



**RESULTS FROM SURVEY ON
HEALTH DATA EXCHANGE 2013**
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THE CHALLENGE TO CONNECT



eHEALTH INITIATIVE

2013 DATA EXCHANGE SURVEY RESULTS

Since 2004, eHealth Initiative has fielded a comprehensive survey assessing the state of data exchange in the United States. Over the past ten years, millions of federal and private dollars have been poured into the development, adoption, and use of electronic health information infrastructures. As the field of health information technology has grown, community-based and enterprise-wide data exchange initiatives have made steady progress. This document presents key findings from eHealth Initiative's 2013 Health Data Exchange Survey.

Health information exchange (HIE) or "data exchange" is the electronic mobilization of healthcare data across organizations within a hospital system, community, region, or state. By providing access to and sharing of accurate, up-to-date information across disparate medical settings, data exchange is critical to the successful coordination and delivery of care. Formal organizations, such as community-based organizations and statewide initiatives providing this service are known as health information exchange organizations. Healthcare data exchange also occurs in organizations that are not formal health information exchange organizations, such as between a hospital and affiliated independent practices. The 2013 Survey covered both types of data exchange.

BACKGROUND ON RESPONDENTS

Data exchange initiatives are rapidly maturing. In 2013, eHealth Initiative identified 315 data exchange initiatives in the nation. Of those groups identified, 199 completed the eHealth Initiative survey. The survey respondents represent a mix of community data exchanges, statewide efforts, and healthcare delivery organizations. Eighty-four (84) organizations have reached advanced stages of operation, sustainability, or innovation (as defined by eHI's developmental framework). Most took one or two years to become operational.

- Among organizations responding in both 2011 and 2013, 27 more have reached stages 5, 6, or 7 in 2013
- Ninety (90) organizations identified themselves as community-based HIEs, 45 identified as the state designated entity (SDE) or state HIE, and 50 identified as healthcare delivery organizations.
- Hospitals and ambulatory care providers are the stakeholders most commonly providing and viewing data. Labs also commonly provide data, and community/public health clinics also commonly view data.
- Twenty-four initiatives (24) report that they have hired staff from ONC's Workforce Development Program. This is an increase since 2011, when only 3 organizations reported hiring program staff.
- Direct is a standards-based protocol for securely exchanging health information over the internet. Ninety (90) organizations currently use Direct, primarily for transitions of care.

There is no single dominant model for data exchange. 125 organizations use a query model, 124 use secure electronic messaging, 111 use end-to-end integration and 84 respondents use a combination of models.

KEY FINDINGS

The following findings were drawn after careful review of the survey results. A number of health information exchange experts were included in this process. More detail is provided below.

1. Achieving interoperability with disparate information systems is a major concern; sixty-eight initiatives have had to connect to more than 10 different systems.
2. To overcome interoperability challenges, exchanges would like to see standardized pricing and integration solutions from vendors.
3. Many exchanges are not sharing data with competing organizations.
4. Exchanges are focusing on functionalities to support health reform and advance analytics.
5. Patient engagement remains low amongst organizations exchanging data.
6. Patient consent for data exchange generally remains an all-or-nothing proposition.
7. In the last 2 years, more data exchange initiatives have become financially viable. However, hospitals and payers are still expected to fund most exchange activity.

KEY FINDING 1: Achieving interoperability with disparate information systems is a major concern; 68 initiatives have to connect to more than 10 different systems.

Concerns about interoperability have become more prevalent as data exchange scales up. 151 respondents have had to build multiple interfaces with disparate systems, and one-fifth (32) of these have had to construct interfaces with more than 25 different systems. In fact, interoperability with other health IT systems was a challenge for 142 organizations. Among organizations responding in both 2011 and 2013, ten more reported this as a challenge in 2013.

KEY FINDING 2: To overcome interoperability challenges, exchanges would like to see standardized pricing and integration solutions from vendors.

Common challenges to interoperability are numerous, including the financial costs of building interfaces (90), difficulty constructing interfaces (75), and encouraging stakeholders to share information (73). To overcome these interoperability challenges, organizations would most like to see standardized pricing and integration solutions from vendors (124), technology platforms capable of “plug-and-play” functionality (113), greater use among providers of consensus-based standards for data, vocabulary, and transport (113), and interoperability solutions that improve provider workflow (109).

KEY FINDING 3: Many exchanges are not sharing data with competing organizations.

Hospitals and ambulatory care providers are the stakeholders most commonly providing and viewing data within data exchange networks. Labs also commonly provide data, and community/public health clinics also commonly view data. However, sharing information outside networks is not as common. Thirty-three data exchange (33) efforts are restricted to entities within a network. Fifty-eight (58) have not connected with other networks, such as a community HIE, SDE, or eHealth Exchange.

