

The Society of Thoracic Surgeons Congenital Heart Surgery Database: 2016 Update on Outcomes and Quality

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The Society of Thoracic Surgeons Congenital Heart Surgery Database is the largest congenital and pediatric cardiac surgical clinical data registry in the world. It is the platform for all activities of The Society of Thoracic Surgeons related to the analysis of outcomes and the improvement of quality in this subspecialty. This article summarizes current aggregate national outcomes in congenital and pediatric cardiac surgery and reviews related activities in the areas of quality measurement, performance improvement, and transparency. The reported data about aggregate national outcomes are exemplified by an analysis of 10 benchmark operations performed from January 2011 to December 2014 and documenting overall discharge mortality (interquartile

range among programs with more than 9 cases): off-bypass coarctation, 1.0% (0.0% to 0.9%); ventricular septal defect repair, 0.7% (0.0% to 1.1%); tetralogy of Fallot repair, 1.0% (0.0% to 1.7%); complete atrioventricular canal repair, 3.2% (0.0% to 6.5%); arterial switch operation, 2.7% (0.0% to 5.6%); arterial switch operation plus ventricular septal defect, 5.3% (0.0% to 6.7%); Glenn/hemiFontan, 2.1% (0.0% to 3.8%); Fontan operation, 1.4% (0.0% to 2.4%); truncus arteriosus repair, 9.6% (0.0% to 11.8%); and Norwood procedure, 15.6% (10.0% to 21.4%).

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The Society of Thoracic Surgeons Congenital Heart Surgery Database (STS CHSD) was founded in 1994 to support quality improvement and patient safety in pediatric and congenital cardiothoracic surgery [1–3]. The STS CHSD is now the largest congenital and

pediatric cardiac surgical clinical data registry in the world, containing records of 354,846 operations as of September 25, 2015. These data are the foundation for assessment of performance (through benchmarking and comparison of individual programmatic outcomes to national aggregate data), sophisticated risk-adjustment models [4–7], quality improvement initiatives, research, voluntary public reporting [8–11], development of reimbursement strategies, and governmental and

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Abbreviations and Acronyms

AMR	= adjusted mortality rate
CI	= confidence interval
CHSD	= Congenital Heart Surgery Database
DCRI	= Duke Clinical Research Institute
EACTS	= European Association for Cardio-Thoracic Surgery
ECHSA	= European Congenital Heart Surgeons Association
IPCCC	= International Pediatric and Congenital Cardiac Code
NQF	= National Quality Forum
O/E	= observed-to-expected ratio
RACHS	= Risk Adjustment in Congenital Heart Surgery
STS	= The Society of Thoracic Surgeons

regulatory collaborations. This article is the first in a series of annual reports summarizing current national aggregate congenital and pediatric cardiac surgical outcomes and detailing quality measurement and performance improvement activities based on the STS CHSD during the past year [12, 13].

Overview of STS CHSD

Collection of detailed clinical data and feedback of risk-adjusted nationally benchmarked results to participating cardiac surgical programs are the primary functions of the STS CHSD [13]. A participant in the STS CHSD is typically a hospital cardiac surgery program, a practice group of cardiothoracic surgeons, or uncommonly, an individual surgeon. Data are submitted to the STS data warehouse and analytical center at the Duke Clinical Research Institute (DCRI). The DCRI harvests the data two times each year, and Feedback Reports are disseminated every 6 months to each STS CHSD participant. These Feedback Reports facilitate internal quality assurance and quality improvement by presenting data about the risk factors and outcomes of the individual participant in comparison with national benchmark data.

The spectrum of individual congenital cardiac malformations is broad, and the variety of types of cardiac disease affecting individuals early in life is large. Consequently, to collect relevant data, a congenital cardiac surgical database must account for nearly 200 individual diagnoses and a roughly comparable number of distinct types of therapeutic interventions. To maintain clinical relevance with evolving surgical practice, data elements in STS CHSD undergo periodic revision to clarify existing variables, harmonize definitions with related national and international databases, add new variables of interest, and remove irrelevant ones. These revisions are performed on a 3-year cycle.

As of September 25, 2015, the STS CHSD included 122 participants comprising 376 surgeons from 39 states in the United States and from four other countries. Of the 354,846 cumulative worldwide operations included in the

STS CHSD, 344,202 have been performed in the United States. The 113 participants in the United States represent 124 hospitals. The report of the 2010 STS Congenital Heart Surgery Practice and Manpower Survey, undertaken by the STS Workforce on Congenital Heart Surgery, estimates that 125 hospitals perform pediatric cardiac surgery in the United States, and eight hospitals perform pediatric cardiac surgery in Canada [14]. Therefore, more than 95% of hospitals that perform pediatric heart surgery in the United States participate in the STS CHSD, and the patient level penetration is even higher. These data suggest that nearly all pediatric cardiac operations performed in the United States are captured in the STS CHSD.

Assessing Outcomes With STS CHSD

To perform meaningful multiinstitutional analyses of outcomes, any database should incorporate the following seven essential elements [15–17]: (1) use of a common language and nomenclature; (2) an established uniform core dataset for collection of information; (3) incorporation of a mechanism to evaluate and account for case complexity; (4) availability of a mechanism to assure and verify the completeness and accuracy of the data collected; (5) collaboration between medical and surgical subspecialties; (6) standardization of protocols for life-long follow-up; and (7) incorporation of strategies for quality assessment and quality improvement. The STS CHSD has made important advances in six of these elements; however, STS CHSD has not yet developed strategies for longitudinal follow-up beyond discharge from the hospital and 30 days after surgery.

The International Pediatric and Congenital Cardiac Code (IPCCC) [18, 19] is the system of nomenclature used in the STS CHSD. The IPCCC was created under the leadership of the International Society for Nomenclature of Pediatric and Congenital Heart Disease through the process of creating a bidirectional crossmap of the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the STS and the European Congenital Heart Surgeons Association (ECHSA)/European Association for Cardio-Thoracic Surgery (EACTS) with the European Pediatric Cardiac Code of the Association for European Pediatric Cardiology. (The IPCCC is freely available at <http://www.IPCCC.NET>.) The IPCCC, and the common minimum database data set created by the International Congenital Heart Surgery Nomenclature and Database Project of STS and ECHSA/EACTS, are now utilized by ECHSA/EACTS CHSD, STS CHSD, and the Japan Congenital Cardiovascular Surgery Database (JCCVSD). The combined dataset of STS CHSD, ECHSA/EACTS CHSD, and JCCVSD contains data from more than 500,000 pediatric and congenital cardiac operations performed beginning in 1998, all coded with the ECHSA/EACTS–STS–derived version of the IPCCC, and all coded with identical data specifications.

Three major multiinstitutional efforts have classified and stratified congenital cardiac surgical operations on the basis of procedural complexity or risk [20–22]: (1) the Risk Adjustment in Congenital Heart Surgery-1

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