Pediatric and Congenital Heart Surgery

Pennsylvania Health Care Cost Containment Council

June 2017

2012-2015 Data

Pediatric and Congenital Heart Surgery

About PHC4

The Pennsylvania Health Care Cost Containment Council (PHC4) is an independent state agency charged with collecting, analyzing and reporting information that can be used to improve the quality and restrain the cost of health care in the state. It was created in the mid-1980s when Pennsylvania businesses and labor unions, in collaboration with other key stakeholders, joined forces to enact market-oriented health care reforms. As a result of their years of effort, the General Assembly passed legislation (Act 89 of 1986) creating PHC4.

PHC4's primary goal is to empower purchasers of health care benefits, such as businesses and labor unions, as well as other stakeholders, with information they can use to improve quality and restrain costs. Nearly 100 organizations and individuals annually utilize PHC4's special requests process to access and use data. More than 840,000 public reports on patient treatment results are downloaded from the PHC4 website annually. Today, PHC4 is a recognized national leader in public health care reporting.

PHC4 is governed by a 25-member board of directors representing business, labor, consumers, health care providers, insurers and state government.

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Acknowledgment

PHC4 wishes to thank the six children's hospitals that voluntarily participated in this project by consenting to have their data publicly reported and to acknowledge the Society of Thoracic Surgeons for supplying the data.

About this Report

Introduction

The Pennsylvania Health Care Cost Containment Council (PHC4) has prepared this report in cooperation with five hospitals in Pennsylvania and one in Delaware that perform cardiac surgery on children:

- Alfred I. duPont Hospital for Children, Wilmington, DE
- Children's Hospital of Philadelphia, Philadelphia, PA
- Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA
- Geisinger Medical Center Children's Hospital, Danville, PA*
- Penn State Children's Hospital, Hershey, PA
- St. Christopher's Hospital for Children, Philadelphia, PA

Believing that transparency and accountability, as provided by public reporting, could serve to improve care and help families of children facing cardiac surgery make informed decisions, surgeons and other representatives from these hospitals joined with PHC4 to develop this outcomes report on pediatric and congenital heart surgery.

The hospitals participating in this project have agreed, voluntarily, to publicly release the data included in this report—data that was collected and aggregated by the Society of Thoracic Surgeons (STS). Hospitals may have commented on the data in this report. Comments are available on PHC4's website.

Data Reported

The data for this report was collected and aggregated by the Society of Thoracic Surgeons (STS).

The report includes combined outcomes for the 4-year period 2012-2015, the most recent years of data available to PHC4.

Reporting results over a four-year period gives a more complete picture of a hospital's experience over a longer time period.

Results will be updated as additional years of data become available to PHC4.

*The Society of Thoracic Surgeons (STS) has indicated that Geisinger Medical Center Children's Hospital was ineligible for inclusion in the operative mortality calculations included in this report; therefore, the only result reported for this facility is the total number of operations performed (Table 11 on page 28).

About this Report

The Importance of Public Reporting

Those involved in the preparation of this report—including hospitals, surgeons, other health care professionals and PHC4—share a commitment to transparency and accountability of cardiac procedure outcomes.

For patients and their families, public reporting provides a basis for making informed treatment decisions. It gives them information to help determine where and from whom they will receive that treatment.

Another important reason for public reporting is quality improvement. Public reporting generates feedback to health care providers on their own performance and that of others in their field. Public reporting allows hospitals and surgeons to monitor and evaluate the outcomes of cardiac surgery, and to focus their improvement efforts on areas that will lead to better patient care. Public reporting aids in establishing standards and benchmarks by which results can be measured. More than two decades of experience shows public reporting can be a motivating force in quality improvement efforts.

About this Report

About Congenital Heart Defects

A congenital heart defect is a problem or abnormality in the heart that is present at birth. Affecting nearly one out of every 100 infants in the United States, or about 40,000 children per year, congenital heart defects are the most common birth defect and the leading cause of deaths related to birth defects.[1, 2, 3]

Congenital heart defects can affect the structure of the heart or the way it functions. Common types of congenital heart conditions include several that prevent blood from traveling from the heart to the lungs to pick up oxygen; a hole in one of the walls that divides the chambers or sides of the heart thus preventing the blood from circulating properly; a too-narrow aorta, the artery that allows blood to flow from the heart to the rest of the body; valves that do not close properly or are malformed; major arteries wrongly positioned; and heart chambers that are too small.

Not all congenital heart defects require surgery. Congenital heart defects range from mild to moderate to severe, from symptom-free conditions that may go undetected for years or repair themselves over time to serious cases that are immediately life threatening to the newborn.

Severe conditions may call for surgery in the early days or weeks of life or may require lifelong attention. More than 1 million adults in the United States are living with congenital heart defects.[2]

In some instances where a complete repair is not immediately possible, multiple surgeries may be necessary over a period of months or years. Cardiac surgeons perform open heart surgery to stitch or patch holes in the heart, widen arteries or repair complex defects.

According to the American Heart Association, the mortality rate for congenital heart defects has been declining steadily over the past three decades. Deaths related to congenital heart defects were 3,051 in 2013.[3]

Additional Resources

American Heart Association
www.heart.org

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/heartdefects/

National Institutes of Health – National Heart, Lung, and Blood Institute
www.nhlbi.nih.gov

Society of Thoracic Surgeons
www.sts.org

[1] Congenital heart defects and CCHD. March of Dimes webite. http://www.marchofdimes.org/complications/congenital-heart-defects.aspx. Reviewed November 2013. Accessed March 6, 2017.

[2] What Are Congenital Heart Defects? National Heart, Lung, and Blood Institute website. https://www.nhlbi.nih.gov/health/health-topics/topics/chd. Updated July 11, 2011. Accessed April 3, 2017.

[3] Mozaffarian D, Benjamin EJ, Go AS, et al. Heart disease and stroke statistics – 2016 Update: A report from the American Heart Association. *Circulation.* 2016;133(4):447-454. doi:10.1161/CIR.0000000000000366

Understanding the Data

What is measured in this report and why are these measures important?

This report provides the public with risk-adjusted **operative mortality** data on ten widely performed heart surgeries in order to help patients and families make evidence-based treatment decisions. These **ten benchmark procedures** are reported as defined by the Society of Thoracic Surgeons. The report also looks at **neonatal outcomes (data for infants up to and including 30 days old)**.

Operative Mortality

Operative mortality measures the number (or percent) of patients who died within 30 days of the surgery (including those who died during the hospital stay in which the procedure was performed regardless of the number of days since the surgery). It is a key measurement in understanding surgical outcomes.

Operative mortality is reported separately for ten benchmark procedures. Operative mortality rates are risk adjusted; that is, the rates account for differences among patients (e.g., patient age, weight, preoperative cardiogenic shock and respiratory failure).

It is important to keep in mind that there is natural variation in mortality rates from year to year, and it is to be expected that hospitals' mortality rates will vary; therefore, a high (or low) mortality rate in one particular year is not necessarily an accurate guide to a hospital's performance overall. As such, the report includes combined outcomes for the 4-year period 2012-2015, the most recent years of data available to PHC4.

