WORLD HEART FEDERATION

WORLD HEART REPORT 2026

CONGENITAL HEART DISEASE

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CONTENTS

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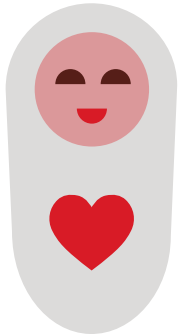
Mussallem Foundation

EXECUTIVE SUMMARY



Congenital heart disease (CHD) is among the most common birth defects globally, with far-reaching impacts for individuals with the disease, their families and society and the economy more broadly. In 2023, 2.3 million children were born with CHD worldwide. That same year, 16 million people were estimated to be living with CHD, an increase on the 11.8 million estimated to have CHD three decades ago.

While there has been minimal change across regions in the CHD incidence rate since 1990, low- and low and middle-income countries (LMICs) suffer from the greatest burden of congenital heart disease, including associated mortality. For example, countries in the Low-Income region have an age standardised mortality rate that is four times higher than those in the High-Income region.

Contributing to the uneven burden of CHD globally are profound inequities in CHD care. Appropriate care requires a systems-level approach over the lifetime for someone with CHD, and depends on clinical excellence and multidisciplinary teams, strong health systems, policy commitment, and sustained investment. In resource-limited settings, developing and executing such programmes faces challenges. For example, paediatric heart programmes and trained professionals specialising in CHD care are largely limited to select large cities in most LMICs, which holds severe implications for timely diagnosis and treatment. Additionally, in most of Africa and many parts of Asia and Latin America, there are no institutions with the capability for infant and newborn heart surgery.

As more people survive into adulthood with CHD, the growing number of this population poses a substantial challenge in even well-resourced settings due to the nuanced level of care required. Adults with CHD can face myriad challenges, including mental health and neurodevelopment conditions, social exclusion, and complications with reproductive health and pregnancy.

There is a path to addressing the shortcomings in CHD care, as the successful implementation of many targeted programmes across both high- and low-resource settings shows. Public investment in centres of excellence, workforce development and the structures required to link CHD care at the community level to tiered systems is a necessary starting point. This must be supported by political commitments that ensure CHD best practice is integrated into the necessary policy and clinical guidelines at national and regional levels. Taking a holistic approach is a crucial step to improving the treatment of CHD and mitigating the far-reaching harms this disease can cause.

To underpin efforts at the national and regional levels, CHD must begin to feature more prominently in the discussion about cardiovascular diseases – an area where it has been all too often neglected. The World Heart Federation (WHF)—with its membership of more than 200 heart foundations, scientific societies, and patient organisations across more than 100 countries—is committed to working with all stakeholders to urgently address inequities in and improve CHD care globally. In support of these efforts, this report provides the following key recommendations:

1 All countries should urgently increase national level capacity across the health system to care for people with childhood onset heart disease, including CHD. This includes developing and scaling centres of excellence, improving referral networks from early detection and diagnosis to surgery, long-term follow-up, and transition to adult care, and integrating congenital heart services into broader maternal, newborn, and child health systems. Ultimately, the goal is to move from episodic, acute care to sustainable, locally led systems capable of delivering timely, high-quality population level services ensuring continuity of care across the lifespan. Such programmes require sustained investment with inclusion of CHD services into UHC benefits packages to avoid financial hardship or catastrophic costs for affected families.

2 Countries should invest in training and building the paediatric and congenital cardiac workforce and strengthening capacity of the adult CHD workforce. This includes training and retaining multidisciplinary specialized paediatric and congenital cardiac care teams and requires developing national CHD health workforce development plans based on population needs forecasting that include development of formal training pathways.

3 Countries and international bodies should work together to improve CHD surveillance and close the data gap to enhance the understanding of CHD epidemiology and determinants. This requires strengthening national health information systems to capture data on CHD prevalence, outcomes, and service delivery, such as through population level registries. Such data should include more granular and comparable information on subtypes of CHD. Better data would enable countries to improve care delivery based on quality improvement metrics, plan and allocate resources more effectively, and track progress over time.

4 Policymakers at international and national level must ensure CHD is reflected in relevant policy frameworks. NCD, maternal and child health and surgical policy initiatives should include measures to improve access to, and quality of, CHD care across the care continuum. This can further support the aims of such policies to reduce NCD and infant mortality, in alignment with the Sustainable Development Goals. Furthermore, policymakers should support the development of national, context-appropriate guidelines to improve implementation of best practice and CHD outcomes.

5 Advocates for CHD care should work to amplify the voices of CHD patients and their families to drive efforts forward. Lived experiences provide unique insights that can inform service delivery, research priorities, and support systems. Empowering patient organisations fosters a patient-centred approach to care and ensures that the needs of those affected are at the forefront of global efforts.

6 Civil society, including national NCD and CVD organizations,should support the campaign for a 2027 WHA Resolution on Childhood-Onset Heart Disease. The resolution will help achieve Universal Health Coverage and reductions in preventable deaths of newborns and children under five, by ensuring countries have paediatric and congenital cardiac care as an integral part of the national health system. Advocates can use resources provided by the Global Coalition for Pediatric and Congenital Hearts to plan and implement national campaigns.

INTRODUCTION

Congenital heart disease (CHD) affects 1.4–2.3% of all children born globally[1] and refers to abnormalities of the heart. It takes many forms with differing levels of severity that have implications for the degree of medical intervention required and the likelihood of morbidity and mortality. Many people who suffer from CHD require care throughout their lifetime.

This fourth annual report from the World Heart Federation (WHF) will explore the different categorisations and levels of severity of CHD before outlining the latest available data on CHD epidemiology, mortality and disability across the world, in addition to CHD's determinants and economic impact. It will overview the CHD care continuum and what is required across the health system to provide people with CHD with appropriate care throughout their lifetimes and explore the vulnerabilities of specific populations along with the global inequities that exist in care provision.

Given the challenges faced by CHD patients and their families around the world, this report aims to equip advocates, policymakers and others with the information they need to improve the diagnosis, treatment and/or ongoing care of CHD and urgently reduce the burden of morbidity and mortality.

For the overview of CHD epidemiology, mortality and disability, the report utilizes data sets from the Institute for Health Metrics and Evaluation's (IHME) Global Burden of Disease study[2].

CONGENITAL HEART DISEASE: AN OVERVIEW

CHD presents at birth and comprises a wide range of structural abnormalities of the heart and great vessels.

While several anatomical diagnoses exist, most CHD globally can be grouped into a small number of clinically meaningful categories based on their physiological impact, urgency of treatment, resources required and long-term care needs. These categories include septal defects (e.g., a hole in the wall between the heart's chambers), obstructive lesions (structural defects that restrict blood flow), and cyanotic CHD (defects that reduce the amount of oxygen delivered to the body) (Figure 1).

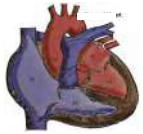
Acquired paediatric heart diseases include Kawasaki disease, rheumatic heart disease, and adolescent hypertension, and can result in cardiovascular morbidity in the young. While the burden of these diseases is sizeable, this report focuses solely on CHD.

Understanding the different categorisations is essential for patients, families, health care providers, and decision makers as the needs of a child with a small, uncomplicated heart defect are fundamentally different from those of a newborn with a life-threatening cardiac malformation. From a public health and policy perspective, the type of CHD determines not only clinical management, but also the level of health system capacity required to provide safe and effective care [3].

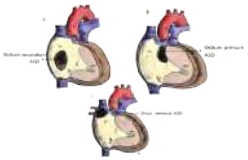
Understanding the different categorisations is essential for patients, families, health care providers, and decision makers

FIGURE 1
An overview of congenital heart disease. This is a simplified version and not a comprehensive classification.

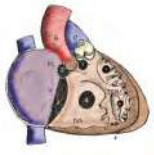
Normal Heart



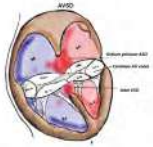
Septal Defects



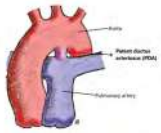
Atrial Septal Defect (ASD): A hole between the atria (upper heart chambers)



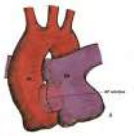
Ventricuar Septal Defect (VSD): A hole between the lowerheart chambers



Atrioventricular Septal Defect (AVSD): A hole in the centre of the heart where the chambers are connected

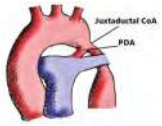


Patent Ductus Arteriosus (PDA): A blood vessel between the aorta and pulmonary artery remains open, cauing abnormal blood flow

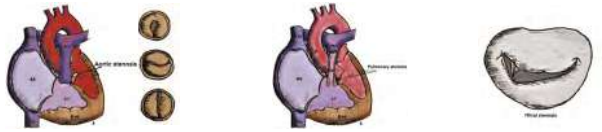


Aortopulmonary Window (APW): A hole btween the aorta and the main pulmonary

Obstructive lesions

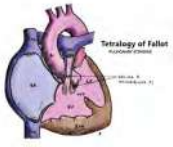


Coarctation of the Aorta: Narrowing of the Aorta, reducing blood flow to the lower body.

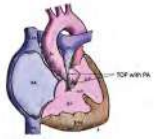


Stenosis: Narrowing of the valves that control blood flow, thereby reducing it.

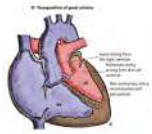
Cyanotic CHD



Tetralogy of Fallot (TOF): A complex combination of 4 defects: VSD, Pulmonary Stenosis, right ventricular hypertrophy (thickening of the heart muscle) and overriding aorta (allows both oxygenated and deoxygenated blood to circulate in the body).



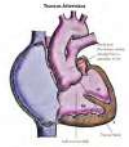
TOF with Pulmonary Atresia: Severe, critical defect where blood flow from heart to lung is blocked.



Transportation of the great arteries: Severe, critical defect where the aorta and pulmonary artery are switched causing oxygenated blood to go to the lungs and deoxygenated blood to go to the body.

Tricuspid Atresia: Rare, severe defect where blood flow from left atrium to left ventricle is blocked.

Hypoplastic Left Heart Syndrome: Rare, severe defect with aortic atresia and an underdeveloped left side, causing the right side to pump blood to both lungs and body.



Truncus Arteriosus: The aorta and the pulmonary artery arise from a single large vessel instead of two seperate ones.

Cardiac illustrations by Dr.Balaji Srimurugan

THE SPECTRUM OF CHD COMPLEXITY

	MINOR/SIMPLE	MODERATE	CRITICAL
PRESENTATION	Include lesions like small atrial septal defects, small muscular ventricular septal defects, mild pulmonary valve stenosis, trivial patent ductus arteriosus in term infants, small post tricuspid shunts, mild isolated outflow tract obstructions.	Includes lesions such as - larger ventricular septal defects, atrioventricular septal defects without early heart failure, tetralogy of Fallot with stable physiology, coarctation diagnosed beyond the neonatal period, severe isolated outflow tract obstructions.	Includes lesions such as - hypoplastic left heart syndrome, transposition of the great arteries, total anomalous pulmonary venous return, pulmonary atresia, duct-dependent systemic and pulmonary lesions, persistent truncus arteriosus.
PROGNOSIS	Generally allows survival into adulthood. Often discovered incidentally, often during routine examinations or later childhood	Potentially fatal/disabling at under 1-2 years of age. Children often require intervention—not always urgently— as soon as possible after diagnosis.	Potentially fatal at under 1 month of age. Without early intervention—often within days or weeks of birth—many of these infants will not survive.
TREATMENT	Usually do not require surgery or catheter-based intervention, and many resolve spontaneously or remain hemodynamically insignificant throughout life	Require timely referral, appropriate medical management and planned surgery or catheter-based intervention in infancy or early childhood. Delays in care can lead to complications such as pulmonary hypertension, growth failure, or recurrent infections	Demands neonatal stabilization, prostaglandin availability, safe transport, advanced imaging, paediatric cardiac surgery or interventional cardiology, cardiac anaesthesia, intensive care, and life-long follow-up.
HEALTHCARE SYSTEM REQUIREMENTS	Main focus is on continuity of care i.e. accurate diagnosis, reassurance of families, periodic follow-up, and clear guidance about warning signs. For these children, care can often be delivered safely at primary or secondary levels of the health system, close to home.	Reliable diagnostic services (especially echocardiography), structured referral pathways, and access to specialised centres capable of performing paediatric cardiac procedures. Requires life-long care with the potential to lead a normal life if regular follow-ups are done and timely care provided for any recurring issues.	Effective community-level screening to enable early diagnosis, reliable and safe transport systems to move critically ill infants to downstream tertiary centres, and hospitals staffed with well-trained, multidisciplinary teams capable of providing advanced perioperative and intensive care.

While the three categorisations apply to the majority of patients with CHD based on diagnosis and timing of intervention, CHD also requires classification based on the surgical options and the expected long-term consequences.

CORRECTIVE

MAJOR LONG-TERM CONSEQUENCES – INCLUDING NEED FOR REOPERATION:

VERY LIKELY		POSSIBLE		UNLIKELY	
TOF repair with the use of a trans-annular patch	Senning or mustard operation	AVSD repair	Valve repairs	VSD closure	ASD closure
Operations requiring use of valved conduits	Resection of sub aortic membrane	Coarctation repair		PDA division	TOF repair *without* the use of trans-annular patch
		Arterial switch operation	ALCAPA repair		

PALLIATIVE

Pulmonary artery band	Atrial Septectomy
BT Shunt	Stage I Norwood (HLHS)
Cavo-pulmonary (Glenn) Shunt	Fontan

FIGURE 2
Surgical options according to CHD type; ASD: Atrial septal defect; AVSD: atrioventricular septal defect, HLHS: Hypoplastic Left Heart Syndrome, PDA: Patent ductus arteriosus, TOF: Tetralogy of Fallot, VSD: Ventricular septal defect

CHD SUBTYPES

Analysing CHD as a singular set of diseases partially limits our understanding of the burden of CHD subtypes. Evidence shows a significant degree of heterogeneity by geography and sex.

Ventricular septal defect (VSD) is the most prevalent subtype worldwide, accounting for 30-40% of cases[20], and has notable variation by ethnicity. For example, subpulmonic VSDs are more common in East Asian populations compared to perimembranous defects in Caucasian populations. Atrial septal defect (ASD) accounts for 7-10% of all CHD, occurs more among women and is the most diagnosed CHD in adulthood. Patent ductus arteriosus prevalence increases at high altitudes, and comprises over 60% of CHD cases in Tibetan regions above 4,000 metres[21] (see Appendix Table 1).

ADULT CHD

CHD survival rates have improved as the diagnosis and treatment of the disease has advanced. As such, there is a growing population of people with adult congenital heart disease (ACHD) worldwide, with the greatest and most complex burden increasingly seen in LMICs.

High-income countries have developed dedicated multidisciplinary services for ACHD and patients are more likely to have benefitted from childhood diagnosis and intervention. However, LMICs face a dual challenge. For example, many patients present in adulthood with unrepaired or late-repaired CHD owing to delayed or no diagnosis, while a growing cohort of surgically corrected or palliated patients develop long-term complications due to limited access to advanced imaging and interventions, and fragmented follow-up. This leads to preventable morbidity and premature mortality[4,5].

ACHD patients can commonly experience residual lesions, arrhythmias, heart failure, pulmonary hypertension, risks specific to women's health, significant mental and neurodevelopmental conditions, as well as socio-economic challenges (e.g. with employment). In LMICs, these issues are compounded by the above challenges.

PATIENT STORY

MARTHA SHIIMI
NAMIBIA, 33-YEAR-OLD WOMAN LIVING WITH CHD

Martha was born in Namibia with Tetralogy of Fallot, a complex congenital heart defect. But the care she needed did not exist in her country.

> "I wanted to create a community so that babies growing up would have people they can look up to"

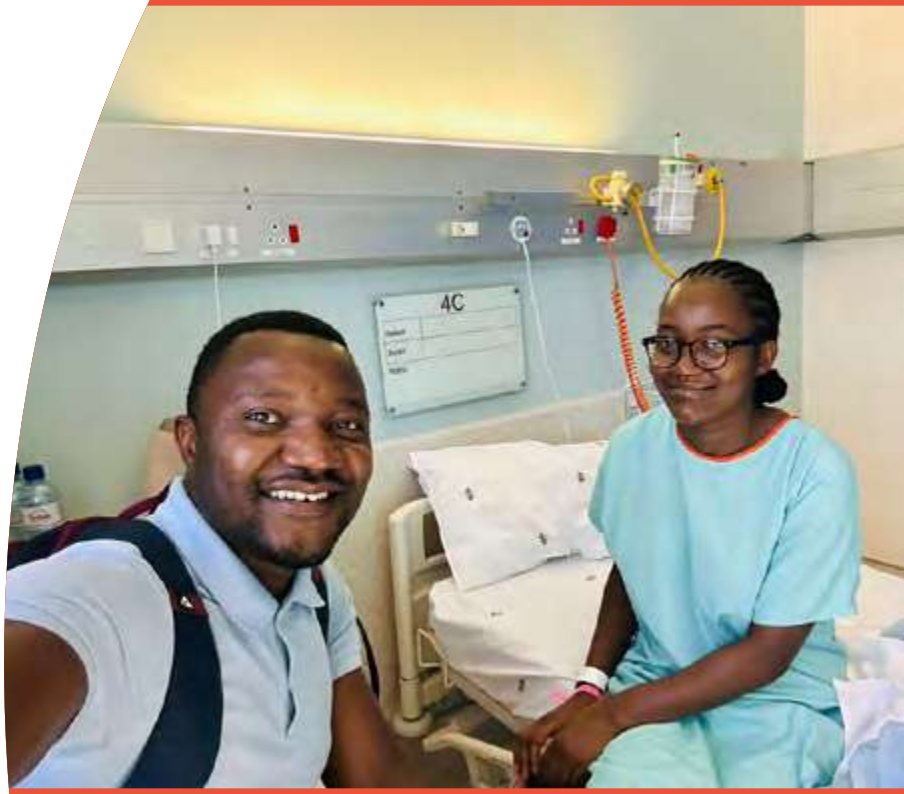
For Martha to survive they had to take her 800km across the border to South Africa, with assistance from the Namibian Government, for surgery. For her parents, it was a desperate trip to save their baby's life. She was just a toddler when surgeons operated on her tiny heart.

