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Quality Measurement Gaps in Pediatric-To-Adult Health Care Transition in the United States: A Framework to Guide Development of New Measures

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A B S T R A C T

Purpose: Pediatric-to-adult health care transition (HCT) is a critical component of care for youth and young adults (Y/YA), especially those with chronic conditions. Positive outcomes in population health, patient experience, and utilization of care for Y/YA with chronic conditions have been associated with a structured HCT approach. Despite these outcomes and professional recommendations, few Y/YA receive HCT guidance from providers. Compounding this problem is the lack of attention to HCT quality measurement to stimulate and evaluate practice improvements and ensure accountability in pediatric and adult care.

Methods: A multistep process was undertaken to develop a new HCT quality measurement framework and identify existing HCT measures from national databases. Based on an environmental scan, the framework was created, measure gaps identified, and measure concepts proposed to fill these gaps. A multistakeholder advisory committee provided guidance throughout this initiative.

Results: The HCT measurement framework has 11 domains: one structure domain (health organization characteristics), three process domains (clinician HCT activities, Y/YA/F activities, continuity of care), four outcome domains (population health, utilization/cost/value of care, patient experience, and clinician experience), and three mediator domains (Y/YA/F-centered care, care coordination, and Y/YA/F characteristics). The search yielded 49 potentially relevant measures but only four qualified as directly relevant to HCT. Fifty four HCT measure concepts were proposed to address these shortcomings.

Discussion: Pediatric-to-adult HCT quality measurement is largely absent in nationally recognized databases. This article provides a comprehensive HCT quality measurement framework, which was used to identify gaps and propose measure concepts as a roadmap for future HCT quality measurement improvements.

IMPLICATIONS AND CONTRIBUTION

Nationally recognized quality measures assess only limited aspects of pediatric-to-adult health care transition, which impedes evaluating transition structure, process, and outcomes. The quality measurement framework and measure concepts developed for this article can be used to guide future health care transition quality measurement.

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Pediatric-to-adult health care transition (HCT) is a critical component of longitudinal care for all youth and young adults (Y/YA) and especially for those with chronic conditions [1]. It is defined as the process of moving from a child-centered to an adult-centered model of health care, with or without a transfer to a new clinician or health care provider (HCP), and it involves helping Y/YA, between the ages of 12 and 26 years, to progressively manage their own health and effectively use health services. In 2018, the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians jointly published a clinical report offering specific quality improvement guidance on the three key components for HCT as part of routine care in the medical home: transition preparation, transfer of care, and integration into adult care [1]. The transition preparation process includes activities to assist Y/YA to gradually attain self-care skills and to feel prepared for care in the adult health care system, where they, not their parents, will be managing their own health and independently navigating health care. The transfer process includes activities that both pediatric and adult practices complete to communicate essential health information with the transitioning Y/YA and with each other before the first appointment in the adult practice. The integration into adult care process focuses on engaging the new YA in the adult practice by welcoming and orienting them, continuing self-management skill-building, and facilitating needed referrals [1].

A growing body of literature finds persistent problems in the provision of recommended HCT services and adverse outcomes associated with lack of these services. Researchers report barriers experienced by Y/YA and families (Y/YA/F) and HCPs with the HCT process, such as inadequate transition preparation from HCPs [2,3], minimal communication and transfer of health information between pediatric and adult health systems [4], and difficulties finding available adult HCPs who serve YA with childhood-onset conditions [5]. They also report suboptimal HCT outcomes, including loss to follow-up [6,7], discontinuity of care [8,9], dissatisfaction with care and worry [10–12], higher rates of hospital admissions [13,14] and emergency room use [15], and excess morbidity [11] and mortality [16].

Contributing to these challenges has been limited attention to HCT quality measurement. Studies have found insubstantial and inconsistent use of quality measures to assess HCT structure, process, and outcomes [17–19]. This impedes standardizing the HCT process, ensuring accountability for quality improvements, and comparatively evaluating HCT interventions. Moreover, to date, HCT quality measurement has primarily addressed HCT preparation, particularly transition readiness, with far less attention to transfer of care and hardly any attention to integration into adult care. Furthermore, HCT quality measurement has been primarily studied from the perspective of individuals with a single disease [20–24]. Notably absent are studies on Y/YA without special health care needs (SHCN) [19]. Additional gaps have been reported in measuring HCP experience and HCT cost-effectiveness [19].

