State of Illinois
Rod R. Blagojevich, Governor

Department of Public Health
Eric E. Whitaker, M.D., M.P.H., Director

Illinois Electronic Health Records Report and Plan

Electronic Health Records Taskforce

December 2006

Illinois Department of
PUBLIC
HEALTH

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December 27, 2006

To the Honorable Members of the Illinois General Assembly:

I am submitting for your consideration this report and plan from the Illinois Electronic Health Records Taskforce. The taskforce, created by Public Act 94-646, was composed of 36 representatives of a broad spectrum of stakeholders in the health care delivery system. This is the result of the hard work and dedication of these individuals and others who assisted them in carrying out their responsibilities under the Electronic Health Records Taskforce Act.

This report presents a series of recommendations for expanding the adoption and use of health information technology to enable the sharing of health information to improve the quality and safety of health care in Illinois. This agenda complements the patient safety and health care improvement initiative outlined by Governor Rod R. Blagojevich in Executive Order Number 8 (2006) and being implemented by the Illinois Department of Public Health (IDPH).

The consensus among the stakeholders of the taskforce, which includes, among others, physicians, hospitals and insurers, speaks to the importance of this issue. The plan addresses the role and interest of the State in meeting appropriate public responsibilities, and with extensive investment decisions by stakeholders and other funding sources in the necessary technology and organization, should enable substantive and continuing improvement in the health care of individuals, the health system and quality of public health in Illinois.

A key element of this agenda is the recommendation that the Department form a public-private partnership with a new non-profit organization governed by stakeholders. IDPH would work with this organization, named the Illinois Health Information Network or ILHIN, on the creation of a state-level health information exchange to facilitate the sharing of health information within Illinois and with other states. (A paramount concern in developing this exchange is the security of the data and the protection of the patient's confidentiality.) The Taskforce has recommended that the Board of ILHIN be appointed by the Governor. This will insure that the public interest of the State is served by the organization; for the same reason, the Department would further recommend that the Executive Director of ILHIN also be appointed by the Governor.

Another key recommendation of the taskforce is for the Department/ILHIN public-private partnership to create an initiative to foster the adoption of electronic health record systems and the development of regional health information exchanges. In arriving at this recommendation, the taskforce recognized that creating a mechanism to facilitate the sharing of health information is more beneficial if more health care providers possess the technology to utilize this capability.

Other states nationally and in the Midwest are moving corresponding initiatives forward, enabling the region and the nation to move ahead with building the National Health Information Network. The challenge now is to identify the necessary resources to move the State forward on this front without sacrificing health initiatives already in place. The Department of Public Health looks forward to working with the General Assembly on this initiative.

Sincerely,

Eric E. Whitaker M.D.

Eric E. Whitaker, M.D., M.P.H.
Director

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Executive Summary

Gov. Rod R. Blagojevich signed House Bill 2345,[1] Public Act 94-646, creating the Electronic Health Records Taskforce on Aug. 22, 2005. The taskforce was charged with producing a plan and submitting it to the General Assembly by Dec. 31, 2006 for the "development and utilization of electronic health records (EHR) in the state in order to improve the quality of patient care, increase the efficiency of health care practice, improve safety, and reduce health care errors." Taskforce membership included representatives of physicians, other clinicians, hospitals, pharmacies, long-term health care facilities, academic health care centers, payers, patients and consumers, and information technology providers.

With the enactment of this legislation, Illinois became the 14th state within the last two years to create a taskforce or other committee to make recommendations on statewide EHR activity.[2]

EHR has become the catchall phrase for a broad range of health information technology (HIT) applications. The International Organization for Standardization (ISO), a network of national standards institutes from 157 countries, defines an EHR designed for an integrated health care system – the focus of this taskforce – as:

> *A repository of information regarding the health of a subject of care, in a form able to be processed by a computer that is stored and transmitted securely and accessible by multiple authorized users using different applications. It has a standardized information model which is independent of an EHR system. Its primary purpose is the support of continuing, efficient and quality integrated health care and it contains information that is retrospective, concurrent and prospective.*[3]

From the patient's perspective, an EHR enables the clinician to have clinical information when it is needed to promote the highest quality of care.

To realize the benefits of EHR, there must be a process for sharing the health information among those providing services. This sharing "process" has been termed health information exchange (HIE). [Adding to this EHR terminology tangle are the different names for the HIE organizational models. Whether referenced as a Regional Health Information Exchange (RHIE), Regional Health Information Organization (RHIO) or Sub-network Organization (SNO), these terms determine the various processes for the same function: how local health care entities connect and exchange the different sources of health information.]

The benefits of sharing health information through a statewide health exchange infrastructure were best described in the "Arizona Health-*e* Connection Roadmap." The report notes the electronic exchange of health information will improve the quality and reduce the cost of health care by:

- *Ensuring health information is available at the point of care for all patients*
- *Reducing medical errors to improve patient safety*
- *Avoiding duplicative medical procedures*
- *Improving coordination of care between hospitals, physicians, and other health care professionals*
- *Furthering health care research*
- *Enhancing public health and disease surveillance efforts*
- *Encouraging greater consumer participation in their personal health care decisions*
- *Enhancing the business environment for both small and large employers and reducing state expenditures by controlling health care costs*[4]

The U.S. Department of Health and Human Services' Agency Healthcare Research and Quality's (AHRQ) report, "*Evolution of State Health Information Exchange: A Study of Vision, Strategy, and Progress,*" identified three keys to the success in the planning and implementation phases of state-level HIE development. These are:

- *Strong state leadership and political support,*
- *broad stakeholder involvement and early engagement of physicians, and*
- *short-term "wins" to demonstrate the HIE value proposition.*[5]

The taskforce enthusiastically believes the time is right for the state to take action to implement health information technology initiatives that contribute to improving the quality and safety of health care.

Governor Blagojevich and the General Assembly have already shown strong stewardship on this front with the passage and signing of the legislation creating this taskforce. Furthermore, the Governor demonstrated his continuing commitment to quality health care and the use of health information technology to meet that end by issuing Executive Order 8 in July 2006 to create the Division of Patient Safety in the Illinois Department of Public Health.

Stakeholder support of the taskforce is another positive sign of Illinois' readiness to undertake this complex issue. The taskforce has seen early health information technology success stories that can serve as the basis for the expanded adoption of EHR and health information exchange. The taskforce believes the state should take a leadership role by developing a public-private partnership with a not-for-profit organization to discharge two major functions of importance to EHR development in Illinois. One will be the establishment of a state-level health information exchange. The second will be the implementation of a program to foster the adoption of EHR among providers and clinicians. It will be this partnership's assignment to set goals that will produce early successes to demonstrate the efficacy of EHR to policy leaders, stakeholders and the public.