For years afterwards, Martha believed the surgery had fixed everything. She grew up like any other child, went to school, lived in a boarding hostel and dreamed of becoming an accountant. But congenital heart disease does not simply disappear. At twelve years old, the exhaustion returned. Her heart valve was leaking. Suddenly hospital visits, medication and medical restrictions were back in her life. That was when she realised she was different.

As she grew older, the questions became heavier. Would her heart hold up long enough to finish university? Could she find work that did not push her body too far?

Would she be able to have children one day? Martha has travelled hundreds of kilometres for medical appointments, waited months on surgical lists and even emptied her savings to pay for heart procedures abroad when care was unavailable at home. For women with congenital heart disease, the challenges are even more complex. Martha often wonders whether her heart could cope, and whether she could give a child the care they deserve, while balancing care for herself.

Yet Martha refuses to let the condition define her life. Today she works in finance and leads a patient support group in Namibia, helping families and young people living with congenital heart disease. Growing up, she never met another person with the same condition. She remembers the loneliness of believing she was the only one. Now she is determined that no child will feel that way again.



GLOBAL LEVELS AND TRENDS OF CHD

Data collection on the incidence of CHD has improved markedly in recent decades. However, significant global gaps remain, in part due to:

- **A lack of standardised comparable global estimates to evaluate the burden of CHD subtypes, including disease levels and trends.**
- **Estimates are often derived from heterogeneous study designs (hospital-based vs population-based), which may limit comparability.**
- **Levels and trends in LMICs might be mostly based on model estimates rather than from direct surveillance, or there may be differences in surveillance structure (e.g., lack of birth registries, or different International Classification of Diseases (ICD) coding for diagnosis varying for complex CHD classifications).**
- **Different perinatal screening routines that may impact incidence.**
- **Patterns in CHD incidence being fundamentally shaped by the effects of selective abortion, which is hard to measure.**

EPIDEMIOLOGY[a,b]

Globally, CHD affects an estimated 2.3-2.5 million newborn each year, representing between 1.4-2.3% of all live births. The progress in early diagnosis and timely and more efficient treatments (e.g., surgery) has improved survival rates and therefore the number of people living with CHD worldwide. In 2023, 16 million people were estimated to be living with CHD worldwide, up from 11.8 million in 1990. In this period, the largest increase was observed in the Lower-Middle-Income region, which accounts for almost 40% of all people living with CHD (Figure 3).

Across regions, the incidence rate of CHD (cases per 100,000 live births) was largely unchanged from 1990-2023 (Figure 4), with the highest level recorded in the Low-Income region, and the lowest in the High-Income region. A modest decline in incidence was observed in the Upper Middle-Income region.

Data show a high degree of heterogeneity across countries. Between 1990 and 2023, the average annual percentage change in the incidence of CHD ranged from -2.2% and +5.7%. Annual reductions above 2% were observed in Puerto Rico, the US Virgin Islands, Albania, Dominica, and the Republic of Korea. Larger increases (above 4%) were recorded in Somalia, Djibouti, Niger, Chad, and Afghanistan, with Sub-Saharan Africa characterised by an increase in the incidence of CHD (Figure 5). Heterogeneity across countries is partly explained by the use of different practices, pregnancy termination laws[6], screening availability[7], and parental decision-making related to pregnancy termination[8].

a Information and figures presented in the epidemiology section is based on Congenital Heart Anomaly data from: Institute for Health Metrics and Evaluation (IHME). GBD Results. Seattle, WA: IHME, University of Washington, 2025. Available from https://vizhub.healthdata.org/gbd-results/. (Accessed 6 May 2026)

b The estimates provided are derived from models and therefore carry associated uncertainties. Where possible, confidence intervals have been included. In general, these estimates should be interpreted cautiously, taking into account the uncertainty inherent in the statistical modelling.

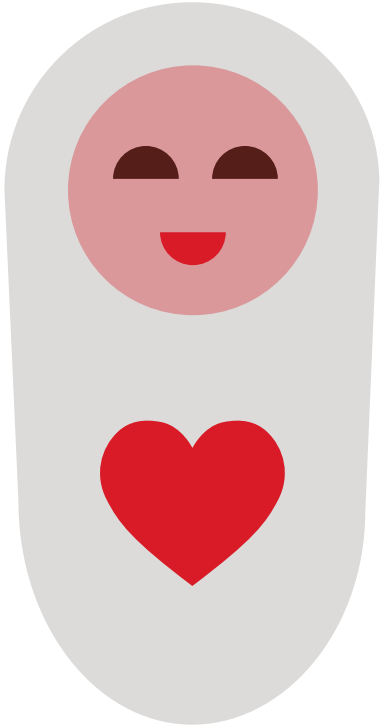


FIGURE 3

Number of people living with CHD by income regions, 1990-2023

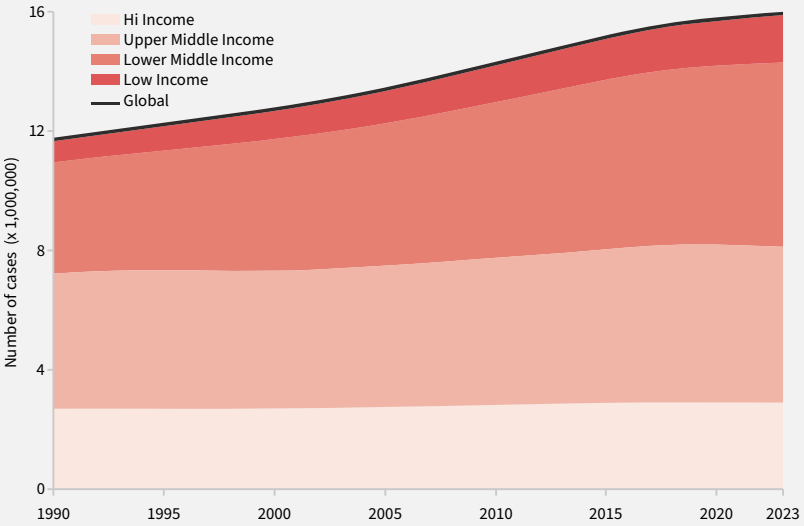


FIGURE 4

CHD Incidence rate by income regions, 1990-2023

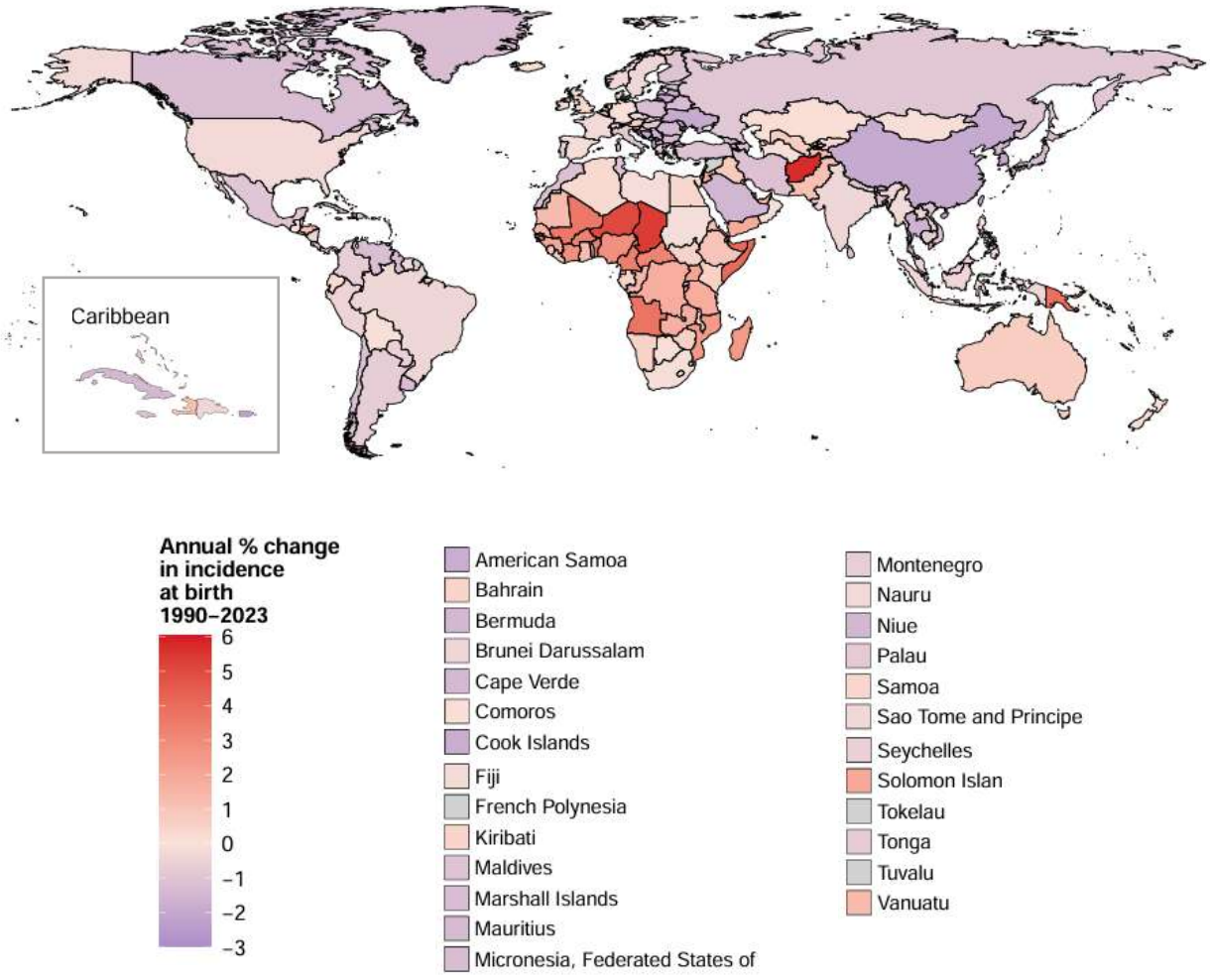
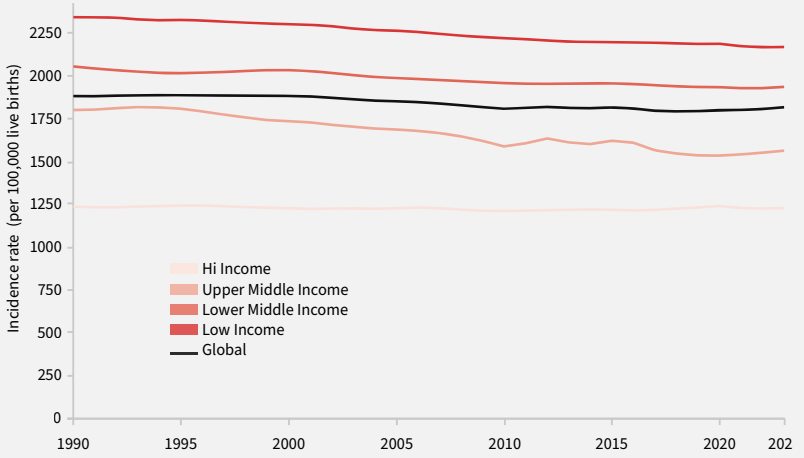


FIGURE 5

Annual percentage change in the CHD incidence rate, 1990-2023



MORTALITY

Between 1990 and 2023, CHD was the leading cause of neonatal and infant mortality (deaths occurring below the age of 28 days and 1 year respectively). among all non-communicable diseases (NCDs) across all regions of the world.

Among *all* causes of infant mortality in 2023, CHD was the second leading cause in the High-Income and Upper-Middle-Income regions (after neonatal preterm birth) and fifth and eighth in the Lower-Middle-Income and Low-Income regions (Table 1). CHD is also a top ten leading cause of neonatal mortality (death occurring within the first 28 days of life) worldwide.

Globally, levels of infant mortality associated with CHD have declined 32.7% since 1990, reaching 162.2 (95% Confidence Interval (CI) 123.0 – 216.3) deaths per 100,000 live births. Countries in the Upper-Middle-Income region experienced the largest decline from 283.9 deaths per 100,000 live births in 1990 (95% CI 224.0 – 351.4) to 126.3 per 100,000 live births in 2023 (95% CI 108.3 – 146.9). All regions, except for the High-Income region, experienced a halt in the decline in 2020 because of the COVID-19 pandemic, with levels not yet returned to previous historical trend lines (Figure 6) .

TABLE 1:
Ranking of CHD among leading causes of death, 1990 and 2023.

REGION	1990		2023	
	INFANT MORTALITY (<1 YEAR)	NEONATAL MORTALITY (<28 DAYS)	INFANT MORTALITY (<1 YEAR)	NEONATAL MORTALITY (<28 DAYS)
GLOBAL	7	8	6	6
HIGH-INCOME	2	3	2	4
UPPER-MIDDLE	5	6	2	4
LOWER-MIDDLE	10	9	5	6
LOW-INCOME	10	11	8	7

Age-standardised[c] CHD mortality rates (all ages included) declined consistently across the world from 1990-2023. In 2023, the age-standardised CHD mortality rate reached 4.7 deaths per 100,000 people globally (95% CI 3.6 – 6.1). Levels of mortality were consistently highest in the Low-Income region (5.7 deaths per 100,000 people; 95% CI: 3.9 – 8.1), with levels observed in the High-Income region four times lower (1.4 deaths per 100,000 people; 95% CI: 1.2 – 2.0) (Figure 7).

IN 2023

THE AGE-STANDARDISED CHD MORTALITY RATE REACHED

4.7 DEATHS

PER 100,000 PEOPLE GLOBALLY

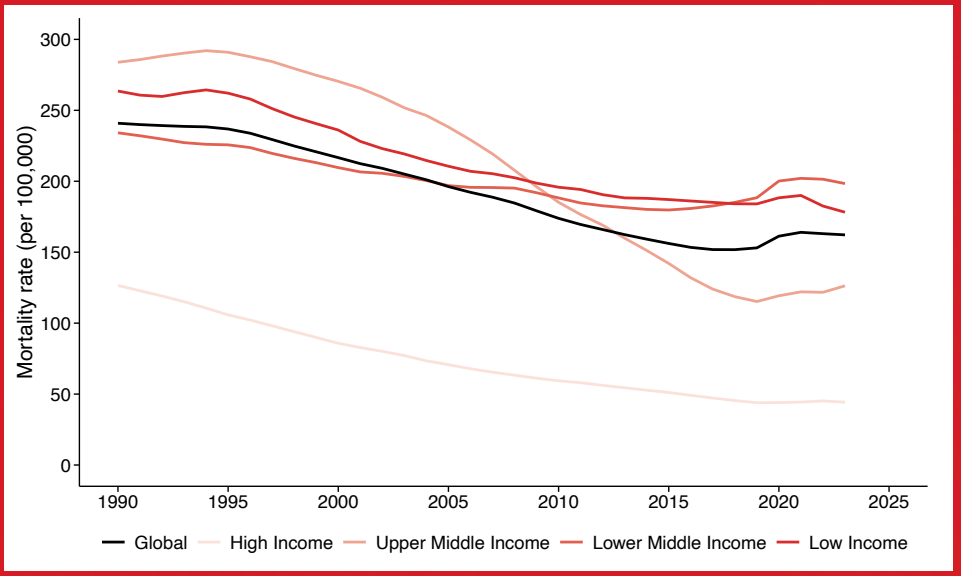


FIGURE 6
CHD infant mortality rate per 100,000 live births by income region, 1990-2023

