SCHD
Structural & Congenital Heart Disease

Tech Science Press

http://doi.org/10.32604/schd.2026.082288

REVIEW

The Advanced Cardiac Therapies Improving Outcomes Network (ACTION): A Multicenter Registry and Learning Health System for Pediatric and Congenital Heart Disease Associated Heart Failure

Anusha Konduri[1,*], Toni Duganiero[2], Lauren Smyth[2], Shahnawaz Amdani[3], Angela Lorts[2], Sabrina Law[4], Jacqueline Lamour[5], Deipanjan Nandi[6], Aryaz Sheybani[7], Sarah Wilkens[8], Thomas Young[9], Mark Bleiweis[10] and Jennifer Conway[11]

[1]Department of Pediatrics, Children's Health, University of Texas Southwestern Medical Center, Dallas, TX, USA
[2]Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA
[3]Division of Cardiology & Cardiovascular Medicine, Cleveland Clinic Children's, Cleveland, OH, USA
[4]Division of Cardiology, New York-Presbyterian Morgan Stanley Children's Hospital, Columbia University Medical Center, New York, NY, USA
[5]Division of Pediatric Cardiology, Mount Sinai Kravis Children's Heart Center, New York, NY, USA
[6]The Heart Center, Department of Pediatrics, Nationwide Children's Hospital, Ohio State University, Columbus, OH, USA
[7]Nemours Cardiac Center, Nemours Children's Hospital, Wilmington, DE, USA
[8]Department of Pediatrics, University of Louisville and Norton Children's hospital, Louisville, KY, USA
[9]Department of Pediatric Cardiology, Ochsner Medical Center, New Orleans, LA, USA
[10]Congenital Heart Center, University of Florida, Gainesville, FL, USA
[11]Department of Pediatrics, Stollery Children's Hospital, Edmonton, AB, Canada
*Corresponding Author: Anusha Konduri. Email: anusha.konduri@utsouthwestern.edu

Received: 13 March 2026; Accepted: 23 July 2026; Published: 31 July 2026

ABSTRACT: Pediatric heart failure is associated with substantial morbidity, mortality, and health care utilization across diverse diagnoses and care settings. Despite major advances in surgical and medical care, evidence-based management of heart failure in the pediatric population, especially with congenital heart disease (CHD), remains limited due to a small patient population, marked anatomic and physiologic heterogeneity, and barriers to conducting traditional randomized clinical trials. Clinical registries have provided important insights into pediatric heart failure, and the increasing complexity of these populations has underscored the value of learning health system approaches to data generation and improvement. The Advanced Cardiac Therapies Improving Outcomes Network (ACTION) was intentionally developed as a collaborative, multicenter learning health system that integrates standardized registry data with quality improvement, pragmatic research, education, and stakeholder engagement. Initially focused on mechanical circulatory support, ACTION has expanded to encompass pediatric and congenital heart failure across the lifespan, including patients with biventricular and single-ventricle physiology, Fontan circulation, neuromuscular disease–associated cardiomyopathy, and emerging populations such as cardio-oncology. This narrative review describes the history, governance, and current state of the ACTION Network, highlighting its registry infrastructure, population-specific initiatives, and demonstrated impact on clinical outcomes, practice harmonization, and device evaluation. We also discuss opportunities and challenges for future growth, including registry-embedded trials, patient-centered outcomes, and pathways for participation. ACTION illustrates how a registry-based learning health system can generate real-world evidence, improve care delivery, and advance research in complex pediatric heart failure.

KEYWORDS: Congenital heart disease; pediatric heart failure; clinical registries; learning health system; advanced cardiac therapies; quality improvement

1 Introduction

Congenital heart disease (CHD) affects approximately 8–10 per 1000 live births worldwide and accounts for nearly 40,000 new cases annually in the United States [1,2]. Advances in surgical and medical care have resulted in more than 90% of affected children surviving into adulthood, creating a growing population living with repaired or palliated CHD [3]. However, heart failure has emerged as a leading driver of morbidity, hospitalization, and mortality in this population [4]. CHD accounts for approximately 60% of pediatric heart failure hospitalizations, with an estimated 14,000 admissions annually in the United States [5,6]. Pediatric heart failure is associated with prolonged hospitalizations, high rates of intensive care utilization, and in-hospital mortality approaching 7% [6]. Outcomes are particularly poor among infants, patients with complex CHD, and those with single-ventricle or Fontan physiology.