Researchers have called on the federal government and standard-setting organizations to establish a common set of measures to evaluate HCT interventions [19]. They have also called for measures to be developed pertinent to all youth, with and without SHCN, and specifically applicable to HCT. An example of a specific HCT measure is evaluating the exchange of a current medical summary between pediatric and adult HCPs and Y/YA, instead of a measure that evaluates health care in general, such as the adoption of health information technology [18]. In addition, researchers recommend outcome measures aligned with the quadruple aim of population health, patient experience, clinician experience, and utilization/cost of care [19,25]. Furthermore, they call for measures that build on HCT theoretical frameworks [1,26–30].

Recognizing the urgent need to identify ways to measure and improve pediatric-to-adult HCT, this article presents (1) a new HCT quality measurement framework, (2) a listing of existing measures specific to HCT from nationally recognized quality measure databases, and (3) proposed HCT measure concepts to address the identified measure shortcomings. This article is intended to lay out a foundation and guide next steps to improve HCT quality measurement. This project builds on prior work by The National Alliance to Advance Adolescent Health/Got Transition working on HCT performance for the past 10 years, which includes conducting three systematic reviews [17–19], co-authoring the 2018 American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians Clinical Report [1], analyzing national HCT performance [2,31], and identifying quality measures for use in value-based payment initiatives [32].

Methodology

This year-long project of The National Alliance/Got Transition team involved a multistep process, working with an expert advisory committee comprised of leaders representing pediatric and adult HCPs, family and disability advocacy, quality measurement, and health services research. The advisory committee met virtually five times and participated between meetings in providing review and feedback on drafts via online surveys, with the aim of achieving consensus.

To inform our methods, we began with an environmental scan, which included a review of selected published reports that address gaps in quality measurement [33,34], a literature review of HCT publications on theory, conceptual models, and measurement to identify domains to consider including in an HCT quality measurement framework [26–30] and key informant interviews with four leaders in family engagement, care coordination, medical home, and HCT quality measurement to elicit guidance on existing measures and measure gaps. Based on the environmental scan findings and approach described in the selected published reports, we undertook a multistep process to (1) create guiding principles, (2) create a conceptual model, (3) create an HCT quality measurement framework, (4) identify and review quality measures based on the new HCT quality measurement framework, and (5) identify measure gaps and propose measure concepts to address these gaps.

A set of guiding principles was developed building on the 2018 Clinical Report [1] and the National Quality Forum (NQF) report on home and community-based services [35]. These overarching principles helped to inform subsequent work. Then, a pediatric-to-adult HCT quality measurement conceptual model was constructed to graphically show the youth/young adult and family (Y/YA/F) at the center of the HCT process along with a high-level depiction of inter-related domains and variables and desired outcomes. This conceptual model was then used to create a foundation for measuring HCT for youth with and without chronic conditions. As such, the HCT Quality Measurement Framework was created with a set of domains and subdomains, drawing in particular on NQF's report on emergency

department transitions of care [33] and a theoretical framework on care coordination [34] identified from the literature review. The domains and subdomains for the framework were selected to reflect the capacity and system infrastructure relevant to HCT, the breadth of HCT activities performed by pediatric and adult HCPs and Y/YA/F, and the range of outcomes to be measured for all youth with and without special needs. Also, the framework included mediator domains and subdomains that may influence structure, process, and outcomes but are not specific to HCT. The conceptual model and framework underwent considerable review and revision from the advisory committee over several meetings.

