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Immunization Registries Can Be Building Blocks For National Health Information Systems

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ABSTRACT Electronic health records and health information exchanges are necessary components of the information infrastructure to support a reformed health care system. However, they are not sufficient by themselves. Merely summing data from electronic health records together will not provide a comprehensive picture of the population, which is essential for tracking disease trends and treatment outcomes. Public health information systems such as immunization registries are an essential component of the information infrastructure and will allow assessment of the impact of changes in health care on the population as a whole.

The health care reform debate has revealed at least four areas of concern to all parties involved: access, quality of care, increased emphasis on prevention, and cost.¹ Each of these areas is dependent on the support and availability of information that is collected, analyzed, and disseminated via existing or newly developed health information systems.

The Information Infrastructure

To the extent that health information technology (IT) has entered the debate, the focus has been on electronic health records as the vehicle by which information can be collected, analyzed, and disseminated. And independent of the health care reform debate, there has been a movement within the medical arena to increase the use of electronic health records as a means of addressing quality and cost. This can occur because electronic health records can help reduce errors and allow for better care coordination, and can help control costs by reducing unnecessary testing.²

ELECTRONIC HEALTH RECORDS There is no commonly understood distinction between the concepts of an electronic health record and an

electronic medical record, and no such distinction has been made uniformly in the literature. The National Alliance for Health Information Technology has attempted to devise a distinction, describing an electronic medical record as “an electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff *within one health care organization*” (emphasis added).³ By contrast, electronic health records are defined by the alliance as an electronic record of the range of services received by a single patient within his or her lifetime *from various providers and across a series of institutions*. Furthermore, the alliance describes an electronic health record as containing “health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization.”³ Electronic health records may be created by sharing the information among different electronic medical records for a given individual. In this paper we use the term “electronic health records” to refer to both.

HEALTH INFORMATION EXCHANGE Along with the push for electronic health records as a tool

to improve the delivery of health services at the point of care has come the notion of the health information exchange. The exchange is promoted as an entity that could link health care providers by facilitating the transfer of patient information. It could thus transform electronic medical records collected by individual institutions into broader electronic health records that compile information about care received by an individual across multiple institutions.⁴

A health information exchange permits “the electronic movement of health-related information among organizations according to nationally recognized standards.”³ Health information exchanges are now being established around the country to provide a centralized means of sharing health information among health care providers, health care institutions, and health departments. These exchanges—some national and some regional—are in place to develop, manage, and maintain conventions and terms, the means of electronic exchange, and standards.

Exchanges will collectively form a major part of the Nationwide Health Information Network, an initiative of the U.S. Department of Health and Human Services (HHS) intended to provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and health care.⁵

The American Recovery and Reinvestment Act (ARRA) of 2009 is providing a major stimulus to the implementation of electronic health records and health information exchanges in order “to modernize the health care system by promoting and expanding the adoption of health information technology by 2014.”⁶

IMMUNIZATION REGISTRIES Electronic health records and exchanges are necessary components of the information infrastructure to support a reformed health care system. However, they are not sufficient by themselves. Although electronic health records may include comprehensive information on an individual within a care setting, merely summing together data from electronic health records will not provide a comprehensive picture of the health of the population, which is essential for tracking disease trends and treatment outcomes. Creation of electronic practice-based networks for comparative effectiveness research⁷ or a national distributed health data network⁸ can support a number of important translational research or quality improvement activities. However, electronic health records based on “encounter” information—what happens when a given patient is seen or treated by a provider—do not provide information about the broad population that is needed to assess health care and disparities. Nor do

they permit assessing the health of entire communities. As recently pointed out, they are “designed to improve the efficiency of individual transactions.”⁹

► **POPULATION HEALTH:** Our thesis is that population-based public health information systems such as immunization “registries” are essential. Without them, we will not have the adequate information infrastructure to assess how well we are doing in a reformed system with respect to access, quality, and outcomes. In addition to the population base, public health information systems can provide important additional information, including environmental influences on health or disease trends and outbreaks. They can provide information about geographic areas that are underserved or that have concentrations of unfavorable health indicators. By providing accurate information about an entire population group—not just those who seek services—these systems also allow assessment of disparities of health status in different population subgroups according to age, sex, race or ethnicity, and other factors.

► **AN EXISTING MODEL:** Immunization registries provide a model for how public health information systems can support clinical decision making, meet public health demands for assessment and assurance, improve quality of care, and contain costs. The registries are “confidential, computerized information systems that contain information about immunizations and children.”¹⁰ Population-based immunization registries include information on all immunizations received by all people living in the geographic area.

Immunization information systems led the way in linking population-based data and health care delivery. They have a longer history of development and standardization than other population-based health information systems and are more mature than most other public health information systems. As of December 2008, data on 75 percent of all U.S. children younger than age six were being recorded in registries.¹¹ Immunization registries possess most of the attributes of a clinical information system; for example, they have individually focused records capturing a longitudinal history of care delivered to children and adults. They are the public health database best suited for clinical decision support.

