Cardiology in the Young

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The Fontan outcomes network: first steps towards building a lifespan registry for individuals with Fontan circulation in the United States

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Abstract

The Fontan Outcomes Network was created to improve outcomes for children and adults with single ventricle CHD living with Fontan circulation. The network mission is to optimise longevity and quality of life by improving physical health, neurodevelopmental outcomes, resilience, and emotional health for these individuals and their families. This manuscript describes the systematic design of this new learning health network, including the initial steps in development of a national, lifespan registry, and pilot testing of data collection forms at 10 congenital heart centres.

The Fontan procedure has transformed the lives of many patients with single ventricle physiology, allowing them the opportunity to survive with good quality of life.[1] Since it was first reported in 1971, indications for the operation have expanded, and iterative modifications have improved both early and late outcomes.[2–5] As a result, greater numbers of individuals with Fontan circulation are reaching adolescence and adulthood.[6] However, a variety of cardiac and extracardiac complications and co-morbidities have been recognised which negatively impact physical and mental health, quality of life, and longevity.[7–10] As demonstrated for other chronic conditions, prevention or early recognition of morbidities, along with standardised management strategies, may lead to better understanding of disease mechanism, risk stratification, and development of targeted therapies.[11–13] Currently, the absence of identified best care practices and effective treatments to maintain circulatory performance and optimise overall patient outcomes presents significant challenges for patients,

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clinicians, and health care systems.[5] To optimise wellness and overcome complications, scientists and care providers must work together to better understand mechanistic origins of single ventricle CHD and its co-morbidities and complications, the trajectory of organ-specific health to predict the course of each patient over time, and prevent and treat complications and co-morbidities to optimise outcome.

Over the last two decades, there has been a shift in the focus of care providers from primarily mortality reduction to preventing long-term morbidity, improving neuropsychologic outcomes, and achieving a high quality of life in children with CHD. In order to accelerate discovery that was impossible through single-centre research, collaboration among congenital heart centres has been enhanced, with an emphasis on patient and family engagement, quality improvement, and research.[14–18] The learning health network is a dynamic platform of multi-institutional collaboration for quality improvement and research, which facilitates identification of best clinical practices, rapid sharing of data to improve outcomes, generation of new knowledge, and translation of research into practice.[19,20] For single ventricle infants, specifically those with hypoplastic left heart syndrome, the National Pediatric Cardiology Quality Improvement Collaborative has improved interstage survival by 40% since 2009 using the learning health network model.[18] More recently using similar model, the Advanced Cardiac Therapies Improving Outcomes Network has reduced stroke rates from 30% to 12% in paediatric ventricular assist device patients.[21] Further, both National Pediatric Cardiology Quality Improvement Collaborative and Advanced Cardiac Therapies Improving Outcomes Network are members of Cardiac Networks United, a consortium of paediatric and congenital networks that aims to accelerate learning and discovery through collaborative sharing of data to maximise return on investment and sustainability for organisations funding and participating in research and quality improvement.[15] These successes of the learning health networks proves the effectiveness of this model and led our group to embrace this model in order to improve outcomes in Fontan patients. The Australian and New Zealand Fontan Registry, also started in 2009, has successfully generated foundational knowledge at the population level. In the United States, while the Alliance for Adult Research in Congenital Cardiology and the Pediatric Heart Network supported clinical trials and cross-sectional studies of Fontan patients, and the American Heart Association and American College of Cardiology sponsored symposia and writing groups, a platform for broader collaboration and collection of longitudinal lifespan data did not exist for this population.

In August 2017, a systematic design process was launched to create a learning health network to improve the long-term outcomes of individuals with Fontan circulation across the nation. The user-centred design process was initiated by key stakeholders – patients, parents, clinicians, and researchers – who have actively worked together to develop the Fontan Outcomes Network, with design and project management support from the National Pediatric Cardiology Quality Improvement Collaborative. Figure 1 summarises the different efforts to improve the outcomes in individuals with Fontan that created the landscape for the Fontan Outcomes Network formation and the momentum about multi-institutional collaboration.

This manuscript describes the systematic design of the Fontan Outcomes Network, including the initial steps in development of the lifespan registry and pilot testing of the feasibility of data collection at 10 Children's hospitals.

