This article describes health information systems used for children in a variety of settings (eg, clinical care, public health, emergency medicine systems, and schools) and their current ability to exchange information. The potential benefits from linking these systems are considered, as well as the barriers to linkage. In addition, an example of efforts linking information systems together is summarized, and conclusions are drawn from this example for future efforts. *Pediatrics* 2009;123:S67–S73

**CLINICAL INFORMATION SYSTEMS**

**Types of Systems**

Currently, information systems range from individual approaches (eg, specific handwritten notes stuck haphazardly into folders) to highly sophisticated electronic systems containing large amounts of data on many persons. Three major automated clinical information systems are emerging, that is, electronic medical records (EMRs), electronic health records (EHRs), and personal health records (PHRs).

The Agency for Healthcare Research and Quality defines an EMR as “the set of databases (or repositories) that contains the health information for patients within a given institution or organization.”1 An EHR “extends the notion of an EMR to include the concept of cross-institutional data sharing.”1 This terminology has not been used uniformly in the literature. In this article, we make no distinction between an EMR and an EHR, and we use the term used by the referenced authors. The PHR2 is an “electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from health care providers and the individual. . . . The PHR does not replace the legal record of any provider.”3

**EHR/EMR**

The American Academy of Family Physicians set a goal of having at least one half of its members using EHRs by 2006. Implementation of EHRs is not keeping pace with this goal. Estimates in December 2007 were that 38% of family physicians have an EHR (Herb Young, MD, oral communication, 2007). National ambulatory medical surveys suggest that EMR use is affected by practice size and ownership.4 Among physicians, 17.6% were using EMRs, ranging from 13.0% in single-physician offices to 38.9% in offices of ≥20 physicians. Among physician- or physician group-owned practices, 15.6% used EMRs, compared with 52.7% of health maintenance organizations. Younger physicians were somewhat more likely to use EMRs than older physicians. Orthopedic surgeons were most likely to use EMRs (~25%) and psychiatrists least likely (~8%).5 Through 2005, Jha et al6 found that the best estimate of EHR use in physician offices was 24%; there were no medium- or high-quality studies giving information on hospital use of EHRs.

**PHR**

Common data elements in a PHR include personal demographic information, general medical information, allergies and drug sensitivities, conditions, hospitalizations, operations, medications, immunizations, clinical tests, and preg-
nancy history. From the individual’s perspective, many consider PHRs to be the ultimate goal of health information systems. The challenge is to make the PHR also function as a customized health information system that facilitates information sharing, thereby empowering children, families, and physicians.7

Significant barriers to the implementation of PHRs exist, including an inability to locate patient information across multiple care settings and concern about how to authenticate each individual. At present there are few EHRs implemented and even fewer to which a PHR can connect. There are no established standards for information contributed by patients and no established business model for consumer-oriented applications. Lastly, the “digital divide” poses a significant barrier for people with low literacy, poor access to technology, and lack of experience with health decision-making.8

PUBLIC HEALTH INFORMATION SYSTEMS

Many public health information systems exist that are dedicated primarily to defined program areas (eg, immunization, sexually transmitted diseases, or surveillance). These systems may be standardized nationally (often by a funding agency such as the Centers for Disease Control and Prevention [CDC]) or may vary from state to state. Most public health information systems are designed to meet the needs of public health departments at local, state, or national levels and, although some may communicate across jurisdictions, most are not currently capable of communicating with one another (“silo” systems). During the past decade, the CDC has worked to define common standards and a framework for building interoperable public health information systems. The Public Health Information Network is a CDC initiative to create an industry standard model, including vocabulary and secure messaging services that support rapid communication across all jurisdictions and ultimately across program areas.9

Since the early 1990s, both medical care and public health needs for tracking children’s immunization status have been addressed by developing population-based immunization information systems (IISs) (immunization registries), which gather information from all immunization providers (both private and public) and consolidate the information so that any authorized user can, at a glance, determine the complete immunization history of a child. This novel approach captures information from all private and public sources and is particularly useful because >25% of US children receive immunizations from >1 provider before their third birthday.10

