

## Development of a Pediatric Cardiology Quality Improvement Collaborative: From Inception to Implementation. From the Joint Council on Congenital Heart Disease Quality Improvement Task Force

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### ABSTRACT

While clinical outcomes in pediatric cardiac disease have improved in recent years, marked institutional and individual cardiology practice variability exists. Quality improvement science has demonstrated that reducing process variation leads to more favorable outcomes, safer practices, cost savings, and improved operating efficiency. This report describes the process undertaken to develop the first collaborative quality improvement project of the Joint Council on Congenital Heart Disease. The project chosen aims to reduce mortality and improve the quality of life of infants with hypoplastic left heart syndrome during the interstage period between discharge from the Norwood procedure and admission for the bidirectional Glenn procedure. The objective of this special article is to inform the pediatric cardiology and cardiac surgery communities of the project to help ensure that the early work by the project pilot participants will spread to clinicians caring for children with cardiovascular disease. It is anticipated that this project will add to our understanding of care for this challenging group of children with hypoplastic left heart syndrome, identifying clinical care changes with the potential to lead to improvements in outcome. It will also introduce the field of pediatric cardiology to the science of collaborative quality improvement and assist in reducing clinical process variation and improving patient outcomes across centers. Finally, it will establish an ongoing network of pediatric cardiologists and their teams linked through a longitudinal data set and collaboration for improvement and research.

**Key Words.** Pediatric; Cardiac; Quality Improvement

### Introduction

Pediatric cardiology serves a growing patient population with rare cardiovascular disorders that manifest broad anatomical and physiological heterogeneity. Providers from many disciplines are often involved on the care team, and teams change membership based upon patient needs, skills of practitioners, and sequencing of diagnostic tests and interventions. The outcome of one care process is often inexorably linked with, and dependent upon, the outcomes of prior care processes. Robust scientific data to inform major care

decisions rarely exist in pediatric cardiology. For all of these reasons, rigorous studies of outcomes are difficult to undertake in this particular field of medicine.

While clinical outcomes in pediatric cardiology have improved dramatically in recent years, studies suggest that marked institutional and individual cardiology practice variability exists.<sup>1-3</sup> Quality improvement (QI) science, when applied to industry or health care, has demonstrated that reducing process variation results in more favorable outcomes, safer practices, cost savings, and

improved operating efficiency.<sup>4-8</sup> Standardization of health-care practices reduces process variation and provides a foundation on which new approaches can be tested more effectively. The more care is standardized (uniform), the more predictable are processes and outcomes of care, and the easier it is for studies of new interventions to detect significant improvements.

Clinical networks, using data for research and improvement, have provided a useful model to improve outcomes and generate new knowledge. Examples of such networks include the Northern New England Cardiovascular Disease Study Group,<sup>7,9</sup> the end-stage renal disease network, the Children's Oncology Group,<sup>10,11</sup> Vermont Oxford Neonatal Network,<sup>12</sup> the Cystic Fibrosis Foundation,<sup>13</sup> and the British National Health Service.<sup>14</sup> These networks have all used databases or registries of patients to achieve improved outcomes. Implementing a registry has been shown in multiple trials to be important in improving care for patients with chronic illness.<sup>15</sup> Such registries enable clinicians to track disease progress for individual patients over time and to assess their performance at the level of their population of patients. In pediatric cardiology and cardiac surgery, registries (e.g., Pediatric Heart Network, Society for Thoracic Surgery Registry, Mid-Atlantic Group of Interventional Cardiology Registry, Pediatric Cardiology Care Consortium, and Pediatric Electrophysiology Society Ablation Registry) have served to generate comparative data, and some have provided the ability to make changes within individual centers or disease processes; however, formal QI activity has not been a part of these registries. QI activities in the pediatric subspecialties, including pediatric cardiology, in part, are driven by the adoption of a new maintenance of certification requirements by the American Board of Pediatrics (ABP).<sup>16</sup> Maintenance of certification emphasizes ongoing assessment and documentation of performance, and participation in QI activities, as a requirement for ongoing certification.

