

Development of a Web-based Database to Manage American College of Emergency Physicians/American Academy of Pediatrics Emergency Information Forms

Lee A. Pyles, MD, Claudia Hines, RN, Michael Patock, BS, Maggie Schied, RN, Jessica Chase, RN, Kathy Jamrozek, RN, Jeffrey S. Schiff, MD

Abstract

Children with special health care needs require special advanced planning for their unique emergencies. A Web site has been developed to allow secure Internet access to a database of Emergency Information Forms developed using the American College of Emergency Physicians/American Academy of Pediatrics format. The content and organization of the Web site, found at <http://www.memscis.org>, are described. A tour of the site is available. A set of XML data elements has been defined. Additional

disaster preparedness elements have been added to the American College of Emergency Physicians/American Academy of Pediatrics Emergency Information Forms. The organization, security, and relationship of the site to electronic health records are described. **Key words:** children with special health care needs; emergency preparedness; emergency information form; Internet. *ACADEMIC EMERGENCY MEDICINE* 2005; 12:257-261.

Striving for quality in health care systems demands that emergency physicians avail themselves of all pertinent information regarding their patients, especially children with special health care needs. This requires rapid, timely access to organized information. The American College of Emergency Physicians (ACEP) and the American Academy of Pediatrics (AAP) have endorsed a minimum data set for use in emergencies that is known as the Emergency Information Form (EIF).^{1,2} Optimally, the EIF is formulated in the special-needs child's primary site of medical care (designated the Medical Home by the AAP) by primary and subspecialty providers in collaboration with the family. Schools, day care, and respite care providers are examples of other constituents who may need to use or contribute to the EIF for a special-needs child.

The need for easy access to the medical history of special-needs children is illustrated by a number of research studies. Carracio et al. interviewed caregivers of 100 children (mean age, 55 months) being brought to a pediatric specialty clinic.³ Fifty-three percent of caregivers were unable to provide their children's specific diagnoses. Of these, one half could provide a lay diagnosis, whereas the remaining one half could only identify the organ system involved or that the child had a significant medical history. For children taking medications, 29% of caretakers could not provide an accurate medication list. The name of the subspecialist and the telephone number of the subspecialty clinic were unknown by 25% of caretakers. On the other hand, in a study of randomly selected parents, Porter showed an 80% concordance between the emergency chief complaint typed into an emergency department tracking system by parents versus the complaint listed by the emergency physician.⁴

The most inclusive definition of children with special health care needs are those children who require resources at a level greater than the norm or who could potentially require such increased levels of resources.⁵ The working definition of "children with special health care needs" for the purpose of EIF planning is those children who are at a risk for a unique emergency that requires special preparation by the child's Medical Home to assist the emergency providers in meeting the child's emergency needs. Formulation of emergency care plans for children with special health care needs has been recommended by the federal Emergency Medical Services for Children

From the Department of Pediatrics, University of Minnesota (LAP), Minneapolis, MN; Children's Health Care of Minneapolis and St. Paul (CH, MS, JC, JSS), St. Paul, MN; Fairview-University Medical Center (KJ), Minneapolis, MN; Image Trend, Inc. (MP), Lakeville, MN; and Emergency Medical Services for Children Resource Center of Minnesota, MN (all authors).

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Address for correspondence and reprints: Lee A. Pyles, MD, Division of Pediatric Cardiology, Mayo Mail Center #94, University of Minnesota, Minneapolis, MN 55455. Fax: 612-626-2467; e-mail: pyles001@umn.edu.

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program through its Children with Special Health Care Needs Task Force Report of January 1997. The report notes, "If the child is at risk for future medical emergencies, the child and family should participate in developing a written emergency care plan." The report advocates training for all participants in the emergency plan as well as ready availability of the plan.^{1,6}

