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Linking the Congenital Heart Surgery Databases of the Society of Thoracic Surgeons and the Congenital Heart Surgeons' Society: Part 2—Lessons Learned and Implications

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Abstract

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Declaration of Conflicting Interests

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Purpose—A link has been created between the Society of Thoracic Surgeons Congenital Heart Surgery Database (STS-CHSD) and the Congenital Heart Surgeons' Society Database (CHSS-D). Five matrices have been created that facilitate the automated identification of patients who are potentially eligible for the five active CHSS studies using the STS-CHSD. These matrices are now used to (1) estimate the denominator of patients eligible for CHSS studies and (2) compare “eligible and enrolled patients” to “potentially eligible and not enrolled patients” to assess the generalizability of CHSS studies.

Methods—The matrices were applied to 40 consenting institutions that participate in both the STS-CHSD and the CHSS to (1) estimate the denominator of patients that are potentially eligible for CHSS studies, (2) estimate the completeness of enrollment of patients eligible for CHSS studies among all CHSS sites, (3) estimate the completeness of enrollment of patients eligible for CHSS studies among those CHSS institutions participating in each CHSS cohort study, and (4) compare “eligible and enrolled patients” to “potentially eligible and not enrolled patients” to assess the generalizability of CHSS studies. The matrices were applied to all participants in the STS-CHSD to identify patients who underwent frequently performed operations and compare “eligible and enrolled patients” to “potentially eligible and not enrolled patients” in following five domains: (1) age at surgery, (2) gender, (3) race, (4) discharge mortality, and (5) postoperative length of stay. Completeness of enrollment was defined as the number of actually enrolled patients divided by the number of patients identified as being potentially eligible for enrollment.

Results—For the CHSS Critical Left Ventricular Outflow Tract Study (LVOTO) study, for the Norwood procedure, completeness of enrollment at centers actively participating in the LVOTO study was 34%. For the Norwood operation, discharge mortality was 15% among 227 enrolled patients and 16% among 1768 nonenrolled potentially eligible patients from the 40 consenting institutions. Median postoperative length of stay was 31 days and 26 days for these enrolled and nonenrolled patients. For the CHSS anomalous aortic origin of a coronary artery (AAOCA) study, for AAOCA repair, completeness of enrollment at centers actively participating in the AAOCA study was 40%.

Conclusion—Determination of the denominator of patients eligible for CHSS studies and comparison of “eligible and enrolled patients” to “potentially eligible and not enrolled patients” provides an estimate of the extent to which patients in CHSS studies are representative of the overall population of eligible patients; however, opportunities exist to improve enrollment.

Keywords

database (all types); outcomes (includes mortality, morbidity); congenital heart disease (CHD); congenital heart surgery

Background

This article is the second in a series of two articles that report the findings of a research project titled: “Linking the Congenital Heart Surgery Database of the Society of Thoracic Surgeons (STS) with the Congenital Heart Surgeons' Society (CHSS) Database.” The first article described the rationale and methodology of the STS-CHSS Link.¹ This second article describes the results of the analysis and summarizes the lessons learned to date from the STS-CHSS Link and their implications.

As described previously,¹ a link has been created between The Society of Thoracic Surgeons Congenital Heart Surgery Database (STS-CHSD) and The Congenital Heart Surgeons' Society Database (CHSS-D). Five matrices have been created that facilitate the automated identification within the STS-CHSD of patients who are potentially eligible for enrollment in each of the five active CHSS studies. As a result of a manual adjudication process and the refinement of the matrices,¹ the sensitivity of the matrices increased from 93% to 100% and the specificity increased from 94% to 98%. The purpose of this article is to report how the STS-CHSS Link is used to (1) estimate the denominator of patients who are potentially eligible for CHSS studies, (2) estimate the completeness of enrollment of patients eligible for CHSS studies among all CHSS sites, (3) estimate the completeness of enrollment of patients eligible for CHSS studies among those CHSS institutions participating in each CHSS cohort study, and (4) compare "eligible and enrolled patients" to "eligible and not enrolled patients" to assess the generalizability of CHSS studies.

Materials and Methods

STS-CHSS Link

The development, refinement, and verification of the five matrices that link the CHSS-D to the STS-CHSD have been described previously.¹ The processes of identification and recruitment of 40 centers that participate in both the STS-CHSD and the CHSS have also been described previously.¹

Estimation of the Denominator of Patients Eligible for CHSS Studies

The five matrices were applied to the STS-CHSD at all 40 consenting institutions. In order to arrive at an estimate the denominator of surgical patients who are potentially eligible for CHSS studies, we determined the number of patients who fit into each of the following three groups for the primary procedures most commonly performed in patients enrolled in each of the four active CHSS studies with suitable enrollment (for the CHSS study of unbalanced atrioventricular septal defect [uAVSD], enrollment has only recently begun at the time of this project; and therefore, we simply report the number of patients identified by the matrix in its five most common primary procedures. This strategy is utilized because the uAVSD study does not yet have suitable enrollment for inclusion in other analyses in this article):

1. Group 1—enrolled patients associated with the 40 consenting CHSS institutions.
2. Group 2—nonenrolled potentially eligible patients associated with the 40 consenting CHSS institutions who also had an enrolled patient found in group 1.
3. Group 3—nonenrolled potentially eligible patients associated with all 40 consenting CHSS institutions regardless of them having or not having an enrolled patient (nb: group 2 is a subset of group 3).

