CHILDREN'S HOSPITAL ASSOCIATION

Champions for Children's Health

Demonstrating Value in Pediatrics

A Measure Menu, Workbook and Guidance for Value-based Care, Payment and Reporting Programs

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Produced in collaboration with

DISCERN HEALTH

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Table of Contents

Introductory Letter

Dear Colleagues,

Value-based care contracts, payment models and reporting programs are becoming more common in pediatrics. As children's hospitals participate in value-based programs, the question of measuring value presents challenges because there are few pediatric acute inpatient and ambulatory specialty care measures in existing national and regional measure sets. In the absence of recognized measure sets, children's hospitals are left to select measures without the benefit of industry experience, or have measures selected for them.

To support children's hospitals' participation in value-based programs, we worked with an expert group of clinicians, administrators, public and private payers, and patient families to compile Demonstrating Value in Pediatrics Measure Menu, a menu of ready-to-use measures appropriate to demonstrating value in children's health care along with guidance on effective selection of measures from the menu. The menu complements existing measure sets and includes the best currently available measures. The measures included in the menu were identified using a criteria-based, systematic consensus process to aid experts and stakeholders in their review.

Value and quality measurement in child health and children's health care are a work in progress, and experience with existing measures is uneven. In the absence of ideal measure sets, the Demonstrating Value in Pediatrics Measure Menu is an important and cogent resource to be used in measure selection for value-based programs. However, it is not intended as a dashboard addressing all aspects of child health quality, nor to represent an ideal set of measures.

This measure menu and guidance and companion workbook are tools you can use to select measures for value-based programs and to evaluate alignment between a program's objectives and selected measures. We welcome your comments and feedback on these tools, your experience in using the measures, and how resources like these support measurement initiatives that are meaningful to patients and families and actionable by providers and systems.

The many contributors' passion and commitment to the health and well-being of all children made this effort possible and we are grateful for the time and energy they gave to this work!

With gratitude,

Amy Wimpey Knight

Amy Wimpey Knight
Chief Operating Officer
Children's Hospital Association

Executive Summary

The U.S. health care system continues to move from fee-for-service toward fee-for-value, or value-based care and payment. Children's hospitals are increasingly under pressure to adopt and report on meaningful quality measures that demonstrate value in the care provided to patients.

Selecting meaningful measures for your hospital's value programs is critically important, complex, and time and resource intensive. There are hundreds, even thousands of pediatric measures in use, but few agreed upon standard measures and measure sets in children's health care. Moreover, the small number of national and regional pediatric measure sets that do exist include few pediatric acute inpatient and specialty care measures. In the absence of recognized measure sets, you are left to select measures, or have measures imposed upon you, without the benefit of industry experience. Common questions providers pose include:

- Where can you go to find out what measures are available?
- What are the measures with real-world application?
- How do you evaluate which measures are best suited to your program?

"Demonstrating Value in Pediatrics: A Measure Menu and Guidance for Value-based Care, Payment and Reporting Programs" released by the Children's Hospital Association (CHA) can save hospitals and health systems significant time and effort in identifying meaningful quality measures for value-based programs. The Demonstrating Value in Pediatric resource includes: the measure menu listing 67 carefully vetted pediatric measures, the measure menu Excel-based workbook to simplify measure selection, the seven steps to successful measure selection and use, and commentary on gaps and opportunities in pediatric quality and measurement.

To create the Demonstrating Value in Pediatrics Measure Menu, CHA worked with an advisory panel of stakeholders and Discern Health. Our objective was to identify measures that:

- ✓ Are recommended by experts—including families and patient advocates, clinicians, hospital administrators, health care systems, and public and private payers— for value-based care and payment programs
- ✓ Minimize challenges commonly faced with pediatric measurement
- ✓ Capture key aspects of care across pediatric sites of care, including inpatient, specialty, primary and behavioral health care
- ✓ Capture aspects of care that matter most to children and their families
- ✓ Are aligned with existing federal, state and private programs

The measure menu is not a dashboard addressing all aspects of child health quality, nor an ideal set of measures. However, in the absence of ideal measure sets and national data sets, the Demonstrating Value in Pediatrics Measure Menu and Guidance can be used as a measure selection resource for value-based programs.

What the Report Covers

Chapter 1. Child Health and Quality Measurement

Children's health care measures must account for the unique physiology and health care needs of children, summarized as the "five Ds":
1. Developmental status and change
2. Differential epidemiology
3. Dependence
4. Demographic patterns
5. Detecting differences

Chapter 2. Demonstrating Value in Pediatrics Pediatric Measure Menu

The Demonstrating Value in Pediatrics Measure Menu was developed with consensus-based recommendations from stakeholders using CHA's measure set selection and evaluation process rooted in industry best practices. The resulting measure menu includes 67 quality measures in four areas of care:

- Acute inpatient care (15 measures)
- Ambulatory specialty care (15 measures)
- Primary care and community engagement (27 measures)
- Behavioral/Mental health care (10 measures)

Demonstrating Value in Pediatrics Measure Menu Workbook includes more detailed measure information.

Chapter 3. Using the Demonstrating Value in Pediatrics Measure Menu Workbook

Seven steps lead to successful measure selection and implementation in value-based programs, starting with defining the objectives and scope of the value-based program, to aligning select program and measure requirements, and ending with ongoing implementation considerations:

1. Define value-based program objectives and scope
2. Anticipate key child quality measurement issues
3. Specify program and measure requirements
4. Select measures from the Demonstrating Value in Pediatrics Measure Menu
5. Evaluate selected measure set
6. Interim testing
7. Implementation

Chapter 4. Gaps and Opportunities for the Demonstrating Value in Pediatrics Measure Menu

We identified three overarching gap areas in measuring quality of care in children's health care including communication and coordination/integration of care, structural and health system areas (e.g. workforce shortages), and clinical care. Measures covering communication and coordination/integration of care were identified as the highest priority gap areas by families, patient advocates, clinicians, payers and hospital administrators alike.

The work also identified ten "emerging measures," representing opportunities for the future. Emerging measures address important topics but require specification revision or refinement, more testing or real-world experience and/or overcoming some other technical obstacle.

White Paper: What Matters Most to Children and Families (Appendix C)

Child health quality measure sets should capture aspects of quality that are meaningful for children and their families. The patient perspective should, in a patient-centered quality program, be a primary focus of decision-making.

This white paper presents a child-centric stakeholder group's examination of "what matters most to children and families" across six domains of quality: communication and coordination, community engagement, effectiveness of care, safety, experience of care, and wellness and prevention.

Three themes touching all or most of these domains were identified:

- Communication and care coordination are foundational, safety is essential, and wellness and effectiveness are objectives.
- Quality care is dependent on all stakeholders knowing and performing their roles.
- What matters most is for some an aspirational idea and for others a realistic expectation.

Four Case Studies on Opportunities for Quality Improvement (Appendix D)

Presents four case studies describing real actions by children's hospitals to improve child health care quality and outcomes, and how quality measures can be used to support, supplement and incentivize quality improvements in pediatric settings. These case studies include examples of the effective coordination of care for children with complex health care needs, adaptation of adult-focused value-based inpatient reimbursement structure, effective use of learning networks, and feasibility and benefit of addressing social needs.

Chapter 1: Child Health and Quality Measurement

- Health care needs for children present unique challenges for quality measurement and use in value-based programs.
- The distinguishing aspects of child health care and measurement include: 1. Developmental status and change, 2. Differential epidemiology, 3. Dependence, 4. Demographic patterns, and 5. Detecting differences.
- Value-based program administrators should assess how much a program's requirements and its selected measures will address or exaggerate measurement challenges.

The U.S. health care system is moving away from fee-for-service payment toward models that incentivize improving value for patients. As a result, children's hospitals and other pediatric care providers are under pressure to adopt and report on meaningful quality measures that demonstrate the value of the care they provide to patients. This presents challenges for child health care providers.

A central challenge for measuring quality in child health care is that the care and treatment of children is different from adults; thus, measure approaches that work in adult health may not work for child health.
The distinguishing aspects of child health care are often referred to as the "four D's." 1. Developmental status and change, 2. Differential epidemiology, 3. Dependence and 4. Demographic patterns. [1] In the context of quality measurement, the "four D's", taken together, lead to a fifth "D": 5. Detecting differences (Table 1).

Table 1: Five Unique Aspects of Child Health Care and Measurement (*The "Five D's"*)	
1. Developmental Status and Change	Addressing the rapid developmental, physical and behavioral changes that occur between birth and adulthood are fundamental to high quality care for children and require different health services.
2. Differential Epidemiology	Children are physiologically different than adults, and overall are healthier and have fewer acute and chronic health issue.
3. Dependence	Children are dependent on their families and caregivers to meet basic needs such as food, shelter, and access to health care. Eating habits, environmental exposures, traumatic events, and health decisions made in childhood have lifelong ramifications for both the child and the national health burden.
4. Demographic Patterns	Children living in areas with high poverty rates are at special risk for negative health effects.
5. Detecting Differences	These distinguishing aspects of child health care have a material impact on how well the quality of care and outcomes can be measured using common measurement schemes and data sources.

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[1] Why Child Health Measures?. Content last reviewed September 2012. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/chtoolbx/why/index.html

We added the fifth "D" to acknowledge the difficulty many child health measures have identifying and differentiating high or poor quality from average quality.[2] This is due to a variety of factors, often caused by small numbers or lacking critical data on other important influences of health. For example, narrow age bands to account for children requiring different types of care at different times in their lives, the relatively few acute or chronic health issues experienced by children, and the dependence of children on others for their well-being, all of which, separately or together, challenge the reliability of measures. Thus, even when the clinical care is designed to tackle these aspects of child health and does so successfully, quality measure results may fail to demonstrate higher or poorer quality of care or outcomes.

Additional measurement challenges for child health include:

- Short-term versus long-term return on investment (ROI): The care and outcomes for children is often under-valued because current business ROI objectives and measurement approaches do not capture outcomes (e.g. cost and quality) far enough into the future. Some important short-term outcomes may be apparent (e.g. preventing flu or mortality), but care provided to infants, children, and adolescents include objectives to improve outcomes in adulthood (e.g. lower substance abuse in adulthood).

- Ethical and funding constraints: Challenges associate with conducting clinical trials when the patient is a child and other funding constraints has limited the number of randomized trials and rigorous studies leaving a thinner evidence base on which to build quality measures.

- Obtaining patient-reported data: Evidence suggest differences between how parents/caregivers report their child's health care experiences and outcomes compared to how the child reports these.[3] Further, while family experiences of care are an important indicator of the quality of care, patient-centered care—core to realizing value in health care—requires that child health measurement approaches also capture the experiences and outcomes reported by children.

Whether a given quality measure overcomes these challenges, and how, may depend in part on the value-based program's reporting requirements and the end users of the measure results. For example, measures used in an internal quality improvement initiative may, by design, be less precise to ensure the capture and resolution of all true adverse quality events, knowing that the measure will also, upon investigation, capture those that prove to be false events. In these types of programs, it is often preferable to spend the resources investigating all potential adverse events, even false events, than to miss even one true adverse event. On the other hand, a measure used for public reporting may be highly precise to support consistent interpretation by the public. A value-based program may effectively use a mix of these more precise or less precise measures. More about how awareness of end user needs affect measure selection are outlined in Chapter 3.

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[2] Jay G. Berry, Alan M. Zaslavsky, Sara L. Toomey, Alyna T. Chien, Jisun Jang, Maria C. Bryant, David J. Klein, William J. Kaplan, Mark A. Schuster. Recognizing differences in hospital quality performance for pediatric inpatient care. Pediatrics Aug 2015, 136 (2) 251-262; DOI: 10.1542/peds.2014-3131

[3] Hargreaves, D. S., Sizmur, S., Pitchforth, J., Tallett, A., Toomey, S. L., Hopwood, B., Schuster, M. A., … Viner, R. M. (2018). Children and young people's versus parents' responses in an English national inpatient survey. Archives of disease in childhood, 103(5), 486-491.

Measures should capture aspects of quality that are meaningful for children and their families. This consideration is often overlooked in favor of a more clinician or administrator-oriented program perspective, but the patient perspective should, in a patient-centered quality program, be the primary focus of decision-making. A white paper on quality topics that matter to children and their families can be found in Appendix C of this report.

A key finding in the "What Matters Most to Children and Families" white paper states, "Effectiveness in health care is not limited to clinical-effectiveness or adherence to clinical guidelines. More holistic definitions of the effectiveness of care are needed…" see Appendix C.

The Demonstrating Value in Pediatrics resource should be used with other quality improvement resources. Pediatric quality improvement collaboratives have been used for decades to identify and resolve safety and quality problems within and across sites of care. Successful examples of these efforts include, the Improving Pediatric Sepsis Outcomes (IPSO) collaborative[4], the Standardized Care to Improve Outcomes in Pediatric Endstage Renal Disease (SCOPE) collaborative[5], and the ImproveCareNow[6] collaborative targeting outcomes for children with Crohn's disease and ulcerative colitis. These, and other quality improvement collaborative efforts allow for the detection of quality and safety issues that practice-, provider-, or even system-level performance reporting might miss. This has allowed child health providers and systems to implement important quality and safety improvements with real, positive impacts on child health outcomes. Thus, measures that assess participation in quality improvement programs demonstrating meaningful quality outcomes may be relevant for some value-based programs.

IMPROVING PEDIATRIC SEPSIS OUTCOMES (IPSO)

Defeating Sepsis: While standardized approaches to measure sepsis quality and outcomes are emerging, we face an urgent need to improve sepsis quality and outcomes. IPSO, a CHA sponsored QI collaborative will span all stages of sepsis across the care continuum, including ED, intensive care, transplant units, pre-hospital and ambulatory settings.

> ~Some 80,000 children are hospitalized annually for sepsis in the U.S. Almost 5,000 will die – more than from cancer -- and 25-50% of those who survive will suffer long-term health consequences. ~

IPSO early successes include: Identification of more sepsis patients, identification of patients earlier (before deterioration to severe sepsis), decrease in hospital days, and decrease in sepsis-related mortality.

These considerations in pediatric measurement are important context for the measures included in the Demonstrating Value in Pediatrics Measure Menu. The menu includes measures available for immediate use that may provide meaningful information and drive quality improvement.

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[4] IPSO: https://www.childrenshospitals.org/Programs-and-Services/Quality-Improvement-and-Measurement/Collaboratives/Sepsis

[5] SCOPE: https://www.childrenshospitals.org/Programs-and-Services/Quality-Improvement-and-Measurement/Collaboratives/SCOPE

[6] ImproveCareNow: https://www.improvecarenow.org/

Chapter 2: Demonstrating Value in Pediatrics: A Pediatric Measure Menu and Menu Workbook

- Includes 67 high priority, ready for use child health measures grouped across four areas: acute inpatient care, ambulatory specialty care, primary care & community engagement, and behavioral/mental health care.
- Builds upon well-known core measure sets, supplementing them with previously absent pediatric acute inpatient and specialty care.
- Suitable for demonstrating value for providers, payers and families in a variety of care settings; however, a measure may not be suitable for all value-based programs and must be evaluated for inclusion in any given program.
- Use along with measure selection and implementation guidance (see Chapter 3).

Menu Overview

The Demonstrating Value in Pediatrics Measure Menu (Menu Workbook) includes 67 quality measures in four areas of care: acute inpatient care, ambulatory specialty care, primary care and community engagement, and behavioral/mental health care. The measure menu builds upon existing national measure core sets (listed in the menu workbook) and includes acute inpatient and ambulatory specialty care measures often absent in these core sets. A CHA-convened advisory panel of expert stakeholders including clinicians, parents, hospital and practice leaders, and public and private payers (see Appendix A) used CHA's stepwise measure selection and evaluation process (see Appendix B) to generate recommendations for the measure menu.

The advisory panel was asked to focus on existing, already-in-use measures suitable for evaluating the quality of pediatric care in a broad array of value-based care and purchasing programs. Measures were not required to be applicable to all types of value-based programs, and in fact, the application of a measure in the menu may not be appropriate for all types of accountability strategies (e.g. public reporting, contracting, internal quality improvement). Measures included in the measure menu were assessed for:

- Importance and relevance in the context of value
- Statistical validity including evidence of adequate testing and/or use
- Feasibility of measure implementation including broad use and experience with measure
- Actionability including evidence that performance can be improved by relevant stakeholders

This is an à la carte menu from which you can select measures best suited to your program (see Chapter 3 for measure selection steps and considerations). When selecting measures from the measure menu, it is critical to assess the suitability of a given measure within the context of a program's population and the "5 D's" of child health and measurement (i.e. developmental status and change, differential epidemiology, dependence, demographic patterns, and detecting differences).

Demonstrating Value in Pediatrics Measure Menu

The measure menu has 67 measures that are grouped into four areas:

- **Acute Inpatient Care** (15 measures)
    - Measures of inpatient care and outcomes, and post-discharge care and outcomes. Some measures focus on highly specialized, high-cost conditions (e.g. pediatric heart surgery) and others on more prevalent conditions/events (e.g. upper respiratory infections) or quality and experience regardless of the condition/event (e.g. surveying parents/caregivers about their inpatient stay experience).
- **Ambulatory Specialty Care** (15 measures)
    - Measures of the care and outcomes for children with complex, often chronic, medical needs (e.g. kidney disease, HIV, sickle cell anemia) and several survey instruments that assess the quality of care provided in the ambulatory care setting.
- **Primary Care and Community Engagement** (27 measures)
    - Measures of primary care and outcomes for services predominantly performed in outpatient pediatric care settings. Community engagement was recognized as an area that should be addressed as part of the menu; however, no measures were identified as directly addressing this topic.
- **Behavioral/Mental Health Care** (10 measures)
    - Measures of the continuum of behavioral/mental health care, from screening and diagnosis to treatment and follow-up. Some (e.g. those that address substance abuse) may only apply to a small subset of the under-18 population and may be impacted by a family's ability to access behavioral health care services.

DEMONSTRATING VALUE IN PEDIATRICS MEASURE MENU WORKBOOK

The **Demonstrating Value in Pediatrics Measure Menu Workbook** includes additional measure information, sort and filter functions, and is downloadable as an Excel workbook. Chapter 3 presents seven steps to select program-specific measures. See Appendix E for a complete list fields included in the measure menu workbook.

The tables in this chapter are an abbreviated view of the Demonstrating Value in Pediatrics Measure Menu Workbook. When selecting measures for programs, use the measure menu workbook, designed to filter on key measure attributes (see Appendix E for a list of these attributes), and the 7 steps presented in Chapter 3.

IMPORTANT: The measure menu is up-to-date as of January 9th, 2019. For detailed specifications or updates to measures, contact the measure steward.

Acute Inpatient Care (15 Measures)

Inpatient care and outcomes and post-discharge care and outcomes.

