Data Standards and Improvement of Quality and Safety in Child Health Care

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ABSTRACT

Progress in using information technology to achieve the goal of high-quality health care is hindered by the lack of coordinated data standards. To accelerate quality improvement in pediatrics, child health providers must participate actively in the creation of health care data standards. To do so will require far greater understanding on the part of pediatricians and other pediatric providers regarding the scope and role of data standards in advancing health information systems for children, as well as how data standards could improve quality in child health, what kinds of data standards hold the most promise for quality improvement in child health, and how child health professionals can engage in the work of creating data standards. Child health professionals in organized and academic medicine should participate in standards development organizations, to present the pediatric point of view as data standards emerge. They also should support efforts to certify electronic health record systems that include pediatric functionality. A major challenge to academic pediatrics is to prove that data standards can lead to improved health outcomes for children; this is only a compelling conjecture as of this writing. Pediatrics 2009;123:S74–S79

The Institute of Medicine specifies 6 attributes of quality in health care, namely, safety, effectiveness, patient-centeredness, timeliness, efficiency, and equitability. The medical community broadly accepts that information technology (IT) and health care information systems will play an important role in implementing and measuring these quality attributes. Progress in using IT to achieve these ends is hindered, however, by the lack of coordinated data standards. To accelerate quality improvement in pediatrics, child health providers must participate actively in the creation of health care data standards. In this report, we describe how data standards could improve quality in child health, what kinds of data standards hold the most promise for quality improvement in child health, and how child health professionals can engage in the work of creating data standards.

TYPES OF HEALTH CARE DATA STANDARDS

Standards exist to allow people in different roles or in different institutions to cooperate efficiently and effectively. For example, because electrical outlets in a given country are standardized, different manufacturers can produce appliances that work in every home. In health care, a standard definition of acute lymphoblastic leukemia assists practitioners in providing similar care to patients in different health care facilities. Time and energy do not need to be expended in converting electrical plugs or redefining acute lymphoblastic leukemia staging, because these standards have been accepted by a wide range of individuals.

There are 3 types of data standards that influence health care IT, that is, terminology standards, messaging standards, and functional standards. Terminology standards specify which terms are to be used in a particular clinical domain and how each term in the system is defined (eg, “weight” versus “birth weight” versus “dosing weight”). Messaging standards specify how data are to be packaged for transmission between systems. Successful messaging between systems leads to the ability of disparate systems to work together (interoperability). Functional standards specify how a system is supposed to operate in the clinical environment.

To a great extent, health care data standards depend on standards of care. If clinicians cannot agree on how or what the process of care should be, then it is difficult to produce data standards that satisfy the clinical needs of most clinicians. Following are some ways in which the use of data standards in clinical information systems could affect the quality of care for children.
DATA STANDARDS AND THE COMPONENTS OF HEALTH CARE QUALITY

Data Standards and Safety

Current Situation
There is no question that information systems can promote certain aspects of patient safety. These improvements usually fall into the areas of prevention of medication errors and adherence to guidelines. Standards for clinical information system functions in the area of decision support might lead to a culture shift among providers toward an expectation for safety-oriented support. At present, the level of decision support is variable from system to system and practitioners, who may interact with a variety of systems, do not know what to expect. When this disorientation about how decision support works is compounded by a tendency for users to experience “alert fatigue” at the numerous prompts a decision support system provides, one quickly appreciates the urgent need for functional standards for decision support systems. Even in the absence of decision support standards, however, it is possible that data standards will allow information systems to penetrate the health care workplace more easily and affect safety indirectly.

Guideline Deployment
To the extent that data standards promote consistent practice, data standards can enhance safety. Results of studies on the use of technology in guideline deployment are mixed; most studies showed effects on processes, rather than outcomes. Another aspect of guideline deployment where data standards may be important is in the area of electronic guideline representation. The motivation behind guideline representation work is that, if guidelines can be encoded in a standard way, then multiple different systems can automate the guidelines at the point of care with minimal custom programming. Pediatricians are involved in this work and in the area of standard approaches to guideline evaluation.

