8 Databases for Assessing the Outcomes of the Treatment of Patients with Congenital and Pediatric Cardiac Disease: The Perspective of Cardiac Surgery

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Abstract

This chapter discusses the historical aspects, current state of the art, and potential future advances in the areas of nomenclature and databases for the analysis of surgical outcomes of treatments for patients with congenitally malformed hearts. We will consider the current state of analysis of outcomes, lay out some principles which might make it possible to achieve life-long monitoring and follow-up using our databases, and describe the next steps those involved in the care of these patients need to take in order to achieve these objectives.

In order to perform meaningful multi-institutional analyses of outcomes, any database must incorporate the following seven essential elements: (1) Use of a common language and nomenclature, (2) Use of a database with an established uniform core dataset for collection of information, (3) Incorporation of a mechanism of evaluating 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 (7) Incorporation of strategies for quality assessment and quality improvement.

During the 1990s, both The European Association for Cardio-Thoracic Surgery and The Society of Thoracic Surgeons created databases to assess the outcomes of congenital cardiac surgery. Beginning in 1998, these two organizations collaborated to create the International Congenital Heart Surgery Nomenclature and Database Project. By 2000, a common

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nomenclature, along with a common core minimal dataset, were adopted by The European Association for Cardio-Thoracic Surgery and The Society of Thoracic Surgeons, and published in the *Annals of Thoracic Surgery*. In 2000, The International Nomenclature Committee for Pediatric and Congenital Heart Disease was established. This committee eventually evolved into the International Society for Nomenclature of Paediatric and Congenital Heart Disease. The original working component of this international nomenclature society was The International Working Group for Mapping and Coding of Nomenclatures for Pediatric and Congenital Heart Disease, also known as the Nomenclature Working Group. By 2005, the Nomenclature Working Group crossmapped the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of The European Association for Cardio-Thoracic Surgery and The Society of Thoracic Surgeons with the European Paediatric Cardiac Code of the Association for European Paediatric Cardiology, and therefore created the International Pediatric and Congenital Cardiac Code (IPCCC), which is available for free download from the internet at [http://www.IPCCC.NET]. This common nomenclature, the International Pediatric and Congenital Cardiac Code, and the common minimum database data set created by the International Congenital Heart Surgery Nomenclature and Database Project, are now utilized by both The European Association for Cardio-Thoracic Surgery (EACTS), The Society of Thoracic Surgeons (STS), and The Japan Congenital Cardiovascular Surgery Database (JCCVSD). As of January 1, 2014, the STS Congenital Heart Surgery Database contains data from 292,828 operations, the EACTS Congenital Heart Surgery Database contains data from over 157,772 operations, and the JCCVSD contains data from over 29,000 operations. Therefore, the combined dataset of the STS Congenital Heart Surgery Database, the EACTS Congenital Heart Surgery Database, and the JCCVSD contains data from over 479,000 operations performed between 1998 and January 1, 2014 inclusive, all coded with the EACTS-STS derived version of the IPCCC, and all coded with identical data specifications.

Three major multi-institutional efforts have attempted to measure the complexity of congenital cardiac surgical operations: **R**isk **A**djustment in **C**ongenital **H**eart **S**urgery-1 methodology (RACHS-1 method), **A**ristotle **B**asic **C**omplexity Score (ABC Score), and **STS**-E**A**C**T**S Congenital Heart Surgery Mortality Categories (STS-EACTS Mortality Categories) (STAT Mortality Categories). RACHS-1 and the ABC Score were developed at a time when limited multi-institutional clinical data were available and were therefore based in a large part on subjective probability (expert opinion). The STAT Mortality Categories are a tool for complexity stratification that was developed from an analysis of 77,294 operations entered into the EACTS Congenital Heart Surgery Database (33,360 operations) and the STS Congenital Heart Surgery Database (43,934 patients) between 2002 and 2007. Procedure-specific mortality rate estimates were calculated using a Bayesian model that adjusted for small denominators. Operations were sorted by increasing risk and grouped into five categories (the STS–EACTS Congenital Heart Surgery Mortality Categories) that

were designed to be optimal with respect to minimizing within-category variation and maximizing between-category variation. STS and EACTS have transitioned from the primary use of Aristotle and RACHS-1 to the primary use of the STAT Mortality Categories.

Collaborative efforts involving The European Association for Cardio-Thoracic Surgery and The Society of Thoracic Surgeons are under way to develop mechanisms to verify the completeness and accuracy of the data in the databases. Under the leadership of The MultiSocietal Database Committee for Pediatric and Congenital Heart Disease, further collaborative efforts are ongoing between congenital and pediatric cardiac surgeons and other subspecialties, including pediatric cardiac anesthesiologists, via The Congenital Cardiac Anesthesia Society, pediatric cardiac intensivists, via The Pediatric Cardiac Intensive Care Society, and pediatric cardiologists, via the Joint Council on Congenital Heart Disease and The Association for European Paediatric Cardiology. Analysis of outcomes must move beyond mortality, and encompass longer term follow-up, including cardiac and noncardiac morbidities, and importantly, those morbidities impacting health related quality of life. Methodologies must be implemented in these databases to allow uniform, protocol driven, and meaningful, long term follow-up and quality improvement.

Keywords

Database • Outcomes • Quality • Pediatric cardiac surgery • Congenital cardiac surgery

Introduction

Although significant progress has been made in the care of patients with pediatric and congenital cardiac disease, complications and death still occur. As a result, optimization of outcomes remains a constant goal. Substantial efforts has been devoted to advancing the science of assessing the outcomes and improving the quality of care associated with the treatment of patients with pediatric and congenital cardiac disease [1–227]. The importance of these efforts is supported by the fact that congenital heart defects are the most common birth anomalies, with moderate to severe variants occurring in approximately 6 per 1,000 live births [228].

In order to perform meaningful multi-institutional outcomes analyses and quality improvement, any database must incorporate the following seven essential elements:

1. **Use of a common language and nomenclature** [1–52, 54, 55, 62–64, 66–71, 75, 77, 79, 81, 82, 87, 88, 93, 94, 96, 100, 103, 104, 110–112, 114–116, 128–140, 148, 152, 155, 162, 167–169, 171, 172, 178, 179, 188, 191, 200–202, 209, 210, 213, 216, 218, 221]
2. **Use of a database with an established uniform core dataset for collection of information** [1–23, 55, 58–60, 63, 64, 71, 77, 79–82, 87, 88, 90, 93, 95, 98, 100, 104–106, 110–113, 115, 117–123, 145, 146, 148, 152–155, 161, 163, 164, 171, 172, 174, 178, 179, 185, 188, 189, 204, 207, 210, 212, 214, 216, 220–227]
3. **Incorporation of a mechanism of evaluating case complexity** [56, 57, 61, 65, 72–74, 76–79, 81–84, 88–91, 97–102, 104, 106, 107, 110–112, 124, 125, 141, 142, 147–150, 152, 178, 179, 188, 204, 215–217, 221]
4. **Availability of a mechanism to assure and verify the completeness and accuracy of the data collected** [77, 81, 85, 86, 88, 100, 104, 110–112, 126, 148, 152, 178, 179, 188, 216, 221]

5. **Collaboration between medical and surgical subspecialties** [81, 100, 104, 110–140, 148, 152, 178, 179, 188, 216, 221]
6. **Standardization of protocols for life-long follow-up** [104, 109–112, 127, 145, 146, 152, 164, 173, 178, 179, 184, 188, 189, 214, 216, 221]
7. **Incorporation of strategies for quality assessment and quality improvement** [108, 110, 115, 143–148, 151, 152, 154, 156–160, 165–167, 170, 175–183, 186–188, 190, 192–199, 203, 205, 206, 208, 210, 211, 216, 219, 221, 222]

The foundation of these seven elements is the use of a common language and nomenclature. The remaining six elements are all dependent on this nomenclature; and therefore, quality improvement in the domain of congenital cardiac disease depends on a solid understanding of cardiac morphology and nomenclature.

Events at Bristol, England [229], Denver, Colorado, United States of America [230–236], Winnipeg, Canada [237], Mid Staffordshire, England [238] and Lexington, Kentucky, United States of America [239] have clearly demonstrated the importance of clinically driven analysis of outcomes. For example, the Bristol Report presents the results of the inquiry into the management of the care of children receiving complex cardiac surgical services at the Bristol Royal Infirmary between 1984 and 1995 and relevant related issues. Approximately 200 recommendations are made, many of which relate to the need for accurate multi-institutional outcomes databases to quantitate outcomes of care rendered to patients with congenital cardiac disease. Perhaps less well-known than the Bristol Report, the Report of the Manitoba Pediatric Cardiac Surgery Inquest presents data from an inquest involving 12 children who died while undergoing, or soon after having undergone, cardiac surgery at the Winnipeg Health Sciences Centre in 1994. Clearly, these events demonstrate the importance of a meaningful and fair method of multi-institutional analysis of outcomes for congenital cardiac surgery.

Nomenclature

Substantial effort has been devoted to the standardization of nomenclature and definitions related to surgery for pediatric and congenital cardiac disease. During the 1990s, both The European Association for Cardio-Thoracic Surgery (EACTS) and The Society of Thoracic Surgeons (STS) created databases to assess the outcomes of congenital cardiac surgery. Beginning in 1998, these two organizations collaborated to create the International Congenital Heart Surgery Nomenclature and Database Project. By 2000, a common nomenclature and a common core minimal dataset were adopted by EACTS and STS and published in the *Annals of Thoracic Surgery* [21]. In 2000, The International Nomenclature Committee for Pediatric and Congenital Heart Disease was established. This committee eventually evolved into the International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD). By 2005, members of the ISNPCHD crossmapped the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and STS with the European Paediatric Cardiac Code (EPCC) of the Association for European Paediatric Cardiology (AEPC), and therefore created the International Pediatric and Congenital Cardiac Code (IPCCC) [114], which is available for free download from the internet at [http://www.IPCCC.NET].

Most international databases of patients with pediatric and congenital cardiac disease use the IPCCC as their foundation. Two versions of the IPCCC are used in the overwhelming majority of multi-institutional databases throughout the world:

1. The version of the IPCCC derived from the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of the EACTS and the STS
2. The version of the IPCCC derived from the nomenclature of the EPCC of the AEPC

These two versions of the IPCCC are also often referred to with the following abbreviated short names:

1. EACTS-STS derived version of the IPCCC
2. AEPC derived version of the IPCCC

The STS Congenital Heart Surgery Database, the EACTS Congenital Heart Surgery Database, and The Japan Congenital Cardiovascular Surgery Database (JCCVSD) all use the EACTS-STS derived version of the IPCCC.

The ISNPCHD has published review articles which provide a unified and comprehensive classification, with definitions, for several complex congenital cardiac malformations: the functionally univentricular heart [92], hypoplastic left heart syndrome [94], discordant atrioventricular connections [96] and cardiac structures in the setting of heterotaxy [103]. These review articles include definitions and a complete listing of the relevant codes and terms in both versions of the IPCCC.

In collaboration with the World Health Organization (WHO), the ISNPCHD is developing the pediatric and congenital cardiac nomenclature that will be used in the eleventh version of the International Classification of Diseases (ICD-11). With a grant funded by The Children's Heart Foundation [http://www.childrensheart-foundation.org/], the ISNPCHD has also linked images and videos to the IPCCC. These images and videos are acquired from cardiac morphologic specimens and imaging modalities such as echocardiography, angiography, computerized axial tomography, and magnetic resonance imaging, as well as intraoperative images and videos [162, 191, 200–202, 209, 213, 218]. These images and videos are available for free download from the internet at [http://www.IPCCC-awg.NET]. The IPCCC itself is available for free download from the internet at [http://www.IPCCC.NET].