Next, we searched national quality measure databases and clearinghouses from NQF, the Centers for Medicare & Medicaid Services (CMS), and the Agency for Health care Research and Quality (AHRQ), to identify and abstract existing measures that were potentially relevant to HCT. Of note, it was beyond the scope of this article to conduct a systematic or scoping review of published and grey literature to identify other measures that have been used. To identify existing potentially relevant nationally recognized measures, authors A.S. and S.I. reviewed more than 2,000 measures in the databases and manually filtered through the names and summary descriptions of each measure to determine if they were potentially relevant to HCT for youth with and without chronic conditions and for pediatric and adult HCPs. Measures were considered potentially relevant to HCT if they aligned with the developed guiding principles, a domain/subdomain from the developed quality measurement framework, and/or were measures of health care for Y/YA. The measures identified as potentially relevant were then reviewed by P.M. and P.W. These existing potentially relevant measures were then brought to an advisory committee meeting for discussion and to come to a consensus on whether they aligned with the guiding principles and framework. After discussion, it was decided by the committee that hospital-to-home transition measures should be excluded because they do not account for the longitudinal aspects of pediatric-to-adult HCT. The remaining existing measures were then organized into the domains and subdomains of the new HCT quality measurement framework. Measures were further classified as (1) structure measures, defined as measures of infrastructure of capacity and systems relevant to HCT; (2) process measures, defined as measures of HCT activities; (3) outcome measures, defined as measures of the quadruple aim effects of HCT; and (4) mediator measures, defined as measures that may support the relationships between structure, process, and outcome but are not specific to HCT. An additional review of these existing measures was conducted to highlight the measures that were directly relevant to pediatric-to-adult HCT, as opposed to health care in general, as recommended by Prior et al. [18]. For example, a measure of lapse in care of more than six months after transfer to adult health care is directly relevant because it is specific to the transfer from pediatric to adult health care, while a measure of having a usual source of health care is relevant to health care in general. The existing measures were reviewed over the course of three meetings with the advisory committee.

After organizing the potentially relevant existing measures into domains and subdomains of the HCT quality measurement framework, P.M., A.S., S.I., and P.W. eliminated all existing measures not directly relevant to HCT, which revealed the extent of the measure gaps. Then the authors proposed HCT measure concepts for all subdomains where the measures were insufficient or absent altogether. These measure concepts went through refinements through an iterative review process with advisory committee members via discussions at meetings and feedback elicited from an online survey. The online survey asked each committee member to review each proposed measure concept's description and to decide whether each measure concept required editing and should be included in the final list.

Box 1. Guiding principles for health[a] care transition quality measurement

1. Importance of youth-centered and/or young adult-centered, strength-based focus[c]
2. Emphasis on family and/or caregiver inclusion, engagement, and support[c,d]
3. Need for parents and caregivers and health care systems to support youth and young adults in building their self-determination and self-care skills, accounting for preferences and needs[c,d]
4. Acknowledgment of individual differences and complexities, including consideration of the need for supported decision-making[c]
5. Recognition of vulnerabilities and need for a distinct, developmentally-appropriate population health approach for youth and young adults[c]
6. Need for early and ongoing preparation of youth, young adults, and families to transition to an adult model of care[c]
7. Consideration of coordinated and sequenced primary and specialty care transitions, including the integration of health care and social services to promote well-being[d]
8. Importance of shared accountability, effective communication, and care coordination among youth/young adults, families, and pediatric and adult clinicians and systems of care[c]
9. Recognition of the influences of cultural beliefs and attitudes as well as social determinants of health[c]
10. Emphasis on achieving health equity and elimination of systemic racism and disparities[c]
11. Support of an appropriately skilled workforce[b] that is stable and adequate to meet the need[d]
12. Engagement of youth, young adults, and families/caregivers in the design, implementation, and evaluation[d]
13. Delivery of—through adequate funding—accessible, affordable, and cost-effective services to those who need them[d]
14. Consideration of the feasibility and acceptance in pediatric and adult care
15. Importance of accountability through measurement and reporting of quality of care and consumer outcomes[d]

[a] The term health encompasses physical and mental/behavioral health.
[b] The terms clinicians and workforce encompass primary, mental/behavioral health, and specialty care.
[c] Modified and/or taken from White PH, Cooley WC, Transitions Clinical Authoring Group, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2018; 142(5):e20182587.
[d] Modified and/or taken from National Quality Forum. Quality in home and community-based services to support community living: Addressing gaps in performance measurement. Washington, DC, 2016.