It is also important to remember that some hospitals have cardiac surgery centers that are relatively new, while others have longer more established programs.

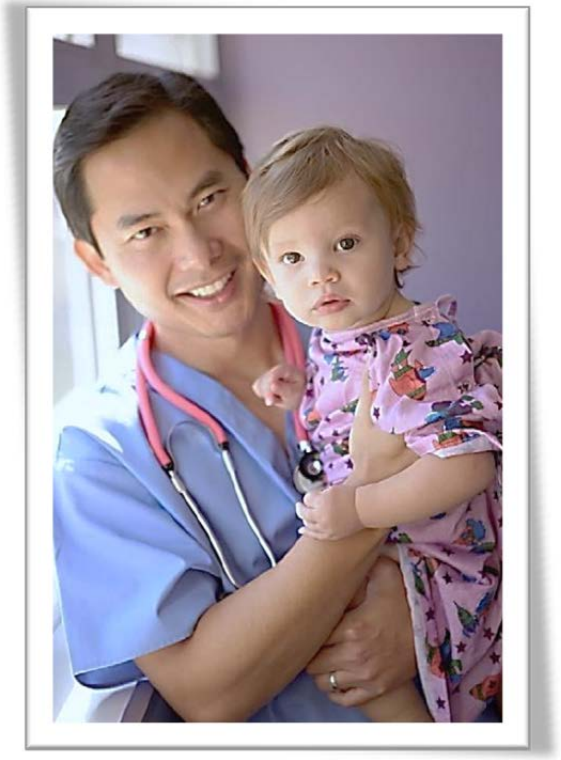
Ten Benchmark Procedures

The ten benchmark procedures have been determined by the Society of Thoracic Surgeons (STS) to be the most common and standardized surgical repairs. As such, these procedures serve as a benchmark for the performance of surgical centers across the country and allow for comparisons based on the outcomes. Together, the ten procedures represent a large proportion of the cases in the STS Congenital Heart Surgery Database: Coarctation of the Aorta Repair, Arterial Switch Operation, Ventricular Septal Defect Repair, Arterial Switch Operation and Ventricular Septal Defect Repair, Norwood Procedure, Glenn/Hemi-Fontan, Fontan, Truncus Repair, Complete Atrioventricular Canal Repair, and Tetralogy of Fallot Repair.

Understanding the Data

Neonatal Outcomes

In this report, patients who require surgery within the first 30 days of life are categorized as neonatal patients. These patients are included in the outcomes for the ten benchmark procedures; and, because of the high level of complexity and risk associated with procedures for neonates, there is also a separate section for neonatal surgical outcomes. Results for neonates, which include all types of procedures, are risk adjusted.



STS Congenital Heart Surgery Database

The data published in this report was provided to PHC4 by the Society of Thoracic Surgeons (STS). The children's hospitals included in this report currently participate in the STS data registry. STS is a not-for-profit organization representing more than 7,200 cardiothoracic surgeons, researchers and allied health professionals worldwide.[1] In 1989, it launched a clinical data registry for cardiothoracic surgery, which includes a component focused on congenital heart surgery. This Congenital Heart Surgery Database includes data from 119 pediatric cardiac programs[2] and contains more than 373,000 congenital cardiac surgeries.[3]

What processes ensure reliability of the data?

To be of value, publicly reported health care data must be as accurate and fair as possible and adhere to sound scientific principles. The Society of Thoracic Surgeons (STS) database is subject to rigorous processes to ensure data integrity and reliability including independent auditing of the data (by Telligen, the state of Iowa's Medicare Quality Improvement Organization) and the implementation of carefully designed control measures that identify questionable data.

[1] About STS. The Society of Thoracic Surgeons website. http://www.sts.org/about-sts. Accessed March 6, 2017.

[2] STS National Database Participation Maps. The Society of Thoracic Surgeons website. http://www.sts.org/sites/default/files/documents /congenitalMap1.13.17.pdf. Published January 2017. Accessed April 7, 2017.

[3] STS National Database Brochure. The Society of Thoracic Surgeons website. http://www.sts.org/sites/default/files/documents /pdf/ndb/2016NationalDatabaseBrochureFINAL.pdf. Published January 2016. Accessed April 7, 2017.

Understanding the Data

Understanding statistical significance in the context of this report

Because hospitals' mortality rates vary, differences in mortality rates between hospitals should be interpreted carefully. Confidence intervals can assist in understanding these differences. In this report, confidence intervals are used to show the range of mortality rates that are likely to be attributable to simple random variation.

Specifically, confidence intervals show whether a hospital's mortality rate is significantly different (higher or lower) than expected after accounting for the risk of the patient.

If a hospital's confidence interval includes the STS actual percent, the hospital's risk-adjusted operative mortality rate is **not significantly different** than expected.

If a hospital's confidence interval is lower than the STS actual percent, the hospital's risk-adjusted operative mortality rate is **significantly lower (better)** than expected.

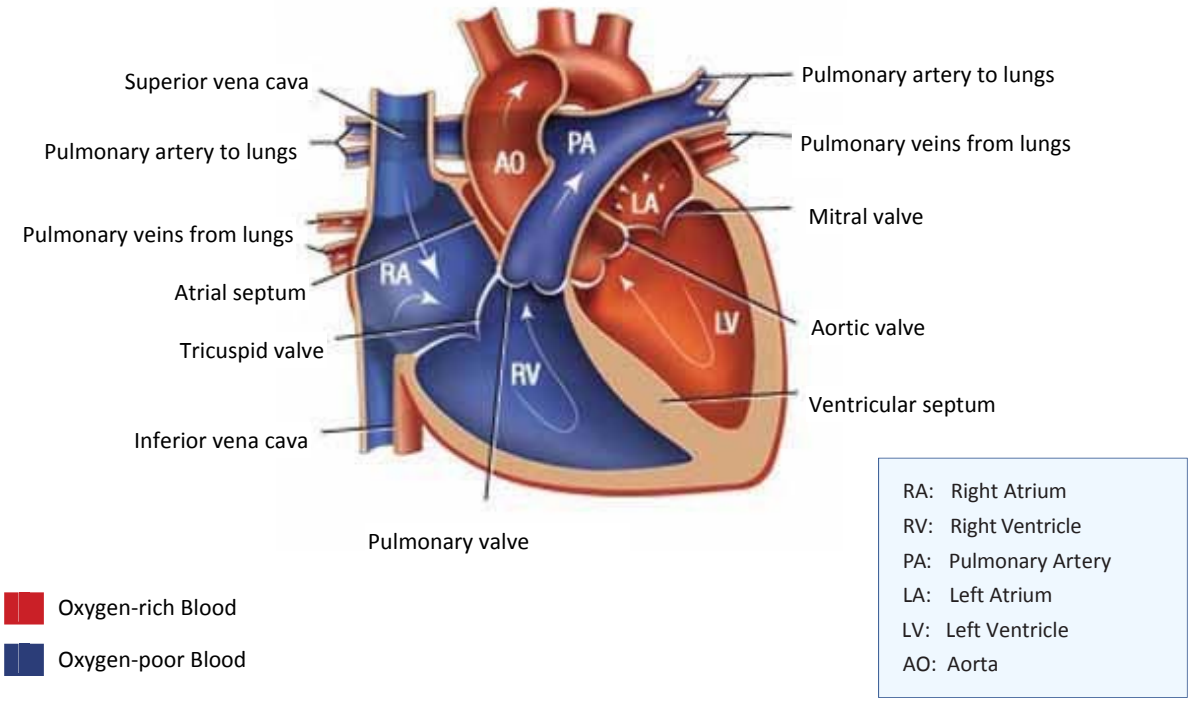
If a hospital's confidence interval is higher than the STS actual percent, the hospital's risk-adjusted operative mortality rate is **significantly higher (worse)** than expected.