Table 2: Acute Inpatient Care Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Catheter-associated Urinary Tract Infection (CAUTI) Outcome Measure	Standardized Infection Ratio (SIR) of health care-associated, catheter-associated urinary tract infections (UTI) will be calculated among patients in bedded inpatient care locations, except level II or level III neonatal intensive care units (NICU). This includes acute care general hospitals, long-term acute care hospitals, rehabilitation hospitals, oncology hospitals and behavior health hospitals	CDC-NHSN
Central line-associated Bloodstream Infection (CLABSI) Outcome Measure	Standardized Infection Ratio (SIR) and Adjusted Ranking Metric (ARM) of health care-associated, central line-associated bloodstream infections (CLABSI) will be calculated among patients in bedded inpatient care locations. This includes acute care general hospitals, long-term acute care hospitals, rehabilitation hospitals, oncology hospitals and behavioral health hospitals	CDC-NHSN
Child Hospital CAHPS (HCAHPS)	The Child Hospital Consumer Assessment of Healthcare Providers and Systems (Child HCAHPS) Survey is a standardized survey instrument that asks parents and guardians (henceforth referred to as parents) of children under 18 years old to report on their and their child's experiences with inpatient hospital care. The performance measures of the Child HCAHPS survey consist of 39 items organized by overarching groups into 18 composite and single-item measures covering provider/staff communication with parent, provider communication with child, attention to safety and comfort, hospital environment, and a global rating (overall and if respondent would recommend the hospital)	AHRQ
Facility-wide Inpatient Hospital-onset Clostridium difficile Infection (CDI) Outcome Measure	Standardized infection ratio (SIR) and Adjusted Ranking Metric (ARM) of hospital-onset CDI Laboratory-identified events (LabID events) among all inpatients in the facility, excluding well-baby nurseries and neonatal intensive care units (NICUs)	CDC-NHSN
Facility-wide Inpatient Hospital-onset Methicillin-resistant Staphylococcus aureus (MRSA) Bacteremia Outcome Measure	Standardized infection ratio (SIR) and Adjusted Ranking Metric (ARM) of hospital-onset unique blood source MRSA Laboratory-identified events (LabID events) among all inpatients in the facility	CDC-NHSN
Influenza Immunization	Inpatients age 6 months and older discharged during October, November, December, January, February or March who are screened for influenza vaccine status and vaccinated prior to discharge if indicated	CMS

Table 2: Acute Inpatient Care Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Influenza Vaccination Coverage Among Health Care Personnel	Percentage of health care personnel (HCP) who receive the influenza vaccination **Considerations/Limitations:** Individuals working in health care settings may include contractors who receive vaccinations offsite. Operationalizing approaches to collect their vaccination information in a timely manner for this measure may be challenging.	CDC-NHSN
Operative Mortality Stratified by the 5 STAT Mortality Categories	Percent of patients undergoing index pediatric and/or congenital heart surgery who die, including both 1) all deaths occurring during the hospitalization in which the procedure was performed, even if after 30 days (including patients transferred to other acute care facilities), and 2) those deaths occurring after discharge from the hospital, but within 30 days of the procedure, stratified by the five STAT Mortality Levels, a multi-institutional validated complexity stratification tool	Society of Thoracic Surgeons (STS)
Participation in a National Database for Pediatric and Congenital Heart Surgery	Participation in at least one multi-center, standardized data collection and feedback program for pediatric and congenital heart surgery that provides benchmarking of the physician's data relative to national and regional programs and uses process and outcome measures **Considerations/Limitations:** This structural measure assesses participation in a program that reports performance and benchmark information to the participants. The measure does not exclude programs that do not provide any other form of reporting or accountability, e.g. require public reporting of results. Thus, this measure may be considered by some payers as an entry-level type measure and more suitable for organizations new to value-based programs.	STS
Pediatric All-Condition Readmission Measure	This measure calculates case-mix-adjusted readmission rates, defined as the percentage of admissions followed by 1 or more readmissions within 30 days, for patients less than 18 years old. The measure covers patients discharged from general acute care hospitals, including children's hospitals. **Considerations/Limitations:** This measure captures readmissions to ***all*** hospitals where a patient had a readmission within 30 days of a discharge, requiring information about admissions to other hospitals to track performance.	Center of Excellence for Pediatric Quality Measurement (CEPQM)

Table 2: Acute Inpatient Care Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Pediatric Lower Respiratory Infection Readmission Measure	This measure calculates case-mix-adjusted readmission rates, defined as the percentage of admissions followed by 1 or more readmissions within 30 days, following hospitalization for lower respiratory infection (LRI) in patients less than 18 years old. The measure covers patients discharged from general acute care hospitals, including children's hospitals. **Considerations/Limitations:** This measure captures readmissions to ***all*** hospitals where a patient had a readmission within 30 days of a discharge, requiring information about admissions to other hospitals to track performance.	CEPQM
PICU Unplanned Readmission Rate	Total number of patients requiring unscheduled readmission to the ICU within 24 hours of discharge or transfer.	Virtual PICU Systems, LLC
Proportion of Infants 22 to 29 Weeks Gestation Screened for Retinopathy of Prematurity	Proportion of infants born from 22 weeks, 0 days to 29 weeks, 6 days gestational age who were in the reporting hospital at the postnatal age recommended for screening for retinopathy of prematurity (ROP) by the American Academy of Pediatrics (AAP) and who received a retinal examination for ROP prior to discharge.	Vermont Oxford Network (VON)
Risk-adjusted Late Sepsis or Meningitis in Very Low Birth Weight Neonates [Nosocomial Infections]	Standardized morbidity ratio and observed minus expected measure for nosocomial bacterial infection after day 3 of life in very low birth weight (VLBW) infants. Late sepsis or meningitis in VLBW neonates is a measure of nosocomial bacterial infection for eligible infants whose birth weight is between 401 and 1500 grams or whose gestational age is between 22 and 29 weeks. Covariates associated with predicting the expected value are included in the multivariable model.	VON
Risk-Adjusted Operative Mortality for Pediatric and Congenital Heart Surgery (Includes non-risk adjusted version)	Percent of patients undergoing index pediatric and/or congenital heart surgery who die, including both 1) all deaths occurring during the hospitalization in which the procedure was performed, even if after 30 days (including patients transferred to other acute care facilities), and 2) those deaths occurring after discharge from the hospital, but within 30 days of the procedure.	STS

Ambulatory Specialty Care (15 Measures)

Care and outcomes for children with complex medical needs.

Table 3: Ambulatory Specialty Care Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Antibiotic Prophylaxis Among Children with Sickle Cell Anemia	Percentage of children ages 3 months to 5 years old with sickle cell anemia (SCA, hemoglobin [Hb] SS) who were dispensed appropriate antibiotic prophylaxis for at least 300 days within the measurement year. This measure is calculated as two rates: the percentage of children who were dispensed preventive antibiotics for at least 300 days, and the percentage of children who received antibiotic prophylaxis for at least 350 days. A higher proportion indicates better performance as reflected by appropriate treatment.	Q-METRIC – The University of Michigan
Adolescent Assessment of Preparation for Transition to Adult Focused Health Care (ADAPT Survey)	The ADAPT is a survey of adolescents (16 – 17 years of age) with a chronic health condition that assesses their experiences with preparation for transition from pediatric-focused to adult-focused health care. The adolescent-reported survey has three composite measures that cover: counseling on transition self-management, counseling on prescription medication, and transfer planning.	CEPQM
Delivered Dose of Pediatric Peritoneal Dialysis (PD) Above Minimum (a.k.a. Pediatric Peritoneal Dialysis Adequacy Measure, a.k.a. Minimum Kt/V for Pediatric Peritoneal Patients)	Percent of pediatric peritoneal dialysis patient-months with Kt/V ≥1.8 Kt/V (dialytic + residual) during the six-month study period	CMS
Ambulatory Care: Outpatient and Emergency (AMB)	This measure assesses use of two kinds of ambulatory services: • outpatient visits • emergency department (ED) visits. ED visits that result in an inpatient stay are excluded from the numerator. **Considerations/Limitations:** This measure captures ambulatory services for a given patient across ***all*** outpatient and ED sites of care.	NCQA/HEDIS

Table 3: Ambulatory Specialty Care Measures		
Title	**Description, CHA Considerations/Limitations (if any)**	**Steward**
CAHPS Health Plan Survey 5.0H – Child Version Including Medicaid and Children with Chronic Conditions Supplemental Items (CPC-CH)	Provides information on parents' experience with their child's payer organization. Results summarize member experiences through ratings, composites, and individual question summary rates. Children with Chronic Conditions supplement includes the following measures: -Access to Prescription Medicines -Access to Specialized Services -Coordination of Care and Services -Family-Centered Care: • Having a Personal Doctor or Nurse who Knows the Child • Shared Decision-making • Getting Needed Information	NCQA/HEDIS
Family Experiences with Coordination of Care (FECC) Measure Set	The Family Experiences with Coordination of Care (FECC) Survey was developed to gather information about the quality of care coordination being received by children with medical complexity (CMC) over the previous 12 months. Ten of the FECC measures are included in the measure menu: FECC-1: Has care coordinator FECC-3: Care coordinator helped to obtain community services FECC-5: Care coordinator asked about concerns and health changes FECC-7: Care coordinator assisted with specialist service referrals FECC-8: Care coordinator was knowledgeable, supportive and advocated for child's needs FECC-9: Appropriate written visit summary content FECC-14: Health care provider communicated with school staff about child's condition FECC-15: Caregiver has access to medical interpreter when needed FECC-16: Child has shared care plan FECC-17: Child has emergency care plan	Seattle Children's Research Institute (COE4CN)
HIV Medical Visit Frequency	Percentage of patients, regardless of age, with a diagnosis of HIV who had at least one medical visit in each 6-month period of the 24-month measurement period with a minimum of 60 days between medical visits. A medical visit is any visit in an outpatient/ambulatory care setting with a nurse practitioner, physician, and/or a physician assistant who provides comprehensive HIV care. **Considerations/Limitations:** Coupling this measure with the HIV Viral Load Suppression measure is advised; the two measures together may help to account for patients who frequently visit their provider but do not achieve adequate viral load suppression.	HRSA - HIV/AIDS Bureau

Table 3: Ambulatory Specialty Care Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
HIV Viral Load Suppression	Percentage of patients, regardless of age, with a diagnosis of HIV with a HIV viral load less than 200 copies/mL at last HIV viral load test during the measurement year **Considerations/Limitations:** Coupling this measure with the HIV Medical Visit Frequency measure is advised; the two measures together may help to account for patients who frequently visit their provider but do not achieve adequate viral load suppression.	HRSA - HIV/AIDS Bureau
HIV/AIDS: Sexually Transmitted Diseases - Screening for Chlamydia, Gonorrhea, and Syphilis	Percentage of patients aged 13 years and older with a diagnosis of HIV/AIDS, who have received chlamydia, gonorrhea, and syphilis screenings at least once since the diagnosis of HIV infection	NCQA
Inflammatory Bowel Disease: Clinical Remission	Percentage of Inflammatory Bowel Disease (IBD) patients in remission after three months of initial treatment. Patients are considered in remission if they have no IBD-related symptoms at their last clinic visit.	ImproveCareNow
Inflammatory Bowel Disease: No Activity Limitations	Percentage of IBD patients or patient's parents (if the patient is under 9 years old) reporting activity limitations at each visit. Patients report whether or not they are experiencing any limitations in activities.	ImproveCareNow
Inflammatory Bowel Disease: Safe and Effective Use of Medications	Percentage of IBD patients using steroids (prednisone) three months after diagnosis. Patients are considered in prednisone-free remission if they have no IBD-related symptoms at their last clinic visit and are no longer taking prednisone.	ImproveCareNow
Minimum spK/V for Pediatric Hemodialysis Patients	Percentage of patient months for all pediatric (<18 years old) in-center hemodialysis patients in which the delivered dose of hemodialysis (calculated from the last measurement of the month using the UKM or Daugirdas II formula) was spKt/V >= 1.2.	CMS
Oncology: Plan of Care for Pain – Medical Oncology and Radiation Oncology	Percentage of visits for patients, regardless of patient age, with a diagnosis of cancer currently receiving chemotherapy or radiation therapy who report having pain with a documented plan of care to address pain. **Considerations/Limitations:** Measure performance is generated from an ASCO registry. While the registry is broadly used among oncologists, access to the registry requires ASCO or ASTRO membership and requires a fee that may be a barrier for some organizations.	American Society of Clinical Oncology (ASCO)
Transcranial Doppler Ultrasonography Screening Among Children with Sickle Cell Anemia	Percentage of children ages 2 through 15 years old with sickle cell anemia (Hemoglobin SS) who received at least one transcranial Doppler (TCD) screening within a year.	Q-METRIC – The University of Michigan

Primary Care and Community Engagement (27 measures)

Primary care and outcomes for services predominantly performed in outpatient pediatric care settings or by primary care physicians (PCPs) [7].

Table 4: Primary Care and Community Engagement Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Acute Otitis Media - Appropriate First-Line Antibiotics (a.k.a. Otitis Media: First-Line Antibiotics for Acute Otitis Media)	The proportion of encounters at which antibiotics prescribed to patients aged 2 months to 12 years for Acute Otitis Media (AOM) conform to the AAP/AAFP recommendation for first-line use of amoxicillin. There is no penalty in the measure in the event that the clinician decides not to prescribe an antibiotic at all. This process measure is structured for feasibility and scalability over large populations and doesn't take into account individual patient characteristics.	The Children's Hospital of Philadelphia Pediatric Quality Measures Program Center of Excellence
Adolescent Well-Care Visits (AWC)	Assesses adolescents and young adults 12-21 years of age who had at least one comprehensive well-care visit with a primary care practitioner or an OB/GYN practitioner during the measurement year. Components of a well-care visit must include ALL of the following: a health history, a physical development history, a mental development history, a physical exam, and health education/anticipatory guidance. Services specific to the assessment or treatment of an acute or chronic condition do not count toward this measure.	NCQA/HEDIS
Annual Dental Visit (ADV)	Percentage of patients 2-21 years of age who had at least one dental visit during the measurement year. This measure applies only if dental care is a covered benefit in the organization's Medicaid contract.	NCQA/HEDIS
Appropriate Testing for Children With Pharyngitis (CWP)	Percentage of children 2–18 years of age who were diagnosed with pharyngitis, dispensed an antibiotic and received a group A streptococcus (strep) test for the episode. A higher rate represents better performance (i.e. appropriate testing). **Considerations/Limitations:** The measure steward, NCQA, is currently evaluating the measure and may release new dimensions of the measure. It was noted that the greatest opportunity for improvement may be in urgent care settings.	NCQA/HEDIS

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[7] When a measure requires a visit with a PCP, be sure to refer to the steward's definition of PCP. PCPs may include physicians or select nonphysicians (e.g., nurse practitioner, physician assistant) who offer primary care medical services, and certified Federally Qualified Health Centers.

Table 4: Primary Care and Community Engagement Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Appropriate Treatment for Children With Upper Respiratory Infection (URI)	Percentage of children 3 months to 18 years of age with a diagnosis of upper respiratory infection (URI) who were not dispensed an antibiotic medication. The measure is reported as an inverted rate (i.e. 1-numerator/denominator) to reflect the number of children that were not dispensed an antibiotic.	NCQA/HEDIS
Asthma Assessment	Percentage of patients who were evaluated during at least one office visit for the frequency (numeric) of daytime and nocturnal asthma symptoms.	American Academy of Asthma, Allergy & Immunology (AAAAI)
Asthma Medication Ratio (AMR)	Percentage of patients 5–64 years of age who were identified as having persistent asthma and had a ratio of controller medications to total asthma medications of 0.50 or greater during the measurement year. The intent of the measure is to have members utilize both controllers and relievers in their regimens, instead of relievers alone thereby minimizing the number of preventable asthma exacerbations. Four age stratifications and a total rate are reported for this measure.	NCQA/HEDIS
Asthma: Pharmacologic Therapy for Persistent Asthma	Percentage of patients aged 5 years and older with a diagnosis of persistent asthma who were prescribed long-term control medication. Three rates are reported for this measure: 1. Patients prescribed inhaled corticosteroids (ICS) as their long-term control medication 2. Patients prescribed other alternative long-term control medications (non-ICS) 3. Total patients prescribed long-term control medication	AAAAI
Audiological Evaluation No Later Than 3 Months of Age (a.k.a. Audiological Diagnostic No Later Than 3 Months of Age)	Percentage of newborns who did not pass hearing screening and have an audiological evaluation no later than 3 months of age.	CDC National Center for Chronic Disease Prevention and Health Promotion

Table 4: Primary Care and Community Engagement Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
CAHPS Clinician & Group Surveys (CG-CAHPS)-Adult, Child	The Consumer Assessment of Healthcare Providers and Systems Clinician & Group Survey (CG-CAHPS) is a standardized survey instrument that asks patients to report on their experiences with primary or specialty care received from providers and their staff in ambulatory care settings over the preceding 12 months. All questionnaires can be used in both primary care and specialty care settings. The child survey is administered to the parents or guardians of pediatric patients under the age of 18. There are five composite measures and one global item: 1. Getting Timely Appointments, Care, and Information (5 items); 2. How Well Providers Communicate With Patients (6 items); 3. Helpful, Courteous, and Respectful Office Staff (2 items); 4. Overall Rating of Provider (1 item); 5. Provider´s Attention to Child´s Growth and Development (6 items); 6. Provider´s Advice on Keeping Your Child Safe and Healthy (5 items).	AHRQ
Childhood Immunization Status (CIS)	Percentage of children 2 years of age who had four diphtheria, tetanus and acellular pertussis (DtaP); three polio (IPV); one measles, mumps and rubella (MMR); three haemophilus influenza type B (HiB); three hepatitis B (HepB); one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (HepA); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday. The measure calculates a rate for each vaccine.	NCQA/HEDIS
Children and Adolescents' Access to Primary Care Practitioners (CAP)	Assesses children and young adults 12 months-19 years of age who had a visit with a primary care practitioner (PCP). The measure reports on four separate percentages: Children 12-24 months who had a visit with a PCP during the measurement year; Children 25 months-6 years who had a visit with a PCP during the measure year; Children 7-11 years who had a visit with a PCP during the measure year or the year prior to the measurement year; Adolescents 12-19 years who had a visit with a PCP during the measurement year or the year prior to the measurement year.	NCQA/HEDIS
Chlamydia Screening in Women (CHL)	Percentage of women 16–24 years of age who were identified as sexually active and who had at least one test for chlamydia during the measurement year	NCQA/HEDIS

