Health Information Exchange

An Information Paper for Emergency Physicians

Draft for Comment

October 2014

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Foreword

In October 2013, the ACEP Council adopted Resolution 29(13): Support of Health Information Exchanges:

- RESOLVED, That ACEP investigate and support Health Information Exchanges;
- RESOLVED, That ACEP work with appropriate stakeholders to promote the development, implementation, and utilization of a national Health Information Exchange;
- RESOLVED, That ACEP develop an Information Paper exploring a national Health Information Exchange.

A work group was created to accomplish the third resolve, resulting in this Information Paper. The task force would like to acknowledge and thank ACEP staff, Stacie S. Jones, Dainsworth Chambers, and Diana Crowley for their tireless efforts in helping to produce this paper.

Introduction

Clinicians use health data to make decisions regarding patient care, but because patients often receive care in multiple locations, a complete record of a patient’s health information is often not available at the point of care. In no other clinical environment is this more evident or problematic than in the fast-paced, information-intensive emergency department (ED). Emergency physicians (EPs) often must make critical, time-sensitive decisions with a paucity of information, despite knowledge that additional health information may exist for their patients, but which they cannot easily access.

Health information exchange (HIE) allows clinicians to access patient health information from multiple sources across the spectrum of care, providing a more complete longitudinal record, which more accurately reflects the way most patients obtain care – across multiple providers and provider organizations. In most cases where HIE currently exists, this is limited to a particular geographical region, but the ultimate goal is to develop a nationwide health information network (NwHIN) that allows patient health information to follow them wherever they seek care across the country.

In April of 2014, the JASON advisory, which has advised the United States government on science and technology matters since 1960 released a report titled “A Robust Health Data Infrastructure” (Jason Report, 2014). This report, commonly referred to as the “JASON” report,
detailed the current landscape of health information technology (health IT) and the obstacles preventing the medical community from evolving into a fully functioning health data infrastructure. Similarly, in June of 2014, The Office of National Coordinator for Health Information Technology (ONC) released a report titled “Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure”, which details challenges, and presents three-, six- and ten-year agendas to achieve these important goals (ONC 10 Year Vision, 2014). The paper we present here does not attempt to reproduce the findings or recommendations of these reports, nor does it attempt to distill the details their detailed analyses or recommendations. Rather, this information paper explores various aspects of HIE that are relevant to emergency medicine and offers guidance to emergency physicians and ACEP in the utilization and promotion of this emerging technology.

Definitions

In 2007, Dr. Carolyn Clancy, Director of AHRQ, succinctly defined HIE as “data following the patient.” (Carolyn Clancy, 2007) Both before and since, others have proposed more formal detailed definitions. The Department of Health and Human Services current definition states “Health Information Exchange is the electronic movement of health-related information among organizations according to nationally recognized standards. The goal of health information exchange is to facilitate access to and retrieval of clinical data to provide safer, timelier, efficient, effective, equitable, patient-centered care.” (HRSA What is HIE)

Historically an HIE refers to the ability to send and receive electronic data between unaffiliated parties. For example, an independent primary care provider might access the ED record for a patient referred to him. But it can also be organized information across a region. For example, a list of all known encounters (e.g., ED visits) a patient has had with the date, location, and presenting complaint. More robust HIEs, might include clinical records, problem list, medication list, allergies, EKGs, and even radiology images. In recent years, the term HIE has also been used to refer to any sort of healthcare data repository where longitudinal records are aggregated and made available, even if only within a single organization.

The terms “RHIO” (Regional Health Information Organization) and “Health Information Exchange” (HIE) are often used interchangeably. However, an HIE is the functional and operational infrastructure, whereas a RHIO is a group of individuals or organizations with a business stake in data exchange and often are responsible for oversight or even operating the HIE.
Background & History

Health Information Exchange (HIE) has been a key goal of healthcare since the advent of the modern computer. Limited, closed exchange networks, primarily for research purposes, emerged in the late 1980's. But it was the propagation of the internet in the early 1990’s that enabled technology to extend exchange beyond institutional walls.

The 1990s saw the establishment of Community Health Management Information Systems (CHMIS) funded by grants from the Hartford Foundation to seven states and cities to implement large centralized databases for use in assessment activities and billing procedures (Vest, Gramm 2010) (Langabeer JHIM 2013) Later came establishment of community health information networks (CHINs), which were largely commercial ventures focused on cost savings associated with moving data between providers, and relied on a transactional network model that allowed each provider to maintain their own database and avoided the need to centralize data (Friedman Mitchell 1997). Both models ultimately failed due to a variety of challenges, including technical issues, including a lack of reliable, high-speed internet connections, competitive and privacy concerns, a lack of standards for integrating data from multiple sources, and a lack of financial sustainability once initial funding ran out.

