Re-defining Public Health Registries

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by

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Introduction

For public health agencies developing integrated health information systems, new risks and benefits are emerging rapidly on the horizon. The ways in which public health is increasingly exchanging information with health-care providers, hospitals, government, insurers, and families demand a closer look at the networked information environment. A public health registry is defines 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 plan 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 Networks (HIEN), in which public health runs the risk of being excluded. Public health can become an integral player in the HIEN scenario by embracing and promoting standards, opening access to its program-based database information, and organizing focus groups of stakeholders to make sure that everyone—including public health—has a place at the table.

Systems Integration

Figure 1

Over the past several years, public health systems 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. **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 system through one 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.

[1] http://www.ncvhs.hhs.gov/9701138b.htm

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 ultimately 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. **Comprehensive**: 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?

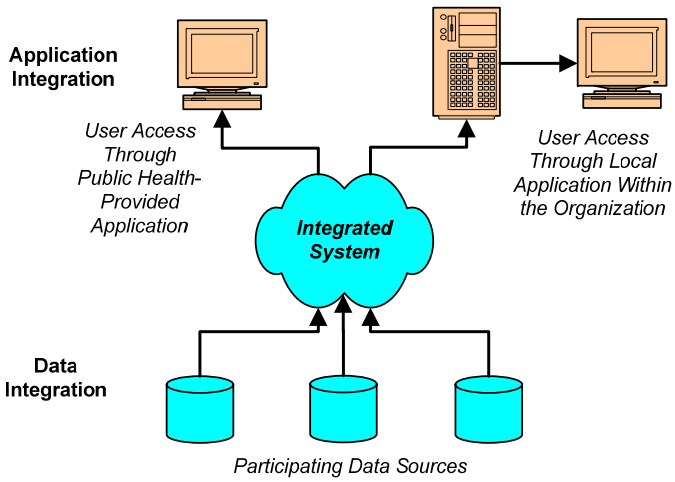

Figure 2

With the current national push toward electronic health records (EHR), public health *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) and 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.

From Integration to Interoperability

New, more complex ways of sharing data are also arising with the advent of the Health Information Exchange Network (HIEN) operated by the Regional Health Information Exchange (RHIO). These collaborative organizations focus on health data exchange in a community, county, or even a state-wide basis **(Figure 3)**. They have a wide and varied set of participants (providers, labs, hospitals, health plans, public health agencies, pharmacies, and patients/citizens).

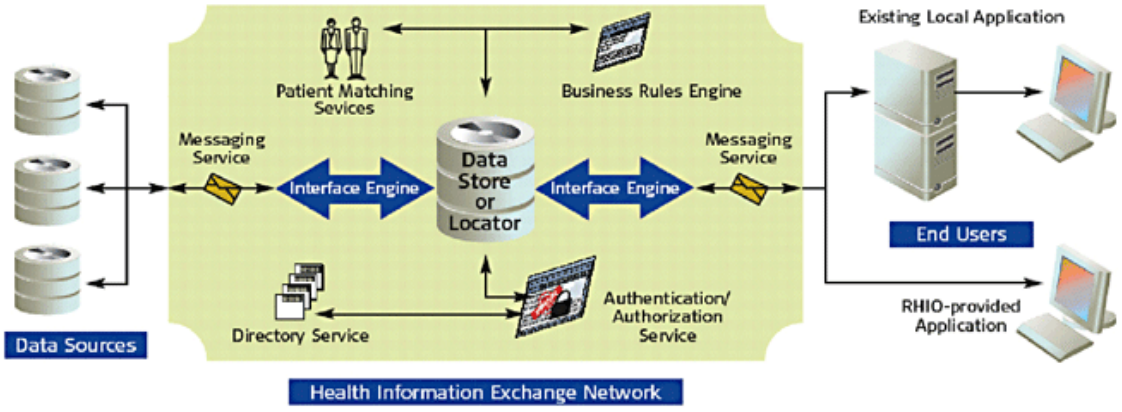

Figure 3

Primarily driven by private-sector participants, RHIOs 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.

