Cardiology in the Young

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Achieving excellence in paediatric cardiac care in resource limited and resource plentiful settings and building successful care networks across different countries

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Abstract

Background: The delivery of paediatric cardiac care across the world occurs in settings with significant variability in available resources. Irrespective of the resources locally available, we must always strive to improve the quality of care we provide to our patients and simultaneously deliver such care in the most efficient and cost-effective manner. The development of cardiac networks is used widely to achieve these aims. *Methods:* This paper reports three talks presented during the 56th meeting of the Association for European Paediatric and Congenital Cardiology held in Dublin in April 2023. *Results:* The three talks describe how centres of congenital cardiac excellence can be developed in low-income countries, middle-income countries, and well-resourced environments, and also reports how centres across different countries can come together to collaborate and deliver high-quality care. It is a fact that barriers to creating effective networks may arise from competition that may exist among programmes in unregulated and especially privatised health care environments. Nevertheless, reflecting on the creation of networks has important implications because collaboration between different centres can facilitate the maintenance of sustainable programmes of paediatric and congenital cardiac care. *Conclusion:* This article examines the delivery of paediatric and congenital cardiac care in resource limited environments, well-resourced environments, and within collaborative networks, with the hope that the lessons learned from these examples can be helpful to other institutions across the world. It is important to emphasise that irrespective of the differences in resources across different continents, the critical principles underlying provision of excellent care in different environments remain the same.

Original Article

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Introduction

In the specialty of paediatric and congenital cardiac care, we are always searching for opportunities to increase the quality of care we provide our patients, within the resources available to our healthcare system. With escalating healthcare costs, the disparity of healthcare delivery in resource-rich environments such as the United States of America and low-income countries and even middle-income countries is growing wider. The scarcity of human and material resources is a stark reality for most low-income countries and middle-income countries, where over 90% of the world's children with heart disease are born.[1] For these regions, building and running centres of excellence using the prevailing western model is not realistic due to the associated extremely high costs. It is clear, therefore, that a "one size fits all" approach to paediatric and congenital cardiac care is not useful. Nonetheless, irrespective of location and available resources, we can all learn from each other for the benefit of our patients. One useful approach to facilitating this mutual learning and improvement of service to our patients is the creation of care networks.

"*Network*" is a word used extensively in healthcare research and in health services. In this context, the word "*network*" can be defined as: "*a co-operative structure where interconnected groups or individuals coalesce around a shared purpose on the basis of trust, respect, and*

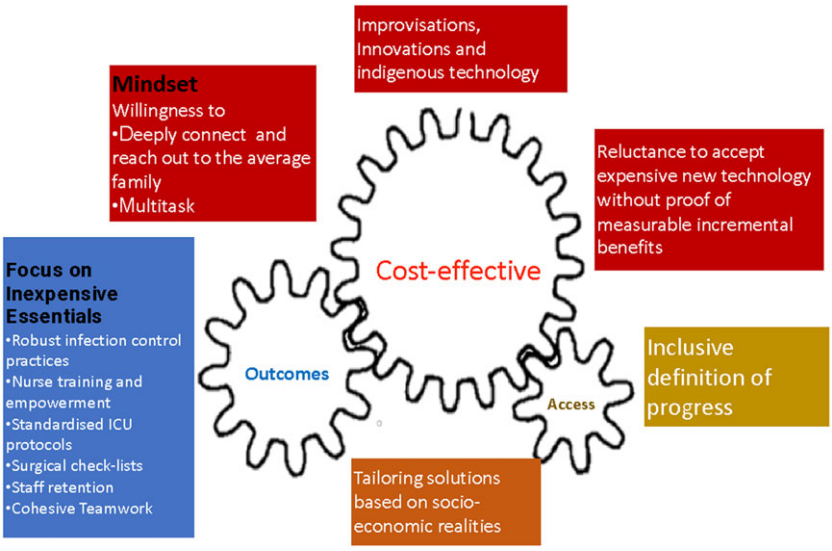

Figure 1. Accessible and affordable care without compromising quality.

reciprocity". The most important potential benefits of clinical networks are to improve clinical care and bring about system-wide change.

