

Our Success | These metrics show the progress we are making to improve the lives of infants diagnosed with hypoplastic left heart syndrome (HLHS). These metrics were developed by parents and clinicians as a ‘snapshot’ of the items that are most important to improve outcomes for these infants.

| This number is the total number of children with HLHS whose information has been added to the NPC-QIC database since July 2008. Having a large database of information allows us to do more research into care for these children.

Survive | This is the percentage of children in the NPC-QIC database who survive the ‘interstage’ period between the time they were discharged from the hospital after their first open heart (‘Norwood’) surgery until they were readmitted to the hospital for their second open heart (‘bidirectional Glenn’ or ‘hemi-Fontan’) surgery.

Satisfactory growth | NPC-QIC has set a goal that infants gain an average of 20-30 grams in weight per day during the interstage period. Each center in NPC-QIC works with parents to adjust their infant’s feeding plan to meet this goal. It is important for infants to gain the proper amount of weight to be ready for their next surgery and recovery. This is the percentage of infants who met their weight goal during the interstage period.

Engaging parents | It is important that parents are partners with centers and NPC-QIC to improve the care that HLHS infants receive. This is the percentage of centers in NPC-QIC who worked with parents in one or more of the following ways in the past 3 months:

- 1) One or more parents serve on their NPC-QIC team
- 2) The NPC-QIC team consulted with one or more parents about specific changes the center is considering
- 3) The NPC-QIC team consulted members of a cardiac-specific Family Advisory Council at their center