

Health information exchanges, also called regional health information organizations and other names, are organizations whose purpose is to link providers to exchange person-centric information relevant to the person's health care.

This paper by the Public Health Informatics Institute provides a concise summary of the forces that have led to the health information exchange movement and the challenge to public health to participate in these organizations. It describes the mutual benefits that public health and health care will derive from a health information exchange if public health is a viable partner. A resource for public health agencies and their health information exchange partners.

Topics

In Public Health Informatics



Public Health Opportunities in Health Information Exchange

Public health participation in health information exchanges presents opportunities for both short-term and transformative impacts on the health system.

National interest in health information exchange has arisen from the convergence of four historic trends: a demand for health care cost containment and quality improvement, the urgent desire for better surveillance and response to public health emergencies, the emergence of technologies capable of providing electronic person-centric health information on demand, and the development of the Internet and technologies that can link information between users with little regard to distance, hardware, or software platforms.

The ability to securely and rapidly exchange patient clinical information between health care providers has been demonstrated in a few model programs. Such collaborations have variously been called local health information infrastructures, regional health information exchanges, sub-network organizations, and regional health information organizations, depending on their scope. No matter what they are called, it appears today that affordable technology solutions are within our grasp, necessary standards are being established (vocabulary, data coding, message format, etc.), and

communities are actively forming health information exchanges. In one regard, the stars appear aligned; there is unprecedented interest among both the public and private sectors in the development and adoption of common architectural standards for health system interoperability.

The Challenge

As interest in health information exchange balloons in the vastly larger private health care sector, it is not clear that public health agencies are keeping pace. A business-to-business (B2B) network model of regional health information networks, one that supports immediate needs of health care practitioners, has been the central focus of emerging health information exchange projects. This model does not necessarily incorporate opportunities to improve health outcomes at the community level.

Public health agencies are mandated to protect and improve the health of all people within their legal jurisdiction, through surveillance of health trends, regulation, health promotion, and disease prevention. These highly information-dependent functions are generally performed in

National Health Information Exchange Issues

A number of issues remain under discussion at national forums on health information exchange. These include:

- What is a sustainable business model for a health information exchange (and the NHIN) and will the model be the same in all regions/communities?
- Which types of health care partners (and what proportion of each) within a trading area are needed for a viable health information exchange?
- Is there a single best governance model and what will be the standards, policies and procedures to which it must adhere? Which types of organizations can serve as trusted neutral parties, and might legally be able to manage, community-wide collections of patient information, such as disease registries?
- How will private physicians be enticed to invest in e-health technologies (electronic health records, networking technologies, etc.)?
- Will the health information exchange address broad, community-level functions, including public health applications, community-level quality and safety initiatives, and creation of community-wide patient registries?

Each of these issues raises questions about roles that might be played by public health and other government agencies in the successful development of health information exchanges. The growing conceptualization of a health information exchange as a business-to-business (B2B) network raises the concern about whether or how these entities will serve health needs on other scales.

partnership with health care providers and organizations, which themselves depend on public health surveillance and guidance. Public health participation in health information exchange is likely to produce mutual benefit, reducing the cost and increasing the speed of surveillance while delivering useful public health information more rapidly to the point of clinical service. It is important for public health leaders and health information exchange stakeholders to explore which types of information exchange and relationships will lead to the greatest benefits for all.

National Context

Significant progress has been made in demonstrating the feasibility of interconnecting multiple provider organizations to exchange person-specific health information and make it available at the point of service. Multiple, active experiments in health information exchange are now underway. For example, the Indiana Health Information Exchange (IHIE), the Massachusetts e-Health Collaborative (MAeHC), and Mendocino County, Calif., have joined to implement a prototype of a national health information exchange or "health information-sharing environment," based on a common framework of policies, principles, guidelines, and technical specifications that is emerging from the work of the Markle Foundation's Connecting for Health initiative.¹ This is the result of a rising collective estimation of the business value of health information exchange for multiple stakeholders.

