

**Transparency in a Pediatric Quality Improvement Collaborative: A Passionate Journey by  
NPC-QIC Clinicians and Parents**

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# **Transparency in a Pediatric Quality Improvement Collaborative: A Passionate Journey by NPC-QIC Clinicians and Parents**

## **Abstract**

Transparency -- sharing data or information about outcomes, processes, protocols and practices – may be the most powerful driver of health care improvement. In this special article, the development and growth of transparency within the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) is described. The NPC-QIC transparency journey is guided by equal numbers of clinicians and parents of children with congenital heart disease working together in a Transparency Work Group. Activities are organized around four interrelated levels of transparency (individual, organizational, collaborative and system), each with a specified purpose and aim.

A number of Transparency Work Group recommendations have been operationalized. Aggregate collaborative performance is now reported on the public-facing web site. Specific information that the TWG recommends centers provide to parents has been developed and published. Almost half of NPC-QIC centers participated in a pilot of transparently sharing their outcomes achieved with one another. Individual centers have also begun successfully implementing recommended transparency activities. Despite progress, barriers to full transparency persist, including health care organization concerns about potential negative effects of disclosure on reputation and finances, and lack of reliable definitions, data and reporting standards for fair comparisons of centers.

The NPC-QIC transparency efforts have been a journey that continues, not a single goal or destination. Balanced participation of clinicians and parents has been a critical element of the collaborative's success on this issue. Plans are in place to guide implementation of additional

transparency recommendations across all four levels, including extension of the activities beyond the collaborative to support transparency efforts in national cardiology and cardiac surgery societies.

**Keywords:** Transparency, Hypoplastic Left Heart Syndrome, public reporting, congenital heart disease, quality improvement collaborative

## Introduction

The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC) began enrolling eligible patients (infants with hypoplastic left heart syndrome [HLHS] and variants discharged home for 'interstage' care after a Norwood Stage 1 palliation) to a registry in late 2008. The NPC-QIC is a longitudinal learning community organized around an adapted Breakthrough Series structure.(1) Participation in NPC-QIC is approved by Institutional Review Boards at all participating centers. The first face-to-face Learning Session (LS1) was held in September 2009.(2) From its inception, parent/family involvement was considered vital to the success of NPC-QIC. A few parents attended LS1 and parent involvement grew rapidly after 2011 when Sisters by Heart, a national organization supporting HLHS parents and families, began partnering with NPC-QIC. At the most recent Learning Session (LS11) in May 2015, 34 parents attended side-by-side with 144 clinicians from 52 of the 57 NPC-QIC centers.

With an overall aim to decrease interstage mortality (Figure 1), NPC-QIC has achieved change in practices and improvement in outcomes.(3) Algorithms to guide nutritional enhancement were identified relatively early (reported in 2013)(4), and spread of optimal nutritional practices led to decreased variation in interstage growth.(5) A substantial reduction in interstage mortality across the collaborative was realized in mid-2013 and reported in 2015.(6)

Despite these accomplishments, parents voiced frustration with the pace of improvement, continued center-level variation in practices,(5,7–9) and their inability to access information to assist in care decisions for their children. In particular, parents cited a lack of transparency among care centers participating in NPC-QIC, and among care centers and parents, as inhibiting future progress. Parents requested individual centers share their data with a goal of enabling **all** to learn and improve more quickly, and to assist parents caring for fragile interstage babies in making evidence-informed care decisions. Motivated by the passionate voice of parents, and cognizant of transparency emphasis by the Institute of Medicine(10) and others,

NPC-QIC leadership determined to begin focusing on transparency during the fall 2013 Learning Session (LS8).