See "Understanding Confidence Intervals and Statistical Significance of STS Data" box on this page.

Understanding Confidence Intervals and Statistical Significance of STS Data

	Risk-adjusted Operative Mortality 2012-2015				
	Number of Patients	Patients who Died			
		Actual Percent	Expected Percent	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	5,000	7.5			
Sample Hospital 1	130	7.7	7.6	7.6 (3.7 to 13.5)	The hospital's confidence interval includes the STS actual percent, so the hospital's risk-adjusted operative mortality rate is **not significantly different** than expected.
Sample Hospital 2	140	2.9	7.7	2.8 (0.8 to 7.0)	The hospital's confidence interval is lower than the STS actual percent, so the hospital's risk-adjusted operative mortality rate is **significantly lower (better)** than expected.
Sample Hospital 3	150	12.0	7.1	12.7 (7.7 to 19.3)	The hospital's confidence interval is higher than the STS actual percent, so the hospital's risk-adjusted operative mortality rate is **significantly higher (worse)** than expected.

How the Normal Heart Works



The heart is a large muscular organ located in the center of the chest. Together the heart and blood vessels supply the body with the oxygen and nutrients needed to survive. Blood flows from the body to the right side of the heart, to the lungs, to the left side of the heart, and back to the body.

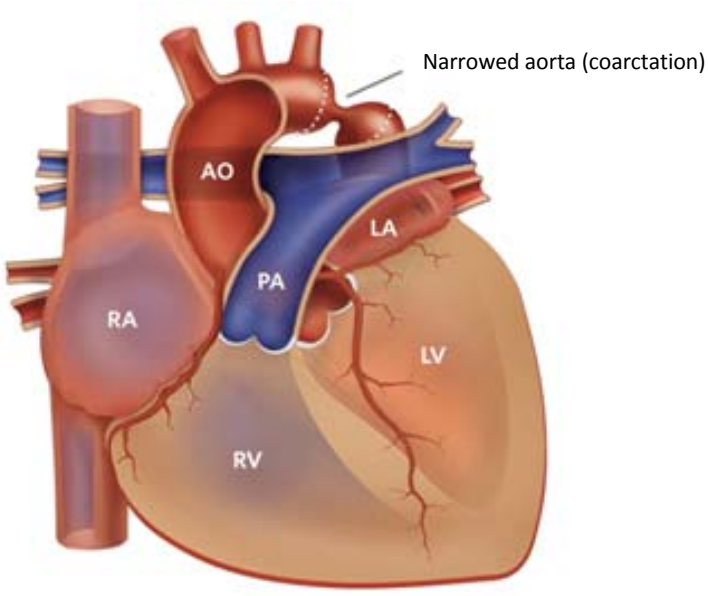
The pulmonary artery carries blood from the right side of the heart to the lungs, and the aorta carries blood from the left side of the heart to the body.

The heart has four chambers: two upper chambers—the right atrium and the left atrium, and two lower chambers—the right and left ventricles. The chambers are separated by a wall of tissue called the septum. Blood is pumped from chamber to chamber through valves with flaps. The flaps open and close so that the blood flows in only one direction.

Normal blood flow patterns

Oxygen-poor (deoxygenated) blood returns to the heart through veins (superior and inferior vena cava) entering the right atrium. The right atrium pumps the blood through the tricuspid valve into the right ventricle. The right ventricle pumps the blood through the pulmonary valve into the pulmonary artery, which takes the blood to the lungs where the blood is reoxygenated. The pulmonary veins then return the oxygen-rich (oxygenated) blood to the left atrium. It is then pumped through the mitral valve to the left ventricle. The left ventricle pumps the blood through the aortic valve to the aorta, which carries the blood to the body.

Coarctation of the Aorta Repair



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Cardiac Anomaly: A coarctation of the aorta is a narrowing in the main artery that carries oxygen-rich blood out of the heart to the body. The narrowing occurs in the part of the aorta that delivers blood to the lower part of the body and causes the left ventricle to pump harder than normal in order to deliver blood through the narrow section of the aorta. Some children with coarctation of aorta also have other heart anomalies.

Surgical Procedure: Treatment depends on the child's health and the severity of the narrowing. If open heart surgery is needed, the narrowed section of the aorta is removed and the remaining ends are sewn back together or the aorta can be enlarged with a patch.

Benchmark Procedures

Table 1. Coarctation of the Aorta Repair

	Risk-adjusted Operative Mortality 2012-2015				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**3,583**	**1.2**			
Alfred I. duPont Hospital for Children	18	0.0	0.9	0.0	(0.0 to 25.2)
Children's Hospital of Philadelphia	106	0.0	1.2	0.0	(0.0 to 3.3)
Children's Hospital of Pittsburgh of UPMC	23	0.0	1.0	0.0	(0.0 to 17.0)
Penn State Children's Hospital	30	0.0	1.8	0.0	(0.0 to 7.8)
St. Christopher's Hospital for Children	20	15.0	3.2	5.6	(1.2 to 14.1)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

Benchmark Procedures

Arterial Switch Operation

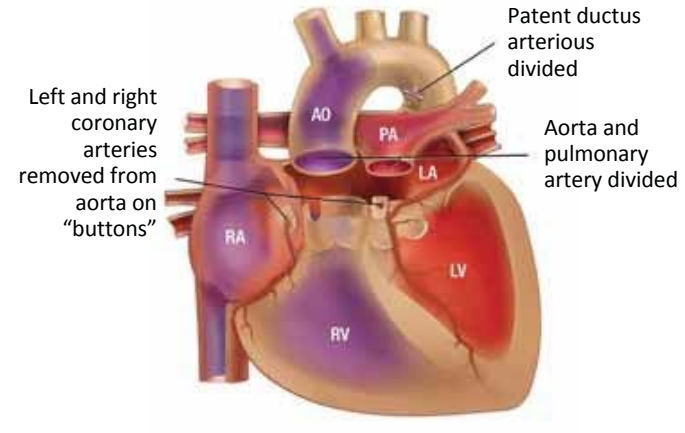
Cardiac Anomaly: Transposition of the great arteries (TGA) is a complex congenital heart defect in which the two large arteries that carry blood out of the heart (the aorta and the pulmonary artery) are connected to the heart abnormally:

- The aorta is attached to the right ventricle, instead of the left.
- The pulmonary artery is attached to the left ventricle, instead of the right.
- The coronary arteries receive oxygen-poor blood from the right ventricle rather than oxygen-rich blood from the left ventricle; therefore, the heart does not receive oxygenated blood.

