



**NPC-QIC Toolkit**

# Patient Management Strategies for Interstage Care

November 2022



**National Pediatric Cardiology**  
*Quality Improvement Collaborative*

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*“...The resources NPC-QIC have provided for interstage patients has been invaluable in advancing the care of our single ventricle patients. We were able to benefit from the hard work previously done by so many institutions. This collaborative effort has allowed us to quickly ramp up our interstage program to the standards of care these patients need and deserve.”*

**– Christine Dillingham, MN, APRN, CPNP-AC/PC, Dell Children’s**

# I. Introduction & Background

The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) launched in 2008 with an aim to reduce mortality and improve the quality of life (QOL) of infants with HLHS and their families during the interstage period. Initial collaborative-wide efforts focused on care centers and parent partners working together to improve care and outcomes during this interstage period. This change package summarizes the successful strategies that led to improved outcomes that have been sustained. This document outlines strategies for NPC-QIC clinicians, parents, and researchers to use as they begin or advance interstage quality improvement (QI) efforts. This change package can be helpful for those care centers wanting to reduce mortality and morbidity during the interstage, as an onboarding resource for new staff, and for those centers who want to review current practices. One of the important lessons highlighted in the NPC-QIC Interstage work was the importance of the clinical team working together to change care and outcomes, e.g. cardiologists, nurse practitioners, nurses, dietitians, social workers, psychologists, primary care clinicians, parents, and family members. It truly “takes a village” to care for these infants.

Of note, more recent NPC-QIC efforts have expanded the timeline of care for infants undergoing staged interventions for management of HLHS from time of diagnosis through first year of life. Several resources are available at <https://www.npcqic.org>.

## **What is a Change Package?**

A change package is a concise and practical document that includes ideas and inspiration for teams seeking to apply QI methods to increasing the effectiveness and efficiency of their care processes and outcomes. Change packages focus on a specific condition, care process, or health system feature and generally include background material; a summary of evidence or best practices; and specific tools, strategies, and examples that can be applied to improvement work.

## **How Was This Change Package Developed?**

This change package was inspired by improvement efforts across NPC-QIC centers and grounded in research completed using the NPC-QIC database. QI approaches, tools, and resources included in this change package have been developed or tested by NPC-QIC centers.

## What is in this Change Package?

This change package is comprised of five sections:

### Section 1 | Introduction and Background

This section provides a general overview of the interstage, quality improvement, and the purpose of a change package.

### Section 2 | Interstage Key Driver Diagram

This section provides a depiction of the NPC-QIC Key Driver Diagram that shows the theory behind the collaborative's improvement efforts.

### Section 3 | Change Strategies and Examples of Changes to Test

This section includes a discussion of change strategies to guide your interstage improvement work and specific examples of changes to test.

### Section 4 | Measures

This section outlines the key care process and outcome measures that NPC-QIC uses to assess our performance and improvement for the interstage period.

### Section 5 | Phase II Learnings to Date

This section provides an overview of NPC's phase II quality improvement learnings to date.

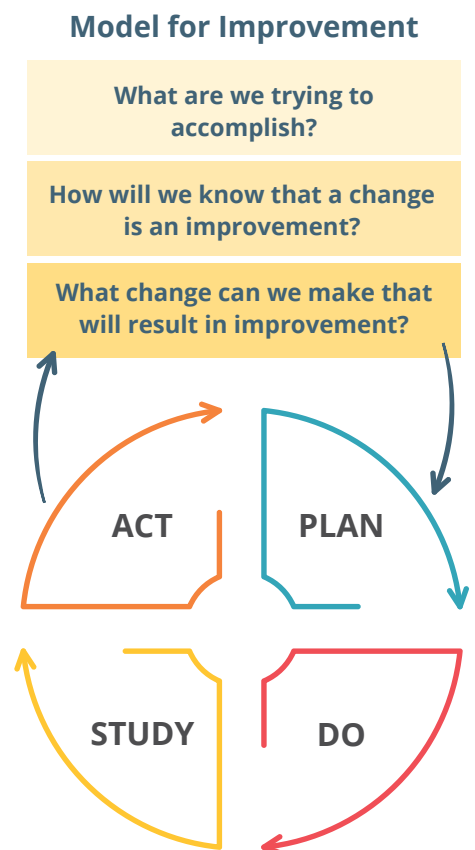
## Quality Improvement Method

The work of quality improvement teams participating in NPC-QIC is guided by the Model for Improvement.<sup>(2)</sup> The Model asks three key questions as teams test changes in care processes: What are we trying to accomplish? How will we know that a change is an improvement? What changes can we make that will result in improvement?

The final element is the Plan-Do-Study-Act (PDSA) cycle in which a change to be tested or implemented is planned and carried out, outcomes are monitored and analyzed, and then, based on the lessons learned, the change is fully implemented or the next change cycle is planned.

A brief video that reviews the model for improvement is available here. NPC-QIC quality improvement teams use a [PDSA Worksheet](#) to plan and track their tests of changes.