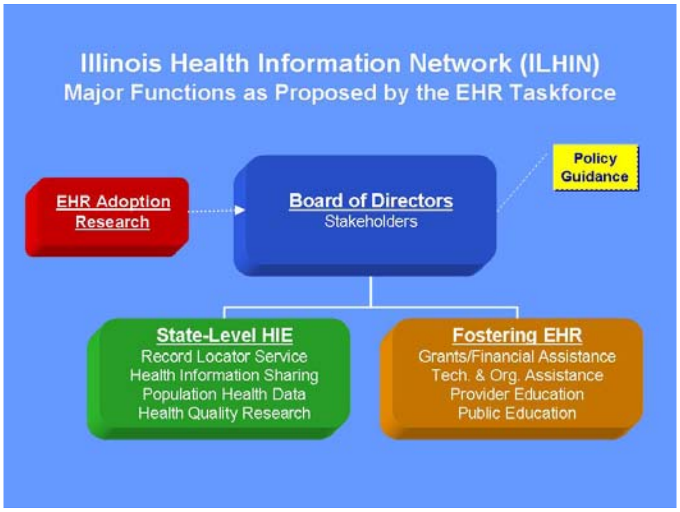
In developing recommendations, the taskforce's overarching concern was the protection of a patient's right to privacy and the security of health information. The following is a summary of the taskforce's consensus recommendations to move Illinois forward with respect to health information technology.

1. Adopt legislation charging the Illinois Department of Public Health (IDPH) with responsibility for advancing Illinois' EHR and health information exchange initiatives and requiring the Department to establish a public-private partnership with a new not-for-profit organization, named the Illinois Health Information Network (**ILHIN**), to be governed by stakeholders in the health care system. IDPH would, over time, discharge its statutory responsibilities through grant and contractual relationships with **ILHIN** and would insure the protection of important public interests. **ILHIN** would be authorized by legislation to accept and implement these responsibilities and provide, in the fast-paced world of EHR, the flexibility that a not-for-profit organizational form allows.

2. The legislation should provide for the governance of **ILHIN** by a 31-member board of directors. Of these directors, 27 would be appointed by the governor with the consent of the state Senate from those persons nominated by generally recognized statewide organizations representing hospitals, physicians, nurses, consumers, third-party payers, pharmacists, federally qualified health centers, long-term care facilities, laboratories, mental health clinics, and home health agencies. The remaining four members would be ex-officio representatives of the Illinois departments of Healthcare and Family Services; Human Services, and Public Health; and the regional administrator, Region 5, Center for Medicare and Medicaid Services, U.S. Department of Health and Human Services.

3. The board of directors of **ILHIN** should elect its presiding officer from among its members and employ an executive director accountable to the board, who may be simultaneously employed by a state agency, to employ and manage such staff as needed to implement the **ILHIN**'s mandates.

4. The legislation should require the establishment of a state-level health information exchange to serve as a "hub" or "highway" to facilitate the sharing of health information among health care providers within Illinois and other states. Functions of the state-level health information exchange include:



   a) Provide a record locator service for Illinois,
   b) securely transfer health information,
   c) collect population health data to meet public health needs, and
   d) facilitate research using de-identified data.

5. The legislation should require the establishment of standards, consistent with applicable federal standards, for accessing the state-level health information exchange by providers and researchers. These standards must provide security and confidentiality protections for patient information and include the ability to impose sanctions for non-compliance.

6. The enabling legislation also should require the establishment of initiatives to foster EHR and health information exchange adoption in Illinois.

   a) The **ILHIN** should be empowered to provide financial assistance to help health care providers adopt EHR systems. The **ILHIN** also will need to look at other mechanisms to help providers with the economic impact. This may include working with vendors to get discounts for interoperable EHR systems.
   b) The **ILHIN** should be authorized to provide technical and organizational assistance. Whether provided by **ILHIN** staff or through grants or contracts to outside entities, this technical and organizational assistance should be directed toward expanding EHR adoption and use

7. The **ILHIN** should stimulate, facilitate, and coordinate research to better understand the implementation and use of EHRs in the state.

8. The enabling legislation should authorize the transfer of the Illinois Health Network assets from IDPH to the **ILHIN** and the taskforce recommends the transfer (or licensing) occur as soon as practicable.

9. The legislation should require health information systems maintained by any state agency meet interoperability standards by 2015.

10. State funding should be appropriated to IDPH to implement the responsibilities of the **ILHIN**.

11. State funding should be appropriated to IDPH to provide for the smooth transition from existing activities to the partnership. The Department can then perform (or provide a grant to other entities, such as the Illinois Health Network, to perform) needed transitional activities and monitor and apply for federal and other funding that may become available to support the adoption of EHRs and health information exchanges.

These recommendations are discussed in more detail in the EHR plan that follows.

Background

States throughout the nation are working on developing health information exchange capabilities. A report by the State RHIO Consensus Project identified 27 states as having some level of statewide[a] health information exchange initiative as of March 2006.[6] Table 1 lists those states and the duration of their initiative. Beyond this list are numerous initiatives related to EHR throughout the nation, including some in Illinois that may not be considered "statewide."

Table 1[7]

State	Duration of Initiative	State	Duration of Initiative	State	Duration of Initiative
Arizona	≤ 2yrs	Maine	> 2yrs	Pennsylvania	≤ 2yrs
California	≤ 2yrs	Maryland	≤ 2yrs	Rhode Island	≤ 2yrs
Colorado	≤ 2yrs	Massachusetts	> 2yrs	Tennessee	≤ 2yrs
Delaware	> 2yrs	Michigan	≤ 2yrs	Utah	> 2yrs
Florida	≤ 2yrs	Minesota	≤ 2yrs	Vermont	≤ 2yrs
Hawaii	≤ 2yrs	Nevada	≤ 2yrs	Virginia	≤ 2yrs
Indiana	> 2yrs	New Mexico	≤ 2yrs	West Virginia	≤ 2yrs
Kentucky	> 2yrs	New York	≤ 2yrs	Wisconsin	> 2yrs
Louisiana	≤ 2yrs	North Carolina	> 2yrs	Wyoming	≥ 2yrs

Illinois EHR Activities

The challenge of expanding EHR utilization in Illinois is underscored by the size of the health care provider network. There are 214 hospitals, approximately 40,000 physicians, 8,304 clinical laboratories, and 1,160 long-term care facilities in Illinois. On the positive side, there have been some significant EHR efforts to build upon. Hospitals, clinics, physicians and public health professionals have been actively pursuing various electronic solutions for some time. Six Illinois hospitals made the *Hospital and Health Network's* 2006 list of the "100 most wired hospitals and health systems."[8] Early efforts by state government agencies have been focused on providing better coordination of maternal and child health services. These include:

> **Cornerstone** – the Illinois Department of Human Services' data management information system that was developed to facilitate the integration of community maternal and child health services.
>
> **Illinois National Electronic Disease Surveillance System (I-NEDSS) –** a Web-based application operated by the Illinois Department of Public Health (IDPH) that establishes a secure and real-time communication link between hospitals, laboratories and other health care providers with state and local health department staff for reporting and managing communicable disease information.

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[a] The RHIO Consensus project noted that "'state-level' does not necessarily imply coverage of the whole state."

