

Review

Global Access to Comprehensive Care for Paediatric and Congenital Heart Disease

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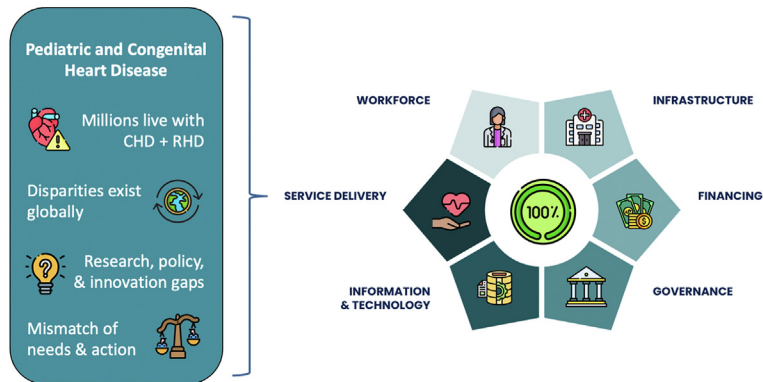
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ABSTRACT

Paediatric and congenital heart disease (PCHD) is common but remains forgotten on the global health agenda. Congenital heart disease is the most frequent major congenital anomaly, affecting approximately 1 in every 100 live births. In high-income countries, most children now live into adulthood, whereas in low- and middle-income countries, over 90% of patients do not get the care they need. Rheumatic heart disease is the most common acquired cardiovascular disease in children and adolescents. While almost completely eradicated in high-income countries, over 30-40 million people live with rheumatic heart disease in low- and middle-income countries. Challenges exist in the care for PCHD and, increasingly, adult congenital heart disease (ACHD) worldwide. In this review, we summarize the current status of PCHD and ACHD care through the health systems lens of workforce, infrastructure, financing, service delivery, information management and technology, and governance. We further highlight gaps in knowledge and opportunities moving forward to improve access to care for all those living with PCHD or ACHD worldwide.

Paediatric and congenital heart diseases (PCHDs) are congenital and childhood-acquired conditions that generally affect individuals throughout their lifetime. Congenital heart disease (CHD) is the most common major congenital anomaly, affecting approximately 1 in every 100 live births globally.¹ Nearly 300,000 people die from CHD each year, of whom approximately two-thirds are infants below 1 year of age, and the highest rates are observed in low- and middle-income countries (LMICs).² Between 1 in 3 and 1 in 2 children born with CHD will eventually require surgical or interventional care.^{3,4} Two-thirds of preventable deaths due to congenital anomalies are due to CHD, whereas 58% of the preventable mortality associated with CHD could be averted if cardiac surgical care would be available.^{5,6} Furthermore, rheumatic heart disease (RHD) is the most common cause of acquired cardiovascular disease in children and the most common cause of mitral stenosis worldwide.⁷ Over 30-40 million people live with RHD, with endemic regions having RHD prevalence rates of up to 5% among children and adolescents.⁷⁻⁹ Although other cardiovascular conditions, such as endomyocardial fibrosis, Chagas cardiomyopathy, and Kawasaki disease sequelae, may present in children, CHD and RHD present the leading forms of PCHD. Their burdens are considerable, especially in LMICs, where access to primary care, paediatric cardiology, and cardiac surgical services is poor.^{10,11} Table 1 summarizes the burden of PCHD relative to other conditions.¹² These data illustrate that PCHDs form one of the leading causes of preventable childhood mortality around the world, particularly in LMICs. As such, they

RÉSUMÉ

Les cardiopathies pédiatriques et congénitales (CPC) sont fréquentes, mais demeurent dans l'angle mort des politiques de santé mondiale. La cardiopathie est l'anomalie congénitale majeure la plus fréquente; elle touche environ 1 naissance vivante sur 100. Dans les pays à revenus élevés, la plupart de ces enfants atteignent désormais l'âge adulte, tandis que dans ceux à revenus faibles ou moyens, plus de 90 % des patients n'obtiennent pas les soins dont ils ont besoin. La cardiopathie rhumatismale est la maladie cardiovasculaire acquise la plus fréquente chez les enfants et les adolescents. Alors qu'elle est pratiquement éradiquée dans les pays à revenus élevés, plus de 30 à 40 millions de personnes en sont atteintes dans les pays à revenus faibles et moyens. À l'échelle mondiale, il existe de nombreux obstacles aux soins des CPC et, de plus en plus, des cardiopathies congénitales chez l'adulte (CCA). Notre article de synthèse présente un résumé de l'état actuel des soins des CPC et des CCA en abordant plusieurs aspects des systèmes de santé : ressources humaines, infrastructures, financement, services offerts, gestion des renseignements, technologies de l'information et gouvernance. Nous mettons également en lumière des lacunes dans les connaissances et des avenues d'amélioration de l'accès aux soins pour les personnes atteintes de CPC et de CCA partout dans le monde.