The EACTS-STS derived version of the IPCCC [110, 112, 114], and the common minimum database data set created by the International Congenital Heart Surgery Nomenclature and Database Project [208], are now utilized by the STS Congenital Heart Surgery Database, the EACTS Congenital Heart Surgery Database, and the JCCVSD. Between 1998 and January 1, 2014 inclusive, this nomenclature and database was used by STS, EACTS, and JCCVSD to analyze outcomes of 479,000 operations.

Several studies have examined the relative utility of clinical and administrative nomenclature for the evaluation of quality of care for patients undergoing treatment for pediatric and congenital cardiac disease. Evidence from four recent investigations suggests that the validity of coding of lesions seen in the congenitally malformed heart via 9th ICD Revision of the International Classification of Diseases (ICD-9) as used currently in administrative databases in the United States of America is poor [116, 210, 240, 241]. First, in a series of 373 infants with congenital cardiac defects at Children's Hospital of Wisconsin, investigators reported that only 52 % of the cardiac diagnoses in the medical records had a corresponding code from the ICD-9 in the hospital discharge database [240]. Second, the Hennepin County Medical Center discharge database in Minnesota identified all infants born during 2001 with a code for congenital cardiac disease using ICD-9. A review of these 66 medical records by physicians was able to confirm only 41 % of the codes contained in the administrative database from ICD-9 [241]. Third, the Metropolitan Atlanta Congenital Defect Program of the Birth Defect Branch of the Centers for Disease Control and Prevention of the United States government carried out surveillance of infants and fetuses with cardiac defects delivered to mothers residing in Atlanta during the years 1988 through 2003 [116]. These records were reviewed and classified using both administrative coding and the clinical nomenclature used in the Society of Thoracic Surgeons Congenital Heart Surgery Database. This study concluded that analyses based on the codes available in ICD-9 are likely to "have substantial misclassification" of congenital cardiac disease. Fourth, a study was performed using linked patient data (2004–2010) from the Society of Thoracic Surgeons Congenital Heart Surgery (STS-CHS) Database (clinical registry) and the Pediatric Health Information Systems (PHIS) database (administrative database) from hospitals participating in both in order to evaluate differential coding/classification of operations between datasets

and subsequent impact on outcomes assessment [210]. The cohort included 59,820 patients from 33 centers. There was a greater than 10 % difference in the number of cases identified between data sources for half of the benchmark operations. The negative predictive value (NPV) of the administrative (versus clinical) data was high (98.8–99.9 %); the positive predictive value (PPV) was lower (56.7–88.0 %). These differences translated into significant differences in outcomes assessment, ranging from an underestimation of mortality associated with truncus arteriosus repair by 25.7 % in the administrative versus clinical data (7.01 % versus 9.43 %; $p=0.001$) to an overestimation of mortality associated with ventricular septal defect (VSD) repair by 31.0 % (0.78 % versus 0.60 %; $p=0.1$). This study demonstrates differences in case ascertainment between administrative and clinical registry data for children undergoing cardiac operations, which translated into important differences in outcomes assessment.

Several potential reasons can explain the poor diagnostic accuracy of administrative databases and codes from ICD-9:

- Accidental miscoding
- Coding performed by medical records clerks who have never seen the actual patient
- Contradictory or poorly described information in the medical record
- Lack of diagnostic specificity for congenital cardiac disease in the codes of ICD-9
- Inadequately trained medical coders.

Although one might anticipate some improvement in diagnostic specificity with the planned adoption of ICD-10 by the United States, it is likely to still be far short from that currently achieved with clinical registries. (ICD-9 has only 29 congenital cardiac codes and ICD-10 has 73 possible congenital cardiac terms.) It will not be until there is implementation of the pediatric and congenital cardiac components of ICD-11 that harmonization of clinical and administrative nomenclature will be achieved with the resolution, therefore, of many of these challenging issues.

Database

The STS Congenital Heart Surgery Database is the largest database in North America dealing with congenital cardiac malformations [117, 152]. It has grown annually since its inception, both in terms of the number of participating centers submitting data, and the number of operations analyzed (Figs. 8.1, 8.2 and 8.3). As of January 1, 2014, the STS Congenital Heart Surgery Database currently has 111 Participating Centers representing 120 hospitals performing pediatric and congenital cardiac surgery in North America: 117 out of an estimated 125 centers from the United States of America that perform pediatric and congenital heart surgery and 3 out of centers 8 from Canada that perform pediatric and congenital heart surgery [95, 174]. (The Report of the 2005 STS Congenital Heart Surgery Practice and Manpower Survey, undertaken by the STS Workforce on Congenital Heart Surgery, documented that 122 centers in the United States of America perform pediatric and congenital heart surgery and 8 centers in Canada perform pediatric and congenital heart surgery [95]. The Report of the 2010 STS Congenital Heart Surgery Practice and Manpower Survey, undertaken by the STS Workforce on Congenital Heart Surgery, documented that 125 centers in the United States of America perform pediatric and congenital heart surgery and 8 centers in Canada perform pediatric and congenital heart surgery [174].)

The STS Congenital Heart Surgery Database therefore contains data from an estimated 93.6 % of hospitals (117 out of 125) performing pediatric cardiac surgery in the United States. With penetrance of over 90 %, the data in the STS Congenital Heart Surgery Database is representative of pediatric and congenital heart surgery in the United States of America. As of January 1, 2014, the number of cumulative total operations in the STS Congenital Heart Surgery Database is 292,828 [19]. The aggregate Participant Feedback Report from the Fall 2013 Harvest of the STS Congenital Heart Surgery Database includes 136,617 operations performed in the 4 year analytic window of July 1, 2009 to June 30, 2013,

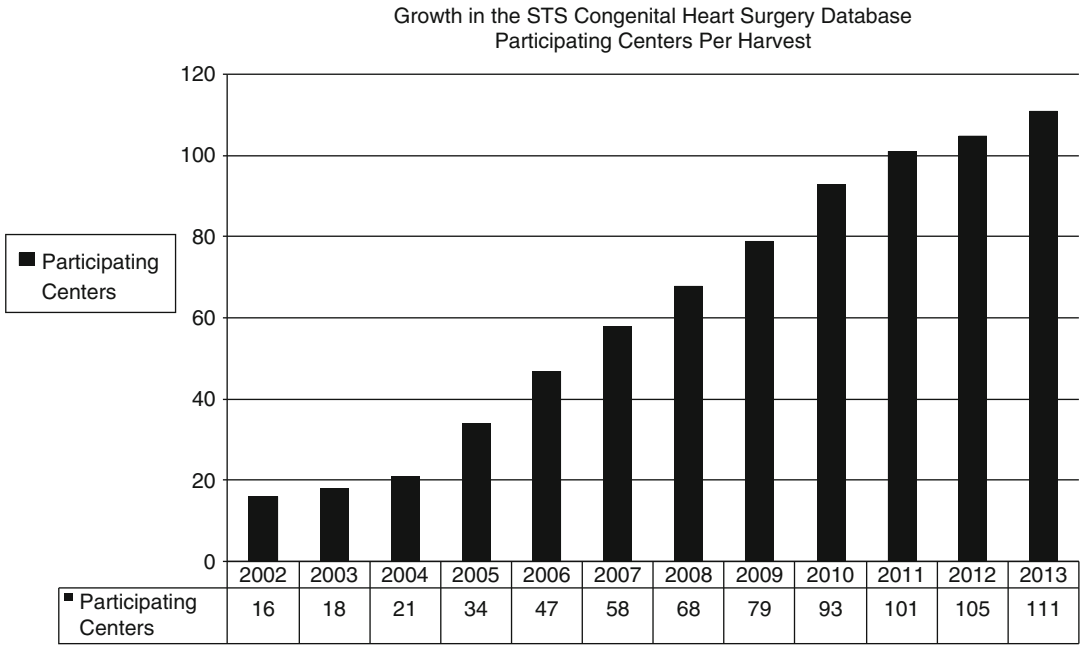


Fig. 8.1 The graph documents the annual growth of the STS Congenital Heart Surgery Database by number of participating centers submitting data. The aggregate report from the Fall 2013 Harvest of the STS Congenital Heart Surgery Database [19] includes data from 111 North American Congenital Database Participants representing 120 Congenital Heart Surgery hospitals in the North America, 117 in the United States of America and 3 in Canada

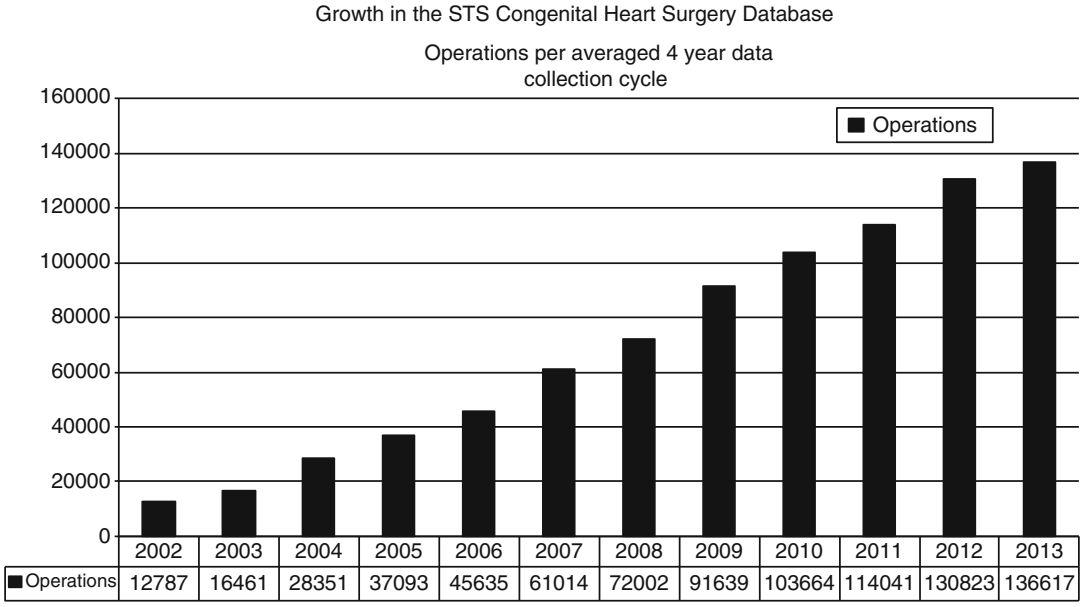
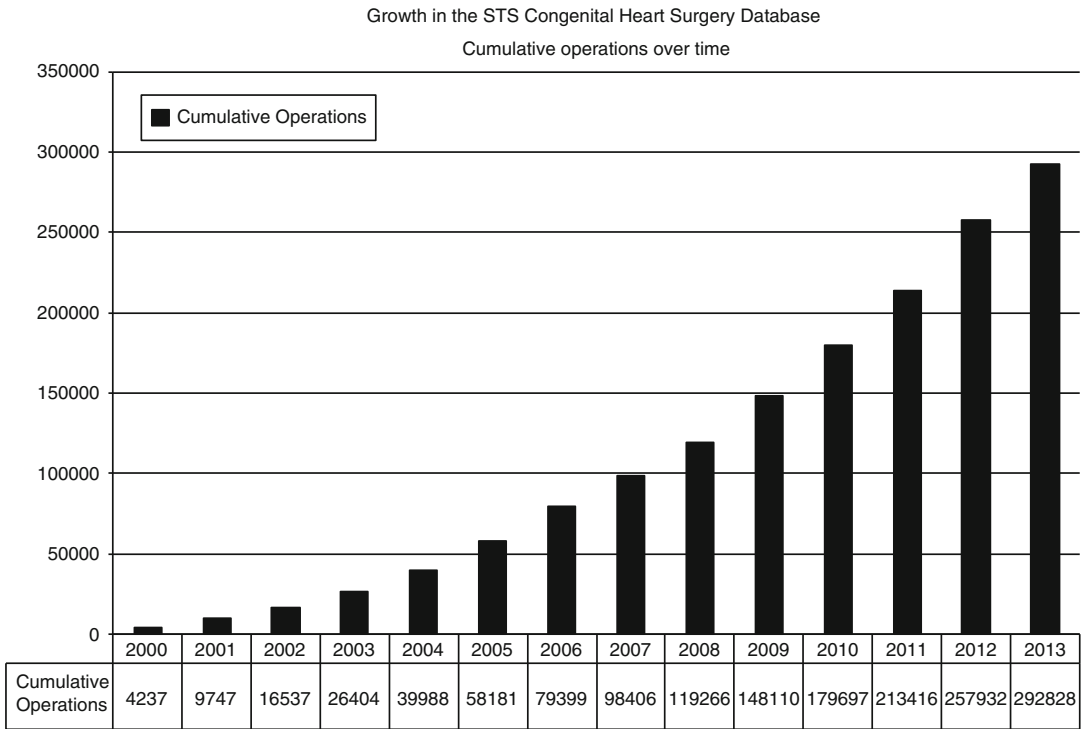


