

# Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care

## Section 1. Basic Measure Information

### 1.A. Measure Name

Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care

### 1.B. Measure Number

0146

### 1.C. Measure Description

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

The ADAPT is a survey of adolescents with a chronic health condition that assesses their experiences with preparation for transition from pediatric-focused to adult-focused health care.

### 1.D. Measure Owner

Center of Excellence for Pediatric Quality Measurement (CEPQM)

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

Not applicable.

### 1.F. Measure Hierarchy

**Please note here if the measure is part of a measure hierarchy or is part of a measure group or composite measure. The following definitions are used by AHRQ:**

- 1. Please identify the name of the collection of measures to which the measure belongs (if applicable). A collection is the highest possible level of the measure hierarchy. A collection may contain one or more sets, subsets, composites, and/or individual measures.**

Not applicable.

- 2. Please identify the name of the measure set to which the measure belongs (if applicable). A set is the second level of the hierarchy. A set may include one or more subsets, composites, and/or individual measures.**

Not applicable.

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

Not applicable.

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

Not applicable.

## **1.G. Numerator Statement**

The ADAPT survey measures the quality of health care transition preparation for youth with chronic health conditions, based on youth report of whether specific recommended processes of care were received. Responses from a survey sample derived from a clinical program or health plan are summarized in three domain-level composite scores.

ADAPT composite scores are calculated using the summation of positive responses to between three and five individual items. For survey items within each composite score, the numerator is the number of respondents with a positive response (item score of 1). Complete instructions for composite score calculations are provided in Section 2, Detailed Measure Specifications (see Supporting Documents).

Another relevant attribute for a survey measure is the survey response rate. The response rate numerator for this measure is the total number of completed surveys. Complete instructions for response rate calculations are provided in Section 2, Detailed Measure Specifications (see Supporting Documents).

## **1.H. Numerator Exclusions**

Not applicable.

## **1.I. Denominator Statement**

ADAPT composite scores are calculated using the summation of positive responses to between three and five individual items. For survey items within each composite score, the denominator is the number of respondents for whom the item is scored as 0 or 1. Complete instructions for composite score calculations are provided in Section 2, Detailed Measure Specifications (see Supporting Documents).

Another relevant attribute for a survey measure is the survey response rate. The response rate denominator for this measure is the total number of surveys mailed but not returned (non-responses), excluding surveys that are undeliverable or returned with a clear indication that the

sampled individual is ineligible for survey completion. Complete instructions for response rate calculations are provided in Section 2, Detailed Measure Specifications (see Supporting Documents).

### **1.J. Denominator Exclusions**

Not applicable.

### **1.K. Data Sources**

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

Survey; child report.

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

Not applicable.

## **Section 2: Detailed Measure Specifications**

**Provide sufficient detail to describe how a measure would be calculated from the recommended data sources, uploading a separate document (+ Upload attachment) or a link to a URL. Examples of detailed measure specifications can be found in the CHIPRA Initial Core Set Technical Specifications Manual 2011 published by the Centers for Medicare & Medicaid Services. Although submission of formal programming code or algorithms that demonstrate how a measure would be calculated from a query of an appropriate electronic data source are not requested at this time, the availability of these resources may be a factor in determining whether a measure can be recommended for use.**

See the Supporting Documents for Detailed Measure Specifications.

## **Section 3. Importance of the Measure**

**In the following sections, provide brief descriptions of how the measure meets one or more of the following criteria for measure importance (general importance, importance to Medicaid and/or CHIP, complements or enhances an existing measure). Include references related to specific points made in your narrative (not a free-form listing of citations).**

### **3.A. Evidence for General Importance of the Measure**

**Provide evidence for all applicable aspects of general importance:**

- **Addresses a known or suspected quality gap and/or disparity in quality (e.g., addresses a socioeconomic disparity, a racial/ethnic disparity, a disparity for Children with Special Health Care Needs (CSHCN), a disparity for limited English proficient (LEP) populations).**

- **Potential for quality improvement (i.e., there are effective approaches to reducing the quality gap or disparity in quality).**
- **Prevalence of condition among children under age 21 and/or among pregnant women.**
- **Severity of condition and burden of condition on children, family, and society (unrelated to cost).**
- **Fiscal burden of measure focus (e.g., clinical condition) on patients, families, public and private payers, or society more generally, currently and over the life span of the child.**
- **Association of measure topic with children’s future health – for example, a measure addressing childhood obesity may have implications for the subsequent development of cardiovascular diseases.**
- **The extent to which the measure is applicable to changes across developmental stages (e.g., infancy, early childhood, middle childhood, adolescence, young adulthood).**

### **Transition from Pediatric to Adult-Focused Health Care: Navigating the Health Care System from Adolescence to Young Adulthood**

Health care transition (HCT) has been defined as a planned, purposeful process in which adolescents and young adults move from pediatric-focused health care delivery to adult-focused delivery (American Academy of Pediatrics [AAP], et al., 2002). The goal of HCT is to maximize lifelong functioning and potential through the provision of uninterrupted, high-quality, developmentally appropriate health care services (AAP, et al., 2002). The lack of effective transition from pediatric to adult-focused health care may contribute to fragmentation of health care and increased risk for adverse health outcomes. Those at highest risk during this period include youth with special health care needs (YSHCN) (Lotstein, McPherson, Strickland, et al., 2005).

The process of HCT involves three key phases: (1) transition planning and preparation; (2) transfer of health care to an adult-focused model; and (3) intake to the adult-focused health system. There is broad consensus that preparation for HCT should start in adolescence and involve individualized planning and ongoing skills development (Cooley, Sagerman, 2011).

In 2002, a consensus statement from the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) envisioned the goal that by 2010, “all physicians who provide primary or subspecialty care to young people with special health care needs (1) understand the rationale for transition from child-oriented to adult-oriented health care; (2) have the knowledge and skills to facilitate that process; and (3) know if, how, and when transfer of care is indicated (AAP, et al., 2002).” For youth receiving care in pediatric-focused health care settings, preparation for HCT includes the acquisition of self-care skills and promotion of increased youth responsibility for chronic condition management. For many youth, transition preparation culminates in a transfer to a new health care setting. However, even for youth who do not change care settings (e.g., those in

family medicine settings), the shift to adult-oriented health care still requires appropriate preparation. Because transition preparation is primarily a series of interactions with clinicians, obtaining reports from youth directly about their experiences is critical to understanding current gaps in health care delivery for this population.

### **Relation of HCT to the Future Health of Children with Special Health Care Needs**

Adolescents and young adults with chronic health conditions are particularly vulnerable to adverse health outcomes related to prolonged interruptions in health care delivery, such as may occur during the periods of HCT (Lotstein, et al., 2005). For example, young adults with asthma were less likely to have a primary care visit, less likely to fill a short-acting beta-agonist prescription, and more likely to visit an emergency department compared with adolescents (Chua, Schuster, McWilliams, 2013). Young adults with diabetes who felt unprepared for transition had an increased likelihood of gaps in care greater than 6 months between pediatric and adult care than those who were more prepared (Garvey, Wolpert, Rhodes, et al., 2012). Other data suggest that youth may be transitioning out of pediatric care without appropriate follow-up, skills or the knowledge needed to succeed in an adult-oriented system (Reiss, Gibson, 2002; Rosen, 1995). Measuring the quality of HCT preparation for YSHCN has great potential to motivate improvements by health care professionals and systems for the patients most likely to benefit. At the same time, approaches to improving HCT preparation for YSHCN could be applied to improve the transition process for all adolescents as they transition to adult-focused care delivery.

