



# **A HIMSS Guide to Participating in a Health Information Exchange**

**HIMSS Healthcare Information Exchange  
HIE Guide Work Group White Paper**

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## Table of Contents

<b>Section 1 – Introduction</b> .....	<b>5</b>
Target Audience(s).....	5
How to Use This Guide.....	5
<b>Section 2 – Defining the HIE</b> .....	<b>6</b>
What is an HIE? .....	6
The National Perspective .....	7
HIE Commonly Offered Services .....	8
HIE Content Examples.....	13
<b>Section 3 - Different Health Information Exchange (HIE) Models</b> .....	<b>14</b>
The Centralized Model.....	15
The Decentralized or Federated Model.....	17
The Hybrid Model.....	19
The Health Record Banking Model .....	20
International Models .....	21
The 2009 HIMSS International HIE white paper provides additional information on health information exchange activities occurring in other countries. Find this white paper at: <a href="http://www.himss.org/content/files/Natl_Internatl_White_Paper051309.pdf">http://www.himss.org/content/files/Natl_Internatl_White_Paper051309.pdf</a> .....	22
State-led versus community-based Models.....	22
Industry Drivers .....	23
The Business Models .....	23
<b>Section 4 - Common Technology Approaches and Data Standards</b> .....	<b>24</b>
Technology Building Blocks .....	24
Network Infrastructure.....	24
HIE Applications.....	25
Middleware .....	25
Integration Engine .....	25
Patient Matching Algorithms and Enterprise Master Person Index (EMPI) .....	25
Proprietary Products .....	26
Open Source Products.....	27
Record Locator Service.....	27
Provider Matching.....	28
Applicable Standards .....	29
About Standards.....	29
Core Standards.....	29
Standards for Transactions .....	30
<b>Section 5 - Evaluating a potential HIE opportunity</b> .....	<b>32</b>
Understanding the Goals and Philosophy of the HIE .....	33
Understanding to what your organization will need to commit by participating in an HIE .....	34
Understanding the prevalence of nationally-accepted standards .....	34
Understanding the value for users of the HIE information and data .....	34
Understanding the Economics and Financial Sustainability of the HIE .....	35
Understanding Risks .....	36
Understanding Applicable Regulations .....	37
Understanding Leadership and Governance .....	37
Understanding the HIE’s Maturity.....	38
<b>Section 6 – Conclusion – Making Your Decision</b> .....	<b>39</b>

<b>Appendix A – HIE Evaluation Checklist.....</b>	<b>41</b>
<b>Appendix B – Understanding Applicable Regulations.....</b>	<b>47</b>
HIPAA .....	47
Privacy Rule.....	47
Security Rule .....	48
American Recovery and Reinvestment Act .....	48
Business Associates .....	48
Marketing/Sale of PHI.....	49
Electronic Health Records .....	49
Disclosures.....	49
Breach Notification.....	49
Education Programs.....	49
Enforcement/Penalties .....	49
State Laws .....	49
<b>Appendix C – SandlotConnect® Case Study .....</b>	<b>51</b>
Background.....	51
Regional Business Environment & Demographics .....	51
Factors Aligning & Driving Local Stakeholders .....	51
Operations .....	51
Vision, Mission, and Guiding Principles.....	51
Governance and Management Structure.....	52
Service Offerings.....	53
Technical Architecture.....	53
Unique Operational Considerations.....	53
Sustainability.....	53
Business Model Summary .....	53
Realized Benefits .....	54
<b>Appendix D – Indiana HIE Case Study .....</b>	<b>55</b>
Background .....	55
Regional Business Environment & Demographics .....	55
Factors Aligning & Driving Local Stakeholders .....	55
Operations .....	55
Vision, Mission, and Guiding Principles.....	55
Governance and Management Structure.....	56
Service Offerings.....	56
Technical Architecture.....	56
Sustainability.....	56
Business Model Summary .....	56
Realized Benefits .....	57
<b>Appendix E – Louisville Health Information Exchange, Inc. (LouHIE) Case Study.....</b>	<b>58</b>
Background .....	58
Regional Business Environment & Demographics .....	58
Factors Aligning & Driving Local Stakeholders .....	58
Operations .....	59
Vision, Mission, and Guiding Principles.....	59
Governance and Management Structure.....	59
Service Offerings.....	60
Technical Architecture.....	61
Sustainability.....	64

Business Model Summary .....	64
Marketing Plan.....	64
Risk Management .....	66
Realized Benefits.....	69
<b>Appendix F – Glossary .....</b>	<b>71</b>
<b>Acknowledgements .....</b>	<b>83</b>

## Section 1 – Introduction

The objective of this guide is to provide individual stakeholders with a *tool* that will assist in the decision making process of whether to join a Health Information Exchange. For the beginner, the tool will provide some basic background information that most people should understand before engaging with a Health Information Exchange. Building upon the background information presented in this paper, a list of questions is provided that a stakeholder may use as a guide to facilitate exploring their participation in a Health Information Exchange. The suggested questions are intended to provide a clear cut decision process to guide the organization's choices. This guide is not intended to be a comprehensive guide nor will it lead a stakeholder in making the right choice.

Participating in a local Health Information Exchange is an important step for an organization that wants to make a difference in health care and establish the foundation for improving the patient safety, quality of care, and decreasing the cost of health related activities. There are many published reports that cite statistics on patients that die every year due to missing or inadequate information at the point of care. Other industries have placed importance on obtaining reliable information used in decision making. This reliance on information has transformed many other industries in the past 15 years. Healthcare has been slow to transform in that the information needed is in so many disparate locations. A Health Information Exchange attempts to pull the disparate information together so that the information becomes more useful. This is hopefully one element of a sustainable model that will help to transform the healthcare industry.

### *Target Audience(s)*

This guide is intended to be used by any type of stakeholder that is faced with the challenge of making a decision on whether to participate in a Health Information Exchange. The stakeholders that can have an interest in providing or obtaining information from a Health Information Exchange are defined as:

- Consumers, especially Seniors;
- Caregivers;
- Physicians;
- Other Clinicians;
- Hospital provider organizations;
- Hospital Administrators;
- Third party payers and Health Plans including Medicare/Medicaid;
- Employers;
- Governmental Agencies;
- Public Health Departments;
- Retail Providers;
- Durable Medical Equipment Providers;
- Educators / Researchers.

### *How to Use This Guide*

This guide is divided into six chapters plus an appendix. The first four chapters provide the background necessary to understanding what a health information exchange is, followed by common approaches and data standards. The appendix includes a few case studies that can be helpful to understand the different models as well as the glossary of terminology. Chapter Five and the checklist

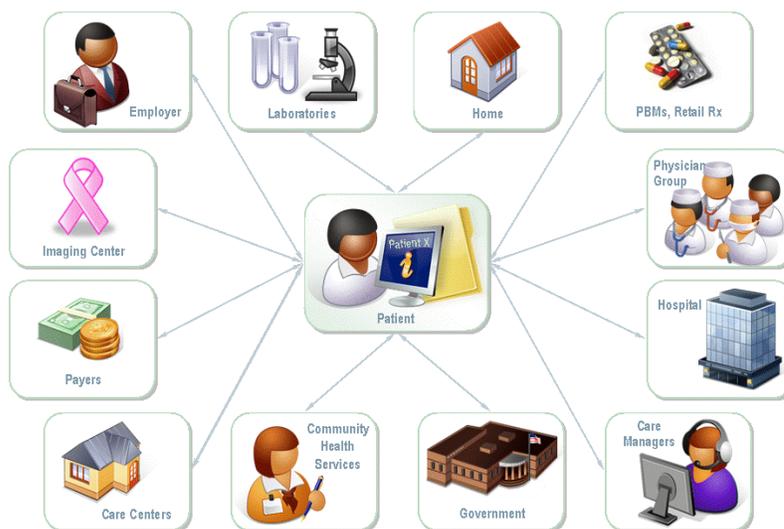
identify the questions that should be asked in evaluating a particular Health Information Exchange opportunity.

## Section 2 – Defining the HIE

### *What is an HIE?*

A Health Information Exchange (HIE) automates the transfer of health related information that is typically stored in multiple organizations, while maintaining the context and integrity of the information being exchanged. An HIE provides access and retrieval of patient information to authorized users in order to provide safe, efficient, effective, and timely patient care. Formal organizations have been formed in a number of states and regions that provide technology, governance, and support for HIE efforts. Those formal organizations are termed Health Information Organizations (HIO) or Regional Health Information Organizations (RHIO).

**Figure 1. HIE Overview**



HIEs are formed by a collective group of stakeholders from a specific area or region to facilitate the electronic exchange of health-related information for the purpose of improving health care for a defined population. Thus, the HIE provides the ability for participating organizations to safely and securely share health information with authorized providers to improve and expedite the clinical decision making process. An HIE is not an information system within a single organization, nor is it one that has a single directional flow of information. A true HIE involves multi-directional flow of information electronically between providers (hospitals, physicians, clinics, labs) and other sources of administrative or clinical information provided by consumers, health plans, employers, local, state or national organizations.

The HIE is a tool to facilitate the aggregation of data into a longitudinal electronic health record for all citizens.

Listed below are a few definitions that are instrumental to understanding what an HIE is and what it is not. Other definitions will be found in the appendix at the end of this white paper. Another industry resource is the [HIMSS Dictionary of HIT Terms, Acronyms and Organizations](#).

**Definitions:** In April 2008, the National Alliance for Health Information Technology (NAHIT) released “Defining Key Health Information Technology Terms.”<sup>1</sup> This report to the Office of the National Coordinator for Health Information Technology was an effort to eliminate the ambiguity of

<sup>1</sup> [http://www.hhs.gov/healthit/documents/m20080603/10\\_2\\_hit\\_terms.pdf](http://www.hhs.gov/healthit/documents/m20080603/10_2_hit_terms.pdf)

meaning and to create a shared understanding of key terms. According to NAHIT, the three network terms are HIE, HIO and RHIO and are defined as:

**HIE:** The electronic movement of health-related information among organizations according to nationally recognized standards.

**HIO:** An organization that oversees and governs the exchange of health-related information among organizations according to recognized standards.

**RHIO:** A HIO that brings together health care stakeholders within a defined geographic area and governs health information exchange among them for the purpose of improving health and care in that community.

The following list defines key terms related to HIE:

**EHR:** An electronic record of health related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization.

**EMR:** An electronic record of health related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization.

**PHR:** An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.

**NHIN:** A goal of the United States government is to "...digitize patients' health records and medical files and create a national network to place the information in."<sup>2</sup> In its developmental stage, the Nationwide Health Information Network (NHIN) will ultimately provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and healthcare. The Office of the National Coordinator refers to NHIN as a "network of networks" (hhs.gov) which connects all healthcare information providers such as health information exchanges (HIE's), health plans, provider care, federal agencies and many more through a national health exchange."<sup>3</sup>

### *The National Perspective*

Congress has recognized the importance of moving the country toward adoption of Electronic Health Records (EHR) and Health Information Exchanges (HIE). In 2004, President Bush provided leadership for the development and implementation of a national Health Information Technology program to improve healthcare quality and efficiency.<sup>4</sup> His executive order created the Office of the National Coordinator for Health Information Technology (then called "ONCHIT", now "ONC") whose mission

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<sup>2</sup> [www.worldprivacyforum.org](http://www.worldprivacyforum.org)

<sup>3</sup> [www.connectingforhealth.nhs.uk](http://www.connectingforhealth.nhs.uk)

<sup>4</sup> The White House Office of the Press Secretary. (4/27/2004). Executive Order: Incentives for the Use of Health Information Technology and Establishing the Position of the National Health Information Technology Coordinator. Washington, DC.

is to provide leadership for developing and promoting Health Information Technology as a means to improve the quality and efficiency of healthcare in the United States. Currently, in 2009, President Obama's 2009 American Recovery and Reinvestment Act (ARRA) stimulus plan requires a minimum of \$300 million to support efforts to build HIEs which promote the usage of EHR's. Grants will be available for states that can demonstrate readiness to develop HIEs. In order to qualify, each state must facilitate the establishment or establish governance structures, build technical infrastructure, and implement privacy and security measures. The state-designated entity could be a state governance structure or a separate nonprofit entity.<sup>5</sup> As more information becomes available regarding the ARRA stimulus plan and the definition of meaningful use, HIE resources and tools will require updating as appropriate.

### *HIE Commonly Offered Services*

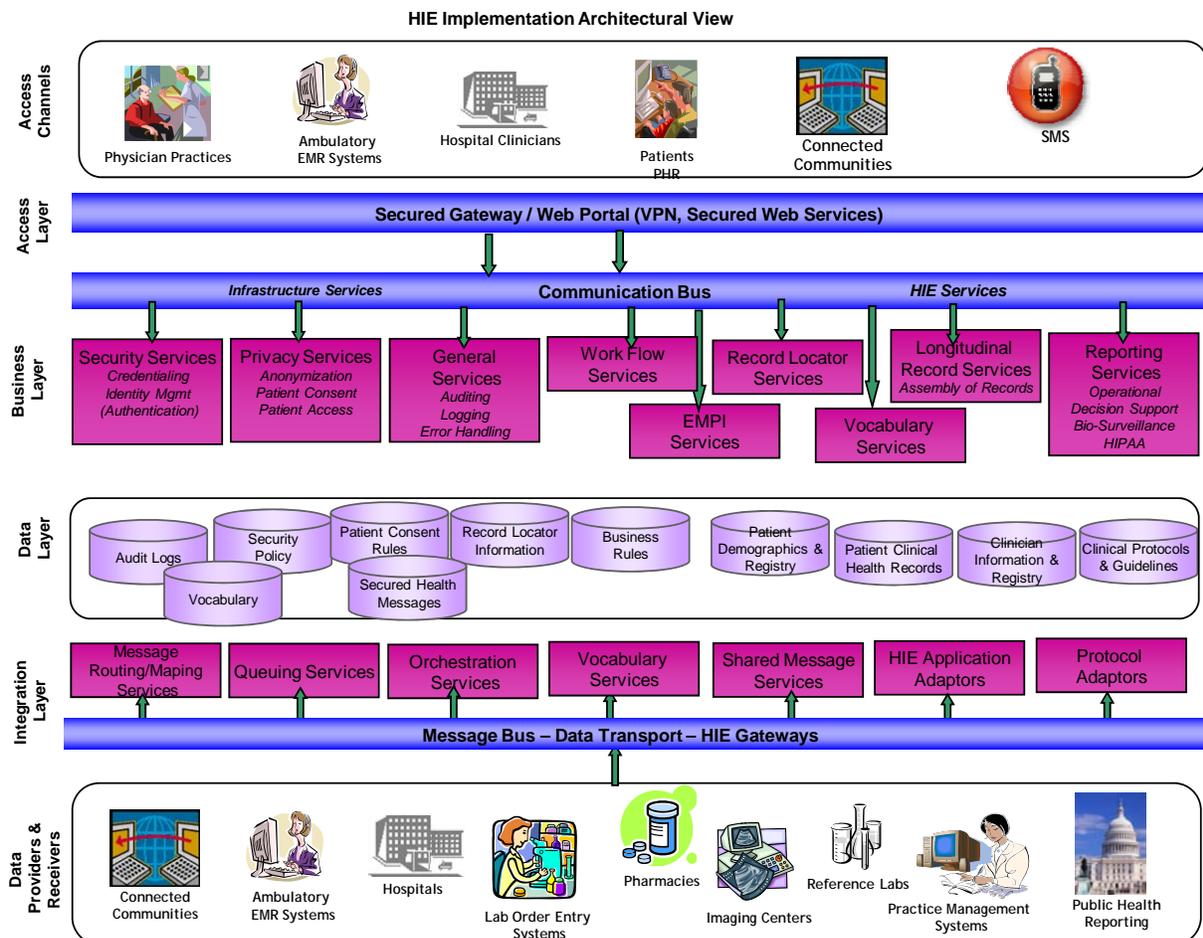
An HIE is a complex set of technologies which enables the aggregation of health related information for an individual as well as offering a number of specialized services for the community it serves. Usually, HIE capabilities are described as a set of electronic "services" that allow the HIE to interact with participating systems in a consistent, reliable way. The illustration below highlights an architectural view of the different services that one can expect from an HIE.<sup>6</sup> From a clinical or business perspective, access channels contain types of services such as physician web portals, personal health records, clinical messaging, clinical interoperability and exchange of data from electronic medical records as well as the common administration of security services necessary to insure that data is used appropriately.

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<sup>5</sup> Advisory Board Daily Briefing, 2-17-2009.

<sup>6</sup> Fairchild Consulting, Greater Rochester IPA Architecture Briefing, 2008.

**Figure 2. HIE Implementation Architectural View**



In order to provide these services, HIEs are architected to use one of two forms of data sharing methods (or both), which are referred to “push” and “pull” technologies. Understanding the difference between how clinical data is obtained in an HIE is important because it will dictate the method in which information is shared. “Portals are a pull (query) technology, requiring physicians to search for the data they need. Push technology, on the other hand, automatically delivers clinical data to the user in the desired format: paper, fax, electronically to a viewer or electronically to an EMR of the physician’s choice. Best in class Push technologies also allow for tailoring of various types of results and data delivery.”<sup>7</sup> In addition, “A good HIE solution should provide a push technology, delivering the vast majority of hospital and other results, while also providing a query solution for the few use cases where there doesn’t yet exist a patient-physician relationship that would enable push delivery.”<sup>8</sup> HIE’s must provide access to information regardless of the technology in use or not in use. There are still a large percentage of physicians who do not have access to electronic medical records in their offices. Understanding this technology is important for determining which methods are most appropriate for obtaining and viewing patient data.

The following information describes the vast number of stakeholder facing (access channels) services that may be rendered from a HIE. Not all HIE’s provide all of these services.

<sup>7</sup> Massengill, Stephanie “Can Portals Deliver?” ADVANCE for Healthcare Information Executives, March 2009. p2

<sup>8</sup> Massengill, Stephanie “Can Portals Deliver for Hospitals and Integrated Delivery Networks?” HIMSS News. March 2009.

**Patient Portals:** Healthcare patient portals were initially created and deployed early by hospitals “...for affiliated or employed physicians as a single place where they could remotely access various hospital-based applications... Single sign-on tools were developed to enable one login event to be used by multiple applications, and context management tools were built to enable patient context to be maintained as the user switched applications.”<sup>9</sup> As a leading example, the physician-driven Ann Arbor Area Health Information Exchange “...started with four group practices that use the same EHR system and access data from two hospitals. Now, the HIE is testing a Web portal to enable other physicians, including those without EHRs, to participate.”<sup>10</sup>

The Western North Carolina Health Network is another example, with 16 independent hospital systems jointly providing geographically dispersed clinicians with timely and comprehensive patient information.<sup>11</sup>

The next section will describe the different types of storage infrastructures for healthcare portals. Some require a centralized data repository where those who seek the information go to one location to search for patient data. Others do not use a centralized data repository but rely on a record locator service to identify the sources of data on the patient. This approach requires all data sources to be available at all times due to its’ real-time secure layer that sits between the requesting provider and the sources of information. Whatever form of storage is used, web portals are a way to centrally search for patient information. Using a portal as a single source to search and access patient information is much more efficient and easier than having to obtain patient-related health records manually or establish individual access from numerous healthcare systems. As more physicians have access to electronic medical records, the portal technology will evolve to make use of automated workflow so that the physician can access his or her own system to retrieve the information on their patients.

**Clinical Messaging:** Clinical messaging, which can utilize either push or pull technology, has become a key service in a successful model of an HIE. Early HIE’s saw this method of sharing information as a way of providing early benefits to the health community. “A clinical message service provides a secure, electronic infrastructure to automate the delivery of health data to any site where clinical patient care decisions are made. For example, a clinical message service can automate result reporting from a laboratory to a clinic (i.e., replace a fax or other printed results with an electronic file). A clinical message service can also enable secure electronic forwarding of reports between clinicians to facilitate patient care.”<sup>12</sup> A thriving Southern Indiana information exchange recognized the importance of having clinical messaging as a primary method for patient data sharing and has utilized this service as a method for delivering clinical results. This effort “...enhanced the value of hospital repositories by mobilizing the data to EMR and non-EMR physician practices.”<sup>13</sup> In the Indiana HIE, clinical messaging is also used as an alternative to a web portal. “With Clinical Messaging, hospitals have less need to support complex single sign-on (SSO) portals, which are getting more difficult to maintain as ambulatory care EMR adoption improves. Besides being isolated from physicians’ IT systems, the principal limitation with portals is that physicians are not notified when new data becomes available. These silos of information are merely storehouses for physicians to access.”<sup>14</sup> Deciding to use clinical messaging, healthcare portals, or a combination of both, is a vital choice that each healthcare organization must make. HIE’s use clinical messaging to improve the timeliness of communication and

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<sup>9</sup> <http://health-care-it.advanceweb.com/editorial/content/editorial.aspx?cc=195508>

<sup>10</sup> Goedert, Joseph, “Lessons from the HIE Front” Health Data Management. February 1, 2009

<sup>11</sup> <http://www.wncn.org/>

<sup>12</sup> <http://www.redwoodmednet.org/projects/hie/index.html>

<sup>13</sup> <http://www.himss.org/ASP/ContentRedirector.asp?ContentID=68905>

<sup>14</sup> <http://health-care-it.advanceweb.com/editorial/content/editorial.aspx?cc=195508&CP=2>.

reduce the cost of communication. Without an HIE with clinical messaging, communication is labor intensive and costly if built with proprietary linkages.