## **Inception**

At LS8, the cardiologist Chair of NPC-QIC (RB) challenged the NPC-QIC community by saying “*Families entrust their children’s lives to our care...Don’t they deserve to know our outcomes?*” and proposed that transparency be considered at three levels: Individual, Organizational, and System. A very robust, and at times difficult, discussion ensued. Parents described an inability to obtain data about outcomes, including mortality and morbidity rates, to aid them in their selection of a care center for their child. A CNN expose’ of pediatric heart surgery death rates at a non-NPC-QIC center prior to LS8 had received considerable social media attention in the congenital heart disease parent community. Some clinician attendees expressed concern that comparisons might not be fair, inadequately risk-adjusted (“apples to apples”), and that data could be used by some for competition rather than improvement. One cardiologist noted that his hospital administration would be concerned that, if fully transparent, “we could end up on TV”. Others observed correctly that NPC-QIC had worked diligently to develop a culture of trust and sharing among parents and centers and that increased transparency was a natural extension of its ongoing improvement work. Some questioned how the collaborative could really learn from one another to improve care for HLHS children if it wasn’t clear about who was achieving what in outcomes. One of the most challenging concerns raised was that “forcing” public transparency could result in some centers closing their pediatric cardiology programs or at least discontinuing treating HLHS infants. While many clinicians saw this as problematic, many parents saw this as a desired outcome, believing that centers with poor outcomes in treating these complex patients should no longer be treating these children. Another concern consistently expressed was that hospitals might turn away complex cases in order to improve their outcomes data.

Stimulated by the LS8 attendee responses, NPC-QIC leadership chartered a Transparency Work Group (TWG) with a charge to define transparency goals, identify potential challenges / barriers, and provide a “roadmap” for the collaborative’s transparency journey. A parent (SL) and a clinician (JK) agreed to serve as co-chairs, supported by NPC-QIC’s QI consultant (LEP) and a project manager and coordinator for administrative support. A call for interested TWG participants was sent out to all 54 NPC-QIC centers at that time and to parents. Sixteen enthusiastic members (8 clinicians and 8 parents) volunteered to participate in the TWG’s initial planning meeting.

## **Journey**

### **Beginning**

The first TWG conference call was held January 10, 2014, during which the group added *Collaborative Transparency* to the 3 levels of transparency proposed at LS8, and finalized definitions for each level.

*Individual Transparency* is within and between members of the care team (e.g., cardiologist, surgeon) and parents/patients, and involves proactively sharing information, including outcomes data, prior to care. These data can help parents choose a care team, and parents can help determine important questions that should be addressed.

*Organizational Transparency* involves ensuring that all clinicians and team members within a center are aware of their center’s outcomes / performance. It can help drive a program’s improvement.

*Collaborative Transparency* is sharing center-specific and aggregate process and outcomes data among members of a multi-center collaborative, such as NPC-QIC. It can be used to identify best practices that can subsequently be spread to other centers.

*System-Level Transparency* was defined as an individual center or a multi-center collaborative sharing data with the public (for example, on a web site). This type of transparent public reporting can drive system-wide improvement.

The TWG's near-term goal was to develop recommendations regarding each of the four levels of transparency to present to the NPC-QIC community. An aggressive schedule of conference calls every 2-6 weeks was undertaken, in addition to frequent communication via email. The TWG utilized several data sources for its work including a Transparency Survey of all centers in NPC-QIC, a review of key articles from the healthcare transparency literature,(11,12) a review of data on public web sites for NPC-QIC centers, and very frank discussions between clinician and parent members. In addition, key informant interviews were held with other patient/family networks and collaboratives to learn about their transparency activities. An entire conference call was devoted to discussion with the Cystic Fibrosis Foundation about the lessons learned during their transparency journey.(13)

### The Next Big Step

The TWG co-chairs presented the workgroup's findings and recommendations (Table 1) to the NPC-QIC community in a plenary session of parents, clinicians and researchers at the April 2014 Learning Session (LS9). The recommendations were categorized by transparency level and directed to both participating centers and to the collaborative as a whole.

*Individual and Organizational Level Transparency Recommendations:* A basic premise for the Individual and Organizational Level recommendations was that clinicians and administrators within organizations need to measure and understand their own individual and center performance as a precursor to sharing this information with parents, with other centers and/or with the public. NPC-QIC clinicians reported during Learning Sessions that transparent sharing of process and outcomes data within their own centers (i.e., internally, within centers) has often



been lacking or a low priority of local leadership. Sub-specialty 'siloes' within cardiology centers (e.g., surgery, intensive care, catheterization, electrophysiology, imaging, transplant, etc.) may be associated with isolation and lack of awareness of local outcomes within and among cardiology subspecialties and surgery. Important system changes and improvements require centers to create environments in which open and honest data sharing can occur within the local team.<sup>(14)</sup>