present an indispensable part of working towards the United Nations' Sustainable Development Goals, especially those related to reducing neonatal and child mortality by 2030.¹³

PCHD, even when operated, is a lifelong condition due to the need for follow-up, risk of reintervention, and risk of comorbidities.¹⁴ However, a lack of primary access to tertiary cardiovascular care¹⁰ as well as high rates of loss to follow-up over time or during transition into adulthood results in poor continuity of care.¹⁵ Disparities have been observed in both high-income countries and LMICs; however, they are most pressing in the latter. Inequities exist both horizontally, with the need for resources and services available within countries to manage PCHD, and vertically, with different populations having different needs and means to meet those needs. Indeed, even in countries where CHD care may be geographically accessible, quality and appropriateness of care are not necessarily ensured. These considerations stress the importance of both a life-course and a systems-wide perspective to PCHD.^{8,16}

In this review article, we provide an overview of global access to PCHD care through the lens of 6 health systems building blocks as proposed by National Surgical, Obstetric and Anesthesia Plans (NSOAPs).¹⁷ NSOAPs are long-term policy plans embedded within countries' national health plans to strengthen surgical systems through workforce, infrastructure, service delivery, financing, information management, and governance. We conclude by highlighting remaining challenges and presenting opportunities to move forward towards a more equitable future in which every child and adult with PCHD has the opportunity to receive the care they need without undue burdens.

Workforce

The workforce involved in PCHD care is multidisciplinary, representative of the complexity of the condition as

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well as the continuum of care. Health care professionals involve community health workers and social workers and extend to tertiary care teams, including paediatric cardiac surgeons, paediatric cardiologists, intensivists, nursing staff, and more. Although these health workers may function in different clinical settings and manage patients in different stages of their care continuum, integration of their work and communication between them are paramount.

Globally, there are approximately 4000 paediatric cardiac surgeons, ranging from 9.51 per million population in high-income countries to 0.07 per million population in low-income countries, representing a more than 130-fold difference in provider density.¹⁸ Regionally and when adjusted for the paediatric population below 15 years of age, disparities are similar; in North America, there are approximately 11.1 paediatric cardiac surgeons per million paediatric population compared with 0.19 in Sub-Saharan Africa and 1.16 in South Asia. In addition, the workforce is likely imbalanced in terms of sex and gender. For example, only 6% of cardiothoracic surgeons in the United States and 11% of cardiovascular surgeons in Canada are women.¹⁹ In Pakistan, less than 2% of cardiothoracic surgical faculty are women,²⁰ whereas data from other LMICs are limited but anecdotally comparable. Data on the global cardiology workforce are scarce, although some estimates exist. Africa, for example, relies on only 2000 cardiologists for a population of 1.2 billion people, including both adults and children;²¹ in comparison, the United States has more than 30,000 cardiologists for a quarter of the population.²² The number and distribution of paediatric cardiologists worldwide are unknown but likely even worse considering the longer training pathways for paediatric cardiologists and the greater complexity of PCHD care.

Training programmes are limited in LMICs, with many health care professionals seeking superspeciality (ie, paediatric cardiac surgery and paediatric cardiology) training abroad, often in high-income countries. However, there are many barriers to enter training elsewhere, such as the need for accreditation or licensing examinations as well as sometimes a need for years of research to be sufficiently competitive, each of which come with their respective financial and administrative (eg, visa) burdens. After training, there is also a risk of brain drain, as individuals may be solicited to remain in their country of training or because they observe greater opportunities in terms of remuneration or academic endeavours. Moreover, there is a need for continued medical education for all members of PCHD heart teams to continue to improve the quality of care for those living with PCHD. Fortunately, developments in open-access virtual medical education are changing the training paradigms globally.²³ Lastly, training in high-income countries only equips specialists with the necessary skills to work in high-income country environments where resources are generally widely available. If specialists return to LMIC settings, especially if working outside private centres or well-established centres of excellence, they are commonly less familiar with managing late presentations and progressive disease, variable levels of staffing and training of other heart team members, limited resources, and other potential barriers to care delivery. As such, there is a great need for local or regional training programmes.