Fig. 8.2 The graph documents the annual growth of the STS Congenital Heart Surgery Database by the number of operations per averaged 4 year data collection cycle. The aggregate report from the Fall 2013 Harvest of the STS Congenital Heart Surgery Database [19] includes 136,617 operations performed in the 4 year period of July 1, 2009–June 30, 2013, inclusive, submitted from 120 hospitals in North America, 117 in the United States of America and 3 in Canada



	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Cumulative Operations	4237	9747	16537	26404	39988	58181	79399	98406	119266	148110	179697	213416	257932	292828

Fig. 8.3 The graph documents the annual growth of the STS Congenital Heart Surgery Database by the cumulative number of operations over time. As of January 1, 2014, the number of cumulative total operations in the STS Congenital Heart Surgery Database is 292,828. The aggregate report from the Fall 2013 Harvest of the STS Congenital Heart Surgery Database [19] includes 136,617 operations performed in the 4 year period of July 1, 2009–June 30, 2013, inclusive, submitted from 120 hospitals in North America, 117 in the United States of America and 3 in Canada

inclusive, submitted from 120 hospitals in North America, 117 in the United States of America and 3 in Canada. In collaboration with EACTS, the STS has developed standardized methodology for tracking mortality and morbidity associated with the treatment of patients with congenital and pediatric cardiac disease [93, 105].

The EACTS Congenital Heart Surgery Database is the largest database in Europe dealing with congenital cardiac malformations (Fig. 8.4) [112, 117]. As of May 2013, the EACTS Congenital Heart Surgery Database contained 157,772 operations performed in 130,534 patients. As of May, 2013, the EACTS Congenital Heart Surgery Database had 348 Centers from 76 countries registered, with 173 active Centers from 46 countries submitting data.

The JCCVSD has recently been operationalized based on identical nomenclature and database standards as that used by EACTS and STS [117]. The JCCVSD began enrolling patients in 2008. By December 2011, over 100 hospitals were submitting data, and by April 2013, over 29,000 operations were entered into the JCCVSD, in just under 5 years of data collection (Fig. 8.5). In Japan, it is mandatory for specialists to enroll in

Fig. 8.5 The graph documents the initial growth of The Japan Congenital Cardiovascular Surgery Database (JCCVSD). The JCCVSD has recently been operationalized based on identical nomenclature and database standards as that used by EACTS and STS. The JCCVSD began enrolling patients in 2008. By December 2011, over 100 hospitals were submitting data, and by April 2013, over 29,000 operations were entered into the JCCVSD, in just under five years of data collection. The developers of the JCCVSD hope to collaborate with their colleagues across Asia to create an Asian Congenital Heart Surgery Database (This graph is provided courtesy of Arata Murakami, MD of The University of Tokyo in Tokyo, Japan)

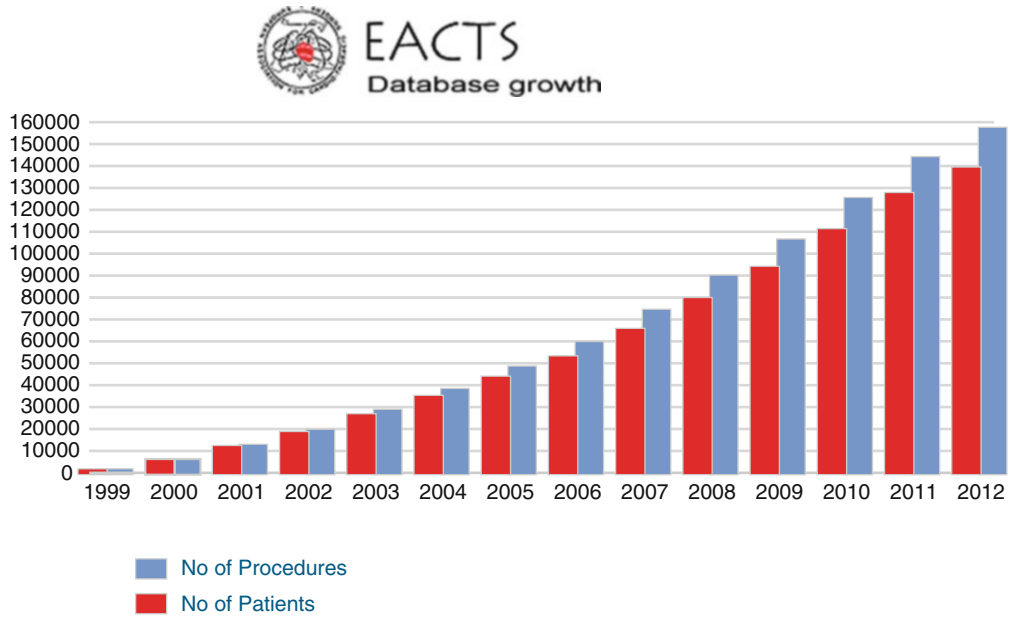
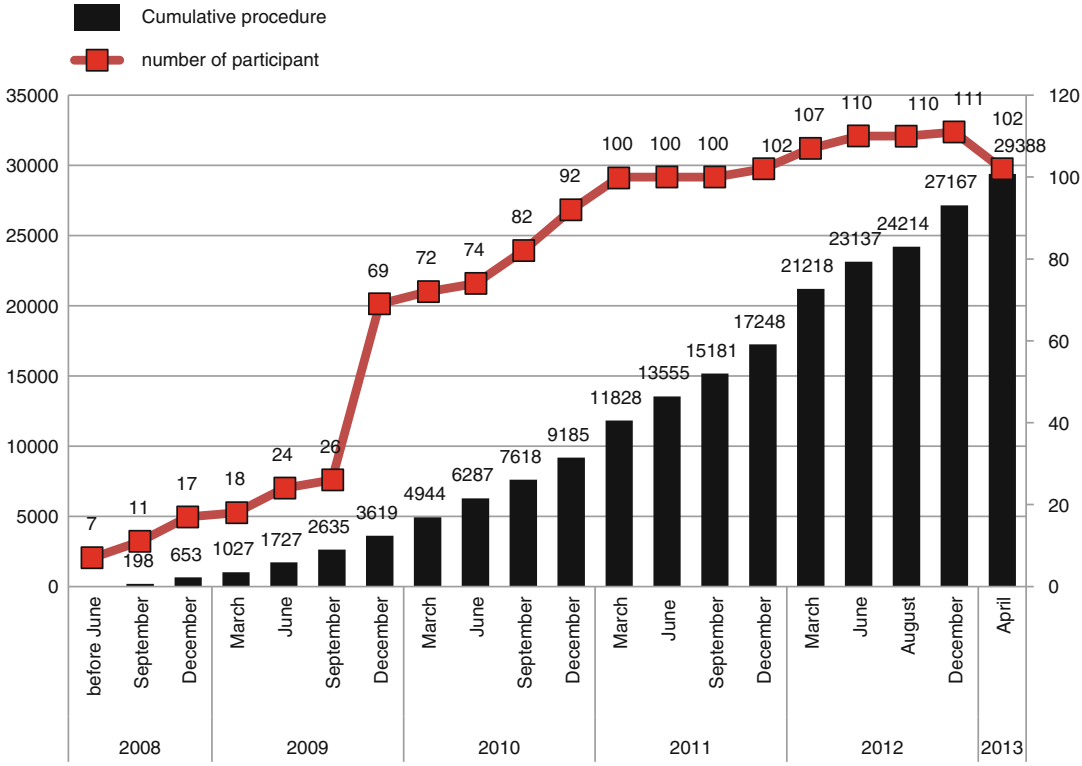


Fig. 8.4 The graph documents the annual growth in The European Association for Cardio-Thoracic Surgery Congenital Database by both number of patients and number of operations. As of May 2013, the EACTS Congenital Heart Surgery Database contained 157,772 operations performed in 130,534 patients. As of May, 2013, the EACTS Congenital Heart Surgery Database had 348 Centers from 76 countries registered, with 173 active Centers from 46 countries submitting data (This graph is provided courtesy of Bohdan Maruszewski of the Children's Memorial Health Institute in Warsaw, Poland, Director of The European Association for Cardio-Thoracic Surgery Congenital Database, and President of The European Congenital Heart Surgeons Association (ECHSA))



this benchmarking project in order to objectively examine their own performance and make efforts for continuous improvement. In the future, certification in Japan is to be performed solely on the basis of empirical data registered by the project. The developers of the JCCVSD hope to collaborate with their colleagues across Asia to create an Asian Congenital Heart Surgery Database.

In the United Kingdom, the United Kingdom Central Cardiac Audit Database (UKCCAD) uses the AEPC derived version of the IPCCC as the basis for its national, comprehensive, validated, and benchmark-driven audit of all pediatric surgical and transcatheter procedures undertaken since 2000 [152]. All 13 tertiary centers in the United Kingdom performing cardiac surgery or therapeutic cardiac catheterization in children with congenital cardiac disease submit data to the UKCCAD. Data about mortality is obtained from both results volunteered from the hospital databases, and by independently validated records of deaths obtained by the Office for National Statistics, using the patient's unique National Health Service number, or the general register offices of Scotland and Northern Ireland. Efforts are underway to link the UKCCAD to The EACTS Congenital Heart Surgery Database. Linkage of the UKCCAD to The EACTS Congenital Heart Surgery Database will require use of the crossmap of the AEPC derived version of the IPCCC (used by the UKCCAD) to the EACTS-STS derived version of the IPCCC (used by the EACTS, STS, and JCCVSD).

