Cardiology in the Young

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Cardiac Networks United: an integrated paediatric and congenital cardiovascular research and improvement network

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Original Article

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Cite this article: Gaies M, Anderson J, Kipps A, Lorts A, Madsen N, Marino B, Costello JM, Brown D, Jacobs JP, Kasnic D, Lihn S, Lannon C, Margolis P, Pearson GD, Kaltman J, Charpie JR, Redington AN, Pasquali SK, on behalf of the Cardiac Networks United Executive Committee and Advisory Board. (2019) Cardiac Networks United: an integrated paediatric and congenital cardiovascular research and improvement network. *Cardiology in the Young* **29**: 111–118. doi: 10.1017/S1047951118001683

Received: 18 July 2018
Accepted: 31 August 2018
First published online: 20 December 2018

Key words:
Clinical registries; quality improvement; paediatric cardiology; collaborative quality improvement; other

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Abstract

Optimising short- and long-term outcomes for children and patients with CHD depends on continued scientific discovery and translation to clinical improvements in a coordinated effort by multiple stakeholders. Several challenges remain for clinicians, researchers, administrators, patients, and families seeking continuous scientific and clinical advancements in the field. We describe a new integrated research and improvement network – Cardiac Networks United – that seeks to build upon the experience and success achieved to-date to create a new infrastructure for research and quality improvement that will serve the needs of the paediatric and congenital heart community in the future. Existing gaps in data integration and barriers to improvement are described, along with the mission and vision, organisational structure, and early objectives of Cardiac Networks United. Finally, representatives of key stakeholder groups – heart centre executives, research leaders, learning health system experts, and parent advocates – offer their perspectives on the need for this new collaborative effort.

Clinical outcomes for children and patients with CHD improved considerably over the past several decades. However, several domains still pose a challenge to clinicians and researchers seeking to optimise care and outcomes for these children and families. Early morbidity and mortality remain high for patients undergoing high-complexity surgery. Data on outcomes from across the lifespan are scant, but those that exist suggest burdensome physical and functional morbidities across multiple domains. Finally, there remains substantial variability in care, outcomes, and costs across hospitals in providing care for these patients.

To find a mechanism to address these challenges, the field of paediatric and CHD has invested considerably in recent years to improve data capture and analysis from multiple sources in order to learn and improve. Although these efforts have led to several notable advances,[1–6] important limitations remain. These include lack of integration across data sources that limits our capabilities to drive discovery across the lifespan, limited mechanisms to translate knowledge gained from these data into tangible improvements in patient care and outcomes, and the overall cost and sustainability of such efforts. Many children's hospitals that participate in clinical data registries and other networks report spending in excess of $500,000–1,000,000 per year to support the necessary personnel and infrastructure, and the key stakeholders have voiced concerns regarding inadequate return on that investment in relation to scientific discovery and improvements in clinical outcomes. A new paradigm for this work is necessary to maximise the value of these data and accelerate discovery and

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improvement in the field. Improving the lives of children with CHD depends on a focus on outcomes, a collaborative community of stakeholders, high quality data, synergy between researchers, and effective application of discovery into clinical practice.[7]

The purpose of this paper is to describe the development of Cardiac Networks United, a "network of networks" committed to aligning and integrating data, expertise, and resources to support novel discovery and enhance translation to improve clinical and functional health outcomes for patients and families. Here we outline the background and rationale behind the development of this organisation, its mission and vision, and initial goals and projects.

Paediatric and CHD scientific infrastructure: current state

Optimising paediatric and CHD scientific discovery and translation to improved clinical outcomes requires engagement by researchers, clinicians, patients, and families to identify important gaps in knowledge, barriers to discovery, and operationalising solutions. Despite successful efforts in collaborative investigation within the field over the past two decades, the scientific landscape remains fragmented with several critical obstacles.[3,8,9]

Inefficient data integration and application

The volume and variety of data captured across numerous sources in the field of paediatric CHD continues to grow exponentially.[10] Data sources include clinical registries, electronic health records, research databases, and administrative/billing information. Emerging sources of data include biomarkers and genetic information, along with physiologic data from hospital devices and wearable technology. This accelerating pace of data generation mirrors trends across medicine and other industries.[11–15] However, in contrast to other industries, we have not yet appropriately leveraged this increasing volume of data to generate new knowledge for clinicians, hospital and health systems, and policymakers to guide the care of patients and families and improve clinical and resource utilisation outcomes. Lack of an integrated data network in the field has been identified as a critical gap by a recent National Heart, Lung, and Blood Institute Working Group,[10] and contemporary data science and integration techniques applied in adult cardiovascular disease along with methods to support alignment of clinical, research, and improvement work within a "learning health system" type model have not yet been extended to the paediatric and CHD population.