This article is based on three talks delivered during a session on Networks held at the 2023 annual meeting of The Association for European Paediatric and Congenital Cardiology (AEPC 2023) that were presented by the authors of this manuscript. The purpose of this article is to present these three different talks with the following objectives:

- Examine the guiding principles, key elements, and challenges related to the building of a centre of excellence in a low resource environment, using the Amrita Hospital in Southern India as an example, where a centre with a quality of care on par with international standards has been created at a fraction of the cost of what is typically required in advanced nations.[2,3]
- Outline the principles which underpin the delivery of high quality care in a well-resourced western country, using Texas Children's Hospital (Houston, Texas, USA) as a model.
- Examine countries where units have come together to provide collaborative patient care, using the All Island CHD Network in the Republic of Ireland and Northern Ireland as an example.

Building a centre of excellence in a resource limited setting (The model of The Amrita Hospital in Southern India)

Guiding principles

This section of this article is based on the experience at The Amrita Hospital in Southern India. The Amrita Hospital has demonstrated that accessible and affordable care in a resource-limited environment does not require a significant compromise in quality (Figure 1). One fundamental requirement is for every team member to develop a mindset that seeks to understand the socio-economic background of the family of every child.[4] This understanding enables cost consciousness at every stage in the care of the child. A second fundamental principle is that individual team members need to multitask. While the prevailing model in Top North American Hospitals of highly specialised care for each of the areas within paediatric cardiology enables exceptional quality of care, it is largely unrealistic in most low- and middle-income settings because of the substantial shortfall of trained manpower in these regions. Over the years we have developed a model at Amrita that seeks to provide the best possible quality with the available manpower (See Table 1). In most circumstances, it is realistic for a paediatric cardiologist to perform non-invasive imaging and invasive procedures, assist in critical care, and interpret common arrhythmias at the bedside. This multitasking enables programmes to be facile and efficient.[4]

A number of systems that are essential to good outcomes cost very little and yield a high return on investment. These systems and programmes include:

- establishment of a robust infection control programme,[5]
- implementation of a surgical safety checklist,
- the continued education and empowerment of nurses, and
- the creation of forums for communication amongst individual team members, enabling cohesion among members of the team and proactively minimising conflict.

Carefully considered decision-making is necessary with relation to the possible acquisition of new and expensive technologies. For example, the acquisition of hybrid operation-catheter laboratory suites or equipment for robotic surgery is likely to make a significant impact for a small proportion of procedures and patients, but is simultaneously likely to increase substantially the overhead costs for all procedures.

Perhaps the most controversial aspect of delivering care amidst cost constraints relates to case selection. A reluctance to perform complex multi-stage palliations in the face of uncertain long-term outcomes is present in most low-income countries and many middle-income countries. Examples include "high-risk" functionally univentricular palliations and also unifocalisation for complex forms of tetralogy of Fallot with pulmonary atresia. These decisions must be carefully tailored, depending on both the clinical condition and socio-economic realities.[6]

Finally, it is essential to use an inclusive definition of progress that prominently incorporates *access to care*. Defying traditional outcome-based metrics, this mindset would emphasise the notion that true progress is perhaps made only when the vast majority of

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children in the region have access to comprehensive paediatric cardiac care.[7]

Key elements of building paediatric cardiac centre of excellence

The most important step in building a cardiac centre is obtaining "buy-in" across the organisation about the value of developing a programme focused on paediatric cardiac care. This "buy-in" requires a shared vision of making an impact on children with acquired and CHD in the region. Embarking on this mission requires clear, consistent, and candid communication from the programme leadership. An extremely compelling argument that supports the investment in paediatric cardiac services is the collateral benefits of improving quality across other paediatric specialties through establishment of robust systems in multiple other domains, including:

- infection control,
- transfusion medicine and blood banking,
- newborn and infant transport, and
- improved quality of nursing and intensive care.

It is also essential to introduce cultural changes from the traditional hierarchical model that exists in the environments of many low-income countries and middle-income countries to a model of shared accountability across diverse health care professionals. The empowerment of nurses and the promotion of continuing medical education are critical steps towards this direction.

Partnering with established paediatric cardiac programmes in the west and the creation and utilisation of networks enables rapid learning of best practices that will ultimately need to be adapted and tailored to local realities. An excellent example is the partnership with International Quality Improvement Collaborative for Congenital Heart Disease that has facilitated significant improvements in numerous programmes in low-income countries and middle-income countries in 37 countries across the globe.[8] The paediatric heart programme at the Amrita Institute of Medical Science and Research Center has been a member of the International Quality Improvement Collaborative for Congenital Heart Disease since 2010. This requires every partnering programme to maintain institutional database that is externally audited by the International Quality Improvement Collaborative for Congenital Heart Disease. This has enabled publishing surgical outcomes that compare well with North American databases. [2,3] Similarly partnering with non-governmental organisations such as Children's HeartLink can facilitate targeted improvements in quality of care. While joining large databases such as the International Quality Improvement Collaborative for Congenital Heart Disease [https://childrensheartlink.org/iqic/] and The World Database for Pediatric and Congenital Heart Surgery [https://www.wspchs.org/world-database/world-database-for-pediatric-and-congenital-heart-surgery] enables periodic assessment of local outcomes benchmarked against aggregate global outcomes, it is equally important to create a culture of periodic introspection through regular internal meetings.