The 2001 report from the National Committee on Vital Health Statistics, *NHII—Information for Health: A Strategy for Building the National Health Information Infrastructure*,²

postulated the national health benefits of large-scale interconnectivity. Since then, the health information exchange concept has progressed to the point where provider, payer, health care information technology, and public health stakeholders have endorsed the goals and general benefits of person-specific information shared on-request between health care providers.

The Connecting for Health Public-Private Collaborative (convened by Markle Foundation and further supported by The Robert Wood Johnson Foundation) has issued several reports addressing issues related to development of health information exchange.³ eHealth Initiative has united diverse stakeholders to promote interest, understanding, and demand for information exchange, including funding nine local exchanges with the Connecting Communities for Better Health projects.⁴

Congress subsequently funded additional projects through the Agency for Healthcare Research and Quality (AHRQ), which awarded FY2004 funds to numerous groups throughout the country to plan or implement elements of the vision. They also negotiated five 5-year, \$1 million/year contracts with states (RI, IN, CO, TN, UT) to implement and/or build upon existing health information exchanges. These projects will contribute to the knowledge and the momentum needed to reach agreement on which technical architectures, governance approaches, and business models can be sustainable. Public health agencies are a convener or a participant in many of these projects.

A Presidential Executive order in 2004 established the Office of the National Coordinator for Health Information Technology (ONCHIT),

with a mandate to assure universal interoperable personal electronic health records by 2014. In June 2005, the Secretary of Health and Human Services announced formation of a private-public collaboration to provide recommendations to HHS on how to make health records digital and interoperable, and assure that the privacy and security of those records are protected.

National, Regional, Local Health Information Exchange

The vision for how health information exchange will occur is evolving rapidly. The 2001 NCVHS report *Information for Health* described the national information infrastructure (NHII) as a standards-based architectural framework to enable more seamless sharing of person-specific health information. It was not described as a singular, national database or information system. It envisioned a network of federated health information infrastructures at the local or regional level exchanging personal health information using compatible standards.

The National Health Information Network (NHIN) is described in greater detail in the 2004 *Framework for Strategic Action: The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care* from ONCHIT.⁵ “A National Health Information Network would link disparate health care information systems together to allow patients, physicians, hospitals, public health agencies and other authorized users across the nation to share clinical information in real-time under stringent security, privacy and other protections.” The NHIN is envisioned as the inter-networked product of

Local Health Information Exchange Issues

Regardless of size/scope, a health information exchange must have several components:

- Governance – formal organizational legal charter; processes for managing stakeholder involvement and needs; processes for negotiating over time changes to the organization’s purpose
- Technology architecture that assures conformance with standards, as needed and/or mandated
- Data use agreements
- Financial and business model supported by appropriate business processes

The stars appear aligned; there is unprecedented interest among both the public and private sectors in the development and adoption of common architectural standards for health system interoperability.

community health information exchanges.

Organizations whose purpose is to link providers together for the purpose of exchanging person-centric information relevant to the person's health care are developing on community and regional levels, as well as across geography. A logical scale for voluntary, collaborative development of information exchange is the regional health care market that geographically contains most patient movement (referrals, emergency department use, etc.) and thus, the greatest need to transfer health information on a day-to-day basis. This has been referred to as the "medical trading area." This is also the scale of face-to-face relationships between providers that maximizes trust, stakeholder involvement, and mutual benefit while minimizing the number of jurisdictions with potentially conflicting laws affecting health information exchange. A sub-network organization, a similar concept, refers to a network of organizations linked by a common purpose but not constrained by geography, such as a nation-wide network of children's hospitals or the Veterans Affairs (VA) medical system.

