A Proven Model for Electronic Health Data Exchange: Immunization Information Systems (IIS) and the American Immunization Registry Association (AIRA) Community of Practice

Standards Adoption and Interoperability

The interstate use of IIS during Katrina, lauded by Secretary Leavitt, provided access to immunization records for children displaced to other states, facilitating their school attendance in a timely manner and saving the healthcare system an estimated $3.04 million in vaccine costs.

Critical success factors—adoption of functional and technical standards and a trusted community (AIRA)—facilitate both emergency and routine exchange of immunization data between public and private stakeholders, including providers, health plans, and schools, and strongly support AHIC focus areas EHR, PHR, and Biosurveillance with infrastructure and lessons for data exchange. History, processes, successful examples, and challenges are described.

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A PROVEN MODEL FOR ELECTRONIC HEALTH DATA EXCHANGE: IMMUNIZATION INFORMATION SYSTEMS (IIS) AND THE AMERICAN IMMUNIZATION REGISTRY ASSOCIATION (AIRA) COMMUNITY OF PRACTICE

The Hurricane Katrina story that follows represents a true success story for the use of standards in an electronic information system to affect the health outcomes of many children, promote the effectiveness and efficiency of health services delivery and reduce healthcare costs. In fact, Health and Human Services Secretary Leavitt, who toured the Gulf Coast after Katrina, highlighted the use of Immunization Information Systems (IIS) to access the immunization records of displaced children as a major HIT achievement. Secretary Leavitt's praise echoes the belief of the American Immunization Registry Association (AIRA) that the IIS community models what it takes to achieve electronic data exchange of individual health records between health systems in different jurisdictions in a standards-based and confidential manner.

Hurricane Katrina forced the relocation of thousands of children from Louisiana to other states just as the 2005-2006 school year was starting. These children, along with thousands of adults, had to flee their homes without any possessions, least of all the written documentation of their immunization status necessary for school entrance. Fortunately, the means to access the immunization status of those displaced children already existed; Louisiana's state IIS, the Louisiana Immunization Network for Kids Statewide (LINKS), had a backup server in Baton Rouge that contained immunization information from many of Louisiana's private provider practices, public health clinics, and community health centers.

Two other factors were necessary to enable LINKS to successfully share its data with the many state and regional IIS around the country: a strong IIS community of practice, and existing, long-term efforts by IIS programs to develop and implement uniform functional and technical standards in their IIS. AIRA, a non-profit association whose members are IIS program staff in public health departments, and other organizations, individuals, and communities and system vendors interested in preventing and controlling vaccine-preventable disease by enhancing the capacity of IIS, was instrumental in helping IIS get both pieces in place long before Hurricane Katrina.

Here's how it happened: Houston-Harris County, a jurisdiction to which a majority of Katrina's displaced people relocated was about to re-immunize the children so that they could begin attending school. Lack of available vaccine and staff meant delays in getting the children immunized, and consequently attending schools. Added to these issues was the cost of the vaccines and their administration, later estimated at $3.04 million when considered across all the jurisdictions that accessed the displaced children's records from LINKS.[1]

Houston-Harris County Immunization System (HHCIS) staff and LINKS joined forces to connect their systems to enable Houston's access to these children's immunization history. LINKS had been developed and managed by Scientific Technologies Corporation (STC), and was using the HL7 messaging standard, an IIS functional requirement developed and maintained by AIRA in partnership with the CDC. HHCIS had contracted with STC to support their existing system and to integrate HL7 capability. The use of this data exchange standard by both systems allowed STC, HHCIS, and LINKS staff to connect HHCIS and LINKS within 24 hours. After carefully testing the connection and signing data-sharing agreements, thousands of immunization records for the displaced children from Louisiana were immediately available through the HHCIS.

[1] Boom, JA, Dragsbaek, AC, Nelson, CS. The Success of an Immunization Information System in the Wake of Hurricane Katrina. Pediatrics. 2007; 119:1213-1217.