Advanced heart failure therapies, including mechanical circulatory support, have substantially expanded treatment options for children with end-stage heart failure. Ventricular assist devices (VADs) have significantly reduced transplant waitlist mortality, and outcomes have improved markedly over the past decade, particularly among patients with dilated cardiomyopathy [7–9]. However, these improvements have not been uniform across diagnostic groups. Infants and children with CHD continue to experience higher rates of complications and mortality during VAD support compared with patients with cardiomyopathy. Neurologic complications remain among the most clinically impactful adverse events. Early neurologic dysfunction occurs in approximately 16% of children supported with paracorporeal pulsatile devices and 18% of those supported with paracorporeal continuous-flow devices, underscoring the persistent morbidity associated with advanced mechanical support despite overall progress [10]. The economic burden is similarly substantive. Pediatric heart failure is also associated with substantial healthcare utilization and cost, particularly among patients requiring advanced therapies such as ventricular assist devices or extracorporeal membrane oxygenation, further emphasizing the need for strategies that improve outcomes and reduce preventable complications [5,11,12].

Despite the clinical and economic burden, evidence-based management of pediatric and congenital heart failure remains limited. Randomized trials are challenging due to low patient volumes, marked anatomic and physiologic heterogeneity, and ethical and logistical constraints. Existing registries have provided important insights, but were not designed to capture the longitudinal heart failure trajectory, congenital anatomy, specific variables, or real-time practice variation necessary to support continuous learning and quality improvement. Unlike traditional registries that primarily serve as repositories of observational data, ACTION was intentionally designed to function as a learning health system in which data collection, benchmarking, quality improvement, education, and research are integrated into a continuous cycle of practice evaluation and improvement (Fig. 1). This distinction has enabled ACTION not only to describe outcomes but also to facilitate care harmonization, generate real-world evidence, and support prospective clinical investigation.

Figure 1: Operational framework of the ACTION learning health system.

2 History and Development of the ACTION Network

The ACTION network was conceived as a multicenter collaborative explicitly designed to function as a learning health system for pediatric and congenital heart failure, as well as advanced cardiac therapies. Initial discussions among pediatric heart failure and mechanical circulatory support leaders began in 2016 and were informed by prior successful pediatric collaborative networks that integrated quality improvement science with real-world data infrastructure [13]. Over approximately one year of structured planning, stakeholders defined the mission, scope, governance model, and operational framework required to support continuous learning across institutions caring for children with advanced heart failure.

ACTION was formally launched in 2017 with a founding group of North American pediatric centers committed to standardized data submission, shared governance, and active participation in collaborative quality improvement. From the outset, the network was intentionally structured to move beyond a traditional registry model. Rather than focusing solely on passive data collection, ACTION integrated afferent processes (data acquisition and analytics) with efferent processes (feedback, quality improvement interventions, education, and change management). This design aligned with Institute of Medicine principles for learning health systems and reflected the specific needs of a low-volume, high-complexity patient population [13,14].

From its inception, ACTION adopted a multidisciplinary model that included clinicians, surgeons, nurses, allied health professionals, researchers, patients, families, industry partners, and regulatory stakeholders. The initial operational focus of ACTION centered on children supported with VADs. This decision

reflected both the high morbidity and mortality associated with pediatric VAD therapy and the feasibility of defining a discrete patient population for early quality improvement initiatives. Early projects targeted the reduction of neurologic injury, with particular emphasis on anticoagulation management, hemodynamic optimization, and team communication. These initiatives employed established quality improvement methodologies, including Plan–Do–Study–Act cycles, and were supported by standardized data definitions and shared learning across sites.

Concurrent with early quality-improvement efforts, ACTION developed a centralized registry infrastructure with standardized enrollment procedures, longitudinal data collection, and centralized regulatory oversight to support future research and quality-improvement initiatives. As the network matured, ACTION expanded beyond its initial VAD-focused scope to encompass a broader pediatric and congenital heart failure population. This expansion included patients with biventricular CHD and systolic dysfunction, single-ventricle physiology at all stages of palliation, including Fontan circulation, infants and neonates requiring advanced therapies, and adults with congenital heart disease. This longitudinal perspective distinguished ACTION from existing inpatient-only or procedure-focused registries and enabled the study of disease progression, treatment patterns, and outcomes over time.

Participation in ACTION grew steadily through active recruitment, professional society engagement, and dissemination of early network successes. The collaborative culture that emerged emphasized transparency, benchmarking, and shared learning across institutions. By aggregating data across centers, ACTION achieved sufficient scale to study rare subpopulations and practice variation that would be impossible to evaluate within individual institutions. Importantly, insights generated through registry analyses were systematically fed back to participating sites through benchmarking reports, collaborative learning sessions, educational initiatives, and quality-improvement activities. This iterative cycle of data collection, analysis, feedback, and practice change enabled ACTION to evolve from a multicenter registry into a mature learning health system capable of supporting quality improvement, observational research, pragmatic trials, and care harmonization across pediatric and congenital heart failure populations.