Several precursors of the current EIF and other sorts of "passports" have been used to disseminate medical information. Emergency Medical Services for Children projects from New Mexico, Wisconsin, Ohio, and Ohio/Kentucky/West Virginia have used wallet cards or one-page summaries that are given to parents.⁷ The wallet cards have separate pages for demographics, diagnoses, conditions, and medications and can be updated by exchanging single cards. In West Virginia, a single-page (front/back) summary was used through the West Virginia Maternal and Child Health Bureau Children with Special Health Care Needs Division.⁸ Adjuncts to the program included window stickers identifying homes of children with special needs and linkage to 911 to alert emergency medical services (EMS) providers to look in the refrigerator for a vial containing the summary. Rhode Island Emergency Medical Services for Children introduced an electronic Web-based system (PEDISTAT).⁹ Sherman and Capen have described a program to streamline and standardize access to care for patients with asthma with a history of life-threatening events.¹⁰ Termed the "Red Alert Program," the parents, primary care providers, EMS providers, schools, and emergency physicians were educated as to the need for early access to aggressive acute treatment of the child's asthma and the parents were given written documentation of the history of severe asthma. In Minnesota, several paper-based programs have heightened local awareness of the need for emergency preparedness for children with special health care needs.¹¹ All of the paper-based systems and wallet-card systems share the weakness of difficulty in maintaining up-to-date information. This report describes development of a system to organize, secure, and make available, via the World Wide Web, EIFs for infants and children with heart disease known as Minnesota Emergency Medical Services for Children Information System (MEMSCIS).

METHODS

Consensus Building. The EIF data elements were determined through a consensus-building process within the AAP and the ACEP, aided by discussion at a 1998 National Association of Children's Hospitals and Related Institutions meeting of various interested parties to discuss emergency planning for children with special health care needs. Committees on pediatric emergency medicine from the ACEP and the

AAP held joint meetings to consider the EIF and emergency preparedness policy statements. The most important point of the ACEP and AAP policies was that the EIF is part of a plan for emergency preparedness for a child with special health care needs. Additional points stressed were as follows: the summary and plan should be jointly formulated by the child's caregivers, primary care provider, and all subspecialty providers; the summary should be regularly updated and maintained in an accessible and usable format; parents and providers should receive training; mechanisms to identify the children with special health care needs should be established with local EMS and hospitals; a standardized form should be used, hence the development of the EIF including the list of standard elements; and 24-hour rapid access to the summary was to be assured. Linkage to 911 systems was recommended. Confidentiality was stressed in the pre-Health Insurance Portability and Accountability Act (HIPAA) document.

Process. The process of developing the MEMSCIS database and Web application began with discussions with parents, providers, discharge planners, subspecialty physicians, and software developers. The software developer, ImageTrend, Inc. (Lakeville, MN), participated in the meetings to design the database and Web application with the stakeholders. A list of programming requirements was presented to ImageTrend, Inc., to help guide design of the database. These include the following: use the ACEP/AAP format for the EIF, safeguard data with passwords and role-specific access and authorship privileges, allow access to the information 24 hours a day/seven days a week, encrypt data for Internet transmission, build linkages to helpful Internet sites, audit Web site access, facilitate feedback from Web site users, and facilitate reporting of patient characteristics and other information. The project investigators and ImageTrend, Inc., reviewed available drafts and adopted HIPAA guidelines to assure development of a HIPAA compliance-capable system.

Database Development. The list of diagnoses and procedures developed by Pediatric Cardiac Care Consortium, a multicenter pediatric cardiology and cardiac surgery quality improvement combine, was used for the database. A hierarchical choice list was developed from the Pediatric Cardiac Care Consortium lists. A search function has also subsequently been added. A formulary of common medications used in the management of children with heart disease was developed. The formulary includes cardiac, gastrointestinal, pulmonary, and immunosuppressive medications and miscellaneous agents such as vitamins. The ImageTrend, Inc., programmers developed a list of XML data definitions for the EIF elements. These XML elements were similar to those

used for the statewide EMS database for the Minnesota EMS Regulatory Board. The plan is to achieve compliance with HL-7 3.0, which will be an XML-based standard as 3.0 becomes operational.

RESULTS

Data Organization. The data are organized in MEMSCIS in six general classes of data (Table 1): patient information, contact information (providers and family), encounter history, resource requirements, advanced directive, and documents. All of the elements recommended in the standard ACEP/AAP EIF and accompanying policy statements are available. The site is organized to provide different looks depending on the class of user that is logged in. The provider goes to the hospital list, selects a patient, and then sees the following menu: patient information, contact information, encounter history, resource requirements, advanced directive, documents, and full EIF. The EIF can either be printed from various views as full disclosures of a historical summary of all encounter entries or as a current EIF (most current information only). New clinical information is entered in a date-specific fashion via an encounter. Encounter type is designated clinic, emergency, parent update, physician/nurse update, EMS, telephone update, and home resource update. Within an encounter, data are organized into demographics, management data, precautions/allergies, immunizations, common problems, and comments. Within the management section is found diagnoses, procedures, medications, and physical findings. Baseline vital signs and findings on physical examination, including neurologic examination, are specified in MEMSCIS, which were not specified in the ACEP/AAP EIF. As part of a response to the need for disaster preparedness, a section for listing home physical resources has been included. The resources include a need for home oxygen, electricity, water, gas, and so on. A free-text section has been created to allow storage of downloaded documents. This section can store text or images. A total of 17 relational tables exist within the SQL server database. The XML data elements are listed in the Web resource section. The category of resource requirements contains data elements that are not in-