**Clinical Interoperability:** Many healthcare organizations throughout the United States have already invested heavily in existing healthcare information systems. The key to a successful HIE is the ability to promote interoperability with disparate systems to ensure that healthcare providers can electronically exchange patient data residing in several different foreign systems. Today, access to important clinical data resides in the silos of electronic medical records. It is impossible to gather all of the necessary information without clinical interoperability. “Health Information Exchange (HIE) is a long-term vision that results in interoperability that will improve health care processes with respect to safety, quality, cost, and other indicators. Progress is being made through planning, pilot programs, standards adoption, and implementing HIE technologies of varying degrees of sophistication. A number of voluntary industry efforts show promise; however, we are still a long way from realizing the goal. The fact is, building a truly interoperable national HIE is not easy, either culturally or technically. The key to reaching the clinical interoperability goal is to capitalize on necessary tools, standards and resources that meet current practical (funded) objectives in such a way that incrementally creates an HIE infrastructure. Then, organizations can add capacity and functionality in order to accommodate complex, bandwidth-intensive clinical information and connectivity, interoperability, and security mechanisms.”<sup>15</sup>

**Electronic Health Record (EHR):** In order to successfully participate in providing patient data to an HIE, healthcare providers must face the challenge of implementing a longitudinal EHR. Such challenges have traditionally been tied to the difficulties relating to institutional adoption and investment commitments required to achieve clinical interoperability with other organizations. One step towards creating an electronic health record requires that individual organizations first implement their own electronic medical records. With ARRA, hospitals and physicians will receive incentives to automate their patient records. Hospital incentives start at \$2 million annually, with an additional reimbursement amount tied to annual Medicare discharge volume, and decrease for each subsequent year during the 5-year incentive period. Non-hospital-based physicians and physician groups can expect to receive funding if they have qualifying EHR systems in place by 2011.<sup>16</sup> Several other qualifying criteria must be met in order to receive the funding and further clarification is needed on various definitions. Details from the Federal government will be forthcoming on the definitions of qualifying criteria and certification standards as outlined in ARRA.

**Personal Health Record (PHR):** The PHR is a tool that individuals can use to collect, track and share past and current information about their personal health or the health of a family member. Sometimes this information can save money and inconvenience of repeating routine medical tests. Even when routine procedures do need to be repeated, the PHR can give medical care providers more insight into an individual’s personal health story. When connected to a HIE, the PHR has the potential of becoming a critical component of the comprehensive, longitudinal health record that serves the individual, physician, insurers, employers, and other stakeholders. Components of a PHR may include: important reminders for health maintenance and preventive care tailor able for each patient and journals that keep track of diet, exercise, appointments, past and current providers, dental and eye records, with links to historical care summaries can provide individuals with a comprehensive healthcare diary for them and their entire family. The PHR must provide for consumer control and data additions as well as integrate with other clinical and educational data sources.

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<sup>15</sup> Watkins, Larry *Making Meaningful Progress Toward HIE*. September 9, 2009.

<sup>16</sup> <http://www.ama-assn.org/amednews/2009/03/16/gvsa0316.htm>

**Record Locating:** The HIE maintains the ability to identify individuals and to link them to potential sources of information through Person Identification (PI) and registry services within a directory structure. Ensuring accurate identification is a challenge in an HIE, as each participating organization will have its own medical record number or person identifiers. In the absence of a national unique identifier for health care, a matching process is used for positive person identification when any participating organization seeks to find information within the HIE for a given person. In addition, a record locator service (RLS) may be needed. In some HIEs where a decentralized (federated) architecture is used, the RLS identifies where data may reside for a given person in order to feed that back to the requesting organization. In a consolidated model, enterprise master patient index (EMPI) identifies the person as the demographic or clinical data is received into the HIE.

Once the patient is identified, common data elements such demographic and insurance information, diagnosis, allergies, problems, medication and other pertinent clinical data are made available.

**Administrative Services:** Simplification of administrative services is highly desirable by providers for accessing claims, authorization, payment systems and data via the HIE network. Administrative services may also support gathering patient demographic and other non-clinical information. In addition, HIE can also facilitate the referral process from both an administrative and clinical standpoint. A comprehensive referral process allows a seamless transfer of information from the primary care provider, to the specialist with a number of stops and checks with insurers. A technically mature HIE should have all of the linkages to streamline this process.

**Disease Management:** Some of the more advanced HIE's include Chronic Disease Management (CDM) as a service offering. CDM typically requires the coordination of care with one or more specialists. The average Medicare patient sees approximately six (6) physician specialists annually. The recent policy efforts to coordinate chronic disease (also called Patient Medical Home, Advanced Medical Home, or Patient-Centered Medical home) recognizes the need for proper information technology (IT) tools and infrastructure to implement this plan. HIEs today provide value to physicians involved with CDM through the aggregation of data from various sources into patient registries (depending upon the disease being monitored), allowing quick and efficient retrieval and analysis of pertinent data without the effort of data re-entry and/or searching many sites. HIEs are an enabler for effective CDM through the exchange of information across the providers. This allows the HIE to be the enabler for various caregivers to coordinate care among the specialists, the primary care physician and patient. Eventually, providers should be able to manage chronic conditions from within their EHR systems with data provided by the HIE.

HIEs can foster the collection of data elements on various chronic conditions in a computer readable form for use in chronic disease profiles, charts of levels of key indicators (e.g., hemoglobin A1C for diabetics), and triggers for recall of patients who have undetected loss of control. Tracking of chronic disease indicators is not yet universal, thus it is important to add these chronic disease measures to the list of data to be exchanged.

The next evolution of HIE is looking to integrate disease management systems with community public and private research programs. The Louisville Health Information Exchange is looking to provide the service based on a consumer consenting to participate in the research programs<sup>17</sup>.

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<sup>17</sup> LouHIE Business Plan, Louisville Health Information Exchange, Inc., May 20, 2008.

**Community and Public Health:** New, more complex ways of sharing data are also arising with the advent of the HIE. These collaborative organizations focus on health data exchange in a community, county, or state-wide basis. They have a wide and varied set of participants (providers, labs, hospitals, health plans, public health agencies, pharmacies, and patients/citizens). HIEs may involve public health as a key player in their formation and operation. While the emphasis is typically on exchanging clinical data to support patient care, some health data exchanges focus on health services data instead of—or in addition to—their clinical needs. As HIEs develop and are deployed, and both public health and private healthcare systems continue to evolve and develop, system integration within public health will no longer be enough. Public health systems will need to become interoperable with other systems both inside of, and especially outside of, the agency.

For public health agencies developing integrated health information systems, new risks and benefits are emerging rapidly on the horizon. The ways in which public health is increasingly exchanging information with health-care providers, hospitals, government, insurers, and families demand a closer look at the networked information environment. A public health registry is defined as, "...an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individual persons who have either a particular disease, a condition (e.g., a risk factor) that predisposes to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects."<sup>18</sup> As systems become more integrated—especially across the public-private boundary—the role of registries will change. In some cases, their very existence may be called into question.

Information is one commodity that gains value the more it is used. Public health stands to benefit from a landscape of increasing opportunity to exchange information with more sources and users. One area is the growth of HIEs in which public health runs the risk of being excluded. Public health can become an integral player in the HIE scenario by embracing and promoting standards, opening access to its program-based database information, and organizing focus groups of stakeholders to make sure that everyone—including public health—has a place at the table.

**Value Added Services:** In the creation of a sustainable financial model, HIEs are starting to offer additional value added services. These value added services may come in the form of additional web-based products or services that an individual can choose to use. Typically, these services are charged separately based on the perceived value to the individual. Examples of value added service may be the receipt of educational notices from the community gardening club, providing access to electronic medical record systems for physicians, or access to a diet counter service. They are services that one can choose to use or not use and individuals will generally pay a subscription fee for the privilege of using services they value.

### *HIE Content Examples*

HIEs are implemented to support specific functional needs of their stakeholders. In information technology parlance these are often referred to as “use cases” or “use narratives.” Over the past several years, a common set of use cases have been examined and HIEs have developed to support them through the services that they offer. In addition to the information below, the appendix also includes a set of case studies which provide additional detail related to services that a few HIE’s in the nation are providing.

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<sup>18</sup> California HealthCare Foundation, *Chronic Disease Registries: A Product Review*, May 2004.

**Testing and Results:** When physicians cannot readily find a lab or x-ray, they will typically reorder the study in order to expedite the clinical process. This is a tremendous waste of resources and has a cost ripple effect throughout the entire continuum of care. Once the HIE has implemented interfaces/access to all diagnostic sources, physicians can view orders and results for labs, radiology, and other clinical values online as part of a streamlined HIE workflow process. Through a common user interface, providers can get a complete view of all current and historical diagnostic studies, reports, as well as images (e.g., X-ray, EKG, etc.) thus being able to provide better care through an expedited diagnostic process by giving physicians the capability to locate critical clinical information anytime, anywhere. By providing ubiquitous access to past orders and results, HIEs can foster a marked reduction in redundant testing and improve care.

**Other Clinical Documentation:** Other pertinent clinical information can be made available on the HIE. Medications, allergies, problem lists and other documentation are just some examples of data providers need to access for each patient visit. For example, on an HIE, active allergies and medications can be codified and stored for each patient. These profiles are then shared so providers can view the entire medication record for drugs that have been prescribed by any/all participating physicians for a particular patient. This can improve patient safety by preventing drug/allergy interactions. In addition, this feature will reduce the amount of time a community physician or specialist will need to spend reviewing medication lists thus providing more available time for discussion and examination of patients.

Active problem lists are also an important clinical data need for HIEs. Specified medical problems related to each particular patient, with specific dates for the onset of a given problem, as well as a date that it was resolved, are key data elements that can be shared on an HIE. Having this data readily available, physicians can provide a more accurate and timely diagnosis by viewing all problems that have been documented by caregivers on the HIE. Thus, therapeutic actions are more efficient and targeted for active and focused problem resolution and specialists spend less time diagnosing known problems and can target efforts for more pressing and urgent issues.

Finally, other documents such as histories, physicals, and progress notes can be stored on the HIE streamlining the documentation process for more accuracy and speed of inter-practice-provider communication. The sharing of clinical documents promotes better, faster, more efficient physician/staff/patient communication and increases ability to for physicians to see more patients because there is less time spent on paper-based administrative tasks freeing up more time for direct patient care.

### **Section 3 - Different Health Information Exchange (HIE) Models**

There are various conceptual models of HIEs; each presents issues of interoperability, development and sustainability, and privacy and security concerns for health environments, clinical providers and, ultimately, the patient. HIMSS outlines three different clinical data exchange models: Centralized, Federated and Hybrid<sup>19</sup>. In addition there are other models, variations on a theme such as the health record banking model. This section introduces several of the HIE models and briefly presents various business models that they may operate under in general terms.

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<sup>19</sup> Just, Beth Haenke, MBA, RHIA, Durkin Stacie, MBA, RNC, RHIA, Clinical Data Exchange Models: Matching HIE Goals with IT Foundations, Journal of AHIMA, February 2008 – 79/2

For healthcare organizations considering joining an HIE, there are many hurdles to overcome as well as consideration of the benefits that might be attained. These hurdles include cooperation with potential competitors, development and agreement on technical standards and system functions, infrastructure development, and financing and sharing the ongoing costs to sustain the activity. Consumers and their providers may also have issues in the area of control, privacy and security.

To date there have been many publications indicating the benefits of an electronic health record (EHR) and physician electronic order entry. Many of these benefits are just starting to be proven since the technology is early in its adoption curve. One example of benefits is the reduction of medication errors and decreasing redundant testing. Many studies confirm not only the cost savings of an EHR but the value of the completeness of the medical record for ensuring quality patient care and lives saved.<sup>20</sup> Given the potential of connecting and sharing data across enterprises, the value that HIE provides could be enormous based on current literature.

The development of a common framework and standard data model has been in process for some time. There are several common frameworks evolving, including CCHIT conformance criteria for EHR system functionality and the HL7 Reference Information Model (RIM) for data modeling. Many examples of the use of these frameworks exist across the nation. Widespread adoption of these frameworks and standards by vendors has been slowed by the expense of applying them to the established product base developed using earlier technology. Many groups and organizations are driving toward a common framework. Partnerships and a reasonable business model are critical to the viability and sustainability of any HIE. Also paramount is the readiness of a community to support the structure of a health information exchange and all it entails.

The models described below ultimately provides for sharing of clinical information, medications, lab results, imaging studies and demographic data to various stakeholders across multi-stakeholder enterprises and regions for the benefit of improving patient safety, quality and decreasing health related costs in a community.

### *The Centralized Model*

In a Centralized Model or warehouse, patient medical related data is collected from local sources but stored in a central repository. With a request from entities for patient data, the transaction is routed through the central repository. Such architecture permits local entities to maintain autonomy but through cooperation provide data at a local or regional level.<sup>21, 22</sup>

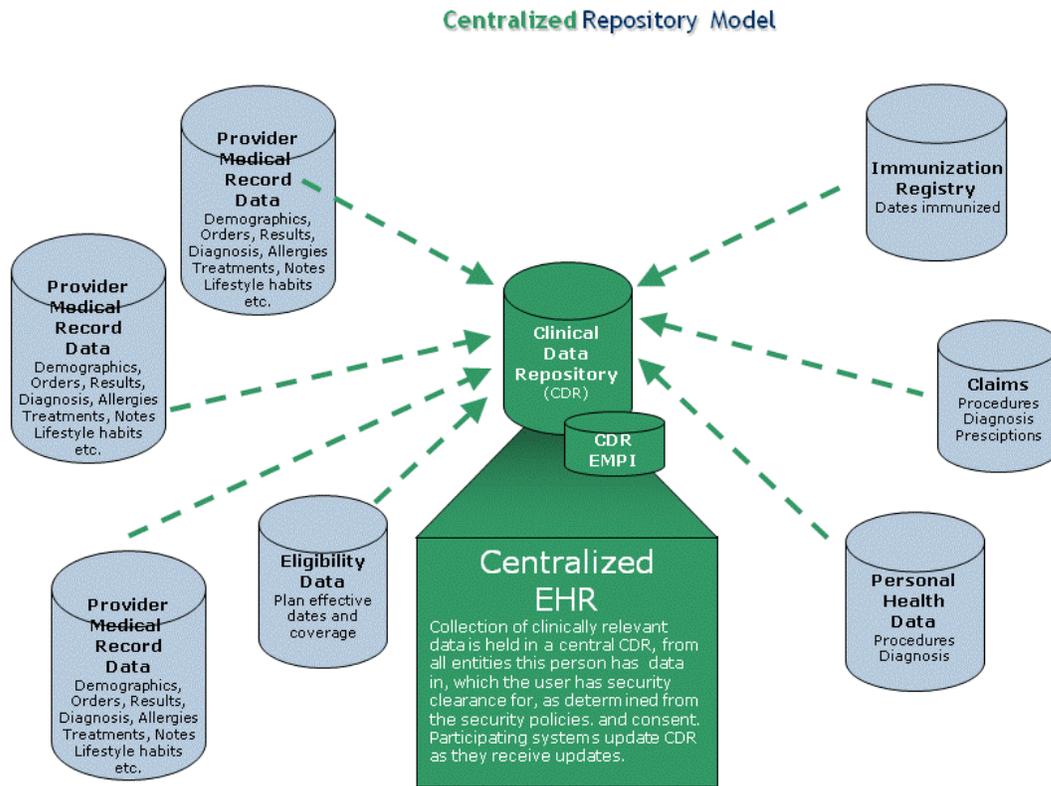
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<sup>20</sup> Leapfrog Group. [http://www.leapfroggroup.org/about\\_us/leapfrog-factsheet](http://www.leapfroggroup.org/about_us/leapfrog-factsheet)

<sup>21</sup> [http://www.techdevresources.com/federated\\_model.htm](http://www.techdevresources.com/federated_model.htm).

<sup>22</sup> Allison, Melanie A, and Matull, Mike. A Review Of Current & Emerging HIE Architecture Models. CalRhio Summer Summit; 6/21/2007.

Figure 3. HIE Centralized Repository Model<sup>23</sup>



A typical centralized architecture is implemented as a logical single large database that aggregates similar data from numerous sources in one location. Because all data exists in a single warehouse, it is very easy and fast to perform queries against it.

In the Centralized Model, all providers send their data periodically to a central repository, usually on a daily basis.

There are many benefits with a Centralized Model:

- The querying system's response to a data request is quicker than other models since all the data is already centrally maintained and consolidated;
- Less real-time dependence on other participating systems for the same reason;
- Facilitates community-wide data analysis since data is available centrally;
- Economies of scale are introduced through the use of large-scale central resources as long as appropriate investments are made;
- Better expertise in managing central resources due to their scale and class of products used; and
- Able to support existing systems well as data needs only to be extracted and sent to the central repository.<sup>24</sup>

<sup>23</sup> Cox, Barbara; State of New York Department of Health Architectural Discussion; 2006

<sup>24</sup> Arzt, Noam H, Development and Adoption of a National Health Information Network. RFI Response, Office of the National Coordinator for Health Information Technology, HLN Consulting, LLC, 1/18/2005.

This model also has a number of limitations:

- Strong central coordination is required since the central database cluster needs to be carefully managed and maintained for this system to work;
- Dependence on large central database for inter-system queries;
- Data timeliness issue: data submission from participating systems to central database may lag resulting in inaccurate consolidated records at query time;
- May require a large effort to keep not only demographic records but *also* clinical records free from duplication since these records will be collected from numerous disparate sources;
- Harder to implement incrementally, as a larger up-front investment in central resources is required; and
- Likely fairly expensive option to implement, not only technically but organizationally.<sup>25</sup>

One of the fundamental challenges of all models is data matching. There is a requirement that there be accurate matching of patient data between the local system and the central repository or other systems. In the absence of shared identifiers, other algorithms or strategies must be employed. If the patient is new to the centralized system there is a significant burden to match records on the repository side. There is risk that data may be linked to the wrong person. If sensitive clinical data is present this may present privacy issues when errors occur.

Finally there is the challenge of database congruency issues from providers where data collection standards, messaging formats and field naming conventions are inconsistent.

The Centralized Model requires the most planning, coordination and development to be successful. From a technology perspective the Centralized Model requires a heavy investment in a single vendor and system integrator to build a logical central repository that makes it functional for all stakeholder organizations.<sup>26</sup>

### *The Decentralized or Federated Model*

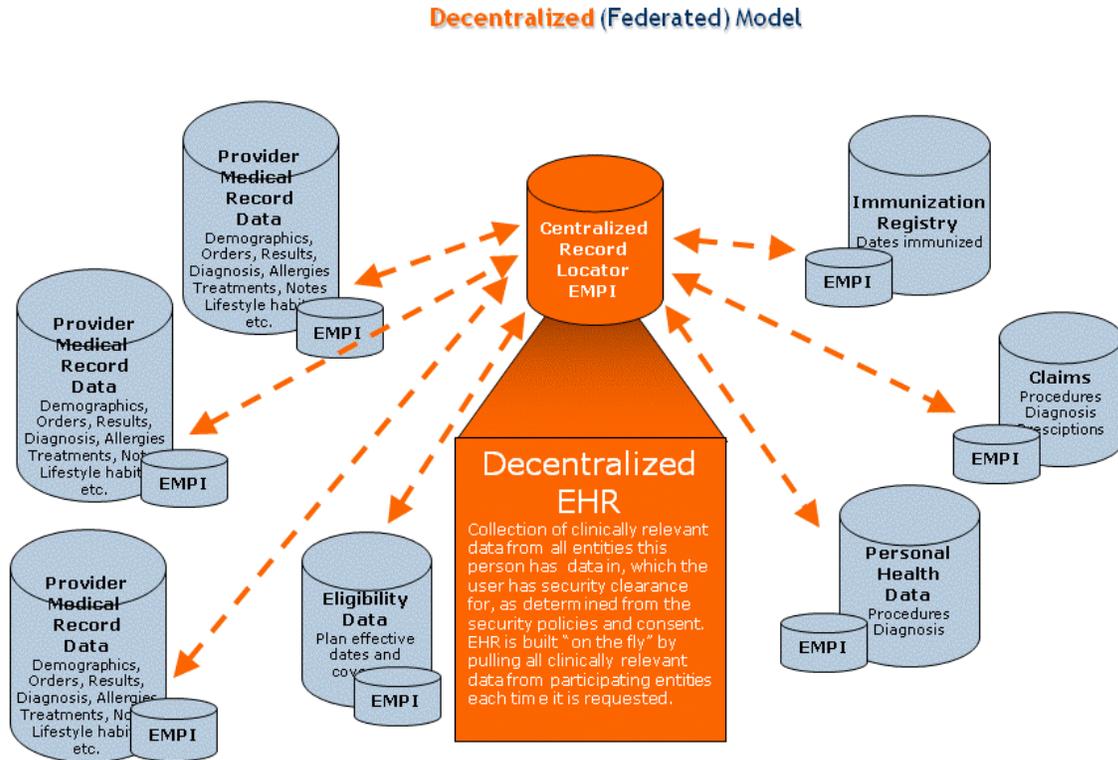
The Decentralized or Federated Model provides organizational control of the healthcare record and provides the framework for data sharing capability to enterprises, perhaps widely distributed across regions or even nationally. The local entity owns their data and the Record Locator Services manages the pointers to the information.

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<sup>25</sup> Arzt, Noam H, Ph.D., Development and Adoption of a National Health Information Network. RFI HLN Consulting, LLC. 1/18/2005

<sup>26</sup> HIMSS. Guide to Establishing a Regional Health Information Organization. 2007

**Figure 4. HIE Decentralized (Federated) Model**<sup>27</sup>



In the Decentralized or Federated Model, updates and access to the healthcare record are only provided when needed. The Decentralized or Federated Model allows the initiator of a health record, such as a provider, to maintain ownership and control over the record while providing access to the record by those authorized to access the record. In this model, providers form into a single administrative entity or governing body at a regional level, with each retaining control of its own internal business activity.

