child has a shared care plan.</p> <p>Care coordinator asked about progress towards goals.</p>
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey, Item Set for Children with Chronic Conditions	<p>In the last 6 months, when there was more than one choice for your child's treatment or health care, did your child's doctor or other health provider ask you which choice was best for your child? (yes/no)</p> <p>When decisions were made in the last 6 months, how often did your child's doctors or other health providers discuss with you the good and bad things about each of the different choices for your child's health care? (never, sometimes, usually, always)</p>
Patient-Centered Medical Home Assessment	Care plans are developed collaboratively, include self-management and clinical management goals, are routinely recorded, and guide care at every subsequent point of service. (Score 1 – 12)



Team-Based Communication

Measurement Tool	Measure
National Survey of Children's Health	<p>During the past 12 months, did this child's health care provider communicate with the child's school, childcare provider, or special education program?</p> <p>During the past 12 months, have you felt that you could have used extra help arranging or coordinating this child's care among the different health care providers or services?</p> <p>During the past 12 months, did this child need a referral to see any doctors or receive any services? If yes, how difficult was it to get referrals?</p>
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey, Item Set for Children with Chronic Conditions	<p>In the last 6 months, did you need your child's doctors or other health providers to contact a school or daycare center about your child's health or health care?</p> <p>Doctor explained care in a way that is easy to understand; doctors listened carefully.</p>
Patient-Centered Medical Home Assessment	<p>Visits are organized to address both acute and planned care needs. Tailored guideline-based information is used in team huddles to ensure all outstanding patient needs are met at each encounter. (Score 1-12)</p>



Child and Family Empowerment and Skills Development

Measurement Tool	Measure
Family Experiences with Coordination of Care (AHRQ)	<p>Care coordinator was knowledgeable, supportive, and advocated for child's needs.</p>
National Survey of Children's Health	<p>Has this child's doctor or other health care provider actively worked with this child to: make positive choices about his or her health; gain skills to manage his or her health and health care?</p>
Patient-Centered Medical Home Assessment	<p>Test results and care plans are systematically communicated to patients in a variety of ways that are convenient to patients. (Score 1 – 12)</p>



Care Coordination Workforce

Measurement Tool	Measure
National Survey of Children's Health	How often did you get as much help as you wanted with arranging or coordinating care? During the past 12 months, did anyone help you arrange or coordinate this child's care among the different doctors or services that this child uses?
Patient-Centered Medical Home Assessment	The practice routinely assesses training needs, ensures that staff are appropriately trained for their roles and responsibilities, and provides cross training to ensure that patient needs are consistently met. (Score 1-12)
Patient-Centered Medical Home Assessment	Non-physician practice team members perform key clinical service roles that match their abilities and credentials. (Score 1 – 12)
Patient-Centered Medical Home Assessment	Linking patients to supportive community-based resources is accomplished through active coordination between the health system, community service agencies and patients and accomplished by a designated staff person. (Score 1-12)
Patient-Centered Medical Home Assessment	Patient comprehension of verbal and written materials is supported at an organizational level by translation services, hiring multi-lingual staff, and training staff in health literacy and communication techniques (such as closing the loop) ensuring that patients know what to do to manage conditions at home. (Score – 12)



Care Transitions

Measurement Tool	Measure
National Survey of Children's Health	Do any of this child's doctors or other health care providers treat only children? If yes, have they talked with you about having this child eventually see doctors or other health care providers who treat adults? Have this child's doctors or other health care providers worked with you and this child to create a plan of care to meet his or her goals and needs? Does this plan of care address transition to doctors and other health care providers who treat adults? Have this child's doctor or other health care provider actively worked with this child to understand changes in health care that happen at age 18?

