
Introduction: Setting the Stage

Purpose

This series of informational briefs are intended to inform middle managers and senior leaders within local and state health departments about some of the key opportunities and challenges in how information is managed and used to inform public health practice and action. The briefs were developed by the Joint Public Health Informatics Taskforce (JPHIT, www.jphit.org), a consortium of ten public health associations seeking to improve public health practice through informatics.¹

This informational series is intended to:

1. Convey basic concepts and current thinking on several key issues related to the information role of public health agencies.
2. Provide a picture of where public health agencies will need to go in response to expanding information responsibilities, new technologies, tighter budgets, and shrinking workforces.
3. Provide concrete action steps that leaders and managers can take within their agency.
4. Most important, serve as a catalyst for collaborative discussion and action at all levels: local, regional, national, and even international.

Background

Healthcare is facing an explosion in the availability of electronic data and in new methods to transport, aggregate, analyze, and effectively use data. Public health must be prepared to make use of increasingly digital data and to move forward in step with these developments: its systems must be modernized; its workforce must be properly trained; and its vision updated to ensure that maximum leverage can be achieved from these new capabilities. The CMS EHR Incentive Programs have brought new exposure to public health data reporting, interoperability, and health information exchange. These new requirements offer an opportunity for public health agencies (PHAs) to build on this visibility to improve its capabilities.

This change, however, will be an incremental process for most agencies. With limited funding, and ever-evolving requirements, modernizing public health systems, staff, and information management processes will feel like a continuous activity, at least for the foreseeable future. The larger healthcare environment is still adjusting to the changes brought on by healthcare reform, increasing consumer engagement, changes in the local, national, and international economy, ongoing standards development, and continuous technology advancements. With incremental change comes continuous assessment; PHAs must develop methods to more nimbly scan their environments and determine where changes in the information environment *outside* the agency require change *inside* the agency.

¹ JPHIT worked in partnership with HLN Consulting, LLC (www.hln.com) to develop these briefs.

Public health practice must become “informatics-enabled.” Information technologies have permeated most aspects of life in industrialized societies, making it possible to change the ways in which we capture and manage significant data for public health action, transform those data into useful information, and communicate with numerous constituencies. PHAs need to be not only more informatics savvy, but also more skilled in information analysis and information sciences generally. A marked increase is anticipated in the scope and the volume of data relevant to measuring and monitoring population health, as well as an increasing number and sophistication of other entities relying on population health data for accountability, quality improvement, and other purposes. Health departments will need to partner with these organizations, and bring expertise that is on par with their partners.

While data exchange between systems continues to be a major focus, it is but a means to an end. PHAs will be expected to *do* more with the data they collect, and in turn, *provide more data* to other stakeholders in the healthcare enterprise. To do this, PHAs will have to think about not only the mechanisms they support to exchange data, their capacity to understand, transform, assimilate, and explain data, but also new audiences who have not traditionally been involved in public health data use.

Key Information Capabilities

Below are some key trends and capabilities that will drive the transformation in public health information technology and its use over the coming years. Each of these is discussed in more detail in the separate briefs that follow:

Big Data – As more and more data flows in and around the healthcare ecosystem, PHAs need to be prepared to receive, process, and analyze more and more data, some of it qualitatively different than current data streams. The tools and skills necessary to do this may differ from current tools and training; just because there is *more* data it is not necessarily *better* data. New techniques and attitudes will need to be developed to deal with both volume and variable quality in data received.

Consumer Engagement – The surge in consumer access to healthcare data will continue to sweep across the healthcare ecosystem. For public health, this means greater expectations on behalf of consumers for population – and even individualized – data about their health, prevention, and risks. Social media will add yet another dimension to consumer health, whereby citizens worldwide will be able to construct their *own* models of public health situational awareness and their *own* health education material which may or may not have efficacy. PHAs need to be prepared to serve these new consumer markets with reliable and responsive data and advice

Interoperability: Semantics – Without common understanding, the goals of information sharing cannot be met. PHAs need to aggressively move to standards-based semantics and coding, and away from local, proprietary, or un-coded data.

Interoperability: Transport – The first challenge of system-to-system interoperability is compatible transport between systems. PHAs need to plan strategies to simplify and leverage transport pathways, whether this means reducing the number of transport protocols in play or looking to more efficient channels such as health information exchanges (HIEs) or public health gateways through which external transmissions are directed.

Clinical Decision Support (CDS) – Decision support is important not only when applied to an individual patient in a clinical setting (CDS), but also when applied to population-based data to evaluate groups of patients for certain conditions or exposures (population decision support). PHAs will need to become more knowledgeable about using decision support techniques to mine data, as well as about providing CDS services to the clinical community to maintain a population's health. Managing CDS knowledge and rules is a shared responsibility between public health and the clinical community.

Information Architecture – Greater interoperability, and simply *more* data, will require PHAs to consider the structure and coherence of its data stores, and the ways in which data is conceptualized, stored, and visualized. Data integration will become the rule not the exception as public health information systems continue to overcome programmatic stovepipe constraints.

Re-visiting Public Health Registries – This extended brief brings together the capabilities discussed in the other briefs, and shows how they impact the design and operations of public health registries.

The line between public health and healthcare will become increasingly blurred in the future, so that people will be less likely to think about two systems, or competing approaches, to improving health. As payors, purchasers, state and federal policy makers, and the public itself increasingly demand improved health outcomes for the dollars spent, both public health and healthcare will be converging around population health improvement and community-centered health. It will be important for public health to stake its claim and be able to clearly describe the role it plays in partnering with the healthcare system to improve population health.

Action Steps for State and Local PHAs

What actions can public health managers and senior leaders take to develop information capabilities that will support their effectiveness in the future? JPHIT recommends the following:²

- **Create a strategic plan for information architecture, management, and technology**, ideally as part of the health department's overall strategic plan. The informatics vision and strategy needs to include the actions described below, and should be used to guide strategies for developing a more integrated and agency-wide approach to information management and IT

² Actions marked with an asterisk were also cited as conclusions in the January 2013 report: *Assessing the Status and Prospects of State and Local Health Department Information Technology Infrastructure*, HHS Office of the Assistant Secretary for Planning and Evaluation, available from http://aspe.hhs.gov/sp/reports/2013/PublicHealthInformatics/hitech_rpt.cfm.

investments. An agency-wide task force or other form of broad input will be critical to successful planning and implementation.*

- Related to the strategic information management plan is to **develop an overall information architecture** for the agency. This is not just about IT networks, but about ensuring technologies and policies are in place and structured to support implementation of the strategic plan.*
- **Upgrade information systems** to use nationally recognized vocabulary standards and code sets, especially those used by healthcare, such as those specified for use in the Meaningful Use program, or recommended by CDC. This will help ensure interoperability among public health information systems, and between public health and healthcare. This may require conducting an inventory of the standards and data exchange partners for each information system within an agency.*
- **Conduct rigorous business process analysis** to document current information flows and staff workflows, uncover inefficiencies, and identify improved ways of “doing business.” *
- Use the results of the business process analysis to **carefully define the information system requirements** needed to effectively support the work being done. Without careful analysis of work and the systems requirements needed to support that work, agencies risk having systems that impede efficient workflow and frustrate staff. *
- **Identify ways to automate routine data management tasks**, such as data quality checks. As the volume of data increases, staff need to be freed up to focus on effectively *using* the data to drive program and policy decisions.
- Work with professional associations and neighboring jurisdictions to identify opportunities for **joint development of shared IT solutions**. This might include exploration of hosting shared solutions in the cloud as a way to minimize costs and other hosting issues.
- **Select a limited number of transport protocols** for all information exchanges with your community partners. This not only saves effort and money for your agency, but will likely be welcomed by your partners.
- **Identify new sources of data** that could contribute to a more comprehensive understanding of community health status, both risks and assets. *
- Explore options for **enabling two-way communication with consumers**, including access to easily understood population health, environmental health, or other appropriate data and models, such as social media, for obtaining input from consumers.
- Ensure appropriate staff members have **access to informatics training** or other sources of knowledge and best practices. The public health associations can suggest good sources for topics of interest to your staff. *

Leadership Steps for National Agencies and Organizations

- Work with state and local agencies to identify opportunities for **joint development of shared IT solutions**.
- Identify, compile, and disseminate **best practice information** to assist PHAs in achieving their new data management imperatives. Leverage routine publications, events, conferences, and

meetings to ensure wide-spread exposure to these ideas for policy, management, and technical audiences. Consider working collaboratively to establish a clearinghouse/library of business process descriptions, system requirements and specifications, and even prototype requests for proposal (RFP) for local PHAs to access and use to jump start their efforts.

- Continue to **actively participate in standards development and harmonization activities**, and to communicate broadly within public health about these efforts.
- Develop **resources for state and local PHAs concerning the legal barriers** at both the federal and state/local levels for sharing data between programs and with external partners.
- Consider embarking on the **development of a national public health information architecture**. Consider how current activities can be redefined, combined, or leveraged to move in this direction.

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Big Data

Key Points

- New techniques and attitudes will need to be developed to deal with both volume and variable quality of data likely to be received by PHAs over the coming years.
- Support for “big data” brings a number of considerations to PHAs which most likely require new ways of thinking about information and information processing, including consideration of cloud computing, use of HIEs as intermediaries, and distributed query rather than traditional data submission.
- To best leverage activities around them, PHAs need to invest in trained informatics and analysis staff to develop relationships, and monitor and participate in local and national activities.
- An agency-wide information/informatics vision is critical in an era of increasingly digital healthcare data and increasing volumes, variety, and velocity of all data sources.

As more and more data flows in and around the health and healthcare ecosystem, public health agencies (PHAs) need to be prepared to receive, process, and analyze more and more data, some of it qualitatively different than current data streams. The tools and skills necessary to do this may differ from current tools and training. Just because there is *more* data does not mean it is necessarily *better* data. New techniques and attitudes will need to be developed to deal with higher volumes, diverse data sources, and variable data quality.

“Big data” usually refers to the rapid growth in volume, variety, and velocity of data available to an industry or field. For public health:

- The increased **volume** comes as healthcare data is increasingly made digital, and digital data can more easily be sent to public health automatically based on business rules. For instance, various studies have shown or estimated a two- to five-fold increase in reportable condition reporting based on automated data reporting from EHRs or Health Information Exchanges (HIEs).¹
- The expanded **variety** of data will in part come of new sources of healthcare data, but also from data sources related to other determinants of individual and population health: economic, retail, transportation, public safety, environmental, even recreational sources of data will take on greater importance to PHAs as we strive as a nation to improve population health outcomes and reduce disparities.² Social media has the potential to provide timely

¹ J. Marc Overhage, Shaun Grannis, and Clement J. McDonald, *A Comparison of the Completeness and Timeliness of Automated Electronic Laboratory Reporting and Spontaneous Reporting of Notifiable Conditions*, Am J Public Health. 2008;98(2):344-350.

² *For the Public's Health: Investing in a Healthier Future*, Institute of Medicine, 2012.

insights into public concerns and awareness (or the lack of). Many of these new sources may be unstructured data, or use standards that are not currently part of the health information arena.

- The increased **velocity** of data comes in part from the automatic flows of digital data, but also how fast it is being created and must be processed to meet public or other expectations.
- Lastly, the **variable quality** relates to the reality that data coming from varied sources and created for varied purposes will not necessarily meet public health's usual standard for structure, completeness, or other factors. Ignoring such data streams, however, could mean not having a complete picture of community risks or assets, or situational awareness about emerging events.

The sheer volume of data has the potential to overwhelm PHAs – their staff, networks, and systems. As older systems mature, their data sets grow and grow; rarely is older data removed, purged, or archived as patient-oriented systems become lifelong repositories and environmental systems accumulate historical data for more accurate trends. Twenty years ago these systems were new and their data sets were often built on a go-forward basis. Now, these ever-increasing databases continue to expand, resting on the foundation of years of routine, successful operation.

Support for “big data” brings a number of considerations to PHAs which most likely require new ways of thinking about information and information processing, including:

- **Evolving server platforms:** As data sets become bigger and bigger, traditional data centers may become too expensive or too inflexible to expand (and potentially contract) as data needs change. Cloud computing allows for computing services and capacity to expand (or shrink) according to users' needs with little impact on the users' experience. Cloud computing services are configured on special, network-accessible platforms so that end users are shielded from the technical issues related to their physical configuration.

With cloud-based resources, PHAs can purchase a flexible quantity of computing services and not worry about provisioning, operation, or availability. This will be an important consideration moving forward.