### **Preparation for Health Care Transition: A Quality Gap**

Nationally, there is a striking lack of attention to implementing recommendations for HCT outlined in consensus statements and little uniformity in approach even within health care systems. In the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN) a minority of parents reported having discussed transition with their child's physician (Lotstein, et al., 2005), and only 30 percent had a plan for addressing transition needs (Scal, Ireland, 2005). In the 2005-2006 NS-CSHCN, this percentage continued to be below 50 percent (Lotstein, Ghandour, Cash, et al., 2009). Application of Maternal and Child Health Bureau (MCHB) transition services quality metrics to these parent-reported data revealed variable State-level performance, with an individual State's performance predicted by the proportion of patients with a medical home and adequate health insurance (Kane, Kasehagen, Punyko, et al., 2009). Compared to the 2005-2006 survey, no significant improvement in rates of transition preparation was found in the 2009-2010 NS-CSHCN (McManus, Pollack, Cooley, et al., 2013). In the 2007 Survey of Adolescent Transition and Health (SATH), approximately half of patients aged 19 to 23 years reported receiving counseling around transition (Sawicki, Whitworth, Gunn, et al., 2011). No national surveys have directly assessed transition preparation from the perspective of adolescents themselves. These findings all suggest considerable room for improvement in HCT preparation for YSHCN. However, this potential will be realized only with adequate measurement, benchmarking of performance, and concerted efforts at improving care.

## **Preparation for Health Care Transition: Lack of Standardized Quality Measurement**

In its 2011 Patient-Centered Medical Home Standards, the National Committee on Quality Assurance (NCQA) included a specific requirement to address care transitions in primary care (NCQA, 2011). The MCHB identified HCT services as a core outcome for the community-based services required for CSHCN under Title V and Healthy People 2000 and reiterated this priority in the Healthy People 2010 and Healthy People 2020 goals (AAP, et al., 2002; Lotstein, et al., 2009; McManus, et al., 2013). However, systematic assessments of transition readiness are rarely incorporated as part of routine health care (McManus, et al., 2013). Measuring the quality of HCT preparation is intended to drive providers to adopt strategies that foster disease self-management among youth and reliably result in safe and effective transfer to adult care (Park, Adams, Irwin Jr, 2011).

### **Disparities in HCT Preparation**

Socioeconomic, racial and ethnic disparities have been documented in the receipt of HCT services (Lotstein, Kuo, Strickland, et al., 2010; Richmond, Tran, Berry, 2011). In the 2005-2006 NS-CSHCN, fewer African-American and Latino respondents reported having discussed shifting their child's care to an adult-focused provider (Lotstein, et al., 2010). In the same survey, the proportion of respondents who met the core performance outcomes for successful transition increased significantly with increasing family income (Lotstein, et al., 2009). Additionally, the 2007 SATH revealed that low-income young adults had poorer access to health care than those with higher incomes (Lotstein, et al., 2010). Such disparities in transition preparation and access to care are likely to result in adverse health outcomes. The ADAPT survey instrument collects data about race and ethnicity to allow for stratified analyses of differences in transition care quality.

### **Fiscal Burden of Ineffective Health Care Transition**

Young adults use less ambulatory and preventive care than individuals in other age groups (Fortuna, Robbins, Halterman, 2009). In 2009, individuals aged 18 to 26 had the lowest health care utilization rates of any age group, and a significant percentage delayed accessing health care due to cost (Lau Adams, Irwin, 2013). Many young adults, particularly those with chronic disease and those with public health insurance, also have delayed HCT (Fortuna, Halterman, Pulcino, et al., 2012). Lack of preventive care and timely ambulatory services is associated with increased overall costs as health conditions progress and require higher levels of care (Strickland, McPherson, Weissman, et al., 2004). Improving transition preparation for at-risk youth may well decrease costs associated with inappropriate or delayed health care utilization.

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

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

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

- **Relevance to the Early and Periodic Screening, Diagnostic and Treatment benefit in Medicaid (EPSDT).**
- **Any other specific relevance to Medicaid/CHIP (please specify).**

Given the higher rates of inadequate HCT preparation among YSHCN from lower income families, measuring transition preparation is particularly important for YSHCN who are covered by Medicaid (Lotstein, et al., 2009; 2010). In general, children with public insurance less often receive care that meets existing standards for HCT preparation, such as discussing adult health care needs, health insurance, and the shift to an adult provider (when applicable), as well as receiving encouragement to take responsibility for their own health (McManus, et al., 2013). A study of the National Ambulatory Medical Care Survey and National Hospital Ambulatory Medical Care Survey between 1998 and 2008 reported that delayed transition was more common among young adults with public health insurance (Fortuna, et al., 2012).

### **Relevance to the Early and Periodic Screening, Diagnostic, and Treatment Benefit (EPSDT) in Medicaid**

Transition preparation and planning services are a key component of addressing developmental health needs for adolescents receiving Medicaid services. EPSDT is designed to ensure access to needed health services for Medicaid-insured children and adolescents, including adolescent preventive care (Health Resources and Services Administration [HRSA], 2014). Federal rules encourage partnerships between State Medicaid and Title V agencies to assure better access to screening, diagnostic, and treatment services offered by Medicaid, and HCT is a component of Title V initiatives in several States. Incorporating a youth-reported quality measure of HCT preparation would provide the opportunity to assess the effectiveness of existing transition programs.

### **3.C. Relationship to Other Measures (if any)**

**Describe, if known, how this measure complements or improves on an existing measure in this topic area for the child or adult population, or if it is intended to fill a specific gap in an existing measure category or topic. For example, the proposed measure may enhance an existing measure in the initial core set, it may lower the age range for an existing adult-focused measure, or it may fill a gap in measurement (e.g., for asthma care quality, inpatient care measures).**

The MCHB's HCT measure, reported as the percentage of YSHCN who received the services necessary to transition to adult-focused health care, is evaluated among YSHCN ages 12 to 17 years but uses only parent/caregiver responses. The Center for Health Care Transition Improvement (CHCTI), funded by MCHB, has developed a practice-level inventory of transition-related processes incorporating six core elements for quality improvement: (1) transition policy, (2) transition tracking and monitoring, (3) transition readiness assessment, (4) transition planning, (5) transfer of care processes, and (6) transfer completion (CHCTI, 2014). These process measures are designed to be assessed by practices and providers but not by individual patients or families.

Transition readiness scales, such as the Transition Readiness Assessment Questionnaire (TRAQ), are clinical and research tools and may facilitate comparative research on HCT readiness and preparation (Sawicki, Lukens-Bull, Yin, et al., 2011). They were not designed or validated to measure the quality of care delivery, make comparisons among health care systems, or track improvement over time.

Currently, there are no known adolescent-reported measures of health care transition preparation. A youth survey captures adolescents' perceptions of care received, making it a valuable tool for measuring patient-centered care. Studies have shown that the association between patient-centeredness and health outcomes is stronger when patient-centeredness is measured by patient report than when it is measured by provider or researcher assessment (Robinson, Callister, Berry, et al., 2008; Stewart, Brown, Donner, et al., 2000). Although surveying youth may be more difficult given logistical challenges such as obtaining parental permission, direct reports from youth are essential in an area such as transition preparation.

We developed the ADAPT survey to serve as a validated, patient-reported instrument to measure transition preparation in youth with chronic health conditions. This tool will enable payers and health care delivery systems to assess provision of key components of transitions preparation and design innovative strategies for improvement, including disease self-management and prescription management education, and planning for the transfer to adult care.

