

Congenital Heart Public Health Consortium

FAQ Fact Sheet—Long Version

What is a congenital heart defect?

Congenital heart defects (CHDs) are problems present at birth that affect the structure and function of the heart. They can affect how blood flows through the heart and out to the rest of the body. Common examples include holes in different areas of the heart and narrow or leaky valves.

There are many types of heart defects, with different degrees of severity based on size, location, and other associated defects. In more severe forms of CHD, blood vessels or heart chambers may be missing, poorly formed, or in the wrong place. In children the most common type of CHD is the ventricular septal defect (VSD), a hole in the wall separating the bottom two chambers of the heart (the ventricles).

Prevalence at birth

- **How many babies are born each year with some form of congenital heart defect (CHD)?**

Of the nearly 4 million infants born in the United States each year, approximately 3% have some type of birth defect.¹ CHDs are the most common birth defect, occurring in about 1 in 110 births, or nearly 1% of births. Thus, in the US nearly 40,000 infants are affected each year.²⁻⁵

- **How many babies are born each year with a complex/potentially life-threatening CHD?**

Approximately 25% of babies born with CHD each year require invasive or other potentially life-saving diagnosis or treatment.⁵

- **How does the prevalence of CHD at birth compare to other childhood and adult disease states and defects?**

For comparative purposes, cystic fibrosis occurs in 1 in 3,000 live births⁶ while childhood cancer is diagnosed in 1 in 6,250 children and teens.⁷ For adult disease, such as breast cancer in 30- to 34-year-old females, the incidence is 0.23 per 1,000 people.⁸ Thus, the public health significance of CHD in terms of numbers of people affected is similar to that of disorders having higher levels of public awareness.

Prevalence across the lifespan

- **How many people with repaired and unrepaired CHD are living in the US?**

In 2000, the total number of adults living with CHD in the United States was estimated to be 800,000⁹ and the estimated number of children living with CHD was 600,000.⁵ Because there is no population-based surveillance of CHD across the lifespan in the United States, no prevalence data are available on children, adolescents, and adults living with CHD. However, based on Canadian data from 1990–2000¹⁰ that was extrapolated to US Census data in 2010, it is estimated that about 2 million people of all ages were possibly living with CHD in the United States in 2010. These estimates include approximately 975,000 to 1.4 million children and between 959,000 and 1.5 million adults. The increase in magnitude of these estimates in the past decade underscores the need for reliable data based in the US general population.

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- **What is the most common form of CHD in children?**

In children, the most common form of CHD is the ventricular septal defect, a hole between both main muscle chambers, or ventricles, of the heart. The severity of the defect depends on its size and other associated anomalies.^{2, 3, 11}

- **What percentage of people with CHD are adults?**

It is estimated that adults constitute more than half the total population of people with CHD. Of these, up to a third have severe or moderately complex disease.⁹⁻¹¹ Resources dedicated to better tracking and monitoring are needed to obtain more precise numbers.

- **How many people are diagnosed with potentially life-threatening CHD in adulthood? How many children are later found to have a complex CHD which was not found at birth?**

The answers to these questions related to adults are unclear. By the late 20th century, the majority of cases of severe CHD in industrialized countries were diagnosed in childhood, particularly in the first few years of life.¹²

Mortality

- **How do CHDs affect the infant mortality rate in the US?**

All birth defects combined account for approximately 20% of infant deaths.¹³ CHDs are the most common cause of infant death related to birth defects, accounting for 28% of deaths due to birth defects in the first month of life and about 50% of the deaths due to birth defects during the first 2 to 12 months.¹⁴

- **How many deaths occur from unrecognized CHD?**

The use of variable definitions and terminology make it difficult to accurately determine the number of deaths from unrecognized CHD. Data from the Baltimore-Washington Infant Study in the 1980s showed that approximately 10% of deaths in infants with CHD occurred before the diagnosis was made.¹⁵ More recent studies have estimated the number of deaths due to unrecognized CHD ranges from approximately 1 in 20,000¹⁶ to 1 in 40,000 live births.^{17, 18} It is estimated that at least 280 infants with unrecognized critical CHD are discharged from the newborn nurseries each year in the United States.¹⁹

- **How many people in the US die each year from CHD?**

From 1999 to 2006 there were 19.4 million deaths in the United States. Of these, 41,494, or 0.21%, were related to CHD.²⁰ However, mortality associated with several types of CHD has decreased among both children²¹ and adults,²² with more people living to adulthood and thereby increasing the prevalence of CHD among adults.