Methods

Initial design process – defining the mission and vision

Since 2017, National Pediatric Cardiology Quality Improvement Collaborative has supported multiple design meetings held during Fontan-specific symposia, cardiology/cardiothoracic surgery national meetings, and the National Pediatric Cardiology Quality Improvement Collaborative semi-annual learning sessions. The design process used previously described methods to successfully develop learning health networks.[19,22] The initial design meetings identified the aim for Fontan Outcomes Network and defined a mission and a vision statement. The Fontan Outcomes Network *vision* is to dramatically improve the outcomes of individuals with Fontan physiology. The Fontan Outcomes Network *mission* is to optimise the longevity and quality of life for individuals with Fontan physiology and their families by improving their physical health and functioning, neurodevelopment, and emotional health and resilience. To accomplish these goals, a longitudinal lifespan registry to include as many individuals with Fontan circulation as possible was thought to be crucial. The registry will collect data on the current status of this population, accelerate learning about the short- and long-term morbidities, determine best practices in monitoring, screening, and testing, and discover and disseminate therapies for Fontan patients. As with the infant single ventricle National Pediatric Cardiology Quality Improvement Collaborative registry, monthly data reports on key metrics will be available to address improvement opportunities as well as provide data to address research questions. Key stakeholders including paediatric cardiologists, cardiac surgeons, adult congenital heart specialists, cardiac advanced practice providers, physicians with quality improvement and collaborative science expertise, data scientists, psychologists, social workers, and importantly, patients and families, were invited to these meetings to shape the Fontan Outcomes Network. The formal mission, vision, and three workgroups were established between January 2017 and April 2018.

Establishment of design workgroups to define outcome aims, measures, and required registry data elements

Following the initial Fontan Outcomes Network meetings, workgroups were established targeting three areas of focus: (1) physical health and functioning, (2) neurodevelopment, and (3) resilience and emotional health. Each workgroup was co-led by a patient or family member and clinician experts. Each of the workgroups developed key driver diagrams, following the Model for Improvement,[23] determining the aims, measures, and necessary data elements to assess longitudinal outcomes aligned with each team's aims. The National Pediatric Cardiology Quality Improvement Collaborative project management staff facilitated this systematic design process. The multidisciplinary workgroups met between April 2018 and October 2019. The development of the measures and data variables was iterative and based on published research on important outcomes in each Fontan Outcomes Network domain and expert consensus. Each team met monthly to create and refine the data collection forms. The final data collection forms consisted of 29 pages with 26 different subsections. A copy of the data collection forms can be found in the supplement.

When designing the forms, the team was mindful to use variables that match data and definitions used in other registries when possible to facilitate future data linkages. These registries included the Society of Thoracic Surgeons, the Pediatric Acute Care

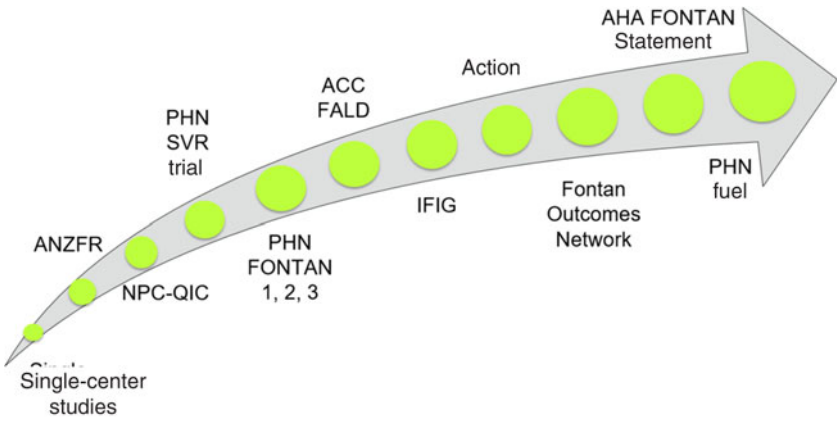

Figure 1. Growing number of multi-centre collaborations for single ventricle CHD. ACC = American College of Cardiology; AHA = American Heart Association; ANZFR = The Australian and New Zealand Fontan Registry; FALD = Fontan-associated liver disease; FUEL = Fontan Udenafil Exercise Longitudinal; IFIG = International Fontan Interest Group; NPC-QIC = National Pediatric Cardiology-Quality Improvement Collaborative; PHN = Pediatric Heart Network; SVR = Single Ventricle Reconstruction Trial.