Structured training programmes that are carefully targeted to developing a multidisciplinary cadre of professionals are vital to the sustainability and scalability of whatever is accomplished in the centre of excellence. Efforts to retain these skilled and trained individuals in the local community are also critical to sustainability and scalability.

Finally, every programme needs an overarching structure of leadership that proactively seeks to accomplish multiple goals, including[9]:

- ensuring harmony within the team,
- developing and pursuing a strategic vision, and
- liaising with the institutional administration.

Overcoming common challenges in low-resource environments

Creation of a new paediatric cardiac programme presents many significant challenges. First, large numbers of patients can overwhelm a centre with limited resources. This challenge requires a pragmatic approach in the initial stages, with gradually building systems to strengthen the programme. For this reason, it is reasonable to not attempt challenging cases in the early stages. In our programme, for instance, we did not attempt neonatal cardiac surgery until 6 months after starting the programme. It is worth investing heavily in the training of nurses in the initial stages of the programme, recognising the pivotal role of nursing care in every aspect of paediatric care, and especially in paediatric cardiac care.

Co-morbidities. A number of co-morbidities tend to complicate the management of patients with paediatric cardiac disease in the environment of low-income countries and middle-income countries. Undernutrition and infection are often the most common among these unique and challenging factors.[10] These challenges require a nuanced approach. We have shown that it is possible to correct common cardiac defects and obtain good outcomes irrespective of nutritional status.[2,10,11] Therefore, we believe that weight thresholds for correcting common left to right shunts like ventricular septal defects are not indicated. Bloodstream sepsis in neonates and pneumonias in infants can complicate management and should be thoroughly investigated and addressed prior to surgical correction.[2,11,12]

Late presentation. Late diagnosis and referrals bring a unique set of challenges and problems. It is critically important to develop standardised protocols for assessment of patients with pulmonary hypertension.[13] Severe hypoxia may necessitate palliation in selected patients with cyanotic defects prior to surgical correction.[14] Systematic challenges of late presentation can only be addressed by improving awareness and working toward transformation of primary care.[15] Universal screening with pulse oximetry and prenatal diagnosis can greatly improve the condition of neonates with CHD by ensuring very early diagnosis and prompt referral and treatment.[15,16]

***Financial Sustainability*:** A significant proportion of patient care costs in many Low and middle income countries (LMIC) programmes are out of pocket expenses borne by patient's families with serious economic consequences. While philanthropic funding from charitable foundations can supplement or supplant costs in selected cases, it cannot be a consistently reliable source and is hard to sustain. Private insurance is poorly developed and can only be afforded by a small fraction of the population. Ultimately robust financial sustainability will require the government to step in through population based programmes.[17] This requires sustained advocacy, coordinated efforts and substantial political will.

The absolute burden of paediatric heart disease in the low resource environments of low-income countries and middle-income countries is massive, and it is only recently that an attempt

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is being made to address this issue through establishment of centres of excellence. These centres serve as sites for

- the development of protocols of management that can be applied elsewhere,
- contextual research, and
- building of capacity through structured training programmes.

Such centres of excellence in resource limited settings have the potential to play a critical role in improving the outlook for a majority of the children with cardiac disease in the world in the coming years.

Building excellence in well-resourced environments (North American model)

The care of patients with paediatric and congenital cardiovascular disease is becoming increasingly complex with every increasing requirement for resources. While superficially it might be obvious to identify differences in approaches to care between resource-limited and resource-sufficient environments, it is important to emphasise that the principles underlying care in different environments remain the same. As a result, we can learn from each other as we aim to provide higher standards of care against a background of increasing patient complexity.

It is clear, that irrespective of financial and societal background against which care is being provided, clinicians must work with patients and their families to integrate a continually evolving evidence base (which is rarely based on clearly prescriptive, controlled studies) with a multitude of patient-related data points including symptoms, signs, imaging findings, preferences, family, and social circumstances to negotiate a treatment plan tailored to that patient and their family.