Table 4: Primary Care and Community Engagement Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Continuity of Primary Care for Children with Medical Complexity	Percentage of children with medical complexity age 1 to 17 years old who have a Bice-Boxerman continuity of care (COC) index of >=0.5 in the primary care setting over a 12-month period **Considerations/Limitations**: Measure is limited to children who had at least four acute or preventive care visits, and therefore, may not capture under-utilizers.	Seattle Children's Research Institute (COE4CN)
Dental Sealants for 6-9 Year-Old Children at Elevated Caries Risk	Percentage of enrolled children in the age category of 6-9 years at "elevated" risk (i.e., "moderate" or "high") who received a sealant on a permanent first molar tooth within the reporting year **Considerations/Limitations:** The measure is currently being reevaluated by the steward to address concerns about its clinical exclusions.	Dental Quality Alliance
Developmental Screening in the First Three Years of Life	Percentage of children screened for risk of developmental, behavioral, and social delays using a standardized screening tool in the first three years of life. Includes three age-specific indicators assessing whether children are screened by 12 months of age, by 24 months of age and by 36 months of age.	Oregon Health and Science University
Immunizations for Adolescents (IMA)	Percentage of adolescents 13 years of age who had one dose of meningococcal vaccine, one tetanus, diphtheria toxoids and acellular pertussis (Tdap) vaccine, and have completed the human papillomavirus (HPV) vaccine series by their 13th birthday. The measure calculates a rate for each vaccine and two combination rates.	NCQA/HEDIS
Lead Screening in Children (LSC)	Percentage of children 2 years of age who received one or more capillary or venous blood tests for lead poisoning on or before their second birthday	NCQA/HEDIS
Non-Recommended Cervical Cancer Screening in Adolescent Females (NCS)	Percentage of adolescent females 16–20 years of age who were screened unnecessarily for cervical cancer	NCQA/HEDIS
Preventive Care and Screening: Influenza Immunization	Percentage of patients aged 6 months and older seen for a visit between October 1 and March 31 who received an influenza immunization OR who reported previous receipt of an influenza immunization	PCPI

Table 4: Primary Care and Community Engagement Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Pediatric Global Health Measure (PGH-7)	A 7-question outcome measure that assesses a child 's overall health. The questions can be answered by children ages 8-17 years-old, or by the parents of children 5-17 years-old. Questions ask about the child's perceptions of their health in general, physical health, mental health, pain, friendships, family life, self- esteem, and feelings of worry and sadness. [Connected to PROMIS survey] **Considerations/Limitations:** This measure is new, with evidence of extensive testing. However, there is little experience in the operationalization and use of the measure in existing programs.	The Children's Hospital of Philadelphia Pediatric Quality Measures Program Center of Excellence
Percentage of Eligibles Who Received Preventive Dental Services	Percentage of individuals ages 1 to 20 years who are enrolled in Medicaid or CHIP Medicaid Expansion programs for at least 90 continuous days, are eligible for Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services, and who received at least one preventive dental service during the reporting period	CMS
Sealants for 10-14 Year-Old Children at Elevated Caries Risk, Dental Services	Percentage of enrolled children in the age category of 10-14 years at "elevated" risk (i.e., "moderate" or "high") who received a sealant on a permanent second molar tooth within the reporting year **Considerations/Limitations:** The measure is currently being reevaluated by the steward to address concerns about clinical exclusions.	CMS
Tobacco Use and Help with Quitting Among Adolescents	Percentage of adolescents 12 to 20 years of age with a primary care visit during the measurement year for whom tobacco use status was documented and received help with quitting if identified as a tobacco user	NCQA
Weight Assessment and Counseling for Nutrition and Physical Activity for Children/Adolescents (WCC-CH)	Percentage of patients 3-17 years of age who had an outpatient visit with a PCP or an OB/GYN and who had evidence of the following during the measurement year: Body mass index (BMI) percentile documentation; Counseling for nutrition; Counseling for physical activity	NCQA/HEDIS
Well-Child Visits in the First 15 Months of Life (W15)	Percentage of children 15 months old who had the recommended number of well-child visits with a PCP during their first 15 months of life	NCQA/HEDIS
Well-Child Visits in the Third, Fourth, Fifth and Sixth Years of Life (W34)	Percentage of children 3-6 years of age who had one or more well-child visits with a PCP during the measurement year.	NCQA/HEDIS

Behavioral/Mental Health Care (10 Measures)

Behavioral health care, from screening and diagnosis to treatment and follow-up

Table 5: Behavioral/Mental Health Care Measures

Title	Description, CHA Considerations/Limitations (if any)	Steward
Behavior Therapy as First-Line Treatment for Preschool-Aged Children with ADHD	Percentage of patients aged 4 through 5 years with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD), for whom ADHD-focused evidence-based behavior therapy was prescribed as the first line of treatment	American Academy of Pediatrics, Pediatric Measurement CoE
Child and Adolescent Major Depressive Disorder (M.D.D): Suicide Risk Assessment	Percentage of consumer visits for those consumers aged 6 through 17 years with a diagnosis of major depressive disorder with an assessment for suicide risk	PCPI
Follow-Up After Hospitalization for Mental Illness: Ages 6–17 (FUH-CH)	Percentage of discharges for patients 6 years of age and older who were hospitalized for treatment of selected mental illness diagnoses and who had a follow-up visit with a mental health practitioner. Two rates are reported: the percentage of discharges for which the patient received follow-up within 30 days of discharge and the percentage of discharges for which the patient received follow-up within 7 days of discharge.	NCQA/HEDIS
Follow-Up Care for Children Prescribed ADHD Medication (ADD)	Percentage of children newly prescribed attention-deficit/hyperactivity disorder (ADHD) medication who had at least three follow-up care visits within a 10-month period, one of which is within 30 days of when the first ADHD medication was dispensed. An Initiation Phase Rate and Continuation and Maintenance Phase Rate are reported.	NCQA/HEDIS
Initiation and Engagement of Alcohol and Other Drug Dependence Treatment (IET)	Percentage of adolescent and adult members with a new episode of alcohol or other drug (AOD) abuse or dependence who received: • Initiation of AOD Treatment: Initiated treatment through an inpatient AOD admission, outpatient visit, intensive outpatient encounter or partial hospitalization, telehealth or medication assisted treatment (MAT) within 14 days of the diagnosis • Engagement of AOD Treatment: Initiated treatment and who had two or more additional AOD services or MAT within 34 days of the initiation visit	NCQA/HEDIS
Metabolic Monitoring for Children and Adolescents on Antipsychotics (APM)	Percentage of children and adolescents 1-17 years of age who had 2 or more antipsychotic prescriptions and had metabolic testing	NCQA/HEDIS
Pediatric Psychosis: Timely Inpatient Psychiatric Consultation	Percentage of children/adolescents age >=5 to <=19 years-old admitted to the hospital with psychotic symptoms who had a psychiatric consult (in person or by telepsychiatry) within 24 hours of admission	COE4CN

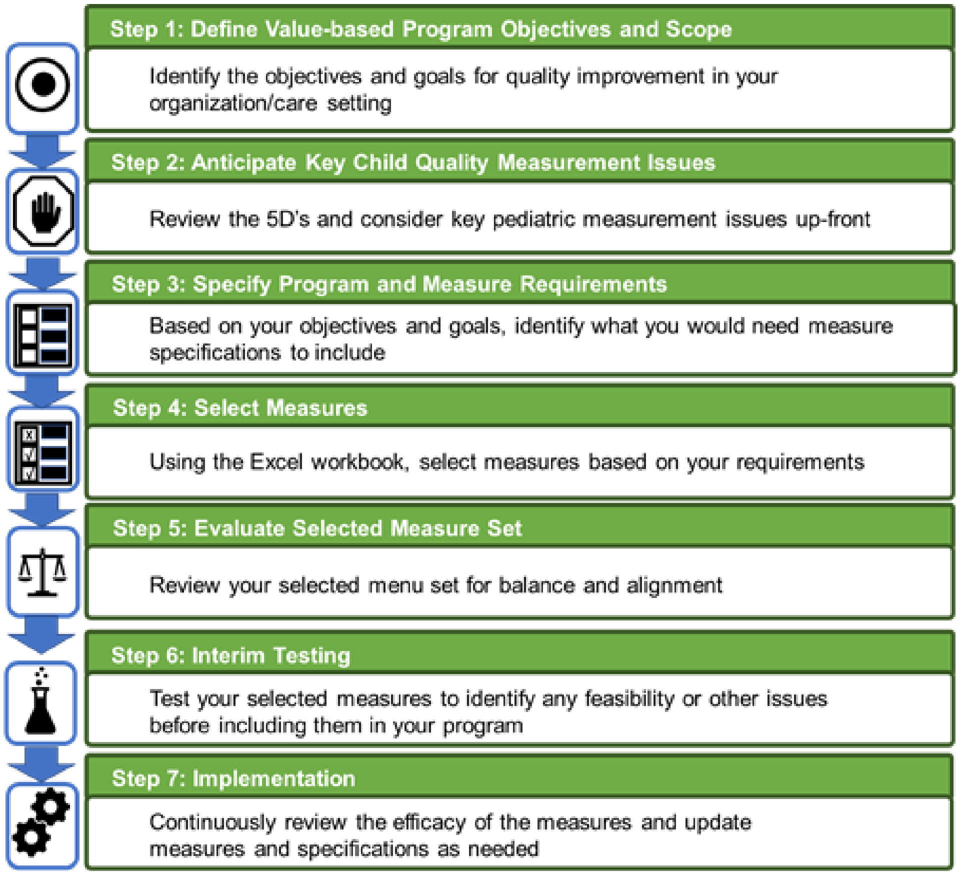
Table 5: Behavioral/Mental Health Care Measures		
Title	**Description, CHA Considerations/Limitations (if any)**	**Steward**
Preventive Care and Screening: Screening for Clinical Depression and Follow-up Plan	Percentage of patients aged 12 years and older screened for clinical depression on the date of the encounter using an age appropriate standardized depression screening tool AND if positive, a follow-up plan is documented on the date of the positive screen	CMS
Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics (APP-CH)	Percentage of children and adolescents 1–17 years of age with a new prescription for an antipsychotic, but no indication for antipsychotics, who had documentation of psychosocial care as first-line treatment	NCQA/HEDIS
Use of Multiple Concurrent Antipsychotics in Children and Adolescents (APC-CH)	Percentage of children and adolescents 1–17 years of age who were treated with antipsychotic medications and who were on two or more concurrent antipsychotic medications for at least 90 consecutive days during the measurement year Considerations/Limitations: An NQF committee evaluating the measure raised concerns about validity, particularly due to the potential for low volume in smaller provider settings.	NCQA/HEDIS

Chapter 3: Using the Demonstrating Value in Pediatrics Measure Menu and Measure Implementation Guidance

- Seven steps to aid in the selection and successful implementation of a measure in value-based programs are outlined.
- Selection and implementation of measures from the Demonstrating Value in Pediatrics Measure Menu should promote and incentivize care improvements, be fair and transparent to those being measured, and adhere to the highest standards of data stewardship and integrity.
- Pre-implementation measure testing, and regular performance feedback are keys to program success.

This chapter provides guidance and considerations for selecting and implementing measures for a value-based program. Seven steps are outlined, starting with defining the objectives and scope of the value-based program, to aligning program and measure requirements, and ending with ongoing implementation considerations.

Figure 1. Steps for Selecting and Implementing Measures



Step 1: Define Value-based Program Objectives and Scope

Identify the objectives and goals for quality improvement in your organization/care setting

Step 2: Anticipate Key Child Quality Measurement Issues

Review the 5D's and consider key pediatric measurement issues up-front

Step 3: Specify Program and Measure Requirements

Based on your objectives and goals, identify what you would need measure specifications to include

Step 4: Select Measures

Using the Excel workbook, select measures based on your requirements

Step 5: Evaluate Selected Measure Set

Review your selected menu set for balance and alignment

Step 6: Interim Testing

Test your selected measures to identify any feasibility or other issues before including them in your program

Step 7: Implementation

Continuously review the efficacy of the measures and update measures and specifications as needed

Step 1: Define Value-based Program Objectives and Scope

Define the specific objectives and scope of the value-based program to ensure selected measures support the program goals. This also allows early elimination of non-relevant measures, saving hours of time spent on reviewing more detailed information for measures that are not relevant to the specific program.

Some questions to consider with respect to your program include:

- **What are the goals and objectives of the value-based program?** These can be broad (e.g. improve access and lower cost) or narrow (e.g. reduce emergency department visits for children with asthma).
- **What quality issues does the program address?** Quality issues may be defined by the value-based program (e.g. a commercial payer transplant excellence program) or left to the organization to identify. If left to the organization, prioritizing quality issues that are central to their value proposition may require empirical and strategic input.
- **What or who is responsible for changes in quality (e.g. individual provider organization, system, or region)?** The levels and types of risk (e.g. public report, shared savings, penalties) are tied to the program's performance and its individual measures. Programs may decide to hold one or more accountable for the program's quality performance—e.g., by individual clinician, group or caregiver team, department, hospital or clinic, network, system, or region/population. Those being held responsible for the program's performance may or may not be participants in the quality improvement efforts.
- **Who should participate in the program to address the quality issues identified, and at what level?** The location and participants in quality improvement efforts tied to program performance must be understood, along with how and the degree to which they may be able to influence performance. Program participants may or may not be held responsible for changes in the selected performance measures. For example, a program may nominally reimburse care coordinators for their time, regardless of program performance, to help a parent navigate complex scheduling. These care coordinators may play a critical role in the quality improvement success, but not held accountable for the outcomes. Participants may be within or across multiple settings or levels (e.g. individual clinician, hospital department or clinic, health plan) or include community and social providers, or even children and their families. Early engagement with these stakeholders may reveal opportunities to take advantage of existing quality improvement efforts and/or measures already in use.

For an example of a children's hospital program working with care centers, patients, families, multidisciplinary clinical teams, and scientists to identify and realize quality goals, see the ***James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center*** *use case in Appendix D.*

- **Are there existing quality activities, efforts or programs related to the quality issue to build from?** Quality improvement programs that build on existing efforts may already have some built-in infrastructure and experience among participants that can be leveraged for a new initiative. This includes select national or multi-site quality improvement collaboratives, and some clinical or patient registries. Some of these efforts may already provide feedback reports, dashboards, and other services, as well as internal quality improvement measures or benchmarks useful for incentive design.

- **What activities will be implemented to help improve performance?** It is important to consider what improvement efforts are needed, and the resources and leadership buy-in to implement them. Measures and incentives alone cannot effectively yield quality improvements in any program: improvements are achieved through actions and activities that help participants understand what they need to do to improve. Activities may include providing regular performance feedback to participants with benchmarking data, learning collaboratives that share best practices and successes, implementing protocols and guidelines designed to focus attention on key care processes, supporting children and families, and investing in infrastructure and tools that bolster the flow of care. In addition, many value-based program administrators and their participants share guidance on documentation and coding practices necessary for the program's measures to capture the care and health outcomes of interest.

A forthcoming tip sheet from the CHA Accountable Health Learning Collaborative[8] will provide useful and actionable information for those being measured on select HEDIS® measures, including tips on documentation and coding requirements, and best practices.

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[8] The CHA Accountable Health Learning Collaborative (AHLC) is comprised of 17 children's hospitals representing a variety of organizational settings, from children's hospitals in systems to independently governed children's hospitals. The AHLC aims to help CHA members be successful in a value-based program. The markets in which these hospitals operate are also diverse, especially with respect to penetration of value-based payment arrangements.

Step 2: Anticipate Key Child Quality Measurement Issues

It is important to examine how a select quality measure does or does not address aspects of child health care and how important the measure's shortcomings are within a given value-based program (the five "Ds" discussed in Chapter 1). A program, by its design and local market, may diminish or exaggerate the challenges in child health measurement associated with these unique aspects of child health care and quality measures.

In child health, small denominators or small numerators (e.g. rare events) make it difficult to detect differences in quality performance. For example, children require different types of health care or treatment depending on their developmental and physiological status. Measures that do account for this may often have smaller measurable populations (e.g., due to narrow age bands), while on the other hand, measures that do not account for this may incentivize the wrong care at the wrong time. Likewise, childhood illnesses often affect a relatively small number of children and may or may not be illnesses in the adult population, which could allow for increasing the size of a measurable population. Consequently, child health condition-specific measures may not yield measurable changes or differences in quality.

The dependence aspect of child health can introduce measurement error and reduce the reliability of results. Where dependence factors that influence a child's health are observable, health quality measures must account for these factors, for example through stratification and/or risk adjustment methods. Further, addressing dependence and child demographic factors (e.g. adequate food) requires targeted strategies to improve health outcomes.

For an example of a children's hospital program that is screening for social determinants and addressing unmet needs see the ***UCSF Benioff Children's Hospital Oakland*** *case study in Appendix D.*

By understanding the target population and how it impacts the interpretation and validity of performance results, value-based programs can select suitable quality measures and accountability schemes. For example, a measure with low reliability may not be suitable for public reporting programs meant to support the selection of a primary care practice but may be suitable for incentives or penalties that account for the measure's low reliability.

Step 3: Specify Program and Measure Requirements

While a measure's quality focus may seem, at face value, relevant for a given program, a measure's requirements (i.e. its "specifications") may limit its applicability or operationalization within a specific program. Using a program's objectives and requirements to create a short list of candidate measures by 'intersecting' them with related measure specifications is a more effective and efficient approach. Table 6 presents a set of questions and corresponding measure specification elements to help you hone in on the most salient program requirements and candidate measures. Most of these measure requirements are included in the Demonstrating Value in Pediatrics Measure Menu Workbook; Step 4 walks through how to use program requirements to create a shortlist of measures from the workbook.

> *Some programs may opt to alter a measure's requirements to align with their program requirements; any deviation from a specification is a different measure. This compromises the ability to compare performance and benchmarking.*

Table 6: Align Program and Measure Requirements Program Requirements Examples:	Select Measure Requirements:
• What are the program objectives? What are the cost or utilization reduction objectives and quality areas of interest? ○ Name and description; target population; clinical condition/event; risk adjustment • What are the specific care settings or participants that the program is targeting for quality improvement (e.g. hospital, primary care, school-based care)? ○ Care setting; data source; patient/episode attribution • What conditions or events (e.g. surgery, utilization) does the program seek to target for quality improvement? ○ Name and description; clinical conditions/events; denominator and numerator; care setting; type of measure • At what level is the program assigning success or failure for changes in quality (i.e. program accountability)? ○ Level of analysis; patient/episode attribution • What are the available data sources for the program? ○ Data source; care setting • Does the program require or favor the use of a structure, process, or outcome measure? ○ Type of measure; data source • What are important characteristics of the patient population that may affect quality performance? ○ Risk adjustment; sampling and stratification; calculation algorithms; data source and elements • Is there a requirement or favorability for a measure to be in current use (e.g. state/national program use)? ○ Program use	☐ Name and description ☐ Target population (e.g. adolescents, medically complex) ☐ Clinical condition/event (e.g. cancer, critical care, surgery) ☐ Topic ☐ Type of measure (process, structure, outcome) ☐ Data source & elements ☐ Denominator and numerator ☐ Exclusions and exceptions* ☐ Timing and time intervals ☐ Care setting ☐ Level of analysis ☐ Patient/episode attribution ☐ Sampling and stratification ☐ Risk adjustment ☐ Calculation algorithms ☐ Program Use

Assessing Available Data Sources

Identify the data sources you have access to for program administration, and the costs and resources necessary to use those sources. Some measures require access to often disparate data sources (e.g., claims and lab data with lab values), while others provide options on which data sources to use (e.g. instructions for manual abstraction or for electronic health record). While the measure menu lists each measure's specified data source, the entire specification is needed to understand the application of these data sources.