Illinois Comprehensive Automated Registry Exchange (ICARE) – IDPH's Web-enabled immunization registry that offers health care providers access through an Internet browser.

Tracking Our Toddlers' Shots (TOTS) – a network-based immunization registry maintained by IDPH that stores more than 12 million immunization records.

Federal funding has fostered several EHR initiatives. In September 2004, the U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality (AHRQ) awarded $139 million in contracts and grants to promote the use of health information technology, including five national Regional Health Information Organization demonstrations from which results and findings will be available this next year. AHRQ also funded five Illinois projects. One of these projects received additional funding on Oct. 6, 2005. (Appendix F)

In January 2005, the Illinois Hospital Research and Educational Foundation, an affiliate company of the Illinois Hospital Association, launched a statewide EHR initiative entitled the "Illinois Health Network." Funded by a grant from IDPH, the network "offers a Web-based gateway interface that enables the secure exchange of health and business-related information and data."[9]

Taskforce Deliberations

The taskforce, convened by the Illinois Department of Public Health in coordination with the Illinois departments of Healthcare and Family Services and Human Services, began its work on March 6, 2006. The taskforce and its committees held 42 meetings during the course of the year. Members heard presentations from national experts on EHR and representatives from Indiana, Massachusetts and Utah health information exchange programs.

EHR Taskforce Mission Statement

To establish a guiding principle for the taskforce, the Steering Committee adopted the following mission statement on May 8, 2006:

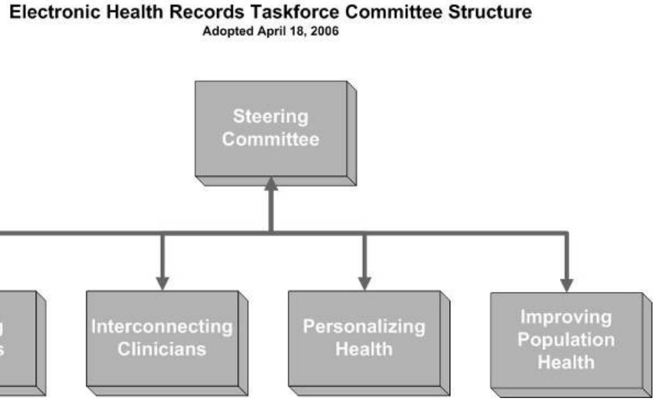
> *The mission of the Electronic Health Records Taskforce shall be to formulate recommendations and an implementation plan on how to best implement secure and standardized electronic health records for Illinoisans and persons served by Illinois providers enabling improvement in patient safety, the efficiency of health care practice and the quality of both individual care and the Public Health.*
>
> *The taskforce will assure that electronic health records in Illinois become interoperable with other states consistent with federal standards; that patients' legal and personal rights to privacy are safeguarded; and that the transport, management and uses of the data are appropriate to enhancing the safe provision of health care for individuals, providers and the public at large.*

The recommendations in this report and plan are fully consistent with the mission statement.

EHR Taskforce Committee Structure

On April 18, 2006, the taskforce adopted a committee structure based upon the *Goals of Strategic Framework* as described by David J. Brailer, M.D., Ph.D., as the first National Coordinator for Health Information Technology, U.S. Department of Health and Human Services.[10]

The four working committees of the taskforce were the Informing Clinicians Committee, the Interconnecting Clinicians Committee, the Personalizing Health Committee, and the Improving Population Health Committee. These working committees reported to the Steering Committee.



The purpose of the **Informing Clinicians Committee** was to recommend a strategic framework that would encourage clinicians in Illinois to adopt interoperable EHR systems.
The goal adopted by this committee was:

> *To facilitate the creation of an efficient, well integrated, and universally accepted electronic health infrastructure and environment, so that clinicians are eagerly and universally seeking to adopt electronic health records in their practices.*

Addressing the infrastructure issues and promoting electronic health information exchange among health care providers in the state was the task of the **Interconnecting Clinicians Committee**. The committee adopted the goal to:

> *Create a supportive environment in Illinois for sharing electronic health information to ensure that every resident's complete and accurate medical history, including test results and medication information, is available to provide optimal care by the treating physician, improve the health care system and the health of the population.*

The purpose of the **Personalizing Health Committee** was to recommend a strategic framework that will enable consumers in Illinois to participate in the management of their own health care using a personal health record (PHR). The goal adopted by this committee was to:

> *Promote a secure environment in which all individuals in Illinois have access to a private electronic PHR that is interoperable with other systems for the purpose of broadening access to patient information and health education.*

The **Improving Population Health Committee** studied how best to utilize the benefits of EHR for public health purposes, including improvement in the health care system, as well as population health. Committee members adopted the following goal:

> *Support a patient privacy protected, streamlined approach for access to population health information to advance bio-surveillance capabilities; increase quality and outcomes of patient care; and propel clinical knowledge from the time of discovery to practice implementation.*

The findings and recommendations of each of these committees fundamentally represent the core of the state EHR Plan. ["Appendix A" contains the full text of all committee reports.]

Related Developments

Several developments influenced the taskforce's deliberations and report.

Health Information Security Privacy Collaboration - Illinois

In June 2006, the Health Information Security Privacy Collaboration (HISPC) – Illinois began a review of a number of the issues to be addressed by the taskforce. This initiative stemmed from a 2005 AHRQ contract with RTI International to "identify variations in privacy and security practices and laws affecting electronic health information exchange, develop best practices and propose solutions to address identified challenges, and increase expertise about health information privacy and security protections at the community level."[11] RTI International issued subcontracts to 34 states and territories to perform this task.

Because of its experience in administering the federal Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services' contracts as the state's Quality Improvement Organization, and for the Doctor's Office Quality – Information Technology initiative to assist physicians adopt EHR, Governor Blagojevich designated the Illinois Foundation for Quality Health Care (IFQHC) to represent Illinois in a bid to become a *HISPC-Illinois* subcontractor.

In June, RTI International awarded IFQHC a $329,000 subcontract for *HISPC – Illinois*. IFQHC worked in conjunction with the taskforce in its review of privacy and security issues surrounding health information technology. This included the selection of the taskforce chair, Jonathan Dopkeen, Ph.D., as chair of the *HISPC – Illinois* Steering Committee. Other taskforce members were on the steering committee, as well as other work groups formed to address privacy and security issues. While the *HISPC – Illinois* final report is not due until early next year, this report and plan draws on much that has been learned by that project. (See Appendix G for the HISPC Interim report on the Variations Working Group, which provides the initial identification of practices that, identified as barriers or facilitators of electronic health information exchange, need to be addressed in both the subsequent work of the contract and acted upon in the implementation of a secure electronic health record in the state.)