Too many silos

Organisational silos

Presently, data, personnel, and methods used to collect data for research and improvement efforts are segregated into infrastructures that are incompatible with one another. Each organisation or registry maintains its own data repository, governance policies, data management and analytics personnel, and separate regulatory and contracting processes. This paradigm creates inefficiencies for researchers, hospitals, and other stakeholders, limiting collaboration between experts, data sharing, discovery, and improvement.

Data silos

Many of the data fields across existing organisations' datasets are redundant or overlapping because the hospitals commonly support teams of data collectors who must enter duplicate information multiple times into each dataset. Dedicated efforts by the International Society for Nomenclature of Paediatric and CHD and the Multi-societal Database Committee resulted in standardised definitions across many clinical registries,[16,17] thus creating opportunities for sharing variables between databases. Despite these advancements, many opportunities to further integrate these data sources remain.

In addition, most existing registries focus on isolated episodes of care. For example, several registries capture in-hospital data related to surgical or catheter-based procedures or data from a patient's cardiac ICU admission. Work to-date has supported numerous initiatives to link information across datasets.[5,18–20] However, most of these efforts have involved 1:1 linkages of one dataset to another, to answer a specific question rather than comprehensive strategies for ongoing integration to support investigation across different episodes of care. Furthermore, many existing registries lack longitudinal data on survival, functional status, and quality of life, limiting the value of the episode-based data to explain important patient- and family-centred outcomes across the lifespan.

Expertise silos

Finally, there are currently numerous silos of expertise within each organisation related to database design, analytic methods, quality improvement scientific methods, and so on, and limited engagement across these and other key stakeholders. Although the Multi-societal Database Committee[17] and others such as the Pediatric Heart Network's Integrated CARdiac Data and Outcomes Collaborative have fostered efforts to bridge these gaps, many opportunities remain to share expertise and work towards common goals.

Impact on scientific discovery and quality improvement

The silos noted above limit discovery and improvement activities for several reasons.

High costs

Redundancies in collecting, maintaining, and analysing unintegrated data sources lead to high infrastructure and personnel costs associated with data collection, analysis, and utilisation.

Limited discovery

The current paradigm of data silos limits the scope of scientific questions we are able to answer, and our ability to move beyond short-term outcomes to addressing important issues across the lifespan. One notable example is the difficulty in understanding how treatments early in life impact long-term health and functional status.

Limited translation

Even when research yields important findings, the delay between discovery and application can take too long, or sometimes does not occur at all. In the current system data are not universally actionable to patients, families, providers, and hospitals, and expertise to facilitate the design and implementation of improvement activities is often lacking, both of which can impede efforts to translate scientific discovery to patient care. Building

https://doi.org/10.1017/S1047951118001683 Published online by Cambridge University Press

Table 1. Founding organisations of cardiac networks united.

Network	Focus area
Pediatric Cardiac Critical Care Consortium (PC4)	Cardiac critical care
Pediatric Acute Care Cardiology Collaborative (PAC3)	Cardiac acute care ward
National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)	Single ventricle patients
ACTION Heart Failure Network	Heart failure/ventricular assist device
Cardiac Neurodevelopmental Outcomes Collaborative (CNOC)	Neurodevelopmental outcomes

improvement and implementation of improved scientific expertise and application of data science and analytic capabilities across networks could accelerate the translation of evidence-based informed strategies into practice.[21] Emerging evidence suggests that engaging patients and families as partners in this work can accelerate this translation.