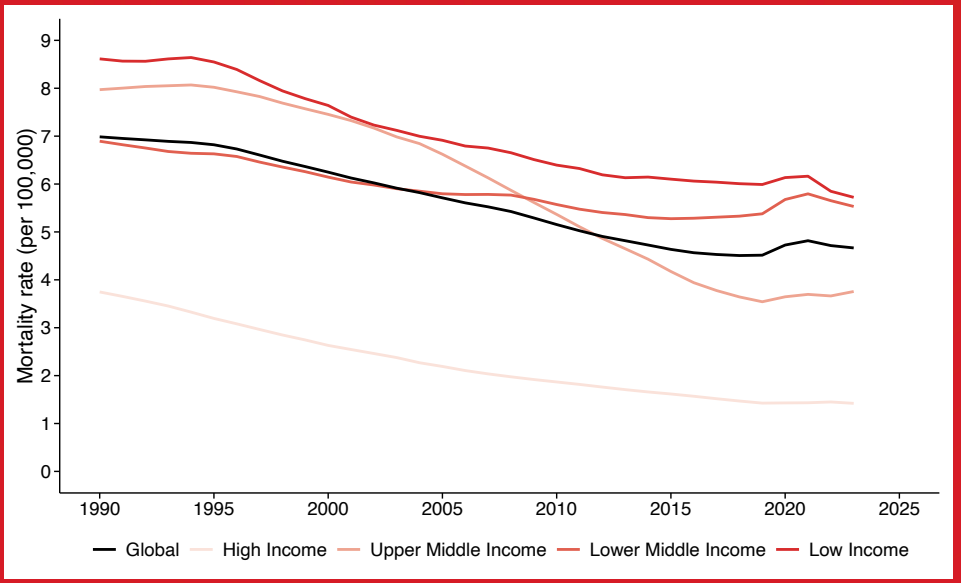


FIGURE 7
Age-standardised CHD mortality rate by income region, 1990-2023

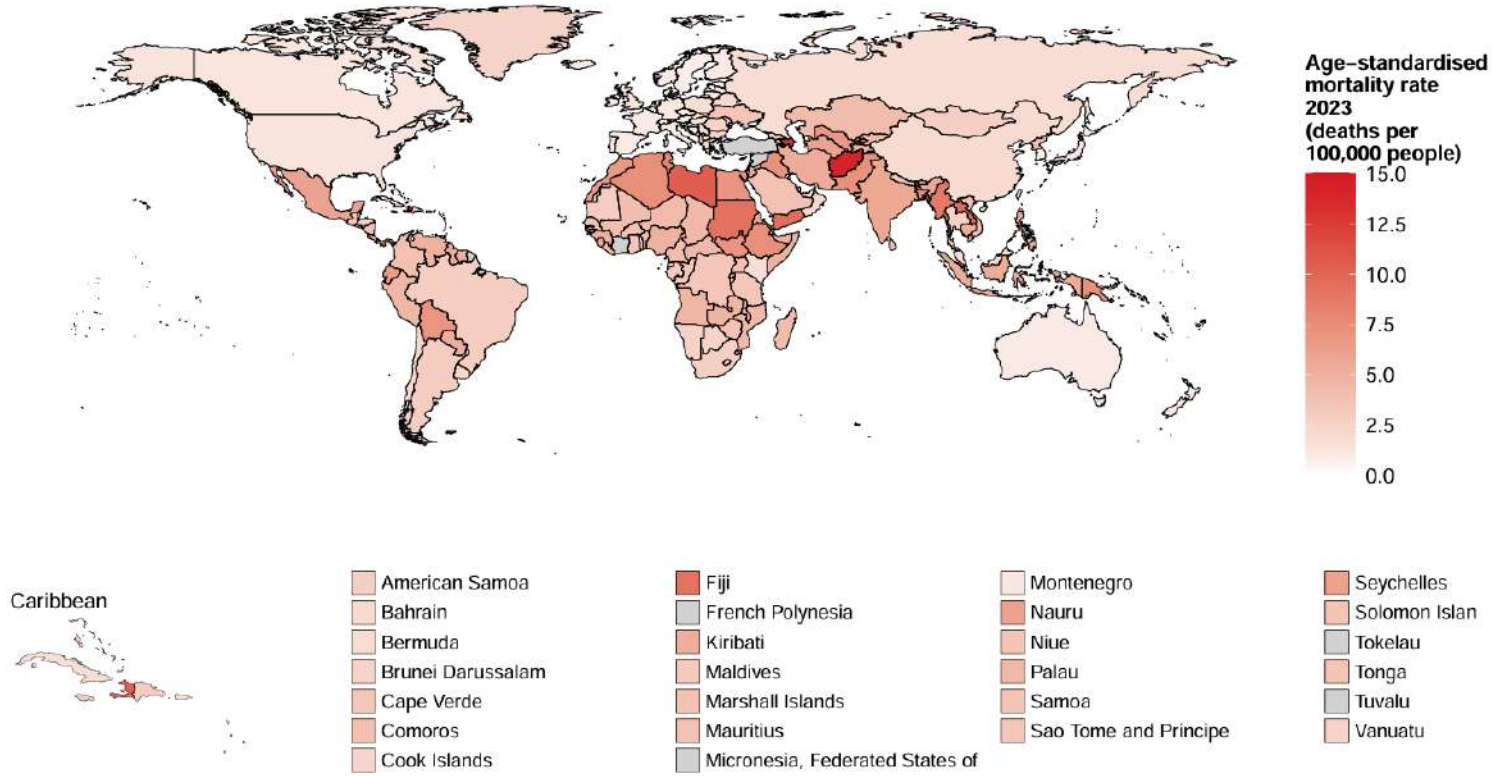
C. Age-standardisation is a technique used to better compare disease outcomes, such as death rates, across populations. It calculates what the disease outcome would be if the population age-structure were the same for all countries. This allows an assessment of whether the observed differences are due to factors related to the disease, rather than the age structure of the population.

Over the past three decades, the decline in the level of mortality has not been the same across the world. The steepest decline was observed in the Upper-Middle-Income region, where levels of CHD mortality more than halved from 8.0 deaths per 100,000 people in 1990 (95% CI 6.5 – 9.7) to 3.8 per 100,000 people in 2023 (95% CI 3.2 – 4.3).. As a result, this region moved from having the second highest levels of CHD mortality (just below the Low-Income region) to the second *lowest* level across the world after the High-income region. The reduction in CHD mortality rates in the Lower-Middle-Income has levelled off since 2008, with levels now in line with those observed in the Low-Income region. Despite the progress observed globally, in 2023 no region in the world had reached the levels observed in the High-income region back in 1990.

At country level, the age-standardised CHD mortality rate is highest in Afghanistan (14.1 deaths per 100,000 people; 95% CI 9.3 – 20.5), Azerbaijan (12.7 deaths per 100,000 people; 95% CI 8.7 – 16.8), Libya and Haiti (both 10.5 deaths per 100,000 people; 95% CI 7.9 – 13.3 and 6.8 – 15.2 respectively), with a large number of countries in the North Africa and Middle East area experiencing high mortality rate levels (Figure 8).

FIGURE 8

Age-standardised mortality rates, 2023



HAITI
10.5 DEATHS PER 100,000 PEOPLE

AFGHANISTAN
14.1 DEATHS PER 100,000 PEOPLE

AZERBAIJAN
12.7 DEATHS PER 100,000 PEOPLE

LIBYA
10.5 DEATHS PER 100,000 PEOPLE

A LARGE NUMBER OF COUNTRIES IN THE NORTH AFRICA AND MIDDLE EAST AREA EXPERIENCING HIGH MORTALITY RATE LEVELS

DISABILITY

In 2023, CHD accounted for 1.0% of the total disability-adjusted life years (DALYs)[D], down from 1.4% in 1990. Below 1 year of age, CHD represented a higher proportion of total DALYs (5.8%).

Globally, the age-standardised DALY rates for CHD declined from 613.3 per 100,000 people in 1990 to 413.7 per 100,000 people in 2023. The Low- and Lower-Middle-Income regions recorded similar levels in 2023 at 495.8 and 487.8 per 100,000 people respectively. These values are almost four times those recorded in the High-Income region (133.3 per 100,000 people).

Between 1990 and 2023, the largest decline was observed in the High- and Upper-Middle-Income regions (average annual percentage change of -1.8% and -1.5% respectively) followed by the Low-Income region (-1.0%) and the Lower-Middle-Income region (-0.6%) (Figure 9).

Globally, the total number of infant CHD-attributable DALYs decreased by a third from 1990-2023, from just above 27.3 million DALYs (95% CI 20.9 – 35.1) to 18.2 million (13.8 – 24.3). This included a reduction in contribution from the Upper-Middle-Income region (from 42.8% to 18.3%) and a significant increase in contribution for the Lower-Middle-Income region (from 39.5% to 59.7%) (Figure 10).

D One DALY represents the loss of the equivalent of one year of full health. DALYs for a disease or health condition are the sum of the years of life lost to due to premature mortality (YLLs) and the years lived with a disability (YLDs) due to prevalent cases of the disease or health condition in a population.

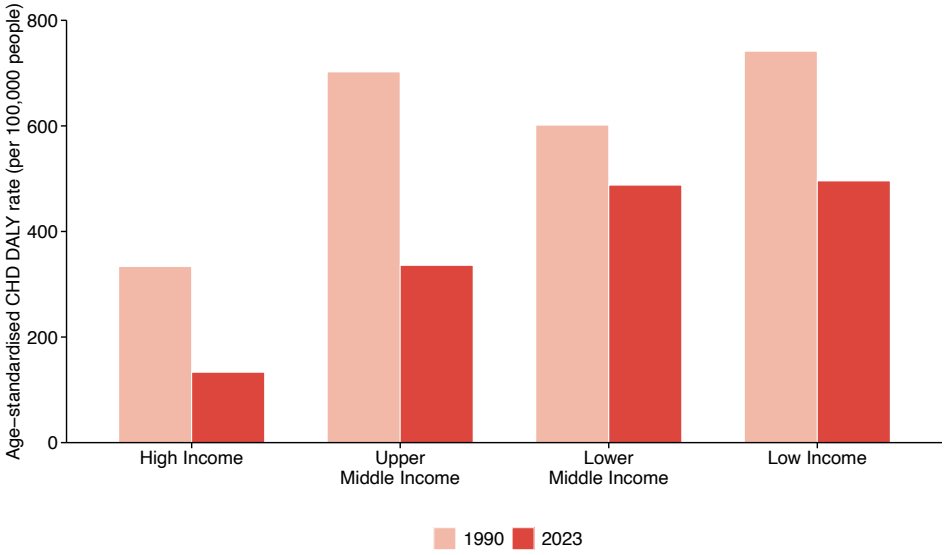


FIGURE 9
CHD age-standardised DALYs (per 100,000 people) by region, 1990 and 2023

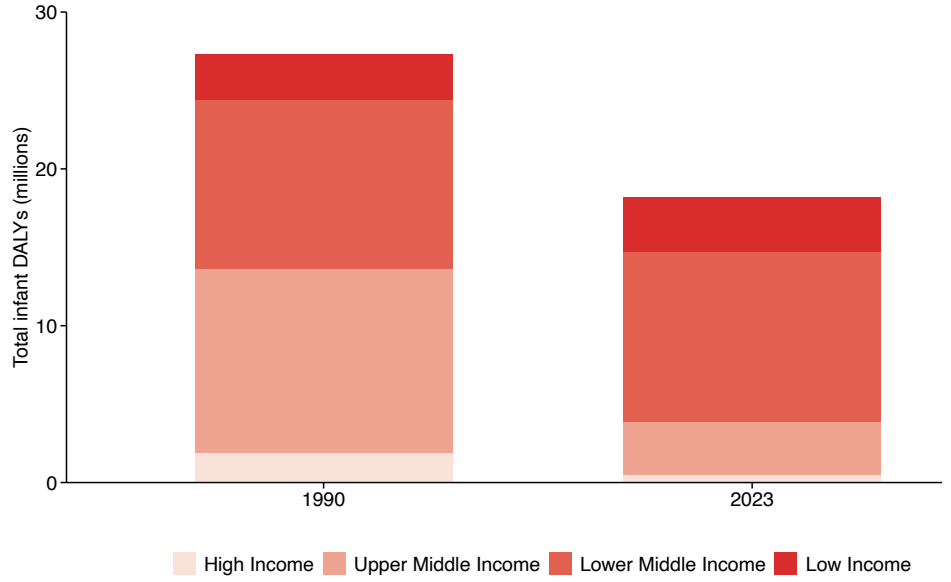


FIGURE 10
Total infant DALYs attributable to CHD by region, 1990 and 2023

MENTAL HEALTH AND NEURODEVELOPMENTAL CONDITIONS FROM CHD

Individuals with CHD have an increased risk of adverse neurodevelopmental and mental health outcomes across life. These include impairments in motor and language skills, attention, learning and cognition, executive function, and social and emotional functioning.

Studies indicate that 30–50% of children with CHD are diagnosed with a neurodevelopmental and/or mental health condition, a rate higher than in the general population[9,10]. The burden is greatest for those with more complex CHD and those with early-life risk factors, including individual (e.g., genetics) and environmental (e.g., prolonged hospitalization, social drivers).

Psychological trauma and post-traumatic stress disorder (PTSD) are increasingly recognised in CHD patients and their caregivers. Among children who have undergone cardiac surgery, estimates suggest 12–31% develop PTSD, while in adults with CHD, PTSD prevalence ranges from 11–30%, which is significantly higher than in the general population and other at-risk groups[10–12]. Traumatic stress in this context is often cumulative, arising from repeated invasive procedures, hospitalisations, and ongoing medical surveillance throughout life. These outcomes have significant consequences for educational, and employment opportunities, functional capacity, quality of life, and longevity. Most available evidence for this burden is derived from high-income countries, with few studies from LMICs[13] – underscoring the need for greater disease surveillance, service development and research in LMICs.

CULTURAL MISCONCEPTION AND SOCIAL STIGMA

Stigma compounds the challenges people with CHD face, as they may experience social exclusion, perceived discrimination, and marginalisation related to both their cardiac condition and associated mental health or neurodevelopmental difficulties.

In many LMICs, CHD is often also accompanied by cultural and community stigmatisation. Cultural beliefs and misconceptions such as blaming mothers for their child's condition, social exclusion, discrimination, or bullying intensify the burden for patients and their families. This can lead to families hiding the condition, missing follow up care, community exclusion, low academic expectations and children's internalisation of prejudices, which may result in psychological distress. It is also a missed opportunity for raising more awareness and changing attitudes towards children with congenital conditions and disabilities[14–19].

PATIENT STORY

TENDAI AND RUDORWASHE GRACE MOYO

Tendai Moyo knew her baby was seriously unwell long before the health system recognised it.

> **My advocacy work grew out of this experience – it is a way to channel grief and ensure other children do not suffer the same fate**

When her daughter Rudorwashe Grace was born in Zimbabwe, she struggled to breathe, her lips turned blue, and feeding was exhausting. Tendai repeatedly sought medical help, but her concerns were dismissed. Because her illness was invisible, Rudorwashe appeared to others like a healthy, chubby baby. Her symptoms were often said to be witchcraft.

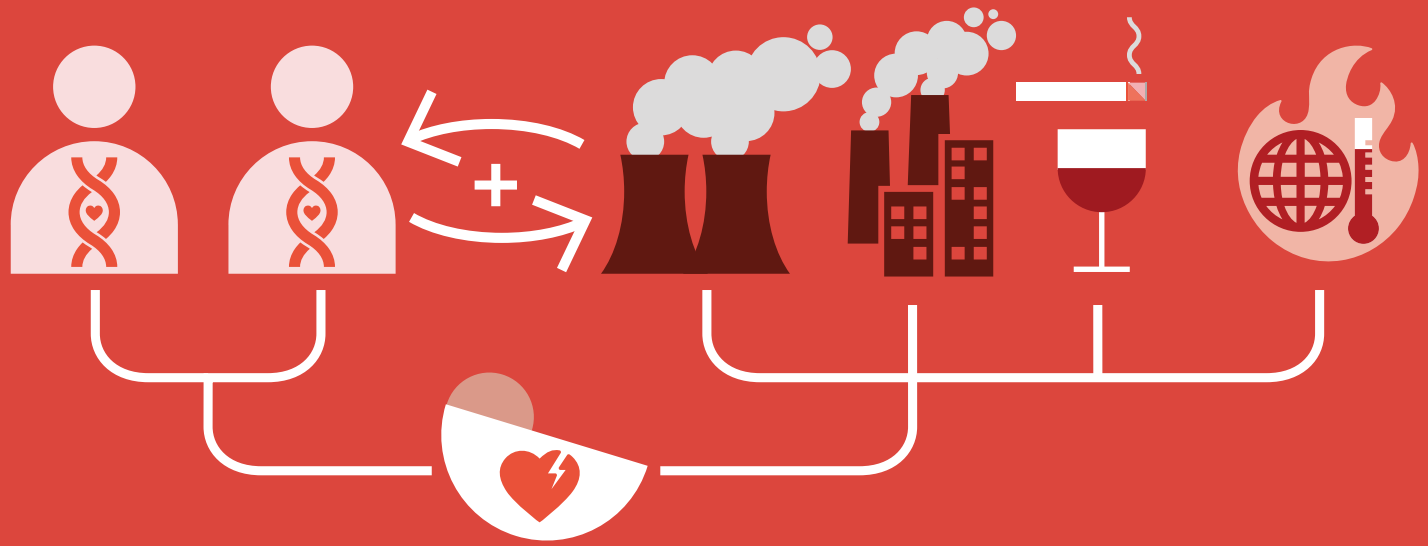
After fighting the system for six months, Rudorwashe Grace was finally diagnosed with tricuspid atresia and cardiomegaly, a serious congenital heart defect. By then, critical time had already been lost. By that time, Zimbabwe had only one paediatric cardiologist, practising privately and located 400 km away in the capital city of Harare, serving a population of around 15 million people. Each year, approximately 4,500 children are born with congenital heart disease, and an estimated 75% die without ever receiving a diagnosis or life saving intervention. The only chance for surgery was overseas. Tendai had to fundraise desperately to send her daughter to India, where the operation cost at that time about including flights and accomodation $20,000 USD.

Rudorwashe Grace died at 10 months old due to systemic delays, barriers, and missed opportunities for care. Her death was not inevitable. It was the result of repeated and catastrophic system failures.

After losing her daughter, Tendai transformed her grief into action. She founded Brave Little Hearts Zimbabwe and now advocates for earlier diagnosis, stronger health systems, and recognition of congenital heart disease so that other families do not endure the same loss.

GENETIC AND ENVIRONMENTAL DETERMINANTS OF CHD

The cause of CHD is multifactorial. Around 60% of CHD likely arises from gene-environment interactions, where multiple genetic variants interact with environmental exposures during critical windows of cardiac development.



Genetic factors alone play a major role, with an estimated 40% of CHD cases linked to identifiable genetic abnormalities, such as chromosomal aneuploidies, copy number variants, and pathogenic mutations in single genes.
For example:

- Gross chromosomal anomalies account for roughly 8%-10% of all CHD cases[22]. Trisomy 21 (Down syndrome) is the most common of these, and about half of all newborns with this condition have CHD, most often presenting with atrioventricular septal defects.
- Copy number variants account for 3-25% of syndromic CHD and 3-10% of isolated cases – the 22q11.2 deletion syndrome occurs in 1 in 4,000 births, while 7q11.23 deletion syndrome (Williams-Beuren) occurs in 1 in 7,500 births[23].
- Single-gene mutations in cardiac transcription factors (NKX2-5, GATA4, TBX5, TBX20) and signalling pathway genes (NOTCH1, JAG1) account for 3-5% of all CHD cases[22]. In a 2025 large-scale exome sequencing, 8% of CHD was attributed to de novo autosomal dominant variant and 2.2% to recessive genotypes[24].

Environmental risk factors account for about 2% of definitively attributable CHD cases. These factors include:

- Maternal pregestational diabetes, which increases the risk of CHD by 2.5-5-fold across multiple subtypes.
- Maternal obesity, which independently raises CHD risk by 29% (Odds Ratio (OR) 1.29; 95% Confidence Interval (CI) 1.22-1.37)[25].
- Teratogenic medications that have established CHD associations, including valproic acid, lithium, retinoic acid derivatives, and ACE inhibitors.
- Maternal folate status, which demonstrates a curvilinear dose-response relationship with CHD risk. While periconceptional folic acid supplementation reduces CHD risk by approximately 21%, recent evidence reveals that both deficiency and excess are harmful[26]. Low maternal serum folate is associated with up to a 3-fold increase in CHD risk and excessively high levels associated with nearly a 2-fold increase[27].