As of January 1, 2014, the STS Congenital Heart Surgery Database contains data from 292,828 operations, the EACTS Congenital Heart Surgery Database contains data from over 157,772 operations, and the JCCVSD contains data from over 29,000 operations. Therefore, the combined dataset of the STS Congenital Heart Surgery Database, the EACTS Congenital Heart Surgery Database, and the JCCVSD, contains data from over 479,000 operations, all coded with the EACTS-STS derived version of the IPCCC [100, 110, 112, 114], and all coded with identical data specifications [208].

Complexity Stratification

The importance of measurement of complexity derives from the fact that analysis of outcomes using raw measurements of mortality, without adjustment for complexity, is inadequate. The mix of cases can vary greatly from program to program. Without stratification of complexity, the analysis of outcomes will be flawed [56, 61, 73, 74, 76, 82, 106, 149, 150].

The analysis of outcomes after surgery requires a reliable method of estimating the risk of adverse events. However, formal risk modeling is challenging for rare operations. Complexity stratification provides an alternative methodology that can facilitate the analysis of outcomes of rare operations. Complexity stratification is a method of analysis in which the data are divided into relatively homogeneous groups (called strata). The data are analyzed within each stratum.

Three major multi-institutional efforts have attempted to measure the complexity of congenital cardiac surgical operations:

1. **R**isk **A**djustment in **C**ongenital **H**eart **S**urgery-1 methodology (RACHS-1 method) [56, 73, 149]
2. **A**ristotle **B**asic **C**omplexity Score (ABC Score) [61, 74, 76, 82, 106, 149]
3. **STS**-E**A**C**T**S Congenital Heart Surgery Mortality Categories (STS-EACTS Mortality Categories) (STAT Mortality Categories) [150].

RACHS-1 and the ABC Score were developed at a time when limited multi-institutional clinical data were available and were therefore based in a large part on subjective probability (expert opinion). The STAT Mortality Categories are a tool for complexity stratification that was developed from an analysis of 77,294 operations entered into the EACTS Congenital Heart Surgery Database (33,360 operations) and the STS Congenital Heart Surgery Database (43,934 patients) between 2002 and 2007. Procedure-specific mortality rate estimates were calculated using a Bayesian model that adjusted for small denominators. Operations were sorted by increasing risk and grouped into five categories (the STS–EACTS Congenital Heart Surgery Mortality Categories) that were designed to be

Table 8.1 Method of modeling procedures. Shows the results of comparing the STS–EACTS Categories (2009) to the RACHS-1 Categories and the Aristotle Basic Complexity Score using an independent validation sample of 27,700 operations performed in 2007 and 2008. In the subset of procedures for which STS–EACTS Category, RACHS-1 Category, and Aristotle Basic Complexity Score are defined, discrimination was highest for the STS–EACTS categories (C-index = 0.778), followed by RACHS-1 categories (C-index = 0.745), and Aristotle Basic Complexity scores (C-index = 0.687)

	Model without patient covariates	Model with patient covariates	Percent of operations that can be classified (%)
STS-EACTS Congenital Heart Surgery Mortality Categories (2009)	C = 0.778	C = 0.812	99
RACHS-1 categories	C = 0.745	C = 0.802	86
Aristotle basic complexity score	C = 0.687	C = 0.795	94

optimal with respect to minimizing within-category variation and maximizing between-category variation.

Table 8.1 compares RACHS-1, the ABC Score, and the STS-EACTS Mortality Categories. Table 8.2 shows the application in the STS Congenital Heart Surgery Database of the STAT Congenital Heart Surgery Mortality Categories [198]. STS and EACTS have transitioned from the primary use of Aristotle and RACHS-1 to the primary use of the STAT Mortality Categories because of three reasons:

1. STAT Score was developed primarily based on objective data while RACHS-1 and Aristotle were developed primarily on expert opinion (Subjective probability)
2. STAT Score allows for classification of more operations than RACHS-1 or Aristotle
3. STAT Score has a higher c-statistic than RACHS-1 or Aristotle.

Meaningful evaluation and comparison of outcomes require consideration of both mortality and morbidity, but the latter is much harder to measure. The STAT Mortality Categories provide an empirically based tool for analyzing mortality associated with operations for congenital heart disease [150]. STS has developed the STAT Morbidity Categories [215] based on major postoperative complications and postoperative length of stay. Both major postoperative complications and postoperative length of stay were used because models that assume a perfect one to one relationship between postoperative complications and postoperative length of stay are not likely to fit the data well. Incorporation of both major postoperative complications and postoperative length of stay allows creation of a much more informative model. The STAT Morbidity Categories provide an empirically based tool for analyzing morbidity associated with operations for congenital heart disease [215].

Table 8.2 Shows the discharge mortality in an analysis of patients in the STS Congenital Heart Surgery Database who underwent surgery between January 1, 2005 and December 31, 2009, inclusive [198], stratified by STAT Mortality Categories (STS–EACTS Congenital Heart Surgery Mortality Categories)

	Total number of operations	Discharge mortality (%)
STAT mortality category 1	15,441	0.55
STAT mortality category 2	17,994	1.7
STAT mortality category 3	8,989	2.6
STAT mortality category 4	13,375	8.0
STAT mortality category 5	2,707	18.4

Data Verification

Collaborative efforts involving EACTS and STS aim to enhance mechanisms to verify the completeness and accuracy of the data in the databases [21, 126]. A combination of three strategies may ultimately be required to allow for optimal verification of data:

1. Intrinsic data verification (designed to rectify inconsistencies of data and missing elements of data)
2. Site visits with "Source Data Verification" (in other words, verification of the data at the primary source of the data)
3. External verification of the data from independent databases or registries (such as governmental death registries)

Data quality in the STS Congenital Heart Surgery Database is evaluated through intrinsic data verification by Duke Clinical Research Institute (DCRI) (including identification and correction of missing/out of range values and inconsistencies across fields). DCRI is the data warehouse and analytic center of the STS Congenital Heart Surgery Database.

In addition to intrinsic data verification by DCRI, each year, approximately 10 % of participants are randomly selected for audits of their center, in accordance with their STS Congenital Heart Surgery Database Participation Agreement. The audit is designed to complement the internal quality controls, with an overall objective of maximizing the integrity of the data in the STS Congenital Heart Surgery Database by examining the accuracy, consistency, and completeness of the data. STS has selected Telligen to perform an independent, external audit of the STS Congenital Heart Surgery Database. As the state of Iowa's Medicare Quality Improvement Organization (QIO), Telligen partners with health care professionals to assure high quality, cost effective health care. As a Quality Improvement Organization, Telligen is compliant with the Health Insurance Portability and Accountability Act of 1996 of the United States of America (HIPAA) and performs audits adhering to strict security policies. Additionally, an STS congenital heart surgeon volunteer leader participates in the audit.

In the STS Congenital Heart Surgery Database, the audit process includes:

- Completion of the STS Data Collection Questionnaire and review of responses with the primary data contact, data manager, and/or other relevant personnel
- Review of the data collection process and documentation to determine case eligibility for submittal to the STS Congenital Heart Surgery Database
- Comparison of facility operative case logs with cases submitted to the STS Congenital Heart Surgery Database
- Data abstraction (from original source documents) of congenital heart surgery records randomly selected by DCRI and all operative mortality cases for the preceding calendar year.
- A summary conference with the surgeon representative, primary data contact, data manager, and/or other relevant personnel to discuss general trends in data collection and submission processes.

In 2013, the audit of the STS Congenital Heart Surgery Database included the following documentation of rates of completeness and accuracy for the specified fields of data:

- Primary Diagnosis (Completeness = 100 %, Accuracy = 96.2 %),
- Primary Procedure (Completeness = 100 %, Accuracy = 98.7 %),
- Mortality Status at Hospital Discharge (Completeness = 100 %, Accuracy = 98.8 %)

In 2014, 11 Participants in the STS Congenital Heart Surgery Database will be audited.

Subspecialty Collaboration

Under the leadership of The MultiSocietal Database Committee for Pediatric and Congenital Heart Disease [110–112], further collaborative efforts are ongoing between congenital and pediatric cardiac surgeons and other subspecialties, including

1. Pediatric cardiac anesthesiologists, via The Congenital Cardiac Anesthesia Society [105, 119, 139, 207],
2. Pediatric cardiac intensivists, via The Pediatric Cardiac Intensive Care Society [190], and
3. Pediatric cardiologists, via the Joint Council on Congenital Heart Disease, the American College of Cardiology, and The Association for European Paediatric Cardiology [118].

Strategies have been developed to link together databases [109, 164, 189, 193, 194, 210, 219]. By linking together different databases, one can capitalize on the strengths and mitigate some of the

weaknesses of these databases and therefore allow analyses not possible with either dataset alone. Linked databases have facilitated both comparative effectiveness research [193, 194, 219] and longitudinal follow-up [145, 146, 173, 214]. Under the leadership of The MultiSocietal Database Committee for Pediatric and Congenital Heart Disease [110–112], further collaborative efforts are ongoing between congenital and pediatric cardiac surgeons and other subspecialties.

The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease has held ten annual meetings, each lasting 1 or 2 days, in 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2012, 2013, and 2014. The 11th Multi-Societal Meeting has already been scheduled for 2015 in Prague, the Czech Republic:

1. The First Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. Chicago, Illinois, Chicago Hilton, Thursday August 25, 2005 and Friday August 26, 2005. (At the inception of this first meeting, the meeting was named the "VPS/STS/PCICS Combined Database Meeting". VPS=The Virtual Pediatric Intensive Care Unit Systems, STS=The Society of Thoracic Surgeons, PCICS=The Pediatric Cardiac Intensive Care Society.)
2. The Second Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. Chicago, Illinois, Thursday August 17, 2006 and Friday, August 18, 2006.
3. The Third Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. Hotel George in Washington, DC, Thursday September 27, 2007 and Friday, September 28, 2007.
4. The Fourth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. Omni Mount-Royal Hotel, Montreal, Canada, Saturday October 4, 2008 and Sunday October 5, 2008.
5. The Fifth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease of The Global Organization for Pediatric and Congenital Heart Disease: "The Transition from Outcomes Analysis to Quality Improvement". The Emory Conference Center, Atlanta, Georgia, Wednesday September 16, 2009 and Thursday, September 17, 2009.
6. The Sixth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease of The Global Organization for Pediatric and Congenital Heart Disease: "Creating a Multidisciplinary Strategy for Improving the Quality of HealthCare Delivered to Patients with Pediatric and Congenital Heart Disease". The Emory Conference Center, Atlanta, Georgia, Thursday, August 26, 2010 and Friday, August 27, 2010.
7. The Seventh Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease: "The relationship between (1) Outcomes Analysis, (2) Quality Improvement, and (3) Patient Safety". University of Cambridge, Cambridge, United Kingdom, Tuesday, September 20, 2011 and Wednesday, September 21, 2011.
8. The Eighth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease: "New Initiatives in Outcomes and Quality". Chair: Jeffrey P. Jacobs, MD, Local Hosts: Robert Campbell, MD and Robert Vincent, MD. The Emory Conference Center, Atlanta, Georgia (404) 712–6000. Thursday, August 23, 2012 and Friday, August 24, 2012.
9. The Ninth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease: "Bridging the Gap from Outcomes to Quality". Chair: Jeffrey P. Jacobs, Local Host: Shakeel Qureshi, President, The Association for European Paediatric and Congenital Cardiology, Meeting held at the 47th Annual Meeting of The Association for European Paediatric and Congenital Cardiology (AEPC), London, England, United Kingdom, Thursday, May 23, 2013.
10. The Tenth Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease: "Dashboards for Pediatric and Congenital Cardiac Care". Chair: Jeffrey P. Jacobs, MD, Local Hosts:

Robert Campbell, MD and Robert Vincent, MD. The Emory Conference Center, Atlanta, Georgia (404) 712–6000. Thursday, September 4, 2014 and Friday, September 5, 2014.

