

AMERICAN ACADEMY OF PEDIATRICS

Task Force on Medical Informatics

Special Requirements for Electronic Medical Record Systems in Pediatrics

ABSTRACT. Electronic medical record (EMR) systems, which are usually designed for adult care, must perform certain functions to be useful in pediatric care. This statement outlines these functions (eg, immunization tracking and pediatric dosing calculations) to assist vendors and standards organizations with software design for pediatric systems. The description of these functions should also provide pediatricians with a set of requirements or desirable features to use when evaluating EMR systems. Particular attention is paid to special aspects of pediatric clinical care and privacy issues unique to pediatrics.

ABBREVIATION. EMR, electronic medical record.

INTRODUCTION

Electronic medical record (EMR) systems that were originally designed for use in adult care are now available to pediatricians.^{1,2} This statement outlines special features necessary for an EMR system to support health care for children. Features of practice management services (billing, accounts receivable, scheduling, payroll, etc), however, are beyond the scope of this document.

An essential function of a pediatric EMR system is to facilitate care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective—termed the “medical home.”³ The purpose of EMR systems is to compile and centralize all pertinent information related to a child’s medical and nonmedical care so as to ensure that optimal pediatric care is provided. In doing so, EMR systems have the capacity to improve the quality of care that children receive from their primary care pediatrician as well as from ancillary health care professionals.

National and international organizations are defining standards for recording, storage, and transmission of patient data.^{4–9} The exceptional diversity of current hardware and software requires implementation of standards for data definition and interchange so that systems can interact.¹⁰ Federal (eg, the Health Insurance Portability and Accountability Act of 1996^{11,12}) and state legislation requires the adoption of standards for transmission of health information in electronic form.¹³ The *International Classification of Diseases, Ninth Revision, Clinical Modification* provides a well-known, standardized terminology

for recording information about diagnoses, but it has proven inadequate to represent detailed information about clinical observations (eg, there is no classification to represent the common finding of fussiness in young infants).¹⁴ Commercial vendors sometimes do not recognize the special needs of pediatric practice. The small size of the pediatric EMR market makes it impractical for many vendors to design and maintain systems specifically for the care of children, so pediatricians often are faced with using a system originally designed for adults.

General attributes of computer-based patient records described by the Institute of Medicine are all vital for pediatric records. These include problem lists, measurement and recording of health status and functional level, statements about the logical basis for all diagnoses and conclusions, linkage with all of a patient’s clinical records across settings and time periods, assurance of confidentiality, widespread accessibility, selective retrieval and formatting, linkage to local and remote knowledge sources, decision support, structured data collection using a defined vocabulary, aiding evaluation of quality and costs of care, and flexibility and expandability to meet evolving practice needs.¹⁰ The intent of this statement is to make vendors and standards organizations aware of special issues in pediatric practice for software design and to provide pediatricians with a set of requirements or desirable features to use when evaluating EMR systems. These include:

DATA REPRESENTATION

- **Growth data.** Attention to the special significance of children’s growth in pediatric practice is essential for any pediatric EMR system. Recording, graphic display, and special calculations of growth patterns is a critical function. The ability to calculate, display, and compare a child’s growth percentiles and body mass index with normal ranges is vital. Because normal growth ranges vary among ethnic and geographic groups, the ability to use different ranges for different patients may be important in some practice settings. Head circumference, an important measurement used almost exclusively for care of pediatric patients, should be a part of these growth monitoring functions. Because small changes in growth parameters may be important to small patients (eg, a few grams’ weight gain in a premature neonate), systems should be able to store data on a small enough scale to represent these changes.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

PEDIATRICS (ISSN 0031 4005). Copyright © 2001 by the American Academy of Pediatrics.

- **Patient identifier.** A universal patient identifier is a desirable but as yet unachieved goal. Any system that is ultimately implemented to assign such identifiers will need to provide for assignment immediately at the time of birth (or even before birth for prenatal procedures performed on the fetus). EMR systems may need to accommodate temporary (ie, changing) data in this key field, including certain identifying data associated with a patient change in the perinatal period. For example, infants are often named with their mother's surname or full name (eg, "Infant Boy Smith" or "Boy June Jones") at the time of birth, and this is changed in the first few days of life. Flexibility of search criteria to allow for changing identification data are desirable in pediatric systems. Systems should be able to maintain a record of multiple names used by a patient.
- **Special terminology and information.** Special terminology is used in pediatric care. EMR systems need to include common pediatric terms (a pediatric lexicon) used to describe pediatric preventive health care (eg, developmental milestones, educational progress, and anticipatory guidance) and physical findings (eg, weak cry, bulging anterior fontanelle, and umbilical granuloma). Currently, standard lexicons are incomplete with respect to pediatric care; system designers will need to provide supplementary nomenclature or allow users to augment supplied lexicons in ways that preserve the value of standard vocabularies and adequately represent pediatric concepts.
- **Age-based normal ranges.** Normal ranges for vital signs and other physiologic parameters change with a child's age. Pediatric EMR systems should allow the user to easily compare a patient's vital signs with age-based normal ranges. The same is true for laboratory values, but normal ranges are usually supplied by the reference laboratory and not the EMR; the EMR should be able to accept normative values provided by the reference laboratory. Systems that allow users to alter normal ranges to represent specific ethnic or geographic populations are desirable.
- **Time of birth.** The time of a child's birth is important in calculating exact age in the first days of life and should not be omitted from EMR systems.