cluded in the EIF but that may be critical during a natural disaster or a mass casualty occurrence (Figure 1).

HIPAA Privacy and Security. A HIPAA privacy and security plan has been formulated for MEMSCIS. Screen names and passwords are assigned when a parent or provider is enrolled. The password is then changed by the new participant with the first access. Subsequently, an automatic password update is required every three months. Parents are able to control routine access to the child's record. The data are stored in a secure data farm in downtown Minneapolis with a dual power grid, physical security, a data recovery plan, and physical separation of data within multiple servers in an SQL server database. Data are stored in encrypted format. The access privilege system is organized to allow a single provider to have a single user name and password and to then be allowed access to a child's record by the parent. The parent will not know the provider screen name or password. Based on varying levels of privileges, parents, providers, relatives, and out-of-hospital providers can be given access to information from a single patient, only their own patients, a single hospital group of patients, or their physician group's patients at several hospitals. HIPAA privacy and security training by providers is required by the various participating institutions. Audit of all Web access is maintained in an SQL server.

A special emergency access that is known as "break the glass" has been created and approved by families as part of the protocol approved by the institutional review boards of the University of Minnesota and children's hospitals and clinics. This access is permissible for anyone who is able to access the Web site and enter a child's first and last name or the last name and date of birth. An attempt is made to establish the identity of the inquirer by asking for a driver's, medical, nursing, or emergency medical technician license number. In addition, the URL of the computer requesting the access is recorded. Upon use of this emergency access, the family and the project director are notified of the data access via e-mail or U.S. mail. The access is in read-only format to the child's current EIF, which is then printable. It is also possible to

TABLE 1. MEMSCIS Data Classes

Patient information	Demographics, insurance information, permit for "break the glass"
Contact information	Names, addresses, telephone numbers, and fax numbers for care providers
Encounter history	Diagnoses, procedures, medications, allergies, baseline physical findings, vital signs, and special precautions/anticipated problems
Resource requirements	See Figure 1. Information useful to respond to disaster needs for children with special health care needs. Sets of EIFs can be assembled for a given geographic area.
Advanced directive	In Minnesota and most other states, the official advanced directive form cannot be supplanted. The Web site notes the existence and location of the form.
Documents	A section available for download/entry of text or images

MEMSCIS = Minnesota Emergency Medical Services for Children Information System.

DISCUSSION

Home Telephone	<input type="radio"/> Yes <input checked="" type="radio"/> No
Home Electricity	<input type="radio"/> Yes <input checked="" type="radio"/> No
Electric Generator	<input type="radio"/> Yes <input checked="" type="radio"/> No
Oxygen Requirement	<input type="radio"/> Yes <input checked="" type="radio"/> No
Oxygen	<input type="text" value=""/>
Running Water	<input type="radio"/> Yes <input checked="" type="radio"/> No
Source of Heat	<input type="text" value=""/>
EMT Availability	<input type="radio"/> Yes <input checked="" type="radio"/> No
First Responder Availability	<input type="radio"/> Yes <input checked="" type="radio"/> No
EMT Response Time	<input type="text" value="0"/> Minutes
Paramedic Availability	<input type="radio"/> Yes <input checked="" type="radio"/> No
Paramedic Response Time	<input type="text" value="0"/> Minutes
Other	<input type="text" value=""/>
Special Considerations for EMS	<input type="text" value=""/>

Figure 1. Home resource requirements and availabilities.

access the Web site emergently via the break-the-glass method and request a report of all enrolled persons requiring a certain resource or living in a certain area. This access also results in notification.

