

## Assessment of Electronic Health Information System Use and Need in US Adult Congenital Heart Disease Centers

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### ABSTRACT

**Objectives.** Efforts to improve care for adult congenital heart disease (ACHD) patients necessitates collection of accurate, detailed, longitudinal data. We sought to document what electronic health record systems are currently available at ACHD centers and to assess national interest in a uniform ACHD-focused system.

**Design.** Directors of ACHD centers in the United States were invited to complete an online questionnaire regarding current health information systems at their institution both for general cardiology and for ACHD. Topics that were surveyed included utility and perceived limitations of currently available systems. The survey also assessed the level of interest in an ACHD-specific system, and its optimal functions.

**Results.** Thirty-four centers responded, representing both pediatric and adult institutions that care for patients with ACHD. Of these, 80% reported using a variety of commercially supported electronic medical record products, whereas only 50% employed an ACHD-specific noncommercial database to supplement their institutional system. Comparison of the two systems revealed that most clinical activities are pursued through the institutional electronic medical record system. Research and tracking of clinical activities were the primary uses of ACHD-specific systems, which have several noted limitations. Strong interest in an integrated ACHD-specific system was found among responders.

**Conclusions.** There is both an unmet need and a strong interest in an ACHD-oriented electronic health record that could facilitate research, outcome tracking, quality assurance, and inter-institutional collaboration, all functions that are lacking in electronic health systems currently in use.

**Key Words.** Adult Congenital Heart Disease; Electronic Health Record; Health Information Technology

### Background

The growing health care needs of adults with congenital heart disease (ACHD) mandates improved multicenter collaboration, research, quality assurance, and data on long-term outcomes.<sup>1</sup> Currently, the lack of a uniform information infrastructure designed to collect data and support this critical mission is widely recognized as a major obstacle to improved care.<sup>2-4</sup> At the center of efforts to fill this gap is the need to create an international standard electronic health information system for collection of clinical data. Standardized data collection across centers could serve as the backbone of such an infrastructure and offer a quantum leap in achieving new levels

of cost-effective, evidence-based, uniformly high-quality care for this complex, pioneer cohort of patients.

We sought to assess current health information resources and needs among ACHD centers in the United States. The general goals of the present study were to assess the quantity and quality of existing health information resources for ACHD centers, and to identify key features essential to a broadly attractive ACHD-specific information system.

### Methods

A five-part survey was developed to assess: (1) institutional characteristics; (2) use and qualities of

an institutional electronic medical record (EMR) in general cardiology; (3) use and qualities of an ACHD-specific electronic information system or database; (4) potential interest in a uniform ACHD-specific system; and (5) specific features desired in such a system. The survey asked questions about the utility and limitations of both general cardiology and ACHD-specific systems on a four-point scale consisting of *always*, *frequently*, *sometimes*, or *never*. Questions regarding desired features of a potential ACHD-specific system were similarly rated on a four-point scale consisting of *critical*, *very important*, *indifferent*, or *not important*. The survey was published online by the investigators. Responses were solicited from the Adult Congenital Heart Association (ACHA) listing of self-identified ACHD centers in the United States (n = 80). Each program was contacted via e-mail, with regular reminders to nonresponders until no further responses were generated. Respondents were asked to identify their institution to ensure no more than one response from each center, but subsequent analysis was done blinded to center/responder. Estimates of patient volume for each center were obtained from self-reported surveys previously collected by the ACHA.

For analysis, categorical responses were expressed as percentage of total responses given. Questions regarding the use and limitations of existing systems were identical for general cardiology systems and for ACHD-specific systems, and answers were compared using Fisher's exact test, where *always* and *frequently* were dichotomously compared with *sometimes* and *never* responses for simplicity. The frequency of individual responses is expressed as percentage of all responses. Total clinic visits/year was compared between centers responding and not responding using nonparametric Mann-Whitney testing. Two-tailed  $P < .05$  were considered statistically significant.

## Results

### Program Characteristics

Thirty-five centers completed the online questionnaire. The most common self-identified role of respondents was director (n = 23, 66%) or cardiologist (adult or pediatric, n = 6). Thirty-one (89%) institutions were classified as academic. Seventeen (49%) centers served both pediatric and adult patients, eight (23%) were exclusively adult centers, and nine (26%) were exclusively pediatric.

Twenty-six centers (74%) stated that over 75% of their practice was ACHD. Clinic volumes based on prior reports of outpatient visits in 2008 were available for all but one responding institution. Total estimated outpatient visits was higher in responding institutions (26 729, 61% of total), than in the nonresponding (17 197, 39% of total). The responding institutions (n = 34) had, on average, a significantly larger number of annual outpatient visits ( $878 \pm 112$ ) compared with the nonresponding institutions ( $419 \pm 50$ ;  $P = .0010$  by Mann-Whitney test).