In the 2000s the concept of the RHIO emerged as a platform for governance and convener of multiple, normally competing healthcare stakeholders. The Office of National Coordinator for Health Information Technology (ONC) was established in 2004 by the U.S. Department of Health and Human Services. ONC was designed to be “a resource to the entire health system to support the adoption of health information technology and the promotion of nationwide health information exchange to improve health care” (About ONC 2014) The Health Information Technology for Economic and Clinical Health (HITECH) portion of the American Recovery and Reinvestment Act (ARRA) was signed in 2009 allocating over $19 Billion to increase the use of electronic health records (EHRs) by physicians and hospitals, including more than $500 million in funding for state-level HIE (State HIE ONC 2014). Additionally, federal funding through the Beacon programs has infused 17 HIEs across the country with over $250 million. Technological advances have now enabled HIE to a point that the computational issues are no longer a barrier. As of the eHealth Initiative 2013 Survey, there are 315 HIE initiatives in the US, with increasing initiatives becoming financially viable, largely due to hospitals and payer funding (eHI Results, 2013). Among initiatives responding in both 2011 and 2013, roughly half (52) indicated they have sufficient revenue from participating entities to cover operating expenses, but 49 derive 50% or more of funding from public sources, despite the precariousness of public funding. Nevertheless, respondents to the survey expect hospitals will be the most important source of funding in the future and expect a greater role for private payers and a decreased role for state and federal government in the future.
HIE Value to EM and Healthcare in General

Patient Crossover

Patients often move among providers and hospitals, with significant patient crossover rates in emergency medicine. One study showed that 25% of patients used more than one ED and those visits composed 19% of all ED visits (Stiell Forster 2003). A similar, more recent study showed that 40% of patients with ED visits during a three-year study period had data at multiple institutions (GNYHA 2005). It is also important to consider crossover beyond ED visits, since decision making in the ED is often based on clinical data generated in other settings. Another study of all visit types found that 41% of patients had visits at multiple facilities during a 23 month study period, accounting for 68% of total encounters (Campion Vest 2013).

Information Fragmentation

These crossover visits lead to fragmentation of the patient record, with estimates from one study that information gaps exist in 32.2% of ED visits, are more common in patients with a higher severity of illness, and the missing information may be essential to care in almost 50% of cases (Stiell Forster 2003). We also know that obtaining clinical information without HIE is problematic, especially in the ED, with one study showing that 72% of emergency physicians stated that attempts to obtain outside data failed more than half the time, that on average it took more than an hour to obtain data when successful, and that despite knowing that the data exist, the majority of emergency physicians attempt to obtain the data less than ten percent of the time (Shapiro Kannry 2007). Though time consuming, in virtually every other healthcare setting there is more opportunity to use telephone and fax to assemble and organize historical healthcare information. For these reasons, HIE is perhaps most needed in the EM environment.

Presumed Benefits of Health Information Exchange and the Current Evidence

HIE intuitively holds promise to improve healthcare quality and safety by putting vital health information in the hands of clinicians, and to decrease costs and improve efficiency by reducing potentially avoidable hospital admissions and duplicate testing (Kaelber Bates 2007). However, the true value of HIE is largely unproven (ONC Robust Health Data Infrastructure). Few studies have employed rigorous methods, such as prospective randomized control trials, but there are a growing number of observational studies that support these presumed benefits.

Hospital admissions are a major driver of potential cost savings. A majority of unscheduled hospital admissions come through the ED and the paucity of information that arrives with patients often follows them into the inpatient setting. More importantly, increasing focus on “appropriate” admissions and observation status make the rapid acquisition of historical data all the more crucial to most effectively disposition patients. According to AHRQ, one in ten inpatient admissions are felt to be avoidable (Stranges Stocks 2008), and a recent study showed
that the odds of admission were 27% lower when the HIE system was accessed (Frisse Johnson 2011). The Indiana Network for Patient Care estimated a $26-per-visit reduction in charges when they had access to data from another hospital (Overhage Dexter 2002). A more global analysis estimated with 113.9 million ED visits per year this would extrapolate to savings of $570M to $2.9 billion in emergency care alone (Shapiro Kannry 2006).

Additional cost savings are presumed to take place through a reduction in potentially avoidable duplicate testing. A host of studies suggest likely reductions in imaging, laboratory and other studies that could have a significant impact on cost of emergency care (Lammers Alder-Milsten 2014) (Hebel Middleton 2012) (Bailey Pope 2013) (Frisse Johnson 2011) (Carr Gilman 2014).

There have also been some large, formal, expert consensus studies published, which estimated the cost of a national health information network at $156 billion in 2015, only 2% of health care spending over 5 years (Kaushal Blumenthal 2005). The financial savings in healthcare costs for having a national HIE was estimated at $78 billion per year (Walker Pan 2005).

**Primary vs. secondary use cases**

Health information exchange is most often implemented for the primary clinical use of an individual provider at the bedside seeking information from outside sources for the care of an individual patient. The technical infrastructure built to support this primary clinical use may be substantial, and the amount of data in some of the larger HIEs may comprise millions of unique patients.

Secondary uses of HIE data and infrastructure, which pertain to any use beyond that for the primarily intended clinical care (Safran Bloomrosen 2007), are now becoming more commonplace. These secondary uses include care management (Moore Shapiro 2012), quality measurement and improvement (Shapiro Johnson 2013), population management (Shapiro Mostashari 2011), public health (Merrill Deegan 2013), (Shapiro Genes 2010), research (Finnell Overhage 2003) and others (Selke 2014).