Limited solutions

The siloed approach across disciplines and stakeholders impedes the design of novel solutions to address the existing challenges and reduce opportunities for collaboration and synergy, and at the same time diminish the return on investment at the organisational level. Engaging all stakeholders in a collaborative effort to make better use of data for improvement, discovery, and innovation will accelerate progress towards improved health outcomes.

The development of Cardiac Networks United

To address the limitations of our current system and achieve improved care and outcomes for patients and families, scientists must connect across the various initiatives in paediatric and congenital cardiology with key stakeholders to foster more efficient use of data for clinical care, improvement and research, and support innovation. In this context, leaders from several research and quality improvement networks met in Cincinnati, OH and Ann Arbor, MI, USA over the course of 2017 to address the current barriers and create a new culture of collaborative science. Earlier works by the Multi-societal Database Committee, National Heart, Lung, and Blood Institute Working Group on an integrated network for CHD research, and the Pediatric Heart Network integrated CARdiac data and outcomes collaboration laid an important framework for these efforts.[10,17] Participants included the leaders from major clinical data registries and quality improvement networks, directors of congenital heart centres, leaders from the National Heart, Lung, and Blood Institute, professional society representatives, experts in research, quality improvement, and data integration methods, CHD foundation leaders, and patient/parent advocates. All these individuals represented these unique stakeholder groups and provided their written perspectives (see Appendix).

Founding organisations and reach

As a result of these stakeholder meetings, five initial networks formed Cardiac Networks United pledging to collaborate and share data and expertise (Table 1). The participants in these five networks span >65 congenital heart programmes and focus on multiple phases of care, including both the inpatient and outpatient setting (Table 1).

Vision and mission

The vision and mission of Cardiac Networks United are displayed in Box table. Cardiac Networks United aims to unite and align networks to advance research and improvement efforts through collaboration. The mission further describes how Cardiac Networks United will address the current limitations and efficiencies highlighted in the preceding sections.

Cardiac Networks United Vision and Mission
Vision
To accelerate improvements in health outcomes for children and CHD patients by *uniting and aligning networks*, organisations, and stakeholders across the field to advance research and improvement efforts through *collaboration*
Mission
Catalyse research and improvement in health outcomes for children and CHD patients by:
• *Sharing data, resources, and knowledge* among current and future paediatric and congenital cardiac networks to foster discovery not otherwise possible within individual silos
• Harmonising data capture and analysis to *eliminate redundancy and improve efficiency*
• Making shared data *open and accessible* to maximise the benefit to the scientific community, caregivers, patients, and families
• *Translating* new scientific discoveries into better care at the bedside, in the clinic, and in communities
• Developing a *flexible infrastructure* to support these activities that is scalable to expand to new partners and emerging data sources.

Organisational Philosophy

Cardiac Networks United was designed on the basis of an "independent yet interdependent" model. Specifically, the goal of each participating network is to maintain its individual leadership, scientific priorities, goals, and projects, and at the same time also fostering greater collaboration across networks, pooling of resources, and sharing of data. We aim to accomplish research and development work that would not be possible within each individual network alone. We also want to encourage and accommodate flexibility and scalability through expansion to other interested networks, and accommodation of emerging data sources in addition to clinical registry data. Finally, shifting to a culture focussed on collaboration versus competition represents a

https://doi.org/10.1017/S1047951118001683 Published online by Cambridge University Press

critical component of Cardiac Networks United. As highlighted earlier, traditional approaches limit sharing of data and expertise due in part to concerns about scientific integrity or receipt of academic credit across organisations or individuals. Attitudes in medicine related to data sharing and collaboration have evolved more slowly than the technical advances necessary to support data integration.[22] However, several multi-centre research and quality-improvement initiatives[2,4,20,21] have recently demonstrated the considerable benefits of collaboration, thus laying a strong precedent for the formation of an organisation like Cardiac Networks United. Parent advocates strongly and uniformly support the philosophy of breaking down walls between organisations and data repositories in order to place the patient at the centre of progress rather than an organisation or investigator. With this in mind, a key aspect of the Cardiac Networks United philosophy is "the more you share, the more you have".[22]

Organisational structure

To support the mission and vision of Cardiac Networks United, the current organisational structure consists of an executive committee comprising Co-Directors and representatives from all five current networks (see Appendix). The executive committee oversees the work of two cores – the data core, based at the University of Michigan that focusses on facilitating data sharing, integration, and management, and the improvement core, based at Cincinnati Children's Hospital that focusses on supporting collaborative learning and quality improvement activities across the networks. In addition, an Advisory Board consisting of leaders from numerous domains provides guidance to the organisation (see Appendix). Start-up funding to support initial work has been provided by the University of Michigan and Cincinnati Children's Hospital.