- **Management of a proliferation of data sources:** As more data originates in electronic form, so, too, do the number and variety of data sources. The administrative overhead and technical

Case Study

The BioSense program³ tracks health problems in the United States as they evolve. It provides public health officials with the data, information, and tools needed to better prepare for and coordinate responses to safeguard and improve the health of Americans. Analysis of data through BioSense provides insight into the health of communities across the country. Such data are vital to guide decision making and actions by public health agencies at local, regional, and national levels. Using the latest technology, BioSense 2.0 integrates current health data shared by health departments from a variety of sources to provide insight on the health of communities and the country. This distributed environment, governed jointly by state, local, and federal representatives, provides local and state stakeholders secure data storage space and analytics tools at no cost to them. Most importantly, it provides a collaborative shared environment to advance public health surveillance practice and activities.

<http://www.iom.edu/Reports/2012/For-the-Publics-Health-Investing-in-a-Healthier-Future.aspx>

³ Compiled from <http://www.cdc.gov/biosense/> and subsidiary pages.

infrastructure required to manage a growing number of data relationships may quickly overwhelm PHAs. HIEs can help reduce this burden by acting as intermediaries for healthcare data collection and transport. But this new intermediation brings with it certain other complexities, including differences in authentication and authorization for data connections, changes in PHA-provider relationships, and new patient matching/linking considerations. Much data of growing interest to public health, however, does not originate in the healthcare sector. Patients and citizens represent new and very different sources of data for PHAs (see *Consumer Engagement* issue brief). Other sources of community health or environmental data, as noted above, represent even more sources. This proliferation of sources requires a comprehensive, agency-wide vision for information management and use. It also requires more tools to automate data processing tasks so staff has time to focus on effective use of the data for decision-making and intervention.

- **Distributed query:** Traditionally, PHAs built operational data stores (ODS) and data warehouses to hold data collected from disparate sources. As more clinical data originates in electronic form, emphasis will likely shift over time to data on demand. Through the use of query “agents,” PHAs will send out requests for data from their sources and aggregate data received as responses to these electronic queries. Expectations about timing, completeness, and consistency of data may need to be adjusted to accommodate this new data access paradigm.
- **New analytical requirements:** With more data come additional requirements, training, and technologies to process and analyze data, including an increasing need to focus on data semantics and potentially clinical decision support (CDS) services to aid analysis, even at a population level (see related Research Briefs in this series). PHAs will need to arm themselves with new tools, skills, and techniques to ensure that the needs of “big data” allow sufficient time for analysis.

Some things will remain remarkably the same:

- **Multiple, simultaneous levels of analysis** in that PHAs will continue to move between aggregated population-level data and individual case data, as both are required.
- **Standards** continue to evolve and develop as the needs for interoperable data supersede the tendency to fixate on specific jurisdictional requirements.
- **Data privacy** will continue to be a big part of the national health information landscape as greater opportunities to share data will yield greater risks to its appropriate use.
- **Metadata** will still be required to describe these data resources and guide users how best to use and interpret the information represented.

Data for its own sake is limited in its usefulness. More data, more complex data, and more varied data, will bring potential new opportunities to *share* data more than ever before with traditional data sharing partners and others (like consumers!).

Action Steps for State and Local PHAs

- Set priorities among data projects, and look for opportunities to leverage activities within the agency, jurisdiction, and community, as well as regional and national activities. This requires trained informatics staff members who are able to juggle a tactical and strategic focus within the agency, develop relationships with local colleges, universities, and health systems, and monitor and participate in relevant national and local professional associations and standards development/harmonization activities.
- Identify other sources of data that contribute to a comprehensive understanding of community health. Evaluate these sources for timeliness, completeness, and value in contributing to a more complete picture.
- Establish an agency-wide task force to create an overall information/informatics vision that can guide the acquisition of new data, the processing and management of current data streams, and the IT infrastructure/platforms needed to support ever growing volumes and variety of data.

Leadership Steps for National Agencies and Organizations

- Identify resources, tools, and training opportunities for PHAs to assist with “big data” requirements.
- Assist state and local PHAs in understanding the policy and legal issues that emerge from “big data” activities.

More Information

<http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2011.300542>

<https://sites.google.com/site/biosenseredesign/?pli=1>

<http://wiki.siframework.org/Query+Health>

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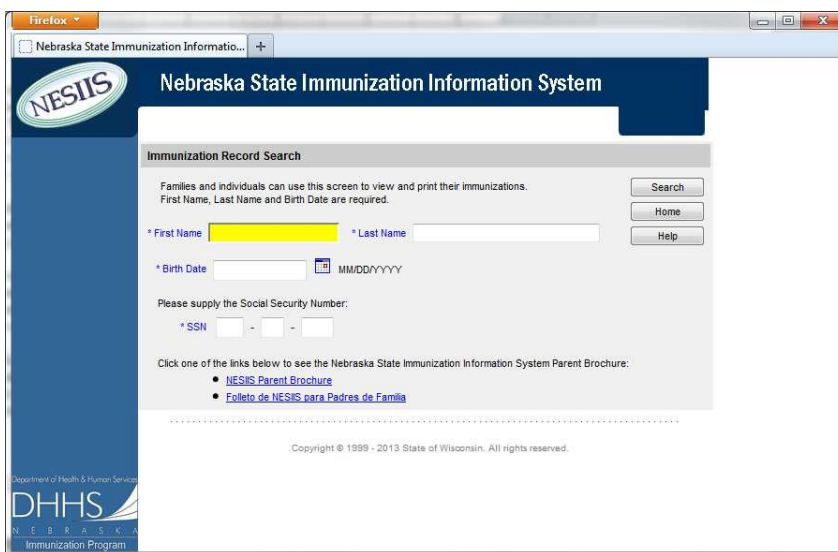
Consumer Engagement

Key Points

- PHAs will face greater expectations on behalf of consumers for population, community, and even individualized data about their health, prevention, and risks.
- Providing consumers with data requires both a high level strategy and technical considerations to ensure information is useful and properly interpreted.
- As a matter of strategy, strive to make complex ideas easier to understand: choose pilot projects thoughtfully, talk to consumers to solicit their feedback, and, if possible, leverage other efforts such as consumer access to their EHRs and open government data initiatives.

The surge in consumer access to data will continue to sweep across the health and healthcare ecosystem. For public health, this means greater expectations on behalf of consumers for population, community, and even individualized data about their health, disease prevention, and risks. Social media will add yet another dimension to consumer health, where citizens use their social networking activity to construct their *own* depiction of health issues,¹ assemble their *own* health education material² (which may or may not have efficacy), or even tip off public health about adverse events.³ Public health agencies (PHAs) need to be prepared to serve these new consumer markets with reliable and responsive data and advice. Public health data ranges from the individual to the aggregate, and across many domain areas.

Why do consumers want access to public health data? Parents want to get immunization histories (and forecasts) for their children for child care, camp, or school enrollment as easily as possible,



without provider involvement (see sample of consumer access to Nebraska State Immunization Information System). Cancer patients want to understand whether there are higher than normal occurrences of a particular disease in a particular location. Consumers want to know if their favorite restaurant has failed an inspection, or if their local hospital has higher (or lower) morbidity or mortality for particular procedures.

¹ For example, see <https://flunearyou.org/>

² For example, see <http://www.patientslikeme.com/>

³ White RW, et al., *Web-scale pharmacovigilance: listening to signals from the crowd*, J Am Med Inform Assoc 2013;20:404-408.

Many people have a thirst for medical knowledge related to specific symptoms or conditions and increasingly turn to the Internet (as opposed to a healthcare professional) for this information. There are many other examples.

Providing consumers with data should be approached deliberately. Will they interpret the data correctly? Will the PHA be able to authenticate a consumer to ensure that, if the data is individualized, a consumer only sees their own personal data and data for their dependents? What if the PHA goes through all this trouble to make public health data available and no one looks?

There are technical considerations as well. Personal health records (PHRs) of various models continue to have relatively slow uptake. On the other hand, smart phones, tablets, and other mobile technologies continue to proliferate and provide handy, personalized tools for data access. Secure email products like Direct are starting to be deployed for physician-to-physician interaction and soon physician-to-patient interaction. Health Information Exchanges (HIEs) are beginning to aggregate data and make it available to consumers themselves. Meaningful Use will soon require providers to make encounter data available electronically to patients whether they ask for it or not.

Action Steps for State and Local PHAs

- **Develop an overall strategy for consumer engagement.** This strategy may be developed in conjunction with a larger jurisdiction-wide consumer data access initiative, and should include your jurisdiction's use of social media to engage with consumers, as well as more traditional online resources.
- **Make complex ideas easier to understand.** Most consumers do not have experience interpreting complex data and statistical information. Public health data offerings have to be straightforward and useful. Expect to experiment and revisit projects and approaches.
- **Choose pilot projects thoughtfully.** It is important for PHAs to experiment with consumer access applications without picking too many paths or going too far in any one direction. Survey the landscape to determine where the largest need seems to be, recognizing that consumers will articulate divergent and varied desires. Include in the scan any open government data initiatives to identify existing public infrastructure that might be leveraged.
- **Talk to consumers.** Consumer feedback is crucial to structuring useful services, but don't expect to necessarily get consistent opinions, let alone consensus. Examine consumer feedback critically and be sure to develop a thick skin!
- **Don't forget providers.** Providers will continue to be the gateway to consumers in most cases. They should be integrally involved in consumer health initiatives as they will likely be on the front line of explanation and support to their patients. It is also important not to allow initiatives to emanate from public health that cannot be readily supported in the community. Stage 2 Meaningful Use will drive the deployment of provider portals which will play an important role in consumer access to health information over the next few years.
- **Leverage other efforts and information.** For both individualized data and aggregate population data, the PHA does not necessarily need to be the face of public health data access. PHRs, HIE portals, and provider EHR systems will offer increasing opportunities for consumer

access to personal health data. Open government data initiatives provide third party developers the opportunity to create applications that engage consumers in ways that government applications often don't. A wealth of healthcare information is available on the Internet, though often it is not curated or conflicting. With limited resources, it is wise for PHAs to continue doing what they do best; provide legitimate, high-quality access to public health data to their traditional customers (providers, health plans) and encourage consumer access through those secondary sources.

Leadership Steps for National Agencies and Organizations

- Participate in national initiatives around consumer engagement, and be prepared to advise your stakeholders about emerging national activities.
- Work across agencies and organizations to ensure a more coherent face to consumers for the initiatives, activities, and information being aimed towards them in this arena.

More Information

<http://www.healthit.gov/patients-families>

<http://www.naphsis.org/Pages/WebbasedDataQuerySystemsWDQS.aspx>

http://www.healthit.gov/sites/default/files/consumer_mediated_exchange.pdf

<http://www.healthdata.gov/>

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Interoperability: Semantics

Key Points

- A major challenge in sharing health information is ensuring the information has the same meaning to both the sender and the receiver (which is known as *semantic interoperability*).
- To facilitate interoperability, agencies need to aggressively move to standards-based semantics and coding and away from local, proprietary, or un-coded values.
- The more that data flows *between* systems to meet public health objectives, the more important standardized vocabularies become to ensure meaning is maintained.
- CDC promotes the use of standard vocabularies through PHIN VADS and provides both interactive and web service interfaces to its contents.
- Retrofitting existing systems and semantic mapping are key strategies to enabling semantic interoperability.

Without common understanding, the goals of information sharing cannot be met. A major challenge in sharing health information is ensuring the information has the same meaning to both the sender and the receiver (which is known as *semantic interoperability*). Both in the U.S. and globally, major efforts are underway to standardize how health information is captured, coded, and exchanged so that semantic interoperability can be achieved and healthcare outcomes improved. To achieve meaningful data exchange, both healthcare organizations and public health agencies (PHAs) need to aggressively move to standards-based semantics and coding, and away from local, proprietary, or un-coded values.

Semantic standards also save time and money. They improve understanding and reduce errors at all levels of data interoperability: within programs, across programs within agencies, and between organizations. Healthcare does not stop at jurisdictional lines, so information needs to flow across those boundaries to follow the patient, the exposure, or the case. Semantic standards are inherently a collaborative endeavor. Organizations must agree and work together to everyone's mutual benefit. PHAs must not only show leadership as key data exchange partners, but must also consider the needs, limitations, and capabilities of those partners in defining semantic standard requirements.

In many cases, semantic standards are embedded within the technical standards that use them (for example, many HL7 version 2 messaging implementation guides include code tables for use in the messages). However, many information systems in healthcare, both within and outside of public health, predate the development of these standards and contain local, proprietary codes to represent data values. Just because semantics are defined for interoperability, does not mean that source systems know how to translate proprietary codes into standard codes, or that they can do this consistently. Although some code sets are remarkably stable (for instance, codes used for race, ethnicity, and gender), others expand, contract, and change as medical knowledge evolves over time (like codes that represent symptoms or diseases), requiring constant attention to semantic coding

issues throughout the lifecycle of a system's use. It may also be less clear how to apply semantic standards to less structured data where meaning may in fact be more contextual than predictable.