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Examples of key questions: Does the measure require the use of data that are:

- ☐ By-products of existing clinical workflows or operational processes (e.g. billing)?
- ☐ Generated and maintained by program administrators? If so, can they be generated through standard workflows without overburdening clinicians, or creating new processes and infrastructures?
- ☐ Maintained by a third party, or are proprietary? Are licensing fees required, and at what cost?
- ☐ HIPAA compliant, and meet responsible data stewardship criteria?
- ☐ Accurate, complete, and inclusive of needed time spans?
- ☐ Well-suited for performance measurement with little end user work?
- ☐ Designed to capture and report on pediatric-specific data?
- ☐ Equipped for timely performance feedback functions (reports and dashboards)? Are feedback report applications using these data readily available, or do they need to be created by program administrators?
- ☐ Generated or maintained through activities known to enhance or diminish the quality of care and outcomes for children and families? What is the impact of measurement activities (e.g. patient reported information) on children and families?

ASSESS DATA SOURCES DURING THE PLANNING PHASES

Experience has shown that program administrators far too often are not fully aware of the processes and resources necessary to access and prepare data for their program's measure prior to committing to the program and finalizing budgets.

The resources need to acquire and prepare data for a program's selected measures can be high, even when using highly standardized data successfully used in other measurement initiatives. This can lead to unexpected resources, often at a rather high expense, to deliver on the measures promised.

Step 4: Select Measures

Now use the Demonstrating Value in Pediatrics Measure Menu Workbook to create a shortlist of candidate measures for more in-depth review based on the program requirements captured in Step 3. The measure menu workbook includes elements from each measure's specifications (also called measure requirements) so you can filter and select values related to your specific program. See Appendix E for a complete list of fields included in the measure menu workbook.

For example, the administrator of a health plan value-based program that aims to reduce medical costs and improve outcomes for children with asthma may identify the following program requirements:

- ☐ **Objectives**: reduce cost and utilization, and improve quality of care and outcomes
- ☐ **Care settings and participants of quality improvement efforts**: Hospitals, primary care practice, school-based care providers
- ☐ **Target conditions/events for quality improvement**: For children with asthma who had at least one hospital stay or emergency department visit, reduce emergency department visits, reduce inpatient admissions, reduce exacerbations, increase/improve quality of primary care visits, improve school-based visits
- ☐ **Program accountability**: Shared accountability of hospitals and primary care practices. School-based care setting is not held accountable for program performance.
- ☐ **Available data sources**: Claims, program activity indicators, no other data sources available
- ☐ **Measure type**: Favor outcome, but all are acceptable
- ☐ **Important characteristics that may affect quality performance**: Size of measurable population, access to care, local primary care practice workforce shortage, school-based care and data acquisition. An existing program that this program will complement focuses on childhood and adolescent immunizations and wellness visits.
- ☐ **Leverage existing programs and measures**: This value-based program patient population is a subset of a patient population in a value-based program focusing on wellness and preventive care.
- ☐ **State/national program use**: Yes, in the Child Medicaid Core set

In this example, note that schools are not being held accountable for the performance of the program's measures. It is possible that the school-based care is compensated for participating in the quality improvement activities, but the amount of compensation is not dependent on the performance. In Step 1, when defining the program objectives and scope, the program administrator will have considered who should participate in the quality improvement activities (note, this may include children and families).

The order you select columns to apply filters matter! *Document the order you select columns, and the filters you apply. Test different orders to ensure you have not inadvertently deselected a measure of interest.*

With these program requirements defined, use the Demonstrating Value in Pediatrics Measure Menu Workbook to create a short list of candidate measures that best meet your program requirements. The filters in the workbook enable you to quickly reduce the number of candidate measures from 67 measures to one measure with a few clicks of the mouse:

1. *Column G "Topic"*: Select topics related to medical utilization and cost, medication, ambulatory care, coordination of care, appropriate care, preventive care, and screening. (Or, if easier, deselect topics that are clearly not relevant to the program, e.g. ESRD). ➔**Yields 50 measures**
2. *Column F "Clinical Condition/Event"*: Select conditions/ events that are inclusive of asthma (e.g. all cause readmissions), specific to respiratory illness, specific to asthma, target overall health, preventive and wellness care, and chronic illness. In this example the user opted to be select measures that are inclusive of asthma conditions/events, but not necessarily restricted to asthma events/conditions. ➔**Yields 21 measures**
3. *Review Column D "Measure Name" for the 21 measures*: Deselect measures in the complementary program (in our example, the other program includes wellness visits and immunization measures, not including influenza). ➔**Yields 12 measures**
4. *Review Column E "Measure Description" for the 12 measures*: Based on measure descriptions, the program administrator decides to eliminate conditions/events related to respiratory illness and antibiotic use.
5. *Column F "Clinical Condition/Event"*: Deselect events/conditions related to respiratory illness and antibiotic use ➔**Yields 10 measures**
6. *Column H "Care Setting"*: The program administrator is interested in all care settings, except long-term care.
7. *Column J "Level of Analysis"*: Select values that list hospitals and primary care; select measures that include multiple levels of analysis if at least one is hospital or primary care. For example, one measure lists "Clinician/Group, Health Plan, Population (State, Region)" as specified levels of analysis; select this filter because it lists "Clinician/Group." Deselect those that do not list at least one of these levels of analysis. For example, one measure lists "Health Plan/IDN" only-- deselect this measure. ➔**Yields 8 measures**
8. *Column K "Data Source(s)"*: Deselect values that do NOT list claim data. Some measures have multiple data sources specified (e.g. Claims, Electronic Health Records, Paper Medical Records, Registry)—do select filters that list claims. ➔**Yields 5 measures**
9. *Review Colum O "2019 Medicaid and CHIP Child Core Set"*: Select "Yes" ➔ **Yields 1 measure**

Notice the number of measures eliminated each time a filter selection is applied to understand the impact of select requirements, which in turn may inform needed program flexibility. In this case, the administrator may want to reconsider the program use requirement if more than one measure is preferable.

Once the short list is identified, contact the measure steward to obtain the most up-to-date measure specification and available information (e.g. benchmarks, challenges, SAS code). Review each measure's specification and performance information against the program's objectives and requirements. Remove measures that do not support the program objectives or meet the program requirements.

Step 5: Evaluate Selected Measure Set

Once a measure or set of measures has been selected for the value-based program, evaluate the measure or measure set against the overarching quality goals, continuum of clinical care, and other high priority child health quality areas. For example, an adolescent mental health value-based program administrator may have selected two different measures, "Suicide Risk Assessment" and "Screening for Clinical Depression and Follow-up Plan," and may be unsure whether to include both. Each measure targets different aspects of care but together they may better cover the desired continuum of care and program's goals. However, selecting the fewest number of measures is important given the increase in resources needed and challenges associated with interpreting results across many measures.

Measure Set Evaluation Criteria may include:

- How well does the set evaluate the quality topic? Are the selected measures sufficient to capture the status of care quality in the program?
- Does the measure set effectively balance cost of care reduction incentives with quality of care and outcomes, and allow for active monitoring of unwanted consequences (e.g. lower cost accompanied with lower quality)? How does the measure set capture these potential unwanted consequences to allow for active monitoring?
- Does the measure set address topics that matter most to children and families? For example, does the set address meaningful and effective communication and coordination with patients? Does it capture patient-reported outcomes?
- Does the measure set address disparities in care?
- Taken together, are the selected measures overwhelming? What added utility does each measure bring, and at what cost? Does the scope of the set and the balance of measure topics clearly reflect the priorities of the organization/program?
- How well do the measures align with each other? Can the same measure be used in all program care settings and varying levels of program accountability or in tandem with other measures (see the Specification and Layered Alignment discussion)? How well do these measures align with and/or support quality measurement and accountability in other quality programs?

All these criteria can be difficult to address, and program administrators must prioritize these, among other priorities, for each program. Some of the lesser understood or less frequently used criteria are those associated with measure alignment. These criteria encompass the strategic vertical and horizontal alignment of measures and program accountability. For the purposes of this fifth measure selection step, we offer two primary types of alignment: 1. specification alignment and 2. layered alignment (see Figure 2).

- ***Specification alignment*** occurs when the ***same measure is used***: a) in all care settings, b) at varying accountability settings, and/or c) in other programs. This type of alignment is important because it allows for shared accountability, performance benchmarking against existing programs, and improved interpretation. Further, using the same measure may reduce burden and frustration of those being measured due to operational costs and interpretation issues associated with the use of similar but materially different measure specifications.
- ***Layered alignment*** occurs when a **measure works in tandem** (by design) to drive improvement within and across the different levels of the health care system. Typically, layered alignment accounts for varying components of quality that key contributors can act on, and that together move them toward a unified quality improvement objective.[9]

Both types of alignment are illustrated by Figure 2: Aligning Measures Within and Across Levels of Care. Federal, state and population measure are "macrosystem" measures; health plan and system, and community measure are "mesosystem" measures; and clinical practice or hospital measure are "microsystem" measures. Measure implementers should consider how a measure might fit into this schematic by consulting with the providers, networks, plans and state agencies with which the program is connected and determine which measures would optimize quality through horizontal and vertical alignment of measures and measure sets.

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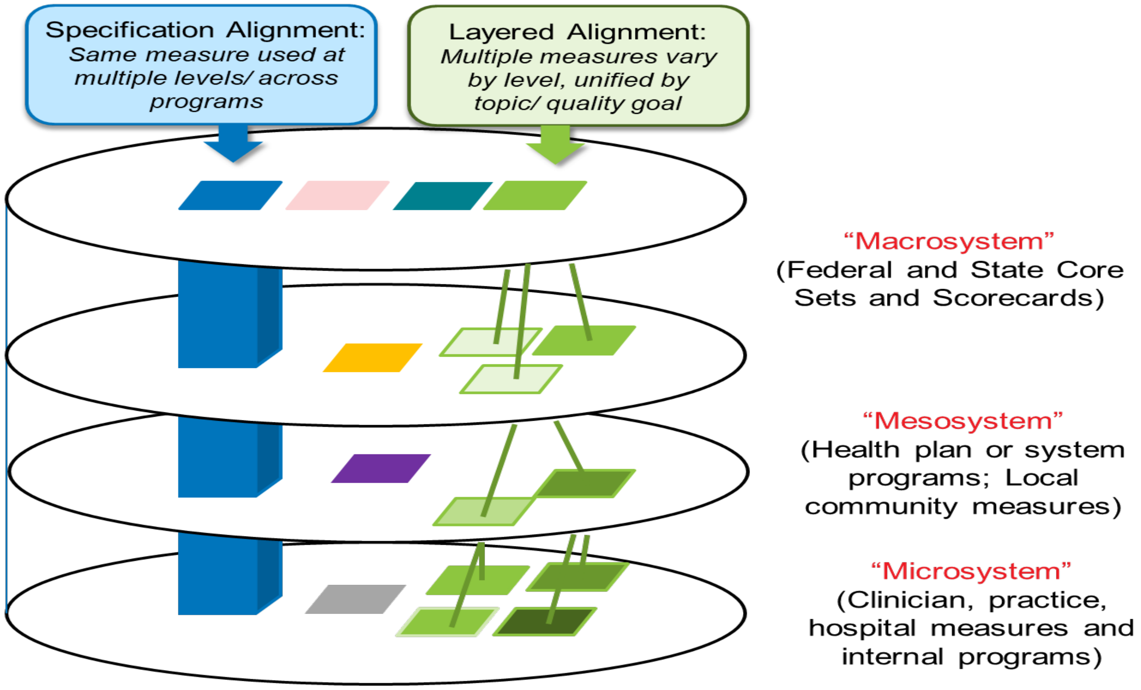
[9] National Pharmaceutical Council. Accountable Care Measures for High Cost Specialty Care and Innovative Treatment. 2014. https://www.npcnow.org/system/files/research/download/accountable-care-measures-for-high-cost-specialty2014-final.pdf.

Figure 2. Aligning Measures Within and Across Levels of Care



Adapted from image generated by Ohio Medicaid

HYPOTHETICAL EXAMPLE OF SPECIFICATION AND LAYERED ALIGNMENT

A state Medicaid program prioritized mental health, and the pressure is on to improve their comparative performance on the CMS Medicaid and CHIP Scorecard. Specifically, they are below the 10th percentile for the "Follow-up After Hospitalization for Mental Illness." The state's Medicaid health plan (HP) has agreed to target this quality issue. The HP launches a mental health value-based program and decides to use a mix of Measure Specification and Layered Alignment to track and incentivize performance of their providers and clinicians

- Macro Level: State, CMS Scorecard on State Health System Performance. Measure(s): "Follow-up After Hospitalization for Mental Illness"
- Meso Level: Health plan, Specification alignment. Measure(s): "Follow-up After Hospitalization for Mental Illness" Objectives: Monitor and incentivize improvement in program performance and state performance.
- Micro: Level: Primary care practices, Layered alignment. Measure(s): "Screening for Clinical Depression and Follow-up Plan"; and "Suicide Risk Assessment" Objectives: Monitor and incentivize care (screening, assessment) that contributes to reduced mental health hospitalizations, readmissions, and related costs.
- Micro Level: Primary care practices and Hospitals, Specification alignment. Measure(s): "Follow-up After Hospitalization for Mental Illness" Objectives: Incentivize coordination of care and increase follow-up care after hospitalization; monitor and improve program performance.

Step 6: Interim Testing

Before attaching incentives to performance, programs should undertake an extended period (typically one year or more) of measure testing and review to ensure feasibility and meaningfulness, with close attention to how well the program can inform those actively engaged in the quality improvement activities. Many of the large national value-based programs (CMS Star Ratings, HEDIS Quality Compass[10], etc.) follow this approach. In situations where testing is not possible, it's important for program administrators to use measures in which there is a high-degree of confidence that measure reporting is feasible, accurately reflect performance, and that results can be used to inform performance improvement.

Interim testing often focuses on three key aspects of measure implementation:

1. **Technical and logistical issues; data reliability**
   Data sources validated for their accuracy and completion may still have issues not previously discovered that directly impact performance results. Experience has shown programs often see an increase in performance during the first and second year that can be attributed to improvement in the capture of data specified by the measure. For example, more attention to accurate diagnostic coding from clinical records, or changing where certain clinical information is housed in the EHR so that it can be retrieved for measurement.

2. **Participant feedback: reporting burden vs. value of the data**
   A critical aspect of pre-implementation testing is feedback from participants about the burden of entering and reporting data and their motivation for doing so. Data management by clinicians is frequently cited as a source of physician frustration and burnout.[11,12] It is likely that any measure that requires effort will be seen as interfering with the flow of care or adding extra work. Implementers must be very selective of measures to ensure that the data are important enough to add value

PROS OF INTERIM TESTING

- **Needed Education:** Share important information on how to interpret measures and change performance. Participants may vary widely in their knowledge of measures and may require educational strategies.
- **Not a Quality Issue:** You may learn that despite other signals, you have targeted an area that is not a quality issue, or that the selected measure fails to capture the quality issue you were targeting.
- **Cost of Implementation:** Asses program costs, including program administration, clinical and supporting staff time, data acquisition, and patient time
- **Implementation Obstacles:** Identify and address obstacles, including removal of problematic measures.

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[10] NCQA. HEDIS 2018 Volume 2: Technical Specifications for Health Plans. http://store.ncqa.org/index.php/performance-measurement.html. Accessed August 1, 2018.

[11] RevCycle Intelligence. Value-Based Care News. CMS: Providers Need Data Access for Value-Based Reimbursement. https://revcycleintelligence.com/news/cms-providers-need-data-access-for-value-based-reimbursement. Accessed August 1, 2018.

[12] AHRQ. Physician Burnout. https://www.ahrq.gov/professionals/clinicians-providers/ahrq-works/burnout/index.html. Accessed August 1, 2018.

commensurate with the resources required to support them and the resulting value of the data to the participants and patients.[13]

3. **Measure use in context of program design**
   It is important to evaluate measure results to ensure that the performance results are useful for the purposes of the program. A rigorous program-specific testing process includes the examination of early results against their relevancy to the program goals before final implementation. Even after scrutinizing the measures, there can be variability in how well they will work within the context of the program's goals or other organizational factors.

Step 7: Implementation

When measures selected from the menu are fully implemented, performance results are reported, and incentives are determined, measure set maintenance should continue to be ongoing, which includes:

- **Continuous performance feedback to participants**
  Feedback to participants is an implicit component of value-based program design. At its core, the purposes of measurement are to capture opportunities for quality improvement and changes in quality.

For an example of a children's hospital program using implementation strategies—real-time dashboards, measure set evaluation-- to support program success see the **Children's Hospital Colorado and Anthem BCBS** *use case in Appendix D.*

- **Measure specification updates**
  Measure specifications often do not remain static. Well-maintained measure specifications are regularly updated to account for changes in evidence-based guidelines, clinical and billing coding practices, or to improve the measure's ability to assess performance or avoid discovered unwanted consequences.[14]

- **Measure set additions/removals**
  Embed in the program schedule an assessment of the program's measure set and reevaluate the suitability of each measure and the set for the program. For example, consider if a measure is now "topped-out" (i.e. where meaningful distinctions and improvement in performance can no longer be made), no longer useful, or if new measures are better suited to the program's goals. It is highly recommended that this process of evaluating the program's measure set include feedback from participants and end users.

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[13] This is in keeping with the Centers for Medicare & Medicaid Services, "Patients Over Paperwork", and "Meaningful Measures" initiatives intended to streamline regulations and reduce unnecessary burden, focused on assessing core issues that are most vital to providing high-quality care and improving patient outcomes.

[14] Updates to measures are performed by measure stewards who are responsible for the continued currency of the measure. The stewards for each measure in the menu have been identified in the measure menu workbook.

Summary of the Seven Steps

These seven steps are intended to guide an organization from setting objectives and goals to implementing measures in value-based initiatives. Remember that no matter how carefully selected the measures are or how well tested, there is no guarantee quality improvement will occur. Improvements at any level require strong and focused leadership, buy-in from all who are accountable, and significant work and resource investment to achieve optimal outcomes for children and their families. Measures are critical to helping leaders assess progress, but whether performance on those measures advances in a meaningful way is determined by other factors, including the efforts of dedicated individuals, control over factors influencing performance, and resources committed to these efforts.

PROGRAMS USING QUALITY MEASURES TO SUPPORT IMPROVEMENT

Appendix D includes four short case studies illustrating the use of quality measures in delivery, practice change, and ongoing quality improvement activities. The case studies include:

- **Case Study 1: Advancing Value at Boston Children's Hospital - Implementing Integrated Care Tools and Measures** Describes how customized care coordination tools with supportive education are being used to facilitate better patient management.
- **Case Study 2: Children's Hospital Colorado and Anthem BCBS**. Describes how a children's hospital and health plan are working together to assess and incentivize pediatric care safety.
- **Case Study 3: James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center**. Describes how Learning Networks and clinical registries are being used to focus on quality issues for key therapeutic areas.
- **Case Study 4: UCSF Benioff Children's Hospital Oakland.** Describes how focused attention on social determinants of health supported by electronic tools, are changing the health care experience for children and families.