11. The Eleventh Annual Meeting of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease: "Improving the quality of congenital cardiology healthcare by harmonizing international databases". Chair: Jeffrey P. Jacobs, MD, Robert Vincent, MD, and Rodney Franklin, MD. Meeting held at the 49th Annual Meeting of The Association for European Paediatric and Congenital Cardiology (AEPC), Prague, the Czech Republic, Wednesday, May 20, 2015.

The various organizations and Societies whose members have participated in the meetings and activities of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease as well as the various participants themselves have previously been published [111], although the group continues to grow and involve multiple professional medical and nursing societies as well as multiple governmental and nongovernmental agencies. Some notable accomplishments of this multidisciplinary group are worth brief mention. At the first meeting of the Multi-Societal Database Committee, initial discussions took place about the possibility of linking together the various databases of the subspecialties of pediatric cardiac surgery, pediatric cardiology, pediatric cardiac anesthesia, and pediatric critical care. The Multi-Societal Database Committee rapidly realized that it would be essential to collaborate in multiple areas:

1. Use of a common language and nomenclature
2. Use of a database with an established uniform core dataset for collection of information
3. Incorporation of a mechanism of evaluating case complexity
4. Availability of a mechanism to assure verification of the completeness and accuracy of the data collected
5. Collaboration between medical and surgical subspecialties,
6. Standardization of protocols for life-long longitudinal follow-up.

Each of these six areas is discussed in detail in the following 530 page Supplement published in Cardiology in the Young by the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease [110]. Initial discussions of the Multi-Societal Database Committee identified that it was essential for the various subspecialty databases to use identical nomenclature in order to allow them to communicate with each other with meaning. Various lists of terminology would need to be harmonized:

1. Diagnoses
2. Procedures
3. Complications
4. Preoperative Factors

The Multi-Societal Database Committee agreed to use The International Pediatric and Congenital Cardiac Code (IPCCC) (http://www.ipccc.net/) as the basis of communication. Mature and well developed Short Lists and Long Lists of Diagnoses and Procedures are available via The International Pediatric and Congenital Cardiac Code, and these diagnostic and procedural lists have been incorporated into the various subspecialty databases and harmonized.

At the second meeting of The Multi-Societal Database Committee, the diagnostic and procedural lists of nomenclature were harmonized across the multiple databases of pediatric cardiac surgery, pediatric cardiology, pediatric cardiac anesthesia, and pediatric critical care. These harmonized lists were based on the IPCCC. Because the diagnostic and procedural lists in The International Pediatric and Congenital Cardiac Code are matured and functional, the Multi-Societal Database Committee adopted these lists and harmonized them across their databases. The Multi-Societal Database Committee then elected to focus on developing a mature list of Complications and defining these complications [110–140].

At the third and fourth meeting of The Multi-Societal Database Committee, the topic of complications associated with the treatment of patients with pediatric and congenital cardiac disease was discussed in detail. The Multi-Societal Database Committee ultimately developed and published a Long List of Complications [110, 140] and a Short List of Complications [110–112], with consensus-based definitions provided in each List:

1. The Long List of Complications contains and defines 2,836 terms and is named: "The Long List of Complications of The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease", with the abbreviated short name: "Multi-Societal Long List of Complications". Although the act of navigating a list with 2,836 terms can initially seem quite daunting, it can become quite simple and enjoyable with the aid of computerized navigation tools designed to support the hierarchal structure of the list.
2. The Short List of Complications contains and defines 56 terms.

At the fifth meeting of The Multi-Societal Database Committee, the Committee transitioned from collaborative efforts related to databases to collaborative initiatives related to quality improvement. The sixth meeting of The Multi-Societal Database Committee focused on "Creating a Multidisciplinary Strategy for Improving the Quality of HealthCare Delivered to Patients with Pediatric and Congenital Heart Disease". The first and second meetings were organized and hosted by the VPS Database, and the National Association of Children's Hospitals and Related Institutions (NACHRI). The third and fourth meetings were organized and hosted by the Society of Thoracic Surgeons (STS), and the fifth, sixth, eighth, and tenth meetings were organized and hosted by Emory University. The seventh meeting was hosted the Pediatric Cardiac Intensive Care Society. The ninth meeting was hosted by The Association for European Paediatric and Congenital Cardiology (AEPC), and the AEPC will host the eleventh meeting. The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease is a platform that facilitates the ability for databases in the domain of pediatric cardiac care to span conventional subspecialty and temporal boundaries.

Longitudinal Follow-Up

The transformation of the STS Database to a platform for longitudinal follow-up will ultimately result in higher quality of care for all cardiothoracic surgical patients by facilitating longitudinal comparative effectiveness research on a national level [127, 173, 184, 214]. Several potential strategies will allow longitudinal follow-up with the STS Database, including the development of clinical longitudinal follow-up modules within the STS Database itself, and linking the STS Database to other clinical registries, administrative databases, and national death registries:

1. Using probabilistic matching with shared indirect identifiers, the STS Database can be linked to administrative claims databases (such as the CMS Medicare Database [145, 146] and the Pediatric Health Information System (PHIS) database [109, 164, 189, 193, 194, 210, 219]) and become a valuable source of information about long-term mortality, rates of re-hospitalization, long-term morbidity, and cost [208].
2. Using deterministic matching with shared unique direct identifiers, the STS Database can be linked to national death registries like the Social Security Death Master File (SSDMF) and the National Death Index (NDI) in order to verify life-status over time [127, 173, 184, 214].
3. Through either probabilistic matching or deterministic matching [184], the STS Database can link to multiple other clinical registries, such as the National Cardiovascular Data Registry (NCDR) of the American College of Cardiology (ACC), in order to provide enhanced clinical follow-up.
4. The STS Database can develop clinical longitudinal follow-up modules of its own to provide detailed clinical follow-up [109, 127, 173, 184, 214].

Quality Assessment and Quality Improvement

The STS Database is increasingly used to document variation in outcomes [182, 198] and measure quality [179, 186]. Funnel plots may be used to demonstrate this variation in outcome and to facilitate the identification of centers that are outliers in performance (Fig. 8.6). Quality improvement initiatives can be initiated in "low

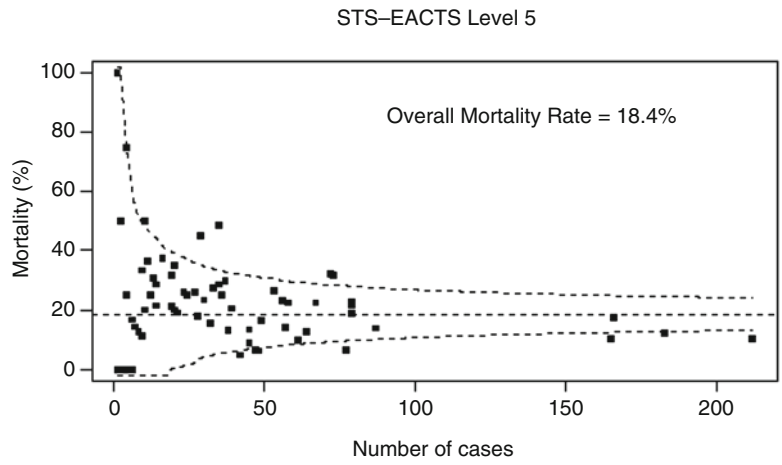


Fig. 8.6 In this graph, data about mortality is displayed as a funnel plot for STAT Category five operations [198]. The horizontal dashed line depicts aggregate STS mortality before discharge. Dashed lines depicting exact 95 % binomial prediction limits were overlaid to make a funnel plot. Squares represent the number of cases and mortality before discharge for individual STS Congenital Heart Surgery Database participants (centers). This analysis includes patients undergoing surgery during the 5 year analytic window of 2005 –2009, inclusive, and includes 70 STS centers in the STS Congenital Heart Surgery Database and 2,707 operations. Centers that were identified as outliers represented 18.6 % of participating centers (13 out of 60): 10 % (7 out of 70) were "high-performing outliers" and 8.6 % (6 out of 70) were "low-performing outliers". Quality improvement initiatives can be initiated in "low performing centers" and best practices can be obtained from "high performing centers". (**STS**-E**A**C**T**S Congenital Heart Surgery Mortality Categories = STS-EACTS Mortality Categories = STAT Mortality Categories [150], *STS* The Society of Thoracic Surgeons, *EACTS* European Association for Cardio-Thoracic Surgery)

performing centers" and best practices can be obtained from "high performing centers".

STS has collaborated with the Congenital Heart Surgeons' Society (CHSS) to develop and endorse metrics to assess the quality of care delivered to patients with pediatric and congenital cardiac disease [186]. Tables 8.3, 8.4, and 8.5 presents 21 "Quality Measures for Congenital and Pediatric Cardiac Surgery" that were developed and approved by the Society of Thoracic Surgeons (STS) and endorsed by the Congenital Heart Surgeons' Society (CHSS). These Quality Measures are organized according to Donabedian's Triad of Structure, Process, and Outcome [242]. It is hoped that these quality measures can aid in congenital and pediatric cardiac surgical quality assessment and quality improvement initiatives. These initiatives will take on added importance as the public reporting of cardiac surgery performance becomes more common [143, 176, 177].

Summary: Bridging the Gap Form Analysis of Outcomes to Improvement of Quality

Clinical registries represent a foundational tool in the following inter-related process:

1. Measuring the outcomes of medical and surgical practices,
2. Developing evidence for best medical and surgical practices,
3. Providing actionable feedback to clinicians, and
4. Improving the quality of care and outcomes.

Clinical registries are the best tool for measuring the outcomes of the processes of care [220, 221]. As described in this chapter, the ability to measure clinical outcomes properly requires using standardized clinical nomenclature, uniform standards for defining elements of data and collecting these data, strategies to adjust for the complexity of patients, techniques

Table 8.3 Quality measures for congenital and pediatric cardiac surgery

1. Participation in a National Database for Pediatric and Congenital Heart Surgery
2. Multidisciplinary rounds involving multiple members of the healthcare team
3. Availability of Institutional **Pediatric ECLS** (**Extracorporeal Life Support**) **Program**
4. **Surgical volume** for Pediatric and Congenital Heart Surgery: Total Programmatic Volume and Programmatic Volume Stratified by the **Five STS-EACTS Mortality Categories**
5. **Surgical Volume** for **Eight Pediatric and Congenital Heart Benchmark Operations**
6. Multidisciplinary **preoperative planning conference** to plan pediatric and congenital heart surgery operations
7. Regularly Scheduled **Quality Assurance and Quality Improvement Cardiac Care Conference**, to occur no less frequently than once every two months
8. Availability of **intraoperative transesophageal echocardiography** (**TEE**) and epicardial echocardiography
9. **Timing of Antibiotic Administration** for Pediatric and Congenital Cardiac Surgery Patients
10. Selection of **Appropriate Prophylactic Antibiotics and Weight-Appropriate Dosage** for Pediatric and Congenital Cardiac Surgery Patients
11. Use of an **expanded pre-procedural and post-procedural** "**time-out**"
12. Occurrence of new post-operative **renal failure** requiring dialysis
13. Occurrence of new post-operative **neurological deficit** persisting at discharge
14. Occurrence of arrhythmia necessitating **permanent pacemaker** insertion
15. Occurrence of **paralyzed diaphragm** (possible phrenic nerve injury)
16. Occurrence of need for **postoperative mechanical circulatory support** (IABP, VAD, ECMO, or CPS)
17. Occurrence of **unplanned reoperation** and/or interventional cardiovascular catheterization procedure
18. **Operative Mortality** Stratified by the Five STS-EACTS Mortality Levels
19. **Operative Mortality** for Eight Benchmark Operations
20. Index Cardiac **Operations Free of Mortality and Major Complication**
21. Operative **Survivors Free of Major Complication**

to verify the completeness and accuracy of data, and collaboration across medical and surgical subspecialties. All of these elements exist in the ideal clinical registry.