HIE networks now provide something that has never been previously available: a real-time community-wide clinical data set. In the past, these types of activities would have been limited to the data available from individual organizations, but we know that patients do not confine themselves to a single provider organization or its affiliates. Patients often seek care at a variety of organizations within a region (Finnell Overhage 2003), (Finnell OVerhage 2011), (Grinspan Abramson 2013) leading to fragmentation of their medical information (Bourgeois Olson 2010), (Stiell Forster 2003), (Smith Araya-Guerra 2005) Administrative data have been used in the past to perform retrospective analyses across entire regions, but these data often are delayed by months or years, (SPARCS NY) may employ sampling, (Shapiro Onyile 2011) and may lack the clinical detail that an HIE has, making them unsuitable for many of these secondary uses. We
have only just begun to explore the possibilities for secondary uses of HIE data, and these uses may prove even more valuable in the long run than the primary use case.

**Increased Value of HIE on a National Scale**

As its name suggests, HIE created by a *regional* health information organization, or “RHIO”, is typically limited to a region or local area. Most individuals tend to receive health care within one region, but exceptions occur when unanticipated care is necessary during travel, when a patient moves due to choice or during a natural disaster such as Hurricane Katrina, or with referrals into large centers for specialized care (Onyile Kuperman 2013). HIE access during these geographically distant transitions in care can ensure that important information is available to the clinician, and that care continuity exists when the patient return home. HIE has increased value with aggregation of health information into larger and larger networks to support these episodes.

The greater value of higher levels of HIE data aggregation also extends beyond the primary clinical use case, and affects many secondary use cases, including public health and quality measurement. Examples relevant to emergency medicine include more accurate 72-hr ED returns and frequent ED user identification using a HIE data instead of that from a single hospital (Shapiro Onyile 2011) (Shapiro Johnson 2013).

As benefits from a nationwide health information network (NwHIN, formerly known as NHIN) are expected to benefit all payers and not just the government, the federal government funded a group to generate a framework for national HIE (NwHIN ONC). The NwHIN began in 2005, and has developed and promulgated policies and standards that are used by a variety of regional HIEs, but we are still a long way from realizing true, fully integrated nationwide health information exchange.
**HIE Market Evolution**

The HIE market has evolved rapidly, and has been quite fluid in recent years, with many mergers and acquisitions among HIEs and HIE platform vendors. The landscape remains somewhat immature with respect to installed-base, and financial viability of vendors. The current market can be broken down into two distinct sectors, each with its own unique needs and requirements.

**Public HIEs**, funded by federal, state, and local governments, typically provide HIE services across a geographical region or state. Many have struggled to define a sustainable business model and wean themselves from diminishing start-up funds. This has created a “churn and burn” phenomenon among some HIEs, where millions were spent on planning, development and deployment, with no plan to provide ongoing funding for expansion of operations, or promotion of adoption.

**Private HIEs** are typically formed by large provider organizations or integrated delivery networks (IDN) as they merge with one another and purchase practices to expand their networks. This has been largely motivated by emerging payment reform models. These models require provider organizations to take on risk and allow them to share in savings by coordinating care across other provider organizations in their region to improve quality and reduce costs. The private HIE allows provider organizations to extend their reach into the community for care coordination, and has the added benefit of driving referrals and testing back to the main hospital. In this case, there is a direct return on investment (ROI) for the provider organization that might not be as apparent with participation in a public HIE. Also, private HIEs usually have less complex governance structures, and can avoid many of the competitive issues that may arise when public HIE try to convene otherwise unaffiliated providers organizations.

**Three Categories of HIE Vendors** have generally emerged (2012 HIE Market Report)

1. **EHR Vendors**: A few large EHR vendors have created or adapted their EMR toward an HIE solution. While some claim multi-stakeholder and multi-EHR clinical data sharing, many fall short. They are generally best suited to a single EHR platform environment, which in reality function as a mere extension of the EMR. One might characterize this as a “tethered HIE”.

2. **Service Providers**: Companies that already have robust data networks (e.g. AT&T, Verizon, etc.) have moved toward providing HIE connectivity in partnership with HIE industry stakeholders. Since a large part of HIE cost is in linking multiple stakeholders, these network platform companies can bring resources and expertise lacking in smaller companies. However, healthcare data is quite different than data types in other
industries, as are the issues surrounding data sharing, and it remains to be seen if any of them will find success.

3. **HIE Platform Vendors**: These are HIE technology providers that have largely developed software platforms from the ground up to provide the majority of requisite HIE capabilities. They usually have dedicated sales, marketing, and partnerships to support their HIE business. To date, this group has dominated the HIE market.

One additional category are home grown HIEs, which until recently were the only option. But few if any organizations have the resources and experience to build their own HIE platform, so it is doubtful many new homegrown HIEs will emerge going forward.

