


Optimizing patient care and outcomes through the congenital heart center of the 21st century

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Abstract

Pediatric cardiovascular services are responding to the dynamic changes in the medical environment, including the business of medicine. The opportunity to advance our pediatric cardiology field through collaboration is now realized, permitting us to define meaningful quality metrics and establish national benchmarks through multicenter efforts. In March 2016, the American College of Cardiology hosted the first Adult Congenital/Pediatric Cardiology Section Congenital Heart Community Day. This was an open participation meeting for clinicians, administrators, patients/parents to propose metrics that optimize patient care and outcomes for a state-of-the-art congenital heart center of the 21st century. Care center collaboration helps overcome the barrier of relative small volumes at any given program. Patients and families have become active collaborative partners with care centers in the definition of acute and longitudinal outcomes and our quality metrics. Understanding programmatic metrics that create an environment to provide outstanding congenital heart care will allow centers to improve their structure, processes and ultimately outcomes, leading to an increasing number of centers that provide excellent care. This manuscript provides background, as well listing of proposed specialty domain quality metrics for centers, and thus serves as an updated baseline for the ongoing dynamic process of optimizing care and realizing patient value.

KEYWORDS

congenital heart disease, outcomes, quality, safety, value

1 | INTRODUCTION

Care for children and adults with pediatric and congenital heart disease illustrate the power and possibility of modern medicine. Continuous advancement of therapies and services available to serve patients and

families has rendered previously untreatable illnesses manageable, with many individuals affected by these conditions now living into adulthood and functioning well in society. Coupled with these successes, and perhaps contributing to them, has been a rising focus by hospitals and providers on measuring patient outcomes and experience and

enhancing transparency regarding quality of care in communication with patients and families.

In 2002, the American Academy of Pediatrics published "Guidelines for Pediatric Cardiovascular Centers."¹ The objective of this statement was to describe critical elements of a pediatric cardiovascular center necessary for achieving the best patient outcomes. When this statement was written multicenter measurement and quality improvement efforts were in their early infancy. Over the past fifteen years there have been advances in our understanding of cardiac physiology, diagnostic tools and therapeutic techniques. Our understanding of important components of care associated with excellent patient outcomes has also improved.

In addition to medical and surgical advances, several other factors impact the structure and practice of congenital heart disease care. First, the volume and variety of data captured at care centers and across data registries has expanded exponentially.² Second, there has been a heightened focus on transparency and reporting of data. This movement has been led by providers inspired by patients/families collaborating to improve practice and outcomes, patients and families seeking information to help make decisions about where to receive care, and payers interested in seeking centers with best outcomes and lowest costs.³⁻⁵ The availability of vast outcome data allowed several external organizations to provide the public with information about hospital performance and even to create rankings of programs. The most prominent examples of public reporting in our field include US News and World Report and the Society of Thoracic Surgeons (STS). While patients and families have fought for access to clinical outcomes data, they have also advocated for systems of care and specific processes that are more patient- and family-centered, promoting shared decision-making principles integral to their child's care.⁶ Finally, clinicians and researchers shifted their focus to quality metrics beyond mortality and morbidity as important factors in defining high-value care. The Institute of Medicine provided one framework for considering outcomes and value holistically and outlined six domains of quality in healthcare: safe, effective, patient-centered, timely, efficient, and equitable.⁷ There is now an increased focus on understanding patient and family experience as a metric of value in care delivered.

The aim of this project was to describe the structure, function, and critical outcome measures that would allow the congenital heart center of the 21st century to achieve the best value for patients with congenital heart disease. Uniquely, this particular project was imagined and executed by providers, rather than centers or external organizations, and has been inspired and guided by the voice of parents and patients, each group demanding a better understanding of what drives great short and long-term clinical outcomes.

2 | METHODS

The topic of programmatic metrics in congenital heart disease centers was the subject of the first Congenital Heart Community Day, held in conjunction with the 2016 American College of Cardiology Annual Meeting. This full day was attended by a broad representative group of

TABLE 1 Domains for metric development

Administration
Adult congenital care
Ambulatory
Cardiothoracic surgery
Cardiac critical care
Electrophysiology
Inpatient units
Interventional cardiology
Noninvasive imaging
Nursing

cardiologists, surgeons, nurses, parents and administrators. Through plenary talks and breakout sessions, groups from multiple domains within the larger cardiac care community began to propose metrics that define great congenital heart programs using several foundational principles. These topics were further discussed and refined at the Twelfth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease (Wednesday, August 24, 2016 and Thursday, August 25, 2016 at the Emory Conference Center, Atlanta, Georgia).

In defining appropriate programmatic metrics we used several foundational principles. Donabedian, a physician and health services researcher, developed a conceptual model that frames health services and quality of care around three categories: structure, process and outcomes. Structure describes the context in which care is delivered, and includes physical structures, supplies and equipment. Process is the flow and interaction of patients through the care delivery system and the interaction with care givers. Finally, outcomes refer to the health status of the patient receiving care in the system.⁸ Porter further delineated the complexity of health outcomes in his model of value in healthcare. Outcomes, according to Porter, include short-term outcomes, such as mortality, but also must include long-term functional outcomes as well.⁹

We followed the frameworks outlined by Donabedian and Porter and organized our discussion of metrics around process, structure and outcome.^{8,9} The first draft of these metrics was created by workgroups during the Congenital Heart Community Day. For each cardiology domain (Table 1) project leaders defined programmatic metrics for their domain based on best available data, evidence and content expertise. Finally, each group defined gaps that currently exist in our knowledge about programmatic quality and outcomes, to act as a guide for future research on more refined metrics. What follows is a description and list of proposed programmatic metrics from each domain.