Figure 2. Excerpts from the key driver diagram reflecting the focus areas of the three work groups. On the left panel is the overarching goal for each work group. On the right panel are the measures used to assess progress towards these goals.

Cardiology Collaborative, and the Pediatric Cardiac Critical Care Consortium. Early on, the Australia New Zealand Registry collaboratively shared all of its data definitions, data dictionary, and forms, which accelerated initial work.

Registry data collection pilot

The purpose of the data collection pilot study was to assess the feasibility of the data collection process as well as the availability of specific data elements across participating pilot centres. We hypothesised that there would be wide variability of medical record documentation between centres – even among those that provide expert care to a large number of patients with Fontan circulation – and that this would impact ease of completion of standardised registry data forms.

Ten congenital heart centres with active participation in the Fontan Outcomes Network workgroups agreed to test the data collection forms for feasibility and usability. After reviewing medical charts and completing the Fontan Outcomes Network data collection forms for individual patients, team members from each participating pilot site were asked to provide feedback about the process using a survey developed by the Fontan Outcomes Network leadership and data team. The survey included 76 multiple-choice and 67 open-ended questions about the forms and the data collection process. The actual Fontan Outcomes Network forms were not returned; no patient data were returned with the survey. A copy of the survey can be found in the supplement. Responses to the open-ended questions were analysed qualitatively to extract insights. The responses were collapsed into categories.

This pilot data collection study was approved by the Institutional Review Board at Cincinnati Children's Hospital Medical Center. No identifiable patient data were collected.

Results

Using standardised quality improvement methodology, each of the three work groups created an overarching goal and outcome measures to achieve this goal. This is summarised in Figure 2.

Nine programmes responded with a median number of four sets of forms completed per programme, on a total of 33 patients. The mean time reported to complete the form was 130 ± 70 (range 32–365) minutes. The forms were completed by a variety of provider types including attending cardiologists, fellows-in-training, nurse practitioners, nurses, and clinical research professionals, consistent with the make-up of the clinical teams caring for this population. Patients included in the pilot data extraction spanned a range of ages with most being below the age of 5 years (35%) followed by individuals greater than 21 years of age (23%). Centres who reported obtaining data on patients < 5 years of age had higher average time of completing the forms compared to centres who did not (161 ± 70 vs 67 ± 28 minutes, $p = 0.02$). The patients whose data were extracted were categorised as "healthy Fontan patients" in 50% of cases, "new" Fontan patients (<1 year post-Fontan surgery) in 19%, and "patients with a failing Fontan circulation" in 19%.

The following summary and opportunities for improvement emerged from the data collection process:

1. All participants supported data collection as an important process to populate the registry, start the improvement cycle, and provide input for research for patients with Fontan. Since the goal of Fontan Outcomes Network is to improve the physical health and quality of life of patients with Fontan, the first step is to have baseline information about this population.
2. The participants identified the importance of the data quality checks and having clear data definitions since much of the

collected data will not fit into diagnostic codes. An example is collecting data on whether the patient has extracardiac gastrointestinal abnormalities such as Fontan-associated liver disease. Fontan-associated liver disease is a wide spectrum from hepatic congestion to compensated or decompensated cirrhosis.[24] Clear definitions of the data are crucial to guarantee data quality.