Initial Experience and Lessons Learned. Ninety-five children have been enrolled in MEMSCIS, and an additional 77 children are serving as control subjects. All of the subjects have undergone surgery or been treated for congestive heart failure or heart arrhythmia. Emergency access has been used several times, including three instances of break-the-glass access. Parents have provided access for emergency personnel and also arrived in emergency departments with their written summaries. Some parents have forgotten to inform the emergency physicians of the study and, in a few instances, emergency physicians have refused to access the EIF Web summary. To date, more than 95% of families are approving the capability for break-the-glass emergency access. The parents are able to switch off this access by accessing the Web site at any time.

The lessons learned from the study start-up present common themes of a need to involve as many stakeholders as possible and to demonstrate to these participants that the site is easily usable. To obtain parental participation, Web site programming has been set up and enhanced to optimize ease of use by persons lacking experience with health-related Web sites and data. To obtain primary and subspecialty provider participation, ease of use remains the primary issue. To obtain emergency provider participation, visits and seminars have been conducted in a number of emergency departments, the parents are given instruction cards and other information to present to the providers, and follow-up is sought via survey after an emergency provider has seen one of the children enrolled in the study, irrespective of whether the MEMSCIS Web site was used.

EIF as Part of an Electronic Health Record. The American Academy of Science Institute of Medicine has recommended institution of a universal electronic medical or health record, stressing the importance of computerized physician order entry in error reduction in health care.^{12,13} The Leapfrog Group has identified the presence of an electronic health record in a health care system as an important quality indicator.¹⁴ The estimate of the amount of multiply entered electronic health information may be as high as 60%. A review of electronic health records by a critical care group estimated that only three of 16 (19%) were organized so as to be useful in an emergency.¹⁵ An emergency summary such as the EIF can be an important component of an electronic health record that can facilitate emergency care, hospital admission, and consultation by additional health care providers, as is recommended by the proponents of the draft continuity of care record proposed by the ASTM and the Massachusetts Medical Society.

Parents as Important Stakeholders. Considerable local and national discussion has focused on the role of parents in maintenance of the health information in a system of EIFs such as MEMSCIS. The parents are the single consistent stakeholders over the continuum of care in the medical model. An accurate emergency summary should help to prevent medication errors at the time of transitions of care such as from the intensive care unit to the pediatric ward or from the hospital back into the home, the rehabilitation and home health services, and the school. The clinical encounter system used in MEMSCIS allows an audit of the information to determine the identity of persons who update the EIF and also the timing of the update.

ImageTrend, Inc., and MEMSCIS as a Trusted Third Party. A major strength of the MEMSCIS Web-based database is the ability to gather information from several health care entities that are providing a number of services that are in direct competition. Due to the unique nature of the delivery of pediatric health care in Minneapolis/St. Paul, a child with special health care needs may receive services at as many as three of the pediatric institutions in the metropolitan area. Significant children's services are provided at the two county hospitals, a children's rehabilitation hospital, a university hospital, and a children's hospital with physical sites in Minneapolis and St. Paul. The ability of MEMSCIS to provide a summary of problem, medication, and past procedure lists gleaned from the several institutions greatly enhances the usefulness of the EIF and emergency plan that are formulated. Parents may be reluctant to allow access to a child's complete health

records, assembled from several institutions, via the Internet. Such a cobbled record will usually lack an overall summarization in the absence of an instrument such as the EIF. In addition, the institutions may be reluctant to share the complete record due to concern to meet the minimum necessary standard and reluctance to allow other institutions to carefully scrutinize the entirety of a patient record. Thus, ImageTrend, Inc., and MEMSCIS can serve the role of a trusted third party, constituted to act only in the best interests of the patient and the health care system.¹⁶

CONCLUSIONS

The concept of the continuity of care record encompasses much of the thinking surrounding the EIF. The cataloging of procedures to be avoided and possible common or recurrent problems is unique to the EIF. This is not a part, for example, of the American College of Cardiology Adult Congenital Heart Disease uniform data set.

Clinical decision making in emergencies can be supported not only with readily accessible information but also with guidelines for the evaluation and treatment of children with unique disease processes.

MEMSCIS, in its network of EIFs, offers the advantage of a medical professional-coordinated summary of the child's information, rather than a strictly patient- or family-driven summary such as that provided by MedicAlert and other proprietary systems.⁹ Formulation of an emergency summary and plan should be an integral part of the medical care plan for any child with special health care needs that are found to be greater than a level usually required by most children in the community, especially when the special needs result in a risk for unique emergencies. The role of the MEMSCIS project in the evolution of the electronic health record is to heighten awareness for the need for emergency planning and continuity of information availability.

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