Patients in Health Information Exchange

Some have argued that at this early stage, health information exchanges are essentially business-to-business (B2B) ventures. That is, they facilitate health care organizations and their providers in the task of delivering care. Consequently, involving patients directly in the flow of electronic patient information unnecessarily complicates the picture. Others have argued that patient-centered, patient-controlled applications are critical to maximizing the impact of the health information exchange

on care, cost, quality, and safety.⁶ The information in a health information exchange could potentially support personalized health promotion and disease prevention tools that are far more effective than current approaches. Thus, there may be a link between patient access to health information exchange information and public health outcomes.

Since there is an inevitable trade-off between privacy and information access, patient-controlled applications may also help gain patient acceptance for exchanging their information in the first place.

Public Health in Health Information Exchange

Given the interdependence of public health agencies and health care organizations, early consideration of public health functionality of health information exchanges can help ensure that benefits to both are maximized.

Public health refers both to a set of legal constructs, as well as a more general concept related to population health. The police powers and obligations of government to protect public health originate in common law and are controlled primarily by local and state statutes. The U.S. Constitution assigns limited roles to the federal government beyond regulation of international and interstate issues, and the ability to raise taxes for the general good. However, local and state public health agencies now depend heavily on funding from federal block and categorical grants, and the federal government has become a major purchaser (and thereby regulator) of personal health care. Thus public health functions in a given locality are the product of complex local, state and federal interactions. Many core public

health functions relate to personal health information and personal care, such as required reporting of health conditions by physicians and laboratories to public health authorities, and the latter's responsibility to advise providers in the face of a community health threat.

Public health is also defined more broadly as "what we, as a society, do collectively to assure the conditions in which people may be healthy."⁷ This recognizes that protecting and promoting health is necessarily a shared responsibility. Government must inform, regulate, and coordinate overall efforts, but, in the final analysis, public health outcomes rely as much on actions of employers, schools, health care providers, business owners and individuals. Modern terminology refers to the "public health system" in which government is but one (albeit central) player. Indeed, the work of public health agencies is increasingly characterized by providing health information and knowledge to other agencies, upon which they rely to perform important public health activities. The contemporary public health model is characterized above all else by interdependency.

Both of these visions of public health (legal mandates and communal action) should inform the interaction of public health with health information exchanges.

Public health is described as having three core functions: assessment of health status, policy development related to health, and assurance of needed conditions and services. The public health system should provide 10 essential services to each community:

- Monitor health status to identify and solve community health problems.

- Diagnose and investigate health problems and health hazards in the community.
- Inform, educate and empower people about health issues
- Mobilize community partnerships and action to identify and solve health problems.
- Enforce laws and regulations that protect health and ensure safety.
- Develop policies and plans that support individual and community health.
- Link people to needed personal health services.
- Assure competent public and private health care workforce.
- Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
- Research for new insights and innovative solutions to health problems.

In most jurisdictions, these services are increasingly shared between public health agencies and other organizations, under many different funding relationships (federal grants, local tax revenues, fee for service, etc.).

The Public Health Information Network (PHIN)

In response to needs for more comprehensive, timely, and accurate population-based information and needs for information to support terrorism threat detection and response, the Centers for Disease Control and Prevention (CDC) formulated the Public Health Information Network (PHIN). PHIN seeks to advance the use of interoperable information systems in five functional areas: detection and monitoring of diseases and health threats and of national health status indicators; analysis of public health information, including live data feeds;

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information resources and knowledge management; providing access to reference materials, decision-support, and distance learning; alerting and communications enabling greater collaboration among agencies and other health system partners; and response systems supporting both emergency and routine public health business processes.