The "interstage" period is most commonly considered the time, typically 3–6 months, between the Norwood surgical procedure (S1P) and the second surgical operation, the Glenn palliation. Quality improvement efforts by NPC-QIC during Phase I focused entirely on this interstage period. There were three primary aims established that served as the foundation whereupon strategies were tested, adapted, and adopted; targeting the established key drivers of change. The three primary aims were (1) decreasing mortality during the interstage, (2) decreasing readmissions from serious events, and (3) improving nutrition and growth.



Stage 1 palliation (S1P) management of infants with HLHS and variants traditionally consists of a Norwood surgical palliation (with systemic-to-pulmonary artery shunt or Sano shunt) or a combination catheter and surgical hybrid approach, both with the goal of achieving unrestricted systemic output, unrestricted pulmonary venous return, and controlled pulmonary blood flow. Over the next several (3–6) months, the infant enters the interstage period, historically a time of high risk for these infants. A second stage surgical palliation (S2P) then is performed with a Glenn anastomosis or comprehensive S2P palliation (for hybrid pathways). Some centers choose to perform an intermediary Hybrid approach initially followed by subsequent surgical Norwood palliation weeks later for infants with additional high-risk features such as prematurity or low birth weight. Some centers have chosen to perform an entirely catheter-based intervention that includes placement of branch pulmonary artery flow restrictors thus avoiding need for a surgical sternotomy during the initial procedure.

### **Decreasing Mortality During Interstage**

During the interstage period, these children are medically fragile and at risk for serious health problems, including heart failure, difficulty feeding, poor growth, and neurodevelopmental concerns. Parents must carefully monitor their child for clinical changes, check weight and blood oxygen levels, and give them multiple medications daily. These children may need home tube feedings and special formulas or calorie fortification, have frequent outpatient office visits and require hospital readmissions with potential need for intervention. Some are not discharged from the hospital between staged palliative procedures.

Preventing interstage mortality remains an important focus of our improvement work for interstage patients. Over the past 10+ years, interstage mortality declined in centers participating in interstage-focused improvement initiative during Phase I of NPC-QIC. Through our improvement work together in NPC-QIC we have seen a sustained reduction in interstage mortality from 10% to ~5% (11). The drivers behind this reduction in interstage mortality are no doubt multiple but include process improvements around discharge, communication, home monitoring, and readmissions. Also contributing to this are improved understanding of risk factors for interstage mortality, some of which are modifiable.

### **Digoxin in the Interstage Patient**

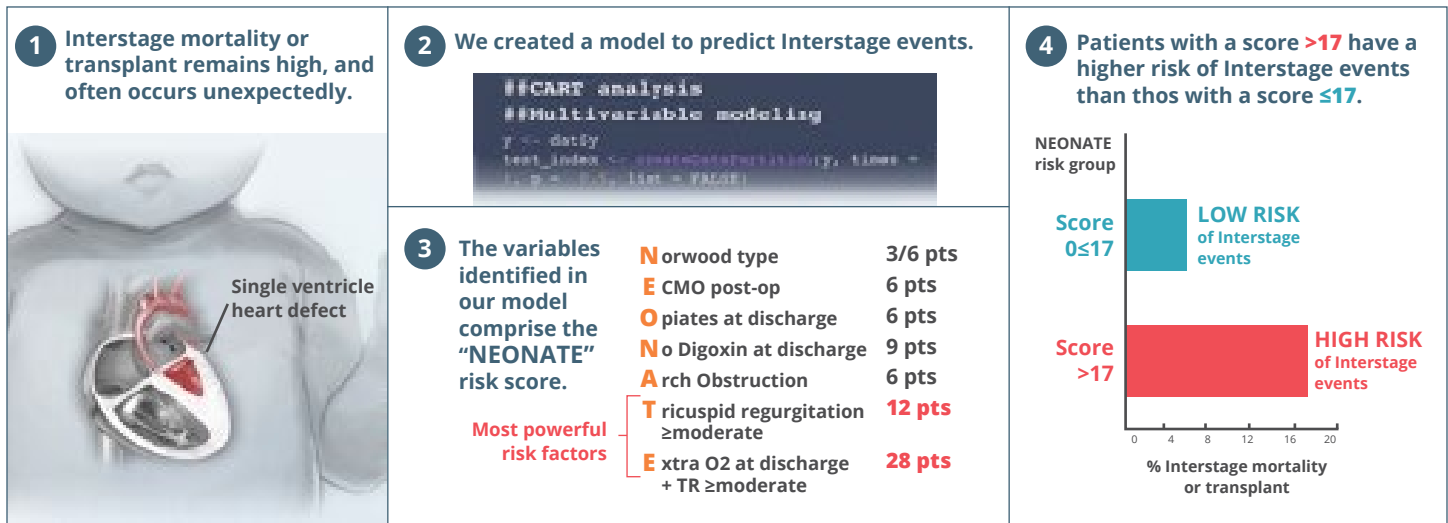
The association of digoxin use with reduced interstage mortality was first demonstrated from a study in the NPC-QIC Phase I database, which found that those on digoxin had an 8-fold reduced risk of interstage mortality (12). This finding was confirmed by investigators in a separate database from the Pediatric Heart Network Single Ventricle Reconstruction Trial (13). Subsequent, as yet unpublished research from NPC-QIC has confirmed this finding in the NPCQIC Phase II database as well. While the precise mechanism by which digoxin may be associated with improved interstage survival has not yet been elucidated, many centers are using digoxin for their interstage patients, with a baseline use of 25% of patients on digoxin prior to these publications to over 60% in recent entries to the NPC-QIC database.

