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The National Pediatric Cardiology Quality Improvement Collaborative

By Robert H. Beekman, III, MD and Carole Lannon, MD, MPH

The Joint Council on Congenital Heart Disease (JCCHD) National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) held its first face-to-face Learning Session at Cincinnati

Children's Hospital on September 11th and 12th, 2009. Clinical teams from 29 pediatric cardiology programs (Table 1) came together with a shared goal of working together to improve care for infants with complex congenital heart disease. The 87 attendees of the Learning Session included parents, pediatric cardiologists, nurses and nurse practitioners, dietitians,

and other health professionals (Figure 1). They attended plenary sessions and breakout sessions, some led by parents and all focused on ways to improve clinical care processes and patient outcomes (Figure 2). The plenary talks included a moving presentation by Michael Katchman, parent of a son with a univentricular heart, and an enlightening discussion on medical



Figure 1. Michael Katchman, parent of a child with a uni-ventricular heart, addressing the Learning Session.

Table 1. Programs Attending Learning Session #1 September 11-12, 2009
Arizona Pediatric Cardiology Consultants
Arkansas Children's Hospital
Children's Hospital Boston
Children's Healthcare of Atlanta
Children's Hospital & Medical Center, Omaha
Children's Hospital Los Angeles - USC
Children's Hospital of Wisconsin
Children's Memorial Hospital
Children's National Medical Center
Cincinnati Children's Hospital Medical Center
Duke University Medical Center
Johns Hopkins University School of Medicine
Mayo Clinic - Rochester
Nationwide Children's Hospital
NYU Medical Center
Oklahoma Children's Heart Center
Oregon Health Sciences University
Pediatric Heart Institute at Vanderbilt Children's
Penn State Hershey Children's Hospital
Primary Children's Medical Center
Riley Hospital for Children
Seattle Children's Heart Center
Stanford Children's
Texas Children's Hospital
UC Davis Children's Hospital
UCLA - Mattel Children's Hospital
University of Chicago Comer Children's Hospital
University of Texas Health Science Center
University of Virginia Children's Hospital

home and care coordination for children with complex healthcare needs led by Chris J. Stille, MD (University of Massachusetts Medical School) and W. Carl Cooley, MD (Crotched Mountain Foundation, New Hampshire). An in-depth plenary talk on methods to optimize nutritional status of infants with complex heart disease was presented by Karen Uzark, RN, PhD (Cincinnati Children's Hospital). Nancy Rudd, MS, RN, CPNP-QC, Medical College of Wisconsin, led breakout sessions on interstage surveillance.



Figure 2. NPC-QIC Collaborative Director Divvie Powell, MSN, RN discusses the structure of the Learning Collaborative.

What is the NPC-QIC?

The JCHD National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) is a multi-center research and improvement network intended to improve care processes and outcomes for children with complex congenital heart disease.¹ The NPC-QIC is led by a taskforce of pediatric cardiologists (Table 2) working closely with the Center for Health Care Quality, which has a track record of success organizing other pediatric improvement networks.

In 2006 the NPC-QIC taskforce agreed on a set of Guiding Principles for the initiative (Table 3). Subsequently, the taskforce defined the key criteria for an initial improvement project:

1. clinically important;
2. potential for improvement;
3. under the purview of pediatric cardiology;
4. specific and measurable; and
5. generates enthusiasm in the field.

Using these criteria, the initial project selected by the taskforce is focused on improving the care of infants during the "interstage" period following a Norwood procedure.

The Initial Improvement Project

The Aim of the NPC-QIC initial project is:

"To improve survival and optimize quality of life for infants between discharge after stage I Norwood and admission for

bidirectional Glenn (i.e., during the "interstage" period)."

The project has two components:

1. A patient registry for clinical and population management, as well as research; and
2. A quality initiative focused on improving care and outcomes.

The Registry

The registry will capture data from participating pediatric cardiology centers on all infants in the "interstage" period after discharge from the Norwood or Norwood-variant procedure and prior to admission for the bidirectional Glenn shunt. Registry data are collected and managed using REDCap (Research Electronic Data Capture developed by Vanderbilt University) electronic data capture tools. Information on "interstage" clinical processes and outcomes for each infant is collected in seven data entry forms: enrollment; neonatal surgery and hospital course; discharge after Norwood; clinic visits; readmissions; Glenn surgery; death. This database is designed to provide robust information that will be valuable for both clinical research, population management and quality improvement projects.

The Quality Improvement Initiative

The project's quality improvement initiative aims to improve care and outcomes for infants with a Norwood procedure during the "interstage" period. Because there are

Table 2. Members of the JCCHD Quality Improvement Taskforce	
Dr. Robert Beekman	Cincinnati Children's Hospital Medical Center, Cincinnati, OH
Dr. Kathy Jenkins	Children's Hospital Boston, Boston, MA
Dr. Tom Klitzner	Mattel Children's Hospital at UCLA, 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	University of Maryland Hospital for Children

no formal published care guidelines for this population, the project team reviewed the medical literature, interviewed parents of these infants, considered expert (Task Force) consensus, and assessed variation to develop a Key Driver Diagram (Figure 3).

A key driver diagram is typically used in a quality improvement project to provide a framework for the proposed changes that focuses on the factors most likely to lead to the goal of improved outcomes for these infants.