Results

Fifteen overarching guiding principles were developed that can be used to improve HCT quality measurement (Box 1). These principles underscore the significance of Y/YA/F engagement in all aspects of HCT, taking into consideration individual differences and emphasizing cultural responsiveness and equity. They

Box 2. Health care transition quality measurement framework

	Structure measures[a]	Process measures[b]	Outcome measures[c]	Mediator measures[d]
Domains and Subdomains	Health Organization Characteristics • Electronic health record • Accountable pediatric and adult HCPs • Use of telemedicine • Workforce availability and access • Capacity of pediatric and adult health care system (infrastructure, training, workforce availability) • Data sources/capabilities/ sharing	Clinician HCT Activities • Transition preparation • Transfer • Integration into adult care Y/YA/F HCT Activities • Proficiency/knowledge and skill development Continuity of Care • Informational continuity/ communication between HCPs and care settings • Management continuity • Relational continuity	Population Health • Self-care • Adherence to care • Disease-specific measures • Patient-reported health status • Quality of life transition • Morbidity, new comorbidity, or mortality Utilization/Cost/Value of Care • Utilization • Cost of care Patient Experience • Experience • Barriers to care Clinician Experience • Experience • Barriers to care	Y/YA/F-Centered Care • Y/YA/F engagement • Representation and equity • Transparency • Individualization • Responsiveness Care Coordination • Communication • Designating accountability • Linking to resources Y/YA/F Characteristics • Developmental capacity/ Functional capabilities • Sociodemographic characteristics • Complexity

[a] Measures of infrastructure of capacity and systems relevant to HCT.
[b] Measures of HCT activities.
[c] Measures of the quadruple aim effects of HCT.
[d] Measures that may support the relationships between structure, process, and outcome, but are not specific to HCT.

also speak to the importance of a coordinated, longitudinal HCT approach in primary, specialty, and behavioral health care along with shared HCT accountability in both pediatric and adult health care settings.

The HCT quality measurement framework (Box 2) consists of 11 domains, with several subdomains for each, which are organized into four measure types: structure measures (one domain), process measures (three domains), outcome measures (four domains), and mediator measures (three domains). The domains are visualized in the conceptual model (Figure 1), which displays the components and outcomes of the HCT process centered around the Y/YA/F.

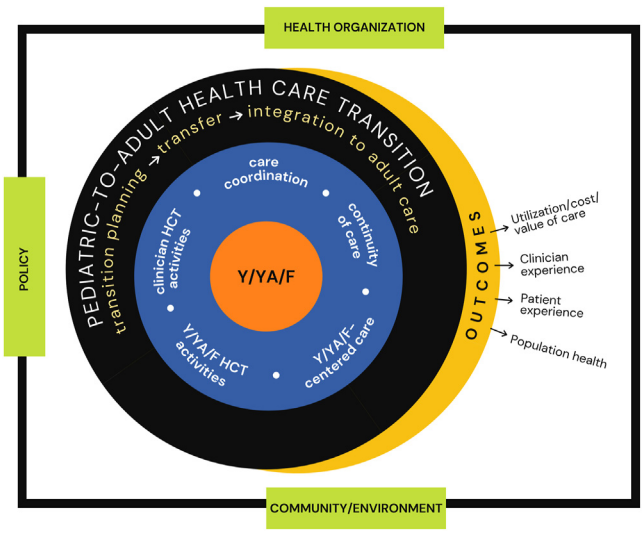

Figure 1. Pediatric-to-adult health care transition quality measurement conceptual model.