In high-income countries, over 95% of children now live into adulthood, resulting in more adults living with CHD

Table 1. Global burden of paediatric and congenital heart disease and select other conditions presented in terms of annual morbidity and mortality rates per 100,000 population

Condition	Overall population		Population <15 y	
	Deaths	DALYs	Deaths	DALYs
CHD	2.80	241.59	9.71	865.55
RHD	3.95	137.95	0.30	35.61
HIV/AIDS	11.16	615.60	3.90	337.87
Malaria	8.32	600.17	20.20	1819.66
Tuberculosis	15.25	607.82	3.35	310.73
Trauma/injury	55.57	3219.71	19.66	1783.25

Data obtained from the Institute for Health Metrics and Evaluation Global Burden of Disease Results Tool.¹²

CHD, congenital heart disease; DALY, disability-adjusted life-years; RHD, rheumatic heart disease.

compared with children in these countries.² In LMICs, the burden of adult CHD (ACHD) remains proportionally smaller albeit not negligible and more commonly in the form of unrepaired or partially palliated CHD, whereas the burden is growing as a result of gradual advances in access to care across the globe. As a result, ACHD-trained workforce is needed but remains even more limited worldwide.^{24,25} In Europe and North America, there are 3.6 and 1.7 ACHD centres per 10 million population, respectively; in stark contrast, South America (0.4), Asia (0.3), and Africa (0.1) rely on 1 centre per 25-100 million people.²⁶ Over time, the number of ACHD specialists has remained stagnant in many high-income countries, highlighting the need for increased engagement and awareness of trainees to prevent further and larger shortages in the future as the ACHD population grows.

Infrastructure

Comprehensive care for PCHD requires a robust infrastructure that can support early investigation, timely referral and transportation, and effective management. Neonatal screening programmes have been implemented in variable-resource contexts by using effective low-cost tools (eg, multimodality screening with pulse oximetry, clinical history and examination, and point-of-care ultrasound) and training health workers in targeted congenital cardiac imaging.^{27,28} In particular, such composite screening protocols may improve the sensitivity of individual screening tools with minimal additional time or resource burdens and can be performed by trained nonspecialist health workers with favourable results.^{29,30} Investing in screening programmes may reveal unrecognized cases, which not only provides an opportunity to treat more children with PCHD but may also motivate further investments into PCHD care.²⁷ However, it is important to recognize that the effectiveness of PCHD screening programmes heavily relies on downstream health care capacity, such as the availability of specialized care to treat the identified patients with PCHD.²⁷

Once a diagnosis is made in nontertiary health care settings, it is critical to ensure timely access to specialized cardiac services with adequate resources and trained professionals, available and functional medical and surgical equipment, and the appropriate medications. More than half of the population in LMICs lives in rural areas,³¹ and patients and families often have to travel long distances to reach health care facilities,

particularly specialized centres that are predominantly located in urbanized areas.^{32,33} Furthermore, many LMICs currently lack organized referral and patient transportation systems, leaving sick patients and their caregivers extremely vulnerable during critical phases of care.³⁴ Successful examples of improving paediatric referral and transport systems have been demonstrated in Kerala, India, by developing an algorithmic referral system based on diagnosis and geography,³⁵ and connecting health care providers involved in neonatal transport using a mobile application to enable real-time sharing of vital clinical data.³⁶ These systems led to earlier arrival of patients with PCHD at specialized centres and in better condition. Specialized paediatric cardiac centres are scarce in LMICs, and investing in such infrastructure is essential for effective PCHD management.¹¹ Crucial components to ensure uninterrupted quality surgical services in tertiary hospitals include trained professionals, operating rooms, intensive care capacity dedicated for paediatric cardiac patients, the necessary imaging infrastructure, and a reliable surgical supply chain for consumables.³⁴ Nevertheless, imaging modalities are poorly available across LMICs, whereas surgical supply chains are fragmented and commonly unreliable.^{37,38}

