

THE PRESENT AND FUTURE

COUNCIL PERSPECTIVES

Development of Quality Metrics in Ambulatory Pediatric Cardiology



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ABSTRACT

The American College of Cardiology Adult Congenital and Pediatric Cardiology (ACPC) Section had attempted to create quality metrics (QM) for ambulatory pediatric practice, but limited evidence made the process difficult. The ACPC sought to develop QMs for ambulatory pediatric cardiology practice. Five areas of interest were identified, and QMs were developed in a 2-step review process. In the first step, an expert panel, using the modified RAND-UCLA methodology, rated each QM for feasibility and validity. The second step sought input from ACPC Section members; final approval was by a vote of the ACPC Council. Work groups proposed a total of 44 QMs. Thirty-one metrics passed the RAND process and, after the open comment period, the ACPC council approved 18 metrics. The project resulted in successful development of QMs in ambulatory pediatric cardiology for a range of ambulatory domains. (J Am Coll Cardiol 2017;69:541-55)

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Congenital heart disease (CHD) is the most common birth defect in the United States, occurring in 40,000 of the 4 million live births a year, or nearly 1% of U.S. births. There are more than 35 types of CHD lesions. CHD affects patients across their lifespan, from fetus through

adulthood. Patients also have unique and complex medical histories, including multiple interventional procedures and operations, which have rapidly changed and evolved in the past few decades. All of these issues make it difficult to create robust evidence to guide practice. Although the field of

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**ABBREVIATIONS
AND ACRONYMS****ACC** = American College of Cardiology**ACHD** = adult congenital heart disease**ACPC** = Adult Congenital and Pediatric Cardiology**ASO** = arterial switch operation**CHD** = congenital heart disease**KD** = Kawasaki disease**QM** = quality metric**RSV** = respiratory syncytial virus**TGA** = transposition of the great arteries**TOF** = tetralogy of Fallot

pediatric cardiology has advanced, with significant improvement in outcomes for children with CHD (1-5), data to guide clinical decisions are lacking in many areas of CHD care.

Consistent with the American College of Cardiology's (ACC's) aim to improve cardiovascular care, the ACC Adult Congenital and Pediatric Cardiology Council (ACPC) Leadership Council (6) recognized the need to develop quality metrics (QMs) to guide practice for pediatric cardiology, and, in particular, the ACPC recognized a void of QMs to guide ambulatory practice (7). This paper reviews the structure established to develop candidate QMs in 5 key areas, a summary of the published reports reviewed, and key issues considered during QM development.

METHODS

PROCESS OF MEASURE DEVELOPMENT: RAND-UCLA MODIFIED DELPHI PROCESS. On the basis of the success of the adult congenital heart disease (ACHD) group, the ACPC leadership and the Ambulatory Pediatric Cardiology group agreed to use similar methodology to develop metrics in ambulatory pediatric cardiology. The RAND-UCLA modified Delphi process (RAND process) (8,9) provided an opportunity to develop structure, process, or outcome metrics for multiple areas simultaneously, and included scoring for validity, thereby allowing development of measures with limited clinical evidence. Within the modified RAND-UCLA methodology is a process of developing quality measures without the need for expert consensus that can be used in situations where there is a paucity of evidence for care. The method consists of developing candidate QMs, and convening an expert panel to score the metrics for validity and feasibility. The metrics are scored by a panel of experts in 2 rounds: 1 alone and 1 in an in-person meeting, with the ability to discuss and refine the metrics before they receive a final score. Each metric is scored for both validity and feasibility on a scale of 1 to 9, with 9 being the most valid or most feasible. A candidate QM will pass, and be accepted as a final metric with a mean validity score of 7 to 9 and a median feasibility score of 4 to 9 without significant spread or dispersion among the scores (e.g., not all 1s and 9s). As each candidate QM is scored independently and there is no need to come to a consensus, there is less of a chance that the outcome will be biased by the input of a single member of a group.

The RAND-UCLA modified Delphi method has been used to develop and evaluate appropriate use and quality measures for many conditions. In cardiology, it has been used to develop QMs for the management of acute myocardial infarction and for percutaneous coronary intervention (10-12). Even in these more common conditions, the metrics are typically related to improving structure and process of care, rather than outcomes. However, in 1 Canadian study, it was estimated that if the QM benchmarks of 90% were met, there would be a 20% reduction in mortality from coronary heart disease conditions (10-13).

IDENTIFICATION OF 5 FOCUS AREAS. The Steering Committee selected 5 areas across a variety of domains to explore the usefulness of the process for various types of care; domains included both condition-specific and crosscutting clinical issues, and areas where guidelines existed, as well as areas with less evidence to guide practice. The 5 selected topic areas and their justification are:

1. *Chest pain*: Chest pain is a common symptom-based reason for referral to an outpatient pediatric cardiology clinic. There is little evidence and few guidelines to inform practice.
2. *Infection prevention*: Infection prevention is not lesion-specific and covers several topics, such as subacute bacterial endocarditis prophylaxis and asplenia prophylaxis, with various levels of evidence and recommendations.
3. *Kawasaki disease*: Kawasaki disease (KD) is a well-defined condition and had published guidelines for ambulatory care. Additionally, a guideline update was under development during the QM development process.
4. *Tetralogy of Fallot*: Tetralogy of Fallot (TOF) is the most common cyanotic heart disease and had been included in the metrics developed by the ACHD, providing an opportunity to develop metrics across the continuum of care, from pediatrics to adults. There are no published guidelines and little evidence to inform practice.
5. *Transposition of the great arteries after arterial switch operation*: Transposition of the great arteries (TGA) after arterial switch operation (ASO) is a well-defined and well-studied condition for which there are published data on longer-term outcomes, but no guidelines. The ACHD metric development effort also included TGA after atrial switch operation (performed more commonly in the past).

CREATION OF TEAMS TO DEVELOP CANDIDATE MEASURES. To develop the proposed candidate

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