Immunization registries and integrated child health information systems are good examples of mature, pre-HIEN deployments. As HIENs develop and are deployed, and both public health *and* private healthcare systems continue to evolve and develop, system *integration* within public health will no longer be enough. Public health systems will need to become *interoperable* with other systems both inside of, and especially outside of, the agency. 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 the information that has been exchanged."[2] The Working Group went further and defined interoperability as consisting of three major components:

1. Technical interoperability: Relates to the structure and syntax of data flowing between systems, including reliable and secure communications.

2. Semantic interoperability: Relates to preserving the meaning of data from sender to receiver, usually by enforcing agreed-upon code sets and meaning.

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.

Public health agencies, however, have a lot to gain by participating in HIEN/RHIO activities, including:

- Many of public health's data trading partners will choose to interoperate with an HIEN and reduce (or eliminate!) what they may perceive to be superfluous, and perhaps costly, additional connections.

- Public health can gain access to data and trading partners who previously might not have participated in its initiatives.

- 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.

In today's broadening data exchange environment, public health agencies 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. This is especially true in hospital and large ambulatory care settings, but this phenomenon also appears in local health departments that deploy more comprehensive services automation systems.

[2] 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>

- Pressure will build for providers to interoperate *solely* through HIENs. This may affect the public health data exchange partnerships as providers may be required to exchange data through the HIEN and may not want to exchange specific data with a public health program database as well. Though many RHIOs are just beginning to focus on clinical data exchange, and public health programs are typically not among their early pilots, with sufficient momentum RHIOs will likely become *the* driving force and context for health information exchange in.

- Richly functional public health systems run the risk of becoming used primarily as data repositories as users lose access to more advanced features. 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 immunization information system (IIS), which may also function as a repository, providers could lose access to algorithms, reminder/recall notice functions, 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.

- While many specialized features are part of the approved HL7 EHR functional specification[3] they are not currently *required* for certification by the Certification Commission for Health Information Technology (CCHIT).[4] This means that as providers are driven to *certified* systems they will find that those systems do *not* include the features needed to support key public health functions.

Three Imperatives for Public Health

For public health agencies, three key imperatives flow from these observations:

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

Public health has traditionally had only 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 public health agencies 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 from among the myriad of standards available a particular set of standards to achieve a specific purpose – has been promoted and coordinated by a set of activities initiates by the Department of Health and Human Services (**Figure 4**).

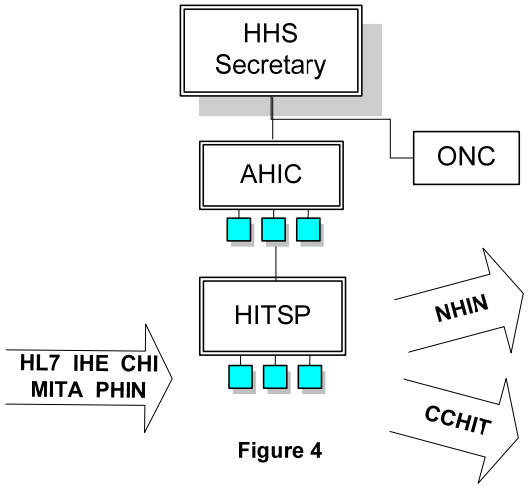

Figure 4

With staff coordination and support from the Office of the National Coordinator for Health Information Technology (ONC), the Secretary convened an advisory board called the

[3] See http://www.hl7.org/ehr/
[4] See http://www.cchit.org/

American Health Information Community (AHIC, reconstituted in November 2008 as "AHIC 2.0," an independent public-private partnership) to determine priorities for interoperability standards harmonization. These priorities were revealed in the form of use cases, narrative documents that describe the application of health information technology to solve a specific scenario. Once approved (after public comment and revision), these use cases were delivered to the Health Information Technology Standards Panel (HITSP), a collaborative organization made up of members of every stakeholder group in healthcare. Through its technical committees, HITSP developed a set of Interoperability Specifications which select standards to fulfill the requirements of the use cases. In some cases, where no standards exist, gaps were identified and documented. Eventually, the Secretary accepts draft specifications, then, once tested, recognizes them as being binding on agencies within his control. The AHIC Successor Organization is anticipating a similar process for identifying candidate use cases for standards harmonization.