The key drivers are:

- **Assuring Safe Care Transitions**
When an infant is discharged home after a Norwood, a number of important care transitions occur. The patient transitions from a highly technical inpatient environment to the home setting; responsibility for most aspects of care shifts from the inpatient team to the family, and a hand-off occurs from the pediatric cardiology subspecialist to a primary caregiver.
- **Optimizing Interstage Nutrition**
Infants with a Norwood procedure fail to grow normally during the interstage period, prior to the Glenn shunt. A recent retrospective study documented poor interstage weight gain in infants with a single ventricle prior to the Glenn, and demonstrated that infants with the poorest pre-op weight gain had worse early post-Glenn outcomes.²

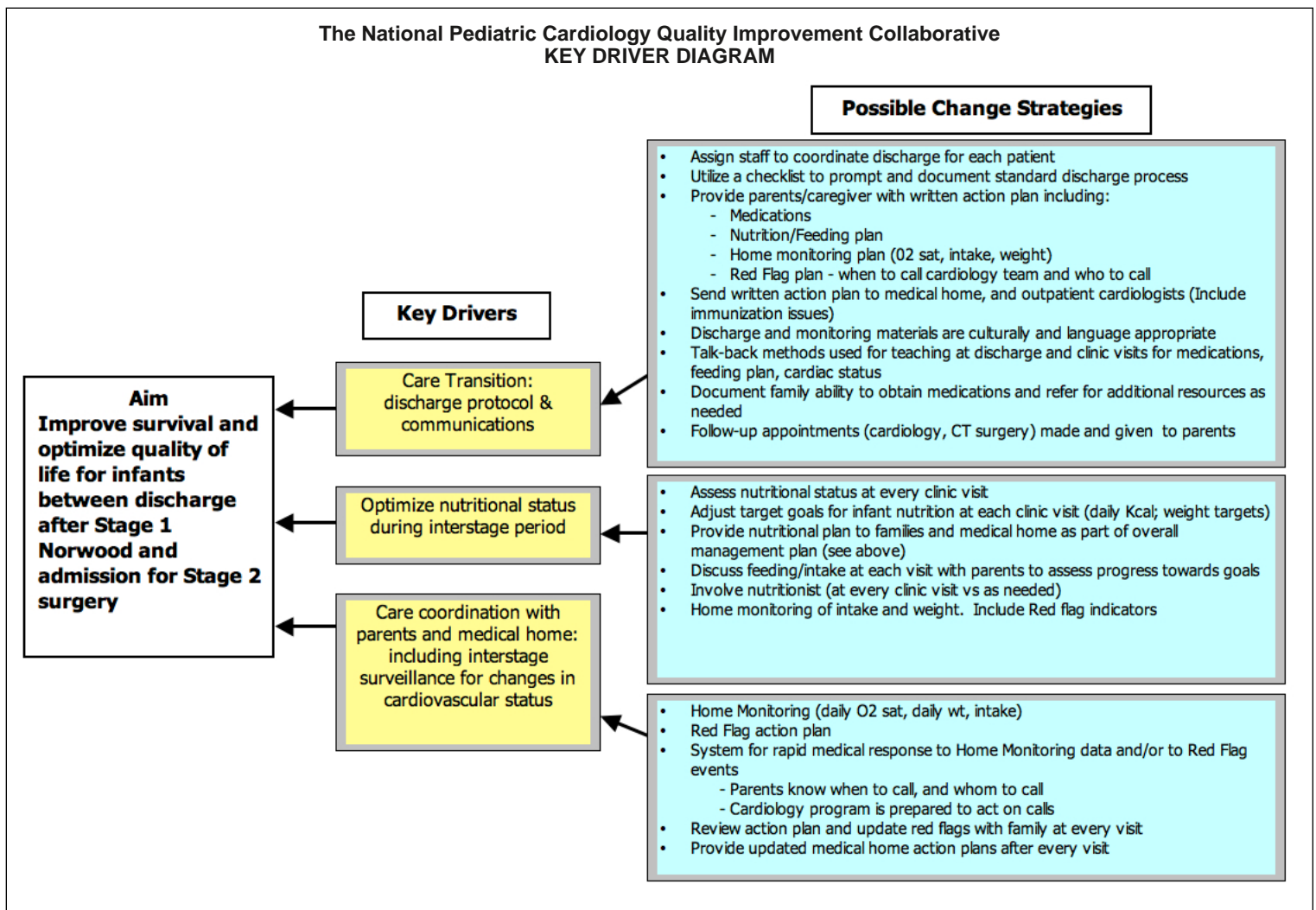


Figure 3. The Key Driver Diagram used to guide the NPC-QIC Quality Improvement efforts.

Table 3: JCCHD NATIONAL QUALITY IMPROVEMENT INITIATIVE

Guiding Principles

Adopted September 18, 2006

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 quality-improvement 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.

• *Facilitating Care Coordination with Parents and the Medical Home*

Interstage care for these infants is complex, with a clear need for improved care coordination among the families, cardiologists, primary care providers and the medical home.

Participating teams are engaging in a series of face-to-face workshops, webinars and a listserv as part of a modified learning collaborative based on the Institute for Healthcare Improvement Breakthrough Series Model. This model involves a 12-month longitudinal learning community that is based in improvement science theory and evidence about continuing education methods.

It is expected that additional useful clinical process changes will be identified through this collaborative network of cardiology

centers. Quality improvement control charts documenting clinical processes and patient outcomes will be provided to each center on a secure, password-protected site. These charts will display data from individual centers to enable them to track their improvements, and to allow comparison against aggregate collaborative data.

Benefits of this collaborative project are likely to extend well beyond the care of infants with a Norwood. It is expected that many of the clinical improvements identified during this project will be generalizable to the care of other infants and children with congenital heart disease. As an added bonus, NPC-QIC will allow cardiologists participating in this project to satisfy the American Board of Pediatrics Part 4 "Maintenance Of Certification" requirements.

References

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For more information about the JCCHD QI Collaborative, and to learn how your program can join, visit the website at:

www.jcchdqi.org

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