### **The NEONATE Score – Evaluating Interstage Risk**

The “NEONATE” score was developed by investigators using the NPC-QIC Phase I database to help risk stratify patients at the time of initial hospital discharge to reduce interstage mortality. The score was derived from modeling performed on a learning cohort of patients in the Phase I NPC-QIC database and was tested internally with a separate validation cohort. The NEONATE risk stratification tool allocated points at the time of S1P discharge based on anatomic, surgical, and discharge characteristics. See Figure 1.1 for an explanation of variables identified in the NEONATE risk score. A NEONATE score of  $\leq 17$  points as a cutoff to define patients as “low risk” predicted freedom from interstage mortality with good specificity (10). While centers may use the NEONATE score differently,

it is important to recognize that some factors associated with interstage mortality in this risk score are modifiable: treating patients with digoxin, avoiding discharge on opiate medications, avoiding discharge with significant tricuspid regurgitation especially on oxygen. While certainly not simple, tricuspid regurgitation in the single ventricle patient presents an important target for future endeavors to further decrease interstage mortality. This could be achieved by a multi-pronged approach that includes innovations in neonatal valve repair, earlier referral to advanced heart failure and transplant evaluation, and/or reconsideration of the safety of discharging these patients prior to the second stage operation.

**Figure 1.1 NEONATE Risk Score**  
**Predicting Interstage Death or Transplant**



Source: Ahmed, H et al, "Development of a validated risk score for interstage death or transplant after Stage 1 palliation for single ventricle heart disease". Journal of Thoracic and Cardiovascular Surgery.

### Decreasing Hospital Readmissions

In addition to decreasing mortality in the interstage, efforts were made to decrease hospital readmissions due to major serious events. Several key drivers were utilized for this all centering on communication. Much attention was directed to standardization of the discharge process with effective care transitions, parental education and support, close home monitoring, follow-up clinic opportunities, and reinforcing red flag action plans with the parents and medical home at all touch points. There was an emphasis placed on transparency and attention to details such that when a red flag was perceived, action was taken by the parent and medical team prior to a serious medical event occurring.

### Improving Nutrition and Growth

Prior to the initiation of Phase I, growth failure within the postoperative Norwood patients was common place (and at times felt to be part of their natural history). With coordinated and standardization of efforts within the network, some of the initial victories were focused on improvement strategies to decrease growth failures during the interstage culminating in a "Growth Bundle" with recommendations published by the NPC-QIC Feeding Working Group (7). There was a relative reduction in growth failures of 28.4% during Phase I.