Considerable effort has gone into defining functional standards for IISs (Table 1).11 IISs are the most comprehensive health information systems that cross the public/private sector divide. A Healthy People 2010 goal was established to increase to 95% the proportion of children <6 years of age participating in fully operational, population-based IISs. At the end of 2006, 65% of such children were participating. However, only 47% of private vaccination provider sites were participating, compared with 71% of public vaccination provider sites (Gary Urquhart, MPH, oral communication, 2007). IISs have demonstrated their usefulness in sending reminder/recall notices to children, generating official immunization records, assessing immunization levels (eg, for the Health Employer Data and Information Set), reducing missed opportunities for provision of immunizations, preventing unnecessary immunizations, recalling for vaccination children who are overdue for a dose or recalling for repeat vaccination children who received vaccine from a lot with identified ineffectiveness, and vaccine inventory management.12

Although IISs have proven their worth and are well advanced, very few are capable of communicating with other health information systems. Most are not yet capable of exchanging information with other IISs, and few are integrated with information systems serving other program areas; therefore, efforts are underway to link IISs with other child health information systems. Four program areas were targeted initially, that is, vital records/registration, immunization, newborn dried blood spot screening, and early hearing detection and intervention. These areas were selected because they apply to all children, begin at or soon after birth, involve both the private sector and the public sector, and are time-sensitive (ie, if procedures are not conducted in a timely manner, then there may be adverse consequences). In addition, these procedures are mandated in all states (although early hearing detection and intervention procedures currently are mandated in only ~40 states, the number is increasing).13

**EMERGENCY MEDICAL SERVICES**

Information systems for children using emergency medical services (EMS) focus primarily on trauma registries and a motor vehicle crash database. Trauma registries exist at local, state, and national levels. Two national trauma registries aggregate data from participating trauma centers and states, that is, the National Trauma Databank, maintained by the American College of Sur-

### TABLE 1 2001 Minimal Functional Standards for Immunization Registries

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Standard</th>
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</thead>
<tbody>
<tr>
<td>Electronically store data on all National Vaccine Advisory Committee-approved core data elements.</td>
<td>Establish registry record within 6 wk after birth for each newborn child born in catchment area.</td>
</tr>
<tr>
<td>Allow access to and retrieval of immunization information in registry at time of encounter.</td>
<td>Receive and process immunization information within 1 mo after vaccine administration.</td>
</tr>
<tr>
<td>Ensure security of health care information.</td>
<td>Protect confidentiality of health care information.</td>
</tr>
<tr>
<td>Automatically determine routine childhood immunizations needed, in compliance with current Advisory Committee for Immunization Practices recommendations, when individual presents for scheduled immunization.</td>
<td>Automatically produce reminder/recall notifications.</td>
</tr>
<tr>
<td>Automatically produce immunization coverage reports according to providers, age groups, and geographic areas.</td>
<td>Automatically produce immunization coverage reports according to providers, age groups, and geographic areas.</td>
</tr>
<tr>
<td>Produce official immunization records.</td>
<td>Promote accuracy and completeness of registry data.</td>
</tr>
</tbody>
</table>

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geons, and the National Pediatric Trauma Registry, maintained by Tufts University. The National Highway Traffic Safety Administration (NHTSA) operates a Crash Outcomes Data Evaluation System to match state data from law enforcement agencies, EMS, and emergency departments and hospitals. As of 2002, the Crash Outcomes Data Evaluation System was being used in 25 states.

The National EMS Information System is being developed as a unifying system to collect information on EMS activities at the national level. The goals and objectives are (1) to implement an electronic EMS documentation system in every local EMS system that can collect and use data based on the NHTSA 2.2.1 dataset standard, (2) to implement a state EMS information system in every state and territory that can receive and use a portion of the local EMS data via the XML standard, and (3) to implement a national EMS database that can receive and use a portion of the state and territorial EMS data via the XML standard.15

In 2003, the National Association of State EMS Directors adopted a resolution to promote and to support EMS data initiatives to conform to the national NHTSA dataset standards and to call on vendors of EMS information system software to use these standards. As of 2006, 31 states had an active data system and 8 states were submitting data to the national EMS database. An additional 16 states reported they would be capable of submitting information in 2007.16 Studies and practical examples of interoperable information exchange from an EMS system directly into emergency department medical records (eg, EHRs) are limited at best.

