



# Congenital Heart Disease in Low- and Lower-Middle-Income Countries: Current Status and New Opportunities

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## Abstract

**Purpose of Review** The paper summarises the most recent data on congenital heart disease (CHD) in low- and lower-middle-income countries (LLMICs). In addition, we present an approach to diagnosis, management and interventions in these regions and present innovations, research priorities and opportunities to improve outcomes and develop new programs.

**Recent Findings** The reported birth prevalence of CHD in LLMICs is increasing, with clear evidence of the impact of surgical intervention on the burden of disease. New methods of teaching and training are demonstrating improved outcomes. Local capacity building remains the key.

**Summary** There is a significant gap in epidemiological and outcomes data in CHD in LLMICs. Although the global agenda still does not address the needs of children with CHD adequately, regional initiatives are focusing on quality improvement and context-specific interventions. Future research should focus on epidemiology and the use of innovative thinking and partnerships to provide low-cost, high-impact solutions.

**Keywords** Congenital heart disease · Low- and lower-middle-income countries · Global access to health care · Children · Adults with congenital heart disease · Cardiac surgery · Cardiac interventions

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## Introduction

“There can be no keener revelation of a society’s soul than the way in which it treats its children. Nelson Mandela (8 May 1995)

Congenital heart disease (CHD) is the most common birth defect and the leading cause of childhood mortality in high-income countries (HICs). Despite this, the prognosis for a child born with CHD in HICs is excellent, compared with five or six decades ago, with over 90% achieving adulthood. For a child affected by CHD in the 81 low- and lower-middle-income countries of the world (LLMICs) [1], the outlook is starkly different. Very few are diagnosed before birth and those with critical congenital heart disease (CCHD) succumb to their lesion in the neonatal period or infancy, often unrecognised. Survivors with significant lesions face an inexorable march toward irreversible pulmonary hypertension (in the case of left-to-right shunts), or deepening cyanosis in the case of more complex lesions. Morbidity and mortality due to CHD in low- and middle-income countries (LMICs) have increased over the past decades. [2••]

The key difference relates almost invariably, but not solely to inadequate access to care; cardiac services for children remain largely in the realm of tertiary or even quaternary care facilities, sorely lacking in many LLMICs. Coupled with competing health priorities, fragile health systems and living within countries in conflict, CHD is seldom a priority. Children with CHD remain ‘invisible’. [2••] Children’s HeartLink (CHL) is a non-governmental organisation dedicated to developing sustainable programs to train medical teams, provide education and transform paediatric cardiac care in underserved and poorly resourced parts of the world. Their series entitled ‘The Invisible Child’ stressed the vast inequality in access to paediatric cardiac care globally and the poor commitment from governments to address CHD within the global health agenda, despite the recent sustainable development goals.

At least 1.5 million children are born each year with congenital heart disease. [3••] Of these, 90% do not have adequate access to essential diagnostics or interventions. [4] CHD diagnostics include both essential and advanced technologies while interventions can be life-saving and life-altering. Surgery for CHD in LLMICs remains an unmet need in almost all regions. There are more adults with congenital heart disease (ACHD) in high-income countries than children living with CHD. [5••] ACHD is now emerging as a discipline in LLMICs that have had a surgical program, and the future burden of these patients for the health system is yet to be considered.

In this review, we will consider the most recent developments in all of these areas, while highlighting areas of advance, innovation, policy and research which attempt to address this underserved area.

## Epidemiology and Burden of Disease in LLMICS

Congenital heart defects are the most common genetic abnormality. In recent years, the reported prevalence of congenital heart disease has risen to approximately 9 per 1000 live births, largely due to increased ascertainment of milder abnormalities. [6••] Data regarding birth prevalence in LLMICs are lacking, with the detailed research infrastructure and vital registration data needed for a robust study absent in areas where data from the global burden of disease (GBD), such as central Africa or remote Asia are also sparse. [7] Yet, there is little to suggest that the birth prevalence of congenital heart disease is any different in LLMICS from the rest of the World. [3••] In fact, according to GBD, 96% of the children born with congenital anomalies in 2010 live in LMICs. [8] This may partially be due to higher fertility rates in these countries, which result in an even greater absolute burden of disease. [9] In addition, although patients with severe disease die early in life, unoperated, non-fatal congenital heart disease adds to the burden of ill-health in poor communities. [10] While there is evidence that environmental conditions may influence the prevalence of congenital heart disease, there are few studies to determine the influence of poverty on the prevalence of CHD. [11, 12] Research suggesting that congenital heart defects are preventable is inconclusive. [11]

GBD 2010 estimates that there are 207,202 deaths due to CHD in LIMCS annually, 14,262,481 years of life lost (YLL), 563,385 years lived with disability (YLD) and a loss of 14,755,312 disability-adjusted live years (DALYS). Higashi et al. estimated that (using CHD amenable to surgical interventions and those not) the burden of disease could be potentially addressed by surgical care by as much as 49%. [13••] The largest potential for addressing burden of disease in CHD is in North Africa and Middle East, where an adequate surgical program could reduce the burden of disease by 73%.