Estimation of the Completeness of Enrollment of Patients Eligible for CHSS Studies

In our analysis, the term completeness is used to refer to the completeness of capture of potentially eligible patients (ie, the rate of enrollment of potentially eligible patients); this definition of completeness has been published previously.² Completeness of enrollment is

calculated for each of the four active CHSS studies with suitable enrollment. Completeness of enrollment was defined as the number of actually enrolled patients divided by the number of patients identified as being eligible for enrollment. For the CHSS study of uAVSD, enrollment has only recently begun at the time of this project. Therefore, for the uAVSD study, we simply reported the number of patients identified by the matrix in its five most common primary procedures and we do not calculate completeness of enrollment.

Two types of completeness are estimated:

1. completeness at centers actively enrolling patients in a given study (completeness at actively participating centers); and
2. completeness of enrollment among the entire cohort of 40 centers participating in this project (completeness at all potential centers).

The numerator for calculation of completeness at actively participating centers is all patients in group 1. The denominator for calculation of completeness at actively participating centers is the sum of all patients in groups 1 and 2.

The numerator for calculation of completeness at all potential centers is all patients in group 1. The denominator for calculation of completeness all potential centers is the sum of all patients in groups 1 and 3.

Comparison of Eligible and Enrolled Patients to Potentially Eligible and Not Enrolled Patients

This analysis is limited to the four active CHSS studies with suitable enrollment (The CHSS study of uAVSD has only recently begun enrollment at the time of this project; and therefore, this cohort is not included in this analysis of representativeness).

For this analysis of representativeness, the four matrices specifically pertaining to the active CHSS studies with suitable enrollment were applied to all centers in the STS-CHSD. In order to facilitate estimation of the representativeness of patients enrolled in the CHSS studies, we performed an analysis in each of the following six groups of the two most commonly performed primary procedures among patients enrolled in each of these four active CHSS studies where suitable enrollment has occurred.

- a. Group A—enrolled patients associated with the 40 consenting CHSS institutions.
- b. Group B—nonenrolled potentially eligible patients associated with the 40 consenting CHSS institutions who also had an enrolled patient found in group A.
- c. Group C—nonenrolled potentially eligible patients associated with all 40 consenting CHSS institutions regardless of them having or not having an enrolled patient (nb: group B is a subset of group C).
- d. Group D—potentially eligible patients associated with the 30 CHSS institutions which did not agree to participate. This is a subset of group E.

- e. Group E—potentially eligible patients associated with both the 30 CHSS institutions which did not agree to participate and all STS institutions which are not CHSS sites.
- f. Group F—all nonenrolled patients who met the inclusion criteria. This consists of group C and group E patients.

The matrices were applied to all participants in the STS-CHSD to identify patients who underwent frequently performed operations and compare “eligible and enrolled patients” to “potentially eligible and not enrolled patients” in following five domains: (1) age at surgery, (2) gender, (3) race, (4) discharge mortality, and (5) postoperative length of stay.

Institutional Review Board Approval

The Duke University Health System Institutional Review Board approved the study and provided a waiver of informed consent. Although the STS data used in the analysis contain patient identifiers, they were originally collected for nonresearch purposes and the risk to patients was deemed to be minimal.³

This article was reviewed and approved by the STS-CHSD Access and Publications Committee. This article was also reviewed and approved by the CHSS Committee on Quality Improvement and Outcomes.

Results

Estimation of the Denominator of Patients Eligible for CHSS Studies

Table 1 documents the number of patients in groups A through C for each of the four active CHSS studies with suitable enrollment. For the CHSS study of uAVSD, Table 1 also documents the number of patients identified by the matrix in its five most common primary procedures (group C only).

Estimation of the Completeness of Enrollment of Patients Eligible for CHSS Studies

Table 2 documents estimated completeness of enrollment at centers actively participating in a given CHSS study and at 40 CHSS centers that could potentially enroll patients.

- For the Tricuspid Atresia (TA) study, for modified Blalock-Taussig shunt (MBTS), completeness at actively participating centers was 30% and completeness at all potential centers was 12%.
- For the pulmonary conduit (PC) study, for truncus arteriosus repair, completeness at actively participating centers was 29% and completeness at all potential centers was 10%.
- For the Critical left ventricular outflow tract obstruction (LVOTO) study, for Norwood procedure, completeness at actively participating centers was 34% and completeness at all potential centers was 11%.

- For the anomalous aortic origin of a coronary artery (AAOCA) study, for AAOCA repair, completeness at actively participating centers was 40% and completeness at all potential centers was 12%.