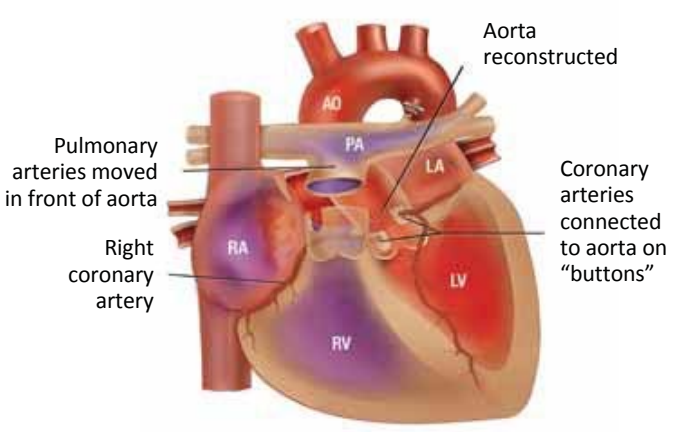
Normally, blood flows from the body to the right side of the heart, to the lungs, to the left side of heart, and back to the body. The pulmonary artery carries blood from the right side of the heart to the lungs, and the aorta carries blood from the left side of the heart to the body. In patients with TGA, the normal pattern of flow is reversed, and the body does not get enough oxygenated blood.

Surgical Procedure: The surgery to correct TGA, the arterial switch operation, is typically performed within a few days of birth. Surgeons reconstruct the heart so that the aorta and the pulmonary artery are attached to the correct ventricles. After the switch, the coronary arteries are reattached to the aorta and deliver oxygen-rich blood to areas of the heart.

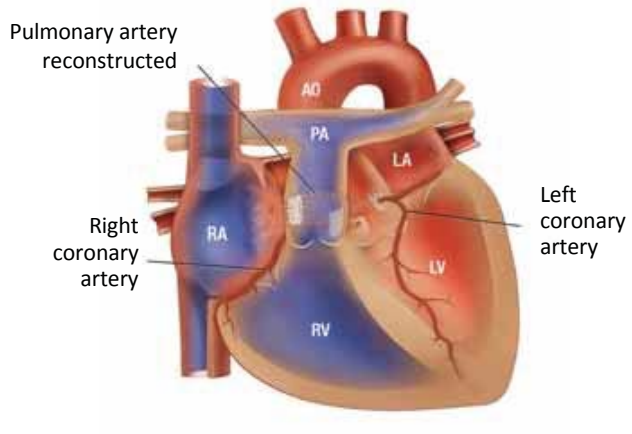
Arterial Switch Operation Step 1



Arterial Switch Operation Step 2



Arterial Switch Operation Step 3



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Benchmark Procedures

Table 2. Arterial Switch Operation

	Risk-adjusted Operative Mortality 2012-2015			
		Patients who Died		
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)
Society of Thoracic Surgeons (STS)	**1,704**	**2.8**		
Alfred I. duPont Hospital for Children	16	0.0	3.2	0.0 (0.0 to 18.0)
Children's Hospital of Philadelphia	73	4.1	3.6	3.2 (0.7 to 8.9)
Children's Hospital of Pittsburgh of UPMC	24	0.0	2.1	0.0 (0.0 to 18.7)
Penn State Children's Hospital	12	0.0	3.8	0.0 (0.0 to 19.0)
St. Christopher's Hospital for Children	NR	NR	NR	NR NR

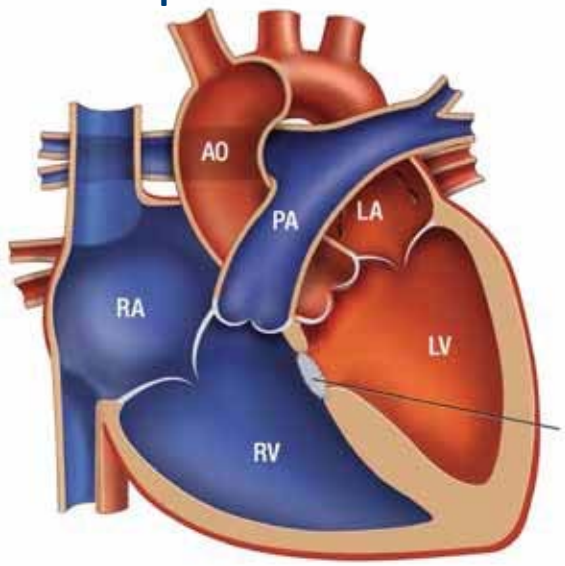
Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

NR: Not reported. Fewer than five cases.

Benchmark Procedures

Ventricular Septal Defect Repair



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Cardiac Anomaly: A ventricular septal defect (VSD) is an opening in the septum (the tissue between the right and left ventricles). A VSD is one of the defects referred to as a hole in the heart. When the VSD is large, the heart may need to pump harder to deliver enough oxygen to the body. Patients with a small VSD are usually symptom free. Sometimes children with a VSD also have other heart abnormalities.

Surgical Procedure: Treatment depends on the child's health and on the size of the VSD. Many small VSDs will close on their own before a child is two years old. If the VSD requires surgery, doctors might wait until the child is older and stronger before performing the procedure. During that time, the child may have to take medication and be on a higher-calorie diet to help relieve the symptoms associated with this defect. If surgery is needed, a patch or stitches are placed to close the hole.

Table 3. Ventricular Septal Defect Repair

	Risk-adjusted Operative Mortality 2012-2015			
		Patients who Died		
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)
Society of Thoracic Surgeons (STS)	**6,574**	**0.6**		
Alfred I. duPont Hospital for Children	58	3.4	0.6	3.5 (0.4 to 12.2)
Children's Hospital of Philadelphia	92	2.2	0.8	1.8 (0.2 to 6.2)
Children's Hospital of Pittsburgh of UPMC	51	0.0	0.5	0.0 (0.0 to 8.0)
Penn State Children's Hospital	45	0.0	0.7	0.0 (0.0 to 6.7)
St. Christopher's Hospital for Children	36	0.0	0.7	0.0 (0.0 to 8.2)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

Benchmark Procedures

Arterial Switch Operation and Ventricular Septal Defect Repair

Cardiac Anomaly: Transposition of the great arteries (TGA, page 10, can occur in conjunction with a ventricular septal defect (VSD, page 12).