Through its Public Health Information Network (PHIN) initiative, the CDC promotes the use of standard vocabularies among its own projects as well as the activities of its federal, state, local, and international partners. CDC's vocabulary services strive to promote semantic interoperability by working closely with relevant standards development organizations (SDO) to ensure public health's place at the table, and by taking the results of these SDO activities and ensuring their availability to public health stakeholders through the PHIN Vocabulary Access and Distribution System (PHIN VADS).

PHIN VADS provides standard vocabularies to CDC and its Public Health partners in one place. PHIN VADS is a web-based enterprise vocabulary system for accessing, searching, and distributing vocabularies used in public health and clinical care practice. It promotes the use of standards-based vocabulary to support the exchange of consistent information among Public Health partners.¹

While primarily created to support the semantic interoperability needs of HL7 version 2 messaging, it has been expanded to include support for clinical document architecture (CDA) document standards as well. Access to PHIN VADS data is available both interactively via a public web page² as well as through a system to system, standards-based web service, which allows local systems to draw upon semantic standards represented in PHIN VADS.³

In order to use *vocabulary* correctly, you need to ensure that the data elements represented by the vocabulary are also being used properly. This is critical, as different systems use different names (or terms) for the same data, and the same names for different data. The United States Health Information Knowledgebase (USHIK) was created as a central repository of data elements and their corresponding attributes and meaning. It allows for query as well as comparison of data elements (or similar data elements). Interestingly, the USHIK database contains not only descriptions of the data elements themselves, but also any relevant vocabulary (called Value Domains in USHIK).

Case Study

As part of its recommendations, the International Society for Disease Surveillance (ISDS) Meaningful Use workgroup created a summary of the core data elements of interest from inpatient and ambulatory clinical settings for syndromic surveillance. Also presented for comparison are the core data elements of interest from the CDC PHIN Messaging Guide for Syndromic Surveillance: Emergency Department and Urgent Care Data (Release 1.1). To ensure that nationally certified EHR technologies can support a reasonable range of variation in data requirements based on state and local laws, ISDS expects that Meaningful Use certification will be required to demonstrate the ability to message all core required (R - Required, RE - Required, but may be sent empty, and C - conditional) and optional elements (O - Optional) defined in the summary.

¹ <http://www.cdc.gov/phinf/tools/PHINVADS/index.html>

² <https://phinvads.cdc.gov/>

³ <https://phinvads.cdc.gov/vads/developersGuide.action>

While adherence to national semantic standards is important, retrofitting an existing system to use these standards can be challenging and time consuming. It has implications not only to system development and maintenance, but also to the data contained within systems, both historic and new. But the more that data flows *between* systems to meet public health objectives, the more important standardized vocabularies become to ensure meaning is maintained.

One useful bridging strategy is semantic mapping, where data encoded using one scheme is mapped to a standard coding scheme before being sent to its destination; for instance, mapping and re-coding proprietary lab result codes to the LOINC standard before sending to public health in an electronic laboratory result (ELR) message. For example, just 15% of eligible hospitals in stage 1 of Meaningful Use attestation conducted a test of reportable lab results submissions to public health.⁴ Given that this measure will move from the menu set to the core set in stage 2, *and* will require use of SNOMED-CT and LOINC, this represents a huge requirement for standards-based semantics in the coming years. The mandated move from ICD-9 to ICD-10 in October 2014 will be equally dramatic. Recoding can take place within the originating system, within an interface engine as data leaves the source organization, at an intermediary (like a health information exchange) as data passes through it, or at the final destination before incorporation into the target system. The challenge is that code value mapping may change over time and require ongoing maintenance to ensure that mapped code sets remain complete.

Action Steps for State and Local PHAs

PHAs need to work proactively to move towards more standard vocabularies through a combination of activities, including:

- Carefully documenting their systems' current data elements, their corresponding vocabularies, and whether it matches a vocabulary required for healthcare organizations/providers by Meaningful Use or other regulation.
- Work with system vendors and developers to ensure all new systems and system enhancements incorporate national vocabulary standards.
- Map local vocabularies-in-use to nationally-defined vocabularies, especially for data involved in health information exchange (both received and sent).
- Consider providing code set translation services to organizations with which you exchange data to facilitate use of standard code sets.

Leadership Steps for National Agencies and Organizations

- Continue to participate in national standards development and harmonization activities and to represent public health interests.
- Continue investments in central resources such as PHIN VADS and USHIK to enhance their effectiveness and use by PHAs and their data trading partners.

⁴ See http://www.healthit.gov/sites/default/files/hitpc_apr2013nn.pdf slide 35.

- Work with other national organizations to encourage the adoption and use of semantic standards that are important to public health, and encourage state and local PHAs to use these standards.

More Information

<http://www.cdc.gov/phinf/tools/PHINvads/index.html>

<http://ushik.ahrq.gov/>

<http://www.hln.com/expertise/hit/hie/hie-standards.php#sem>

This paper is part of a series of information briefs for local and state public health officials and managers, developed by the Joint Public Health Informatics Taskforce in partnership with HLN Consulting, LLC. The full series of seven briefs can be downloaded at no cost from www.jphit.org.

Interoperability: Transport

Key Points

- Compatible transport is required for system-to-system interoperability, which requires data trading partners to be in sync with their transport strategies.
- Many transport styles and protocols are in use today, often making it challenging to choose the right strategy.
- PHAs need to narrow their transport options and leverage HIEs and other intermediaries inside and outside of government. Fewer options simplify the technical environment and reduce overall cost of deployment and support.

For health information to be useful, it must be available at the right time, and with the right person, to help make the right decision. As health information increasingly becomes digital, this means that health information systems—whether in healthcare or public health—must be able to communicate digitally in standardized ways. This is what is meant by interoperability, which is, “the ability of two or more systems or components to exchange information and to use the information that has been exchanged.”¹ The first challenge of system-to-system interoperability is compatible transport between systems. This is separate and distinct from a transmission’s *format*, which represents the *content* that a transport protocol is transmitting.

Different protocols for transport are in use today to support everything from ATM transactions to email to the secure exchange of health information. Even within the health arena, several transport protocols exist to support different types of exchange. Ideally, all senders and receivers of health information, including public health agencies (PHAs), should support just a few nationally-selected protocols for health information exchange. While the national discussion is coalescing around a few choices, PHAs, which often have a long tradition of information exchange, find themselves with many data transport strategies already deployed. This presents a challenge for public health, which needs to plan strategies to simplify and leverage transport protocols. This can mean reducing the number of protocols in play or looking to more efficient

Case Studies

Tennessee is setting up a HISP (Health Information Service Provider) that will enable state agencies to send and receive patient information using Direct secure e-mail. The first use case is to enable the department of health to receive HL7 immunization registry messages using Direct secure e-mail as a transport mechanism.

Rhode Island deployed HTTPS Post a number of years ago to support submission of immunizations to KIDSNET, their integrated child health system. Using CDC interoperability grant funding, RI is implementing SOAP-based web services for both submission and query of immunization data using the CDC/AIRA developed standards.

¹ See Patricia Gibbons, et al, *Coming to Terms: Scoping Interoperability for Health Care*, Health Level 7 Electronic Health Record Interoperability Work Group, February 2007. <
<http://www.hl7.org/documentcenter/public/wg/ehr/ComingtoTerms2007-03-22.zip>>

channels, such as health information exchanges (HIEs) or public health gateways, through which external transmissions are directed.

Different use cases require different architectures and different styles of data transport, from “push” transactions where the data provider is responsible for pushing the data out, to “pull” transactions whereby the burden of getting the data is on the receiver (Figure 1).



Figure 1: HIE Transaction Continuum

For “push” transactions, the sender and receiver are known before the transaction begins. Any content can be sent, and this one-way “push” has no real provision for a response. With “push” strategies, exchange relationships can be established on the fly rather easily within a trusted community of users. For “pull” transactions, the receiver queries a data source (an HIE, a PHA, or some other entity) for records. If data is found, the entity returns records from one or more sources. Often web services are used, and specific data sets must be pre-defined for query and response. Business relationships and technical infrastructure between participating organizations—and even programs within an agency—need to be established before any exchange takes place. More sophisticated transactions require careful planning before a transport protocol is selected; you cannot make decisions about transport without considering the types of interoperability *transactions* you want to support and ensuring that the desired transport technology is compatible.

Many different transport protocols can be used, and they vary in their degree of maturity and in the ease with which they can typically be adopted (see Figure 2 and Table 1).

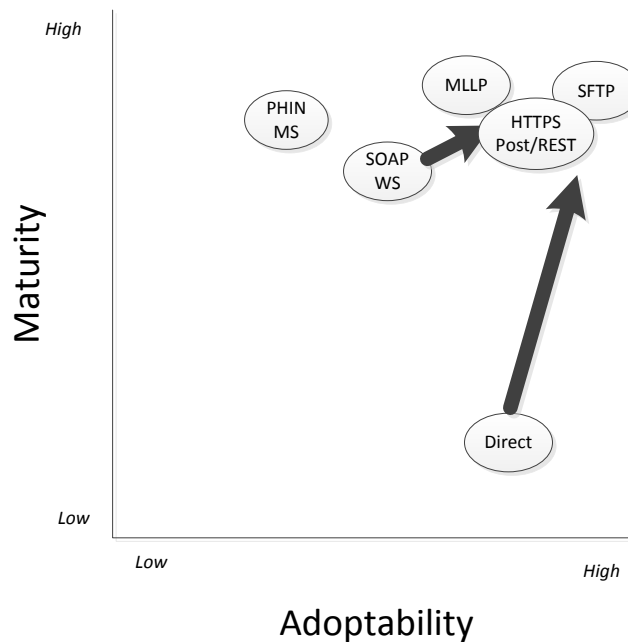


Figure 2: Transport Technology Spectrum

Method	Description
Direct	Simple, secure, scalable, standards-based way for participants to “push” encrypted health information directly to known, trusted recipients over the Internet
HTTPS POST/REST	Common form of transport used by web browsers to send data to web services and receive a response
MLLP	Relatively simple form of message transport over TCP/IP
PHINMS	CDC-created software for public health data exchange that uses a “drop box” approach for sending and receiving messages
SFTP	Internet standard for point-to-point interactive or “batched” secure file transfer
Web Services	SOA-based strategy for enabling systems to send and receive data securely supporting fairly sophisticated options

Table 1: Transport Technologies Defined

In their respective domains, web services (“pull”) and Direct (“push”) are emerging as the most preferable transport options. Many EHR, HIE, and public health system implementations are leveraging web services as part of a services-oriented architecture²— web services are also the basis of

² See Arzt NH, Service-oriented architecture in public health, *J Healthc Inf Manag*. 2010 Spring;24(2):45-52.

the national eHealth Exchange.³ The Office of the National Coordinator for Health IT (ONC) has been a strong proponent of Direct as a way to jump start information exchange, especially among participants with less sophisticated technical capabilities.⁴

Many PHAs already contend with too many transport strategies which is unsustainable in the long run, and costly to support in the short run. There is tension between the desire to choose the correct architecture and transport for a particular need, and the risk that an organization will end up with too many different protocols to support. PHAs may be forced to compromise simply to reduce the number of protocols and strategies being used, for example, using a more sophisticated technology for a relatively simple task (e.g., using SOAP-based web services merely to carry a unidirectional data report), or using a simpler technology for a more sophisticated task (e.g., using a pair of asynchronous Direct messages to simulate a query/response).

HIEs have begun to intermediate in public health reporting services. Today, HIEs typically rely on existing means of connectivity which often use proprietary vendor protocols delivered over virtual private network (VPN) connections. Some HIEs provide value-added services (such as semantic coding or message filtering), while others simply transport the data from source to destination. While compatibility with *de facto* or emerging standards is important, HIEs are in a good position to provide the necessary gateways and translations for their members, including PHAs. Many states are also focusing their connectivity options through a single state gateway or portal, providing leveraged connections for simpler, less costly, and less redundant data exchange.

Action Steps for State and Local PHAs

- Inventory the transport protocols currently supported by your agency, the types of exchanges (e.g., electronic laboratory reporting, immunizations, cancer reports), the types of data trading partners involved, and the number of partners. Consider also any legal requirements or restrictions on transport in your jurisdiction.
- Identify which transports are preferred by your data trading partners.
- Regardless of how wedded your agency is to current transport protocols, identify one to two protocols that are likely to deliver the greatest value (support the broadest number of types of exchanges with the most partners) and longevity, limiting the number of data exchange protocols deployed for interoperability to those few.
- Consider the use of health information exchanges (HIEs) to simplify the number of interfaces between the PHA and the community.

