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Special Requirements of Electronic Health Record Systems in Pediatrics

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CLINICAL REPORT

Special Requirements of Electronic Health Record Systems in Pediatrics

S. Andrew Spooner, MD, MS, and the Council on Clinical Information Technology

Guidance for the Clinician in Rendering Pediatric Care

ABSTRACT

Some functions of an electronic health record system are much more important in providing pediatric care than in adult care. Pediatricians commonly complain about the absence of these “pediatric functions” when they are not available in electronic health record systems. To stimulate electronic health record system vendors to recognize and incorporate pediatric functionality into pediatric electronic health record systems, this clinical report reviews the major functions of importance to child health care providers. Also reviewed are important but less critical functions, any of which might be of major importance in a particular clinical context. The major areas described here are immunization management, growth tracking, medication dosing, data norms, and privacy in special pediatric populations. The American Academy of Pediatrics believes that if the functions described in this document are supported in all electronic health record systems, these systems will be more useful for patients of all ages.

INTRODUCTION

Child health care providers often find that clinical information systems have limited usefulness in pediatrics,^{1,2} because they seem to be designed for adult care. For the purposes of this report, we use the definition of the electronic health record (EHR) system proposed by the Institute of Medicine:

“An EHR system includes (1) longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or health care provided to an individual; (2) immediate electronic access to person- and population-level information by authorized, and only authorized, users; (3) provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care; and (4) support of efficient processes for health care delivery. Critical building blocks of an EHR system are the electronic health records (EHR) maintained by providers. . .and by individuals (also called personal health records).”³

The definition proposed by the Institute of Medicine is functional in nature. It assumes that an EHR system must provide these features to be of value. Even for child health care providers, this definition is valid, and this set of features is likely to provide value to most practitioners. However, as has been noted previously,² when viewed from the perspective of the child health care provider, these features may fall short either in the details of how they are implemented or by omitting functions that are more routine in pediatric care than in any other primary care practice. This report provides a look at these key functional requirements through the lens of the child health care provider and augments these requirements with

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

Key Words

electronic health record, pediatrics, technology

Abbreviations

EHR—electronic health record
AAP—American Academy of Pediatrics
HL7—Health Level Seven
NCVIA—National Childhood Vaccine Injury Act
CCHIT—Certification Commission for Health Information Technology
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the additional functions that child health care providers use in their daily practice of medicine. This report focuses on the clinical functions of the EHR system operated by the health care provider, as opposed to the more administrative functions in the practice-management system (such as appointment management, insurance eligibility determination, and billing). However, it is assumed that the EHR system in the pediatric setting is fully connected to the practice-management system through an appropriate interface or through software integration of the 2 systems.

PEDIATRIC FUNCTIONS

In 2001, the American Academy of Pediatrics (AAP) published a description of the features that would be desirable in a clinical information system to be used in pediatrics.² Almost none of these features were purely pediatric. For example, that statement called for medication dosing by weight and for opportunities to record information about guardianship. There are certainly instances of medication dosing by body weight in adult medicine, and many adults have guardians. Yet, these features are vastly more important in pediatrics, so it is appropriate to refer to them as “pediatric functions.” Several of these functions that are of critical importance to pediatric practice are discussed in greater detail here. Others are of less general importance but have been identified as desirable by members of the Pediatrics Data Standards Special Interest Group of Health Level Seven (HL7),⁴ an international health data standards development organization in which the AAP participates (www.hl7.org).

CRITICAL PEDIATRIC EHR FUNCTIONAL AREAS

There are some functional areas that are so critical to the care of infants, children, and adolescents that their absence results in the system impeding quality pediatric care.

