



Revisiting Public Health Registries

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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.

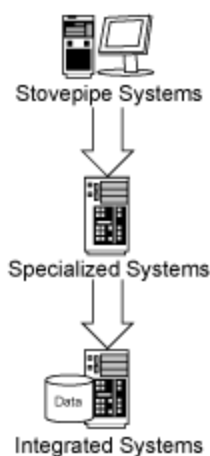


Figure 1

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.

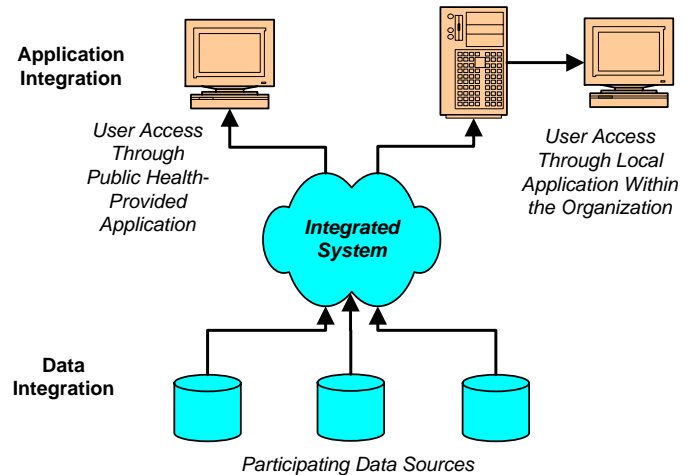


Figure 2

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.

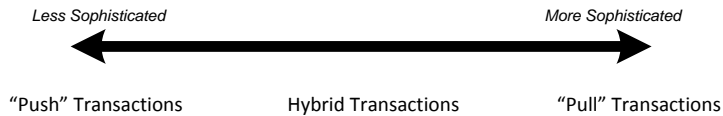


Figure 3

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

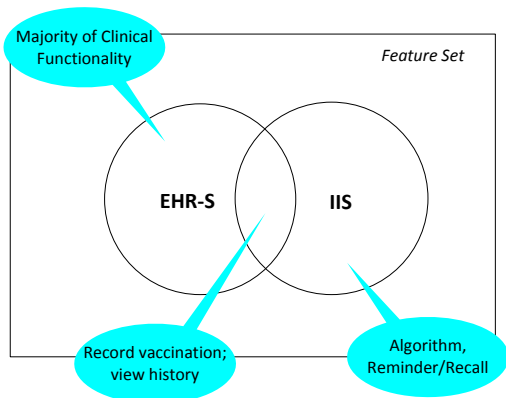


Figure 4

application features (through web-based application interfaces). These systems often developed as healthcare providers had limited access to clinical systems locally, and even more limited access to decision support applications. Over time, the deployment of EHR-S has enhanced the capabilities of clinician practices large and small. As the penetration of EHR-S continues, and the capabilities of EHR-S continue to develop, users at provider sites will increasingly be directed to use their local applications for most, if not all, functions. Pressure (if not prohibition) will build to decrease the use of outside applications as organizations attempt to not only bring more coherence to their users’ computing

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 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.

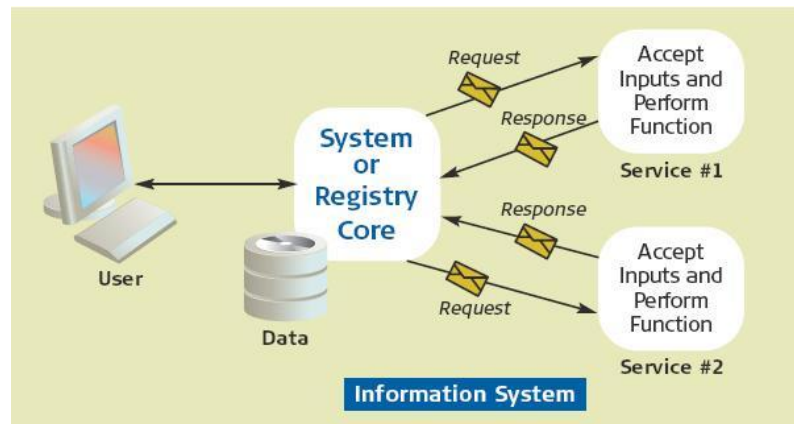


Figure 5

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.

