Pediatric and Congenital Heart Surgery

Pennsylvania Health Care Cost Containment Council

February 2015

2009-2012 Data

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.

Table of Contents

About this Report 1

Understanding the Data 5

How the Normal Heart Works 7

Outcomes for Benchmark Procedures 8

- Arterial Switch Operation 8
- Ventricular Septal Defect Repair 10
- Arterial Switch Operation and Ventricular Septal Defect Repair 12
- Norwood Procedure 14
- Glenn/Hemi-Fontan Procedure 16
- Fontan Procedure 18
- Truncus Repair 20
- Complete Atrioventricular Canal Repair 22
- Tetralogy of Fallot Repair 24

Total Number of Operations Performed 26

Outcomes for Neonates 27

Acknowledgment

PHC4 wishes to thank the five 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

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

- Children's Hospital of Philadelphia, Philadelphia, Pa.
- Children's Hospital of Pittsburgh of UPMC, Pittsburgh, Pa.
- Geisinger Children's Hospital, Danville, Pa.
- Nemours A.I. duPont Hospital for Children, Wilmington, Del.
- Penn State Hershey Children's Hospital, Hershey, Pa.

Over the past several years, surgeons and other representatives from these five hospitals met with the Pennsylvania Health Care Cost Containment Council (PHC4) to discuss a joint project on reporting outcomes for pediatric cardiac procedures. Initiated by the pediatric heart surgeons associated with these facilities, this voluntary project includes the use of data collected and aggregated by the Society of Thoracic Surgeons (STS).

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, plans emerged to develop an outcomes report on pediatric and congenital heart surgery. While PHC4 has issued reports on adult cardiac surgery for many years, this project represents one of the few, if not only, efforts at statewide public reporting on pediatric cardiac surgery outcomes.

Hospitals may have commented on this report. Comments are available on PHC4's website.

Data Reported

This report includes combined outcomes for the 4-year period 2009-2012, 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 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 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]

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 3,196 in 2010.[2]

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] March of Dimes Foundation. Congenital heart defects and CCHD. March of Dimes. http://marchofdimes.org. Reviewed November 2013. Accessed December 9, 2014.

[2] Go AS, Mozaffarian D, Roger VL, et al. Heart disease and stroke statistics – 2014 Update: A report from the American Heart Association. *Circulation.* January 2014; 129:399-410. Also available online http://circ.ahajournals.org/content/129/3/e28.

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

The report provides the public with **discharge mortality** data on nine widely performed heart surgeries in order to help patients and families make evidence-based treatment decisions. These **nine 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)**. Neonatal results are displayed separately given the specific complexities associated with such surgeries.

Discharge Mortality

Discharge mortality measures the number (or percent) of patients who died during the hospital stay in which the procedure was performed and is a key measurement in understanding surgical outcomes.

Observed mortality is reported separately for nine benchmark procedures. Observed mortality is not risk adjusted for patient age or other risk factors. However, reporting by type of procedure helps to account for the differences in complexity among the various congenital heart defects and surgical procedures. Results for neonates, which include all types of procedures, are risk adjusted.

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 2009-2012, 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.

Nine Benchmark Procedures

The nine 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 nine procedures represent a large proportion of the cases in the STS Congenital Heart Surgery Database: 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.

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 nine benchmark procedures; and, because of the high level of complexity and risk associated with procedures for neonates, there is also a special section for neonatal surgical outcomes.

Understanding the Data

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 6,900 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 111 pediatric cardiac programs and contains approximately 292,000 congenital cardiac surgeries.[2]

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 the Iowa Medical Center Foundation) and the implementation of carefully designed control measures that identify questionable data.

[1] The Society of Thoracic Surgeons. About STS. http://sts.org. Accessed December 9, 2014.

[2] The Society of Thoracic Surgeons. 2014 STS National Database Participation Manual. http://sts.org. Accessed December 9, 2014.

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 the STS average.

