



## Key Tenets of Transparency

**Conquering CHD supports the full development of the following elements:**

- ♥ Transparency should occur across multiple domains:
  - Between clinicians and patients (direct, patient-centered communication about expectations and outcomes)
  - Among clinicians (peer review)
  - Between institutions (regional or national collaboratives)
  - With the public (public reporting)
- ♥ All families, upon diagnosis, should be provided with a list of questions that facilitate transparent conversations with their providers (e.g. Conquering CHD's Guided Questions Tool)
- ♥ All congenital heart programs should utilize a formal review program and regularly assess performance measures and outcomes
- ♥ All congenital heart programs should participate in available national databases in order to benchmark their outcomes
- ♥ All congenital heart programs should publicly report their outcomes to a national public reporting system (e.g. Conquering CHD's Hospital Navigator) that adheres to the following tenets:
  - Full disclosure
  - Standardized key variables
  - Long-term outcomes data collection
  - Ability to compare institutions with risk-adjusted data (adjusting for differences in case-mix and patient factors)
  - Presented geographically
  - Include common benchmark lesions
  - Validated
  - Includes information regarding the patient experience
  - Value (cost per outcome)
  - Supportive materials for parents that enable data interpretation

**Working together to improve transparency, congenital heart programs, patients and families can improve outcomes and save lives. Congenital heart disease data may be complicated, but sharing information need not be so.**