### Different Types of HIE

According to the Office of the National Coordinator for Health Information Technology (ONC), currently there are three key forms of health information exchanges (Williams Mostashari 2012):

1. **DIRECTED EXCHANGE**: ability to send and receive secure information electronically between care providers to support coordinated care

   Directed exchange is used between providers to easily and securely share identifiable patient information such as laboratory orders and results, patient referrals, or discharge summaries. This information is sent over the internet in an encrypted, secure, and reliable way based on standards set forth by the federal government (see “Messaging Services” below, under “Technical Overview” for more detail) and is commonly compared to sending a secured email. This form of information exchange is often enabled between two EHR implementations and enables care coordination, and transitions of care between providers in different care settings.

2. **QUERY-BASED EXCHANGE**: ability for providers to find and/or request information on a patient from other providers

   Query-based exchange is used by providers to search for and discover clinical data sources from outside of the treating providers practice environment on a particular patient. This type of exchange is used when delivering unscheduled care such as an ED visit, and is the primary focus of this paper.

3. **CONSUMER-MEDIATED EXCHANGE**: ability for patients to aggregate and control the use of their health information among providers

   Consumer-mediated exchange provides patients with online access to their health information, allowing management of their healthcare in a similar fashion to managing finances through online banking. When in control of their own health information,
patients can actively participate in their care coordination by: furnishing other providers with their health information, identifying and correcting wrong or missing health information, identifying and correcting incorrect billing information, and tracking and monitoring their own health (ONC What is HIE)

**Architectural Overview**

HIEs generally fall into one of three basic architectures. One is the **centralized model**, which employs a monolithic database that includes data from all stakeholder organizations. The next is the **federated model**, where each stakeholder organization maintains either physical or virtual “edge” servers, that allow them to maintain stewardship over the data they contribute. In the case of having a physical edge server that they maintain behind their own firewall, they have the added advantage of being able to literally pull the plug on their server if serious issues ever arise. In the case of a federated architecture, each edge server contains a common data structure, allowing the network of edge servers to function as a single, distributed database from functional standpoint. The third is the **hybrid model** which is a combination of both federated and centralized functions.

**Technical Overview**

The following are ten essential elements of fully functioning Health Information Exchange. A basic understanding of these technical elements is integral to the discussion of HIEs. It facilitates consensus building within the community and aligns goals.

**Master Patient Index (MPI)**

A Master Patient Index (MPI) is a fundamental component of an HIE. It includes a database of patient demographic information and a matching engine that employs various statistical techniques with probabilistic and deterministic algorithms to assure accurate identification of patients across the exchange as unique individuals (Grannis Overhage 2003) (Grannis Overhage 2002). As an HIE receives patient data from multiple unaffiliated data sources, these data are sent to a central MPI that allows a longitudinal view of the patients health information to be constructed across multiple data sources. With the technology available today, the CEOs of several sophisticated HIEs (Maine HealthInfoNet, Colorado Regional Health Information Organization, Michiana Health Information Network) have reported over 99% confidence level with the MPI matching tools in use (F. Chan, MPH, personal communication, September 1, 2014).
Record Locator Service (RLS)
A Record Locator Service (RLS) is a function maintained by the HIE that maps available records for a single patient across different locations or data sources. When a user requests information about a patient, the RLS locates data wherever they reside across various edge servers and creates pointers to the data elements so that they can be displayed in a consolidated manor to end users through a clinical portal, an EMR or through some other means.

Clinical Data Repository (CDR)
The meaning of the term Clinical Data Repository (CDR) may vary according to the data sharing model of the HIE, as described in the architectural overview section. If an HIE employs a centralized data model, the CDR refers to the aggregated data from all contributors on the centralized database. If an HIE employs either the Federated or Hybrid data model, a CDR represents the distributed database across all edge servers in the HIE.

With the current technology, a sophisticated HIE is able to provide a virtual CDR to its end users regardless of the data sharing model of the HIE. Using a robust MPI to link the different identifiers used by different providers, and comprehensive RLS that provides the linkage to locate, retrieve and present all pertinent records upon request, the end user’s access to medical records from different sources are not affected by how the data are being stored.

Access and Authorization
With the advent of HIPAA in 1996, which was further refined by the Omnibus rule mandated by the HITECH Act of 2009, healthcare organizations are required to implement policies and procedures to safeguard patient privacy, implement security and limit access to medical information to the minimum necessary to any one provider treating the patient. The stringent patient privacy rules in many ways complicate efforts to promote exchange of health information among healthcare organizations. Through the funding provided by the ARRA of 2009, the Office of National Coordination of Health IT (ONC) supported the effort in many states to develop the legal and policy framework that reconciled the need to protect patient privacy while minimizing the impact to sharing of medical information. Participation authorization and role-based access are two of the most important outcome that HIEs have come up with.

As users of HIEs have the ability to access comprehensive and meaningful information about patients, the risk of improper access, or privacy breach, increase significantly. The governance of most HIEs typically includes policies and procedures to screen and verify the identity of potential users to ensure that only eligible professionals in good standing with the Federal (e.g., CMS) and State Licensure Board are allowed access to medical information hosted by the HIE. The amount of medical information that the user is allowed to access is then determined based
on the role of the user. For example, an ED Physician is allowed full access to all information available on the HIE, whereas a practice manager in a clinic is allowed to access only patients who are associated with the clinic; and extra steps are required for a practice manager to assert a relation with a new patient and access the patient’s records through the HIE.

