

# The Creation of a Pediatric Health Care Learning Network: The ACTION Quality Improvement Collaborative

ANGELA LORTS,\*† LAUREN SMYTH,† ROBERT J. GAJARSKI,‡ CHRISTINA J. VANDERPLUYM,§ MARY MEHEGAN,¶ CHET R. VILLA,\*†  
JENNA M. MURRAY,|| ROBERT A. NIEBLER,# CHRISTOPHER S. ALMOND,\*\* PHILIP THRUSH,†† MATTHEW J. O'CONNOR,‡‡  
JENNIFER CONWAY,§§ DAVID L. SUTCLIFFE,¶¶ JODI E. LANTZ,¶¶ FARHAN ZAFAR,††††, DAVID L.S. MORALES,††††,†  
DAVID M. PENG,‡‡ AND DAVID N. ROSENTHAL\*\*

**Improving the outcomes of pediatric patients with congenital heart disease with end-stage heart failure depends on the collaboration of all stakeholders; this includes providers, patients and families, and industry representatives. Because of the rarity of this condition and the heterogeneity of heart failure etiologies that occur at pediatric centers, learnings must be shared between institutions and all disciplines to move the field forward. To foster collaboration, excel discovery, and bring data to the bedside, a new, collaborative quality improvement science network—ACTION (Advanced Cardiac Therapies Improving Outcomes Network)—was developed to meet the needs of the field. Existing gaps in care and the methods of improvement that will be used are described, along with the mission and vision, utility of real-world data for regulatory purposes, and the organizational structure of ACTION is described. ASAIO Journal XXX; XX:00–00.**

**Key Words:** quality improvement, heart failure, ventricular assist device, collaborative, learning network

From the \*Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, Ohio; †The Heart Institute, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; ‡Division of Cardiology, Nationwide Children's Hospital, Columbus, Ohio; §The Department of Cardiology, Boston Children's Hospital, Harvard School of Medicine, Boston, Massachusetts; ¶Division of Cardiology, St. Louis Children's Hospital, St. Louis, Missouri; ||Division of Cardiology, Lucille Packard Children's Hospital, Palo Alto, California; #Division of Pediatrics, Children's Hospital of Wisconsin, Milwaukee, Wisconsin; \*\*Division of Cardiology, Stanford University School of Medicine, Palo Alto, California; ††Ann & Robert H. Lurie Children's Hospital, Northwestern University Feinberg School of Medicine, Chicago, Illinois; ‡‡Division of Pediatric Cardiology, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; §§Division of Pediatric Cardiac Surgery, Stollery Children's Hospital, Edmonton, Alberta, Canada; ¶¶Division of Cardiology, Children's Medical Center/UT Southwestern, Dallas, Texas; †††Department of Surgery, University of Cincinnati College of Medicine, Cincinnati, Ohio; and ††††Division of Cardiology, C.S. Mott Hospital, University of Michigan, Ann Arbor, Michigan.

Submitted for consideration September 2019; accepted for publication in revised form December 2019.

Disclosures: Initial funding for the network was obtained by the following device companies: Berlin Heart, Medtronic, and Abbott.

The network has received funding from Berlin Heart, Medtronic, and Abbott and received additional initial funding from the Cincinnati Children's Hospital Medical Center.

Correspondence: Angela Lorts, MD, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave, Cincinnati, OH 45229. E-mail: angela.lorts@cchmc.org.

Copyright © 2020 by the ASAIO

DOI: 10.1097/MAT.0000000000001133

A learning health system offers an effective approach to improving clinical outcomes in a given patient population. Learning health systems, as defined by the Institute of Medicine, combine both afferent approaches of data collection and analytics, with efferent approaches that apply lessons learned through quality improvement science, cultural change, and change management.<sup>1</sup> The objective is to improve outcomes through discovery of new knowledge and application of existing knowledge, in ways that are complementary to traditional clinical research and not merely a new means to conduct clinical investigations. Components of a learning health system include multistakeholder collaboration, quality improvement science, and data analytics. Numerous examples exist of such systems and offer testimony to the magnitude of impact that such a system can have on a patient population.