## **Section 4. Measure Categories**

**CHIPRA legislation requires that measures in the initial and improved core set, taken together, cover all settings, services, and topics of health care relevant to children. Moreover, the legislation requires the core set to address the needs of children across all ages, including services to promote healthy birth. Regardless of the eventual use of the measure, we are interested in knowing all settings, services, measure topics, and populations that this measure addresses. These categories are not exclusive of one another, so please indicate "Yes" to all that apply.**

**Does the measure address this category?**

- a. Care Setting – ambulatory: Yes.**
- b. Care Setting – inpatient: No.**
- c. Care Setting – other – please specify: No.**
- d. Service – preventive health, including services to promote healthy birth: No.**
- e. Service – care for acute conditions: No.**
- f. Service – care for children with acute conditions: Yes.**
- g. Service – other (please specify): No.**
- h. Measure Topic – duration of enrollment: No.**
- i. Measure Topic – clinical quality: Yes.**
- j. Measure Topic – patient safety: No.**
- k. Measure Topic – family experience with care: Yes.**
- l. Measure Topic – care in the most integrated setting: No.**
- m. Measure Topic other (please specify): No.**
- n. Population – pregnant women: No.**



- o. **Population – neonates (28 days after birth) (specify age range):** No.
- p. **Population – infants (29 days to 1 year) (specify age range):** No.
- q. **Population – pre-school age children (1 year through 5 years) (specify age range):**  
No.
- r. **Population – school-aged children (6 years through 10 years) (specify age range):**  
No.
- s. **Population – adolescents (11 years through 20 years) (specify age range):** Yes; 16 to 18 years of age.
- t. **Population – other (specify age range):** No.
- u. **Other category (please specify):** Not applicable.

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

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

### **5.A. Research Evidence**

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

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

### **Goals of the Literature Review**

We conducted a comprehensive literature search to identify published articles and existing survey instruments that evaluate adolescent and young adult experiences of health care during the period of transition to adult-focused health care. Our aims were to examine evidence on the evaluation of transition preparation as a measure of health care quality and to identify essential domains for incorporation into the ADAPT survey.

Research evaluating parent, youth, and young adult patient perspectives on health care transition, including transition preparation, has been conducted in diverse pediatric populations, including patients with cystic fibrosis, congenital heart disease, developmental disabilities, diabetes, human immunodeficiency virus, inflammatory bowel disease, mental illness, neurologic disease,

rheumatologic disease, and sickle cell disease, and in those with multiple complex chronic conditions. Table 1 (see Supporting Documents) summarizes the key studies related to experiences and perspectives of youth undergoing health care transition, organized by specific major categories of chronic condition. We selected articles that met the following criteria: (1) original research; (2) conducted in the United States or Canada; (3) English language; (4) focused on adolescents or young adults with special health care needs (4) greater than or equal to 25 subjects; (5) parent, youth, or young adult report; (6) emphasis on health care transition preparation, transition readiness, or experience of transfer to adult care. Overall, these articles highlight the pervasiveness of poor transition preparation, inadequate implementation of expert consensus guidelines of transition care, and patient dissatisfaction with the lack of preparation for health care transition. In aggregate, the current literature base underscores the need for a patient-reported measure of quality of transition preparation processes.

In addition to patient and parent perspectives reviewed in Table 1 (see Supporting Documents), several studies document health care provider reports of the quality of transition for youth with chronic illness. These survey studies demonstrate inconsistent delivery of pediatric health care transition services (Davis, Geller, Hunt, 2006; deBeaufort, Jarosz-Chobot, Frank, et al., 2010; McLaughlin, Diener-West, Indurkha, et al., 2008; Sobota, Neufeld, Sprinz, et al., 2011), pediatric provider dissatisfaction with current delivery of transition preparation (Camfield, Gibson, Douglass, 2011; Fernandes, Khairy, Fishman, et al., 2012), barriers to the implementation of effective transition preparation (Eshelman-Kent, Kinahan, Hobbie, et al., 2011; Fernandes, et al., 2012), and the need for strategies to more uniformly implement transition preparation and care coordination (Kuhlthau, Warfield, Hurson, et al., 2014).

### **Transition Preparation as a Focus of Quality Measurement**

Measurement of transition preparation is essential to assess and improve the quality of transition care in the United States and beyond. Research findings (Table 1, see Supporting Documents) underscore the need for more purposeful transition planning across the spectrum of pediatric chronic conditions and have led to consensus regarding the importance of improving transition preparation. This consensus is manifest in recommendations outlined by national organizations such as the American Academy of Pediatrics (2002). Consequences of failure to provide adolescents with effective transition services to the adult-centered medical system have been described, including high rates of emergency care utilization among adults ages 20-29 in the United States (Fortuna, et al., 2009) and pediatric hospitalizations for young adults with chronic conditions (Goodman, Mendez, Throop, et al., 2002; Nakhla, Daneman, To, et al., 2009). At present, however, there is a paucity of data linking adequate transition preparation and readiness (the desired goal of preparation) with improved adult health outcomes. A small number of quasi-experimental studies, all conducted in patients with type 1 diabetes, have shown that transition preparation interventions were associated with improved frequency of post-transition medical follow-up (Cadario, Prodam, Bellone, et al., 2009; Holmes-Walker, Llewellyn, Farrell, 2007; Van Wallegem, Macdonald, Dean, 2008). Because transition preparation must be tailored to adolescents' evolving self-management skills and level of independence, direct assessment of youth experiences with the health care system is an important means of quality measurement.

Adolescents are best able to judge how well their providers are meeting their needs. Notably, the association between patient-centered care and health outcomes has been shown to be stronger when patient-centeredness is measured by patient report rather than provider or researcher

assessment (Stewart, et al., 2000; Theunissen, Vogels, Koopman, et al., 1998). Such assessment is likely to stimulate additional improvements in patient-centered processes and outcomes of care.

Research in adolescents has indicated that youth self-report is reliable in evaluation of health service delivery (Klein, Graff, Santelli, et al., 1999; Santelli, Klein, Graff, et al., 2002). Because consensus recommendations for transition preparation identify 14-15 years as the ideal age to initiate the development of a patient-specific transition plan (Cooley, et al., 2011), querying patients at 16-17 years captures their input at a time by which some transition preparation generally should have occurred. A review of 43 transition studies published from 1982-2003 found that the most frequently cited age range for ideal transition was between 16 and 22 years old. Only few studies have reported initiation of transition planning at 15 years or younger (Betz, 2004).

### **Identification of Key Domains for Transition Preparation**

Although there are few existing measures of the quality of transition preparation, recent consensus statements recommend that health care providers prepare their patients by discussing realistic goals, creating a timeline, and developing a transition plan starting at age 14 (Cooley, et al., 2011). Explicit discussion of transfer to adult care is a key component of existing parent-reported measures. Other domains of transition preparation include development of self-management skills, appropriate adolescent autonomy, improved youth-provider communication, and skills for self-advocacy. Examples of self-management and self-advocacy skills include scheduling one's own medical appointments, obtaining medications and prescription refills, having one-on-one conversations with medical providers, being familiar with one's medical history, understanding health insurance coverage, and feeling empowered to manage one's own medical conditions. Many of these skills have been incorporated into transition readiness scales (Ferris, Harward, Bickford, et al., 2012; Gilleland, Amaral, Mee, et al., 2012; Sawicki, et al., 2011). However, adolescent reports of receipt of counseling regarding these skills have not been included previously in measures of health care quality.

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

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

See Section 5.A, above, for details regarding the association between transition preparation and clinical outcomes.

## **Section 6. Scientific Soundness of the Measure**

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

## **6.A. Reliability**

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

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

### **Overview of Survey Development Process**

We developed the ADAPT survey to measure the quality of transition preparation by obtaining self-reported experiences of adolescents. The development process included an extensive review of the literature and existing quality measures, interviews with national leaders in health care transition, parent and adolescent focus groups, cognitive testing, pilot testing of the draft survey, a national field test of the survey, psychometric analysis, and composite development.

The Agency for Healthcare Research and Quality (AHRQ) submitted a Federal Register Notice to solicit public comments on potential domains to include in the measure. Input for the measure was included from the literature review, expert interviews, and public comments in response to the Federal Register Notice. To inform survey development, we conducted focus groups to help us learn more about experiences with transition preparation in all relevant domains from the perspectives of both parents and adolescents. We generated the final survey through iterative revisions of each item based on cognitive interviews with adolescents and on additional expert input. The final version used in field tests incorporated feedback from all of these sources.