If a hospital's 95% confidence interval includes the STS average mortality rate, then the difference between the hospital's mortality rate and the STS average is not statistically significant. If the STS average is greater than the hospital's confidence interval, the hospital's mortality rate is significantly lower (better) than the STS average. If the STS average is less than the hospital's confidence interval, the hospital's mortality rate is significantly higher (worse) than the STS average. See "Understanding Confidence Intervals and Statistical Significance" box on this page.

Understanding Confidence Intervals and Statistical Significance

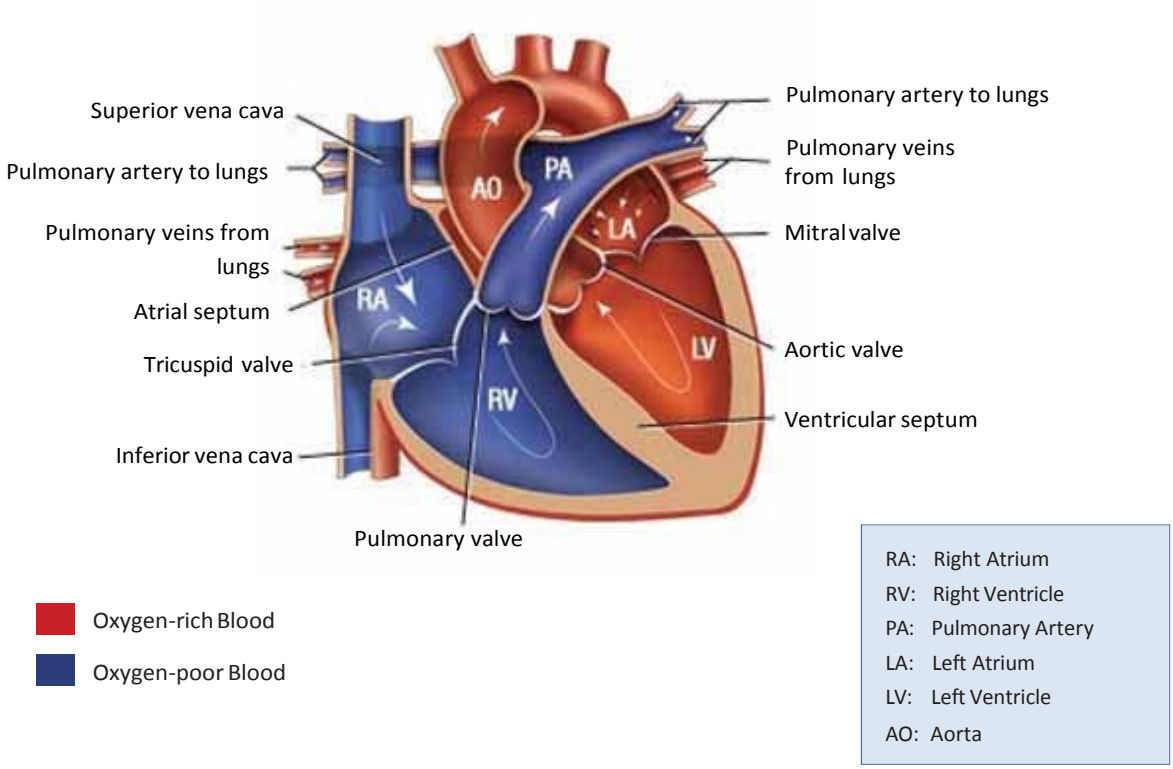
	Percent of Patients who Died (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	**2.0**	**(1.9 to 2.2)**
Sample Hospital (**STS average**)	2.1	(0.6 to 5.2)
Sample Hospital	0.7	(0.2 to 1.6)
Sample Hospital	4.9	(3.0 to 7.5)

STS average is within the hospital's confidence interval, so the hospital's rate is **not significantly different** than the STS average.

STS average is greater than the hospital's confidence interval, so the hospital's rate is **significantly lower (better)** than the STS average.

STS average is less than the hospital's confidence interval, so the hospital's rate is **significantly higher (worse)** than the STS average.

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.