The characteristics of a learning health system are especially valuable to low volume, high complexity orphan patient populations, which are often not effectively served by traditional clinical research and for whom the knowledge base for care is often inadequate. The ACTION (Advanced Cardiac Therapies Improving Outcomes Network), multicenter learning health network, was developed to harness the benefits of a learning health system for the pediatric population with heart failure across inpatient and outpatient domains. In this longitudinal focus on the entire arc of heart failure, ACTION differs fundamentally from inpatient registries and networks such as PC4 (Pediatric Cardiac Critical Care Consortium) and ELSO (Extracorporeal Life Support Organization). The formation and initial objectives of the network are described in this article.

## Current State

### *Pediatric Heart Failure: Outcomes and Challenges*

In the United States, 11,000–14,000 children are hospitalized annually with a diagnosis involving heart failure.<sup>2</sup> Congenital heart disease (CHD) comprises approximately 60% of all pediatric heart failure hospital admissions. Children with heart failure experience very high morbidity and mortality, with median length of stay exceeding 17 days, and mortality of 7%.<sup>2,3</sup> Nearly 50% of children diagnosed with dilated cardiomyopathy, the most common phenotype of cardiomyopathy, succumb to their disease or undergo heart transplant within 5 years of diagnosis.<sup>4</sup>

Patients with severe, refractory heart failure listed for heart transplant face a high overall waiting list mortality of 8%.<sup>5</sup> Increasingly, children with severe heart failure are supported with ventricular assist devices (VADs) to aid in

stabilization while awaiting heart transplantation.<sup>6</sup> Although VADs have improved waiting list survival by more than 50%,<sup>5</sup> overall mortality on VAD support is still 19%.<sup>7</sup> In certain subgroups, survival is considerably worse. The youngest patients, less than 1 year of age at the time of VAD implant, have less than 50% survival at 6 months if they remain on a VAD.<sup>7</sup> Children supported with a VAD with CHD have much higher mortality rates and lower transplant rates than those without CHD.<sup>8</sup>

In addition, children on VAD experience a high rate of serious adverse events. Nearly 30% of children with paracorporeal VADs suffer some type of neurologic event (stroke, hemorrhage or seizure) in the first 3 months of support, and neurologic dysfunction is the leading cause of death on VAD overall.<sup>7</sup> Other common adverse events include bleeding, infection, and device malfunction.<sup>9</sup>

Finally, the cost of treating pediatric heart failure is high and is rapidly increasing. Between 2000 and 2009, the median cost of a pediatric heart failure hospitalization nearly doubled (from \$35,000 to \$72,000).<sup>3</sup> When VADs are used, the median hospitalization cost climbs steeply to \$750,000 with a median hospital stay of 81 days.<sup>10</sup>

Pediatric health care centers experience many challenges when treating pediatric patients with heart failure, especially when VADs are deployed. There is high variability in anatomy, neurodevelopmental status and somatic growth, as well as frequent end-organ dysfunction and genetic malformations, necessitating a multidisciplinary team approach to care for these complex and fragile patients.<sup>11</sup> Low patient volumes at any one center make it difficult for providers and teams to standardize care and improve outcomes for this patient population.

The challenges of managing pediatric heart failure are amplified in the VAD treatment group. The Pedimacs registry data indicate that over a 3 year period, 43% of centers implanted only a single pediatric device and only 17% of centers implanted more than 5 devices.<sup>12</sup> Inevitably, low patient volume results in variability in care delivery, staff experience, knowledge, and practices. Low patient volume has been previously associated with decreased survival.<sup>8,13</sup> It is difficult for individual centers to improve the care of complex heart failure and VAD patients that present in low volumes as learning and quality improvement for care delivery arise from experience. As it is currently, many at-risk children are unable to access the most experienced, specialized, and resourced centers. Individual centers suffer slow learning curves unless collaboration across centers is present.<sup>14</sup>

#### *Need for Learning Health System for Pediatric Heart Failure*

The challenges described above highlight a critical need for the development of a collaborative learning health system for pediatric patients with heart failure.