Additional CHA Resources

The Accountable Health Learning Collaborative (AHLC), a collaborative supported by CHA, is an interdisciplinary group of peers from 18 children's hospitals who are leaders in the delivery transformation and payment innovation necessary for moving to accountable care. In 2018, and in parallel with CHA's measure menu effort, the AHLC created measure use tip sheets for 14 NCQA HEDIS measures identified as being frequently used by AHLC members.

Tips for Providers Using Outpatient Measures in Value-based Programs: This forthcoming tip sheet shares the collective experience of practitioners and their efforts improve performance in selected measures. Tips cover documentation and coding practices, delivery of care and best practice examples. Designed to be used with primary care providers in clinically integrated networks.

5 Quality and Safety Projects Ready for Replication: If any part of your day at a children's hospital focuses on improving the quality and safety of care, on-demand recorded sessions from the 2018 Quality and Safety in Children's Health Conference can give guidance or spark ideas for better care. Members representing more than 90 hospitals convened in San Diego March 4-9, 2018 to share the progress and

pitfalls they encountered when implementing quality improvements.

Accountability Data Tool: Quality Measures and Program Participation in Children's Hospitals: A tool for strategic decision-making about your hospital's participation in accountability programs and hospital quality operations. Based on 2016 Children's Hospital Survey on Accountability Programs and Quality Measures.

National Survey Results: Accountability Programs and Quality Measures in Children's Hospitals: In 2016, the CHA launched a survey on accountability measures — the first in the nation — to gain insight into hospitals' exposure to programs of accountability that use quality and the measures used by children's hospitals.

Measure Selection Framework for Pediatric Quality Accountability Measures: CHA developed a Quality Measures Selection Framework to evaluate measures for their suitability in accountability programs applied to pediatrics (e.g. accountable care organization programs). It also serves as a pathway for children's hospitals and other stakeholders to recommend specific measures for specific programs.

Sepsis Collaborative: Improving Pediatric Sepsis Outcomes (IPSO) aims to reduce sepsis mortality by 75 percent and reduce hospital-onset severe sepsis by 75 percent. IPSO is addressing all stages of sepsis across the care continuum, including the emergency department, intensive care, general care, hematology/oncology and bone marrow transplant units initially, and NICU, pre-hospital, and ambulatory settings in subsequent phases.

Child Health Patient Safety Organization (PSO): The Child Health Patient Safety Organization (Child Health PSO) enables children's hospitals to share safety event information and experiences to accelerate the elimination of preventable harm.

Coordinating All Resources Effectively Award: The Coordinating All Resources Effectively (CARE) Award is a landmark national study focused on improving outcomes and reducing the cost of health care for children with medical complexity (CMC) enrolled in Medicaid.

Chapter 4: Gaps and Opportunities for the Demonstrating Value in Pediatrics Measure Menu

- Lists ten measures that are “almost ready” for use (i.e., ten emerging measures) and highlights opportunities with the AHRQ Pediatric Quality Indicators (PDIs)
- Priority areas with no available measures (priority measure gaps) were identified
- Efforts to leverage the status quo (measurement approach, data infrastructures/sources) to address gaps are ongoing. Some critical gaps may not be addressed using common or existing approaches or data infrastructures.

The Demonstrating Value in Pediatrics Measure Menu covers many important aspects of child health care quality but is not comprehensive because there are gaps in measures available for many areas of care. Here we address opportunities based on emerging measures and priority measure gaps.

Emerging Measures

Emerging measures are those that address important topics but require (a) specification revision or refinement, (b) more testing or real-world experience, or (c) overcoming some other technical obstacle. Efforts to move these measures forward toward readiness for implementation would be beneficial for pediatric quality measurement. Ten Emerging Measures are in Table 7.

Table 7: Emerging Measures for Pediatric Value-Based Programs

Title	Description	CHA Notes	Steward
Acute Inpatient Measures			
Global Assessment of Pediatric Patient Safety (GAPPS): Rate of Preventable Adverse Events per 1,000 Patient-days Among Pediatric Inpatients	Number of preventable adverse events per 1,000 patient-days among pediatric inpatients. It is designed to compare rates across institutions and over time. The GAPPS measure utilizes the GAPPS trigger tool to identify adverse events.	Further experience is needed. Further information is needed about the cost and administrative burden associated with the trigger tool, how to incorporate the trigger tool into work flow, and the tie to quality improvement and value.	CEPQM
Standardized Adverse Event Ratio for Children <18 Years of Age Undergoing Cardiac Catheterization	Ratio of observed to expected clinically important preventable and possibly preventable adverse events, risk-adjusted	Specification revision or refinement needed. Data reliability concerns need to be addressed.	Boston Children’s Hospital

Table 7: Emerging Measures for Pediatric Value-Based Programs			
Title	**Description**	**CHA Notes**	**Steward**
Ambulatory Specialty Care Measures			
No emerging measures identified for ambulatory specialty care.			
Primary Care and Community Engagement Measures			
Asthma Control: Minimal Important Difference Improvement	Percentage of patients aged 12 years and older whose asthma is not well-controlled as indicated by the Asthma Control Test, Asthma Control Questionnaire, or Asthma Therapy Assessment Questionnaire and who demonstrated a minimal important difference improvement upon a subsequent office visit during the 12-month reporting period	Further testing is needed.	AAAAI
Community-Based Service Systems are Organized so that Families of Children with Special Health Care Needs Can Easily Use Them	Percentage of Children with Special Health Care Needs (CSHCN) who have families who have encountered difficulties or delays in accessing health care services for their children in the past 12 months.	Further testing is needed. More information about how to use in value-based program context is needed.	HRSA Maternal and Child Health Bureau
Lung Function/Spirometry Evaluation (Asthma)	Percentage of patients ages 5 and older with asthma who had documentation of a spirometry lung function evaluation in their medical record	Further testing is needed.	AAAAI
Screening for Reduced Visual Acuity and Referral in Children	Percentage of children who received visual acuity screening at least once by their 6th birthday; and if necessary, were referred appropriately	Further testing is needed.	CMS
Behavioral Health Measures			
Depression Remission or Response for Adolescents and Adults	Percentage of members 12 years of age and older with a diagnosis of depression and an elevated PHQ-9 score, who had evidence of response or remission within 5 to 7 months of the elevated score	This is a HEDIS Electronic Clinical Data Systems (ECDS) measure. These measures are being evaluated by NCQA and are optional for HEDIS reporting.	NCQA/HEDIS

Table 7: Emerging Measures for Pediatric Value-Based Programs

Title	Description	CHA Notes	Steward
Pediatric Psychosis: Screening for Drugs of Abuse in the ED	Percentage of children/adolescents age >5 to <19 years-old admitted to the hospital with psychotic symptoms who had a psychiatric consult (in person or by telepsychiatry) within 24 hours of admission	Specification revision or refinement needed. More information about how to use in value-based program context is needed.	Seattle Children's Research Institute (COE4CN)
Utilization of PHQ-9 to Monitor Depression Symptoms for Adolescents and Adults	Percentage of members 12 years of age and older with a diagnosis of major depression or dysthymia, who had an outpatient encounter with a PHQ-9 score present in their record in the same assessment period as the encounter. Stratified for 12-17 age group	This is a HEDIS Electronic Clinical Data Systems (ECDS) measure. These measures are being evaluated by NCQA and are optional for HEDIS reporting.	NCQA/HEDIS

Priority Gaps in Child Health Quality Measures

There are gaps in available measures, which we have grouped into overarching areas: 1) communication and coordination/integration of care, 2) structural and health system and 3) clinical care (see Table 8). These themes are critical to a high-value health care system and need valid, feasible and meaningful quality measures.

Communication and coordination/integration of care quality topics ranged from anticipatory guidance, coordination with school services, progress on plan of care, to returns to operating room.

Structural and health system quality topics ranged from access and cost to workforce burnout and shortage. The important roles of market structure (e.g. adequate access and affordability) and workforce (e.g. clinicians with appropriate competency, or reasonable working hours) is absent in many quality discussions, and yet critical to achieving high quality.

For an example of a children's hospital using quality measures and tools to improve care coordination, reduce fragmentation, and improve patient/family experience see the ***Advancing Value at Boston Children's Hospital - Implementing Integrated Care Tools and Measures*** *case study in Appendix D.*

Clinical care quality topics range from appropriate CT and NICU use to opioid addiction screening.

Table 8: Priority Gaps in Available Quality Measures

Description	Example Measure Gap Topics Identified
Communication and Coordination/Integration of Care This area was deemed a critical dimension of quality to achieve high-value care. About a third of the measure gaps identified directly addressed issues of communication and coordination. This included meaningful communication and services meant to inform and support children/parents and clinicians, as well as coordinating care within and across providers.	• Anticipatory guidance for parents/caregivers at discharge • Clinical care coordinated with school and community services • Emergency care plans • Follow-up after medical visits for chronic/complex conditions • Home child health management assessments/education • Palliative care consultation with family • Progress on plan of care • Transitions of care to avoid readmissions • Returns to operating room (OR) • Condition-specific readmissions, e.g. sickle cell anemia, bipolar
Structural and Health System This area was highlighted as a measure gap area where aspects of care that were not overtly clinical, but which supported quality clinical care through systemic improvements, were identified.	• Access to behavioral health services • Cost of care • Health information technology related to pediatric care • Clinician burnout, quality of life, safety and competency • Work force shortages
Clinical Care This area includes specific clinical quality topics.	• Overuse balance measures (e.g. appropriate CT utilization to balance imaging overuse measures) • Neonatal Abstinence Syndrome • Contraception counseling/reproductive health • Mental health assessments for caregivers at home • NICU appropriateness, quality, and safety • Pediatric opioid addiction screening and referral • Pediatric sepsis prevention and treatment • Peri- or post-surgical care outcomes, post-tonsillectomy care • Pressure ulcers • Screening for abuse and neglect

Measure gaps in behavioral/mental health, chronic conditions and complex care, and neonatal intensive care are especially noteworthy.

- **Behavioral and mental health quality**: The need for improvement in this area generally, and quality measures specifically, is urgent, including gaps in care delivery, systems that impede quality of care, factors related to local access of behavioral health care services, and workforce shortages. A recent example of system efforts to drive improvement in quality include behavioral and mental health care provided via telehealth. Health care researchers and measure developers are currently assessing appropriate telehealth care, and existing and emerging measures capture of this type of care.[15,16,17]
- **Chronic conditions and complex care quality**: A challenge to measure due to small numbers, lack of evidence-based guidelines, and other issues, chronic conditions and complex care are viewed as areas where quality and cost strategies and performance are critical to children and their families, hospital administrators, and payers. For example, a pediatric diabetes[18] (predominantly Type I) measure was not identified for measure menu, despite it being a complex, difficult-to-manage condition, that is very well-measured in adult-focused programs. Innovative measurement strategies that can avoid these measurement challenges are needed.
- **Neonatal/NICU quality**: The most common diagnoses for all hospital stays is *Pregnancy, childbirth* (11.7%), followed by *Newborns, neonates* (11.2%). While not all *Newborns, neonates* involve a NICU stay, evidence suggests a high-degree of unexplained variation in its use with little understanding of outcomes. The NICU is a high-cost, high-risk site of care, and carries emotional and financial implications for families.[19,20] NICU-appropriate use measures, as well as those that focus on quality of care and outcomes (during and after discharge) are needed. NICU quality measure development should be a priority focus for measure developers and funding.

AHRQ PEDIATRIC QUALITY INDICATORS

AHRQ develops and maintains the Pediatric Quality Indicators (PDIs). The PDIs include **hospital-level** and **area-level** (e.g. county, state) indicator sets.

The **hospital-level PDIs** screen for problems that occur as a result of exposure to the health care system. These problems may be preventable at the system or provider level. While initially developed for internal QI purposes, the measures are very specific or targeted. Consequently, they were too narrow in scope for the measure menu.

The **area-level PDIs** detect quality and patient safety events at a county or regional level. While there was a high degree of interest in them, after consultation with AHRQ, it was determined that the existing risk adjustment is not adequately tested for provider-level attribution in value-based programs. Thus, they were not included in the measure menu at this time.

AHRQ's Pediatric Quality Measures Program produced several measures on the menu.

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[15] CDC. Improving Access to Children's Mental Health Care. https://www.cdc.gov/childrensmentalhealth/access.html

[16] NCQA. NCQA Updates Quality Measures for HEDIS® 2019. https://www.ncqa.org/news/ncqa-updates-quality-measures-for-hedis-2019/.

[17] NQF. Telehealth Framework to Support Measure Development 2016-2017. http://www.qualityforum.org/ProjectDescription.aspx?projectID=83231.

[18] Specialty societies focused on diabetes, such as JDRF, have begun to define outcomes for Type 1 diabetes that may ultimately become useful measures.

[19] Jergens S, Bosslet C. Needing More from your NICU: Improving Efficiency, Care, and Cost. 2016. *ECG Management Consultants*. http://s3.amazonaws.com/ecgmc.com/images/Needing-More-From-Your-NICU-INTERACTIVE-V1.0.pdf?mtime=20160831172630.

[20] Ho T, et. al. Improving Value in Neonatal Intensive Care. 2017. *Clin Perinatol.* 44:617-625.

While these learnings are important to share, this information does not replace other systematic gap analyses. For more information, see child health quality gap reports available from the National Quality Forum, [21] Agency for Health Care Quality and Research[22], and the National Academy of Medicine[23].

Call to Action

There may be no available measures for aspects of care quality that you want to assess and incentivize. Stakeholders such as children's hospital administrators, clinicians, pediatricians, and children/families must advocate for the resources and infrastructure needed to enhance and improve upon available measures for value-based programs.

- **Communicate the need for priority quality measures**: Where institutional priorities or quality improvement needs are impeded by a lack of available measures, such needs should be shared with other stakeholders, including government and commercial plans, with the goal of catalyzing measure development and implementation.
- **Attain or provide financial resources**: Measure development requires ample resources for identification of evidence in the literature and clinical guidelines, expert and stakeholder scrutiny, pilot testing, public and end user scrutiny, and (in some cases) endorsement status. The most likely and reliable funding sources are from those who have an interest in measures becoming available (potentially including federal, state, commercial, professional society or other interests).

CHILD AND FAMILY PERSPECTIVE

Effective care requires meaningful communication and coordination, integration of care. Effective clinical care is necessary and a critical component of effective care, but not enough. Other equally important components of effective care include patient wellness, functional status, and quality of life.

- **Collaborate**: Measure development and implementation benefit from well-designed collaborations, including with children and families. Measure development and testing often require collaboration among measurement and health data experts, end users, patients/families, clinicians and multiple sites of care. Testing may cover interpretation, quality improvement, solving technical glitches, and the collection/reporting burden that includes capital investment, staff hours and patient/family hours. Equally important is collaboration with owners of relevant data assets and assessment of the data and use for measurement. Users may make organizational resources, including technical support, institutional data and other resources available to support progress on measures of interest. Including patients/families early in the collaborative process is critical.
- **Engage in the quality measures and value-based environment**: Staying informed about progress in quality measures, quality improvement activities and improvement incentive methodologies contributes to moving measure development and revisions forward. A few resources include the Children's Hospital

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[21] NQF. Pediatrics 2016-2017 Final Report. http://www.qualityforum.org/Publications/2017/08/Pediatrics_2016-2017_Final_Report.aspx.

[22] AHRQ PQMP resource page. https://www.ahrq.gov/pqmp/about/publications-and-materials/index.html.

[23] Institute of Medicine, Report Brief, April 2011: Child and Adolescent Health and Health Care Quality: Measuring What Matters. https://www.nap.edu/catalog/13084/child-and-adolescent-health-and-health-care-quality-measuring-what

Association (CHA) website, National Quality Forum (NQF) tools, including the "Quality Positioning System (QPS)" and the "Measures Application Partnership (MAP)" process for identifying measures for CMS programs.

Not all measure gaps can be filled by revising existing measures or developing new measures using existing care pathway and data infrastructures. For example, effectiveness of care measures that account for the child and family perspective may be difficult to develop and implement due to the lack of patient generated data and the interoperability of these data with health systems and clinical data. As health system reform efforts continue, new and valuable opportunities for measurement may emerge.