³ <http://healthewayinc.org/>

⁴ <http://www.healthit.gov/policy-researchers-implementers/direct-project>. Many public health agencies feel under pressure to support the Direct protocol, in large part because Direct has become the transport most emphasized in Meaningful Use and in the state HIE cooperative agreements from ONC. The main driver and goal for Direct is a simple one: Get as many exchanges going as possible so we can prove it works and so that healthcare improves through more timely and complete patient health information. Public health agencies need to balance any desire to support those goals with support transport protocols that meet their needs and those of their data trading partners.

- Consider the deployment of a single point of interface, or gateway, between public health and outside data trading partners to simplify paths into and out of the agency and reduce costs. HealthWay provides one such set of services which may increasingly interconnect HIEs to each other and provide a useful connection point for PHAs to the outside world.
- Finally, be sensitive to the needs of individual programs as agency-wide decisions are made. The cost of change can be significant to a program even if overall agency efficiency is increased.

Leadership Steps for National Agencies and Organizations

- Continue to work at the national level to focus and streamline the variation in transport protocols that are supported for interoperability in the larger healthcare ecosystem.
- Provide guidance, direction, and expert consulting to PHAs that require assistance in evaluating their data transport alternatives.

More Information

<http://www.hln.com/expertise/hit/hie/hie-standards.php#trans>

<http://www.syndromic.org/meaningfuluse/IADData/Architecture>

<http://www.healthit.gov/policy-researchers-implementers/nationwide-health-information-network-nwhin>

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Clinical Decision Support

Key Points

- CDS has traditionally been used to support clinicians at the point of care.
- PHAs have specific content knowledge and techniques to contribute to the CDS community, and should make those resources available to improve CDS capability and accuracy overall.
- As CDS becomes more and more effective for *individual* patients, it will become more useful in examining *populations* of patients.

As health information technology in both healthcare and public health settings matures, it is expected to provide tools to support decision making, whether applied to an individual patient in a clinical setting or to groups of patients who might share certain conditions or exposures. While decision support in public health agencies (PHAs) focus on a wide variety of data, from case data, to environmental data, to community-based data, *clinical* data continues to be an important input into the public health decision support process. PHAs will need to become savvier about using tools and techniques for Clinical Decision Support¹ (CDS) to assist in data mining and analytics, as well as to provide CDS services to the clinical community to improve healthcare outcomes and population health. While there are other types of decision support systems and tools that are also important to a PHA's operations (e.g., financial decision support), CDS represents a special capability unique to healthcare.

CDS has traditionally been used to support clinicians at the point of care. Through a number of techniques, CDS systems bring medical knowledge to bear in the context of a specific patient's medical history to assist in diagnosing a patient's condition and recommending treatment options. Many, though not all, CDS systems are rule-based; by evaluating patient data against a specific set of rules that leverage published medical knowledge, they help the clinician determine a diagnosis and often suggest a course of treatment. Though commonly used for applications like drug-to-drug interaction, CDS is also used to support classic public health functions, like immunization forecasting and detecting cases of notifiable disease that should be reported to public health.

The CMS EHR Incentive Programs (Meaningful Use) are focusing more attention on CDS. One of the core set of measures in both stage 1 and stage 2 of Meaningful Use involves implementation of CDS to support clinical quality. All indications suggest that stage 3 will raise the bar even further and expect even more use of CDS. This added focus will provide richer opportunities for PHAs to leverage both increasingly-digitalized medical knowledge and CDS capabilities that will become more dominant features in clinical systems. They also provide an important opportunity for public health to translate

¹ The Health Information Management and Systems Society defines CDS as "a process for enhancing health-related decisions and actions with pertinent, organized clinical knowledge and patient information to improve health and healthcare delivery."

expert knowledge about disease/condition prevention, detection, diagnosis, and treatment into computable rules that can be used by CDS systems.

As one example of public health providing expert resources to improve CDS capability and accuracy overall, the following is a screen image from the business rule editor for ICE – the open source Immunization Calculation Engine being developed by the NYC Department of Health and Mental Hygiene and its partners. Built upon the open source OpenCDS product, this editor allows for the development and maintenance of complicated rules defined by the Advisory Committee on Immunization Practices (ACIP). ICE provides a bi-directional interface to its CDS engine and rules via an Internet-based web service which accepts a patient’s immunization history, date of birth, gender, and disease immunity and then returns the validity of each immunization in the history, as well as a forecast of immunizations due or overdue. Though developed initially for PHAs and immunization information systems, ICE has already been incorporated into a major ambulatory EHR product used heavily in NYC, thereby promoting a CDS assessment consistent with that provided by the Citywide Immunization Registry (CIR), and saving the EHR vendor from having to develop a completely new immunization forecast product.

Rule Editor

Rule Business Rules Dslr

When +

1. The Patient has Immunity to a Disease
 - a. - The Vaccine Group affected by the reported Immunity is **HepB**
2. Administered Shot **oTargetDose1**
3. There is a Series **oTargetSeries1**
 - a. - the Series belongs to the Vaccine Group **HepB**
 - b. - the Series also contains Dose **oTargetDose1**

Then +

2. Mark the Dose **oTargetDose1** as Accepted for this series due to "Proof of Immunity"
3. Specify that evaluation of this shot **oTargetDose1** is complete and therefore should not be evaluated or overridden by any other rules

As CDS becomes more and more effective for *individual* patients, it will become more useful in examining *populations* of patients. Over time, interactive use of CDS tools within systems will be supplemented by “batch” use of CDS; taking a set of person-specific data for a cohort, cluster, or geographic region and applying CDS rules to determine if certain characteristics are present in the group. In this way, a PHA could assess a defined population for immunization up-to-date status, identify the proportion of a population at-risk for diabetes or some other chronic condition, or even perform syndromic surveillance if the data markers were present. This new type of data mining goes beyond simple observation and aggregation of data by applying CDS techniques to reach conclusions more rapidly. Emerging requirements for quality measures to support Meaningful Use, the movement to Accountable Care Organizations (ACOs), chronic disease initiatives, or other elements of health care

reform increase the pressure on healthcare organizations to understand population health metrics which can be driven at least in part by the outcome of CDS-enabled analysis.

Action Steps for State and Local PHAs

- Examine your portfolio of data systems and determine how they could benefit from CDS services. The marketplace – as well as the open source community – will increasingly provide software objects that can be integrated effectively into existing systems and should be considered for use within the agency.
- Consider defining data mining and analysis in CDS terms and determine if some of your objectives can be better satisfied with a CDS approach.
- Managing CDS knowledge and rules is a shared responsibility between public health and the clinical community, so partner with local medical societies, academic clinical informatics groups, and clinicians to collaboratively maintain rules that meet your jurisdiction's needs.
- Develop a strategy for how a CDS becomes part of a larger decision support "system of systems" to serve your overall public health decision process. This could involve examining your broader public health decision process requirements, including where information/data is coming from and going to, and how those data are used to support decision making.

Leadership Steps for National Agencies and Organizations

- Explain and promote the use of CDS technology to your programs and members.
- Identify areas where national guidance and standards for various CDS capabilities would be beneficial, and organize collaborative projects to develop materials to support its use.

More Information

<http://www.opencds.org/>

<http://www.cdc.gov/vaccines/programs/iis/interop-proj/cds.html>

<http://www.partners.org/cird/cdsc/default.asp>

Dixon BE, et al. *Towards public health decision support: a systematic review of bidirectional communication approaches*. J Am Med Inform Assoc 2013;20:577-583. [requires subscription]

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Information Architecture

Key Points

- With increasing amounts of data coming to public health agencies (PHAs) electronically because of Meaningful Use and other factors, pressure will build within PHAs to critically re-think how they receive, store, use, and visualize information to support programmatic goals and agency missions.
- Greater interoperability, and simply *more* data, will require PHAs to consider the structure and coherence of its data stores, and the ways in which data is conceptualized, stored, and visualized.
- An information architecture is a blueprint for how PHAs at all levels of government invest in information technology (IT), facilitate improved system interoperability, reduce duplication of development, and help ensure the greatest return/value on investment.
- Public health needs to work collectively to develop the shared models and architectures necessary to reduce or eliminate data redundancy, and create systems that share data, especially when they support related processes. Steps need to be taken at the local/state level as well as the national level to move public health in this direction.

With increasing amounts of data coming to public health agencies (PHAs) electronically because of Meaningful Use and other factors, pressure will build within PHAs to critically re-think how they receive, store, use, and visualize information to support programmatic goals and agency missions. In other words, a PHA will need to reconsider its information architecture. *This is absolutely foundational to the future effectiveness of PHAs given that information is the very lifeblood of a PHA.*

Perhaps the greatest challenge for a PHA in re-considering how it conceptualizes the structure and coherence of its data stores is overcoming the historic programmatic stovepipe constraints of separate, non-interoperable “silo” systems. As PHAs look to address current and future information challenges, data integration will become the rule, not the exception.

An information architecture is a blueprint for how PHAs at all levels of government invest in information technology (IT), facilitate improved system interoperability, reduce duplication of development, and help ensure the greatest return/value on investment. A successful agency-level information architecture will prioritize support of public health goals and objectives but within the context of central IT goals and constraints. Taken to a nationwide scale, an overall information architecture for public health could enable it to function more as a nationwide enterprise when it comes to IT, while still allowing jurisdictional flexibility to account for unique needs. As the broader healthcare enterprise moves away from a disease-based model to a more integrated, population health-based model over the next decade, a shared information model will allow public health to take a more consistent, unified, and efficient approach to collecting, storing, and processing the information it creates, collects, and uses.

An information architecture is based on a vision for a public health enterprise that is effectively supported by IT. This vision would support a PHA's well-articulated problem statements that objectively describe current challenges with public health IT funding, and information system development, use, and management. The vision is extended by a set of principles and best practices to guide IT investments that would address those problem statements. Only then can strategic priorities/policies be articulated to operationalize the vision.¹

Information architecture represents the intersection of business process description and information modeling. Business process development begins with a critical examination of how PHAs do what they do and why. Only by understanding and improving processes can the systems and data necessary to support them be properly developed and deployed. A comprehensive information model describes the data required by *all* systems across the PHA and the relationships between data.² Moving forward, PHAs need to think comprehensively about data, strive to reduce or eliminate data redundancy, and create systems that share data, especially when they support related processes. Information technology is then acquired to build and interconnect systems.

Case Study

Most states have individual protocols for the acquisition and analysis of newborn dried bloodspot specimens (NDBS), dissemination of screening results, and the mechanism of data input and information exchange. This does not allow for the easy flow and exchange of critical information between the public and private sectors within the newborn screening system. PHIT convened a workgroup to carry out the business process analysis (BPA) of NDBS from birth through long-term follow-up. The workgroup applied BPA methodology to describe the core activities within the NDBS system. Defining these core activities is the initial step in defining requirements for intrastate and interstate information systems. These information exchange systems can support the informational needs of all the stakeholders involved in the overall NDBS system.

The sequence for developing a public health information architecture would include:

- Collaboratively establishing the domains for public health, and achieving widespread agreement.
- Completing the business process analysis and re-design for areas of public health not already documented (including environmental health and other areas not related to information exchange with healthcare), harmonizing the products from the disparate projects as needed, and assigning each to the appropriate domain of public health.
- Collaboratively developing a limited number of simple but powerful guiding principles in order to establish a clear direction and set of shared values.³

¹ See the Public Health Data Standards Consortium's *Towards Public Health Sector Transformation and Unity: Strategic Plan 2012-14* for an example of many of these elements.

² The Health Level Seven (HL7) Reference Information Model, or RIM, is one such articulation, though it is far from easy to understand and apply (see <http://www.hl7.org/implement/standards/rim.cfm>).

³ See NHSIA's key concepts as an example (www.acf.hhs.gov/sites/default/files/assets/o_01_overviewviewpointdescription_d02.pdf)

- Collaboratively developing the three main components of the architecture: the business, or process, model (which would build on the domains), the information model, and the information technology model. Leveraging other architectures, including the Medicaid Information Technology Architecture (MITA), the Federal Health Architecture (FHA), the Federal Health Information Model (FHIMS), the HL7 Reference Information Model (RIM), CDC's Public Health Information Network (PHIN), and the many business process and data model developments that have already been done at the national and state/local levels.
- Aligning federal funding and IT policy to advance the architecture's principles and priorities.
- State and local enterprise architecture (EA) planning and implementation could proceed based on a widely-accepted public health information architecture. This would include developing agency roadmaps for modernizing information systems based on enterprise goals, platforms, etc., and enhancing capacity for information management and analysis.

