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Research Update

EHR data from more than 1.2 million children harnessed for research

from the **AAP Department of Research**

A new source of clinical data from the electronic health records (EHRs) of more than 1.2 million U.S. children soon will be available to child health researchers.

Data were collected through an initiative called Comparative Effectiveness Research through Collaborative Electronic Reporting (CER²). The goal of CER² is to engage U.S. researchers to consider using these data to generate knowledge and improve health care for children (Fiks AG, et al. *Pediatrics*. July 2015).

Led by the AAP Pediatric Research in Office Settings (PROS) network, CER² established a consortium of partners to link data from PROS with data from independent practices and health systems. CER² includes pediatric patients seen in 222 urban, suburban and rural private and public sector practices and clinics in 27 states (see map).

The Institute of Medicine hails clinical data as "...a basic staple of health learning" and "... the resource most central to health care progress." Although electronic records are used increasingly to explore questions in adult health and hospital care, CER² is one of the first data sources designed to focus entirely on questions important to child health. Examples of such questions include pediatric medication use, safety and effectiveness, as well as preventive care, treatment of acute conditions and management of chronic health conditions.

Consortium members have worked for more than three years to collect data from EHRs and do the programming needed to turn clinical information into data that can be analyzed for research. This is necessary because 1) scores of vendors sell EHR systems for primary care, each with different database structures written in different programming languages; and 2) EHRs have been built primarily as systems for data input rather than for data extraction.

It is difficult to extract data from EHRs because some elements may be entered inconsistently (e.g., age may be entered as year old, yr. old, y.o. or yo), or may be missing; free text entries are especially challenging for data extraction. Other elements need to be calculated from clinical data before they can be used for research (e.g., body mass index can be calculated from date of birth, date

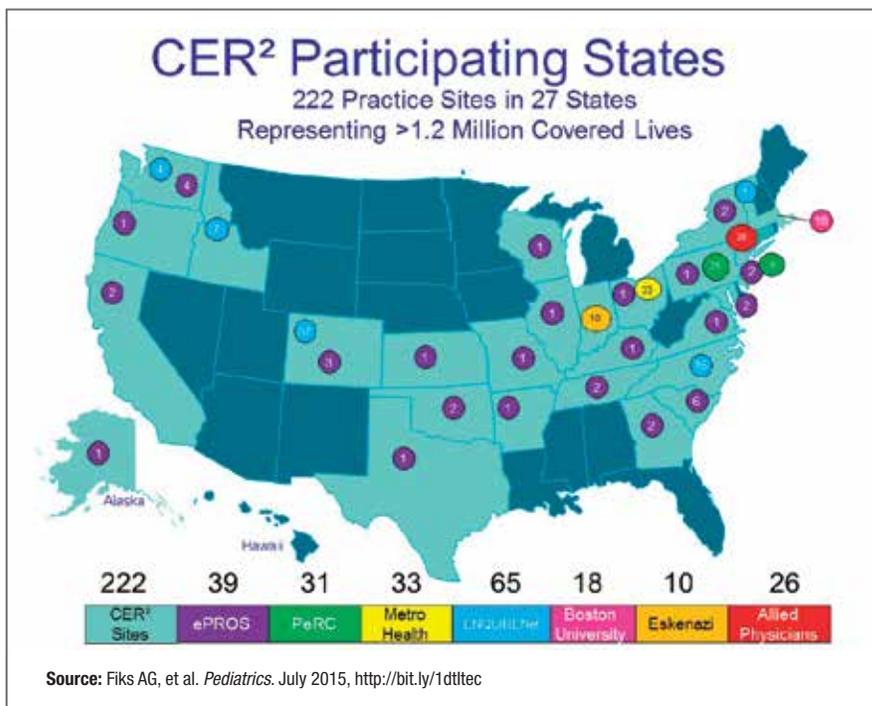
of visit, gender, height and weight). All data elements must be complete to do this.

Still other data must come from more than one part of the record. Identification of asthma, for example, must come from one or more of five elements that are used differently by different clinicians in different record systems: ICD codes, problem lists, pulmonary function tests and prescriptions for bronchodilators or inhaled steroids.

This process, therefore, involves careful review to flag missing data, outliers and implausible values (e.g., a 10-year-old whose weight is recorded in ounces instead of pounds).

Consortium members also had to develop procedures for governance and decision-making, data security and management, and protection of patient and pediatrician privacy. Consolidated data are stored securely in a coordinating center at The Children's Hospital of Philadelphia (CHOP), and approved collaborators will be granted permission to access limited data.

The team is working on four proof-of-concept studies that relate to the Best Pharmaceuticals for Children Act (BPCA) and represent questions that can be studied using CER² data:



- prevalence of the use of specific atypical antipsychotics,
- effects of exposure to atypical antipsychotics on metabolic indicators, including weight and growth,
- prevalence of on- and off-label use of asthma medications frequently prescribed to children, and
- rates of psychotropic polypharmacy and associated measures of drug safety, efficacy and potential side effects.

All four studies include children 3-18 years old and compare results by race/ethnicity, gender and age. Among the many strengths of such a large dataset are the ability to detect rare events, identify patterns or potential questions for further study, and track trends over time.

CER² is a collaboration among the Academy and researchers at CHOP and the CHOP Pediatric Research Consortium; the

RESOURCES

- To learn more about how researchers can get involved with CER², contact Laura Shone, Dr.P.H., M.S.W., in the AAP Division of Primary Care Research, at lshone@aap.org or 800-433-9016, ext. 7910.
- For more information about CER², visit <http://www2.aap.org/pros/CER2.htm>.
- For more information about using electronic health records for health services research, visit <http://bit.ly/1M15gcK>.

American Academy of Family Physicians' Electronic National Quality Improvement and Research Network; The MetroHealth System/Case Western Reserve School of Medicine; Boston Medical Center; Allied Physicians; Eskenazi Health in Indiana; and the University of Vermont.

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