Throughout HITSP's work a number of important standards development organizations (SDO) and Federal initiatives are considered, including:

Health Level Seven (HL7),[5] an ANSI-accredited SDO focused on enabling interoperability of clinical and administrative healthcare data.

Integrating the Healthcare Enterprise (IHE), an initiative that "promotes the coordinates use of established standards… to address specific clinical need in support of optimal patient care."[6]

The **Consolidated Health Initiative,**[7] whose objective is to enable sharing of health information between various federal agencies by adopting existing standards.

Medicaid Information Technology Architecture (MITA),[8] which is intended to promote integrated business and IT across the Medicaid enterprise to improve the administration of the Medicaid program.

Public Health Information Network (PHIN),[9] a the Centers for Disease Control and Prevention's (CDC) 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 public health agencies, CDC, private health entities, and other national, state, and local organizations.

The results of HITSP's work affects the specifications for products certified in the healthcare arena by such organizations as the CCHIT, and products and strategies selected for adoption by the Nationwide Health Information Network (NHIN) Collaborative which is funded to pilot health information exchange in select communities around the country. Organizations like the Public Health Data Standards Consortium (PHDSC) work with public health to improve participation in standards-development activities, and to promote the use of data and interoperability standards wherever possible.

[5] See http://www.hl7.org/
[6] See http://www.ihe.net/
[7] See http://www.hhs.gov/healthit/chiinitiative.html
[8] See http://www.cms.hhs.gov/MedicaidInfoTechArch
[9] See http://www.cdc.gov/phin/

2. Enable "special functions" of public health systems to be accessed directly by 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 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 electronic health record systems 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 support 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 typically are *not* found in local EHR-S and are often *not* incorporated into CCHIT conformance criteria for EHR-S to meet functionally. Rather than have users lose these functions entirely, public health systems architects must find new ways for these specialized functions to be offered to external systems.

Immunization Information Systems (IIS, or immunization registries) provide a good case in point. When it comes to clinical information support, EHR-S usually provide 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 5**). There, however, 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 – IIS provides an assessment of a patient's immunization history against a complicated set of decision rules 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.

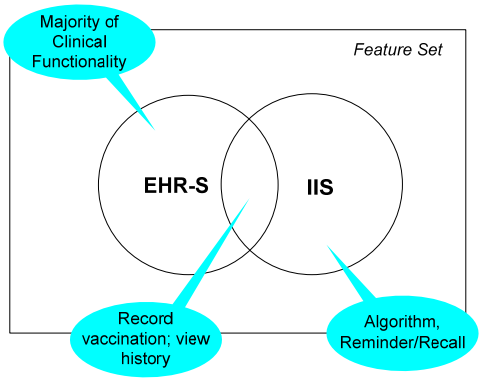

Figure 5

- Reminder and Recall to ensure a patient returns when an immunization is due – 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.

- 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.

- 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 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 loosing access to those special functions of systems like IIS that 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 6**). 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.