2.1 | Administration

The congenital heart center Administration domain requires close alignment with clinical care. Physician and administrative leadership optimally function through a dyad relationship, to ensure that all aspects of the congenital heart center meet the needs of patients and families. Physician leadership input regarding strategic direction, financial

TABLE 2 Administration metrics

Metric	Domain	Definition
1.	Structure	Core certifications for Physicians, APPs, and Nurses (Board Certification, APP Certification, CCNC)
2.	Structure	Nurse to Patient Ratio
3.	Structure	Core Accreditation/Credentialing/Recognition: Joint Commission, Beacon, Magnet, Sub-Specialty Accreditation Programs
4.	Structure	Dedicated Services/Programs/Facilities: Dedicated Cardiac ORs; Dedicated Cardiac Anesthesia Services; Inpatient Cardiology Consultation; Cardiac Intensive Care Unit; Remote monitoring of Cardiac patients (telemetry); Noninvasive cardiac imaging, CT and MRI; Cardiac Interventional Cath Lab/Diagnostic Cath Lab/EP Lab; Adult Congenital Heart Program; ECMO; Heart Transplant and Heart Failure Program; Mechanical Device Program; Cardiac Genetics Clinic; Cardiac Neurodevelopmental Care Program; Pediatric Cardiac Anesthesia services; Diagnostic modalities (Echo, CT, cMRI); Cardiopulmonary Exercise testing; Telemedicine; Specialty Programs (Fetal Cardiology, Aortopathy, Arrhythmia, Pulmonary Hypertension, Preventive Cardiology, etc). Consultative services to manage noncardiac issues in the cardiac patient (neurology, nephrology, GI, infectious disease, nutrition, social work, pharmacy, transfusion services, etc).
5.	Structure	Participation in Core Clinical Registries/Collaboratives: STS Congenital Cardiac Surgery; STS Congenital Cardiac Anesthesia Society; NCDR-IMPACT; C3PO-QI; PC ⁴ or VPS; PAC3; National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC); Solutions for Patient Safety Collaborative (SPS); ELSO
6.	Structure	Engaged Cardiac Patient/Family Advisory Group
7.	Process	Transparency of Surgical Outcomes
8.	Process	Transparency of Patient Experience
9.	Process	Surgery cancellation rate (not related to patient illness or cause)
10.	Process	Standardized physician communication for inpatient care and discharge, postdischarge follow-up care

decisions, programs, and clinician performance metrics is vital. Communication with all members of the program ensures alignment with mission and heightens engagement of staff. Structure and process are cornerstones of the Administration domain, to ensure that comprehensive clinical facilities, equipment, skilled personnel, and pertinent resources are available. Patients with complex congenital heart defects require advanced clinical services and therapies/treatments, advanced technology (eg, ECMO, mechanical ventricular assist device), clinical support services, and seamless transition or continuation to adult congenital heart care. Comprehensive specialty programs, (arrhythmia, pulmonary hypertension, aorta and vascular, neurodevelopmental care, etc) and services support need to be readily available. A comprehensive outpatient network allows local care to be delivered locally in the communities, also ensuring efficient and effective communication with the inpatient center through the use of electronic medical records. Advanced health information technology is now the standard and becomes a cornerstone for accountable care organizations or clinically integrated networks. Timely access to care (perhaps best quantitatively measured as cancellation rate for surgical procedures or time to third next available appointment in the outpatient arena) has become an important outcome measure for busy and at-capacity heart centers. Centralized cardiac patient scheduling and concierge services assist with coordination of care and patient experience.

The Administration domain is also responsible for the documentation of quality for providers and the heart program. Certification of programmatic structures and processes and the credentialing of clinical care providers and staff, including maintenance of certification, becomes the responsibility for the congenital heart center. Children's hospitals and pediatric cardiac programs are now ranked through an annual US News and World Report survey. Centers are externally accredited

through Joint Commission, Magnet, or Beacon recognition, and other subspecialty accreditation programs. Centers should participate in key national clinical registries and patient care and safety collaboratives for benchmarking and adoption of best practices, generation of center-specific registry-documented results, and transparency through public reporting. Engagement of the patient and family is essential in improving operations and their experience. Use of a survey instrument such as HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) measures patients' perceptions of their hospital experience.¹⁰ The HCAHPS survey is an example of an experience survey that provides a national standard for collecting and publicly reporting information about patient experience. The engagement of families who actively participate in a formal advisory role will assist the center in improving the day-to-day operations and patient/family experience.

For the business of medicine, it is expected that centers will begin transitioning from volume-based care (fee for service) to a value-based reimbursement structure (fee for value) with evolving contract and reimbursement strategies. Fee for value payment models prompt a center to deliver the best care at the lowest cost. As centers aim to respond to the changing market forces, they may consider involvement with clinically integrated networks for demonstrating patient care coordination. Participation with group purchasing organizations may allow for competitive pricing on supply/equipment resources.¹¹ Physician-developed clinical pathways can reduce error and eliminate unnecessary variability which may improve quality of care and reduce costs. Implementing team-based models utilizing advance practice providers (APPs) to extend physicians and to manage clinical programs may allow for more effective and efficient far reaching care delivery. Suggested administrative metrics can be found in Table 2.

2.2 | Adult congenital

The care of adults with congenital heart disease and the subspecialty cardiovascular field of adult congenital heart disease (ACHD) have rapidly developed over the past several decades and in parallel the recognition and importance of ACHD quality metrics (QM). The ACHD domain benefited from ACHD patient and family collaboration, leading the way to shared decision making and definition of meaningful quality metrics. The 2008 ACC/AHA guidelines for the management of adults with congenital heart disease set the stage for future ACHD quality measures and metrics.¹² By providing for the first time weighted, evidence-based guidelines, structured in a lesion-specific format, the blueprint was in place for lesion-specific quality metrics. Developed over a several-year process, 55 quality indicators were proposed for 6 ACHD conditions in 2013.¹³ The process to derive the first set of ACHD quality indicators was based on utilizing an expert panel reviewing previously published ACHD guidelines and proposing indicators that met standards for validity and feasibility, eventually paring down to the final set of measures. During this same time, the ACC through the ACPC council developed the Quality Metric Working Group to propose CHD QMs. The ACHD working group in cooperation with the quality metric working group developed the first CHD QM—Complete Aortic Evaluation for Adults with Repaired Coarctation of the Aorta. The 24 QMs listed through the ACPC section can be found on the ACPC Quality Network website.¹⁴