Creating such a comprehensive architecture is daunting. State and local PHAs cannot wait for a top-down initiative to define their processes, information, and information technology needs and goals. The development of a national public health information architecture is desirable, but PHAs need to find ways to begin this development in their local environments.

Action Steps for State and Local PHAs

- Start moving your agency in the right direction by examining business processes, developing guiding principles, and raising awareness within the agency about relevant national initiatives.
- Seek out opportunities to work with other agencies to define information architecture collaboratively. Seek out government and foundation funding in this area.
- Focus interoperability with outside data trading partners through a single connection with your agency. This will start to move the agency towards thinking about data strategically and comprehensively, as well as potentially save money on redundant interfaces and focus available expertise.
- Improve the level of informatics training within the agency to improve the overall capacity of the agency to address information architecture issues. Collaborate with state IT resources that may have training and interest in these areas. Particular focus should be placed on business process analysis and requirements development methodologies/capabilities.

Leadership Steps for National Agencies and Organizations

- Consider working collaboratively to establish a clearinghouse/library of business process descriptions, system requirements and specifications, and even prototype requests for proposal (RFP) for local PHAs to access and use to jump start their efforts.
- Continue to actively participate in standards development and harmonization activities, and to communicate broadly within public health about these efforts.
- Develop resources for state and local PHAs concerning the legal barriers at both the federal and state/local levels for sharing data between programs and with external partners.

- Consider embarking on the development of a national public health information architecture based on the outline above. Consider how current activities can be redefined, combined, or leveraged to move in this direction.

More Information

<https://www.hln.com/assets/pdf/UT-White-Paper-Final.pdf>

<http://phdsc.org/about/pdfs/PHDSC Strategic Plan 2012-2014 FINAL.pdf>

<http://www.phii.org/what-we-do/requirements-laboratory>

<http://www.fhims.org/>

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Revisiting Public Health Registries

September 2013

by

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Introduction

For public health agencies (PHAs) developing integrated health information systems, new risks and benefits are rapidly emerging. The ways in which public health is increasingly exchanging information with healthcare providers, hospitals, government, insurers, and families demands a closer look at the networked information environment. A public health registry is defined as, "...an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individual persons who have either a particular disease, a condition (e.g., a risk factor) that predisposes to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects."¹ As systems become more integrated – especially across the public-private boundary – the role of registries will change. In some cases, their very existence may be called into question. This paper will discuss the evolution of public health registries, and other systems, and will highlight the new role they can play in the world of interoperable systems.

Information is one commodity that gains value the more it is used. Public health stands to benefit from a landscape of increasing opportunity to exchange information with more sources and users. One area is the growth of Health Information Exchange (HIE) networks, in which public health runs the risk of being excluded. Public health can become an integral player in the HIE scenario by embracing and promoting standards, opening access to its program-based database information, and organizing stakeholder focus groups to make sure that everyone – including public health – has a place at the table.

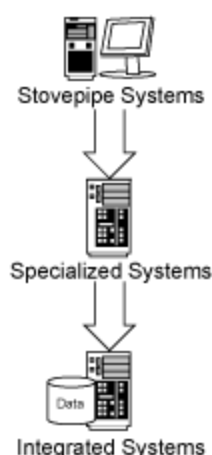


Figure 1

This paper is an update to one published by HLN Consulting in 2008. Much has changed since then. Healthcare is facing an explosion in the availability of electronic data and in the availability of new methods to transport, aggregate, and analyze it. The CMS EHR Incentive Programs ("Meaningful Use") have provided the foundation for the digitalization of clinical data from the bottom up.² Public health must be prepared to make use of this data and to move forward in step with these developments: its systems must be modernized, its workforce must be properly trained, and its vision must be updated to ensure that the most leverage can be achieved from these new capabilities.

Registry Evolution: Systems Integration

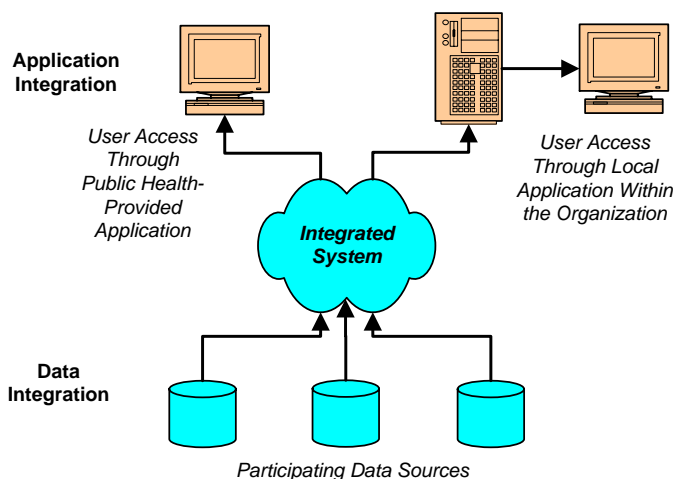
Over the past several years, public health registries have evolved from program-specific, stove-pipe systems often based on aging mainframe or personal computer technologies, to more robust specialized systems using modern database management systems on more reliable platforms. Some have evolved into integrated systems supporting a wider variety of patient-centered or case-centered functions (Figure 1). Two distinct types of integration are important:

¹ <http://www.ncvhs.hhs.gov/9701138b.htm>

² See <http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/EHRIncentivePrograms/>

1. **Data integration:** This involves forming valid relationships between data sources through actual data *consolidation* in a common data structure.
2. **Application integration for data presentation:** This involves making data available to users by presenting a unified or integrated view of data to a user through a computer application (“computer” being broadly defined as anything from a personal computer, to a web browser, to a smart card).

These two types of integration ultimately come together in the tools, applications, and data that the end user can access and use. In the lower portion of the diagram in Figure 2, participating data sources (usually distinct public health programs) contribute data to an integrated registry through one of several data integration models. The integrated system enables the presentation of that data to end-users in a variety of ways, identified in the upper part of the diagram through one of several application integration models. How does an agency know what kind of data or application integration model to deploy? First, a project must determine its functional requirements, and then determine which of the data integration or application integration models represents a good fit.



Here are some more common factors to consider:

1. **Timeliness:** How quickly will data be available to the end user given that it is likely coming from multiple, disparate sources? Timeliness may depend more on the habits and capabilities of the participating programs than the attributes of the integrated system since availability of data rises and falls on the ability of participating programs to supply it.
2. **Reliability:** How reliable is the quality of the data being presented? Have the pieces of the record assembled from different sources been properly compiled? Is the original source of the data authoritative and accurate?
3. **Comprehensiveness:** How comprehensive is the data being presented? Are parts of the record missing or unavailable?
4. **Cost:** How expensive is the proposed solution, both to the agency centrally and to participating programs?

With the current national push toward electronic health records (EHRs), public health registry *applications* may become less important, and users will increasingly want to access data through their *existing* institutional systems. This access will likely be enabled by “back-end” data exchange between EHR systems (EHR-S), public health registries, and other systems transparent to users, who will see

integrated data appear within their applications. The benefits of seeing a richer base of data without the additional cost of manual data entry will help drive provider participation in data exchange.

We are also seeing new phenomena emerge in the public health systems landscape. Cloud computing allows for computing services and capacity to expand (or shrink) according to users' needs with little impact on the users' experience since services are configured on special, network-accessible platforms whose true, physical configuration is maintained behind-the-scenes. With cloud-based resources, PHAs can purchase a flexible quantity of computing services and not worry about its provisioning, operation, or availability. BioSense 2.0 is a good example of cloud computing implementation in public health.³ This will be an important consideration moving forward as PHAs gain new ways to deploy and support their data and applications.

A second new phenomenon is the surge in consumer access to data which will continue to sweep across the healthcare ecosystem⁴. For public health, this means greater expectations on behalf of consumers for population – and even individualized – data about their health, prevention, and risks. Social media will add yet another dimension to consumer health, whereby citizens worldwide will be able to construct their *own* models of public health situational awareness and their *own* health education material, which may or may not have efficacy. PHAs need to be prepared to serve these new consumer markets with reliable and responsive data and advice.

Public health data ranges from the individual to the aggregate, and across many domain areas. For instance, parents want to get immunization histories (and forecasts) for their children for child care, camp, or school enrollment as easily as possible, without provider involvement. Cancer patients want to understand whether there are higher than normal occurrences of a particular disease in a particular geography. Consumers want to know if their favorite restaurant has failed an inspection, or if their local hospital has higher (or lower) morbidity or mortality for particular procedures. These new *types* of users will change the way PHAs think about data, applications, and access.

Registry Evolution: From Integration to Interoperability

Historically, public health registries receive data from *outside* of the agency, either through unsophisticated methods like manual data entry into a web application or more sophisticated methods like electronic data transfer from an external system. Until recently, there was not very much electronic data of interest to PHAs located in systems outside of the agency. With a general move towards more automated systems, more and more data of interest to PHAs is originating in electronic form. These new sources of electronic health data provide new opportunities for PHAs to rapidly acquire more data that can be put to use quickly. These external systems, however, are out of public health's control and operation – to acquire data *from* them, public health must *interoperate* with them from *outside* of the organizations that control them. Moving forward, PHAs need to think comprehensively about data, strive to reduce or eliminate data redundancy, and create systems that share data, especially when they support related processes. Information technology is then acquired to build and interconnect systems.

³ See <http://www.cdc.gov/biosense/features.html#cloud>

⁴ See the JPHIT/HLN information brief on Consumer Engagement that is part of this series, available at www.jphit.org.

After examining more than 100 different definitions, the HL7 Interoperability Working Group defined interoperability as, “the ability of two or more systems or components to exchange information and to use the information that has been exchanged.”⁵ The Working Group went further and defined interoperability as consisting of three major components:

1. **Technical interoperability**⁶ relates to the structure and syntax of data flowing between systems, including reliable and secure communications. A key challenge of system-to-system interoperability is compatible transport between systems. PHAs need to plan strategies to simplify and leverage transport pathways, whether this means reducing the number of transport protocols in play or looking to more efficient channels such as HIEs or public health gateways through which external transmissions are directed. There is a tension between the desire to choose the correct architecture and transport for a particular need, versus the risk that an organization will end up with too many different architectures to support. PHAs may be forced to compromise simply to reduce the number of protocols and strategies being used, for example, using a more sophisticated technology for a relatively simple task (e.g., using SOAP-based web services merely to carry a unidirectional data report), or using a simpler technology for a more sophisticated task (e.g., using a pair of asynchronous Direct messages to simulate a query/response).
2. **Semantic interoperability**⁷ relates to preserving the meaning of data from sender to receiver, usually by enforcing agreed-upon code sets and meaning. Without common understanding, the goals of information sharing cannot be met. PHAs need to aggressively move to standards-based semantics and coding and away from local, proprietary, or un-coded values. In many cases, semantic standards are embedded within the technical standards that use them (for example, many HL7 V2 messaging implementation guides include code tables for use in the messages). Just because semantics are defined for interoperability, however, does not mean that the source system(s) know how to translate proprietary codes into standard codes, or that they can do this consistently. Although some code sets are remarkably stable (for instance, codes used for race, ethnicity, and gender), others expand, contract, and change as medical knowledge evolves over time (the transition from ICD-9 to ICD-10 is a good example of this). While adherence to national semantic standards is important, retrofitting an existing system to use these standards can be challenging and time consuming. It has implications not only to system development and maintenance, but also to the data contained within systems, both historic and new. The more that data flows *between* systems to meet public health objectives, the more important standardized vocabularies become to ensure that meaning is maintained.
3. **Process interoperability** relates to how data is used to support the workflow in organizations, and ensuring that data is properly and consistently used when sent to another organization or program. Information architecture represents the intersection of business process description and information modeling. Understanding and improving those workflows begins with a critical

⁵ See Patricia Gibbons, et al, *Coming to Terms: Scoping Interoperability for Health Care*, Health Level 7 Electronic Health Record Interoperability Work Group, February 2007. < <http://www.hl7.org/documentcenter/public/wg/ehr/ComingtoTerms2007-03-22.zip>>

⁶ See the JPHIT/HLN information brief on Interoperability: Transport that is part of this series, available at www.jphit.org.

⁷ See the JPHIT/HLN information brief on Interoperability: Semantics that is part of this series, available at www.jphit.org.

examination of how PHAs do what they do and why. Only by understanding and improving processes can the systems and data necessary to support them be properly developed and deployed.

