SUPPLEMENT ARTICLE

The Public Role in Promoting Child Health Information Technology

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ABSTRACT

The public sector plays an important role in promoting child health information technology. Public sector support is essential in 5 main aspects of child health information technology, namely, data standards, pediatric functions in health information systems, privacy policies, research and implementation funding, and incentives for technology adoption. Some innovations in health information technology for adult populations can be transferred to or adapted for children, but there are also unique needs in the pediatric population. Development of health information technology that addresses children’s needs and effective adoption of that technology are critical for US children to receive care of the highest possible quality in the future. Pediatrics 2009;123:S125–S127

FEDERAL AND STATE governments, as well as nongovernmental organizations, are increasingly playing a role in encouraging the adoption and effective use of health information technology (HIT). By executive order in 2004, President George W. Bush established the Office of the National Coordinator for Health Information Technology in the US Department of Health and Human Services, to promote the goal of access to an interoperable electronic medical record by the majority of US individuals by 2014.\textsuperscript{1} US Department of Health and Human Services Secretary Michael Leavitt chartered the American Health Information Community, a federal advisory committee with private and public sector participants, to accelerate the development and adoption of HIT in pursuit of this goal.\textsuperscript{2} The majority of work to date by the American Health Information Community, the federal government, and other public sector organizations has focused, at least implicitly, on adults. Therefore, opportunities exist to build on current progress and to expand the public role in promoting the development and adoption of HIT that can support improvements in children’s health and health care. Elements of effective HIT use in health care for adults can be tailored to children, but there are also unique issues that need to be addressed for the pediatric population. HIT is the foundation to support quality improvement programs, outcome measurements, health services and comparative effectiveness research, efficient data-sharing, and many other initiatives aimed at improving the quality of care delivered to children.

SUMMARY OF PUBLIC SECTOR ROLES

The public and private sectors need to promote 5 main aspects of child HIT, that is, data standards, pediatric functions in health information systems (HISs), privacy policies for pediatric populations, research and implementation funding, and incentives for adoption.

DATA STANDARDS

The Office of the National Coordinator for Health Information Technology has contracted with the Certification Commission for Health Information Technology to certify electronic health record (EHR) system software. Patient care scenarios used to certify EHR products should include pediatric cases and should encourage incorporation of data standards and functionalities specific to pediatric needs. For example, weight in the neonatal period should be able to be recorded in grams. Health Level 7, an organization that sets international standards for how health information is exchanged, has a Pediatric Data Standards Special Interest Group that works to define and to agree on pediatric data standards.\textsuperscript{3} The federal government and the American Health Information Community should continue striving to incorporate the work of Health Level 7 and others to ensure that pediatrics-specific data standards (eg, standards to support interoperable sharing of immunization information) are included and harmonized. The Office of the National Coordinator for Health Information Technology can further incorporate pediatric data standards by

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Key Words
health information technology, pediatric data standards, electronic health record, public policy

Abbreviations
HIT—health information technology
HIS—health information system
EHR—electronic health record
PHR—personal health record

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including these interoperability standards in their work to foster health information exchanges as part of the National Health Information Network.4

Children with special health care needs who receive services in both health and social services programs represent a unique challenge and opportunity for states. The capacity to exchange information between health care and social service providers could support effective coordination and communication. A few state Medicaid programs have begun to support implementation of a personal health record (PHR) that functions as a common communication vehicle for multiple providers. Identifying the standards needed to apply this approach to children with special health care needs will be essential for sharing and using health information easily.

NEEDED HIS FUNCTIONS

Encourage Pediatric Key Functions
There are several key functions particularly relevant to children that the public sector can encourage by fostering incorporation into HISs through certification, requirements, incentives, and/or other mechanisms. The examples below are intended to be illustrative, rather than comprehensive. Of note, several require clinical decision support, an area that is still developing, and methods for incorporating into systems and certification criteria are evolving for both adults and children.

Immunization Information Systems
Immunization data capture incorporated in the certification of EHRs could support public health tracking efforts through linkage to state and local immunization information systems or registries.3,5 Decision support has been shown to increase significantly the capture opportunities for immunization and immunization rates; therefore, this functionality should be encouraged.6

Weight-Based Dosing
An important cause of avoidable medication errors in children is the lack of weight-based dosing capability in electronic prescribing systems and EHRs. Preferably, the EHR should calculate the dose and allow for overriding (with a reason given) and rounding; at a minimum, the weight should be provided at the time of prescription writing for manual calculation.3

Pediatric Normative Values and Growth Charts
As a child ages and grows, normative values for laboratory test results, growth parameters, and vital signs change. Electronic HISs need to express these changes appropriately to be effective for pediatric usage. Growth charts, with calculation of BMI and percentiles and electronic graphing, are important tools for pediatric primary care practice and should become increasingly important to address the emerging problem of childhood obesity.

