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

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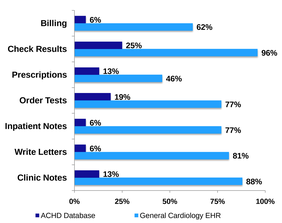
Background and Objective

Adults with congenital heart disease (ACHD) are the fastest growing population in cardiology. Survey data show that most centers use an electronic health record (EHR) but not a similar tool for ACHD care (Figure 1).[6]

Objective: 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.

Figure 1. Comparison of EHR Systems to CONGENERATE[6]

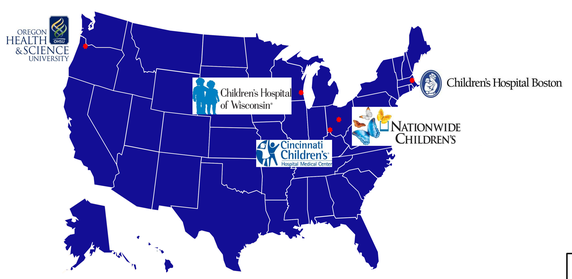


Methods

To profile a large ACHD cohort:

- Clinical information from existing EHRs at 5 ACHD centers (Figure 2) was integrated with CONGENERATE, an ACHD-specific clinical research information system.
- Patients >18 years old with documented congenital heart defects seen by an ACHD provider were identified.
- Pre-defined demographic and clinical variables were collected.
- Billing (diagnosis) codes were used to identify anatomic defects.
- Patients stratified into mild, moderate, or severe disease complexity.

Figure 2. Participating ACHD Centers



IT teams at each center were responsible for cross-mapping data that resided in their institutions' EHR to center-specific installations of CONGENERATE.

Data exports of de-identified data were provided for this meta-analysis from 4 of the 5 centers (Figure 3). Patients were stratified by CHD diagnosis complexity (mild, moderate and severe).[1]

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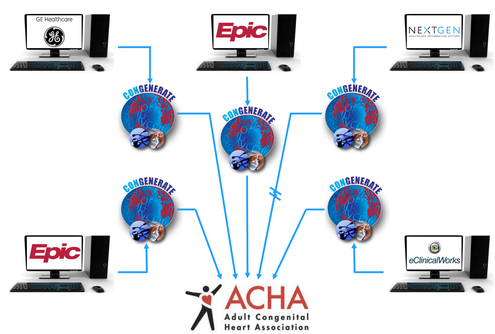
Definitions and Coding

Data variables were those that existed in current EHR systems in discrete fields. The data exports consisted of demographic and diagnoses data that had been cross-mapped and imported into center specific installations of CONGENERATE for all patients >18 years old with at least one CHD-related office visit at one of the hospitals during July 2009 to June 2010.

Figure 3. Standardized Dataset Generation: EHR Systems to CONGENERATE



Cross-mapping between EHR and CONGENERATE was complicated by multiple EHR systems and coding standards. CONGENERATE was built to accommodate international standards and multiple languages but issues that arose during integration of data included mapping diagnoses from centers that used different codes (Table 1).

Diagnoses that were cardiac-related were standardized by:

- EPCC Codes mapped to ICD-9[3,4]
  - → ICD-9 to EPCC mapping was impractical due to the "one-to-many" relationship
  - → 2 sites use ICD-9 and 2 sites use EPCC

Each original diagnosis description was mapped to complexity then each patients' highest complexity level was determined.[1]

Table 1. Standard Coding Systems Used by Centers

Diagnoses

- IPCC – International Paediatric Cardiac Codes
- EPCC – European Paediatric Cardiac Codes
- ICD-9 – International Classification of Diseases & Injuries, 9th revision
- SNOWMED

Procedures

- ICD-9 CM - International Classification of Procedures, 9th revision
- CPT® - Current Procedural Terminology
- IPCC – International Paediatric Cardiac Codes
- EPCC – European Paediatric Cardiac Codes

Medications

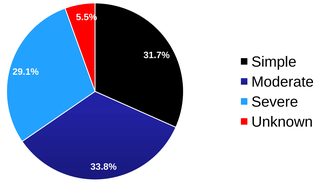
- AHFS – American Hospital Formulary System
- RxNorm
- NDDF – National Drug Data File
- GPI – Generic Product Index
- NDF-RT – National Drug File-Reference Terminology
- NDC – National Drug Code
- ULMS® - Unified Medical Language System