- **What percentage of people with CHD survive to be discharged from the hospital?**

In the last decade, of people undergoing heart surgery for severe or complex CHD in experienced centers in the US and Canada, the percentage of patients who left the hospital alive included 91% of newborns, 97% of infants, and 98% of children or adults.²³

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- **What percent of patients treated for complex CHD are still alive at age 18?**

Overall, 85-90% of patients born with CHD in the last two decades are expected to survive to age 18.^{5, 24} However, in the data from Belgium, survival continues to vary widely, with fewer than 50% of patients born in the 1990s with the most severe forms of CHD surviving to age 18.²⁴

Risk factors and causes

- **What factors can lead to CHD?**

Although some CHDs have been linked to genetic disorders, maternal conditions, and environmental factors, the causes for the majority of CHDs are unknown.²⁵

- **What genetic factors have been linked to CHD?**

At least 15% to 20% of CHDs have been linked with known genetic disorders. Of these, the more commonly seen are Down syndrome and other types of trisomies, Turner syndrome, and 22q11.2 deletion. With the use of available new technology, the ability to identify genetic disorders that are related to CHDs will increase.^{26, 27}

- **What environmental factors have been linked to CHD?**

Maternal chronic conditions associated with an increased risk for CHD include preexisting diabetes, obesity, and maternal phenylketonuria. Maternal periconceptional use of medications such as isotretinoin, valproate, and phenytoin also has been associated with CHD risk. Maternal early-pregnancy respiratory illness also may be linked with risk for some CHD, and maternal smoking has been linked with risk for some CHDs.^{25, 28}

More research is needed to clarify other potential risk factors. For example, there is some suggestion that maternal prenatal exposure to organic solvents may be related to CHD. Although maternal medications such as certain antihypertensive and antidepressant medications have been associated with risk for some CHDs, it is difficult to differentiate the effects of the medications from those of the underlying maternal conditions for which the medications were prescribed or taken.²⁵

- **Do most people with CHD have other family members with these conditions?**

Some persons with CHD do have other family members with similar conditions. This familial association is more common with parents and siblings than with other relatives. The types of CHD that may occur among family members may be different, however. The majority of persons with CHD have no other family members exhibiting CHD.²⁶

- **Are people with CHD more likely to have children with CHD? How much more likely?**

Parents with CHD are more likely to have children with CHDs than those without CHD. An infant born to a family without a close relative with CHD has about a 1% chance of having CHD. The risk increases about three-fold for a family in which the mother, father, or sibling has CHD.²⁶

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- **Do people with CHD have other physical abnormalities?**

About 20% to 30% of persons with CHD have other birth defects or genetic disorders, and may have developmental and cognitive disorders. Such physical abnormalities and developmental disorders may differ among those with different types or even the same type of CHD.²⁹⁻³¹

- **What can I do to minimize the chance that my child will have CHD?**

Prospective mothers should discuss any medical conditions and health behaviors that may affect a pregnancy, such as nutrition, physical activity, lifestyle, and occupation, with their health care providers.

In particular, women of childbearing age should take multivitamins containing folic acid on a daily basis both before and during pregnancy, avoid tobacco and alcohol use, use only medications necessary for maternal health, and achieve a healthy weight before pregnancy. Women with diabetes should be in good glycemic control before becoming pregnant.^{25, 32} Planning for pregnancy may help avoid inadvertent harmful exposures to the fetus in the first trimester, when mothers may not yet realize they are pregnant.

In addition, women of childbearing age should obtain preconception and prenatal care, including testing for diabetes and past rubella exposure. They should discuss any medication use with their physicians, and avoid contact with anyone who is ill, especially with febrile respiratory illnesses.^{25, 28}

Morbidity

- **How many surgeries are performed on children each year to treat CHD?**

Many infants with CHD require intervention such as surgery to survive. According to information from a database with records from 96 North American surgical congenital heart centers, representing nearly 90% of all congenital heart surgeries, there were 20,636 people with CHD who underwent cardiovascular surgery in 2010. Of those, 55% were newborns or infants and 38% were children between 1 and 18 years old.²³

- **How many surgeries does an adult with CHD have during his or her lifetime?**

Many people with CHD are not cured with one surgery. They may develop problems that need additional surgeries or interventions. The need for more surgery depends on the type of CHD, initial operation type, and the year it was performed. In one specialized cardiac center, almost 50% of adults with CHD who had surgery for their condition had two or more operations.⁹

- **Are other procedures besides surgery available for children and adults with CHD?**

Yes, with improved technology, catheter-based interventions for CHD have increased markedly.³³

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- **How is a patient’s lifespan affected by CHD?**

In 2005, among all those with CHD who were less than 55 years of age living in the United States, 192,000 total years were not lived in good health because of their condition. This loss in years of good health is approximately comparable to the many years of good health lost due to leukemia, prostate cancer, and Alzheimer’s disease combined.³⁴

- **What is the risk of a CHD-related disability for those with CHD?**

In general, the risk for becoming disabled is highly variable, depending on the type and severity of CHD and any co-occurring problems. Many people with CHD have a quality of life comparable to that of the general population and experience little or no disability. Others, however, may develop a disability over time or have progression of disability. Factors that may be associated with an increase in the risk or progression of a disability include underlying genetic disorders or health conditions associated with or due to the CHD.