3. The centres acknowledged the time needed to complete these forms which ranged from 32 to 365 minutes. Collecting this data will be a significant investment for the centres participating in this network registry.
4. Source data for multiple variables were not available for adult patients, for example, details of prior surgical interventions and the early post-operative course. This is a known challenge in the care of adults with CHD and stems from being cared for at multiple institutions or before the era of electronic medical records.[25,26]
5. Some of the data that were often missing were variables related to extracardiac end-organ disease, neurodevelopmental testing, mental health diagnosis and therapy, and measures of quality of life which were available in only 44% of the cases. This was either due to the lack of assessment or the lack of access to this information. This also reflects that information is often housed in the different health systems where patients have received care. Connecting information from electronic medical record systems and across various health systems will be helpful. The lack of information on emotional health and neurodevelopmental testing was not surprising and reflects opportunities for improvement.
6. There is a need to incorporate patient-reported outcomes and quality of life measures into clinical practice and, therefore, into the data collection forms. We received positive feedback about the importance of these data elements; however, currently many institutions do not collect this type of information during clinical visits. Assessing these broader aspects of health and well-being and reviewing results of patient- or parent-reported outcomes during visits is likely to require some additional training and extra time from the clinical teams.[27]

Discussion

We report the initial steps in the design and establishment of a data registry as a key infrastructure component of the Fontan Outcomes Network to improve care and outcomes for individuals with Fontan physiology followed in the United States. This is an important and unique database as it will collect baseline data and follow the patients with Fontan circulation longitudinally. Collecting these data is critical to better understand mechanistic origins of single ventricle CHD and its co-morbidities and complications, the trajectory of organ-specific health to predict the course of each patient over time, and prevent and treat complications and co-morbidities over time in order to optimise outcome. The Fontan Outcomes Network registry will provide needed infrastructure for the Fontan Outcomes Network learning network to improve care, accelerate research, and identify innovations that may be disseminated across the learning network to support the outcomes of individuals with Fontan circulation.

Current care models for patients with Fontan in the United States

Individuals with Fontan circulation have many health needs in the context of a wide spectrum of clinical complexity, functional capacity, end-organ disease, idiosyncratic complications, neurodevelopmental, and behavioural challenges. Over the past decade, multiple CHD centres have developed multidisciplinary clinics to provide standardised subspecialty care for this patient population.[13] Other centres have a specialised Fontan clinic within cardiology and refer to subspecialists on an as needed basis. Within these models, some patients receive longitudinal follow-up in academic or hospital-based practices, while others are followed in private paediatric cardiology clinics. Recently, there has also been an emphasis on the inclusion of heart failure/transplant teams early in the care of these patients. Given the lack of evidence about optimal monitoring and interventions, congenital heart centres are trying to bridge the gaps between clinical care and investigation. This has resulted in wide variation in practice patterns among programmes in testing strategies and in the type of data collected related to cardiac health and co-occurring conditions. This variation became apparent during feasibility testing, as we discovered which data points were or were not available across centres. As a guideline to help centres consider a rational approach to longitudinal care, the American Heart Association published a scientific statement with suggestions for the types and frequency of testing in patients after the Fontan operation.[10] This statement is an initial and important step that Fontan Outcomes Network will use to facilitate standardising the care of individuals with Fontan physiology.

The challenges and potential solutions moving forward with the data collection for patients with Fontan in the United States

Although consensus from the feedback on the data collection forms included the need to obtain comprehensive baseline data, actual data collection is time-consuming and there is wide variability regarding the availability of data between centres. To overcome some of these challenges, we predict the data collection process will go through significant evolution over the next few years.[28] The Australia and New Zealand Fontan data registry collects focused longitudinal data in Fontan survival and has been successful in facilitating important discoveries regarding Fontan-related morbidity and mortality.[28] The advantages of this model is that it requires fewer resources for data collection, may allow wider participation of many centres in the country, and may incur fewer missing data elements in the registry as a result. The disadvantage of this approach is that it provides less granular data, particularly when it comes to understanding extracardiac Fontan-associated morbidities and psychosocial functioning status, it does not involve the ability to use real-time data to assess emotional health, and it does not allow for the use of rapid turnaround of data for quality improvement. Fontan Outcomes Network will take an approach that supports the use of data for clinical care, improvement, and research. It will continue with the comprehensive data collection approach used in the pilot forms, tolerating missing data and developing strategies to reduce the burden of data collection for the participating centres. Ultimately if a variable has a collection rate of 50%, it may still provide important information when collected in aggregate from multiple centres and could lead to an improved preliminary understanding of Fontan circulation complications, accepting some limitations of the data and recognising the potential for selection bias in the cohort. Importantly, the Fontan Outcomes Network is planning to make the data available for ongoing improvement which requires frequent and rapid turnaround of data. This type of registry and data collection has been successful in the ImproveCareNow

network which currently has data on over 30,000 individuals with inflammatory bowel disease.[29] Additionally, the Fontan Outcomes Network is developing a "return on investment" strategy for the participating centres to emphasise the value of collecting and learning from this data. For example, the centres will receive monthly reports on key metrics and performance dashboards will be available.