Laboratory Results

- LOINC® - Logical Observation Identifier Names and Codes terminology

Results

Figure 4. Distribution of Highest Diagnosis Complexity



Data from **2,161 patients** were obtained from 4 sites. Almost two-thirds of patients had moderate or severe CHD (Figure 4). Diagnoses were inadequate for complexity stratification in 119 cases (5.5%). Mean BMI was 27.0± 6.4 kg/m^2 with 24.5% classified as obese, less than the general US population of 35.7% (Table 2).[5]

Table 2. Demographics by Patient Highest Diagnosis Severity

		Diagnosis Complexity[1]		
	All Patients^	Simple	Moderate	Severe
	N= 2161	N = 684 (33.5)	N = 730 (35.7)	N = 628 (30.8)
	N (%)	N (%)	N (%)	N (%)
Gender				
Female	1198 (55.4)	382 (55.8)	406 (55.6)	353 (56.2)
Male	963 (44.6)	302 (44.2)	324 (44.4)	275 (43.8)
Race				
Asian	40 (1.9)	19 (2.8)	8 (1.1)	11 (1.8)
Black	83 (3.8)	25 (3.7)	32 (4.4)	18 (2.9)
Caucasian	1839 (85.1)	538 (78.7)	633 (86.7)	565 (90.0)
Native American	7 (0.3)	3 (0.4)	4 (0.5)	0 (0)
Other	192 (8.9)	99 (14.5)	53 (7.3)	34 (5.4)
Ethnicity				
Asian	6 (0.3)	3 (0.4)	2 (0.3)	1 (0.2)
Hispanic/Latino	58 (2.7)	9 (1.3)	14 (1.9)	30 (4.8)
Non-Hispanic/Non-Latino	1531 (70.8)	500 (73.1)	491 (67.3)	455 (72.5)
Unknown	566 (26.2)	172 (25.1)	223 (30.5)	142 (22.6)
	Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD
Age (years)	37.0 ± 13.8	39.5 ± 15.2	36.6 ± 12.8	35.5 ± 12.8
Height (cm)	167.5 ± 11.6 (1923)	168.4 ± 11.4 (615)	167.2 ± 12.3 (646)	166.7 ± 11.1 (560)
Weight (kg)	76.1 ± 20.0 (2017)	76.7 ± 19.4 (636)	76.7 ± 20.3 (677)	75.1 ± 20.4 (598)
BMI (kg/m^2) (N*)	27.0 ± 6.4 (1922)	27.0 ± 6.1 (614)	27.3 ± 6.4 (646)	26.9 ± 6.6 (560)
Normal (< 25.0)	22.0 ± 2.2 (852)	22.0 ± 2.0 (261)	21.9 ± 2.3 (270)	21.9 ± 2.3 (261)
Overweight (25.0 to 29.9)	27.3 ± 1.4 (599)	27.2 ± 1.4 (213)	27.5 ± 1.4 (208)	27.3 ± 1.4 (156)
Obese (> 30)	35.8 ± 5.8 (471)	35.7 ± 4.5 (139)	35.6 ± 5.8 (168)	35.6 ± 6.2 (143)
Body surface area[2,*] (m^2)	1.9 ± 0.3 (1922)	1.9 ± 0.3 (614)	1.9 ± 0.3 (646)	1.9 ± 0.3 (560)

N, number of observations; SD, standard deviation; Normal BMI < 25.0 kg/m^2; Overweight BMI ≥ 25.0 and < 30.0 kg/m^2; Obese BMI ≥ 30.0 kg/m^2
(N* calculated when available)
Percentages (%) may not add to 100 due to rounding.
^ Includes all participants, including those that did not have a diagnosis provided
* Mosteller formula used to calculate body surface area = ([Height(cm) x Weight(kg)]/3600)$^{1/2}$

Validation

Data validation checks included reviewing all missing fields, as well as minimum and maximum values. 10 patients were excluded from the analysis due to age < 18 years old. Initial analysis also revealed height and weight columns were switched for one site when BMI was calculated using height and weight variables.

30 patients' data were validated by physician chart review. Each investigator compared a short list of patients' data from a centers' EHR system to the data entered in CONGENERATE and then provided in the data extract. One error was identified and corrected in the dataset in two patients at a single center. (Height and weight variables were incorrectly entered in EHR).

Conclusions

- First study to report the application of a tailored clinical research information system for ACHD.
- Automated acquisition of existing EHR data to a multicenter database can be achieved with accurate demographic information, whereas more uniformity in anatomical detail is required.
- The population sampled was predominantly female, Caucasian/non-Hispanic and nearly two-thirds of patients had moderate or severe congenital heart disease.
- Obesity prevalence was similar to published US averages.

Key References and Acknowledgements

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Disclosures

No authors have any disclosures relevant to this work