

Testing the Consensus-Based Emergency Information Form

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In the current issue of *Pediatrics*, an innovative article by Abraham et al¹, “Impact of emergency information forms for children with medical complexity: a simulation study” presents an excellent example of the use of emergency scenarios to study otherwise difficult-to-observe events in emergency and critical care; specifically, emergencies of medically complex children. The emergency information form (EIF) organizes emergency-focused medical information for children with special health care needs (CSHCN). Before the advent of electronic health records (EHRs) in the 1990s, the EIF began as sets of wallet cards promoted by state Emergency Medical Services for Children Programs in New Mexico and Ohio that listed medications and diagnoses. This was carried forward by Sacchetti and Gerardi who created a concise 1-page paper summary with a unique added focus of an advice section that listed a child’s special problem, emergencies likely to arise from this problem, and recommended treatments.²

In the initial joint American Academy of Pediatrics (AAP) and American College of Emergency Physician Committee on Pediatric Emergency Medicine policy statement, “Emergency Preparedness for CSHCN”, it is recommended that primary and specialty caregivers join with the family to prepare the emergency-focused summary.³ The AAP–American College of Emergency Physician instrument and policy statement were reviewed in a consensus-driven process by a wide spectrum of those organization’s committees. In addition, the renewal in 2010 included

broad-based input from the Emergency Nurses Association, the National Association of EMS Physicians, and the federal EMS for Children Program, among others.⁴

What the EIF initiative has always lacked is hard evidence of efficacy or a basis for the choice of elements.⁵ Irmiter and coworkers⁶ from American Medical Association developed a set of data elements for a disaster health record from a consensus process, but again, this only represented opinion. The current article by Abraham et al validates the usefulness of this EIF summary.

The strength of the Abraham et al¹ work lies in the use of an experimental methodology to investigate the use of the EIF for a simulated emergency, which allowed evaluation of concrete performance outcomes. The choice of subjects and scenarios limited the study of the EIF’s capacity to solve communication barriers for parents and patients. Previous investigations have only explored parental and provider impressions of the impact of the EIF. The impact in actual emergencies proved difficult to study. A drill in which actual CSHCN participated altered impressions of need for emergency-focused summaries by providers and parents, but lacked performance outcomes.⁷

Health informatics aspects of the EIF were considered in the 2010 AAP Revision of Statement, jointly submitted by the Committee on Pediatric Emergency Medicine and the AAP Council on Clinical Information Technology. The uniformity of the EIF presentation format and information

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adds value for the emergency and critical care provider, but the instrument is still underrecognized and underutilized. Widespread adoption of personal health records (PHR) promotes public acceptance for a standardized EIF format, but also highlights the lack of EHR interoperability. The use of a clinical document architecture or other interoperable format for the EIF can create a set of EIF data element values that will promote data sharing.

Privacy, security, interoperability, and adaptation to change are the major remaining challenges to widespread adoption of an EIF system. A critical mass of EIF users, sufficient to drive community adoption, has not been assembled in a locale to date. A state or other entity, such as an accountable care organization, could decide to incentivize EIF completion to stimulate adoption. A self-contained, Web-based EIF instrument to be accessed by a provider in an emergency department was met with resistance in the Minnesota study and resulted in poor emergency use of the EIF in children with heart disease.⁸ Parents have reported reticence of health care entities to plug an external data source, such as the parent's flash drive, into the system. Recent hostile takeovers of EHRs and hospital information systems will only heighten this concern.⁹ The 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act extended Health Insurance Portability and Accountability Act safeguards to PHRs hosted by health care entities.¹⁰ Patients are not bound by the Health Insurance Portability and Accountability Act, but patient groups hosting PHR data repositories and functioning as a health care clearinghouse are included in the 2011 Office of National Coordinator PHR Model Privacy Notice Guideline.¹¹ A single, well-motivated family with CSHCN in isolation is still best off to carry a paper EIF.

In summary, the article by Abraham and colleagues¹ demonstrates the potential impact of the availability of an EIF system to improve emergency care of a child with complex medical care. The implementers of an EIF system can consider the issues under discussion. Only adoption by the public and providers remains a significant challenge. Adoption of an EIF program to improve emergency care for CSHCN will continue as an example of a stakeholder-driven exercise in community development for sustainable improvement that can be undertaken by an Emergency Medical Service for Children Program, a Children's Hospital or a state CSHCN program. The information presented by Abraham and coworkers¹ will inform any widespread adoption of the EIF.

ABBREVIATIONS

AAP: American Academy of Pediatrics
 CSHCN: children with special health care needs
 EHR: electronic health record
 EIF: emergency information form
 PHR: personal health record

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