Comparison of Eligible and Enrolled Patients to Eligible and Not Enrolled Patients

Data pertaining to the potential extent of representativeness of CHSS data for the two most common operations in each of the four active CHSS studies with suitable enrollment are provided in Tables 3 to 10. For the TA study, we report data on the following two operations:

1. Primary procedure, 1590 = Shunt, Systemic-to-pulmonary, MBTS
2. Primary procedure, 1640 = Pulmonary artery banding (PAB)

For the PC study, we report data on the following two operations:

1. Primary procedure, 230 = Truncus arteriosus repair
2. Primary procedure, 380 = Tetralogy of Fallot repair, Right ventricle-to-pulmonary artery conduit

For the critical LVOTO study, we report data on the following two operations:

1. Primary procedure, 870 = Norwood procedure
2. Primary procedure, 1640 = PAB

For the AAOCA study, we report data on the following two operations:

1. Primary procedure, 1305 = AAOCA repair
2. Primary procedure, 1310 = Coronary artery procedure, Other

As a representative example of these data, for the Norwood Operation, discharge mortality was 15% among 227 enrolled patients and 16% among 1768 nonenrolled potentially eligible patients from the 40 consenting institutions. Median postoperative length of stay was 31 days and 26 days for these enrolled and nonenrolled patients.

Discussion

This article is the second in a series of two articles describing the results of the STS-CHSS Link. This first article described the rationale and methodology of the STS-CHSS Link. This second article describes the type of data that can be provided in feedback reports to centers participating in both the STS-CHSD and the CHSS-D and discusses some of the lessons learned to date from the STS-CHSS Link and the implications of this analysis.

The STS-CHSS Link allows estimation of the penetration, completeness, and representativeness of the data in the CHSS-D.² In 2013, STS-CHSD contains data from 117 of the 125 hospitals with pediatric heart surgery programs (93.6% penetrance by hospital) in the United States and 3 of the 8 centers with pediatric heart surgery programs in Canada.⁴⁻⁶ The CHSS includes 74 institutions from the United States and Canada, corresponding to a penetration of 55.6% of the 133 hospitals in the United States and Canada that perform

pediatric and congenital heart surgery. Completeness of enrollment in CHSS studies at centers actively participating in these studies ranged from 29% to 40% across CHSS studies. For the most common operations performed on patients who enrolled in the CHSS cohorts, approximately one-third of eligible patients are actually enrolled at those CHSS member institutions that are actively enrolling patients in a given study, and approximately 10% to 15% of potentially eligible patients are enrolled across the entire CHSS. This analysis of available data suggests that opportunities exist to improve enrollment in CHSS studies. Determination of the denominator of patients eligible for CHSS studies and comparison of “eligible and enrolled patients” to “potentially eligible and not enrolled patients” provide an estimate of the extent to which patients in CHSS studies are representative of the overall population of eligible patients.

The STS-CHSS Link has facilitated analyses not feasible with either database alone. The limitations of the STS-CHSS Link have been described previously.¹ The STS-CHSS Link can address the major weaknesses of each database. The major weakness of the STS-CHSD is its lack of information about longitudinal follow-up and long-term outcomes. Follow-up information in the STS National Database is currently collected for two short-term end points: (1) status at discharge from the hospital after surgery and (2) status 30 days after surgery. The major weakness of the CHSS-D is its voluntary enrollment and the associated inherent unlikelihood that this method will capture all eligible patients. Furthermore, although the CHSS has 74 North American member institutions, participation in CHSS research studies is voluntary and not all member institutions participate in CHSS studies. Therefore, the potential denominator of eligible patients for any given CHSS protocol is not known. Furthermore, there has never before been a mechanism to estimate the extent to which the enrolled patients are representative of the entire population of patients potentially eligible for CHSS studies, a concept that has potential ramifications regarding the generalizability of inferences drawn from studies of CHSS cohorts. The STS-CHSS Link provides a reasonable estimate of the denominator of patients eligible for CHSS studies and provides an estimate of the representativeness of CHSS enrolled patients with respect to the parameters that were analyzed. Because the STS-CHSD does not currently allow for longitudinal follow-up, the CHSS-D can allow for longitudinal follow-up of select cohorts of interest.

Future Directions

Ideally, the creation of the STS-CHSS Link will help to bring about increased enrollment in CHSS studies. Beginning with the Fall 2013 STS-CHSD feedback report, every six months, STS-CHSD participants will receive a list of the registry record numbers of all patients identified as potentially eligible for CHSS studies over the previous four years, using a rolling four-year time window (see Table 6 of Part 1 of this series of articles¹). In addition, every six months, STS-CHSD participants will receive a comparison of their own institution's enrolled patients with their own institution's potentially eligible but nonenrolled patients from STS. This comparison will be similar to Tables 3 to 10 of this current article but will only compare enrolled patients with potentially eligible nonenrolled patients at a given institution.