Using this framework, a total of 49 existing measures were identified from NQF, CMS, and AHRQ databases as potentially relevant to HCT (Appendix A). Of these, only four measures were considered to be directly relevant to pediatric-to-adult HCT (Table 1). Two of the four measures—supporting electronic referral loops as part of a transition of care or referral—are structure measures relevant to the health organization characteristics domain. The other two are process measures that fall within the clinician HCT activities domain. One process measure examines receipt of transition preparation among youth with SHCN, aged 12–17 years, as reported by parents. The other process measure is the ADAPT survey, which examines the receipt and quality of transition preparation by youth, aged 16–17 years, with a chronic condition. The ADAPT survey is also an outcome measure in the patient experience domain. While an additional 45 existing measures were identified as potentially relevant to HCT, they were not considered to be directly relevant to pediatric-to-adult HCT. For instance, some of these measures evaluate health care in general (e.g., child and adolescent well visit) and were not specific enough to HCT. The full compendium of directly and indirectly relevant existing measures can be found in Appendix A.

A total of 54 HCT quality measure concepts were proposed to address the measure gaps identified (Table 2). Of these measure concepts, 16 pertain to structure measures, eight pertain to process measures, 18 pertain to outcome measures, and 12 pertain to mediator measures. This comprehensive list of HCT measure concepts offers a roadmap for future HCT quality measurement.

Discussion

The new HCT quality measurement framework consists of inter-related domains that are vital components of quality pediatric-to-adult transitional care. The health organization

Table 1
Existing health care transition quality measures

Structure measures: Measures of infrastructure of capacity and systems relevant to HCT			
Domain: Health organization characteristics Subdomain: Electronic health record	Measure Description	Steward	Ages
Support Electronic Referral Loops By Receiving and Reconciling Health Information (MIPS # PI_HIE_4)	For at least one electronic summary of care record received for patient encounters during the performance period for which an MIPS eligible clinician was the receiving party of a transition of care or referral or for patient encounters during the performance period in which the MIPS eligible clinician has never before encountered the patient, the MIPS eligible clinician conducts clinical information reconciliation for medication, medication allergy, and current problem list.	MIPS	All
Support Electronic Referral Loops By Sending Health Information (MIPS # PI_HIE_1)	For at least one electronic summary of care record received for patient encounters during the performance period for which an MIPS eligible clinician was the receiving party of a transition of care or referral or for patient encounters during the performance period in which the MIPS eligible clinician has never before encountered the patient, the MIPS eligible clinician conducts clinical information reconciliation for medication, medication allergy, and current problem list.	MIPS	All
Process Measures: Measures of HCT activities			
Domain: Clinician HCT Activities Subdomain: Transition preparation	Measure Description	Steward	Ages
Children with Special Health Care Needs (CSHCN) who Receive Services Needed for Transition to Adult Health Care (NQF 1340)	% of youth with special health care needs who receive services needed for transition to adult health care services.	CAHMI	12–17
Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care (NQF 2789)	The Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care measures the quality of preparation for transition from pediatric-focused to adult-focused health care as reported in a survey completed by youth ages 16–17 years old with a chronic health condition. The ADAPT survey generates measures for each of the 3 domains: (1) Counseling on Transition Self-Management, (2) Counseling on Prescription Medication, and (3) Transfer Planning.	Center of Excellence for Pediatric Quality Measurement	16–17
Outcome Measures: Measures of the quadruple aim effects of HCT			
Domain: Patient Experience Subdomain: Experience	Measure Description	Steward	Ages
Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care (NQF 2789)	The Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care measures the quality of preparation for transition from pediatric-focused to adult-focused health care as reported in a survey completed by youth ages 16–17 years old with a chronic health condition. The ADAPT survey generates measures for each of the 3 domains: (1) Counseling on Transition Self-Management, (2) Counseling on Prescription Medication, and (3) Transfer Planning	Center of Excellence for Pediatric Quality Measurement	16–17

characteristics domain specifies the infrastructure and capacities needed for HCT. The clinician HCT activities domain establishes the three components of transition, with pediatric clinicians taking the lead on transition preparation, both pediatric and adult clinicians involved in transfer, and adult clinicians leading the integration into adult care. The Y/YA/F activities domain acknowledges their central role in self-care skill-building. The continuity of care domain highlights the bidirectional communication and longitudinal continuity called for during HCT. The population health measure domain identifies a variety of subdomains often measured in HCT evaluation studies. The utilization/cost/value of care domain recognizes that HCT has a potential influence on regular use of ambulatory care, higher cost emergency room, and hospital services. Both the patient and clinician experience domains acknowledge the importance of how responsiveness and supports may facilitate or impede HCT. The final three domains of Y/YA/F-centered care, Y/YA/F-centered