### **Development of the Advanced Cardiac Therapies Improving Outcomes Network**

#### *Mission*

The mission of ACTION is to improve critical outcomes and the patient/family experience for children with heart failure by developing an international collaborative learning health

network that unites all key stakeholders (patients, families, providers, researchers, industry, and regulatory bodies).

#### *Logic Model*

An outcomes-focused logic model was developed to examine the assumptions, inputs, activities, outputs, and outcomes of the challenges to be overcome by participants. The model incorporates external factors that act as barriers to achieving improvement. **Figure 1** provides an overview of the model.

**Assumptions.** The assumptions of this model rest on the characteristics of the pediatric population with heart failure detailed above and include the combination of low volume with high complexity, for which a multi-institutional collaborative learning health system can potentially improve outcomes.<sup>11,15</sup>

**Inputs.** The model includes several input resources, listed below.

- Content expertise: Clinicians such as pediatric cardiologists, nurses, and coordinators specialized in heart failure and VAD care assist with the design of the data repository, collection of clinical data, and implementation of quality improvement initiatives.<sup>16</sup>
- Patient and family engagement: Measured outcomes expand beyond clinical end-points to include both quality of life and patient experience measures.<sup>15</sup>
- Data analysts and researchers: These are essential for analyzing and interpreting data so that quality improvement projects can be evidence-driven and outcomes can be appropriately measured and communicated.<sup>17</sup>
- Industry stakeholders: Improve design and labeling of devices for use in pediatrics.<sup>9</sup>