Telemedicine platforms offer promising solutions for bridging the gap in care accessibility. Teleconsultations can facilitate communication between specialized centres and primary centres, optimizing initial management and recognition of urgency for referral to specialized facilities.³⁹ For example, a teleconsultation programme operating in Brazil was found to be cost-effective, preventing 81% of referrals to distant high-level centres, with 97% of users expressing satisfaction with the system.³⁹ The effectiveness of telemedicine in PCHD care can be greatly enhanced by using simple and low-cost technology and fostering a trusting relationship between users through face-to-face interactions (eg, site visits and training sessions).³⁹ Accordingly, digital health technologies may be leveraged to help bridge the infrastructural gap in cardiovascular care delivery for PCHD.⁴⁰

Although providing advanced care with limited resources is challenging, delays in PCHD care can be minimized with a robust, integrative infrastructure that seamlessly supports patients from the screening process at primary centres to specialized care at tertiary centres and beyond.

Service Delivery

The met and unmet needs for PCHD care and procedures vary substantially worldwide. Whereas most children with PCHD receive the care they need in high-income countries, over 90% of children cannot access cardiovascular care in LMICs.¹⁰ A considerable part of the global cardiac surgical care is delivered by nongovernmental organizations (NGOs), which perform over 10,000 cardiac surgical procedures each year.⁴¹ A majority (81/86, 94.2%) of NGOs are involved with PCHD care, of which most (56/86, 65.1%) are exclusively focused on paediatric populations. However, most efforts through NGOs are nonlocal and remain limited in long-term sustainability, which require locally driven health systems solutions. Historically, most visiting teams have been service-focused rather than training-focused and building local capacity. Although this has changed in recent years, as more NGOs seek to support capacity-building, these efforts are

often secondary to other priorities. As such, NGOs should be supported and empowered to continue their efforts but be reflective in their activities, whereas local teams and health systems should consider visiting teams an opportunity to grow rather than to replace or adhere to a volumetric status quo. Simultaneously, visiting teams and NGOs increasingly stem from LMICs themselves, whereby so-called South-South collaborations may ensure greater and more contextual sustainability. For example, Children's HeartLink's Centers of Excellence are regional training centres for paediatric cardiac care in India, Malaysia, and China, helping train individuals from various LMICs.⁴² Such centres of excellence can simultaneously improve and scale the care provided for patients treated at these centres, while providing training, research, and career development infrastructure for local health workers, thereby reducing the risks of brain drain.

Countries have further increasingly recognized that delivering local care may benefit both patients and the health care system more than financing patients to receive care abroad. For example, the cost of cardiac surgery performed in Ghana is approximately USD\$50,000 less per patient compared with sending them abroad; moreover, locally, patients would be closer to home and surrounded by people with the same culture and language, whereas investments into the local health system result in a larger health workforce and spillover effects for other health services.^{43,44} This may particularly benefit countries who are spending large amounts of their health budgets on sending patients abroad: for example, several island states spend up to 15% of their health budgets to send patients to nearby countries to receive cardiovascular care, even when local population sizes are large enough to justify investments in a local cardiac centre.^{43,45}

Mere access to care does not equate to access to high-quality care. Low-quality care may cause greater morbidity and mortality than no care,⁴⁶ emphasizing the need to embed value-based health care mindsets from the start. For example, in Pakistan, the integration of value-based health care principles for CHD care resulted in improved patient-family satisfaction and clinical outcomes over time while reducing resource utilization, suggesting feasibility and impact in LMIC contexts.⁴⁷ This requires a commitment by all team members and a culture of quality improvement. Moreover, misconceptions surrounding the care delivered in private vs public sectors, especially when the latter is free for patients at the point of care, should be addressed.⁴⁸ Free or low-cost care does not necessarily mean low-quality care, whereas expensive or private care does not imply high-quality care. Quality metrics and quality improvement can and should be embedded along the entire PCHD care continuum in order to properly evaluate and improve the quality of care provided to patients with PCHD, regardless of the country of practice or level of care.⁴⁹

It is important to recognize that patients in LMICs commonly present with important comorbidities, such as infection, under- and malnutrition, and complications from CHD progression, such as pulmonary artery hypertension.⁵⁰ These present critical challenges for the management of patients and increase both the operative and nonoperative risks for the patient. These challenging presentations are particularly unfamiliar to visiting teams, who more commonly treat patients with a timely or early diagnosis and, thus, less

progressive or complicated pathology, further stressing the importance of locally led solutions.