In 2003, the Joint Council on Congenital Heart Disease (JCCHD) was formed as a leadership alliance to enhance communications and improve coordination among the various societies representing pediatric cardiologists, congenital heart surgeons, and adult congenital heart disease specialists (Table 1). Within this structure, goals expanded to include the development of a QI project to allow pediatric cardiologists to satisfy the ABP requirement for recertification utilizing

**Table 1.** The Inaugural Members (2003) of the Joint Council on Congenital Heart Disease and Their Representative Societies

Members	Society
Chairman David Sahn	American College of Cardiology
Robyn Barst	American Heart Association
Stephen Daniels	American Heart Association
William Davidson	International Society for Adult Congenital Cardiac Disease
Thomas Klitzner	American Academy of Pediatrics
John Kugler	American Board of Pediatrics
Gerard Martin	American Board of Pediatrics
Constantine Mavroudis	Congenital Heart Surgery Society
John Moore	American Academy of Pediatrics

a QI project focusing on care of a specific subgroup of infants and children with heart disease. In September 2006, a set of guiding principles was adopted that outlined the overall goals in some detail (Table 2). Through these efforts, the JCCHD initiated the Pediatric Cardiology National QI Collaborative. Its mission is to dramatically improve the outcomes of care for children with congenital heart disease through a national QI collaborative network of providers working together to collect longitudinal data and conduct QI research intended to accelerate the development and transition of new knowledge into practice. In addition, participating in the collaboratives was designed to meet Board requirements for maintenance of certification standards.<sup>16</sup>

This report describes the process undertaken to develop the first collaborative QI project of the JCCHD (Table 3). The objective of this special article is to inform the pediatric cardiology and cardiac surgery communities of the project to help ensure that the early work by the project pilot participants will lead to the participation of most, if not all, clinicians caring for children with cardiovascular disease. Furthermore, a discussion of the development process of the JCCHD QI Collaborative may help to inform and guide the development of similar clinical networks in other pediatric subspecialties.

### Project Development

In 2005, the JCCHD committed to develop the Pediatric Cardiology National QI Collaborative, and a task force was formed to lead the initiative (Table 4). With the encouragement of the ABP leadership, the guiding principles of the Institute

**Table 2.** The Joint Council on Congenital Heart Disease (JCCHD) National Quality Improvement (QI) Initiative Guiding Principles

1. The goal of the QI Initiative is to improve care and outcomes for children with cardiovascular disease.
2. The JCCHD will determine the major directions in the development of this QI initiative through its delegation to the QI Initiative Steering Committee. A strategy will be developed and implemented to facilitate communication about the initiative with the larger pediatric cardiology community.
3. The QI initiative, through multiple improvement projects, will address the spectrum of pediatric cardiovascular inpatient and outpatient care, including case finding, diagnosis, treatment, recovery, discharge, and follow-up (including handoffs). The initiative will begin with an initial well-focused project.
4. A national, multi-institutional database for the purpose of supporting QI projects will be a part of this initiative. Where related databases exist that may be beneficial to the QI initiative, they will be utilized to the extent possible.
5. The QI initiative will seek to involve all pediatric cardiology programs and practices, from small to large. We will make an effort to emphasize inclusion of all programs with pediatric cardiology fellowships because they are our future.
6. Quality improvement science, emphasizing the Model for Improvement, will be the preferred approach taken by these projects.
7. An emphasis will be placed on including patients, parents, and families in the design and implementation of projects. We will strive to be inclusive of diverse cultures and values.
8. The QI initiative will take a collegial approach to the involvement of important related specialties, including cardiothoracic surgery, pediatric critical care medicine, anesthesia, nursing, social work, and child life.

Adopted, September 18, 2006.