Formulating a treatment plan will result in a multidimensional outcome for the patient and family experiences as they navigate through the system. Unfortunately, irrespective of context, the ability of the clinician and the system to learn from these outcomes and apply them to the next patient is limited, as it is rare that the clinician is provided with feedback about these patient experiences in a timely, meaningful fashion. If we wish to learn from our patients and their experiences, we need to[18,19]:

1. develop *a culture of learning* within our organisations;
2. strengthen the *relationships between clinicians, patients, and other stakeholders*;
3. provide our clinicians with *timely, meaningful data* related to clinical outcomes and patient experience; and
4. create *incentives* for clinicians and organisations to improve.

A learning culture

One of the most powerful determinants of improving a service is the strength of its culture of learning.[20] We can consider organisational culture to be the beliefs, values, and assumptions held within the organisation. These tenets drive behaviour which in turn determines results. If we wish to improve our results, we need to reflect and define the culture and then proceed to negotiate and model behaviours. The leadership of the team and its members should work actively to create and nurture a culture of learning based on trust[21] and psychological safety.[22] Without a strong culture of trust and elevated levels of psychological safety to explore the inevitable failures that occur in every organisation, then we will never optimally learn.[23,24] An important outcome from this elevated level of psychological safety will be the opportunity to create open, transparent forums for quality review and empowerment of nursing which, as has been discussed, are essential to the enhancement in care everywhere.

Partnerships

As we learn to improve the care delivered to patients, we must strengthen our partnerships with our stakeholders[25]:

- our patients,
- their families, and
- our professional colleagues.

The traditional paradigm in healthcare is that the large academic centre is the gold standard for care and is where the most talented physicians practice. This traditional "ivory tower" has been replaced by a new paradigm based around service, as now the most valued care includes a more personable, convenient, efficient, and communicative environment. And so, if we truly want to innovate in healthcare, if we truly wish to learn, we need to peer beyond the walls of our healthcare institutions and form true partnerships with our community.[26] This outwardly looking perspective, based on a spirit of service will not only facilitate earlier referral to cardiac centres of excellence in resource-limited environments, but will facilitate better holistic care for the patient with complex multi-system disease in better-funded health systems. The importance of such partnerships within our systems is becoming an issue of increasing importance in the setting of subspecialisation of care as the numbers of subspecialists providing input to the care of an individual patient progressively increases.

Data

Developing a learning healthcare system requires access to timely clinical and patient experience data.[27] Few health care systems exist in which this level of responsiveness has been developed. All too often what occurs is that clinicians provide data to a centralised administrative data set and the data returns to them in the distant future in a format that is not applicable for treating the patients at the bedside. As a result, the term "*data rich, information poor*" exists. Hope exists for developing meaningful and timely information arising from the electronic health record, although significant further improvements will need to occur over the next decades.[25] An important opportunity from the big data movement includes visualisation of this information in real time, so that we can extract actionable insights.[28,29]

Incentives

Central to the creation of a learning healthcare system are the incentives for inducing change. The comfort of established approaches to patient care, the organisational silos, and competing priorities developed over decades need to be overcome with incentivised opportunities for learning and improvement. Incentives need to be developed in a way that provides advantages to the organisation beyond a simple return on investment, but also in terms of reputation and the presence of the organisation in the community. Payers need to be incentivised to support the acquisition of appropriate evidence and its use as they help to drive improvement,[30] while clinicians at every level must be supported to work in innovative teams with high levels of

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psychological safety and with explicit plans for their professional development. As discussed, buy-in from hospital leadership is a crucial step in the successful development of an integrated care facility for patients with complex disease, whether this complexity results from delayed presentation, poor nutrition or coexistent infection, as has been described above in the patient presenting to a centre in a resource-limited environment or one with coexisting extra-cardiac or genetic abnormalities, who present for care to resource-appropriate centres. Our patients and their families must be supported as they work with professionals towards new models of care, which will ultimately provide better outcomes and experience for them and their loved ones.

Building a collaborative care networks (The model of The All Island CHD Network)

The advances that have occurred in the treatment of children with CHD include complex surgical and interventional catheter procedures linked to very sophisticated postoperative care, which often are only deliverable in large centres. The logic of this regionalisation is to concentrate the surgical and interventional catheterisation expertise and complex postoperative care including extracorporeal life support in larger centres to maximise case volumes and consequently improve outcomes.

These elements are, however, only some of the elements of the complete package of care needed to achieve the best outcome for the child with CHD.

