

# DIGGING DEEPER WITH DATA IS ESSENTIAL TO UNDERSTANDING CONGENITAL HEART DISEASE

Congenital heart disease (CHD) is the #1 birth defect, affecting 40,000 births a year in the United States alone. It is estimated that about 2.4 million people of all ages were living with CHD in the United States in 2010. This growing population requires lifelong specialized care to improve outcomes and reduce healthcare costs.

In the era of “big data,” numerous data sources are available and could be used to evaluate health outcomes, establish standards of care, and identify opportunities to advance care.

**However, the inability to meaningfully and reliably connect data sources is a major barrier to effective use of data, with significant consequences:**

- Inability to appropriately counsel patients based on the scarcity of individual and population-based longitudinal outcomes data. This includes barriers to integration of data from multiple sources, leading to a lack of understanding of disease progression
- Difficulty evaluating healthcare needs, access, and costs across the lifespan
- Excessive burden on healthcare institutions committed to contributing data

**Some challenges to linking data sets include:**

- Challenges in negotiating data use agreements may preclude linkages
- Datasets may use differing data collection and reporting mechanisms
- Submitting data to multiple databases places burdens on healthcare institutions and providers
- Increased costs may prevent the use of existing data

**These actionable activities can considerably improve data usage:**

- Collecting/following data from a single patient over time in a way that addresses privacy and consent issues
- Standardizing minimum data set requirements and reporting mechanisms
- Minimizing the burden of redundant data collection
- Increasing awareness among patients and families about the importance of data use and data sharing

## HOT OFF THE PRESSES

The article “*Databases for Congenital Heart Defect Public Health Studies Across the Lifespan*” (JAHA, October 2016) sheds light on the complex constellation of databases that include CHD data.

- Frame work with database categories and examples
- Opportunities to combine databases across categories

<http://bit.ly/2hx6fcA>

## CONSIDER THE STORY OF SARAH

- ♥ Sarah is born with a CHD which was repaired surgically at less than 1 year of age. Data from newborn screening results and surgery outcomes are stored independently and not easily accessed by future providers for health care planning needs.
- ♥ Sarah grows to live a healthy, productive life and falls out of cardiology care at age 13 because she feels healthy and the need for continuous cardiology care was understated or misunderstood by her parents. Some of her pediatric medical records were archived, limiting access for current and future providers.
- ♥ Now a young woman, Sarah graduates from college, moves several times, marries and becomes pregnant. Sarah is unaware of risks for heart failure or rhythm abnormalities that can occur late after heart surgery and that may be worsened by pregnancy. Neither her primary care provider nor her obstetrician will be watching for such problems as they are unaware of the long term implications of CHD. They also have no documentation of the details of her CHD or surgical history. Sarah does not understand her own history well enough to communicate to her current providers. Sarah develops heart failure that results in preterm labor and prolonged hospitalization after delivery.
- ♥ Sarah’s case illustrates several problems posed by the absence of systems to maintain continuity of care and of medical records access for CHD patients as they survive and move into adulthood.

*For more information, visit: <https://www.chphc.org>*