Governor Issues Executive Order Creating the Division of Patient Safety

Another action of interest to the taskforce was Governor Blagojevich's issuance on July 13, 2006 of Executive Order 8 that created the Division of Patient Safety within the Illinois Department of Public Health. The new division is to consolidate the state's efforts for dealing with medical errors and focus on improving patient safety. Governor Blagojevich gave this new division an important electronic health information role as part of its patient safety mandate with respect to prescription drug safety. Among other provisions, the Governor charged it with the responsibility:

- To encourage all medical providers to utilize e-prescribing programs by 2011. E-prescribing allows a physician to legibly write and electronically send prescriptions to reduce the risk of medication errors.
- To evaluate the areas within Illinois in need of enhanced technology to support e-prescribing programs.
- To determine the types of technology needed to implement the e-prescribing program.[12]

The Governor also directed the division to work with the Illinois Department of Financial and Professional Regulation, the Illinois Department of Healthcare and Family Services and respective physician organizations, researchers, pharmacists, and other health care providers to issue recommended medication practices to all providers. His announcement also suggested that the new division explore the idea of giving "low-interest loans through the Illinois Finance Authority to physicians to purchase technology so they can access medical databases and patient information."[13]

This initiative recognizes the importance of electronic health information technologies for improving the quality of patient care. In implementing its mandate, the Division of Patient Safety will be an effective partner in the development of EHR within Illinois.

Federal Directive on Interoperable Health Information Technology

A major issue facing the taskforce was how to encourage health care providers to adopt EHR. One approach surfaced in an executive order issued by President George W. Bush on August 22, 2006. The executive order, entitled *Promoting Quality and Efficient Health Care in Federal Government Administered or Sponsored Health Care Programs*, requires federal agencies and their health care contractors to promote the use of interoperable health information technology products, so that data can be easily shared.

Specifically, the executive order states:

> *a) Health Information Technology.*
>
> > *(1) For Federal Agencies. As each agency implements, acquires, or upgrades health information technology systems used for the direct exchange of health information between agencies and with non-Federal entities, it shall utilize, where available, health information technology systems and products that meet recognized interoperability standards.*
> >
> > *(2) For Contracting Purposes. Each agency shall require in contracts or agreements with health care providers, health plans, or health insurance issuers that as each provider, plan, or issuer implements, acquires, or upgrades health information technology systems, it shall utilize, where available, health information technology systems and products that meet recognized interoperability standards.*[14]

Federal agencies are to comply with the requirements of the order by Jan. 1, 2007.

Two key principles demonstrated by this executive order were not lost on the taskforce. First, government must take a leadership role by adopting interoperable systems. Second, the adoption of EHR is facilitated by making the use of interoperable EHR a requirement for health care providers to do business with government.

EHR Plan

Focused State-level Leadership

Taskforce committees quickly identified the need for the creation of an entity to provide focused state-level leadership for Illinois' efforts to support a framework for interoperable health information exchange (HIE) and to encourage the widespread adoption of EHR systems among state health care providers. To address this need, the taskforce recommends that the General Assembly pass legislation creating such entity to be governed by stakeholders in the health care system. Primary functions of this entity will be: the establishment of a state-level HIE and the implementation of a comprehensive program to foster the adoption of EHR.

A major question before the taskforce was how the entity should be legally constituted. Of the nine "state-level health information exchange" efforts studied by the State Regional Health Information Organization (RHIO) Consensus Project, eight had governing entities that were either a non-profit organization or planning to become one.[15] The taskforce heard presentations from three of these states -- Indiana, Massachusetts, and Utah. The argument for a non-profit organization leading an HIE initiative stems from the belief that the public and other non-profit organizations would be more supportive than if the effort was led by a government entity.

After listening to the presentations and reviewing the studies, the taskforce agrees with this premise and recommends the General Assembly adopt legislation charging the Illinois Department of Public Health (IDPH) with responsibility for advancing Illinois' EHR and HIE initiatives and requiring the Department to establish a public-private partnership with a new not-for-profit organization, named the Illinois Health Information Network (**ILHIN**) governed by stakeholders in the health care system. IDPH would, over time, discharge its statutory responsibilities through grant and contractual relationships with **ILHIN** and would insure the protection of important public interests. **ILHIN** would be authorized by legislation to accept and implement these responsibilities and would provide, in the fast-paced world of EHR, the flexibility that a not-for-profit organizational form allows.

The taskforce identified the following functions for the **ILHIN**:

- Developer of a central HIE hub to link the state, local HIEs and interoperable EHR systems to share health information with other state and national HIEs;
- educator of the public and providers on the benefits of HIE, EHR and personal health record to encourage adoption;
- provider of technical assistance and support to local HIE/EHR efforts;
- facilitator of funding local HIE and EHR efforts, if any (not necessarily be the source of funding, but rather assist and facilitate funding);
- convener of stakeholders; and
- leader in the development of public policy for statewide HIE and EHR goals, and to identify and to propose solutions addressing statewide barriers to HIE and EHR adoption,

and to identify and remedy gaps in attaining full coverage of HIE and EHR capabilities (e.g., underserved areas).[16]

State-level Health Information Exchange

The taskforce recommends that one of the **ILHIN**'s primary functions be the establishment of a state-level health information exchange to serve as a "hub" or "highway" to facilitate the sharing of health information among health care providers within Illinois and other states. The "**ILHIN**'s state-level HIE" is not intended to be the sole HIE within Illinois, but it will function as a link to those that may be formed, and to those outside the state.

Illinois Health Information Network (ILHIN)
Major Functions as Proposed by the EHR Taskforce

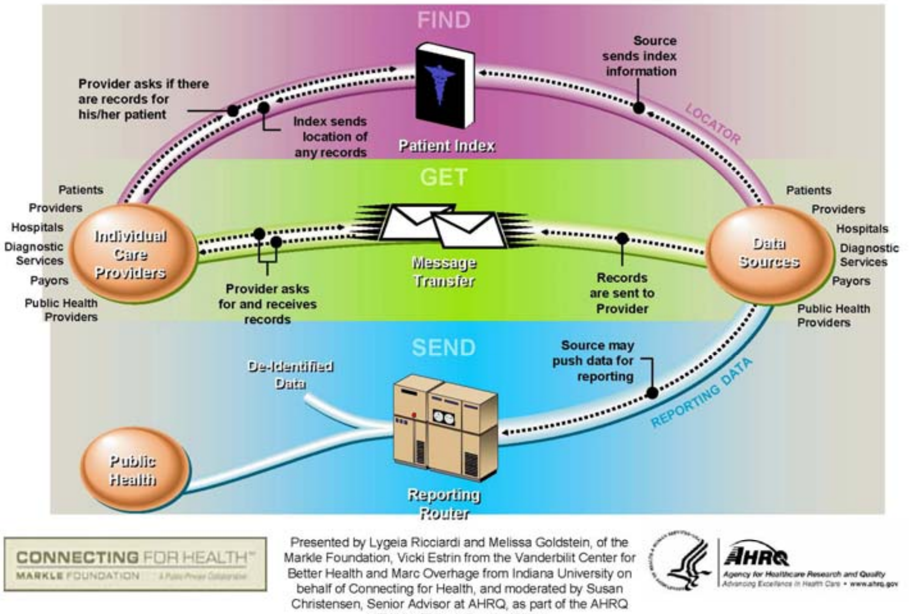
State-Level HIE
Record Locator Service
Health Information Sharing
Population Health Data
Health Quality Research

This function is adapted from one of the models reviewed by the taskforce, "**Connecting for Health** Common Framework: Resources for Implementing Private and Secure Health Information Exchange." It was developed by Connecting for Health, a public-private collaborative convened by the Markle Foundation, and released in April 2006. The Common Framework consists of 16 documents discussing policy, technical, and legal issues involved in creating a HIE infrastructure.