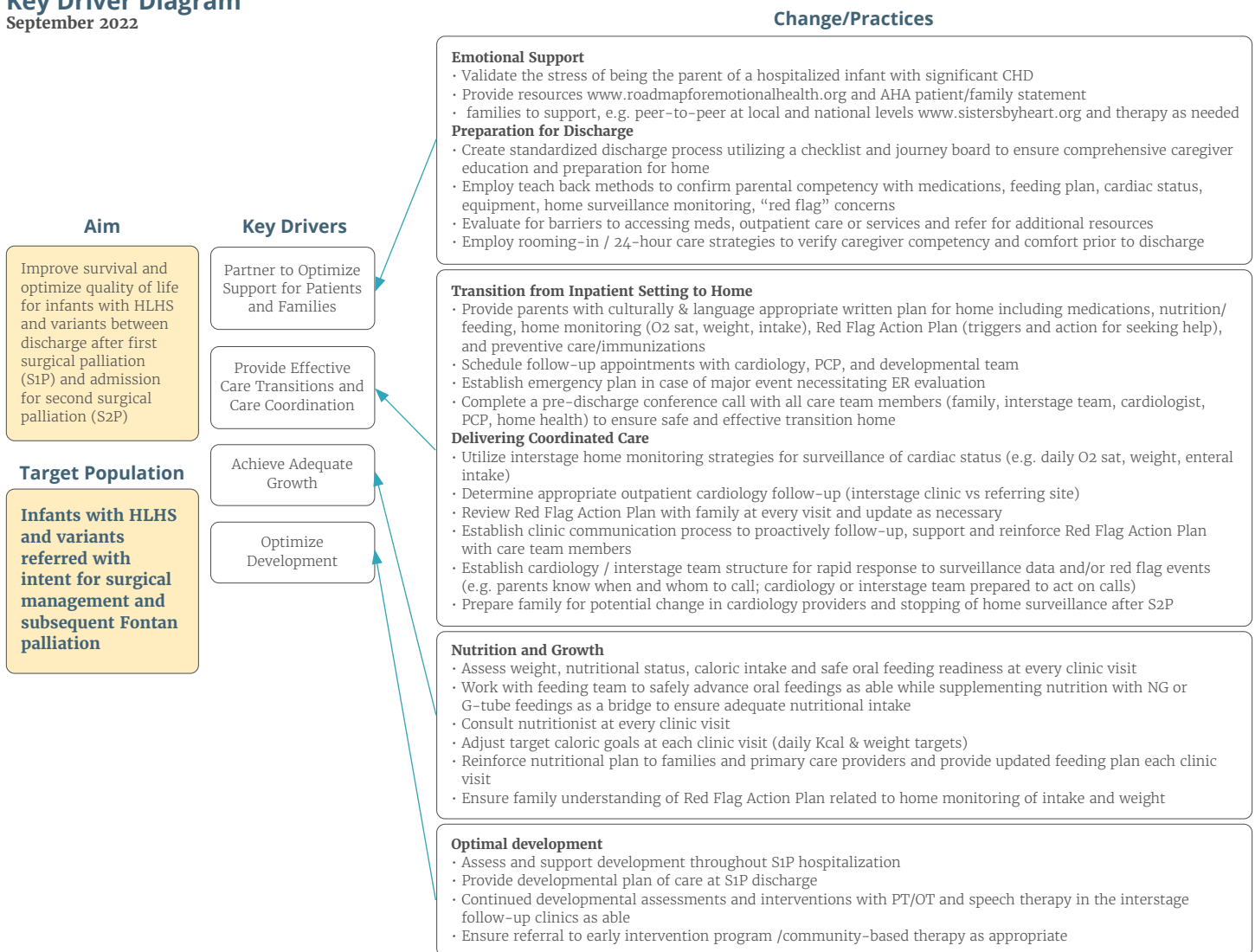
## II. Interstage Key Driver Diagram

A Key Driver Diagram is a visual depiction of the theory behind an improvement effort—a roadmap of sorts. It illustrates the linkages between an overall aim (in this case, improving survival, neurodevelopment, and patient/family support), key drivers (the conditions that need to be in place for you to achieve your aim), and the interventions that can help you get there (changes like those included in this change package).

The current NPC-QIC key driver diagram for the interstage period is depicted on the next page. Evidence (literature, where available) and expert opinion were used to identify clinical practices expected to be related to improvement in NPC-QIC aims. These care processes are grouped into four domains or key drivers: 1) partner to optimize support for patients and families; 2) provide effective care transitions and care coordination; 3) achieving adequate growth; and 4) optimizing development. Over time, the collaborative will likely identify additional drivers and interventions that will lead to improvement.

If you would like additional information on creating and using key driver diagrams, a tutorial is available [here](#), and you can view a short [video](#) on the purpose and value of a driver diagram.

### Key Driver Diagram September 2022



## III. Change Strategies & Examples of Changes to Test

### Change Strategies

Change strategies are “big ideas” for the kinds of actions that are likely to yield improvement. These change strategies will help focus your team on what matters most for interstage care, but it’s up to you to determine the specific ideas to test that will have the most impact for your care center and patient population.

### From Change Strategies to Concrete Ideas to Test at Your Care Center

Starting on the next page are specific examples of strategies to test as you work to improve interstage care. These ideas and examples are organized around each of the key drivers outlined above.

**A Change Strategy** is a general notion or approach to change found to be useful in developing specific ideas that lead to improvement.

<http://www.ihl.org/resources/Pages/Changes/UsingChangeConceptsforImprovement.aspx>





## Partner to Optimize Support for Patients & Families

NPC-QIC encourages care centers to partner with parents and engage them in center improvement efforts. <https://www.npcqic.org/get-involved-families>

In 2022, NPC-QIC is launching a Community Building and Engagement effort which will support teams and parents' involvement in various network activities.

Support for patients and families in the interstage period comes from members of the care team, and from other families who have children with HLHS. Many resources exist that have been developed by parents for parents who are in the interstage period.

### RESOURCES

NPC-QIC's **Single Ventricle Journey: A Guide for Parents and Families**. Co-developed by parents and clinicians, the purpose of the Guide is to offer support, information, and resources to families from birth to Fontan and beyond with HLHS.

NPC-QIC's **Parent's Guide to HLHS**. Co-developed by parents and clinicians and are in the format of a bulletin of different topics during from prenatal diagnosis through Fontan. Available in English and Spanish.

**Sisters by Heart** – providing support, education and empowerment patients and families affected by HLHS. Available in English and Spanish.

**Linked by Heart** – provides regional and local support and resources to families affected by HLHS

**Conquering CHD's Talk to Your Care Team: Guided Questions Tool**. Available in English and Spanish.

**The Roadmap Project** – Proactive support form clinical teams to foster emotional health.

**Ollie Hinkle Heart Foundation** – Supporting free mental health services for heart families. Interested families can check to see if these services are available.