As a result, an increasing need exists for paediatric cardiac care to be delivered within clinical networks with the combined input of professionals of many disciplines working across linked institutions. To be successful, the key partners must a have a shared purpose that is built around providing the highest quality of care for the patient, independent of personal or institutional priorities. That shared purpose must be to provide the highest quality care for the child and family. The pursuit of this goal often is facilitated by challenging existing thinking on models of healthcare delivery, and resistance to such efforts can be the biggest barrier to positive change.

The Health Foundation UK in its 2014 report "effective networks for improvement"[31] outlined the key elements of successful networks, as summarised in Figure 2.

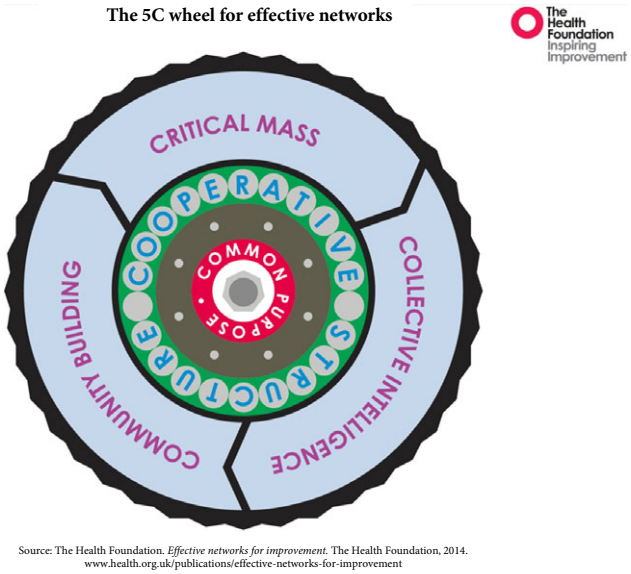

Figure 2. Key elements of successful networks.

Building a successful CHD Network

Over the past 10 years, we have developed a paediatric cardiology and cardiac surgery network on the island of Ireland, with the common goal of building a world class patient centred clinical service. The aim is to build a service that provides all the care needed to patients and families right through the journey from antenatal diagnosis to the stage of transition to services for adults with CHD. It has been a major challenge developing a clinical network across two political jurisdictions with different healthcare systems on both parts of the island of Ireland. This obstacle has been overcome by keeping the focus on getting the best care for the patient regardless of their place of birth.

The network model which has evolved has been designed to incorporate all the elements highlighted in Figure 2. That experience has highlighted the importance of having a cooperative structure; and therefore, we have structured our network model as summarised in Figure 3.

The All Island CHD Network Board has an oversight and strategic direction role only. The clinical aspects of the service delivered by the network are guided and shaped by the clinical advisory group, service delivery group, and family engagement group in a partnership, rather than a hierarchical model.

A vital element is that the structure makes best use of the pooled expertise working across the participating organisations. When making major changes to the way in which a service is delivered, it is vital to include all stakeholders in the process. In our experience, one of the most beneficial elements was to include the effected families as an integral part of the structure in the "Family Engagement Group".

In 2011, the "Safe and Sustainable" review of children's congenital heart services in the United Kingdom[32,33] recommended Paediatric Cardiac surgical services being concentrated in centres providing 400 surgeries per year delivered by a TEAM of four surgeons. Twelve years later, very few centres have been able to achieve this goal. Our All Island CHD Network delivers 450 surgical procedures per year and more that 600 catheter procedures. Further key elements of the network are:

1. Establishment of 5 centres (Figure 4) having a paediatrician with specialist expertise in paediatric cardiology, supported by clinical cardiac physiologists and paediatric cardiac nurse specialists.
2. All-Island training programme for paediatric cardiologists with rotation between the major centres.
3. Building a strong collaborative research programme on an all-island basis.
4. All-island educational courses for postgraduate nurse training.
5. High quality Informational Technology systems to facilitate case discussion and image exchange.
6. Joint hosting by the network of international paediatric cardiology conferences.

The model of specialist cardiology centres working in a network arrangement with local cardiology centres having paediatricians with specialist expertise in paediatric cardiology is now also well established in England. Examples of this approach include the South-West Network and the East Midlands Network.