Additional environmental and occupational risk factors include organic solvents (OR 1.82; 95% CI 1.23-2.70)[25] and maternal smoking (OR 1.16; 95% CI 1.07-1.25), which are associated with increased risk at the population level. PM2.5 exposure (ambient air pollution) during the second and third trimesters is associated with a 23% increased CHD risk (OR 1.23; 95% CI 1.14-1.32)[28] per 10 µg/m^3 increment, while prenatal cadmium exposure is associated with increased ventricular septal defect risk (OR 1.51; 95% CI 1.19-1.93)[29]. Maternal exposure to extreme heat events during weeks 3-8 post-conception is associated with increased risk of CHD in offspring (OR 1.12; 95% CI 1.04-1.34), with effects most pronounced in temperate climate zones (OR 1.35; 95% CI 1.23-1.48)[30]. As global temperatures continue to rise, projection models in the United States estimate thousands (7,000)[31] of additional CHD cases in the coming decade. Maternal rubella infection, although now rare in high-income settings due to effective immunisation programs, remains a preventable cause of CHD in regions with low vaccination coverage.

“As global temperatures continue to rise, projection models in the United States estimate thousands (7,000)[31] of additional CHD cases in the coming decade”

While most of the evidence on modifiable risk factors for CHD has centred on maternal exposures, paternal factors also warrant consideration. Advanced paternal age, especially above 35 years, has been associated with a 16% increase in CHD risk[32], as have paternal smoking, alcohol use, and occupational exposure to chemical agents[33,34]. The effect sizes are smaller relative to established maternal risk factors, but they reinforce the case for preconception counselling that addresses both parents.

PATIENT STORY

SABRINA PUIG

USA, 18-YEAR-OLD WOMAN LIVING WITH CHD

Sabrina Puig was just nine days old when doctors realised something was terribly wrong.

> **"It was another attempt to fix the pulmonary artery that had collapsed, but that surgery went very, very bad. It did not go as planned at all. I had an ischemic stroke on the right side of my brain and I lost mobility on my entire left side. I was paralysed on the left side of my body and I was only nine years old"**

Suddenly she was rushed to hospital, diagnosed with hypoplastic left heart syndrome, and taken straight into open-heart surgery a few days after. It was the first of many operations that would shape her life.

Her childhood became a cycle of hospitals, surgeries and long journeys between Mexico City and San Diego for specialised care. Growing up was not easy. Living in Mexico City's high altitude left Sabrina constantly short of breath. Her lips and fingernails often turned blue from low oxygen while other children ran and played around her.

Eventually doctors delivered a devastating reality to her parents that if Sabrina was going to survive, the family would need to leave their beloved home in Mexico and move to the United States to live closer to medical treatment. With two other children to care for, her parents rebuilt their lives in a new country so their daughter could stay alive.

When she was nine, her fifth surgery went catastrophically wrong. Sabrina suffered a stroke that paralysed the entire left side of her body. Months of rehabilitation followed as she fought to relearn how to move and walk again. Following this, doctors warned her family that her heart was failing and that she would likely need a transplant. Her parents pushed for a second opinion. Instead of a transplant, surgeons attempted a complex reconstruction of her pulmonary artery — her sixth open-heart surgery.

The surgery was a success, leading to another difficult moment. Just one week after surgery, while still recovering in hospital, surgeons and her parents agreed the Fontan procedure should be completed immediately. But the final decision was Sabrina's. At just sixteen years old she had to decide whether to face a seventh open-heart surgery only days after the last one. It was one of the hardest decisions of her life.

The surgery transformed her life. For the first time her oxygen levels rose into the nineties. She could breathe more easily. She could exercise. She could begin to imagine a future that once seemed impossible. Today, Sabrina is able to look toward the future with choices. As she considers where to study and build her life, she can weigh those opportunities alongside the medical care that has helped her survive and thrive. Her future is full of hope, possibility and determination as she steps into the next chapter of her life.

WOMEN, THEIR REPRODUCTIVE JOURNEY AND CHD

Women with CHD experience unique reproductive health challenges throughout their lifespan, which are characterised by complex medical risks alongside significant psychosocial burden[41].

They must navigate a reproductive journey marked by clinical uncertainty and inadequate healthcare support. For example, from puberty onwards, women with CHD—especially those with complex cardiac lesions or receiving anticoagulation therapy—commonly experience menstrual irregularities[42]. Evidence shows that clinical discussions surrounding sexual health, contraception, and family planning are entirely absent in routine care. This has led to unplanned pregnancies that put women with CHD's heart health at greater risk. Additionally, some women report receiving contradictory advice, initially being told pregnancy was impossible, only to later learn it was feasible.

The emotional dimensions of decision-making for women with CHD are often overlooked. These women face high-stakes decisions with lifelong implications, frequently described as "life and death" choices about theirs and their babies' health. The psychological burden is compounded by concerns about potentially passing CHD to offspring, fears about survival during pregnancy and childbirth, and worries about being physically present for their children's development. Many women rely on their own inner strength or personal support networks for emotional support, as healthcare systems offer limited psychological resources despite the degree of these decisions. Women also report feeling that pregnancy-related decisions are excessively medicalised, with insufficient consideration of their preferences in birth planning. This further compromises their sense of autonomy over reproductive choices.

The transition to menopause presents additional challenges for women with CHD. As the cardioprotective effects of oestrogen diminish, these women face heightened risks of thromboembolism, weight gain, elevated cholesterol, diabetes, and atherosclerosis[43,44]. Even contraceptive pills or hormone replacement therapy present complex therapeutic dilemmas due to potential cardiac complications[45]. Addressing these gaps requires integrated, multidisciplinary care that extends beyond clinical risk management to include psychological support and patient-centred decision-making throughout the reproductive lifespan. Increasing the workforce capacity to highlight specialised women's health and CHD specialists is essential.

PATIENT STORY

BELEN BLANTON

VENEZUELA, 61-YEAR-OLD WOMAN LIVING WITH CHD

Belén Blanton was born in Venezuela in 1965 with a complex congenital heart condition that doctors believed she would not survive.

> **"When that baby in Venezuela died, I realised I had a purpose… Now I help children get treatment because I know what happens if they don't"**

At six months old, she was flown to the United States for a life-saving procedure, returning home as what many considered a miracle.

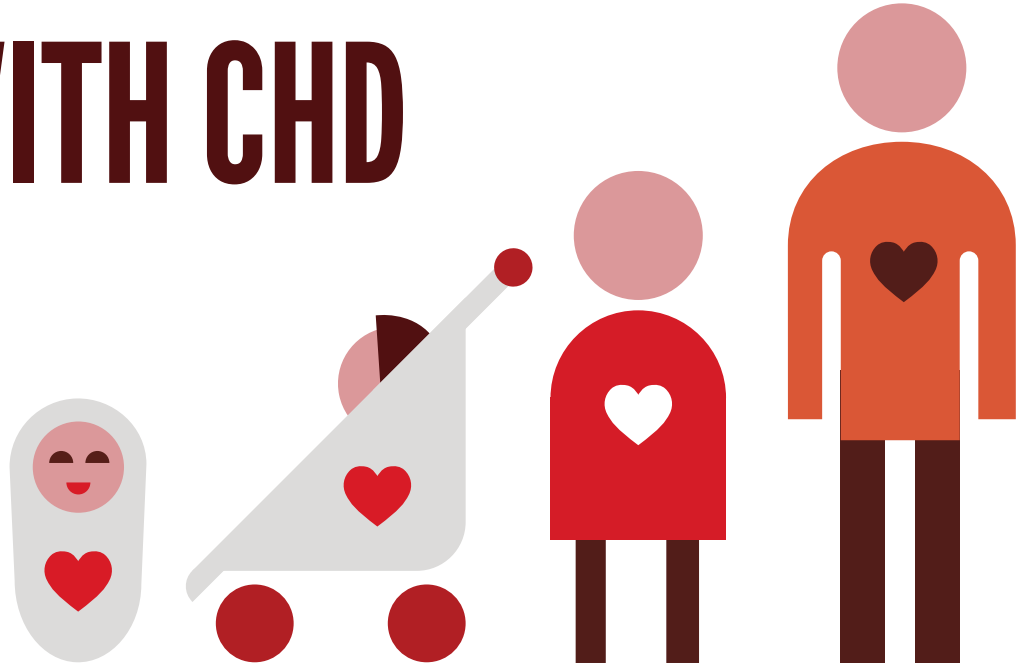
As an adult, her challenges evolved but did not ease. She lives with advanced complications, including pulmonary hypertension, and the daily awareness that her health remains fragile. As a woman, her condition has intersected with every stage of her life, from debilitating menstrual symptoms to a deeply distressing pregnancy shaped by medical pressure, and a menopause that destabilised her heart without explanation or support. Time and again, she sought answers and was met with silence or dismissal.

But Belén's story is not defined by what she was denied. It is defined by what she chose to do with it. After witnessing a child just like her in Venezuela die due to lack of access to care, she refused to accept that this was inevitable. She turned her experience into action, building pathways for other children to receive the treatment she once fought for. Today, she leads an organisation that has helped save dozens of lives and brought hope to families who would otherwise have none

CARE FOR PEOPLE WITH CHD

REQUIREMENTS FOR CHD CARE

For a child with CHD to survive, thrive and grow into adulthood, an effective and timely collaboration between healthcare professionals across all levels of the health system is required and can be achieved through a systems-level approach.

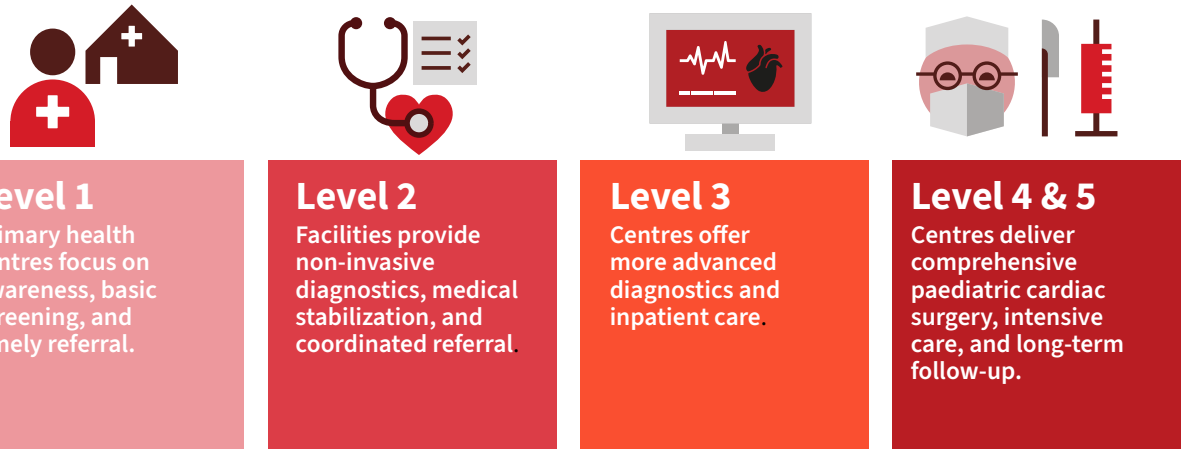


Outlining a continuum to integrate CHD services into the broader health system is imperative to help lower childhood mortality from CHD. When elements of the continuum are weak or fragmented, health systems struggle to deliver consistent, safe care, which can be detrimental to a child's health.

A well-functioning CHD care continuum depends both on clinical excellence and on multidisciplinary teams, strong health systems, policy commitment, and sustained investment to ensure that people with CHD can receive the care they need across the life course. This type of framework proposes a tiered system of care, from community-based services to highly specialized children's hospitals, each with clearly defined capabilities and responsibilities.

At Level 1, primary health centres focus on awareness, basic screening, and timely referral. Level 2 facilities provide non-invasive diagnostics, medical stabilization, and coordinated referral. Level 3 centres offer more advanced diagnostics and inpatient care, while Level 4 and 5 centres—often tertiary or national children's hospitals—deliver comprehensive paediatric cardiac surgery, intensive care, and long-term follow-up[3].

Crucially, the framework argues that attempting to offer high-risk interventions without first establishing strong foundations at lower levels anchored in quality care, leads to poor outcomes and loss of trust in the health system[33,46].



CHD CARE FROM BIRTH TO ADULTHOOD

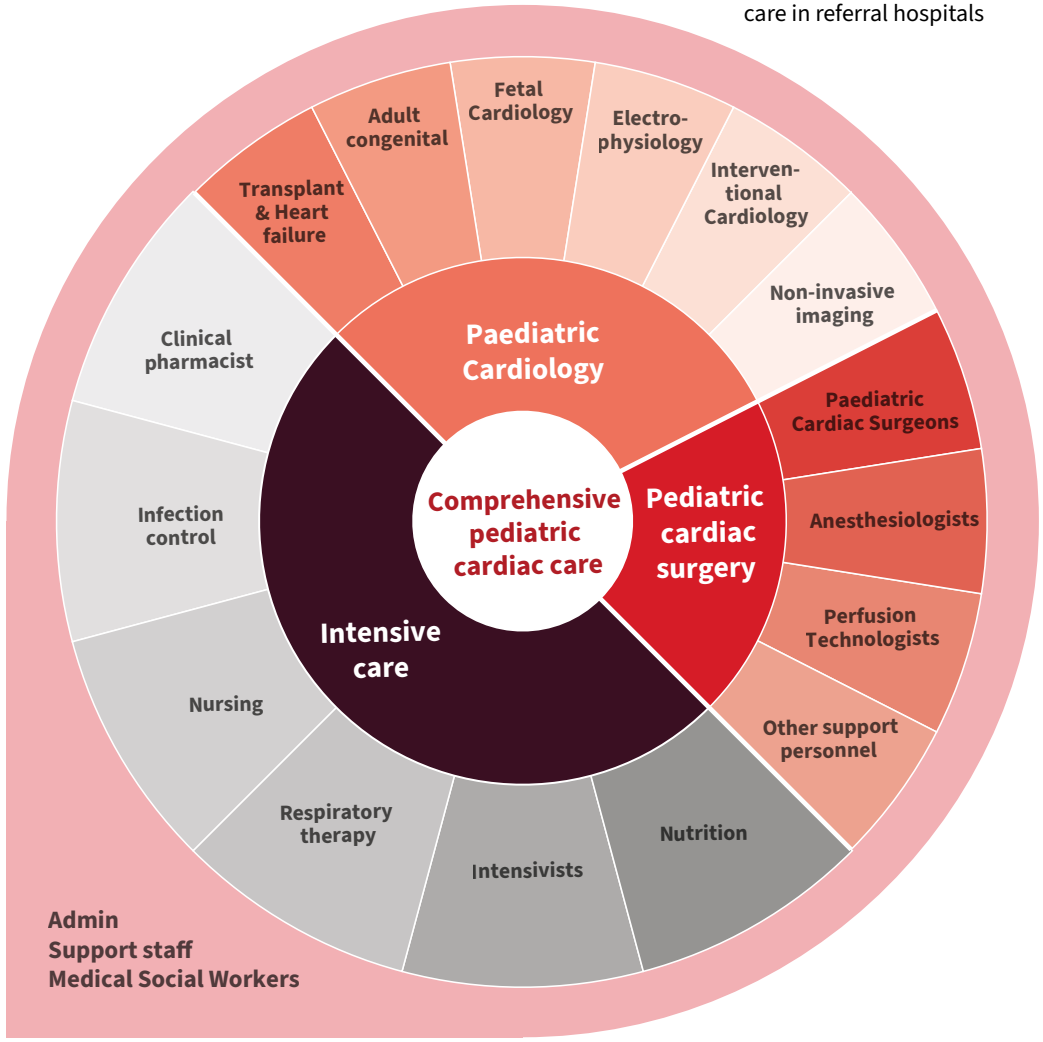
The CHD continuum of care can begin with antenatal services and extend across the entire lifespan, with specialised coordinated and timely care.

Screening for CHD is critical for early detection and can happen as part of quality antenatal care, in the first days of life via pulse oximetry and physical examination, or in early infancy as part of well-child visits. Identification of possible CHD through screening should be followed by timely referral for definitive diagnosis by foetal echocardiography or after birth, and be supported by transportation of critical patients, which is often needed for very sick newborns. This step is often hampered in low resource settings by lack of access to trained paediatric cardiologists, and missed or late diagnoses remain common.

At its core, a functional CHD care system (particularly for infants with CHD), requires a trained multidisciplinary workforce that includes paediatric cardiologists, paediatric cardiac surgeons, cardiac anaesthetists, perfusionists, intensivists, and highly skilled nursing and allied health professionals (Figure 11) [47].

Enabling resources are critical, including reliable diagnostic imaging—at a minimum, high-quality echocardiography—well-equipped neonatal and paediatric cardiac intensive care units, and robust perioperative support services. These support services include safe and responsive blood banks, strong infection prevention and control services, an effective pharmacy capable of managing complex cardiac medications, biomedical support and a patient quality and safety department that continuously monitors outcomes and adverse events (Figure 12).

FIGURE 11
Essential elements of CHD care in referral hospitals



Adapted from: Kumar, R. K. Delivering pediatric cardiac care with limited resources. Annals of Pediatric Cardiology 7, 163 (2014).