3 Governance and Strategic Partnerships

The ACTION Network operates under a formal governance structure designed to support transparency, shared accountability, and sustained collaboration across participating institutions. The network's operational and administrative core is housed at Cincinnati Children's Hospital Medical Center, which serves as the coordinating center and provides centralized oversight for data management, analytics, quality improvement coordination, regulatory compliance, and dissemination activities. This centralized infrastructure supports consistency in operations while enabling broad participation across geographically and institutionally diverse sites.

Strategic oversight is provided by a Steering Committee composed of representatives from participating ACTION centers. Membership reflects a balance of clinical disciplines, institutional experience, and geographic representation, ensuring that governance decisions are informed by diverse practice environments. The Steering Committee is responsible for setting the network's strategic priorities, approving major initiatives, overseeing the research and quality improvement portfolio, and ensuring alignment with ACTION's mission. Leadership roles within the committee are distributed across institutions to reinforce shared ownership.

Operational oversight is supported through standing committees and disease-specific working groups that guide scientific priorities, quality-improvement initiatives, educational activities, and data stewardship. Standardized policies govern data submission, access, sharing, and publication processes to ensure scientific

rigor, protect patient privacy, and promote equitable participation across centers. This flexible structure allows ACTION to adapt to emerging clinical priorities while maintaining consistency in registry operations and collaborative activities.

Patient and family engagement is incorporated into governance processes to ensure that network activities remain aligned with patient-centered priorities. Patients and caregivers contribute perspectives regarding quality-of-life outcomes, communication strategies, educational resources, transition planning, and shared decision-making. These perspectives have informed the development of patient-facing educational materials and have helped broaden network priorities beyond traditional clinical outcomes to include patient experience and long-term functional status.

The Steering Committee establishes network priorities, oversees research and quality-improvement activities, and ensures alignment with ACTION's mission through a shared governance model. ACTION's sustainability is supported through a diversified funding model that includes institutional participation dues, peer-reviewed research funding, philanthropic support, and carefully governed partnerships with industry stakeholders. This diversified approach helps maintain registry operations, quality-improvement activities, educational programming, and clinical research infrastructure while minimizing reliance on any single funding source.

ACTION maintains active engagement with professional societies, including the American Heart Association, the American College of Cardiology, the International Society for Heart and Lung Transplantation, and the Pediatric Heart Transplant Society. These relationships support alignment with guideline development, scientific statements, and educational initiatives, enhancing the translation of registry findings into broader clinical practice. In addition, ACTION collaborates with other cardiovascular registries and consortia, including efforts coordinated through Cardiac Networks United, to promote interoperability, reduce redundant data collection, and improve efficiency across the pediatric and congenital registry landscape.

Finally, partnerships with regulatory bodies and research consortia have supported the development and adoption of standardized data elements and reporting frameworks for pediatric and congenital populations, improving consistency across registries and enhancing the translational value of ACTION data. Through its governance structure and strategic partnerships, ACTION provides a durable framework for collaboration, data stewardship, and shared learning. This governance model supports the network's dual role as both a registry and a learning health system, enabling sustained quality improvement, rigorous research, and meaningful engagement with stakeholders across the pediatric and congenital heart failure community.

4 Current State of the ACTION Network

The ACTION currently functions as a mature, multinational learning health system integrating prospective registry data with quality improvement, pragmatic research, and education across pediatric and congenital heart failure populations. Nearly all major pediatric heart failure and mechanical circulatory support programs in the United States and Canada now participate, enabling comprehensive capture of contemporary practice patterns and outcomes across diverse diagnoses, age groups, and therapeutic strategies. As of the most recent reporting period, 52 participating sites contribute data to the registry, underscoring the network's scale and representativeness.

5 Registry Infrastructure and Data Reporting

Registry data are collected across participating centers using standardized data definitions and submission protocols. Data collection is performed by site-based data coordinators using structured abstraction

from clinical documentation and electronic health records, with quality-control procedures including completeness assessments and periodic review of submitted data. This approach balances the need for detailed clinical information with scalability across a geographically distributed network.

ACTION maintains a modular registry architecture that supports multiple disease- and therapy-specific programs while preserving standardized core variables and harmonized adverse event definitions. Data are collected across participating centers and curated centrally, with participating sites able to access near real-time analytics through interactive dashboards. This infrastructure allows centers to benchmark outcomes, identify practice variation, and rapidly assess the impact of targeted interventions. The modular registry architecture allows the incorporation of new disease-specific populations while maintaining a common core dataset. Depending on the scientific objectives and feasibility of individual initiatives, newly introduced modules may include prospective enrollment alone or retrospective enrichment of selected variables. This flexible approach supports both longitudinal analyses and efficient expansion into emerging clinical populations while minimizing site-level burden.