### **National Field Testing**

National field testing was conducted at both the health plan and clinical program levels, since the survey was designed to be used in both of these settings. In all cases, the survey was mailed to the parent or guardian of the identified patient with a cover letter seeking permission for the adolescent patient to participate. This process was developed in response to concerns raised by health plan leaders that sending a survey directly to adolescents (minors) would not be allowed by many plans and hospitals. Parents were asked to provide the questionnaire to the adolescent to complete based on his or her own experience. Each field test used the same mailing protocol. A survey packet containing a cover letter, questionnaire, and postage-paid return envelope was sent to the parent/guardian. After approximately 30 days, a second survey packet was sent to non-respondents. Respondents received an incentive of a gift card worth \$10 for completing the survey.

For the hospital-based clinical program field test, we mailed surveys to 623 Boston Children's Hospital (BCH) outpatients with a wide variety of chronic illnesses receiving care in 10 different clinical programs. This test provided insight into how the survey might be used by hospitals or clinical programs within a subspecialty or other defined population. In all, 293 surveys were returned (response rate 47 percent).

For the health plan field tests, two health plans, AmeriHealth Caritas Pennsylvania (AHCP)—a Medicaid managed care health plan serving individuals across two regions in Pennsylvania—and

Texas Children’s Health Plan (TCHP) —a pediatric-focused Medicaid health plan serving individuals in Texas—each distributed 3,000 mailed surveys to their members. Both entities used the protocol detailed in the Detailed Measure Specifications (see Supporting Documents). Survey recipients were identified by analysis of health plan claims using the Pediatric Medical Complexity Algorithm (PMCA) (Simon, Cawthon, Stanford, et al., 2014). This publicly available algorithm uses International Classification of Diseases, Ninth Revision, Clinical Modification diagnosis codes in health plan claims to identify youth with either complex chronic disease (C-CD) or noncomplex chronic disease (NC-CD). We received 1,339 surveys (780 from AHCP and 559 from TCHP; response rates were 27.5 percent and 20.7 percent, respectively).

Respondent characteristics for the three field test samples are presented in Tables 1a-c (see Supporting Documents). Female respondents outnumbered males in all three samples. Approximately 40-45 percent of respondents in each sample were 16 years old, with the remaining respondents 17 years old. The samples were diverse in race/ethnicity. Among the BCH respondents, 29 percent were insured by Medicaid, as were all respondents in the two health plan samples. Of note, all of the samples included individuals with a broad range of self-reported health status; 40 percent or more of each sample reported their overall health as only good, fair, or poor.

Respondents and non-respondents were generally similar in all three samples. Compared to non-respondents, there was a higher proportion of 17 year-old adolescents in the AHCP respondent sample only ( $p < .05$ ). There were lower proportions of black patients in the respondent samples compared to non-respondents in the BCH sample (5 percent vs. 12 percent) and AHCP (24 percent vs. 35 percent) (both  $p < .01$ ), but the proportion of Hispanic adolescents among respondents and non-respondents was similar for all three sites.

The ADAPT survey incorporates quality measures in three domains of HCT preparation: (1) Counseling on Transition Self-Management; (2) Counseling on Prescription Medication; and (3) Transfer Planning. The scoring algorithm for these domains is described in the Detailed Measure Specifications (see Supporting Documents). These domains were designed to capture key areas of transition preparation identified by expert interviews, focus groups, and cognitive interviews (see Section 10, Understandability).

### **Internal Consistency Reliability**

Internal consistency reliability is a measure of the degree of consistency of responses to different questions intended to measure the same construct. Of the available statistical indicators for internal consistency, the ordinal reliability coefficient (ordinal alpha), which uses a polychoric correlation matrix, is appropriate for items with dichotomous responses; such responses predominate in the ADAPT survey. For questions with few response categories, the ordinal indicator more accurately estimates reliability compared to the more commonly used Cronbach’s alpha (Gadermann, Guhn, Zumbo, 2012).

In order to summarize processes associated with the quality of transition preparation, composite measures were developed that incorporate multiple individual survey items. Each composite assesses the extent to which the components of preparation for a specific aspect of health care transition occurred, as reported by the adolescent. The three composite measures included in the ADAPT survey are: (1) Counseling on Transition Self-Management; (2) Counseling on

Prescription Medication; and (3) Transfer Planning. Each composite was designed to measure a single underlying construct of transition preparation. The ordinal alpha provides reliability results for all composites. In general, internal consistency reliability of .7 or greater is desirable. The ordinal alpha is provided for each of the composite measures in each of the three field test sites (Table 2; see Supporting Documents). All composite measures in all sites had an internal consistency of .7-.8, with the exception of a single composite measure in one site.

### **Comparison of Responses Across Field Test Sites**

Another measure of reliability is the extent to which measure results are reproducible across different care settings that would be expected to have relatively similar care quality. Although the test sites in our field testing varied widely in their geographic location and demographic characteristics, composite scores and responses to individual items were similar across the three field tests. Table 3 (see Supporting Documents) presents composite scores for each of the three domains by site, and Table 4 (see Supporting Documents) presents descriptive data on selected individual item responses by site.

## **6.B. Validity**

**Validity of the measure is the extent to which the measure meaningfully represents the concept being evaluated. The method for establishing the validity of a measure will depend on the type of measure, data source, and other factors.**

**Explain your rationale for selecting the methods you have chosen, show how you used the methods chosen, and provide information on the results (e.g., R2 for concurrent validity).**

A “gold standard” does not exist for determining the criterion validity of patient-reported measures of quality. However, to ensure the validity of the ADAPT survey results, we followed rigorous procedures representing best practices within the field to develop the survey. To ensure the content validity of measures of the transition experience from patients’ perspectives, we used qualitative methods, including both focus groups and cognitive interviews, to inform development of the survey items. We used quantitative methods, including confirmatory factor analysis, internal consistency reliability, item-to-composite correlations, and composite-to-composite correlations to evaluate both the reliability and the validity of the final survey. Furthermore, in order for patient-reported measures to provide valid comparisons across health care settings, it is important to use standardized data collection methods and scoring (Goldstein; Farquhar, Crofton, et al., 2005); we provide detailed instructions for these processes in the Detailed Measure Specifications (see Supporting Documents).

### **Focus Groups**

We conducted focus groups early in the survey development process to ensure that the instrument covered topics of greatest importance to adolescent patients and their parents or guardians. Focus groups were conducted in Boston, Chicago, and Los Angeles, in both English and Spanish. A summary of the focus group analysis and findings is provided in Section 10, Understandability.

## **Cognitive Interviews**

Survey development experts suggest cognitive interviews to elicit feedback on draft versions of a survey as a means of determining whether respondents understand questions in the way the developers intended (Levine, Fowler, Brown, 2005). Cognitive interviews use a standardized protocol that provides scripted probes to gain insight into respondents' cognitive processes as they answer survey items, elicit feedback about confusing or otherwise problematic wording, and assess the comprehensiveness of the survey. Developers can thereby identify items for revision that might otherwise significantly compromise the validity and reliability of the survey. See Section 10, Understandability, for a summary of the cognitive interviews conducted during ADAPT survey development.

## **Factor Analysis**

### **Methods**

Because the domains of the ADAPT survey and their associated questions were pre-defined, the validation of the domains is most appropriately performed through confirmatory factor analysis (CFA). In addition, since the questions (items) in these domains (factors) were designed with dichotomous responses, polychoric correlation coefficients are most appropriate for assessing the pair-wise correlations among the domain variables (Brown, 2006; Muthén, Muthén, 2012). CFA was performed only for the first two ADAPT domains because the sample sizes for the Transfer Planning domain were insufficient to conduct CFA reliably.