Scientific Statement from the American Heart Association on **“Psychological Aspects of Living with Congenital Heart Disease: Information for Parents and Families”**.

*“People gravitate toward peer support because of its humanizing effect on our challenging health care system. And we love that it provides that personal connection to better understand physical and emotional impacts of chronic illness and it is 100% patient-centered . . . peer-to-peer supports looks different for everyone, but that feeling of validation and understanding by someone who has walked in your shoes—we learn from each other and gain tools to live healthier lives as parents, patients, and siblings.”*

**– Stacey Lihn, President, Sisters by Heart**

## Provide Effective Care Transitions & Care Coordination

Engagement of care team members and families is needed for a coordinated, effective, and safe transition from hospital to home.

Parent/caregiver education and preparation for home should begin early in the inpatient hospitalization allowing time for caregivers to become competent and confident in the home monitoring duties.

Checklists for the care team and planning tools for parents can facilitate pre-discharge preparation and education.

A period of extended care or rooming-in by parents, typically 24–48 hours, during which they perform home cares is an established practice for promoting successful transition to home.

A list of concerns or “red flags” clearly outlined for the family is a key component to interstage surveillance.

A Red Flag Action Plan is list of concerns or red flags clearly outlined for the family and is a key component to interstage surveillance. This plan provides the family specific criteria to watch for (e.g., feeding or breathing problems, worsening cyanosis, poor weight gain, fever or parental concern) as well as how to contact their interstage team if these flags occur.

### RESOURCES

NPC-QIC’s **transition bundle** of 11 key activities for effective transition from inpatient to interstage care

**Resource** for management of hospitalized interstage patient working towards discharge from Evelina London Children’s Hospital

**Teach back** to confirm parents’ understanding of information

List of top **10 ways** hospitals can prepare parents for the interstage developed by Sisters by Heart

**Discharge Preparation and Education Checklist** Table 2 from the AHA Scientific Statement on Interstage Home Monitoring for Infants with Single Ventricle Heart Disease

**Journeyboard** (in English) created by Phoenix Children’s Hospital along with additional example from **Nationwide Children’s**

**Sample of content** covered during 24-hour care preparation for discharge.

**Red Flag Action Plan Template** designed by NPC-QIC teams and parents

**Red Flag Action Plan** from Duke Children’s Hospital & Health Center

**Spanish translation** of their Red Flag Action Plan from Boston Children’s Hospital

**Wallet card** from Children’s Healthcare of Atlanta with Red Flags on one side and information for PCPs or emergency physicians on the other

## Provide Effective Care Transitions & Care Coordination

Building a supportive network is invaluable in managing the various needs of the interstage infant. This network includes parents, cardiology and interstage team providers, dietitians, primary care provider / medical home, home health services, and outpatient therapists.

NPC-QIC recommends a conference call prior to discharge to review interstage care goals and facilitate open communication. Call participants should include parents, discharging care team, outpatient primary care provider, and local cardiologists.

Many NPC-QIC centers share management guidelines with local emergency medical personnel to facilitate timely care delivery in the event of physiologic instability that include recommendations such as rapid transport to referral center, appropriate use of oxygen, and immediate contact with interstage cardiac providers.

Ongoing communication between the interstage cardiology team and local providers can ensure timely evaluation and management of any interstage concerns.

Key components of care during the Interstage include:

- Interstage surveillance of the child's CV status including O<sub>2</sub> saturation monitoring, daily weight, and assessment and documentation of caloric intake (9)
- Reviewing medications and red flags with family & care team at every visit
- Establishing a system for rapid medical response to red flag events

### RESOURCES

Cardiac **shunt-dependent patient discharge instructions** from Children's Healthcare of Atlanta

Hospital **discharge conference call checklist** from Nationwide Children's Hospital

Template **letter for communication** from the discharging hospital to the PCP from Nicklaus Children's Hospital

Introduction to **single ventricle physiology for PCPs** from Lucille Packard Children's Hospital

**Discharge Communication to Health Care Providers Checklist**, Table 3 from the AHA Scientific Statement on Interstage Home Monitoring for Infants with Single Ventricle Heart Disease

**Telephone Triage Plan** when parents call with a potential red flag at Children's National Medical Center

Children's Wisconsin Hospital provides families with a **home monitoring binder** for data recording and tracking

Daily **home monitoring worksheet** from University of Iowa Children's Hospital

How families should **contact the care team during the interstage period** from Lurie Children's Hospital (Spanish)

**Use of Telemedicine Virtual Visits** during interstage to optimize virtual care during the interstage from Children's Hospital of Philadelphia

Examples of digital home monitoring platforms/ applications include **Locus Health** and **CHAMP**

## Achieve Optimal Oral Feeding & Adequate Growth

Infants with congenital heart disease (CHD) are at risk for poor nutrition and growth. Inadequate nutrition has been associated with increased hospital length of stay and mortality following cardiac surgery in children. (3-5) NPC-QIC Phase I efforts identified a “growth bundle” of clinical processes that are associated with improved infant growth during the interstage (6). These nutritional processes were common to NPC-QIC centers reporting positive infant weight gain during the Interstage period:

- Using a standard post-Norwood feeding evaluation.
- Use of a home scale for Interstage weight monitoring.
- Specific weight gain/loss “red flags” to identify patients with growth failure in the interstage.
- Regular phone contact with families during the Interstage regarding nutrition and growth.
- Having a dietitian available for each cardiology outpatient visit during the interstage

During Phase I of NPC-QIC, a Feeding Work Group was convened to identify helpful nutritional practices in order to improve growth in this high-risk population. Their 2013 published guideline outlines evidence-based feeding and nutrition practices during the pre-Norwood, post-Norwood, and interstage phases.



*“I continue to be amazed at the advances in nutritional care of our single ventricles over the last 10 years. Not only have we reduced interstage mortality but these children continue to grow and thrive during the interstage. Growth failure has been reduced to <15% (per NPC research) during the interstage. Additionally, more efforts are being made to increase their oral feeding during interstage with a goal to wean off their feeding tube by first birthday.”*

**– Megan Horsley, Dietitian, Cincinnati Children’s Hospital**

## Achieve Optimal Oral Feeding & Adequate Growth

Achieving adequate interstage growth begins with ensuring that parents are prepared, competent and comfortable with growth-related activities including oral or tube feedings, fortification of breast milk or formula (if necessary) and monitoring their child's weight and intake.

Infants with HLHS and its variants are at risk for poor growth particularly during the interstage period. The etiology of growth failure in this population is multifactorial and reasons include high metabolic demand and feeding intolerance.

Nutritional interventions and care practices to assess readiness to feed, optimize oral feeding (pre-op and post-op), evaluate enteral feeding concerns such as blood stools, and improve growth during the interstage have been developed and shared by participating centers.

### RESOURCES

Example discharge form including a **feeding plan for parents** from Children's Mercy Hospital

**Powder formula mixing recipes** created by members of the Feeding Work Group

Spanish version of **nutritional management and goals** sheet from Boston Children's pgs. 21-22

**Pre-operative and post-operative feeding pathways** from Children's Wisconsin to guide enteral nutrition management for infants with single ventricle heart disease

A guide for **management of bloody stool and reflux/aspiration** concerns shared by Monroe Carell Jr. Children's Hospital at Vanderbilt

**Interstage Feeding Program** for SV infants developed by the NPC-QIC Feeding Work Group

**Journal article** outlining nutritional algorithms from birth through Interstage from Feeding Work Group

**Relevant resources for before and after the interstage period include:**

Before Interstage: **Oral Feeds Prior to Stage 1 Palliation Toolkit**

After Interstage: **Tube Weaning Toolkit**

## Optimize Development

Improved operative and peri-operative management over the past several decades for infants with HLHS has led to improved survival, prompting a paradigm shift to focus more on decreasing postoperative morbidities, including improved neurodevelopmental outcomes and quality of life parameters.

Children with CHD are at risk for developmental delays or disabilities. Their patterns of deficits are typically characterized as “high prevalence – low severity” with multiple mild impairments in areas such as motor function, cognitive function (mild), social interaction, communication (language and pragmatics), inattention, executive functioning, and emotional/behavioral functioning.



Infants with HLHS physiology and variants are at even more increased risk, especially for fine and gross motor delay compared with infants with other cardiac anomalies. They present with numerous vulnerabilities for neurodevelopmental impairment. They are born with brains that are more premature than their gestational age. These infants undergo multiple surgeries and procedures, often with a high hospital day burden in the first year of life. They are exposed to neuro-sedative medications, noxious environmental sensory stimulation, delayed oral feeding initiation, sternal precautions, restrictions in holding, historical limitation of therapies such as tummy time, and variable opportunities for parental bonding.

It is important to detect developmental concerns early and intervene. Although babies with HLHS have “been through a lot”, being delayed should not be considered “normal” and dismissed. Common concerns seen early on in the HLHS population while in the hospital include feeding difficulties, oral motor coordination deficits, state regulation impairment, impaired tone, decreased mobility, and sleep difficulties. Development impacts quality of life of both the infant and family. Development is cumulative: a delay in one domain will eventually impact others. Issues often are more easily addressed the sooner they are detected. Proactive attention to neurodevelopmental cares is recommended in the preoperative and postoperative time periods as well as a goal-directed plans in the outpatient setting. Effective therapies and interventions are available, such as Early Intervention and outpatient therapies (e.g., Physical Therapy, Occupational Therapy, and Speech Therapy).

Given the heightened understanding of its importance, NPC-QIC intentionally modified its KDD for Phase II to specifically address optimizing development. You can learn more about NPC-QIC’s neurodevelopment work in the [gross motor toolkit on our website](#).