*Collaborative Level Transparency Recommendations:* The TWG believed that an opportunity existed within NPC-QIC to demonstrate a strong example of transparent sharing among participating centers. Centers sign a Data Use Agreement (DUA) when they join NPC-QIC. The current DUA stipulates that data submitted to the registry can be used for quality improvement and for research. However, the DUA states that NPC-QIC may not be report data in any fashion that links program identities to their specific data (e.g., it is allowable to refer to center A, B, C,...N, but center identities must not be revealed). The TWG recommended that the DUA be modified to allow center-level performance to be identified to other centers within NPC-QIC.

*System Level Transparency Recommendations:* Recommendations at this level focused on public data sharing. It was clear from discussions at LS8 that a wide spectrum of philosophy and action at this level existed among NPC-QIC centers. Those centers not sharing any data publicly identified several barriers to public transparency (see further discussion below). Centers that were actively engaged in public reporting of data did so only with select data in a non-standardized manner (since there is no standardized reporting of data, which precluded comparisons<sup>i</sup>).

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<sup>i</sup>The Society of Thoracic Surgery (STS) has recently begun public reporting of a subset of standardized surgical data from centers who have agreed to provide this information. Currently, a minority of NPC-QIC centers participate in the public reporting component.

## Accomplishments

Since LS9, the TWG has shifted its emphasis from formulating to implementing its transparency recommendations. In addition to ongoing monthly conference calls, TWG “mini-retreats” have been held during recent NPC-QIC Learning Sessions. The four transparency levels structure and the recommendations for each are used to monitor progress and plan next steps.

To share NPC-QIC aggregate center performance with the public (parents, patients and clinicians), the TWG developed an “infographic” of key metrics from the collaborative’s QI reports (Figure 2). Posted on the home page of the NPC-QIC website (<https://icchdqj.org/>) and updated quarterly, it includes links to definitions and education about the salience of the measure (e.g., Satisfactory Growth: This is the percentage of infants who met their weight goal during the interstage period. It is important for infants to gain the proper amount of weight to be ready for their next surgery and recovery). It also includes a measure of the concrete, active engagement of parents as partners in care improvement, such as through Single Ventricle Family Advisory Councils.

TWG discussions identified a number of potential facilitators and barriers to transparency based on role (e.g., clinician, hospital administrator, care center lawyer). To explore these issues, they organized a Transparency Panel Discussion at LS10. The discussion was moderated by an HLHS mother who is also an attorney, and panelists included a pediatric cardiac surgeon, a cardiologist, a hospital General Counsel, and a hospital marketing representative. Each discussed key considerations for center or public level transparency from the unique perspective of their role.

NPC-QIC parents report considerable variability in the type and completeness of information provided them by care centers, especially around the stressful time of their child’s diagnosis.

The TWG generated a 19-item list of suggested questions for parents to ask the cardiac team and surgeon regarding their child's care (e.g., How many Norwood/Hybrid procedures has your program done in the last year?). The questions were refined and co-produced by NPC-QIC and Sisters by Heart in a "Single Ventricle Q&A Booklet" (Table 2). Available to download from the Sisters by Heart web site,<sup>(15)</sup> the booklet is included in each Sisters by Heart "care package" provided to newly-diagnosed HLHS families. It was also provided to all NPC-QIC care centers to use as a resource as to the questions that they should be prepared to be asked by parents and that they should proactively answer for parents, whether asked or not.

The TWG organized a Transparency Pilot for centers to voluntarily self-identify their process and outcome data with one another for the purpose of accelerating improvement. Prior to the Spring 2015 LS11, 31 of the 56 Centers active in NPC-QIC at the time indicated they would participate in the Transparency Pilot; 22 subsequently did so. Centers were asked to select from among two process and two outcome measures; one they felt was a strength (for which they could teach or help other centers learn) and the other where they would like assistance in improving. In a series of preparatory calls, ground rules were established, including that the data not be used for marketing or promotional purposes, the data not leave the premises of the Learning Session and not be publicized in any form, including shared on social media, and that no protected patient information or personal identifiers be shared. The Transparency Pilot was held in a plenary session at LS11. Centers presented not only their data, but also the context for their results – the practices associated with their successes and an honest appraisal of opportunities for improvement. A lively question/answer segment followed during which parents and clinicians discussed many aspects of the data sharing, focusing on improvement. Attendees subsequently gave high ratings of the session; no breaches of the ground rules have been identified. A follow up survey will be launched soon to determine how the process worked for the

centers that participated and how many of the non-participating centers would choose to participate next time, having now seen it modeled by others.