"The concept underlying the **Connecting for Health** approach is that information exchange can take place among existing and future health care networks over the Internet if all participants adhere to a small set of shared rules — a 'Common Framework' of technical and policy guidelines."[17]

This *federated* approach enables direct care providers to retain possession of their own records. The taskforce took a strong stand against the alternate data model of maintaining a *central repository* for all patient health records. Implementing a *federated* model would allow health information sharing to occur quicker and at lower cost than the *central repository* model. The Interconnecting Clinicians Committee recognized the ultimate model will be a practical hybrid of the two approaches. However, the use of health information repositories will be restricted to the internal use by regional or affiliated organizations [RHIOs or sub-network organizations (SNOS)], and the exchange between these organizations will be *federated*. However, it was noted and acknowledged that the state-level HIE must have the means to capture population health data, and that this may necessarily have to exist in a repository specific to population health functions.

Figure 1 depicts the Common Framework model. It demonstrates the three stages in the process for sharing health information. First is the need to "FIND" a patient's records. This task is performed by a "Record Locator Service" (RLS), which is an index of patients whose records are maintained by providers connected to the network. The RLS may also maintain an index for providers, as well as an index of standardized medical terms, and diagnostic, procedure, and service codes. The patient index contains demographic information and the location of a patient's medical records. It does not contain an individual's clinical information. Local HIEs would decide whether to participate in the RLS. The taskforce recommends that the **ILHIN** state-level HIE function as the RLS for Illinois.



Presented by Lygeia Ricciardi and Melissa Goldstein, of the Markle Foundation, Vicki Estrin from the Vanderbilt Center for Better Health and Marc Overhage from Indiana University on behalf of Connecting for Health, and moderated by Susan Christensen, Senior Advisor at AHRQ, as part of the AHRQ HIT Web Teleconference Series.

Slide 3, Connecting for Health Common Framework: Resources for Implementing Secure Health Information Exchange presentation, AHRQ Resource Center for Health Information Technology National Teleconference, July 25th 2006

Figure 1

The "GET" stage in the Common Framework model involves the RLS receiving a request for patient information from an individual care provider. After searching the index, the RLS would advise the requestor of the locations, or "Data Sources," of the patient's records. The requestor would then contact the data sources directly to request the data. The data would be sent if the requestor meets the data source's standards of trust, as outlined in contractual agreements between the sharing parties. According to the Common Framework, "all health information exchange, including in support of the delivery of care and the conduct of research health reporting, must be conducted in an environment of trust, based upon conformance with appropriate requirements for patient privacy, security, confidentiality, integrity, audit, and informed consent."[18] In practical terms, the transactions need to be electronic, and most effectively will work through participant agreements.

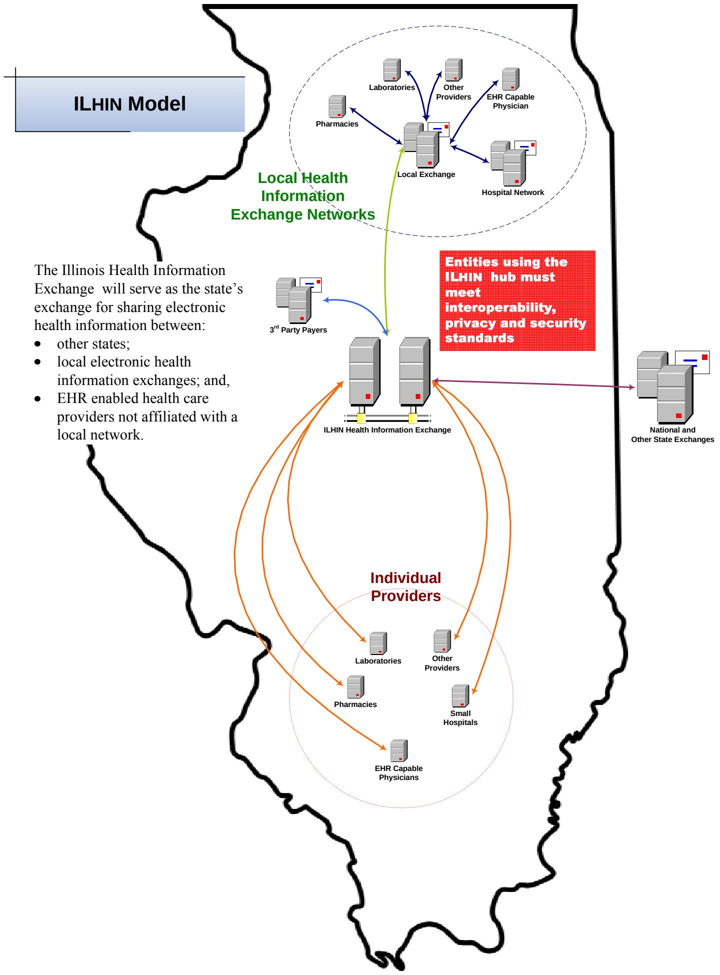
The taskforce recommends the **ILHIN** adopt a streamlined approach to the "GET" process. Instead of simply notifying the requestor of the location of the records and then requiring a separate communication with the data sources, the data sharing should be facilitated by the state-level HIE. Retrieving needed health information in an expeditious manner must be the priority.

One aspect of the two-step approach is the verification of a trust relationship between the requestor and the data source. The taskforce believes the **ILHIN** must assume that role by ensuring all parties connecting to the state-level HIE meet minimum standards. These standards are analogous to the "rules of the road." The **ILHIN** will need to ensure parties accessing the exchange (the highway) have interoperable systems to exchange data, use established data standards, and can be trusted to maintain the confidentiality of the information sent or received. For the purpose of meeting standards and efficiently transacting requests, the electronic requests must identity the requesting agent and include verifiable authorizations and credentials.

The standards adopted for Illinois's state-level HIE must be consistent with national standards to ensure patient health information can be shared with other state HIEs.

Public acceptance of health information sharing also depends upon maintaining the trust relationship. The **ILHIN** can only permit parties to participate in the state-level HIE if they meet standards of trust. Conversely, the **ILHIN** must be able to act swiftly to address instances where that trust is breached. The taskforce strongly recommends the **ILHIN**'s standards include the ability to impose sanctions for non-compliance with its standards. However, the taskforce sought to affirm the positive benefits of HIE and envisioned sanctions in term of suspension or termination of exchange rights, and not as financial fines or penalties requiring a significant bureaucracy.