Clinical registries can be used as a platform for developing evidence for best medical practices and performing comparative effectiveness research. The NIH-funded linkage of the STS Congenital Heart Surgery Database to the Pediatric Health Information System (PHIS) Database exemplifies this approach [164, 189, 193, 194, 210, 219]. This linkage of clinical and administrative data facilitated comparative effectiveness research in the domains of perioperative methylprednisolone and outcome in neonates undergoing heart surgery [193] and antifibrinolytic medications in pediatric heart surgery [194]. Similarly, The NIH-funded ASCERT trial (American College of Cardiology Foundation—Society of Thoracic Surgeons Collaboration on the Comparative Effectiveness of Revascularization sTrategies trial) also used linked clinical and administrative data to compare surgical and transcatheter strategies of coronary revascularization [243, 244]. Although randomized trials have been considered by many to be the gold standard of comparative effectiveness research, recent efforts have examined the possibility of using a clinical registry as a platform for randomized trials [245, 246], potentially accomplishing the dual objectives of decreasing the cost of the trial and increasing the generalizability of the patients enrolled.

Clinical registries can provide actionable feedback to clinicians and therefore aid in initiatives to improve quality. Clinical registries can provide practitioners with accurate and timely feedback of their own outcomes and can benchmark these outcomes to regional, national, or even international aggregate data [182, 198, 247–249].

The ultimate goal of clinical registries is to improve quality of care and outcomes. Clinical

Table 8.4 Definitions of quality measures for congenital and pediatric cardiac surgery

	Number	Type	Title of indicator	Description
1	S-1	Structure	Participation in a National Database for Pediatric and Congenital Heart Surgery	Participation in at least one multi-center, standardized data collection and feedback program that provides regularly scheduled reports of the individual center's data relative to national multicenter aggregates and uses process and outcome measures
2	S-2	Structure	Multidisciplinary rounds involving multiple members of the healthcare team	Occurrence of daily multidisciplinary rounds on pediatric and congenital cardiac surgery patients involving multiple members of the healthcare team, with recommended participation including but not limited to: cardiac surgery, cardiology, critical care, primary caregiver, family, nurses, pharmacist, and respiratory therapist. Involvement of the family is encouraged
3	S-3	Structure	Availability of Institutional Pediatric ECLS (Extracorporeal Life Support) Program	Availability of an institutional pediatric Extracorporeal Life Support (ECLS) Program for pediatric and congenital cardiac surgery patients. Measure is satisfied by availability of ECMO equipment and support staff, but applies as well to Ventricular Assist Devices (including extracorporeal, paracorporeal, and implantable)
4	S-4	Structure	Surgical volume for Pediatric and Congenital Heart Surgery: Total Programmatic Volume and Programmatic Volume Stratified by the Five STS-EACTS Mortality Categories	Surgical volume for Pediatric and Congenital Heart Surgery
				STS version 2.5: All Index Cardiac Operations (A Cardiac Operation is defined as an operation of Operation Type "CPB" or "No CPB Cardiovascular".)
				STS version 3.0: Same
				Surgical volume for pediatric and congenital heart surgery stratified by the five STS-EACTS Mortality Levels, a multi-institutional validated complexity stratification tool
				See *J Thorac Cardiovasc Surg* 2009;138:1139–1153. **O'Brien et al. An empirically based tool for analyzing mortality associated with congenital heart surgery. Table 1, pp 1140–1146**
5	S-5	Structure	Surgical volume for Eight Pediatric and Congenital Heart Benchmark Operations	Surgical volume for Eight Benchmark Pediatric and Congenital Heart Operations:
				These 8 Eight Benchmark Pediatric and Congenital Heart Operations are tracked when they are the primary procedure of an Index Cardiac Operation. (A Cardiac Operation is defined as an operation of Operation Type "CPB" or "No CPB Cardiovascular")
				Procedure type Abbreviation STS–CHSDB diagnostic and procedural inclusionary and exclusionary criteria

	1. VSD repair	VSD	**Procedural inclusionary criteria**:
			100 = VSD repair, Primary closure
			110 = VSD repair, Patch
			120 = VSD repair, Device*
			*(Please note that this measure is applicable when one or more septal occluder devices are implanted in the course of a surgical operation for which the Primary Procedure of an Index Cardiac Operation is VSD repair. [A Cardiac Operation is defined as an operation of Operation Type "CPB" or "No CPB Cardiovascular".] A VSD device that is placed as a purely transcatheter technique and not as a component of a cardiac operation is classified as an Interventional Cardiology Procedure and is not tracked as part of this measure.)
			Diagnostic inclusionary criteria:
			71 = VSD, Type 1 (Subarterial) (Supracristal) (Conal septal defect) (Infundibular)
			73 = VSD, Type 2 (Perimembranous) (Paramembranous) (Conoventricular)
			75 = VSD, Type 3 (Inlet) (AV canal type)
			77 = VSD, Type 4 (Muscular)
			79 = VSD, Type: Gerbode type (LV-RA communication)
			Diagnostic exclusionary criteria:
			80 = VSD, Multiple
	2. TOF repair	TOF	**Procedural inclusionary criteria:**
			350 = TOF repair, No ventriculotomy
			360 = TOF repair, Ventriculotomy, Nontransanular patch
			370 = TOF repair, Ventriculotomy, Transanular patch
			380 = TOF repair, RV-PA conduit
			Diagnostic inclusionary criteria:
			290 = TOF
			2140 = TOF, Pulmonary stenosis
			Diagnostic exclusionary criteria
			300 = TOF, AVC (AVSD)
			310 = TOF, Absent pulmonary valve
			320 = Pulmonary atresia
			330 = Pulmonary atresia, IVS
			340 = Pulmonary atresia, VSD (Including TOF, PA)
			350 = Pulmonary atresia, VSD-MAPCA (pseudotruncus)
			360 = MAPCA(s) (major aortopulmonary collateral[s]) (without PA-VSD)

(continued)

Table 8.4 (continued)

Number	Type	Title of indicator	Description	
		3. Complete AV canal repair	AVC	**Procedural inclusionary criteria**
				170 = AVC (AVSD) repair, Complete (CAVSD)
				Diagnostic inclusionary criteria:
				100 = AVC (AVSD), Complete (CAVSD)
				Diagnostic exclusionary criteria:
				110 = AVC (AVSD), Intermediate (transitional)
				120 = AVC (AVSD), Partial (incomplete) (PAVSD) (ASD, primum)
				300 = TOF, AVC (AVSD)
		4. Arterial switch	ASO	**Procedural inclusionary criteria**:
				1110 = Arterial switch operation (ASO)
				Procedural exclusionary criteria:
				1120 = Arterial switch operation (ASO) and VSD repair
				1123 = Arterial switch procedure + Aortic arch repair
				1125 = Arterial switch procedure and VSD repair + Aortic arch repair
				1050 = Congenitally corrected TGA repair, Atrial switch and ASO (double switch)
		5. Arterial switch + VSD repair	ASO + VSD	**Procedural inclusionary criteria**:
				1120 = Arterial switch operation (ASO) and VSD repair
				Procedural exclusionary criteria:
				1110 = Arterial switch operation (ASO)
				1123 = Arterial switch procedure + Aortic arch repair
				1125 = Arterial switch procedure and VSD repair + Aortic arch repair
				1050 = Congenitally corrected TGA repair, Atrial switch and ASO (double switch)
		6. Fontan	Fontan	**Procedural inclusionary criteria**:
				950 = Fontan, Atrio-pulmonary connection
				960 = Fontan, Atrio-ventricular connection
				970 = Fontan, TCPC, Lateral tunnel, Fenestrated
				980 = Fontan, TCPC, Lateral tunnel, Nonfenestrated
				1000 = Fontan, TCPC, External conduit, Fenestrated
				1010 = Fontan, TCPC, External conduit, Nonfenestrated
				1030 = Fontan, Other
				2340 = Fontan + Atrioventricular valvuloplasty
				Procedural exclusionary criteria:
				Exclude patients age≥7 years
				1025 = Fontan revision or conversion (Re-do Fontan)

				7. Truncus repair	Truncus	**Procedural inclusionary criteria**:
						Primary procedure must be:
						230= Truncus arteriosus repair
						Procedural exclusionary criteria:
						Exclude any operation if any of the component procedures is:
						240 = Valvuloplasty, Truncal valve
						2290 = Valvuloplasty converted to valve replacement in the same operation, Truncal valve
						250 = Valve replacement, Truncal valve
						2220 = Truncus + Interrupted aortic arch repair (IAA) repair
				8. Norwood	Norwood	**Procedural inclusionary criteria**:
						870 = Norwood procedure
6	P-1	Process	Multidisciplinary preoperative planning conference to plan pediatric and congenital heart surgery operations	Occurrence of a pre-operative multidisciplinary planning conference to plan pediatric and congenital heart surgery cases. This conference will involve multiple members of the healthcare team, with recommended participation including but not limited to: cardiology, cardiac surgery, anesthesia, and critical care		
				This measure will be coded on a per operation basis. Reporting of compliance will be as a fraction of all Cardiac Operations. A Cardiac Operation is defined as an operation of Operation Type “CPB” or “No CPB Cardiovascular”		
7	P-2	Process	Regularly scheduled Quality Assurance and Quality Improvement Cardiac Care Conference, to occur no less frequently than once every 2 months	Occurrence of a regularly scheduled Quality Assurance and Quality Improvement Cardiac Care Conference to discuss care provided to patients who have undergone pediatric and congenital cardiac surgery operations, including reporting and discussion of all major complications and mortalities, and discussion of opportunities for improvement		
				Reporting of compliance will be by reporting the date of occurrence. Annual compliance of 100 % equals no fewer than six conferences per year		
8	P-3	Process	Availability of intraoperative transesophageal echocardiography (TEE) and epicardial echocardiography	Availability of intraoperative transesophageal echocardiography (TEE) and appropriate physician and sonographer support for pediatric and congenital cardiac operations. Epicardial echocardiography and appropriate physician and sonographer support should be readily available for those patients in whom TEE is contraindicated or less informative. Availability means presence and availability of equipment and staff		
				This measure will be coded on a per operation basis. Reporting of compliance will be as the fraction of all Cardiac Operations with availability (as opposed to use) of TEE and/or epicardial echocardiography. (A Cardiac Operation is defined as an operation of Operation Type “CPB” or “No CPB Cardiovascular”)		
9	P-4	Process	Timing of Antibiotic Administration for Pediatric and Congenital Cardiac Surgery patients	Measure is satisfied for each Cardiac Operation, when there is documentation that the patient has received prophylactic antibiotics within the hour immediately preceding surgical incision (2 h if receiving vancomycin). (A Cardiac Operation is defined as an operation of operation type “CPB” or “No CPB Cardiovascular”)		

(continued)

Table 8.4 (continued)