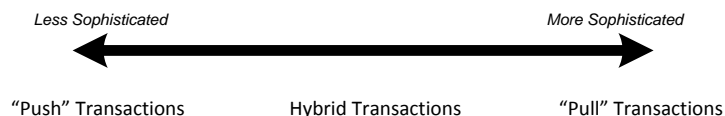


Figure 3

Interoperability is achieved through a number of mechanisms, some simple and some more complex (Figure 3). "Push" transactions (sometimes called unidirectional transactions) are simpler and can be achieved through a variety of

protocols including a secure email-like protocol called Direct.⁸ "Pull" transactions (sometimes called bi-directional or query/response transactions) are usually more sophisticated and require technologies which are more difficult to deploy and support. Table 1 provides a list of common attributes of each approach.

"Push" Transactions	"Pull" Transactions
<ul style="list-style-type: none"> • Sender and receiver known before transaction begins • Patient identity agreed to by sender and receiver • One-way "push" - no provision for response • Any content can be sent • Direct uses email paradigm • Secured with digital certificates and accepted "trust" domain/community • Exchange relationships can be established on the fly rather easily (within trust domain) 	<ul style="list-style-type: none"> • Receiver queries HIE for records - if data found, HIE returns multiple records or consolidates response • Patient identity established by HIE • Often uses web services • Specific data sets must be pre-defined for query and response • Business relationships and technical infrastructure needs to be established before any exchange takes place

Table 1

For submission of data to public health registries, "push" transactions may be sufficient. The more data PHAs accumulate, however, the more desirable it may be to share that data (within law and policy) with other stakeholders. Some core public health registry applications, like Immunization Information Systems (IIS), provide clinical records as well as decision support to providers (and even patients) in the community. Support for "pull" transactions that provide query/response support will increasingly be key features of the public health system landscape. Traditionally, PHAs built operational data stores (ODS) and data warehouses to hold data collected from disparate sources. As more clinical data originates in electronic form, emphasis will likely shift over time to data on demand – through the use of query "agents", PHAs will send out a request for data to their sources and aggregate data received as

⁸ See <http://wiki.directproject.org/>

responses to these electronic queries. Note that this may be just as relevant for interoperability between systems *within* an agency as it is with systems outside of the agency.⁹

HIEs will increasingly support these new, more complex ways of sharing data. These collaborative organizations focus on health data exchange in a community, county, or even a state-wide basis (see Appendix C), and have a wide and varied set of participants (providers, labs, hospitals, health plans, PHAs, pharmacies, and patients/citizens).

In today's broadening data exchange environment, PHAs face some risks if their information systems integration and interoperability planning does not take into account evolving technologies, methodologies, relationships, and standards. These risks include:

- Public health registries or other applications targeted at users in provider settings may have slower adoption rates as organizations encourage (or require) users to stay with institutionally-supported applications, like EHR-S. This is especially true in hospital and large ambulatory care settings, but this phenomenon also appears in local health departments that deploy more comprehensive service automation systems.
- Pressure will build for providers to interoperate *solely* through HIEs. This may affect public health data exchange partnerships, as providers may be required to exchange data through the HIE and may not want or be allowed to exchange specific data with a public health program as well. To some degree, CMS EHR Incentive Program requirements will draw more HIEs to cooperate with PHAs in order to fulfill Meaningful Use requirements.
- As more and more users do not access public health registry systems through PHA-provided portals, users lose access to more advanced features. Richly functional public health systems run the risk of becoming used primarily as data repositories. For instance, chronic disease registries contain disease pathways that define special prevention or treatment protocols typically not found in an EHR system. If providers are prevented from accessing the chronic care registry directly, they stand to lose access to these features. In the case of an IIS, which may also function as a repository, providers could lose access to algorithms, reminder/recall notice functions, vaccine ordering/management, and practice-level coverage assessment, which also are not typically found in their local systems. As they look to improve the functionality of their information systems in the future, public health needs to consider the best way to continue to offer these services and reach the largest number of providers effectively.

The Future of Registries: Four Imperatives for Public Health

For PHAs, four key imperatives flow from these observations:

- 1. Embrace national standards for system interoperability, and modify systems to accommodate those needs.**

⁹ See Arzt, Noam H. with contributions by Susan Salkowitz, *Evolution of Public Health Information Systems: Enterprise-wide Approaches*, July 2007. (<http://www.hln.com/assets/pdf/UT-White-Paper-Final.pdf>)

Public health has traditionally had limited involvement in many aspects of health information technology (HIT) standards development and harmonization. With the increasing importance of system interoperability, it is incumbent upon PHAs to take national standards more seriously, to *use* them where relevant, and participate in their development where possible. There are many organizations, associations, and venues where HIT standards are discussed, agreed-upon, and documented. Since 2006, interoperability standards harmonization – the process of selecting a particular set of standards to achieve a specific purpose from among the myriad of standards available – has been promoted and coordinated by a set of activities initiated by the Department of Health and Human Services. Increasingly, public health has taken it upon itself to initiate its own standards harmonization activities by building upon existing and emerging interoperability standards and tailoring them for public health’s own needs (see Appendix D).

In order to participate effectively, PHAs need to both *train* their staff in informatics, but also *allow* their staff the time to be active in relevant initiatives (see below). Workforce development is a key aspect of this readiness. Informatics training and participation can also be an effective form of career development for targeted staff with an interest and aptitude for this work.

2. Enable “special functions” of public health registry systems to be accessed directly by end-user systems.

Public health systems that are outwardly-focused (like registries, surveillance systems, and alerting systems) have typically offered users access to both data (through centralized databases) and special

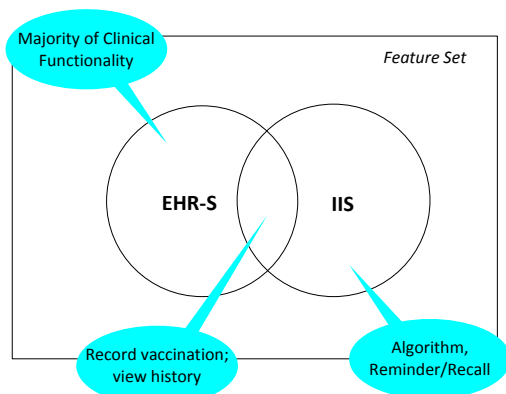


Figure 4

environments, but to minimize user support costs caused by confusion over internal and external application functionality.

Registry applications will retain their critical role as consolidation points for data to enable effective decision support as well as epidemiological analysis, however the specialized functions of the *applications* that come with these registries will be threatened due to this user pressure to stay within local application environments. Here lies the rub: the specialized functions offered by registries typically are *not* found in EHR-S products, or, if they are, the functionality is not adequate. Rather than have users lose these functions entirely, public health system architects must find new ways for these specialized functions to be offered to external systems.

IIS provides a good case in point. When it comes to clinical information support, EHR-S usually provides a rich set of features. They share some important core features with IIS as well: the ability to record immunizations administered and view immunization histories for patients (overlap area in Figure 4). However, that is where the similarity usually ends. Several critical clinical features are not often supported by EHR-S but are considered to be core functions of IIS:

- **Recommendations for next immunization due:** One of those important areas of functionality is clinical decision support (CDS)¹⁰. CDS has traditionally been used to support clinicians at the point of care. Through a number of techniques, CDS systems bring medical knowledge to bear in the context of a specific patient's medical history to assist in diagnosing a patient's condition. The CMS EHR Incentive Programs are focusing more attention on CDS. One of the core set of measures in both stage 1 and stage 2 of Meaningful Use involve implementation of CDS to support clinical quality. All indications are that stage 3 will raise the bar even further and expect even more use of CDS. This added focus will provide richer opportunities for PHAs to leverage both increasingly-digitalized medical knowledge, and CDS capabilities that will become more dominant features in clinical systems. IIS provides an assessment of a patient's immunization history against a complicated set of decision rules¹¹ to determine if new immunizations are due now or in the future. EHR-S do not usually reproduce this set of decision rules accurately, nor maintain it routinely.
- **Reminder and recall to ensure a patient returns when an immunization is due:** There is a surge in the desire for consumer access to data. PHAs need to be prepared to serve these new consumer markets with reliable and responsive data and advice. Today, IIS provides features to assist practices in generating contact lists and correspondence to help ensure that patient's come back when immunizations are due or overdue. EHR-S do not usually support these special reports and features, in part because their accuracy is dependent on the correct determination of immunizations due (see above). While PHAs need to be sure that *clinicians* do not lose access to these services, they also need to be aware of patient expectations for access to and control of these services directly.
- **Vaccine ordering and order processing:** Especially for childhood vaccines, many providers rely on the Federal Vaccines for Children (VFC) program or other state vaccine programs for provision of the inventory. Many IIS provide functions to manage vaccine lots, ordering, recall, and reporting/accounting of vaccine use. These functions are not typically supported in EHR-S. With the wide scale deployment of CDC's Vaccine Tracking System (VTrckS)¹² functionality in IIS, PHAs need to examine the implications to EHR-S carefully, ensuring that the functionality expected in EHR-S is present for interoperability with IIS for vaccine ordering and accountability for its use.
- **Practice-level assessment of up-to-date status:** IIS provides summary statistics and assessments of up-to-date status primarily for pediatric patient populations. These measures are used by

¹⁰ See the JPHIT/HLN information brief on CDS that is part of this series, available at www.jphit.org.

¹¹ Detailed business rules for immunization CDS is available from CDC at <http://www.cdc.gov/vaccines/programs/iis/interop-proj/cds.html>

¹² See <http://www.cdc.gov/vaccines/programs/vtrcks/index.html>

insurance companies as part of their Healthcare Effectiveness Data and Information Set (HEDIS) quality metrics. Once again, due to the dependence on the recommendation algorithm, most EHR-S do not offer this reporting.

As providers with access to IIS face pressure to stay *within* their EHR-S and not to access applications elsewhere, they will risk losing access to the special functions of systems like IIS they rely upon for patient treatment and decision support that cannot yet be found in their local systems. To accommodate that need, systems like IIS will have to turn to new technology paradigms instead of offering traditional “fingers on keyboard” applications. One such

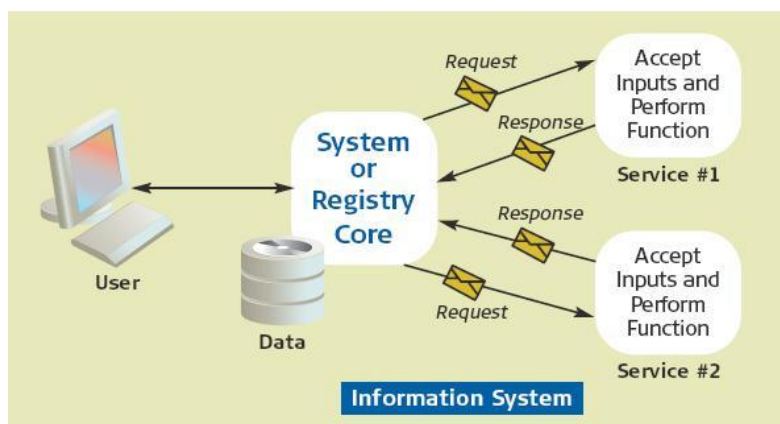


Figure 5

paradigm is Service-oriented Architecture (SOA). This building-block approach to system construction allows complex systems to be broken down into reusable components that can be arranged, re-arranged, and invoked through standard programming interfaces (Figure 5). While originally conceived of as a way to support applications *within* an organization, SOA has become an architecture upon which system interoperability *between* organizations can be supported.

The New York City Department of Health and Mental Hygiene’s Citywide Immunization Registry (CIR) is an example of a system that is moving in this direction. Operating since 1997, the CIR provides access to immunization histories and forecasts to all immunization providers in NYC. In addition, it is integrated with another system, LeadQuest, operated by the Lead Poisoning Prevention Program, allowing providers to access blood lead level test information about their patients (and record new tests they might administer). When originally developed, it contained a CDS engine called the Immunization Calculation Engine, or ICE2 (it is the second version of this software module), which provided clinically accurate evaluation for thirteen immunization series. The software itself, however, was complex and cumbersome to maintain, and required professional programmers to make even the slightest of changes to the code. Testing procedures for changes involve a series of manual steps performed by at least three different sets of individuals: the contract programmers who verify their modifications or additions, the contract business analysts working with the programmers who verify the changes against the agency’s specifications, and agency personnel who do one final test to ensure that the changes have been made to their satisfaction.