TGA is a complex congenital heart defect in which the two large arteries that carry blood out of the heart (the aorta and the pulmonary artery) are connected to the heart abnormally:

- The aorta is attached to the right ventricle, instead of the left.
- The pulmonary artery is attached to the left ventricle, instead of the right.
- The coronary arteries receive oxygen-poor blood from the right ventricle rather than oxygen-rich blood from the left ventricle; therefore, the heart does not receive oxygenated blood.

A VSD is an opening in the septum (the tissue between the right and left ventricles). A VSD is one of the defects referred to as a hole in the heart.

Surgical Procedure: The surgery to correct TGA, the arterial switch operation, is typically performed within a few days of birth. Surgeons reconstruct the heart so that the aorta and the pulmonary artery are attached to the correct ventricles. After the switch, the coronary arteries are reattached to the aorta and deliver oxygen-rich blood to the areas of the heart. To repair a VSD, a patch or stitches are placed to close the hole.

See pages 10 through 13 for additional detail on Arterial Switch Operation and Ventricular Septal Defect Repair, including images and separately reported hospital data for these two procedures.

Benchmark Procedures

Table 4. Arterial Switch Operation and Ventricular Septal Defect Repair

	Risk-adjusted Operative Mortality 2012-2015				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**710**	**5.4**			
Alfred I. duPont Hospital for Children	NR	NR	NR	NR	NR
Children's Hospital of Philadelphia	18	5.6	7.3	4.1	(0.1 to 20.0)
Children's Hospital of Pittsburgh of UPMC	9	0.0	5.2	0.0	(0.0 to 34.9)
Penn State Children's Hospital	5	0.0	5.7	0.0	(0.0 to 49.2)
St. Christopher's Hospital for Children	NR	NR	NR	NR	NR

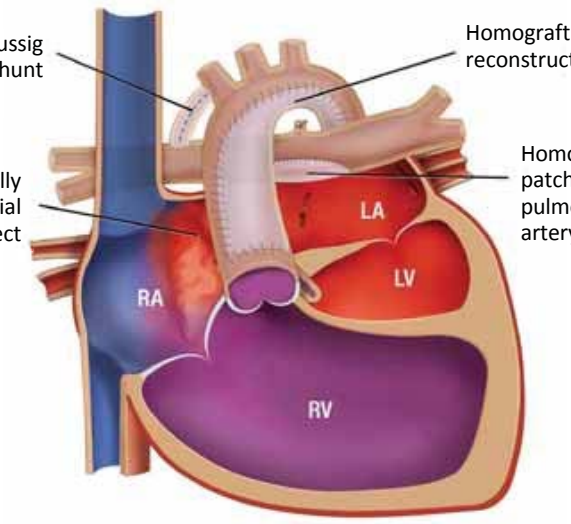
Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

NR: Not reported. Fewer than five cases.

Benchmark Procedures

Norwood Procedure



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Cardiac Anomaly: Hypoplastic left heart syndrome (HLHS) is a severe congenital defect in which the left side of the heart is underdeveloped. Normally, the heart's left side pumps oxygenated blood into the aorta, which carries blood to the body. In HLHS cases:

- The mitral valve, which separates the left atrium and ventricle, is too small or completely closed.
- The left ventricle is very small.
- The aortic valve, which separates the left ventricle and the aorta, is too small or completely closed.

HLHS is part of a group of defects called single ventricle congenital heart defects in which one of the pumping chambers is too small to pump blood adequately. The usual treatment is a series of three operations leading to the Fontan procedure. After the Fontan procedure, blood flows directly to the lungs without a pumping chamber and the single ventricle pumps blood to the body. In HLHS cases, the first operation is the Norwood procedure.

Surgical Procedure: The Norwood procedure, usually performed soon after birth, is most often the first of three separate procedures to treat patients with HLHS. The second is the Glenn/Hemi-Fontan procedure (page 18) and the third is the Fontan procedure (page 20). As part of the Norwood procedure, a shunt is created to carry blood to the lungs. The shunt is an artificial tube that carries blood from the aorta to the pulmonary arteries (modified Blalock-Taussig shunt) or from the heart to the pulmonary arteries (right ventricle to pulmonary artery conduit or Sano shunt).

Alternative types of shunts may be used based upon individual anatomy. For a small number of children, alternative approaches to the Norwood procedure may be recommended, such as heart transplantation or a hybrid procedure combining surgery and catheter-based treatment. Each case requires an individualized approach. Families should discuss options with their doctor, including why one particular approach might be recommended.

Benchmark Procedures

Table 5. Norwood Procedure

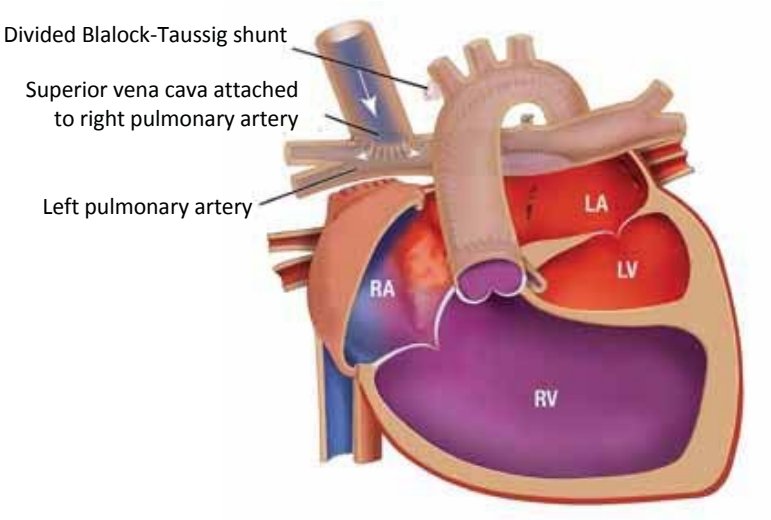
	Risk-adjusted Operative Mortality 2012-2015				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**2,605**	**15.5**			
Alfred I. duPont Hospital for Children	9	0.0	9.5	0.0	(0.0 to 55.0)
Children's Hospital of Philadelphia	118	17.8	14.4	19.2	(12.3 to 28.0)
*Children's Hospital of Pittsburgh of UPMC	30	0.0	13.9	0.0	(0.0 to 13.0)
Penn State Children's Hospital	29	17.2	21.1	12.7	(4.3 to 26.3)
St. Christopher's Hospital for Children	NR	NR	NR	NR	NR

Table Notes:

*Hospital's risk-adjusted operative mortality rate is significantly lower (better) than expected. Risk-adjusted operative mortality rates for all other hospitals are not significantly different than expected.

NR: Not reported. Fewer than five cases.

Glenn/Hemi-Fontan Procedure



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Cardiac Anomaly: Hypoplastic left heart syndrome (HLHS) is a severe congenital defect in which the left side of the heart is underdeveloped. Normally, the heart's left side pumps oxygenated blood into the aorta, which carries blood to the body. In HLHS cases:

- The mitral valve, which separates the left atrium and ventricle, is too small or completely closed.
- The left ventricle is very small.
- The aortic valve, which separates the left ventricle and the aorta, is too small or completely closed.