Initial objectives of Cardiac Networks United

Sharing resources and learning among networks

As described earlier, one major limitation in the current state relates to the existing organisational silos and redundancies. To address this, a Cardiac Networks United project manager functions across participating networks to organise joint activities, many of which are described in further detail later. In addition, to fostering further collaboration and consolidate resources, Cardiac Networks United is planning a joint annual meeting of all participant networks beginning in 2019. This will allow for cost reduction associated with meeting, hosting, and travel and also allow organisations to come together for joint sessions to further promote collaborative projects and exchange of ideas. Bringing networks together to learn methods and strategies from each other can accelerate learning among all networks.

The data core: improving data collection and integration

The Cardiac Networks United data core functions to support integrated data collection across networks to reduce redundant data capture, and the associated costs, and to foster novel projects with shared data that otherwise would not be possible. Solutions to these problems are tailored individually to the member organisations. For example, with new registries, the goal is to collect only unique variables not captured in existing Cardiac Network United databases and to share common variables necessary for science and improvement across participating networks. This can significantly reduce data collection burden at individual sites, minimise resources needed to maintain and analyse overlapping datasets, and promote data standardisation. In this context, Pediatric Cardiac Critical Care Consortium (PC4), paediatric acute care cardiology collaborative (PAC3), and cardiac neurodevelopmental outcomes collaborative (CNOC) have designed their clinical registries specifically to complement one another. Centres participating in PAC3 and CNOC do not need to recapture the baseline demographic and clinical data from the ICU already available within the existing PC4 dataset, and instead can focus on the unique data applicable to a patient's non-ICU and neurodevelopmental outcomes, such as CNOC. The data will be seamlessly integrated for benchmarking, research, and improvement purposes at the Cardiac Networks United data core.

This approach improves the current state where data abstraction teams within the same hospital collect duplicate information on data elements common to multiple registries and enter them into separate and unlinked datasets housed in distinct data-coordinating centres. For example, CNOC would separately collect all relevant surgical and ICU data that are already captured in PC4, which is necessary in order to be able to identify eligible patients and understand their baseline characteristics for CNOC analyses. The Cardiac Networks United paradigm – which involved planning and collaboration in the design phases of both the PAC3 and CNOC registries and integration with existing PC4 data – should prove more efficient and cost-effective than traditional approaches. Our initial estimate of the full-time equivalent for data collection across all three registries – PC4, PAC3, CNOC – is 30–50% less than what it would be if these organisations worked separately. Further, the software startup costs for PAC3 and CNOC are 50–80% below the usual cost to build a new clinical database.

Integration methods are slightly different for established network partners such as National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) and ACTION, which have existing data platforms. Efforts are underway to determine the degree of overlap between the NPC-QIC and ACTION variables and those contained in PC4, PAC3, and CNOC, potentially offering strategies to minimise redundant data capture within NPC-QIC and ACTION. NPC-QIC and ACTION will share data variables unique to their registries for collaborative projects across Cardiac Networks United.

To facilitate data linkages across registries, we plan to develop and test tracking methods of episodes of care for the same patient in different registries and across different hospitals over the lifespan. In addition, Cardiac Networks United is in the process of creating a complete map of variables and definitions across all participating networks to aid integrated analyses and minimise startup and redundant data collection for any new project or network.

The improvement core: harnessing quality improvement expertise and the learning health system model

Cardiac Networks United aims to improve the translation of scientific discovery to improvements in care and outcomes for children, patients, and families impacted by CHD. Collaborative efforts using advanced scientific methods[22] have been effective in changing outcomes across centres in our field.[3,8,23] Cardiac Networks United aims to provide an improved scientific infrastructure for member organisations that will build capacity and

https://doi.org/10.1017/S1047951118001683 Published online by Cambridge University Press

capability across the networks and participating centers.[24] A key tenet of the collaborative improvement science is that partnership of clinicians and scientists with patients and families leads to an emphasis on outcomes that matter and accelerates translation and results.