### Current Use of Health Information Systems or Databases

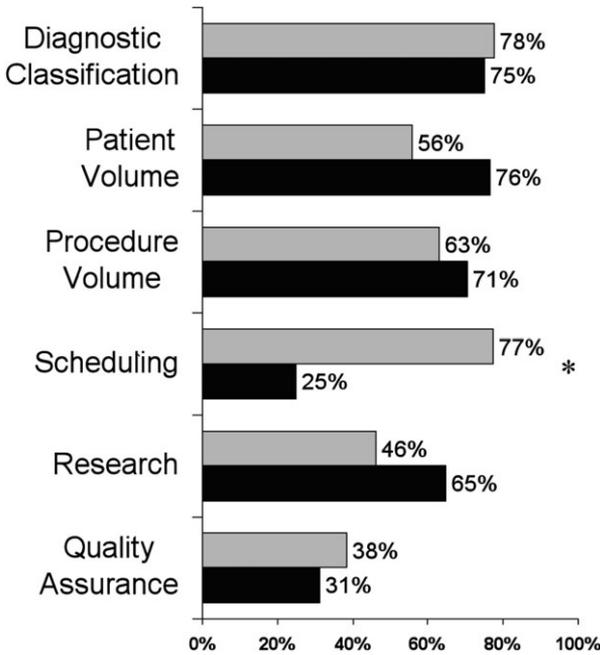
Out of the 35 responders, 27 (79%) reported currently using an EMR. General cardiology systems used were nearly all commercially supported clinical software (Table 1). Seven centers listed at least two separate systems in place; the bulk of these were combination adult/pediatric ACHD programs. In contrast only 17 (49%) centers reported using an ACHD-specific system or database. These were typically Microsoft Excel (eight centers, 47%) or Access (five centers, 29%) databases rather than commercial software. One center used CAPS (Cardiac Ambulatory Patient System), a system specifically designed to manage cardiac ambulatory clinics for adult congenital patients.

Major uses and specific tasks performed on existing systems were compared (Figures 1 and 2). Institutional EMRs were far more commonly used for routine clinical management including preparing outpatient clinic notes, generating letters, inpatient notes, ordering tests, writing prescriptions, checking test results, scheduling, and billing. Classification of anatomic diagnosis was commonly used in both. ACHD-specific systems were more commonly used for tracking patient

**Table 1.** Current Systems in Use for General Cardiology Purposes

Vendor	n (%)
EPIC	13 (37)
Cerner	4 (11)
Eclipsys	3 (9)
GE Healthcare	3 (9)
Cardio IMS	3 (9)
Lumedx	2 (6)
Hospital-specific	4 (11)
Other*	5 (15)
Unknown	1 (3)

\*Other includes Allscripts, McKesson, Citrix, StarPanel, PCIMS.



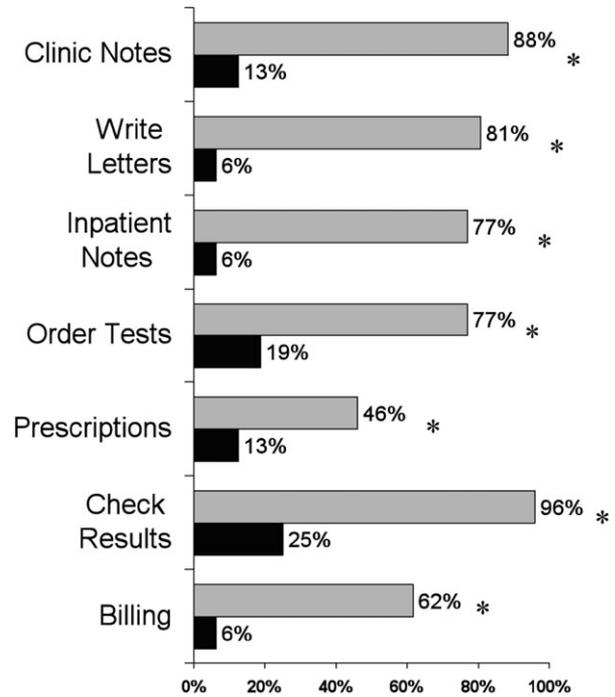
**Figure 1.** Comparison of reported major uses of health information systems for general cardiology (gray bars) vs. adult congenital heart disease care (black bars) of centers indicating existing use of either system, percentage of responses of *always* or *frequently* for each specific task are shown. \* $P < .05$  by Fisher's exact test.

volume, procedural volume, or research. Use of quality assurance prompts or reminders was not commonly used in either type.

Perceived limitations of both data systems were also compared. ACHD-specific systems were more often considered “to contain limited information” (59% vs. 38%), “not kept up regularly” (63% vs. 46%), “accessible from only a single computer” (29% vs. 8%), or “not accessible remotely” (35% vs. 4%).