STC, an AIRA member, then turned to AIRA to spread the word to other IIS trying to get immunization data for the displaced children now living in their jurisdictions. AIRA spread the word and also updated the IIS community with daily progress reports. Two months later, nine IIS were using HL7 to exchange data with LINKS, 52 IIS had lookup access, and over 41,000 patient records in the Louisiana IIS had been securely accessed by other registries.

LOOKING BACK A LITTLE FURTHER

The successful exchange of data following Hurricane Katrina was not coincidental; IIS had historically undertaken many activities to reach the point where they could experience this successful outcome. Development of IIS, formerly called immunization registries, began in the 1990s. These public health systems were pioneer HIEs, exchanging data directly with public and private providers, along with WIC (Women Infant and Children) clinics, schools, childcare, Medicaid, and other health plans. The routine use of IIS has been significant in improving immunization rate coverage, but until Katrina, they were largely unrecognized as systems that could document immunization status, prevent disease, and allow children to attend school without re-vaccination following an emergency or disaster.

Funding for bioterrorism after 9/11 and the HIT initiatives arising out of the National Framework positioned IIS to participate fully in HIEs and RHIOs and to exploit the technical, privacy, security, data quality, and governance infrastructure IIS developed through AIRA under its cooperative agreement with CDC. Through AIRA, IIS worked to establish relationships with stakeholders within the potential data sharing community and collaborated with each other and those stakeholders to establish data standards.

BUILDING TRUST AND A COMMUNITY OF PRACTICE

A critical success factor of the IIS deployment following Katrina was familiarity with and a sense of trust between those working on the data exchange—the IIS sharing immunization data, and the IIS vendor that worked with the IIS to create that data bridge between the systems. Launched in 1999, AIRA's members knew each other through face-to-face annual meetings, workgroups that met to address issues of importance to IIS and public health, and other AIRA-sponsored meetings and events. As a result, in the middle of an emergency situation AIRA was in a position to immediately reach out to all IIS programs, connecting them with the STC and LINKS staff. Of the more than 60 IIS contacted by AIRA to participate in the data exchange, not a single one refused to participate. AIRA was able to serve as the trusted communications conduit for these groups.

Over the years, AIRA has also built partnerships with provider organizations such as the American Academy of Pediatrics (AAP) and other stakeholders such as America's Health Insurance Plans (AHIP). Ongoing meetings with these groups have opened communication between their members and IIS, helping all parties understand the opportunities and barriers to participating in and sharing data with IIS. These relationships continue to expand the community of practice established by AIRA.

A HISTORY OF CONTRIBUTING TO STANDARDS DEVELOPMENT AND DATA QUALITY

The other key to the success of Katrina and to the current readiness of IIS to participate in data exchanges stems from efforts by AIRA and its members to foster the development and adoption of both functional and technical standards for IIS.

Functional Standards Efforts

Back in 1997, through the National Immunization Program's Technical Working Group, IIS began defining the minimum functional standards an IIS should have to effectively do its job.[2] These functional standards define the core set of data items an IIS should capture and eleven other standards that address data quality,

[2] IIS: 2001 Minimum Functional Standards for Registries. http://www.cdc.gov/vaccines/programs/iis/stds/min-funct-std-2001.htm.

privacy and confidentiality, HL7 capacity, data use, and reporting capabilities. The original functional standards were amended in 2001. Then in February 2007, in consultation with AIRA and CDC, the National Vaccine Advisory Board approved a new set of core data items that are available on the CDC web site.[3] While currently no certifying body exists for these functional standards, IIS programs annually report the status of their IIS to the CDC. AIRA also posts the functional requirements and the annual report on its web site against which IIS programs voluntarily assess their IIS.