Immunization Management

Recording Immunization Data

The ability to record multiple immunizations efficiently is critical for pediatric health maintenance activities. State and federal regulations add a complexity to the process of recording immunization administration that is absent for medications. Systems designed to record adult immunizations and other medications naturally allow the practitioner to record data such as the manufacturer, lot number, date, site, route of administration, and expiration date. The nature of immunization practices in children adds some requirements to this list, in particular, data required by the Vaccines for Children (VFC) program⁵ and the National Childhood Vaccine Injury Act (NCVIA) of 1986 (42 USC §§300aa-1–300aa-34).^{6,7} The VFC program, a federal program by which eligible chil-

dren are provided vaccine at no charge, requires providers to maintain a separate stock of vaccine, to assess eligibility for the program, and to submit reports to the program. All of these activities require support from the information system used to track immunization data. The NCVIA has numerous implications for immunization data recording. Among these is the requirement to deliver to the parent (or equivalent health decision-maker) a vaccine information statement (VIS) and to record when it was given and which version of the VIS was given. The NCVIA also mandates that health care providers report adverse events associated with vaccines; although this applies equally to adult providers, automation of this reporting capability would be of particular interest to child health care providers, who give the bulk of vaccines. The Centers for Disease Control and Prevention’s National Immunization Program (www.cdc.gov/nip) specifies these information-management requirements in detail. EHR systems also need to manage the record of consent for vaccine administration. Vaccine refusal⁸ by a parent or patient requires the recording of refusal reasons and recording of which refused vaccines were offered.

Linking to Immunization Information Systems

Most states and several local jurisdictions have electronic immunization-information systems or registries.^{9–11} The EHR should allow interoperability with these systems, including the ability to download, upload, and synchronize a child’s immunization history. Some technical standards already exist for immunization information system functions and communications with them.^{12,13}

Immunization Decision Support

Systems for encoding rules about which immunizations are due and when they are projected to be due in the future have been in existence for years.¹⁴ For an EHR system to fully support pediatric practice, it must be able to take previous immunization data and derive, at the point of care, logical conclusions about the currency of immunization and recommend the appropriate immunizations. This functionality requires an understanding of the individual antigens present in each vaccine and analysis of when, in what form, and at what age in the child’s life each antigen was—or was supposed to be—administered. There may also be local variations in this functionality based on local epidemiology. These functions might be built into the system or be derived from immunization registries or third-party programs accessed via a network. If the logic is built into the EHR system itself, there should be a way to easily update the logic to reflect changes to immunization rules and to handle new vaccines and new antigen combinations.

Growth Tracking

Graphical Representation

Child health care providers make important judgments about a child's health by visual inspection of a plot of a child's body measurements (usually weight, height, head circumference, BMI) over time. Plots show the progression of measured values over time against curves of predicted growth or percentile curves. Ideally, the visual plot should be visible at the top level of an individual record or require minimal effort for viewing. The EHR system should allow the representation of percentile curves from a usual source (Centers for Disease Control and Prevention [www.cdc.gov/growthcharts]) or other sources that may provide these curves for special populations.¹⁵ The system should allow magnification ("zooming") of the plot to allow inspection of areas of the plot in which measurements have been frequently made. Users ought to be able to derive growth-velocity data from 2 selected data points. The system should distinguish height from length. Also, the system should accommodate corrections for preterm birth in the graphical display of body measurements.

Percentile Calculations

In addition to representation of body measurements, the percentile value of any particular body measurement against a defined distribution is desirable. Such percentile values should be calculated and displayed at the time of data entry. Percentile values should also be available for decision-support functions of the EHR system.

Medication Dosing

Dosing by Body Weight

The predominant method for calculating pediatric drug dosages is to compute them on the basis of body weight. When a current body weight is available, the EHR system should be able to incorporate it into the prescribing process and suggest doses on the basis of accepted references. Failing this, the EHR system should make weight visible in all displays associated with drug dosing. When a current body weight is not available, the system should react to this appropriately by requesting its input. For medications that require adjustment of dose as the child's weight increases, the intended dosage per unit of body weight should be recordable and maintained as an aspect of the prescription. Systems should be able to determine if a body weight obtained in the past is too old to be used in decision support (eg, last month's weight would be appropriate for an adolescent but not a neonate). Entries of height, weight, and head circumference should be checked against age-based norms so that users can be warned of possible errors. As in adult care, medication dosing by body surface area or ideal weight should also be available; however, the equations for the

estimation of body surface area and ideal body weight in children are different from those in adult care.