## IV. Measures

Measurement is the way we answer the second question in the Model for Improvement: “How do we know that a change is an improvement?” Collecting and reporting measurement data allows us to determine if progress is being made toward our aim. The measures below are recommended as teams continue to track their progress towards improving care processes. Not all of these are included in the registry but may be helpful as you monitor the changes you are making.

Process measures evaluate the particulars of care that a patient receives, and outcome measures, such as mortality, evaluate the end results of care.

## Phase II Proposed Process and Outcome Measures

Measure Name	Measure Description	Numerator	Denominator
<b>Care Team Surgical and Perioperative Communication</b>	Percent of patients whose care team delivered surgical and perioperative communication bundle out of those who had Stage 1 Palliation	Number of patients with structured preoperative briefing from surgeon to care team, preoperative time out, standardized handoffs using checklist, and at least hourly communication with parents/caregivers during the procedure	Number of patients who had Stage 1 Palliation
<b>Discharged on Digoxin with No History of Arrhythmia</b>	Percent of patients discharged on digoxin out of those discharged home after Stage 1 Palliation and with no history of arrhythmia	Number of patients discharged on digoxin	Number of patients discharged home after Stage 1 Palliation and with no history of arrhythmia
<b>Developmental Plan at Stage 1 Palliation Discharge</b>	Percent of patients whose parents are given a written, up-to-date developmental plan at Stage 1 Palliation discharge out of those patients discharged home after Stage 1 Palliation	Number of patients whose parents are given a written, up-to-date developmental plan at Stage 1 Palliation discharge	Number of patients discharge home after Stage 1 Palliation
<b>Average Daily Weight Achieved For Patients Discharged Home After Stage 1 Palliation</b>	Percent of patients with at least minimum age-appropriate weight gain at Stage 2 Palliation out of patients that were discharged home from Stage 1 Palliation and had Stage 2 Palliation	Number of patients achieving a minimum age-appropriate daily weight gain between Stage 1 Palliation discharge and Stage 2 Palliation. Average daily weight gain is calculated as the weighted average based on the following table for Age and Expected daily weight gain: 0-3 months (0 to <=90days)=20gms/day; 3-6 months (>90 to <=180days)=15gms/day; 6-12 months (>180 to <=365days)=10gms/day; and >12 months-10yrs (>365days)=5gms/day.	Number of patients discharged home after Stage 1 Palliation and had Stage 2 Palliation
<b>Growth Failure P Chart For Patients Discharged Home After Stage 1 Palliation</b>	Percent of patients for whom the weight for age z-score change < -.5 from Stage 1 Palliation discharge to Stage 2 Palliation out of patients discharged home after Stage 1 Palliation and had Stage 2 Palliation	Number of patients who had a weight for age z-score change < -.5 from Stage 1 Palliation discharge to Stage 2 Palliation	Number of patients discharged home after Stage 1 Palliation and who had Stage 2 Palliation
<b>Mortality, Stage 1 to Stage 2 Palliation After Discharged Home P Chart</b>	Percent of patients who die after being discharged home following stage 1 palliation who did not reach stage 2 palliation (Provisional rate represents months where >10% of data is missing)	Number of patients who die after being discharged home following stage 1 palliation who did not reach stage 2 palliation	Number of Patients who had stage 1 palliation who were discharged home
<b>Mortality, Stage 1 Palliation to Stage 2 Palliation while Hospitalized P Chart</b>	Percent of patients who die while still hospitalized following stage 1 palliation who did not reach stage 2 palliation (Provisional rate represents months where >10% of data is missing)	Number of patients who die while still hospitalized following stage 1 palliation who did not reach stage 2 palliation.	Number of Patients who had stage 1 palliation



## V. Phase II Learnings To Date

### Phase II QI Summary

NPC-QIC's Phase II quality improvement journey continues to build upon the learnings and successes reflected in the Phase I change package. Phase II aims to improve quality of life and reduce mortality of infants with single ventricle congenital heart disease from birth to first year of life by fifty percent. The network key driver diagram (Figure 1.3 below) outlines the core network improvement strategies and key drivers that impact these aims.

Each improvement strategy represents a network-wide and self-sustaining improvement project that has completed rigorous design, data tracking, and testing of interventions to improve outcomes in infants with HLHS.

Several of these network efforts are ongoing at this time:

**Unplanned Reinterventions:** This project's focus is to improve survival of infants between stage 1 and stage 2 surgery by reducing the need for an unplanned reintervention in our single ventricle patient population. There are currently 9 centers actively testing strategies to reduce the impact of the need for reintervention on stage 1 mortality by reducing unplanned reoperation or catheterization and reducing mortality associated with reintervention.

**Surgical Coaching:** This project's aim is to implement a surgical coaching model where visiting surgeons are identified for coaching on the Norwood Procedure. For any congenital heart surgeon, either transitioning in the infancy of one's career to a technically competent surgeon or as a more experienced surgeon desiring the opportunity to learn a new technical approach can be challenging. Our subspecialty is one with much lability in work force. Operations such as stage I palliation for Hypoplastic Left Heart Syndrome continue to be a benchmark procedure for the transparent study of surgical approach and outcomes. A formalized traveling surgical coaching program would benefit this unique issue.