### **Interpretation of Confirmatory Factor Analysis (CFA) Findings**

The goal of the CFA was to test the construct validity of the survey using a two-factor structure for (1) Counseling on Transition Self-management (five questions – two levels) and (2) Counseling on Prescription Medication (three questions – two levels). Results from these analyses supported the hypothesis that the individual items within each of the two domains are associated with one another and that there is some association between the two domains. Both of these findings are desirable. The plots summarizing the two-factor structure are included in Figure 1 (see Supporting Documents) for each field test site. The standardized solutions for the two-factor models measuring independence of each domain are included in Table 5 (see Supporting Documents). CFA results were similar across the three sites, providing further confirmation of the findings. Mplus (Statistical Analysis with Latent Variables) software was used to conduct the CFA for each domain.

### **Interpretation of Item-to-Composite and Composite-to-Composite Correlations**

For BCH, the p-values of the loading factor estimates (standard errors) within each domain as shown in Figure 1 and Table 5 (see Supporting Documents) are <.001 (with one exception, Question 10). All questions with a significant p-value can be interpreted to be independently associated with their domain. The p-value of the chi-square test of fit is .013, indicating that the observed covariance matrix is statistically significantly different from the expected matrix. However, such a result is common with large samples, and the adequacy of the fit of the two-factor model is reflected by the root mean squared error of approximation (RMSEA = .064, 90 percent CI = .028, .098) and the descriptive fit indices (Comparative Fit Index (CFI) = .892,

Tucker Lewis Index (TLI) = .826). The association between the two domains is also significant ( $p < .001$ ).

Similarly, for AmeriHealth Caritas Pennsylvania and Texas Children's Health Plan, the fact that the p-values of the estimates within the domain are  $\leq .001$  indicates that each question is independently associated with its domain. The adequate fit of the two-factor model for AmeriHealth Caritas Pennsylvania is indicated by the RMSEA (.081, 90 percent CI = .061, .103) and the descriptive fit indices (CFI = .792, TLI = .664), even though the chi-square test of fit p-value is  $< .001$ . The fit for the Texas Children's Health Plan model is adequate as shown by the RMSEA (.026, 90 percent CI = 0, .062) and the descriptive fit indices (CFI = .974, TLI = .958); the chi-square test of fit p-value is .244. Finally, the association between the two domains is also significant for both AmeriHealth Caritas Pennsylvania and Texas Children's Health Plan models ( $p < .001$  for each model).

Together, these analyses confirm that questions grouped together on conceptual grounds are also empirically related.

In addition, construct validity can be viewed in terms of convergent or discriminant validity. In other words, some survey items would theoretically be expected to be related to others, while others would theoretically not be expected to be related to others. Prior literature on HCT preparation suggests that scores should increase with age as youth are closer to the age of potential transfer. In contrast, there would be no reason to expect differences in scores based on gender. Tables 6-7 (see Supporting Documents) show the extent of variation in ADAPT composite scores based on these two patient characteristics. In two of the three field test sites, respondents 17-18 years old had higher scores on average in the Transfer Planning domain only. However, as expected, there was no difference based on gender. These findings support the validity of the ADAPT survey as a measure of provision of HCT preparation.

## Section 7. Identification of Disparities

**CHIPRA requires that quality measures be able to identify disparities by race, ethnicity, socioeconomic status, and special health care needs. Thus, we strongly encourage nominators to have tested measures in diverse populations. Such testing provides evidence for assessing measure's performance for disparities identification. In the sections below, describe the results of efforts to demonstrate the capacity of this measure to produce results that can be stratified by the characteristics noted and retain the scientific soundness (reliability and validity) within and across the relevant subgroups.**

### 7.A. Race/Ethnicity

To assess racial/ethnic disparities in provision of HCT preparation, we conducted field tests in diverse populations and assessed differences in ADAPT domain scores by race/ethnicity. Adolescent race/ethnicity is determined on the ADAPT survey using two items based on those used by the Office of Minority Health: "Are you of Hispanic, Latino, or Spanish origin?" and "How would you describe your race?"



Among the respondents in the Boston Children's Hospital field test, 2.4 percent were Asian/Pacific Islander, 4.8 percent were black, and 6.5 percent were Hispanic. Among respondents in the AmeriHealth Caritas Pennsylvania field test, 4.6 percent were Asian/Pacific Islander, 24.0 percent were black, and 16.0 percent were Hispanic. For respondents in the Texas Children's Health Plan field test, 5.7 percent were Asian/Pacific Islander, 18.0 percent were black, and 59.0 percent were Hispanic. For the analyses of differences in ADAPT scores by race/ethnicity, we therefore categorized responses into the following groups: Asian/Pacific Islander, black, Hispanic, white, and other.

ADAPT scores by race/ethnicity are shown in Table 8 (see Supporting Documents). In general, scores for the Transition Self-Management domain, stratified by race, were higher in AHCP than TCHP, though this difference was only statistically significant for black patients. In the other two domains, no differences between health plans were observed. Within the AHCP, we observed higher Transition Self-Management Scores for black patients compared to white patients, but no significant within health plan differences by race/ethnicity were observed in TCHP. No differences were detected between white and Hispanic patients in either health plan. There were too few patients of Asian/Pacific Islander race/ethnicity in either health plan for comparison with white patients. It should be noted that this field test was not designed to provide statistical power to detect differences between racial or ethnic groups. If such comparisons are desired, we recommend a sample size of 300 respondents per group being compared. This would likely require oversampling of patients of less common race/ethnicity in a health plan. Given the range of scores in each of the three domains, a sample size of 300 respondents per group would provide 80 percent power to detect approximately a 10 percent difference in both the Counseling on Transition Self-Management domain and the Counseling on Prescription Medication domain, and a 5 percent difference in the Transfer Planning domain.

## **7.B. Special Health Care Needs**

The ADAPT survey is designed for adolescents with special health care needs, as defined by the presence of at least one chronic condition. However, experiences with HCT preparation may vary depending on the type of chronic condition. Therefore, we assessed differences in ADAPT scores based on patients' type of chronic health condition as identified in one of two ways. For the Boston Children's Hospital (BCH) field test, we assigned patients' type of condition according to the subspecialty of the clinical program (e.g., endocrinology, pulmonary) in which they received care. For the two Medicaid plan field tests, we determined the type of condition by applying the Pediatric Medical Complexity Algorithm (PMCA) to claims data from the health plans. As described in detail below (Tables 9-12, see Supporting Documents), overall ADAPT domain scores did not differ significantly by clinical program, chronic condition type, or presence of mental health conditions. However, as with the race/ethnicity analyses, statistical power was insufficient to detect differences in composite scores by these variables.

For BCH respondents, we evaluated the four clinical programs with at least 25 respondents: endocrinology, gastroenterology, immunology, and pulmonary (Table 9, see Supporting Documents). We found no significant differences in ADAPT scores across these programs, although the scores in the Transfer Planning domain spanned a wider range across programs.

For the two Medicaid plan field tests, we identified patients' type of chronic condition using the PMCA, which categorizes chronic conditions by body system. We evaluated variation in ADAPT domain scores associated with special health care needs in several ways. First, we compared scores among respondents with non-complex chronic diseases (NC-CD) with those with complex chronic diseases (C-CD) and found no significant differences in any of the domain scores (Table 10, see Supporting Documents). Within the NC-CD group, we compared scores based on body system affected by the chronic condition for those systems with at least 25 respondents: cardiac, endocrinologic, musculoskeletal, neurologic, and pulmonary-respiratory. We found no significant differences by body system (Table 11, see Supporting Documents). Finally, to evaluate whether mental health co-morbidities are associated with disparities in provision of HCT preparation, we compared ADAPT scores within the C-CD group for adolescents with and without mental health conditions (Table 12, see Supporting Documents). There were no significant differences in ADAPT scores based on the presence of a mental health co-morbidity.