Another ultimate goal of the STS-CHSS Link is not only to identify patients who are potentially eligible for CHSS studies but also to eliminate the duplication of effort involved in data collection for both STS-CHSD and CHSS-D. In the future, it is hoped that a system can be created where all of the basic data collected for STS-CHSD will immediately populate the CHSS data set. Creation of such a system will minimize the burden of entering data and make it possible that a single act of data entry can populate both the STS-CHSD and the CHSS-D. Such a system will be facilitated and enhanced by using the international nomenclature used in the STS-CHSD (The International Pediatric and Congenital Cardiac Code [<http://www.ipccc.net/>])¹ at the time of inception of new CHSS cohorts when developing inclusionary and exclusionary criteria. If all of the basic data collected for STS-CHSD immediately populated the CHSS-D, CHSS could then send the partially completed data set derived from STS-CHSD to a center's data manager, pointing out what additional data is required.

Conclusion

The CHSS-D has been successfully linked to the STS-CHSD. Algorithms have been developed for all five active CHSS protocols to identify patients in STS-CHSD who are eligible for CHSS studies. Determination of the denominator of patients eligible for CHSS studies and comparison of “eligible and enrolled patients” to “eligible and not enrolled patients” provides an estimate of the extent to which patients in CHSS studies are representative of the overall population of eligible patients; however, opportunities exist to improve enrollment.

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This article is the second in a series of two articles that will report the findings of a research project generously funded by the Children's Heart Foundation (<http://www.childrensheartfoundation.org/>) titled: “Linking the Congenital Heart Surgery Database of the Society of Thoracic Surgeons (STS) with the Congenital Heart Surgeons' Society (CHSS) Database.” The first article will describe the rationale and methodology of the STS-CHSS Link. This second article will describe the lessons learned to date from the STS-CHSS Link and the implications of this analysis.

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Abbreviations and Acronyms

AAOCA	anomalous aortic origin of a coronary artery
CHSS-D	Congenital Heart Surgeons' Society Database
LVOTO	left ventricular outflow tract obstruction
PC	pulmonary conduit
PAB	pulmonary artery banding
STS-CHSD	Society of Thoracic Surgeons Congenital Heart Surgery Database
TA	Tricuspid Atresia

uAVSD

unbalanced atrioventricular septal defect

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Table 1

Number of Patients Enrolled in CHSS Studies and Eligible for CHSS Studies.

Primary Procedure	Number of Patients		
	Group 1 ^a	Group 2 ^a	Group 3 ^a
TA study			
1590 = Shunt, Systemic-to-pulmonary, MBTS	29	69	209
1640 = PAB	13	13	64
1600 = Shunt, Systemic-to-pulmonary, central (from aorta or to main pulmonary artery)	10	12	53
1670 = BDCPA (bidirectional Glenn)	4	13	112
1700 = HemiFontan	2	5	13
PC study			
230 = Truncus arteriosus repair	56	135	489
380 = TOF repair, RV-PA conduit	23	101	280
420 = Pulmonary atresia-VSD (including TOF, PA) repair	13	14	120
760 = Ross-Konno procedure	12	28	122
1150 = Rastelli	12	43	246
Critical LVOTO study			
870 = Norwood procedure	227	447	1768
1640 = PAB	26	36	123
2180 = Hybrid approach "Stage 1," Stent placement in arterial duct (PDA) + application of RPA & LPA bands	11	12	82
2160 = Hybrid Approach "Stage 1," Application of RPA and LPA bands	5	11	27
2010 = Cardiac procedure, Other	4	13	40
AAOCA study			
1305 = AAOCA repair	20	30	111
1310 = Coronary artery procedure, Other	14	38	145
uAVSD study			
170 = AVC (AVSD) repair, CAVSD			2061
1640 = PAB			164
870 = Norwood procedure			141
1590 = Shunt, Systemic-to-pulmonary, MBTS			116
1670 = BDCPA (bidirectional Glenn)			110

Abbreviations: AVC, atrioventricular canal; AVSD, atrioventricular septal defect; AAOCA, anomalous aortic origin of a coronary artery; BDCPA, bidirectional cavopulmonary anastomosis; CAVSD, complete atrioventricular septal defect; CHSS, Congenital Heart Surgeons' Society; LVOTO, left ventricular outflow tract obstruction; LPA, left pulmonary artery; MBTS, modified Blalock-Taussig shunt; PAB, pulmonary artery banding; PC, pulmonary conduit; PA, pulmonary artery; TOF, tetralogy of Fallot; PDA, ductus arteriosus; RV-PA, right ventricle-to-pulmonary artery; RPA, right pulmonary artery; TA, Tricuspid Atresia; VSD, ventricular septal defect; uAVSD, unbalanced atrioventricular septal defect.

^aGroups 1, 2, and 3 are defined in Materials and Methods section of this article.

Table 2

Estimated Completeness of Enrollment of Patients Eligible for CHSS Studies.