Arterial Switch Operation

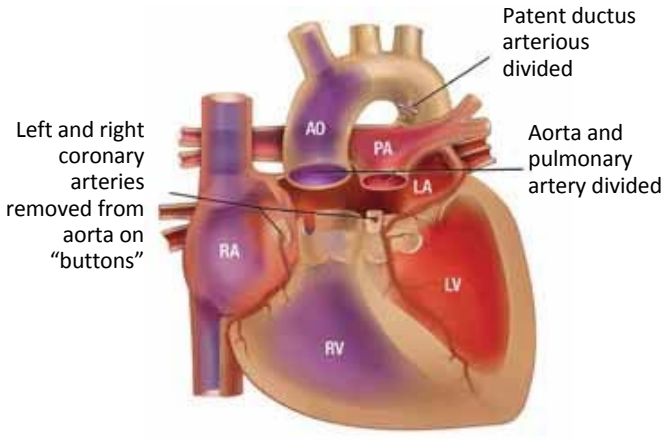
Cardiac Anomaly: Transposition of the great arteries (TGA) is a complex congenital heart defect in which the two large arteries that carry blood out of the heart (the aorta and the pulmonary artery) are connected to the heart abnormally:

- 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.

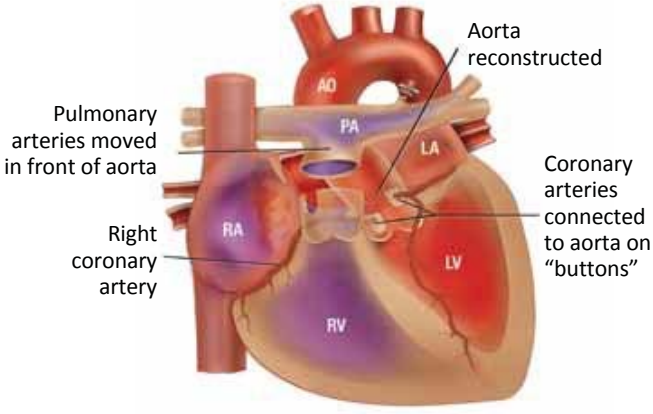
Normally, blood flows from the body to the right side of the heart, to the lungs, to the left side of heart, and back to the body. The pulmonary artery carries blood from the right side of the heart to the lungs, and the aorta carries blood from the left side of the heart to the body. In patients with 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.