DATA PROCESSING

- **Prescribing of medications.** Prescribing of medications for pediatric patients is based on the age and weight or body surface area of the child. Prescription tools that supply standard recommended adult doses and do not include pediatric dose calculation functions are unlikely to be useful to pediatricians and may be misleading or potentially dangerous in the pediatric context. Functions that facilitate calculation of drug doses based on available data are essential for pediatric care. Decision support tools supplied to assist in selecting medications and preventing errors should include pediatric-specific data.
- **Immunizations.** Efficient recording (data input) and effective display of immunization data are

essential. Mechanisms for immunization decision support (eg, deficiency alerts) that include easy updating as recommendations change should be included.¹⁵ For effective interaction with immunization registries, the ability to flexibly format immunization data and support electronic data interchange with registries is vital. Because physicians who treat infants and children are asked to provide data about immunization completeness in multiple formats, flexibility in a system's ability to provide immunization reports is highly desirable. Features that support reminder systems to prevent missed immunizations would be desirable; these reminder systems can take the form of messages sent to parents, flags for providers during acute care, or other forms.

- **Parents' special documentation requirements.** Parents may ask to review or append chart information. Federal regulations (ie, Health Insurance Portability and Accountability Act privacy regulations¹²) dictate procedures and limitations of parental appendices to a child's chart. Systems should also support the generation and maintenance of summary reports for parents and other health providers regarding children with special health care needs.
- **Reporting.** The ability to easily customize reports to match mandated formats (eg, school or camp physicals or reports to school nurses) would be particularly valuable to pediatric practitioners.

SYSTEM DESIGN

- **Special privacy issues.**
 - * *Adolescent privacy:* Privacy laws regarding adolescents' medical information (especially sexual and mental health and behavior issues) vary from state to state, and policies addressing the protection of adolescents' health information vary from practice to practice. EMR systems must be able to respond to these privacy needs by allowing restriction of access to this information according to these laws and policies.¹²
 - * *Genetic information:* EMR systems must provide protection of information on a patient's genetic information, including newborn metabolic screening results. This protection must extend to those who are genetically unrelated to their parents (eg, those born after donor embryo procedures).
 - * *Guardianship data:* A child's guardian may be different from his or her biological parents, and EMR systems should be able to reflect this.
 - * *Adoption issues:* EMR systems must be able to represent relationships in families involving adopted children.
 - * *Foster care:* Physicians are often asked to evaluate children in foster care. Systems should support reporting requirements of social service agencies in these cases and protect the privacy of these patients after changes in a child's foster-care status.
 - * *Abuse and neglect:* State laws vary regarding the use of data in cases of abuse and neglect. Sys-

tems need to be able to protect data in ways consistent with these laws.

* *Financial responsibility data*: Sometimes, a parent or guardian is not the financially responsible person. Systems should allow enough flexibility in a patient's chart to allow identification of this distinct role.

- **Pediatric work settings.** Data entry (documentation) tools must work in busy pediatric settings. For example, speech interfaces may be impractical in noisy environments. Computers in examination rooms with curious children may also present special challenges for system design.
- **Family member links.** EMR systems should be able to maintain links to records of other family members (who may have different surnames) in the EMR system. Because an interaction with one family member often triggers an encounter with another family member (typically a sibling), EMR systems should support easy movement between records of children within in the same family.
- **Registry linkages.** EMR systems should promote linkage to newborn screening systems at the hospital, state, and/or national level so as to ensure optimal communication including timely notification and follow-up.¹⁶
- **Consideration of national policy statements.** The American Academy of Pediatrics has published policy statements that may affect the design and use of EMR systems.^{3,13,17-28} These policies should be considered in the design of software systems for use in pediatric health care.