Primary Procedure	Completeness, %	
	Actively Participating Centers	All Potential Centers
TA study		
1590 = Shunt, Systemic-to-pulmonary, MBTS	30	12
1640 = PAB	50	17
1600 = Shunt, Systemic-to-pulmonary, central (from aorta or to main pulmonary artery)	46	16
1670 = BDCPA (bidirectional Glenn)	24	3
1700 = HemiFontan	29	13
PC study		
230 = Truncus arteriosus repair	29	10
380 = TOF repair, RV-PA conduit	19	8
420 = Pulmonary atresia-VSD (including TOF, PA) repair	48	10
760 = Ross-Konno procedure	30	9
1150 = Rastelli	22	5
LVOTO study		
870 = Norwood procedure	34	11
1640 = PAB	42	17
2180 = Hybrid approach "Stage 1," Stent placement in arterial duct (PDA) + application of RPA and LPA bands	48	12
2160 = Hybrid approach "Stage 1," Application of RPA and LPA bands	31	16
2010 = Cardiac procedure, Other	24	9
AAOCA study		
1305 = AAOCA repair	40	15
1310 = Coronary artery procedure, Other	27	9

Abbreviations: AAOCA, anomalous aortic origin of a coronary artery; BDCPA, bidirectional cavopulmonary anastomosis; CHSS, Congenital Heart Surgeons' Society; LVOTO, left ventricular outflow tract obstruction; LPA, left pulmonary artery; MBTS, modified Blalock-Taussig shunt; PAB, pulmonary artery banding; PC, pulmonary conduit; PA, pulmonary artery; TOF, tetralogy of Fallot; PDA, ductus arteriosus; RV-PA, right ventricle-to-pulmonary artery; RPA, right pulmonary artery; TA, Tricuspid Atresia; VSD, ventricular septal defect.

Table 3

Tricuspid Atresia: Shunt, Systemic-to-Pulmonary, MBTS.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	9		9		36		22		47		83	
Number of patients	29		69		209		173		258		467	
Number of operations	29		69		209		174		259		468	
Age, days	29	29.7	69	18.4	209	17.4	174	22.8	259	22.1	468	27.3
Median		9.0		5.0		7.0		9.0		9.0		8.0
25th		5.0		4.0		4.0		5.0		5.0		4.5
75th		52.0		15.0		19.0		38.0		34.0		26.0
Gender												
Missing	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Male	12	41.38	40	57.97	125	59.81	105	60.34	155	59.85	280	59.83
Female	17	58.62	29	42.03	84	40.19	69	39.66	104	40.15	188	40.17
Ambiguous	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Race—White												
Missing	0	0.00	1	1.45	14	6.70	12	6.90	13	5.02	27	5.77
No	13	44.83	46	66.67	109	52.15	78	44.83	117	45.17	226	48.29
Yes	16	55.17	22	31.88	86	41.15	84	48.28	129	49.81	215	45.94
Hispanic												
Missing	0	0.00	1	1.45	25	11.96	17	9.77	20	7.72	45	9.62
No	23	79.31	43	62.32	135	64.59	133	76.44	200	77.22	335	71.58
Yes	6	20.69	25	36.23	49	23.44	24	13.79	39	15.06	88	18.80
Discharge mortality												
Missing	0	0.00	0	0.00	2	0.96	0	0.00	0	0.00	2	0.43
No	28	96.55	67	97.10	197	94.26	164	94.25	242	93.44	439	93.80
Yes	1	3.45	2	2.90	10	4.79	10	5.75	17	6.56	27	5.77
Postoperative length of stay												
Mean	29	18.0	69	12.7	209	22.6	174	16.8	259	16.9	468	19.4
Median		11.0		9.0		12.0		10.0		10.0		11.0
25th		8.0		6.0		7.0		7.0		7.0		7.0
75th		24.0		16.0		24.0		18.0		18.0		20.0

Abbreviation: MBTS, modified Blalock-Taussig shunt.

^aPatients with admission dates after 31 December, 1998 and a birth date after 30 September, 1998. Primary procedure, 1590 = Shunt, Systemic-to-pulmonary, MBTS. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 4

Tricuspid Atresia: PAB.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	8		6		27		19		34		61	
Number of patients	13		13		64		56		86		150	
Number of operations	13		13		64		56		86		150	
Age, days	13	30.1	13	25.9	64	36.3	56	86.6	86	73.6	150	57.6
Mean												
Median		21.0		14.0		23.0		32.0		33.0		26.5
25th		8.0		7.0		12.0		16.5		16.0		13.0
75th		44.0		25.0		37.5		64.5		64.0		50.0
Gender	0	0.00	1	7.69	1	1.56	1	1.79	1	1.16	2	1.33
Male	7	53.85	5	38.46	30	46.88	29	51.79	47	54.65	77	51.33
Female	6	46.15	7	53.85	33	51.56	26	46.43	38	44.19	71	47.33
Ambiguous	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Race—White	0	0.00	0	0.00	3	4.69	2	3.57	3	3.49	6	4.00
Missing	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
No	3	23.08	9	69.23	30	46.88	27	48.21	39	45.35	69	46.00
Yes	10	76.92	4	30.77	31	48.44	27	48.21	44	51.16	75	50.00
Hispanic	0	0.00	0	0.00	4	6.25	1	1.79	2	2.33	6	4.00
Missing	12	92.31	10	76.92	48	75.00	44	78.57	67	77.91	115	76.67
No												
Yes	1	7.69	3	23.08	12	18.75	11	19.64	17	19.77	29	19.33
Discharge mortality	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Missing	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
No	13	100.00	13	100.00	63	98.44	54	96.43	83	96.51	146	97.33
Yes	0	0.00	0	0.00	1	1.56	2	3.57	3	3.49	4	2.67
Postoperative length of stay	11	19.2	13	30.4	64	17.7	56	17.5	86	17.7	150	17.7
Mean												
Median		9.0		10.0		7.0		8.0		7.0		7.0
25th		8.0		8.0		5.0		5.0		5.0		5.0
75th		23.0		38.0		15.0		14.0		14.0		14.0