**Table 3.** The Joint Council on Congenital Heart Disease (JCCHD) Project Design and Development Timeline

Fall 2005:	JCCHD commitment and charters JCCHD quality improvement task force
January 2006:	Expert consensus meeting
April 2006:	Task force ownership/funding proposal submitted
Fall 2006–September 2007:	Design phase
	Monthly calls and meetings of task force
	Selection of topic and key drivers
	Parent and staff interviews
October 2007–May 2008	Development of measures
	Development of registry
	Initial pilot testing of measures
June 2008–August 2009	Pilot testing measures, registry, and strategies
	Selection of pilot teams from task force sites
	Testing of data entry and analysis
	Piloting and refining change strategies and tools
	Recruitment of additional sites
	Presentations at meetings
	Informational calls
	Support with institutional review board
	Prework: collection of baseline data
September 2009	First learning session

of Medicine and the Institute for Healthcare Improvement (IHI) were followed to provide structure to the process (see Table 2). As an initial step, an expert conference comprised of QI leadership experts, pediatric cardiologists, and representatives from pediatric critical care and cardiac surgery was held in January 2006 in Dallas. The expert group developed concepts for an improvement collaborative and a shared database for QI in pediatric cardiology; defined sufficient detail for the QI initiative to pursue funding; and generated buy-in, excitement, and ownership for the QI initiative within the JCCHD.

Criteria for the selection of an initial QI project were subsequently developed by the task force. It was deemed essential to choose a clinically important condition that (1) had potential for improvement; (2) involved most clinical subspecialists within pediatric cardiology, as well as those who practice outside of medical centers in which neonatal surgery is performed; (3) was under the purview of pediatric cardiology; (4) had clinical outcomes that are specific and measurable; and (5) was capable of generating enthusiasm.

Following the Dallas meeting, the task force submitted a successful proposal to the Children's Heart Association of Cincinnati, and received funding for project design and initial implementation activities. The task force engaged the Center for Health Care Quality at the Cincinnati Children's Hospital Medical Center (CCHMC) to provide QI design and implementation support for the project. The Center for Health Care Quality, a leader in improvement science and education for children's health,<sup>17–28</sup> has worked with the American Academy of Pediatrics and the ABP on multiple QI projects involving networks of practices.

In fall 2006, the task force began to conduct monthly conference calls and a series of face-to-face meetings. Initial major tasks included selecting a project focus, identifying the aim and key driver diagram, and drafting a written project charter. The key driver diagram, typically used in the design of a QI project, provides a graphic framework of the proposed aim, key factors necessary for improvement, and potential change strategies. The diagram is a means to identify and focus on the most important factors likely to impact the desired outcome. Database measures

**Table 4.** Members of the Joint Council on Congenital Heart Disease Quality Improvement Task Force

Lead Representative	Pediatric Cardiology Center
Dr. Robert Beekman	Cincinnati Children's Hospital Medical Center, Cincinnati, OH
Dr. Kathy Jenkins	Boston Children's Hospital, Boston, MA
Dr. Tom Klitzner	Mattel Children's Hospital at University of California Los Angeles, Los Angeles, CA
Dr. John Kugler	Children's Hospital & Medical Center, Omaha, NE
Dr. Gerard Martin	Children's National Medical Center, Washington, DC
Dr. Steven Neish	Texas Children's Hospital, Houston, TX
Dr. Geoffrey Rosenthal	Pediatrics Institute, Cleveland, OH

and the framework for an improvement effort were then developed and implemented.