	Number		Type	Title of indicator Description
10	P-5	Process	Selection of appropriate prophylactic antibiotics and weight-appropriate dosage for pediatric and congenital cardiac surgery patients	Measure is satisfied for each Cardiac Operation, when there is documentation that the patient received body weight appropriate prophylactic antibiotics as recommended for the operation. (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular")
11	P-6	Process	Use of an expanded pre-procedural and post-procedural "time-out"	Measure is satisfied for each Cardiac Operation when there is documentation of performance and completion of an expanded pre-procedural and post-procedural "time-out" that includes the following four elements (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular"):
				1. The conventional pre-procedural "time-out", which includes identification of patient, operative site, procedure, and history of any allergies
				2. A pre-procedural briefing wherein the surgeon shares with all members of the operating room team the essential elements of the operative plan; including diagnosis, planned procedure, outline of essentials of anesthesia and bypass strategies, antibiotic prophylaxis, availability of blood products, anticipated or planned implants or device applications, and anticipated challenges
				3. A post-procedural debriefing wherein the surgeon succinctly reviews with all members of the operating room team the essential elements of the operative plan, identifying both the successful components and the opportunities for improvement. This debriefing should take *place prior to the patient leaving the operating room or its equivalent*, and may be followed by a more in-depth dialogue involving team members at a later time. (The actual debriefing in the operating room is intentionally and importantly brief, in recognition of the fact that periods of transition may be times of instability or vulnerability for the patient)
				4. A briefing and execution of a hand-off protocol at the time of transfer (arrival) to the Intensive Care Unit at the end of the operation, involving the anesthesiologist, surgeon, physician staff of the Intensive Care Unit (including critical care and cardiology) and nursing

12	O-1	Outcome	Occurrence of new post-operative renal failure requiring dialysis	For each surgical admission (Index Cardiac Operation) code whether the complication occurred during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer (A Cardiac Operation is defined as an operation of operation type “CPB” or “No CPB Cardiovascular”): STS version 2.5: 220 = Acute renal failure requiring temporary dialysis 230 = Acute renal failure requiring permanent dialysis STS version 3.0: 230 = Renal failure – acute renal failure, acute renal failure requiring dialysis at the time of hospital discharge 223 = Renal failure–acute renal failure, acute renal failure requiring temporary dialysis with the need for dialysis not present at hospital discharge 224 = Renal failure–acute renal failure, acute renal failure requiring temporary hemofiltration with the need for dialysis not present at hospital discharge Please note: Unless a patient requires dialysis prior to surgery, renal failure that requires dialysis after surgery constitutes an operative complication, despite the fact that pre-operative diminished renal perfusion may have contributed to the development of this complication This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery mortality categories)

(continued)

Table 8.4 (continued)

	Number	Type	Title of indicator	Description
13	O-2	Outcome	Occurrence of new post-operative neurological deficit persisting at discharge	For each surgical admission (Index Cardiac Operation) code whether the complication occurred during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular"):
				320 = Neurological deficit, neurological deficit persisting at discharge
				This measure tracks "new post-operative neurological deficits" that (1) occur during the time interval beginning at admission to operating room and ending at the time of hospital discharge and (2) persist at discharge
				Such new post-operative neurological deficits may or may not be related to a stroke. If the new post-operative neurological deficit is the result of a stroke (that occurs during the time interval beginning at admission to operating room and ending at the time of hospital discharge) and the neurological deficit persists at discharge, then the following two complications should both be selected:
				320 = Neurological deficit, neurological deficit persisting at discharge
				420 = Stroke
				Thus, this complication (320 = Neurological deficit, neurological deficit persisting at discharge) should be coded in situations where a patient has a stroke (during the time interval beginning at admission to operating room and ending at the time of hospital discharge) and the neurological deficit persists at discharge
				This measure does not include a neurologic deficit (which may or may not be related to a stroke) that does not persist at discharge
				Please note that this complication (320 = Neurological deficit, neurological deficit persisting at discharge) should be coded even in the situation where the patient has a neurological deficit that is present prior to admission to operating room and this neurological deficit worsens (or a new neurological deficit develops) during the time interval beginning at admission to operating room and ending at the time of hospital discharge
				This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)
14	O-3	Outcome	Occurrence of arrhythmia necessitating permanent pacemaker insertion	For each surgical admission (Index Cardiac Operation) code whether the complication occurred during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular".):
				STS version 2.5:
				60 = Postoperative AV block requiring permanent pacemaker
				STS version 3.0:
				74 = Arrhythmia necessitating pacemaker, permanent pacemaker
				This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)

15	O-4	Outcome	Occurrence of paralyzed diaphragm (possible phrenic nerve injury)	For each surgical admission (Index Cardiac Operation) code whether the complication occurred during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular"):
				STS version 2.5:
				300=Phrenic nerve injury/paralyzed diaphragm
				STS version 3.0:
				300=Paralyzed diaphragm (possible phrenic nerve injury)
				This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)
16	O-5	Outcome	Occurrence of need for Postoperative mechanical circulatory support (IABP, VAD, ECMO, or CPS)	For each surgical admission (Index Cardiac Operation) code whether the complication occurred during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular".):
				STS version 2.5:
				40=Postoperative mechanical circulatory support (IABP, VAD, ECMO, or CPS)
				STS version 3.0:
				40=Postoperative/Postprocedural mechanical circulatory support (IABP, VAD, ECMO, or CPS)
				Please note that this complication should be coded even in the situation where the patient had preoperative mechanical circulatory support if the patient has mechanical circulatory support postoperatively at any time until 30 days post-operatively or the time of hospital discharge, whichever is longer
				This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)

(continued)

Table 8.4 (continued)

	Number		Type	Title of indicator Description
17	O-6	Outcome	Occurrence of unplanned reoperation and/or interventional cardiovascular catheterization procedure	For each surgical admission (Index Cardiac Operation) code whether the complication occurred during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer (A Cardiac Operation is defined as an operation of operation type "CPB" or "No CPB Cardiovascular"):
				STS version 2.5:
				20 = Reoperation during this admission (unplanned reoperation)
				240 = Bleeding requiring reoperation
				STS version 3.0:
				22 = Unplanned cardiac reoperation during the postoperative or postprocedural time period
				24 = Unplanned interventional cardiovascular catheterization procedure during the postoperative or postprocedural time period
				26 = Unplanned non-cardiac reoperation during the postoperative or postprocedural time period
				240 = Bleeding, Requiring reoperation
				n.b. does not include delayed sternal closure
				This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)
				This measure counts all patients who require any additional unplanned cardiac or non-cardiac operation and/or interventional cardiovascular catheterization procedure occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention
				A cardiac operation is defined as any operation that is of the Operation Type of "CPB" or "No CPB Cardiovascular"
				The following operations will always be coded as "Planned Reoperation": (1) Delayed Sternal Closure, (2) ECMO Decannulation, (3) VAD Decannulation, (4) Removal of Broviac catheter
				The following operations will always be coded as "Unplanned Reoperation": (1) Reoperation for bleeding, (2) Reoperation for infection, (3) Reoperation for hemodynamic instability, (4) Reoperation for initiation of ECMO or VAD, (5) Reoperation for residual or recurrent lesion
18	O-7	Outcome	Operative Mortality Stratified by the Five STS-EACTS Mortality Levels	Operative mortality stratified by the five STS-EACTS Mortality Levels, a multi-institutional validated complexity stratification tool
				See *J Thorac Cardiovasc Surg* 2009;138:1139–1153. O'Brien et al. **An empirically based tool for analyzing mortality associated with congenital heart surgery. Table 1, pp 1140–1146**
19	0–8	Outcome	Operative Mortality for Eight Benchmark Operations	Operative Mortality for Eight Benchmark Pediatric and Congenital Heart Operations:
				These 8 Eight Benchmark Pediatric and Congenital Heart Operations are tracked when they are the Primary Procedure of an Index Cardiac Operation. (A Cardiac Operation is defined as an operation of Operation Type "CPB" or "No CPB Cardiovascular")
				(These 8 Eight Benchmark Pediatric and Congenital Heart Operations are listed and described in this table in Measure Number S-5)

20	O-9	Outcome	Index Cardiac Operations Free of Mortality and Major Complication	"Index Cardiac Operations free of mortality and major complication" is defined as the percent of pediatric and congenital heart surgery Index Cardiac Operations free all of the following: (1) Operative mortality, (2) any one or more of the following major complications occurring or diagnosed during the time interval beginning at admission to operating room and ending 30 days post-operatively or at the time of hospital discharge, whichever is longer:
				(a) Renal failure. Acute renal failure requiring temporary or permanent dialysis (220, 230, 223, 224)
				STS version 2.5:
				220=Acute renal failure requiring temporary dialysis
				230=Acute renal failure requiring permanent dialysis
				STS version 3.0:
				230=Renal failure – acute renal failure, Acute renal failure requiring dialysis at the time of hospital discharge
				223=Renal failure – acute renal failure, Acute renal failure requiring temporary dialysis with the need for dialysis not present at hospital discharge
				224=Renal failure – acute renal failure, Acute renal failure requiring temporary hemofiltration with the need for dialysis not present at hospital discharge
				(b) Neurological deficit, neurological deficit persisting at discharge
				STS version 2.5:
				320=Postoperative neurological deficit persisting at discharge
				STS version 3.0:
				320=Neurological deficit, Neurological deficit persisting at discharge
				(c) Arrhythmia necessitating pacemaker, Permanent pacemaker (60, 74)
				STS version 2.5:
				60=Postoperative AV block requiring permanent pacemaker
				STS version 3.0:
				74=Arrhythmia necessitating pacemaker, Permanent pacemaker
				(d) ECMO/VAD. Postop mechanical circulatory support (IABP, VAD, ECMO or CPS) (40)
				STS version 2.5:
				40=Postoperative mechanical circulatory support (IABP, VAD, ECMO, or CPS)
				STS version 3.0:
				40=Postoperative/Postprocedural mechanical circulatory support (IABP, VAD, ECMO, or CPS)
				(e) Paralyzed diaphragm (possible phrenic nerve injury)
				STS version 2.5:
				300=Phrenic nerve injury/paralyzed diaphragm
				STS version 3.0:
				300=Paralyzed diaphragm (possible phrenic nerve injury)
				(f) Unplanned reoperation. (20, 22, 26 or 240)
				STS version 2.5:

(continued)

Table 8.4 (continued)