Standardization of data elements and definitions across programs allows for consistent longitudinal tracking of patients and therapies, facilitates cross-initiative analyses, and supports scalable expansion into new disease populations. By emphasizing data completeness, timeliness, and usability, ACTION's registry infrastructure functions as the backbone of the network's learning health system, translating routine clinical data into actionable insights that inform practice, research, and quality improvements in care. Standardization is supported through comprehensive data dictionaries, predefined variable definitions, and harmonized adverse event classifications. The ACTION Academic Research Consortium (ACTION-ARC) initiative established standardized definitions for adverse events in pediatric and congenital heart disease patients supported with ventricular assist devices, improving consistency across institutions and facilitating comparison of outcomes across studies and populations. Ongoing review of registry variables and definitions ensures consistency as new disease-specific initiatives are incorporated into the network.

ACTION operationalizes the learning health system model through a continuous cycle of data capture, analysis, feedback, and improvement. Registry data are analyzed to identify outcome variation, emerging safety concerns, and opportunities for care harmonization. Findings are disseminated through dashboards, benchmarking reports, working groups, and collaborative learning activities, enabling participating centers to implement targeted quality-improvement interventions. Ongoing registry surveillance then evaluates the effectiveness of these interventions and informs subsequent improvement efforts.

6 Population-Specific Focus Areas and Outcome Improvements

6.1 ACTION-VAD

Mechanical circulatory support remains a core focus of the ACTION Network. The ACTION-VAD registry captures detailed data on device type, indication, duration of support, adverse events, and outcomes in infants, children, adolescents, and adults with congenital heart disease supported with VADs. To date, the registry includes 2265 subjects enrolled across 52 participating sites, reflecting broad contemporary experience across diverse patient populations and practice settings. Early registry analyses identified substantial variability in anticoagulation practices and neurologic event rates across centers. In response, ACTION collaborated with the Academic Research Consortium to develop standardized adverse-event definitions (ACTION-ARC), improving consistency in reporting and facilitating multicenter quality-improvement efforts [15].

Historical pediatric VAD cohorts, including the Berlin Heart EXCOR IDE trial, reported stroke rates approaching 30% [16]. In contrast, contemporary ACTION registry data demonstrate substantially lower

rates of ischemic and hemorrhagic stroke, generally in the range of 10–15%, despite inclusion of higher-risk populations such as neonates, infants, and patients with complex congenital heart disease [17]. In parallel with registry-based surveillance and standardized adverse event definitions, ACTION implemented coordinated quality improvement initiatives targeting anticoagulation management, perioperative care, standardized neurologic surveillance, and interdisciplinary communication. These initiatives were accompanied by standardized care pathways and collaborative quality-improvement efforts across participating centers.

Collectively, these efforts have been associated with reductions in neurologic adverse events, improved survival, and enhanced post-market device surveillance, while also supporting regulatory decision-making and pediatric device evaluation [10,17,18]. Together, ACTION-VAD illustrates how a multicenter registry embedded within a learning health system can translate harmonized definitions and collaborative improvement into measurable reductions in morbidity and improved survival for pediatric and congenital heart failure patients requiring mechanical circulatory support. Table 1 shows major disease-specific initiatives within the ACTION Network. Each program leverages a shared registry infrastructure while addressing unique clinical questions relevant to specific pediatric and congenital heart-failure populations.

Table 1: Population-specific programs within the ACTION network.

Program	Population	Participating Sites	Enrolled Subjects	Major Contributions
ACTION-VAD	Pediatric and congenital heart disease patients supported with ventricular assist devices	52	2265	Adverse-event standardization, neurologic event reduction initiatives, device evaluation, Industry partnership, and facilitating clinical trials
ACTION-HF	Pediatric and congenital heart failure without mechanical support	39	1084	Characterization of medical therapy patterns, care harmonization initiatives
ACTION-FON	Fontan circulation and single-ventricle heart failure	20	258	Standardized surveillance strategies and referral pathways
ACTION-MD	Duchenne, Becker, and related muscular dystrophy-associated cardiomyopathy	33	1437	Characterization of treatment variation and care standardization
Emerging Programs	Cardio-oncology and rare cardiomyopathies	Growing	Ongoing enrollment	Expansion into evolving heart-failure populations

Note: ACTION-VAD, ACTION-Ventricular Assist Devices; ACTION-HF, ACTION-Heart Failure; ACTION-FON, ACTION-Fontan; ACTION-MD, ACTION-Muscular Dystrophy.