**Auditing and Logging**

As part of safeguarding the privacy of patients, the HIPAA/HITECH rules also stipulated that HIPAA Covered Entities (CEs) and Business Associates (BAs) of the CE maintain comprehensive records so that upon request of a patient or the patient’s legal representative, complete records can be produced by the CEs and BAs to account for the date, time, person(s) and usage of the patient’s medical information.

As BAs to Health Systems, Hospitals and Clinics, HIEs must manage comprehensive programs and tools that record all activities of users and produce the audit trail reports upon request. Designated officials at HIEs often also conduct periodic, random audits looking for unusual activities to identify potential inappropriate access of protected health information (PHI) by its users.

**Transport and Content Standards**

The ONC, through ARRA funding, has also launched several initiatives to encourage adoption of health IT to facilitate implementation of standards that make health data interoperability feasible. Unstructured data is not easily computable, though improvements in natural language processing may change that. Generally, narrative, unstructured data in an HIE can only be displayed as text, and cannot be easily used for other purposes such as reporting or clinical decision support. Similarly, structured data that does not adhere to standards cannot be easily aggregated or trended across multiple provider organizations in an HIE. For example if one site sends “potassium” results and another sends “serum pot” results, and neither is mapped to a standard like LOINC, there will be no way to place the results in the same place in the HIE’s data structure, or to trend potassium results for the patient over time. Only by adoption of standards can systems synthesize and appropriately present information in a customized fashion. Some of the standards used in healthcare include Health Level 7 (HL7) which is a messaging standard that allows data to be structured in a standardized way for sending between systems includes the CCD (Continuity of Care Document — an XML document standard that can produce a standardized patient care summary that is both human- and machine-readable), DICOM (an imaging standard), LOINC (a laboratory data standard mentioned above), and SNOMED-CT (a clinical terms standards).
Messaging Services

Recognizing the complexity of implementing interoperability standards needed to have meaningful sharing of medical data, in 2010, the ONC decided to adopt the Direct standard that allows for secure communications between health care providers. At its core, the Direct standard is similar to secure email and state-of-art encryption technology. To ensure that participants using Direct can confidently share protected health information (PHI) with each other, the secure exchange is mediated by a health information service provider (HISP). The HISP serves as the certificate authority (CA), that authenticates the security certificates used by Direct participants to encrypt their email messages, and as the registration authority (RA), who verifies that participants are legitimate healthcare professionals, and authorizes their secure exchange of PHI.

Between 2010 and 2013, all HIEs who receive ONC funding were required to implement Direct secure messaging (DSM) as part of their cooperative agreement, and serve as a HISP to build trust among participants. In 2012, CMS also included use of Direct technology to share transition of care documents when patients are transitioned from one care setting to another as one of the core requirements for eligible hospitals, health systems and healthcare providers to receive Meaningful Use stage two incentives. In 2013, the ONC further extended the Direct standard by specifying that external data representation standard (XDR) be used among domains within the same HISP.

The net effect of Direct + XDR (sometimes also referred to as SOAP + XDR) is to assure end-to-end secure transport of PHI between disparate provider organizations, often mediated by an HIE.

User Interface

The User Interface is the name given to the screen views and the interaction patterns between the user and the computer and the user (e.g., the physician). It includes the screens, the workflow, the keystrokes, the buttons, etc. Since vast amounts of data from disparate sources are being created in HIE, it is important for the user to be able to access the data in an orderly manner. The user must be able to make treatment decisions without being mired in information overload. This can only be accomplished by an iterative development process that integrates user feedback to define and properly implement user requirements, which will likely differ significantly from one medical specialty to the next. Ultimately the vast trove of data must be distilled down so that the most important data are presented the most prominently in the user interface, and are the easiest and quickest to find.
System Interfaces
System interfaces refer to the communication between machines, and in an HIE environment, this usually means the link between ancillary systems (e.g. laboratory, radiology, etc.) or an interface engine at participating provider organizations and the HIE’s centralized server or edge server. These interfaces generally send HL7 2.X structured data, or as is becoming increasingly common, CCD-based XML documents.

Consent Management
As stipulated by HIPAA and the HITECH Omnibus Rule, patients have the right to request to opt-out of HIE participation, so that their medical records would not be shared with another health care provider. While HIPAA also allows for exception to covered entities to share medical records and PHI for treatment, payment and healthcare operations, the exceptions do not apply to HIEs, who are business associates to covered entities. States in the US adopt either an opt-in or an opt-out model of patient-consent. When a state adopts the opt-in model, HIEs in the State must obtain patient consent before PHI can be shared. HIEs must also have procedures that allow the patient to revoke his or her consent.

When a state adopts the opt-out model, HIEs in the state can share PHI with participants without specific patient consent. However, HIEs in states that adopt the opt-out model must implement procedures that allow a patient, or the patient’s legal representative, to opt-out of sharing information. HIEs must also then implement procedures that allow the patient to “opt-back-in.”

Challenges to HIE Success
The 2014 “JASON” report detailed the current landscape of health information technology (health IT) and the obstacles preventing the medical community from evolving into a fully functioning health data infrastructure. This paper does not attempt to reproduce the findings or recommendations of the JASON report, nor does it attempt to distill the details of this report. Rather, this paper’s purpose is to put forward an independent review of health information exchange.