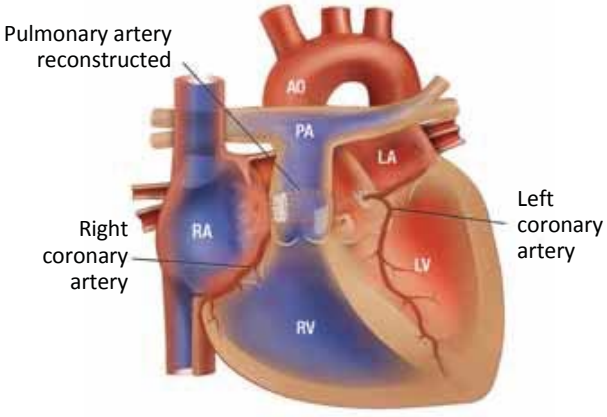
Arterial Switch Operation Step 1



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

Table 1. Arterial Switch Operation

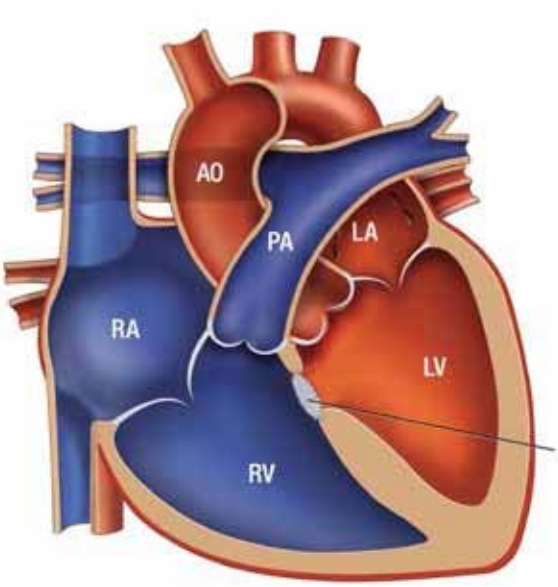
	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	1,747	43	2.5	(1.8 to 3.3)
Children's Hospital of Philadelphia	60	0	0.0	(0.0 to 6.0)
Children's Hospital of Pittsburgh of UPMC	28	0	0.0	(0.0 to 12.3)
Geisinger Children's Hospital[‡]	2	—	—	—
Nemours A.I. duPont Hospital for Children	23	0	0.0	(0.0 to 14.8)
Penn State Hershey Children's Hospital	23	0	0.0	(0.0 to 14.8)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

[‡]Discharge mortality is not reported since data was available for only three of the four years.

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 2. Ventricular Septal Defect Repair

	Discharge Mortality 2009-2012		
		Patients who Died	
	Number of Patients	Number	Percent (95% Confidence Interval)
Society of Thoracic Surgeons (STS)	6,659	41	0.6 (0.4 to 0.8)
Children's Hospital of Philadelphia	111	1	0.9 (0.0 to 4.9)
Children's Hospital of Pittsburgh of UPMC	70	0	0.0 (0.0 to 5.1)
Geisinger Children's Hospital‡	6	—	— —
Nemours A.I. duPont Hospital for Children	82	1	1.2 (0.0 to 6.6)
Penn State Hershey Children's Hospital	61	1	1.6 (0.0 to 8.8)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

‡Discharge mortality is not reported since data was available for only three of the four years.

Arterial Switch Operation and Ventricular Septal Defect Repair

Cardiac Anomaly: Transposition of the great arteries (TGA, page 8), can occur in conjunction with a ventricular septal defect (VSD, page 10).

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 areas of the heart. To repair a VSD, a patch or stitches are placed to close the hole.

Please see pages 8 through 11 for additional detail on Arterial Switch Operation and Ventricular Septal Defect Repair, including images and separately reported hospital data for these two procedures.

Table 3. Arterial Switch Operation and Ventricular Septal Defect Repair

	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	791	43	5.4	(4.0 to 7.3)
Children's Hospital of Philadelphia	23	0	0.0	(0.0 to 14.8)
Children's Hospital of Pittsburgh of UPMC	11	0	0.0	(0.0 to 28.5)
Geisinger Children's Hospital‡	0	—	—	—
Nemours A.I. duPont Hospital for Children	2	NR	NR	NR
Penn State Hershey Children's Hospital	4	NR	NR	NR

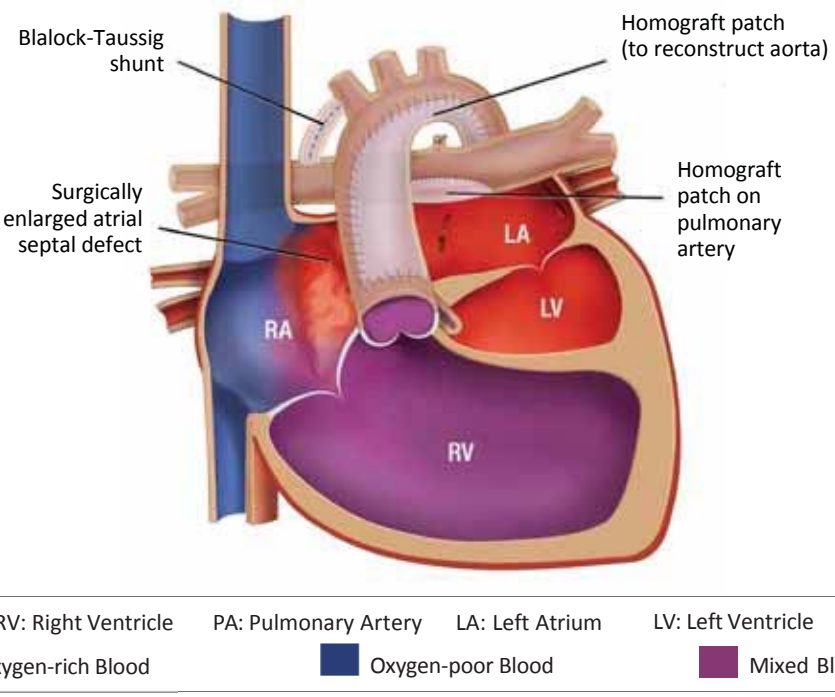
Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

‡Discharge mortality is not reported since data was available for only three of the four years.