Although the field of ACHD had made great strides through the 2008 ACC/AHA ACHD Care Guidelines and the 2013 ACHD lesion specific quality indicators, there still was great need to develop more structured QMs. As early as 2001, with the 32nd Bethesda Conference on the *Care of the Adult with Congenital Heart Disease*, experts had proposed the development of ACHD care centers and specific ACHD training for cardiologists interested in caring for this population.¹⁵ ACHD care centers/programs would create a care model that included not only the ACHD cardiologist, but advanced practice practitioners, and subspecialists in related fields that care for the ACHD patient; for example, interventional cardiology, electrophysiology, cardiothoracic surgery, echocardiography, intensive care. To this point only proposed as an important QM, Marelli and colleagues demonstrated as an outcome QM that patients referred to specialized ACHD programs in Canada experienced a significant reduction in mortality.¹⁶ In 2012, the Adult Congenital Heart Association (ACHA) took on the challenge to develop accredited ACHD Care Centers meeting criteria standards through a detailed application and a site visit. The ACHA Program Accreditation process embeds QM throughout the proposed standards and criteria that must be met to become accredited.¹⁷ There are 19 sections and over 100 individual ACHD care criteria. The accredited care centers will develop quality initiatives through the QM sharing among the centers.

To meet the needs of the ACHD patients and the standards of an ACHD care center, in 2007 a proposal was submitted to the American Board of Internal Medicine and simultaneously to the American Board of Pediatrics to create a subspecialty board certification for ACHD. In 2012, ACHD subspecialty certification was approved by the American

TABLE 3 Adult congenital metrics

Metric	Domain	Definition
1.	Structure	ACHD lesion-specific quality indicators as published ¹³
2.	Structure	Physicians caring for ACHD patients are ACHD ABIM/ABP Board Certified
3.	Structure	Program is ACHD Accredited
4.	Structure	ACHD cardiologists complete an AGME approved fellowship training program

Board of Medical Specialties and in October 2015, the first ACHD certifying board examination was administered. Accreditation Council for Graduate Medical Education (ACGME) approval for ACHD training followed board certification, and a 2-year curriculum was approved to be completed after either internal medicine or pediatric cardiology training. Both ABIM/ABP ACHD board certification and ACGME ACHD training programs are structured QMs meeting the highest standards for training and certifying physicians in the US.

Both process and structure QMs have been developed in ACHD to improve the care of ACHD patients and form a basis for quality improvement. We now have ABM/ABP board certified cardiologists incorporated into an ACHA-accredited program collecting QM data and developing multispecialty quality initiatives. The field is primed for improved access and quality of care delivered to this underserved population. Suggested Adult congenital metrics can be found in Table 3.

2.3 | Ambulatory

Measurement of quality care in ambulatory pediatric cardiology has lagged behind other domains of the service line, for example, cardiac intensive care unit, interventional catheterization laboratory, and cardiac surgery. While many pediatric outpatients are followed for complex cardiac diagnoses after multiple interventional and surgical procedures, another large volume of patients is evaluated for what ultimately proves to be noncardiac signs and symptoms. In the adult cardiology sphere, the NCDR PINNACLE registry is the largest observational outpatient cardiac registry in the world, for patients with coronary disease, hypertension, heart failure, or atrial fibrillation.¹⁸ Similar evidence-based physician performance metrics do not yet exist for pediatric cardiology. Only recently, the ACC has undertaken a process to develop quality metrics in 5 areas of interest—chest pain, postoperative tetralogy of Fallot, postoperative arterial switch repair for transposition of the great arteries, Kawasaki disease, and infectious disease issues (flu vaccine, SBE prophylaxis, Synagis, rheumatic fever). A description of the development of these metrics has been published.¹⁹ These metrics are currently being operationalized through the ACC ACPC Quality Network (QNet).²⁰ Most of these metrics are process measures; efforts to develop patient outcome measures should be supported.

The development of, and endorsement of, multicenter clinical care pathways may help guide outpatient diagnosis and treatment and eliminate unnecessary variability. Appropriate use criteria for

echocardiography during the initial evaluation of patients represent a first step to direct imaging based on vetted criteria.²¹ The National Pediatric Cardiac Quality Improvement Collaborative (NPCQIC) has proven highly successful to advance best practice care for the management of interstage patients with hypoplastic left heart syndrome.²² This multi-center collaboration amongst physicians, other cardiac care team staff, and families has generated protocols and check lists that are optimizing patient outcome.

Another methodology that has demonstrated improvement in approaches to outpatient management has been the Standardized Clinical Assessment and Management Plans (SCAMPs) program.²³ SCAMPs act as clinical guidelines but permit knowledge and experience-based diversions from suggested guidelines. This approach has been applied to diverse pediatric cardiology conditions such as pediatric chest pain, syncope, balloon dilation for congenital aortic stenosis, and the postoperative management of the arterial switch operation, demonstrating reductions in resource utilization while maintaining quality of care.^{24–27} This standardized approach to cardiac care, along with methods such as appropriate use criteria, improve care while minimizing overutilization of resources.

Access to care, and cost of delivering these services, is becoming a focal point for cardiac service lines. Time to third next available appointment has been proposed as a standard process measure but may not be applicable to specialty programs such as pulmonary hypertension, aortopathy, and so forth. that meet infrequently. Provision of comprehensive noninvasive diagnostic services in outpatient offices is an expensive proposition, which may be offset through the alternative care delivery model of telemedicine and/or the development of team-based care, with advanced practice providers supplanting physicians.

One of the major changes in delivery of ambulatory care is the development of integrated practice units (IPUs) which engage multidisciplinary specialists and nonclinical staff to provide comprehensive care of complex patients. Examples include single ventricle survivorship programs and neurodevelopmental assessment programs, now present in many large US congenital heart disease programs. Similarly, arrhythmia services and sudden cardiac arrest programs, heart failure programs, pulmonary artery hypertension and aortopathy programs are now being developed at many centers to provide care for these complex patient subsets.

The field of ambulatory pediatric cardiology provides a ripe target for the development of objective structure, process, and patient outcome metrics. Collaboration among programs, which can be advanced through the ACC ACPC Section, should be furthered. Suggested adult congenital metrics can be found in Table 4.