Abbreviations: PAB, pulmonary artery banding.

^dPatients with admission dates after 31 December, 1998 and a birth date after 30 September, 1998. Primary procedure, 1640 = PAB. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 5

Pulmonary Conduit: Truncus Arteriosus Repair.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	8		8		37		25		57		94	
Number of patients	56		135		489		381		558		1047	
Number of operations	56		135		491		383		560		1051	
Age, days												
Mean	56	29.9	135	23.6	491	36.6	383	24.2	560	27.2	1051	31.6
Median		11.5		9.0		12.0		9.0		10.0		11.0
25th		7.0		5.0		6.0		5.0		6.0		6.0
75th		27.5		25.0		37.0		21.0		25.0		29.0
Gender												
Missing	0	0.00	0	0.00	1	0.20	1	0.26	1	0.18	2	0.19
Male	23	41.07	62	45.93	235	47.86	173	45.17	263	46.96	498	47.38
Female	33	58.93	73	54.07	255	51.93	207	54.05	294	52.50	549	52.24
Ambiguous	0	0.00	0	0.00	0	0.00	2	0.52	2	0.36	2	0.19
Race—White												
Missing	1	1.79	3	2.22	29	5.91	26	6.79	29	5.18	58	5.52
No	14	25.00	60	44.44	203	41.34	149	38.90	221	39.46	424	40.34
Yes	41	73.21	72	53.33	259	52.75	208	54.31	310	55.36	569	54.14
Hispanic												
Missing	0	0.00	6	4.44	60	12.22	31	8.09	37	6.61	97	9.23
No	48	85.71	113	83.70	336	68.43	297	77.55	436	77.86	772	73.45
Yes	8	14.29	16	11.85	95	19.35	55	14.36	87	15.54	182	17.32
Discharge mortality												
Missing	0	0.00	1	0.74	5	1.02	4	1.04	4	0.71	9	0.86
No	56	100.00	122	90.37	449	91.45	343	89.56	493	88.04	942	89.63
Yes	0	0.00	12	8.89	37	7.54	36	9.40	63	11.25	100	9.51
Postoperative length of stay												
Mean	56	21.5	135	34.0	489	29.9	380	28.2	557	28.1	1046	28.9
Median		14.5		19.0		16.0		17.0		17.0		17.0
25th		10.0		11.0		10.0		10.0		10.0		10.0
75th		23.5		43.0		33.0		31.0		31.0		31.0

^aPatients with a date of surgery after 31 December, 2001 and who are <2 years old. Primary procedure, 230 = truncus arteriosus repair. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 6

Pulmonary Conduit: TOF Repair, RV-PA Conduit.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	9		8		33		26		53		86	
Number of patients	23		101		280		211		323		603	
Number of operations	23		101		280		211		323		603	
Age, days	23	201.1	101	194.1	280	202.7	211	196.6	323	202.8	603	202.7
Median		134.0		171.0		179.5		182.0		188.0		184.0
25th		60.0		51.0		50.0		16.0		44.0		49.0
75th		364.0		292.0		303.5		302.0		303.0		303.0
Gender	0	0.00	0	0.00	0	0.00	1	0.47	1	0.31	1	0.17
Male	8	34.78	55	54.46	137	48.93	114	54.03	168	52.01	305	50.58
Female	15	65.22	46	45.54	143	51.07	96	45.50	154	47.68	297	49.25
Ambiguous	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Race—White	2	8.70	3	2.97	14	5.00	5	2.37	10	3.10	24	3.98
No	8	34.78	47	46.53	139	49.64	105	49.76	147	45.51	286	47.43
Yes	13	56.52	51	50.50	127	45.36	101	47.87	166	51.39	293	48.59
Hispanic	2	8.70	5	4.95	27	9.64	11	5.21	15	4.64	42	6.97
No	20	86.96	84	83.17	193	68.93	159	75.36	250	77.40	443	73.47
Yes	1	4.35	12	11.88	60	21.43	41	19.43	58	17.96	118	19.57
Discharge mortality	0	0.00	2	1.98	3	1.07	0	0.00	0	0.00	3	0.50
No	23	100.00	97	96.04	270	96.43	204	96.68	311	96.28	581	96.35
Yes	0	0.00	2	1.98	7	2.50	7	3.32	12	3.72	19	3.15
Postoperative length of stay	23	17.0	101	23.5	279	20.0	211	23.2	323	20.3	602	19.7
Median		9.0		11.0		9.0		11.0		10.0		10.0
25th		6.0		7.0		6.0		7.0		7.0		6.0
75th		18.0		17.0		17.0		19.0		18.0		18.0

Abbreviations: TOF, tetralogy of Fallot; RV-PA, right ventricle-to-pulmonary artery.