NR: Not reported. Fewer than five cases.

Norwood Procedure



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 16) and the third is the Fontan procedure (page 18). 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 the options with their doctor, including why one particular approach might be recommended.

Table 4. Norwood Procedure

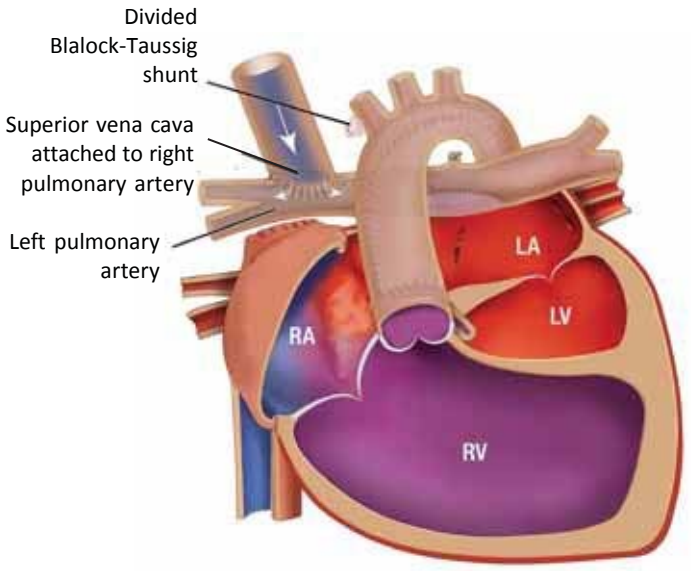
	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	2,764	446	16.1	(14.8 to 17.6)
Children's Hospital of Philadelphia	130	18	13.8	(8.4 to 21.0)
Children's Hospital of Pittsburgh of UPMC	36	4	11.1	(3.1 to 26.1)
Geisinger Children's Hospital‡	5	—	—	—
Nemours A.I. duPont Hospital for Children	17	2	11.8	(1.5 to 36.4)
Penn State Hershey Children's Hospital	17	2	11.8	(1.5 to 36.4)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

‡Discharge mortality is not reported since data was available for only three of the four years.

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 14) is divided and may be removed. After the operation, deoxygenated blood from the upper body goes to the lungs without passing through the heart.

Table 5. Glenn/Hemi-Fontan Procedure

	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	3,889	65	1.7	(1.3 to 2.1)
Children's Hospital of Philadelphia	138	1	0.7	(0.0 to 4.0)
Children's Hospital of Pittsburgh of UPMC	45	0	0.0	(0.0 to 7.9)
Geisinger Children's Hospital[‡]	4	—	—	—
Nemours A.I. duPont Hospital for Children	35	0	0.0	(0.0 to 10.0)
Penn State Hershey Children's Hospital	36	1	2.8	(0.1 to 14.5)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

[‡]Discharge mortality is not reported since data was available for only three of the four years.