2.4 | Cardiac critical care

Cardiac critical care represents a key discipline necessary to achieve excellent outcomes at successful congenital heart centers. It is imperative to develop a clear understanding of the critical care team's impact on patient outcomes and the quality of care provided in cardiac intensive care units (CICU). Multiple databases now exist to measure and understand variation in practice and outcomes. Two primarily North

TABLE 4 Ambulatory metrics

Metric	Domain	Definition
1.	Structure	Participation in quality improvement programs: NPCQIC, ACC QNet
2.	Structure	Availability of comprehensive noninvasive imaging, on-site or through telemedicine
3.	Structure	Availability of IPU programs and cardiac subspecialists, including electrophysiology, heart failure, preventive cardiology, adult congenital, cardiovascular genetics, cardiac neurodevelopmental follow up, fetal cardiology, pulmonary hypertension
4.	Process	ACC approved ambulatory quality metrics ¹⁹
5.	Process	Utilization of standardized clinical guidelines for outpatient management
6.	Process	Measurement of patient access to outpatient clinics
7.	Process	Timely structured communication to referring physicians

American databases—the Virtual PICU System (VPS, LLC, Los Angeles) and the Pediatric Cardiac Critical Care Consortium (PC⁴) clinical registry—focus solely on critically-ill patients, while many others include some data related to critical care (eg, surgical databases). Of these, the PC⁴ clinical registry is the only database exclusively dedicated to the cardiac critical care population.

Outcome measures used for pediatric cardiac critical care quality assessment should reflect the competence and performance of the CICU team, and be independent of care provided and outcomes realized prior and subsequent to the CICU admission. Ideal metrics of CICU quality would be outcome measures (as opposed to structure or process measures) and appropriately risk-adjusted to account for patient factors. Existing risk-adjustment models used in cardiac surgical and general pediatric critical care outcomes assessment are insufficient for measuring CICU performance, particularly when considering quality of postoperative care. Further, most existing methods focus on mortality as the clinical endpoint, and several nonmortality metrics such as complications, functional status at discharge, and resource utilization may be important markers of quality in the CICU. A number of properly adjusted metrics will be available in the near future. When considering structure and process measures, evidence to support an association between these measures and outcomes in CICU patient populations is weak at best.

Further complicating the approach to outcomes assessment and defining quality in the CICU is the heterogeneity of hospital inpatient service structure and the interdependence of CICU and non-ICU/ward resources. Potential metrics such as CICU readmissions and CICU length of stay can be difficult to measure and/or hard to interpret across hospitals due to these system differences. Proposed metrics should account for these differences and reflect the quality of CICU care and decision making independent of what structures and resources exist in non-CICU wards. Further efforts to integrate quality assessment with clinicians and researchers focusing on non-ICU inpatient

TABLE 5 Cardiac critical care metrics

Metric	Domain	Definition
1.	Outcome	Adjusted CICU postoperative mortality (standardized mortality ratio or adjusted rate) calculated using either (a) PC4 surgical mortality model or (b) VPS PICSIM model
2.	Outcome	Adjusted CICU medical mortality (standardized mortality ratio or adjusted rate) calculated using either (a) PC4 medical mortality model or (b) PRISM-III
3.	Outcome	Risk-adjusted rate of unplanned CICU readmissions within 48 hours of transfer or discharge
4.	Outcome	Risk-adjusted postoperative CICU length of stay
5.	Outcome	Risk-adjusted extubation failure rate (% reintubation within 48 hours after planned extubation)
6.	Outcome	Risk-adjusted cardiac arrest incidence rate
6.	Outcome	Device-associated infection rates (CLABSI, CAUTI)
8.	Structure	Participation in a multi-institutional ICU clinical registry and/or quality improvement collaborative
9.	Structure	Program to provide ECLS
10.	Structure	Aggregate nursing education/experience and staffing (hours per patient day)
11.	Process	Resuscitation debriefing program
12.	Process	Structured OR to ICU handoff following surgical procedures

care will be imperative to best inform congenital heart centers on outcomes and performance. Suggested Cardiac Critical Care metrics can be found in Table 5.

2.5 | Cardiothoracic surgery

The Society of Thoracic Surgeons (STS) and the Congenital Heart Surgeons' Society (CHSS) have endorsed 21 metrics to assess the quality of care delivered to patients with pediatric and congenital cardiac disease undergoing cardiac surgery.²⁸ Published in 2012, these 21 "Quality Measures for Congenital and Pediatric Cardiac Surgery" were developed by STS and are organized according to Donabedian's Triad of Structure, Process, and Outcome, with 5 structure measures, 6 process measures, and 7 outcome measures.⁸ Of these 21 quality measures published by STS and CHSS, three have been endorsed by the National Quality Forum. In addition, the National Quality Forum has endorsed a fourth quality measure developed by STS: Risk-adjusted operative mortality.

Risk-adjusted operative mortality for pediatric and congenital heart surgery is reported using the 2014 STS Congenital Heart Surgery Database (CHSD) Mortality Risk Model, which facilitates description of Operative Mortality adjusted both for procedural factors and for patient level factors.²⁹⁻³² This model, which includes procedural factors as well as individual patient factors, is the most comprehensive and most sophisticated risk model for congenital and pediatric heart surgery in use at the present time.³² Assessment of model fit and discrimination in the development sample and the validation sample revealed overall C statistics of 0.875 and 0.858, respectively. Coefficients for variables in the model are re-estimated every six months to ensure that the model remains well calibrated for its use as a platform for benchmarking programmatic outcomes to national aggregate data and also for public reporting of pediatric and congenital cardiac surgical programmatic outcomes. In the future, when models have been developed that encompass other outcomes in addition to mortality, it will be

possible to assess pediatric and congenital cardiac surgical performance using a multidomain composite metric that incorporates both mortality and morbidity, adjusting for the operation performed and for patient-specific factors.²⁹ It is expected that, in the future, the entirety of this information will also be publicly reported.