Public Health and health information exchange: A two-way value relationship

Every visual conceptualization of a health information exchange has shown at least a one-way information arrow leading from the health

Table 1: *Potential value added by public health*

- Providing individual patient information similar to other providers (e.g., immunizations, laboratory results)
- Reduced cost and labor of mandated reporting
- Providing epidemiologic information to improve diagnostic accuracy (e.g., alerts of outbreaks; populating a “prior probability calculator” for Bayesian analysis of test results)
- Personalized information facilitating disease management or care coordination (e.g., program eligibility; identification of nearby and language-compatible services; reporting patient utilization of referred services; communication with case managers; electronic service referrals and result reporting)
- Easy access to guidance for management of public health problems (e.g., infection control, lead screening, tobacco cessation)
- Personalized point-of-service tools for diagnosis, management or patient education, through embedded EHR guidelines sensitive to local prevalence and service information (e.g., screening reminders for members of local at-risk groups, local resources for disease management)
- Automated tools for quality improvement (e.g., immunization audits)
- Alerts for providers (and patients enrolled in registries) regarding urgent health-relevant issues (e.g., air quality alerts for asthma, congestive heart failure)
- Serving as a trusted neutral manager for confidential information such as chronic disease registries
- Maintenance of participant directories, role authorization and authentication systems
- Maintenance of a community master patient index
- Access to public infrastructure resources
- Providing an accountable point of contact for community or political leader concerns

information exchange to public health, indicating passive data listening. This overlooks the potential for public health to provide substantial information that is useful to clinicians at the point of service (e.g., both information related to specific patients, such as immunization records or case management information) as well as higher-level knowledge derived from population-level information (e.g., illness trends or expert guidance).

Public health agencies typically manage large amounts of data of great potential value to health care providers, but struggle with converting and delivering it as useful information for the practice of medicine. Standardized electronic information could radically improve the process. It would enable near-real-time data capture, partial automation of data analysis to create useful information, and rapid transmission of that information to providers. Further, knowledge could be delivered in a form and context most useful at the point of care (e.g., “This patient lacks a

record of any MMR immunization”; or “Consider diagnosis of pertussis in light of patient’s symptoms and current outbreak”).

Additionally, public health agencies may have unique legal or organizational attributes (e.g., a trusted neutral party experienced with maintaining confidential health information; a potential connector to public sector high-bandwidth infrastructure) that could substantially aid health information exchange governance and architecture. Table 1 lists the potential value that public health can bring to a health information exchange.

At the same time, public health stands to benefit by a health information exchange. Table 2 lists some of the potential value received by public health from a health information exchange.

While public health agencies may have unique attributes that would warrant involvement in health information exchanges, many questions remain. For example, do some pub-

Public health participation in health information exchanges is likely to be essential to their long-term viability.

Table 2: *Potential value received by public health*

- More timely and complete receipt of disease reports
- Faster transmission of better information to public health case managers (for communicable disease control, newborn screening follow-up)
- Easier identification and analysis of gaps in preventive health services (immunization, Pap smears) and of patterns that could improve performance
- Easier identification and analysis of follow-up failures (treatment of STDs; environmental evaluation of lead poisoning) and of patterns that could improve performance
- Analysis and display of geographic distribution of illness or injury to focus public health interventions or services
- Analysis and display of the temporal and geographic epidemic spread
- Improved ability to communicate with selected provider and patient populations

Table 3: *Short-term Opportunities*

1. Optimize reporting to public health.

The most obvious immediate benefit of a health information exchange to public health lies in improving mandated public health reporting. Standardizing and streamlining reporting processes will reduce complexity and costs to providers. Notifiable disease reports will be made simple and immediate. Other health system reporting, such as hospital discharge summaries, can be faster and more efficient. Laboratory specimen referral (e.g., clinical lab to public health lab) and associated results reports will be more timely to all stakeholders.

2. Coordinate and improve continuity of care through communication and collaboration.

Shared patient data creates the opportunity for public health case management capabilities and expertise to be shared with providers to assist continuity of care. Assurance, one of public health's major functions, demands that agencies support a number of legally mandated follow-up programs (e.g., at risk children identified through newborn metabolic and hearing screening). Most of these functions represent an obligation to assist with coordination of care. Public health participation in a health information exchange offers the opportunity to improve communications, improve efficiency, and reduce cost of care coordination.