SCHOOL HEALTH INFORMATION SYSTEMS
School health services systems either are independent, stand-alone systems residing within a school clinic and not linked to any other system or represent a formal linkage with another health care institution where records (from both the school clinic and other health care providers) are accessible to other enterprise caregivers. There are no clear examples of schools that interface their school-based records with an EHR.

The Family Educational Rights and Privacy Act (FERPA) provides that "Generally, schools must have written permission from the parent or eligible student to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions . . . appropriate officials in cases of health and safety emergencies."17 Although interpretations vary among the states, interpretations of FERPA generally have meant that the exchange of health-related information has been in 1 direction, with schools receiving health information about students from the public health and health care systems but not providing health information to those systems without previous parental consent. It is unclear whether records of school clinics maintained separately from the school system would be considered part of the educational record and therefore subject to the provisions of FERPA. It is difficult to document the health implications of the FERPA restrictions. According to a study of school nurses, 5.6% of students require medications at school. Although 98% of nurses reported having medication guidelines, nearly one half (48.5%) reported a medication error in the preceding year; only 20.7% documented adverse effects. Whether health care providers received information about the medication errors or adverse effects (and whether they had direct health effects) is not known. What is clear is that the current interpretations of FERPA make it difficult to achieve ready exchange of health information between the educational system and the public health/health care systems and this could have negative effects on the health of children.

NATIONAL INITIATIVES
Several national initiatives that have major implications for the development of integrated health information systems are currently underway. These are described in several of the other articles in this supplement.

Health information exchanges (HIEs) are being established around the country to promote health information sharing among health care providers, health care institutions, and health departments. HIEs will collectively form a major part of the National Health Information Network, a Department of Health and Human Services initiative intended to link disparate health care information systems together to allow patients, physicians, hospitals, public health agencies, and other authorized users across the nation to share clinical information in real time, under stringent security, privacy and other protections.19

A definitive count for the number of HIEs does not exist. The fourth annual survey of HIEs in 2007, announced through e-mail, listservs, and distribution of surveys at conferences and meetings, elicited responses from 130 HIEs.20 Thirty-two were considered fully operational. Key drivers for HIE were increasing quality and safety and decreasing inefficiencies. Of the HIEs surveyed, 34% exchange laboratory data and 32% exchange data related to outpatient episodes. Development of a sustainable business model is the greatest challenge for all HIE efforts. Although upfront and ongoing operational funding relies heavily on the federal government, alternative funding sources for ongoing sustainability are emerging: 61% of respondents receive ongoing operational funds from hospitals, 37% from physician practices, and 31% from payers. Without a major, ongoing, federal-level commitment, developing these alternative funding sources will be critical to the success of the HIE/regional health information organization (RHIO) model. Some HIEs are not successful (5 HIEs that were included in the 2006 survey were no longer moving forward), but 15 new HIEs responded in 2007 that were not included in the 2006 survey.

CHALLENGES AND BARRIERS
Some of the most important barriers to the development of integrated information systems are the lack of agreement on standards for data exchange and the lack of
clarity on developing statements of required functionality. Shortliffe\textsuperscript{21} described 3 types of barriers to effective use of information technology in health care, namely, cultural barriers, making the business case, and structural barriers. Johnson\textsuperscript{22} provided an elegant analysis of the barriers to adoption of information technology in pediatrics. He categorized the barriers in the following way: situational barriers, cognitive and/or physical barriers, liability barriers, and knowledge and attitudinal barriers. He also described possible approaches to overcoming these various barriers, outlined gaps in our knowledge concerning the barriers, and concluded that involvement of all stakeholders, including industry, consumer groups, professional societies, and government agencies, is critical to overcoming the barriers.