Because over 95% of programs performing pediatric cardiac surgery submit data to the STS CHSD, the current national aggregate congenital and pediatric cardiac surgical outcomes contained in STS CHSD can serve as a platform for benchmarking performance and improving quality. These activities of outcomes analysis and quality improvement will ultimately allow congenital heart centers to provide better care for patients. Suggested Cardiothoracic surgery metrics can be found in Table 6. The full set of 21 "Quality Measures for Congenital and Pediatric Cardiac Surgery" developed by STS have been previously published.⁸

2.6 | Electrophysiology

Arrhythmia management, particularly cardiac ablation procedures and cardiac implantable electronic devices (CIEDs) – implantable cardiac

TABLE 6 Cardiothoracic surgery metrics

Metric	Domain	Definition (* = NQF endorsed)
1.	Outcome	*Risk-adjusted operative mortality
2.	Outcome	*Operative Mortality Stratified by the Five STS-EACTS Mortality Levels
3.	Structure	*Participation in a National Database for Pediatric and Congenital Heart Surgery
4.	Structure	*Surgical volume for Pediatric and Congenital Heart Surgery: Total Programmatic Volume and Programmatic Volume Stratified by the Five STS-EACTS Mortality Categories

The full set of 21 "Quality Measures for Congenital and Pediatric Cardiac Surgery" developed by STS have been previously published.⁸

TABLE 7 Electrophysiology metrics

Metric	Domain	Definition
1.	Outcome	Proportion of manifest and concealed accessory pathways with an acute outcome of "elimination of anterograde conduction"
2.	Outcome	Proportion of AV nodal reentrant tachycardia procedures with an acute outcome of either Elimination of slow pathway conduction or persistence of slow pathway conduction (with single echos but no inducible tachycardia)
3.	Outcome	Proportion of atrial tachycardia procedures with acute procedural outcome of "substrate eliminated"
4.	Outcome	One year recurrence rate after acutely successful procedure for #1-4 above
5.	Outcome	Proportion of diagnostic and ablation electrophysiology procedures with a major intra or postprocedure adverse event
6.	Outcome	Dose Area Product (cGy-cm ²) during cardiac ablation procedure
7.	Structure	Participation in national database for pediatric electrophysiology diagnosis and treatment
8.	Structure	Intersocietal Accreditation Commission Accreditation of Electrophysiology Program
9.	Structure	Participation in a CIED (cardiac implantable electronic devices) registry, documenting indications, procedural complications, approach, procedure success
10.	Structure	Presence of a dedicated electrophysiology/arrhythmia program, including (a) 24/7/365 pacemaker and ICD interrogation and management, (b) comprehensive electrophysiology procedure laboratory including dedicated EP staff and technological support, radiofrequency and cryoablation technology, and EP mapping systems, (c) outpatient channelopathy and sudden cardiac arrest program.
11.	Process	Preprocedure conference with extended timeout
12.	Process	Use of a formal (written) protocol/checklist for post procedure handoff to ICU, ward, or recovery unit
13.	Process	Use of a radiation reduction protocol-strategy and radiation exposure tracking; establish absolute radiation dose target for above (#1-4) tachycardia ablation substrates

defibrillators, pacemakers, cardiac resynchronization therapies – lends itself toward quality metric and outcomes measurement. Data for quality metric and outcome measurement in pediatric electrophysiology was first considered by the Pediatric Electrophysiology Society, which began informally meeting in the early 1980s to discuss pediatric patients with arrhythmias. The name subsequently changed to the Pediatric and Congenital Electrophysiology Society (PACES) to reflect the inclusion of the growing adult congenital population, with additional providers and centers. The Pediatric Radiofrequency Catheter Ablation Registry (1991–1999), a voluntary procedural registry, evaluated early procedural successes and failures, procedure and fluoroscopy times, arrhythmia recurrence following initially successful procedures, and demonstrated the concept of a procedural learning curve.³³ Prospective Assessment after Pediatric Cardiac Ablation (PAPCA) was a 1999–2003 prospective study and clinical registry.³⁴ PAPCA further defined successes, complications, and recurrences of procedures stratified by the underlying electrophysiological substrate, documented a modest decrease in average fluoroscopy times compared to the initial ablation registry, and identified no substantive evidence for inadvertent injury to cardiac valves or coronary arteries as a result of a radiofrequency ablation procedure. These registries have come and gone, now replaced with the Multicenter Pediatric and Adult Congenital EP Quality (MAP-IT) registry, affiliated with the IMPACT registry through the NCDR. MAP-IT has the promise and potential to define current era outcomes in the presence of new ablation technologies (eg, cryoablation), the use of advanced imaging and diagnostic modalities (eg, fluoroless imaging), and an increasing ACHD patient

population.^{35,36} This registry should provide the infrastructure for quality assurance and multicenter research. All 3 registries have provided individual center and provider performance relative to national performance benchmarks. The adoption of standardized quality of life surveys for subjective assessment of arrhythmia relief and the development of longitudinal long-term outcomes should be pursued.

CIEDs represent expensive and effective treatment options for many patients, and thus warrant outcome measurement and reporting. Published guidelines exist for appropriate implantation of these devices.³⁷ Outcome measures can and should include indication for implantation, underlying substrate (electrophysiologic substrate and/or the presence of structural heart defects), procedural approach (epicardial, transvenous, subcutaneous), as well as acute and long-term outcomes including successes and complications. Pediatric and ACHD patients can be tracked through the currently available NCDR ICD registry.

In addition to outcome metrics, pediatric electrophysiology has learned from other procedural fields to incorporate safety process measures to their procedures, especially in the areas of procedural communication and utilizing checklists. Finally, as with other specialties, it is felt that participation in data sharing and learning from others through national registries is an important marker of quality in pediatric electrophysiology. Suggested Electrophysiology metrics can be found in Table 7.

2.7 | Inpatient care

Hospital-based cardiac care outside of the intensive care unit is an emerging field of interest and investment within pediatric cardiology.

Care on these inpatient units, increasingly referred to as Acute Care Units, aims to achieve excellent, efficient, and cost-effective surgical and medical outcomes. As a result, there has been a recent sea change of collective attention directed toward the unique elements of care in these units.