- **What are the most common health problems experienced by those living with CHD?**

The types and severity of health problems experienced by those with CHD varies widely depending on the type of CHD, surgery or interventions needed, and the person’s overall health. Some people with CHD may have serious and life-long problems that may change over time and with age.³⁵⁻³⁷ Even those with mild CHD may have some health problems,^{37, 38} which may require intervention and/or medications.

Some health issues facing people with CHD may include:

- Increased nutritional needs
- Exercise intolerance or restrictions
- Developmental, behavioral, or cognitive issues
- Irregular heartbeats, or arrhythmias, which affect up to 50% of adults with CHD³⁴
- Valve dysfunction
- Heart failure
- Pulmonary hypertension
- Infection in the heart (Infective endocarditis)
- Thrombosis or stroke

People with CHD can also have other diseases³⁸ that may interact with their CHD condition, including:

- Acquired heart diseases such as atherosclerosis and high blood pressure
- Obesity
- Diabetes
- Epilepsy
- Kidney disease

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It is important that patients discuss possible complications associated with their specific CHD with a cardiologist. CHD is now the most common form of heart disease during pregnancy in the United States.³⁵ Most notably, women with CHD should discuss their health concerns with a doctor before becoming pregnant to determine how the pregnancy may affect them or their baby.

- **What forms of CHD are most likely to develop additional health problems?**

Many types of CHD including tetralogy of Fallot, transposition of the great arteries, and single-ventricle physiology, are commonly linked to additional health problems in adulthood.³⁵ The presence of health problems in people with CHD may depend on the presence of genetic or other birth defects.

Healthcare Access and Cost Challenges

- **What is the national cost burden for treating congenital heart disease?**

Online estimates from a nationwide database capturing approximately 80% of pediatric discharges indicate that there were more than 27,000 discharges of children less than 18 years old who were treated primarily for CHD in 2009. The hospital cost of these children was nearly \$1.5 billion, while the hospital cost for roughly 12,000 adults treated primarily for CHD during the same year was at least \$280 million.³⁹

However, these are minimum cost estimates for all those with CHD, as they do not reflect the total reimbursement hospitals actually received and do not include costs for: discharges where CHD was not the primary condition, inpatient doctor care, medications, outpatient care, or nonmedical costs to families such as transportation, lost wages, or child care.³⁹

In the US, admissions to the hospital via the emergency department increase during transition years from pediatric to adult care settings.⁴⁰ All adults with CHD, even those with mild to moderate disease, have significantly higher rates of health care utilization than their age-matched peers. Data from Canada have shown that adults with severe CHD use three to four times more health services and those with other forms of CHD use twice as many health services than the general population.⁴¹

Among privately insured children in 2005 in the United States, it was estimated that the average medical cost for children with CHD younger than 3 years old was 10 to 20 times greater than for children of the same age without CHD. The greatest cost difference was in the care of infants less than 1 year old.⁴²

- **How does insurance status affect access to treatment for CHD?**

The analysis of hospital discharges for children less than 18 years old indicated that Medicaid was the major payer, accounting for 47% of discharges. Only 2% of children treated for CHD in the hospital were uninsured at discharge, compared to nearly 10% of people aged 18 to 44 who were treated for CHD in the hospital.³⁹

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It is of interest that roughly 9% of US residents under 18 years of age were uninsured at the time of a 2009 national survey.⁴³ Under current law, it is illegal to deny children health insurance coverage due to CHD.⁴⁴ Furthermore, children with CHD are now allowed to stay on their parent's health plan until age 26.⁴⁵

- **What are some of the insurance challenges facing adults with CHD?**

An estimated 10% to 22% of adults with CHD have no health insurance, while 67% of adults with CHD report experiencing insurance problems.⁴⁶ These problems include changing jobs to guarantee coverage, being denied coverage or being charged more for coverage due to their CHD, and lack of access to desired care settings.⁴⁶

Beginning in 2014, it will no longer be legal to deny insurance or charge more to persons with CHD.⁴⁴

- **What percentage of adults with CHD receive care at a specialty adult congenital heart defect program?**

It is estimated that less than 10% of adults who might benefit from adult congenital heart defect programs are in such programs.⁴⁷

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