^aPatients with a date of surgery after 31 December, 2001 and who are <2 years old. Primary procedure, 380 = TOF repair, RV-PA conduit. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 7

Critical Left Ventricular Outflow Obstruction: Norwood Procedure.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	12		12		40		27		62		102	
Number of patients	227		447		1768		1497		2194		3962	
Number of operations	227		447		1768		1497		2194		3962	
Age, days	227	7.7	447	8.0	1768	6.7	1497	6.6	2194	7.0	3962	6.8
Mean												
Median		7.0		6.0		5.0		5.0		6.0		6.0
25th		4.0		4.0		4.0		4.0		4.0		4.0
75th		8.0		8.0		7.0		7.0		8.0		8.0
Gender	0	0.00	0	0.00	4	0.23	2	0.13	2	0.09	6	0.15
Missing												
Male	147	64.76	252	56.38	1048	59.28	899	60.05	1316	59.98	2364	59.67
Female	80	35.24	195	43.62	716	40.50	594	39.68	873	39.79	1589	40.11
Ambiguous	0	0.00	0	0.00	0	0.00	2	0.13	3	0.14	3	0.08
Race—White	1	0.44	12	2.68	40	2.26	94	6.28	116	5.29	156	3.94
Missing												
No	48	21.15	176	39.37	810	45.81	581	38.81	848	38.65	1658	41.85
Yes	178	78.41	259	57.94	918	51.92	822	54.91	1230	56.06	2148	54.22
Hispanic	25	11.01	94	21.03	173	9.79	150	10.02	188	8.57	361	9.11
Missing												
No	192	84.58	297	66.44	1239	70.08	1145	76.49	1688	76.94	2927	73.88
Yes	10	4.41	56	12.53	356	20.14	202	13.49	318	14.49	674	17.01
Discharge mortality	0	0.00	3	0.67	6	0.34	5	0.33	8	0.36	14	0.35
Missing												
No	194	85.46	362	80.98	1477	83.54	1234	82.43	1775	80.90	3252	82.08
Yes	33	14.54	82	18.34	285	16.12	258	17.23	411	18.73	696	17.57
Postoperative length of stay	227	40.2	443	45.1	1744	38.4	1491	37.5	2181	38.4	3925	38.4
Mean												
Median		31.0		29.0		26.0		25.0		26.0		26.0
25th		15.0		18.0		16.0		15.0		16.0		16.0
75th		48.0		53.0		46.0		45.0		46.0		46.0

^aPatients with an admission date after 31 December, 2004 whose age is 30 years or younger. Primary procedure, 870 = Norwood procedure. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 8

Critical Left Ventricular Outflow Obstruction: PAB.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	6		6		29		18		34		63	
Number of patients	26		36		123		73		157		280	
Number of operations	26		36		123		73		157		280	
Age, days	26	15.4	36	17.5	123	12.7	73	9.1	157	9.8	280	11.0
Mean												
Median		6.0		13.0		8.0		7.0		8.0		8.0
25th		3.0		5.5		5.0		3.0		4.0		4.0
75th		14.0		25.0		18.0		13.0		13.0		13.5
Gender	0	0.00	0	0.00	1	0.81	0	0.00	0	0.00	1	0.36
Male	16	61.54	22	61.11	72	58.54	43	58.90	94	59.87	166	59.29
Female	10	38.46	14	38.99	50	40.65	30	41.10	63	40.13	113	40.36
Ambiguous	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Race—White	0	0.00	0	0.00	6	4.88	8	10.96	8	5.10	14	5.00
Missing	5	19.23	21	58.33	54	43.90	25	34.25	65	41.40	119	42.50
No	21	80.77	15	41.67	63	51.22	40	54.79	84	53.50	147	52.50
Yes	0	0.00	0	0.00	15	12.20	8	10.96	10	6.37	25	8.93
Hispanic	25	96.15	27	75.00	86	69.92	54	73.97	121	77.07	207	73.93
Missing	1	3.85	9	25.00	22	17.89	11	15.07	26	16.56	48	17.14
No	0	0.00	1	2.78	2	1.63	0	0.00	1	0.64	3	8.93
Discharge mortality	23	88.46	21	58.33	79	64.23	46	63.01	111	70.70	190	73.93
Yes	3	11.54	14	38.89	42	34.15	27	36.99	45	28.66	87	17.14
Postoperative length of stay	26	56.0	35	45.5	120	47.0	73	49.5	155	42.3	275	44.4
Mean												
Median		50.0		32.0		31.5		29.0		24.0		27.0
25th		28.0		18.0		16.0		14.0		12.0		13.0
75th		71.0		64.0		64.0		68.0		56.0		60.0

Abbreviations: PAB, pulmonary artery banding.