Establishing trust goes beyond the users of the state-level HIE. The **ILHIN** itself must be vigilant in protecting the data flowing through the state-level HIE.



ILHIN Model

The Illinois Health Information Exchange will serve as the state's exchange for sharing electronic health information between:

- other states;
- local electronic health information exchanges; and,
- EHR enabled health care providers not affiliated with a local network.

Entities using the ILHIN hub must meet interoperability, privacy and security standards

In reviewing existing electronic data related activities in the state, the taskforce noted the data exchange efforts of the Illinois Health Network (IHN). While not operating at the full level of an HIE, the IHN has been working on health information sharing projects for hospitals, local health departments, and other health professionals in a manner that serves as a precursor to implementing a full service exchange. In discussing the creation of a state-level HIE, taskforce members were concerned about the development costs. They felt strongly that the state should maximize available resources to accomplish the task of building an effective HIE. The Interconnecting Clinicians Committee noted the need to utilize existing resources to minimize cost. Since the IHN was created using a grant from IDPH, the Department owns the assets of IHN. The taskforce recommends that IDPH make the benefits of the IHN available to the **ILHIN** and that the **ILHIN** enabling legislation include a provision permitting the transfer of the IHN assets from IDPH to the **ILHIN**, if the Department so determines. This will provide the **ILHIN** with operational capabilities that will serve as an important starting point for the development of the state-level HIE.

As noted in a draft of the Improving Population Health Committee's goal, objectives, and issues document, "one of the critically valuable deliverables of the exchange of electronic health records is the ability to improve the health of individuals, communities, state, and nation by ongoing disease surveillance systems; accelerating the speed of clinical research; and improving quality of care." The state-level HIE needs to incorporate procedures to enable state agencies to capture data that will improve population health in Illinois.

Although the research benefits to be derived from the state-level HIE will be years down the road, this will become an inevitable and important function. However, access to this information must be carefully controlled to ensure protection of patient privacy and confidentiality. The **ILHIN** must adopt research standards to ensure this result.

The Improving Population Health Committee proposed requests for research be reviewed by an internal review board. The taskforce concurs and recommends requests for research be reviewed by a federally qualified institutional review board appointed or designated by **ILHIN**.

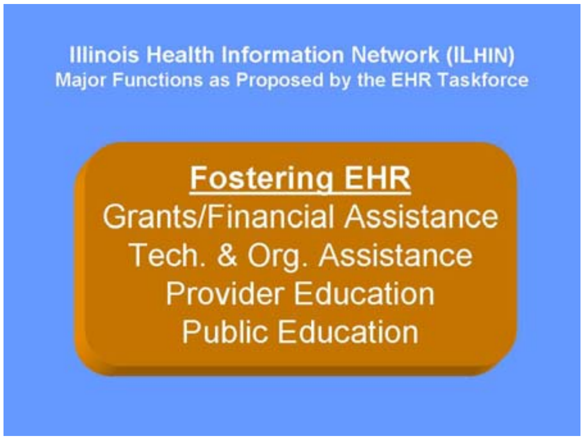
The taskforce also believes that the **ILHIN** will need the flexibility to respond to emerging technology and/or models as it develops the state-level HIE. It is anticipated that adopting tested technologies from other states and demonstrations will provide financial savings. Consequently, technical recommendations have been deferred until the **ILHIN** is convened, and when it can work with the substantive results of the federal demonstration projects and other current state initiatives.

Fostering the adoption of EHR

Health information technology's promise for improving patient care, the health care system, and population health is dependent upon the adoption of EHRs by health care providers. While there is no specific information regarding the level of EHR adoption in Illinois, national studies estimate that 17 percent to 25 percent of physician offices have EHR systems. Among solo practitioners, the adoption level ranges from 13 percent to 16 percent. From 19 percent to 57 percent of large physician offices (defined as 20 or more physicians by one study) have adopted EHRs.[19] Estimates for hospital adoption range from 16 percent to 59 percent. (The term EHR is being used loosely here to indicate the use of electronic patient records. but much of this data, in fact, refers to adoption of electronic medical records, which are a facility or practice-based records, while the EHR more precisely refers to the full electronic health record with data from multiple and even unrelated providers. The source data here are recognizing estimates of prevalence of adoption of electronic patient records, and do not reflect judgments of the highest systems integration or interoperability.)

The taskforce recommends that **ILHIN**'s other primary function be to foster EHR adoption among Illinois health care providers. This will require the **ILHIN** to identify and address barriers to EHR adoption. Taskforce committees spent considerable time discussing the economic, training, legal, and public acceptance barriers. The state's HISPC contract with RTI International will provide more information on barriers and solutions for EHR adoption in the spring of 2007.

Economic considerations are continuously cited as the greatest barrier to EHR adoption. Almost 55 percent of the respondents to a 2005 American Academy of Family Practitioners (AAFP) survey indicated they could not afford EHR systems. More than one quarter of the respondents also cited decreased productivity as a reason for delaying the purchase of EHRs. The estimated first year cost for implementing EHRs was placed at $50,000 or more by more than 6 percent of the respondents.[20]



Illinois Health Information Network (ILHIN)
Major Functions as Proposed by the EHR Taskforce

Fostering EHR
Grants/Financial Assistance
Tech. & Org. Assistance
Provider Education
Public Education

A 2005 survey of hospitals also identified costs as the "#1 barrier to greater adoption." Fifty-nine percent of all hospitals responding to the survey identified initial costs as "significant" barriers to HIT adoption.[21] Ongoing costs were cited as a significant concern for one-third of hospital respondents. The survey also noted a greater concern about costs among rural hospitals.

To address this barrier, the taskforce recommends the **ILHIN** be empowered to provide financial assistance to help health care providers adopt EHR systems. The **ILHIN** will also need to look at other mechanisms to aid providers with the economic impact. This may include working with vendors to get discounts for interoperable EHR systems.

Training and technology knowledge issues have been cited as another significant barrier, especially among smaller practitioners. More than 11 percent of the physicians responding to the AAFP survey noted the following training and knowledge-based concerns about implementing EHRs:

- Complex contracts and pricing,
- lack of expertise to make good decisions,
- lack of time to make good decisions,
- data entry is too difficult, and
- technology is too burdensome.

Assistance with the training and knowledge-based barrier to EHR adoption was identified as a major issue by the Informing Clinicians Committee. The committee heard a presentation about the educational and technical assistance benefits of Doctor's Office Quality – Information Technology – a federally funded initiative to guide physicians through the process of adopting EHRs. The Interconnecting Clinicians Committee also identified training and knowledge-based issues as a barrier to HIE initiatives.

The taskforce recommends that the **ILHIN** be authorized to provide technical and organizational assistance. Whether provided by **ILHIN** staff or through grants or contracts to outside entities, this technical and organizational assistance should be directed toward expanding EHR adoption and use, and not as a measure for lowering a provider's vendor support cost for existing systems. Additionally, advancing adoption among providers serving populations of public health interest, such as the uninsured, rural, and under-served, should be a priority for the **ILHIN's** technical resources.