A data dictionary with definitions of the data fields is currently being finalised based on the data collection detailed in this manuscript to facilitate data accuracy and allow multiple health care providers to collect and enter the data into the registry with high reliability. To further reduce data collection burden, processes will be developed to extract data from local databases directly into the registry avoiding multiple data entry steps. Development and implementation of electronic infrastructure within different healthcare information systems has the potential to be a relatively lengthy process. In the interim, each institution will likely find solutions that work within the available infrastructure although solutions could be shared between teams. An example of a strategy to avoid duplicate data entry would be the use of the data collected in other network registries such as the partner registries in Cardiac Networks United – Pediatric Cardiac Critical Care Consortium, Pediatric Acute Care Cardiology Collaborative, the Cardiac Neurodevelopmental Outcomes Collaborative, Advanced Cardiac Therapies Improving Outcomes Network, and the already existing National Pediatric Cardiology Quality Improvement Collaborative resources. Developing a method to link these current and emerging cardiology networks to the Fontan Outcomes Network registry has the potential to save multiple data collection steps. The collaboration among data scientists, cardiologists, and information system specialists will be key to the success of the Fontan Outcomes Network registry by improving the data collection process.[15] Furthermore, the advancements in artificial intelligence and natural language processing are promising for solving medical record data collection challenges.[30]

While improvements in facilitating the ease of data collection are made, there will also be efforts to learn from the network centres. There is an urgency to improve ongoing care and to develop the infrastructure for research and innovation to improve outcomes.

Summary and conclusions

As the number of individuals with the Fontan circulation rapidly grows, an improved understanding of their physical, neurodevelopmental, and emotional health needs is critically needed. Fontan Outcomes Network is designed as a registry-based, multi-centre, learning network to improve our understanding of the healthcare needs of the Fontan population through collaboration, quality improvement, research and innovation, and the learning network has taken important initial steps towards establishing a national registry of Fontan patients in the United States.