Number		Type	Title of indicator	Description
				20 = Reoperation during this admission (unplanned reoperation)
				240 = Bleeding requiring reoperation
				STS version 3.0:
				22 = Unplanned cardiac reoperation during the postoperative or postprocedural time period, exclusive of reoperation for bleeding
				24 = Unplanned interventional cardiovascular catheterization procedure during the postoperative or postprocedural time period
				26 = Unplanned non-cardiac reoperation during the postoperative or postprocedural time period
				240 = Bleeding, Requiring reoperation
				This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)
21	0–10	Outcome	Operative survivors free of major complication	"Operative survivors free of major complication" is defined as the percent of all surviving (live at discharge and 30 days postoperatively) pediatric and congenital heart surgery index operations free all of the following itemized major complications:
				(a) Renal failure. Acute renal failure requiring temporary or permanent dialysis (220, 230, 223, 224)
				STS version 2.5:
				220 = Acute renal failure requiring temporary dialysis
				230 = Acute renal failure requiring permanent dialysis
				STS version 3.0:
				230 = Renal failure – acute renal failure, Acute renal failure requiring dialysis at the time of hospital discharge
				223 = Renal failure – acute renal failure, Acute renal failure requiring temporary dialysis with the need for dialysis not present at hospital discharge
				224 = Renal failure – acute renal failure, Acute renal failure requiring temporary hemofiltration with the need for dialysis not present at hospital discharge
				(b) Neurological deficit, Neurological deficit persisting at discharge
				STS version 2.5:
				320 = Postoperative neurological deficit persisting at discharge
				STS version 3.0:
				320 = Neurological deficit, Neurological deficit persisting at discharge
				(c) Arrhythmia necessitating pacemaker, Permanent pacemaker (60, 74)
				STS version 2.5:
				60 = Postoperative AV block requiring permanent pacemaker
				STS version 3.0:
				74 = Arrhythmia necessitating pacemaker, permanent pacemaker
				(d) ECMO/VAD. Postop mechanical circulatory support (IABP, VAD, ECMO or CPS) (40)
				STS version 2.5:
				40 = Postoperative mechanical circulatory support (IABP, VAD, ECMO, or CPS)

	STS version 3.0:
	40 = Postoperative/Postprocedural mechanical circulatory support (IABP, VAD, ECMO, or CPS)
	(e) Paralyzed diaphragm (possible phrenic nerve injury)
	STS version 2.5:
	300 = Phrenic nerve injury/paralyzed diaphragm
	STS version 3.0:
	300 = Paralyzed diaphragm (possible phrenic nerve injury)
	(f) Unplanned reoperation. (20, 22, 26 or 240)
	STS version 2.5:
	20 = Reoperation during this admission (unplanned reoperation)
	240 = Bleeding requiring reoperation
	STS version 3.0:
	22 = Unplanned cardiac reoperation during the postoperative or postprocedural time period, exclusive of reoperation for bleeding
	24 = Unplanned interventional cardiovascular catheterization procedure during the postoperative or postprocedural time period
	26 = Unplanned non-cardiac reoperation during the postoperative or postprocedural time period
	240 = Bleeding, requiring reoperation
	This measure will be reported as percentage of all Index Cardiac Operations. This measure will also be reported stratified by the 5 STS-EACTS Congenital Heart Surgery Mortality Categories. (STS is developing Congenital Heart Surgery Morbidity Categories. When these STS Congenital Heart Surgery Morbidity Categories are published and available, this metric will be stratified by the STS Congenital Heart Surgery Morbidity Categories instead of the STS Congenital Heart Surgery Mortality Categories)

Table 8.5 Consensus definitions of the morbidities

Measure	Organ system	Complication	Definitions
12	Renal	Renal failure – acute renal failure, Acute renal failure requiring dialysis at the time of hospital discharge	Renal failure – acute renal failure (ROOT Definition) + With new postoperative/postprocedural requirement for dialysis, including peritoneal dialysis and/or hemodialysis. Code this complication if the patient requires dialysis at the time of hospital discharge or death in the hospital. (This complication should be chosen only if the dialysis was associated with acute renal failure.) {"Renal failure – acute renal failure" ROOT Definition = Acute renal failure is defined as new onset oliguria with sustained urine output < 0.5 cc/kg/h for 24 h and/or a rise in creatinine >1.5 times upper limits of normal for age (or twice the most recent preoperative/preprocedural values if these are available), with eventual need for dialysis (including peritoneal dialysis and/or hemodialysis) or hemofiltration. Acute renal failure that will be counted as an operative or procedural complication must occur prior to hospital discharge or after hospital discharge but within 30 days of the procedure. (An operative or procedural complication is any complication, regardless of cause, occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention. Operative and procedural complications include both intraoperative/intraprocedural complications and postoperative/postprocedural complications in this time interval.) The complication is to be coded even if the patient required dialysis, but the treatment was not instituted due to patient or family refusal}
12	Renal	Renal failure – acute renal failure, Acute renal failure requiring temporary dialysis with the need for dialysis not present at hospital discharge	Renal failure – acute renal failure (ROOT Definition) + With new postoperative/postprocedural requirement for temporary dialysis, including peritoneal dialysis and/or hemodialysis. Code this complication if the patient does not require dialysis at the time of hospital discharge or death in the hospital. (This complication should be chosen only if the dialysis was associated with acute renal failure.) {"Renal failure – acute renal failure" ROOT Definition = Acute renal failure is defined as new onset oliguria with sustained urine output <0.5 cc/kg/h for 24 h and/or a rise in creatinine >1.5 times upper limits of normal for age (or twice the most recent preoperative/preprocedural values if these are available), with eventual need for dialysis (including peritoneal dialysis and/or hemodialysis) or hemofiltration. Acute renal failure that will be counted as an operative or procedural complication must occur prior to hospital discharge or after hospital discharge but within 30 days of the procedure. (An operative or procedural complication is any complication, regardless of cause, occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention. Operative and procedural complications include both intraoperative/intraprocedural complications and postoperative/postprocedural complications in this time interval.) The complication is to be coded even if the patient required dialysis, but the treatment was not instituted due to patient or family refusal}

Table 8.5 (continued)

12	Renal	Renal failure – acute renal failure, Acute renal failure requiring temporary hemofiltration with the need for dialysis not present at hospital discharge	Renal failure – acute renal failure (ROOT Definition) + With new postoperative/postprocedural requirement for temporary hemofiltration. Code this complication if the patient does not require dialysis at the time of hospital discharge or death in the hospital. (This complication should be chosen only if the hemofiltration was associated with acute renal failure.) {"Renal failure – acute renal failure" ROOT Definition = Acute renal failure is defined as new onset oliguria with sustained urine output <0.5 cc/kg/h for 24 h and/or a rise in creatinine >1.5 times upper limits of normal for age (or twice the most recent preoperative/preprocedural values if these are available), with eventual need for dialysis (including peritoneal dialysis and/or hemodialysis) or hemofiltration. Acute renal failure that will be counted as an operative or procedural complication must occur prior to hospital discharge or after hospital discharge but within 30 days of the procedure. (An operative or procedural complication is any complication, regardless of cause, occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention. Operative and procedural complications include both intraoperative/intraprocedural complications and postoperative/postprocedural complications in this time interval.) The complication is to be coded even if the patient required dialysis, but the treatment was not instituted due to patient or family refusal}
13	Neurologic	Neurological deficit, Neurological deficit persisting at discharge	Newly recognized and/or newly acquired deficit of neurologic function leading to inpatient referral, therapy, or intervention not otherwise practiced for a similar unaffected inpatient, With a persisting neurologic deficit present at hospital discharge. In other words, new (onset intraoperatively or postoperatively – or intraprocedurally or postprocedurally) neurological deficit persisting and present at discharge from hospital
13	Neurologic	Stroke	"Stroke" ROOT Definition = A stroke is any confirmed neurological deficit of abrupt onset caused by a disturbance in blood flow to the brain, when the neurologic deficit does not resolve within 24 h
13	Neurologic	Spinal cord injury, Neurological deficit persisting at discharge	Spinal cord injury (ROOT Definition) + With a persisting neurologic deficit present at hospital discharge. {"Spinal cord injury" ROOT Definition = Newly acquired or newly recognized deficit of spinal cord function indicated by physical exam findings, imaging studies, or both}
13	Neurologic	Peripheral nerve injury, Neurological deficit persisting at discharge	Peripheral nerve injury (ROOT Definition) + With a persisting neurologic deficit present at hospital discharge. {"Peripheral nerve injury" ROOT Definition = Newly acquired or newly recognized deficit of unilateral or bilateral peripheral nerve function indicated by physical exam findings, imaging studies, or both}
14	Arrhythmia – Arrhythmia necessitating pacemaker	Arrhythmia necessitating pacemaker, Permanent pacemaker	Implantation and utilization of a permanent pacemaker for treatment of any arrhythmia including heart block (atrioventricular [AV] heart block)

(continued)

Table 8.5 (continued)

Measure	Organ system	Complication	Definitions
15	Neurologic	Paralyzed diaphragm (possible phrenic nerve injury)	Presence of elevated hemi-diaphragm(s) on chest radiograph in conjunction with evidence of weak, immobile, or paradoxical movement assessed by ultrasound or fluoroscopy
16	Mechanical support utilization	Postoperative/Postprocedural mechanical circulatory support (IABP, VAD, ECMO, or CPS)	Utilization of postoperative/postprocedural mechanical support, of any type (IABP, VAD, ECMO, or CPS), for resuscitation/CPR or support, during the postoperative/postprocedural time period. Code this complication if it occurs (1) within 30 days after surgery or intervention regardless of the date of hospital discharge, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention
17	Operative/procedural	Unplanned cardiac reoperation during the postoperative or postprocedural time period, exclusive of reoperation for bleeding	Any additional unplanned cardiac operation occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention. A cardiac operation is defined as any operation that is of the operation type of "CPB" or "No CPB Cardiovascular". The following operations will always be coded as "Planned Reoperation": (1) Delayed Sternal Closure, (2) ECMO Decannulation, (3) VAD Decannulation, (4) Removal of Broviac catheter. The following operations will always be coded as "Unplanned Reoperation": (1) Reoperation for bleeding, (2) Reoperation for infection, (3) Reoperation for hemodynamic instability, (4) Reoperation for initiation of ECMO or VAD, (5) Reoperation for residual or recurrent lesion
17	Operative/procedural	Unplanned interventional cardiovascular catheterization procedure during the postoperative or postprocedural time period	Any unplanned interventional cardiovascular catheterization procedure occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention
17	Operative/procedural	Unplanned non-cardiac reoperation during the postoperative or postprocedural time period	Any additional unplanned non-cardiac operation occurring (1) within 30 days after surgery or intervention in or out of the hospital, or (2) after 30 days during the same hospitalization subsequent to the operation or intervention

registries have been used to create standardized measures of quality that have been endorsed by multiple professional medical societies and the National Quality Forum [186, 250]. Compliance with these measures and the public reporting of these measures should lead to improvements in the overall quality of care delivered to our patients [143, 176, 177].

Figure 8.7 is a Venn Diagram that demonstrates the close and overlapping relationships between the three domains of this textbook: Outcomes Analysis, Quality Improvement, and Patient Safety. These relationships compose the underlying theme of this textbook and are fundamental to improving the state of the art of pediatric and congenital cardiac care.

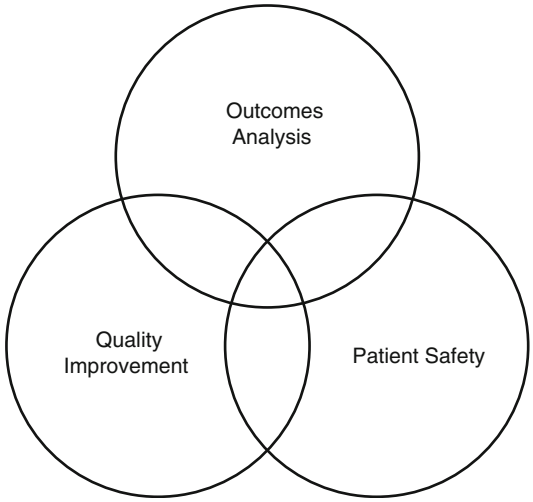


Fig. 8.7 This Venn Diagram demonstrates the close and overlapping relationships between the three domains of this textbook: outcomes analysis, quality improvement, and patient care. These relationships compose the underlying theme of this textbook and are fundamental to improving the state of the art of pediatric and congenital cardiac care

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