6.2 ACTION–Heart Failure (ACTION-HF)

Beyond device therapy, ACTION has expanded to include a longitudinal heart failure registry capturing hospitalizations, medical therapy, and outcomes in patients managed without mechanical support. The ACTION-HF registry currently includes 1084 subjects enrolled across 39 participating sites, providing a broad view of contemporary medical management practices in pediatric and congenital heart failure [19,20]. Registry data have highlighted substantial variability in the use and titration of guideline-directed medical therapy across centers. These insights have informed the development of consensus-driven care pathways and educational initiatives aimed at standardizing therapy, with the goal of improving consistency in medication use and promoting earlier referral for advanced therapies in high-risk patients [21]. Key contributions of ACTION are shown in Table 2.

Table 2: Key contributions of ACTION to pediatric heart failure care.

Domain	Example Contributions
Quality Improvement	Reduction in neurologic complications during VAD support
Standardization	ACTION-ARC adverse-event definitions
Real-World Evidence	Multicenter analyses of pediatric heart failure populations
Device Evaluation	Post-market surveillance and device assessment
Clinical Research	Berlin Heart Active Driver trial
Education	Consensus pathways and care harmonization initiatives

Note: VAD, Ventricular Assist Devices; ACTION-ARC, The ACTION Academic Research Consortium.

6.3 ACTION-Fontan (ACTION-FON)

Patients with Fontan circulation experience substantial morbidity and limited evidence-based guidance for advanced heart-failure management [22]. ACTION-FON was developed to promote standardized surveillance, earlier recognition of Fontan failure, and timely referral for advanced heart-failure evaluation [23]. The initiative has demonstrated the feasibility of multicenter collaborative efforts to harmonize care in this high-risk population.

6.4 ACTION–Muscular Dystrophy (ACTION-MD)

ACTION-MD was established to characterize cardiomyopathy associated with Duchenne, Becker, and related muscular dystrophies. Registry analyses identified substantial variation in cardioprotective medication use across centers, leading to educational and care-harmonization initiatives that increased adoption of recommended therapies [24,25]. Collaboration with other ACTION programs has also improved understanding of advanced heart-failure therapies in this population [26].

Emerging initiatives in cardio-oncology and rare cardiomyopathies further extend ACTION's population-specific approach, leveraging shared infrastructure to address evolving clinical needs.

7 Pragmatic Research and Embedded Trials

ACTION increasingly serves as a platform for pragmatic research and prospective evaluation of therapies and devices. The registry supports post-market surveillance of VADs and embedded studies evaluating novel device components, such as the Berlin Heart EXCOR Active Driver [27]. The Active Driver investigational device exemption (IDE) trial was conducted across 15 ACTION-affiliated sites and enrolled 40 IDE subjects, all of whom reached the study outcomes endpoint. Following IDE completion, an additional 199 patients were enrolled under a Continued Access Protocol (CAP), with 185 subjects reaching the study outcomes endpoint, further demonstrating the network's capacity to support efficient trial execution and longitudinal follow-up. By integrating research activities into routine clinical data collection, ACTION reduces barriers to participation and enhances the generalizability of findings, particularly in populations traditionally excluded from randomized trials [28].

Although real-world data provide important opportunities to study rare and heterogeneous pediatric populations, observational analyses remain susceptible to confounding, selection bias, and differences in case mix across participating centers. ACTION studies therefore frequently employ risk-adjustment methodologies, multivariable modeling, propensity-based approaches, and sensitivity analyses when appropriate to strengthen causal inference. Importantly, ACTION is intended to complement rather than replace randomized clinical trials. By providing an established infrastructure for patient identification, data collection, and longitudinal follow-up, the network can facilitate both registry-based investigations and

prospective clinical trials, as demonstrated by the successful execution of the Berlin Heart EXCOR Active Driver trial.

8 Education, Technology, and Care Harmonization

Education and dissemination are central to ACTION's current activities. The network develops clinician-facing tools, consensus pathways, and patient- and family-centered educational materials informed directly by registry findings. These resources support shared decision-making and facilitate the spread of best practices across centers.

ACTION is also piloting innovative technologies, including wearable devices and implantable hemodynamic monitors, to improve outpatient surveillance and early detection of clinical deterioration. These efforts reflect a broader shift toward proactive disease management enabled by continuous data capture and feedback.

9 Scientific Output and Impact

The network's productivity is reflected in a growing body of peer-reviewed publications, multicenter registry analyses, and consensus statements addressing mechanical circulatory support, heart failure management, population-specific outcomes, and standardized adverse event definitions. To date, ACTION investigators have produced 61 published manuscripts and 92 accepted abstracts, underscoring the breadth of scholarly output generated by the network. Collectively, these outputs demonstrate that ACTION has progressed beyond a traditional registry to a learning health system in which data-driven insights lead directly to measurable improvements in care delivery and outcomes for children with heart failure.