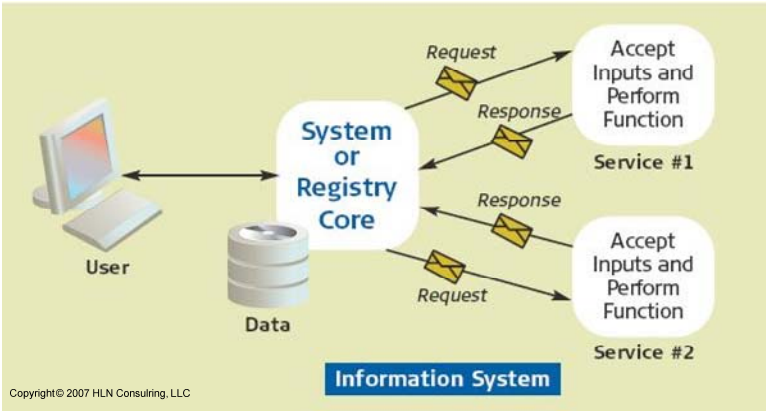

Figure 6

KIDSNET, the integrated child health system developed in the State of Rhode Island, is an example of the beginning of such an architectural transformation. Operating for more than ten years, KIDSNET provides access to a wide variety of child health data to authorized providers in the community through a web-based interface. When originally developed, it did not contain a strong algorithm to help determine when immunizations are recommended for patients. Rather than completely re-architect their system to embed this complex algorithm within it, Rhode Island decided to incorporate the algorithm used by the State of California in a set of its regional IIS and deploy it in an SOA framework (**Figure 7a**). WISER was deployed on a separate server – in a completely different technology than the rest of KIDSNET – and was able to be integrated into the system quickly and easily through the use of Web Services, one type of SOA technology.

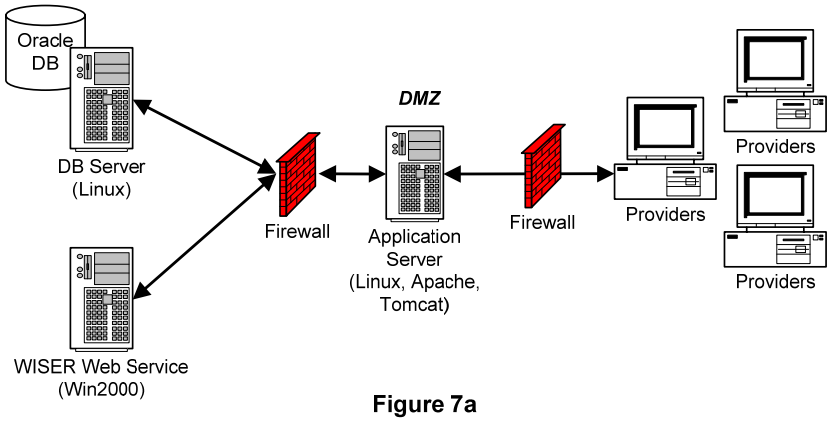

Figure 7a

Though not yet deployed in this fashion in Rhode Island, it would be only a small step forward for KIDSNET to be able to offer the WISER service to providers using EHR-S. If an authorized EHR-S provided the same inputs to the WISER service as KIDSNET (patient date of birth, gender, and immunization history: note that no name or other identifying information is necessary) it could receive the decision support recommendations from the immunization algorithm just as KIDSNET does today (**Figure 7b**). And WISER could provide this capability while it is supporting KIDSNET without any impact on that system. Other special features of the IIS could be offered in a similar fashion as they are developed.

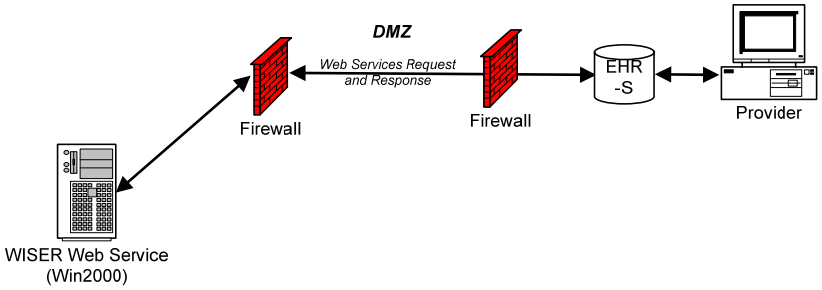

Figure 7b

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

Public health agencies must develop the internal capability not only to development their own systems, 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 activities 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 to build 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, as well as 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 Management and Systems Society (HIMSS), the Public Health Data Standards Consortium (PHDSC), Health Level Seven (HL7), and 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.