HLHS is part of a group of defects called single ventricle congenital heart defects in which one of the pumping chambers is too small to pump blood adequately. The usual treatment is a series of three operations leading to the Fontan procedure. After the Fontan procedure, blood flows directly to the lungs without a pumping chamber and the single ventricle pumps blood to the body.

Surgical Procedure: For infants born with HLHS and other types of single ventricle congenital heart defects, the second procedure leading to the Fontan operation is called the Glenn shunt or Hemi-Fontan procedure. The Glenn/Hemi-Fontan procedure is typically performed when the patient is between 4 and 6 months old. The superior vena cava (SVC), the large vein that returns deoxygenated blood to the heart from the head and upper body, is disconnected from the right atrium and attached to the pulmonary artery so the blood flows directly to the lungs. The SVC is usually on the right side of the body, but in a few patients it may be on the left side or there may be one on each side. The shunt placed during the Norwood procedure (Blalock-Taussig shunt or right ventricle to pulmonary artery conduit, page 16) is divided and may be removed. After the operation, deoxygenated blood from the upper body goes to the lungs without passing through the heart.

Benchmark Procedures

Table 6. Glenn/Hemi-Fontan Procedure

	Risk-adjusted Operative Mortality 2012-2015			
		Patients who Died		
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)
Society of Thoracic Surgeons (STS)	**4,432**	**2.4**		
Alfred I. duPont Hospital for Children	22	0.0	2.1	0.0 (0.0 to 17.9)
Children's Hospital of Philadelphia	177	1.1	2.7	1.0 (0.1 to 3.6)
Children's Hospital of Pittsburgh of UPMC	56	0.0	3.7	0.0 (0.0 to 4.1)
Penn State Children's Hospital	37	0.0	1.6	0.0 (0.0 to 14.7)
St. Christopher's Hospital for Children	11	9.1	2.4	9.0 (0.2 to 40.8)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

Benchmark Procedures

Fontan Procedure

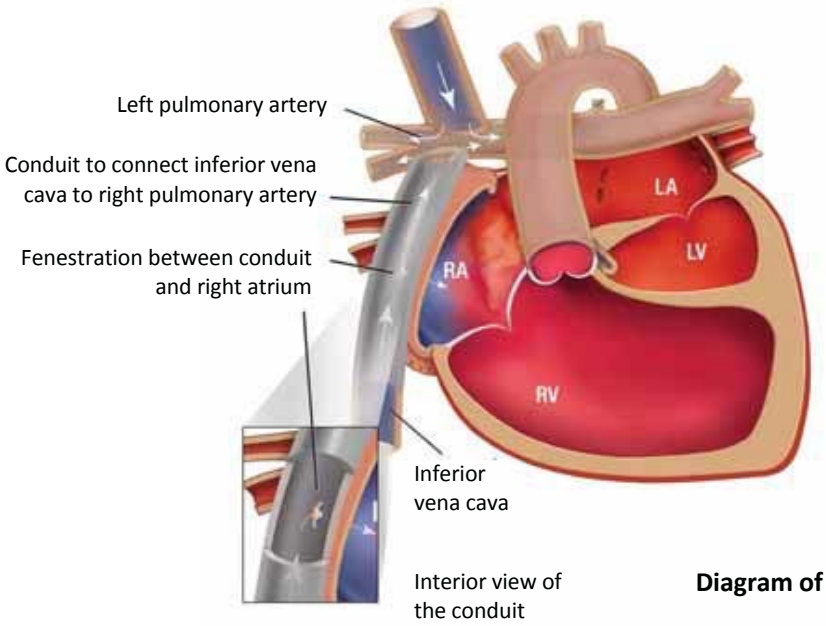


Diagram of extra-cardiac conduit Fontan

RA: Right Atrium	RV: Right Ventricle	PA: Pulmonary Artery	LA: Left Atrium	LV: Left Ventricle	AO: Aorta
Oxygen-rich Blood		Oxygen-poor Blood		Mixed Blood	

Cardiac Anomaly: Hypoplastic left heart syndrome (HLHS) is a severe congenital defect in which the left side of the heart is underdeveloped. Normally, the heart's left side pumps oxygenated blood into the aorta, which carries blood to the body. In HLHS cases:

- The mitral valve, which separates the left atrium and ventricle, is too small or completely closed.
- The left ventricle is very small.
- The aortic valve, which separates the left ventricle and the aorta, is too small or completely closed.

HLHS is part of a group of defects called single ventricle congenital heart defects in which one of the pumping chambers is too small to pump blood adequately. The usual treatment is a series of three operations leading to the Fontan procedure.

After the Fontan procedure, blood flows directly to the lungs without a pumping chamber and the single ventricle pumps blood to the body.

Surgical Procedure: The third procedure to treat HLHS and other forms of single ventricle congenital heart defects, the Fontan, is typically performed on patients between 18 months to 3 years of age. In the Fontan procedure, blood from the inferior vena cava (IVC) is directed to the pulmonary arteries so that all of the deoxygenated blood flows directly to the lungs without a pumping chamber. This may be accomplished using a tube to connect the IVC to the pulmonary arteries (extra-cardiac conduit Fontan) or by using a patch inside the right atrium (lateral tunnel Fontan). Sometimes a small hole (fenestration) is created to allow a small amount of deoxgenated blood to bypass the lungs.