10 Future Directions and Engagement in ACTION: Opportunities, Challenges, and Pathways to Participation

As ACTION matures from an initial VAD-focused collaborative into a comprehensive learning health system for pediatric heart failure, cardiomyopathy, CHD, and related populations, its future trajectory presents both substantial opportunities and important challenges. Central to this evolution is the network's ability to leverage high-quality real-world data to address persistent evidence gaps, support innovation, and expand meaningful participation across institutions and stakeholders.

10.1 Opportunities for Growth and Impact

A major opportunity for ACTION is the expansion of its learning health system infrastructure to additional pediatric and congenital cardiovascular populations. Building on established success in advanced heart-failure therapies, the network is increasingly positioned to support longitudinal studies of cardiomyopathy, Fontan circulation, neuromuscular disease–associated cardiomyopathy, cardio-oncology, and other emerging populations. The shared registry infrastructure provides a scalable platform for generating real-world evidence, harmonizing care practices, and identifying evidence gaps across diverse patient groups. Beyond device-related investigations, ACTION is well positioned to address important unanswered questions in pediatric and congenital heart-failure care, including optimization of medical therapy, timing of referral for advanced therapies, center-level practice variation, and long-term outcomes such as functional status, neurodevelopment, and quality of life. Integration of quality-improvement initiatives within the registry infrastructure enables iterative evaluation of care-harmonization strategies and their impact on patient outcomes. ACTION also provides an increasingly valuable platform for registry-embedded clinical trials and prospective investigations. Existing governance structures, contracting mechanisms, and data

infrastructure reduce barriers to study implementation and facilitate efficient enrollment and longitudinal follow-up. The successful execution of the Berlin Heart Active Driver trial demonstrated the feasibility of leveraging the ACTION infrastructure to support prospective pediatric cardiovascular research.

10.2 Challenges and Persistent Data Gaps

Despite these strengths, several challenges must be addressed to realize ACTION's full potential. First, as the network expands beyond VAD-supported patients, ensuring consistent data completeness and quality across diverse clinical domains will require ongoing investment in data definitions, training, and auditing. Pediatric heart failure is highly heterogeneous, making it challenging to capture disease-specific variables consistently across participating centers.

Second, important data gaps persist. These include limited representation of patients in low- and middle-income settings, incomplete longitudinal follow-up after transition to adult care, and relatively sparse patient-reported outcomes. Additionally, while ACTION has generated robust short- and intermediate-term outcome data, long-term morbidity, neurocognitive outcomes, and health care utilization beyond hospitalization remain less well characterized. Addressing these gaps will be critical to informing lifelong care strategies for children with chronic heart disease.

Sustainability is another challenge. Learning networks depend on continued engagement from clinicians, institutional support, and diversified funding streams. As ACTION grows, balancing academic productivity, quality improvement priorities, and regulatory-grade data collection will require careful alignment of incentives and transparent governance.

10.3 Pathways to Participation and Engagement

ACTION is intentionally structured to promote broad participation while maintaining data integrity and scientific rigor. Institutions interested in joining the network may enroll as participating centers, with engagement tailored to their clinical scope (e.g., VAD, heart failure, cardiomyopathy, CHD). Enrollment typically includes execution of a participation and data use agreement, business associate agreement, IRB approval of the ACTION umbrella protocol and patient consent, and annual dues of USD 4000/year (2026 rate).

Investigators seeking access to ACTION data may submit structured data requests for descriptive analyses, hypothesis-generating studies, or regulatory and quality improvement purposes. Requests are reviewed through established governance processes to ensure scientific merit, alignment with network priorities, and protection of patient confidentiality. Importantly, ACTION emphasizes collaborative scholarship, encouraging multicenter investigator teams and inclusive authorship models.

Beyond data contribution and analysis, participants may engage through leadership roles within disease-specific working groups, involvement in quality improvement initiatives, or collaboration on registry-embedded trials. Educational offerings, shared learning sessions, and dissemination of best practices further extend the network's impact beyond traditional research outputs.

11 Limitations

This narrative review has several limitations. As a narrative rather than a systematic review, it does not follow a formal search protocol or evidence grading, and topic selection reflects the authors' perspective. The ACTION Network, despite its impact, faces challenges, including ensuring consistent data completeness across diverse clinical domains. Important data gaps persist, including limited representation from low- and middle-income settings, incomplete longitudinal follow-up after transition to adult care, and sparse

patient-reported outcomes. The registry remains predominantly North American, limiting generalizability to other healthcare systems. Sustainability requires continued engagement and diversified funding. Finally, while ACTION employs risk-adjustment methodologies, causal inference from registry data remains subject to confounding and selection bias. Despite these limitations, ACTION represents a maturing and impactful model for collaborative pediatric cardiovascular research and improvement.