#### *Rationale for the Initial Collaborative Project*

The task force chose to address a population of children whose clinical outcomes are clearly in need of improvement. The risk of mortality and morbidity for infants born with hypoplastic left heart syndrome (HLHS) is among the highest for pediatric cardiology and cardiac surgery patients. Even those who survive Norwood palliation, and are discharged home while awaiting their next surgery (interstage) of the bidirectional Glenn shunt (BDG), are at risk for poor outcomes, with mortality rates estimated at 10–15%.<sup>29</sup> Surviving infants experience significant morbidities, including poor feeding, chronic cyanosis, recurrent laryngeal or phrenic nerve injury, and delayed growth and development. This group often requires numerous unscheduled clinic visits and re-admissions to address these and other problems.<sup>30</sup> Thus, the interstage period for infants with HLHS presents children and families with major health-care challenges that provide an opportunity for caregivers to improve clinical processes and outcomes. Because this interstage is time-limited to approximately 4–6 months, the committee felt that it would be an ideal interval target for improvement efforts. Finally, the task force felt that it was likely that improved care processes identified through the study of children with HLHS would be generalizable to infants with other types of congenital heart disease.

Although the team at Children's Hospital of Wisconsin in Milwaukee has pioneered innovative aspects of care,<sup>31,32</sup> there are few additional data about clinical practice for infants with HLHS. Anecdotal evidence suggests that wide variation in clinical practice across centers appears to exist.<sup>31,33,34</sup> Furthermore, there are too few patients with HLHS at any one center to accumulate sufficient data to define optimal care. As with most guidelines, when new information about improv-

ing care for these children is available, its dissemination is usually slow and inefficient.

