

## **A Specific Health Information System for Adult Congenital Heart Disease Integrated with Electronic Health Records Can Facilitate Multicenter Research**

**Background:** Adults with congenital heart disease (ACHD) are the fastest growing population in cardiology. We piloted a tailored clinical-research information system that could support data sharing. Our objective was to determine if automated acquisition of existing electronic health records (EHR) to a common multicenter database can facilitate ACHD research by enabling analysis of patients across centers.

**Methods:** To profile a large ACHD cohort, clinical information from existing EHRs at 5 ACHD centers was integrated with CONGENERATE, an ACHD-specific clinical-research information system. Patients >17 years old with documented congenital heart defects seen by an ACHD provider were identified. Predefined demographic and clinical variables were collected. Billing codes were used to identify anatomic defects and stratify patients into mild, moderate, or severe disease complexity. In 30 randomly selected patients, acquired data were validated by physician chart review.

**Results:** Data on 2,410 patients (62% female, age  $37.4 \pm 13.7$  years) were obtained. Mean BMI was  $27.1 \pm 6.3$  kg/m<sup>2</sup>. 24.7% were classified as obese, slightly less than the general US population (39.5%). Race/ethnicity representation was 4.7% African-American, 1.7% Asian, 0.3% native American, 5.5% other, 3.3% Hispanic, and 88% were Caucasian/non-Hispanic. 6.5% had no racial/ethnic identifier. Diagnoses were inadequate for complexity stratification in 32%. Of patients who could be stratified, 37% had mild, 39% moderate, and 24% severe congenital heart disease. No errors or misclassifications were identified among the patients selected for physician review.

**Conclusions:** This is the first study to report the application of a tailored clinical-research information system for ACHD. Automated acquisition of existing EHR to a multicenter database can be achieved with accurate demographic information, whereas more uniformity in anatomical detail is required. In this first harvest of data collection, the population sampled was predominantly female, Caucasian/non Hispanic and nearly two-thirds of patients had moderate or severe congenital heart disease.