Appendix A: CHA's Pediatric Value-Based Care Measures Advisory Panel

Demonstrating Value in Pediatrics Measure Menu, Workbook & Guidance Expert Stakeholders			
Patients and Parents		Task Force	Advisory Panel
Amy Basken	Director of Programs Pediatric Congenital Heart Association (Madison, WI)	x	x
Terrence Gallagher	Family Advisory Council Member Children's Mercy Kansas City (MO)	x	x
Teresa Jurado	Parent Mentor Lucile Packard Children's Hospital (Palo Alto, CA)	x	x
Porscha Hall Davis	Child and Family Perspective Sickle Cell Disease (Washington, DC)	x	x
Practicing Child Health Clinicians			
Lauren Clary, Ph.D.	Clinical Psychologist and Director, Division of Endocrinology & Diabetes Children's National Health System (Washington, DC)	x	x
Aditya Gaur, M.D.	Clinical Director, Dept. of Infectious Diseases St. Jude Children's Research Hospital (Memphis, TN)	x	X
Sheryl Morelli, M.D.	Chief Medical Officer, Seattle Children's Care Network Seattle Children's (WA)	x	x
Jonathan Thackeray, M.D.	Chief Medical Community Health Officer Dayton Children's Hospital (OH)	x	x
Patient Advocates			
Lee Beers, M.D.	Medical Director, Child Health Advocacy Institute, Children's National Health System (Washington, DC)	x	x
Ellen Albritton	Senior Policy Analyst Families USA (Washington, DC)	x	x
Social/Community Providers			
Dayna Long, M.D.	Health Equity Initiatives, Center for Community Health and Engagement UCSF Benioff Children's Hospital Oakland (CA)	x	x
Nisha Sachdev, Dr.P.H., Psy.D.	Senior Director of Evaluation Bainum Family Foundation (Bethesda, MD)	x	x
Children's Hospital Leaders			
Katie Burns	Vice President, Network Strategy and Development Children's Hospital of Wisconsin (Milwaukee)	x	x
Dave Cronan, MBA	Vice President, Reimbursement Strategy and Contracting Children's Hospital of Philadelphia (PA)		x
Shahab Dadjou	SVP Strategy & Integration and Chief Strategy Officer CHOC Children's (Orange, CA)		x
Bob Duncan, MBA	Executive Vice President Children's Hospital of Wisconsin (Milwaukee)	x	x

Demonstrating Value in Pediatrics Measure Menu, Workbook & Guidance Expert Stakeholders			
Fiona Levy, M.D., MBA	Executive Director, Sala Institute for Child and Family Centered Care, Hassenfeld Children's Hospital at NYU Langone (New York, NY)		x
CHA Governance Bridge and Quality Expert			
Andrea Benin, M.D.	Senior Vice President, Quality and Patient Safety *Formerly of* Connecticut Children's Medical Center (Hartford, CT)	x	x
Quality Experts			
Lalit Bajaj, M.D., M.P.H.	Medical Director, Clinical Effectiveness Children's Hospital Colorado (Aurora, CO)	x	x
Jim Bost, Ph.D.	Research Division Chief of Biostatistics and Study Methodology, Co-Director of the BERD CTSI-CN Children's National Health System (Washington, DC)		x
Sepheen Byron, M.H.S.	Assistant Vice President, Performance Measurement National Committee for Quality Assurance (NCQA) (Washington, DC)		x
Gary Freed, M.D., M.P.H.	Professor, Division of General Pediatrics C.S. Mott Children's Hospital (Ann Arbor, MI)	x	x
Margaret Morris	Senior Director for Managed Care IPRO (Lake Success, NY)	x	x
Sara Toomey, M.D., M.P.H.	Chief Experience Officer and Director of Performance Improvement Boston Children's Hospital (MA)	x	x
Representatives from Federal and State Agencies			
Terry Adirim, M.D., M.P.H., MBA	Deputy Assistant Secretary of Defense, Health Services Policy and Oversight Military Health System (Falls Church, VA)		x
Jeanne Alicandro, M.D., M.P.H.	Medical Director, Office of Quality and Patient Safety New York State Department of Health (Albany, NY)		x
Renee Fox, M.D., FAAP	Medical/Health Policy Advisor Centers for Medicare & Medicaid Services (Baltimore, MD)		x
Kamila Mistry, Ph.D., M.P.H.	Senior Advisor for Child Health and Quality Improvement Agency for Health care Research and Quality (AHRQ) (Rockville, MD)	x	x
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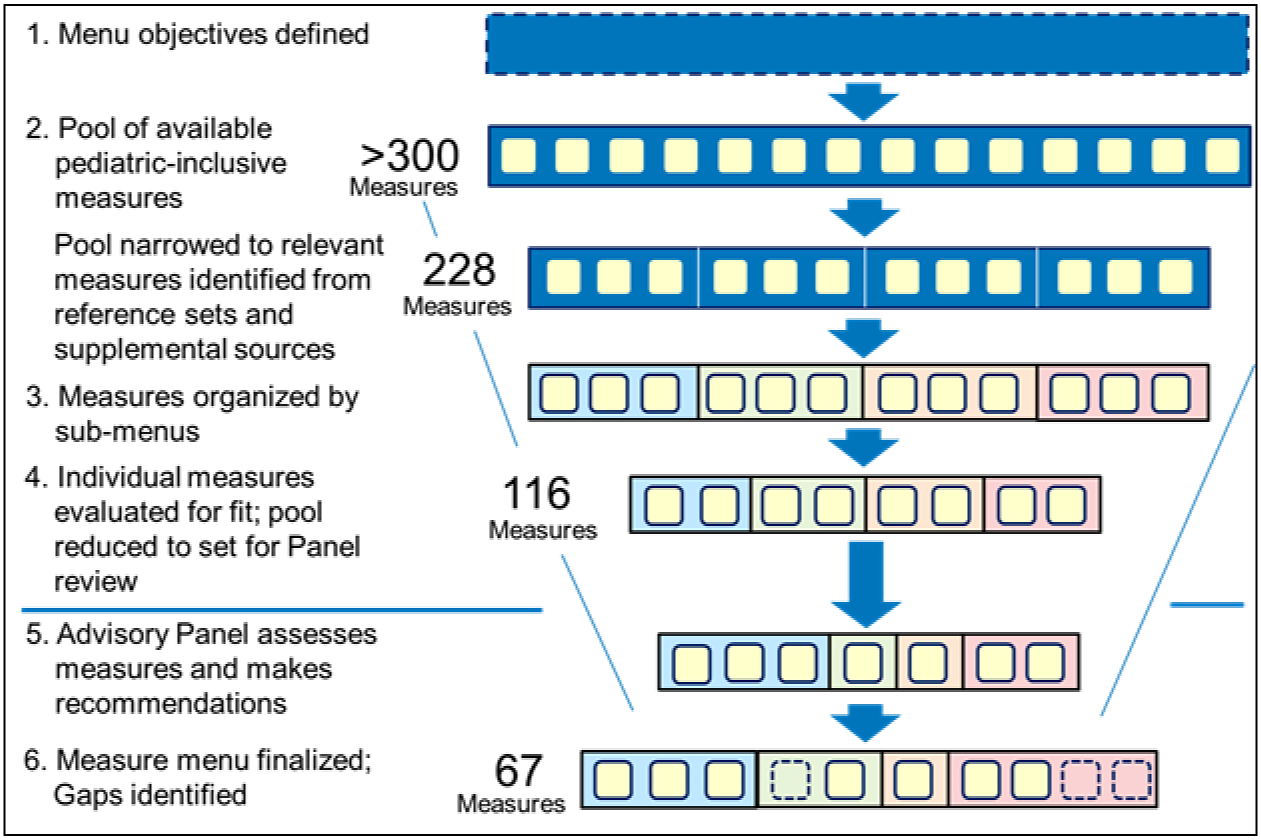
Amy Helwig, M.D., M.S., FAAFP	Chief Quality Officer & Vice Presidents, Quality Improvement and Performance UPMC Health Plan		x
Amy Richardson, M.D., MBA	Senior Clinical Solutions Medical Director Aetna Medicaid, A CVS Health Company		x
Karen Shea	Vice President, Maternal Child Services Anthem, Inc		x

Appendix B: How We Selected the Measure Menu

The 67 measures in the Demonstrating Value in Pediatrics Measure Menu were selected using the Children's Hospital Association Measure Selection Framework for Pediatric Quality Accountability Measures, a criteria-based, systematic consensus process to aid experts and stakeholders in reviewing measures. The process is summarized in Figure 3.

Figure 3. Overview of Measure Selection and Evaluation Process



Step One: Define Measure Menu Objectives

Objectives:

- Create a menu of high-priority child health measures that can be immediately used in value-based models to demonstrate the value of care provided by children's hospitals and by other child health providers and networks across a variety of care settings. While there are a multitude of existing and emerging value-based approaches, existing core sets don't adequately address hospital and specialty care uses for these programs.

- Create a menu that offers a balance between measures that address prevention and wellness as well as those that address the needs of children with medical complexity and chronic conditions. Most children are healthy and require only preventative and primary care, and existing core measure sets focus primarily on these children. While measures to assess the quality of care for children with complex and chronic needs exist, they are often not reflected in core sets.

Important principles for measure use in value-based programs include:[24]

- measures selected must be appropriate for program objectives and participants
- measures appropriate for one program may not be appropriate for use for another (for example, some measures used for internal quality improvement may not be suitable for comparisons across providers)
- programs must be fair and transparent in their use of measures
- measures may provide data/feedback to support actionable quality improvement efforts

Step Two: Select Initial Measure Set

We conducted a preliminary measure scan of reference measure sets (Table 9) and supplemental sources including *U.S. News and World Report* hospital survey questions, the "Buying Value Measure Selection Tool", custom children's hospital or system measures and other measures from the "NQF Quality Positioning System (QPS)," and other measures databases. Measure specifications were evaluated for pediatric-specific, pediatric-inclusive, or age-neutral denominators (e.g. "ages 17 or younger" or "64 and younger") for inclusion in the initial set, resulting in more than 300 measures. Measures that did not include ages 17 and younger were excluded.

Table 9: Measure Reference Sets

Name	Description
Medicaid/CHIP Core Measure Set 2019	A core measure set established by CMS for voluntary use by state Medicaid administrators, encompassing physical and mental health
AHIP/CMS Core Set 2017	Core set created in collaboration between America's Health Insurance Plans (AHIP) and CMS to promote alignment across programs
Pediatric Measures Considered for Endorsement 2016-2017	Pediatric-inclusive measures reviewed by NQF for endorsement, with findings detailed in NQF reports
CMS Measure Inventory (including measures for MIPS, IQR, OQR programs)	Comprehensive inventory of measures in use by (and previously considered for use by) CMS programs
AHRQ PQMP Measures (Stage 1 and 2)	Measures developed with sponsorship by AHRQ by various organizations in the U.S.
SAMHSA Metrics and Quality Measures for Behavioral Health Clinics 2016	Measures identified for use for Certified Community Behavioral Health Clinics
CHA 2016 Hospital Measure Survey	Survey conducted by CHA of >800 hospitals asking information about the measures that they report and the programs in which they participate

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[24] CHA Measure Selection Framework 2016

CHA 2016 Networks for Children with Medical Complexity Project	Measure set aggregated by CHA to specifically address care for children with complex medical needs
HEDIS 2019	NCQA measure set used primarily by health plans
Various state measure sets	Other state Medicaid and health system sets, including those from Oregon, New York, and Minnesota, were referenced

Detailed information pertaining to each measure was compiled from open access, publicly available online sources:

- measure description
- care setting
- ages covered
- NQF-endorsement status
- condition or therapy addressed
- level of analysis
- data source
- feasibility
- validity and reliability
- importance
- usability
- current use in health plans
- inclusion in reference/core sets, registries, state programs, and other measure sets compiled by CHA or other pediatric health stakeholders

Through this process, additional measures were eliminated, resulting in 228 pediatric-inclusive measures.

Step Three: Organize Measures

Measures were organized into four areas: acute inpatient care, ambulatory specialty care, primary care and community engagement, and behavioral/mental health care. In addition to selecting care setting-specific measures for each of the four areas, we included coordination of care across settings, patient experience, patient-reported outcomes, lowering cost of care, and social influencers of health.

Step Four: Evaluate Measures for Fit in Sub-Menu and Use in Value-Based Programs

Measures were evaluated to ensure they were important to achieving meaningful measurement of pediatric health care within and across settings (Table 10). We eliminated those not focused on pediatrics (e.g. those focused primarily on maternity care).

Table 10: Measure Evaluation Criteria

Factor	Criteria
Importance	1. Must capture an aspect of care or outcomes for the pediatric population and their families that is important to: (a) the hospital, (b) the plan/purchaser, and/or (c) the child or family 2. Evidence of high cost or prevalence for the measure topic 3. Improvement needed: data must show evidence of a performance gap, or evidence that the measure is not already topped out
Validity/Reliability	1. Measures may be either (a) NQF Endorsed, OR (b) have a demonstrable level of validity and reliability testing performed 2. Evidence of reliability in each setting of care/program
Feasibility	1. Measures must have a data source that is accessible to most hospitals, specialty, and/or pediatric practices 2. Measures must not have known impediments to feasible collection or reporting 3. The cost or burden of measure collecting/reporting may be taken into account
Usability	Measures evaluated based on comments or other evidence related to experience with using the measure
Actionability	Measures must support action towards improvement on performance

This process concluded with 116 measures identified for evaluation by the advisory panel.

Step Five: Advisory Panel Evaluation

A pre-meeting survey to solicit initial feedback on the measures was used to identify where the advisory panel held consensus or had strong opposing opinions surrounding a single measure or group of measures. Survey respondents were also asked to comment on their own experience with the measures and the conditions or topics that they cover. Panelists could choose a "neutral" option if they did not have an opinion or feel they had enough information to make a clear decision on a given measure or question.

In June 2018, an advisory panel convened in Washington, D.C. A total of 31 members participated in the meeting. Four groups (representing each part of the menu) discussed measures for which there was no clear consensus as well as gaps (see Chapter 4) and general considerations important to pediatric measurement. Moderators guided each group to discuss the following topics:

- Challenges and opportunities of different types of measures for value-based care and payment programs
- Implementation challenges unique to the pediatric population

Measures were either recommended, not recommended or recommended with limitations/considerations. Measures recommended with limitations/considerations are those that the advisory panel recommended for inclusion in the menu but with noted technical or other issues that they believed were important to flag to end users of the menu.

Step Six: Determine Final Measure Menu

After the advisory panel's evaluation, the remaining measures were reorganized as appropriate into the four categories plus a category called "emerging measures." The emerging measures are listed in Chapter 4 of the report.

The advisory panel re-convened in July 2018 to consider follow-up research as well as updated recommendations and discussion resulting in the final measure menu.

Appendix C: White Paper: What Matters Most to Children and Families

- Effectiveness in health care is not limited to clinical effectiveness or the adherence to clinical guidelines. While clinical effectiveness is necessary (and expected) to achieve effective care, effective care encompasses the achievement of personal goals care. Thus, effective care includes multi-directional engagement in care and expectations and optimizing patient wellness, functional status, and quality of life.
- Communication and coordination/integration of care is critical to achieve high-value care, and these types of care span all domains of quality.
- The accountability for outcomes in quality do not entirely rest on providers--children and families, and the community increasingly have a role; measures should account for these roles.
- Experience of care should be assessed; approaches need to be streamlined and easy for children and families to provide their experience information.

On February 13, 2018, the What Matters Most Task Force convened in Washington D.C. Task force participants included patients and parents, practicing clinicians, patient advocates, child social and community providers, children's hospital leaders, quality leaders, CHA leadership, and federal agency liaisons. The objective of the task force was to discuss "what matters most to children and their families in health care" with an emphasis on the child and family perspective—a perspective that has been underrepresented in prior considerations of quality measurement.

The task force considered six categories of health care quality from common measure domains, including the National Quality Strategy (NQS). Four sub-categories were added to each domain to help participants consider their potential scope (see White Paper-Appendix 1: Quality Domains and What Matters Most, Figure A).

Findings of the Task Force

Category 1 - Communication and Coordination

Communication and coordination are foundational to quality health care for children and families. Quality communication requires listening, mutual trust, respect, cultural competency and clear delineation of roles.

The task force repeatedly raised the concepts of communication and coordination in all the other category discussions. Many of the specific examples and experiences that task force members used to help articulate their thoughts about the other categories could be classified as examples of effective communication and coordination.

The task force considered these concepts to be essential for: successful community engagement, evaluating and ensuring safety, assessing the effectiveness of care given, promoting and recording positive patient experience, and promoting wellness and prevention. The task force considered communication between providers and children and families from many different angles, including patient goal-setting, patient education, comprehensive wellness counseling, and consideration for unique cultural differences and circumstances. They discussed communication as needing to be both clear and empathetic.

The task force determined that coordination included the deliberate, multi-directional synchronization of activities and information across the health care system. They considered that coordination, from the perspective of children and families, requires not only that members of care teams talk to each other, but that each individual and group involved of the care of the child (in or out of the health system) clearly understands their responsibilities relative to the others. They found that it strongly matters to children and families that communication and coordination happen in a timely and efficient manner. Some task force members noted that when different providers communicate with the children and family, but they each repeatedly ask the same things that other providers ask, coordination is not effective, and time and learning are wasted for everyone involved.

Category 2 - Community Engagement

Health systems and their communities must each support and learn from the other to achieve the best child health outcomes. Sustainable, bi-directional engagement between the hospital and community emerges from relationships built on trust.

The task force discussed whether the health care system was, or should be, considered a part of a continuum with the community; some acknowledged that community workers often see the health care system as a separate and distinct entity. Nevertheless, all agreed that a three-way connection between the health care system, the child and family/caregiver, and the community was necessary to ensure that children and families receive all the support and resources that they need.

The task force focused on interactions between the health system and the schools to ensure that the schools were aware of physical, behavioral, and social needs of individual children. One parent described an experience in which a primary care physician went to their child's class to educate the class on that child's needs so that they could help maintain a safe and understanding environment. One also told of a primary care physician going to a child's church to promote better understanding of a child's health needs among the congregation. These types of outreach may not be typical but are helpful and greatly appreciated. The task force also pointed out that such outreach is not typically compensated, and that a sustainable model of community engagement would likely require more consistent support than it currently receives.

Another example was offered of a child admitted to the hospital whose issues were determined to be a result of malnourishment due to food insecurity. The most effective intervention would be to provide the child with food over time. But, it is important to understand what the role of the hospital is in providing food to the child versus the role of the community. The task force used this example to highlight how the distinction between the roles of the hospital and the roles of the community are not always clear, but that both need to work together to define those roles at their local level so that children and families are able to access all the resources they need when they need them.

While the task force came to no definitive answer, the conclusion was that hospital and community leaders needed to have that discussion and work toward a solution together.

Category 3 - Effectiveness of Care

Health care providers administer effective care when the perspectives and expectations of children and families are understood. Effective care helps achieve child- and family-defined clinical and functional goals, minimizes cost burdens, and maximizes quality of life.

While this category has typically been understood to by closely aligned, and by some synonymous with clinical effectiveness (clinical outcomes and evidence-based practices), the task force determined that it was important for health care stakeholders to consider the concept of effectiveness from the child and family perspective. For example, stakeholders should ask:

- What is the value of a treatment or intervention to the patient?
- Is the care addressing a core need?
- Is there a standard of care for the condition and was it followed? If not, why not? And, if so, is the standard sufficient to meet the child or family needs?

The discussion on effectiveness of care ranged from baseline expectations of disease control (providers curing disease when possible) to aiming for positive acute and long-term clinical and functional outcomes. They considered such topics as maintaining quality of life, child and family engagement in care, management of child and family expectations, care coordination and shared responsibility across team members, and others closely tied to the other categories to all be a part of what a child or family would deem "effective care." The task force suggested that a child or family may not care so much about the evidence supporting their treatments as much as they care about outcome and the achievement of personal goals.

One group put forward the hypothetical scenario of an individual with serious behavioral and social issues who frequented the ED. In this scenario, the ED clinicians may, during the ED visit, provide effective and evidence-based treatment for the individual. However, if the underlying, non-medical issue for why the patient was going to the ED was not addressed, then is the care "effective care?" Was the patient just seeking social interaction and a sense of caring? Were they going to escape from an unsafe environment? Was there a home care need that was not being met? Solutions that address core needs or prioritizing needs were determined to all be part of the child and family's definition of effectiveness of care.

Category 4 - Safety

Safety is broader than the prevention of avoidable harm in the hospital setting. Effective communication between providers and families fosters a sense of safety and confidence, extending from the family's sense of safety while under a provider's care to their confidence and sense of safety back at home. Trusting that the family knows their child best is key to safety.

The task force determined that safety is the highest priority of the health care system, but that care should not be delivered if it is not safe. Providers can gain the confidence of children and families and build mutual trust by building safety into their culture. Safety requires communication across providers and with children and families, particularly regarding the demands of care imposed upon a parent or caregiver. Furthermore, stakeholders should be aware that what is considered "avoidable harm" may change over time. Continuous learning and transparency are key to avoiding errors.

Much of the task force conversation on safety centered on safety in the home. It was clear to task force members that the capacity of families and caregivers to provide at-home clinical care should be holistically evaluated because asking too much of them before they are ready is a safety risk for the child. They considered support from the health care system and from other community resources to be necessary for ensuring that safety is considered across the child's daily life and environment, and that anticipatory, proactive steps should be taken to ensure safety. Some raised that what might be considered safe by providers, and what the family and caregivers express as desires or needs, may not always be compatible, and that close and effective communication were needed to appropriately asses any given situation where what is truly "safe" for the child is not necessarily clear for all parties involved.