In response to the System-level recommendation that NPC-QIC publicize its transparency efforts to accelerate progress, a recurring transparency column in the weekly electronic newsletter appraises the NPC-QIC community of TWG and center-level transparency activities between Learning Sessions.

In the wake of a CNN series on high mortality rates for pediatric cardiac surgery in a Florida hospital,(16) the June 2015 monthly NPC-QIC conference call was dedicated to a collaborative-wide discussion of national calls for public transparency. Both NPC-QIC and Sisters by Heart also issued public statements, calling on pediatric heart programs to release their outcomes data so that parents and families can make evidence-informed decisions.

Finally, TWG and collaborative leadership have spoken about the NPC-QIC transparency journey at a number of regional and national conferences.(17–20)

#### Center-specific Transparency Activities: A Case Example

In addition to NPC-QIC-specific activities, the transparency journey has generated changes and action at a number of individual centers that participate in the collaborative. After participating in LS9, one center's team returned to their institution and initiated a new Cardiovascular Transparency and Improvement (CVTI) conference to enhance "organizational level" transparency. In addition to an increased interest in transparency, the center had struggled with Fellow participation in improvement projects and transparency education. The goal of the CVTI conference was to promote data sharing within the hospital cardiac service line (cardiology and cardiothoracic surgery), organizational transparency and improvement in Fellow participation. The conference was scheduled monthly at 7:00-8:00 a.m., immediately before a pre-existing

major weekly cardiology-surgery conference. To indicate its importance, cancellations are not allowed; if conflicts arise, the meeting is rescheduled. Administrators are invited. Each sub-specialty service is assigned a month, and quarterly, a Fellow presents at a sub-conference within CVTI entitled Morbidity – Mortality and Improvement Case Conference. The goals for this Fellow conference were drawn from the Fellowship goal requirement within System-Based Practice Milestones(21) and include working in inter-professional teams to enhance patient safety and improve patient care quality, and advocating for optimal patient care systems. The conference has become one of the most highly-attended at that center and the schedule pre-booked several months in advance with volunteers who have asked to present. Support for transparency is growing among most Cardiac Service Line members as well as among the administrators who attend.

### **Barriers and Potential Mitigators**

NPC-QIC's transparency journey has not been without challenges, many of which are aptly summarized in the recent *Shining a Light* publication:

*“...transparency in health care is about much more than public reporting, and significant barriers exist to achieving it at all levels, including concerns about patient privacy, the integrity of shared data, the burdens of collecting and analyzing data, and medical liability.”*

Starting with LS8, and continuing since TWG inception, discussions about transparency, although always frank and respectful, have at times been difficult. Collaborative leadership have stressed that a degree of discomfort is to be expected and in fact represents a positive sign of progress. Although transparency discussions in NPC-QIC have been professional, constructive, and respectful, there is not consensus between clinicians and parents nor among all clinicians. The issue of trust has also been a barrier. For example, parents were deeply offended at a suggestion by a clinician that parents (but not clinician attendees) be required to sign a form

indicating they would not share outcomes data on social media before participating in the Transparency Pilot.

Some center teams have been slowed in progress toward transparency by fears about conflict, disclosure, and/or potential negative effects on reputation and finances at the level of their institution's senior leadership or legal counsel. The most common reason cited by teams who initially indicated they would participate in the Transparency Pilot and subsequently did not was lack of institutional permission to share their NPC-QIC data with other centers.