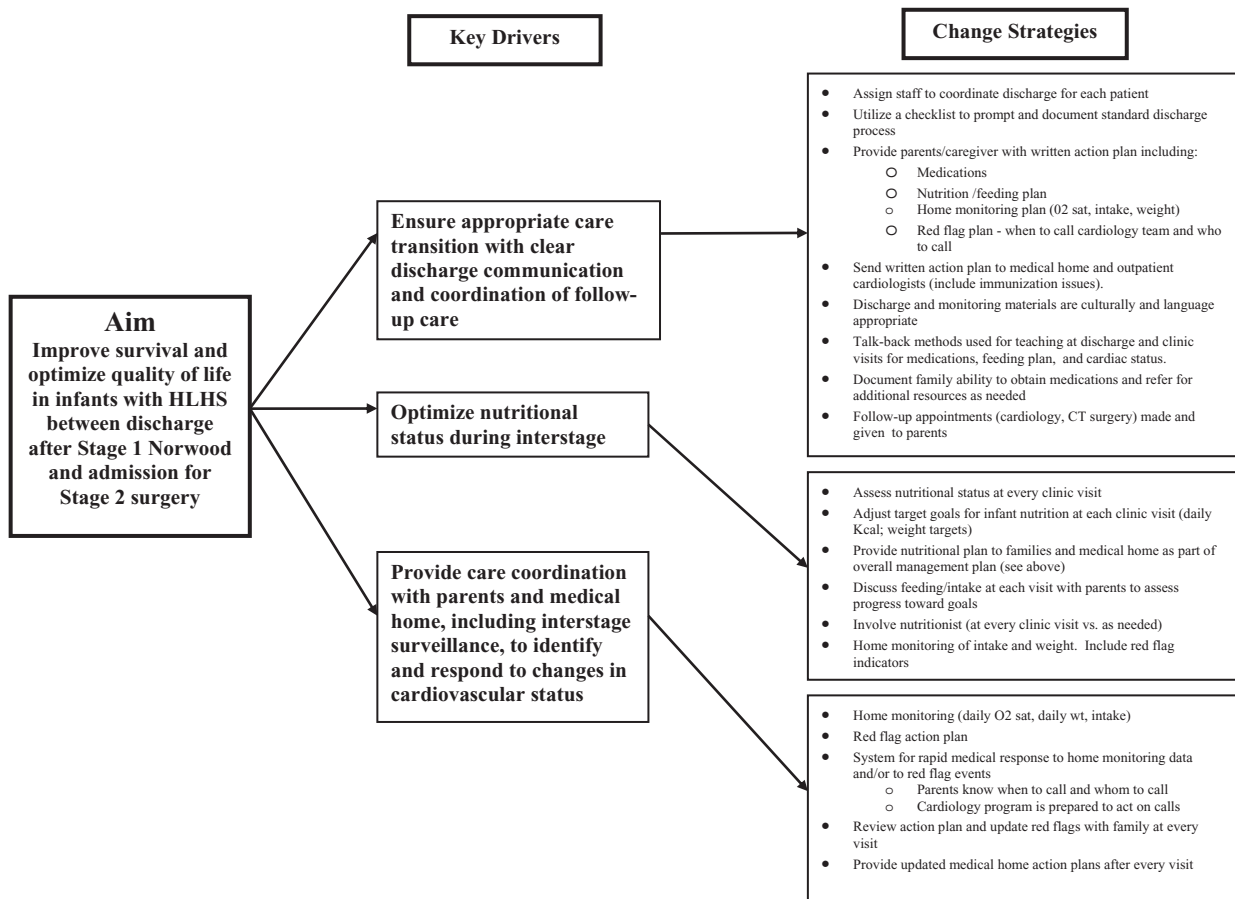
#### *The Aim and Key Drivers*

The JCCHD QI task force defined the project aim: "To reduce mortality and improve the quality of life of infants with HLHS during the interstage period between discharge from the Norwood and admission for the bidirectional Glenn procedure" (Figure 1). The task force then identified three "key drivers" or specific areas of focus that were determined to be necessary to achieve the goal of improved outcomes for these infants during the interstage period. These key drivers are the following:

1. Ensure appropriate care transitions with clear discharge communication, teaching, and coordination of follow-up care.
2. Optimize interstage nutritional status.
3. Provide care coordination with parents and medical home, including interstage surveillance, to identify and respond to changes in cardiovascular status.

#### **Ensuring Appropriate Care Transitions with Clear Discharge Communication and Follow-up Coordination**

Improving outcomes during care transitions is a priority identified by multiple national organizations focused on quality.<sup>35</sup> Multiple studies document the challenges involved in transitions of care and the lack of attention to the needs and concerns of family members. In a survey of parents of children with special health-care needs, only 31% reported having a written care plan for their child.<sup>36</sup> However, 86% believed such a plan was important and would improve the quality of health care their child receives in different settings, aid transitions between hospital and home, facilitate communications between parents and health-care professionals, and summarize health information such as medications, therapies, and treatments. Parents suggested that written care plans be



**Figure 1.** Key driver diagram. The key driver diagram, used in the design and implementation of a quality improvement project, provides a framework for the proposed aim, key factors (or drivers) necessary for improvement, and potential change strategies. The diagram is a means to identify and focus on the most important factors likely to impact the desired outcome. HLHS, hypoplastic left heart syndrome; CT, cardiothoracic; sat, saturation; wt, weight.

simple, brief, and flexible. It is also recognized that handoff communication at discharge to caregivers assuming responsibility for the subsequent outpatient care is often lacking. Data in chronically ill adult patients indicate that improved discharge communication and handoffs improve subsequent outpatient care and outcomes, and minimizes rehospitalizations.<sup>37</sup>

#### Ensuring Optimal Nutritional Status during the Interstage Period

Studies indicate that interstage nutritional management is variable and weight gain is poor in infants with HLHS.<sup>38</sup> Data from a retrospective review of 98 consecutive infants with a univentricular heart undergoing a BDG at CCHMC documented that weight gain prior to BDG is less than optimal for this group and that poor preoperative nutritional status negatively impacts short-term surgical outcomes.<sup>38</sup> Patients with lower

weight at admission for BDG had longer intensive care unit stays ( $P < .003$ ), longer ventilator times ( $P < .02$ ), longer chest tube durations ( $P < .003$ ), and had decreased likelihood of meeting clinical pathway discharge goals from both the intensive care unit ( $P < .04$ ) and the hospital ( $P < .004$ ).