The task force found that timeliness and efficiency of care were considered keys to safety. Poor coordination or the delay of key pieces of information in a transfer of care could contribute to poor safety. Active listening on the part of providers and children and families may help prevent safety issues. Children and families would expect hospitals to have safety protocols in place, though hospitals should balance the desire to communicate about those safety protocols against the possibility of creating anxiety in children and families. While some may go to the hospital to feel safer, others may feel very unsafe in a health care setting for any number of reasons, not the least of which is the sense that hospitals are risky because they are full of sick people. Clinicians should convey and exemplify confidence and competence to help children and families feel and be as safe as possible.

Category 5- Experience of Care

Children and families want their providers to value their contribution to care and be aware of what is going on in their lives, both in and outside of the walls of the care setting. During their interactions with providers, children and families expect professionalism, teamwork, and clear and respectful communication to address their personal and clinical needs and preferences.

The task force determined that children and families appreciate the feeling that their provider values them and is aware of what is going on in their lives, both in and outside of the walls of the care setting. Interactions between providers, children and families should be aligned with their personal and clinical needs and preferences. Children and families expect the following from their providers:

- Professionalism
- Knowledge in care
- Positive interactions with the health team, even during times when they experience a negative health outcome
- Teams to work together to provide a coordinated, convenient-to-access, affordable, and timely experience
- Sensitivity to culture- and socioeconomic-specific issues
- Streamlined, relevant and individualized communication from providers

The discussion on experience of care also ranged beyond clinician interactions and the walls of health care settings to other aspects of the experience of children and families, including the travel time to the care setting, ease of parking, anxiety around costs, waiting room times and resources, post-visit follow-up and the stresses that accompany the responsibility of home care. Experience of care may be different between acute hospital care and outpatient care, and their differences should be addressed.

The task force discussed how positive patient experience was primarily about managing expectations and adjusting to perceptions. Much of the conversation on experience of care could be reduced to a single question asked by children and families: "Did they know me?" In other words, did those who administered care know their names, know something about them, listen to them, express a desire to help, show respect, express empathy, build trust and help them navigate the care pathway? One clinician described how the care team at the clinician's office (including the nurses and staff workers) communicated internally to anticipate the needs, emotional state and status of the children and families that came to the office and to ensure that those factors were addressed during the visit. The clinician's office made notes not only of clinical needs, but small details, name preferences, and other things that the patient may find important so that they could be remembered and recalled during conversation.

Category 6-Wellness and Prevention

Provider guidance on wellness should incorporate physical, mental, emotional, developmental, educational and environmental considerations. Shared decision-making between providers, children and families surrounding wellness can enable realistic goal-setting aimed at helping the child reach optimal health based on the child's individual capacity.

The conversation on wellness and prevention necessitated a listing of all aspects of health: physical, behavioral/mental, social, developmental, spiritual, etc. What constituted "wellness" was considered to be defined primarily at a personal level, which was part of the rationale for the goal-centered conclusion of the group: providers should be aware of goals when determining what the expectation of wellness for the child means, while balancing against a provider's judgement of what the child should do to prevent harm or injury. This category was linked to the discussions of what "effectiveness of care" and "safety" meant for children and families and the need for helping the child and family to return to a state that the child and family considered "normal" or "optimal."

The health system should assess risks and be proactive in helping children and families get what they need without necessarily requiring them to return to care settings.

The topic of prevention was also closely linked to the community engagement category, particularly to enforce laws that promote safety, to provide a clean community environment (clean water, clean air, etc.) and to provide helpful access to access community resources. The community role in prevention also extended to communication and transportation infrastructures that would facilitate health care access.

Common Themes Across Categories

The following were themes were noticed across discussion of multiple categories:

Theme 1: In comparing and contrasting the categories, communication and care coordination are foundational, safety is essential, and wellness and effectiveness are objectives

During the meeting, the task force quickly determined that the scopes for each of the six categories were closely connected and often overlapping, but that they related to each other in different ways. While the categories were not ranked or prioritized in a formal manner, some stood out as fulfilling important roles relative to the others.

"Communication and care coordination are foundational": Communication and coordination was the category that was integral to quality of care across all others. There was no aspect of quality related to any other category that was not supported by or enhanced by effective communication across providers, between providers and patients, or between the health care system and the community (as Theme 2 will describe).

"Safety is essential": The safety of the child, it was agreed, should be the top priority for the health care system—not just to ensure that the child is appropriately care for and placed in competent and well-equipped care settings, but also to ensure that the child and family feel safe in accessing health care and are educated and equipped to maintain that safety in their own homes and in the community.

"Wellness and effectiveness are objectives": The goals of health care delivery were determined to center on helping the child and family achieve their wellness goals and to yield positive outcomes for the child and family.

Theme 2: Quality care is dependent on all stakeholders knowing and performing their roles

The task force agreed that an essential part of coordination was ensuring that every stakeholder understood their role in providing and maximizing care, including children and families. Understanding roles is important for reducing unnecessary redundancy as well as ensuring that there are no gaps in care through which children and families may fall. These roles are not always clear to everyone, but attempts must be made to constantly and consistently define them.

Provider roles are to provide care as safely and effectively as they can. Moreover, they listen, consult, educate and do their best to engage children and families in care that will help them meet their goals. Providers also partner with community resources to ensure that children and families have what they need to maintain their safety and wellness outside the walls of health care settings.

Community roles are to provide resources to children and families who need them, including social work, counseling, support groups, environmental protections and other resources related to health and wellness. The community responds to outreach from the health care system, including from clinicians and hospitals, to ensure that children and families get the access that they need to perpetuate and build on the care that they receive.

Child and family roles are to become educated about health care needs and to communicate with providers about their needs and expectations. Also, to make self-care decisions, reaching out to community resources as needed.

Theme 3: What matters most is for some an aspirational idea and for others a realistic expectation

Because the parameters given to the task force about what they were to discuss were intentionally broad, much of the discussion by the task force revolved around what could and should be done in the health care system. Inevitably, conversation returned to determining which of things that mattered most to children and families were feasible and should be expectations, versus what was still aspirational and not yet fully possible in the health care system. Many of the topics discussed were found to be somewhere between aspirational and reasonably expected. For example, care coordination (acknowledged as being foundational to quality) was also considered by the task force to be occurring at efficiency levels below the expectations of children and families in many instances.

Expectations of providers include conforming to high standards of professionalism, evidence-based care and efforts to ensure the safety of the children and families under their care. Furthermore, they are expected to provide clear and meaningful communication to children and families about their acute and long-term wellness. Providers aspire to maintain constant, sustainable and effective coordination with other providers and with community members. Providers further aspire to be fully anticipatory and proactive in their engagement with children, families and their community.

Expectations of community include providing resources to ensure the public safety and security of children and families, including a clean public environment, school resources that can accommodate the health needs of children, and social services to assist families in attaining stability and security. The community aspires to incorporate the health care system as a seamless community partner.

Expectations of children and families include that their interactions with the health care system will provide them with the services that they need to recover from or manage illness and injury, and that they will have an active, prioritized and appreciated voice in how those services are delivered. They further expect that they will be provided with all the information and resources they need to effectively manage health care at needs in provider care settings, in the home, at school and elsewhere in the community. Children and families aspire to being full, educated partners in their care, and to be able to interact with the health care system in a way that is minimally confusing, complicated and stressful. Some children and families also aspire to feeling completely valued, safe and secure in health care settings in which they may be minorities, culturally distinct or otherwise disadvantaged.

Conclusions: Applications to A Pediatric Measure Menu

The goal of the task force discussion was to identify "what matters most to children and families," in the health care they seek and receive. The outcomes from these discussions are important and were used to directionally inform the selection of a measure menu, and gaps and opportunities for future measure development.

Key findings include:

- Effectiveness in health care is not limited to clinical effectiveness or the adherence to clinical guidelines. While clinical effectiveness is necessary (and expected) to achieve effective care, effective care encompasses the achievement of personal goals care. Thus, effective care includes multi-directional engagement in care and expectations and optimizing patient wellness, functional status, and quality of life.
- Communication and coordination/integration of care is critical to achieve high-value care, and these types of care span all domains of quality.
- The accountability for outcomes in quality do not entirely rest on providers--children and families, and the community increasingly have a role; measures should account for these roles.
- Experience of care should be assessed; approaches need to be streamlined and easy for children and families to provide their experience information.

The concepts and ideas discussed by the task force helped shed light on the aspects of care that children and families prioritize and drew attention to the ways in which current quality measure science may be challenged to capture those aspects of care. Some of what matters most to children and families is difficult or burdensome to measure and would be considered aspirational. However, the task force findings are a needed reminder of the gaps in available quality measures and inform the elevation of measure sets that aspire to more patient-centric.

White Paper-Appendix 1: Quality Domains and What Matters Most, Figure A

Child and Family Perspective: What Matters Most

Communication and Coordination	Community Engagement	Effectiveness of Care	Safety	Experience of Care	Wellness and Prevention
Patient-Clinician Relationship	Community-Based Resource Access	Evidence-Based Treatment	Adverse Event Rates	Patient-centered service	Disease Prevention
Shared Goal-Setting and Care Planning	Social/ Environmental Assessment	Patient Monitoring	Medication Management	Time Management	Complication Prevention
Education and Cultural Competence	School-Health Coordination	Physical Health Outcomes	Adverse Event Response from Providers	Cost Management	Physical Wellness Counseling
Coordination Between Providers	Public Health Education/ Awareness	Behavioral Health Outcomes	Home-Based Safety	Opportunities for Patient Feedback	Behavioral Wellness Counseling
Other	Other	Other	Other	Other	Other

White Paper-Appendix 2: Standard Definitions of Categories of Quality Care

These were standard definitions that were used in the task force meeting to facilitate discussions among the groups about each of the categories. Definitions were adapted from the "National Quality Strategy" and other sources.

Category 1 Communication and Coordination: the deliberate synchronization of activities and information across health care and community services to improve health outcomes by ensuring that care recipient and families' needs, and preferences are understood and met

Category 2 Community Engagement: the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests or similar situations with respect to issues affecting their health and well-being

Category 3 Effectiveness of Care: providing care processes supported by scientific evidence to achieve health care outcomes. Effective care includes services that are of proven value and have no significant tradeoffs; that is, the benefits of the services so far outweigh the risks that all patients with specific medical conditions should receive them.

Category 4 Safety: the prevention and mitigation of harm caused by health care errors of omission or commission, including establishing operational systems and processes that minimize the likelihood of errors and maximize the likelihood of intercepting errors when they occur

Category 5 Experience of Care: encompasses patient perceptions of their interactions with the health care system, including the services they receive from clinicians (doctors, nurses, and other professionals), physician practice staff, health care facilities and health plans

Category 6- Wellness and Prevention: a focus on health that considers multiple influences and consequently multiple modalities for preventing disease (e.g. education or immunizations), as well as promoting optimal well-being

White Paper - Appendix 3: Summaries of Research on Patient, Family and Advocate Perspectives in Health Care

Addario *et al.*
Patient value: Perspectives from the advocacy community. 2017
Population: Patient advocates
About: Patient advocates explore varying definitions of patient value and make positive recommendations for working to strengthen the patient voice into value frameworks.

American Society of Clinical Oncology (ASCO) Quality Care Symposium 2017
Advancements in Quality Care: Incorporating the Patient Voice. 2017
About: Tells us about the value of patient voices generally and specifically for oncology.

American Institutes for Research (AIR)
Principles for Making Health Care Measurement Patient-Centered. 2017
About: A multi-disciplinary stakeholder group was convened to develop five principles for patient-centered measurement. The principles describe the essential elements and characteristics of patient-centered measurement.

Avalere & FasterCures
Integrating the Patient Perspective into the Development of Value Frameworks. 2016
About: Discusses the development of a patient-perspective value framework. Provides specific examples of how patients are or aren't included in processes. Example: NCCN - Evidence Blocks for cancer regimens are created by panels of multidisciplinary expert clinicians – do not seem to involve patients or patient advocates in the process.

Committee on Hospital Care and Institute for Patient- and Family-Centered Care
Patient- and Family-Centered Care and the Pediatrician's Role. 2012
About: Policy statement that outlines core principles, summarizes literature linking patient- and family-centeredness to improved patient outcomes and lists other benefits of engaging in this practice.

Cox *et al.*
Parent Perceptions of Children's Hospital Safety Climate. 2013
Population: Parents of children in the hospital
About: Study sought to evaluate a parent-reported version of the Agency for Health care Research and Quality (AHRQ) Hospital Survey on Patient Safety Culture and to relate parent-reported responses to parental need to watch over their child's care to ensure mistakes aren't made. Findings suggest parents can provide valuable data on specific safety climate domains. Opportunities exist to improve our safety climate's impact on parent burden to watch over their child's care, such as targeting overall perceptions of safety as well as handoffs and transitions.

Dyson *et al.*
Which Outcomes are Important to Patients and Families who have Experienced Pediatric Acute Respiratory Illness? Findings from a Mixed Methods Sequential Exploratory Study. 2017
Population: Parents of child patients
About: Study of the outcome priorities of parents with children who had experienced acute respiratory infection and found that parents' priorities did not always align with commonly researched outcomes. The authors conclude saying that appealing and efficient strategies to engage patients and parents in research should be developed.

Foster *et al.*
The Parent's, Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting. 2015
Population: Parents, hospitalized children, and health care provider
About: A synthesis of quantitative research to highlight that communication tailored to meet the parents' and child's needs is the key to facilitating family-centered care and positive health outcomes.

Institute for Health care Improvement
"What Matters" – A Vision for "What Matters to You?" Article
About: Touches on 2012 perspective article in NEJM on Shared Decision Making by Michael Barry. The NEJM article goes into the origins of patient-centeredness and this may be great to pull from for the introduction of this report.

Lindly *et al.*
Family-Centered Care Measurement and Associations with Unmet Health Care Need Among US Children. 2017. Academic Pediatrics.
Population: Children (0-17)
About: Study aimed to develop a family centered care (FCC) measurement model with Medical Expenditure Panel Survey (MEPS) items to determine temporal associations between FCC and unmet health care needs.

Mohammed *et al.*
Creating a Patient-centered Health Care Delivery System. 2014
Population: Patients (general)
About: Systematic review of 36 studies that identified 10 quality dimensions perceived by patients: communication, access, shared decision making, provider knowledge and skills, physical environment, patient education, electronic medical record, pain control, discharge process, and preventative services. Communication was found to be the most common indicator of health care quality.

NEJM Catalyst
Measuring What Matters and Capturing the Patient Voice. 2017
About: The "Insights Council" served as a roundtable – made up of clinical leaders, clinicians, and health care executives – that discussed how to incorporate the patient voice into health care delivery. *No patients or patient advocates were a part of the roundtable*

Rasmussen
Children's perspectives in family-centered hospital care. 2017
Population: Child patients
About: Study's aim was to ask children to share the narratives of their experience of hospitals and hospitalization in New Zealand, to consider multiple factors influencing their experience in hospital. The study found that parent and child experience differ, children's stories may not be consistent with family's, and children's agency in the hospital is variable.

University of Utah Health
The State of Value in U.S. Health Care. 2017
Population: Consumers (patients), providers, and employers
About: Leavitt Partners with University of Utah Health conducted a nationwide survey to find out what three key

audiences – consumers, providers, and employers- think about the component parts of value: quality, service, and cost. The findings emphasize the disconnect between providers and their patients. While top indicators of high-value care for patients were affordable out-of-pocket costs, the ability to schedule a timely appointment, confidence in the provider's expertise, and that the office was conveniently located, physicians who responded to the survey said the best indicators of high-value were that they knew and cared about their patient, ordered the right labs and exams, their patient's health improved and they could spend a sufficient amount of time with their patient.

Appendix D: Opportunities for Quality Improvement: Case Studies

The following four case studies are examples of real actions by children's hospitals to improve child health care quality and outcomes and how quality measures can be used to support, supplement, and incentivize quality improvements in pediatric settings.

- Case Study 1: Advancing Value at Boston Children's Hospital—Implementing Integrated Care Tools and Measures
- Case Study 2: Children's Hospital Colorado and Anthem BCBS
- Case Study 3: James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center
- Case Study 4: UCSF Benioff Children's Hospital Oakland

Case Study 1: Advancing Value at Boston Children's Hospital—Implementing Integrated Care Tools and Measures

Report Topics Addressed: *Value-based Care Design; Care Coordination; Integrated Care Management for Children and Youth with Chronic Conditions; Patient-reported Outcome Measurement; Interprofessional Training in Care Coordination*

Overview

Effective care coordination (CC) is a critical component of high-quality health care, especially for children and adolescents with complex needs.[25] Despite their importance across the care continuum, activities and outcomes related to patient- and family-centered CC are rarely documented. As a result, the value of these in health delivery models remains largely undefined.

The Integrated Care Program at **Boston Children's Hospital**, in collaboration with subspecialty colleagues in neurology, gastroenterology, urology, anesthesia, and complex care, has developed and implemented tools, processes, and quality measures designed to standardize CC, reduce fragmentation of care across settings, and improve patients' and families' experiences of care, with the broader aim of improving overall value. Importantly, the collaborators include community-based, primary care affiliates and family partners. Some tools are utilized by the personnel performing CC, while others directly measure the experience of patients and families who receive care from multiple providers.

Here, we highlight three tools that have been successfully integrated into practice in pediatric health care at Boston Children's Hospital. In conjunction with the National Center for Care Coordination Technical Assistance, funded by the U.S. Maternal and Child Health Bureau, and in partnership with the National Resource Center for Patient/Family-Centered Medical Home at the American Academy of Pediatrics, these tools have been deployed in multiple settings across the U.S.

> The Care Coordination Measurement Tool (CCMT) enables members of the multidisciplinary care team to document key features of CC encounters, including the complexity level of the patient requiring CC, the activities performed, and the outcomes that occurred or that were prevented. This data can then be used to optimize allocation of resources in a variety of health settings to improve the quality of CC and to inform a more accurate reflection of the value of CC overall, which is essential as systems move toward value-based care delivery. The CCMT ensures that multidisciplinary staff are performing at the top of their training. The data generated by the CCMT assists hospital finance leaders in developing a value-based approach to reduction of overuse of high-cost resources common in pediatric care, such as unnecessary emergency department visits or hospitalizations.
> The Oregon Health & Science University (OHSU) **Doernbecher Children's Hospital** Pediatric Outpatient Parenteral Antibiotic Therapy (pOPAT) program was an early adopter of the CCMT. The CCMT was used by the pOPAT team because it was a novel measure of capturing preventable events, which translated into savings for the hospital system. The CCMT was crucial in advocating for additional personnel and both quantifying and qualifying the various non-billable activities that went into ensuring optimal patient outcomes. Due to its success

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in the pOPAT program, the CCMT has subsequently been adopted by the pediatric foster care program at this hospital to examine the role of social work in care coordination activities in this vulnerable group.