Lastly, patients' health-related quality of life (HRQoL) should be recognized throughout the PCHD care continuum.^{51,52} Although most studies stem from high-income countries, HRQoL in patients with CHD, especially if having undergone congenital heart surgery, is almost consistently lower than in those without CHD and particularly affects the emotional functioning of patients.⁵¹ These effects are positively associated with the complexity of CHDs, whereby more complex defects result in lower HRQoL. In LMICs, observations are similar, provided that patients received the necessary care in the first place.⁵² Late diagnosis or delayed surgical care may not consistently result in poorer functional outcomes, but often still affect psychosocial functioning, requiring holistic approaches to the management of PCHD.⁵³ By extension, the goals of care should be well defined. Apart from cultural nuances unrelated to countries' cardiovascular capacity, there may be differences in the goals of care between and within countries depending on access to care (eg, late presentation and risk of complications requiring complex care, need for palliation, and burdens on families prohibiting work).

Financing

PCHD can impose an overwhelming health and financial burden on families, especially in LMICs, where out-of-pocket health care payments are common.^{54,55} In India and Vietnam, cardiac surgery is performed at costs as low as USD\$1500–3000, whereas in Nigeria, the cost of an open-heart surgery for PCHD ranges from USD\$6000 to USD\$11,000, which is comparable to most cardiac programmes in LMICs.^{54,56} These costs are lower than those observed in high-income countries but disproportionately burdensome for families in LMICs, where salaries and insurance coverage are much lower.⁵⁷ In addition, the costs of comprehensive care for PCHD extend beyond the surgical costs, including diagnostic tests, medications, and follow-up care and transportation, that must be considered as part of the cost equation. As a result, the risk of catastrophic health expenditure due to PCHD care is high.

Paediatric cardiac surgery programmes in LMICs have been found to be highly cost-effective, whereby for every USD\$171 spent one disability-adjusted life-year was averted.⁵⁸ In addition, a modelling study indicated that investing in secondary and tertiary care for RHD in the African Union would produce significant health and economic benefits that far exceed the health care costs and would deliver far greater returns on investment compared with investments in primary prophylaxis of acute rheumatic fever alone.⁵⁹ These data emphasize the importance of providing greater financial support, both locally and globally, to paediatric cardiac care programmes to meet population needs and simultaneously contribute to economic growth. To enhance cost-effectiveness without compromising quality, implementation of feasible practices such as bulk-purchasing and reesterilizing surgical consumables has been suggested, particularly in settings with present or projected high surgical volumes.¹¹ Furthermore, by reducing levels of poor-quality and low-value care, outcomes may be improved and unnecessary spending (eg, on managing preventable complications) avoided.

Although international organizations play an important role in supporting PCHD programmes in LMICs,⁴¹ it is essential to invest in local capacity development and expand domestic investments to ensure sustainable services.^{43,60,61} Despite the 2001 commitment made by all African countries in the Abuja Declaration to allocate 15% of annual government budgets to health care, nearly all countries have not met this target. Similar observations may be made for LMICs in other world regions. Therefore, there is a pressing need for renewed commitment from local governments in LMICs to increase health care funding, especially targeting health systems areas that have long been neglected, such as surgical and noncommunicable disease care. Without such commitments, meeting the Sustainable Development Goals by 2030 will be impossible. Financial risk protection schemes, such as health insurance and government subsidies, are also crucial to reduce the financial burden on patients and families and ensure equitable access to quality care. Financing pooling mechanisms have been implemented in some LMICs, such as governmental subsidies for life-threatening cardiac conditions in Nepal and a cofinancing model of Narayana Health in India, where wealthier patients share the financial burden of poorer patients.⁵⁴ Hence, to alleviate the financial burden on families for PCHD care, a multifaceted approach is needed. This includes expanding health care expenditure by local governments, implementing effective financing schemes, and encouraging continued support from the international bodies. This approach may reduce the reliance on out-of-pocket funding, which is an important step towards ensuring global access to quality PCHD care.