Along with the transparency recommendations, the TWG has developed a set of recommendations to mitigate barriers to transparency, including:

- Need to have a *local champion* at each center who is respected among all stakeholders
- *Build trust* and work in a stepwise fashion
- Change *culture* (locally, collaborative-wide and beyond)
- *Standardize metrics* reported across institutions
- Develop institutional and surgeon *buy-in*

## **Future Plans and Goals**

Going forward, the TWG of the NPC-QIC has an ambitious plan to enhance and promote transparency at all four levels. In addition to reviewing and refining all of the existing recommendations, the current list includes:

### Individual and Organizational Levels

-Encourage centers to meet internally, discuss, and provide center-specific answers to the questions outlined in the Single Ventricle Q&A Booklet to prepare for parent questions during consultations.

-Develop, pilot and launch a “Transparency Report Card” that local NPC-QIC teams can use to make action plans and monitor their progress on implementing TWG transparency recommendations.

-Propose revised versions of consent forms that include reference to having been given data and sufficient explanation to understand the provider’s performance.(22)

### Collaborative Level

-Ask participating centers to volunteer to share their center’s answers to the questions in the Single Ventricle Q&A Booklet (Table 2).

-Develop and send a survey to NPC-QIC centers in follow-up to the LS11 Transparency Pilot, exploring benefits and additional activities among those who participated, and perceived barriers among those who did not participate.

-Obtain Transparency Report Card (TRC) data on a semi-annual basis to monitor each center’s progress. Share these data with all NPC-QIC centers transparently.

-Revise the collaborative’s Data Use Agreement to allow for transparent sharing of data between participating care centers.

### System Level

-Proactively become involved in national advocacy efforts (beyond the NPC-QIC collaborative) to promote transparency (e.g., tell our collaborative transparency story at national venues).

-Support work by national cardiology and surgery societies to develop standardized public reporting of data. Standardization of data reporting has become a major focus for the TWG. One possible goal would be to achieve agreement within the pediatric and congenital cardiology and surgical community and their societies to develop uniform data reporting aimed at patients and parents.

-Respond to national transparency events (e.g., responsibly as an organized group participate officially in blogs and social media).

## **Summary**

Together, the clinicians and parents of NPC-QIC have accomplished significant progress toward transparency over an 18-month period. It is a journey, not a moment in time, and can be frustrating for those who ask “Why does it have to be so hard and take so long?” There are lives at stake and there are some who want to move faster than others feel comfortable. Under the guidance of the Transparency Work Group, the NPC-QIC collaborative has committed to continue efforts until complete transparency is achieved for patients and their families.

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## References

1. Kilo CM. A framework for collaborative improvement: lessons from the Institute for Healthcare Improvement's Breakthrough Series. *Qual Manag Health Care*. 1998 Sep;6(4):1–13.
2. Kugler JD, Beekman Iii RH, Rosenthal GL, Jenkins KJ, Klitzner TS, Martin GR, et al. Development of a pediatric cardiology quality improvement collaborative: from inception to implementation. From the Joint Council on Congenital Heart Disease Quality Improvement Task Force. *Congenit Heart Dis*. 2009 Oct;4(5):318–28.
3. Clauss SB, Anderson JB, Lannon C, Lihn S, Beekman RH, Kugler JD, et al. Quality improvement through collaboration: the National Pediatric Quality improvement Collaborative initiative. *Curr Opin Pediatr*. 2015 Jul 23;
4. Slicker J, Hehir DA, Horsley M, Monczka J, Stern KW, Roman B, et al. Nutrition algorithms for infants with hypoplastic left heart syndrome; birth through the first interstage period. *Congenit Heart Dis*. 2013 Apr;8(2):89–102.
5. Anderson JB, Beekman RH, Kugler JD, Rosenthal GL, Jenkins KJ, Klitzner TS, et al. Use of a learning network to improve variation in interstage weight gain after the Norwood operation. *Congenit Heart Dis*. 2014 Dec;9(6):512–20.
6. Anderson JB, Beekman RH, Kugler JD, Rosenthal GL, Jenkins KJ, Klitzner TS, et al. Improvement in Interstage Survival in a National Pediatric Cardiology Learning Network. *Circ Cardiovasc Qual Outcomes*. 2015 Jul;8(4):428–36.
7. Baker-Smith CM, Neish SR, Klitzner TS, Beekman RH, Kugler JD, Martin GR, et al. Variation in postoperative care following stage I palliation for single-ventricle patients: a report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative. *Congenit Heart Dis*. 2011 Apr;6(2):116–27.
8. Brown DW, Connor JA, Pigula FA, Usmani K, Klitzner TS, Beekman III RH, et al. Variation in Preoperative and Intraoperative Care for First-stage Palliation of Single-ventricle Heart Disease: A Report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative: Intraoperative Variation for Single Ventricle. *Congenit Heart Dis*. 2011 Mar;6(2):108–15.
9. Schidlow DN, Anderson JB, Klitzner TS, Beekman RH, Jenkins KJ, Kugler JD, et al. Variation in interstage outpatient care after the Norwood procedure: a report from the Joint Council on Congenital Heart Disease National Quality Improvement Collaborative. *Congenit Heart Dis*. 2011 Apr;6(2):98–107.
10. Committee on the Learning Health Care System in America; Institute of Medicine; Smith M, Saunders R, Stuckhardt L, et al., editors. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. [Internet]. Washington (DC): National Academies Press; 2013. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK207216/>