As with other HIE models, similar to a large healthcare system of multiple entities, providers, medical groups, labs, imaging services organization and other healthcare groups form a cohesive group organized in a framework to support the exchange of healthcare information. This information may include medical history, medical exam and lab results, diagnostic images and demographic information about the patient.<sup>28</sup>

The setup of Decentralized or Federated Model systems is complex, expensive and costly to maintain. The consumer may also have concerns with data distributed far and wide in interconnected set of frameworks. There are also many potential points of failure both in data maintenance, confidentiality and security of the

<sup>27</sup> Cox, Barbara, State of New York Department of Health Architectural Discussion; 2006

<sup>28</sup> [http://www.techdeveresources.com/federated\\_model.htm](http://www.techdeveresources.com/federated_model.htm)

Some advantages of the Decentralized or Federated Model include:

- Data is stored locally at the point of services and accessed only when needed for exchange. There is no conflict of who owns the data except for the ownership rights of the consumer;
- Data is always current;
- Failure of a single system doesn't cripple the whole or others in the exchange but may make some patient data unavailable at the time of a query;
- Any EHR system can be connected to any other, but assumes common interface standards; and
- More repositories or compartmentalization means a smaller amount of data is available to potential hackers with a single system penetration, though this is arguable as penetration of a Record Locator Service could provide access to the same quantity of patient data. The data would just have to be retrieved to collect it in a central file – the function of an RLS.<sup>29</sup>

Disadvantages of a Federated Model:

- Need to ensure authorized and legitimate access to third party systems connected;
- Need to capture consumer consent to opt in and opt out of the decentralized network thus ensuring legitimacy for data usage;
- Data control and availability is not guaranteed thereby limiting the value that can be achieved by the providers; and
- Standards and profiles are still being defined.<sup>30</sup>

### *The Hybrid Model*

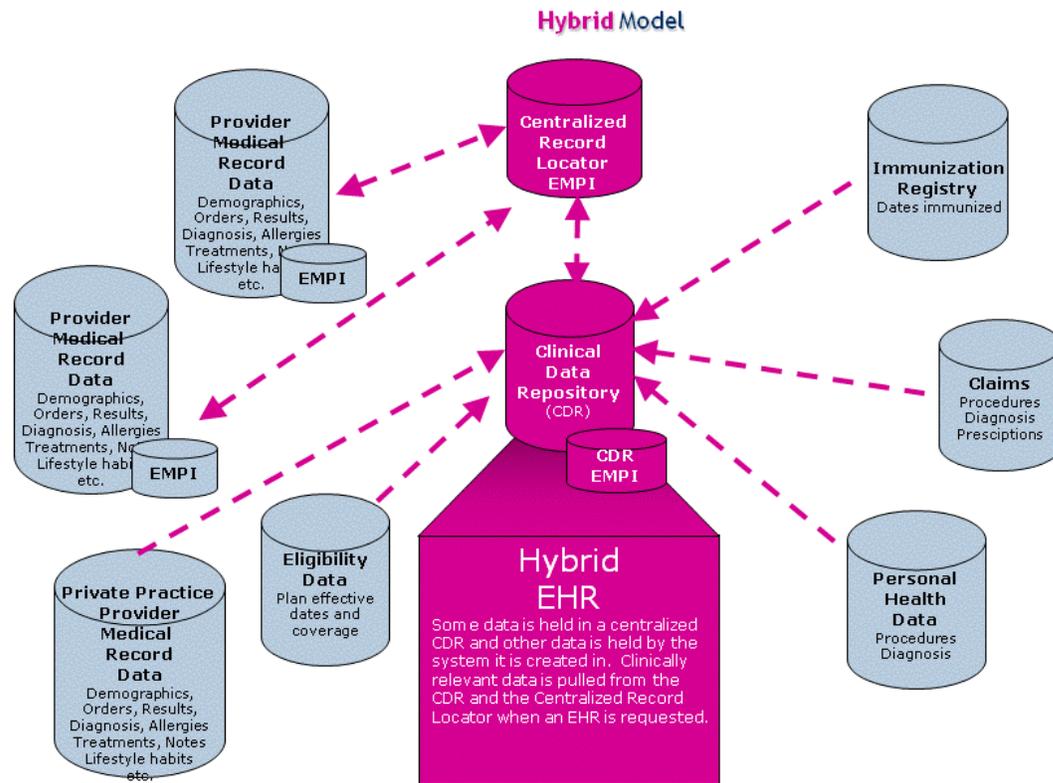
The Hybrid Model is a cross between a centralized and decentralized architecture. A Hybrid Model provides the interface engine for which organizational entities in the HIE communicate. “For example, the eHealth Volunteer Initiative in Tennessee uses a system where the data is physically stored and managed in a central location, but the data is logically separated into ‘vaults’ controlled by each organization that contributes data.”<sup>28</sup>

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<sup>29</sup> Arzt, Noam H, Ph.D., Development and Adoption of a National Health Information Network. RFI HLN Consulting, LLC. 1/18/2005

<sup>30</sup> Gantenbien, Rex. A Lightweight Approach to Federated Health Information Exchange; University of Wyoming presentation. Powerpoint presentation; January 2008.

Figure 5. HIE Hybrid Model <sup>31</sup>



The Hybrid Model stores key record identifiers and requests for the information that is distributed across the network. The record locator key is used to gather and transfer medical information to the requesting healthcare provider. Algorithms exist within the applications in the network to ensure positive probability of gathering candidate patient records.<sup>32</sup>

In hybrid architecture only some of the actual data is replicated to the central data repository. The hybrid model may also include elements where data is produced locally and the original is stored centrally, but the centralized repository and locator registry are dependent on federated EHR adapters for production of links to the original patient information. In addition to the required data to identify the patient, the central database may store a minimum of clinical data. This is commonly referred to as a “minimum clinical data set” and may include such information as current medications, current diagnoses, and allergies. In addition to these few elements, there are also pointers to where additional data is housed.

### *The Health Record Banking Model*

The Health Record Banking model endeavors to provide control to the consumer regarding who can access their record housed in a central system repository. There is a belief among proponents that by

<sup>31</sup> Cox, Barbara, State of New York Department of Health Architectural Discussion; 2006

<sup>32</sup> Allison, Melanie A, and Matull, Mike. A Review Of Current & Emerging HIE Architecture Models. CalRhio Summer Summit; 6/21/2007.

placing health records under the control of the consumer that many of the HIPAA/Privacy issues disappear since the consumer can authorize access to personal medical information freely even under the most restrictive state law.<sup>33</sup> Medical information would be transferred like a financial transaction to a requester given access by the consumer.

Health Record Banking (HRB) is a conceptual model where a system is designed and setup to maintain the lifetime healthcare record of the consumer who can direct, control and provide access to the electronic record stored in central repository, like a financial deposit into a bank. There is increasing interest in this type of model. Communities such as with Louisville, KY and States of Washington, Kansas and Tennessee are each exploring the model. Vendors, like Cerner and ICW are developing a systemic framework to support such a model.<sup>34</sup>

The HRB is a secure centralized information repository to house patient data records. Like a bank, the consumer controls their data, can monitor it and grants access to it electronically. During a clinical encounter the consumer authorizes access to their health record via the internet or a compatible electronic record from a connected system. Once authorized the information is transferred to the provider. After the encounter, data may be transferred back to the system repository to close the loop by adding to the electronic medical record. Transfer of information based on the financial services analogy provided could be a fee based service or philanthropy driven service such as with the Louisville Health Information Exchange (LouHIE)<sup>35</sup>. With a fee based service, a provider ensures there is payment for the effort, a potential method for offsetting their cost to participate.

### *International Models*

Canada Health Infoway is a countrywide initiative to interconnect systems across every province and territory. Canada Health Infoway is an independent, federally-funded, not-for-profit organization that is accelerating the development of electronic health records across Canada. As a strategic investor, they work with Canadian provinces and territories with a goal to have an electronic health record (EHR) for 50% of Canadians by 2010. Infoway's members are Canada's 14 federal, provincial and territorial Deputy Ministers of Health.<sup>36</sup>

Infoway was created in 2000 through consensus between Canada's federal, provincial and territorial governments. Canada has invested in provincial electronic health record systems infrastructure and in doing so has made the Infoway initiative a catalyst for developing a consistent EHR vision and collaborative vehicle for standards across Canada. The mission of the Canada Health Infoway is to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis.

In building this International Model concept, Canada set standards of interoperability up front and set the expectation that all electronic health systems installed must comply with the interoperability standards. Canada promotes the idea that EHRs are a significant opportunity for ongoing international collaboration. Canada has developed liaisons with most of the major standards development

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<sup>33</sup> Deloitte Center for Health Solutions. Health Information Exchange (HIE) Business Models: The Path to Sustainable Financial Success; 2006. p. 5

<sup>34</sup> Thornewill, Judah and Esterhay, Robert J. Capitalizing the NHIN: A Strategy for Funding an Integrated Nationwide Network of Community HIEs. JHIM; Summer 2007, Vol. 21, No. 3. pp. 18-24.

<sup>35</sup> LouHIE Business Plan, Louisville Health Information Exchange, Inc., May 20, 2008.

<sup>36</sup> Mendelson, David S. MD., IHE presentation; Achieving Interoperability and Adoption of the Electronic Health Record. January 2008.

organizations, to ensure that at some point in the future data sharing could ostensibly be accomplished across borders.<sup>37, 38</sup>

In Finland, The Hospital District of Helsinki and Uusimaa (HUS) is composed of 24 hospitals in the province of Uusimaa which includes Helsinki, the capital city. As a joint authority it was founded in 2000 to provide health services for over a million residents in its 31 member municipalities. Named Navitas, this federated model HIE is at its core a record locator service. It is a service which maintains a regional directory of links pointing to patient and treatment information located in any of the connected health care information repository systems in the region. Each participating organization has its own patient information system in addition to stand-alone patient information systems in HUS.

Provider access is by web browsers and includes both inpatient and outpatient clinical and demographic information. All data is sorted according to social security coding, which is standard procedure in Finland. The data transfer is encrypted and data is transferred via private dedicated networks. Viewing of the patient data through the links requires the patient's informed consent.

The Navitas locator service is available today for all health care professionals in the Hospital District. The directory contains information from 1.4 million citizens. Currently there are over 40 million links in the database. The number of links has been minimized in order to make it easier for the professional to get a holistic view on the patient's medical history.<sup>39</sup>

The 2009 HIMSS International HIE white paper provides additional information on health information exchange activities occurring in other countries. Find this white paper at: [http://www.himss.org/content/files/Natl\\_Internatl\\_White\\_Paper051309.pdf](http://www.himss.org/content/files/Natl_Internatl_White_Paper051309.pdf)

### *State-led versus community-based Models*

State-led HIE models promote information exchange for the common good and encourage, promote and facilitate the creation of regional information data exchange and are in a better position to take on many of the tasks necessary for implementation.<sup>40</sup>

Most important is the setting of standards of interoperability until national standards are defined. States share in the responsibility for ensuring the privacy and security of personal information. They may also be better sources of funding to develop the infrastructure necessary to support a regional network.

Are community based models are better suited to the specific needs of the community? Potential HIEs at the local level are not bound by standards unless mandated by state law. Requiring states to use nationally-recognized standards such as those selected by the Health Information Technology Standards Panel (HITSP) could facilitate a more rapid development of data sharing between entities.<sup>41</sup>

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<sup>37</sup> Mendelson, David S. MD., IHE presentation; Achieving Interoperability and Adoption of the Electronic Health Record. January 2008.

<sup>38</sup> Gardner, Neil. Electronic Health Record (HER) Strategy – a Canadian view on the Important of Interoperability. IHE North American Conference. January 29, 2008.

<sup>39</sup> Harno, Kari. Shared Healthcare in a Regional eHealth Network. In: "Handbook of Research on Information Technology Management and Clinical Data Administration in Healthcare" 2009; 383-397. Ed. A. Dwivedi, IGI Global USA, UK.

<sup>40</sup> Deloitte Center for Health Solutions. Health Information Exchange (HIE) Business Models: The Path to Sustainable Financial Success; 2006

<sup>41</sup> Health Information Technology Standards Panel, HITSP, <http://www.hitsp.org/>

The role of the state in HIEs is not yet clearly established. Each state is making its own decisions about the role it chooses to serve. Whether it is an “operator” of an HIE or a facilitator of many local HIEs directly or through a State Designated Entity is still to be determined.

### **Industry Drivers**

One such facilitator is a collaborative called Integrating the Healthcare Enterprise (IHE). IHE is an initiative by healthcare professionals and industry to improve the way computer systems in healthcare share information. IHE promotes the coordinated use of established standards such as DICOM and HL7 to address specific clinical needs in support of optimal patient care. Systems developed in accordance with IHE communicate with one another better, are easier to implement, and enable care providers to use information more effectively.<sup>42</sup>

Connecting for Health is a public-private collaborative with representatives from more than 100 organizations across the spectrum of health care stakeholders. Its purpose is to catalyze the widespread changes necessary to realize the full benefits of health information technology (HIT), while protecting patient privacy and the security of personal health information. Connecting for Health is continuing to tackle the key challenges to creating a networked health information environment that enables secure and private information sharing when and where it’s needed to improve health and health care.<sup>43</sup>

The real industry driver is the need to transform healthcare to be affordable for everyone. We all must work together to insure the transformation is attained in our lifetime.

### ***The Business Models***

The Deloitte Center for Health Solutions points to four basic business models that HIEs operate in regardless of the practical structural model:<sup>44</sup>

- Not for Profit – Usually local, these HIE organization are driven by their nonprofit healthcare charter within the community for which they operate and provide services. Tax exempt status and potential tax credits or incentives may assist such organizations in mitigating their costs. An emerging variation to the not for profit model is the ability to use philanthropy to drive the sustainability of an HIE. This model is similar to how many hospitals operate today as well as national public radio.
- Public Utility – These HIEs are created and maintained with the assistance of federal/state funds that provide direction by the federal/state government through laws and regulations. This type of business model has tight fiscal controls and funding sources can be problematic given economic conditions.
- Physician and Payor Collaborative – Usually local, this mutually benefiting collaborative organization is created for or by payors and physicians for the strategic benefit within a region. Medical groups are the better analogy for this type of HIE business model.

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<sup>42</sup> Integrating the Healthcare Enterprise (IHE). <http://www.ihe.net/>

<sup>43</sup> Connecting for Health. <http://www.connectingforhealth.org/aboutus/index.html>

<sup>44</sup> Deloitte Center for Health Solutions. Health Information Exchange (HIE) Business Models: The Path to Sustainable Financial Success; 2006. p. 5

- For Profit – The For Profit HIE is created with private funding and it has a clear return on investment strategy. They hope to benefit from the medical and technology services they provide. A healthcare organization acting as local application service provider hopes to benefit financially from their usually advanced systems by providing hosting services to less technically feasible groups for systems recordkeeping functions. Transaction based fees or fee for services is a common sustainable funding approach for a for profit organization.

While not-for-profit business models seem to dominate the HIE industry, the long term financial sustainability and governance continue to be major issues. As with every business, a well thought out business plan must exist which includes start-up operational fees as well as sustainable revenue to offset the continuing operations.<sup>45, 46</sup>

## Section 4 - Common Technology Approaches and Data Standards

This chapter discusses the key technological factors involved with participating in an HIE. The first section deals with networking requirements and sources of software to facilitate HIE and interfaces used. The second section describes what we call middleware. Generally, the term middleware is used for software that functions between computer applications and the operating system. In the HIE model, *middleware* is comprised of service modules that perform functions for the HIE applications. The third section deals with standards that apply to HIE.

### Technology Building Blocks

There are two likely models for the exchange of patient related health information. As mentioned in the previous chapter, these models include (1) a record locator service in which the patient's medical information is housed on computers at the various sites of his or her care and this information is queried and aggregated from these sites at the time of a request; and (2) a central repository model in which all known data on the patient is brought together in a single logical database called a repository and that database is accessed when data is needed.

### Network Infrastructure

In each of the two models noted above, transmission of patient information is the key element of the process. Any sharing of patient information among providers requires that the providers be linked over a network. While it would be feasible to transmit patient data over a slow network such as dial-up, the expectation of the industry is that high-speed, reliable, secure connections be available. Some physician offices may use DSL (digital subscriber line) connections which have fast download speeds, typically 1.5 mbps, and slower upload speeds but most major organizations will have T-1 connections, typically with 1.5 mbps download and upload speeds. Larger organizations may have even faster connections. Reasonable response times require these high-speed connections. Slower communication speeds would present a disincentive to use linked systems, thereby discouraging providers from attempting to retrieve linked data retrieved over the network.

One of the realities of current connectivity is that high-speed networking is readily available in urban areas but may not be available in semi-rural and rural areas, much of the geography of the country. In an effort to modernize the networking environment, the Federal Communications Commission (FCC)

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<sup>45</sup> American Health Information Management Association (AHIMA). HIM Principles in Health Information Exchange (Practice Brief).

<sup>46</sup> Hall, Mark A. Property, Privacy and the Pursuit of Integrated Electronic Medical Records

and the U.S. Department of Agriculture (USDA) oversee programs that provide funding for broadband deployment in rural areas. The USDA provides low-interest loans that may be used to build new and modernize existing telecommunications networks in rural areas, and the FCC's Schools and Libraries Universal Service Program and Rural Health Care Support Program provide financial support for broadband services to schools, libraries, and rural health care providers.<sup>47</sup>

### *HIE Applications*

The HIE networking infrastructure discussed above facilitates the delivery of various HIE applications and services which may be procured from a commercial software vendor, or developed by a system integrator or consulting organization, or provided by a potential HIE participant. There are several emerging Open Source software solutions are emerging and may be considered to be provided as services over the HIE networking infrastructure. A critical component of the HIE infrastructure that facilitates the integration of data and services is the middleware which is discussed in the next section.

### *Middleware*

As noted in the introduction, we use the term *middleware* to mean service modules that facilitate the integration of data and application software to exchange health data. This section addresses four types of middleware: integration engine, master person index (MPI, or EMPI), record locator service (RLS), and national provider identifier (NPI). Briefly defined, an integration engine translates data from one format to another and adjusts for differences in coding structure in the different data sets. The integration engine also provides for connectivity to multiple systems to move the data that is translated from the sending system to the receiving system. The MPI supports patient matching software and consolidates the results. The RLS identifies the location of existing sources of data and points the HIE to it. The NPI is provider matching software. One can read a full technical view of the actual steps by following one of the standard transactions on the Health Information Standards Panel website.<sup>48</sup>

### **Integration Engine**

This element of middleware is used to effectively and efficiently connect multiple computer systems and applications together. The integration engine is an invention that started in the late 1980's and generally accepted as one of the vehicles to achieve interoperability. Interface engines use standard protocols and transactions sets to improve the way in which these computer systems communicate. Additionally, the better interface engines have management tools which enable the ability to manage the connectivity, start, re-start, send, and re-send transactions.

### *Patient Matching Algorithms and Enterprise Master Person Index (EMPI)*

**Need for matching algorithms.** HIPAA regulation required the Secretary of the Department of Health and Human Services to develop a proposed rule for a national set of patient identifiers but these have been deferred because of public opposition to providing the ability for an entity to track all healthcare related information for an individual. The alternative is that many identifiers are used for an individual and medical records; information must be matched based on information about the individual – name, gender, date of birth, address, telephone, etc.

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<sup>47</sup> FCC, Broadband Opportunities for Rural America, quoted from [http://wireless.fcc.gov/outreach/index.htm?job=broadband\\_home](http://wireless.fcc.gov/outreach/index.htm?job=broadband_home), May 2, 2009.

<sup>48</sup> HITSP website, <http://www.hitsp.org/>, May 2, 2009.

**Conceptual process.** Matching of patient records and data must be performed by considering the known demographic (and, potentially, some medical data, e.g., blood type) data for the patient. Some data are more important in matching than other data. For example, last name and date of birth would be expected to be more important than phone number and address due to the frequency of the number of times data may change for many people. Substantial effort has been made using common sense and other methods to develop algorithms for patient matching. Some techniques use carefully-designed rule sets (referred to often as deterministic matching) while other techniques use more complex statistical methods (referred to often as probabilistic matching). The resulting aggregation of data by these algorithms is typically called a *master patient (or person) index* (MPI) or an *enterprise master patient index* (EMPI).

A mapping process divides all possible record pairs into three categories: (1) matched, (2) not matched, and (3) undetermined. The *sensitivity* of a matching rule is the probability that the rule indicates a match when the data, in fact, match. The *specificity* of a rule is the probability that the rule indicated a non-match when the data do not match. The goal is to have both measures as high as possible. False matches and failures to match data both have undesirable consequences which can impair patient care and undermine the credibility of the system and the using institution.<sup>49</sup>

**Functional process.** Matching of the patient data is substantially enhanced if the data are properly prepared. Best practices include data cleaning (removing punctuation in names and removing non-alphabetic data), data standardization (remove difference in upper and lower case, map nick names to standard names, use the U.S. Postal Service address service to put addresses in standard form), putting names in phonetic form (Soundex), and other processes. The matching may be required to make some exact matches among factors (e.g., last name, gender). Once the initial matches are made, a set of factors may be applied to remaining candidate near-matches to determine the most likely matches. Manual intervention may be required for those persons not matched by the process.

There are a number of solutions that provide MPI/EMPI capabilities. Those solutions can be categorized into proprietary enterprise/niche and open-source products.

### Proprietary Products

**Enterprise systems.** There are a number of patient matching algorithms used by various proprietary systems. Some of the larger vendors and organizations have gone through a substantial development process to produce effective EMPI modules. In the national category, several vendor EMPIs have been ranked best by KLAS as presented in web articles by those receiving the top ranking. (Actual KLAS data was not available). Examples include the following for the years indicated:

**Table 1. Sample KLAS Top Ranking EMPI Products**

Vendor	Product	Year
Initiate Systems	Initiate Patient (formerly Initiate Identity Hub)	2008
QuadraMed Corp.	QuadraMed MPI	2007
Madison Information Technology	Enterprise Master Patient Index	2003
Madison Information Technology	Enterprise Master Patient Index	2002

<sup>49</sup> California HealthCare Foundation, An Open Source Record Locator Service Built with CDE Code, [https://openhie.projects.openhealthtools.org/files/documents/42/73/chcf\\_os-cde\\_20070620n.pdf](https://openhie.projects.openhealthtools.org/files/documents/42/73/chcf_os-cde_20070620n.pdf), August 3, 2007.

The cost of these MPIs can be expected to be greater than \$100,000.

**Niche systems.** The California HealthCare Foundation published a report in August 2004 entitled *Patient Data Matching Software: A Buyer's Guide for the Budget Conscious*. This report focused on MPI systems with the total cost of ownership of less than \$50,000. Each of four MPI systems was evaluated with a data test and three of the four were recommended. These are:

**Table 2. 2004 CA HealthCare Foundation Niche MPI Product Evaluation**

Vendor	Product	Score
Intercon Systems	DataSet V Suite	4.1
LinkageWiz Software	Linkage Wiz	3.6
DQ Global	SureMatch	3.3

Neither of the above lists is meant to be a basis for selection but to be a starting point for investigating MPIs.