^aPatients with an admission date after 31 December, 2004 whose age is 30 years or younger. Primary procedure, 1640 = PAB. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 9
Anomalous Aortic Origin of a Coronary Artery: Anomalous Aortic Origin of Coronary Artery (AAOCA) Aorta Repair.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	8		6		24		17		38		62	
Number of patients	20		30		111		56		138		248	
Number of operations	20		30		111		56		138		248	
Age, days	20	4358.7	30	4967.9	111	4616.4	56	4622.2	138	4601.7	248	4603.1
Median		4602.5		5572.0		5077.0		5231.5		5026.5		5043.0
25th		3255.5		4357.0		3515.0		3499.0		3588.0		3551.0
75th		5480.5		6153.0		5848.0		5752.0		5745.0		5760.0
Gender	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Male	17	85.00	22	73.33	76	68.47	44	78.57	106	76.81	181	72.98
Female	3	15.00	8	26.67	35	31.53	12	21.43	32	23.19	67	27.02
Ambiguous	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Race—White	0	0.00	2	6.67	5	4.50	3	5.36	3	2.17	8	3.23
Missing	10	50.00	17	56.67	63	56.76	29	51.79	83	60.14	145	58.47
No	10	50.00	11	36.67	43	38.74	24	42.86	52	37.68	95	38.31
Yes	6	30.00	9	30.00	24	21.62	6	10.71	6	4.35	30	12.10
Missing	12	60.00	21	70.00	76	68.47	37	66.07	105	76.09	180	72.58
No	2	10.00	0	0.00	11	9.91	13	23.21	27	19.57	38	15.32
Yes	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Discharge mortality	20	100.00	30	100.00	111	100.00	56	100.00	138	100.00	248	100.00
No	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Yes	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Postoperative length of stay	20	3.5	30	4.0	110	3.9	56	4.0	138	4.2	248	4.1
Median		4.0		4.0		4.0		4.0		4.0		4.0
25th		3.0		3.0		3.0		3.0		3.0		3.0
75th		4.0		4.0		4.0		4.0		5.0		4.0

Abbreviation: AAOCA, anomalous aortic origin of a coronary artery.

^aPatients with an admission date after 31 December, 1997 whose age is 30 years or younger. Primary procedure, 1305 = AAOCA aorta repair. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.

Table 10

Anomalous Aortic Origin of a Coronary Artery: Coronary Artery Procedure, Other.^a

	Group A		Group B		Group C		Group D		Group E		Group F	
	N	%	N	%	N	%	N	%	N	%	N	%
Potential number of institutions	40		40		40		30		72		112	
Number of institutions	6		5		23		14		31		54	
Number of patients	14		38		145		30		95		240	
Number of operations	14		38		145		30		95		240	
Age, days	14	3668.3	38	4928.1	145	4677.3	30	4652.2	95	4760.0	240	4710.1
Median		3525.5		5052.0		5013.0		5272.0		4927.0		4977.0
25th		1923.0		4289.0		3745.0		3676.5		3683.0		3714.0
75th		4849.0		5708.0		5549.0		5850.0		5850.0		5654.0
Gender												
Missing	0	0.00	0	0.00	3	2.07	0	0.00	0	0.00	3	1.25
Male	9	64.29	25	65.79	100	68.97	24	80.00	75	78.95	175	72.92
Female	5	35.71	13	34.21	42	28.97	6	20.00	20	21.05	62	25.83
Ambiguous	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Race—White												
Missing	0	0.00	2	5.26	6	4.14	0	0.00	0	0.00	6	2.50
No	6	42.86	19	50.00	83	57.24	19	63.33	59	62.11	142	59.17
Yes	8	57.14	17	44.74	56	38.62	11	36.67	36	37.89	92	38.33
Hispanic												
Missing	0	0.00	2	5.26	14	9.66	2	8.33	4	4.21	18	7.50
No	12	85.71	35	92.11	102	70.34	24	75.00	80	84.21	182	75.83
Yes	2	14.29	1	2.63	29	20.00	4	16.67	11	11.58	40	16.67
Discharge mortality												
Missing	0	0.00	0	0.00	0	0.00	2	6.67	0	0.00	0	0.00
No	14	100.00	38	100.00	145	100.00	24	80.00	95	100.00	240	100.00
Yes	0	0.00	0	0.00	0	0.00	4	13.33	0	0.00	0	0.00
Postoperative length of stay												
Mean	14	3.5	38	3.4	145	4.5	30	4.6	95	4.3	240	4.4
Median		3.5		3.0		4.0		4.0		4.0		4.0
25th		3.0		3.0		3.0		3.0		3.0		3.0
75th		4.0		4.0		4.0		5.0		5.0		4.0

^a Patients with an admission date after 31 December 1997 whose age is 30 years or younger. Primary procedure, 1310 = Coronary artery procedure, Other. Groups A, B, C, D, E, and F are defined in Materials and Methods section of this article.