Table 2
Health care transition quality measure concepts to address measure gaps

Structure Measure Concepts		
Domain	Subdomain	Measure Concept
Health Organization Characteristics	Electronic health record	• Exchange of medical summary from pediatric HCP to transition-aged youth and new adult HCP • Reconciliation of medical summary by new adult HCP and shared with YA
	Accountable pediatric and adult HCPs	• Pediatric HCP who accepts responsibility for transition planning, preparation of medical summary, and transfer assistance with new adult HCP • Adult HCP who accepts responsibility for accepting new YA patient, coordinating with past pediatric HCP, and facilitating integration into adult care
	Use of telemedicine	• Evidence of joint telehealth visit with pediatric and adult HCP and transferring patient with chronic conditions
	Workforce availability and access	• Availability of adult primary care HCP to care for new YAs transferring into adult health care • Availability of subspecialty care and ancillary services for new YAs transferring into adult health care • Availability of adult behavioral health for new YAs transferring into adult behavioral health care • YA's access to primary care HCP • YA's access to subspecialty care and ancillary services • YA's access to behavioral health care • Wait times for initial adult primary care visit • Wait times for initial adult subspecialty care and ancillary services • Wait times for initial adult behavioral health visit
	Capacity of pediatric and adult health care system (infrastructure, training, workforce availability)	• Evidence of structured HCT process in pediatric and adult settings
	Data sources/capabilities/sharing	• Availability of structured fields specific to HCT in EHRs
Process Measure Concepts		
Domain	Subdomain	Measure Concept
Clinician HCT Activities	Transition preparation	• Receipt of transition preparation services by pediatric HCPs among youth without special health care needs
	Transfer	• Receipt of transfer assistance by pediatric and adult HCPs among Y/YA with and without special health care needs
	Integration into adult care	• Receipt of facilitated integration into adult care by adult HCPs among YAs with and without special health care needs
Y/YA/F HCT Activities	Proficiency/knowledge and skill development	• Y/YA/F developing HCT readiness and self-care skills (e.g., making own appointments, taking own medications)
Continuity of Care	Informational continuity/communication between HCPs and care settings[a]	• Availability/exchange of current medical summary between pediatric and adult HCPs and Y/YA
	Management continuity[b]	• Evidence of collaborative planning between pediatric and adult HCP with transferring patient with chronic conditions. • Treatment goals for youth and YAs with chronic conditions consistently used in pediatric and adult care
	Relational continuity[c]	• Patient/HCP respect and trust in adult care
Outcome Measure Concepts		
Domain	Subdomain	Measure Concept
Population Health	Self-care	• Self-care skill attainment
	Adherence to care	• Adherence to care (e.g., adherence to medicines/ treatment/appointments)
	Disease-specific measures	• Disease-specific measures (e.g., A1c levels)
	Patient-reported health status	• Patient-reported health status post transfer in adult care
	Quality of life transition	• Health-related quality of life post transfer in adult care
	Morbidity, new comorbidity, or mortality	• Changes in symptoms, severity, functional status, or mortality post transfer in adult care