3. Enable patients and providers to improve health through access to and use of personal health record information.

As the consumer movement in health services continues to bloom, patients and doctors need ways to interact that promote adherence to treatment and simultaneously document patient actions related to prescribed treatment. Public health authorities and medical practitioners need efficient ways to incorporate prevention information into communications with patients. Patients want access to and a measure of control over where and how their personal health information is used. In the short-term, public health can assist in linking patients to health risk appraisals and creating personal health records. Public health agencies presently maintain preventive service systems, such as immunization registries, that can provide complete information to both doctors and patients. Health information exchanges offer an opportunity to improve point-of-service information delivery of preventive health information.

4. Integrate and consolidate information for better health and health care.

Public health agencies can contribute and benefit by participating in efforts to refine patient matching, merging and record linking protocols and algorithms. Public health has national efforts underway to bring about larger-scale integration of systems such that more complete information on individuals can be made available to authorized providers and aggregated for population-based analyzes. Improved integration among provider organizations and public health agencies will improve our understanding of patterns and disparities of care, improve care coordination, and facilitate provider-patient communication through a shared view of the entire health record.

lic health agencies have health care regulatory roles that interfere or conflict with their ability to be full partners in the health information exchange governance or information exchange? Do certain health information exchange business models or information architecture characteristics either enhance or inhibit the achievement of community-level public health applications? Is it most practical to sort public health/health information exchange functionality based on types of information to be exchanged, the types of health problems or populations to be addressed, or the types of functions (e.g., alerting, decision-support, case management) to be performed?

Opportunities for Public Health

A meeting of 12 private health care and public health experts in early 2005 identified opportunities for public health agency engagement in health information exchanges.⁸ By assuming an ideal health information exchange, the workgroup enumerated a total of 22 significant and feasible health system functions associated with an ideal health information exchange. Many of these functions would benefit public health by improving task efficiencies (e.g., eliminating redundant data entry for notifiable conditions), accelerating reports of diseases and conditions of interest to public health authorities, or expanding the breadth of understanding of local health dynamics.

A number of functions are made possible by having public health as an active participant in this idealized health information exchange.

The list of health system capabilities were further prioritized by examining which capabilities would benefit most with public health sector involvement within the next five years (see Table 3, Short-term Opportunities) and/or which capabilities would be most transformative of the health system given public health involvement (see Table 4, Transformative Opportunities).

Conclusion

Health information exchanges offer significant promise for improving the health and well-being of every citizen. Public health participation in health information exchanges is critical and is likely to be essential to their long-term viability. Exploring the role public health plays must begin with the formative steps to create a community or regional health information exchange. Public health involvement will, by its very nature, help the health information exchange maintain a focus that goes beyond the provider-to-provider focus and the immediate business case for health information exchange.

Assuring that personal health records include prevention information is among the most urgent needs. This can be accomplished by identifying high-value prevention elements for personal health records, assuring public health needs have an effective and timely voice with standards and industry groups (e.g., Public Health Data Standards Consortium), and mobilizing federal partners (e.g., AHRQ, CDC, HRSA) to help bring prevention elements into personal health records and electronic health record standards.

Table 4: *Transformative Opportunities*

1. Enable patients and providers to improve health through access to and use of personal health record information.

Person-centric health information should link individuals to all resources that help them understand the dynamics of their own health and the health of the community. The workgroup deemed patient involvement in their care as the most transformative outcome that should be associated with broadly capable health information exchanges. Patient involvement should extend far beyond a simple patient-to-doctor episode of care interactions. Health information exchanges should facilitate and empower individuals to involve families and other community support elements in supporting healthy lifestyles, encouraging healthy communities, and taking the best steps in their own health care. In the future, public health can assist this transformation by using personal health record information to better define personal and community risks, needs, and assets.

2. Coordinate and improve continuity of care through communication and collaboration.

Using the ideal health information exchange as a basis for looking into the future, one can envision that a common care plan, viewable by all agencies involved with a patient, will be possible. Implementing flags that enhance communication among necessary parties should reduce redundant care and improve opportunities for prevention. Chronic disease care stands to benefit significantly by reorienting patient support from provider alone to a more integrated network of family and community resources.