#### Providing Care Coordination with Parents and Medical Home, with Emphasis on Interstage Surveillance to Identify and Respond to Changes in Cardiovascular Status

This component focuses on care coordination between the cardiology center and the infant's family and medical home to ensure continued emphasis of the strategies initiated at discharge and monitored during clinic visits.<sup>39,40</sup> A single-center report by Ghanayem et al. describing outpatient surveillance in 24 infants with HLHS after the Norwood surgery suggests that home monitoring of weight and oxygen saturation may

decrease interstage mortality.<sup>32</sup> Anecdotal evidence suggests that many institutions are adopting home surveillance or variations. There are no formal guidelines, however, specifying recommended interstage surveillance approaches.

No protocols or guidelines exist to specifically address any of the three key driver components that occur with an infant with HLHS who is discharged home after the Norwood operation. The clinical changes to be tested in each key driver domain were chosen based on existing literature and expert opinion. Additional “best practices” will be identified and tested through the collaborative process described below.

### Parents’ Perspectives

Using the framework of the IHI Curriculum on Partnering with Patients and Families to Accelerate Improvement program, a series of institutional review board-approved interviews with parents of young infants with HLHS were conducted to ensure that the initiative targeted issues that are important for parents. Parents were asked open-ended questions such as “What do you think parents need in order to provide their babies with the best possible care between their first and second surgeries?” and “If you were talking to another family who was taking their baby home, what would you tell them to look out for?” Parents were involved in refining the project aims, outcome measures, and probable testing strategies.

### Development of a Patient Registry and Database

The three key drivers were used to develop process measures and data variables; the outcome measures relate to mortality, morbidity, and growth. A selected sample of measures is listed in

Table 5. These clinical process measures may help identify changes in interstage care processes that lead to identified changes in patient outcomes.

Next, a registry database was created in REDCap, a Web-based database that permits secure data entry from remote clinical sites. The registry consists of seven data modules: Enrollment (including data regarding clinical status on presentation); Neonatal Surgery and Hospital Course; Discharge from Norwood Surgical Admission; Interstage Clinic Visits (scheduled and unscheduled); Interstage Re-admissions (scheduled and unscheduled); Bidirectional Glenn Surgery (capturing some data regarding Glenn outcome); and a Death Module. Where possible, data elements and definitions were aligned with the Society for Thoracic Surgeons’ nomenclature project.<sup>41,42</sup>

The task force attempted to balance the somewhat conflicting goals of creating a robust registry database with which to study current clinical processes and outcomes with the need for a more abbreviated set of measures to support improvement. In the end, a moderate-sized database was created, with anticipation that, by studying current care processes and outcomes at many centers, it will assist in identifying the best practices to test and spread within the collaborative. The data entry modules were tested and refined through several iterations by the clinical teams at the task force members’ centers.

### Methods: The Learning Collaborative Structure

#### Participating Teams

Teams from each of the seven task force members’ institutions will participate in an ongoing data collection and a learning collaborative. Teams

**Table 5.** Outcome Measures (Selected Examples)

Primary outcome measures	
Percent of patients who survive the interstage period from neonatal surgery to bidirectional Glenn	
Percent of infants > 10th percentile weight for age and weight for length at admission for Stage 2 surgery	
Care transitions, including discharge communication and coordination of follow-up care	
Percent of patients discharged with all component measures for hospital discharge process bundle (e.g., written list of medications, written expectations of care and “red flag” action plan, and written nutrition plan)	
Percent of patient families who receive a written list of medications including name, dose, and route of administration at discharge	
Percent of patients with documented communication to primary care clinician (e.g., medications, nutrition plan, and preventive care)	
Percent of patient families who receive a written nutrition plan at discharge	
Clinic visit process	
Percent of patients who have a nutritional assessment and classification at each visit	
Percent of patient families who receive an updated written list of medications including name, dose, and route of administration at each visit	
Care coordination, including surveillance strategies	
Percent of patients with various home surveillance strategies (e.g., home oximeter and scale, home oximeter only, and home scale only)	

from each center are comprised of a physician champion, nursing representative, administrative representative, discharge coordinator, and a nutritionist. Teams are encouraged to involve a parent or family representative. Additional teams have been invited to participate through an invitation circulated on the American Academy of Pediatrics Section on Cardiology and Cardiac Surgery list-serve, as well as through multiple presentations at pediatric cardiology meetings. In early 2009, the task force held a series of three informational teleconferences to provide information about this project to centers with potential interest; 42 different pediatric cardiology programs participated in these calls. Currently, at least 12 additional centers are in the process of obtaining their institutional review board approval to participate.