Competitive Concerns
Although health data is owned by the patient, many provider organizations consider their stewardship and control of the patient data they generate to be a business asset and may be reluctant to share data with their competitors. Provider organizations may be concerned that if data flow freely, patients may have less reason to remain loyal, or that data might be used by competitors to create a strategic market advantage. It has been historically difficult to promote HIE under these common conditions, however, having a trusted entity, such as a regional
hospital organization, public health authority or state governmental entity act as convener, and
a governance structure with strict policies regarding appropriate data use has led to many
successes.

Leadership and Governance
Until recently, there was often an absence of leadership models for the advancement of HIE,
with no clearly recognized organization in some regions to convene stakeholders. Now, with
the federally-funded State Cooperative Agreement program through the HITECH portion of the
ARRA, which supported the development of state-level entities to advance HIE, all 50 states
have some form of HIE services (State HIE ONC 2014). However, many of these efforts are still
in pilot stages or only operating at a regional level.

Data Quality
Data from electronic health records are a common source for quality measurement and
reporting, and for this reason the need for a systematic approach to assessment and reporting
of electronic data quality has been recently described (DQC White Paper 2012) (Kahn Raebel
2012) (Weiskopf Weng 2013) (Garge Kuperman 2014) (Fleischman Lowry). Problems in small
data (e.g. data entry errors in a patients electronic record, or coding errors with a laboratory
test being mapped to the wrong standard code), become exponentially larger with increasing
levels of data aggregation, leading to big data problems as we approach the level of a
nationwide health information network. Without significant effort being put forward to
improve and ensure the quality of electronic data at the local level, the data that enters a
health information exchange may be of limited value (Health Affairs Brief: Interoperability
2014).

Standards
Although there is substantial work being conducted through support of state and federal
governments, including the Healthcare Information Technology Standards Panel
(HITSP), a cooperative partnership between the public and private sectors formed
for the purpose of harmonizing and integrating standards to meet clinical and
business needs HIE, there is still much work that needs to be done, and many HIE
have not adopted or implemented recognized standards despite these efforts.
Without adoption of common standards, HIE will remain limited in scope and
functionality.

Patient Matching
Because there is no unique patient identifier in the United States, the MPI systems are used to
match unique patients based on demographic information, across different provider
organizations and care settings. However, performance of matching algorithms can be an issue.
A major challenge is tuning the matching algorithms to a low false-positive rate (to avoid data from one patient being inappropriately comingled with the data of another patient – creating the potential for serious patient safety problems), but this is often at the expense of creating a higher false-negative rate (which would fail to link records that should be linked, making a patient data inaccessible across sites). Some have called for the creation of a national health ID number which would largely solve this problem, though creation of this would likely be an uphill battle politically (Fernandes 2008).

**Usability and Functionality**

As discussed above in the “Technical Overview” section, poorly designed user interfaces that do not followed long supported usability heuristics (Nielsen 1994b), and lack of important functionality, such as the ability to trend common results across sites and time are major barriers to successful HIE implementation. It is imperative that these issues be addressed early on in the design of an HIE by involving end users in the process. It is important the emergency physicians know enough about HIE and be given the opportunity to provide input in order to advocate for their specific needs.

**Workflow**

Similarly, lack of proper workflow integration and optimization is a key barrier to HIE success (Thorn Carter 2014). Optimal workflow integration can be achieved through several methods. The first is to create one-click access to the HIE through context management. In this scenario, a link to the HIE is placed in the user’s EHR, allowing automatic launching of an HIE portal window from within an individual patient EHR record, passing their login credentials and the patients information, obviating the need for a user login or patient lookup. Another form of workflow integration is to push an alert to clinicians, letting them know that external data exists in the HIE. This can be done through highlighting the patient on the tracking monitor or placing a flag in the EHR. A third way to optimize workflow integration is through integrating HIE patient data directly into the EHR. This can be done by importing CCDs created by the HIE into the EHR record. This can provide a seamless experience for the user, where they are always viewing results in their familiar EHR user interface, but in these cases it is important the data’s origin is made known to differentiate internal from external data sources.

**Adoption and Usage**

A lack of standards, problems with patient matching, poor usability and functionality, and lack of workflow optimization all lead to significant problems with adoption and usage (Genes Shapiro 2011) (Rudin Volk 2011). If a provider goes to look for information in an HIE that should be there, and repeatedly does not find it because of a high false negative matching rate, that provider is not likely to continue using the HIE. Similarly, if the provider knows that it will take a long time to sort through volumes of poorly organized data, that can not be organized by type
or trended over time, that provider will be less likely to use the HIE. When there are too many clicks for a provider to navigate through a system, adoption rate and usage are often quite low, but are increased when the information is complete and conveyed through a user-friendly interface (Halamka 2013).

Technology and Vendors
Although technological capability is not a true barrier, the implementation of technology and execution of use cases by HIEs and their vendors remain a major barrier. Lack of standard implementation approaches and best practices, and lack of vendors with significant experience or broad implementation bases has made many HIE implementation costly, and at times doomed to failure.