11. Gawande A. The Bell Curve: What happens when patients find out how good their doctors really are? The New Yorker [Internet]. 2004 Dec 6; Available from: <http://www.newyorker.com/magazine/2004/12/06/the-bell-curve>
12. Henke N, Kelsey T, Whately H. Transparency—the most powerful driver of health care improvement? Health Int. 2012;(11).
13. B. Marshall, MD. VP of Clinical Affairs. Cystic Fibrosis Foundation. 2014.
14. National Patient Safety Foundation's Lucian Leape Institute. Shining a Light: Safer Health Care Through Transparency [Internet]. Boston, MA: National Patient Safety Foundation; 2015. Available from: <http://www.npsf.org/?shiningalight>
15. Sisters by Heart. Single Ventricle Q&A Booklet [Internet]. Available from: <http://www.sistersbyheart.org/content/new-care-package-items>
16. Cohen E, Bonifield J. CNN report on high mortality rate for babies at Florida hospital leads to inquiry. CNN. 2015 Jun 5;
17. Quality and Safety in Children's Health Conference 2015. Children's Hospital Association; 2015 Mar 8; San Francisco, CA.
18. American College of Cardiology - Cardiovascular Summit. 2015 Jan 22; Orlando, FL.
19. Learning Networks CHILD Workshop. Cincinnati Children's Hospital Medical Center; 2015 Jun 19; Cincinnati, OH.
20. Mended Little Hearts National Symposium. 2014 Jul; Indianapolis, IN.
21. The Pediatrics Milestone Project [Internet]. p. 85–9. Available from: [http://www.acgme.org/acgmeweb/Portals/0/PDFs/Milestones/320\\_PedsMilestonesProject.pdf](http://www.acgme.org/acgmeweb/Portals/0/PDFs/Milestones/320_PedsMilestonesProject.pdf)
22. Beekman RH III. Transparency and Truly Informed Consent: A Modest Proposal [Internet]. American College of Cardiology in Touch Blog. 2015. Available from: <http://blog.acc.org/post/transparency-truly-informed-consent-modest-proposal/#sthash.eC9ozixW.dpuf>

## **Figure Legends**

**Figure 1: Key Driver Diagram outlining the NPC-QIC theory for improvement, including key drivers for optimal transition / discharge care, nutritional status, coordination of care, and parent support and engagement**

**Figure 2: Infographic of aggregate (collaborative-wide) performance on key metrics as of May 2015**

## Tables

**Table 1: Transparency Work Group Recommendations**

### Individual Level

*Team members from centers should:*

- Familiarize themselves with the questions that parents have
  - Ask their center Family Advisory Council
  - Review the HLHS Information Page at <http://hlhsinfo.homestead.com/questions.html>
- Identify what information they currently share with parents
- Fill the “gaps” between parent questions and what is currently provided
- Provide the answers *even if the parents do not know to ask the question*

### Organizational Level

*Centers should:*

- Internally share all of their outcomes
- Regularly review their monthly NPC-QIC measure reports with their cardiac team
- Share outcomes, reports with hospital administration