### Open Source Products

There are several known open source systems with examples below:

**Table 3. Sample Open Source Products**

Vendor	Product
Browsersoft	OpenHRE
Medsphere	Master Patient Index
WebReach, Inc.	Mirth

These open source systems are available at no cost other than possible support from the vendor or other resource familiar with the code.

### Record Locator Service

In an HIE, a record locator service is the part of the system that determines what records exist for a member and where the source data is located. The original model for a record locator service was documented by the Markle Foundation Connecting for Health Common Framework, using the design for Massachusetts SHARE, though some systems were in operation prior to that date. The key concept behind having a record locator service is that information sharing will develop as inter-networked regional and local health information networks. The decision was made because the expert panel thought that providers consider themselves as owners of the records and would want records to remain under local control rather than being included in a larger central repository (e.g., super-regional or national database). The Common Framework and the U.S. Nationwide Health Information Network effort are both based on this federated approach. However, in recent past, the value of centralized databases has emerged as organizations have sought to achieve greater value from the data that is shared.

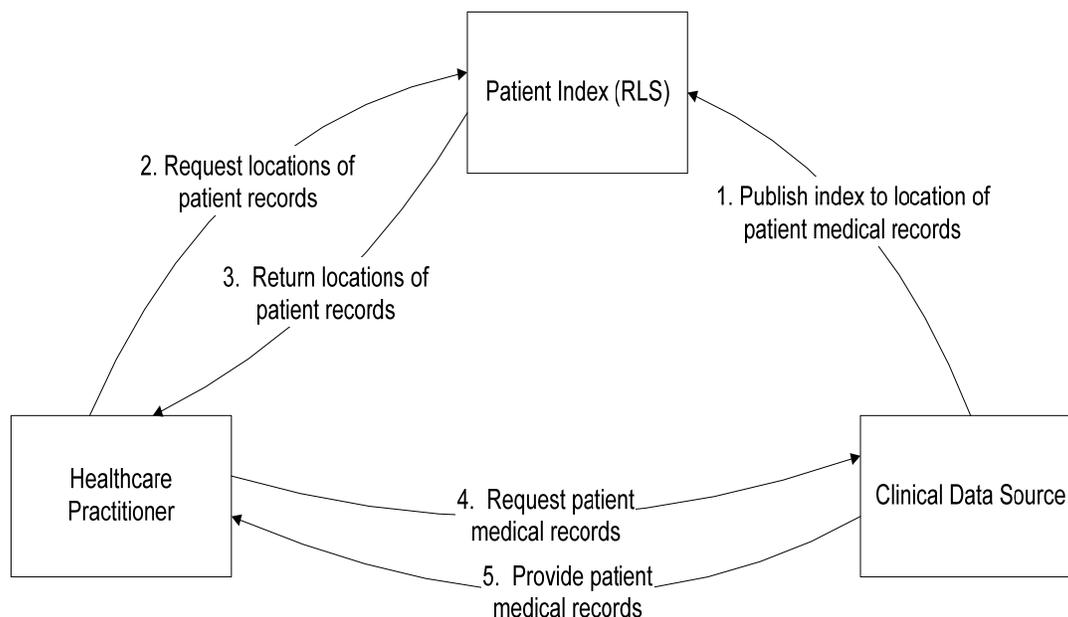
The record locator service includes these distinct functions:

- Manage participating provider identities;
- Maintain and publish a patient index;
- Match patients using an algorithm;
- Look up patient record locations (but not the records themselves);
- Communicate securely and maintain an audit log; and
- Manage patient consent to record sharing (under state laws and the new ARRA).

Note that the exchange of the identified patient records is part of the clinical data exchange and not of the record locator service.

The conceptual view of the record locator service (RLS) is shown below (from the Connecting for Health Common Framework).

**Figure 6. Conceptual View of the Record Locator Service**



This model is used for record locator services that supports a federated HIE model.

### *Provider Matching*

Several years ago, the situation with provider matching would have been similar to patient matching. In the later part of 2008, a National Provider Identifier (NPI) system was implemented under Medicare (and within a few months for at least some state Medicaid programs). While there have been some issues in the implementation, most of those have been navigated and there is a single NPI for most providers in the U.S.

From the point of view of systems, each organization should have developed its own cross-reference mapping of prior provider identification numbers to the new NPIs and be able to navigate to records using whatever designator is indicated for pre-NPI files.

## Applicable Standards

**Types of standards.** There are three types of standards involved in health data exchange. The first two are widely recognized and the third becomes apparent when one implements the first two. The types are (1) transactions standards – what data fields are transmitted and how they are organized for transmission, (2) semantic standards – the taxonomy of each code used in a data field, e.g., the ICD9 coding system, and (3) process standards – in what order do the transmissions fit into the workflow of the organization. Each of these is discussed below, following a clarification of what standards are.

### About Standards

It is useful to understand how standards organizations work because the process explains why the standards have become so generalized and complex in an attempt to satisfy all comers. There is one overarching standards guidance organization, the American National Standards Institute (ANSI). All standards development organizations (SDOs) in the U.S. and many overseas are members of and governed by the rules of ANSI. ANSI requires member SDOs to adhere to a *consensus* process, involving *all interested parties*. The normal lay definition of a *standard* is “something established by authority, custom, or general consent as a model or example” (Merriam-Webster). In fact, the “standards” developed by SDOs under ANSI are not standards in the normal lay sense of the term, but rather are aggregations of all commonly used data elements agreed to by the volunteers that staff SDOs.

An SDO that has had a fair amount of success in the Health Industry is Health-Level Seven (HL7). HL7 emerged in the late 1980’s and is still involved in establishing the various standards that are being used today or considered for use in the future.

### Core Standards

These are basic standards that are use in exchange of all information over the Internet.<sup>50</sup>

**Table 4. Core Standards**

Standard	Meaning	Comment
TCP/IP	Transmission Control Protocol/Internet Protocol	General standard for the Internet and most internal networks.
HTTP	Hypertext Transfer Protocol	Basic language of web pages. May also include Java, Javascript, Active Server Pages, and other languages.
LDAP	Lightweight Directory Access Protocol	Application protocol for querying and modifying directory services running over TCP/IP. May be used to access the person directory of a record locator system. (Wikipedia)
SSL or TLS	Secure Sockets Layer (or, more recently Transport Layer Security)	Cryptographic protocols that provide security and data integrity for communications over TCP/IP networks such as the Internet. (Wikipedia)

<sup>50</sup> Vermont Health Information Technology Plan: Strategies for Developing a Health Information Exchange Network, July 1, 2007, pp. 45-48.

Standard	Meaning	Comment
3DES	Triple Data Encryption Standard	This is three-time successive application of DES designed to overcome the limitation of a 56-bit key without changing the encryption algorithm. (Wikipedia)
URL	Uniform Resource Locator	Specifies where an identified resource is available and the mechanism for retrieving it. Translates to a Web address of the form nnn.nnn.nnn.nnn.

### Standards for Transactions

There are many standards development organizations and standards applicable to health systems and health data transactions. A few examples of the more important ones related to HIEs are listed in the two tables below. Note that many of these are “standards families”, not particular standards.

**Table 5. Transactional Standards**

Standard	Meaning	Comment
Message Formats		
HL7	Health Level Seven	A family of standards used in many aspects of health data exchange.
X12 (or ANSI ASC X12)	Official designation of the U.S. national standards body for the development and maintenance of Electronic Data Interchange (EDI) standards (Wikipedia)	Includes many XML standards for healthcare and insurance.
NCPDP	National Council for Prescription Drug Programs	A family of pharmacy data standards.
DICOM	Digital Imaging and Communication in Medicine	Standard for handling, storing, printing, and transmitting information in medical imaging. Both a transaction and a semantic standard.
IHE Integration Profiles	Integrating the Healthcare Enterprise Integration Profiles	IHE developed a family of interoperability profiles by utilizing HL7 standards for specific purposes.
HITSP Interoperability Specifications	Health Information Technology Standard Panel	HITSP has developed a whole system of specifications including creating processes to harmonize standards, certify EHR applications, develop nationwide health information network prototypes and recommend necessary changes to standardize diverse security and privacy policies.
CDA	Clinical Document Architecture	XML-based “standard” intended to specify the encoding, structure and semantics of clinical documents for exchange.

Standard	Meaning	Comment
CCR	Continuity of Care Record	Patient health summary standard developed by ASTM, several medical societies and a number of vendors.
CCD	Continuity of Care Document	XML-based markup “standard” intended to specify the encoding, structure and semantics of a patient summary clinical document for exchange. The CCD specification is a constraint on the HL7 CDA (further limits it). HITSP has selected the CCD (not the CCR).
<b>Message Transport</b>		
SOAP	Simple Object Access Protocol	Protocol specification for exchanging structured information in the implementation of Web Services in computer networks. Used with XML.
XML	Extensible Markup Language	Data exchange language using tags to designate variables. Simple and powerful.

### Semantic Standards

Semantic or data standards define the range of values that descriptive variables may have including the meaning of each value. When bringing data together from disparate systems, the standards used will vary therefore normalizing the data is very important to the provider when treating the patient. The standards listed below are particularly important to HIE’s if the HIE is to provide the utmost value to the provider.

**Table 6. Semantic Standards**

Standard	Meaning	Comment
ICD	International Classification of Diseases	Published by the World Health Organization
CPT	Current Procedural Terminology	Describes medical, surgical, and diagnostic services. Maintained by the American Medical Association.
HCPCS	Healthcare Common Procedure Coding System	Based on CPT and designed to provide a standardized coding system for describing the specific items and services provided in the delivery of health care. Used for reporting to Medicare, Medicaid and other payers.
LOINC	Logical Observation Identifiers Names and Codes	Database and universal standard for identifying medical laboratory observations developed by Regenstrief Institute.
SNOMED	Systematized Nomenclature of Medicine	A multi-axial, hierarchical classification system where 11 axes represent classification features.

RxNorm	Standardized nomenclature for clinical drugs	Produced by the U.S. National Library of Medicine.
NDC	National Drug Code	Universal product identifier for human drugs.

### Process Standards

Processes that are communicated in standard transactions and data standards often follow different workflows in different settings. If the workflow is different, the sequence of construction of a standard transaction with standard data may logically follow in one setting but not the next because some essential information is not available as the transaction is constructed. There is little systematic reporting of process standard needs but those who implement standards deal with these issues and realize the need is real.

The closest the industry has to process standards is the use cases that have been developed. The HITSP HIE use cases are examples of recent HIE Use Case information.

## **Section 5 - Evaluating a potential HIE opportunity**

Based on the last data set available in the web based State Dashboard, there are at least 475 health information exchange (HIE) type projects and regional health information organizations (RHIO) located around the nation, and many other initiatives around the world.<sup>51</sup> Most of these HIEs are driving the application of technology to help providers:

- Improve patient safety by reducing medication and medical errors;
- Increase efficiency by eliminating unnecessary paperwork and handling;
- Providing caregivers with clinical decision support tools for more effective care and treatment;
- Eliminate redundant or unnecessary testing;
- Improving public health reporting and monitoring;
- Engaging healthcare consumers regarding their own personal health information;
- Improving healthcare quality and outcomes; and
- Reducing health related costs.

As these HIE efforts mature and grow, more and more providers are faced with the question of whether they should join a HIE effort or an existing RHIO. The recent federal stimulus package, which sets HIE as a priority, will only spur this growth as providers make use of the funding to adopt electronic health records and share data with other providers.

This section, along with the HIE Evaluation Checklist in Appendix A, will help an organization define and understand their value proposition, or perceived benefit, from participating in a HIE and guide them through the decision making process. It will guide readers as they identify the synergy between their organization and other participants by outlining questions that should be asked before deciding to participate and allocate resources. The objective of any evaluation is to ensure a shared vision and better prepare both organizations for transition process.

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<sup>51</sup> <http://www.himss.org/StateDashboard/>

## *Understanding the Goals and Philosophy of the HIE*

The initial questions asked should be aimed at determining whether there is a cultural fit between the ultimate goals and vision of both organizations. In the early stage of evaluating the HIE opportunity, it is important to identify common or shared elements between your organization's and the HIE's mission, goals, priorities and resources.

- Ask to review organizational documents (i.e., the charter, business plan, organization chart) that describe the mission, vision and/or philosophy of the HIE, as well as, any goals and objectives that may have already been established. Also review other documents, such as, technology specifications, presentations, proposals, and papers that describe how the HIE expects to reach its goals and objectives. The latter are sometimes developed after the organizational documents and often reflect more refined strategies or changes in approach or tactics.
- Determine whether the needs of patients, physicians and others providers have been addressed and the priorities balanced against the identified needs. Determine whether this HIE initiative will serve the entire population, or only specific groups, before expanding across the community.
- If the HIE has already adopted a model or approach (as described in Chapter 3) to address interoperability, does it fit with the expectations of your organizational objectives? If one hasn't been selected, how will your organization participate in this decision making process? How will you uncover the value proposition that the HIE's model will offer to your organization, other stakeholders and the community as a whole?

The HIE vision is to readily share clinical information electronically between providers, capture and analyze clinical information for improved decision support and public health reporting, and support health and wellness information for use by consumers. However, at this early stage the scope and complexity of each HIE will vary and new participants will need to understand whether the HIE will work towards incremental improvements by focusing on one or two initiatives at a time or using a "big bang" approach to push for a radical or massive transformation. If it is the latter, is your organization ready to make a big jump, too?

- Talk to the HIE's current members and representatives from organizations planning to join. These will be your business partners going forward so it is important to know diverse perspectives are represented and stakeholder representatives are prepared for cooperation and collaboration. Also identify those key stakeholder organizations that haven't yet joined or have refused. It is important to explore the reasons why and identify potential barriers or issues that may arise for your organization.

Widespread HIE will require a public-private collaborative approach. It is important to evaluate the potential competitive barriers that may exist for your organization with these business partners. If barriers do exist, work with these business partners and your organization to overcome these for the important work that lies ahead.

More and more we can expect to see multiple HIE initiatives operating in a community as the national health information infrastructure is built out.<sup>52</sup> If there are multiple efforts, determine whether they will compete with or compliment the work of the other(s).

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<sup>52</sup> <http://aspe.hhs.gov/sp/NHII/Documents/NHIIReport2001/default.htm>

- Based upon your review of information provided by the HIE and conversations with stakeholders and others, is there alignment between the goals and philosophy of the HIE and those of your organization? If so, you now need to turn your attention to whether your organization has the resources and is prepared to participate in an HIE.

### *Understanding to what your organization will need to commit by participating in an HIE*

Participation in a HIE is a serious undertaking. It is important to determine whether your governing body is ready for a significant commitment of resources. This may include participation or subscription membership fees, upgrade(s) to IT systems and infrastructure and access to capital. It may involve time commitment of several key positions/departments such as the CFO, CEO, CIO, CMO, Compliance Officer, Information Technology, Finance staff, Compliance staff, Health Information Management staff, Medical staff as well as other Clinical Departments. It may also result in some lost revenue and productivity due to changes in workflow processes and during training and implementation periods.

Participation in an HIE requires written formal agreements between partner organizations (business associates), data users and data providers. These agreements describe the sharing of clinically relevant information with the HIE, requirements, terms and the responsibilities of each party.

- Your organization will need to be prepared to enter into an agreement that fits with your function in the HIE.
- If the HIE doesn't already have business associate, data provider and/or data user agreements, they should have one developed before the first patient data is ever exchanged.

### *Understanding the prevalence of nationally-accepted standards*

An effective HIE will be based upon use of established standards and certification which helps facilitate this migration process and establish trust in all stakeholders. HITSP has selected interoperability standards to support a specific set of use cases, and is working to generalize those selections for additional use. The Certification Commission for Healthcare Information Technology (CCHIT) has defined a process confirming that a system or component complies with its specified requirements and is acceptable for operational use.<sup>53</sup> CCHIT certification has been divided into two separate processes, the development of certification requirements and the practical certification by an authorized organization using previously developed certification requirements.

The HIE and its participant organizations will need to establish and fulfill regulatory, functional, technical and other mandatory requirements. The EHR systems connected to the HIE will need to possess the same level of functionality, security and privacy protection.

The reliability and validity of the data is important to ensuring improved patient care and minimizing the risk of errors. Review the HIE's policy on matching demographic data and determine the number of data points used to produce positive matches.

### *Understanding the value for users of the HIE information and data*

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<sup>53</sup> <http://www.cchit.org/index.asp>

As research indicates, most HIE participants are looking for secure IT systems that offer complete documentation and charting capabilities, computerized practitioner order entry, digital images, medication administration and ePrescribing, decision support and a single sign-on. Assess the HIE's ability to incorporate consumer, provider and other stakeholder interests into the development of their business plan. Without having direct knowledge of specific interests, the HIE may be evolving into a community solution that will not be widely used.

The existence of the technology and data exchange capabilities will not automatically generate actual value and user satisfaction. For example, a Finland study at three hospital districts looked at usability and benefits.<sup>54</sup> The federated information system consists of a record locator service as a central reference database containing links to patient data stored in their legacy systems. Provider access was through web browsers and patient information included visits, critical data laboratory results, images and reports and referral and discharge reports.

Results from this study demonstrate the importance of user testing and training. More active users reported definite advantages and tended to be more satisfied than less active users, however, 41% of the physicians had difficulty logging in and 62% had difficulty using links of the locator service or finding patient information from the legacy systems.

- Ask the HIE leaders and physicians about the usability of the system and usefulness of the information and/or data provided, if it is already being tested or has been fully implemented. There should be a certain level of ease of logging on, navigating through the system and finding data and information. Users should also test the quality of the data to ensure it is accurate, timely, and complete. Your organization should also confirm that the same data/information is not already and more easily available elsewhere for less cost.
- Identify the interface capabilities and whether there are limitations with legacy systems, which are older systems that may have difficulty communicating with newer ones. Determine if your organization or other participating organizations have legacy systems required to interface with the HIE and whether there are plans for upgrades to enable the sharing of clinical information.
- Identify the data sources that are not currently available to the HIE, such as, independent laboratory or pharmacy, and plans for adding this information in the future.

### *Understanding the Economics and Financial Sustainability of the HIE*

Identify the specific benefits of the HIE and to whom they accrue. Misalignment of incentives, especially with payment and competition, will threaten the long term stability of the effort. For example, one of the most widely accepted key benefits of an HIE is the reduction in duplicate or redundant ancillary testing, but this usually results in a reduction in revenue for the hospital and some clinics. While the reduction may be beneficial for some facilities who are working to reduce test volume due to staff and facility limitations, others will see the real benefit (cost savings) accrue only to the payers, unless steps have been taken to ensure savings are shared across all participants and/or investments are proportional.

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<sup>54</sup> Harno, Kari., Healthcare Information Exchange in Regional eHealth Networks, Implications for Initiatives in Advancing Shared Care, presented at eTelemed 2009; Cancun 1,-7.2.; to be published

Australia recognized that the largest component of the costs associated with implementation is most often absorbed by providers with a fairly even split between the replacement costs of their existing electronic medical records and the costs of building interfaces.<sup>55</sup>

- Determine whether your organization's participation in the HIE requires a return on investment (financial or otherwise) or if participation is viewed as a cost of doing business or in support of the public good. Understand the accrual of benefits, to whom they accrue and in what proportion. If some stakeholders accrue a significant proportion of the benefits, ask if they share proportionately in responsibility for the costs.
- Identify past and future funding streams, such as grants, transaction fees, service fees, subscription fees, licensing/maintenance fees, member dues, etc. What is the estimated cost to your organization and is there an expected financial benefit to your organization? Is your organization prepared to make the necessary commitment of internal resources, such as upgrading IT systems and infrastructure?
- Determine the needs that are being addressed or services provided to the community, both currently and planned for the next 6 to 12 months. Does the HIE bring information to the point of care? If it doesn't, determine whether there is an anticipated or planned timeline to do so or how the technology adds value to the HIE and for which stakeholders.

Some benefits are difficult to quantify and value, but they are equally if not more important to the economic and sustainability of the HIE:

- Improved quality outcomes;
- Increased patient safety and satisfaction;
- Improved staffing efficiency and productivity;
- Reduced liability;
- Disaster recovery capabilities; and
- Enhanced reputation in the community and increased goodwill.

The important question here is does your organization buy into the stated benefits and expect to realize value by participating in this HIE? If so, is your organization willing to pay their fair share to support this effort.

### *Understanding Risks*

The Australian study also recognized that the greatest risk was not achieving value from interoperability, but whether or not rigorous standards are developed and implemented.

- Review participation, data user/sharing and/or business associate agreements to determine the assignment of liability and the potential impact upon your organization. Consideration should be made to who the other HIE participants will be and whether there is a downside to joining or not.

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<sup>55</sup> The economic benefits of health information exchange interoperability for Australia, Peter Sprivilis; et al, Australian Health Review; Nov 2007; 31, 4; ABI/INFORM Global page 531.

- Determine if your organization is joining as a participant or will have a seat on the governing body. If the latter, your organization will need to be especially cognizant of the fiduciary responsibilities.
- Determine whether the HIE has defined how success and/or failure will be defined and measured. Understand existing or potential threats to success and look for any signs of weakness, such as, lack or waning of interest by other participants, misalignment of incentives, decreasing focus on identifying and addressing participant or stakeholder needs, etc.

The cost of participation in an HIE will most likely cause some amount of competition for internal resources (capacity, skills, funding, etc) and may impact other initiatives.

- Determine whether your participation in the HIE will result in delays, re-work, or discontinuation of other projects and identify those that might be adversely impacted or threatened.

### *Understanding Applicable Regulations*

The exchange of private health information whether on paper or electronically is a delicate matter and closely regulated. The speed of the Internet increases concerns about the potential of unintended disclosures and misuse. As a result, a careful analysis of the HIE's efforts to comply with regulations, including HIPAA, ARRA and state laws is needed prior to your organization becoming a member of the HIE. While the current HIPAA regulations do not adequately govern HIEs, new regulations and revisions are expected to be released.

- Involve your compliance and privacy officer and/or legal counsel early in the evaluation phase. Identify the safeguards that are in place to ensure privacy and security and understand the process used for reconciling and reporting breaches.

This white paper does not include a detail discussion around the privacy rules and regulations.