Consequently, immunization registries are a suitable platform for creating a regional mechanism to use in collecting comprehensive health information. They also provide a logical basis for establishing health information exchanges that can link to electronic health records as well as other health information systems. At the same

time, however, integrating electronic health records and immunization registries into effective public health information exchanges will require significant planning and effort.

Electronic Health Records

Both former President George W. Bush and President Barack Obama have publicly stated that all Americans should have electronic health records by 2014.^{12,13} In addition to the presidential commitment to the use of electronic health records, professional associations have committed themselves to the cause. The American Academy of Family Physicians had a goal of “at least half of its members using electronic health records by 2006.”¹⁴ In July 2008, 42 percent of its members were using electronic health records, and an additional 13 percent were in the process of implementing them.¹⁵

Although the American Academy of Pediatrics has not established a similar numerical target, a members’ meeting in September 2004 produced the following statement: “adoption of electronic health records by a majority of American Academy of Pediatrics members in the next 5–10 years is at the highest priority.” In 2007 the academy published a statement on the special requirements of electronic health record systems in pediatrics,¹⁶ and a child health functional profile for Health Level 7 (HL7) standards was also published that year.¹⁷

In 2008 the Certification Commission for Healthcare Information Technology adopted criteria applicable to child health. Its child health workgroup is charged with ensuring that electronic health record products and networks address the health IT requirements of “caring for this special population by developing criteria and test scripts.”¹⁸ Through the organization’s review and certification process, some critical pediatric electronic health record functionalities—such as immunization management (including linking to immunization information systems), growth tracking, medication dosing, patient identification, norms for pediatric data, privacy, pediatric terminology, and data precision—have been or will be incorporated in electronic health records.

Despite some progress, implementation of electronic health records is not keeping pace with the rhetoric. Through 2005, Ashish Jha and colleagues found that electronic health records were in use in just 24 percent of physicians’ offices.¹⁹ Jha reported in an article published in 2009 that only 1.5 percent of hospitals had comprehensive electronic health record systems in 2008. Basic electronic health record systems were in place in 7.6 percent of hospitals, and

17.0 percent of hospitals were using computerized provider order entry for medications.²⁰

Health Information Exchanges

No definitive count exists of the number of health information exchanges that exist in the United States. However, an annual survey by the e-Health Initiative—a collaboration of independent, nonprofit organizations that promote health care information technology—provides some useful information. The group’s sixth annual survey of health information exchanges in May 2009 elicited responses from 150 exchanges. An additional forty-three exchanges that had responded in 2008 but not in 2009 were contacted and were found to still be active.

Therefore, there were at least 193 health information exchanges active in the United States at the time of the survey. Fifty-seven were considered to be fully operational, compared with forty-two in 2008 and thirty-two in 2007. Forty of the operational exchanges reported reductions in health care costs, and about half reported positive impacts on health care delivery. For the first time, health information exchanges reported that “addressing privacy and confidentiality issues” was the most pressing challenge they faced, surpassing “developing a sustainable business model.”

Nearly half (71 of 150 exchanges) reported that they are not dependent on federal funding. A total of eighty-three exchanges in forty-three states and Washington, D.C., reported state or local government involvement in their efforts. The five most commonly exchanged forms of data were inpatient laboratory results, medication (including outpatient prescriptions), outpatient laboratory results, outpatient episodes, and radiology results. Public health data, such as immunizations, did not make the list of the top-fifteen types of data exchanged.²¹

The National Governors Association State Alliance for e-Health recently issued the *State Guide For Electronic Health Information Exchange*, which describes state roles and responsibilities in establishing exchanges.²² The guide calls on states to take a number of steps, including preparing or updating plans for health IT adoption, engaging stakeholders, establishing state leadership offices, and implementing privacy and security strategies. The guide also encourages states to develop operational and business models for exchanges, create communications strategies, and develop workforce capacity through health IT training and education.

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Million People

The immunization status and records of nearly 95 million people are included in immunization registries across the country.