The Primary Care Clinic at **Children's Healthcare of Atlanta**, Hughes Spalding, has also adopted the CCMT as part of its creation of two nurse navigator positions for designated care coordination, which was part of its journey to acquire Patient Centered Medical Home (PCMH) designation/certification. At the time, there were no existing clinical standards for this role at Children's Healthcare of Atlanta. Role development was led and continues to be led by nurse navigators in these positions. The CCMT tool was adapted for use with EMR in 2015 and has since been used by the nurse navigators who focus on the care of children with medical and socioeconomic complexity. Key elements captured by the tool include level of complexity, activities, and outcomes, as well as time spent for each encounter. With PCMH certification and as the nurse navigator program evolves, the CCMT helped Children's Healthcare of Atlanta at Hughes Spalding identify the need for outcomes which are more specific and meaningful to the population served.

The Pediatric Integrated Care Survey (PICS) was developed in partnership with families of children and youth with special health needs and was designed to measure the family/patient experience of care integration across providers, settings, disciplines and sectors. The PICS is a validated survey which evaluates care integration in five domains: access to care, communication with care team members, family impact, care goal creation/planning and team functioning/quality. The PICS is a true outcome measure of family experience. It is often implemented at the beginning of a redesign project so that care teams can prioritize their intervention strategies.

For example, **Nationwide Children's Hospital** in Columbus, Ohio chose the PICS tool to reach one of the two primary aims for *Navigate My Care*, an organization-wide quality improvement program aimed at helping families with children affected by medical complexity navigate the health care system. The program's aims are 1) to reduce avoidable care and 2) to concurrently improve the patient and family's experience with the integration of care. Nationwide Children's chose the PICS over other patient-reported outcome measures because of the importance of measuring the family's experience, rather than the presence or absence of certain aspects of care (e.g. presence or absence of a care plan, care coordinator, etc.). Data obtained from the PICS is being used to improve the environment of care according to the five specific PICS domains, and improving the overall composite score is a primary outcome measure for the project.

The Pediatric Care Coordination Curriculum, funded by the U.S. Maternal and Child Health Bureau, is about to be released in its 2nd Edition. It is designed as an interprofessional education resource, enabling multidisciplinary teams (including nursing, social work, case managers, physicians, trainees, community health workers, and community organizations such as family support, home visiting, early intervention, special education) to learn standardized and measurable approaches to implementing CC. It provides a common language to guide CC implementation as well as performance metrics which enable evaluation of outcomes related to care delivery for patients with chronic and complex needs.

Findings and Implications for Children's Quality

By implementing these tools and measures, Boston Children's Hospital generates important data on aspects of value-based, integrated care that matter most to children and their families— highly reliable, safe care that is coordinated across all providers and settings. Hospitals like Nationwide Children's, OHSU Doernbecher Children's, and Children's Healthcare of Atlanta that have also put them into practice have demonstrated the tools' utility in a variety of programs to improve the quality of care delivered to their patients.

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Citations and Resources

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To see all tools of the Integrated Care Program at Boston Children's Hospital http://www.childrenshospital.org/integrated-care-program

Additional Resources Are Available via the National Center for Care Coordination Technical Assistance http://www.childrenshospital.org/integrated-care-program/national-center-for-care-coordination-technical-assistance

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Case Study 2: Children's Hospital Colorado and Anthem BCBS

Report Topics Addressed: *Engagement with Commercial Health Plans, Quality Measurement, Value-based Incentives*

Overview

This case study demonstrates how an established, adult-focused value-based inpatient reimbursement structure can be adapted to meet the quality needs of the pediatric population and illustrates how pediatric-focused quality measures can be implemented to support such programs.

In 2014, discussions began between Children's Hospital Colorado in Denver and Anthem Blue Cross and Blue Shield to develop a risk-based contract focused on improving pediatric quality of care. The pilot program, called "Quality-in-Sights®: Hospital Incentive Program" (Q-HIP®) for Children's Facilities", is derived from Anthem's original Q-HIP program, which was introduced in 2003 to incentivize hospitals to meet quality measures for general adult care. The new Children's Facilities program, which went live in 2017, adapts the original concept to the unique quality challenges and value of a children's hospital.

The Q-HIP program attaches financial incentives to performance on measures of surgical site infections, asthma and upper respiratory care, sepsis and appropriate imaging for children. Selection of these metrics was a collaborative process between the hospital and Anthem to identify a measure set that balanced quality areas like safety, effectiveness, and patient satisfaction. Performance is evaluated against benchmarks that are set based on past experience and is tracked through real-time dashboards. The set is evaluated each year to see which measures may be retired or added.

Findings and Implications for Children's Quality

Children's Colorado Q-HIP completed its first year with positive responses from clinicians and other stakeholders, and is currently focused on improving results in the second year. Performance on the metrics is made available to the care teams on regular intervals using dashboards. The alignment of better care with financial outcomes has helped sustain resources and programs devoted to quality improvement that may have been difficult to sustain without the partnership. The measures, which are self-reported by providers, are part of a core set of metrics that are followed closely by hospital leaders. Children's Colorado is working to partner with other major payers to expand the program and reach more patients in the future.

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Case Study 3: James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center

<u>Report Topics Addressed:</u> *Implementation of Measures, Internal Quality Improvement, Learning Networks*

<u>Overview</u>

The Anderson Center for Health Systems Excellence has led the development of several successful learning networks: multicenter collaboratives engaged in continuous quality improvement in pediatric care. The networks are comprised of care centers and teams of patients, families, multidisciplinary clinical teams and scientists that are aligned around a common goal of improving the health of a defined population. Members of the network share tools, resources, knowledge and standards to improve outcomes through continuous engagement and collaboration at the network, care center and individual levels. Ways by which sites stay connected include online forums, calls, educational webinars and in-person seminars hosted by different sites. By participating in learning networks, care teams can share replicable strategies and standards within and across their network to help each other address common challenges and improve outcomes

The learning networks offer several benefits to participating sites. These include QI training, coaching, and tools; daily and monthly reports on measure performance, patient status, population management, and pre-visit planning; model guidelines; robust research and measure development opportunities through registries and other data sharing opportunities; and position at the front line of testing and using new health care innovations. The networks have been shown to improve health outcomes through the sharing of data and ideas across multiple sites, and through engaging patients, families, clinicians and scientists in evidence-based quality improvement initiatives that matter most to them. As a result of their success, many of the networks are approved as collaborative QI activities eligible for credit towards practitioners' "Maintenance of Certification" requirements.

Some of the learning networks include:

> **ImproveCareNow (ICN) Quality Improvement Collaborative for Pediatric Inflammatory Bowel Disease (IBD):** a network focused on improving chronic care delivery and outcomes for children and adolescents with irritable bowel disease. The ICN measure set includes measures in 4 categories (clinical remission, adequate nutrition and growth, model classification and model treatment). (*Note: 3 measures in the Demonstrating Value in Pediatrics Measure Menu are ImproveCareNow IBD measures*).
>
> **The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC):** the first learning network within pediatric cardiology. The NPC-QIC was established to improve care and outcomes for children with hypoplastic left heart disease, specifically to (1) improve interstage mortality, (2) decrease interstage growth failure, and (3) reduce interstage hospital readmissions for major medical events.
>
> **Ohio Perinatal Quality Collaborative (OPQC):** a state-wide voluntary network of Ohio perinatal clinicians, hospitals, professional organization, and state agencies with a mission to reduce preterm births and improve outcomes for infants. Participating hospitals and clinicians are supported by a central staff with QI expertise and an administrative and data management infrastructure. The OPQC conducts projects that generate benchmarks

for best practices that are based on robust research, expected to have significant population effects on perinatal outcomes, supported by the clinical community, and are feasible to test, adapt, implement and measure.

Children's Hospitals' Solutions for Patient Safety (SPS) Network: a 120+ site collaborative that serves 50% of all children hospitalized in the U.S. As part of this collaborative, hospital sites implement SPS Prevention Bundles, which include high-reliability organizational (HRO) principles and quality improvement science methods to maximize institutional safety culture. Measures used in SPS programs include "Adverse Drug Event Rate", "Catheter-Associated Urinary Tract Infection Rate", "Central Line Associated Blood Stream Infection Rate", "Falls (Moderate or Greater Injury) Rate", "Pressure Injuries Rate", "Readmission within 7 Days Rate", "Surgical Site Infections Rate" and "Venous Thromboembolism Event Rate."

Findings and Implications for Children's Quality

Learning networks share a common framework and methods which collectively result in a replicable process for improving outcomes across multiple diseases and conditions. Many have shown tangible improvements. For example:

- The NPC-QIC has led to a reduction in mortality rate of 44% across all centers since 2013.
- The SPS Network has saved 9,600+ children from serious harm.

Participants in the learning networks have found that the use of measures to enable the successful performance of continuous quality improvement has the potential to address gaps in care and to improve outcomes in children and adolescents with complex disease. In the future, measures used by networks are expected to be integrated into value-based contracting to help children's hospitals already participating in the learning networks succeed in the value-based purchasing environment.

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Case Study 4: UCSF Benioff Children's Hospital Oakland

Report Topics Addressed: *Communication and Coordination, Community Engagement, Application of Health IT*

Overview

The following case study illustrates the feasibility and benefit of addressing social needs as part of a comprehensive approach to health care in the hospital setting. It shows that communication and coordination, aided by technology and evaluated with measures that capture both clinical and social outcomes, can help preserve the health of children in ways that will yield positive long-term results.

The UCSF Benioff Children's Hospital Oakland serves a diverse population. Many of their patients, particularly children of color or who were in a low socioeconomic bracket, face harsh social conditions that have a significant impact on their health. About half of all parents and caregivers surveyed at the emergency room expressed concerns about running out of food or losing their housing or concerns that their child was unsafe in their neighborhood or at school. Researchers found that reports of concerns about mental health issues, violence and substance abuse within their child's home were more common if respondents were surveyed electronically rather than in-person, suggesting that these issues may be underreported to clinicians at the hospital.

In response to these pressing needs, researchers and clinicians at UCSF executed an intervention to evaluate the effectiveness of social needs screening and in-person resource navigation services on children's health and social well-being. Families who were screened at the hospital were provided with written information on relevant community services. Some received additional in-person navigation services. Those who provided the screening were trained on how to apply patient-centered principles, demonstrate cultural humility, and avoid imposing more trauma on already-traumatized families.

These interventions utilized in-person and electronic screening tools in the acute care setting to better understand and address needs that otherwise may have gone unmet at a critical point in care. They were supported by information technologies like FINDConnect: a mobile, cloud-based application that can be integrated into the existing electronic medical record (EMR) system that enables fast screening and referrals for children and families and can thereafter track their progress.

UCSF Benioff used multiple process measures to evaluate the program, including measures of individuals screened, follow-up and referral rates, and the volume of resources applied. Through their EMR, they could link program participants with data on hospital utilization to better understand program outcomes. Participants were also given surveys to evaluate patient experience.

This program is one of many UCSF Benioff initiatives administered through the hospital's Department of Community Health and Engagement (DCHE). Other programs focus on improving nutrition, literacy, and early education for the children and families served by the hospital.

Findings and Implications for Children's Quality

Families that received assistance to identify and connect with relevant community resources in the acute care setting reported an increase in the number of needs resolved and significant improvements in patient-reported child health status. The results of the program show that screening for social determinants of health is feasible and helpful to children and families. A next step for UCSF Benioff is to scale up the program to screen all patients who come into the hospital.

Performance results from the program are being evaluated on an ongoing basis, though preliminary performance on patient experience is very positive.

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Appendix E: Measure Menu Details

Demonstrating Value in Pediatrics: A Measure Menu, Workbook & Guidance for Value-based Care, Payment and Reporting Programs

For each measure that is included in the menu, the following information is included:

Col	Menu Field Title	Brief Description	Program Requirement
A	CHA Measure Area	Designation to one of the four measure areas used in the menu and accompanying report	Aligns with program goals
B	CHA "What Matters Most" Measure Area	Designation to one of six categories that were used by the CHA *What Matters Most Task Force*	Informative for patient-centric programs
C	Menu Considerations or Limitations (if any)	CHA captured considerations and limitations identified during the project that end-users of the menu may want to further investigate.	Informational; may inform feasibility or relevance
D	Measure	The title of the measure	Useful for specification alignment
E	Description	A description of what the measure captures	Informs alignment with program objectives, clinical/event target.
F	Clinical Condition/Event	A designation of the condition or therapy addressed by the measure	Aligns with program goals, objectives
G	Topic	A short designation of the measure topic to support sorting and filtering of measures in the menu	Aligns with program goals, objectives
H	Care Setting	The setting(s) at which the care captured in the measure is(are) rendered	Align with program requirement
I	Age	The applicable age range for the measure	Align with program target population
J	Level of Analysis (also referred to as the Level of Accountability)	The level (e.g. plan, clinician) at which information from the measure is assessed, and accountability is assigned	Align with accountability requirements, who is being incentivized for quality performance

K	Data Source(s)	The primary source(s) of data required to implement the measure. There may be more than one data source required.	Ensure program has access to all needed data sources. Refer to measure specifications for details on required versus supplemental data.
L	Steward	The organization that maintains the measure	Contact organization for information on the use of the measure, and most up-to-day measure specifications and experience
M	Link to Measure Description Resources	When available, links to measure information is provided. All links are active as of January 2019	
N	NQF ID	Designation given by the National Quality Forum (if available)	
O	NQF Endorsement Status	Endorsement status, if applicable	
	Program Use Information		
P	2019 Medicaid and CHIP Child Core Set	Y/N Measures used in the 2018 Child Core measure set https://www.medicaid.gov/medicaid/quality-of-care/performance- measurement/child-core-set/index.html	
Q	AHIP Core Measure	Y/N Measures included in the *Core Quality Measures Collaborative core sets* , led by the America's Health Insurance Plans for use across payers. The Collaborative released eight core sets: https://www.ahip.org/ahip-cms-collaborative-announces-core-sets- of-quality-measures/ OR https://www.cms.gov/Medicare/Quality Initiatives-Patient-Assessment-Instruments/QualityMeasures/Core- Measures.html	
R	AHRQ PQMP Measure	Y/N Agency for Health care Research and Quality (AHRQ-CMS) children's health care quality measures developed as part of the Pediatric Quality Measures Program (PQMP): https://www.ahrq.gov/pqmp/measures/index.html	

S	CDC-NHSN Measure	Y/N Measures used for reporting to the Center for Disease Control's (DC's) National Health care Safety Network: https://www.cdc.gov/nhsn/index.html
T	SAMHSA Behavioral Health Clinic Quality Measures	Y/N Measures included in the Substance Abuse and Mental Health Services Administration (SAMHSA) Metrics and Quality Measures.
U	State Programs	Y/N Measures reported to at least one known state program.
V	ImproveCareNow Network	Y/N Measures reported to ImproveCareNow Network https://www.improvecarenow.org/program-details
W	Vermont Oxford Network	Y/N Measures reported to the Vermont Oxford Network
X	Virtual PICU	Y/N Measures used by the Virtual PICU registry
Y	Select Additional Programs:	Contains information on other state, federal, or commercial programs (NOT AN ALL-INCLUSIVE)
	AHRQ Pediatric Quality Measures Program (PQMP)	https://www.ahrq.gov/pqmp/measures/index.html
	American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI®) Program	https://practice.asco.org/quality-improvement/quality-programs/quality-oncology-practice-initiative/qopi-related-measures
	Buying Value Measure Selection Tool	http://www.buyingvalue.org/resources/toolkit/#step3
	CMS Marketplace Quality Rating System (QRS)	https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/ACA-MQI/ACA-MQI-Landing-Page.html
	CMS Merit-based Incentive Payment System (MIPS)	https://qpp.cms.gov/mips/overview
	CMS Physician Compare	https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/physician-compare-initiative/
	CMS Physician Feedback/Quality and Resource Use Reports (QRUR)	https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeedbackProgram/2016-QRUR.html
	HRSA Ryan White HIV Quality Measures (HIVQM) Module	https://hab.hrsa.gov/clinical-quality-management/quality-care
	Medicare Shared Savings Program (MSSP)	https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/sharedsavingsprogram/about.html
	NYS Total Care for General Population (TCGP)/Integrated Primary Care (IPC)	https://www.health.ny.gov/health_care/medicaid/redesign/dsrip/vbp_library/quality_measures/2018_tcgp_qms.htm

Appendix F: Glossary of Abbreviations

AAAAI - American Academy of Allergy Asthma and Immunology

AAP - American Academy of Pediatrics

ACO - Accountable Care Organization

AHIP - America's Health Insurance Plans

AHLC - Accountable Health Learning Collaborative

AHRQ - Agency for Healthcare Research and Quality

AOD - Alcohol and Other Drug

ASCO - American Society of Clinical Oncology

CAHPS - Consumer Assessment of Healthcare Providers and Systems

CC - Care Coordination

CCMT- Care Coordination Measurement Tool

CDC - Centers for Disease Control and Prevention

CEPQM - Center of Excellence for Pediatric Quality Measurement

CHA - Children's Hospital Association

CHIP - Children's Health Insurance Program

CMS - Centers for Medicare & Medicaid Services

COE - Center of Excellence

DCHE - Department of Community Health and Engagement

ED - Emergency Department

EHR - Electronic Health Record

EMR - Electronic Medical Record

ER - Emergency Room

FCC - Family Centered Care

GAPPS - The Global Assessment of Pediatric Patient Safety

HCP - Healthcare personnel

HEDIS - Healthcare Effectiveness Data and Information Set

HRO - High-Reliability Organization

HRSA - Health Resources and Services Administration

IBD - Inflammatory Bowel Disease

ICS - Inhaled Corticosteroids

IPSO - Improving Pediatric Sepsis Outcomes

MEPS - Medical Expenditure Panel

NCCN - National Comprehensive Cancer Network

NCQA - National Committee for Quality Assurance

NEJM - New England Journal of Medicine

NHSN - National Healthcare Safety Network

NICU - Neonatal Intensive Care Units

NPC-QIC - The National Pediatric Cardiology Quality Improvement Collaborative

NQF - National Quality Forum

NQS - National Quality Strategy

OPQC - Ohio Perinatal Quality Collaborative

PCMH - Patient Centered Medical Home

PCP - Primary Care Physician

PCPI - (No acronym- it is the organization's name)

PDI - Pediatric Quality Indicators

PHQ-9 - Patient Health Questionnaire-9

PICS - Pediatric Integrated Care Survey

PQMP - Pediatric Quality Measures Program

Q-HIP - Quality-in-Sights®: Hospital Incentive Program

QI - Quality Improvement

SAMHSA - Substance Abuse and Mental Health Services Administration

SPS - Solutions for Patient Safety

STS - Society of Thoracic Surgeons

VON - Vermont Oxford Network

CHILDREN'S HOSPITAL ASSOCIATION

Champions for Children's Health

About

Children's Hospital Association is the voice of more than 220 children's hospitals, advancing child health through innovation in the quality, cost and delivery of care.

Contact

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