### **7.C. Socioeconomic Status**

The ADAPT survey does not include any assessment of respondent socioeconomic status (SES). Additionally, the AmeriHealth Caritas Pennsylvania and Texas Children's Health Plan field tests were conducted in exclusively Medicaid-insured patients. Therefore, we were not able to conduct any analyses comparing scores based on SES. If a health plan or practice has access to SES data for respondents, they may consider analyzing scores by these variables.

### **7.D. Rurality/Urbanicity**

We considered assessing disparities in provision of HCT preparation for respondents in the two Medicaid plan field tests based on the rurality/urbanicity of their county of residence, but we ultimately did not perform this analysis because we found that the vast majority of respondents were from urban counties. We classified rurality/urbanicity using the Rural-Urban Continuum Codes (RUCC) developed by the Economic Research Service of the U.S. Department of Agriculture. The RUCC system uses Bureau of Census Urbanized Area and Urban Cluster definitions together with information on work commuting patterns to characterize Census tracts. Using data obtained from health plan administrative records, we applied the RUCC to classify respondents' county of residence as either urban or rural. For both the AmeriHealth Caritas Pennsylvania and Texas Children's Health Plan surveys, the respondent samples were overwhelmingly urban (>97 percent). As a result, we did not proceed with analyzing differences in ADAPT scores based on rurality/urbanicity.

### **7.E. Limited English Proficiency (LEP) Populations**

We created the ADAPT survey concurrently in English and Spanish, conducting three focus groups in Spanish as part of the initial survey development, and included both the English and Spanish versions in the Medicaid plan field tests. For the AmeriHealth Caritas Pennsylvania field test, the Spanish survey was sent to individuals upon request. For the field test for Texas Children's Health Plan, which serves a region with relatively higher rates of Spanish-speaking households, we mailed the survey in both English and Spanish to all recipients to make it easier

to complete the survey in Spanish. Even under these conditions, only a small number of Spanish surveys were returned. Only 18 Spanish surveys were returned by AmeriHealth Caritas Pennsylvania respondents, and only 11 Spanish surveys were returned by Texas Children's Health Plan respondents. Because of the small numbers of Spanish surveys, we were unable to analyze differences in ADAPT scores based on survey language.

## **Section 8. Feasibility**

**Feasibility is the extent to which the data required for the measure are readily available, retrievable without undue burden, and can be implemented for performance measurement. Using the following sections, explain the methods used to determine the feasibility of implementing the measure.**

### **8.A. Data Availability**

#### **1. What is the availability of data in existing data systems? How readily are the data available?**

Assessment of the quality of HCT preparation is based on adolescent-reported responses collected in the ADAPT survey, rather than on existing data. However, the instrument is designed to use a variety of existing data sources to identify patients who meet eligibility criteria for participation; this flexibility makes generation of a sample frame highly feasible. Potential data sources include patient registries held by clinical programs or delivery systems, electronic health records (EHRs), or providers' patient panels. Alternatively, administrative data can be used to identify participants by application of the Pediatric Medical Complexity Algorithm (PMCA) (described in detail in the Detailed Measure Specifications, see Supporting Documents) for identification of youth with chronic conditions (Simon, et al., 2014). Administrative data for this purpose offer the advantages of high levels of completeness and widespread availability.

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

Increasing proportions of practices and hospitals are adopting EHRs, which are becoming more sophisticated in supporting quality measurement. Health systems that care for adolescents with chronic disease could use data from EHRs to identify adolescents with chronic conditions who would be eligible for participation in the ADAPT survey. In addition, health systems could incorporate data from the ADAPT survey into EHRs to monitor patient experiences with transition preparation.

Health care delivery systems are increasingly using patient registries and provider-level patient panels for quality improvement efforts. As quality measures such as the ADAPT survey become available, they could be applied to such registries or panels or be implemented in conjunction with other self-reported quality measures for an identified patient population.

In addition, CMS maintains databases for quality reporting for adult patient experience measures. It would be possible for the ADAPT survey data to be captured in a similar national database, which would allow national comparisons on HCT preparation.

## **8.B. Lessons from Use of the Measure**

### **1. Describe the extent to which the measure has been used or is in use, including the types of settings in which it has been used, and purposes for which it has been used.**

During national field testing, the ADAPT survey was used by one freestanding pediatric hospital (in Massachusetts) and two Medicaid plans (in Pennsylvania and Texas). For the hospital field test, a survey vendor mailed the survey to 626 parents/caregivers of adolescents identified as receiving care in one of 10 subspecialty pediatric clinics. A total of 291 surveys were returned (response rate 47.4 percent). In Pennsylvania, a survey vendor mailed the survey to 3,000 parents/caregivers of adolescents identified as having chronic conditions using the PMCA. In Texas, a similar process was used except that the survey was mailed directly by the Texas Children's Medicaid Health Plan to 3,000 families. The survey was fielded in both English and Spanish. A total of 1,355 surveys were completed as part of the health plan field tests, with a response rate of 27.5 percent in Pennsylvania and 20.7 percent in Texas.

### **2. If the measure has been used or is in use, what methods, if any, have already been used to collect data for this measure?**

The data collection methods described in the Detailed Measure Specifications (see Supporting Documents) were used during the ADAPT survey field test.

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

The ADAPT survey national field test demonstrated the feasibility of participant identification and fielding of the instrument in both hospital programs and Medicaid health plans. Both of the health plans approached were extremely interested in having a quality measure for adolescent transition preparation. The response rates demonstrate that, even with the added complication of mailing the adolescent instrument to parents first, a reasonable response rate can be achieved with the level of incentive used in these tests. These response rates are comparable to other adolescent survey studies (Richards, Wiese, Katon, et al., 2010) using the data collection methods described in the Detailed Measure Specifications (see Supporting Documents).

## **Section 9. Levels of Aggregation**

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

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

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

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

***State level\* Can compare States***

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

Yes.

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

No.

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

We recommend a sample consisting of at least 300 completed surveys per State Medicaid program. Comparisons of unadjusted scores among State Medicaid programs may not account for potential differences in the samples in clinical or demographic characteristics. To fully standardize scores for these potential differences in case mix would require analysis of data from a large number of States or health plans. A national database would be ideal for this purpose and would allow for development of case-mix adjustment models for the ADAPT survey domains.

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

No.

***Reliability & Validity: Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?***

No.

***Unintended consequences: What are the potential unintended consequences of reporting at this level of aggregation?***

None known.

***Other geographic level: Can compare other geographic regions (e.g., MSA, HRR)***

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

No.

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

No.

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

It would be possible to use this measure at some other level of geographic variation if Medicaid health plan samples could be aggregated to represent the geographic region.

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

No.

**Reliability & Validity:** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

**Unintended consequences:** What are the potential unintended consequences of reporting at this level of aggregation?

No.

**Medicaid or CHIP Payment model:** Can compare payment models (e.g., managed care, primary care case management, FFS, and other models)

**Intended use:** Is measure intended to support meaningful comparisons at this level?

(Yes/No)

Yes.

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

No.

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

We recommend a sample consisting of at least 300 completed surveys per payment model. Comparisons of unadjusted scores among Medicaid programs may not account for potential differences in the samples in clinical or demographic characteristics. To fully standardize scores for potential differences in case mix would require analysis of data from a large number of payment models.

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

No.

**Reliability & Validity:** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

**Unintended consequences:** What are the potential unintended consequences of reporting at this level of aggregation?

None known.

***Health plan\*:*** *Can compare quality of care among health plans.*

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

Yes.

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

No.

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

We recommend a sample consisting of at least 300 completed surveys per health plan. Comparisons of unadjusted scores among health plans may not account for potential differences in the samples in clinical or demographic characteristics. To fully standardize scores for these potential differences in case mix would require analysis of data from a large number of health plans.

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

No.

***Reliability & Validity:*** **Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**

No.

***Unintended consequences:*** **What are the potential unintended consequences of reporting at this level of aggregation?**

None known.