The improvement core of Cardiac Networks United will include standard quality improvement educational programmes for all member networks and teams, guidance regarding improvement project design and implementation, access to planning and statistical process control analytic tools to carry out improvement projects, and coaching from quality improvement experts. These structured methods can facilitate systematic sharing of expertise, data, tools, and resources that accelerate learning and improvement. By centralising these improvement resources, Cardiac Networks United aims to accelerate the quality improvement work of participant networks and obviate the need for each network to create its own improvement infrastructure, thereby significantly reducing the cost and resources needed for individual networks and teams to carry out meaningful quality improvement efforts. Examples describing the initial work of the improvement core are described later.

Streamlining legal and regulatory processes

Developing uniform regulatory and contracting practices represents a critical step for data sharing and streamlining startup across networks. PC4, PAC3, and CNOC use a common data use agreement and services agreements with software vendors, thus allowing participating hospitals to sign only one set of contracts inclusive of all three collaboratives. This modular agreement significantly accelerates the development of a new network; new data use agreements can take years of review before hospital legal teams agree to the terms. Our approach eliminates this impediment to launching data-collection efforts for PAC3 and CNOC at hospitals that have already signed agreements for PC4. Collaboration with NPC-QIC and ACTION is ongoing to further extend standard language across these existing networks to support data sharing. Cardiac Networks United is also working to develop shared regulatory practices to streamline research activities, including central Institutional Review Board review.

Sharing expertise across networks and cores

The five initial networks and the data and improvement cores of Cardiac Networks United harbour unique and complementary strengths that can be integrated to foster innovative projects that otherwise would not be possible. For example, using the data expertise of PC4 and the improvement expertise of NPC-QIC has supported the design and implementation of a multi-centre cardiac arrest prevention project that will take place within PC4-participating hospitals. PC4 data and the reporting platform, representative of the data core, have been used to understand variation in cardiac arrest rates across hospitals, highlight high-risk patients as targets for a focussed prevention strategy, and understand practices at high performers. However, NPC-QIC expertise, representative of the improvement core, has partnered with PC4 investigators in the development of quality improvement bundles and implementation strategies. Complementary health services and statistical process control methodology will be used to analyse practices and outcomes over time and determine the impact of the project on patient outcomes. This project highlights the potential advantages of collaboration across the network and served as a model for the development of the data and improvement cores, as well as future projects within Cardiac Networks United.

Integrating data to support novel investigation

Building on initial efforts in the field,[1,3,5,20,23] several projects are underway to demonstrate how integrating datasets can allow us to study outcomes across episodes of care and a patient's lifespan. One project demonstrating the value of this approach involves integrated PC4 and PAC3 data to understand differences across hospitals in cardiac ICU versus inpatient ward length of stay, to inform and target initiatives aimed at reducing postoperative length of stay. A second project plans to integrate NPC-QIC, PC4, and eventually PAC3 data to understand ICU and Norwood hospitalisation factors impacting inter-stage outcomes in single ventricle patients. Additional projects integrating PC4, PAC3, and ACTION data are under development to determine contemporary stroke rates across hospitals associated with ventricular assist devices and outcomes specific to ventricular assist device outcomes in Fontan patients to inform improvement activities led by ACTION.

Although the focus of our data integration has started with clinical registry data, the founding organisations of Cardiac Networks United have initiated efforts to use other emerging data sources. For example, PC4 has successfully merged clinical data from their registry with real-time physiologic data captured by ICU monitors and devices to facilitate predictive analytics and with a patient-reported outcomes module that captures longitudinal annual follow-up from patients and families regarding survival, quality of life, and other important morbidities.[25] A planned future project includes merging data from CNOC and PC4 to understand ICU factors and physiologic profiles impacting neurodevelopmental outcomes.