Information Management and Technology

Health outcomes should be tracked to inform institutional practices (ie, quality improvement) and further clinical knowledge (ie, research). Databases are ideally maintained within institutions, although the costs may be considerable due to the need for data entry—and thus workforce time—as well as electronic data infrastructure. Institutional and local registries may allow for quality improvement projects (eg, examining early extubation after surgery) and opportunities for integrated case management. In Kerala, India, the introduction of a web-based application for case logging, referral triaging, and longitudinal tracking in real time resulted in an increase in congenital heart surgery volume (from 208 to 1227 surgeries per year) and a reduction in CHD-related infant mortality in the state (41.0% reduction) between 2017 and 2019.³⁵ Similar applications to better register and follow-up on patients may be translated across different settings with shared learnings to reduce costs and circumvent common hurdles.

Meanwhile, national and international databases provide opportunities for pooling data to generate larger datasets and, thus, increase sample sizes (eg, for rarer CHDs) or compare outcomes across settings (eg, high-income countries vs LMICs). The World Database for Pediatric and Congenital Heart Surgery, for example, involves 39 centres across 22 countries, with the number of LMIC centres slowly increasing.⁶² Similarly, the International Quality Improvement Collaborative unites 73 centres across more than 25 LMICs.^{63,64} Participating centres collect standardized data on

Table 2. Challenges and opportunities to address the global burden of paediatric and congenital heart disease (PCHD)

Domain	Challenges	Opportunities
Workforce	Low numbers and maldistribution of cardiovascular specialists Scarcity of training programs for PCHD and ACHD care Gender gaps and under-representation Brain drain	Political and financial commitments E-learning and international capacity-building Removing sex-based barriers and introducing unconscious bias training Infrastructural and career support, including local centres of excellence and South-South collaborations
Infrastructure	Insufficient cardiac centres globally, especially for PCHD Inadequate imaging and diagnostics capacity Fragmented supply chains	Political and financial commitments Careful public-private partnerships Point-of-care diagnostic modalities Industry engagement and more local supply chains, including locally priced (or subsidized) supplies
Service delivery	Frequent reliance on visiting teams and/or care abroad Variable outcomes of PCHD care No or limited quality improvement culture Lack of patient-reported and patient-centred outcome evaluation	Recognizing superiority of local care delivery for patients and health system Outcomes research and quality improvement Connect reimbursement and/or recognition policies to outcomes (ie, reduce low-value care) Better evaluating health-related quality of life and patients'/families' needs and wishes
Financing	Low funding for surgical care and noncommunicable diseases Earmarked global health financing for non-PCHD foci Misconceptions surrounding the cost-effectiveness of PCHD care	Innovative financing instruments and increased domestic spending on health Removing earmarking and increasing health systems financing Expanding economic evaluations and health economics research for PCHD
Information management and technology	Loss of follow-up of patients and limited patient-centredness Scarcity of electronic health records and limited outcomes research Limited data infrastructure and human resources	Telemedicine services to support diagnosis and follow-up Local, national, and international registries for quality improvement and clinical research Locally developed and scaled electronic health records Explore areas for AI/ML applications
Governance	Low policy prioritization and political buy-in Fragmentation of advocacy efforts Poor recognition of PCHD and PCHD care in global surgical policy	Increased and streamlined advocacy and research Integration of PCHD and cardiovascular care in NSOAPs Regional collaboration between countries

ACHD, adult congenital heart disease; AI, artificial intelligence; ML, machine learning; NSOAPs, National Surgical, Obstetric, and Anesthesia Plans.

the outcomes of CHD procedures, whereas the International Quality Improvement Collaborative supports centres through virtual capacity-building and on-the-ground data validation and training. Ultimately, locoregional databases, especially when managed by and supported through local stakeholders and bodies, are the most effective way of generating contextual clinical evidence, benefiting patients, the health system, and society at large.⁶⁵ Furthermore, patient-centred and patient-reported outcomes may be incorporated, whereas clinical outcomes may be standardized in clinical registries, thereby improving the precision and validity of research within and between databases. For CHD, the International Consortium for Health Outcomes Measurement recently established a consensus set of clinical and patient-reported outcomes that may guide existing and budding databases.⁶⁶ Nevertheless, most patient-reported outcome measures are high-income-country-centric and not tailored to LMIC contexts or the specific challenges faced by patients with PCHD in LMICs. As such, tools need to be validated, adapted, and informed by patients and other stakeholders from local settings and translated into local languages to be properly used outside high-income countries.