Benchmark Procedures

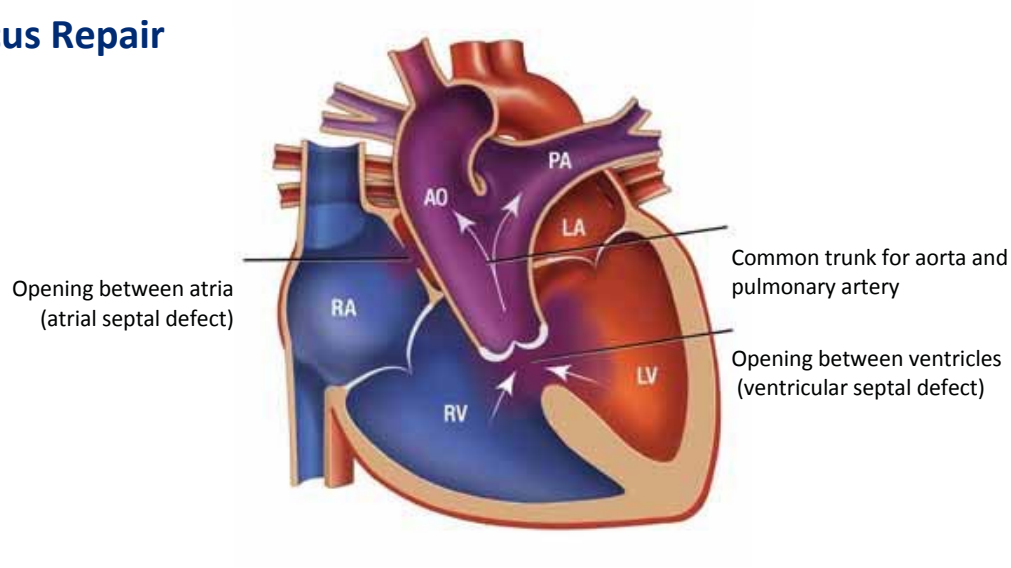
Table 7. Fontan Procedure

	Risk-adjusted Operative Mortality 2012-2015			
		Patients who Died		
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)
Society of Thoracic Surgeons (STS)	**3,843**	**1.2**		
Alfred I. duPont Hospital for Children	25	0.0	0.6	0.0 (0.0 to 28.2)
Children's Hospital of Philadelphia	195	1.0	1.4	0.8 (0.1 to 3.0)
Children's Hospital of Pittsburgh of UPMC	41	0.0	1.3	0.0 (0.0 to 7.9)
Penn State Children's Hospital	34	0.0	0.5	0.0 (0.0 to 23.1)
St. Christopher's Hospital for Children	6	0.0	1.1	0.0 (0.0 to 47.3)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

Truncus Repair



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Cardiac Anomaly: Truncus arteriosus or persistent truncus arteriosus (the trunk persists) is an anomaly characterized by the failure of the truncus arteriosus to divide into two arteries, as is the case in normal heart development, that carry blood out of the heart. In normal heart development:

- The pulmonary artery is attached to the right ventricle, which further divides into two arteries that carry deoxygenated blood to each lung.
- The aorta is attached to the left ventricle, which carries oxygenated blood to the body.

When truncus arteriosus occurs, the undivided trunk is attached to the heart as one artery straddling the bottom chambers and then divides into arteries taking blood to the lungs and body. The deoxygenated blood from the right ventricle and the oxygenated blood from the left ventricle mix together when pumped into the truncus arteriosus, and an abnormal amount of blood flows back into the lungs making it harder for the infant to breathe. All children with this anomaly also have a large ventricular septal defect (VSD, page 12).

Surgical Procedure: In truncus repair, the pulmonary arteries are separated from the truncus arteriosus and connected to the right ventricle using different types of conduits or tubes. The remaining trunk is repaired to function as the aorta. The truncal valve, which functions as the aortic valve after the repair, is frequently abnormal and often leaks. To repair a VSD, a patch or stitches are placed to close the hole. Other repairs may be required, based on each patient's unique needs.

Table 8. Truncus Repair

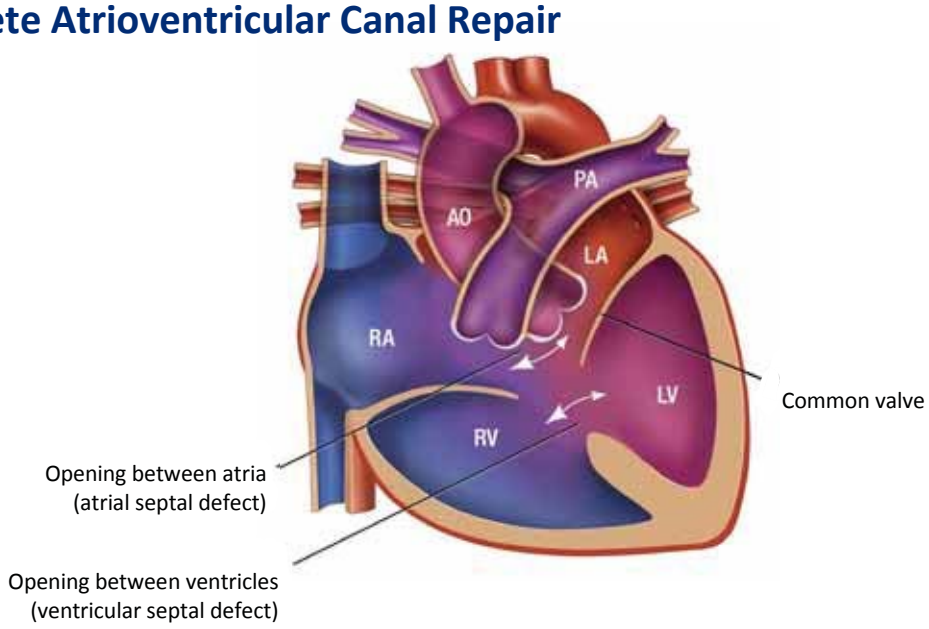
	Risk-adjusted Operative Mortality 2012-2015				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**585**	**10.1**			
Alfred I. duPont Hospital for Children	NR	NR	NR	NR	NR
Children's Hospital of Philadelphia	19	0.0	10.2	0.0	(0.0 to 17.5)
Children's Hospital of Pittsburgh of UPMC	11	9.1	11.2	8.2	(0.2 to 37.3)
Penn State Children's Hospital	NR	NR	NR	NR	NR
St. Christopher's Hospital for Children	NR	NR	NR	NR	NR

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

NR: Not reported. Fewer than five cases.

Complete Atrioventricular Canal Repair



RA: Right Atrium RV: Right Ventricle PA: Pulmonary Artery LA: Left Atrium LV: Left Ventricle AO: Aorta

Oxygen-rich Blood Oxygen-poor Blood Mixed Blood

Cardiac Anomaly: Complete atrioventricular canal (CAVC) is a severe defect in which there is a large hole in the septum (the tissue that separates the left and right sides of the heart). The hole is in the center of the heart, where the atria and the ventricles meet. Also, one large valve develops rather than two valves and may not close correctly. In a normal heart, two valves separate the atria and ventricles of the heart. More specifically, the tricuspid valve separates the right chambers and the mitral valve separates the left chambers.

As a result of the abnormal passageway between the two sides of the heart, the blood from both sides mixes causing too much blood to flow back to the lungs before traveling through the body. The condition causes the heart to work harder than it should and become enlarged and damaged if the problems are not repaired.

Surgical Procedure: CAVC defects require surgery, usually within the first two or three months of life. The hole is closed by placing one or two patches over the CAVC defect. The single large valve is separated into two valves and, depending on the child's heart anatomy, reconstructed to be as close to normal as possible.