Endnotes

1. National Academy for State Health Policy. National Care Coordination Standards for Children and Youth with Special Health Care Needs. Washington, DC, National Academy for State Health Policy, October 2020. <https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-1>
2. Medicaid and CHIP Payment and Access Commission. Value-based payment. <https://www.macpac.gov/subtopic/value-based-purchasing/>
3. National Academy for State Health Policy. State Strategies for Medicaid Quality Improvement for Children and Youth with Special Health Care Needs. Washington, DC, National Academy for State Health Policy, November 2017. <https://www.nashp.org/wp-content/uploads/2017/11/MQM.pdf>.
4. Schultz EM, et al., “A systematic review of the care coordination measurement landscape.” BMC health services research. 2013. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3651252/>
5. Agency for Healthcare Research and Quality. Care Coordination Measures Atlas Update, Chapter 3. Care Coordination Measurement Framework. <https://www.ahrq.gov/ncepcr/care/coordination/atlas/chapter3.html>
6. Toomey S, Chile A, Elliot M, et al., Disparities in Unmet Need for Care Coordination: The National Survey of Children’s Health. Pediatrics. 2013.
7. Cooker T, Rodriguez M, Flores G, Family-centered care for US children with special health care needs: who gets it and why?. Pediatrics. 2010.
8. National Academy for State Health Policy. National Care Coordination Standards for Children and Youth with Special Health Care Needs. Washington, DC, National Academy for State Health Policy, October 2020. <https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-1>
9. Ibid.
10. Schultz EM, et al., “A systematic review of the care coordination measurement landscape.” BMC health services research. 2013. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3651252/>
11. Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.
12. Council on Children With Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. Pediatrics. 2014;133(5).
13. “Care Coordination Measures Atlas Update”, Agency for Healthcare Research and Quality, June 2014, <https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html>.
14. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3651252/>
15. Lipika S., et al., “Care Coordination gaps due to lack of interoperability in the United States: a qualitative study

- and literature review,” BMC Health Services Research. 2016. <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-016-1373-y>
16. Agency for Healthcare Research and Quality. Prospects for Care Coordination Measurement Using Electronic Data Sources. <https://www.ahrq.gov/research/findings/final-reports/prospectscare/prospectscare1.html>
 17. Julie Bynum, “Measuring What Matters Most to People with Complex Needs,” Health Affairs, 2018. <https://www.healthaffairs.org/doi/10.1377/hblog20180622.306574/full/>
 18. Jorina M, et al., “Advancing the Measurement of Care Coordination in Pediatric Behavioral Health,” Journal of Developmental Behavioral Pediatrics. 2016. <https://pubmed.ncbi.nlm.nih.gov/27642685/>
 19. Centers for Disease Control and Prevention. Mental Health-Related Emergency Department Visits Among Children Aged <18 Years During the COVID-19 Pandemic – United States, January 1-October 17, 2020. <https://www.cdc.gov/mmwr/volumes/69/wr/mm6945a3.htm>
 20. The National Survey of Children’s Health. <https://www.childhealthdata.org/learn-about-the-nsch/NSCH>
 21. Measures: Family Experiences with Care Coordination measure set (FECC) https://www.ahrq.gov/sites/default/files/wysiwyg/policymakers/chipra/factsheets/chipra_15-p002-ef.pdf
 22. Agency for Healthcare Research and Quality. CAHPS Item Set for Children with Chronic Conditions. <https://www.ahrq.gov/cahps/surveys-guidance/item-sets/children-chronic/index.html>
 23. Patient-Centered Medical Home Assessment (PCMH-A) <https://qualishealth.org/sites/default/files/PCMH-A.pdf>

Acknowledgements

The National Academy for State Health Policy (NASHP) extends its thanks and appreciation to the Lucile Packard Foundation for Children’s Health for its support of this work.

This resource was written by NASHP Research Analyst Eskedar Girmash and NASHP Project Director Kate Honsberger. Many thanks to NASHP Senior Program Director Karen VanLandeghem and NASHP Policy Associate Olivia Randi for contributing to the work through input, guidance, and draft review.



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