Lastly, the recent growth in artificial intelligence applications and machine learning models for outcome predictions presents opportunities to support research and clinical decision-making, especially in workforce-constrained settings.^{67,68} For example, machine learning may accurately

diagnose CHD in the absence of cardiovascular specialists or serve as a physician decision support system in the presence of cardiovascular specialists.⁶⁷ Similarly, artificial intelligence tools may be used to support research (eg, help identify literature or troubleshoot analytic codes), bridge linguistic barriers (eg, translate English guidelines and publications), and even strengthen health systems through health chatbots and streamlining data processes.⁶⁹ Nevertheless, the recency of these applications still questions the long-term effectiveness and impact,⁷⁰ as well as the ethics, privacy issues, ownership, and accuracy associated with artificial intelligence-generated or machine learning-based applications, requiring caution and scrutiny.

Governance

Health care delivery is influenced by health systems and policymaking, requiring engagement of policy- and decision-makers as well as governance planning at different levels of the health system. To date, 8 LMICs have developed and launched NSOAPs,¹⁷ with dozens of other countries in the process of developing theirs. Among published policy plans, only 1 (Zambia) mentioned cardiac surgery; although 2 NSOAPs (Pakistan and Nigeria) prioritize paediatric surgery, no plan has thus far specified PCHD.^{17,71} This neglect of cardiac surgical care can also be observed at an international level, where official policy documents by the World Health

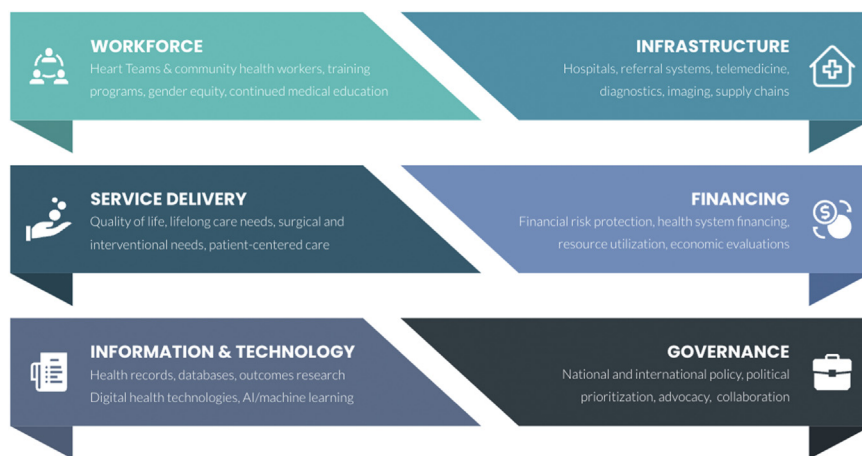


Figure 1. Requirements for access to comprehensive care for paediatric and congenital heart disease. AI, artificial intelligence.

Organization, United Nations, and World Bank rarely mention cardiac surgery, even when describing broader access to surgical care or focusing on specific conditions, such as RHD.⁷² This gross lack of policy prioritization may at least be partially attributed to fragmentation in efforts and messaging within the surgical, cardiovascular, and PCHD communities;^{73,74} however, without being invited to the table, generating action and agreement remains difficult.⁷⁵

Challenges and Opportunities

There remain many misconceptions surrounding the role of PCHD care in global health and health services research, which are partially responsible for the neglect thereof.⁴⁸ Historically, cardiac surgery was considered a luxury or afterthought in the context of global health or considered too costly, not cost-effective, or not feasible to scale in LMICs. Yet, a growing body of evidence suggests that tertiary care for PCHD is highly cost-effective,⁵⁸ provides positive economic returns on investment,⁵⁹ can be performed at very low costs,⁴³ and can be scaled safely and effectively even in low-income countries.^{76,77} However, minimal such research has been conducted, which is partially the result of a disconnect between major funders of global health research (eg, Gates Foundation, UNICEF, USAID, and World Bank) and resulting agendas in LMICs on the one hand and the actual health care needs in a country on the other hand. For example, over 50% of all global health financing is allocated to malaria, tuberculosis, and HIV/AIDS, despite making up less than 5% of the global burden of disease.⁷⁸ By contrast, noncommunicable diseases make up 74% of all deaths each year,⁷⁹ yet receive less than 2% of global health funding.⁷⁸ In addition to policy, research, and funding discrepancies, workforce challenges perpetuate disparities. There is a low baseline workforce to manage PCHD, resulting in few training programmes in countries affected by these shortages. Moreover, the long duration of training (eg, for congenital heart surgeons and paediatric cardiologists) requires both considerable personal investments and long times away from one's country if needing to train abroad. This is accompanied by high training costs and delayed benefits to local health systems, which may not be politically appealing, especially