TASK FORCE ON MEDICAL INFORMATICS, 2000-2001
James Lustig, MD, Chairperson
Edward M. Gotlieb, MD, Vice Chairperson
Larry Deutsch, MD
Robert Gerstle, MD
Allan Lieberthal, MD
Richard Shiffman, MD
S. Andrew Spooner, MD
Melvin Stern, MD

STAFF

Rebecca Levin-Goodman

REFERENCES

1. Shiffman R. Informatics and computers in pediatrics. In: Green M, Haggerty RJ, Weitzman M, eds. *Ambulatory Pediatrics*. 5th ed. Philadelphia, PA: WB Saunders Co; 1999:62-67
2. Dickens M, Lighter DE, Lustig JV, Zurhellen W, Zimmerman E, eds. *Computers in the Primary Care Office*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 1995
3. American Academy of Pediatrics, Ad Hoc Task Force on Definition of the Medical Home. The medical home. *Pediatrics*. 1992;90:774
4. Taragin MI, Lauer M, Savir M, Sivan E, Siesel D. HCFA documentation guidelines and the need for discrete data: a golden opportunity for applied health informatics. *Proc AMIA Annu Fall Symp*. 1998;653-657
5. Coffey RM, Ball JK, Johantgen M, Elixhauser A, Purcell P, Andrews R. The case for national health data standards. *Health Aff (Millwood)*. 1997; 16:58-72
6. Health Level Seven Web site. Available at: <http://www.hl7.org>. Accessed April 20, 2000
7. American Society for Testing and Materials. Committee E31 on Health-care Informatics. Available at: <http://www.astm.org/cgi-bin/SoftCart.exe/COMMIT/COMMITTEE/E31.htm?L+mystore+ocow3633+952979939>. Accessed April 20, 2000
8. SNOMED International Web site. Available at: <http://www.snomed.org>. Accessed April 20, 2000
9. International Organization for Standardization Web site. Available at: <http://www.iso.ch>. Accessed April 20, 2000
10. Institute of Medicine. *The Computer-Based Patient Record: An Essential Technology for Health Care*. Dick RS, Steen EB, Detmer DE, eds. Washington, DC: National Academy Press; 1997
11. Fitzmaurice JM. A new twist in US health care data standards development: adoption of electronic health care transactions standards for administrative simplification. *Int J Med Inf*. 1998;48:19-28
12. Health Insurance Portability and Accountability Act, 42 USC §201 (1996)
13. American Academy of Pediatrics, Pediatric Practice Action Group, Task Force on Medical Informatics. Privacy protection of health information: patient rights and pediatrician responsibilities. *Pediatrics*. 1999;104: 973-977
14. McDonald CJ. Quality measures and electronic medical systems. *JAMA*. 1999;282:1181-1182
15. Miller PL, Frawley SJ, Brandt C, Sayward FG. A prototype Web site for immunization knowledge maintenance. *Proc AMIA Annu Fall Symp*. 1997;293-297
16. Health Resources and Services Administration, American Academy of Pediatrics, Newborn Screening Task Force. Serving the family from birth to the medical home. *Pediatrics*. 2000;106(suppl):383-427
17. American Academy of Pediatrics. Confidentiality in adolescent health care. *AAP News*. April 1989;5:9
18. American Academy of Pediatrics, Committee on Pediatric Emergency Medicine. Consent for medical services for children and adolescents. *Pediatrics*. 1993;92:290-291
19. American Academy of Pediatrics, Task Force on Medical Informatics, Section on Computers and Other Technologies, Committee on Practice and Ambulatory Medicine. Safeguards needed in the transfer of patient data. *Pediatrics*. 1996;98:984-986
20. American Academy of Pediatrics, Committee on Injury and Poison Prevention. The hospital record of the injured child and the need for external cause-of-injury codes. *Pediatrics*. 1999;103:524-526
21. American Academy of Pediatrics, Committee on Early Childhood, Adoption, and Dependent Care. Initial medical evaluation of an adopted child. *Pediatrics*. 1991;88:642-644
22. American Academy of Pediatrics, Committee on Genetics. Prenatal genetic diagnosis for pediatricians. *Pediatrics*. 1994;93:1010-1015
23. American Academy of Pediatrics, Committee on Child Abuse and Neglect. Public disclosure of private information about victims of abuse. *Pediatrics*. 1991;87:261
24. American Academy of Pediatrics, Task Force on Pediatric AIDS. Adolescents and human immunodeficiency virus infection: the role of the pediatrician in prevention and intervention. *Pediatrics*. 1993;92:626-630
25. American Academy of Pediatrics, Committee on Adolescence. Contraception and adolescents. *Pediatrics*. 1999;104:1161-1166
26. American Academy of Pediatrics, Committee on Substance Abuse. Testing for drugs of abuse in children and adolescents. *Pediatrics*. 1996;98: 305-307
27. American Academy of Pediatrics, Committee on Adolescence. The adolescent's right to confidential care when considering an abortion. *Pediatrics*. 1996;97:746-751
28. American Academy of Pediatrics, Committee on Early Childhood, Adoption, and Dependent Care. Issues of confidentiality in adoption: the role of the pediatrician. *Pediatrics*. 1994;93:339-341