### ***Provider Level***

***Individual practitioner:*** *Can compare individual health care professionals*

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

No.

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

No.

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

Not applicable.

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

No.

**Reliability & Validity:** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

**Unintended consequences:** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

**Provider Level**

**Hospital:** *Can compare hospitals*

**Intended use:** Is measure intended to support meaningful comparisons at this level?

(Yes/No)

No.

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

No.

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

Not applicable.

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

No.

**Reliability & Validity:** Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?

No.

**Unintended consequences:** What are the potential unintended consequences of reporting at this level of aggregation?

Not applicable.

**Provider Level**

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

**Intended use:** Is measure intended to support meaningful comparisons at this level?

(Yes/No)

Yes.

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

No.

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



For comparisons of performance among large delivery systems (e.g., large multispecialty practices or hospitals with a number of outpatient programs), we recommend a sample consisting of at least 300 surveys. When the survey is administered for an individual clinical program, the sample size may vary with the available patient pool and the intended use. While further study is needed to determine the recommended sample size required for comparisons across clinical programs, an individual program may use this measure over time to guide and assess improvement efforts.

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

No.

***Reliability & Validity:* Is there published evidence about the reliability and validity of the measure when reported at this level of aggregation?**

No.

***Unintended consequences:* What are the potential unintended consequences of reporting at this level of aggregation?**

None known.

## **Section 10. Understandability**

**CHIPRA states that the core set should allow purchasers, families, and health care providers to understand the quality of care for children. Please describe the usefulness of this measure toward achieving this goal. Describe efforts to assess the understandability of this measure (e.g., focus group testing with stakeholders).**

### **Incorporation of Relevant Survey Domains**

Assessing patient perspectives about transition preparation and transfer process experiences is integral to the development of a valid, self-reported survey of the quality of transition preparation. To understand the health care transition experiences of greatest salience to patients and families, we conducted a series of focus groups. Our objective was to identify the critical elements in the preparation for transition to independent self-care and the transfer to adult medical care for patients with a variety of chronic illnesses.

Focus groups were conducted with adolescent (age 16-18 years) and young adult (age 19-26 years) patients with one or more chronic health conditions, as well as parents/guardians of youth or young adults with chronic health conditions. Although the ADAPT survey is designed to be completed by youth aged 16-17 years as they prepare for transition, we conducted focus groups with young adults who had already transitioned to better understand the actual process of transfer to adult care and to ensure the relevance of the measure to all stages of the transition experience. In addition, to understand the role and perspective of caregivers in the transition process, we conducted focus groups with parents/guardians of both adolescents and young adults with chronic health conditions.

In total, we conducted 11 focus groups in Boston, Chicago, and Los Angeles (Table 10.1): three with adolescents, four with young adults, and four with parents/guardians. One of the young

adult groups and two of the parent/guardian groups consisted of participants whose primary language was Spanish, so those focus groups were conducted in Spanish. The focus groups included a diverse spectrum of patients with regard to gender, race, ethnicity, and type of chronic health condition.

**Table 10.1. Focus groups conducted for ADAPT survey development**

Group Description	Primary Language and Location	
	English	Spanish
Patients aged 16-18 years	1 Boston; 1 Chicago; 1 Los Angeles	None
Patients aged 19-26 years	2 Boston; 1 Chicago	1 Los Angeles
Parents or guardians	1 Chicago; 1 Los Angeles	1 Chicago; 1 Los Angeles

During each focus group, a trained moderator facilitated discussion on the following domains: changing disease self-management responsibilities, readiness for transition, transition preparation, and health insurance during transition. In groups of post-transition young adults or parents/guardians of post-transition young adults, the moderator also asked about experiences of the transfer to adult health care.

Key findings that informed survey development included:

- Adolescents reported that they had thought little about transition to adult-focused care prior to focus group participation and infrequently discussed these issues with others.
- Very few adolescents perceived purposeful transition preparation on the part of pediatric health care providers.
- Adolescents frequently expressed ambivalence about taking charge of their own health, as well as frustration that their health care providers did not consistently involve them in discussions about their health.
- Post-transition young adults reported a near-complete lack of pediatric counseling regarding independent self-care or transfer to adult care.
- Young adults described feeling responsible for locating new adult providers with little support or guidance from pediatric health care providers.
- Both adolescents and young adults reported poor understanding regarding how health insurance works.
- Parents/guardians of adolescents and young adults were unsure of their roles relative to health care provider roles in counseling their children about disease self-care.
- Parents/guardians expressed great concern about gaps in care or inconsistent care during transition and the potential for related declines in their children’s health.

### **Evaluation of Survey Understandability**

We synthesized focus group findings with data from our extensive literature review and expert interviews to develop a draft survey. We then conducted cognitive interviews to assess whether the intended respondents, 16- to 17-year-old adolescents with chronic health conditions, understood each of the draft survey items as intended. Before the cognitive interviews, participants were asked to respond to the survey. The interview protocol contained candidate

questions from the draft survey followed by pre-specified cognitive probes to evaluate the understandability of specific words and phrases and to clarify participant thought processes in answering the questions. Participants were also given the opportunity to suggest alternative language for specific items.

We performed four rounds of 26 total cognitive interviews of youth respondents in English and Spanish in Boston, Chicago, and Dallas. The goals of sequential rounds of interviews were to test versions of questions about transition and to make minor revisions to items that were not uniformly understood. After four rounds, the results generally demonstrated that adolescents responded to most of the survey items in the intended way. The English and Spanish versions of the survey elicited similar responses. Responses to many of the survey questions showed variation as expected based on the range of experiences of the participants.

The analysis of the cognitive interview data resulted in simplification and/or clarification of some survey items, refinement of skip patterns, and deletion of items that were not clear to respondents and deemed to be less essential to assessing transition preparation than originally hypothesized. The survey development team met weekly to analyze findings and make iterative revisions to the survey after each round of cognitive interviews.

After the four rounds of cognitive interviews were complete, the ADAPT survey was field tested in three populations, as described in Section 4, Scientific Soundness of the Measure. Findings from these tests (presented in Sections 4, Scientific Soundness of the Measure, and Section 7, Identification of Disparities) generally confirmed the understandability of the intended meaning of items, item construction, survey administration process, and skip patterns. However, analysis of field test results led to additional small revisions in survey wording. These minor changes were then tested in an additional round of cognitive interviews in Boston with six 16- to 17-year-old adolescents with chronic health conditions. These interviews confirmed the understandability of each of the items in the final ADAPT survey, and no additional changes were made.

## **Section 11. Health Information Technology**

**Please respond to the following questions in terms of any health information technology (health IT) that has been or could be incorporated into the measure calculation.**

### **11.A. Health IT Enhancement**

**Please describe how health IT may enhance the use of this measure.**

The candidate measure relies on survey responses from adolescents with a chronic health condition and, as such, does not require electronic health record (EHR) data. Administrative claims data from health plans can be used to identify the sampling frame for the ADAPT survey using the Pediatric Medical Complexity Algorithm (PMCA) as described in the detailed measure specifications (see Supporting Documents). In the future, as EHRs are adopted by more health systems and include more capabilities for quality measurement, the measure could be modified to incorporate additional EHR data. Clinical data systems could also be designed to directly capture adolescent-reported data at the time of clinical encounters.

## **11.B. Health IT Testing**

**Has the measure been tested as part of an electronic health record (EHR) or other health IT system?**

No.

**If so, in what health IT system was it tested and what were the results of testing?**

Not applicable.

## **11.C. Health IT Workflow**

**Please describe how the information needed to calculate the measure may be captured as part of routine clinical or administrative workflow.**

Not applicable.

## **11.D. Health IT Standards**

**Are the data elements in this measure supported explicitly by the Office of the National Coordinator for Health IT Standards and Certification criteria (see [healthit.hhs.gov/portal/server.pt/community/healthit\\_hhs\\_gov\\_\\_standards\\_ifr/1195](http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__standards_ifr/1195))?**

No.