compared with quick and visible “wins.” Furthermore, PCHD is inherently team based, requiring expertise and involvement of multidisciplinary health care professionals. Team-based training is hereby preferred, albeit more challenging, especially if no local training programmes exist.⁸⁰ Lastly, PCHD disparities are a global problem, one which high-income countries are not immune against. Disparities in PCHD care have been observed as a result of socioeconomic status, race, ethnicity, rurality, and immigration status, among other factors. As a result, thousands of children with PCHD in high-income countries receive suboptimal care each year.⁶ Thus, it is paramount for health workers and policymakers to recognize health systems barriers, biases in care, and patients' social determinants of health anywhere in the world.

Despite these challenges, several opportunities arise (Table 2, Fig. 1). Recently, a comprehensive, multidisciplinary framework to scale PCHD services was developed by a global group of clinicians, patients, and researchers.⁴⁹ The framework applies a population-based, public health, and integrative approach to PCHD care as part of existing health systems to ensure integration rather than further siloing. Furthermore, the pandemic has accelerated interest and investments in virtual platforms for care delivery and education, highlighting opportunities to further leverage online learning and remote simulation training.^{81–84} These platforms reduce the need to travel for short-term training that may be conducted remotely, thereby reducing financial and administrative burdens while keeping health care workers within their own environments, whereas they allow more people to participate globally. Several of these educational efforts are driven or complemented by NGOs. For example, Heart University and the Global Surgery Foundation's SURGhub are open-access learning platforms for cardiovascular and surgical continued medical education.^{81,85} NGOs can further expand their efforts, both educationally and clinically, by improving collaboration between themselves, especially when working in the same region, country, or even hospital.⁸⁶ Moreover, they may strengthen their advocacy efforts by, for example, streamlining messaging and co-organizing events and campaigns.⁸⁷ Ideally, there should be support to local NGOs to catalyse more South-South collaborations. Meanwhile, professional societies play a leading role in advancing the PCHD agenda. For example, the Congenital

Heart Surgeons' Society involves dozens of PCHD centres across North America to facilitate multicentric and methodologically rigorous clinical research to inform clinical practice, whereas the World Society for Pediatric and Congenital Heart Surgery is extending its World Database to more and more LMICs. Similarly, for ACHD, the International Society for Adult Congenital Heart Disease convenes health care professionals and trainees involved with or interested in ACHD care globally.⁸⁸ Furthermore, governments should seek to better support PCHD care and research, which will require political commitment and non earmarked funding amidst current funding inequities. Governments may explore regional collaborations with neighbouring countries to share experiences, brainstorm solutions, and facilitate South-South collaborations.⁸⁹ Lastly, but importantly, patient-family and community engagement are foundational to ensure patient-centred care.⁹⁰ The Global Alliance for Rheumatic and Congenital Hearts is a global alliance of more than 50 patient-family organizations working on CHD and/or RHD worldwide, with approximately half of its organizational membership and leadership based in LMICs.⁹¹ The Global Alliance for Rheumatic and Congenital Hearts supports its member organizations through regular capacity-building and mentorship to support advocacy efforts on the grounds, resulting in more grassroots advocacy efforts led by patients and families.

Conclusions

Access to care for PCHD remains highly variable worldwide and is especially poor in LMICs. Barriers to care are prominent and present differently across different parts of the health system and different points in patients' lifetime. Multidisciplinary, collaborative efforts are necessary with patients, families, and communities at the centre to help all patients with PCHD live their lives to the fullest potential.

Ethics Statement

The authors confirm that ethics approval is not applicable to this article, as the article involves a review of the literature (ie, not human subjects research).

Patient Consent

The authors confirm that patient consent is not applicable to this article, as the article involves a review of the literature (ie, not human subjects research).

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