### *Understanding Leadership and Governance*

As a collective group, the governing body is responsible for accountability, authority and oversight.<sup>56</sup> Many HIEs start with a project steering committee and later identify the need to establish a formal organizational and governance structure, a RHIO, as the number of partners increase, clinical and technology plans are brought into focus and implementation nears. The strength of the HIE's leadership and organizational structure is an important indicator of success. As a result, leaders should have a shared vision and represent various disciplines, cultures and perspectives to avoid narrow views. The leadership, and/or governing body members, should have balanced representation and strengths (clinical, technical, administrative, financial, management, legal). They should be effective leaders and champions who can build trust, facilitate the creation of shared vision and goals, engage stakeholders, communicate and most importantly be accountable to the community as a whole, and not to their individual interests.

As the HIE progresses, it should begin to function more like a business and less like a collaborative project.

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<sup>56</sup> HIMSS RHIO Guide

- Review the flow of control and decision making and ask for a written board profile, job descriptions, and organizational chart to determine whether the structure seems appropriate.
- If your organization has a seat on the governing body, be prepared to actively participate and accept fiduciary responsibility for establishing policy and oversight.
- If your organization joins as a member or participant of the HIE, understand the process(es) for communicating the needs of your organization and influencing policy and oversight.

### *Understanding the HIE's Maturity*

The maturity of the HIE may play a significant role in the decision making of how your organization may wish to participate. Your organization may want to be in the front end formation and invest fairly substantially in terms of resources to form, guide and build the HIE, or your organization may want to wait until the HIE is already formed and operational before they decide to invest in it. Regardless of the organizational goals, one must understand the typical stages that most HIEs are going through from concept stage to a fully functional, self-sustaining operation.

The stages can be divided into finer classifications but typically they include:

- **Concept** - In this stage there is a recognition that an HIE can help improve the quality of care and reduce health care costs for its community (local, state, region, etc). Generally, a group of stakeholders identify this need and embark on research to determine the validity of its hypothesis. Once the hypothesis is viewed as credible, they are ready to move into the next stage.
- **Formation** - At this stage the stakeholders who developed the concept move toward getting organized. They expand the membership, develop a structured committee complete with a defined charter, they ask for membership participation, and then they move to create a business plan which should include: what the HIE business will be, what services to be offered, the funding mechanism, the technologies required to support the business, the marketing program and the governance and organization structure. Once a solid business plan exists, the HIE is ready to move into the next stage.
- **Fundraising** - By this stage an agreed upon business plan exists and funds are raised to run the operation of the HIE. There are many models across the country being used to raise capital to start these operations including: grants, membership fees and donations. Once the initial capital has been raised, the HIE is ready to move into the next phase.
- **Start-up** - In this stage the initial team to run the operation is put into place and the technology secured, marketing is started and the operations can begin. The more successful business models include running the operations as if it were a true business operation and not an outgrowth of a development project. Once the start-up operations has benefits accruing, revenue flowing, and new members are involved beyond the initial stakeholder set of members, the HIE is ready to move into the next stage.
- **Growth** - At this point the marketing efforts of the HIE are fixed on growing the business. The goals of the HIE to improve quality of care and reduce health care costs are achieved when the majority of the stakeholders in the community are part of the HIE. At this point, depending on the business plan revenue stream (i.e., subscription, transaction, grants, donations), the HIE should be able to run the operations successfully.
- **Sustainability** - The operation is able to sustain the growth, expand its technical capabilities and services and add value into the community. Once this stage is reached, the community should be able to see the tangible results of the HIE operations. The goal of any HIE should be to reach this stage.

As the HIE gathers the information focused on these areas, an understanding can be developed as to where the HIE fits along the continuum and what work is left before the initiative is fully implemented.

Ultimately, the HIE initiative should mature into a formal business venture with strong oversight. If the initiative is not progressing through the typical stages of maturity, it may be a sign that the viability of the business plan is in jeopardy.

At this point, it can be clearly seen how close the HIE is to reaching the ultimate goal of connecting with the National Health Information Infrastructure (NHII) later called Nationwide Health Information Network (NHIN), which is:<sup>57</sup>

- An initiative set forth to improve the effectiveness, efficiency and overall quality of health and health care in the United States;
- A comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that would improve decision-making by making health information available when and where it is needed;
- The set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health; and
- Voluntary.

The NHIN is NOT a centralized database of medical records or a government regulation, but rather a way of connecting a HIE in a community. It is needed to:

- Improve *patient safety* (alert for medication errors, drug allergies, etc);
- Improve *healthcare quality* (includes having the availability of complete medical records, test results and x-rays at the point of care, integrating health information from multiple sources and providers, incorporating the use of decision support tools with guidelines and research results, etc);
- For *Bioterrorism* detection (NHIN will enable real-time aggregation of health data to detect patterns);
- Better inform and empower health care consumers regarding their own personal health information; and
- Better understand health care *costs*.

Local, regional and state-wide *HIE* efforts wishing to connect to the NHIN must adopt technologies that meet established standards and coordinate efforts to exchange information within and outside of their network. The ultimate goal is to move away from silos of information (whether in paper or electronic) and toward portable health information that is available at the point and time of care each and every time.

## **Section 6 – Conclusion – Making Your Decision**

It's not a matter of whether to join an HIE, it's a matter of when to join. This paper was designed to facilitate an organization understanding of HIEs and assist in evaluating their assessment with engaging in an HIE. It described the different models being implemented across the nation and the various standards that must be considered. Having the background information supports using section 5 which is a guide or list of questions to consider when assessing to join an HIE. Participating in an

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<sup>57</sup> <http://aspe.hhs.gov/sp/NHII/FAQ.html>

HIE is a business venture that must be given careful thought. After all, it takes an entire community (all stakeholders) to make a difference in trying to help transform healthcare and achieve the many benefits.

## Appendix A – HIE Evaluation Checklist

Here is a link to a Microsoft Excel version of this document: <http://www.himss.org/content/files/HIEEvaluationChecklist.xls>

[Company/Hospital Name]

HIE Evaluation Checklist				
[Select a criteria score of 1 to 5] <b>5 = Strong</b> <b>3 = Neutral (neither helps nor hurts)</b> <b>1 = Needs Improvement</b>  <b>NA = Not Applicable</b>	Complete	Quality of Item	Aligns with Organization Philosophy	Item Description
	(✓, ✗)	(1 - 5, NA)	(Y, N)	
<b>HIE General Information - understanding the goals and philosophy of the HIE</b> The most basic questions will help determine if there is a fit between the ultimate goals and vision of both organizations or your organization and the existing HIE. In the early stage it is important to determine that there is a fit with your organization's mission, goals and priorities.				
1	Does this HIE have Governing Principles? What is the legal structure of the HIE?			
	Is there a governing body/Board of Directors/steering committee in place?			
	Are providers directly involved at the governance level?			
	Is there a written board profile and board member description?			
	Does the governing body/Board of Directors/steering committee make final decisions and are they accountable for those decisions?			
	Are there executive officers of the HIE?			
	Are there organizational requirements for joining this HIE?			
2	Does this HIE have a Business Plan? What value does the HIE offer?			
	Are there serious underlying business/technical/financial issues?			
	Is there an existing project plan/rollout schedule?			
	Is the project plan/rollout schedule realistic?			
	What services are currently being provided? What services are planned for the next 6 – 12 months?			
	What is the overall timeline of the HIE?			
	Are the needs of the providers being addressed?			
	Are the needs of the consumers being addressed?			
	Is there a 'Go-to-Market' plan?			
	Is there a change management process/plan identified/created for your participants?			
	Is there a plan for training the local community and patients/consumers?			
3	Does this HIE have a mission statement, vision, and end goal?			

HIE Evaluation Checklist			
<p>[Select a criteria score of 1 to 5]  <b>5 = Strong</b>  <b>3 = Neutral (neither helps nor hurts)</b>  <b>1 = Needs Improvement</b></p> <p><b>NA = Not Applicable</b></p>			
	Complete	Quality of Item	Aligns with Organization Philosophy
	(✓, ✗)	(1 - 5, NA)	(Y, N)
<p>4 Is there a definable scope to this HIE?</p> <p>5 Is there a quantifiable measurement of success or failure? Does this HIE fall into one of the standard models or approaches?</p> <p>6 Are there other organizations in the HIE?</p> <p>7 Are other organizations considering participation?</p> <p>8 Have any organization declined to join this HIE?</p>			
<p><b>Financial Commitment and Benefits</b> - understanding the economics and sustainability of the HIE</p> <p>You will need to be aware of the financial costs and benefits of participation in an HIE.</p>			
<p>1 Has there been external funding of the HIE? Is there a participation cost to our organization (capital vs. on-going subscription fees, transaction fees, licensing/maintenance fees, etc)?</p> <p>2 Is there a promised financial benefit to this HIE? What are the costs (financial, in-kind, or other resources)?</p> <p>3 Fixed, variable? Projected over time?</p> <p>4 What return on investment will our organization realize? What benefits accrue to others? Do they share in responsibility for the costs?</p>			
<p><b>Organization Internal Commitment</b> - understanding the internal requirements of participating in an HIE</p> <p>You will need to determine if your organization is willing to commit to this endeavor at the expected level.</p>			
<p>1 Is the HIE opportunity aligned with our own strategic direction? Can we afford the investment (people and technology) needed to pursue this opportunity?</p> <p>2 Is Executive Management willing to sponsor and support this endeavor?</p>			

HIE Evaluation Checklist																																															
<p>[Select a criteria score of 1 to 5]  <b>5 = Strong</b>  <b>3 = Neutral (neither helps nor hurts)</b>  <b>1 = Needs Improvement</b></p> <p><b>NA = Not Applicable</b></p> <p>Are there dedicated resources?                      (time commitment of several key positions/departments - CFO, CEO, CIO, CMO, Compliance Officer, Information Technology, Finance, Compliance, Information Management, Medical Staff, Clinical Departments, etc.)</p> <p>4 Do the resources have the proper skills and talent to be successful?</p> <p>5 If additional resources are needed, can we get what we need?</p> <p>6 Are additional partners (outside vendors) needed to accomplish our goals?</p> <p>7 If additional partners (outside vendors) are needed will they complicate our situation/goals?</p> <p>8 Can our IT infrastructure handle such an endeavor?</p> <p>9 Are our providers onboard or will there be an internal power struggle?</p> <p>10 Is there a provider champion onboard?</p>	<table border="1"> <thead> <tr> <th>Complete</th> <th>Quality of Item</th> <th>Aligns with Organization Philosophy</th> <th>Item Description</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">(✓, ✗)</td> <td style="text-align: center;">(1 - 5, NA)</td> <td style="text-align: center;">(Y, N)</td> <td></td> </tr> <tr><td> </td><td> </td><td> </td><td> </td></tr> </tbody> </table>	Complete	Quality of Item	Aligns with Organization Philosophy	Item Description	(✓, ✗)	(1 - 5, NA)	(Y, N)																																							
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(✓, ✗)	(1 - 5, NA)	(Y, N)																																													
<p><b>Technical Information</b> - understanding the technology behind the HIE                      Ensure that your organization can handle all technical requirements.</p>																																															
<p>Are requirements clearly defined and are they technically feasible?</p> <p>1</p> <p>2 What type of data model will be used?                      Who is responsible for maintaining the data model (service/support)?</p> <p>3</p> <p>4 Is there a proof-of-concept?                      Has the decision been made if the technical solution is "buy or build"?</p> <p>5</p> <p>6 Is there a vendor requirement to join? Must you have like technologies at some level?</p> <p>7 Does this solution involve new or unproven technologies?</p> <p>8 Is the solution scalable for future growth opportunities?</p>	<table border="1"> <tbody> <tr><td> </td><td> </td><td> </td><td> </td></tr> </tbody> </table>																																														





[Company/Hospital Name]

**Cell:** D4

**Comment:** Has the HIE considered this point?

**Cell:** E4

**Comment:** How important is this point to your organization?

**Cell:** F4

**Comment:** Does this point help validate your organization's own Mission Statement, Values and/or Goals?

## Appendix B – Understanding Applicable Regulations

### HIPAA

The Health Insurance Portability and Accountability Act (HIPAA) was enacted by the U.S. Congress in 1996. Title II of HIPAA, known as the Administrative Simplification provisions, addresses, among other things, the privacy and security of individuals' health information by establishing a federal standard for the use and disclosure of health information. This federal standard generally preempts state privacy laws except for those that establish stronger protections.

The use and disclosure provisions of HIPAA apply to “covered entities” which include health plans (and employer-sponsored plans), healthcare clearinghouses such as billing services, and health care providers that transmit health care data in a way that is regulated by HIPAA.<sup>58</sup> Pursuant to the requirements of Title II, DHHS promulgated five rules regarding Administrative Simplification. Two are of interest here: the Privacy Rule and the Security Rule.

#### Privacy Rule

The HIPAA Privacy Rule regulates the use and disclosure of certain information held by covered entities. It establishes regulations for the use and disclosure of Protected Health Information (PHI). PHI is any information held by a covered entity which concerns health status, provision of health care, or payment for health care that can be linked to an individual.<sup>59</sup> This is interpreted to include an individual's medical record and payment history.

A covered entity may disclose PHI to facilitate treatment, payment, or health care operations<sup>60</sup> or if the covered entity has obtained authorization from the individual.<sup>61</sup> When a covered entity discloses PHI, it must make a reasonable effort to disclose only the minimum necessary information required to achieve its purpose.<sup>62</sup>

Other provisions of the Privacy Rule require that covered entities provide copies of PHI to the individual within 30 days of requesting it<sup>63</sup>, give individuals the right to request corrections of inaccurate PHI<sup>64</sup>, and require covered entities to keep track of disclosures of PHI.<sup>65</sup> Other provisions require that a covered entity designate a privacy officer<sup>66</sup>, establish privacy and disclosure policies to comply with HIPAA<sup>67</sup>, train employees with respect to privacy policies<sup>68</sup>, establish sanctions for employees who violate privacy policies, accept requests not to disclose PHI for certain purposes, issue a privacy notice to patients concerning the use and disclosure of their protected health information, and establish administrative systems to respond to complaints.

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<sup>58</sup> 45 C.F.R. 160.103.

<sup>59</sup> 45 C.F.R. 164.501.

<sup>60</sup> 45 C.F.R. 164.524(a)(1)(ii)

<sup>61</sup> 45 C.F.R. 164.502(a)(1)(iv)

<sup>62</sup> 45 C.F.R. 164.502(b)

<sup>63</sup> 45 C.F.R. 164.524(b)

<sup>64</sup> 45 C.F.R. 164.526

<sup>65</sup> 45 C.F.R. 164.528

<sup>66</sup> 45 C.F.R. 164.530(a)

<sup>67</sup> 45 C.F.R. 164.528

<sup>68</sup> 45 C.F.R. 164.530(b)

## Security Rule

The HIPAA Security Rule specifically focuses on the safeguarding of electronic protected health information (E PHI).<sup>69</sup> Three types of security safeguards are required for compliance: administrative, physical, and technical.<sup>70</sup> For each of these types, the Rule identifies various security standards, and for each standard, it names both required (must have) and addressable (at discretion of covered entity) implementation specifications.

Administrative safeguards include written procedures and a security officer, clearly identified employees or classes of employees who have access to E PHI, employee training program regarding handling of PHI, vendor PHI policies for vendors providing outsourced services, disaster recovery procedures, provision for periodic internal security audits, and procedures for addressing and responding to security breaches.<sup>71</sup>

Physical safeguards deal with controlling physical access to protect against inappropriate access to PHI. Physical safeguards include control of introduction and removal of hardware and software from the network to assure that PHI is not compromised, control of access to equipment containing PHI, controlling access to hardware and software used with PHI, facility security (including security plans, maintenance records, and visitor sign-in and escorts, workstations not in high-traffic areas and monitor screens not viewable, and similar provisions) and training required of subcontractors.<sup>72</sup>

Technical safeguards deal with controlling access to computer networks and to ensuring that only the intended recipient receives a communication. Information sent over an open network must be encrypted. Each covered entity is responsible for assuring that PHI under its control is not inappropriately altered or deleted. Covered entities must authenticate other covered entities it communicates with using one of various methodologies. Risk analysis and risk management programs must be documented.<sup>73</sup>

## *American Recovery and Reinvestment Act*<sup>74</sup>

The American Recovery and Reinvestment Act of 2009 (ARRA) adds a number of provisions to HIPAA. These HIPAA provisions are contained in the portion of ARRA called the Health Information Technology for Economic and Clinical Health Act (HITECH Act). These modifications and additions pertain to the status of business associates, marketing and sales of PHI, electronic health records, disclosures of the limited or minimum necessary data set, privacy and security breaches, education programs, changes in enforcement, and penalties for violations of privacy.

## Business Associates

Under ARRA, HIPAA standards apply directly to business associates.<sup>75</sup> New entities that were not contemplated when HIPAA was passed such as personal health record vendors, regional health information organizations, and health information exchanges are required to have business associate agreements and thus are subject to the privacy and security rules of covered entities.<sup>76</sup>

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<sup>69</sup> 45 C.F.R. 164.105.

<sup>70</sup> 45 C.F.R. 164.306(c).

<sup>71</sup> 45 C.F.R. 164.308.

<sup>72</sup> 45 C.F.R. 164.310.

<sup>73</sup> 45 C.F.R. 164.312.

<sup>74</sup> This section closely follows the HIMSS webinar on ARRA Privacy and Security by Lisa Gallagher, Feb 23, 2009.

<sup>75</sup> American Recovery and Reinvestment Act of 2009 (ARRA), §13404.

<sup>76</sup> ARRA, §13408.

## **Marketing/Sale of PHI**

ARRA provides new restrictions which prohibit the sale of PHI for various health-related purposes. Marketing communications are not considered health care operations. ARRA prohibits a covered entity or business associate from receiving payment for PHI without authorization from the individual.<sup>77</sup>

## **Electronic Health Records**

If an individual's PHI is maintained in an electronic health record, ARRA provides an individual the right to receive an electronic copy of his/her PHI or have it transmitted to a third party.<sup>78</sup> Such an individual may request an accounting of disclosures of his/her PHI made in the three years prior to the request. The Secretary may take into account the usefulness of the information and the cost burden for such disclosure accounting.<sup>79</sup>

## **Disclosures**

A covered entity should limit disclosures to the limited data set or to the minimum necessary data (to be described by the Secretary within 18 months) to fulfill the needs of the disclosure.<sup>80</sup>

## **Breach Notification**

The ARRA establishes a federal security breach notification requirement in the event of a breach of PHI. This requires that each individual be notified if his/her unsecured PHI is accessed, acquired or disclosed as a result of the breach. The covered entity is required to notify the Secretary of HHS and prominent media outlets if data from more than 500 individuals is involved. The Secretary shall make public such breaches on a website.<sup>81</sup>

## **Education Programs**

The Office of Civil Rights will develop and maintain a national education initiative regarding the uses of PHI, including programs to educate individuals about the potential uses of their PHI, the effects of such uses, and the rights of individuals with respect to such uses. Such programs shall be conducted frequently and in a variety of languages.<sup>82</sup>

## **Enforcement/Penalties**

ARRA allows for criminal penalties to apply to individuals who disclose PHI without authorization.<sup>83</sup> The act provides a system of higher civil monetary penalties and provides a system for distribution of the penalties collected. ARRA institutes periodic audits of covered entities and business associates and allows state attorneys general to bring civil actions on behalf of residents of the state.<sup>84</sup>

## **State Laws**

HIPAA rules take precedence over state laws unless state laws are more restrictive than HIPAA. Many state laws that impose additional (or different) privacy requirements address health diagnoses involving a high degree of personal sensitivity or social stigmatization (e.g., HIV AIDS, substance abuse, behavioral/mental health and genetic testing). Such state laws often require covered entities to

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<sup>77</sup> ARRA, §13405-13406.

<sup>78</sup> ARRA, §13405(e).

<sup>79</sup> ARRA, §13405(c).

<sup>80</sup> ARRA, §13405(b).

<sup>81</sup> ARRA, §13402.

<sup>82</sup> ARRA, §13403.

<sup>83</sup> ARRA, §13409.

<sup>84</sup> ARRA, §13410.

obtain some form of legal permission before they are authorized to disclose the health information for purposes other than those expressly identified in the state law. This can have two impacts. If the information is collected electronically, the covered entity may need to obtain permission before transferring it. But, the information may not be collected and stored with other information so users of the patient data may simply have an incomplete picture of the patient's health. Certain drugs that would indicate the sensitive conditions may not be in the electronic files so another treating physician may not know all the patient's medications.

## Appendix C – SandlotConnect® Case Study

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**Organizational Contacts:** Telly Shackelford, 817-810-5219, [tshackelford@sandlotmd.com](mailto:tshackelford@sandlotmd.com)

### *Background*

#### **Regional Business Environment & Demographics**

Sandlot, LLC was developed by North Texas Specialty Physicians, a 600 doctor IPA in Fort Worth, TX, to build SandlotConnect®. SandlotConnect® currently serves the residents and physicians of Tarrant County. There are approximately 1.7 million citizens living in Tarrant County, with over 1,100,000 unique patients participating in SandlotConnect®. Sandlot looks to expand its products and services into additional geographic locations to better serve physicians and patients outside Tarrant County. Sandlot growth and development will also likely include additional interoperable EMRs and a patient health record with patient access.

Tarrant County, Texas is one of the fastest growing urban counties in the United States. Tarrant County is home to Texas Health Resources, one of the largest non-profit health care delivery systems in the United States. Texas Health Resources currently operates seven hospitals that are connected to and feed clinical information into SandlotConnect®. Also connected to SandlotConnect® are 350 Tarrant County physicians who are utilizing or are in the process of implementing Electronic Medical Record systems. Clinical data from these physicians feed into SandlotConnect®, providing the remaining physicians who are not on an EMR with access to this data. There are also two national laboratories and one radiology group connected to SandlotConnect®.