The burden of disease of CHD on the clinical services in LLMICs is well demonstrated in small and single-centre studies. The health impact of CHD in LLMICs is clear from the literature. For example in Uganda, CHD was responsible for 35% of childhood presentations with heart failure [14]; and 82.2% of 73 patients in Nigeria. [15] CHD is also now commoner than RHD among patients younger than 15 years old referred for cardiac evaluation in Nigeria [16]. The patterns of presenting CHD vary greatly with resources available across the regions, but are generally similar in retrospective reviews from India [17], Bangladesh [18] and Cuba [19].

The resource-related challenges that LLMICs countries face in caring for patients with CHD and their families are thus compounded by the lack of a basic epidemiological understanding of the CHD population. There are few population-based data regarding prevalence, demographics or long-term outcomes of even the most common CHD conditions, within the modern era of cardiac surgery, in LLMICs. Only once the

extent of the problem is known and accurately defined can appropriate preventive and treatment programs be developed, maintained and expanded consistent with local resources. There is a clear and urgent need to address this gap.

### Diagnostics: Essential and Advanced

In an under-resourced area where not making an exact CHD diagnosis had few consequences in the patient who could never be offered surgery, the development of a therapeutic service now depends on accurate diagnosis as well as knowledge of timing of interventions, be they surgical or percutaneous. Since this diagnosis may depend on medical officers or general paediatricians, rather than cardiologists, basic knowledge and clinical skills may need to be enhanced. Developing educational programs in the context of LLMICS may take innovative forms, with long-distance learning gaining prominence. [20•] In Malawi, an educational program was initiated to allow for the appropriate referral of patients to other countries. Access to the traditional ‘next steps’—CXR and ECG—needs to be enhanced. Tablet-based 12-lead ECG machines or no-frills standard models of both ECG and X-ray machines are available in some areas of the world. [21]

Screening for CHD, which will also result in increased awareness of the condition among primary caregivers, should include a focused physical examination for CHD in all newborns after delivery and at immunisation clinic visits (which ideally is recorded in a patient-held health chart) and will undoubtedly improve the CHD detection rate. Pulse oximetry (now increasingly available and inexpensive) has the potential to detect CCHD early (with up to 82% overall sensitivity for all CHD) and significantly improve outcomes in countries with established and emerging paediatric cardiac programs. [22, 23] In a large study in China, the combination of pulse oximetry screening and clinical examination was shown to have the highest sensitivity and specificity (95.5% and 98.8% respectively) for the detection of CHD in the early neonatal period. [24•] In LLMICs, saturation screening will have the additional benefit of detecting non-cardiac diseases rather than only CCHD.

The single most important diagnostic tool in CHD is echocardiography. Even with a mid-range machine, most cases of CHD can be diagnosed accurately. It has been shown that up to 80% of the major congenital heart defects that will undergo primary complete repair do not need any other imaging prior to surgery. [25] New and emerging programs in LLMICs should focus on detection of basic cardiac lesions by appropriately trained echo technologists or community doctors and paediatricians using inexpensive portable or handheld machines [22, 26]. This can be achieved at primary and secondary level hospitals as well as at mobile diagnostic clinics within the community. This ‘low-hanging fruit’ or ‘KISS’ (keep it simple and safe) approach enables the detection of the majority (up to 85%)

of clinically significant CHDs comprising the eight commonest lesions (ventricular, atrial and atrioventricular septal defects, patent ductus arteriosus, pulmonic and aortic stenosis, tetralogy of Fallot, aortic coarctation). [27, 28]

Portable and handheld echocardiography machines are increasingly available (some require only a probe attached to a smartphone or tablet) and inexpensive, and these can provide a reasonable degree of accuracy. [29•, 30, 31] A further significant advantage of mobile, ‘pocket’ echocardiography is in telehealth—the ability to transmit images to an expert in a remote centre for diagnostic and management support. [32•, 33•]

In order to offer comprehensive services to populations in LLMICs, the hegemony of the paediatric cardiologist over echocardiography has to be broken. Task-sharing of diagnostic echo skills has been shown to improve outcomes in Guyana. [34•] A paediatric program was introduced following the development of an *adult* focused echocardiographic skills program which resulted in the recognition of large numbers of children with congenital heart disease. [34•] As neonatal programs develop in LLMICs, neonatologist-performed echocardiography will provide additional early diagnostic opportunities. [35]