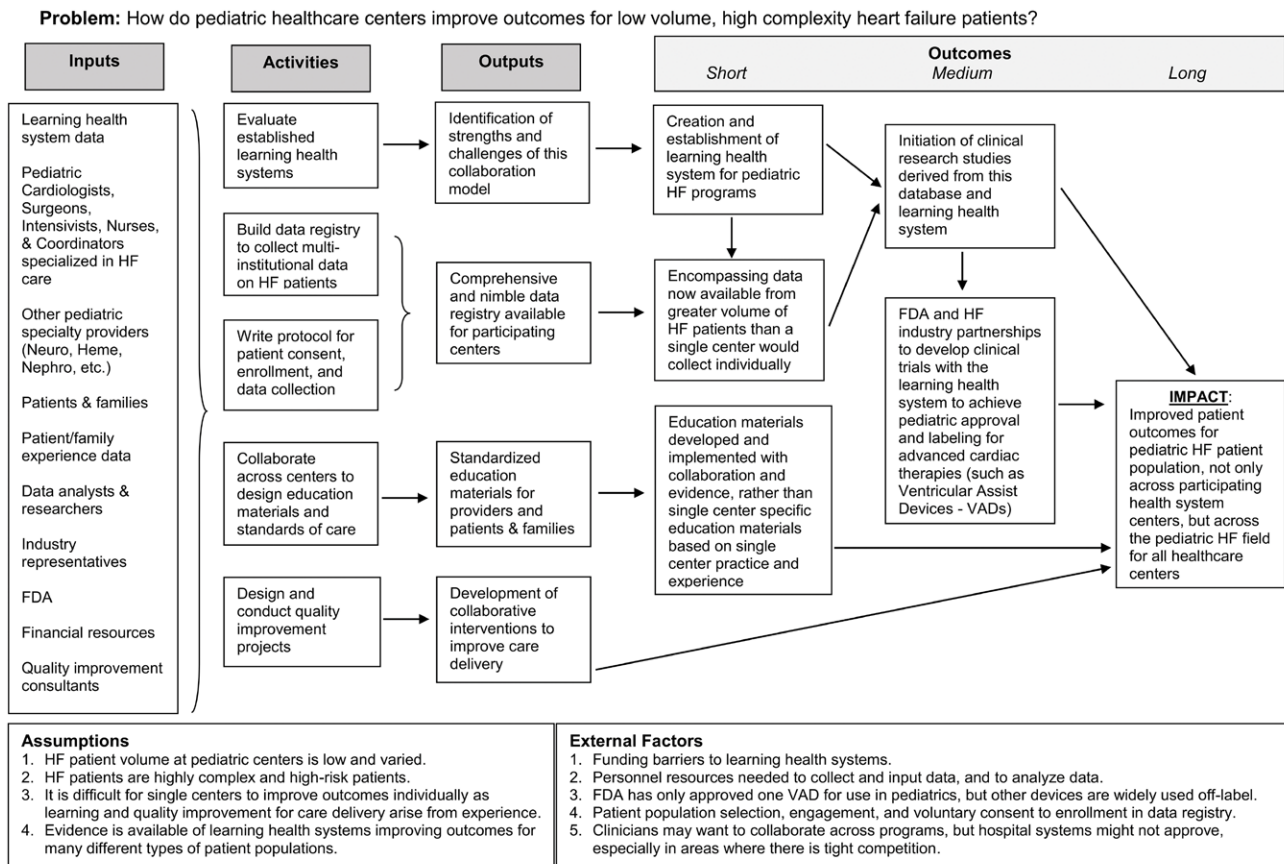
#### **Activities.**

- Evaluating established learning health systems
- Building a multi-institutional data repository
- Developing a protocol to guide patient consent, enrollment, and data collection<sup>15</sup>
- Developing educational materials for patients and providers
- Conducting quality improvement projects across the learning health system<sup>17</sup>

**Outputs.** There are numerous outputs of this model.

- Identification of strengths and challenges of this collaboration system
- Comprehensive data registry available for participating system centers<sup>16</sup>
- Standardized and accessible education materials for providers, patients, and families
- Systematic and effective development of collaborative interventions designed to improve care delivery in real time<sup>15</sup>

**Outcomes.** The logical end-points for this model are the development of short-, medium- and long-term outcomes. An immediate short-term outcome includes the creation and establishment of a learning health system for participating pediatric heart failure centers. Other outcomes follow from this, such as incorporation of a comprehensive data set that far exceeds the volume of VAD patients available to any single



Adapted from University of Wisconsin-Extension, Program Logic Model

action

**Figure 1.** Learning health system approach to improving outcomes for pediatric heart failure (HF) patients, outcome logic model. FDA, Food and Drug Administration; VAD, ventricular assist device.

pediatric center.<sup>15</sup> Another short-term outcome is the preparation and distribution of education materials created through collaboration and best-practice evidence, rather than through center-specific practices and experiences.<sup>16</sup>

Medium-term outcomes include the initiation of clinical research studies derived from the learning health system data repository. The aim of these studies, in part, would be to foster Food and Drug Administration (FDA) and VAD industry partnerships which would facilitate clinical trial development designed to obtain pediatric approval and labeling for other VADs.<sup>9</sup> The long-term outcome of this learning health system would be improved patient outcomes for the entire pediatric heart failure and VAD patient community. The impact of this program is that knowledge and best practices for heart failure and VAD patient care delivery will spread beyond the learning health system to the entire field, and, in turn, outcomes will be improved on a large scale for all patients independent of where they receive their health care.<sup>18</sup>

**External factors.** The external factors in this model include barriers and factors that affect the situation and problem. Funding is necessary to develop and operationalize a learning health system, and availability of funding (or lack thereof) is a major external factor to be considered. Hospital systems are already financially burdened as they have been facing financial difficulty and fiscal constraints in the last decade because of economic decline. Therefore, funding and

financing a learning health system and paying for personnel required to staff the system is a prominent external factor to consider.<sup>19</sup> Hospital administrators may also be skeptical about close collaboration in areas with tight geographical competition.