KEY FINDING 4: Exchanges are focusing on functionalities to support health reform and advance analytics.

The essentials of information sharing, such as patient matching, results delivery, and summary of care document exchange, are proven services and represent a stepping stone on the way to advanced functionalities

like analytics. Data exchanges are building on a set of core functionalities to support organizations as they navigate new care models under health reform. More than 100 initiatives currently offer connectivity to EHRs, health summaries for continuity of care, a master patient index, and results delivery. Sixty-five are already supporting or participating in an accountable care organization (ACO). To support ACOs and other advanced payment models, organizations plan to offer alerts to providers (83), connectivity to other networks (83), patient access to their information (78), analytics (74), and image exchange (69) in the future. Ninety organizations currently use Direct, primarily for transitions of care.

KEY FINDING 5: Patient engagement remains low among organizations exchanging data.

Only thirty-one organizations currently offer patients the ability to access their information. Seventeen report that patients can provide data to the exchange, and thirty-seven report that patients can view data. Patient-reported data is accessible to providers in thirty data exchanges. Only a handful of organizations offer simple patient engagement services, such as the ability to make appointments (24), access to educational materials (26), or medication refill requests (25). Though 102 initiatives plan to offer patients access to their data, 56 have no plans to do so.

KEY FINDING 6: Patient consent for data exchange generally remains an all-or-nothing proposition.

Opt-out is the most common consent model. 109 organizations do not offer patients the ability to limit sharing of their information based on data type or source. Of those that do, allowing patients to limit the sharing of sensitive information is most common (43). In most organizations, providers remain the gatekeepers of privacy. Patients are most frequently notified that their data is available to others through the exchange by their providers (123).

KEY FINDING 7: In the last 2 years, more data exchange initiatives have become financially viable. Hospitals and payers are still expected to fund most exchange activity.

Many organizations are reporting greater revenues and have received enough revenue from participants to cover operational expenses. Revenue has grown since 2011. Among organizations responding in both 2011 and 2013, six fewer organizations are reporting revenues under \$1 million. Seventeen more are reporting revenues greater than \$1 million. Fifty-two initiatives indicated that they received sufficient revenue from participating entities to cover operating expenses, while fifty-one have not. Twenty-four took one or two years to achieve sustainability and twenty-two took three or more years. Of the fifty-one non-sustainable organizations, thirty-one receive more than 50 percent of their funding from the federal government and twenty-two report that they are an SDE. Among respondents completing the survey in both 2011 and 2013, only sixteen reported they were sustainable in 2011 and thirty-five reported they were sustainable in 2013.

Similar to past years, respondents still expect hospitals will be the most important source of funding in the future, but also expect a greater role for private payers, and a decreased role for state and federal government. Despite continued reliance on public funding by some, organizations realize the precariousness of this revenue source and are working to achieve full sustainability by offering valuable services for a fee.

Forty-nine (49) organizations derive 50 percent or more of their funding from public sources. Of these, seventeen (17) anticipate that public funding will remain their most substantial funding source in the future.

Hospitals, state/federal government, ambulatory care providers, private payers, and Medicaid are currently the most common funders of data exchange.

LOOKING AHEAD

For ten years, the eHealth Initiative has tracked the progress of health information exchange. As health data exchange initiatives evolve in 2013 and beyond, it will be critical for community stakeholders, healthcare organizations, and policymakers to address emerging challenges – particularly in light of the growing complexity of the landscape and the expected changes that will occur as a result of federal funding and support winding down. This year’s results illustrate that many challenges still need to be addressed. Three themes emerged from the survey results: interoperability concerns have not been adequately addressed; health reform is providing exchanges an opportunity to shine; and patient engagement services are still being provided infrequently.

INTEROPERABILITY CONCERNS NEED TO BE ADDRESSED

Despite the incorporation of new meaningful use policies, it is clear that interoperability issues are still stifling organizations’ ability to connect. The survey results reveal that interoperability remains a great hurdle with little relief in sight. Respondent suggestions for standardized pricing and integration solutions from vendors, “plug-and-play” functionality, use among providers of consensus-based standards, solutions that improve provider workflow, suggests that groups are turning to the private sector for change, rather than policymakers. Respondents are hopeful that vendors and providers may be able to significantly impact interoperability through pricing and integration solutions. In the next year it will be important to watch and see how vendors and providers respond to these requests.