Fontan Procedure

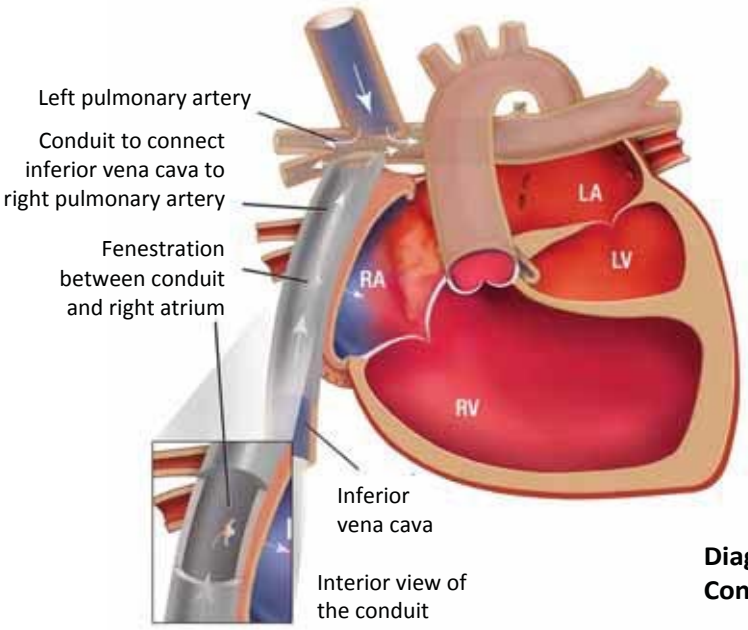


Diagram is of extra-cardiac Conduit Fontan

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.

Table 6. Fontan Procedure

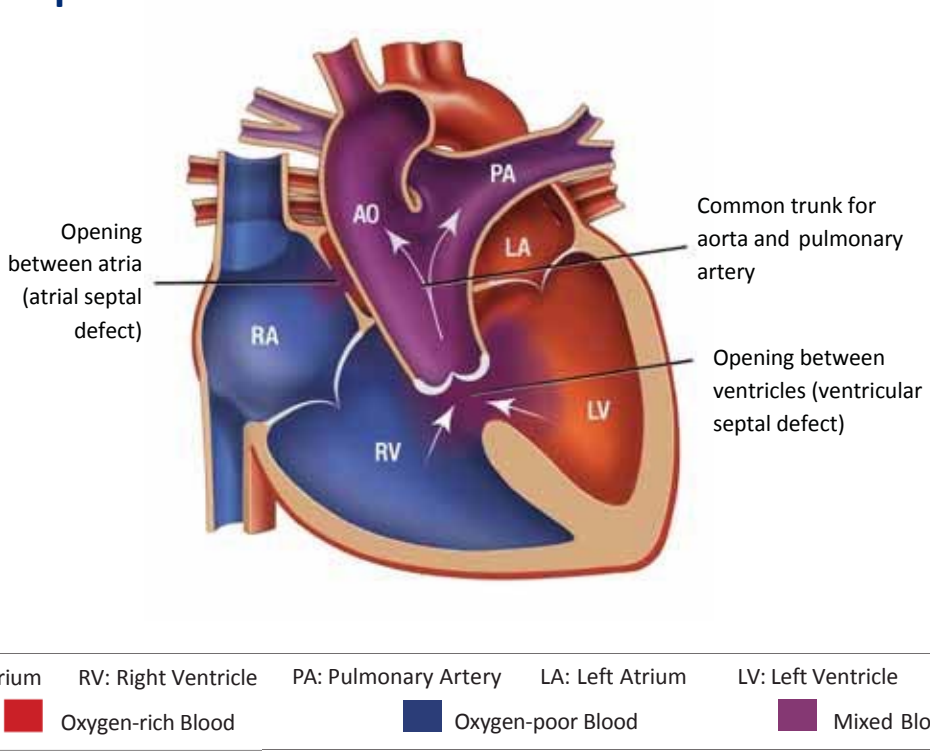
	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	3,901	47	1.2	(0.9 to 1.6)
Children's Hospital of Philadelphia	190	1	0.5	(0.0 to 2.9)
Children's Hospital of Pittsburgh of UPMC	34	0	0.0	(0.0 to 10.3)
Geisinger Children's Hospital[‡]	7	—	—	—
Nemours A.I. duPont Hospital for Children	32	0	0.0	(0.0 to 10.9)
Penn State Hershey Children's Hospital	25	0	0.0	(0.0 to 13.7)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

[‡]Discharge mortality is not reported since data was available for only three of the four years.