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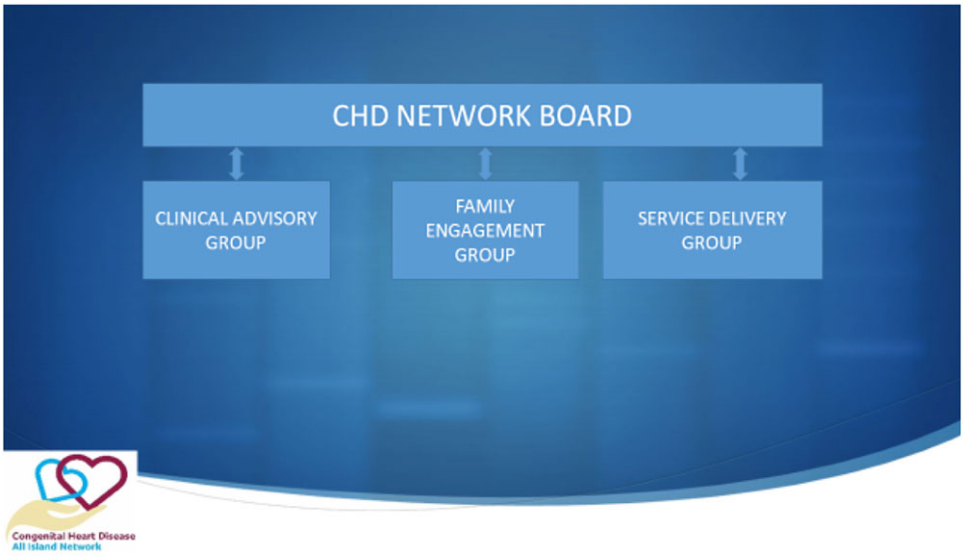

Figure 3. Structure of the All Island CHD Network.

Figure 4. Location of centres in Ireland in the All Island CHD Network. *Other outreach centres also exist in Letterkenny and Sligo in the Republic of Ireland.

A definite advantage of working in a collaborative network is that we have seen the "collective intelligence" of all professional groupings improve as a result of the interaction. Key to this has been joint participation in case management discussions. In addition, the development of shared training and teaching programmes harnesses and enhances educational expertise and builds relationships. This educational collaboration in turn helps develop the sense of community that is vital to the maintenance of productive working relationships. The benefits of this type of "Learning Health System" have also been highlighted by Bowker and colleagues.[34] Anderson and colleagues[35] reported the effectiveness of a learning network in achieving reduction in mortality for children with hypoplastic left heart syndrome in Canada.

To be successful, a network must bring clear benefits to all the institutions and staff working within it, as well as to the patients under their care. One of the tensions than can occur in such networks is that staff in the "smaller" partner hospitals may fear the loss of skills and the disintegration of the service in their institution. It is here that mutual respect and reciprocity are crucially important. A process of building professional relationships and trust takes time and requires strong leadership with a clear vision of what the shared purpose is.

There is also often anxiety and strong resistance from parent groups who have a strong allegiance to individual hospitals and clinical teams and are fearful of change.

Clinical networks developed to provide patient care also provide opportunities to collaborate on research. Establishing a shared research programme working in parallel with and integrated into the clinical service brings mutual benefits to both.

Technology

Working across different paediatric cardiology centres in a network arrangement requires efficient exchange of data including imaging. It also requires frequent videoconference calls for case

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discussion. Therefore, a properly functioning Paediatric Cardiology Network needs to be underpinned by high quality reliable and safe Information Technology systems.

Telemedicine links to provide remote diagnosis for newborns born at peripheral centres within a paediatric cardiology network are an extremely valuable addition to the clinical care package. In our service we have an ongoing research interest in the applications of telemedicine to the diagnosis and home monitoring of infants with major CHD and have integrated those applications into daily clinical practice to good effect.[36–38]

Opportunities for research and training

Networks may also afford the opportunity to enhance training and education of doctors and allied healthcare staff, including the potential for interdisciplinary or collaborative learning.[39–42] Clinical networks that bring together institutions across regions or countries enhance the opportunities to involve greater numbers of patients in multi-centre studies. Key benefits of this collaboration are the development of databases and data sharing across centres, greatly enhancing the power of research initiatives. A number of such CHD research networks exist in the United States of America and Canada,[43–46] but they are less well developed in Europe.

Lessons learnt from the All Island CHD Network

Strong clinical leadership with a commitment to and belief in the benefits the network can bring is the key to success. Particularly in the early stages of establishing a network, the leadership must be resilient to setbacks and the resistance to change.

This success of the leadership of team can only be achieved by building strong personal relationships with people in key clinical and managerial roles. Haines and colleagues in 2018[47] studied the key features of successful clinical networks in Australia, and they concluded that leadership and effective network management encompassing both strategic and operational elements were central to success. Several papers about the Canadian experience of clinical networks have highlighted as key issues[48–50]:

- leadership support,
- multilevel engagement,
- alignment, and
- coordination with clinical, research and community partners.