To date, 8 visiting surgeons have been accepted into the project and there are still 2 remaining spots available. The first visiting surgery took place summer 2022.

**Health Equity:** This improvement project will work toward reducing or eliminating disparities in outcomes based on race, ethnicity, and insurance type by identifying and removing barriers to prenatal care, including prenatal diagnosis and coordinated delivery of mothers of infants with congenital heart disease.

**Roadmap to Emotional Health:** This improvement effort began with funding from the American Board of Pediatrics with an aim to improve the emotional health of children with chronic conditions and their families. The resources ([www.roadmapforemotionalhealth.org](http://www.roadmapforemotionalhealth.org)) were co-designed and produced with patients, parents, clinicians, and psychologists. Fifteen cardiology teams are participating in an improvement effort.

Several of these network-wide and self-organizing improvement projects have compiled their learnings from the design and/or testing phases into QI toolkits. These toolkits have been developed to spread evidence-informed strategies and project specific improvement theory to the entire collaborative. NPC-QIC has developed a resource guide for pediatric cardiology centers to utilize the tools and resources presented within each toolkit. Please visit the [for our How to Use NPC-QIC Toolkits resource](#).

Below are descriptions of project-specific toolkits that further explore Phase II improvement priorities:

**Optimizing Neurodevelopment & Supporting Gross Motor Outcomes:** The NPC-QIC Gross Motor Improvement Project, a multicenter quality improvement project, was designed to improve gross motor outcomes for infants by 12 months of age. This toolkit was created to share intervention strategies to promote optimal neurodevelopmental care practices with a focus on gross motor strategies for both hospital and home settings.

**Tube Weaning:** At the time of development of this project in 2020, aggregate reporting patient data available from the NPC-QIC database indicated that only 53% of patients were exclusively orally fed by their first birthday. The toolkit was developed after initial pilot centers utilized knowledge gained from the literature to establish successful weaning programs. Their learnings served as the framework for the education modules found within the toolkit.

**Oral Feeds Prior to Stage 1:** The Preoperative Feeding Project was established to improve the quality of life for infants with single ventricle heart disease and their families by increasing opportunities for nutritional and neurodevelopmental oral feeding experiences prior to Stage I surgical palliation. The Preoperative Feeding Toolkit is designed to provide expert guidance on identifying candidates for preoperative feeding and instituting a preoperative feeding protocol.

### NPC-QIC Phase II: Key Driver Diagram

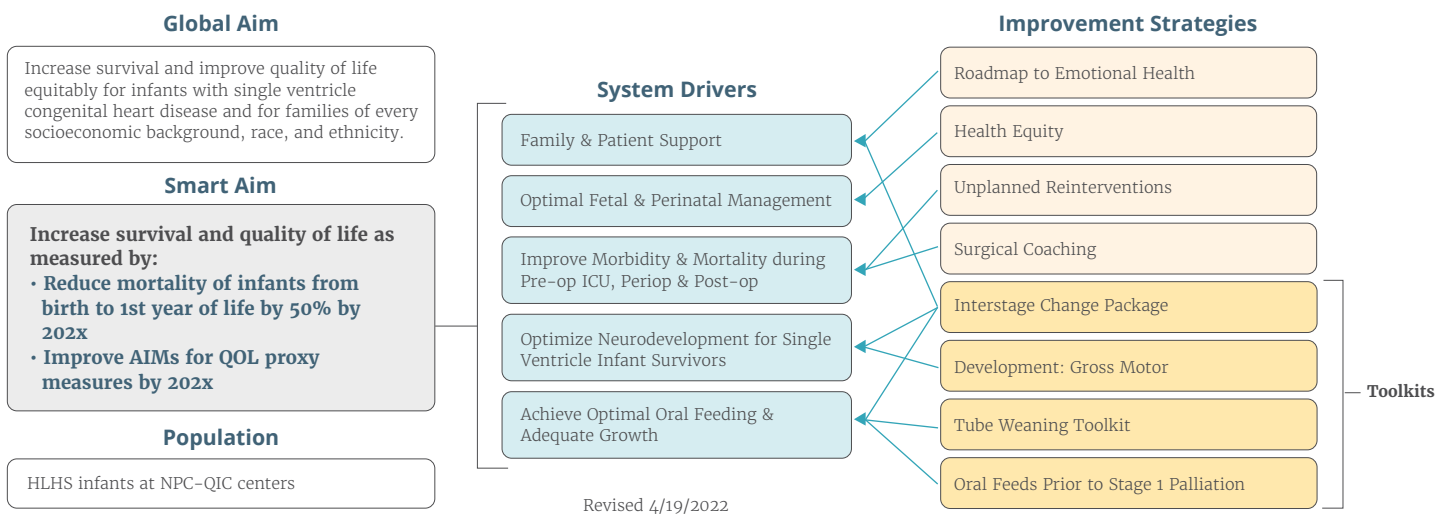


Figure 1.3

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