Immunization Information Systems

A goal set by the HHS Healthy People 2010 initiative seeks to have 95 percent of children younger than age six participating in fully operational, population-based immunization information systems.²³ With that goal in mind, all states (except Kentucky, Massachusetts, and New Hampshire) have or are developing population-based immunization information systems. For a child to be included in one of these immunization registries, he or she must have received at least two immunizations. The National Vaccine Advisory Committee released progress reports on immunization registries in 2001²⁴ and 2007.^{25,26}

In total, the immunization status and records of nearly ninety-five million people are included in immunization registries across the country. Although these systems are increasingly considered lifelong information systems, they do not yet contain information on as high a proportion of adults as of children and therefore do not fully represent the total population of a given area. Among public immunization provider sites, 75 percent are submitting data to immunization registries, as are 37 percent of private immunization provider sites. Nineteen states, the District of Columbia, Philadelphia, and New York City reported that data on more than 95 percent of children younger than age six are being collected in immunization registries (Exhibit 1).¹¹

In 2005, America's Health Insurance Plans surveyed members about a variety of immunization-related activities, including participation in an immunization information system. Of 140 plans surveyed, only 61 (44 percent) responded; 85 percent of these managed care organizations and preferred provider organizations reported that they were currently sharing information with an existing immunization registry in their service area or state.²⁷ Even if none of the non-respondents were sharing information with immunization registries, this represents 37 percent of the total.

In 2006, 86 percent of Centers for Disease Control and Prevention (CDC) immunization program grantees reported using their immunization information systems for routine coverage assessments of "series-complete" immunization of children ages 19–35 months. Eighty percent of grantees were using registries for coverage assessments in practices for Healthcare Effectiveness Data and Information Set (HEDIS) reports. Sixty-seven percent of grantees were using registries to identify geographic "pockets of need," and 61 percent were using them to ensure the compliance of new school entrants with school immunization laws. Notably, 70 percent of CDC grantees had the capacity to track vaccination

coverage of people in all age groups.²⁸

Immunization registries have demonstrated their usefulness in consolidating immunization records from multiple sources, improving immunization coverage, reducing missed opportunities to carry out immunization, supporting vaccine safety, increasing the timeliness of immunization, helping providers reach coverage goals, studying effectiveness and efficiency, and keeping managed care records up-to-date.²⁹ They represent an important example of population-based information systems that serve the needs of both clinical management at the point of care and public health assessment, or tracking health trends and treatment outcomes.

Clinical And Public Health Information

STANDARDS, INTEROPERABILITY, CERTIFICATION

Optimal use and exchange of person-specific data for patient care and assessing the health of entire populations requires the creation of an information infrastructure that facilitates integration of information at the point of care. Doing so effectively hinges on establishing a framework that drives the health system at large toward adopting "interoperable systems." These are systems that have process interoperability, in that they treat work and business processes consistently; that have data interoperability, which means that they define data according to nationally recognized standards; and that have semantic interoperability, which means that they can make meaning out of the standardized encoding of data.

When HHS established the Office of the National Coordinator for Health Information Technology, it sent a signal that information technologies must be deployed in a way that supports improvement in the quality, safety, and efficiency of care. If agreements can be reached on the major information architectural stan-

EXHIBIT 1

U.S. Participation In Immunization Information Systems, By Population Category, 2002 And 2008

Category	2002	2008
Children under age 6 (2+ doses)	43%	75% (17.7 million)
Adolescents ages 11–18 (2+ doses)		65% (23.3 million)
Adults age 19 and older (enrolled)		24% (53.9 million)

SOURCES For 2002: Immunization Information Systems annual report (IISAR) data [Internet]. 2002 map. Atlanta (GA): Centers for Disease Control and Prevention; 2008 [cited 2010 Mar 9]. Available from: <http://www.cdc.gov/vaccines/programs/iis/rates/default.htm>. For 2008: Centers for Disease Control and Prevention. Progress in immunization information systems—United States, 2008. MMWR. 2010;59:133–5.

dards, including data, transmission, security, and so-called meaningful use as defined in forthcoming federal regulations; on appropriate approaches to governance; and on business models demonstrated to be viable, then regional health information exchanges will be able to assist in the transformation of health care delivery across the nation.

Arriving at agreements and standards and demonstrating effective business models are not easy tasks, and some regional health information organizations have faltered.³⁰ The decentralized approach in the United States can be contrasted with more centralized approaches in many other countries, such as the United Kingdom, Australia, and Brazil.

Many immunization information systems have demonstrated an ability to interact with electronic health record systems through a variety of techniques, but few yet have the ability to interact with them seamlessly. Currently, most electronic exchanges between electronic health record systems and immunization information systems are accomplished daily or weekly. This occurs by exchanging information on a number of records, or batch files, rather than immediate, real-time exchange between an individual electronic health record and the immunization information system. Because immunizations—although a large part of pediatric practice—are not a major part of electronic health records at present, motivating electronic health record vendors to adapt their systems to exchange information with immunization information systems is a key concern.

SECURE EXCHANGE OF PROTECTED INFORMATION Health information exchanges have successfully demonstrated the ability to exchange protected information securely within a particular geographic region—usually within a single state. More problematic is the exchange of information across state lines. Some states have signed memorandums of understanding, typically termed “data-sharing agreements,” with neighboring states to allow such exchange. But it has often been difficult and time-consuming to reach these agreements.