### Collaborative Level

*NPC-QIC should:*

- Revise the Data Use Agreement (which is a condition of participation) to allow the collaborative to share center-specific measure reports internally between participating centers
- Immediately convene a pilot group of centers who volunteer to self-identify their outcome and process measure results and care processes with one another for the purpose of identifying best practices and accelerating improvement

## **System Level**

### *Centers should:*

- Know which data they currently share publicly
- Work with institutional leadership to ensure the data are accurate, up-to-date, easy to locate and address parent questions
- Inform current and prospective parents of the existence and location of the information

### *Centers who do not share data with the public should:*

- Advocate with institutional leadership to do so

### *NPC-QIC should:*

- Develop a list of what parents want shared by each participating center on their web site
  - Provide it to collaborative members to use in their internal efforts to advocate for transparency
- Provide a venue for centers to regularly share learning from their transparency efforts with one another to accelerate progress
- Publicize its transparency efforts to accelerate progress
- Share and regularly update aggregate collaborative quality measure performance on the public NPC-QIC web site
- Work toward a process to be publicly transparent at the center level

## **Table 2: List of questions in the Single Ventricle Q&A Booklet**

### **SUGGESTED QUESTIONS TO ASK THE CARDIAC TEAM**

#### **About Your Hospital/Cardiac Center:**

1. Can you tell me more about your center? Why is your center the best option for the care of my child? How many Norwoods/Hybrids has your program done in the last year? Over the last 5 years?
2. What are your surgeon's expected survival rates from birth through the second surgery (Glenn)? What are your center's overall survival rates from birth through Glenn? How do your survival rates compare with other centers' survival rates?
3. What are the most common complications following a Norwood/Hybrid? At your center, what percentage of babies need re-intervention (cardiac catheterization or surgery) in the 1<sup>st</sup> year of life?
4. Do your surgeons hold sub-specialty certification in congenital cardiac surgery? When can I meet with the surgeon who will perform my child's surgeries?
5. Does your program participate in the National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC), Society of Thoracic Surgeons (STS) Database, and/or Impact Registry?
6. How am I included in decision-making regarding my child? How can I communicate with the surgical team before, during, and after surgery? Who is on my child's care team and what are their roles (i.e. primary cardiologist, surgeon, ICU team, outpatient team, etc.)?
7. How do you decide when my child will have each surgery - Norwood, Glenn, and Fontan? Do you have certain criteria (weight, age, etc.) my child must meet prior to each surgery?

#### **About Your Hospital Stay:**

8. How long can I expect my child to be in the hospital after the Norwood? Glenn? May I

participate in daily clinical “rounds” when my child’s health is discussed with the care team?

9. What are your visiting policies? Am I allowed to stay with my baby overnight? Can you help prepare siblings for hospital visits?
10. What are my options for when, where and how to deliver my baby? When and how do you communicate with my OB/GYN regarding delivery and perinatal care?
11. When and how do you communicate with my child’s pediatrician following birth, procedures, and surgeries? When do I need to identify a pediatrician for my child and can you provide guidance in my search?
12. Who will care for my baby between birth and his/her first procedure? After the procedure? Do you have a dedicated Cardiac Intensive Care Unit (CICU)? Can I tour your heart center? Are physicians in the CICU board certified in both cardiology and critical care?
13. Will I be able to hold my baby before and after his/her Norwood? If so, when and how?
14. How will I feed my baby before and after their first surgery? Can I breastfeed? If so, what supports do you have for breastfeeding? What percentage of babies eat by mouth when they are released from the hospital after the Norwood?
15. Will my baby be sent home after his/her Norwood recovery? How will you prepare me to care for my baby at home? Does your center require interstage monitoring? If so, who is responsible for my baby’s care during the interstage period?
16. What support is available for me and my family? Do you provide any professional or peer support? Do you provide financial, nutritional, mental health, and developmental guidance?

**Looking Ahead:**

17. What can I expect for the next few years as my child develops and grows? Can he or

she play sports? Are there potential life-long complications my child may experience?

18. Developmentally and socially, what can I expect for my child as a preschooler, school-age child, a teenager, and as an adult? Do you have a neuro-developmental program my child can participate in?

19. Do you have a plan for transitioning my child from pediatric to adult care?