Privacy and Security
Security refers to how an organization protects its data from breaches, and the use of auditing and exception reports looking for unusual patterns of use (e.g. looking up of consecutive medical record numbers). Privacy refers to which users should be able to view which types of data on which patients, and addresses potential issues around special classes of protected health information (e.g. psychiatric, HIV, drug treatment, etc.). This is managed through implementation of consent policies, and role-based policies to manage authorization and access, which are discussed above. HIPAA allows clinical data to be shared electronically among providers for treatment purposes, however, as discussed above, states may adopt a variety of consent and privacy policies regarding HIE, and state laws can supersede HIPAA. This has led to a high degree of variability across states, and is a major barrier to the realization of a true nationwide HIE.

Medical Legal Implications
The typical electronic health record allows access to much more data than a single provider or team can fully review in the course of a patient encounter. This problem is further compounded by HIE allowing aggregation of data from multiple EHRs. This is especially true for patients with complex histories and emergency conditions. To our knowledge, there is no case law involving a provider being held liable for failure to review all of the data available through an HIE, but the concern for this possibility persists among some providers. It is imperative that a standard of care and best practices be established for what an emergency physician should access, and on which patients. It is unrealistic that this standard of care require a full review of all records on every patient. It is also imperative that systems be built that bring the most pertinent data within easy reach of the provider in easily digestible format. This may include summaries corresponding to the patient’s past history, current complaints, or their age. It is the duty of the physician is to make the best medical decision possible using the information
tools at their disposal and without careful consideration of this issue, advocacy by physician
groups, and possibly legal protections, there may be continued resistance among some
providers to HIE adoption.

**Business and Sustainability**

Determining which stakeholders in the healthcare system accrue benefit from HIE has been
difficult (i.e. provider, patient, payer, employer, government, etc.). This also varies depending
on the particular region. In a region with a single dominant provider or payer, the business case
might become clear, and either stakeholder might be willing to provide funding for an HIE. In
regions that are more competitive, and the market more fragmented, finding willing
participants to fund HIE has proven more challenging. Although there are some noteworthy
successes (McDonald Overhage 2005), there are also numerous failures, some highly publicized
(Frohlich Karp 2007). As mentioned previously, many HIEs were started with funding through
state and federal grant programs, but lack of a sustainable business plan to continue
development and long-term operations remains one of the greatest barriers to many HIE
efforts across the country (Alder-Milstein Bates 2013).

**HIE Case Studies: Successes and Failures**

**Indianapolis Network for Patient Care (INPC) (Indiana HIE), est 1995:** INPC is arguably the most successful and mature HIE to date (Biondich Grannis 2004). With innovative
leadership from the Indiana University School of Medicine and the Regenstrief Institute, INPC
managed to succeed where many to follow would fail.

The network includes information from encounters covering over 90% of care provided at
hospitals in the Indianapolis area. With over a million secure transactions daily and 14.7 million
unique patients, it contains more than 4.7 billion pieces of clinical data, 80 million radiology
images, 118 million text reports, and 750,000 EKG readings, plus discharge summaries,
operative notes, pathology reports and medication records, among other information. A key to
its success are patient abstracts and the ability to query results, trend and graph data, print
round reports, and link to knowledge sources.

As successful as INPC has been, its scope is limited to the greater Indianapolis area, roughly 6
million people or 1.9% of the US population.

**Maine’s HealthInfoNet (HIN) (About HealthInfoNet), est. 2006:** Going live in 2009,
HIN now contains records for nearly all Maine residents and is connected to the majority of
health care facilities in Maine, e.g. hospitals, physician practices, federally qualified health
centers, long-term care and home health facilities, behavioral health providers, and
independent laboratories. The organization is funded through fees charged for products and
services as well as state and federal grants or contracts. About 1 million individuals (79% of Maine’s population) have a HealthInfoNet record with only about 1% having opted-out. 35% of individuals have information from 2 or more connected facilities. 1/3 of Maine’s hospitals and over 240 ambulatory practices are connected with nearly 7000 clinicians with access to the system.

**Wisconsin Health Information Exchange (WHIE),** est 2005: The WHIE launched its “ED Linking Project” in 2007, with clinical use beginning in 2008. At its peak, the WHIE included 22 institutions across five different health systems. It was one of the first HIEs to show demonstrable economic benefit with an estimated $29 per ED visit queried savings (Pemble 2011) and show that fixed annual subscriptions can be a successful business model for HIEs (Sridhar Brennan 2012). Yet, despite its many virtues, the WHIE ultimately fell victim to untoward consequences of the HITECH Act that created a yet to be realized opportunity for a publically funded statewide Wisconsin Statewide Health Information Network (WISHIN), est. 2011. The WHIE lost local private funding support once the promise of public funding for a statewide HIE was announced. Three years after inception, WISHIN has yet to share its first data as of this writing.