The greatly improved pediatric cardiology mortality statistics have cast a spotlight on other measures of clinical care associated with hospitalization, such as complications, medium- and long-term morbidities, and the cost and resources necessary to deliver desired outcomes.³⁸ Critical care databases, namely the Virtual PICU System (VPS, LLC, Los Angeles) and the Pediatric Cardiac Critical Care Consortium (PC⁴) clinical registry as mentioned previously, aim to measure and understand variation in practice and outcomes.

In 2015, the Pediatric Acute Care Cardiology Collaborative (PAC³) emerged to improve care and outcomes in Acute Care Units. The aim of PAC³ is to improve the safety and quality of pediatric inpatient cardiac care with a focus on in-hospital short- and long-term outcomes and the associated transition to outpatient care in a fashion that is thoughtful, validated, transparent, sustained, and shareable. The approach of PAC³ is intended to dovetail with the quality measures of PC⁴ with an emphasis on outcome measures. The registry will be appropriately risk-adjusted to account for case-mix patient factors.

Multiple cardiac centers across North America participate in PAC³. The data dictionary for the PAC³ registry has been developed and data will be collected starting in 2018. Ultimately, the goal is to develop risk-adjustment models that can be used to transparently compare valuable outcome data across member centers (in an effort to provide an enhanced continuum of newly acquired knowledge, data definitions have been standardized with those of PC⁴ and STS whenever possible). Comparison of data is intended to drive multicenter quality improvement work similar in scope to what was achieved by the early extubation trial conducted by the Pediatric Heart Network.³⁹ The first such PAC³ effort is an ongoing multicenter quality improvement project with the objective to collectively reduce postoperative chest tube duration, in an attempt to ultimately shorten hospital length of stay, lower costs, and provide immediate patient benefit. Additionally, structure and practice variation measures have already been collected across all PAC³ member sites. Evidence to support an association between these measures and the desired outcome measures will require time to determine. Suggested Inpatient unit metrics can be found in Table 8.

2.8 | Interventional cardiology

Clinical outcomes in the cardiac catheterization laboratory are central to overall clinical outcomes in a congenital heart program. There have been several clinical registries related to outcomes for cardiac catheterization procedures over the last several decades. The Valvuloplasty and Angioplasty of Congenital Anomalies (VACA) registry in the early 1990s was a voluntary registry of 27 institutions that published outcomes on several different procedures and included some rudimentary safety data.^{40,41}

Food and Drug Administration (FDA) device trials for ASD, VSD, and PDA devices gathered safety and efficacy data on device

TABLE 8 Inpatient unit metrics

Metric	Domain	Definition
1.	Outcome	Postoperative inpatient acute care unit length of stay (Risk-adjusted)
2.	Outcome	Rate of hospital discharge before noon
3.	Outcome	Rate of unplanned inpatient readmission within 7 and 30 days of hospital discharge (Risk-adjusted)
4.	Outcome	Rate of unplanned ICU readmissions within 48 hours of transfer to the inpatient acute care unit (Risk-adjusted)
5.	Outcome	Rate of unplanned ICU transfer at any time in the hospitalization that leads to critical escalation of care within one hour (intubation, initiation of inotropes, ECMO) (Risk-adjusted)
6.	Outcome	Chest tube replacement (% chest tube replacement within 48 hours after removal) (Risk-adjusted)
7.	Outcome	Device-associated infection rates (CLABSI, CAUTI)
8.	Outcome	Total cost of postsurgical care for STS benchmark surgeries
10.	Structure	Participation in multi-institutional inpatient acute care unit clinical registry and/or quality improvement collaborative
11.	Structure	Aggregate nursing education/experience and staffing (hours per patient day)
12.	Structure	Utilization of a dedicated inpatient unit clinical staff (physicians and midlevel providers)
13.	Structure	Postsurgical ambulation program (patients > 3 years of age)
14.	Process	Program to communicate summary of hospitalization with primary cardiologist at the time of discharge
15.	Process	Unplanned event debriefing program (rapid escalation of care for transfer to CICU or less than 7-day hospital readmission)
16.	Process	Structured transfer handoff from ICU to inpatient acute care unit.

performance.⁴² The MAGIC (Mid-Atlantic Group of Interventional Cardiology) registry collected data on long-term outcomes on 8 interventional procedures.⁴³ Over 2400 procedures from 18 centers were collected and analyzed. C3PO (Congenital Cardiac Catheterization Project on Outcomes) started as an AHA funded project with 7 centers. Data were collected on all catheterization procedures and served as the basis for the Catheterization for Congenital Heart Disease Adjustment for Risk Method (CHARM) method to allow for differences in case mix between institutions and providers.^{44,45} CCISC (Congenital Cardiovascular Interventional Study Consortium) is an international voluntary consortium of adult and pediatric providers with a focus on complications and risk stratification as well as specific procedural outcomes.⁴⁶

The IMPACT Registry of the National Cardiovascular Data Registry (NCDR) is a voluntary registry open to all centers and practices. Its

TABLE 9 Interventional metrics

Metric	Domain	Definition
1.	Outcome	Clinical outcomes as detailed in the ACC IMPACT registry ⁵³
2.	Outcome	Proportion of diagnostic and interventional procedures with a major intra or postprocedure adverse event.
3.	Outcome	Proportion of patients who receive radiation dose greater than 95th percentile of benchmark data (procedure specific). ⁵⁴
4.	Structure	Participation in a national database for pediatric and congenital heart disease cardiac catheterization and intervention.
5.	Structure	Participation in local quality improvement efforts or national pediatric quality improvement network (eg, radiation reduction) within focus on improving process or outcomes in the cardiac catheterization laboratory.
6.	Structure	Standardized adverse event (O/E) ratio reporting
7.	Process	Precatheterization conference or extended time out for all patients undergoing a catheterization procedure
8.	Process	Use of a formal and documented protocol/checklist for postcatheterization to ICU, ward or recovery room.

intent is to gather information on diagnostic and interventional catheterization procedures on all pediatric patients and adult patients with congenital heart disease to ultimately improve patient outcomes. As of April 2016, IMPACT v.2 also collects safety and outcome data on pediatric electrophysiology procedures and transcatheter pulmonary valve replacement (TPVR). IMPACT v.2 is currently the only registry that is audited, validated and adjudicated. Risk adjustment was also added to IMPACT v.2 in 2016.⁴⁷⁻⁵⁰ Process and outcome measures refined in these registries now help define quality in a pediatric cardiac catheterization program.^{51,52}

Patient safety is critical in providing excellent clinical outcomes in interventional cardiology. Monitoring and improving safety in the interventional lab is a marker of a quality program. Quality programs incorporate procedural communication and checklists as well as take steps to reduce procedural related risks, such as radiation exposure. As with other areas of congenital heart care, participation in programs that track and share outcomes in an effort at collaborative learning is encouraged. Suggested Interventional metrics can be found in Table 9.