Truncus Repair



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 10).

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 is placed to close the hole. Other repairs may be required, based on each patient's unique needs.

Table 7. Truncus Repair

	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	540	43	8.0	(5.8 to 10.6)
Children's Hospital of Philadelphia	18	1	5.6	(0.1 to 27.3)
Children's Hospital of Pittsburgh of UPMC	7	0	0.0	(0.0 to 41.0)
Geisinger Children's Hospital‡	0	—	—	—
Nemours A.I. duPont Hospital for Children	3	NR	NR	NR
Penn State Hershey Children's Hospital	2	NR	NR	NR

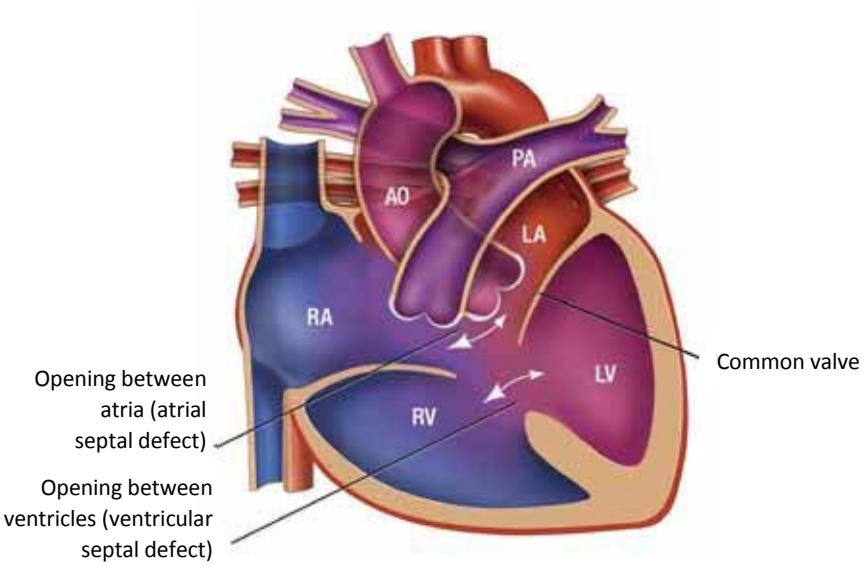
Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

‡Discharge mortality is not reported since data was available for only three of the four years.

NR: Not reported. Fewer than five cases.

Complete Atrioventricular Canal Repair



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 8. Complete Atrioventricular Canal Repair

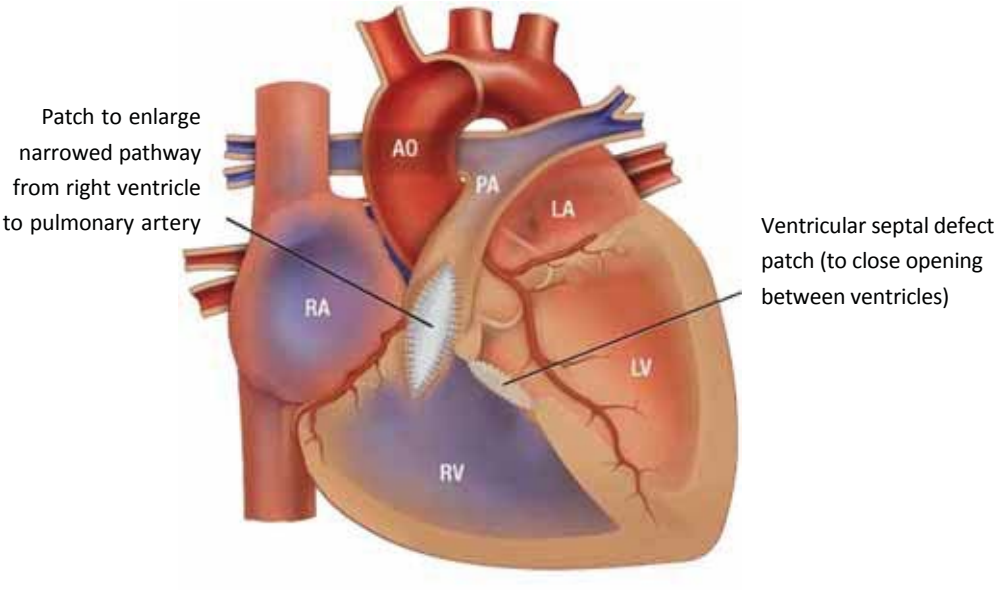
	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	2,830	77	2.7	(2.2 to 3.4)
Children's Hospital of Philadelphia	79	3	3.8	(0.8 to 10.7)
Children's Hospital of Pittsburgh of UPMC	29	0	0.0	(0.0 to 11.9)
Geisinger Children's Hospital[‡]	1	—	—	—
Nemours A.I. duPont Hospital for Children	21	1	4.8	(0.1 to 23.8)
Penn State Hershey Children's Hospital	16	0	0.0	(0.0 to 20.6)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