Potential barriers

With any endeavour such as this, funding Cardiac Networks United is a major potential challenge. As described earlier, we hope to present a "business case" for the organisation by creating efficiencies and opportunities for cost savings, particularly to the hospitals that pay to participate in multiple registries supported by Cardiac Networks United. The leadership will seek other funding including extramural grants, philanthropy, and possibly crowdfunding to support the work of the organisation and the vital infrastructure. Both the University of Michigan and Cincinnati Children's Hospital provided generous start-up funds for the data and improvement cores, respectively.

Incorporating existing databases into the Cardiac Networks United shared data repository represents another potential barrier. The PC4/PAC3/CNOC model serves as a template for developing new registries that can be easily integrated. However, there are several existing databases, some long established, that could be valuable if linked with other Cardiac Networks United registries. However, each of these databases has a unique data structure, unique contracts that dictate where and how data can be transferred, and varying degrees of identifying information needed to link databases together. All of these potential barriers must be negotiated to achieve the most complete and integrated data repository inclusive of the full breadth of paediatric and congenital cardiac care. They are not unmanageable but do require thoughtful dialogue between leaders from the different organisations that manage these databases and willingness to share.

https://doi.org/10.1017/S1047951118001683 Published online by Cambridge University Press

Summary

Cardiac Networks United aims to align and integrate efforts across networks in paediatric CHD and cardiology to foster novel and impactful science across the lifespan that would not otherwise be possible without such collaborative efforts, accelerate the translation of discovery to improvements in clinical care, and support greater efficiency through sharing resources. We aim to create an infrastructure around the founding five networks that is scalable to accommodate other collaborative partners and diverse data sources. The overall goal of our efforts is to improve outcomes for children and families impacted by congenital cardiovascular disease and improve the return on investment and sustainability for organisations funding and participating in this work.

Why we need Cardiac Networks United – perspectives of key stakeholders

The heart centre executive's perspective – Andrew Redington and John Charpie

Leaders of paediatric heart centres are responsible for balancing the occasionally aligned, but often competing interests of clinicians, researchers, hospital administrators, and, most importantly, patients and families. In our subspecialties of paediatric cardiology and cardiac surgery, important scientific advancements have occurred slowly, often without the benefit of the gold standard of a randomised placebo-controlled clinical trial. In paediatrics, randomised controlled trials are difficult to perform. They are expensive but rarely garner industry support, lengthy, and subject to bias because of relatively small numbers of subjects and a lack of equipoise. Partly in response to these inherent limitations of randomised trials, and also from a desire to rapidly improve outcomes, the last decade or so has been marked by several new clinical registries, learning networks, and databases. Each has unique attributes and has enhanced the richness of our understanding of outcomes, and clear clinical benefit is now being realised for some of our patients. However, in our world of increasing financial scrutiny, we will inevitably need to justify the return on the very considerable investment that is required to sustain these activities.

In this regard, the development of Cardiac Networks United is particularly timely. Integration of networks is an obvious next step. Much of the data that are gathered is common to all the networks, and the efficiencies of having common or mappable templates are clear. The combined datasets will be a rich resource for analysis. There is clearly a false distinction between surgical and ICU outcomes reported in PC4, in-patient outcomes recorded in PAC3, and neurodevelopmental outcomes in CNOC. In reality, these datasets describe a continuum of care for our patients, and if we are truly to understand and improve care, all elements of the patient journey should be incorporated into our calculations. Indeed, reduction of costs and improved value should be a key part of the mission of Cardiac Networks United. If hospital leadership sees a financial return on their investment, then future funding will be assured and future initiatives are encouraged.

It is not all about the money though. Our patients will also benefit. A more comprehensive dataset will allow for a more robust assessment of the variables that contribute to outcomes. Although the uniqueness of the individual networks and the particular learnings that evolve from them must never be lost, it seems inconceivable that there will not be benefits from a more encompassing big-data approach. Indeed, as a specialty we might think seriously about consolidating all our data from all of our patients, including genomic profiles, neurodevelopmental outcomes, and the impact on other organ systems. Cardiac Networks United is the first step on a potentially very exciting journey for our field.