2.9 | Noninvasive imaging

Noninvasive cardiac imaging is an integral component of the congenital heart center, with accurate diagnostic imaging playing a key role in patient outcomes in all clinical areas of the center. The link between quality of imaging and patient outcome such as mortality or morbidity is not usually direct; hence, many quality metrics in this area focus on structure and process, with newer metrics focusing on other outcome measures related to safety, accuracy and value.

Structurally, a comprehensive congenital heart center should provide, or have ready access to, the full range of noninvasive imaging modalities: echocardiography (transthoracic, transesophageal, and fetal); cardiac MRI, and cardiac CT. Many centers will also use additional imaging modalities such as intracardiac echo or intravascular ultrasound. Imaging may be purely diagnostic, or may be integrated with interventions, such as the use of echocardiographic guidance in the operating or catheterization suites.

Process metrics in imaging focus on appropriateness of patient selection as well as study performance, interpretation, and reporting. Most of the available metrics focus on echocardiography given its role as the initial and primary noninvasive cardiac imaging modality. The Intersocietal Accreditation Commission (IAC) has established standards for the structure and processes of adult and pediatric echocardiography labs in North America. The standards are based on published guidelines related to training, structure, and performance of an echocardiography lab.⁵⁵⁻⁵⁹ However, these standards are considered a minimum and apply equally to small practices and large tertiary heart centers. It is expected that comprehensive congenital heart centers will meet metrics over and above the minimum standards for IAC accreditation.

To that end, a team established by the ACC's ACPC section has developed additional quality metrics specific to echocardiography, the use of which should be standard in a state of the art congenital heart center. Metrics currently available include: critical results reporting; adverse events with sedated pediatric echocardiography; comprehensive pediatric echocardiographic examination score; pediatric echocardiographic image quality score; pediatric echocardiographic diagnostic accuracy in pediatric transthoracic echocardiography. Additional quality metrics in development include: diagnostic accuracy in fetal echocardiography; appropriateness of pediatric outpatient echocardiography; adverse events with transesophageal echocardiography; comprehensive CMR examination score; and adverse events with pediatric CMR. These metrics begin to address the relationship between quality diagnostic imaging and patient outcomes.

Unlike subspecialties such as pediatric electrophysiology and interventional cardiology, to date there are no clinical data registries for pediatric/congenital noninvasive imaging. The American Society of Echocardiography (ASE) will be launching the first data registry for echocardiography in 2017, initially with a basic set of echo measurements, not unique to congenital heart disease including: LV size and function, aortic valve gradient, pulmonary artery pressure, and presence/absence of pericardial effusion. Over time, the complexity of data elements will be increased with the potential to add data elements applicable to congenital heart disease and the ability to further associate the quality of noninvasive imaging with patient outcome.⁶⁰ For example, the Pediatric Heart Network is currently carrying out a study "to establish a Z-score database for common echocardiographic measurements based on a uniformly defined and racially diverse population of normal children from multiple centers over a wide geographic area."⁶¹ Suggested Noninvasive imaging metrics can be found in Table 10.

In addition to these noninvasive imaging metrics that should be considered currently, there are additional metrics that should be

TABLE 10 Noninvasive imaging metrics

Metric	Domain	Definition
1.	Outcome	Adverse events with sedated pediatric echocardiography metric
2.	Outcome	Pediatric TTE diagnostic accuracy metric
3.	Structure	Participation in ACPC Quality Network
4.	Structure	Comprehensive Noninvasive cardiac imaging program: Transthoracic Echo; Transesophageal Echo; Fetal Echo; Cardiac MRI; Cardiac CT; Stress echo
5.	Structure	Intersocietal Accreditation Commission Accreditation of Echocardiography Program
6.	Process	Pediatric TTE image quality metric
7.	Process	Comprehensive pediatric TTE metric
8.	Process	Critical results reporting in pediatric echocardiography metric

discussed as potential next steps in measurement. These include: (1) comprehensive fetal echo metric, (2) fetal echo diagnostic accuracy metric, (3) TEE adverse events metric, (4) comprehensive CMR study metric, and (5) CMR adverse events metric.

2.10 | Nursing

Nurses have a significant role in inpatient and outpatient clinical practice. It is critical to measure their contribution to the provision of safe, effective, efficient, equitable, timely, and patient/family centered care.^{62–65} Over the last decade, evidence linking the impact of pediatric nursing care on pediatric cardiovascular patient outcomes has supported the identification and development of nurse-sensitive quality measurement.^{66–72} The translation from evidence to implementation of pediatric cardiovascular nursing measurement for national benchmarking was the result of a charge received in 2008 from the American College of Cardiology (ACC) Pediatric Quality Metric Working Group (QMWG). To develop a nursing sensitive metric, the nursing project leader engaged expert clinicians, administrators and nurse scientists from 15 different institutions. Through consensus, the importance of nutrition for children with cardiac disease was highlighted and further identified as a critical component of pediatric cardiac nursing care that contributed to overall patient outcomes. Additionally, documentation of daily fluid intake was identified as a standardized activity performed by nurses, but there was no consistent documentation of assessment or measurement of nutritional intake of infants during hospitalization.