Another key element is building trust across the network partners. The building of trust depends on good communication that is inclusive of all disciplines working in the care team, coupled with a culture of mutual respect. It is vital that all participants in the network can see the benefits, as opposed to being "threatened" by the proposed partnerships.

The flow of services in a true network arrangement should not be in one direction only (towards the larger institution); instead, each participating institution should be encouraged to build local expertise in key areas, so that they add value to the arrangement. This arrangement brings about sustainability to the partners involved. In this context, clearly defined service level agreements are essential.

In the Irish context, we have also learnt that engagement with and involvement of the parents using the service in the planning and establishment of the network structures helps shape them in a way that deals with concerns and anxieties about change. This parental engagement is particularly important in the setting of people coming from different cultural and political backgrounds.

The sense of community within a network takes time to evolve and is built on the basis of the following concepts:

- personal working relationships growing out of working together in patient care and
- developing new ways of working.

Sharing of teaching and training across all professional groups enhances the sense of unity.

In our experience, shared workshops and conferences that include a social element help foster the sense of belonging to the network.

Benefits of networks

Effective networks are increasingly important in the care of children with CHD, particularly as treatments become more specialised and the population of patients consists of more surviving patients with complex CHD.

Working within networks allows for pooling of resources, but also needs to be supported by adequate funding for staffing and infrastructure. The All Island CHD Network in Ireland owes at least some of its success to the investment of funds in staffing and infrastructure from the health departments in both Northern Ireland and Republic of Ireland. A further benefit is the opportunity for improved governance and ongoing quality improvement initiatives.

Finally, the increased *Collective Intelligence* across the care team drives innovation and research. Any world class clinical service must be integrated with a strong culture of research and innovation, and this generation of new knowledge will feed through to improvements in patient outcomes.

Properly constructed and resourced networks will enhance the outcome for patients with CHD and their families. Good clinical leadership that facilitates inclusion of all disciplines and service users in shaping the care delivered, coupled with a culture of innovation and research, is the key to success. In the context of CHD, the aim should be to create a network that can safely deliver as much of the package of care as close to the patient's home as possible.[51]

As the complexity of care continues to evolve, clinical networks will become increasingly important at a national and international level.

Discussion

Advances in technology have made the global medical community much smaller and opened opportunities for cross-cultural pollination of practices. While there are socio-economic and cultural differences amongst the various paediatric cardiac programmes, paediatric cardiac programmes are uniquely poised to collaborate and learn from one another in an effort to create centres of excellence and help our patients.

As previously mentioned, the traditional view of patient outcomes has been the standard in determining "excellence" both in performance and patient care. However, it is becoming clear that one model does not fit all. It has also become clear that depending on resource availability and cultural differences, centres from both high resource communities and low resource communities have learned to navigate their environments successfully. By extending

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Table 1. Comparison of resources and outcomes for all 4 centres

Centre Country	Amrita Institute India*	TCH USA	All Island CHD Network*** Dublin / Belfast
Programme Founded Year	1998	1954	CHD Network 2016 1954 / 1932
No. paediatric CT surgeons	3	7	3
No. paediatric cardiologists	5	70	9 / 5.5
Total no. surgeries per annum	737	1073	445
No. CPB cases per annum	712	1150	270
Overall survival rate cardiac surgery	99%	98.4%	98%
Stage 1 Norwood survival rate*	80%	98.7%	92%
CV outcomes monitoring	IQIC	STS	NICOR/ NCHDA
All cardiac surgeries performed	Yes, except paediatric transplant	Yes	Yes except paediatric transplant
Number cardiac ICU beds Dedicated cardiac ICU (Yes/ No)	11 Yes	48 Yes	23**** / 16 ****ICU beds of which 6-8 are floating CICU beds
All specialist cardiac services	No dedicated EP or transplant service	Yes	Yes but shared care transplant service
ECMO/VAD programme	No formal ECMO/VAD programme; ECMO available for selected postoperative cases	Yes	No formal paediatric VAD programme but ECMO available for select cases
Total no. cardiac cath. per annum	545	1750	665
Outreach programme to regional centres	Four Outreach clinics in the region	Three Outreach hospitals	Five Republic Ireland / Five Northern Ireland
Total population served	~ 34 million	Statewide population of 30million. National referral base for several programmes	5.08 million / 1.9 million (Total 6.98 million)
Regulatory authority	Amrita University	Not-for-profit hospital	Health Service Executive (HSE) / National Health Service
Funding model (Public/ private/hybrid)	Hybrid: Private and public sources and charitable donations*	Privately insured, Medicaid and medicare	Publicly funded service (primarily) Limited outpatient private service
Training programme (Accredited)			
Paediatric Cardiology	Yes	Yes	Yes
Paediatric CT surgery	Yes	Yes	Yes