The researcher's perspective – Gail Pearson and Jonathan Kaltman

The value of Cardiac Networks United for paediatric cardiovascular researchers lies in its ability to integrate data and thus streamline the ability to answer research questions. This integration expands the range of questions that can be asked and answered. The 21st century Cures Act has provisions requiring National Institutes of Health to focus on research across the lifespan, and the data integration envisioned through Cardiac Networks United will give researchers a new tool to achieve this goal. Another potential value is the ability to query the combined data to answer important questions during the design of clinical trials, such as the number of patients eligible to enrol in a trial given specific inclusion and exclusion criteria. Furthermore, we hope that Cardiac Networks United could provide a suitable platform for a registry-based trial, as has been done in adult cardiology. At the other end of the translational spectrum, Cardiac Networks United can potentially be an excellent source for the phenotype data necessary to complement research on the genetic and genomic components underlying paediatric cardiovascular outcomes. Finally, any resource that can increase the efficiency of research is likely to increase the return on investment of public and private research dollars.

The organisers of Cardiac Networks United should be commended for including parent advocates during early planning discussions. A clear trend in clinical research is active collaboration with patients and patient advocacy groups during planning and implementation of strategic research directions – see All of Us Research Program; https://allofus.nih.gov. Patients and their families can be powerful advocates when navigating policy hurdles. They can also helpfully advise when project goals are being prioritised to ensure that patient needs are being addressed. Finally, having patient-derived use case(s) drive implementation of Cardiac Networks United will maintain the patient-centric nature of the programme.

The learning health system perspective – Carole Lannon and Peter Margolis

Over the last decade, families, clinicians, and scientists have co-designed, developed, and implemented learning health system networks with the aim to improve care and outcomes for children. The four most mature of these learning networks have achieved substantial improvements in outcomes. In addition, these networks have spawned innovation and fostered discovery and research. The key components of the successful learning health system model are a focus on outcomes, data transparency, the use of improvement science methods – including statistical process control – network processes that promote and support sharing among all key stakeholders, like patients, families, clinicians, and scientists, and utilisation of collaborative infrastructure and standardised policies.

There are many barriers to achieving the learning network vision. Developing a collaborative infrastructure that allows the efficient sharing of ideas, best practices, and data is a key step in

https://doi.org/10.1017/S1047951118001683 Published online by Cambridge University Press

addressing these barriers. The shared efforts of the registries and networks of Cardiac Networks United have significant potential to overcome barriers, accelerate discovery and innovation, and facilitate improved results for children with cardiac disease.

Linking families, clinical teams, and scientists from across the registries and networks in paediatric cardiology is an exciting next step in efforts to improve care and outcomes for children with heart disease. Cardiac Networks United is an important approach to link patients, families, clinicians, and researchers across paediatric cardiology and to share data more effectively for both improvement and research. Cardiac Networks United can serve as a model of collaboration and learning in improving health outcomes.

The parent's perspective – Stacey Lihn and David Kasnic

Parents desire the best possible outcomes for children living with CHD, in both quality of life and survival. We often feel our children are racing against a clock. Cardiac Networks United offers an opportunity to slow the clock by conducting holistic research and identifying improvements in the treatment of congenital heart defects. Although our ultimate goal is to eliminate CHD, we must focus on maximising longevity with fewer physical health, educational, and emotional comorbidities. Unfortunately, the clinical experience provides only a snapshot into the life of a CHD patient. Engagement with patients and families offers the opportunity to accurately view the bigger picture. In order to accomplish best possible outcomes, improvement efforts and research must engage patients, families, and clinicians in identifying critical, unanswered questions.

Cardiac Networks United offers great hope by providing a unique, robust evolution of research through increased collaboration and data sharing. This network of networks has incredible potential to improve our understanding, and treatment, of the multi-faceted impact of CHD across the lifespan. Cardiac Networks United's platform for the CHD community allows us to learn better, faster, and together. We are hopeful that this model will not only move paediatric cardiac medicine to another dimension, but effectuate change for all paediatric chronic illness.

Acknowledgements. None.

Financial Support. This research received no specific grant from any funding agency or from commercial or not-for-profit sectors.

Conflicts of Interest. The views expressed in this manuscript are those of the authors and do not necessarily represent the views of the National Heart, Lung, and Blood Institute; the National Institutes of Health; or the U.S. Department of Health and Human Services.

Appendix

Cardiac Networks United Leadership
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