Legal barriers were the subject of the HISPC – Illinois project. Those legal barriers not acted upon by the time the **ILHIN** is implemented, should be followed up by the **ILHIN**. The **ILHIN** also needs to monitor and make recommendations to IDPH regarding the impact of state and federal legislation on Illinois EHRs.

All taskforce committees raised the issue of educating the public on the benefits of EHR and the safeguards available to prevent disclosure of personal health information. A 2005 Harris Interactive Poll demonstrated the public's lack of knowledge of HIT when it found only 29 percent of respondents had heard or read about electronic medical records.[22] The survey also noted a strong concern about the privacy risks of EHRs. When asked if the expected benefits of "electronic medical record" systems outweighed potential risks to privacy, 48 percent agreed the benefits outweighed the risks, while 47 percent felt the privacy risks outweighed the expected benefits.[23]

The Personalizing Health Committee also addressed the need for the public to be educated as to the benefits and use of personal health records.

Financial assistance to providers, local HIEs, RHIOs, or SNOs, and low-income personal health records users was a need identified by three taskforce committees. The Personalizing Health Committee considered tax incentives or direct subsidies to help persons in medically underserved areas access personal health records.

Whether this assistance is through grants or loans, the role of bonding in providing the funding for these initiatives remains an open question.

Funding facilitator

Arguably, cost is the greatest barrier to the widespread adoption of EHR and HIE. Consequently, addressing this barrier will be one of **ILHIN's** most difficult undertakings. In its role as facilitator of funding, the **ILHIN,** as well as IDPH, will need to seek monies from a variety of sources. While the ultimate goal is for the **ILHIN** to develop a business sustainability model that will cover its expenses, EHR/HIT initiatives throughout the nation have shown the need for state financial assistance.

Following is a sampling of other state EHR funding initiatives:

- Missouri's fiscal year 2007 budget includes $25 million for a new Healthcare Technology Fund to support an EHR program, in addition to other projects that can improve the delivery of care, reduce administrative burdens, and address fraud, waste, and abuse.

- The Michigan legislature approved $9 million for pilot projects to develop or implement local HIEs.[24]
- The Rhode Island legislature approved a $20 million revenue bond to support the building of an HIE.[25]
- In 2005, the Florida legislature appropriated $1.5 million for the Florida Health Information Network grants program and another $2 million in 2006.[26]
- The Minnesota Legislature, as part of the Governor's 2006 e-Health initiative, has made $1.3 million in grants available to support the adoption and use of interoperable electronic health records in rural and underserved areas.[27]
- On May 24, 2006, Gov. George E. Pataki announced that 26 regional health care networks across the state were provided $52.9 million in grant awards as part of New York's Health Information Technology initiative. These projects will help expand the use of technology in New York's health care system and improve the quality of care for patients.[28]
- In California, "the Governor instructed the agencies and the Department of Managed Health Care to 'devise financing strategies to allocate at least $200 million in investment funds and $40 million in grant monies previously secured from California health plans' for health IT for rural areas, safety-net providers and medical groups."[29]

The taskforce recommends that Governor Blagojevich and the General Assembly provide state funding through IDPH to implement the responsibilities of the **ILHIN**.

Another potential funding source is the federal government. One study indicated that "AHRQ administers more than $166 million in grants and contracts throughout 41 states to support and stimulate investment in HIT (especially in rural and underserved areas), increase adoption of HIT systems, improve patient safety and quality of care, and conduct research on challenges to adoption and use."[30] Funding also is available from other federal agencies. In July 2006, the federal Centers for Medicare and Medicaid Services announced the availability of Medicaid "transformation grants" to increase the quality and efficiency of care. States applying for the $150 million, two-year grants could use the money for EHR initiatives to reduce patient error rates.[31] The partnership should aggressively seek federal funding opportunities.

Philanthropic foundations provide another source of funding that must be pursued by the partnership.

The taskforce also recommends that the partnership review funding opportunities from those groups who benefit from EHR and HIE programs.

Stakeholders Convener

The development of an electronic health information infrastructure to meet the goals of improving the quality of patient care, increasing the efficiency of health care practice, improving safety, and reducing health care errors requires the active participation of all stakeholders within the health care system. Bringing all players to the table was a recurring point made during the taskforce's deliberations. Having representatives from stakeholder groups governing the **ILHIN** ensures their commitment to the successful implementation of HIE and EHR. As the convener, there is an explicit recognition by all parties of the new governance entity as trustworthy, objective, and fair.

Policy Development

The public-private partnership will need to be a strong advocate for HIE and EHR initiatives within Illinois. It must be the focal point for identifying and providing solutions for barriers to the HIE and EHR. The partnership also must identify and address where there are gaps in adopting HIE and EHR capabilities.

ILHIN Governance

The tasks of implementing HIE and EHR adoption are daunting and require the strong commitment of stakeholders to achieve the desired goal. AHRQ and the RHIO Consensus Project studies on state-level HIE both noted the importance of broad stakeholder involvement.[32]

To guarantee this commitment, the taskforce concluded the **ILHIN** needed to be governed by stakeholders. The taskforce recommends the **ILHIN** be governed by a 31-member board of directors. After considerable deliberation on the professional and institutional roles, functions, associations, and interests of impacted stakeholders, the taskforce recommends that the composition of the board be as follows:

- Three hospital representatives, including one representing a small rural hospital.
- Five physicians – one from a rural practice, one primary care physician, one specialist, one from a small group practice, and one from a multi-specialty clinic.
- Three consumers.
- Five payer and employer representatives – one from a Health Care Service Corporation; one commercial insurer, one local payer; one self-insured employer, and one employer recommended by a generally-recognized employer trade organization that represents a broad base of employers within the state.
- Three pharmacists – one representing a large chain, one independent pharmacist, and one employed by a health care institution or a consultant pharmacist to care organizations.

- Two representatives from federally qualified health centers as defined in Section 1905 (l)(2)(B) of the Social Security Act;
- Two long-term care facility representatives -- one representing an organization of five or more facilities located throughout the state and one from an independently-owned facility.
- One representative of a home health agency.
- One representative of a mental health clinic or facility.
- One nurse.
- One representative of a diagnostic center.
- Director or designee from the departments of Healthcare and Family Services, Human Services and Public Health.
- Regional Administrator, Region 5, federal Centers for Medicaid and Medicare Services

The 27 non-governmental directors would be appointed to three-year staggered terms by the Governor, with the consent of the state Senate, from those persons nominated by generally recognized statewide organizations representing hospitals, physicians, nurses, consumers, third-party payers, pharmacists, federally qualified health centers, long-term care facilities, laboratories, mental health clinics, and home health agencies.

Organizationally, the taskforce recognizes the need for the board to develop its own governance procedures, which may include electing a voting executive committee. The taskforce also recommends that the board should elect its presiding officer from among its members and employ an executive director accountable to the board, who may be simultaneously employed by a state agency, to employ and manage such staff as needed to implement **ILHIN** mandates.