CONGENITAL HEART CARE: ELEMENTS

CHD CARE CONTINUUM

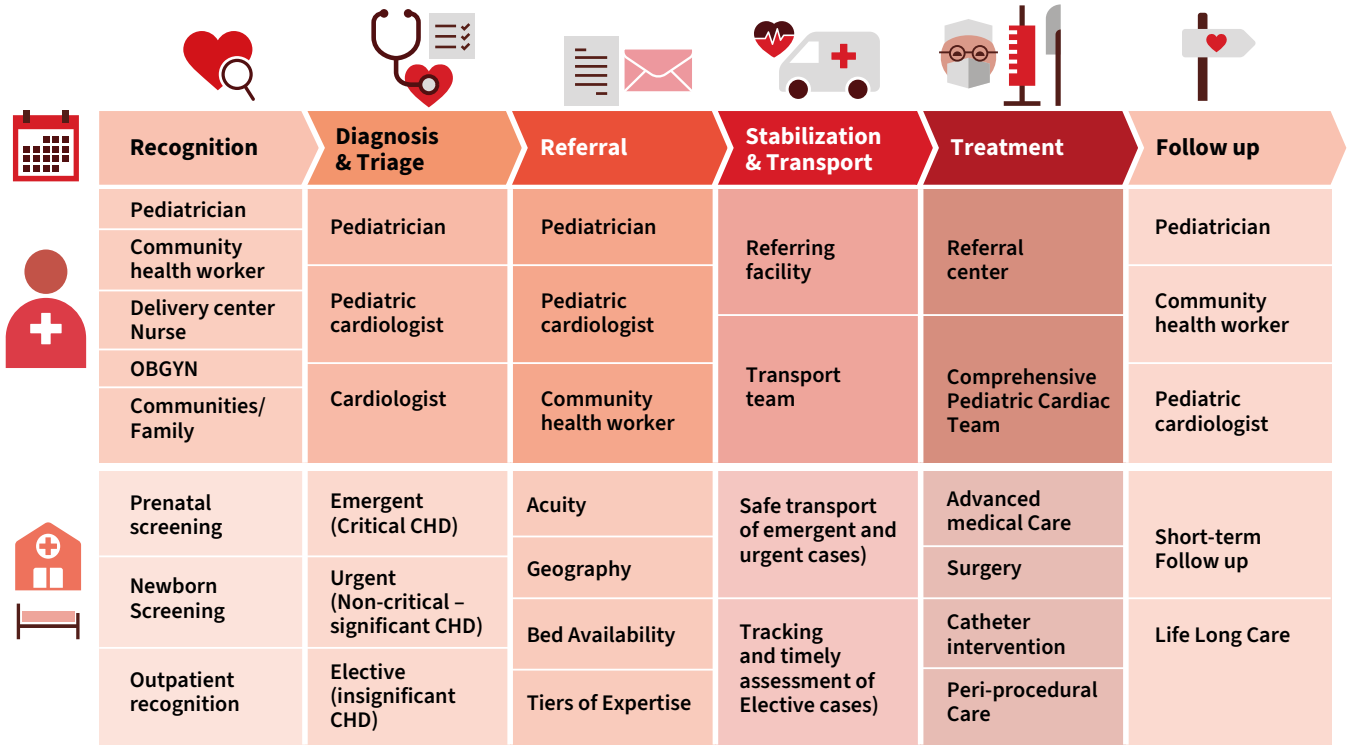


FIGURE 12
Elements of the CHD care continuum

Adapted from: Nair, S. M. et al. A Population Health Approach to Address the Burden of Congenital Heart Disease in Kerala, India. Global heart 16, (2021).

As CHD programmes mature, it is important to also develop systems for neurodevelopmental follow up and transition of care as patients grow into adulthood. While dedicated multidisciplinary facilities for adults with CHD may not be easy to establish in low resource environments, suitable avenues must be explored in partnership with adult cardiologists and other adult caregivers.

In many low-resource settings, the absence of even one health system component—such as ICU capacity, perfusion services, or safe blood availability—can undermine the entire CHD programme, rendering technically feasible surgery ineffective and placing patients at avoidable risk. Further, delays in diagnosis, late presentation, malnutrition, sepsis, and limited ICU capacity markedly increase mortality, such that procedures carried out in low resource settings carry substantially higher risk than in high-income countries where survival rates typically exceed 95%[48,49].

Evidence from Peru[14] illustrates that screening without downstream readiness can cause more harm than benefit. In the Peruvian maternal–perinatal experience, early detection of CHD did not translate into improved survival for many infants because referral delays, limited surgical capacity, and administrative barriers prevented timely treatment. One-year survival was markedly different depending on access to better-resourced systems, highlighting that diagnosis alone does not save lives.

CHD care does not end with hospital discharge after surgery. Children and adults with CHD require lifelong care that includes regular cardiology consultations, management of residual or progressive disease, reproductive care, mental and neurodevelopmental support, and planned transition from paediatric to adult CHD services. Patient and family education, and primary care and community-based follow-up are key to sustaining long-term outcomes and quality of life.

GLOBAL INEQUITIES IN CHD CARE

Significant inequities exist globally in the quality of CHD care, and arise mainly from the unequal distribution of resources across the health systems required to support people with CHD (Figure 13) [50].

Globally, only a handful of countries have the capacity to diagnose, let alone address CHD in children. In LICs and LMICs, for example, most children with CHD are likely to remain undiagnosed and will die prematurely, or present late, often with advanced disease and preventable complications that are sometimes inoperable[48]. This contrasts with high-income settings, where systematic antenatal screening, newborn pulse oximetry, and well-established referral pathways enable early intervention and markedly improve survival.

In LMICs, care options, including specialised paediatric cardiac services, may be geographically concentrated and the availability of diagnostic echocardiography, interventional cardiology, and cardiac surgery limited to a single tertiary institution in the country's capital. As such, children in rural and peri-urban regions face substantial care barriers related to distance, cost, and delayed referral[51]. These in-country structural constraints mirror broader global patterns of the misaligned distribution between disease burden and service availability, with the impact especially pronounced in decentralised health systems (Figure 14). In such settings, primary health care workers and other health professionals need to be trained to recognise the basic signs and symptoms of CHD in children to help ensure timely diagnosis and intervention.

ACCESSIBILITY

Sub-Saharan Africa has 1 center per **13 million people**; North America, Europe, and Central Asia 1 per **0.6 million**

CAPACITY

HICs have **140-180x** as many cardiac surgeons as LICs

QUALITY

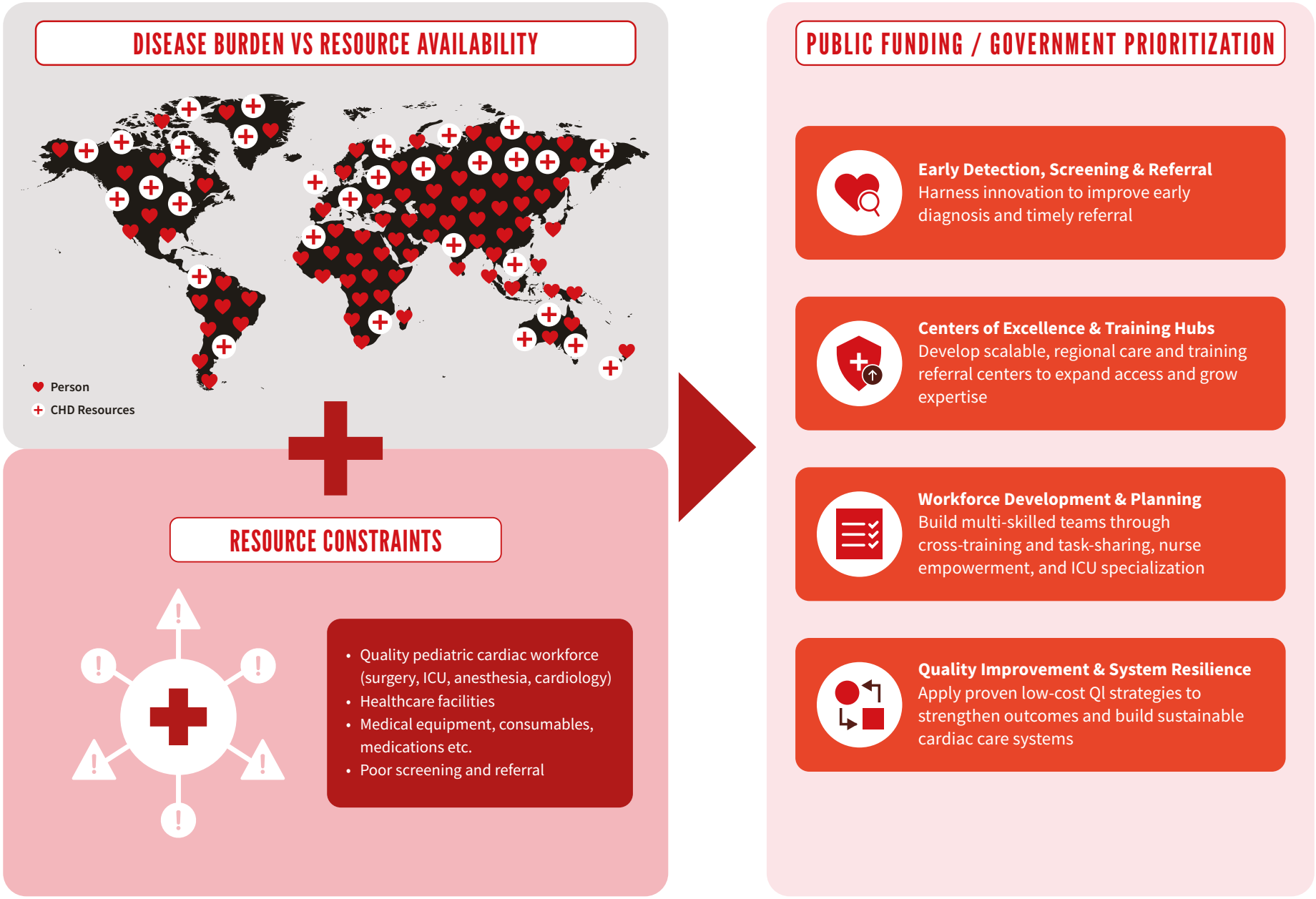
Various LMIC centers achieve **similar/better** outcomes than HICs

AFFORDABILITY

Cardiac surgery is expensive but can cost as little as **US$1,500**

FIGURE 13
Global inequalities in CHD care examples

FIGURE 14
Resource constraints and priorities for public funding



The challenges faced by LICs and LMICs in CHD care are not solely due to limited resources, but structural misalignment between disease burden, workforce capacity, financing mechanisms, and policy prioritisation. Addressing these gaps demands sustained political commitment, contextually appropriate service models, and integration of CHD into national health system planning (Figure 15). Without such action, CHD will remain a largely invisible cause of avoidable childhood mortality in low resource settings, reflecting and reinforcing wider patterns of global inequity.

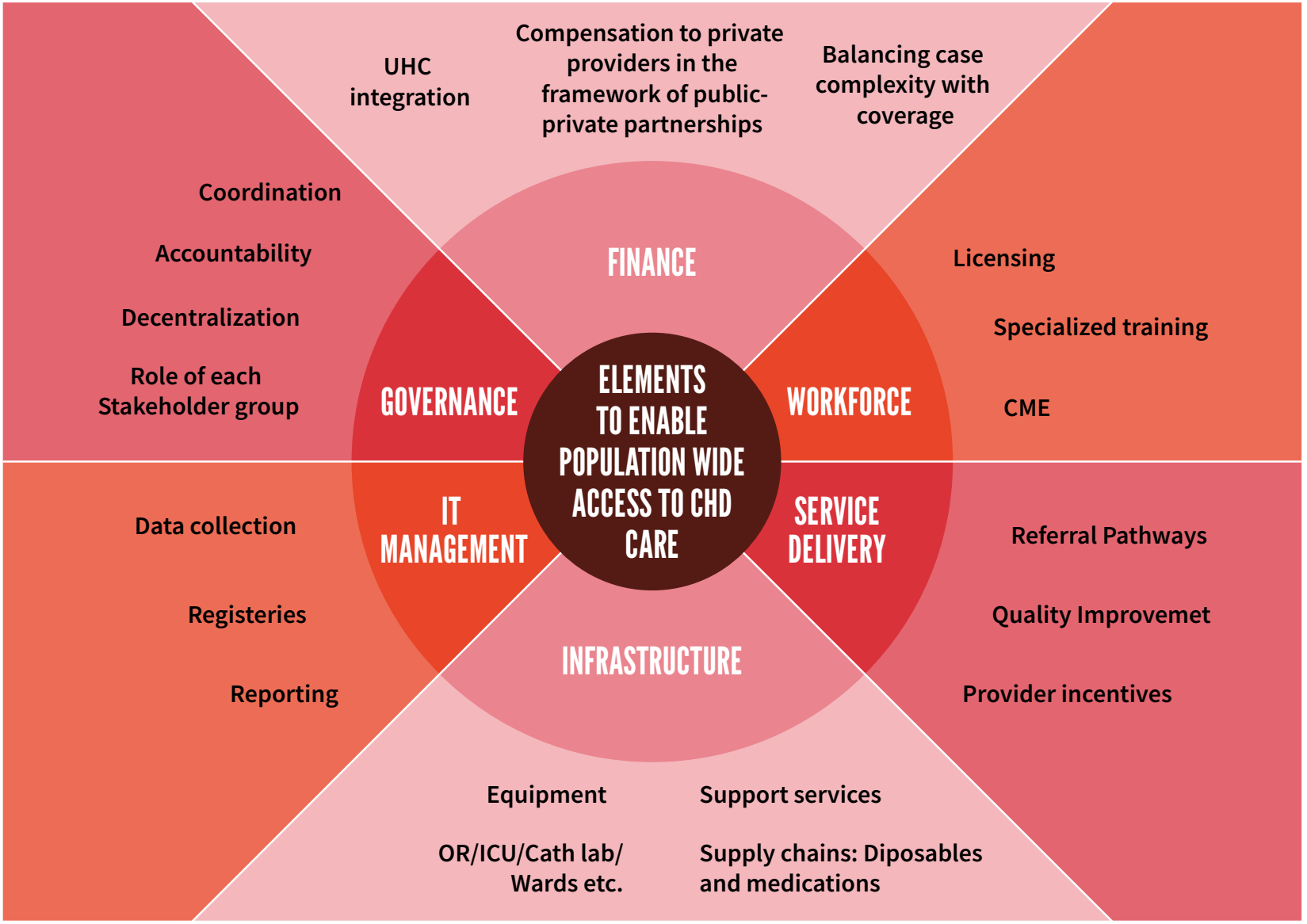


FIGURE 15
Elements to enable population wide access to CHD care

Adapted from: Vervoort, D. *et al.* Global Access to Comprehensive Care for Paediatric and Congenital Heart Disease. *CJC pediatric and congenital heart disease* **2**, (2023).

WORKFORCE AND INFRASTRUCTURE CONSTRAINTS

Workforce shortages are among the most critical bottlenecks for CHD care in LMICs and LICs (Figure 16). In these settings, there are few locally trained paediatric cardiologists, cardiothoracic surgeons with paediatric expertise, cardiac anaesthetists, perfusionists, and specialised nurses relative to population need.

The absence of sustained, in-country training pipelines perpetuates dependence on external training or visiting surgical missions, neither of which provides a scalable or sustainable solution to domestic capacity issues. Moreover, existing specialists often face excessive clinical workloads, limiting opportunities for teaching, research, and system development [53].

Additionally, evidence shows that poor-quality care—rather than lack of access alone—is now the dominant driver of excess mortality in LMICs. As a highly complex and longitudinal condition, CHD is especially vulnerable to quality failures at every stage—from inaccurate community-level detection and unsafe transport to suboptimal perioperative care and fragmented follow up.

While the burden of CHD remains greater in LMICs, many of these countries lack the resources and healthcare systems needed to effectively address the problem (Table 2).

Infrastructure limitations further constrain service delivery. Establishing and maintaining cardiac catheterisation laboratories, operating theatres, and paediatric cardiac intensive care units requires not only capital investment but also reliable power supply, biomedical engineering capacity, and consistent access to consumables. Intermittent equipment downtime, supply chain disruptions, and limited maintenance capacity undermine continuity and quality of care. These challenges illustrate how fragile health system foundations magnify inequities in highly specialised services [54].

	LOW INCOME	LOW & MIDDLE INCOME	HIGH INCOME
NEWBORN SCREENING FOR CHD	None	Few countries	Most countries
PRENATAL SCREENING	None	Limited but increasing	Standard of care for all pregnancies
SECURE INFANT AND NEWBORN TRANSPORT	No data available	Inconsistent and of poor quality	Available but quality varies
ACCESS TO INFANT HEART SURGERY, %	0-5	3-50 (15)	>80

TABLE 2
Variation in congenital heart care in high-income versus low- and middle-income regions[48]. Data Source: United Nations, World Population Prospects (2024).

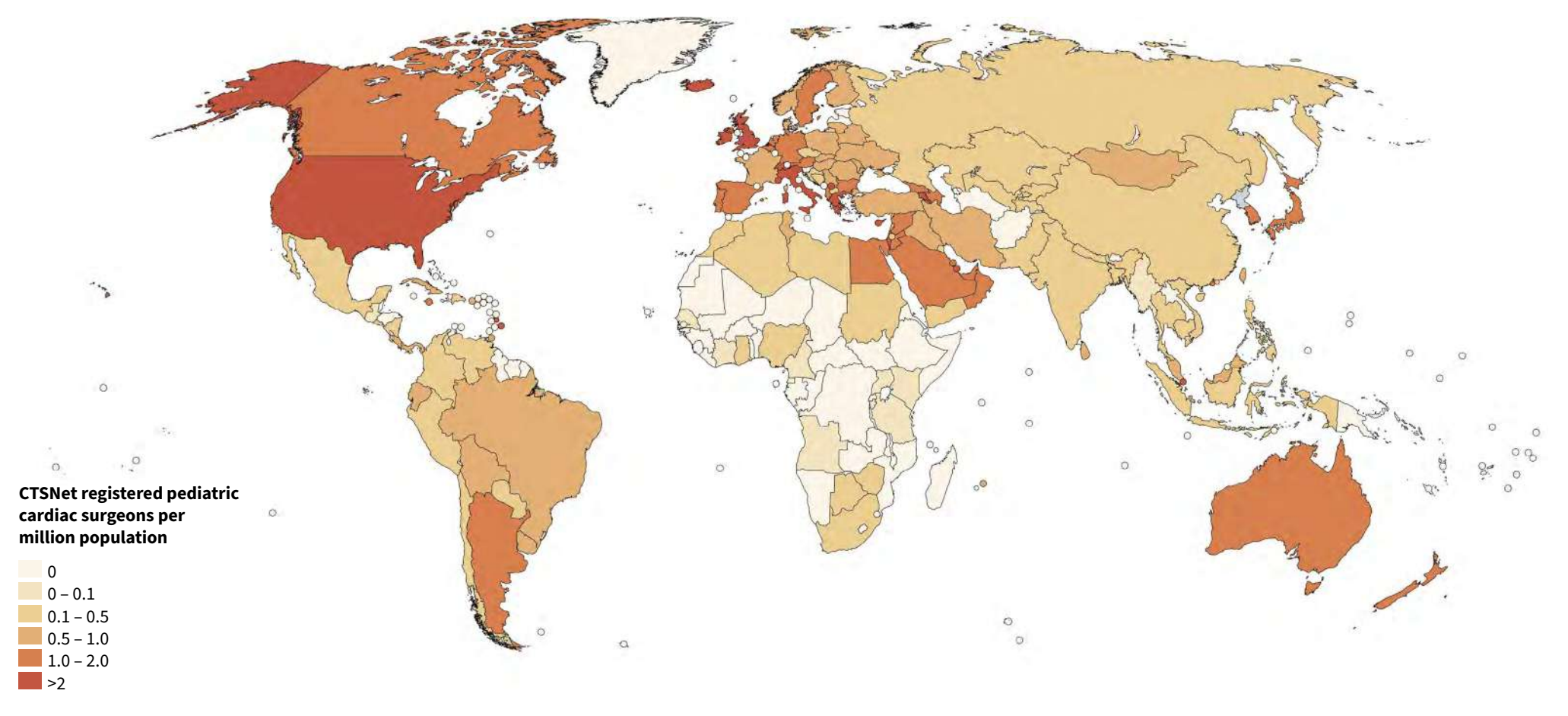


FIGURE 16
CTSNEt registered paediatric cardiac surgeons per million population (reprinted from Vervoort et al[52] with permission from Elsevier)

FINANCING AND ACCESS LIMITATIONS

Financial barriers are a major determinant of inequitable access.