Error Reporting
Error reporting can make care safer if reporting can be performed as a byproduct of care and not as part of the typical “incident report” process. Data standards for communicating between systems must exist for universal error reporting to bear fruit for patient safety. Terminology for error reporting in pediatrics must align with important types of errors in pediatrics. The National Quality Forum has addressed this issue by endorsing an overall patient safety event taxonomy, to which all patient safety reporting systems, including pediatric reporting systems, would be mapped. There is an ongoing effort by the National Quality Forum to link this taxonomy to existing terminologies, including the Systematized Nomenclature for Medicine-Clinical Terms terminology system and International Classification of Diseases, Ninth Revision, Clinical Modification codes. Few pediatrics-specific measures of safety exist in quality-reporting literature. Data standards could improve safety if error reporting could be built into the process of documenting and administering care.

Data Standards and Efficiency
One of the main reasons for the existence of standards development organizations (SDOs) is to make it possible for different information systems to interoperate, that is, to function independently for their designed purposes while sharing electronic data in such a way that reentry of data is unnecessary. Information systems personnel in health care organizations know that getting different systems to “talk to one another” is an expensive activity, despite the existence of a large body of messaging standards. Interoperability would mean clearer faster communication within the health care enterprise. In turn, this communication should result in more-timely care. Data from computerized physician order entry studies suggest this is true; better interoperability, as a result of better data standards, could contribute to easier and safer implementation of computerized physician order entry.

Studies of decision support in computerized physician order entry suggest that lengths of stay can be reduced through the use of technology, and data standards could contribute to these efficiencies. Standards also could contribute to efficiency in cases in which clinicians must move from one complex system to another. This has been termed “the cockpit problem” because, in the airline industry, making a pilot switch between complex control sets has been recognized as being inefficient and unsafe. To the extent that interoperability can give users access to a broader array of data sources, data standards could reduce the rate of redundant tests and procedures; this is the most often-cited economic motivation for data-sharing projects.

Data Standards and Timeliness
Timeliness, as a component of quality, applies to acts that must occur according to a schedule or at a point in a disease process at which waiting would result in poorer outcomes. It also applies to delays in coordination between different health care organizations. In child health care, immunizations and health supervision provide most of the opportunities for scheduled care. In the ideal case, one’s “medical home” is in one physical location; the reality of modern health care for children is that the medical home involves many different settings, especially for children with special needs. Interoperable systems based on data standards could reduce the delays in care that a physically fragmented health care system presents.

Data Standards and Effectiveness
Consistent practices can promote effectiveness, and technology can promote consistency in the application of guidelines and documentation in primary care. Evidence for their effect on outcomes is sparse.
Data Standards and Equity
Data standards can have 2 basic effects on equity in the health care system, that is, ensuring that information systems provide the same levels of benefits to all populations (via functional standards) and making regional health data interchange networks possible (via messaging and terminology standards). For this boost in equity to be realized, strong mechanisms must be in place to induce providers to deploy information systems with standard functions. Furthermore, the popular regional health information organization movement, in which hundreds of data-sharing projects are being developed, must succeed. Data standards are a prerequisite to the success of regional health information organizations and the improvements in health care equity that they promise.31

Data Standards and Patient-Centeredness
The personal health record (PHR), in which consumers (or, in the case of pediatric patients, their parents or guardians) manage their own health information, could promote patient-centered care. Parents have used paper-based PHRs for their children for decades, especially outside the United States, and there is at least one example of an operating electronic PHR system for children.32 For PHR systems to work on a large scale, they must be portable among a variety of information systems. Such portability requires data standards that do not exist yet, although the Continuity of Care Record33 is cited as a standard that might lead to interoperable PHR systems in the near future. Also, a group within Health Level 7 is working toward development of a standard functional model for PHR systems.

Additional Benefits
In addition to supporting quality care for children, use of pediatric data standards could help child health care providers (1) to reduce system implementation costs attributable to duplicative efforts in customizing systems for child health care, (2) to improve the interchange of comparable national pediatric performance measurements, and (3) to access pay-for-performance opportunities.