To overcome many of these limitations, NYC and a number of partner agencies embarked on a project to redesign and redevelop ICE2 on a new platform.¹³ Built on an Open Source CDS platform and itself being released into the Open Source community, the design goals included the ability to support multiple schedules, a fully automated testing process to speed up testing and make it less labor intensive, simultaneous processing of multiple requests for CDS for speedier response as the

¹³ See <http://www.hln.com/ice/>

volume of requests increases, and the ability of less technical, more clinically-oriented subject matter expert staff to update and maintain the detailed rules that drive the algorithm. Finally, this new algorithm uses a service-oriented architecture which allows it to be accessed from *multiple* systems. In this way, NYC can invoke ICE from within the CIR to accommodate its internal CDS needs, and EHR-S can invoke ICE from *outside* of the agency and receive the same, high-quality decision support as the CIR without the need for the EHR-S vendor to program or maintain the complex algorithm. Already one major ambulatory EHR vendor has incorporated ICE into its standard product.

Service-oriented architectures often go hand-in-hand with cloud-based computing (see above) as more modular systems do not necessarily need to rely on proximity to fulfill even complex functions.

3. Consider new ways for sharing resources and opportunities across public health programs and agencies.

The information technology landscape across the globe continues to evolve, almost like the swing of a pendulum. Our earliest computers were timesharing services where large, centralized computers provided access to their services and data through “dumb terminals” located close to the user. Network limitations prevented those access points from being too far from the servers themselves. Users demanded more location independence and more computing power, so simultaneously personal computers, minicomputers (for those who remember them), and local area networks developed. Soon, wide area networks, including the Internet, became crucial as the focus shifted to information sharing and collaboration. The interconnectedness of many business processes became mirrored by the interconnectedness of our information infrastructure to the point that “the network *is* the computer” became the mantra.

We continue to march down this path. Leveraging service-oriented architecture concepts, applications are becoming more modular and more network-based. The introduction of cloud computing allows application providers to move more functionality to servers on the network whose provisioning can be easily scaled up (or down) based on need or budget. This notion of Platform as a Service (PaaS) allows an organization to flexibly acquire computing resources that can adjust as needs (and budgets) change. In the clinical world, the CMS EHR Incentive Programs have promoted the deployment of EHR-S particularly among small providers, but increasingly these systems are being deployed off-site and offered on shared environments (see Figure 6). This Software as a Service (SaaS) removes burdens of platform operation, software version control and updating, backup and disaster avoidance/recovery from the practice, and allows for much quicker movement from decision to deployment. EHR-S vendors who are hosting data for many organizations can facilitate interoperability of this data *among* these organizations much more efficiently than they can between disparate products.

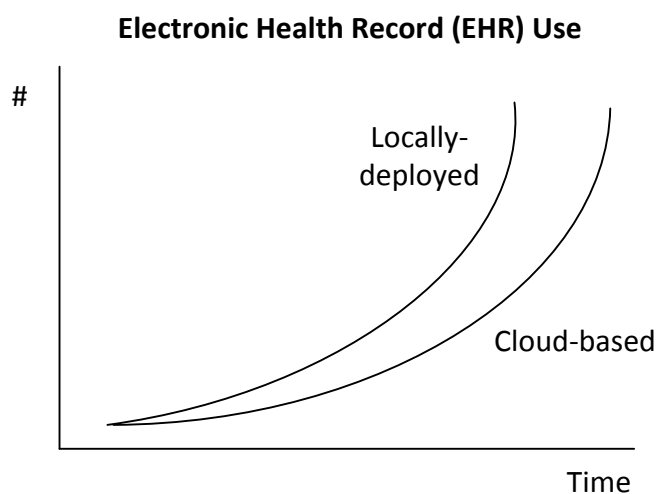


Figure 6

Software and strategies developed with the public health arena do not carry the intellectual property constraints that often come with products and strategies developed in the private sector. The steady rise of high-quality, well-tested Open Source solutions for key public health application areas also improves the supply of low-cost applications available for public health use. As PHAs take more and more sophisticated approaches to information management, more attention needs to be paid to the use of strategies that encourage modular, configurable, and reusable components. In addition, shared approaches to software and services that leverage the Internet, cloud computing, PaaS and SaaS concepts, should become the rule not the exception within public health. Leveraging these opportunities can only happen if a concomitant change in attitude happens within PHAs, namely:

- PHAs need to focus on what makes them more *similar* to their sister agencies in other jurisdictions, rather than what sets them apart, as the basis for improving their potential to share software and services that were not developed in-house or procured against hyper-detailed requirements.
- PHAs need to be willing to share their own products and strategies and to encourage cooperative development with other agencies and vendors moving forward. Management of agency-developed products within the Open Source community provides access to products developed with public funds, while allowing service providers to develop expertise and charge clients for providing that expertise in developing, supporting, and integrating solutions.
- PHAs need to look for ways to continue driving down cost by sharing SaaS environments with other PHAs as they become available, and by moving software and services to the cloud as secure, cost effective environments become available. Encourage your own vendors to consider the efficiencies that SaaS models may provide to their business offerings and operations.
- In the not-too-distant future, it may be possible for a PHA to assemble an application from modular building blocks loosely coupled by a service-oriented architecture and operated on a cloud platform. Imagine selecting a front-end application, a database back-end, and a set of software services (like person matching/MPI services, data validation services, terminology services) independently and deploying them together, configured specifically for the agency's needs. Software development is moving increasingly in this direction.

These new, shared computing strategies also enable new opportunities to share data. Traditionally, PHAs built operational data stores (ODS) and data warehouses to hold data collected from disparate sources. As more clinical data originates in electronic form, emphasis will likely shift over time to data on demand. Through the use of query “agents,” PHAs will send out requests for data from their sources and aggregate data received as responses to these electronic queries. Expectations about timing, completeness, and consistency of data may need to be adjusted to accommodate this new data access paradigm. Surveillance activities often rely on the timely availability of data from multiple sources to make inferences about conditions that might not be evident (or easily noticeable) in their native environments. These new environments make not only active, but passive surveillance easier to achieve. For example, the Electronic Support for Public Health (ESP) project in Massachusetts continues to collect data from EHR-S, aggregate that data, and detect suspected cases of particular

notifiable conditions.¹⁴ A more natively-shared data environment and/or distributed query capabilities might further reduce the burden on participating EHR-S and improve the volume and timeliness of data.

4. Organize a formal informatics focus or program in the agency to engage in and support local, regional, and national initiatives.

PHAs must develop the internal capability not only to develop their own registries, but to participate and influence the development of national standards as well. The creation and support of a medical informatics function within the agency allows the intellectual development and exposure to external industry, policy, and standards improvements that are necessary to ensure interoperability into the future. This informatics focus should be distinct from the information technology operations typically performed by a chief information officer (CIO) and staff directly responsible for system development and tactical support. This function should report to a senior agency official to ensure that an informatics perspective is recognized and consulted strategically by the agency.

Not all agencies will be able to establish a well-developed informatics function quickly. There are a number of strategies that can be employed to begin building this capability within an agency in the absence of the funding or talent for a formal position or office:

- Develop relationships with informatics programs at local universities. These programs are often found in schools of medicine, schools of public health, or academic medical centers. Many agencies already have well-developed relationships with these institutions to support epidemiological research, recruitment, or knowledge sharing. Leverage those existing relationships or seek out new ones.
- Encourage membership in professional organizations and societies that promote and support medical informatics. Attend their conferences, webinars, and meetings. Many of these organizations provide in-depth training that can be leveraged as a feature of membership. Many also have local, regional, and national venues for training, mentoring, and exchange of ideas, as well as internal “consultants” from other organizations who can provide advice to agencies about their informatics direction. Suggested organizations include the American Medical Informatics Association (AMIA), Healthcare Information and Management Systems Society (HIMSS), the Public Health Data Standards Consortium (PHDSC), Health Level Seven (HL7), the American Health Information Management Association (AHIMA), and the National Association for Public Health Statistics and Information Systems (NAPHSIS).
- Establish relationships with other organizations in your area that also require a public health informatics perspective, including health information research organizations, and other government or not-for-profit entities such as healthcare quality improvement organizations or professional societies. By pooling resources together, these organizations may be able to support activities that they are unable to support on their own.

¹⁴ See <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5714a4.htm#tab>

Several jurisdictions have been successful in providing and promoting informatics in this way. The state of Minnesota established the Center for Health Information Technology (previously the Center for Health Informatics), and the Utah Department of Health established an Office of Public Health Informatics. Both serve as models to other states of how informatics can be leveraged within and outside of the agency. The Public Health Informatics Institute (PHII) is an example of an independent not-for-profit organization that promotes health and public health informatics through its funded projects and collaborations.

Conclusion

Public health registries continue to evolve and develop in response to increasingly more sophisticated information needs, as well as growing requirements for interoperability with systems both within and outside of the agency. Careful planning is required to ensure that agencies can meet the information demands that will be placed on them. As the external medical community continues to invest in information systems technology, public health will need to learn, monitor, and invest in solutions of its own to benefit from these developments. Public health cannot afford to sit by the sidelines and miss an opportunity to improve the quality of its services and information.

The reality of constrained budgets, staff reductions, and the flight of technical talent from the public to the private sector will become increasingly challenging. It will be difficult for public health programs and agencies to retrofit existing registry systems to function in this new paradigm. It is critical, however, that investments in new systems and enhancements to existing systems be carefully scrutinized to ensure valuable opportunities are not lost in moving beyond old ways of doing things towards standards-based approaches that leverage other activities in the community. A strategic informatics focus – whether basic or more sophisticated – will help ensure that these opportunities are not ignored. In addition, pressure should be brought to bear on the CDC, as a major funder of public health systems initiatives, to continue encouraging and providing incentives for systems developed and deployed using standards, and to continue promoting greater efficiency through leverage of cross program resources.

Public health practice must become informatics-enabled. Information technologies have permeated most aspects of life in industrialized societies, making it possible to change the ways in which we capture and manage data of significance to public health action, transform those data into useful information, and communicate with numerous constituencies. Consequently, the informatics-enabled core public health sciences of epidemiology and laboratory diagnostics, formerly distinct disciplines, have now merged in ways that change each and make them inseparable when it comes to achieving the highest level of public health practice.

PHAs not only need to be more informatics-savvy, but also need to be more expert in information analysis, user interfaces, consumer engagement, and information sciences generally. They need to increase their ability both to give information and to get information. This is because of the marked increase anticipated in both the scope and the volume of data relevant to measuring and monitoring population health, as well as the increasing complexity and sophistication of other entities relying on population health data for accountability, quality improvement, and other purposes. Within this vision, health departments will partner with these organizations, and will need to bring expertise that is on par with their partners and commensurate with the significance of the public health mission.

This white paper was intended to promote and inspire a critical examination of public health informatics practices, investments, and strategies, but only so much change can be spurred from the top down. PHAs need to examine themselves critically and consider their own choices and activities. No one can predict the future, but it is important that PHAs take concrete steps to help prepare them for the uncertainty ahead, including:

- Identify special features available in your registry(ies) that are needed by providers and other stakeholders outside of your program or agency but which are unlikely to be provided (or provided well) in an EHR-S. Inventory current registries and identify similar services or functions that could be shared (e.g., provider directories, record de-duplication engines, etc.). Consider offering services to fill those needs.
- Critically re-examine current and future user access and information needs based on growing EHR-S adoption and improvements in electronic data exchange. These trends will continue to improve over time and can be leveraged for public health purposes.
- Develop a plan for upgrading to relevant vocabulary standards (e.g., LOINC, SNOMED, CVX, etc.) to improve the quality of your agency's interoperability with other healthcare entities.
- Work with other registries in your agencies, your central IT department, and your chief information officer to explore architectural approaches (SOA, cloud computing) that better support current and future needs for your data/registries users, both internal and especially external.
- Look for new ways to cooperate and collaborate with other agencies and programs.

While interoperability between systems continues to be a major focus, it is only a means to an end. PHAs will be expected to *do* more with the data they collect, and to in turn *provide timely, relevant information for decision support* to other stakeholders in the healthcare enterprise. To do this, PHAs will have to think about not only the mechanisms they support to exchange data, their capacity to understand, transform, assimilate, and explain data, but also new audiences who have not traditionally been involved in public health data use.

The line between public health and healthcare will become increasingly blurred in the future, so that PHAs and other stakeholders will be less likely to think about two systems, or competing approaches, to improving health. As payors, purchasers, state and federal policy makers, and the public itself increasingly demand improved health outcomes for dollars spent, both public health and healthcare will be converging around population health improvement and community-centered health. It will be important for public health to clearly describe to itself and others the role it plays in partnering with the healthcare system to improve population health.

This paper is part of a series of information briefs for local and state public health officials and managers, developed by the Joint Public Health Informatics Taskforce in partnership with HLN Consulting, LLC. The full series of seven briefs can be downloaded at no cost from www.jphit.org.