Another external factor concerns the FDA's involvement in the VAD field. Currently, the FDA has approved only one VAD for use in pediatrics, though many devices are widely used off-label within pediatric health care centers.<sup>9</sup> In addition, the heart failure and VAD patient population itself is an external factor. Patients and families must be willing to engage with clinicians and researchers, to consent to data collection and analysis, and participate as key stakeholders in the learning health system for quality improvement efforts and other system initiatives to succeed.<sup>10</sup>

### Stakeholders

Beginning in April 2017, participating centers initiated a series of meetings to better understand the key elements and core objectives of ACTION. The present state of ACTION, and the collaborative culture that characterizes the current state of the network, emerged from approximately 1 year of discussion and refinement of the initial ideas. Current centers to date are listed in **Table 1**. The structure of ACTION was envisioned from the outset to be broadly interdisciplinary. As such, an inclusive



**Table 1. Participating Centers To-Date (September 2019), Listed Alphabetically**

|   |   |
|---|---|
| Boston Children's Hospital                      | Lurie Children's Hospital of Chicago                        |
| C.S. Mott Children's Hospital                   | Monroe Carell Jr. Children's Hospital at Vanderbilt         |
| Children's Health Dallas                        | Morgan Stanley Children's Hospital of New York Presbyterian |
| Children's Healthcare of Atlanta                | Nationwide Children's Hospital                              |
| Children's Heart Center at Mount Sinai Hospital | Norton Children's Hospital                                  |
| Children's Hospital at Montefiore               | Ochsner Hospital for Children                               |
| Children's Hospital of Colorado                 | Phoenix Children's Hospital                                 |
| Children's Hospital of Philadelphia             | Primary Children's Hospital                                 |
| Children's Hospital of Pittsburgh               | Riley Hospital for Children                                 |
| Children's Hospital of Wisconsin                | Seattle Children's Hospital                                 |
| Children's Mercy Kansas City                    | St. Louis Children's Hospital                               |
| Children's National Medical Center              | Stollery Children's Hospital                                |
| Children's of Alabama                           | Texas Children's Hospital                                   |
| Cincinnati Children's Hospital Medical Center   | The Hospital for Sick Children                              |
| Cleveland Clinic Children's Hospital            | UCSF Benioff Children's Hospital                            |
| Duke Children's Hospital                        | UF Health Shands Children's Hospital                        |
| Le Bonheur Children's Hospital                  | University of Minnesota Masonic Children's Hospital         |
| Loma Linda University Children's Hospital       | Yale New Haven Children's Hospital                          |
| Lucile Packard Children's Hospital Stanford     |   |

approach was taken to identify key stakeholders and the goals of their participation or nature of claim (**Table 2**). The resulting participants include patients and family members, independent patient-advocacy organizations, health care providers from multiple disciplines (*i.e.* physicians, surgeons, nurses, coordinators, and perfusionists), as well as industry representatives, regulatory representatives, and health care payors. Through this broad representation, a truly inclusive and comprehensive view of challenges and objectives has emerged and will continue to evolve.

### Organizational Structure

The organizational structure that emerged from the year-long design discussions is shown in **Figure 2**. The key features of this structure include co-chairs from different institutions; an executive leadership group with broad oversight responsibility; a broad leadership group to provide focused feedback on specific initiatives; a number of committees (described below in further detail) which are long-lived and will have varying focus over time; and a stakeholder group to ensure that broad input cuts across different committees and projects. Additional committees can be seen in **Figure 2**.

### Initial ACTION Projects

Although ACTION, from its inception, was envisioned as a tool to improve outcomes for pediatric heart failure, a number of pragmatic considerations have led to an initial

focus on pediatric VAD patients. This group is both more discrete and more readily defined than the global pediatric population with heart failure, and in addition, these children bear an extraordinary burden associated with VAD therapy. The initial goal of ACTION, in response to these circumstances, is to reduce the frequency and severity of stroke associated with VAD care in children. The key components most amenable to intervention that have emerged from the design process include the following:

1. Improved management of anticoagulation in VAD patients
2. Improved hemodynamic management in VAD patients
3. Improved communication among the providers in the inpatient VAD care team.