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References

1. Fontan F, Baudet E. Surgical repair of tricuspid atresia. Thorax 1971; 26: 240–248.
2. d'Udekem Y, Iyengar AJ, Cochrane AD, et al. The Fontan procedure: contemporary techniques have improved long-term outcomes. Circulation 2007; 116: I157–I164.
3. Tseng SY, Alsaied T, Barnard K, Hahn E, Divanovic AA, Cnota JF. Tricuspid atresia with restrictive foramen ovale: a rare combination with implications on fetal growth. Echocardiography 2019; 36: 800–802.
4. Alsaied T, Bokma JP, Engel ME, et al. Predicting long-term mortality after Fontan procedures: a risk score based on 6707 patients from 28 studies. Congenit Heart Dis 2017; 12: 393–398.
5. Alsaied T, Bokma JP, Engel ME, et al. Factors associated with long-term mortality after Fontan procedures: a systematic review. Heart 2017; 103: 104–110.
6. Jacobs JP, Mayer JE Jr, Pasquali SK, et al. The Society of Thoracic Surgeons Congenital Heart Surgery database: 2019 update on outcomes and quality. Ann Thorac Surg 2019; 107: 691–704.
7. Diller GP, Kempny A, Alonso-Gonzalez R et al. Survival prospects and circumstances of death in contemporary adult congenital heart disease patients under follow-up at a large tertiary centre. Circulation 2015; 132: 2118–2125.
8. Mellion K, Uzark K, Cassedy A, et al. Health-related quality of life outcomes in children and adolescents with congenital heart disease. J Pediatr 2014; 164: 781–788 e1.
9. Marino BS, Tomlinson RS, Wernovsky G, et al. Validation of the pediatric cardiac quality of life inventory. Pediatrics 2010; 126: 498–508.
10. Rychik J, Atz AM, Celermajer DS, et al. Evaluation and management of the child and adult with Fontan irculation: a scientific statement from the American Heart Association. Circulation 2019:CIR0000000000000696. Online ahead of print. PMID: 31256636.
11. Daniels CJ, Bradley EA, Landzberg MJ, et al. Fontan-associated liver disease: proceedings from the American College of Cardiology stakeholders meeting, October 1 to 2, 2015, Washington DC. J Am Coll Cardiol 2017; 70: 3173–3194.
12. Di Maria MV, Barrett C, Rafferty C, et al. Initiating a Fontan multidisciplinary clinic: decreasing care variability, improving surveillance, and subsequent treatment of Fontan survivors. Congenital Heart Dis 2019.
13. Di Maria MV, Brown DW, Cetta F, et al. Surveillance testing and preventive care after Fontan operation: a multi-institutional survey. Pediatr Cardiol 2019; 40: 110–115.
14. Jenkins KJ, Beekman Iii RH, Bergersen LJ, et al. Databases for assessing the outcomes of the treatment of patients with congenital and paediatric cardiac disease–the perspective of cardiology. Cardiol Young 2008; 18 (Suppl 2): 116–123.
15. Gaies M, Anderson J, Kipps A, et al. Cardiac Networks United: an integrated paediatric and congenital cardiovascular research and improvement network. Cardiol Young 2019; 29: 111–118.
16. Anderson JB, Brown DW, Lihn S, et al. Power of a learning network in congenital heart disease. World J Pediatr Congenit Heart Surg 2019; 10: 66–71.
17. Clauss SB, Anderson JB, Lannon C, et al. Quality improvement through collaboration: the National Pediatric Quality improvement collaborative initiative. Curr Opin Pediatr 2015; 27: 555–562.
18. Anderson JB, Beekman RH, 3rd, Kugler JD, et al. Improvement in interstage survival in a National Pediatric Cardiology Learning Network. Circ Cardiovasc Qual Outcomes 2015; 8: 428–436.
19. Britto MT, Fuller SC, Kaplan HC, et al. Using a network organisational architecture to support the development of learning healthcare systems. BMJ Qual Saf 2018; 27: 937–946.
20. Olsen LA, Aisner D, McGinnis JM eds. The Learning Healthcare System: Workshop Summary. National Academies Press, Washington (DC), 2007.
21. Lorts A, Smyth L, Gajarski RJ, et al. The creation of a pediatric health care learning network: the ACTION quality improvement collaborative. ASAIO J 2020; 66: 441–446.

22. Kugler JD, Beekman Iii RH, Rosenthal GL, et al. Development of a pediatric cardiology quality improvement collaborative: from inception to implementation. From the Joint Council on Congenital Heart Disease Quality Improvement Task Force. Congenit Heart Dis 2009; 4: 318–328.
23. Gerald J. Langley RDM, Nolan KM, Nolan TW, Norman CL, Provost LP. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance. Jossey-Bass A Wiley Imprint, 2009: 15–25.
24. Gordon-Walker TT, Bove K, Veldtman G. Fontan-associated liver disease: a review. J Cardiol 2019; 74: 223–232.
25. Khan A, Ramsey K, Ballard C, et al. Limited accuracy of administrative data for the identification and classification of adult congenital heart disease. J Am Heart Assoc 2018; 7: e009395 .
26. Mutluer FO, Celiker A. General concepts in adult congenital deart disease. Balkan Med J 2018; 35: 18–29.
27. Marino BS, Cassedy A, Drotar D, Wray J. The impact of neurodevelopmental and psychosocial outcomes on health-related quality of life in survivors of congenital heart disease. J Pediatr 2016; 174: 11–22 e2.
28. Iyengar AJ, Winlaw DS, Galati JC, et al. The Australia and New Zealand Fontan registry: description and initial results from the first population-based Fontan registry. Inter Med J 2014; 44: 148–155.
29. Improve Care Now. https://www.improvecarenow.org/purpose-success. Accessed on 5-15-2020.
30. Chang AC. Artificial intelligence in pediatric cardiology and cardiac surgery: irrational hype or paradigm shift? Ann Pediatr Cardiol 2019; 12: 191–194.