The Office of the National Coordinator has created the Certification Commission for Healthcare Information Technology, a federally sanctioned private organization to ensure standards certification of EHR products, and the Health Information Technology Standards Panel to harmonize industry-wide health information technology standards development, maintenance, and refinements over time.\textsuperscript{23} The Health Information Technology Standards Panel chair (Dr John Halamka) asserted that the main challenges in developing a uniform health information infrastructure on a national scale are consistent standards, addressing privacy and security, and establishing pluralism. Dr Halamka proposed a common framework for information exchange, consisting of the essential technical and policy requirements. Given that >300 communities are currently engaged in creating HIEs, there is an urgent need to establish that common framework.\textsuperscript{24}

The All Kids Count project\textsuperscript{21} summarized 10 lessons learned for health information systems projects, as follows. (1) Involve stakeholders from the beginning. (2) Recognize the complexity of establishing a population-based information system. (3) Develop the policy/business/value case for information systems. (4) Define the requirements of the system to support users’ needs. (5) Develop information systems according to current standards. (6) Address common problems collaboratively. (7) Plan for change. (8) Plan boldly but build incrementally. (9) Develop a good communication strategy. (10) Use the information (even if it is not perfect).

**BENEFITS OF LINKING CHILD HEALTH INFORMATION SYSTEMS**

Although the costs of investing in health information systems represent a potential barrier to their adoption, a Rand study indicated that effective EMR implementation and networking could eventually save more than $81 billion per year by improving health care efficiency and safety.\textsuperscript{25} Using health information technology (HIT)-enabled prevention and chronic disease management could double the savings, while increasing health and other social benefits. Overall estimated annual savings would be $142 billion to $371 billion. Another author described these savings as a mixture of “hype and hope.”\textsuperscript{26} Safety benefits would accrue from reducing adverse drug events in both inpatient and ambulatory set-

ings. Health benefits would accrue from using HIT for short-term preventive care, near-term chronic disease management, and long-term chronic disease prevention and management. Costs would include adoption costs for hospitals and physicians. Barriers to adoption include acquisition and implementation costs, slow and uncertain financial payoffs, and disruptive effects on practices. Although providers absorb the costs of EMR systems, consumers and payers are most likely to reap the savings. Given these market disincentives, interoperability and robust information exchange networks may fail to develop. Consequently, government may play a substantial role through policies that facilitate widespread diffusion of interoperable HIT.

Existing health information systems have demonstrated that they can improve health and health services, although most are not able to share information. Additional benefits are bound to accrue when, for example, a pediatrician seeing a child for a well-infant visit is alerted by the information system that the child failed a newborn hearing screening test but has not yet been fully evaluated, diagnosed, or treated. Because so few information systems are currently integrated, it is not yet possible to document these benefits. An effort is underway (supported by the Robert Wood Johnson Foundation and the federal Maternal and Child Health Bureau) to develop the business case for integrated child health information systems.\textsuperscript{27} This effort is focusing on vital registration, newborn dried blood spot screening, early hearing detection and intervention, and immunization, but the model is capable of incorporating activities from other program areas.

**CASE STUDY OF HIE IN COLORADO**

Colorado was awarded 1 of 6 Agency for Healthcare Research and Quality state and demonstration projects for health information technology. A basic organizational premise of that work was to convene stakeholders through a neutral convener (Colorado Health Institute) and to include all who wanted to participate, including various stakeholders in the governance, policy, technical, and clinical domains. Within Colorado, a number of local or regional projects are being developed for localized markets, whereas the Agency for Healthcare Research and Quality-funded project focuses on developing the statewide interoperable network. A functioning statewide RHIO would include public health agencies, the Colorado IIS, and health care providers (both safety-net and private) for large numbers of children.

To promote clarity, Colorado’s RHIO used a use case to describe a situation where HIE services would be beneficial. The use case describes a 4-year-old boy seen for a seizure at 1 of the 4 partner institutions (Fig 1). Use of this schematic has improved the ability to understand policy, business process analysis,\textsuperscript{29} and functional requirements for the statewide interoperable system.