#### **Factors Aligning & Driving Local Stakeholders**

North Texas Specialty Physicians (NTSP) understood that quality patient care relies on advanced technology that provides clinical information at the point of care. There was not currently a system available to physicians in North Texas that connected doctors on disparate EMR products, as well as physicians without an EMR product. Creating a system that would allow EMRs and physicians to communicate is a revolutionary way of improving the clinical services that a patient receives. NTSP physicians wanted to be able to communicate quickly and seamlessly, and transfer patient clinical information in a HIPAA compliant manner, no matter what particular EMR system they are on, if any. NTSP founded Sandlot, LLC, in 2006 as a wholly owned subsidiary to build and operate an interoperable health information exchange, called SandlotConnect®. SandlotConnect® went live into production in December of 2008 with a current count of over 700 users, which includes physicians and their staff.

### *Operations*

#### **Vision, Mission, and Guiding Principles**

EMRs as a way to improve quality of care are receiving considerable national attention. CMS has stated that EMR implementation will be criteria for determining various pay-for-performance incentives. In addition, several state governments have established EMR funding initiatives. Finally, payors have stated their support for EMR implementation as a differentiating point within their contracted networks.

In stark contrast to these priorities, nationally, less than 15% of all physicians are presently on an EMR system. In addition, these physicians are on EMR systems that are limited to communicating information within the provider's practice. At best, the provider is part of a physician/hospital EMR system which allows for the transmission of information between the physician and his/her hospital system. Although much discussion has occurred around the concept of Regional Health Information Organizations (RHIO), only a few communities across the country have made significant progress in establishing a system which allows the sharing of patient information from disparate EMRs either at the hospital or physician level.

Creating a system of EMR's that can talk to each other was thought to be a revolutionary way of improving the clinical services patients will receive. They will improve quality of care and cut duplication and inefficiencies from the system. Previous EMR efforts have resulted in limited silos of information. However, Sandlot's effort will not only expand the number of providers on EMR systems but will connect these systems to each other along with the information contained in each via a Health Information Exchange.

The value that will be gained from this project is an improvement in patient care by connecting physicians with information from disparate systems at the time that information is required. Therefore Sandlot's mission includes:

- The development of application systems to enhance the efficiency, quality, availability and accessibility of patient information among providers and their patients.
- The development of a health information exchange system for the sharing of patient data
- The implementation of electronic medical record capabilities
- An operational system for providing support related to the above services.

In order for Sandlot to complete its mission, specific goals associated with SandlotConnect<sup>®</sup> were determined. Those goals include:

- Improved quality of care through the effective use of technology
- Facilitate physician-to-physician communication using advanced technology
- Accelerate adoption of EMR at the practice level
- Develop an infrastructure that will support data integration from other health care entities disparate systems in the future
- Enable physicians to view the entire patient record across providers
- Create a central repository for patient information accessible via the internet
- Offer different EMR systems to increase the rate of adoption
- Offer a competitive differentiator with employers, payors and patients.

### **Governance and Management Structure**

Sandlot, a wholly owned subsidiary of NTSP and as such Sandlot's Board will be nominated by the NTSP Board. Sandlot will receive its initial funding and capitalization from NTSP.

Sandlot will enter into a contractual agreement with various vendors who will provide services to Sandlot for the establishment of the health information exchange and EMR capabilities.

Sandlot will also enter into contractual Data Exchange Services Agreements with providers and data source providers interested in participating in the electronic health record service.

## Service Offerings

Sandlot delivers a health information exchange that includes the following capabilities:

- Health Information Exchange Interoperability Platform
- Shared Record Patient Data Repository
- EPR – Person Identity Resolution via Initiate Hub
- Clinician Desktop w/Results Viewer and Secure Messaging
- Referral Management Application
- Hospital Connectivity
- Allscripts, NextGen and other EMR Licenses, Hosting and Maintenance Services
- EMR Interoperability (Allscripts, NextGen and other CCHIT certified EMRs) to HIE
- Two Connected National Reference Lab (Orders and Results)
- EMR Training Services and In-Office Workflow Support
- Pharmacy Interfaces
- Payor Interfaces

## Technical Architecture

The technical architecture includes a central repository for SandlotConnect<sup>®</sup> and the use of HL7 interfaces and Clinical Documents including Continuity of Care Records (CCRs) to transfer clinical information between data sources and EMR systems.

## Unique Operational Considerations

The amount and types of services Sandlot offers and the manner in which Sandlot completed the EMR interoperability with SandlotConnect<sup>®</sup> makes Sandlot unique and a differentiator in the market place.

## Sustainability

### Business Model Summary

Sandlot offers business services such as EMR implementation and training, HIE access, and e-prescribing usability to better facilitate patient care, physician communication, and increase office efficiencies. Sandlot's business model caters to all of those contributing factors which must live harmoniously in order to operate a successful healthcare system. This system functions through various revenue streams from data source providers which includes hospitals, laboratories, and radiology services, and physician groups.

These connected sources cluster into three main service types and act as a subscription model.

1. Contributors - data sources such as laboratory providers that supply clinical data but do not to retrieve data
2. Consumers - sources like physician offices that retrieve clinical data but are unable contribute data into the exchange
3. Amalgams - sources such as EMR users who are able to consume as well as contribute clinical data

Sandlot also markets and demonstrates its products to congressional delegations and health care leaders to pursue federal grants which will help further the interest of information technology and allows Sandlot to grow its services in other communities.

### **Realized Benefits**

Currently Sandlot has achieved a majority of its original goals and has realized benefits in several areas though the key benefit has been improved quality of patient care by providing clinical information at the point of care at the right time. Previously treating providers had to request and then wait for information from other practices or hospital systems.

## Appendix D – Indiana HIE Case Study

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### *Background*

#### **Regional Business Environment & Demographics**

The Indiana Health Information Exchange (IHIE) is based in the Indianapolis healthcare market. The Indianapolis medical service area is comprised of 9 counties with a population of about 1.7 million citizens. In addition to the Indianapolis market, IHIE is expanding to serve several other Indiana population centers. Once fully implemented, IHIE will serve half the state's population or just over 3 million people.

Indianapolis is a competitive, urban and suburban healthcare market with 5 major health systems and several smaller systems in outlying areas. About 35 hospitals operate in the 9 county area. Indianapolis is also home to several significant healthcare organizations including Eli Lilly, WellPoint, Roche Diagnostics, and the Regenstrief Institute. The Regenstrief Institute is an internationally known independent healthcare informatics research institute. The technology on which IHIE is based was developed and proven by Regenstrief.

#### **Factors Aligning & Driving Local Stakeholders**

IHIE was founded as a supporting not-for-profit organization in February of 2004 by a broad group of stakeholders including the 5 major health systems and other healthcare leaders in the Indianapolis market. The organizations driving the creation of IHIE included the Regenstrief Institute, BioCrossroads (an Indianapolis-based healthcare and life sciences business catalyst organization), and iCareConnect (ICC). ICC was a grass-roots group of physicians and other healthcare leaders bent on improving the quality and efficiency of healthcare in Indiana. ICC eventually settled on community-wide clinical messaging as their focus. This project led to the creation of IHIE and ICC was dissolved when IHIE was created.

It is helpful to note that the creation of IHIE occurred in 2004 in a market where the Regenstrief Institute created the first electronic medical record in 1972 and the first large-scale community wide health information exchange system (called the Indiana Network for Patient Care) in 1994. IHIE was not founded in a “normal” healthcare market.

### *Operations*

#### **Vision, Mission, and Guiding Principles**

The Indiana Health Information Exchange (IHIE) is a non-profit venture backed by a unique collaboration of Indiana health care institutions. Our vision is to use information technology and shared clinical information to:

- Improve the quality, safety, and efficiency of health care in the state of Indiana,
- Create unparalleled research capabilities for health researchers,
- Establish a model of health information exchange for the rest of the country.

## Governance and Management Structure

To a great extent, each of IHIE's service offerings (described below) has its own governance. The oldest and most sophisticated governance body is called the Indiana Network for Patient Care Management Committee (see INPC below). The INPC management committee is made up of representatives from all organizations that are members of the network – those that provide and access data from the INPC. The group sets policy and direction for the INPC and meets quarterly. Representatives on the committee are typically CIOs, CMOs, and/or CMIOs at their respective organizations.

## Service Offerings

IHIE, with its technology partner, the Regenstrief Institute, have several service offerings. They include:

- **DOCS4DOCS® Clinical Messaging Service:** Electronic delivery of clinical results from their source (e.g. hospital or lab) to the physicians that require the result for patient care
- **Indiana Network for Patient Care (INPC):** INPC is a community-wide clinical data repository, with “push” and “pull” mechanisms, that provides relevant clinical information from a patient's aggregated community healthcare record to clinicians at the point of care.
- **Public Health Emergency Surveillance System (PHESS):** PHESS is a statewide bio-surveillance system that monitors, in real-time, the primary complaint of patients entering emergency departments in 75 hospitals across the state.
- **Quality Health First® program (QHF):** QHF is a clinical quality and value-based reimbursement service. The program provides doctors with patient-specific actionable alerts and reminders based on best-practice healthcare measures. It also provides participating health plans with an analysis and administration service supporting their value-based reimbursement programs.

## Technical Architecture

The technical architecture underlying the various service offerings varies as is warranted by the needs and demands of each service. However, it is a key success factor that multiple service offering re-use and rely upon a common core infrastructure. The core of the INPC is a centrally-managed federated model. Each participating member organization has its own data repository – logically separated from other participant's data. However the data reside within and is managed within a common data center. This is optimal for system performance, efficiency of maintenance, and consistent levels of security. Each data source organization continues to “own” its own data and control how the data can be used through its endorsement of specific data use agreements. There are now over 50 organizations participating in the INPC.

## Sustainability

### Business Model Summary

IHIE views health information exchange as a business, and like any businesses, it develops and offers services for which there is a need in the marketplace and which can be offered at a cost that is below their value to customers. Each service offering described above has its own sustainable “service model”. Service models are derived from the answers to the questions:

- To whom in the healthcare supply chain does value accrue?
- How much value does a given customer accrue?

- Is that customer willing to pay a cost less than that value, but greater than the cost of providing the service?

IHIE offers services to both healthcare providers and health plans. Having multiple services aimed at various participants across the healthcare supply chain is conducive, and perhaps, absolutely necessary, for a sustainable HIE business. Since HIE services frequently deliver value, in varying degrees, across multiple organization types in the chain, having multiple service with various service models enables an exchange to generate revenue from both provider and payor organizations – avoiding the perception of inequality.

### **Realized Benefits**

Consistent with our mission, IHIE's services deliver benefits aimed at improving the quality, safety, and efficiency of healthcare. While there are many 'soft' benefits, our paying customers fully expect a concrete return on their investment. IHIE's services have been shown to reduce hospital operating costs and reduce the overall cost of caring for patients in specific clinical settings, like the emergency department. Other quantitative studies of the value of HIE services are also underway.

## Appendix E – Louisville Health Information Exchange, Inc. (LouHIE) Case Study

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Judah Thornewill past Executive Director

### *Background*

#### **Regional Business Environment & Demographics**

In March, 2006, the Louisville Health Information Exchange, Inc. (LouHIE for short), a nonprofit organization, was formed to support development of a community-wide health information exchange to improve quality and contain rising costs of health care. A governance structure developed by researchers at University of Louisville was used to obtain balanced input and ongoing participation from all interested parties in the community. Starting in January, 2007, LouHIE raised funds and hired an outside firm to conduct an independent, comprehensive market research study as a basis for developing a business plan.

LouHIE is focused on the Greater Louisville metropolitan area, which includes 10 counties containing the city of Louisville (and surrounding suburbs--including those in Indiana), with a total population of over 1.2 million. Counties included at the launch were: Clark, Floyd, Jefferson, Bullitt, Hardin, Spencer, Shelby, Oldham, Henry and Trimble.

#### **Factors Aligning & Driving Local Stakeholders**

The business plan was developed based on market wants/needs identified through the research program, conducted August – November, 2007 and included over 1200 responses. The results of the research are available in “The Greater Louisville e-Health Research 2007 Report” which is available at <http://www.louhie.org/Research%20Reports.htm>.

At a national level, the Department of Health and Human Services has recently taken a major step forward with developing the NHIN through the trial implementations of interoperability between HIEs. A major vendor recently offered “free of charge” a global personal health record that is available to all. The solution offered may not meet all the stakeholder needs but will drive other vendor solutions in the marketplace to become more interoperable. At a state level, initiatives that have been underway for some time boast nearly 100% penetration to households and businesses by providing broadband network access to the state of Missouri. This state-wide infrastructure initiative is enabling care providers in both rural and metropolitan areas with access to a state-wide broadband network, and that communications infrastructure is in place to facilitate health information exchange across multiple communities throughout the state. Additionally partnership efforts have been working to bring together major health care organizations in Missouri to develop a common web portal for provider-payer communications enabling secure access to clinical information and simplified and standardized administrative tasks.

Analysis within the regional marketplace provided the following information:

- Over 75 personal health record systems and over 300 electronic health record/electronic medical record systems.

- Less than ¼ of physician practices use an electronic health record (EHR) system.<sup>85</sup> As a consequence, ¾ of physicians do not have the technical capability to capture and share electronic health records with a personal health bank record system.
- Pharmacy retailers could get higher reimbursements through Medication Therapy Management authorized under Medicare Part D and would need a simplified documentation procedure.
- Medical Products suppliers need to integrate their systems with LouHIE.
- From a consumer perspective, the revealed sentiment includes deep concern over the privacy and security protection for their consumer health records.

In response to these forces, LouHIE fills a valid need as a trusted nonprofit service offering the consumer health record bank account maintaining the interest of consumers and protecting data, while offering unrestricted, “free” access to all consumers, beginning with medications and medication reconciliation.

## *Operations*

### **Vision, Mission, and Guiding Principles**

The vision and mission can be summarized in the points identified below:

- Access for Life.
- Everyone Has a Seat at the Table.
- Commitment to Consumer Consent.
- Integration with Workflow.
- Integration with State and National Networks.
- Encouraging a Vibrant Marketplace for e-Health Vendors.
- Transparency.
- Contribution Funding System.
- Investment of Excess Contributions to Benefit those Most in Need.
- Supporting Cutting Edge Research.

### **Governance and Management Structure**

LouHIE, Inc. will operate as a Missouri-based A 501(c) (3) nonprofit organization; this structure was chosen based on research from consumers and other stakeholders which openly discussed concern with a for-profit entity in managing the interests of the community. The concern indicated that a community-based not-for-profit entity would be most trusted to provide these services to the community. LouHIE’s organizational model includes:

- The board of directors is “multi-stakeholder” including representation from all key participants in the healthcare ecosystem for the Greater LouHIE area. It is believed that this board structure has contributed to the development of the community’s **social capital** as LouHIE’s plans have developed since 2006.
- A temporary management team has been developed using executives drawn from University of Louisville and major healthcare organizations in the community.
- The permanent management team will include an executive director, chief financial officer, chief information officer, chief medical officer, chief development officer, compliance officer, benefits realization manager and administrative support.

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<sup>85</sup> [FierceHealthcare](#), “EHR adoption held back by multiple issues,” Jan. 28, 2007

- The core-services vendor subcontracted by LouHIE to provide technology services to the HIE’s customers.

### Service Offerings

LouHIE has created the Health Record Bank of Greater Louisville, offering free health record banking services for all (1.2 million) citizens in the greater Louisville area, including Southern Indiana. LouHIE will launch the services focused on medications, medication reconciliation and patient demographics, and will include the following currently offered or planned services:

Service	Definition
<p><b>Core Health Record Banking Service</b>  <i>For consumers, employers, government, physicians and providers</i></p>	<p>LouHIE’s core health record banking service to consumers, benefits purchasers, providers and payers will include:</p> <ol style="list-style-type: none"> <li>1. Health Record Bank Account: a permanent, longitudinal record of the consumer’s health information – beginning with medications, demographics and allergies.</li> <li>2. Integrated Enrollment system: supports enrollment through payer networks, at point of care, web, cell-phone, or, over time, kiosks.</li> <li>3. Deposit Window: supports deposits of health information from physicians, pharmacies, consumers and other authorized health information sources.</li> <li>4. Withdrawal Window: supports transfer of consumer’s health information to providers or others with consumer authorization.</li> <li>5. Individual controls –consumer ability to control access to the record at different levels of granularity, including suppressing specific information such as a medication.</li> <li>6. Organization Views: authorized organizations are able to access/view information through windows tailored to their needs. For example, a physician summary page will be provided according to physician requirements.</li> <li>7. Integrated registration, eligibility, and contribution processing services.</li> <li>8. Integrated research capabilities.</li> </ol>
<p><b>Research Services</b></p>	<p>With consumer consent, LouHIE provides researchers access to data for research purposes. Consumers control what kind of data is available, and whether it is de-identified or identifiable. Special controls are put into place to insure only authorized researchers access data. Researchers pay LouHIE a fee for data-access.</p>
<p><b>Non-core Vendor Services</b></p>	<p>LouHIE provides health information product and services vendors with the ability to link their services to LouHIE’s health record bank, thereby enhancing their product/service value, while opening new markets. Vendors are asked to contribute administrative and/or volume fees to be linked to LouHIE. Types of vendors who may be interested in LouHIE’s vendor services include providers of EMR, eRX, Health Risk Assessment, wellness programs, smartcards, daily diaries, payer eligibility and claims submission, product recall services and etc.</p>
<p><b>Personalized Messaging and Content Services</b></p>	<p>Personalized messaging services may include automated reminders such as an “appointment reminder” or “prescription refill reminder” on a cell-phone. Personalized content services may include personalized recommendations for books, articles and other healthcare information.</p>
<p><b>Future Services</b></p>	<p>Future services may be developed based on customer interest. Examples of additional services include:</p> <ol style="list-style-type: none"> <li>1. Lists of providers</li> <li>2. Environmental data</li> <li>3. Standardized state reporting</li> <li>4. Consumer surveys</li> <li>5. Job recruiting</li> <li>6. Dictionaries of terms</li> <li>7. Educational content</li> <li>8. Comparison shopping</li> <li>9. Formulary lists by payer plan</li> </ol>

## Technical Architecture

Data for LouHIE comes from a variety of sources:

- Provided directly from users
- Documented by healthcare provider activities and outcomes
- Contributed via claims based information sources
- Submitted by ancillary service providers (i.e. labs) regarding services they have rendered

LouHIE has developed a well defined strategy and structure to receive, process, store and manage these streams of data. LouHIE is not a supplier of technology infrastructure services. Instead, it manages purchases services from one or more core services vendor(s) (CSV). The CSV are expected to deliver necessary hardware and networking infrastructure, software development and deployment capabilities, operational procedures and processes, and to be able to help manage the complex relationship between itself, LouHIE and the various participating individuals and organizations that make up the LouHIE user and consumer community, and has included the standards of the Health Record Banking Alliance (HRBA) in defining their organization and the associated functional requirements. These standards also have significant implications for the technical architecture.

The major privacy and security principle related to LouHIE is simply this:

- Individuals maintain ownership of their own healthcare information.

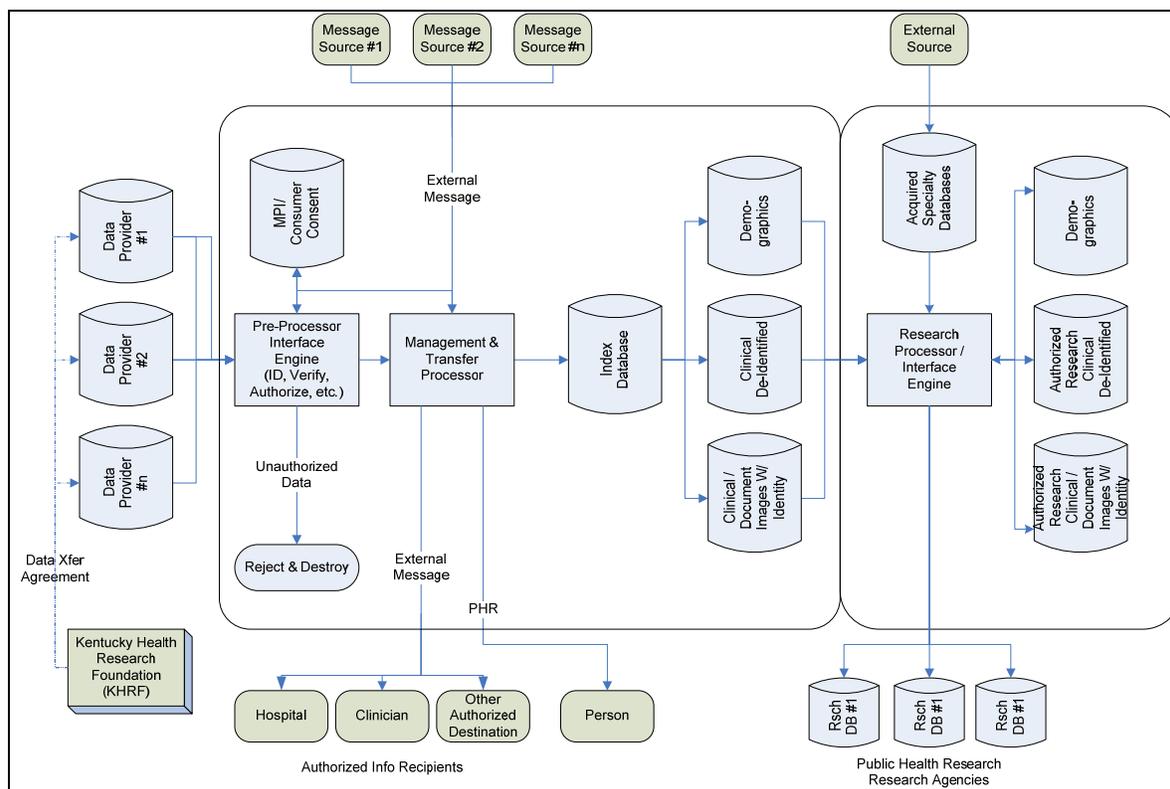
However, LouHIE's defined limits in the context of data ownership are as follows:

- Owners may NOT delete or request deletion of data selectively – they grant permission for LouHIE to collect data or not.
- Owners may NOT alter the content of data. Any challenges with the contents or the accuracy of data would need to be discussed with the originator of that data, and changes would need to be initiated from that originator before it would be updated in the LouHIE environment.
- Owners do have the ability to select what person or organizations may access their data, either selectively or in total (i.e. – access to certain data may be restricted to only select accessors, other data may be available to all accessors). NO access is possible without prior authorization from owners.
- Owners will have the ability to know what accesses of their identifiable information have occurred, and by whom.
- Owners will have the ability to designate someone other than themselves to manage their health data.