Technical Standards Efforts

AIRA has also supported the development and adoption of standards by IIS, forming committees and workgroups like its Data Exchange Standards (DES) Steering Committee to address these issues. Products and results the workgroup has delivered include the Data Definitions Workgroup's Data Codebook, a guide that documents the data items collected and used in the IIS, making it easier for systems to share their data. In addition, AIRA's DES Steering Committee worked with the CDC to create an IIS HL7 implementation guide that provides guidance on using the HL7 messaging standard to send and receive immunization data between systems.

AIRA also participates in the standards development efforts by other organizations. AIRA works with the Public Health Data Standards Consortium (PHDSC) on issues around HL7 and other data standards that impact IIS. As a member of the HL7 organization, several AIRA members sit on HL7 workgroups. IIS also participate in PHIN standards activities through their departments as many use PHIN-MS as a messaging standard. While other health entities have specific requirements for data exchange that go beyond the lists of vaccine codes and manufacturers that IIS require, there is also much common ground. Every health entity exchanging data needs to address issues like patient identification and provider identification, and to come up with strategies for managing duplicate data—areas in which the IIS community has a wealth of experience.

Data Quality Guidelines

The decisions that one entity makes about its data impact the other entity with which they share data. For example, if one IIS reviews its data for duplicate entries once a month, but shares data with another IIS that only reviews for duplicate entries twice a year, it adds a burden to the most diligent system. AIRA has always focused significant effort on promoting high data quality as a goal for *all* IIS. AIRA's recent and ongoing work with its Modeling of Immunization Registry Operations Workgroup (MIROW) has already developed best practice guidelines for improving the quality of data being entered into the IIS, defining patient status to help improve immunization coverage, and de-duplicating immunization records. When implemented, these best practices ensure that each IIS is held to the same high standard for data quality.

BARRIERS TO SHARING DATA

Health IT is indeed the tool for driving the change needed to improve health care. But as we move from a world where paper records are the standard to a world where health information is collected and managed electronically, there are new challenges.

Privacy and Security Issues

Clearly electronic records are more portable, and can be potentially accessed quickly in a medical emergency, but their existence calls for security measures to assure that they are used appropriately. Much of the early work in Health IT has been in solving these security issues. Privacy issues and consent have emerged as one of the significant barriers to health information exchange, encompassing areas beyond HIPAA. AIRA has done pioneering work in privacy and confidentiality in collaboration with the CDC. A prime example of these efforts is with the functional standards for an IIS that require both policy and technology approaches to assuring the protection of private health information. And IIS have faced and addressed complex issues like the application of HIPAA standards to data exchange. Reporting information

[3] http://www.cdc.gov/vaccines/programs/iis/stds/coredata.htm.

to public health is HIPAA exempt, but sharing that information with covered entities, such as providers and health plans, is not, and requires an understanding of interpretations of HIPAA for data sharing.

Lag Time in EHR Adoption and Non-standards Based EHRs

One of the biggest issues IIS encounter with sharing data with providers is the ability of providers to send and receive data electronically in any form, and if they can, whether they can transmit in a standards-based format. The adoption of electronic health records (EHRs) shows promise, but a June 19, 2008 article in the online version of the New England Journal of Medicine stated that only four percent of providers had a fully-functional EHR, where fully functional is described as an EHR that has a broad range of capabilities including order entry capabilities and clinical decision support. It stated that only 14 percent had a basic EHR, defined as an EHR with a minimum set of functionalities such as recording laboratory data and clinical notes and electronic prescribing. EHR vendors build EHRs that meet the needs of the provider practice. However, to enable data exchange, EHRs will need adopt standards to promote interoperability and data sharing across all systems that must share the data.