12 Conclusions

In aggregate, ACTION represents a maturing model for collaborative pediatric cardiovascular research and improvement, one that integrates data generation, clinical innovation, and stakeholder engagement. Continued success will depend on strategic expansion, thoughtful stewardship of data, and sustained participation from the pediatric heart failure and CHD communities. Through population-specific initiatives such as ACTION-VAD, ACTION-HF, ACTION-FON, and ACTION-MD, the network has generated real-world evidence, supported device evaluation, and advanced care standardization. By addressing existing gaps and lowering barriers to involvement, ACTION is well-positioned to shape the future evidence base for some of the most vulnerable patients in pediatric cardiology.

Acknowledgement: None.

Funding Statement: The authors received no specific funding for this study.

Author Contributions: The authors confirm their contributions to the paper as follows: Conceptualization and design of the review: Anusha Konduri, Toni Duganiero, Lauren Smyth, Shahnawaz Amdani, Angela Lorts, Sabrina Law, Jacqueline Lamour, Deipanjan Nandi, Aryaz Sheybani, Sarah Wilkens, Thomas Young, Mark Bleiweis and Jennifer Conway; writing—original draft preparation: Anusha Konduri; writing—review and editing: Anusha Konduri, Toni Duganiero, Lauren Smyth, Shahnawaz Amdani, Angela Lorts, Sabrina Law, Jacqueline Lamour, Deipanjan Nandi, Aryaz Sheybani, Sarah Wilkens, Thomas Young, Mark Bleiweis and Jennifer Conway; supervision: Anusha Konduri. All authors reviewed and approved the final version of the manuscript.

Availability of Data and Materials: Not applicable. This review article did not generate or analyze new datasets. All information discussed is derived from previously published literature and publicly available descriptions of the ACTION Network.

Ethics Approval: Not applicable. This review article does not involve human or animal subjects and does not require institutional review board approval.

Conflicts of Interest: The authors declare no conflicts of interest.

References

1. van der Linde D, Konings EE, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJ, et al. Birth prevalence of congenital heart disease worldwide: A systematic review and meta-analysis. J Am Coll Cardiol. 2011;58(21):2241–7. [CrossRef].
2. Reller MD, Strickland MJ, Riehle-Colarusso T, Mahle WT, Correa A. Prevalence of congenital heart defects in metropolitan *Atlanta*, 1998–2005. J Pediatr. 2008;153(6):807–13. [CrossRef].
3. Diller GP, Arvanitaki A, Opotowsky AR, Jenkins K, Moons P, Kempny A, et al. Lifespan perspective on congenital heart disease research: JACC state-of-the-art review. J Am Coll Cardiol. 2021;77(17):2219–35. [CrossRef].
4. Brida M, Lovrić D, Griselli M, Riesgo Gil F, Gatzoulis MA. Heart failure in adults with congenital heart disease. Int J Cardiol. 2022;357:39–45. [CrossRef].
5. Amdani S, Marino BS, Rossano J, Lopez R, Schold JD, Tang WHW. Burden of pediatric heart failure in the United States. J Am Coll Cardiol. 2022;79(19):1917–28. [CrossRef].