HEALTH REFORM PROVIDES DATA EXCHANGES WITH OPPORTUNITY TO SHOW VALUE

The recent difficulties faced by the launch of insurance exchanges illustrate the problematic nature of connecting data. New health reform models and accountable care organizations require connections between extremely complex systems and analysis of large volumes of data. In response, health information exchanges are now offering more advanced services. Data exchanges are building on a set of core functionalities to support organizations as they navigate to accountable care models under health reform. Analytic services will be critical as the nation moves forward. Showing value has been a struggle for many initiatives in the past. Data exchanges now have an opportunity to demonstrate their value as vehicles for population analysis.

PATIENT ENGAGEMENT REMAINS POOR

Unfortunately, patient engagement continues to remain low among organizations exchanging data. Only a handful of organizations are offering patient engagement services. In some cases, patient engagement services are offered through provider groups and not through the data exchange. For years consumer groups have advocated for health information exchange initiatives to engage patients in the delivery of services. While this year’s survey shows that little progress has been made in this area, more research is needed to understand what is preventing organizations from offering these services. A better understanding of the landscape is needed. For example, if patient engagement services are being provided through different venues, that would help explain the lack of services. However, if financial constraints, limited resources or privacy concerns are creating barriers to patient engagement, these challenges need to be addressed head on.

In the coming year, eHealth Initiative will continue its education, research and advocacy efforts to help groups navigate the complexities of exchanging health data. More exploration of this survey data will contribute to that work. In addition, eHealth Initiative will continue to gather insights from groups “on the ground” to identify best practices and provide guidance to groups across the country.

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2013 LIST OF SURVEY RESPONDENTS

- Alabama's State HIE, One Health Record (Alabama Medicaid Agency)
- Alaska eHealth Network
- Allergy Partners, P.A.
- AOAExcel, Inc.
- Arizona Medicaid
- Arkansas Office of Health Information Technology
- Atlantic Coast Health Information Exchange
- Atrius Health
- Baptist Health South Florida
- Barbara M Saracino DO, PC
- Bronx RHIO
- Brooklyn Health Information Exchange (BHIX)
- Cabarrus Health Alliance
- Camden HIE
- Capital area health consortium
- CareAccord
- Carondelet
- Central Florida Regional Health Information Organization (CFRHIO)
- Central Illinois Health Information Exchange
- Central Oregon Health Information Exchange
- Chatham Health Link of Chatham County Safety Net Planning Council
- Chesapeake Regional Information System for our Patients (CRISP)
- Children's Health Alliance
- Children's National Medical Center - Children's Integrated Quality Network (CIQN)
- ClinicalConnect HIE
- Coastal Connect HIE
- Colorado Regional Health Information Organization (CORHIO)
- Community Health Information Collaborative
- Community Medical
- Community Partnership of Southern Arizona (CPSA)
- ConnectHealthcare
- Connecticut - HITE-CT
- ConnectVirginia
- Crescent City Beacon Community/Greater New Orleans HIE (GNOHIE)
- CT Health Information Network
- Delaware Health Informaiton Network (DHIN)
- Dignity Health
- District of Columbia Health Information Exchange
- East Tennessee Health Information Network (eTHIN)/Innovation Valley Health Information Network (Ivhin)
- East Texas Medical Center Regional Healthcare System (FirstNet HIE)
- Eden Park Pediatrics
- eHealth Network of Long Island
- Electronic Health Network, Inc.
- Electronic Medical Records Exchange-South Jersey (EMRX)
- eLINCx
- Emory Healthcare
- Florida Health Information Exchange
- Franciscan Northwest Physicians Health Network
- Genesis Health System
- Georgia Health Information Network (GaHIN)
- Gorge Health Connect, Inc
- Great Lakes Health Information Exchange
- Greater Cincinnati HealthBridge, Inc.
- Greater Dayton Area Health Information Network
- Greater Houston Healthconnect
- Group Health Cooperative
- Gulf Coast HIE
- Gundersen Health System
- Hartford HealthCare
- Hawaii Health Information Exchange
- Hawaii Island Beacon Community
- Health Information Network of Arizona
- Health Information Network of South Texas (HINSTX)
- Health Record Bank/HIE-Community Choice
- Healthcare Access San Antonia
- HealtheConnections RHIO Central New York
- HEALTHeLINK
- HealthHIE Nevada
- HealthInfoNet
- Healthix, Inc
- HealthLINC HIE
- HealthShare Bay Area
- HealthShare Exchange of Southeastern Pennsylvania, Inc.
- HealthShare Montana
- Healthy Ocala
- Henderson County Department of Public Health
- Hennepin County Medical Center
- HIE Networks
- Highmark
- Hixny
- Humana Inc.
- Huntington Hospital
- Idaho Department of Health and Welfare
- Idaho Health Data Exchange (IHDE)
- Illinois Gastroenterology Group
- Illinois Health Information Exchange (ILHIE)
- Indiana Health Information Exchange
- Indiana Health Information Technology
- Inland Empire Health Information Exchange (IEHIE)
- Inland Northwest Health Services
- Inova Health System
- Inspira Health Network
- Integrated Care Collaboration
- Interboro RHIO
- Iowa e-Health
- Jackson Community Medical Record (JCMR)
- Jefferson Health Information Exchange
- Jersey Health Connect
- Kaiser Permanente
- Kansas Department of Health and Environment
- Kansas Health Information Network
- Kentucky Health Information Exchange
- Keystone Health Information Exchange (KeyHIE)
- Latinas Contra Cancer
- Lewis and Clark Information Exchange
- Lincoln Land Health Information Exchange and Illinois Health Exchange Partners
- Los Angeles Network for Enhanced Services (LANES)
- LouHIE
- Louisiana Health Information Exchange/Louisiana Health Care Quality Forum
- Lourdes Health System