As these projects gain momentum, other efforts will be targeted at stroke reduction using Plan-Do-Study-Act methodology. In concert with these QI projects, ACTION members are developing educational materials for both patients and providers.

### Lessons Learned

The ACTION network has made great strides in its first years of existence. Through steady word of mouth, active recruitment through meetings and personal connections, and promotion through Twitter and our website, participation has now expanded to 37 sites (as of September 2019) across North America with tremendous membership engagement. The launch process has been prolonged in large part because of the protracted processes of securing institutional review board (IRB) approval with a central IRB and establishing data use agreements (DUAs) among all institutions. We believe that the delays from a central IRB will be recovered with ease of long-term maintenance, but that remains to be seen. The time required to establish DUAs in an era of growing privacy regulation has been substantial and will continue to be a significant factor governing the evolution of additional networks in the future. Nevertheless, to date, 22 of 37 sites have established complete DUA and IRB regulatory approval.

**Table 2. Stakeholders and Nature of Claim**

| Stakeholder Group             | Nature of Claim   |
|-------------------------------|---|
| Parents/families<br>Providers | Improved care by standardization and innovation<br>Standard consensus and protocols to decrease unnecessary variation |
| Administrators                | Better improve outcomes, decrease cost, and improve hospital flow   |
| Industry                      | Build relationships with clinicians to improve devices, better outcomes   |
| Regulators                    | Work with industry and clinicians to improve the device labeling process  |
| Payors                        | Decrease unnecessary hospital utilization   |

|                                 |  |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
|---------------------------------|--|----------------|----------------------|---------------------------------------|----------------------|----------------------------------|-------------------------|-------------------------------|--------------------------|---------------------------------|
| ACTION Organizational Structure |  | Weekly Calls   | Co-Chairs            |                                       |                      |                                  |                         |                               |                          |                                 |
| March 2019                      |  |                | Preside over network |                                       |                      |                                  |                         |                               |                          |                                 |
| 60 Min Call per Month           | <b>Executive Leadership</b>  |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
|                                 | <i>Establish policies &amp; strategic planning for management, operations, and quality improvement, provide governance and sponsorship of other committees, and make decisions on major network issues</i> |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
| 30 Min Call per Month           | <b>Leadership</b>  |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
|                                 | <i>Leaders of committees and learning labs; responsible for strategy, development, and project execution for their respective areas</i>  |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
| 60 Min Global QI Call per Month | QI Resource Committee  | Data Committee | Research Committee   | Patient & Family Experience Committee | Education Committee  | Discharge & Outpatient Committee | Harmonization Committee | Utilization & Value Committee | Peds/Adult CHD Committee | Heart Failure Phase 2 Committee |
|                                 | ←————→   |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
| 60 Min Global QI Call per Month | QI / Research Proposals<br>(discussed on monthly leadership call)  |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
|                                 | <b>REDUCING STROKE</b><br>Anticoagulation<br>Hemodynamics/Blood Pressure<br>Communication  |                |                      |                                       |                      |                                  |                         |                               |                          |                                 |
| <b>STAKEHOLDERS</b>             |  |                |                      |                                       | <b>SUPPORT STAFF</b> |                                  |                         |                               |                          |                                 |

Figure 2. Structure. CHD, congenital heart disease.

**Next Steps**

*Heart Failure expansion*

Phase 2 of the ACTION network will focus on children with acute decompensated heart failure requiring hospitalization for heart failure therapy. Discussions are currently underway regarding the specific patient definition for inclusion, the data collection strategy, and other operational details. It is anticipated that specific efforts in heart failure care improvement will commence sometime in 2019.