**Santa Barbara County Care Data Exchange (SBCCDE),** est. 1999 (Miller Bradley 2007): SBCCDE was one of the most ambitious and publicized HIE projects. The lessons learned from SBCCDE helped shape much of federal health IT policy, according to former National HIT Coordinator David Brailer, MD, who led the Santa Barbara initiative before being appointed to his federal post. It began with a $10 million grant from the California HealthCare Foundation to a publically traded company CareSciences (later acquired by Quovadx). Yet, after 8 long years it never succeeded in providing any meaningful data exchange. According to a Health Affairs article (Miller Bradley HA 2007), lack of a compelling "value proposition" for potential investors was the main cause of the project’s demise. But other reports say it was liability concerns by Quovadx after it discovered confidential health information related to HIV had inappropriately been transmitted. It ceased operations in December 2006 after funding was withdrawn, more than eight years after its inception.

**Recommendations**

ACEP should advocate for and adopt policies that support a system of effective national HIE that can rapidly and efficiently yield useful clinical information to clinicians, especially in the emergency care setting. These policies should include support for emergency physician access to all relevant patient information, in properly summarized understandable form in order to provide safe, efficient and effective emergency care.

The HIE Workgroup recommends the following actions:
1. ACEP should recognize and promote the tremendous opportunity and need for HIE in emergency care, focusing on cost, quality, and safety.

2. All stakeholders should recognize and promote that the full value of healthcare data is only truly realized once these data are aggregated, automatically analyzed/organized and relevant information readily available to providers and, where appropriate, to patients.

3. ACEP should seek to educate stakeholders, public officials, the media, etc. on the value of HIE and to dispel myths about HIE and data sharing. This would include a better balance between privacy and availability of critical data.

4. ACEP should support a set of standards for exchange of health information through federal legislative and regulatory efforts. This effort should include:
   a. Developing and prioritizing data elements relevant to emergency care
   b. Prioritizing EM specific user interface and workflow requirements
   c. Developing care standards and protocols for effective integration of HIE in emergency departments

5. ACEP should support efforts to improve patient matching both regionally and nationally, including the consideration of a national patient healthcare identifier.

6. ACEP should support opt-out HIE (vs opt-in) and seek removal of limitations on types of data (e.g., psychiatric & certain diseases).

7. HIEs should report adoption and usage data not simply operational data since this allows more accurate measurement of effectiveness and value.

8. ACEP should promote federal and state level HIE funding for infrastructure development, research, and HIE operational sustainability.

9. ACEP should promote well defined, comprehensive, and highly summarized data within HIE.

10. ACEP should develop a policy on the standard of care for review and inclusion of HIE data in the EHR in the emergency care setting, potentially including
    a. Clinicians should review the HIE for appropriate patients where workflow optimization (e.g., one-click access) brings HIE information to view.
    b. Pertinent HIE data, including consent status, should be available within the EHR user interface rather than requiring a separate clinician request or action.
    c. Promote liability protection related to HIE use, to include inadvertent failure to review all available data, action taken due to missing or inaccurate data, inadvertent access of the wrong patient, etc.

11. ACEP should support local chapters participating with HIEs to provide appropriate data for emergency physicians, and should consider conducting pilot programs with HIEs to improve the focus on emergency care.

12. ACEP should assign and support representatives to participate in ONC-related activities.

**Acronyms and Glossary**

**Business Associates Agreement (BAA)** A business associate agreement is a contract between a covered entity and an entity conducting functions of behalf of a covered entity that is used to protect personal
health information (PHI) in accordance with HIPAA guidelines. (Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule, 2003)

Covered entity Under the HIPAA Privacy Rule, a covered entity is an organization or individual that handles personal health information. Covered entities include providers, health plans, and clearinghouses (Shortliffe 2013).

Electronic Health Record (EHR) A repository of electronically maintained information about an individual’s lifetime health status and health care, stored such that it can serve the multiple legitimate users of the record (Shortliffe 2013).

Electronic Medical Record (EMR) The electronic record documenting a patient’s care in a provider organization such as a hospital or a physician’s office. Often used interchangeably with Electronic Health Record (EHR), although EHRs refer more typically to an individual’s lifetime health status and care rather than the set of particular organizationally based experiences (Shortliffe 2013).

Health Information exchange (HIE) The process of moving health information electronically among disparate health care organizations for clinical care and other purposes; or an organization that is dedicated to providing health information exchange. (Shortliffe 2013)

Health Information Technology (HIT) The use of computers and communications technology in healthcare and public health settings (Shortliffe 2013).

Health Record Bank (HRB) An independent organization that provides a secure electronic repository for storing and maintaining an individual’s lifetime health and medical records from multiple sources and assuring that the individual always has complete control over who accesses their information (Shortliffe 2013).

Personal health record (PHR) A collection of information about an individual’s health status and health care that is maintained by the individual (rather than by a health care provider); the data may be entered directly by the patient, captured from a sensing device, or transferred from a laboratory or health care provider. It may include medical information from several independent provider organizations, and may also have health and well-being information (Shortliffe 2013).

Protected Health Information (PHI) Individually identifiable health information that is transmitted or maintained in any form or medium (electronic, oral, or paper) by a covered entity or its business associates, excluding certain educational and employment records. (Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule, 2003)
Regional Health Information Organization (RHIO) A community-wide, multistakeholder organization that utilizes information technology to make more complete patient information and decision support available to authorized users when and where needed. (Shortliffe 2013).

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