**Interest in ACHD-specific Software and Desired Functionality**

Regarding interest in a freely available ACHD-specific information system, 17 centers (49%) indicated “very interested, would eagerly sign on as a test site” and 16 (46%) indicated “interested, would want to learn more.” One center selected “not interested, we don't have the resources to keep up a database right now.” To the question, “Would you expect to benefit from a comprehensive ACHD-specific information system?”, 25 centers (71%) answered “It will surely help us, we need it,” as opposed to seven (20%) answering “It might help us, but we're doing fine now.”



**Figure 2.** Comparison of reported specific services of health information systems for general cardiology (gray bars) vs. adult congenital heart disease care (black bars) of centers indicating existing use of either system, percentage of responses of *always* or *frequently* for each specific task are shown. \* $P < .05$  by Fisher's exact test.

Only three (9%) centers indicated short-term plans (about 1 year) to install an ACHD-specific system, seven (17%) medium-term plans (within 2–4 years), and 21 (60%) indicated no plans in place.

Regarding the importance of specific potential features of a theoretical ACHD-specific system (Table 2), there was moderate interest in features related to patient management such as scheduling and billing. There was near universal interest in other program administration tasks such as reports of clinical or procedural volume. Nearly every program indicated an interest in multicenter cooperation such as a registry, research contributions, quality assurance programs, or comparing data across centers. Desired functions also included the ability to be fully integrated with existing systems, ability to import existing data, and ease of upgrades.

**Discussion**

The major findings of the survey are: (1) majority of responding centers already have EMR resources

**Table 2.** Interest in Specific Functions of an ACHD-specific System, if Available

Task	%
Patient evaluation	
Patient notes	63
Classify diagnoses	97
Writing prescriptions	34
Ordering tests	34
Generate/send letters	72
Checking test results	56
Inpatient notes/sign outs	50
Inpatient consultation	50
Program administration	
Scheduling	63
Patient billing	45
Summary reports of patient volume	97
Tracking procedures/surgeries	97
Conduct a research project locally	97
Provide quality assurance reminders	94
Database management	
Fully integrated with existing system	94
Import existing data	91
Accessible throughout the institution	94
Accessible remotely/from home	94
Easy updates and/or upgrades	100
Generate my own queries/reports	100
Multicenter collaboration	
Contribute to multicenter registry	100
Contribute to multicenter research	100
Using the same software as other ACHD institutions internationally	85
Outcomes review of my center compared with others	97

ACHD, adult congenital heart disease.

for general cardiology use, which means that abundant clinical information on ACHD patients is already available in electronic format; (2) in contrast, a majority of responding centers either have no or very limited information technology (IT) resources for ACHD-specific use; (3) there is strong interest in a comprehensive, integrated ACHD system, and belief in the value of such a system; and (4) there is strong interest in multicenter collaboration through an ACHD system.

Widespread use and government incentives for EMR adoption creates extraordinary opportunities for health care improvement which should also extend to the ACHD community. To reap the benefits of EMRs for tracking outcomes, quality assurance, and clinical research for a small subset such as ACHD, new IT tools are needed to collect and share this data.

Our results suggest that although clinical data on ACHD patients exists in electronic format, it is generally not being harvested in a way that facilitates ACHD program building or multicenter data sharing. We found considerable heterogeneity of clinical software currently in use, sometimes even within the same program. Therefore, relevant data

for specific research topics may be difficult to extract from a general utility EMR. This was encountered in one implementation of a research-oriented database for diabetic patients in Sweden.<sup>5</sup> Template-based data entry has been advocated as a solution to this problem.<sup>6</sup>

For other populations or specific procedures, centralized databases extracted from EMRs have been both advocated and implemented. Quality assurance is one important application, as has been accomplished for colonoscopy.<sup>7</sup> A system for tracking outcomes of treatment for chronic obstructive pulmonary disease has been described but implementation has not been reported.<sup>8</sup> The Veterans Affairs (VA) medical system has broadly implemented a patient-centered EMR that is nationally linked. Backus et al. report on a clinical registry that has successfully been employed to identify and track patients in the system with HIV and hepatitis C virus infections.<sup>9</sup> These examples highlight the opportunity to enhance care at multiple levels with respect to specific constituencies by extraction of specialized data from generalized EMRs.

While efforts to create and establish a successful multicenter collaborative program in congenital heart disease, with uniform collection of clinical data across centers, assessments of existing resources and perceived needs becomes vitally important. Data presented here will be useful in accurate planning and fund-raising efforts.

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### Authorship Contributions

Dr. Weiss participated in data analysis, manuscript authorship, and manuscript submission. Dr. Marelli proposed the study, participated in study design, data review, and manuscript review. Mr. Maurais, BSc MBA was the primary builder of the online survey contributing to its design and publication, as well as primary data collection and first analysis. Dr. Grant and Mr. Rehel were both instrumental in study design, survey design and execution, as well as manuscript review and approval. Dr. Chetaille also participated in designing the survey tool for the study and its publication. Dr. Khairy was influential in study design, data analysis, manuscript review, as well as funding. Dr. Broberg

oversaw the entirety of the study from study design, execution, analysis, and manuscript preparation to manuscript submission.

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