Prenatal Data and Newborn Identification
Many EHR systems depend on government-issued numbers, such as Social Security numbers, that may not be issued until significantly after birth. Prenatal data should be able to be stored in a HIS with a temporary identifier and then linked to the postnatal record once it is established in the system with a permanent patient identification number. EHRs also should be able to capture maternal prenatal and family history data in a standard format.

PRIVACY POLICIES FOR PEDIATRIC POPULATIONS
Federal and state governments have multiple laws governing the privacy and security of health information, the most notable being the Health Insurance Portability and Accountability Act of 1996.7 The US Department of Health and Human Services is charged with educating the public and enforcing the Health Insurance Portability and Accountability Act. The Department of Health and Human Services, including the Office of the National Coordinator for Health Information Technology, has been working to harmonize state laws regarding electronic health information and to educate the public about their privacy and security rights. As new aspects of HISs, such as PHRs, gain acceptance, the department will need to define a basic framework for the privacy issues that need to be considered and addressed with patients and their families.

Pediatric HISs should be able to address several important privacy issues in pediatrics; examples include adolescent privacy, foster and guardian care, and consent for treatment. Adolescents’ rights to privacy concerning certain sensitive health information (eg, pregnancy and sexually transmitted diseases) and the laws regarding parental notification vary depending on the state. Electronic HISs should allow for differential treatment of certain protected information as needed.8,9 Because of the prevalence of foster and guardian care, pediatric electronic HISs should have the ability to identify and to change guardian status easily. Multiple states are developing electronic HISs to maintain improved health records for children in foster care; the ability to transfer this information securely to providers also is needed.10 Electronic health information consent documentation should allow for consent by parents and guardians, consent by proxy when necessary, and consent by pediatric patients (including situations in which it is preferable for both the pediatric patient and the parent or guardian to consent). Federal and state governments play an important role in addressing these privacy issues through statute, regulations, and education of the public.

RESEARCH AND IMPLEMENTATION FUNDING
Federal and state governments, as well as nongovernmental organizations, have made significant investments in implementing HIT and researching its effects. Since 2004, the Agency for Healthcare Research and Quality has funded more than $216 million in HIT research and implementation grants.11 The Centers for Medicare and Medicaid Services have provided more than $150 million in Medicaid transformation grants, largely focused on HIT, including interoperability of systems and data.12 Nongovernmental organizations, such as the Robert
Wood Johnson Foundation, also have made investments in HIT, especially projects focused on how to improve quality. The majority of this funding has been focused on adult populations. As the public role develops, the pediatric community should engage federal and nonfederal funding organizations and communicate the need for implementation funding, especially in resource-poor settings, and research on the uses and effects of HIT in the pediatric population. This is particularly important because the private sector, including payers, has focused its products and investments predominantly on adult-focused HIT. Finally, the evidence base for the effects on quality and costs of implementing HIT, such as EHRs, PHRs, and disease registries in pediatrics, is in its infancy; therefore, research funding directed at developing this evidence base would advance the field significantly.

INCENTIVES FOR ADOPTION

In a national survey, only 21% of pediatric practices used an EHR. Even lower rates of adoption of EHRs were reported for solo practitioner and small practices (2–5 providers), that is, 3.5% and 14.2%, respectively. The greatest barriers to EHR adoption were the expense of implementation and the inability to find an EHR that met the pediatric practice’s requirements. Of the pediatric practices with EHRs, 94% thought that the EHRs improved access to patient records and 90% thought that they improved the quality of care. The federal government recently announced a demonstration project, involving 1200 physician practices and an estimated 3.6 million Medicare beneficiaries, in which physicians will receive additional payments over a 5-year period for use of a certified EHR and performance on quality measures. Given the potential of EHRs for improvements in quality and decreased costs, state government Medicaid programs and private payers should consider providing similar incentive programs for EHR adoption in pediatric practices. These projects not only could increase the adoption of EHRs but also could measure the effects of EHRs after adoption. Finally, incentives directed at regional health information exchanges and development of PHRs should include pediatrics-focused projects and data content.

CONCLUSIONS

The public sector has increasingly promoted HIT in an effort to realize the technology’s potential for higher quality and more-efficient care. Because the majority of care and costs exist in the adult population, it was reasonable to focus initial efforts predominantly on adults, but now is the time to increase the public role in promoting pediatric HIT. The pediatric population has some unique needs for data standards, health information functions, and privacy considerations. The child health community needs to engage federal and state policymakers to promote child health information technology and capture the opportunity to improve the health of all children.

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