Historically, CHD has been marginalised within most LIC and LMIC national health priorities, particularly compared to infectious diseases and maternal and child health issues that are more readily addressed through primary care interventions. Country-level data from Africa show how the number of paediatric cardiothoracic surgeons per million population is far below the international recommended ratio (a median of 0.04 vs 1.25) (Figure 17).

Ghana's experience is illustrative. The country's National Health Insurance Scheme, for example, is regarded as a significant achievement in health financing, yet coverage for complex paediatric cardiac investigations and surgery is limited. Families are therefore frequently required to make substantial out-of-pocket payments, leading to catastrophic expenditure or foregone care. Philanthropic and non-governmental support has enabled life-saving interventions for some children, but such arrangements are inherently episodic and insufficient to address population-level need.

Across many LICs and LMICs, a strategic shift is required from reliance on isolated centres and charitable models towards system-oriented approaches – something that advocacy efforts are supporting with calls to integrate CHD care into universal health coverage, workforce planning, and national NCD strategies [48,55]. Such a strategic shift would include the development of centres of excellence linked to regional referral networks, investment in multidisciplinary workforce training, and embedding CHD services within publicly financed health programmes. International experience demonstrates that these models can deliver high-quality outcomes even in resource-constrained settings when aligned with strong governance and quality improvement frameworks [55,56].

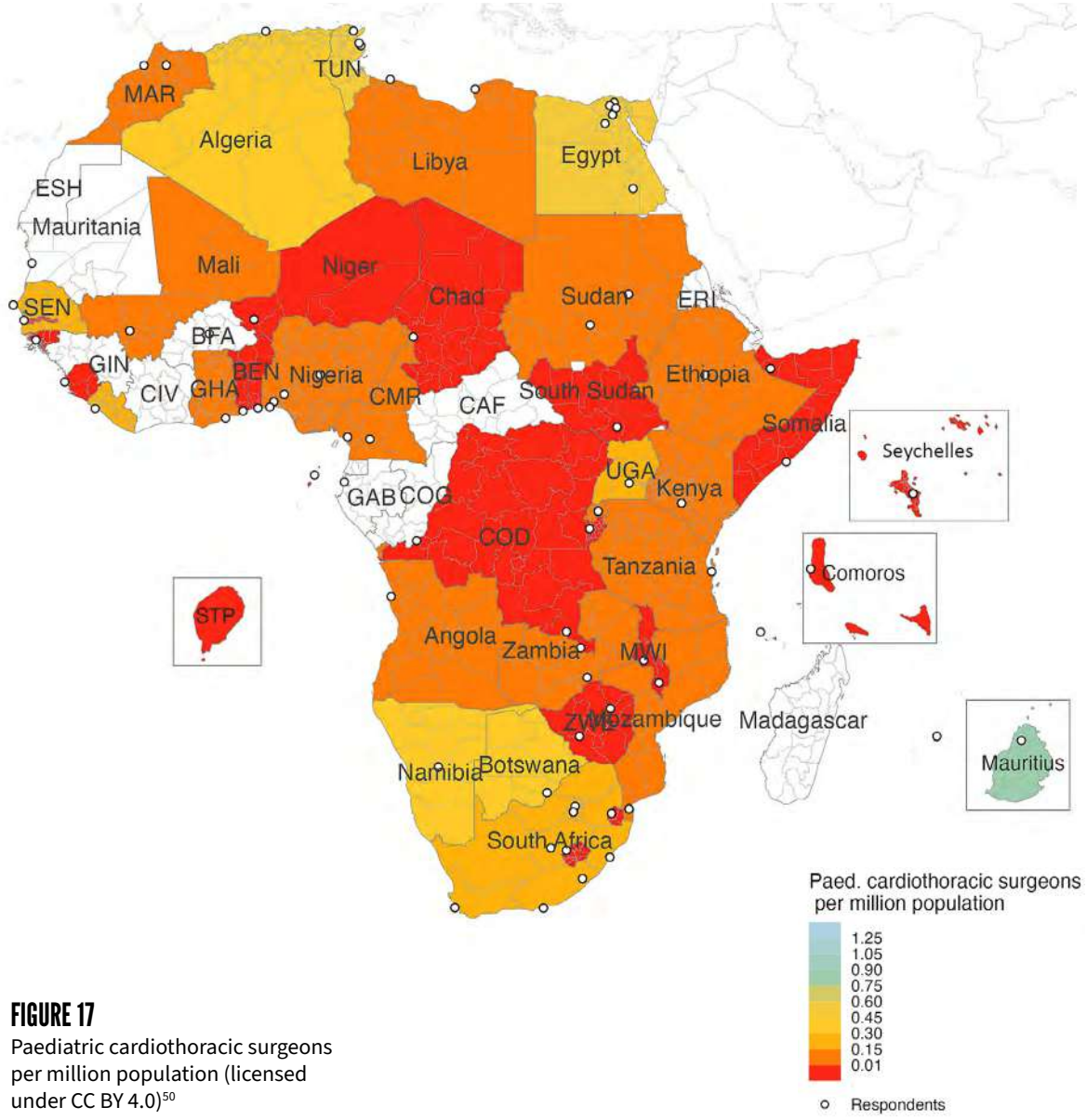


FIGURE 17
Paediatric cardiothoracic surgeons per million population (licensed under CC BY 4.0)[50]

THE ECONOMIC COST OF CHD

SURGICAL COSTS IN LMICS ARE LOWER IN ABSOLUTE TERMS YET OFTEN REPRESENT CATASTROPHIC EXPENDITURE RELATIVE TO HOUSEHOLD INCOME

The economic burden of CHD varies substantially across geographic and economic contexts, and encompasses direct healthcare costs, out-of-pocket expenditures, and broader societal impacts.

In the United States, lifetime costs for complex CHD average US$2.1 million per patient, of which 43-63% are indirect costs that are paid by patients and their families. One third (31%) of these costs are incurred in the first five years of life. Families bear a disproportionate share, paying an average of US$190,000 out-of-pocket. Across the United States, the annual economic burden is estimated at US$74 billion, with the total lifetime economic impact exceeding US$3.35 trillion [35].

In China, data from Gansu province report a mean inpatient cost of just below US$3,300 and an average hospital stay of 10.1 days, with infants under 1 year of age incurring the highest costs due to the intensive care requirement of early surgeries. Nationally, CHD accounts for more than 12.6 billion RMB in annual healthcare costs [36].

Surgical costs in LMICs are lower in absolute terms yet often represent catastrophic expenditure relative to household income. In Rwanda, median surgical costs are US$7,700, with ASD and VSD repairs costing US$4,593.82 (±1,199.09) and US$6,565.87 (±2,134.91) respectively[37]. These figures are less than treatment abroad but are substantial given a GDP per capita under US$1,000. In Belgium, mean hospitalisation costs range from €11,106 for atrial septal defect repair to €33,865 for Norwood operation, with complications increasing costs by 65-252%[38]. In India, median surgical admission costs are INR 201,898, though costs vary by hospital type; for example, ASD closure ranges from INR 65,000 to 450,000; VSD closure from INR 65,000 to 350,000; PDA ligation from INR 10,000 to 200,000[38,39]. Many patients and families are forced to sell assets, borrow money, or deplete savings, with the majority relying on government schemes or charitable support. In Nigeria, ASD repair averages around US$6,230, representing 2-3 times the per capita gross national income [40].

ADDRESSING INEQUITIES

Advancing CHD care requires building integrated, robust systems that link early community-based detection to safe transport, a tier-based health system along the care continuum, centres of excellence delivering lifelong care, robust quality improvement frameworks, and smart use of digital and technological solutions. These elements comprise scalable, equitable models that have demonstrated success and can be adapted across diverse settings[57,58]

CLINICIAN STORY

DR JUAREZ MEXICO, PAEDIATRIC CARDIOLOGIST

Dr Fabiola Perez Juarez still remembers the first time she listened to a heartbeat. Standing beside her father, a physician, she placed a stethoscope to a patient's chest and felt something shift.

> **"Her work is driven by skill, but sustained by something deeper. Every patient she has treated, and every one she has lost, stays with her. We carry every patient with us."**

"It felt like I was in an even better place in the world," she says. From that moment, her path was set.

Today, nearly 20 years into her career as a paediatric cardiologist in Mexico City, Fabiola carries that same sense of wonder into every patient interaction. But her journey has not been easy. During her training, she was told repeatedly that cardiology was "not for women". Surrounded by male professors, she faced doubt and resistance. Still, she persisted. "It was my dream," she says simply. "So I kept going."

In her work, the stakes are high. Many of her patients travel long distances to access care, navigating a fragmented healthcare system where access depends on income, geography, and insurance. Some families wait months, even a year, for life-saving surgery. Others arrive too late, having had little or no prenatal care. These realities weigh heavily.

And sometimes, despite everything, a child does not survive.

"I remember the first time I lost a patient," she says. "My heart was broken." There is no training for that moment. No guide for how to carry the grief of families, or the memory of a child who should have lived. "Nobody teaches us how to live with losing a patient."

Yet it is this same depth of feeling that defines her care. Fabiola does not see patients as cases. She sees them grow up. She sees them come back years later, holding their own children. "There is no money that can replace that feeling," she says.

She is also helping to build the future of care in Mexico, supporting the transition of patients into emerging adult congenital heart disease programs and working across government, private hospitals, and foundations to reduce barriers. For Fabiola, the goal is clear: "Healthcare should be the same for everyone, regardless of income or where you live."

EARLY DETECTION, SCREENING AND DEFINING A CARE PATHWAY

Early diagnosis is the foundation of survival and long-term quality of life for children with CHD. Countries must place strong emphasis on universal newborn screening, including pulse oximetry, and ensure that CHD screening is fully integrated into maternal, newborn, and child health programmes. This should be supported by clear and efficient referral pathways that link community-level detection to tertiary care services, along with standardised diagnostic and treatment algorithms that guide timely decision-making[59].

KERALA'S SUCCESSFUL CHD CARE INITIATIVE

The experience in Kerala, India, provides one of the most compelling real-world examples of applying an integrated systems approach to CHD[57-59].

Faced with stagnant infant mortality rates and recognition that congenital anomalies—particularly CHD—were a major contributor, Kerala reframed CHD as a population health problem rather than a series of isolated surgical cases. Through the Hridyam program, Kerala introduced statewide antenatal and newborn screening, and paired this with a real-time digital registry, clear triage algorithms, guaranteed financing, and coordinated referral to capable centres. Children were supported across the entire care continuum, from suspicion of CHD to diagnosis, treatment, and follow-up, ensuring that no child was "lost" along the way.

Several features stand out in the Kerala model. Embedding CHD screening within existing maternal and child health services rather than operating as a stand-alone program helped integrate CHD care with existing public health programmes. A centralised system was created that matched patients to hospitals based on urgency, expertise, and bed availability, leading to better coordination. Investments were made in surgery, transport, intensive care, nursing, and data systems, helping to build care capacity. Finally, public financing reduced catastrophic out-of-pocket expenditure for families [57,58].

DEVELOPING CENTRES OF EXCELLENCE

Not every hospital needs to perform heart surgery, but every country must ensure access to high-quality CHD care through designated centres of excellence.

These centres should maintain adequate case volumes to preserve expertise and quality outcomes[60,61], and should be embedded within regional referral networks that allow patients to move smoothly through the system.

Regionalisation of CHD services consistently improves outcomes, enhances efficiency, and supports a stable and skilled workforce[62]. Equally important is the development of regional training hubs that are closely linked to service delivery, ensuring that education and clinical care reinforce one another. Such centres should also conduct contextual research to generate locally relevant evidence and data[63].

Sustainable, international long-term partnerships—rather than short-term mission-based approaches—are also essential for building durable capacity[64–66]. These partnerships may be between institutions from high income countries and those in LMICs or between centres based across different LICs and LMICs, which may be a more sustained, efficient and contextually relevant[66].

WORKFORCE DEVELOPMENT

Workforce development and teamwork is central to any successful CHD programme.

Effective strategies must include the training of paediatric cardiologists, adult CHD cardiologists, cardiac surgeons, anaesthetists, intensivists, nurses, and perfusionists[4]. Additionally, partnerships to form teams with multidisciplinary backgrounds, including primary care physicians, neurologists, and allied health professionals such as psychologists and nutritionists can play a key role in improving the overall quality of care and transitioning to lifelong support for people with CHD.

Thoughtful task sharing where appropriate can help safely distribute work. Examples include nurse-led follow-up clinics or targeted echocardiography training for non-physician providers [67]. Retention strategies and clear career pathways are vital to prevent workforce attrition[68] and cross-country collaborations can play a valuable role in skills transfer and mentorship [68–70]. In many settings, human resources—rather than technology—remain the most significant limiting factor in expanding CHD care. A focused, dedicated leader present on ground within the local context is essential for the establishment of a successful CHD programme[69,71].

Underpinning all this needs to be population health approaches for workforce planning and forecasting, including ensuring that patients in remote areas can access the specialised care they need. Careful planning and forecasting of workforce needs, and by extension capacity and infrastructure needs, will involve consultative processes in each country where different stakeholders can debate and recommend the best approaches that fit the needs of their population.

IMPROVING QUALITY OF CARE AND SYSTEM RESILIENCE

Quality improvement (QI) science is central to improving outcomes for CHD across the entire care continuum in LMICs[72,73]. Embedding QI metrics across this continuum may enable improvements in screening accuracy, referral efficiency, transport safety, and surgical and postoperative outcomes[73].

Multi-institutional learning initiatives, such as the International Quality Improvement Collaborative (IQIC), demonstrate how systematic data collection, benchmarking, and feedback can substantially reduce mortality and infection rates in LMIC CHD programmes [7475], narrowing outcome gaps with high-income settings especially in simple cases of CHD[76].

High-quality CHD care also depends on continuous QI and resilient health systems that can adapt to changing conditions and growing populations of adults with CHD. Priority actions include participation in CHD registries, systematic outcome tracking, and the routine use of standardised indicators, such as mortality, major infection rates, and reintervention as benchmarks to drive QI efforts. Regular morbidity and mortality reviews and the integration of QI processes into everyday practice further foster a culture of learning and accountability. These systems are typically more resilient and are better equipped to maintain safe and effective CHD care even during periods of crisis, including pandemics, workforce shortages, or disruptions in supply chains.

INTEGRATING TECHNOLOGY AND DIGITAL HEALTH SOLUTIONS

Technology and digital health solutions offer powerful and often low-cost opportunities to strengthen CHD care, particularly in resource-constrained settings.

Tele-echocardiography and remote consultations can extend specialist expertise to underserved areas, while digital referral and follow-up systems improve continuity of care. Online education platforms and simulation-based training enhance workforce development, and electronic registries and dashboards support real-time quality monitoring.

When implemented thoughtfully and aligned with clinical workflows, digital health tools can substantially reduce geographic inequities and amplify the impact of limited specialist resources. Work done in Brazil demonstrates how telemedicine can be used to strengthen community-based CHD screening by training paediatricians to perform basic echocardiography with remote cardiologist support[77,78]. Over seven years, paediatricians received focused initial training, then performed bedside echocardiograms that were supervised live or reviewed asynchronously by paediatric cardiologists. Nearly 4,000 studies were analysed, showing progressive improvement in paediatricians' diagnostic accuracy and agreement with specialists, rising from poor to moderate–good concordance over time[67]. The programme improved early CHD detection, optimised referrals, and reduced unnecessary transfers, illustrating a scalable, low-cost telemedicine model to integrate education, screening, and referral across the CHD care continuum in resource-limited settings [67,77,78].

IMPROVING ACCESS TO CHD MEDICAL INTERVENTIONS

The biomedical and pharmaceutical industry plays a critical role in the CHD care ecosystem. Cardiac surgery and postoperative care are impossible without a multitude of technologies, consumables, pharmaceuticals, and devices critical for sustaining a high-quality surgical service. Yet access to life-saving surgery, especially in low-income countries, is constrained by unreliable access to paediatric-specific cardiac devices and consumables, high unit costs, fragmented procurement, and limited supply-chain predictability. Many countries are often reliant on donations or ad-hoc purchasing that do not create sustainable access or incentives for manufacturers to serve these markets long-term. Consumables and device manufacturers perceive the markets as unreliable in volume and quality of treatment and are reluctant to invest in their development. There is a serious need for the biomedical and pharmaceutical industry to step up and address these inequities. For example, they can support local production and distribution of essential medical devices and implants. This includes partnering with governments and nonprofit organizations to establish supply chains for affordable consumables, investing in research of new therapies tailored for paediatric populations, or tiered pricing models to ensure accessibility.

ADVANCING CHD CARE THROUGH POLICY AND ADVOCACY

Policy and legislative action are essential to support integration and care quality for CHD. In the United States, for example, the Congenital Heart Futures Reauthorization Act (2018) and the Advancing Care for Exceptional Kids Act (2019) have enhanced research, surveillance, and the establishment of specialized health homes for children with medically complex conditions, including CHD[81].

Evidence further demonstrates that guidelines and specialised centres improve outcomes for patients with CHD: for example, after publication of the Canadian Cardiovascular Society ACHD guidelines in 1998, referrals to specialised centres increased markedly, and high-volume institutions are associated with lower mortality across multiple cardiovascular conditions [82].