Occasionally, additional imaging is required especially for extracardiac vascular structures that are not completely defined by echocardiography, e.g. pulmonary arteries in Tetralogy of Fallot. Computed tomographic angiography (CTA) is probably best suited for this purpose since this modality is generally available in most regional centres with access to cardiac surgery. [36] There is evidence that this can be performed in less-resourced areas. [37] More advanced modalities such as cardiac magnetic resonance imaging (cMRI) and fetal and 3D echocardiography are usually not readily available in LLMICs but are desirable to further improve diagnostic capabilities once a basic service is established.

A key aspect of addressing the burden of CHD in LLMIC is the fostering of appropriate research in each of the relevant areas relating to CHD. (Table 1) In diagnostics, studies to establish normal values for cardiovascular structures and echocardiographic z-score nomograms for children in LLMICs are essential to be locally relevant as ethnic and population differences undoubtedly exist. [38]

### Interventions: Essential and Advanced

The shortage of cardiac catheterisation facilities (cath labs) in LLMICs is well known, especially of those serving paediatric patients. The World Bank estimates that there is less than one cath lab per million people in Africa and Asia, but in most low-income countries in Africa there are no functioning cath labs at all. In addition, the majority of the population do not have access to tertiary health care facilities. While it is laudable to improve the detection of CHD in newborns and children worldwide, one must then link

**Table 1** Summary of needs and opportunities for CHD research, diagnosis, management and research in low- and lower-middle-income countries

Challenges and Research Priorities					
<ul style="list-style-type: none"> <li>• Lack of antenatal ultrasound and prenatal diagnoses.</li> <li>• Poor rubella immunisation coverage.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of human resources in early diagnostics, interventions and treatment.</li> <li>• Perfusion and bypass equipment/techniques and costs.</li> </ul>	<ul style="list-style-type: none"> <li>• Poor visibility for children in the global health agenda.</li> <li>• Significant completing health priorities.</li> <li>• Myocardial protection.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of dedicated funding for CHD surgery and interventions.</li> <li>• Few regional centres of excellence.</li> <li>• Need for cardiac ICU/ICU staff</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of consistent pre-conceptual counselling messages.</li> <li>• Non-communicable diseases and CHD.</li> </ul>	<ul style="list-style-type: none"> <li>• Few specialised adults with CHD units.</li> <li>• Poor transitional care: differing age of transfer to adult units in different centres.</li> </ul>
<ul style="list-style-type: none"> <li>• Epigenetics</li> <li>• Role of ARVs, indoor pollutants, diabetes</li> </ul>	<ul style="list-style-type: none"> <li>• Birth prevalence data</li> <li>• CHD registries</li> <li>• Costing data</li> </ul>	<ul style="list-style-type: none"> <li>• Morbidity studies.</li> <li>• Definitive surgical approaches.</li> </ul>	<ul style="list-style-type: none"> <li>• Quality improvement.</li> <li>• Low-cost devices.</li> </ul>	<ul style="list-style-type: none"> <li>• Effect of pregnancy on specific CHD lesion.</li> </ul>	<ul style="list-style-type: none"> <li>• Unique cohort of natural survivors.</li> <li>• Quality-of-life studies.</li> </ul>
<ul style="list-style-type: none"> <li>• Training of obstetricians to diagnose CHD.</li> </ul>	<ul style="list-style-type: none"> <li>• mHealth and eHealth to improve first 1000 days.</li> <li>• Pulse-oximetry screening to</li> </ul>	<ul style="list-style-type: none"> <li>• Utilising South-South training opportunities.</li> </ul>	<ul style="list-style-type: none"> <li>• IQIC/C3PO and CHL.</li> <li>• Innovative cath training initiatives</li> </ul>	<ul style="list-style-type: none"> <li>• Multidisciplinary clinics for complex cardiac patients including</li> </ul>	<ul style="list-style-type: none"> <li>• Shared decision making.</li> <li>• Leveraging global</li> </ul>