In its final form “Documentation of Nutrition” is a metric of daily recording of feeding status and calorie intake for all infants one month or older admitted for surgical intervention or medical intervention/management for more than one 24-hour period. Following an internal and external review and endorsement of the measure, 15 pediatric cardiovascular programs implemented the measure and successfully improved the practice of daily documentation of nutrition. The ACC QMWG nursing experience demonstrated a number of successes: (1) development of a collaborative, consensus-based approach among

pediatric cardiac nurse scientists, administrators, and clinical experts to identify and develop a quality nursing measurement; (2) feasibility of implementing a measure and data collection strategy in 15 institutions across the country; and (3) a commitment in identification and testing of other measures in a consensus based manner.

This effort provided the impetus for the inception of the Consortium for Congenital Cardiac Care Measurement of Nursing Practice (C4-MNP).⁶² Donabedian’s framework of structure, process and outcomes along with the Institute of Medicine’s quality domains are used to guide a national community of researchers, administrators and expert clinicians committed to rigorous measurement of the quality of care required by nurses who participate in achieving optimal outcomes for children with cardiac disease.^{8,62,73} Today the C4-MNP has expanded the scope of nurse sensitive quality measurement to inform optimal staffing models, work environments and evidence based practice with collaboration of 32 pediatric cardiovascular programs in the United States.^{8,62,73}

In 2015 the ACC published a health policy statement on cardiovascular team-based care and the role of advanced practice providers.⁷⁴ This manuscript emphasized the role of nurses and advanced practice providers, as well as other clinical support staff (eg, pharmacy, discharge coordinators, nutritionists) to enhance efficiency and patient clinical outcomes. With every team member functioning at top of license, patient outcomes such as medication compliance and decrease in unplanned readmissions can be measured. Importantly, these teams help to coordinate patient care between the inpatient and outpatient arenas. Suggested Nursing metrics can be found in Table 11.

3 | DISCUSSION

This manuscript provides guidance to programs responsible for the care of patients with congenital heart disease. Building on the 2002 American Academy of Pediatrics published “*Guidelines for Pediatric Cardiovascular Centers*,” this work applied the Donebadian model to identify important outcome, structure and process metrics currently used

TABLE 11 Nursing metrics

Metric	Domain	Definition
1.	Structure	Overall Years of Nursing Experience: Unit-level measure of the percentage of registered nursing staff providing patient care that has 0–2 years of any clinical experience
2.	Structure	Bachelor of Science in Nursing (BSN) Education: Unit-level measure of the percentage of registered nursing staff who are at least BSN-prepared
3.	Structure	Nursing Certification: Unit-level measure of the percentage of registered nursing staff providing patient care who are CCRN or CPN certified
4.	Process	Documentation of Nutrition: Monthly measure of daily documentation of feeding status and received calories/kg/day for infants <= 30 days of age admitted for surgical or medical intervention for > 24-hour period

or proposed by groups of clinicians, administrators, and patients/families.¹ The intent of this work is to provide standardization around how congenital heart centers might measure their program characteristics in areas that are felt to be related to high value, safe clinical care resulting in excellent clinical outcomes.

This approach to defining metrics was unique given that we took a broad collaborative approach to define potentially important measures. While we used the Donabedian framework of focus on process, structure and outcome metrics, we emphasize that patient outcomes and the value they provide to patients should be central to what programs measure and report. Our methodology allowed clinicians, administrators, and parents to collectively decide what matters most. While these metrics may not be perfect, they will allow us to understand some of the variability that may exist among centers caring for patients with congenital heart disease. It has been shown in a broad range of industries, including healthcare that reduction in process variation typically results in better overall outcomes.^{75,76} This concept has been demonstrated by a number of groups within the field of congenital heart disease.^{77,78} Once we understand the variation that exists among care center structure and processes we can collaboratively work to reduce that variability and expect to see improved overall outcomes.

Measuring a standard set of outcome, structure and process metrics at a program level is especially important for our families. As noted by those involved in the data transparency movement, patients and families are clamoring for comparable information from programs as they decide where to seek care for themselves or their loved ones.⁴ As clinicians, we have the responsibility to provide accurate and impactful data to our patients to help them make informed decisions about their care. In nearly every domain of metric development (Table 1) there is need for more and better measures of short- and long-term outcomes. Because outcomes are the heart of what these centers strive for, and what patients demand, it is critical for clinicians and programs to close this outcome metric gap in the near future.

While we believe that the metrics listed in this report are important to track at centers caring for patients with congenital heart disease, we make these recommendations fully aware of the environment of “over measurement” in which we currently operate clinically. We are in a period where healthcare has been flooded with measurement, often mandated by regulatory bodies and at times self-imposed. A recent NIH workgroup has addressed the issue of exponentially increasing data and the need for collaborative agreement regarding key quality metrics and the concept of big data.⁷³ As noted by Berwick, “intemperate measurement is as unwise and irresponsible as is intemperate healthcare.”⁷⁹ Specific to our field, Redington recently noted similar frustrations with collecting massive amounts of information into clinical registries, and the cost associated with this work.⁸⁰ Part of the angst around the abundance of metrics in healthcare is the cost of collecting the data required to report many metrics.⁸¹ As we propose additional metrics for our field, we agree with the sentiment that we need to focus on “measuring what matters” and doing so in the most efficient and affordable way possible. The current effort, initiated at the 2016 Congenital Heart Community Day, provides an opportunity for clinicians, patients and administrators to collaboratively define

“what matters.” Going forward, it will be wise for these metrics to be matched to ongoing or existing work, rather than to invent new methods to measure and track these metrics. Some examples of potential systems that might be used to track program level metrics include the American College of Cardiology Adult Congenital and Pediatric Quality Network (QNet) or using this group of metrics to influence the metrics chosen for measurement by the US News and World Report.²⁰

4 | CONCLUSION

Dynamic forces such as the change in healthcare reimbursement, increasing demand for transparency of outcomes, and evolving diagnostic and treatment technology and procedures provide the rationale for collaboration amongst pediatric cardiology centers today. This collaborative effort has helped to define the most critical quality metrics which can lead to development of established center-level national benchmarks. The elimination of unnecessary variability is an important local concept, ensuring consistent care amongst providers, but also can be applied to the national effort between and among centers. Engagement of patients and families to define meaningful structure, process, and outcome metrics will ensure the greatest return on the investment of our time and collective efforts.

CONFLICTS OF INTEREST

None

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