6. Blume ED, Kirsch R, Cousino MK, Walter JK, Steiner JM, Miller TA, et al. Palliative care across the life span for children with heart disease: A scientific statement from the American heart association. Circ Cardiovasc Qual Outcomes. 2023;16(2):e000114. [CrossRef].
7. Zafar F, Castleberry C, Khan MS, Mehta V, Bryant R, Lorts A, et al. Pediatric heart transplant waiting list mortality in the era of ventricular assist devices. J Heart Lung Transpl. 2015;34(1):82–8. [CrossRef].
8. Dipchand AI, Kirk R, Naftel DC, Pruitt E, Blume ED, Morrow R, et al. Ventricular assist device support as a bridge to transplantation in pediatric patients. J Am Coll Cardiol. 2018;72(4):402–15. [CrossRef].
9. Peng DM, Koehl DA, Cantor RS, McMillan KN, Barnes AP, McConnell PI, 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 Transpl. 2019;38(4):420–30. [CrossRef].
10. Adachi I, Peng DM, Hollander SA, Simpson KE, Davies RR, Jacobs JP, et al. Sixth annual pediatric interagency registry for mechanical circulatory support (pedimacs) report the society of thoracic surgeons pedimacs annual report. Ann Thorac Surg. 2023;115(5):1098–108. [CrossRef].
11. Amdani S, Lopez R, Schold JD, Tang WHW. 30- and 60-day readmission rates for children with heart failure in the United States. JACC Heart Fail. 2024;12(1):83–96. [CrossRef].
12. Nandi D, Lin KY, O'Connor MJ, Elci OU, Kim JJ, Decker JA, et al. Hospital charges for pediatric heart failure-related hospitalizations from 2000 to 2009. Pediatr Cardiol. 2016;37(3):512–8. [CrossRef].
13. Lorts A, Smyth L, Gajarski RJ, VanderPluym CJ, Mehegan M, Villa CR, et al. The creation of a pediatric health care learning network: The ACTION quality improvement collaborative. ASAIO J. 2020;66(4):441–6. [CrossRef].
14. Olsen L, Aisner D, McGinnis JM. The learning healthcare system: Workshop summary. Washington, DC, USA: National Academies Press; 2007. [CrossRef].
15. Lorts A, VanderPluym C, Adachi I, Perry T, Alexander PMA, Almond CS, et al. ACTION-ARC pediatric and adult congenital heart disease ventricular assist device adverse event definitions-2023. ASAIO J. 2024;70(11):911–9. [CrossRef].
16. Fraser CD Jr, Jaquiss RDB, Rosenthal DN, Humpl T, Canter CE, Blackstone EH, et al. Prospective trial of a pediatric ventricular assist device. N Engl J Med. 2012;367(6):532–41. [CrossRef].
17. Edelson JB, Raskin A, Absi M, Adachi I, Aljohani O, Alzubi A, et al. The ACTION VAD registry: A collective five-year experience. J Heart Lung Transpl. 2025;44(4):530–40. [CrossRef].
18. Mokshagundam D, Rosenthal DN, Smyth L, Lorts A. Bridging gaps in pediatric device development: The power of ACTION—A collaborative learning network. J Heart Lung Transpl. 2025;44(4):541–4. [CrossRef].
19. Butts R, Nandi D, Hong B, Ryan TD, Sublett-Smith J, Ahmed H, et al. Use of SGLT2 inhibitors in pediatric heart failure: A multi-center study. Pediatr Cardiol. 2025:1–8. [CrossRef].
20. Stidham J, Feingold B, Almond CS, Burstein DS, Krack P, Price JF, et al. Establishing baseline metrics of heart failure medication use in children: A collaborative effort from the ACTION network. Pediatr Cardiol. 2021;42(2):315–23. [CrossRef].
21. Nandi D, Wright LK, Sublett-Smith J, Brax A, Bansal N, Almond CS, et al. Suboptimal titration of heart failure medications in pediatric patients: Baseline data from ACTION. J Card Fail. 2025;31(4):741–5. [CrossRef].
22. Chen S, Shezad MF, Lorts A, McCormick AD, Mao CY, Simpson KE, et al. Outcomes after initial heart failure consultation in Fontan patients. Cardiol Young. 2024;34(5):989–96. [CrossRef].
23. Lubert AM, Cedars A, Almond CS, Amdani S, Conway J, Friedland-Little JM, et al. Considerations for advanced heart failure consultation in individuals with fontan circulation: Recommendations from ACTION. Circ Heart Fail. 2023;16(2):e010123. [CrossRef].
24. Wittlieb-Weber CA, Birnbaum BF, Castleberry CD, Cunningham TW, Esteso P, Gambetta KE, et al. Cardiac medication use in ACTION for Duchenne muscular dystrophy cardiomyopathy. Pediatr Cardiol. 2026;47(4):1439–50. [CrossRef].
25. Villa C, Auerbach SR, Bansal N, Birnbaum BF, Conway J, Esteso P, et al. Current practices in treating cardiomyopathy and heart failure in Duchenne muscular dystrophy (DMD): Understanding care practices in order to optimize DMD heart failure through ACTION. Pediatr Cardiol. 2022;43(5):977–85. [CrossRef].
26. Nandi D, Auerbach SR, Bansal N, Buchholz H, Conway J, Esteso P, et al. Initial multicenter experience with ventricular assist devices in children and young adults with muscular dystrophy: An ACTION registry analysis. J Heart Lung Transpl. 2023;42(2):246–54. [CrossRef].

27. Zafar F, Conway J, Bleiweis MS, Al-Aklabi M, Ameduri R, Barnes A, et al. Berlin Heart EXCOR and ACTION post-approval surveillance study report. J Heart Lung Transpl. 2021;40(4):251–9. [CrossRef].
28. O'Connor MJ, Shezad M, Ahmed H, Amdani S, Auerbach SR, Bearl DW, et al. Expanding use of the HeartMate 3 ventricular assist device in pediatric and adult patients within the Advanced Cardiac Therapies Improving Outcomes Network (ACTION). J Heart Lung Transpl. 2023;42(11):1546–56. [CrossRef].