To ensure continuity of care across the life course, CHD should be reframed as a lifelong NCD within policy frameworks. Integrating CHD into NCD strategies, particularly through the lens of SDG 3.4 (reducing premature mortality from NCDs), allows for the development of life-course strategies that address chronic needs[83], including transition protocols for adolescents moving into ACHD programmes[84] and attention to the unique reproductive health needs of women with CHD[84,85].

CHD-related services, such as antenatal screening, essential medicines or post-partum follow-up must be explicitly included in universal health coverage benefit packages. Isolated progress is being made—for example, eight LMICs have developed and launched national surgical, obstetric, and anaesthesia plans, with many others in progress[86].

At the international level, major organisations, including the WHO, United Nations, and World Bank rarely address cardiac surgery in policy guidelines, even when discussing surgical access or specific conditions such as CHD. In LMICs, this policy neglect seems to stem from the lack of prioritisation of CHD in health policies, insufficient funding, and fragmented health systems that fail to integrate CHD care into broader surgical and cardiovascular initiatives. Finally, governments can strengthen CHD care and research by committing non-earmarked funding and supporting regional collaboration [51].

ADDRESSING CHD IN PREGNANCY

The importance and urgency of addressing congenital and acquired heart disease in pregnancy is increasingly recognised within the cardiovascular community[1]. However, CHD care remains unevenly integrated within national health planning frameworks, particularly in LMICs[3] and despite being the most common congenital condition[3,51] and a major contributor to maternal, perinatal, and child morbidity and mortality [79,80].

This is particularly problematic in maternal health. As survival from CHD into adulthood improves, increasing numbers of women are entering pregnancy with adult CHD[80]. Maternal ACHD is associated with a higher risk of pregnancy complications, such as emergency caesarean delivery, postpartum haemorrhage, and cardiac complications, as well as adverse foetal and neonatal outcomes[80]. Whereas most children with CHD now survive into adulthood in high-income countries, in many LMICs over 90% of affected children lack access to timely care[51,80], resulting in "hidden" mortality that hinders progress toward Sustainable Development Goal (SDG) 3.2 (ending preventable deaths of newborns and children under 5).

Effective integration of CHD care begins with prevention and early detection, ensuring that antenatal and preconception care policies incorporate cardiovascular risk assessment, screening, and counselling. Many prevalent forms of cardiovascular disease affecting pregnancy may not be identified until antenatal visits. This gap is particularly pronounced in LMICs, where up to one-third of antenatal cardiovascular disease cases may be first diagnosed during pregnancy.

National guidelines are needed to standardise antenatal assessment protocols and enable early identification of pre-existing heart disease and guiding pregnancy management. Most disease-specific clinical guidelines now include dedicated sections on pregnancy, including those addressing congenital, valvular, and aortic disease . The European Society of Cardiology and the American Heart Association have issued comprehensive guidance emphasising early diagnosis, risk stratification, optimisation of care, and - where possible - preconception counselling delivered by multidisciplinary teams . Further, risk stratification tools, such as the modified WHO classification, can support identification of high-risk patients who should be managed in specialised centres with appropriate diagnostic and therapeutic capacity.

Limited evidence suggests that up to 30% of CHD cases may be attributable to modifiable environmental or behavioural factors [79], highlighting a critical gap in prevention. Further, the establishment of coordinated, multidisciplinary models of care, particularly through cardio-obstetrics teams are essential. These teams bring together skilled professionals with expertise across the spectrum of cardiovascular disease to support women throughout the continuum of care: from preconception to the post-partum period. Given that cardiovascular disease is the leading cause of pregnancy-related morbidity and mortality globally, investment in cardio-obstetrics teams represents a cost-effective and high-impact health system intervention.

ADVANCING CHD CARE THROUGH POLICY AND ADVOCACY CONTINUED

CHD-specific policies cannot be successful on their own. While CHD requires special attention due to the specialised nature of the disease, the most successful approaches are integrated into maternal, newborn, and child health policies, and NCD and chronic illness frameworks.

By embedding CHD screening, diagnosis and long-term management within broader health policies, countries can ensure that these policies are part of a broader child health agenda and ensure children receive timely interventions and that families are supported throughout the continuum of care. This integration can help to raise awareness and educate healthcare providers and the public, further fostering earlier detection and better long-term outcomes. The goal is not to create vertical or horizontal approaches, but rather to embed care diagonally across the system8[7].

A key component of policy development in CHD care should be development of standards of care. Successful examples of this exist mostly in high-income countries, such as those developed in the NHS in England[88] and by HeartKids in Australia[89]. However, more LMICs have been trying to move similar efforts forward, notably Argentina[90] where they developed a federal care network for CHD to regionalise high-volume centres and set common standards of care and, most importantly, outcomes.

In most cases, CHD care is unaffordable to patients and families and can lead to significant financial hardship, and sometimes catastrophic expenditures. The development of specialised policies, therefore, requires increased and sustained investment by funders, including governments, multilateral organizations, and philanthropy. Without adequate financial support, progress in CHD care will remain uneven and slow, and countries will have to think how financing of CHD care will be implemented as part of policies for UHC, or broader healthcare financing. In India, for example, the RBSK program[91], and later the Ayushman Bharat scheme[92], set predetermined reimbursement rates for different types of procedures that are used by states to reimburse public and private hospitals for providing care. While this has been a major improvement in access to surgical and hospital care, it has not resolved the issue of families having to pay out of pocket for pre-hospitalisation investigations or post-discharge care, such as medications and any rehabilitation services.

THE ROLE OF RESEARCH IN ADVANCING POLICY

Aligning global research priorities and establishing standardised registries to track the burden of CHD, evaluate the effectiveness of interventions, and identify emerging challenges, is vital to improve CHD-related policy.

One such example is the IQIC[93], a global QI initiative with the goal of reducing CHD surgery mortality by providing access to an LMICs registry for benchmarking data and guiding quality improvement efforts. While this is not a research database *per se* and doesn't provide longitudinal and population level data for different countries, it is an important effort that can inform national and global policies and priorities. Ultimately, all countries need to integrate CHD surveillance into national registries and combine them with data from surgical databases to ensure long-term outcomes and access to lifelong care for the patients. The Hridyam[57] project in Kerala, India, developed a state-wide registry that is aiming to do that, similarly to the national population level data that Denmark collects for all CHD patients[94] in its national registry.

COORDINATING ADVOCACY

Easily accessible learning opportunities exist to support the advancement of CHD care, including through advocacy.

NGOs such as Heart University provide online learning resources "for all providers of care to children and adults with CHD or children with acquired heart disease" which can amplify clinical and advocacy efforts[95]. The World Heart Federation, through its World Heart Report on Congenital Heart Disease, further contributes to advancing awareness and action. Professional societies also play a critical role: the World Society for Pediatric and Congenital Heart Surgery, for example, is expanding its World Database to LMICs [51].

Addressing the global burden of CHD requires a unified and sustained advocacy effort within and across national borders. To achieve the goals of Universal Health Coverage (UHC) and SDG 3.2, countries must ensure that paediatric and congenital cardiac care is an integral part of the national health system. To close these gaps, collective action on several fronts is essential. WHF proposes an advocacy framework for development of policies that specifically address CHD, the goal being for every country to develop a national strategy or national action plan for CHD, including service delivery, workforce development, infrastructure, financing, and governance.

Advocacy is always more impactful when done together. The Global Coalition for Pediatric and Congenital Hearts, a coalition of patients and families, professionals and NGOs, formed in 2024 and has launched a campaign advocating for a 2027 World Health Assembly (WHA) Resolution on Childhood-Onset Heart Disease Care to be adopted by the 194 Member States of the WHA, the highest multilateral health policy-setting body. This Resolution would aim to scale up and integrate paediatric and congenital heart care into health systems as part of UHC and compel governments to put in place effective policy responses supported by adequate financial investments to address the growing needs of all with childhood-onset heart diseases (Figure 18)[96].

CALLING ON GOVERNMENTS TO TAKE ACTION

A WHA Resolution on Childhood-Onset Heart Disease Care will emphasize the need for a comprehensive agenda to help countries develop national heart care strategies and adequate workforce, infrastructure, capacity and financing of pediatric and congenital heart services.

In recognition of the 2023 WCPCCS Call to Action, a 2027 WHA resolution would include the following:

Increase capacity to care for people with childhood-onset heart diseases

Build the pediatric and congenital cardiac workforce

Close the data gap

Finance childhood-onset heart disease care

FIGURE 18
Campaign for a WHA resolution on childhood-onset heart disease (reproduced from Ref. 96 with permission)

WORLD HEART FEDERATION

KEY RECOMMENDATIONS

All countries and stakeholders must urgently work together to accelerate efforts to address gaps in CHD care globally through the implementation of evidence-informed public health and clinical interventions.

Without such action, CHD will remain a largely invisible cause of avoidable childhood mortality, reflecting and reinforcing wider patterns of global inequity.

WHF RECOMMENDS THE FOLLOWING KEY ACTIONS:

1 All countries should urgently increase national level capacity across the health system to care for people with childhood onset heart disease, including CHD. This includes developing and scaling centres of excellence, improving referral networks from early detection and diagnosis to surgery, long-term follow-up, and transition to adult care, and integrating congenital heart services into broader maternal, newborn, and child health systems. Ultimately, the goal is to move from episodic, acute care to sustainable, locally led systems capable of delivering timely, high-quality population level services ensuring continuity of care across the lifespan. Such programmes require sustained investment with inclusion of CHD services into UHC benefits packages to avoid financial hardship or catastrophic costs for affected families.

2 Countries should invest in training and building the paediatric and congenital cardiac workforce and strengthening capacity of the adult CHD workforce. This includes training and retaining multidisciplinary specialized paediatric and congenital cardiac care teams and requires developing national CHD health workforce development plans based on population needs forecasting that include development of formal training pathways.

3 Countries and international bodies should work together to improve CHD surveillance and close the data gap to enhance the understanding of CHD epidemiology and determinants. This requires strengthening national health information systems to capture data on CHD prevalence, outcomes, and service delivery, such as through population level registries. Such data should include more granular and comparable information on subtypes of CHD. Better data would enable countries to improve care delivery based on quality improvement metrics, plan and allocate resources more effectively, and track progress over time.

4 Policymakers at international and national level must ensure CHD is reflected in relevant policy frameworks. NCD, maternal and child health and surgical policy initiatives should include measures to improve access to, and quality of, CHD care across the care continuum. This can further support the aims of such policies to reduce NCD and infant mortality, in alignment with the Sustainable Development Goals. Furthermore, policymakers should support the development of national, context-appropriate guidelines to improve implementation of best practice and CHD outcomes.

5 Advocates for CHD care should work to amplify the voices of CHD patients and their families to drive efforts forward. Lived experiences provide unique insights that can inform service delivery, research priorities, and support systems. Empowering patient organisations fosters a patient-centred approach to care and ensures that the needs of those affected are at the forefront of global efforts.

6 Civil society, including national NCD and CVD organizations,should support the campaign for a 2027 WHA Resolution on Childhood-Onset Heart Disease. The resolution will help achieve Universal Health Coverage and reductions in preventable deaths of newborns and children under five, by ensuring countries have paediatric and congenital cardiac care as an integral part of the national health system. Advocates can use resources provided by the Global Coalition for Pediatric and Congenital Hearts to plan and implement national campaigns.

REFERENCES

1. Call to Action on Addressing the Global Burden of Pediatric and Congenital Heart Diseases. *World Heart Federation* https://world-heart-federation.org/news/call-to-action-on-addressing-the-global-burden-of-pediatric-and-congenital-heart-diseases/ (2023).
2. Institute for Health Metrics and Evaluation (IHME). Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2023 (GBD 2023). https://www.healthdata.org/research-analysis/gbd (2025).
3. Hasan, B. S. *et al.* Recommendations for developing effective and safe paediatric and congenital heart disease services in low-income and middle-income countries: a public health framework. *BMJ global health* **8**, (2023).
4. Babar S. Hasan, M. & Dm, R. K. K. Adapting the 2025 ACC/AHA/HRS/ISACHD/SCAI Guideline for Management of Adults With Congenital Heart Disease to Low Resource Settings. *Journal of the American College of Cardiology* (2026) doi:10.1016/j.jacc.2025.12.062.
5. Saxena, A. Adult With Congenital Heart Disease in Developing Country: Scope, Challenges and Possible Solutions. *Current treatment options in cardiovascular medicine* **17**, (2015).
6. Rates of Congenital Heart Defects Rise in States With Restrictive Abortion Laws. *American College of Cardiology* https://www.acc.org/Latest-in-Cardiology/Articles/2025/03/25/14/24/Rates-of-CHDs-Rise-in-States-With-Restrictive-Abortion-Laws-acc-2025.
7. Tomek, V. *et al.* Pregnancy Termination and Postnatal Major Congenital Heart Defect Prevalence After Introduction of Prenatal Cardiac Screening. *JAMA Network Open* **6**, e2334069 (2023).
8. Nakao, M. *et al.* Association between parental decisions regarding abortion and severity of fetal heart disease. *Scientific Reports* **14**, 15055 (2024).
9. Miles, K. G. *et al.* Mental Health Conditions Among Children and Adolescents With Congenital Heart Disease: A Danish Population-Based Cohort Study. *Circulation* **148**, 1381–1394 (2023).
10. Kovacs, A. H. *et al.* Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association. *Circ Cardiovasc Qual Outcomes* **15**, e000110 (2022).
11. Meentken, M. G., van Beynum, I. M., Legerstee, J. S., Helbing, W. A. & Utens, E. M. W. Medically Related Post-traumatic Stress in Children and Adolescents with Congenital Heart Defects. *Frontiers in Pediatrics* **5**, 20 (2017).
12. Simeone, R. M. *et al.* Post-traumatic stress disorder, anxiety, and depression among adults with congenital heart defects. *Birth defects research* **114**, 124 (2021).

13. Entsua-Mensah, K. *et al.* Psychological Distress and Its Associated Factors Among Parents of Children With Congenital Heart Disease: A Cross-Sectional Mixed Method Study at the National Cardiothoracic Center, Ghana. *World journal for pediatric & congenital heart surgery* **15**, (2024).

14. Carhuayo-Chura, J. *et al.* Short-Term Results of Early Detection of Critical Congenital Heart Disease: The Peruvian Maternal Perinatal Experience. *JACC. Advances* **4**, (2025).

15. The Role of Congenital Heart Disease Patient Organizations in Advocacy, Resources, and Support Across the Lifespan. *CJC Pediatric and Congenital Heart Disease* **2**, 256–266 (2023).

16. Vasilescu, S. *et al.* Comprehensive Review of the Psychosocial Impact on Parents of Newborns With Congenital Heart Disease: A Significant Problem in Low- and Middle-Income Countries. *Cureus* **16**, e68532 (2024).

17. Moro, C., Iudici, A. & Turchi, G. P. Parents of Children with Congenital Heart Disease (CHD): A Narrative Study of the Social and Clinical Impact of CHD Diagnosis on Their Role and Health. *Behavioral Sciences* **15**, 269 (2025).

18. Zhang, Y. *et al.* Families under pressure: A qualitative study of stressors in families of children with congenital heart disease. *Stress and health : journal of the International Society for the Investigation of Stress* **39**, (2023).

19. Violant-Holz, V., Muñoz-Violant, S. & Rodrigo-Pedrosa, O. Challenges of inclusive schooling for children and adolescents with congenital heart disease: A phenomenological study. *Psychology in the Schools* **60**, 4946–4966 (2023).

20. Chaithra, S., Agarwala, S. & Ramachandra, N. B. High-risk genes involved in common septal defects of congenital heart disease. *Gene* **840**, (2022).

21. Białkowski, J. *et al.* Patent ductus arteriosus at low and high altitudes: anatomical and haemodynamic features and their implications for transcatheter closure. *Kardiologia polska* **69**, (2011).

22. Pierpont, M. E. *et al.* Genetic Basis for Congenital Heart Disease: Revisited: A Scientific Statement From the American Heart Association. *Circulation* (2018) doi:10.1161/CIR.0000000000000606.

23. Russell, M. W., Chung, W. K., Kaltman, J. R. & Miller, T. A. Advances in the Understanding of the Genetic Determinants of Congenital Heart Disease and Their Impact on Clinical Outcomes. *Journal of the American Heart Association: Cardiovascular and Cerebrovascular Disease* **7**, e006906 (2018).

24. Dong, W. *et al.* Recessive genetic contribution to congenital heart disease in 5,424 probands. *Proceedings of the National Academy of Sciences* **122**, e2419992122 (2025).

25. Wu, L., Li, N. & Liu, Y. Association Between Maternal Factors and Risk of Congenital Heart Disease in Offspring: A Systematic Review and Meta-Analysis. *Maternal and Child Health Journal* **27**, 29 (2022).

26. Wondemagegn, A. T. & Afework, M. The association between folic acid supplementation and congenital heart defects: Systematic review and meta-analysis. *SAGE Open Medicine* **10**, 20503121221081069 (2022).

27. Qu, Y. *et al.* Maternal Serum Folate During Pregnancy and Congenital Heart Disease in Offspring. *JAMA Netw Open* **7**, e2438747–e2438747 (2024).

28. Sun, L. *et al.* Maternal exposure to ambient air pollution and risk of congenital heart defects in Suzhou, China. *Frontiers in Public Health* **10**, 1017644 (2023).

29. Jin, S., Yoon, S. Z., Choi, Y. J., Kang, G. & Choi, S. U. Prenatal exposure to air pollutants and the risk of congenital heart disease: a Korean national health insurance database-based study. *Scientific Reports* **14**, 16940 (2024).

30. Krishnakumar, M. *et al.* Impact of exposure to extreme heat events during pregnancy on the incidence of congenital heart disease in offspring: a meta-analysis. *BMJ paediatrics open* **8**, (2024).

31. Climate change may increase congenital heart defects. *EurekAlert!* https://www.eurekalert.org/news-releases/616167.

32. Joinau-Zoulovits, F., Bertille, N., Cohen, J. F. & Khoshnood, B. Corrigendum. Association between advanced paternal age and congenital heart defects: a systematic review and meta-analysis. *Hum Reprod* **35**, 2638 (2020).