**Table 1** (continued)

<ul style="list-style-type: none"> <li>• Apps to aid pulse-oximetry screening by CHW.</li> </ul>	<ul style="list-style-type: none"> <li>diagnose CCHD.</li> </ul>	<ul style="list-style-type: none"> <li>• Point-of-care ultrasound diagnostics.</li> </ul>	<ul style="list-style-type: none"> <li>such as CathChat.</li> <li>• Low-cost interventions and applications.</li> </ul>	<ul style="list-style-type: none"> <li>obstetric team.</li> </ul>	<ul style="list-style-type: none"> <li>initiatives to increase access to safe anaesthesia, obstetrics, and general surgery for increased cardiac surgery.</li> </ul>
<ul style="list-style-type: none"> <li>• Point-of-care ultrasound</li> <li>• Artificial intelligence</li> </ul>	<ul style="list-style-type: none"> <li>• Transfusion algorithms.</li> <li>• Miniaturisation of bypass circuits.</li> </ul>	<ul style="list-style-type: none"> <li>• Echo-guided cath interventions.</li> <li>• Inexpensive 3D printing</li> </ul>	<ul style="list-style-type: none"> <li>• Ozaki, RV outflow patch, new procedures.</li> </ul>	<ul style="list-style-type: none"> <li>• Medical education and telemedicine, telehealth and cloud solutions.</li> </ul>	<ul style="list-style-type: none"> <li>• Engineered heart valves for LLMICs.</li> </ul>
<b>Opportunities, Innovations and Technological advancements</b>					

ARVs, antiretrovirals; CHD, congenital heart disease; ICU, intensive care unit; CHW, community health workers; mHealth, mobile health; eHealth, electronic health; CCHD, critical congenital heart disease; IQIC, International Quality Improvement Collaborative; C3PO, Congenital Cardiac Catheterization Project on Outcomes; CHL, Children’s HeartLink; RV, right ventricle; LLMIC, low- and lower-middle-income countries

detection to the provision of effective management of detected CHD. [22] This may include heart surgery as well as cardiac catheterisation: both haemodynamic and interventional. Haemodynamic catheterisation may be expedient for countries able to send children for corrective heart surgery elsewhere to ensure that repair is possible, by excluding irreversible pulmonary hypertension. [39] Where there are cardiac catheterisation laboratories, many are utilised infrequently due to the lack of skilled staff and frequently used only by the personnel from ‘medical safaris’ that often fail to foster sustainable local expertise. [40, 41]

To address CHD, heart surgery is an essential but expensive health resource, always requiring admission to an intensive care unit post-operatively, yet another expensive resource. Interventional cardiac catheterisation, on the other hand, can begin to address the need for curative management

of CHDs and is comparatively less resource intensive than heart surgery: the patient generally does not require admission to an ICU, and is usually admitted for only 2–3 days in a general ward. In Rwanda, effective interventional cardiac catheterisation procedures have been performed for relatively simple lesions (ASD, PS and PDA), without access to regular cardiac catheterisation laboratory equipment. [42•]

Local interventional catheterisation expertise is best fostered by visiting expert teams that build, train and mentor local teams to be able to do interventional procedures safely. This model has been shown to be effective in Ethiopia. [43] Initially, procedures may address simpler lesions with an aim to develop team skills and expertise and gradually progress to correct lesions requiring more complex procedures. It is important to develop the skills of the entire team. Too often, a local cardiologist receives training in interventional

catheterisation abroad and, on returning, encounters a team unable to perform at the skill level of the newly trained interventionalist. The resulting skills disparity then induces the trained cardiologist into leaving to join a well-trained team elsewhere, usually in a HIC. By building partnerships with visiting interventional experts, it is possible to develop teams with the infrastructure, expertise and experience, by a program of progressive mentorship. [43]

Epidemiologically, the six most common lesions (ASD, PS, AS, coarctation of the aorta, VSD and PDA) comprise 67% of CHD at birth. [3••] While not all of these lesions are amenable to interventional correction, many subsets are, and may contribute to as many as 30% of all detected CHD. [44] By focusing on the interventionally correctable subsets of these lesions, it is possible to reduce the morbidity and mortality caused by these lesions. In addition, it will allow the catheterisation team to develop experience and expertise to tackle more complex subsets of these lesions. It has been shown that competent cath lab teams in developing countries may achieve results with low complication rates that compare well to those reported by centres in developed countries. [45]

It is worth bearing in mind that a mortality rate of less than 5% for surgical correction of these lesions is deemed acceptable. Interventional cardiac catheterisation is by its nature less risky than heart surgery, particularly if the surgery requires cardiopulmonary bypass. In Angola, it has been shown that complex cardiac surgery (single ventricle palliation) carries a mortality of 45%. [46] A cath lab team that has built up expertise may go on to tackle more complex lesions with far lower risks, as in China, where the incidence of severe adverse events (not mortality) during cardiac catheterisation was only 1.4%. [47] More complex procedures may include life-prolonging palliative procedures, for example stenting the right ventricular outflow tracts of patients with Tetralogy, or PDAs of duct-dependent lesions or residual lesions of those patients that may have received surgery elsewhere, e.g. residual aortic coarctations, pulmonary stenoses or the occlusion of residual VSDs. The palliated patients may then benefit from surgical correction later, in the same centre or elsewhere.