Table 2
Continued

Outcome Measure Concepts		
Domain	Subdomain	Measure Concept
Utilization/Cost/Value of Care	Utilization	• Adolescents who had a visit with a PCP during the measurement year or the year prior to the measurement year • Missed outpatient visits in pediatric care 3 years before transfer to adult care, among youth with chronic conditions • Missed outpatient visits in adult care 6 months after transfer, among YAs with chronic conditions • ER visits for ambulatory care-sensitive conditions between last pediatric visit and first adult visit • Avoidable inpatient hospital admissions between last pediatric visit and first adult visit
	Cost of care	• Total per capita costs to payer of care provided by accountable pediatric and adult HCPs for year before and after transfer • Total cost of transition-related services (preparation, transfer, and integration to adult care) by accountable pediatric and adult HCPs • Total out of pocket cost to Y/YA/F for year before and after transfer
Patient Experience	Experience	• Y/YA/F experience with the HCT process
	Barriers to care	• Barriers to care (e.g., transportation, work schedule, leave available, cost of care, language, culture)
Clinician Experience	Experience	• HCP experience with HCT
	Barriers to care	• Barriers to care (e.g., communication with and between HCPs and Y/YA/F)
Mediator Measure Concepts		
Domain	Subdomain	Measure Concept
Y/YA/F-Centered Care	Y/YA/F engagement	• Modified goal attainment scale
	Representation and equity	• Specification of race and ethnicity and primary language spoken in HCT registry
	Transparency[d]	• Y/YA/F involvement in and awareness of the practice's HCT process (planning, transfer, and integration into adult care)
	Individualization[e]	• Plan with HCT goals and action steps developed with the Y/YA/F
	Responsiveness[f]	• Y/YA/F HCT experience
Care Coordination	Communication	• Evidence of communication/joint telehealth visit between pediatric and adult HCP and YA
	Designating accountability	• Assigned pediatric and adult HCPs for transfer of care
	Linking to resources	• Current list of available adult HCPs and community resources/services • Documentation of resources shared and of follow-up with Y/YA/F to confirm receipt of the recommended resources.
Y/YA/F Characteristics	Developmental capacity/Functional capabilities	• Developmental/functional assessment scales
	Sociodemographic characteristics	• Documentation of socioeconomic status (SES) and social determinants of health in the HCT registry
	Complexity	• Method to account for risk (medical, behavioral, developmental, and social complexity) during HCT

[a] Perceptions that the clinicians have shared the patient's health care information with one another.[34]
[b] Perceptions that clinicians in all settings share the same treatment plan.[34]
[c] Perceptions that previously established patient-clinician relationships are maintained.[34]
[d] Provides the information and supports family leaders and organization staff need to partner and participate to their maximum potential in the systems-level initiative.[36]
[e] Care is personalized to the patient's feelings, preferences, and desired level of involvement in care.[34]
[f] Patient needs are met in a caring and attentive manner.[34]

characteristics, and care coordination include subdomains that have been shown in the literature to influence the provision of HCT services but these subdomains do not represent stand-alone measures of HCT.

Within nationally recognized quality measure databases, there are few pediatric-to-adult HCT quality measures. The four existing, directly relevant HCT quality measures identified in this analysis examine only limited aspects of HCT (e.g., transition preparation for 16–17 year olds with chronic conditions, exchange of health information during transition). Thus, this analysis uncovered major gaps in pediatric-to-adult HCT quality measurement. The 54 HCT measure concepts were proposed for consideration by clinicians, researchers, measure developers, payers, policymakers, and large health system leaders as options

for future development of measures and for improving the quality of pediatric-to-adult transitional care.

With respect to structure measures, only two existing measures were found that assess electronic health record functionalities during a transition. No existing measures were identified that assess other recommended HCT infrastructure, including workforce availability and designation of pediatric and adult HCPs responsible for HCT. With respect to process measures, no existing measures were identified that evaluate Y/YA's receipt of all three components of a structured HCT process (planning, transfer, and integration), Y/YA's HCT readiness and self-care skill development, or Y/YA's continuity of care. With respect to outcome measures, no existing measures were identified that examine population health, utilization/cost/value of care, or clinician experience outcomes that are specific to HCT. While the ADAPT survey measures patient experience with transition preparation, it is limited in that it only applies to youth aged 16–17 years with chronic conditions and only measures certain aspects of HCT (counseling on HCT self-management, counseling on prescription medication, and transfer planning). Finally, with respect to mediator measures, no measures were identified that examine Y/YA/F-centered care; medical, behavioral, developmental, and social complexity; and care coordination supports specifically in the context of HCT.