#### *Pilot Testing Data Collection Tools and Intervention Strategies*

A pilot test of the database and selected intervention strategies is being conducted by multidisciplinary teams from five of the seven pediatric cardiology centers represented by the task force.

The teams are utilizing the registry to collect patient data, participating in monthly conference calls and webinars, and providing feedback on practical tools and methods for implementing practice changes. Experts in care transitions, nutritional assessment, and surveillance will be invited to help review and refine the implementation strategies. Over a period of 6 months, it is expected that these teams will hone and improve the suggested tools and practice strategies for addressing the key drivers.

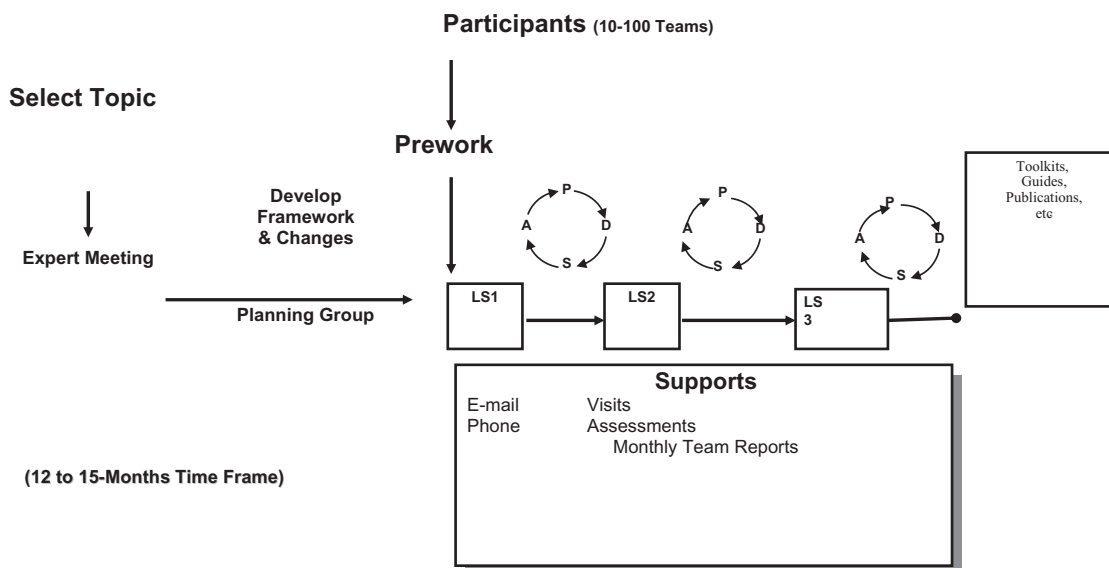
#### *A Learning Collaborative*

The pilot teams, as well as additional invited centers, will participate in a series of face-to-face workshops and webinars as part of a modified learning collaborative based on the IHI Breakthrough Series model (Figure 2).<sup>43</sup> The Breakthrough Series Collaborative model involves a 12-month longitudinal learning community that is based in improvement science theory and evidence about continuing education methods.<sup>5,44,45</sup> This model utilizes several 1 to 2-day learning sessions involving multidisciplinary clinical teams with



### IHI Breakthrough Series

An improvement method that relies on spread and adaptation of existing knowledge to multiple settings to accomplish a common aim



