

National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)

About Us: NPC-QIC was founded in 2008 with a mission to decrease mortality and improve quality of life for infants with single ventricle congenital heart disease and their families. There are 69 participating cardiology care centers across the US, Canada, and the UK. NPC-QIC has close to 2,000 participants including physicians/researchers, team members (e.g., nursing, administrative and research), and parent/patients. NPC-QIC's registry has more than 5700 patients in its Phase I and Phase II registries. NPCQIC has reduced interstage mortality by 40%, identified a growth bundle and reduced growth failure by 30%, developed a risk score for interstage mortality, and significantly increased the use of a medication associated with survival. For more information: www.npcqic.org

Our Vision: Our vision is to dramatically improve the outcomes of care for children with cardiovascular disease.

Our Current Goals:

- Focus on Health Equity initiative in collaboration with other pediatric cardiology networks
- Spread project from 9 pilot centers to all 69 sites to reduce unplanned reinterventions post-surgery
- Support use of toolkits to improve quality of life outcomes: 1) oral feeding (pre-operative & tube weaning) and 2) gross motor development and assess impact on related outcome measures

Exciting Work: Using co-produced toolkits, the network aims to increase the % of infants who can eat cake at their first birthday (!) and increase the % of infants followed with a developmental plan. A workgroup will begin design to support infants from 1st birthday to Fontan surgery (at about 3-4 years).

Summary of Core Strategic Priorities:

Leadership & Project Teams: [Our Team — NPC-QIC \(npcqic.org\)](http://www.npcqic.org)

Network Structure (e.g., org chart):



Network Toolkits & Change Packages:

[Oral Feeds Prior to Stage 1 Surgery Toolkit](#)

[Optimizing Neurodevelopment & Supporting Infant Gross Motor Outcomes Toolkit](#)

[Access the Tube Weaning Toolkit](#)

[The NPC-QIC Updated Interstage Change Package](#)

Measures:

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Description of Data Repository (e.g., # patients, etc.):

- Data collection: REDCap
- # of patients enrolled: 3597

Funding Sources:

- Care Center Participation Fees

Publications: [Research Publications — NPC-QIC \(npcqic.org\)](https://npcqic.org/research-publications)

Additional resources you identify:

Site List/Geographic Spread:

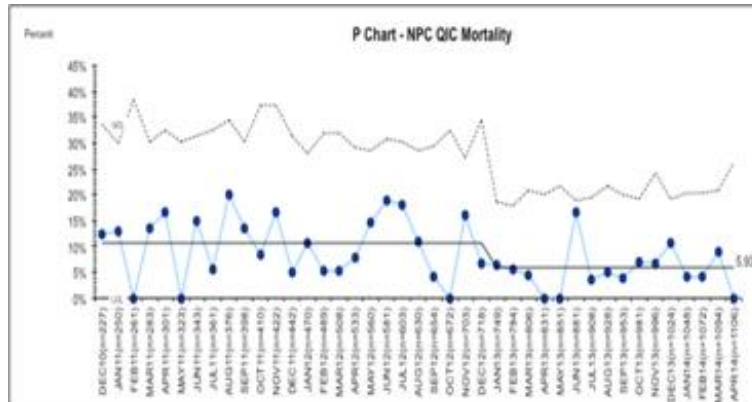
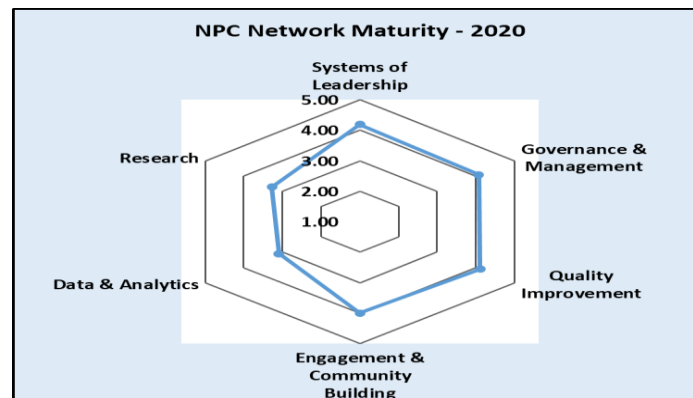
Advocate Children's Hospital
Akron Children's Hospital
Ann & Robert H. Lurie Children's Hospital of Chicago
Arkansas Children's Hospital
Arnold Palmer Hospital for Children
Boston Children's Hospital
Brigham & Women's Hospital
Children's Health of Dallas
Children's Healthcare of Atlanta - Emory University
Children's Hospital & Medical Center of Omaha
Children's Hospital New Orleans
Children's Hospital of Orange County
Children's Hospital of Philadelphia
Children's Hospital Colorado
Children's Hospitals and Clinics of Minnesota
Children's Mercy Kansas City
Children's National Medical Center
Children's Hospital Los Angeles
Children's of Mississippi
Cincinnati Children's Hospital Medical Center
Cleveland Clinic Children's
Cook Children's Medical Center
Children's Hospital of Wisconsin/Medical College of Wisconsin
Doernbecher Children's Hospital
Duke University Medical Center
Evelina London Children's Healthcare

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Inova Children's Hospital
Dell Children's Medical Center of Central Texas
Johns Hopkins All Children's Hospital
Kravis Children's Hospital at Mount Sinai
Le Bonheur Children's Hospital
Levine Children's
Maria Fareri Children's Hospital at WMCHealth
Monroe Carell Jr Children's Hospital at Vanderbilt
MonteFiore Medical Center
Intermountain Primary Children's Hospital
Nemours Alfred I. DuPont Hospital for Children
Nemours Children's Hospital
New York-Presbyterian Morgan Stanley Children's Hospital
Nicklaus Children's Hospital
Medical University of South Carolina
Norton Hospitals
NYU Langone Hospital- Long Island Children's Medical Center
Ochsner Clinic Foundation
Penn State Hershey Children's Hospital
Phoenix Children's Hospital
Primary Children's Cystic Fibrosis Center
Rady Children's Hospital - San Diego
Riley Hospital for Children at Indiana University Health
Nationwide Children's Hospital
SSM Health/Cardinal Glennon Children's Hospital
St. Louis Children's Hospital
Sutter Medical Center, Sacramento
Texas Children's Hospital
The Hospital for Sick Children
The MetroHealth System
UC Davis Children's Hospital
UCLA Mattel Children's Hospital
Seattle Children's Hospital
University of Florida Board of Trustees
University of Iowa Hospitals and Clinics
University of Maryland Children's Hospital
University of Michigan Health System
University of Pittsburgh
University of Rochester Medical Center - Golisano Children's Hospital

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University of Texas Health Science Center, San Antonio (UTHSCSA) at University Hospital
University of Virginia Children's Hospital
University of Wisconsin Hospitals and Clinics
University: The Governors of the University of Alberta
UPMC Children's Hospital of Pittsburgh
UH/Rainbow Babies & Children's Hospital



NPC-QIC reduced interstage mortality by 40%, significantly increasing the number of infants with hypoplastic left heart syndrome who survive to their second open heart surgery.