Linkage of Colorado-based information has occurred in a number of ad hoc ways to date. None of these are based specifically on Colorado’s RHIO activities but rather demonstrate the value of a collaborative environment and the potential of “infomediaries.”\textsuperscript{30} Through
mutual trust and shared stakeholder perspectives, linkages are possible. The Colorado Department of Public Health and Environment collected data to evaluate asthma care in 2 large health care providers in the Denver metropolitan region. Injury data are currently being linked between law enforcement motor vehicle crash findings, the EMS prehospital system, inpatient care, and the trauma registry. Funded by a CDC grant, the work identified “hot spots” for motor vehicle crashes and related those to measures of costs of care. Another linkage has been between school-based health centers and the vertically integrated, safety-net institution that supports them (Denver Health). School-based clinic use was inversely associated with emergency/urgent care center use and was associated with improved quality care markers (ie, increased receipt of recommended vaccines). School-based clinics were an important source of care for uninsured adolescents.
As RHIO/HIEs work to define the value proposition and a sustainable business model, we need to ensure that we are addressing local end-user needs. The Colorado IIS is one component of the stakeholder group. End-users perceive Colorado’s RHIO as an integrated data resource, where a master patient and provider index resolves identity management issues and supports retrieval of federated or distributed data through a record locator service. A common vocabulary engine permits data standardization and then aggregation, to present in a user-friendly screen for review. Decision support systems permit clinical guideline applications at the point of care and in population-aggregated views. Use of the common vocabulary engine allows organization of data along a “concept” or disease. The information about the 4-year-old boy in the use case would be organized around “seizure disorder,” with most of the desired information available in a single, clear, chronological view.

A decision support system is being designed to assist both personal health care providers and public health officials to monitor the health of individuals and populations, respectively. An example of such decision support is a knowledge management system that knows that a child has asthma (from previous administrative records that coded visits with International Classification of Diseases code 493 or previous inhaler prescription use) and alerts the provider (when the child is in the office) that this child should be counseled to receive influenza vaccine or should be offered the vaccine if it is timely or not recorded in the Colorado IIS. If a child had a reaction to a previous vaccine or a contraindication to future use that was recorded in the medical record (but not in the Colorado IIS), then an integrated system would alert the provider.

At the population level, a practice administrator, health plan, public health official, or health services researcher could ask the same question for the entire population cared for by a practice, health plan, or jurisdiction. Registry functionality is a key component, and decision support runs once a population with certain attributes has been identified. Monitoring permits data reuse and assists in the design of feedback to providers or specific messages to patients.

CONCLUSIONS

Activity directed at developing child health information systems is accelerating with newer technologies. Recent efforts have integrated child health information systems successfully. The larger national initiatives dealing with HIEs offer great promise, but we are far from realizing the potential of fully integrated/linking health information systems. At present, our conclusions are as follows. (1) Technology is not the limiting factor. The technology to link information systems together exists today. (2) Involvement of all stakeholders (parents/patients, providers, payers, health plans, and system developers) is essential to define the requirements of the linked systems. (3) Standards are necessary for implementation of the requirements. (4) National coordination of efforts is essential and should proceed through a public-private sector collaboration, rather than through government dominance. (5) Development of a RHIO/HIE is a multi-year effort and is expensive. The RHIO/HIE should consider an array of potential services that may have different returns on investment but that are valuable for achieving a broad strategic coalition. Short-term investment is extensive, and strategies to cover both initial capital costs and sustainability need to consider short-term and long-term value. In the long run, the process is worthwhile.

ACKNOWLEDGMENTS

Dr Hinman was supported in part by the Robert Wood Johnson Foundation. Dr Davidson was supported by the Agency for Healthcare Research and Quality (contract 290-04-0014, Colorado State and Regional Demonstration Project).

REFERENCES


32. Van Bramer LH, McCling M, Davidson A, et al. Spatial analysis of motor vehicle crashes and crash severity using GIS. Presented at the Society of Academic Emergency Medicine Conference; May 18, 2006; San Francisco, CA
Linking Children's Health Information Systems: Clinical Care, Public Health, Emergency Medical Systems, and Schools
Alan R. Hinman and Arthur J. Davidson
Pediatrics 2009;123;S67
DOI: 10.1542/peds.2008-1755D

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/content/123/Supplement_2/S67.full.html