Dose-Range Checking

With or without dosing decision support, an EHR system should be able to check drug doses posthoc by using accepted pediatric references and advise the user when no pediatric references exist.

Rounding to Safe and Convenient Doses

Many medications for infants and young children are supplied in liquid form. Because parents and other caregivers must measure a volume of liquid for each dose of medication, child health care providers must compute a volume for each dose, round it to a convenient volume, and spend time educating caregivers on the proper volume to administer. EHR systems that facilitate prescribing should support prescriptions expressed in the volume of drug to be administered and avoid expressing the prescription solely in terms of the mass of the drug.

Age-Based Dosing Decision Support

For the case in which dosing guidelines or formulary benefits vary with age or gestational age,¹⁶ the system should incorporate those data into its decision support.

Dosing for the School Day

Pediatricians must often write prescriptions in which the medication is divided in 2 labeled packages—one for home administration and one for administration during the day at school, child care, or another care setting. EHR systems should provide the capability to generate instructions to the pharmacy to dispense a medication in this way.

Patient Identification

Newborn Identification

Although many EHR systems depend on the use of a government-issued identification number (usually the Social Security number), newborn infants do not receive these numbers for a significant period of time after birth. EHR systems should allow the registration of patients without such identifiers and allow retrieval of information on the basis of any temporary identifiers that may be used.

Prenatal Identifiers

An EHR system that allows storage of prenatal data (eg, from a fetal imaging procedure) should allow the logical connection of these data to the postnatal record once the child's record is established in the system.

Name Changes

Infants undergo name changes because of changes in family structure or the need to change the temporary

name assigned at the birth hospital. Because clinical data are connected to the old names, EHR systems need to support retrieval of data via search on previous names.

Ambiguous Sex

In the case of a child with ambiguous genitalia, an EHR system ought to allow the assignment of sex as unknown and to operate normally until the sex of the patient is assigned.

Norms for Pediatric Data

Numeric Data

Norms for almost all numeric data (such as laboratory results, body measurements, scores on standardized assessments, and vital signs) change as the child grows. For many of these data, norms change continuously with age, so it is insufficient to provide merely a handful of normative ranges. Developers should assume that all numeric data collected in a pediatric context have changing norms over the lifespan and should provide ways of flagging abnormal values at any age. Percentile values and *z* scores (number of SDs from the mean) should be available for those few data for which the distributions are known, such as height, weight, head circumference, and BMI.

Nonnumeric Data

Whenever an EHR system distinguishes normal from abnormal in nonnumeric data (eg, flagging the presence of a physical sign as abnormal), it should consider age in the interpretation of normality. For example, if “unable to feed self” is considered to be a universally abnormal finding in the interpretation of a functional assessment, then the system is not taking the functional capabilities of young children into account.

Complex Normative Relationships

Not all normative data are based solely on age. In the case of blood pressure, normative values are determined by age (to the nearest month), gender, and height percentile.¹⁷ Similarly, peak flow meter norms depend on age, height, and gender.¹⁸ Methods for flagging abnormal values that are based on age alone are insufficient for blood pressure and peak expiratory flow and may be insufficient for other measurements in pediatric patients.

Gestational Age

For neonates, chronologic age (expressed simply as the time since birth) is insufficient for medication-prescribing decision support, normative ranges for laboratory data, normative definitions for physical examination findings, and guideline-application support. Gestational age, chronologic age, and corrected age are each unique and important ways to present age of a neonate¹⁶; EHR

systems need to record each of these expressions for age and allow for their use in decision support.