[‡]Discharge mortality is not reported since data was available for only three of the four years.

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 10).
- 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 9. Tetralogy of Fallot Repair

	Discharge Mortality 2009-2012			
		Patients who Died		
	Number of Patients	Number	Percent (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	4,105	39	1.0	(0.7 to 1.3)
Children's Hospital of Philadelphia	146	2	1.4	(0.2 to 4.9)
Children's Hospital of Pittsburgh of UPMC	40	1	2.5	(0.1 to 13.2)
Geisinger Children's Hospital[‡]	8	—	—	—
Nemours A.I. duPont Hospital for Children	31	0	0.0	(0.0 to 11.2)
Penn State Hershey Children's Hospital	39	0	0.0	(0.0 to 9.0)

Table Notes:

Hospitals' discharge mortality rates are not significantly different than the STS average.

[‡]Discharge mortality is not reported since data was available for only three of the four years.

Total Number of Operations Performed

The preceding pages show results for nine frequently performed benchmark procedures; however, there are also other types of pediatric and congenital heart surgeries. To show overall hospital volume, Table 10 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 10. Number of Operations Performed

	2009-2012
	Number of Patients
Society of Thoracic Surgeons (STS)	108,822
Children's Hospital of Philadelphia	2,691
Children's Hospital of Pittsburgh of UPMC	1,722
Geisinger Children's Hospital[‡]	180
Nemours A.I. duPont Hospital for Children	920
Penn State Hershey Children's Hospital	800

Table Notes:

[‡]Data was available for only three of the four years.

Typically pediatric and congenital heart surgery is performed on patients under age 18, particularly those undergoing the nine 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 some patients with congenital heart defects have heart surgery at facilities other than the children's hospitals included in this report. These patients are most likely older than 18 years.

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 nine benchmark procedures as well as other types of pediatric and congenital heart surgeries.

The outcome, discharge mortality, is risk adjusted for factors such as age, weight, and type/complexity of procedure. Table 11 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 the STS rate (see page 6 for more detail on confidence intervals).

Table 11. Neonates – Risk-adjusted Discharge Mortality Rates

	Risk-adjusted Discharge Mortality 2009-2012				
		Patients who Died			
	Number of Patients	Percent Actual	Percent Expected	Risk-adjusted Rate (95% Confidence Interval)	
Society of Thoracic Surgeons (STS)	15,286	9.3	9.9	8.7	(8.2 to 9.2)
Children's Hospital of Philadelphia	509	8.6	11.2	7.2	(5.3 to 9.5)
*Children's Hospital of Pittsburgh of UPMC	180	3.3	10.2	3.1	(1.1 to 6.5)
Geisinger Children's Hospital‡	28	—	—	—	—
Nemours A.I. duPont Hospital for Children	161	9.3	9.4	9.2	(5.3 to 14.8)
*Penn State Hershey Children's Hospital	141	2.8	8.9	3.0	(0.8 to 7.4)

Table Notes:

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

‡Discharge mortality is not reported since data was available for only three of the four years.

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