The specific capabilities required to accomplish these principles include the following:

- Filtered inbound data streams designed to allow processing and storage of only those records where authorization has been received from the individual involved,
- Dynamic access to establish, maintain and revoke LouHIE's authorization to collect and distribute data.
- Specificity in the management of data access, and data type and user access; including delegate user management for consumers of health information.
- Complete auditing of person-identifiable information needs to be available to the owner for their review.

The LouHIE plan for data management is a centralized model, chosen due to the benefits that facilitate management of the exchange. Participants in a centralized model will still have to arrange agreements with LouHIE that meet their individual privacy needs, but once such agreements are in place, LouHIE will be able to operate according to the one standard set of privacy rules – providing for greater transparency and ease of administration. A sample of the logical rule/messaging flow control diagram is as follows:



LouHIE Data Architecture and Process

The primary technical challenge for LouHIE will be accepting data from disparate sources in varying formats and translating that data (in content and format) into a single data model for storage in the LouHIE repositories. In order to minimize the effort required of data providers (and therefore to maximize their likelihood of contributing data to LouHIE), the data feeds will be accepted in any structured, definable, electronic form. LouHIE has assumed the responsibility of defining the data mapping (assisted by the contributing organization) and executes the reformatting/translation of the data from the source-format exchange format. The architecture for LouHIE envisions the storage of data in two separate repositories – one for operational purposes, one for research purposes. The objectives of establishing two repositories are several, including:

- Separating high-frequency-access data (operational) from low-frequency-access data (research)
- Enabling more thorough de-identification of data in the research repository
- Allowing for the likelihood that the two repositories may utilize different data models
- Supporting the possibility that separate vendors will maintain the two repositories

In the architecture diagram, the repositories are further separated into sub-repositories for demographic data, de-identified clinical data (non-image or document-based), and document or image-based data. The goal of further separating the data is primarily increased security and privacy by limiting

inappropriate access to the demographic or clinical data sections. Note that it is not possible to de-identify the image/document-based information, as personal information is likely a part of the documents and images that would be stored. LouHIE has also assumed responsibility for managing the data filtering process, allowing data sources to transmit complete data files containing information on all relevant persons making LouHIE responsible as well for selecting and processing data only for those who have given their consent to participate in the exchange. All other data is discarded, consistent with the privacy and security procedures of LouHIE and the data provider. Only after filtering and formatting is data applied to the repositories. The LouHIE architecture requires the creation and maintenance of a Master Person Index (MPI). Establishment of the MPI requires inputs from inbound data processing (to identify potential matches of new persons with established entries in the MPI) as well as manual validation (where the identified new matches are not exact). The other functions of the MPI include storing data access authorizations associated with the person, tracking sponsorship/underwriting information (i.e. - name of the sponsoring organization), and tracking identified interests/concerns to be used to tailor customized content.

The portal infrastructure will be the primary means for the consumer and provider LouHIE users to access their information as well as the associated administrative functions. The consumer portal is a presentation framework that consists of several components and capabilities:

- Registration – to support the initial establishment of the consumer and provider (user) as a registered user of the LouHIE solution. It enables the user to give permission to the system to receive and process data for both operational and research data stores, and to modify that permission as required by the user. It also allows for the de-registration of users who chose to end their participation in LouHIE;
- Access management – to allow the user to establish, manage and suspend access to the various types of data by user type (physician, hospital, emergency room, researcher) and by data type;
- Clinical data viewer – to allow the user to see the contents of data stored in the operational data store. The user can review the data for purposes of validating it, tracking it over time, initiating a request to correct it, recording it for use in interacting with caregivers, etc;
- Targeted content provider – to store of information provided by LouHIE partner organizations that will be presented to the users based on 1) rules identifying appropriate content based on user attributes and 2) level of contribution of the user (higher levels of contribution equate to more focused and less frequent content being presented).
- Notifications and Alerts
- Cell-phone access
- **Providers** would have access to linked systems and services such as ePrescribing and Electronic Medical Record (EMR) – LouHIE intends to provide access to an EMR capability to physicians who are active in participants and who do not currently have such a capability of their own.
- **Consumers** may also be accessible through linked portal services such as payer portals or external PHR portals.
- **Employers and Health Plans** receive special interfaces and services to gain access to information for which they are authorized. For example, employers may wish to have access to special “group” reports through their payer network.

LouHIE anticipates being able to provide data in support of approved research activities in a number of formats, including research-specific data stores, data extracts, and reports.

There are no easy answers to the problem of identifying the standards that should or should not be included in the development of LouHIE technical capabilities. While some are recommended (or

required) as a means to meet external requirements (NHIN, for example), others will be entirely up to LouHIE and the CSV to determine. LouHIE has adopted flexible standards and is able capable of adjusting as needed as standards evolve and change. LouHIE supports interactions with many partners who have adopted a variety of standards (or none at all) in their own internal operation. LouHIE seeks to consistently apply standards within their own organization, and to provide a consistent means of mapping, storing and presenting information. LouHIE does NOT mandate their partners to adhere to exchange-supported standards as a condition of participation.

## *Sustainability*

### **Business Model Summary**

As a nonprofit, LouHIE relies on donations, contributions, grants and sponsorships. Start-up costs are funded through major gifts and grants, plus a community fund-raising campaign. Ongoing services are funded through consumer contributions, employer and health-plan contributions, government and non-government grants and contracts, and revenues from special services.

The first two years of operation were primarily funded by start-up contributions, including donations, gifts and grants. Subsequent years were increasingly funded by services contributions as more people and organizations contribute based on the value of the service.

### **Marketing Plan**

People enroll through their doctor, hospital, pharmacist, employer, insurance plan, or other healthcare provider, or online. Once enrolled, people have the option of receiving special “Health Record Bank of Greater LouHIE” access cards. Community-wide all-channels marketing effort will occur to enable area consumers and organizations to access and use the Health Record Bank of Greater LouHIE. The objective of the LouHIE marketing activities is to present a compelling vision of those goals and benefits to the public in such a way that they will actively seek to participate. Only through this participation can the exchange gain sufficient “critical mass” to deliver the benefits that LouHIE envisions, and remain financially strong enough to support the financial projections for the exchange. The critical factors to developing a sense of engagement among the desired participants in LouHIE have been identified as follows:

- Begin with clear, simple, value-adding service
- Explain the benefits to attract participation
- Establish and sustain participant growth within reasonable timeframes
- Quickly gain traction and credibility as an ongoing entity
- Educate key participants and groups on cultural and procedural changes that will enable LouHIE to deliver the expected community benefits.

Marketing LouHIE to the community is a multi-channel effort, requiring different activities for various market segments. The marketing plan encourages and sustains the interest of potential participants in using, and contributing financially to, the new electronic capabilities to coordinate, collaborate and utilize the new electronic data gathering and sharing capabilities to get the right information to the right person at the right time and enhance their ability to manage patient care and improve outcomes. These participants include physicians, hospital groups, employers, health plans, laboratories, pharmacies, governmental agencies, and other entities such as safety net providers, research institutions and civic organizations.

LouHIE's customers are the ~1.2 million consumers living in the greater Louisville area and the 12 types of organizations working to deliver quality healthcare services to them. Since organizations and individuals may approach LouHIE through multiple channels for multiple purposes, a "many to many" marketing strategy is appropriate. Several channels are defined, each of which may help market to others. This strategy is appropriate for internet based services like LouHIE, which require different marketing efforts than traditional retail operations. The sections below describe different customer segments and channels and the marketing approaches to be used.

LouHIE's focus on the general consumer presents the opportunity to generate revenue from a number of new or expanded sources. In their research, consumers found value in the services that LouHIE proposes to offer, and a significant percentage of those consumers felt that the services were worth paying for.

In marketing to individual consumers (actually the households that contain one or more individual participating consumers), the focus is on the set of services and capabilities that will better enable consumers to:

- track their own health information – initially focused on medications and allergies.
- enable multiple providers to access consumer information to better collaborate care
- reduce the number of appointments necessary to replicate missing or misplaced results
- receive access to tailored and relevant health information
- have limits placed on the presentation of less-tailored health information
- eventually reduce costs to the consumers through overall reduction in healthcare costs in the community

Two approaches will be used to reach individual consumers. The first is public relations activities and marketing focused on general publicity and exposure to LouHIE services, capabilities and results. Through this approach, consumers will become familiarized with the LouHIE concept, and early adopters will be able to go online, register for the free service and begin using it. However, this approach is not initially expected to generate large numbers of contributing users of LouHIE services directly. The second approach to consumers is through the various organizations which serve them, especially their physicians and hospitals, but also through benefits sponsors, payers, technology providers and research organizations.

Healthcare services organizations and their providers have been offered free basic exchange services--including a provider portal--with a standardized patient clinical summary that initially includes medications history and demographics. Enrolled providers are able to offer all incoming patients free access to the service. Providers serve as a key distribution channel to consumers, by making enrollment in the HIE a part of their patient registration process.

Employer sponsors would most likely present LouHIE services as a component of a benefit package to their members or employees. As a benefit, the costs could be absorbed by the sponsoring entity, or passed through to the members or employees through increases in the total cost of benefits.

Payers stand to benefit from services directly, and in terms of increased satisfaction by their members and clients. LouHIE will benefit payers with options that include the ability to offer LouHIE service to payer members and providers (through their unique portal), to integrate identity services, to integrate identity and enrollment services. These options produce significant potential for financial savings.

Payers will be contacted directly by LouHIE, and will be encouraged by employer sponsors to support LouHIE.

LouHIE is committed to creating a vibrant market of health information product and service vendors who can link their services to the Health Record Bank of Greater LouHIE. Vendors may offer products like EMRs, e-prescribing, medical devices, monitoring devices, smartcards, and much more, all of which could have added value by being linked to LouHIE. LouHIE will approach these vendors as potential clients, seeking to help them develop new markets, test products and increase their sales. In some cases, LouHIE will create an “oligopoly” market, offering 2-3 winning vendors an opportunity to be integrated with LouHIE, and have a favored position in the LouHIE area marketplace for a period of time. Some of these vendors are likely to seek LouHIE out; in other cases, LouHIE will seek out national vendors and offer them opportunities to come to LouHIE. As the LouHIE vendor segment develops new markets in the LouHIE area, they will also be helping to “market” LouHIE to the consumers, providers and other organizations which they serve. Once linked, these vendors will promote LouHIE services when they promote their own.

Integrated research activities will be developed to add increasing value to the various other consumer and organizational customers of LouHIE. Research will help increase awareness of the value of LouHIE, and increase the perceived value of LouHIE’s services.

LouHIE will develop an active program for applying for grants and contracts to support e-health related initiatives with potential to benefit the community. Both “development” and “services” grants will be sought.

As a community nonprofit, LouHIE will be able to draw significantly on the use of public relations tools, community events, and word-of-mouth to spread the word about LouHIE. LouHIE will maintain an active public relations presence with support from professional public relations firms and marketers as required. Community events such as town meetings, TV and Radio shows, and other forums will be an active part of LouHIE’s development approach. LouHIE’s chief marketing officer and other team members will set-up meetings with employers, payers, and government entities, to set-up consumer sponsorships. In addition, meetings will be held to set-up hospitals and physicians as free distribution points for the service.

LouHIE branded Health Record Bank of Greater LouHIE Access Cards may be developed and offered through sponsoring organizations. Several versions of these cards may be made available – ranging from simple cards with a bar code and mag-stripe, to future “smart cards” with chips.

By using a multi-channel approach to reach the community, it becomes easy for consumers to access the service when and where they need it, while facilitating rapid adoption by consumers, providers, employers, health plans, government and other entities.

### **Risk Management**

For any new endeavor, it is important to identify potential risks that *could* effect business planning, and to develop appropriate strategies to manage and mitigate against those risks. LouHIE’s plan considers and addresses five key risks:

1. Fragmentation Risk
2. Community Trust Risk
3. Political Risk

4. Economic Risk
5. Implementation Risk

### Fragmentation Risk

Given the movement into the personal health record market of several large national companies (Microsoft, Google, Dossia, etc.), there is a risk that if the LouHIE community moves too slowly in launching this service, that there could be consumer and employer fragmentation across multiple PHR services. These services make it more difficult to effectively integrate PHR systems with hospital and physician systems in the community.

**Response:** LouHIE will develop its technologies so that the health record bank can “link” to external PHR services, allowing consumers to use an external PHR, while also allowing LouHIE to share accurate information on a ubiquitous basis with area providers.

### Community Trust Risk

Consumers expressed deep concerns about the risks to them and their families if their personal health information is accessed and used by unauthorized parties. To succeed, LouHIE must have an architecture that all parties can trust as trustworthy to protect all parties from these kinds of liabilities and risks.

#### **Response:**

##### **A. LouHIE Positioning as a neutral community-based nonprofit**

By positioning itself as a nonprofit, neutral community-based organization, committed to meeting the needs of all consumers AND all organizations which serve them, including employers, government, payers, hospitals, pharmacies, public health, physicians and others, LouHIE seeks to earn the trust of all parties and to place the interests of the community above any individual stakeholder.

##### **B. The Health Record Banking Alliance Framework**

In order to provide a trusted and trustworthy service for all parties, LouHIE developed its operations in accordance with the privacy and security principles of the Health Record Banking Alliance (HRBA). These have been carefully developed by a group of over 100 experts from across the country, and are designed to comply with the most stringent consumer and healthcare laws at federal and state levels, in order to assure the highest level of trust and trustworthiness for health record banks.

In addition to this, the HRBA principles require use of a highly secure and robust physical and logical security to protect the data from hacking or unauthorized access, a robust identity management system to ensure people are who they say they are, and have proved it; and an auditing trail that clearly identifies any party who accesses any part of consumer health record bank account for any reason.

##### **C. Risk Management Methodologies**

However, even with clear policies and procedures, best-in-class technologies, and consumer and physician review of information in the account, problems or misunderstandings may still occur. A number of methods will be used to protect LouHIE and those it serves from risks of these kinds. Some of the types of privacy/security risks which will be identified and managed by the LouHIE, Inc. management team, addressed in the legal framework and covered by insurance policies include:

Disclaimers	Liabilities
Privacy/ Confidentiality (HIPAA and HRBA)	Personal information is collected, used, retained, and disclosed in conformity with the LouHIE's privacy notice
Security	Entities that can verify and secure the site must be in place in order to adhere to trust and privacy warranties.
Availability/Business interruption or failure to perform	Availability of information is operational and maintained to limit disruptions in service
Accessibility	Access to information through different sources internet, smartcard, etc.
Defamation, libel, slander	LouHIE will monitor system and may need to take action to maintain compliance with its defined policies.
Unauthorized access or use	Measures in place to prevent or maintain breach of information
Damage to data or systems related to hackers or viruses	Information is protected physically and logically
System Integrity	System processing is complete, accurate, timely, and authorized.
Direct or indirect punitive damages using information	LouHIE will monitor system and may need to take action to maintain compliance with its defined policies.
Utilization of information	Information should be utilized for information purposes only and should not be deemed as medical advice or diagnosis.
Partners and access to other sites	Information and products provided by partners is provided solely for consumer convenience and does not reflect LouHIE

### Political Risks

Political risks relate to changes in Federal, state and local political leadership, which could create potential changes in policy or regulation. For example, certain types of state or Federal legislation could create undue burdens on an organization like LouHIE, or, even, render a LouHIE obsolete.

**RESPONSE:** LouHIE will manage this risk by 1.) staying flexible as new political agendas and directions are better understood; 2.) actively working with the Missouri e-Health Network board and e-health leadership to build and maintain alignment with the state; 3.) working closely with the Health Record Banking Alliance and other national organizations to monitor and help shape legislation and approaches which favor the health record banking approach; 4.) working with other communities and states across the country to build and maintain a national presence in Washington; and 5.) putting a stake in the ground as soon as possible.

### Economic Risks

There is increasing concern in the news about the ongoing recession in 2009-2010, which in turn means that consumers, businesses and government entities have fewer funds available to contribute for LouHIE thus harming the ability for LouHIE and its Core Services Vendors to operate a financially viable business.

**RESPONSE:** LouHIE's conservative plan option is designed to allow it to weather the storm, if indeed purse-strings tighten so much that LouHIE cannot build and sustain operations at this stage.

### Implementation Risks

There is a risk that as an early adopter, LouHIE and/or its Core Services Vendor(s) will stumble in the implementation process, delivering services that end up not satisfying consumers and/or organizations.

**RESPONSE:** LouHIE will seek a partnership with a Core Services Vendor that can mitigate this risk. Criteria LouHIE will use in selecting a vendor will include thorough knowledge of the

industry, a track –record of excellence, ability to use proven technologies that work; careful use of market research and pilot testing prior to roll-outs. In addition, LouHIE and its vendor will work actively with other health record banking organizations around the country, to share best-practices and technologies to mitigate these risks. Finally, LouHIE will start simple – with medication data – and make that work, before trying to get overly complex.

### Realized Benefits

Benefits to be gained by providers can include improved ability to care for patients, increased efficiency in medication reconciliation, and streamlined ability to access current patient data profiles.

LouHIE has potential to provide immediate benefits from making *medication data* available across the community. This can benefit hospitals and physicians by streamlining *medication reconciliation*, help consumers receive safer, better care in emergencies and office visits and help employers and health plans reduce avoidable expenses. Studies show that *up to 1% of all hospitalizations could be avoided* by making more complete medication information available at the point of care.

A community based, interoperable health information infrastructure can help transform the current situation.<sup>86</sup> LouHIE has a unique opportunity to facilitate healthcare improvements by increasing the quality of care, decreasing the cost of healthcare, and encouraging consumers to take an active role in their health.

In principle, most healthcare professionals recognize the potential clinical and administrative benefits which can occur through the implementation and use of electronic health record technologies. However, they also recognize the challenges of exchanging electronic information across different platforms. Therefore, it is understood that in order to ensure successful health information exchange, the interests and benefits for all stakeholders need to be aligned around a common platform for electronic health information storage and exchange. In September, worked with 26 different focus and functional groups designed to identify the understanding, interest, benefits and barriers e.g. (perspectives) for each stakeholder group related to electronic health information in LouHIE.

Every group identified medication data as the most valuable information to gather first. Consumers saw value in having medication data in a health record bank, accessible by their physician, in the emergency room, and when they travel. Caretakers of chronically ill children, elderly parents and relatives saw high value in an online system for keeping track of multiple medications and dosages. Physicians and hospitals saw high value in having a “medication reconciliation” capability, as part of a *patient clinical summary*, to verify which medications a patient is on. Pharmacies would value ability to reduce administrative costs of verifying medications. Employers and health plans saw benefit in helping consumers and physicians make better choices about medications, such as encouraging use of generics and in avoiding duplications and errors. Thus, the first benefit LouHIE will deliver is *medications and medication reconciliation*, accessed by providers through the *patient clinical summary* and by consumers through their *health record bank account* or a *linked portal*.

Hospitals and physicians estimate that medication reconciliation services could save them 5-8 minutes of time per patient. Studies have shown that up to 1% of hospitalizations could be avoided if current, accurate medication information were available. Finally, more accurate medication records linked to medication management systems and formularies have potential to reduce prescription costs.

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<sup>86</sup>Gold & Ball, The Health Record Banking Imperative: A conceptual model, IBM systems journal, Vol. 46, No. 1, 2007

After LouHIE develops the community-wide medication information service, it will focus on bringing together other types of data for the community, including problem lists, allergies, labs and tests, immunizations, and other clinical data which can be captured electronically. In addition, LouHIE will support integration with existing electronic medical record systems, e-prescribing systems, and other clinical support technologies. Over time, the result of these activities is anticipated to be a community-wide service that delivers increasingly valuable benefits to all stakeholders: consumers, employers, government, payers, health IT firms, healthcare educators, researchers, pharmaceuticals, hospitals and institutions, pharmacies and retailers, public health, physicians and nurses.

To provide ability to measure these longer-range benefits, the following benefits model was developed by . It reflects potentially achievable benefits identified by the consumers, the twelve stakeholder groups, and the selected functional groups who provided input during the Greater LouHIE e-Health Research 2007 project.

## Appendix F – Glossary

### A

#### **Accredited Standards Committee (ASC) X12**

ASC develops electronic data interchange (EDI) standards and related documents for national and global markets. Includes many XML standards and is used heavily between providers and payors.

<http://www.x12.org/>

#### **American Medical Association (AMA)**

A nonprofit professional association of physicians in the United States, including all medical specialties. Its purpose is to assist its members in providing the highest professional and ethical medical care to the citizens of the United States and to serve as an advocate for the advancement of the profession.

<http://www.ama-assn.org/>

#### **American National Standards Institute (ANSI)**

Founded in 1918, ANSI is an independent organization of trade associations, technical societies, professional groups, and consumer organizations. ANSI's primary goal is to maintain the enhancement of global competitiveness of U.S. business and the American quality of life by promoting and facilitating voluntary consensus standards and conformity assessment systems and promoting their integrity. It is formerly known as the United States of America Standards Institute (USASI or ASI), and previously as the American Standards Association (ASA). ANSI is the U.S. member body to ISO and IEC.

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

#### **American Recovery and Reinvestment Act (ARRA)**

Signed in February 2009, it is bill to create jobs, restore economic growth, and strengthen America's middle class through measures that modernize the nation's infrastructure, enhance America's energy independence, expand educational opportunities, preserve and improve affordable health care, provide tax relief, and protect those in greatest need, and for other purposes. ARRA includes the HITECH Act which includes over \$20 billion to aid in the development of a robust IT infrastructure for healthcare and to assist providers and other entities in adopting and using health IT.

<http://www.opencongress.org/bill/111-s1/show>

<http://www.himss.org/content/files/HIMSSSummaryOfARRA.pdf>

#### **ASTM International**

Originally known as the American Society for Testing and Materials (ASTM) and formed in 1898, ASTM International is one of the largest voluntary standards development organizations in the world-a trusted source for technical standards for materials, products, systems, and services.