In HIC settings, where health care facilities have established both heart surgery and interventional catheterisation programs, it is prudent to undertake interventions only where a cardiac surgeon is on standby to assist with potential serious adverse events. In LLMICs, a staged development of skills (that includes training in the retrieval of embolised devices) will minimise these risks to less than those acceptable for surgery, [48] allowing for a cath lab program without a cardiac surgeon on standby.

A final consideration is the difficulty of acquisition and cost of consumables for cardiac catheterisation, and particularly of interventional devices. While the interventional correction of CHD is more cost efficient than heart surgery, for some LLMICS, the costs to maintain and stock an

interventional cardiac catheterisation laboratory may remain prohibitive. Here, public–private partnerships and twinning collaborations with international centres of expertise have the potential to boost paediatric cardiac services that are often lacking in LLMIC state facilities through measures such as local and exchange training programs, infrastructure support and donation/maintenance of equipment. [49, 50•]

### Adults with Congenital Heart Disease in Low- and Lower-Middle-Income Countries

The prevalence, status and challenges of ACHD are vastly different in LLMICs than in HICs. In HICs, almost all children with CHD will be diagnosed during ante-natal screening, in infancy or latest in childhood, while more than 90% of children born with CHD will survive into adulthood due to the available facilities for intervention. In most LIMCs, the diagnosis of CHD is dependent on available health systems and advanced human resources, still sorely lacking in the poorest low-income countries.

The prevalence of ACHD has been estimated in a systematic review (only including the global north) to be close to 3000 per million population. [5••] A direct extrapolation to Africa (population of 1.2 billion people), would imply almost 500,000 patients with ACHD in Africa alone. However, this figure uses patients from HICs who have survived childhood and who have had exposure to interventions. An updated systematic review of CHD has again reiterated the findings of Van der Linde et al. in 2011 [51••], with Africa reporting the lowest prevalence (2.315/1000 (95% CI 0.429–5.696)) and Asia the highest (9.342/1000 (95% CI 8.072–10.704)) [3••] reflecting the low rates of detection and high rates of mortality due to CHD in LLMICs.

Patients with ACHD in LLMICs represent two scenarios: that of natural survivors with late presentation (simple and more complex lesions), and those who were fortunate enough to have had intervention, in many cases not in their own countries or by visiting operating teams to their country. Both groups have particular challenges. An additional challenge is emerging in countries with more advanced programs and the trend to increased survival is the urgent need for ACHD training and skills. Few robust data exist in this population; however, single-centre experiences exist to demonstrate that reasonable surgical outcomes are possible in developing programs, [52, 53] while higher-middle-income countries in Africa and Asia have demonstrated excellent surgical outcomes and a growing ACHD population. [54•] The challenges of this group are universal: reproductive planning, quality of life, palliative care and then ongoing need for intervention within the context of ACHD. However, the lack of dedicated ACHD programs [55], continued lack of regional centres of surgical and interventional excellence and fragile health systems will remain paramount until early diagnostics and

interventions are introduced. The number of ACHD centres per 10-million population was highest for Europe (3.6), followed by North America (1.7), Oceania (1.5), South America (0.4), Asia (0.3) and Africa (0.1). There is a growing appreciation for this important patient group with a need for research into patient, community and hospital acquired factors within LLMICS. [56] Research should include health economic considerations [57], epidemiological trends [58] and appropriate interventional approaches as encouraged in regional congresses such as Africa PCR and the various regional meetings of the CSI group (Asia and Africa).

### Cardiac Disease in Pregnancy: The Role of CHD

Although the major burden of CVD mortality in pregnancy in LLMICs is rheumatic heart disease (RHD), Registry Of Pregnancy And Cardiac disease (ROPAC)—an international, prospective, observational registry of pregnant women with CHD, valvular heart disease (VHD), cardiomyopathy (CMP) or ischaemic heart disease (IHD)—demonstrated that CHD constituted 57.4% of the cohort, compared with under 30% RHD, across all income-groups. [59••] Thus, the importance of pre-conceptual counselling in girls and teenagers with cardiac lesions—native or residual—is extremely important, especially in LLMICs. [60] Unoperated left-to-right shunts with resultant Eisenmenger syndrome represent a particular high-risk group with the ESC guidelines suggesting termination of pregnancy or permanent sterilisation. [61••] In many LLMICs, however, there remain significant cultural and

personal reasons for reproductive intent which needs to be taken into context. A proactive approach from early childhood is advised as well as a multidisciplinary cardio-obstetric clinic, where possible. [62, 63]