33. Peng, J. *et al.* The non-genetic paternal factors for congenital heart defects: A systematic review and meta-analysis. *Clin Cardiol* **42**, 684–691 (2019).

34. Su, X. J., Yuan, W., Huang, G. Y., Olsen, J. & Li, J. Paternal age and offspring congenital heart defects: a national cohort study. *PLoS One* **10**, e0121030 (2015).

35. Pickles, D. M. & Keller, K. The economic burden of complex CHD in the United States. *Cardiology in the young* **35**, (2025).

36. He, Q. *et al.* Inpatient costs of congenital heart surgery in China: results from the National Centre for Cardiovascular Diseases. *The Lancet Regional Health: Western Pacific* **31**, 100623 (2022).

37. Ejigu, Y. *et al.* Direct medical costs of congenital heart surgery for isolated lesions in Rwanda. *PLOS Global Public Health* **5**, e0004462 (2025).

38. Willems, R., Tack, P., François, K. & Annemans, L. Direct Medical Costs of Pediatric Congenital Heart Disease Surgery in a Belgian University Hospital. *World journal for pediatric & congenital heart surgery* **10**, (2019).

39. Faisal, N. V., Handa, A. & Ramakrishnan, S. Pediatric cardiac procedures in India: Who bears the cost? *Annals of Pediatric Cardiology* **17**, 1 (2024).

40. Falase, B. *et al.* The cost of open heart surgery in Nigeria. *The Pan African Medical Journal* **14**, 61 (2013).

41. Amato, M., Adeoye, M., Schofield, R. & Di Cesare, M. Reproductive journey in women with congenital heart disease: a systematic review of mental health implications. *BMJ Open* **16**, e112904 (2026).

42. Leroy-Melamed, M., Katz, A. & Shew, M. L. Menstrual Dysfunction and Treatment Among Adolescents With Congenital Heart Disease. *Journal of pediatric and adolescent gynecology* **33**, (2020).

43. El Khoudary, S. R. *et al.* Menopause Transition and Cardiovascular Disease Risk: Implications for Timing of Early Prevention: A Scientific Statement From the American Heart Association. *Circulation* **142**, (2020).

44. Ahem, M. *et al.* Cardiovascular health after menopause transition, pregnancy disorders, and other gynaecologic conditions: a consensus document from European cardiologists, gynaecologists, and endocrinologists. *European heart journal* **42**, (2021).

45. Cho, L. *et al.* Rethinking Menopausal Hormone Therapy: For Whom, What, When, and How Long? *Circulation* (2023) doi:10.1161/CIRCULATIONAHA.122.061559.

46. Mohsin, S. *et al.* Developing Congenital Cardiac CT Services in Low-Resource Settings: A Quality Improvement Approach. *Pediatric cardiology* (2025) doi:10.1007/s00246-025-03996-1.

47. Kumar, R. K. Delivering pediatric cardiac care with limited resources. *Annals of Pediatric Cardiology* **7**, 163 (2014).

48. Kumar, R. K., Zheleva, B. & Hasan, B. Confronting Global Inequity in Pediatric Cardiac Care: From Crisis to Opportunity. *Journal of the American College of Cardiology* **86**, (2025).

49. Iyer, K. S. & Sivalingam, S. Congenital heart disease in low- and middle-income countries: can India show the way? *Indian journal of thoracic and cardiovascular surgery* **41**, (2025).

50. Aldersley, T. *et al.* A Landscape Analysis of Pediatric and Congenital Heart Disease Services in Africa. *World journal for pediatric & congenital heart surgery* **16**, (2025).

51. Vervoort, D. *et al.* Global Access to Comprehensive Care for Paediatric and Congenital Heart Disease. *CJC pediatric and congenital heart disease* **2**, (2023).

52. Vervoort, D., Meuris, B., Meyns, B. & Verbrugghe, P. Global cardiac surgery: Access to cardiac surgical care around the world. *The Journal of thoracic and cardiovascular surgery* **159**, (2020).

53. Kumar, R. K. Training pediatric heart surgeons for the future: A global challenge. *Annals of Pediatric Cardiology* **8**, 99 (2015).

54. Wamala, I. *et al.* Infrastructure Availability for the Care of Congenital Heart Disease Patients and Its Influence on Case Volume, Complexity and Access Among Healthcare Institutions in 17 Middle-Income Countries. *Global heart* **16**, (2021).

55. Zheleva, B. *et al.* Advocacy at the Eighth World Congress of Pediatric Cardiology and Cardiac Surgery. *Cardiology in the young* **33**, (2023).

56. McMahon, C. J. *et al.* Achieving excellence in paediatric cardiac care in resource limited and resource plentiful settings and building successful care networks across different countries. *Cardiology in the young* **34**, (2024).

57. Nair, S. M., Hesslein, P. S., Zheleva, B. & Kumar, R. K. A Population-Based Approach to Congenital Heart Disease in Kerala, India. *Pediatrics* **156**, (2025).

58. Nair, S. M. *et al.* A Population Health Approach to Address the Burden of Congenital Heart Disease in Kerala, India. *Global heart* **16**, (2021).

59. Zheleva, B., Nair, S. M., Dobrzycka, A. & Saarinen, A. Considerations for Newborn Screening for Critical Congenital Heart Disease in Low- and Middle-Income Countries. *International journal of neonatal screening* **6**, (2020).

60. Preston, L. *et al.* Is there a relationship between surgical case volume and mortality in congenital heart disease services? A rapid evidence review. *BMJ open* **5**, (2015).

61. Welke, K. F. *et al.* Contemporary Relationship Between Hospital Volume and Outcomes in Congenital Heart Surgery. *The Annals of thoracic surgery* **116**, (2023).

62. Vervoort, D. Centralization and regionalization of congenital heart surgery in a globalized world. *The Journal of thoracic and cardiovascular surgery* **161**, (2021).

63. Hasan, B. S., Rasheed, M. A., Wahid, A., Kumar, R. K. & Zuhlke, L. Generating Evidence From Contextual Clinical Research in Low- to Middle Income Countries: A Roadmap Based on Theory of Change. *Frontiers in pediatrics* **9**, (2021).

64. Dindi, K. *et al.* Building cardiac surgical programs in lower-middle income countries. *JTCVS open* **13**, (2023).

65. Argaw, S., Genetu, A., Vervoort, D. & Agwar, F. D. The state of cardiac surgery in Ethiopia. *JTCVS open* **14**, (2023).

66. Ferreira, V. V. *et al.* Cardiac Surgery in Sub-Saharan Africa: Anthills of the Savannah. *JACC: Advances* (2025) doi:10.1016/j.jacadv.2024.101223.

67. Mattos, S. D. S. *et al.* Echocardiography Learning by Pediatricians While Screening Congenital Heart Disease with the Aid of Telemedicine. *Telemedicine journal and e-health : the official journal of the American Telemedicine Association* **26**, (2020).

68. McMahon, C. J., Hickey, E. J., Nolke, L. & Penny, D. J. Organizational Culture as a Determinant of Outcome in Teams: Implications for the Pediatric Cardiac Specialist. *Pediatric cardiology* **44**, (2023).

69. Murala, J. S. K., Karl, T. R. & Pezzella, A. T. Pediatric Cardiac Surgery in Low-and Middle-Income Countries: Present Status and Need for a Paradigm Shift. *Frontiers in pediatrics* **7**, (2019).

70. Francis, J., George, J., Peng, E. & Corno, A. F. The role of teamwork and mentorship in pediatric and congenital heart surgery. *Translational Pediatrics* **13**, 1870 (2024).

71. Kim, S., Seshadrinathan, S., Jenkins, K. J. & Murala, J. S. Can the Public-Private Business Model Provide a Sustainable Quality Pediatric Cardiac Surgery Program in Low- and Middle-Income Countries? *World journal for pediatric & congenital heart surgery* **14**, (2023).

72. Zheleva, B. & Zühlke, L. Congenital Heart Disease Surgery in Low-Resource Settings: Quality Improvement Is Key. *JACC. Advances* **3**, (2024).

73. Mohsin, S., Hasan, B., Zheleva, B. & Kumar, R. K. Enhancing Quality of Congenital Heart Care Within Resource-Limited Settings. *Pediatric cardiology* **46**, (2025).

74. Khan, A. *et al.* Impact of International Quality Improvement Collaborative on Congenital Heart Surgery in Pakistan. *Heart (British Cardiac Society)* **103**, (2017).

75. Balachandran, R. *et al.* Impact of the International Quality Improvement Collaborative on outcomes after congenital heart surgery: A single center experience in a developing economy. *Annals of Cardiac Anaesthesia* **18**, 52 (2015).

76. Wittenberg, R. E. *et al.* Associations With Adverse Postoperative Outcomes in Children Undergoing Atrial Septal Defect Closure in Lower-Resource Settings. *JACC. Advances* **3**, (2024).

REFERENCES

CONTINUED

77. de Araújo, J. S., Regis, C. T., Gomes, R. G., Mourato, F. A. & Mattos, S. D. Impact of Telemedicine in the Screening for Congenital Heart Disease in a Center from Northeast Brazil. *Journal of tropical pediatrics* **62**, (2016).

78. Mattos, S. S. *et al.* A telemedicine network for remote paediatric cardiology services in north-east Brazil. *Bulletin of the World Health Organization* **93**, (2015).

79. Chou, H. H. *et al.* Association of maternal chronic disease with risk of congenital heart disease in offspring. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne* **188**, (2016).

80. Ramage, K., Grabowska, K., Silversides, C., Quan, H. & Metcalfe, A. Association of Adult Congenital Heart Disease With Pregnancy, Maternal, and Neonatal Outcomes. *JAMA network open* **2**, (2019).

81. Chowdhury, D. *et al.* Health Care Policy and Congenital Heart Disease: 2020 Focus on Our 2030 Future. *Journal of the American Heart Association* **10**, (2021).

82. Mylotte, D. *et al.* Specialized adult congenital heart disease care: the impact of policy on mortality. *Circulation* **129**, (2014).

83. Integration across the life course: Bridging noncommunicable diseases and sexual, reproductive, maternal, newborn, child and adolescent health. *United Nations Population Fund* https://www.unfpa.org/resources/integration-across-life-course-bridging-noncommunicable-diseases-and-sexual-reproductive.

84. Moons, P. *et al.* Transition to adulthood and transfer to adult care of adolescents with congenital heart disease: a global consensus statement of the ESC Association of Cardiovascular Nursing and Allied Professions (ACNAP), the ESC Working Group on Adult Congenital Heart Disease (WG ACHD), the Association for European Paediatric and Congenital Cardiology (AEPC), the Pan-African Society of Cardiology (PASCAR), the Asia-Pacific Pediatric Cardiac Society (APPCS), the Inter-American Society of Cardiology (IASC), the Cardiac Society of Australia and New Zealand (CSANZ), the International Society for Adult Congenital Heart Disease (ISACHD), the World Heart Federation (WHF), the European Congenital Heart Disease Organisation (ECHDO), and the Global Alliance for Rheumatic and Congenital Hearts (Global ARCH). *European heart journal* **42**, (2021).

85. Bright, C. & Saraf, A. Reproductive Health in Congenital Heart Disease. *Pediatric annals* **54**, (2025).

86. Vervoort, D. National Surgical, Obstetric, and Anesthesia Plans: Bridging the Cardiac Surgery Gap. *The Thoracic and cardiovascular surgeon* **69**, (2021).

87. Vervoort, D., Verstappen, A., Nair, S. M., Eu, C. C. & Zheleva, B. Health Systems Strengthening to Tackle the Global Burden of Pediatric and Congenital Heart Disease: A Diagonal Approach. *Congenital Heart Disease* **19**, 131–138 (2024).

88. Congenital HeartDiseaseStandards &Specifications:https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf.

89. Sholler, G. F., AM *et al.* Australian National Standards of Care for Childhood-onset Heart Disease (CoHD Standards). 1st Edition. *Heart Lung Circ* **33**, 153–196 (2024).

90. The Establishment of Argentina'sFederal Network for the Care ofCongenital Heart Defectshttps://www.effectivecooperation.org/system/files/2021-06/gdi_case_study_argentina_chds_english.pdf.

91. PROCEDURES AND MODEL COSTING FOR SURGERIES:https://nhm.gov.in/images/pdf/programmes/RBSK/Training-Modules/RBSK-Procedures-and-Model-costing-for-surgeries_English_2014.pdf.

92. Iyer, H. *et al.* Assessing Surgical Care under the Government-Funded Health Insurance Scheme-Pradhan Mantri Jan Arogya Yojana in India. *Ann Glob Health* **91**, 85 (2025).

93. Home Page IQIC. https://iqic.chboston.org/.

94. Olsen, M., Videbæk, J. & Johnsen, S. P. The Danish Register of Congenital Heart Disease. *Scandinavian journal of public health* **39**, (2011).

95. Tretter, J. T. *et al.* Heart University: a new online educational forum in paediatric and adult congenital cardiac care. The future of virtual learning in a post-pandemic world? *Cardiology in the young* **30**, (2020).

96. Global Coalition for Pediatric and Congenital Hearts - Children's HeartLink. *Children's HeartLink* https://childrensheartlink.org/global-impact/global-advocacy/global-coalition-for-pediatric-and-congenital-hearts/ (2024).

97. Liu, Y. *et al.* Global birth prevalence of congenital heart defects 1970-2017: updated systematic review and meta-analysis of 260 studies. *International journal of epidemiology* **48**, (2019).

98. Zhao, Q. M. *et al.* Prevalence of Congenital Heart Disease at Live Birth in China. *The Journal of pediatrics* **204**, (2019).

99. Liu, F. *et al.* Prevalence of Congenital Heart Disease in Xinjiang Multi-Ethnic Region of China. *PLOS ONE* **10**, e0133961 (2015).

100. Zhang, L. *et al.* Epidemiology of Congenital Heart Disease in Jinan, China From 2005 to 2020: A Time Trend Analysis. *Front. Cardiovasc. Med.* **9**, 815137 (2022).

101. Abdulkadir, M. & Abdulkadir, Z. A systematic review of trends and patterns of congenital heart disease in children in Nigeria from 1964-2015. *African health sciences* **16**, (2016).

102. Namuyonga, J. *et al.* Pattern of congenital heart disease among children presenting to the Uganda Heart Institute, Mulago Hospital: a 7-year review. *African Health Sciences* **20**, 745 (2020).

103. Saxena, A. *et al.* Birth prevalence of congenital heart disease: A cross-sectional observational study from North India. *Annals of Pediatric Cardiology* **9**, 205 (2016).

104. Sawant, S. P., Amin, A. S. & Bhat, M. Prevalence, pattern and outcome of congenital heart disease in Bhabha Atomic Research Centre Hospital, Mumbai. *Indian journal of pediatrics* **80**, (2013).

105. Nicholson, C. *et al.* A national Australian Congenital Heart Disease registry; methods and initial results. *International Journal of Cardiology Congenital Heart Disease* **17**, 100538 (2024).

106. Brida, M. *et al.* Atrial septal defect in adulthood: a new paradigm for congenital heart disease. *European heart journal* **43**, (2022).

107. Chun, H. *et al.* High prevalence of congenital heart disease at high altitudes in Tibet. *European journal of preventive cardiology* **26**, (2019).

108. Prevalence of Congenital Heart Disease at Extremely High Altitudes in Tibet and the Establishment of a New Free Treatment Model. *Congenital Heart Disease* **17**, 709–716 (2022).

109. Majani, N. G. *et al.* Spectrum of Heart Diseases in Children in a National Cardiac Referral Center Tanzania, Eastern Africa: A Six-Year Overview. *Global heart* **19**, (2024).

110. Bhat, N. K. *et al.* Prevalence and pattern of congenital heart disease in Uttarakhand, India. *Indian journal of pediatrics* **80**, (2013).

111. Sadoh, W. E., Uzodimma, C. C. & Daniels, Q. Congenital heart disease in Nigerian children: a multicenter echocardiographic study. *World journal for pediatric & congenital heart surgery* **4**, (2013).

112. Danso, K. A. *et al.* Prevalence of Congenital Heart Disease in Children and Adolescents Under 18 in Africa: A Systematic Review and Meta-Analysis. *World Journal for Pediatric and Congenital Heart Surgery* (2025) doi:10.1177/21501351241299405.

APPENDIX

APPENDIX TABLE 1
Global distribution of common CHD subtypes

CHD SUBTYPE	GLOBAL PREVALENCE	COUNTRIES/REGIONS WITH NOTABLE PATTERNS	EXAMPLES (KEY STUDIES)
VENTRICULAR SEPTAL DEFECT (VSD)	30-40% of all CHD[97]	Commonest vsd worldwide. Subpulmonic VSD common in: China, Japan, Taiwan, Thailand, Korea.	**China**: VSD 3.3/1,000 live births[98]. Northwestern China 29.2%[99]. Jinan 1.18/1000 live births[100]. **Nigeria**:40.6% of all CHD[100,101] **Uganda**: 27.2%[102] **India**: North 5.7/1,000[102,103]. Mumbai 42.86%[104] **Australia**: 25%[104,105]
ATRIAL SEPTAL DEFECT (ASD)	7-10% of all CHD	Commonest CHD diagnosed in adulthood. Secundum ASD accounts for 80% of ASDs[106]. More common in women	**Australia**: 10%[105] **China:** Jinan 3.07/1000 live births[100] **Uganda**:9.4%, 88% secundum[100,102]
PATENT DUCTUS ARTERIOSUS (PDA)	<10% of CHD	Higher in high altitudes[21]	**Tibet Nagqu** (4,200-4,900m): 66.3% of all CHD[21,107] **Ngamring**: 55.42% [108] **Tanzania**:19.1%[109]
TETRALOGY OF FALLOT (TOF)	0.3-0.5 per 1,000 live births. 3% -5% of all CHD	Most common cyanotic CHD	**UK:** 6.5% **India (Uttarakhand)**: 5.45%[110] **Nigeria**:7.8% [111] **Africa**:0.52/1000 live births[112]
TRANSPOSITION OF GREAT ARTERIES (TGA)	0.2 and 0.4 per 1,000 live births globally. 4-5% of all CHD	Male predominance is universal. Limited survival data in LMICs due to lack of neonatal surgery.	

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CONGENITAL HEART DISEASE

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