Privacy

Adolescent Privacy

Laws about age of consent vary from state to state¹⁹ and according to presenting problem.^{20–22} Adolescents who present for treatment of mental health disorders, for example, may consent to their treatment at an earlier age than the age of majority in most states.^{19,23} Some states also have laws regarding parental notification whereby interpretation is based on the patient’s age and presenting problem.²⁴ Practices that serve adolescents typically have policies with respect to what portion of an adolescent’s care should be handled with special privacy protections (eg, in some jurisdictions, the adolescent must give explicit permission for the parent to review his or her records). These privacy protections may require the flagging of protected information. Therefore, EHR systems should support privacy policies that vary by age and according to presenting problem and diagnosis and be flexible enough to handle the policies of individual practices. Furthermore, if an EHR system handles record-keeping for consent for treatment, it should provide for the recording of assent for treatment (from an underaged adolescent or child) combined with parental informed permission^{25,26} as well as consent for treatment (from an adolescent) combined with a record of parental involvement.²⁵ The separation of the patient’s consent and the parent’s or guardian’s consent is particularly important in the area of testing for drugs of abuse.²⁷ Pregnancy is another area in which the records of patient and parental consent, assent, and permission may be less straightforward than in adult care.²⁸

Children in Foster or Custodial Care

When a child is removed from the care of his or her parents, as in the case of foster care, complex issues of confidentiality of medical information arise.²⁹ Licensed foster parents may consent to routine medical and dental treatment for minors placed with them pursuant to a court order or with the voluntary consent of the person having the legal custody of the minor. The pediatrician should document the authority of a foster parent to give consent to medical treatment by obtaining a copy of the court order. Parents who no longer have custody may still have the right to access their children’s medical records and be involved with health care decisions unless their parental rights have been terminated. EHR systems that purport to manage consent for treatment and information access will need to be able to record these details.

Consent by Proxy

Children often present for nonurgent health care in the company of an adult who is not the custodial parent or

guardian. The best way to prevent confusion about consent for care in this situation is to record the custodial parents' wishes as to which adult can consent to which child's care and under what limitations.³⁰ EHR systems that manage consent for treatment should support this sort of data-recording.

Adoption

Records of children who are undergoing adoption proceedings or who have been adopted may need special privacy handling, as in a case where state law offers special protections for the identity of adoptees. The EHR systems should allow flagging of these data for special privacy protection. In some states, the preadoption record may need to be separated entirely from any post-adoption record by using 2 distinct patient identities.

Guardianship

The identity of a child's guardian and guarantor, although most commonly the parent, can become complicated outside the bounds of the "typical" 2-parent household. The EHR system must provide the flexibility to indicate the broad variety of adults in the child's life who may play some role in medical or financial decision-making. The system should draw a distinction between the patient's guardian and his or her financial guarantor. In those cases in which a court has appointed a guardian for a minor, the ability of the guardian to consent to medical treatment depends on the type of treatment being sought and the scope of authority the court has granted. If more than routine care is required, the pediatrician should document the authority of the guardian to give consent by obtaining a copy of the official certified letters of guardianship. The EHR system should support this record-keeping.

Emergency Treatment

When EHR systems support the recording of consent and assent for treatment, they should be flexible enough to allow for the emergency treatment of minors, in which the parent or legal guardian may be absent, and the usual procedures for consent must change.²⁰

PEDIATRIC TERMINOLOGY

Some of the barriers that child health care providers encounter in the application of EHR systems relate not to functions of the system but to the inappropriate terminology used to express concepts (eg, physical examination findings, developmental milestones, diagnoses) in the EHR system's user interface. These terminology systems differ from systems such as the *International Classification of Diseases, 9th Edition, Clinical Modification*,³¹ which is used to encode diagnoses for insurance claims. Rather, these terminology systems are used to allow the precise encoding of clinical concepts by the user in lieu of free text.³² EHR systems generally use a terminology devel-

oped by a third party or by the EHR system developers themselves. A complete treatment of special terminology requirements is outside the scope of this report. The AAP and its members should advocate for the inclusion in these systems of historical findings, psychosocial risk factors, family structural details, social history, physical examination findings, developmental problems, behavioral issues, congenital syndromes, and diagnoses of particular importance to pediatrics. The US government's Consolidated Health Informatics Initiative,³³ which specifies which terminology system should be used in which clinical domain within government-sponsored health-information systems, should help focus the advocacy effort of the AAP. It is important to note, however, that no health-information system directly managed by the US federal government deals primarily with children.