### Surgical Capacity and Results

We maintain that the lack of access to cardiac surgery in LLMICs is unacceptable. [64–67] However, assuming the commitment has been made to commence with a surgical program, there are many factors unique to LLMICs that have to be understood, addressed and taken into account in order to successfully shape future direction of a comprehensive program. [68]

The current reality is that most patients present late, or for the first time with an associated infection and in a very poor nutritional state with severe failure to thrive—a very different scenario from that of a high-income country [69••, 70, 71]. In general, the health care providers are faced with a high-risk group of patients that necessitates experienced caregivers. Training and capacity need to address these issues from the outset if a unit is to succeed.

The challenges of starting a unit in a developing country are multiple, but central to its success is the commitment to the concept of excellence from the outset [72]. Figure 1 was created by a paediatric cardiologist who was involved in setting up a paediatric cardiology unit in Namibia over a period of 8–10 years. [39] Of paramount importance is the identification and enablement of excellent training of the founding complement of staff, including ongoing commitment to their professional development. In most cases, the initial training of staff has to be

An Enabling Environment Within Which to Develop Sustainable Cardiac Care for Children with Heart Disease						
		WHO YOU NEED		WHAT YOU NEED		WHAT YOU CAN DO
Phase 1 - Thinking	<i>Integrated nursing services</i>	Champions for children	<i>Team building and team work</i>	Political will Financial commitment Public-private partnership	<i>Management and management systems</i>	Start the process
Phase 2 - Planning		Cardiac service director		Training Site visits Budget		Determine infrastructure & human resource requirements Produce a strategic plan
Phase 3 - Starting		Paediatric cardiologist Paediatric cardiac technologist		Out-patient clinics Elementary cardiac Portable 2D echo		Diagnostic services Out referrals to surgical centre's within the region
Phase 4 - Delivering		Paediatric cardiac surgeon Paediatric cardiac anaesthetist Cardiac perfusionist		Dedicated operating theatre and personnel		Non-complex lesions
Phase 5 - Expanding		Interventional paediatric cardiologist		Cardiac catheterisation laboratory		Diagnostic and interventional cardiology
Phase 6 - Maturing		Paediatric intensivist		Paediatric intensive care		More complex surgery for more complex disease
Monitoring, evaluation, quality improvement and collaboration						
<i>In service teaching, training &amp; mentoring</i>						

Fig. 1 Personal reflection: developing a paediatric cardiac program

done in well-established international units. Ideally, these international training units will be committed to foster a supportive and ongoing collaborative relationship between themselves and the home unit of the trainee [73, 74••]. Once a unit has been established, an immediate early goal should be the implementation and ongoing development of a local training program. Particularly important is attention to staff retention strategies. One or two well-trained surgeons can deal with a large number of patients; providing adequate and ongoing training is one area where the international surgical community can and should help. There are far too many obstacles, often administrative, preventing surgeons with excellent ability from LLMICs receiving adequate training in HICs. In addition, significant focus and support has to be placed on the development of other members of the team, in particularly a very empowered nursing team. [75] Many units are partially or completely dependent on visiting teams and often little surgery takes place after their departure. This safari style is a flawed model and may be doomed to failure. However, if local team development is actively supported and achieved, such sustained international collaboration is very worthwhile. [41, 76, 77•] In South Africa, local units have supported and trained several countries in the region (Fig. 2).

From the outset, the goal of the newly established unit should be to offer high-quality surgical treatment as is appropriate to the setting. For instance, it may be appropriate to defer a neonatal program or single ventricle palliation until infrastructure has been adequately developed. [46] Despite significant challenges, excellent results can be achieved with time and commitment. [78, 79]

A rigorous culture of research and audit, ideally in collaboration with international groups such as the International Quality Improvement Collaborative (IQIC), is critical. [80] Through such collaboration, the importance of adherence to