3. Facilitate linkage of decision-support tools to patient and population information.

Establishing the semantics that will make the capture and exchange of health data a feasible and routine part of care delivery remains an urgent task. Pursuing standardization of data and communications will impact health care and public health and is an activity that must be crafted jointly by all parties. Codifying care and prevention guidelines and related decision-support tools will enhance opportunities for prevention. For example, public health prevention guidelines (e.g., CDC's Prevention Guidelines) should be translated into machine interpretable code and embedded in future electronic health record systems to aid providers in giving the best information at the point of service. Linking records by public health will allow for more precise population-level assessment of the impact of prevention strategies.

4. Broaden diverse participation and linkage of health care system to community.

In its fullest realization, a health information exchange can help individuals establish electronic health collaboration zones where they can safely share health information with others (e.g., clergy, case managers, family) who are helping them stay healthy, recover from illness, or deal with chronic or life-ending illness. Appropriate, controlled access to information can also allow parents to involve school nurses and other resources to support children with special health care needs.

“Creating a collaboration for information sharing is about relationship building and bringing value and credibility to the table.”

Dr. Virginia Caine
Director, Marion County
Health Department, IN

Resources

AHRQ National Resource Center for Health Information Technology

Provides technical assistance to AHRQ health IT projects and shares new knowledge and findings that have the potential to transform everyday clinical practice.

<http://healthit.ahrq.gov/home/>

Connecting Communities for Better Health

Develops, shares, and disseminates knowledge, resources and tools to facilitate and support community-based health information exchange. A program of the eHealth Initiative.

<http://ccbh.ehealthinitiative.org/default.aspx>

Connecting for Health

A public-private collaborative designed to address the barriers to development of an interconnected health information infrastructure. A program of the Markle Foundation, with additional funding and support from the Robert Wood Johnson Foundation.

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

ihealthbeat

A free, daily news digest reporting on the Internet's impact on health care from the California HealthCare Foundation.

National Center for Vital Health Statistics

The mission of the National Committee on Vital and Health Statistics (NCVHS) is to advise on shaping a national information strategy for improving the population's health.

<http://www.ncvhs.hhs.gov/>

National Library of Medicine

The National Library of Medicine's Commission on Systemic Interoperability is developing a

strategy to make health care information instantly accessible at all times, by consumers and their health care providers.

http://www.nlm.nih.gov/csi/csi_home.html

Office of the National Coordinator for Health Information Technology (ONCHIT)

Implements the President's vision for widespread adoption of interoperable electronic health records (EHRs) by 2014.

<http://www.hhs.gov/healthit/>

Public Health Data Standards Consortium

Develop, promotes, and implements data standards for population health practice and research.

<http://phdatastandards.info/default.htm>

Public Health Informatics Institute

Advances public health practitioners' ability to manage and apply health information systems.

www.phii.org

Public Health Information Network (PHIN)

CDC's vision for advancing fully capable and interoperable information systems in the many organizations that participate in public health.

<http://www.cdc.gov/phn/index.html>

Recommended Reading

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Health Information Exchange Partners

The partners in a health information exchange vary by locale. Typically the following categories of organizations are involved:

- Consumer and patient groups
- Employers and health care purchasers
- Health information technology suppliers
- Health plans and payers
- Hospitals and other providers
- Pharmaceutical and medical device manufacturers
- Pharmacies, laboratories and other ancillary providers
- Practicing clinicians and clinician groups
- Public health agencies
- Quality improvement organizations
- State, regional and community-based health information organizations

Notes

- ¹ <http://www.connectingforhealth.org>
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The Public Health Informatics Institute is dedicated to advancing public health practitioners' ability to strategically apply and manage information systems.

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Our services provide clarity about the information systems problems to be solved and identify the solutions to those problems.

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