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

### B

## C

### **Centralized HIE**

An approach to data sharing and the interchange of electronic information emphasizing full control over data sharing through a centralized repository. Components in a centralized architecture refer to the Central Data Repository (CDR) and the requestor. The CDR authenticates the requester through a technological means, authorizes the transaction, and records it for audit and reporting purposes.

### **Certification Commission for Health Information Technology (CCHIT)**

The Certification Commission is a private nonprofit organization with the sole public mission of accelerating the adoption of robust, interoperable health information technology by creating a credible, efficient certification process.

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

### **Chronic Care Model**

A model for the care of patients with chronic disease first proposed by EH Wagner in 1998. The hypothesis of the model is that chronic disease requires an ongoing team approach to provision of care that involves specially designed delivery systems, supporting clinical information systems, a decision support system based on clinical and functional data about each patient, and an agreement with the patient to undertake certain self-management of his/her condition.

[http://www.improvingchroniccare.org/index.php?p=The\\_Chronic\\_Care\\_Model&s=2](http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2)

### **Chronic Disease**

A disease that is long-lasting or recurrent. The term chronic describes the course of the disease, or its rate of onset and development. A chronic course is distinguished from a recurrent course; recurrent diseases relapse repeatedly, with periods of remission in between.

### **Clinical Data Repository (CDR)**

A real-time database that consolidates data from a variety of clinical sources to present a unified view of a single patient. It is optimized to allow clinicians to retrieve data for a single patient rather than to identify a population of patients with common characteristics or to facilitate the management of a specific clinical department. Typical data types which are often found within a CDR include: clinical laboratory test results, patient demographics, pharmacy information, radiology reports and images, pathology reports, hospital admission, discharge and transfer dates, ICD-9/ICD-10 codes, discharge summaries, and progress notes.

### **Clinical Document Architecture (CDA)**

CDA is a document markup standard that specifies the structure and semantics of a clinical document (such as a discharge summary or progress note) for the purpose of exchange. A CDA document is a defined and complete information object that can include text, images, sounds, and other multimedia content. It can be transferred within a message and can exist independently, outside the transferring message.

[http://www.openclinical.org/std\\_cda.html](http://www.openclinical.org/std_cda.html)

### **Clinical Messaging Systems**

Any electronic system that allows the transfer of clinical data such as laboratory tests, radiology results, transcriptions, prescriptions, and clinical orders quickly from provider to provider.

### **Computerized Provider Order Entry (CPOE)**

A computer application that allows a physician's orders for diagnostic and treatment services (such as medications, laboratory, and other tests) to be entered electronically instead of being recorded on order sheets or prescription pads. The computer compares the order against standards for dosing, checks for allergies or interactions with other medications, and warns the physician about potential problems.

[http://healthit.hhs.gov/portal/server.pt?open=512&objID=1256&parentname=CommunityPage&parentid=2&mode=2&in\\_hi\\_userid=10741&cached=true](http://healthit.hhs.gov/portal/server.pt?open=512&objID=1256&parentname=CommunityPage&parentid=2&mode=2&in_hi_userid=10741&cached=true)

### **Connecting for Health**

A public-private collaborative with representatives from more than 100 organizations across the spectrum of health care stakeholders. Its purpose is to catalyze the widespread changes necessary to realize the full benefits of health information technology, while protecting patient privacy and the security of personal health information.

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

### **Continuity of Care Document (CCD)**

An XML-based markup standard intended to specify the encoding, structure and semantics of a patient summary clinical document for exchange. In February of 2007, HL7 and ASTM announced that CCR and CDA were integrated to create the CCD. Subsequently, the U.S. Healthcare Information Technology Standards Panel endorsed the CCD as one of its standards.

[www.hl7.org/documentcenter/public/pressreleases/20070212.pdf](http://www.hl7.org/documentcenter/public/pressreleases/20070212.pdf)

### **Continuity of Care Record (CCR)**

A patient health summary standard expressed in XML. It is a way to create flexible documents that contain the most relevant and timely core clinical information about a patient, and to send these electronically from one care giver to another or to provide them directly to patients.

[www.centerforhit.org/online/etc/medialib/chit/documents/project/astmccr.Par.0001.File.tmp/chit\\_ccrnyc.pdf](http://www.centerforhit.org/online/etc/medialib/chit/documents/project/astmccr.Par.0001.File.tmp/chit_ccrnyc.pdf)

### **Current Procedural Terminology (CPT)**

A code set maintained by the American Medical Association through the CPT Editorial Panel. The CPT code set accurately describes medical, surgical, and diagnostic services and is designed to communicate uniform information about medical services and procedures among physicians, coders, patients, accreditation organizations, and payers for administrative, financial, and analytical purposes.

<http://www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/cpt.shtml>

## **D**

### **Data Repository**

An independent platform that stores sanitized data retrieved from legacy, transaction-oriented systems for display and use in formats conducive to a specific purpose (research, outcomes analysis, etc.).

### **Department of Health and Human Services**

The United States government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. ONC falls under HHS.

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

### **Digital Imaging and Communication in Medicine (DICOM)**

A standard for handling, storing, printing, and transmitting information in medical imaging. It includes a file format definition and a network communications protocol. The National Electrical Manufacturers Association (NEMA) holds the copyright to this standard. It was developed by the DICOM Standards Committee, whose members are also partly members of NEMA.

<http://medical.nema.org/>

## *E*

### **Electronic Health Record (EHR)**

An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization.

[http://www.hhs.gov/healthit/documents/m20080603/10.1\\_bell\\_files/textonly/slide4.html](http://www.hhs.gov/healthit/documents/m20080603/10.1_bell_files/textonly/slide4.html)

### **Electronic Health Record System (EHR-S)**

An electronic system that holds health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization.

[http://en.wikipedia.org/wiki/Electronic\\_health\\_record](http://en.wikipedia.org/wiki/Electronic_health_record)

### **EHR-Lab Interoperability and Connectivity Specification (ELINCS)**

Initiated in February 2005, ELINCS was developed by the Oakland, Calif.-based California HealthCare Foundation, in collaboration with national health care information technology organizations, to facilitate lab results delivery directly from vendors to ambulatory EHRs.

[http://www.himss.org/Content/files/digital\\_office\\_enews/digitaloffice\\_200606.html](http://www.himss.org/Content/files/digital_office_enews/digitaloffice_200606.html)

### **Electronic Medical Record (EMR)**

An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization.

[http://www.hhs.gov/healthit/documents/m20080603/10.1\\_bell\\_files/textonly/slide4.html](http://www.hhs.gov/healthit/documents/m20080603/10.1_bell_files/textonly/slide4.html)

### **Enterprise Master Patient Index (EMPI)**

A database that contains a unique identifier for every patient in the enterprise. EMPI organizes patient IDs from external systems, allowing cross-referencing of patient records and access to them using their medical record numbers from external or legacy systems. Also known as MPI.

### **Extensible Markup Language (XML)**

Introduced in 1998, XML is an open standard data exchange language for describing and defining data elements on a Web page, business-to-business, clinical (etc.), documents.

## *F*

### **Federated HIE**

A decentralized approach to the coordinated sharing and interchanging of electronic information emphasizing partial, controlled sharing among autonomous databases.

## *G*

## H

### **Health Information Exchange (HIE)**

The electronic movement of health-related information among organizations according to nationally recognized standards.

[http://www.hhs.gov/healthit/documents/m20080603/10.1\\_bell\\_files/textonly/slide6.html](http://www.hhs.gov/healthit/documents/m20080603/10.1_bell_files/textonly/slide6.html)

### **Health Information Organization (HIO)**

An organization that oversees and governs the exchange of health-related information among organizations according to nationally recognized standards.

[http://www.hhs.gov/healthit/documents/m20080603/10.1\\_bell\\_files/textonly/slide6.html](http://www.hhs.gov/healthit/documents/m20080603/10.1_bell_files/textonly/slide6.html)

### **Health Information Technology Standards Panel (HITSP)**

Created by ANSI in 2005 as part of efforts by the Office of the National Coordinator for Health Information Technology, HITSP is a cooperative partnership between the public and private sectors. The Panel was formed for the purpose of harmonizing and integrating standards that will meet clinical and business needs for sharing information among organizations and systems.

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

### **Health Insurance Portability and Accountability Act (HIPAA)**

Also known as the "Kennedy-Kassebaum Act (1996)," this U.S. law protects employees' health insurance coverage when they change or lose their jobs (Title I) and provides standards for patient health, administrative and financial data interchange (Title II). The latter also governs the privacy and security of health information records and transactions. HIPAA, developed by the Department of Health and Human Services, took effect in 2001 with compliance required in phases up to 2004.

<http://www.hhs.gov/ocr/privacy/index.html>

### **Health Level Seven (HL7)**

An ANSI-accredited, all-volunteer, not-for-profit organization involved in development of international healthcare standards. HL7, a Standards Developing Organization, and its members provide a framework for the exchange, integration, sharing and retrieval of electronic health information. The standards, which support clinical practice and the management, delivery, and evaluation of health services, are the most commonly used in the world. Within the standard, the "7" comes from application layer 7 in the OSI model, which is the highest level where programs talk to each other.

<http://www.hl7.org/>

### **HL7 Development Framework (HDF)**

The Development Framework Methodology Specification is a product of the HL7 Development Framework (HDF) project. The purpose of an HDF Project is to analyze, design, and document the processes, policies, and artifacts associated with development of HL7 standards. HDF is a replacement for and an extension to the HL7 Message Development Framework (MDF). The HDF differs from the MDF in terms of the following; scope of coverage, use of UML Notation, and Life cycle Management.

<http://www.hl7.org/>

### **HL7 Reference Information Model (RIM)**

The Reference Information Model (RIM) is the cornerstone of the HL7 Version 3 development process and an essential part of the HL7 V3 development methodology. RIM expresses the data content needed in a specific clinical or administrative context and provides an explicit representation of the semantic

and lexical connections that exist between the information carried in the fields of HL7 messages. The RIM is essential to increasing precision and reducing implementation costs.

<http://www.hl7.org/>

### **HL7 v2.x**

The most widely implemented standard for healthcare information in the world, v2 defines a series of electronic messages to support administrative, logistical, financial as well as clinical processes. V2 standards that date back to 1987.

<http://www.hl7.org/>

### **HL7 v3.0**

V3 uses an object-oriented development methodology and a Reference Information Model (RIM) to create messages. The messages are also based on an XML encoding syntax. Development of version 3 started around 1995, resulting in an initial standard publication in 2005.

<http://www.hl7.org/>

### **Health Record Bank**

Health record banks centrally store copies of consumer's health records, which providers "deposit" into the accounts. Consumers control which providers can contribute information and which providers and individuals can view their records.

<http://journal.ahima.org/2009/03/30/first-health-record-bank-pilot-launches/#more-272>

### **Healthcare Common Procedure Coding System (HCPCS)**

Commonly pronounced Hicks-Picks and based on the American Medical Association's CPT codes, HCPCS provide a standardized coding system for describing the specific items and services provided in the delivery of health care. Used for reporting to Medicare and Medicaid.

<http://www.cms.hhs.gov/MedHCPCSGeninfo/>

### **Health Information Technology for Economic and Clinical Health Act (HITECH)**

The HITECH Act was incorporated into the American Recovery and Reinvestment Act of 2009 budgeting roughly \$19 billion. It includes three sets of provisions to promote HIT adoption;

The HITECH Act includes three sets of provisions to promote HIT adoption. First, it would codify the Office of the National Coordinator for Health Information Technology (ONCHIT) within the Department of Health and Human Services (HHS). Second, the HITECH Act would through a number of mechanisms provide financial incentives for HIT use among health care practitioners.

Finally, the HITECH Act includes a series of privacy and security provisions that would amend and expand the current HIPAA requirements.

<http://www.himss.org/content/output/666386BF38BB424AAE093FFCAFE7AA18.pdf>

### **Hybrid HIE**

A combination of the Federated and Centralized HIE models. For example, pharmacy transactions may occur using the federated model while lab data is shared through the centralized model.

## **I**

### **Integrating the Healthcare Enterprise (IHE)**

HE is an initiative by healthcare professionals and industry to improve the way computer systems in healthcare share information. IHE promotes the coordinated use of established standards such as DICOM and HL7 to address specific clinical need in support of optimal patient care. Systems

developed in accordance with IHE communicate with one another better, are easier to implement, and enable care providers to use information more effectively.

<http://www.ihe.net/>

### **IHE Integration Profiles**

IHE Integration Profiles organize and leverage the integration capabilities that can be achieved by coordinated implementation of communication standards. They do not replace conformance to standards, rather provide a more precise definition of how standards are implemented. They define a specific implementation of standards that are designed to meet identified clinical needs.

### **Infection Control Monitoring**

The act of using the policies and procedures published to minimize the risk of spreading infections, especially in hospitals and health care facilities.

### **Insurance Eligibility Checking**

The act of verifying if a patient has medical insurance. Older eligibility verification practices relied on making phone calls to payers or accessing multiple payer-specific web sites, but many new hospital information systems have such technology built in.

### **Integrated Justice Information Systems (IJIS)**

Any computer network, system, or architecture that allows justice practitioners and agencies to electronically access and share information between systems and/or across jurisdictional lines. It also includes sharing information with traditionally non-justice agencies such as other governmental agencies, health and human services organizations, treatment service providers, schools and educational institutions, licensing authorities, and with the public.

<http://www.ncsl.org/programs/lis/intjust/report01.htm>

### **Interface**

A boundary across which two independent systems meet and act on or communicate with each other.

### **Interface Engine**

Software that enables many disparate systems to pass information back and forth using a set of defined standards. Interface engines typically perform functions such as; store and forward of messages, message translation, message routing, management tools, and alerts and monitoring.

### **International Classification of Diseases (ICD)**

Published by the World Health Organization, these diagnostic codes are designed for the classification of morbidity and mortality information for statistical purposes, for the indexing of hospital records by disease and operations, and for data storage and retrieval.

<http://www.who.int/classifications/icd/en/>

### **Interoperability**

The ability of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of healthcare for individuals and communities.

<http://www.who.int/classifications/icd/en/>

*J*

*K*

## L

### **Lightweight Directory Access Protocol (LDAP)**

Application protocol for querying and modifying directory services running over TCP/IP.

<http://www.webopedia.com/TERM/L/LDAP.html>

### **Logical Observation Identifiers Names and Codes (LOINC)**

A database and universal standard for identifying laboratory observations. It was developed and is maintained by the Regenstrief Institute, Inc., an internationally-recognized non-profit medical research organization, in 1994. LOINC was created in response to the demand for an electronic database for clinical care and management and is publicly available at no cost.

<http://loinc.org/>

## M

### **Master Patient Index (MPI)**

*See EMPI*

### **Middleware**

Software that serves as an intermediary between systems software and an application, allowing them to exchange data.

<http://www.webopedia.com/TERM/m/middleware.html>

## N

### **National Council for Prescription Drug Programs (NCPDP)**

Founded in 1977, a not-for-profit, ANSI-accredited, Standards Development Organization with over 1500 members representing virtually every sector of the pharmacy services industry, the NCPDP creates and promotes the transfer of data related to medications, supplies, and services within the healthcare system through the development of standards and industry guidance.

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

### **National e-Health Collaborative (NeHC)**

The National eHealth Collaborative (formerly AHIC Successor, Inc.) is a public-private partnership driving the development of a secure, interoperable, nationwide health information system. The National eHealth Collaborative was founded in 2008 to build on the accomplishments of the American Health Information Community (AHIC), a federal advisory committee initiated by Secretary of Health and Human Services Mike Leavitt in 2005.

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

### **Nationwide Health Information Network (NHIN)**

A network of networks, it is a set of harmonized standards-based specifications for the exchange of health information sharing between Nationwide Health Information Exchanges (NHIEs).

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

### **National Provider Identifier (NPI)**

The National Provider Identifier (NPI) is a Health Insurance Portability and Accountability Act (HIPAA) Administrative Simplification Standard. The NPI is a unique identification number for covered health care providers. Covered health care providers and all health plans and health care

clearinghouses will use the NPIs in the administrative and financial transactions adopted under HIPAA. The NPI is a 10-position, intelligence-free numeric identifier (10-digit number).

<http://www.cms.hhs.gov/NationalProvIdentstand/>

## *O*

### **Office of the National Coordinator for Health Information Technology (ONC)**

The Office of the National Coordinator for Health Information Technology (ONC) provides counsel to the Secretary of HHS and Departmental leadership for the development and nationwide implementation of an interoperable health information technology infrastructure. The ONC also provides management of and logistical support for the American Health Information Community (AHIC).

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

### **Open source systems**

Term coined in March 1998 following the web browser Mozilla release to describe software distributed in source under licenses guaranteeing anybody rights to freely use, modify, and redistribute, the code. The intent was to be able to sell the hackers' ways of doing software to industry and the mainstream by avoiding the negative connotations.

## *P*

### **Patient matching software**

Type of middleware that matches patients across independent systems. See EMPI.

### **Patient Privacy Rights Foundation**

Patient Privacy Rights is a 501(c) (3) non-profit organization located in Austin, TX. Founded in 2004 by Dr. Deborah Peel, Patient Privacy Rights is dedicated to ensuring Americans control all access to their health records.

<http://www.patientprivacyrights.org/site/PageServer>

### **Personal Health Record (PHR)**

An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.

[http://www.hhs.gov/healthit/documents/m20080603/10.1\\_bell\\_files/textonly/slide4.html](http://www.hhs.gov/healthit/documents/m20080603/10.1_bell_files/textonly/slide4.html)

### **Personal Health Record System (PHR-S)**

An electronic system that stores health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.

### **Physician Web Portals**

Middleware that allows a physician working from any location to log into their affiliated EMR.

### **Provider matching software**

Type of middleware that matches providers across independent systems.

### **Protected Health Information (PHI)**

PHI is any information held by a covered entity which concerns health status, provision of health care, or payment for health care that can be linked to an individual. This is interpreted to include an individual's medical record and payment history.

### *Q*

### *R*

### **Record Locator Service (RLS)**

A file of the locations of patient records, able to be queried only by authorized participants. In an HIE, it is a type of middleware that determines what records exist for a member and where they are located. A RLS will manage participating provider identities, maintain and publish a patient index, match patients using an algorithm, look up patient record locations (but not the records themselves), communicate securely and maintain an audit log, and manage patient consent to record sharing (under state laws and the new American Recovery and Reinvestment Act).

[http://www.connectingforhealth.org/resources/collaborative\\_response/appendices/glossary.php](http://www.connectingforhealth.org/resources/collaborative_response/appendices/glossary.php)

### **Regional Health Information Exchange (RHIO)**

A health information organization that brings together health care stakeholders within a defined geographic area and governs health information exchange among them for the purpose of improving health and care in that community. A RHIO is a type of HIO.

[http://www.hhs.gov/healthit/documents/m20080603/10.1\\_bell\\_files/textonly/slide6.html](http://www.hhs.gov/healthit/documents/m20080603/10.1_bell_files/textonly/slide6.html)

### *S*

### **Secure Messaging**

Server based approach to protect sensitive data when sent beyond the corporate borders and provides compliance with industry regulations such as HIPAA, GLBA and SOX.

### **Secure Sockets Layer (recently Transport Layer Security) (SSL or TLS)**

A protocol developed by Netscape for transmitting private documents via the Internet. SSL uses a cryptographic system that uses two keys to encrypt data – a public key known to everyone and a private or secret key known only to the recipient of the message.

<http://www.webopedia.com/TERM/S/SSL.html>

### **Service-oriented Architecture (SOA)**

SOA provides methods for systems development and integration where systems package functionality as interoperable services. A SOA infrastructure allows different applications to exchange data with one another. Service-orientation aims at a loose coupling of services with operating systems, programming languages and other technologies that underlie applications. SOA separates functions into distinct units, or services, which developers make accessible over a network in order that users can combine and reuse them in the production of applications.

[http://en.wikipedia.org/wiki/Service-oriented\\_architecture](http://en.wikipedia.org/wiki/Service-oriented_architecture)

### **Simple Object Access Protocol (SOAP)**

A lightweight XML-based messaging protocol used to encode the information in Web service request and response messages before sending them over a network. SOAP messages are independent of any

operating system or protocol and may be transported using a variety of Internet protocols, including SMTP, MIME, and HTTP.

<http://www.webopedia.com/TERM/S/SOAP.html>

### **Standardized nomenclature for clinical drugs (RxNorm)**

RxNorm provides normalized names for clinical drugs and links its names to many of the drug vocabularies commonly used in pharmacy management and drug interaction software, including those of First Databank, Micromedex, MediSpan, Gold Standard Alchemy, and Multum. By providing links between these vocabularies, RxNorm can mediate messages between systems not using the same software and vocabulary.

<http://www.nlm.nih.gov/research/umls/rxnorm/>

### **Standards Development Organizations (SDO)**

Any entity whose primary activities are developing, coordinating, promulgating, revising, amending, reissuing, interpreting, or otherwise maintaining standards that address the interests of a wide base of users outside the standards development organization.

[http://en.wikipedia.org/wiki/Standards\\_organization](http://en.wikipedia.org/wiki/Standards_organization)

### **State-Led HIE**

An HIE model where the state defines the entire HIE including infrastructure, vision, oversight, and its use.

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

### **Systematized Nomenclature of Medicine – Clinical Terms (SNOMED-CT)**

A systematically organized computer processable collection of medical terminology covering most areas of clinical information such as diseases, findings, procedures, microorganisms, pharmaceuticals etc. It allows a consistent way to index, store, retrieve, and aggregate clinical data across specialties and sites of care. It also helps organizing the content of medical records, reducing the variability in the way data is captured, encoded and used for clinical care of patients and research.

[http://en.wikipedia.org/wiki/SNOMED\\_CT](http://en.wikipedia.org/wiki/SNOMED_CT)

## *T*

### **Triple Data Encryption Standard (3DES)**

This is three-time successive application of DES designed to overcome the limitation of a 56-bit key without changing the encryption algorithm.

<http://www.answers.com/Triple%20Data%20Encryption%20Standard>

## *U*

### **Uniform Resource Locator (URL)**

Uniform resource locator or universal resource locator; an addressing scheme used by World Wide Web browsers to locate resources on the Internet.

<http://www.answers.com/url>

## *V*

## *W*

*X*

*Y*

*Z*



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