*Cardiac Networks United and Other Partnerships*

As has been identified by other observers, the current landscape of registries and learning health systems represents a series of siloed observations and data collection among similar patient populations. Although each unique initiative brings together expertise and engagement, this model simultaneously faces challenges in scaling up with each silo introducing inefficiencies related to redundancy of purpose and operations. Cardiac Networks United has been developed as an attempt to bring diverse registries and networks together to realize operational efficiency and cost-reduction. ACTION is an active participant in these efforts, with the goal of sharing data across networks and reducing data entry and extraction efforts.<sup>20</sup>

*Secure Funding Model*

A central challenge to all of the existing and proposed networks is the issue of ongoing funding. No single solution to this

challenge has emerged, with some networks relying on philanthropic support, whereas others have secured (at least for now), support from hospitals. ACTION is no different from other networks in this regard. In the early phase of development, ACTION was supported by a combination of philanthropy and support from Cincinnati Children’s Hospital Medical Center. More recently, ACTION has achieved a more balanced funding model that includes ongoing support from Cincinnati Children’s Hospital Medical Center, grant funding from private philanthropic organizations, site fees, and industry support, both for operations and in support of specific data needs. Because of the multiple sources of funding, site fees have been kept at a modest level that has been acceptable to participating sites regardless of VAD volume. Due to a focus on VAD initiatives, there is potential for support from industry partners to a larger degree than might be possible for networks with other areas of focus.

**Conclusions**

The learning health system model is an effective, feasible, and sustainable approach to improving outcomes for rare orphan pediatric populations. The low volume, high complexity pediatric heart failure and VAD population is an example of a population that will benefit greatly from collaboration. Such a model of collaboration and improvement increases the speed, efficiency, and effectiveness of knowledge generation, innovation, and dissemination. This allows for the development of care practices by content experts, leading to standardization

of best practices and outcomes improvement across the system.<sup>21</sup>

The overall impact of the learning health system model is that knowledge and best practices for care delivery are spread across an entire field rather than individual systems. As a result, outcomes will be improved on a large-scale regardless of a patient's location of care, and a momentous impact can be realized across entire fields of medicine.<sup>18</sup> Established learning health systems such as NPC-QIC, ICN, and PR-COIN demonstrate the effectiveness of this approach to standardizing and spreading best practices and for improving patient outcomes.<sup>22–24</sup> ACTION affords the opportunity and provides the means by which collaboration between administrators, clinicians, researchers, regulators, payors, industry, patients, and families can improve the critical outcomes in this population.

### Acknowledgment

The authors thank all ACTION members.