**Figure 2.** The Institute for Healthcare Improvement's (IHI) Breakthrough Series Model.<sup>43</sup> This multisite mode was developed over a decade ago and uses what is known from improvement science and continuing education. It will be used to provide a framework for testing and implementing the Joint Council on Congenital Heart Disease project changes. LS, learning session.

intervals known as Action Periods. Prior to the first workshop or learning session, teams will collect data about patient status and care processes. The first learning session will bring together expert faculty with members of all teams and also will include representatives from patient families. It will serve as a forum to share current knowledge about care transitions for children with complex illness, the interstage care of infants with HLHS, appropriate nutritional assessment, education in QI methods,<sup>46,47</sup> including instruction on the theory and practice of improving and tracking performance, and assistance to teams in planning and testing practice changes. Each learning session provides the teams with an opportunity to share information, report on their progress and what they have learned, and do some collaborative problem solving with their colleagues. The most critical part of each learning session is the time each team spends planning for real changes within its system, coached and facilitated by the experts in content and process.

During the intervals between learning sessions, project staff provide support to teams via monthly conference calls, the listserv, and individual coaching as needed. Teams are expected to collect data on patient status and care processes, post monthly reports of their progress, develop reports for senior leadership, and continuously test ideas using the Model for Improvement,<sup>46,47</sup> in order to move closer to their collaborative aims and goals.

#### **Data Collection and Analysis**

Visit-specific information at the individual patient level is entered into a secure electronic database (REDCap) using a Web-based interface. This information includes data regarding care processes as well as clinical data that are detailed and visit specific. These data are used to calculate values for process and outcome measures that were explicitly defined a priori. The results will be graphically displayed in the form of time series-run charts and statistical process control charts, as appropriate. Results will be reported (on a password-protected Web site) monthly for the collaborative (aggregate), and quarterly for each individual center. Results will be analyzed using accepted rules for time series-run and statistical process control chart interpretation.<sup>48</sup>

Careful handling of the data and descriptive analyses will precede all inferential analyses. A hierarchical mixed-modeling approach will be used as the data will be longitudinal and patients will be clustered within centers, resulting in cor-

related outcomes. The analysis described here will provide the preliminary information needed to estimate the expected magnitude of effect, the potential impact that could be anticipated in improvements in disease outcome from care standardization, the lag time between changes in care delivery and changes in outcomes, and the variation within and among centers. This information will be essential to estimate sample sizes required for future comparative studies as well as their design.

#### **Funding and Support**

In addition to funding provided by the Children's Heart Association of Cincinnati, additional infrastructure support is provided by the Pediatric Center for Education and Research in Therapeutics at CCHMC, funded by the Federal Agency for Healthcare Research and Quality. Costs of centers' team participation are the responsibility of each center.

#### **Implications and Expectations**

A national repository of clinical process and outcomes data related to the care of children with HLHS will enhance future QI and clinical research studies in pediatric cardiology. Detailed clinical databases will allow a more effective assessment of individual patients as well as new therapeutic and practice approaches, and the opportunity for enhanced dissemination, providing timely and optimal patient care. The collaborative network and improvement science approach will decrease the variability of clinical practice by standardizing care processes. Quality improvement activities will be broadly encouraged, standardized, and assessed, leading to better patient care and outcomes.<sup>49</sup>

In summary, this project will add to our understanding of care for children with HLHS, a population of children with an enormous mortality and morbidity burden currently, identifying clinical care changes that have the potential to lead to improvements in outcome. It involves families in the design and evaluation of clinical improvement efforts, and it will establish an ongoing network of pediatric cardiologists linked through a longitudinal data set and collaboration for improvement and research. The improved care processes identified in this effort are highly likely to be generalizable to infants with many other forms of congenital heart disease. By using the umbrella of the six Institute of Medicine aims for the

health-care system (safe, effective, efficient, timely, patient oriented, equitable) and the structure of the IHI Breakthrough Series for conducting the collaborative, significant progress toward successful achievement of our goals is expected.

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