Lack of Resources and Interest

Cutbacks in funding and reduced interest in public health IT makes it more difficult to initiate and sustain systems like the IIS. IIS were able to exploit the largely private sector HIT initiatives from the ONC because of their work with private providers. They could also benefit from the efforts of Homeland Security emergency preparedness because the Smallpox vaccination, the post Anthrax actions, and flu pandemic planning involved immunizations and vaccines. This funding breathed new life into IIS both from a program and financial standpoint. The initiatives gave IIS the opportunity to interact with the private sector vendors and attract more interest because IIS were a public health activity that both the private providers and vendors could embrace. AIRA continues to work tirelessly to highlight the successes of IIS in data exchange activities so that they may continue to participate in RHIO/HIE, NHIN, and other electronic health data sharing initiatives. Unfortunately, financial constraints on providers delay their purchasing new systems, and uncertain financial sustainability of large scale HIE and RHIO and public health efforts threaten the progress that has been already been made toward interoperable record exchange.

Surprising Consequences

Although IIS development anticipated their use in disease outbreaks, a disaster on the scale of Katrina was unforeseen. The experience of successfully sharing immunization data in the wake of Hurricane Katrina was a fortuitous result of the efforts AIRA had put toward developing an IIS community and toward developing and encouraging adoption of IIS functional and technical standards. Following this experience, AIRA also found that many individuals and organizations now began turning to them with requests that were beyond the vision and mission of the organization. One of the challenges AIRA faces is determining where to focus their energy and resources to ensure they further the Association and its members' goals.

IIS DATA EXCHANGE SUCCESS STORIES

In spite of the barriers, IIS have indeed been successful in exchanging data with many different health information systems and continue to increase that capacity. Hurricane Katrina is perhaps the most newsworthy exchange, but the following examples of routine IIS use highlights their importance to public health and healthcare in general.

IIS Using Standards to Exchange Data

Health IT professionals have long known that "going electronic" means that systems will need to talk with one another: Health Information Exchange (HIE) networks exist specifically to facilitate this. Therefore, it is critical to build the infrastructure that allows information to move between practices, specialists, and hospitals. There is a tremendous amount of ongoing work to create the "roadmaps" for the secure exchange of information. But it is also critical to establish whether the information the sender sends using the roadmap can be understood and easily used by the message recipient. As a result of national HIT initiatives, EHR developers are beginning to recognize the need for building EHR solutions that can send and receive messages that can be understood. In addition CCHIT's certification process of EHR products adds pressure

for EHR developers to include this capability. However, even when providers and other purchasers of EHRs select a CCHIT-certified product, emerging and evolving standards and the sheer number of different EHR products deployed will impact the time it takes to effect seamless data exchange.

IIS, which have been in place in many states since the mid 1990's, were one of the first public health systems to broadly implement data exchange with the healthcare delivery system. From the start, they imported immunization data from external sources such as public and private providers and health plans. The latter provided mainly administrative data When EHRs began to appear, but then began importing immunization records as clinical data, and in some states, were able to establish real-time connections. When Hurricane Katrina struck, it was the IIS community that was able to make state-to-state data sharing a reality. What the IIS community has learned is that building secure systems for data sharing is important—but it is equally important to establish standards for the content and quality of the messages being shared.

San Diego Regional Immunization Registry Reaches into Provider's Offices and Provides Model for Other Integration

In San Diego County, the immunization information system was started in the mid 1990s, at least ten years before the Federal push in 2004 for information technology solutions in the medical practice. The IIS was quickly adopted by San Diego County clinics in the public sector once the technology became available to link the different systems with telephone dial-up connections. In the last five years with the advent of new vaccines and the growing complexity of the immunization schedule, the IIS now provides not only all public health and community clinics, but increasingly more private health care providers with the means to make immediate, accurate and informed decisions on what immunization an individual needs.

Today, the San Diego Regional Immunization Registry (SDIR), developed by an AIRA vendor member, and part of the California Immunization Registry (CAIR), continues to be a mature web-based, public health developed and maintained tool for medical practitioners who work in all types of settings. Whether the setting is in pediatrics, a family practice, an emergency room, a specialty practice, or even a retail store walk-in clinic, the IIS assists the immunization providers in making decisions via a Service Oriented Architecture (SOA) delivered forecasting algorithm. This algorithm is based on data found in a web-based health record that has contributions by other providers in the community.