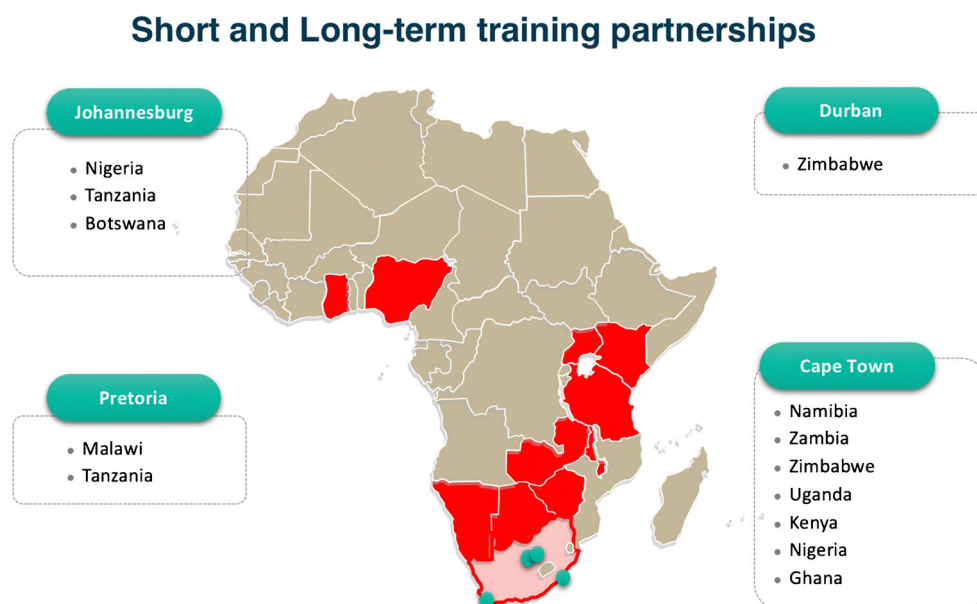
basic principles of infection control and avoidance of preventable ICU-related complications have been highlighted. In addition, the IQIC for instance provides a relevant benchmark of the outcome of units working under similar constraints and allows practitioners to compare like with like. [75, 81••]

Only with rigorous analysis of data can appropriate treatment strategies and philosophies be developed. For instance, given the poor overall state of patients due to the consequences of long-standing cardiovascular disease in association with a sub-optimal nutritional baseline, a core question may be as follows: ‘Is surgical palliation effective in optimizing perceived high-risk patients prior to repair, or is definitive repair preferable even under perceived high-risk situations?’. In answering this question, for example, it is essential to take into account that in many instances people simply cannot return to the hospital for multiple procedures. Adequate follow-up is thus not possible due to socio-economic and geographical constraints. Data from our unit in South Africa suggest that an overall strategy of definitive repair yields more optimal results and better utilisation of limited resources as compared with a strategy of initial palliation [82], a strategy that has now been incorporated into our clinical practice.

### Innovations and Initiatives to Improve Outcomes of CHD in Low- and Lower-Middle-Income Countries

Mobile phone network distribution across LLMICs is an example of the ‘disruptive innovation’ that may facilitate better care of children with CHD. [83] Access to peers in other countries (even in the form of text and moving image messaging) allows for management advice and referral. Platforms such as Skype or dedicated telemedicine facilities [84] allow for case conferences between emerging surgical units and larger units in the Northern Hemisphere. Conventional

**Fig. 2** Short- and long-term training within Africa includes paediatric cardiology, cardiac surgery and intensive care





**Table 2** Global initiatives that align with the need to provide access to cardiac care

Current state of play	Child-specific recommendations and inclusions in health and equality	Improving visibility of children in global action plans
<ul style="list-style-type: none"> <li>• Children are affected by all four of the common NCDs: cardiovascular disease, chronic obstructive pulmonary disease, diabetes and cancer.</li> <li>• Children risk being systematically excluded from the NCD discourse.</li> <li>• A life course approach is key to prevention, promotion and protection against NCDs.</li> <li>• Children should be a primary consideration.</li> <li>• NCDs in adults have significant secondary impacts on children.</li> <li>• Being a child carer/worker has a gross impact on social and educational development.</li> </ul>	<ul style="list-style-type: none"> <li>• International Covenant on Economic, Social and Cultural Rights (ICESCR)</li> <li>• Convention on the Rights of the Child (CRC)</li> <li>• Declaration of the Rights of the Child (an expansion on the Geneva Declaration of the Rights of the Child)</li> <li>• African Charter on Human and Peoples' Rights</li> <li>• African Charter on the Rights and Welfare of the Child</li> <li>• Constitution of the Republic of South Africa</li> <li>• The Global Action Plan on NCDs 2013–2020</li> <li>• The Framework Convention on Tobacco Control</li> <li>• The Political Declaration from the 2011 UN High-level Meeting</li> <li>• The Sustainable Development Goals</li> <li>• World Heart Federation Mexico declaration</li> <li>• World Heart Federation 2nd Global Summit on Circulatory Health</li> <li>• World Health Assembly resolution against Rheumatic Fever and Rheumatic Heart Disease</li> </ul>	<ul style="list-style-type: none"> <li>• Children must be included in all NCD recommendations: what is still needed?</li> <li>• Leadership: sustained high-level support, funding, and empower and enable children.</li> <li>• Prevention: National policies, integrated care and newborn screening.</li> <li>• Diagnostics and treatment: strengthen health systems, delivery mechanisms and investment in human resources.</li> <li>• International cooperation: raising the priority and increased child-specific funding, knowledge sharing for strategies, systematic and sustainable change.</li> <li>• Monitoring, reporting, research, and accountability: targets and indicators and being held accountable.</li> <li>• Children are the most powerful agents for change and are remarkable peer educators.</li> </ul>
<p>'The health of women and children is the key to progress on all developmental goals'            'Time to deliver on the promise of health and a better future for every woman and every child.' Bang-Ki Moon.</p>		

