



Making sense of surgical data is difficult. We hope that Hospital Navigator makes it a little easier for patients and families to get the information they need to be actively involved in making important decisions about their congenital heart care. However, to fully understand the data, it is important to talk with your health care team.

We continue to advocate for new and better datapoints in keeping with our Tenets of Public Reporting*. Here are a few examples:

Mortality by STAT Category: This number is provided to the hospital by the Society of Thoracic Surgeons (STS). It combines information from many surgical procedures into 5 large buckets based on mortality associated with the surgery. As patients and families, we are advocating for the data to be shown by type of procedure, along with or instead of, the large STAT buckets.

Risk Adjusted Mortality: At Conquering CHD we believe data should be adjusted for risk. This levels the playing field for hospitals that take on more risky patients than those who don't. However, the math formula for how risk is determined is not well understood. Some hospitals believe the current formula (observed-to-expected ratio) may not accurately portray programs, whose surgical practices are defined by unusual populations that are not appropriately captured in this formula.

As the voice of patients and families, we look forward to data points that are presented in a way that is meaningful to patients and families – risk adjusted, and with adequate context to help patients and families understand, no matter their health literacy level.

*Tenets of Public Reporting may be reviewed here:

<https://www.conqueringchd.org/wp-content/uploads/2020/04/Transparency-Key-Tenets.pdf>