In addition, San Diego's IIS has been replicated as a model for other community health purposes. The San Diego County Medical Society Foundation has used the SDIR as a template for a new electronic system. The San Diego Emergency Department Medical Home Project (EDMH) refers discharged patients from area hospitals to community clinics for continuing care and includes financial assessment for eligibility for Medicaid and other state funded healthcare programs. Although the EDMH is not currently focused on immunizations, the fact that the IIS is the prototype for other regional health program activities in San Diego County means that, when needed, an interfaced network between the two systems will be easily implemented.

Another adaptation of the SDIR is its use as a master patient index for the county's community clinic network. Overall, although a public health built platform, the IIS contains the kind of technical and medical functionality that health care providers caring for patients want and need. Increasingly IIS serve as a backbone infrastructure and architecture for health delivery, emergency preparedness, child health, and other public health and public-private health system integration.

Data Quality Standards Help Washington State's IIS

Washington State's IIS, known as the CHILD Profile Immunization Registry, has existed since 1993, but only in the past five years has web-enabled technology made it truly easy for providers to participate. With 80 percent of providers in Washington State now using the IIS and depending on the accuracy of its records for immunization decision-making, it has become especially important to assure the quality of the IIS' data. But ensuring that quality is increasingly challenging as the sources of the data multiply and evolve. Data enters the system from birth records, health plans, providers that manually enter data via the IIS web

interface, providers that send billing data in flat file format, and finally, and most recently, providers sending real-time HL7 messages from their EHRs.

While Washington State's IIS staff have always monitored the data for anomalies and discrepancies, AIRA's best practice guideline for Data Quality Assurance enabled them to analyze their procedures and improve and formalize the processes they use to ensure that incoming data meets the IIS' standards for acceptance. Establishing an understanding with other systems and partners about data quality standards will be increasingly important for the IIS community, especially as they engage in bidirectional data exchanges.

LOOKING AHEAD

In the future, AIRA and the IIS community hope to share their experiences by becoming key, formal contributors to eHealth Initiative efforts. AIRA plans to continue bringing IIS programs together with different stakeholders and players such as private providers through AAP and AAFP; health plans though AHIP; and IIS and EHR vendors to further the progress of sharing important health information. AIRA will continue its efforts toward promoting the use of functional and technical standards. In collaboration with CDC and other partner organizations, AIRA will continue its work in updating the HL7 IIS implementation guide to reflect the updated version of the HL7 standard. Additionally, AIRA, through the Public Health Data Standards Consortium has begun to engage with the Integrated Health Enterprise (IHE) to assure that public health standards and functionality are included in the work of major software vendors. Two immunization profiles have been accepted and are being worked through the IHE PROCESS. AIRA also intends to continue developing consensus-based operational best practices through its MIROW initiative. Many of the tools and resources AIRA has developed for the IIS community can be downloaded from the AIRA web site at www.immregistries.org.

THE IIS—A MODEL FOR WHAT IT TAKES TO ACHIEVE DATA EXCHANGE

AIRA promotes the common belief that IIS are an ideal model to analyze to learn what it takes to create an environment that supports electronic sharing of health data. IIS can provide a master patient index, best practices for improving data quality, experience developing and using functional and technical standards, and experience with interstate data-sharing. In addition, everyone is familiar with immunizations and understands the value they provide in protecting the public's health. Immunization information is an element of the four AHIC focus areas: electronic health records, biosurveillance, disease management and personal health records. And Immunization information is also a component of flu pandemic planning and a requirement for travel and entrance to schools—even colleges. IIS are geographically dispersed, so no matter where health data exchange activity may be taking place, an IIS is sure to be nearby. The IIS can certainly be said to collect, evaluate, and manage immunization information so that it can be used in HIEs to support all of these uses in a person centric, electronically delivered manner consistent with public health and National HIT priorities.