- Marana Health Center
- Maricopa County Correctional Health Services
- Marion County Public Health Dept., Indianapolis, IN
- Mass Hlway
- Medical Information Network - North Sound
- MedVirginia
- Memorial Hermann Information Exchange (MHIE)
- Michiana Health Information Network (MHIN)
- Michigan Health Connect
- Michigan Health Information Network Shared Services
- Mississippi Health Partners - MHPCConnect
- Missouri Health Connection
- MLK Community Hospital
- Montefiore
- MyHealth Access Network
- Nebraska Health Information Initiative Inc. (NeHII)
- Nevada Department of Health and Human Services Office of Health IT
- New England Healthcare Exchange (NEHEN)
- New Hampshire Health Information Organization
- New Mexico Department of Health
- New Mexico Health Information Collaborative
- New York State Department of Health
- NewYork-Presbyterian Hospital
- NJ Dept of Health
- NJ SHINE
- North Carolina Health Information Exchange
- North Carolina Healthcare Exchange (NCHEX)
- North Coast Health Information Network
- North Dakota Health Information Network
- North Shore-LIJ Health System
- North Texas Accountable Healthcare Partnership
- Northeast Valley Health Corporation
- NYU Langone Medical Center Community Connect
- Oakwood Healthcare System
- OCHIN
- Oklahoma Association of Optometric Physicians
- Oklahoma Health Information Exchange Trust
- Oklahoma Physicians Health Exchange (OPHX)
- Oklahoma State Medical Association
- OneHealthPort HIE – Washington Statewide HIE
- Orange County Partnership Regional Health Information Organization (OCPRHIO)
- PA eHealth Partnership Authority (previously PA eHealth Collaborative)
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- Paso del Norte Health Information Exchange
- PinnacleHealth System
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- ProHEALTH ACO
- Quality Health Network
- RAIN Live Oak Health Information Exchange and Telemedicine Network
- Redwood MedNet
- Rhode Island Quality Institute
- Rio Grande Valley HIE
- Rio One Health Network, Inc.
- Rochester RHIO
- SacValley MedShare
- SAFEHealth
- Salem Memorial District Hospital
- San Diego Beacon HIE
- San Joaquin Community HIE
- Santa Cruz Health Information Exchange
- Settlement Health and Medical Services
- Sharp HealthCare Health Information Exchange
- Sheffield Care Center
- Sisters of Charity - St. Mary's Hospital
- SMRTNET
- Sonora Quest Laboratories
- South Carolina Health Information Exchange (SCHIE)
- South Dakota Health Link
- Southeast Michigan Beacon Community
- Southeast Texas Health System
- Southern Tier HealthLink (STHL, Inc.)
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- State of Tennessee
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- SunCoast RHIO
- Sutter Health
- Tampa Bay RHIO
- Tenet Healthcare
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- Texas Health and Human Services Commission- Office of e-Health Coordination
- The Ohio Health Information Partnership
- Tiger Institute for Health Innovation
- Trenton Health Team
- Tulare-Kings HIE (TKHIE)
- UC Davis Health System
- UCLA Health
- UnitedHealthcare
- Upper Peninsula Health Information Exchange
- UT Southwestern
- Utah Health Information Exchange
- Vale-U-Health RHIO
- Venture-Med
- Vermont Information Technology Leaders (VITL)
- Virtua Health, Inc., owner/operator of the Virtua HIE
- Visiting Nurse Service of New York
- West Virginia Health Information Network
- Whatcom Health Information Network, LLC (HInet)
- Whittier IPA
- Wisconsin Statewide Health Information Network (WISHIN)
- WNC Data Link
- Wright State HealthLink
- Wyoming e-Health Partnership