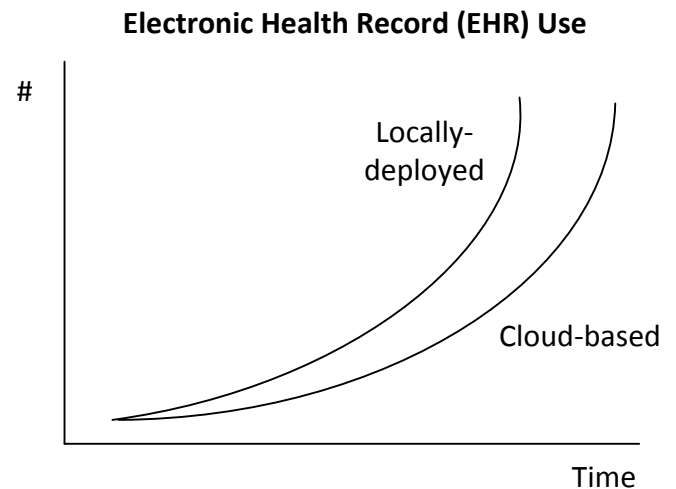


Figure 6

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

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<http://www.hln.com/noam/ONCHIT-RFI-HLNConsulting.pdf>.

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>.

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<http://www.hln.com/noam/JHIM-SOA-Spring2010.pdf>.

Gibbons, Patricia, et al, *Coming to Terms: Scoping Interoperability for Health Care*, Health Level 7 Electronic Health Record Interoperability Work Group, February 2007.
<http://www.hln.com/assets/pdf/Coming-to-Terms-February-2007.pdf>.

Public Health Data Standards Consortium, *Business Case on the Role of Public Health in the National Health IT Standardization Process*, 2009.
http://www.phdsc.org/standards/business_case.asp.

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).

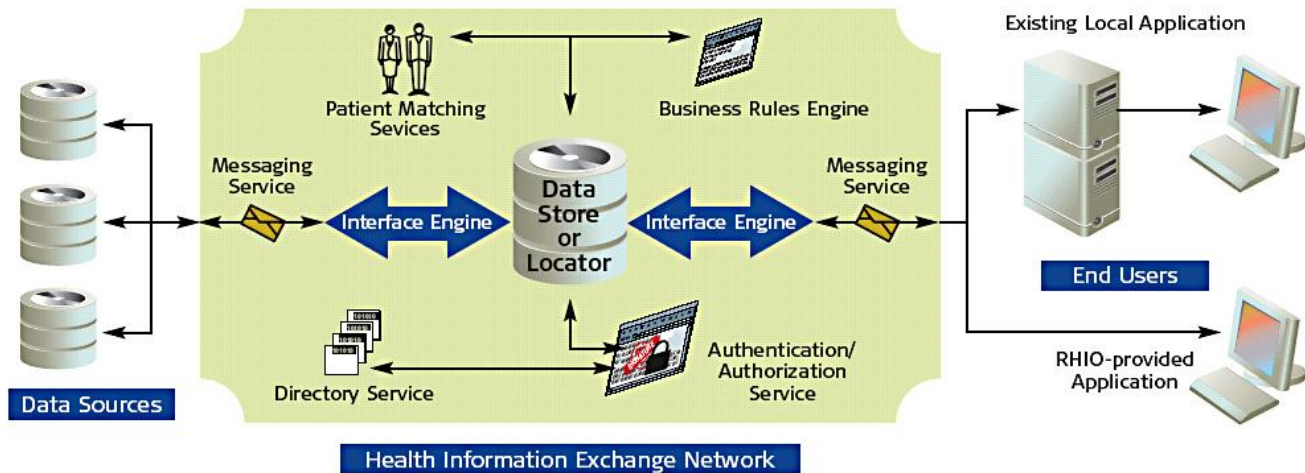


Figure C-1

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.

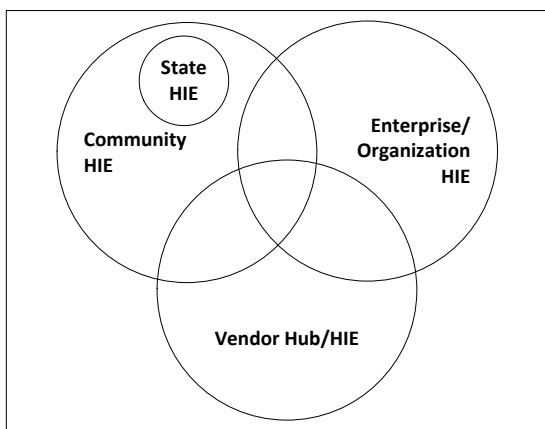


Figure C-2

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/phn/>