Recently the Health Information Security and Privacy Collaboration has developed an *Action and Implementation Manual* summarizing the work of seven other collaboratives. Among other topics, the manual addresses harmonizing state privacy laws, policy options for intrastate and interstate consent, interstate disclosure and patient consent requirements, and interorganizational agreements. Among the tools developed are a model data-sharing agreement for public health, with a modification specific to immunization information systems, and a model data-

sharing agreement for private entities.³¹

FINANCING The cost of implementing electronic health records has been a long-standing concern and an impediment to their widespread adoption. This cost is typically borne by the institution or practice implementing the records. Immunization information systems have been largely funded through federal immunization grant funds authorized by Section 317 of the Public Health Service Act. Health information exchanges have secured funding from a variety of sources, both public and private.

As noted earlier, financing is still a concern but is no longer the leading concern. The American Recovery and Reinvestment Act provides billions of dollars for health IT projects (the midrange estimate is \$20 billion over five years. This sum will include support for individual practices to implement electronic health records as well as grants to states to facilitate and expand the use of electronic health information using nationally recognized standards.⁶ It is not yet possible to determine the impact of this infusion of funds.

As required under ARRA, the Office of the National Coordinator for Health Information Technology recently published a Notice of Proposed Rule Making defining several characteristics of electronic health record systems that physicians will be required to incorporate in order to qualify for full reimbursement.³² This federal guidance includes a section on population health that requires the electronic health record system to be able to submit data to multiple users, including immunization information systems (or registries as stated in the guidance), biosurveillance systems, and electronic depositories for lab results. The clear intent is to assure a future in which essential population health functions, such as immunizations, are incorporated into the fabric of information used to measure progress toward improving and protecting the health of all Americans. The requirement that certified electronic health record systems link to these essential public health functions validates our premise that only by measuring population-level impact will we know if our health investments have been wisely placed.

INERTIA Another challenge to the implementation of a comprehensive network of health information systems in both the clinical and public health arenas is the existence of a large number of existing systems that are single-purpose, stand-alone, or so-called silo systems. These have been developed over a number of years using different platforms, often without standardization. Nonetheless, they may well be meeting individual program needs satisfactorily.

Programmatic and emotional attachment to these existing systems, coupled with the techni-

cal difficulties and expense of modifications to enable them to participate in health information exchanges, can result in a lack of enthusiasm for making any changes. Overcoming this inertia is difficult but can be facilitated by strong executive sponsorship in addition to funding and technical assistance.

Conclusions

To assess how well we are doing with a reformed health system, we must have a network of pop-

ulation-based, comprehensive health information systems. Simply examining individual or even pooled encounter-based information will not give an accurate reflection of how well the system is working for the population as a whole. Accurately assessing the impact of health reform on access, disparities, and health outcomes requires population-based health information to allow comparisons among different population groups. Public health information systems such as immunization registries can provide the population base needed for this assessment. ■

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families around the world. It is affiliated with Emory University and the Carter Center.

At the institute, Hinman has argued forcefully for the tremendous untapped potential of information systems to improve population health outcomes. Public health as a sector "is not as involved as it should be in the current electronic information revolution," he says. His paper in this issue of *Health Affairs* argues the case for marrying immunization registries with electronic health records as one means of rectifying that deficiency—and of taking advantage of the opportunity such systems offer to improve health.

Before joining the Task Force for Global Health, Hinman had a long career with the Centers for Disease

Control and Prevention (CDC). He served as an officer with the Epidemic Intelligence Service (EIS) in the 1960s. Subsequently, he was director of the Immunization Division, director of the National Center for Prevention Services, and senior adviser to then CDC director David Satcher. He also worked in state health departments in New York and Tennessee and achieved the rank of assistant surgeon general in the U.S. Public Health Service. He has authored more than 300 scientific publications, many on the topic of vaccines and public health.

Hinman credits his interest in public health in part to his father, who also worked in the field and whose own career took him to El Salvador, Mexico, and

later, Puerto Rico as dean of the medical school and school of public health. After graduating from Cornell and attending medical school at then-named Western Reserve University, the younger Hinman joined the EIS, where he was assigned to work for the California Department of Health investigating everything from outbreaks of waterborne diseases and plague to tuberculosis and measles. He was also sent to Honduras to investigate a national outbreak of polio and organize an immunization campaign.

The Honduras experience "cemented the view that most of our serious health challenges are global, not just local, and that global solutions are needed," Hinman recalls today. He says that these experiences

impressed upon him the "greater impact one could have [working in public health] on population, as contrasted with individual, health." That realization reinforced his decision to eschew clinical practice for what would eventually be a more than four-decade career as a public health practitioner, researcher, and planner.

"We Americans have a lot to give in terms of developing interventions and helping implement them in other countries," Hinman says. At the same time, "we have a lot to learn from how other countries, with fewer resources, are addressing the same challenges"—including making use of information and informatics to improve health.