**If yes, please describe.**

Not applicable.

## **11.E. Health IT Calculation**

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

As with any self-report mailed survey, there may be missing or ambiguous responses to the ADAPT survey. Guidance on how to address missing or ambiguous answers in the scoring of the survey and its composite domains can be found in the detailed measure specifications (see Supporting Documents).

## **11.F. Health IT Other Functions**

**If the measure is implemented in an EHR or other health IT system, how might implementation of other health IT functions (e.g., computerized decision support systems in an EHR) enhance performance characteristics on the measure?**

Not applicable.

## Section 12. Limitations of the Measure

**Describe any limitations of the measure related to the attributes included in this CPCF (i.e., availability of measure specifications, importance of the measure, evidence for the focus of the measure, scientific soundness of the measure, identification of disparities, feasibility, levels of aggregation, understandability, health information technology).**

The ADAPT survey has several limitations; many of these are true of patient surveys in general.

1. The ADAPT survey cannot evaluate all important facets of HCT preparation. For example, patients cannot reliably assess whether a practice-level transition policy exists, as has been recommended. As with any patient-reported measure, patients may not recall a specific discussion or may recall erroneously one that did not occur. However, adolescents are the best information source regarding other aspects of HCT preparation that are not recorded in standard ways by providers or included in claims.
2. A parent's/guardian's assessment of his or her child's care is commonly accepted for a variety of methodological and logistical reasons (Campo, Comer, Jansen-McWilliams, et al., 2002; Hays, Valentine, Haynes, et al., 2006; Janicke, Finney, Riley, 2001; Varni, Limbers, Burwinkle, 2007). Parents/guardians may be able to provide better information than adolescents about some aspects of HCT preparation. However, the ultimate metric of the adequacy of HCT preparation is whether it meets the needs of the adolescent, so the ADAPT survey was developed for adolescent respondents.
3. Adolescent health surveys are often administered in school-based settings (CDC, 2013; CDC, 2014; Saewyc, Bauer, Skay, et al., 2004). Instead, the ADAPT survey is mailed to parents/guardians, who are instructed that the survey is to be completed by the adolescent. Health care organizations have reported response rates of 20 percent on mailed surveys to adolescents, with better response rates when there is telephone follow-up of the initial mailings (Richards, et al., 2010). Similar response rates were achieved in the ADAPT health plan field tests with an incentive of \$10 for completing the survey. We have no information on response rates without such incentives. Postcard reminders following the initial survey mailing or follow-up phone calls can also be used to improve survey response rates. A mail-based approach for a survey of adolescents and young adult cancer survivors yielded a response rate of 43 percent (Harlan, Lynch, Keegan, et al., 2011). Published findings together with our field test results thus suggest that adolescents are accessible via mailed surveys with response rates that allow for comparisons across practice settings.
4. The ADAPT survey is written at a 5th grade reading level and therefore may not be appropriate to assess HCT preparation for adolescents who have cognitive or developmental delay. Transition preparation in this population has been evaluated via parent-reported surveys such as the NS-CSHCN (Lotstein, et al., 2005, 2009; Strickland, et al., 2004). In the future, the ADAPT survey could be modified to include responses from proxy respondents to gather information about this patient population.
5. The ADAPT survey sample includes youth with a variety of chronic health conditions. The survey cannot be used to evaluate experiences unique to small subgroups of patients with specific clinical conditions. Although specific subgroups can be oversampled to supplement the primary sample, the survey is designed to assess aspects of care that are common to many

patients. Because we mailed the surveys first to parents, privacy concerns precluded inclusion of adolescents with only mental health conditions, even though conditions such as depression, anxiety, and ADHD are common in adolescents (Merikangas, He, Burstin, et al., 2010).

6. The ADAPT survey focuses specifically on transition preparation and is not designed to address later aspects of HCT. It does not provide an assessment of processes related to transfer of care to an adult-focused health system including transfer of medical information, nor does it assess care processes for youth who have already transferred care to an adult-focused provider. Identification of youth who are nearing transfer or those who have recently transferred is not yet feasible using administrative claims data. In fact, many youth lose or change health coverage at the time of transfer and thus would be difficult to track given current data systems.

## Section 13. Summary Statement

**Provide a summary rationale for why the measure should be selected for use, taking into account a balance among desirable attributes and limitations of the measure. Highlight specific advantages that this measure has over alternative measures on the same topic that were considered by the measure developer or specific advantages that this measure has over existing measures. If there is any information about this measure that is important for the review process but has not been addressed above, include it here.**

Poor quality health care transition (HCT) from pediatric-focused to adult-focused care delivery may contribute to fragmentation of clinical care, increased utilization of emergency services, and increased risk for adverse health outcomes. Those at highest risk during this period include youth with special health care needs (YSHCN). Expert consensus guidelines underscore the importance of high-quality transition preparation, including facilitation of self-management and purposeful transfer planning. Because effective transition preparation consists of specific interactions with health care providers, obtaining reports from youth directly about their experience will help identify current gaps in HCT. To date, no existing surveys have directly assessed transition preparation from the perspective of adolescent patients.

The Adolescent Assessment of Preparation for Transition (ADAPT) survey is a validated, patient-reported instrument designed to measure transition preparation in youth with chronic health conditions. The ADAPT survey fills a critical gap in quality measurement by assessing adolescent experiences of transition preparation in three key areas: self-management, prescription medications, and planning for transfer of care.

Development of the ADAPT survey included extensive review of the HCT literature; expert interviews; parent, adolescent, and young adult focus groups in three large U.S. cities; and cognitive interviews in three cities. This development process, including end-user testing, provides confidence that the ADAPT survey is understandable by a range of respondents. A national field test showed that the ADAPT measure is feasible to field in clinical subspecialty programs, as well as in health plans; the health plans can select samples of eligible patients using administrative claims. If the ADAPT were to become widely used as a quality measure, it would

be possible to compare the quality of transition preparation among clinical programs or health plans.

While survey-based quality measures are generally more expensive to implement than those calculated from automated data, high quality HCT preparation primarily involves facilitating self-management skills. The quality of this facilitation can only be assessed by direct report. The ADAPT survey was extensively tested to ensure that the topics included are those on which patients can reliably and validly report and for which adolescent patients are generally the best source of information. The instrument is designed to be brief and understandable in order to promote the best response rate possible from diverse patient samples. The use of a standard, publicly available algorithm for sample selection should allow development of similar sampling frames for data comparisons.

The ADAPT survey cannot evaluate all components of high-quality transition preparation recommended by current expert consensus. For example, this measure is unable to evaluate experiences or outcomes of the actual transfer to adult health care. However, improving transition preparation for youth with chronic conditions is a critical first priority. The low scores in all ADAPT survey domains seen in our field test suggest substantial gaps in the quality of transition preparation. The ADAPT measure should stimulate interventions in clinical practice designed to improve the quality of transition preparation, and it can be used to measure their success. Approaches to improving HCT preparation for YSHCN, informed by the ADAPT survey, may also be expanded to improve the transition process for all adolescents as they transition to adult-focused care delivery.

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## **Section 14: Identifying Information for the Measure Submitter**

**First Name:** Mark  
**Last Name:** Schuster  
**Title:** William Berenberg Professor of Pediatrics, Harvard Medical School  
Chief of General Pediatrics and Vice-Chair for Health Policy,  
Department of Medicine, Boston Children's Hospital  
**Organization:** Center of Excellence for Pediatric Quality Measurement  
**Mailing Address:** Boston Children's Hospital, 300 Longwood Avenue  
**City:** Boston  
**State:** MA  
**Postal Code:** 02115  
**Telephone:** 617-355-5859  
**Email:** cepqm@childrens.harvard.edu

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

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

### **Public Disclosure Requirements**

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

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