Several jurisdictions have been successful in providing and promoting medical informatics in this way. The Centers for Disease Control and Prevention (CDC) established the National Center for Public Health Informatics (NCPHI) to spearhead activities within their own agency and to provide an example to jurisdictions elsewhere. The State of Minnesota established the Center for Health Informatics and this organization serves as a model to other states of how informatics can be leveraged within the agency and outside. The Public Health Informatics Institute (PHII) is an example of an independent not-for-profit organization that promotes medical informatics through its funded projects and collaboratives.

Conclusion

Public health systems continue to evolve and develop in response to increasingly more sophisticated information needs as well as growing requirements for interoperability with system 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 systems to function in this new paradigm. It is critical, however, that investments in new systems and in enhancements to existing systems be carefully scrutinized to ensure that valuable opportunities are not lost to move beyond old ways of doing things towards more standards-based approaches that leverage other activities going on in the community. A strategic informatics–whether basic or more sophisticated–focus will help ensure that these opportunities are ignored. In addition, pressure should be brought to bear on the CDC, as a major funder of public health systems initiatives, to continue to encourage and provide incentives for systems developed and deployed using standards, and to continue to promote greater efficiency through cross program leverage of resources.

Appendix A: Terms and Acronyms

AHIC	American Health Information Community http://www.hhs.gov/healthit/community/background/
AHIMA	American Health Information Management Association http://www.ahima.org/
AMIA	American Medical Informatics Association http://www.amia.org/
CDC	Centers for Disease Control and Prevention http://www.cdc.gov/
CCHIT	Certification Commission for Health Information Technology http://www.cchit.org/
CHI	Consolidated Health Initiative (Federal) http://www.hhs.gov/healthit/chiinitiative.html
CIO	Chief Information Officer
EHR/EHR-S	Electronic Health Record/Electronic Health Record System
HEDIS	Healthcare Effectiveness Data and Information Set http://www.ncqa.org/tabid/59/Default.aspx
HHS	US Department of Health and Human Services http://www.hhs.gov/
HIE/HIEN	Health Information Exchange/Health Information Exchange Network
HIT	Health Information Technology
HITSP	Health Information Technology Standards Panel http://www.hitsp.org/
HL7	Health Level Seven http://www.hl7.org/
IHE	Integrating the Healthcare Enterprise http://www.ihe.net/
IIS	Immunization Information System
KIDSNET	Integrated child health system operated by the Rhode Island Department of Health http://www.health.state.ri.us/family/kidsnet/index.php

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/
NCPHI	National Center for Public Health Informatics, Centers for Disease Control and Prevention http://www.cdc.gov/ncphi/
NHIN	Nationwide Health Information Network http://www.hhs.gov/healthit/healthnetwork/background/
ONC	Office of the National Coordinator for Health Information Technology http://www.hhs.gov/healthit/onc/mission/
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/
RHIO	Regional Health Information Organization
SDO	Standards Development Organization
SOA	Service-oriented Architecture http://www.webservices.org/
VFC	Vaccines for Children Program http://www.cdc.gov/vaccines/programs/vfc/default.htm
Web Services	One specific technology for implementing a Services-oriented Architecture (SOA) http://www.webservices.org/

Appendix B: Selected Readings

Noam H. Arzt 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>

Noam H. Arzt, Response to Request for Information, *Development and Adoption of a National Health Information Network*, Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, January 18, 2005. <http://www.hln.com/noam/ONCHIT-RFI-HLNConsulting.pdf>

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.hln.com/assets/pdf/Coming-to-Terms-February-2007.pdf>