These widespread measurement gaps are serious impediments to improving HCT. Lack of quality measures prevents monitoring pediatric and adult HCPs and health care systems who are accountable for facilitating the transition from pediatric to adult health care. This may further contribute to the overall poor performance on the receipt of HCT services for Y/YA nationally. The inability to monitor family burden, Y/YA agency over their own health care, and gaps in care cannot be assessed. These measure gaps can also negatively impact HCPs since they lack information on the quality of HCT services they provide—quality that depends on the infrastructure and resources available to them.

Several steps can be taken to advance the field of pediatric-to-adult HCT quality measurement, using the measurement framework described in this article. Key stakeholders, such as NQF and the U.S. Department of Health and Human Services, could convene a multistakeholder group, including large health system leaders, to review and prioritize the pediatric-to-adult HCT quality measurement gaps and suggested measure concepts to improve HCT quality measurement. Future efforts to update the Medicaid Child and Adult Core Measure Sets could consider HCT as a specific clinical area to provide useful quality measures. State Medicaid agencies and commercial payers could expand their quality performance requirements to ensure that their contracted managed care entities measure HCT quality [37]. Accreditation entities, such as the Joint Commission and the Accreditation Council for Graduate Medical Education, could incorporate HCT requirements into their performance standards.

Since research shows that having a planned HCT approach is associated with improved outcomes [17–19], prioritizing specific measurement framework domains with HCPs, Y/YA/F, researchers, and policymakers is warranted. For instance, within structure measures, there are several measure gaps in the health organization characteristics domain that could be prioritized on related to HCT infrastructure and capacity building in both pediatric and adult systems. In addition, within process measures, several measure gaps under clinician HCT activities could be prioritized to address the low proportion of Y/YA/F receiving guidance on HCT preparation [38]. Under outcome measures, the patient experience and the utilization/cost/value of care measure gaps are important to prioritize during this early phase in HCT measurement. Finally, it is also important to bring attention to understanding which specific HCT structure and process measures influence which outcomes.

An important consideration going forward is whether pediatric-to-adult HCT should be part of a larger measurement effort (e.g., for medical home, consumer experience, care coordination) or be a separate endeavor on its own to ensure greater fidelity to professional recommendations. The tradeoff is one between being part of a larger measurement effort that affords a broader reach but less depth in what aspects of HCT quality is being assessed. For example, as part of the National Committee for Quality Assurance's patient-centered medical home certification requirements, there are criteria pertaining to care transitions [39], but these criteria address the development of a care plan while other aspects of HCT are not included. Clearly, establishing HCT quality measurement priorities will help to inform how best to incorporate HCT into new and ongoing measurement efforts.

Increasingly, federal agencies have included HCT in their funding portfolios. Among these agencies are the Maternal and Child Health Bureau (within the Health Resources and Services Administration), AHRQ, Patient-Centered Outcomes Research Institute, National Institute of Child Health and Human Development (within the National Institutes of Health), and the Administration on Community Living. Going forward, it will be important to encourage an increased emphasis on HCT quality measurement by federal funding agencies.

This analysis has three important limitations. First, existing measures were only searched for in the AHRQ, CMS, and NQF databases. Thus, all identified measures are U.S.-based and measures that did not appear in these databases were not considered. However, the three databases are reasonably comprehensive and generally represent measures that are available for use in national programs. Second, there was not a broader vetting or use of a Delphi process to elicit additional feedback. However, the advisory committee members were specifically selected to offer a wide range of expertise and perspectives. Third, while other reports on gaps in quality measurement incorporated a prioritization of the measure concepts themselves in terms of importance and feasibility that was outside the scope of this project.

Conclusion

Pediatric-to-adult HCT quality measurement is largely absent in national quality measurement databases despite the fact that transitional care is considered an essential part of the medical home for all Y/YA. This article provides a comprehensive framework for measuring the quality of HCT, which was used to identify gaps among existing measures and propose measure concepts for future efforts to improve the quality of pediatric-to-adult transitional care.

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Supplementary Data

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