DATA STANDARDS THAT HOLD THE MOST PROMISE FOR QUALITY IMPROVEMENT IN CHILD HEALTH
Current Needs
Data standards are most urgently needed in areas in which the standards of care are best defined. The field of pediatrics suffers from a paucity of evidence-based guidelines.34-36 This paucity limits the scope of pediatric data standards development. Although pediatrics is behind adult medicine in its compilation of evidence, there exist enough evidence-based guidelines to allow progress in this area.34

Terminology Standards
General Considerations
Some terminology systems are designed to be interpreted by human users of the system, whereas others are used for storage, retrieval, or classification.36 The Current Procedural Terminology system published by the American Medical Association, which is used to code procedures, is a standard terminology system familiar to all US practitioners.37 Use of a terminology system ensures consistent definitions of terms among users.

Pediatric Terms
Terminology systems naturally include terms that apply to adults. In cases in which these adults are caretakers of children, these terms need a form that indicates their connection to the child. For example, if there is a term that indicates that a woman had gestational diabetes during her pregnancy, then there needs to be a corresponding term (or form) that expresses that concept for the child produced by that pregnancy. As another example, in one widely used terminology system there are terms to describe the patient’s smoking habits but no terms to describe the parent’s smoking habits. Simply attaching a “paternal history of” modifier to “finding of tobacco smoking consumption” (concept 365982000) does not suffice, because family history usually connotes events in the past, rather than ongoing modifiable factors that affect the child’s health directly. The same applies to connections to siblings as well.

Health Maintenance
Pediatricians spend substantial time managing well care and prevention. Terminology systems that are strongly oriented toward descriptions of disease states or risk factors may miss descriptions of the progress of well care or the patient’s medical strengths. Designing of terminology systems should include child health professionals familiar with the design and operation of a high-quality medical home.

Pediatric Diseases
There are diseases that affect children disproportionately, such as congenital conditions and disturbances of growth and development. Terminology systems that focus on adult care tend to gloss over these terms.38

Messaging Standards
Registry Communication
Standards exist for terminology, messaging, and functions of immunization registries.39 This same approach needs to be extended to the systems that communicate with the registries, namely, the electronic health record (EHR) system used at the point of care. Messaging standards to specify the communications between EHR systems and registries exist and should be promoted within the EHR system vendor community.

Extension of the Medical Home
Children receive a significant quantity of their health care through their schools, which parents strongly desire.40 Communication between physicians’ offices and schools is important for the management of chronic diseases and for children with special health care needs. No data standards exist to enhance interoperability be-
Electronic Prescribing Standards
Electronic prescribing is expected to receive a strong boost from the Medicare Modernization Act, which specifies standards for transmitting electronic prescriptions. These standards may require modifications to yield benefits for children, given the age group at which Medicare regulations are aimed.

Adolescent Privacy
Adolescent care is complicated by the need to balance the patient’s privacy with the parents’ autonomy. State laws define who can consent to what at what age and who can be informed of what result. EH systems could help clinicians manage the complexity of adolescent privacy, provided there are standard ways of labeling sensitive data and standard logic rules about data display and reporting.

Functional Standards
Immunization Decision Support
One of the most complex activities in a pediatric office is the management of correctly timed and properly administered immunizations. Research has shown that EHRs, properly deployed for immunization decision support, demonstrate the clearest benefit to the quality of child health care. The rules for what immunizations should be delivered when and under what clinical circumstances can be embedded in an EHR, but most pediatricians report that their EHR system lacks this function.

Growth Monitoring
Computers can easily handle the tedium of plotting height, weight, head circumference, and BMI data on appropriate normative graphs (including graphs developed for populations affected by particular diseases or of particular ethnic backgrounds), so that clinicians can review the graphical representation for growth disturbances. There are no true standards for how this is done, although the Centers for Disease Control and Prevention recommend a de facto standard in the United States. Computer systems can go one step further by analyzing growth and flagging problems that might otherwise be overlooked, but there are no standards of care to drive data standards in this particular area.