DATA PRECISION

There is a broad category of functionality that may limit an EHR system's usefulness in pediatric practice: the ability to handle data at an appropriate numeric precision and graphical resolution. For example, body weight to the nearest gram is commonly accepted as an appropriate precision in neonatal facilities. As another example, an EHR system may present growth curves of height, weight, and head circumference, complete with appropriate normative curves for comparison. However, if those curves are available in only 1 graphical resolution, measurements obtained frequently (daily weight measurements, weekly head circumference measurements, etc) may become impossible to analyze visually. Age in the newborn nursery should be expressed in units at least down to the hour, if not to the minute. The units for age (days, weeks, months, years) need to grow with the age of the child, as appropriate. Developers of EHR systems should consider how the small changes in numeric data that one sees in the care of young patients affect data-recording and display.

OTHER PEDIATRIC FUNCTIONS

This report outlines the major areas of functionality that are relatively more important in pediatric care than in adult care. There are, of course, many other functions that are important, such as the ability to:

- archive and manage patient data for a statutorily defined period of time;
- provide educational materials that are appropriate to both parents and children and at varying reading levels;
- create pedigree diagrams;
- display age at all times throughout the user interface;
- select age-based documentation templates and order sets on the basis of a patient's age;

- indicate whether a guideline applies to a patient on the basis of age; and
- indicate the source of patient data, especially when the source is not the patient or the parent (eg, the school teacher or child care worker).

PEDIATRIC EHR SYSTEM FUNCTIONALITY STANDARDS

HL7 is an organization that was founded in 1987 to set international standards for how health information is exchanged between information systems. It expanded its scope beyond data interchange to include specifications for EHR system functions through its Electronic Health Record Technical Committee. The Electronic Health Record Technical Committee, which was founded in 2001, published its first balloted standard for EHR system functions in 2004.³⁴ This standard is being used as the basis for the EHR system certification process specified by the federal Office of the National Coordinator for Health Information Technology (created by Executive Order 13335, April 28, 2004, and authorized by Congress [FR Doc No. 05-16446, Filed August 18, 2005]). The purpose of certification is to set a minimum level of functionality that EHR systems will have to meet to qualify for special treatment, such as participation in pay-for-performance programs.^{35,36} By contract with the Office of the National Coordinator for Health Information Technology, the Certification Commission for Health Information Technology (CCHIT [www.cchit.org]) is charged with establishing a certification process by which EHR system software may be declared eligible for pay-for-performance incentives designed to promote care facilitated by an information system. The CCHIT has several pediatricians working on its committees to ensure that pediatric functions are incorporated into the certification process. As of this writing, patient-care scenarios of the CCHIT that were designed to test functionality exclude infants. The HL7 Pediatric Data Standards Special Interest Group is working with the HL7 Electronic Health Record Technical Committee to ensure that the pediatric functions mentioned in this statement are included in the HL7 EHR functional model and, therefore, will become a part of EHR system certification processes in the future. The current EHR system functional model may be obtained from the HL7 Web site (www.hl7.org).

THE FUTURE OF THE PEDIATRIC EHR SYSTEM

In the wake of the rapid uptake of EHR systems in the years since the first AAP statement,^{37,38} national groups have expressed increased interest in standardizing the features of EHR systems and certifying their functions.³⁹ Child health care providers want to be sure that pediatric functions, terminology, and data precision are built into these standards and certification processes. They want this not only to make their own systems more effective

in improving the health of children but also to make all EHR systems more useful for patients of all ages. The AAP is working proactively to ensure that knowledgeable pediatricians who can thoroughly explain child health care issues are invited to address the groups that set these standards. This report should serve as a guide for these efforts to represent the interests of child health care providers and present a guide to individual practitioners who are evaluating a given system's ability to perform in the pediatric environment.

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