*Data shown here is from annual statistics for 2023.
IQIC: International Quality Improvement Collaborative for Congenital Heart Disease; **Experience with Norwood operation is only limited to 20 patients. NICOR/ NCHDA = National Congenital Heart Disease Audit (https:/www.nicor.org.uk); STS = Society Thoracic Surgeons.
***Cardiac surgery and cardiac catheterisation procedures performed in Dublin, NICOR data provided for 2023.
****General intensive care beds of which 6-8 are floating cardiac ICU beds.

the definition of excellence to include parameters such as catchment areas (or communities reached) and careful determination of quality of life (long-term outcomes) for families and patients (including financial, emotional, and resource-drive burdens), cardiac programmes can begin to question and reframe ways in which they can serve their communities best both within and beyond the confines of the hospital.

Establishing cardiac networks is another plausible avenue that expands beyond the pure view of a single hospital system. Many models have been purported to advance this directive, but ultimately, the goal is to expand the reach of cardiac programmes to ensure patients are treated and families do not need to make significant sacrifices to seek out the best care.

Cardiac networks can also be a looser definition that is not strictly based on the proximity of programmes geographically. Successful twinning of programmes can lead to improved quality of care and bidirectional exchange of knowledge.[52–57] Such twinning does not need to be limited by geographical boundaries.[52–57] Other forms of shareable resources also include

- intellectual capital,
- data-sharing and federated data,
- training and medical education of trainees, and
- research/innovation collaborations between programmes that could be separated by thousands of miles.

Technology has enabled physicians and patient families alike to connect on a global scale, and it is reasonable to also explore the creation of more intricate networks on a global scale that contribute both towards the development of robust cardiac centres as well as having a more diverse data-rich environment for research.

Education and training benefits uniquely from networking opportunities.[57] Bidirectional sharing of knowledge has been demonstrated by linking fellowship training programmes. Trainees gain valuable insights into practice variation between different centres, medical uncertainty and cognitive overload theory.[57] Other programmes have developed multilateral sharing of educational resources across multiple programmes in the Cardiology Across Continents framework (personal communication KR Kumar).

Challenges in networks and collaborations

Unique challenges exist for cross-border collaborations. The All Island CHD Network faces many of these challenges, despite there being a relatively open border between Northern Ireland and the Republic of Ireland. Specific challenges include:

- Equity of access to care irrespective of place of residence. This was ensured by creating a common waiting list for cardiac surgery and interventional catheterisation for all patients.
- Rigorous contractual arrangements between Departments of Health in both jurisdictions. These are Service Level agreements to ensure that the necessary patient services are funded and delivered.
- Governance of outcome measures. This was a key consideration for the parents of patients being treated within the network. This was achieved by Children's Health Ireland joining the UK centres in submitting outcomes of all cardiac surgical and interventional catheter procedures to The National Institute for Cardiovascular Outcomes audit process. These outcomes are readily accessible by the general public.
- Data exchange. Formal agreements for exchange of medical data are in place and essential imaging is accessible through an image exchange protocol.

Other potential barriers may arise from competition that may exist among programmes in unregulated and especially privatised health care environments. These barriers might prevent "learning from each other" in a collaborative framework. This lack of collaboration can lead to very little communication between centres and a lot of mistrust. This problem may even be witnessed within the same cities, resulting in both duplication of care and wasted resources associated with competing programmes often clustered in those same large cities.

Conclusion

In conclusion, this article highlights the key components involved in establishing successful programmes of congenital cardiac care both in countries with limited and plentiful resources. Achieving excellent outcomes are possible with limited resources when the model of care includes key components of innovation and affordable solutions. Furthermore, models of care can prove highly effective within a collaborative learning network model, as evidenced in the All Island CHD Network model of care. This article examines the delivery of paediatric and congenital cardiac care in resource limited environments, well-resourced environments, and within collaborative networks, with the hope that the lessons learned from these examples can be helpful to other institutions across the world. The key principles in providing excellent care remain consistent, which often flourish through the establishment of networks, irrespective of resource disparities across different continents.

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