### References

- Institute of Medicine Roundtable on Evidence-Based Medicine: The National Academies Collection: Reports funded by National Institutes of Health. In: McGinnis JM, Aisner D, Olsen L (eds), *The Learning Healthcare System: Workshop Summary*. Washington, DC, National Academic Press, 2007.
- Rossano JW, Kim JJ, Decker JA, et al: Prevalence, morbidity, and mortality of heart failure-related hospitalizations in children in the United States: A population-based study. *J Card Fail* 18: 459–470, 2012.
- Nandi D, Lin KY, O'Connor MJ, et al: Hospital charges for pediatric heart failure-related hospitalizations from 2000 to 2009. *Pediatr Cardiol* 37: 512–518, 2016.
- Towbin JA, Lowe AM, Colan SD, et al: Incidence, causes, and outcomes of dilated cardiomyopathy in children. *JAMA* 296: 1867–1876, 2006.
- Zafar F, Castleberry C, Khan MS, et al: Pediatric heart transplant waiting list mortality in the era of ventricular assist devices. *J Heart Lung Transplant* 34: 82–88, 2015.
- Rossano JW, Cherikh WS, Chambers DC, et al: The International Thoracic Organ Transplant Registry of the International Society for Heart and Lung Transplantation: Twenty-first pediatric heart transplantation report-2018; Focus theme: Multiorgan transplantation. *J Heart Lung Transplant* 37: 1184–1195, 2018.
- Blume ED, VanderPluym C, Lorts A, et al; Pedimacs Investigators: Second annual Pediatric Interagency Registry for Mechanical Circulatory Support (Pedimacs) report: Pre-implant characteristics and outcomes. *J Heart Lung Transplant* 37: 38–45, 2018.
- Peng DM, Koehl DA, Cantor RS, et al: Outcomes of children with congenital heart disease implanted with ventricular assist devices: An analysis of the Pediatric Interagency Registry for Mechanical Circulatory Support (Pedimacs). *J Heart Lung Transplant* 38: 420–430, 2019.
- Rosenthal DN, Almond CS, Jaquiss RD, et al: Adverse events in children implanted with ventricular assist devices in the United States: Data from the Pediatric Interagency Registry for Mechanical Circulatory Support (PediMACS). *J Heart Lung Transplant* 35: 569–577, 2016.
- Rossano JW, Cantor RS, Dai D, et al: Resource utilization in pediatric patients supported with ventricular assist devices in the United States: A multicenter study from the Pediatric Interagency Registry for mechanically assisted circulatory support and the pediatric health information system. *J Am Heart Assoc* 7: e008380, 2018.
- Mehegan M, Oldenburg G, Lantz J: Pediatric VAD discharge and outpatient care. *ASAIO J* 64: e156–e160, 2018.
- Rossano JW, Lorts A, VanderPluym CJ, et al: Outcomes of pediatric patients supported with continuous-flow ventricular assist devices: A report from the Pediatric Interagency Registry for Mechanical Circulatory Support (PediMACS). *J Heart Lung Transplant* 35: 585–590, 2016.
- Morales DL, Zafar F, Rossano JW, et al: Use of ventricular assist devices in children across the United States: Analysis of 7.5 million pediatric hospitalizations. *Ann Thorac Surg* 90: 1313–1318; discussion 1318, 2010.
- Blume ED, Rosenthal DN, Rossano JW, et al; PediMACS Investigators: Outcomes of children implanted with ventricular assist devices in the United States: First analysis of the Pediatric Interagency Registry for Mechanical Circulatory Support (PediMACS). *J Heart Lung Transplant* 35: 578–584, 2016.
- Clancy CM, Margolis PA, Miller M: Collaborative networks for both improvement and research. *Pediatrics* 131(Suppl 4): S210–S214, 2013.
- McGinnis JM: Evidence-based medicine - engineering the Learning Healthcare System. *Stud Health Technol Inform* 153: 145–157, 2010.
- Margolis PA, Peterson LE, Seid M: Collaborative Chronic Care Networks (C3Ns) to transform chronic illness care. *Pediatrics* 131(Suppl 4): S219–S223, 2013.
- Seid M, Margolis PA, Opari-Arrigan L: Engagement, peer production, and the learning healthcare system. *JAMA Pediatr* 168: 201–202, 2014.
- Dong GN: Performing well in financial management and quality of care: evidence from hospital process measures for treatment of cardiovascular disease. *BMC Health Serv Res* 15: 45, 2015.
- Gaies M, Anderson J, Kipps A, et al: Cardiac Networks United: An integrated paediatric and congenital cardiovascular research and improvement network. *Cardiol Young* 29: 111–118, 2019.
- Daley K. A continuously learning health care system in the United States. 2013.
- Anderson JB, Beekman RH 3rd, Kugler JD, et al; National Pediatric Cardiology Quality Improvement Collaborative: Use of a learning network to improve variation in interstage weight gain after the Norwood operation. *Congenit Heart Dis* 9: 512–520, 2014.
- Egberg MD, Kappelman MD, Gulati AS: Improving care in pediatric inflammatory bowel disease. *Gastroenterol Clin North Am* 47: 909–919, 2018.
- Favier LA, Taylor J, Loisel Rich K, et al: Barriers to adherence in juvenile idiopathic arthritis: A multicenter collaborative experience and preliminary results. *J Rheumatol* 45: 690–696, 2018.