Appendix A: Terms and Acronyms

ACO	Accountable Care Organization
AHIMA	American Health Information Management Association http://www.ahima.org/
AMIA	American Medical Informatics Association http://www.amia.org/
ANSI	American National Standards Institute http://www.ansi.org/
CDC	Centers for Disease Control and Prevention http://www.cdc.gov/
CDS	Clinical Decision Support
CDSi	Clinical Decision Support for Immunizations http://www.cdc.gov/vaccines/programs/iis/interop-proj/cds.html
CIO	Chief Information Officer
CMS	Centers for Medicare and Medicaid Services https://www.cms.gov/
EHR/EHR-S	Electronic Health Record/Electronic Health Record System
FHA	Federal Health Architecture http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__federal_health_architecture/1181
FHIMS	Federal Health Information Model http://www.fhims.org/
HEDIS	Healthcare Effectiveness Data and Information Set http://www.ncqa.org/tabid/59/Default.aspx
HIE	Health Information Exchange/Health Information Exchange Network
HIMSS	Healthcare Information and Management Systems Society http://www.himss.org/
HIT	Health Information Technology

HITSP	Health Information Technology Standards Panel http://www.hitsp.org/
HL7	Health Level Seven http://www.hl7.org/
ICE	Immunization Calculation Engine http://www.hln.com/ice/
IDN	Integrated Delivery Network
IHE	Integrating the Healthcare Enterprise http://www.ihe.net/
IIS	Immunization Information System
MITA	Medicaid Information Technology Architecture http://www.cms.hhs.gov/MedicaidInfoTechArch
NAPHSIS	National Association for Public Health Statistics and Information Systems http://www.naphsis.org/
NIEM	National Information Exchange Model https://www.niem.gov/Pages/default.aspx
ODS	Operational Data Store
ONC	Office of the National Coordinator for Health Information Technology http://www.hhs.gov/healthit/onc/mission/
OSELS	Office of Surveillance, Epidemiology, and Laboratory Services (CDC) http://www.cdc.gov/osels/
PHA	Public Health Agency
PHDSC	Public Health Data Standards Consortium http://www.phdsc.org/
PHII	Public Health Informatics Institute http://www.phii.org/
PHIN	CDC's Public Health Information Network http://www.cdc.gov/phin/
S&I	Standards & Interoperability Framework http://wiki.siframework.org/

SDO	Standards Development Organization
SOA	Service-oriented Architecture http://www.webservices.org/
SOAP	Simple Object Access Protocol http://en.wikipedia.org/wiki/SOAP
VFC	Vaccines for Children Program http://www.cdc.gov/vaccines/programs/vfc/default.htm
VPN	Virtual Private Network
VTrckS	Vaccine Tracking System (CDC) http://www.cdc.gov/vaccines/programs/vtrcks/index.html

Appendix B: Selected Readings

Arzt, Noam H., *Architectures and Transport Mechanisms for Health Information Interchange of Clinical EHR Data for Syndromic Surveillance*. International Society for Disease Surveillance, 2012.
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Appendix C: Health Information Exchange and Public Health

HIEs support new, more complex ways of sharing data. These collaborative organizations focus on health data exchange in a community, county, or even a state-wide basis (Figure C-1) and have a wide and varied set of participants (providers, labs, hospitals, health plans, PHAs, pharmacies, and patients/citizens).

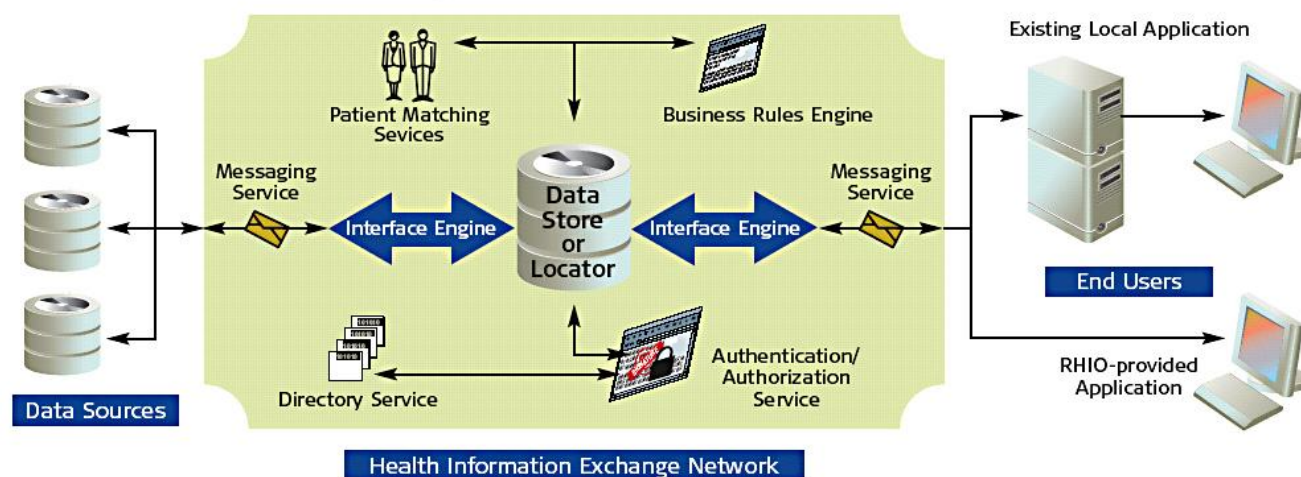


Figure C-1

Primarily driven by private-sector participants, HIEs may involve public health as a key player in their formation and operation. While the emphasis is typically on exchanging clinical data to support patient care, some health data exchanges focus on health services data instead of – or in addition to – their clinical needs. HIEs have begun to intermediate in public health reporting services. Today, HIEs typically rely on existing means of connectivity which often use proprietary vendor protocols delivered over virtual private network (VPN) connections. Some HIEs provide value-added services (such as semantic coding or message filtering), while others simply transport the data from source to destination.

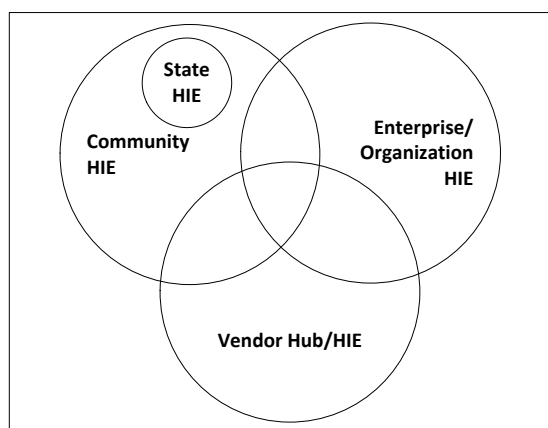


Figure C-2

The HIE landscape continues to get more complex as different styles of HIE have developed and in some cases are vying for their position in the interoperability “marketplace” (see Figure C-2). Community HIEs are supported within a medical trading area, community, or state and can be the most challenging to sustain. Some states – particularly smaller ones – have single, state-level HIEs while others pursue a “hub and spoke” model, where they provide interconnection between sub-state HIEs. Still others merely facilitate HIE through a selection of standards or deployment of lighter strategies, such as directed exchange. Most community HIEs continue to work hard on developing an appropriate business model and sustainability plan as the

spike of government funding over the last several years subsides.

Enterprise or organization HIEs are deployed and supported within a single organization or integrated delivery network (IDN) and may or may not interoperate beyond organizational boundaries. Many IDNs have become complex organizations connecting hospitals, clinics, tertiary care centers, and small practices together. The movement to Accountable Care Organizations (ACO) will further promote the development of these HIEs to serve the information exchange needs of medical homes and their supporting clinical locations. Finally, a third type of HIE, the vendor hub, has emerged as many EHR-S vendors offer interoperability between installations of their products and often will provide less expensive external interfaces to/from these hubs. For the EHR-S vendor, this is a matter of strategic leverage. For providers, this becomes a matter of lower cost. For communities, these hubs may or may not make interoperability more efficient as the hub focuses less on interconnecting a logical set of data trading partners as it does on the idiosyncrasies of who happens to be using a particular EHR-S.

While compatibility with *de facto* or emerging standards is important, HIEs are in a good position to provide the necessary gateways and translations for their members, including PHAs. Many states are also focusing their connectivity options through a single state gateway or portal, providing leveraged connections for simpler, less costly, and less redundant data exchange. PHAs, however, have a lot to gain by participating in HIE activities, including:

- **Achieving public health goals:** This includes increased data collection and dissemination.
- **Supporting Meaningful Use:** Along with Meaningful Use, PHAs should support other objectives of the CMS EHR Incentive Program, since many of the interoperability objectives and measures involve public health.
- **Connectivity:** Many of public health's data trading partners will choose to interoperate with an HIE and reduce (or eliminate!) what they may perceive to be superfluous, and perhaps costly, additional connections, even to public health.
- **Gaining new sources of data:** Public health can gain access to data and trading partners who previously might not have participated in its initiatives.
- **Inclusion:** It's better to be an insider than an outsider. As the healthcare community moves in this direction, public health should be an active participant—or risk being left out of the network.

And similarly, public health has a lot to contribute to HIEs, including:

- **"Quick start":** By leveraging existing public health interoperability activities, including interfaces to labs and providers, HIEs can move ahead more quickly with interface deployment.
- **Existing data:** PHAs already have systems and applications that have consolidated and population-based data, including master person index systems that can be leveraged by HIEs for broader access.

- **Expertise:** PHAs have experience in key technical areas that are critical to HIE operations and success, including patient matching and de-duplication, database management, web-based portal development and support, and HL7 messaging.
- **Existing relationships:** For years, PHAs have developed coalitions of stakeholders, including providers, payers, professional associations, and even citizens. These are often the same stakeholders who need to be involved in HIE activities.
- **Governance:** PHAs have experience in negotiating and implementing data sharing agreements.

Appendix D: National Efforts

Standards development organizations (SDO) develop standards, but a variety of other efforts work to *harmonize* standards, that is, they help the industry select appropriate standards from those available for particular tasks. These are the major standards development and harmonization organizations relevant to health information (especially interoperability):

Health Level Seven (HL7), an ANSI-accredited SDO focused on enabling interoperability of clinical and administrative healthcare data.¹⁵

Integrating the Healthcare Enterprise (IHE), an initiative that “promotes the coordinated use of established standards... to address specific clinical need in support of optimal patient care.”¹⁶

Public Health Data Standards Consortium (PHDSC), a membership organization that advocates for public health technology standards and actively participates in many standards development and harmonization activities.¹⁷

Standards and Interoperability Framework (S&I), sponsored by the Office of the National Coordinator for Health Information Technology (ONC), is a “collaborative community of participants from the public and private sectors who are focused on providing the tools, services and guidance to facilitate the functional exchange of health information.”¹⁸ This effort largely replaced the earlier Health Information Technology Standards Panel (HITSP) whose work is still referenced and used.¹⁹

These are the major over-arching federal initiatives that influence standards development, though not always in a consistent way:

Federal Health Architecture (FHA), which “brings together all federal agencies that need to share electronic health information to support citizen health care and streamline healthcare-related benefits.”²⁰

Federal Health Information Model (FHIMS), “a model of healthcare data developed for the FHA partner agencies.”²¹

Medicaid Information Technology Architecture (MITA),²² which promotes integrated business and IT across the Medicaid enterprise to improve the administration of the Medicaid program.

¹⁵ See <http://www.hl7.org/>

¹⁶ See <http://www.ihe.net/>

¹⁷ See <http://www.phdsc.org/>

¹⁸ See <http://wiki.siframework.org/>

¹⁹ See <http://www.hitsp.org/>

²⁰ See http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__federal_health_architecture/1181

²¹ <http://www.fhims.org/>

²² See <http://www.cms.hhs.gov/MedicaidInfoTechArch>

National Information Exchange Model (NIEM), aims to be the "best practice" for intergovernmental information exchange (though there has not yet been much focus on healthcare).²³

National Human Services Interoperability Architecture (NHSIA) is a framework to support: common eligibility and information sharing across programs, agencies, and departments; improved efficiency and effectiveness in delivery of human services; improved detection and prevention of fraud; and better outcomes for children and families. It will consist of business, information, and technology models to guide programs and states in improving human service administration and delivery through improved interoperability of business processes and information technology (IT) – focusing on sharing information and reusing IT capabilities.²⁴

Public Health Information Network (PHIN),²⁵ is CDC's vision for organizing, standardizing, and managing the collection and dissemination of public health information. It requires the use of fully interoperable information systems in the many organizations that participate in public health. PHIN requires policy, technology, and vocabulary standards for interoperability between PHAs, CDC, private health entities, and other national, state, and local organizations.

²³ See <https://www.niem.gov/Pages/default.aspx>

²⁴ See <http://www.acf.hhs.gov/initiatives-priorities/interoperability>

²⁵ See <http://www.cdc.gov/phinf/>