NCD, noncommunicable disease

moving image platforms may however not provide the resolution required to allow real-time assistance or advice from remote centres for intricate techniques. At Red Cross Hospital in Cape Town, a system called 'CATHCHAT' has been developed to provide an online teaching and learning platform specific to CHD. This video-conferencing technique which uses the national research and education networks (NRENs) across the African continent (as opposed to commercial networks) allows live interaction between colleagues and allows the specialised field of interventional cardiac catheterisation to cross geographical borders. In doing so, the audience online- is able to log in and watch while experienced interventionalists perform procedures of varying complexity. The online audience is able to communicate with the cath lab team, allowing them to engage in procedure-related/case discussions. As the number of cardiac catheterisation labs in Africa and other lower-income countries continues to grow, CATHCHAT makes it possible for the Red Cross cardiology team to offer real-time support to less experienced cardiologists and receive advice themselves. The platform is flexible and allows the user to control the transmission bandwidth should they be using a slower commercial network. [85]

LLMICs (and those countries which have recently moved to UMIC status such as Thailand) may act as sources of innovation themselves allowing for the manufacture of interventional devices at a cheaper cost. A recent paper describes an Indian centre's experience with a device made in Thailand. [86]

Advances in ultrasound technology may have similar disruptive benefits. Newer cardiac centres may be able to skip the acquisition of expensive diagnostic equipment such as high-end echocardiography machines by purchasing handheld devices for echocardiography, for example [29•]. Higher-end echo machines, in turn, may be able to support cardiac interventions with device implantation occurring using echocardiographic imaging alone, dispensing with the need to purchase a catheterisation laboratory. [87]

The funding for new surgical and interventional programs will remain difficult given the need for imported technologies, capital cost of equipment and the complex pathways for obtaining consumable supplies; it is important that the cost of interventions is at the expense of the state or part of a private public partnership, since costs

have the potential to plunge a family into poverty if they bear these costs themselves. [40] New funding models are urgently required. Recently, Philips and the government of the Netherlands have embarked on a cooperative model in Ethiopia where all components (from the building to the consumable equipment) are supplied for the duration of a long-term contract. [88] Newer sociopolitical relationships with growing economies (with different economies of scale) such as China may also facilitate the installation of theatres and catheterisation laboratories.

Open source computing services such as open access database tools (e.g. RedCap) will facilitate the recording and reporting of epidemiological needs as well as the growth of new programs. Research from such centres will thus be used to guide other LLMIC countries embarking on similar programs. Programs aimed specifically at quality improvement in countries outside of the upper income group like (IQIC use web-based registries to compile data on surgical and cardiac catheterization performance.

Simulation techniques to train medical students and specialists are widely used in upper income countries. While the cost of high-end simulation equipment needed to train individuals in vascular access and surgical techniques might preclude their use in LLMICs, ‘low-fi’ systems (using dolls and tablet based software) can easily be used to train individuals how to care for and resuscitate ill patients in the post-operative unit, for example. [89]

## Conclusion

In summary, 96% of the children born with congenital anomalies—the most common of which is congenital heart disease—live in LLMICs, and the vast majority of those with significant defects have a bleak prognosis, due to inadequate access to life-saving and life-altering diagnostics, interventions and care. We urgently need key datasets to provide context to the scope of the problem and develop appropriate preventive and treatment programs, which must be maintained and expanded consistent with local resources. Innovative methods for teaching, treatment and funding are key and collaborations need to empower and build local capacity. The global cardiovascular community has to advocate for CHD patients within political and socio-economic circles by aligning these with other advocacy initiatives (Table 2) so that the vast inequality that exists between children born with CHD in different-income countries is sufficiently addressed.

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## Compliance with Ethical Standards

**Conflict of Interest** Liesl Zühlke is funded by the Medical Research Council of South Africa, the National Research Foundation of South Africa and the Medical Research Council of United Kingdom through the MRCUK/Dfid African Research Leader Scheme.

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**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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