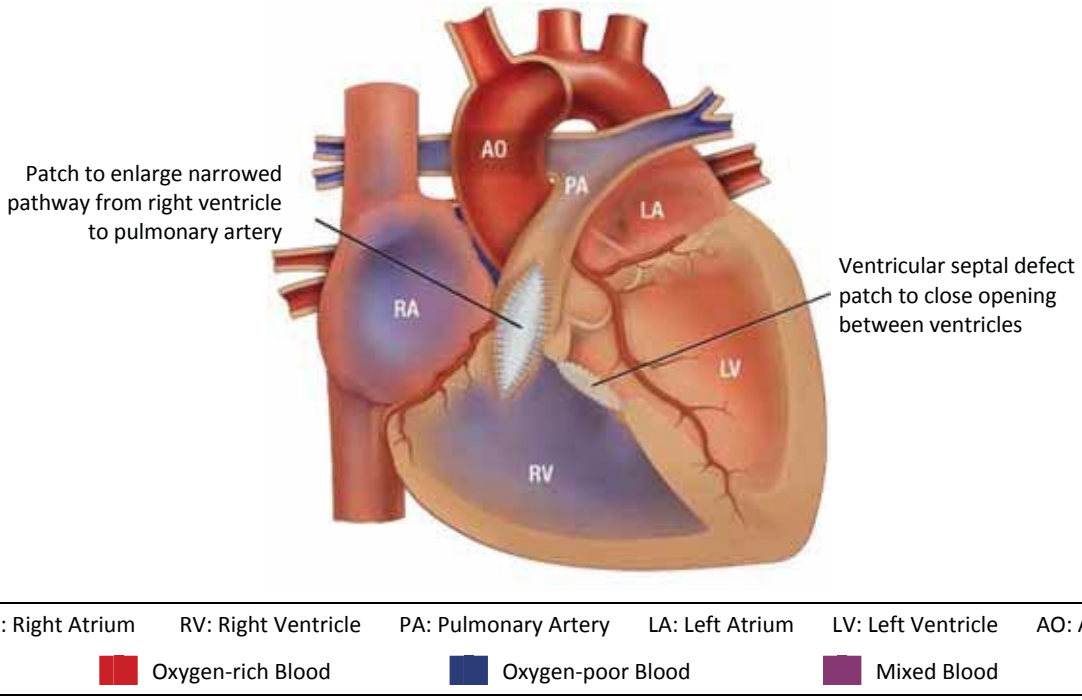
Table 9. Complete Atrioventricular Canal Repair

	Risk-adjusted Operative Mortality 2012-2015			
		Patients who Died		
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)
Society of Thoracic Surgeons (STS)	**2,912**	**2.9**		
Alfred I. duPont Hospital for Children	24	4.2	3.6	3.4 (0.1 to 17.0)
Children's Hospital of Philadelphia	76	3.9	3.2	3.6 (0.8 to 10.2)
Children's Hospital of Pittsburgh of UPMC	36	0.0	2.8	0.0 (0.0 to 10.1)
Penn State Children's Hospital	18	0.0	2.7	0.0 (0.0 to 20.0)
St. Christopher's Hospital for Children	14	7.1	3.2	6.6 (0.2 to 31.2)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

Tetralogy of Fallot Repair



Cardiac Anomaly: There are four anomalies associated with tetralogy of Fallot:

- Ventricular septal defect (VSD) – There is a hole between the right and left ventricles (page 12).
- Overriding aorta – The aorta, the large artery that carries blood to the body, is on top of both ventricles, instead of just the left ventricle as in a normal heart.
- Pulmonary stenosis – There is a narrowing of the pulmonary valve or the pulmonary arteries, which carry deoxygenated blood to the lungs.
- Right ventricle hypertrophy – The right ventricle is thicker and more muscular than normal as a result of working harder to pump blood through the narrow pulmonary valve or pulmonary arteries.

Surgical Procedure: Typically, surgery to close the VSD with a patch and widen the pulmonary valve or artery is performed in the first few months of life. This increases the amount of blood that reaches the lungs, thus increasing the amount of oxygen in the blood. In some cases, a temporary repair is done until a complete repair can be performed. The temporary repair is most commonly a modified Blalock-Taussig shunt, an artificial tube connecting a branch of the aorta to the pulmonary arteries to increase pulmonary blood flow.

Table 10. Tetralogy of Fallot Repair

	Risk-adjusted Operative Mortality 2012-2015				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**4,272**	**0.9**			
Alfred I. duPont Hospital for Children	31	0.0	2.1	0.0	(0.0 to 4.8)
Children's Hospital of Philadelphia	142	1.4	1.5	0.9	(0.1 to 3.0)
Children's Hospital of Pittsburgh of UPMC	58	0.0	1.1	0.0	(0.0 to 4.9)
Penn State Children's Hospital	26	0.0	1.3	0.0	(0.0 to 9.2)
St. Christopher's Hospital for Children	23	4.3	0.9	4.2	(0.1 to 21.3)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

Total Operations

Total Number of Operations Performed

The preceding pages show results for ten frequently performed benchmark procedures; however, there are also other types of pediatric and congenital heart surgeries. To show overall hospital volume, Table 11 displays the total number of operations performed by each hospital. This information can be helpful in understanding a hospital's overall experience with pediatric and congenital heart surgery.

Table 11. Total Number of Operations Performed

	2012-2015
	Number of Patients
Society of Thoracic Surgeons (STS)	**120,391**
Alfred I. duPont Hospital for Children	907
Children's Hospital of Philadelphia	2,815
Children's Hospital of Pittsburgh of UPMC	1,813
*Geisinger Medical Center Children's Hospital	182
Penn State Children's Hospital	694
St. Christopher's Hospital for Children	493

Table Notes:

Typically pediatric and congenital heart surgery is performed on patients under age 18, particularly those undergoing the ten benchmark surgeries reported on the preceding pages. A hospital's overall number of operations, as reported above, includes some patients age 18 and older. Note, too, that congenital heart surgery is performed in Pennsylvania facilities other than the children's hospitals included in this report. These patients are most likely older than 18 years.

*Geisinger Medical Center Children's Hospital was without a dedicated pediatric cardiac surgeon 2014-2015.

Neonates

Outcomes for Neonates

Infants 0 to 30 days of age at the time of surgery are categorized as neonates. Outcomes for these patients are described here in a special section because of the high level of complexity and risk associated with surgery for infants within the first 30 days of life. The surgeries performed include the ten benchmark procedures as well as other types of pediatric and congenital heart surgeries.

The outcome, operative mortality, is risk adjusted for factors such as age, weight and type/complexity of procedure. Table 12 displays the number of neonates who underwent surgery, the actual percent of patients who died, the expected percent, and the risk-adjusted mortality rate. The confidence interval assists in understanding the risk-adjusted rate, by showing whether a hospital's risk-adjusted rate is significantly different (higher or lower) than expected (see page 6 for more detail on confidence intervals).

Table 12. Neonates – Risk-adjusted Operative Mortality Rates

	Risk-adjusted Operative Mortality 2012-2015				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**16,004**	**8.9**			
Alfred I. duPont Hospital for Children	139	9.4	10.6	7.9	(4.3 to 13.0)
Children's Hospital of Philadelphia	567	8.6	9.0	8.5	(6.4 to 11.1)
Children's Hospital of Pittsburgh of UPMC	193	4.7	8.0	5.2	(2.4 to 9.6)
Penn State Children's Hospital	120	5.0	9.4	4.8	(1.8 to 10.1)
St. Christopher's Hospital for Children	60	20.0	13.3	13.4	(7.2 to 21.7)

Table Notes:

Hospitals' risk-adjusted operative mortality rates are not significantly different than expected.

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