Medication Dosing
Dosing of most medications according to body weight is standard practice in pediatrics. Medications are labeled by Food and Drug Administration-approved processes to be dosed within certain ranges. In actual practice, some dosing traditions vary from the Food and Drug Administration-approved product labeling. Doses also are often rounded to convenient amounts, especially in the case of medicines provided as liquid preparations for infants and young children. Some medications can be rounded quite liberally, but others require tighter adherence to the specified dosage. Practice guidelines regarding how dosing and rounding should occur are not available. As a result, few information systems offer much help to practitioners for dosing calculations. As electronic prescribing matures under the influence of the Medicare Modernization Act, functional standards for dosing according to body weight should find support in the IT marketplace.

Display of Pediatric Normative Values
Quantitative data (e.g., laboratory test values and body measurements) and some qualitative data (e.g., certain physical signs) change with age, but EHR systems often display these values without any indication of whether they are normal for the patient’s age. This may be an unsafe method of operation for EHR systems that should be eliminated with a functional standard regarding the display of pediatric normative values.

CHILD HEALTH PROFESSIONALS AND THE WORK OF CREATING DATA STANDARDS
Creation of Standards
Data standards are created in a number of ways, that is, through ad hoc processes, as a de facto feature of the marketplace (as a result of an information system vendor’s large market share), through government mandate, and through a consensus method within a SDO. The latter method, in particular, is one over which child health professionals currently have some control.

Role of Organized Medicine
Through the Alliance for Pediatric Quality, a joint effort of the American Academy of Pediatrics, the American Board of Pediatrics, the Child Health Corporation of America, and the National Association of Children’s Hospitals and Related Institutions, the pediatric community is aligning with respect to a common strategy to build consensus on child health care data standards and to influence the adoption of those standards. In particular, the alliance supports the work of the Health Level 7 Pediatric Data Standards Special Interest Group, an active volunteer group consisting primarily of child health practitioners, chief medical information officers, and informaticists. Participants work together to develop data standards important for child health care. The alliance also brings together the pediatric community to influence the adoption of data standards by endorsing aligned pediatric interests to decision-making organizations, such as the Certification Commission for Health Information Technology, which formed a child health expert panel in 2007 to identify child health certification criteria for EHR systems.

Organized groups need to continue to represent the needs of child health clearly to SDOs and the organizations that put standards into practice. Without this representation, data standards will be made under the assumption that patients are adults and that children are merely smaller versions of adults. This type of representation requires a tremendous amount of time, because terminology systems, messaging formats, and functional
descriptions require the specification of minute details to make them usable. Because the work of SDOs is performed by volunteers, who are often clinicians and other busy health professionals, continued support from national pediatries organizations is necessary.

National organizations should also be aware of the quality measurement movement and the progress that has been made in developing pediatrics-specific measures. Because these measures require data collection that is impractical for providers to perform with manual systems, national organizations should make consideration of these measures a high priority in data standards, so that quality measurement can become a byproduct of care, rather than a separate data collection effort.

Role of Academic Medicine

The link between IT and quality is being forged in research programs in individual specialties. Multiple, specialty-driven, IT standard-focused initiatives have been undertaken by the American College of Physicians, the American Academy of Family Practice, and the American Medical Association, among others. The mark of these programs is that they are occurring outside the purview of traditional IT SDOs, which makes these efforts less likely to produce common standards. Perhaps the most visible effort in producing common standards by physician organizations has been the creation of a standard for the American Society for Testing and Materials International Continuity of Care Record, in which representatives of pediatric organizations were involved. Technology, and its role in improving child health care quality, is becoming a common theme in the pediatric literature. As information systems penetrate the market, opportunities to test this link should arise more frequently.

Medical informatics research and training are not an integral part of most pediatric departments at academic medical centers, and little emphasis is placed on training in pediatric residency training programs. Clearly, for the pediatric data standards movement to increase its impact, an underlying academic medical informatics infrastructure to support research and training for pediatricians is required.

CONCLUSIONS

Once technology is implemented more completely in health care, the role of IT standards in promoting health care quality and safety should become clear. Child health professionals in organized and academic medicine should participate in SDOs to present the pediatric point of view as data standards emerge. They also should support efforts to certify EHR systems that include pediatries functionality. A major challenge to academic pediatrics is to prove that data standards can lead to improved health outcomes for children; this is only a compelling conjecture as of this writing.

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