Interoperability a State Responsibility

In discussions about the adoption of interoperable health information technology, emphasis has been placed on health care providers. While private sector adoption is the major task to be addressed, the public sector or government must also be part of the equation.

To ensure that state government data systems become interoperable with provider systems, the taskforce recommends that legislation be adopted requiring health information systems maintained by any state agency meet interoperability standards by 2015.

This proposal is similar to the executive order issued by President Bush on Aug. 22, 2006 that imposed similar requirements on federal agencies. The major difference between the president's executive order and the taskforce recommendation is the imposition of a deadline for conversion to interoperable systems. Taskforce members noted the qualified nature of the federal requirement. Section 3(a)(1) of the executive order stated:

> *As each agency implements, acquires, or upgrades health information technology systems used for the direct exchange of health information between agencies and with non-Federal entities, it shall utilize, where available, health information*

> *technology systems and products that meet recognized interoperability standards.*[33]

The deadline provides some certainty with respect to Illinois government implementation.

Timetable for Success

On Jan. 20, 2004, President Bush announced an ambitious goal of assuring that most Americans have electronic health records within the next 10 years.[34] In his State of the Union Address, the president stated, "by computerizing health records, we can avoid dangerous medical mistakes, reduce costs, and improve care."[35] Thus, the president set a national time-based goal to expedite the momentum for adopting EHRs.

Illinois not only needs to meet the goal of EHR adoption by 2014, Governor Blagojevich has set a 2011 goal for medical providers to utilize e-prescribing programs. To achieve these goals, action must be taken quickly to ensure Illinois continues to make progress. The first step is for the General Assembly to introduce and approve legislation in the spring 2007 session creating the **ILHIN** and authorizing the public-private partnership between IDPH and the **ILHIN**.

Taskforce members also recognized that the **ILHIN** would take some time to become operational, if and when the General Assembly and governor approve the enabling legislation. A transition process must be put in place to ensure no funding opportunities are missed and that the **ILHIN** is up and running as expeditiously as possible. IDPH must play a key role in this process and the taskforce recommends that funding be appropriated to the Department to provide for this transition. The Department can then perform (or provide a grant to other entities, such as the IHN to perform) needed transitional activities and monitor and apply for federal and other funding that may become available to support the adoption of EHRs and HIEs.

The first years of **ILHIN**'s existence will be devoted to designing the state-level HIE, supporting pre-cursor HIE activities and pilot projects, and funding initiatives to foster EHR and HIE adoption. Actual HIE activities will occur only after proper planning and testing by the **ILHIN**. Failure to properly plan may increase the cost of HIE activities and potentially lead to privacy and security problems.

A goal would be for the **ILHIN** to achieve financial sustainability by 2014. The development of an operational and self-sustaining business model is recognized as impracticable during the developmental and implementation process, given the need to develop common infrastructure and provider-based adoption.

To provide valuable policy information to the **ILHIN** and to decision makers reviewing the **ILHIN**'s achievements, reliable EHR adoption data needs to be available. A recent Robert Wood Johnson Foundation report found research on EHR adoption levels lacking.

> *The existing research allows some general inferences, but it cannot be used to generate precise, valid and reliable estimates of rates and patterns of dissemination and use at any point in time or longitudinally. This research also*

> *cannot systematically identify areas where adoption and use are lagging, such as safety net institutions or other facilities serving vulnerable populations.*[36]

Members of the Informing Clinicians Committee discussed the need to close this information gap as it pertained to the **ILHIN**'s ability to assess the effectiveness of its fostering EHR adoption efforts. The taskforce agreed and recommends the powers and duties of the **ILHIN** include helping to stimulate, facilitate, and coordinate research for better understanding the implementation and use of EHRs in the state.

Appendix A

EHR Taskforce Committee Reports

Informing Clinicians Committee Final Report

Adopted Nov. 14, 2006
Amended Dec. 18, 2006

The purpose of the Informing Clinicians Committee was to recommend a strategic framework that would encourage clinicians in Illinois to adopt interoperable Electronic Health Record (EHR) systems. In the *Goals of Strategic Framework,* David J. Brailer, M.D., Ph.D., National Coordinator for Health Information Technology, U.S. Department of Health and Human Services, states: "Use of EHRs can result in workflow efficiencies in clinicians' offices and higher quality of care for patients."[37] Unfortunately, only a fraction of all clinicians use electronic health records and many clinicians who started with EHR systems have discarded them due to a lack of technical support or insufficient training to workflow changes. To assist with EHR adoption, it is important that barriers to EHR adoption are defined and solved. A recent study listed multiple EHR barriers including: funding, workflow, technological, and legislative barrier to EHR adoption.[38]

To achieve this goal, the Informing Clinicians Committee listed three objectives to successful EHR adoption:

1. Create a catalyzing and coordinating agency to assess the current state of EHR adoption and national guidelines for EHR certification, interoperability, privacy, and security.

2. Assist clinicians to overcome EHR adoption barriers by becoming a vehicle for funding of successful EHR adoption initiatives. The investment in EHR is a shared one that will benefit patients, insurance companies, hospitals, state, and federal agencies. Funding sources should be sought from all who benefit.

3. Educate clinicians to the benefits of a fully integrated EHR system and train them to better prepare for technological and workflow barriers.

Goal

To facilitate the creation of an efficient, well-integrated, and universally accepted electronic health infrastructure and environment, so that clinicians are eagerly and universally seeking to adopt electronic health records in their practices.

Our definition of clinicians includes all providers of medical care including: physicians, nurse practitioners, physician assistance, pharmacists, nurses, occupational and physical therapists, chiropractors, dieticians, dentists, hospice and long term care facility caregivers, health educators, and any other providers of medical care.

Objectives

Objective 1:

Provide input: Provide clinical and clinician's input and perspective into the statewide EHR activities to ensure interoperability and decrease redundancy as a cornerstone of this EHR.

In particular, we want to help promote the easy access and exchange of the personal health record including medication information, problem lists, immunizations, allergies, test results, consultations, hospital discharge summaries, and operative reports.

Recommendations for Implementing the Objective:

The state should allow for standards of information and support an entity that will catalyze and coordinate the transfer of information from clinician-to-clinician. To accomplish these tasks, the state should authorize a third party that will:

1. Define the current datasets used in Illinois in order to reduce redundancy.
2. Encourage the federal government to proceed with certifying electronic health systems (CCHIT) that promote accurate and efficient information exchange.
3. Support clinicians who comply with these standards.
4. Promote e-prescribing by eliminating financial and legal barriers. Clinical prescriptions should not become proprietary and should be shared by all pharmacies and providers.
5. Continue to promote guidelines and legislation that ensure the security and privacy of electronic health records.

The ultimate goal of this effort should be to have interoperable EHR system that acts as a personal health record (PHR) for the nation.

Issues for Further Consideration:

1. The committee understands that many organizations including ONCHIT and HIMSS are certifying EHR vendors, and defining standards for EHR connectivity. The committee decided that Illinois clinicians should take an active role in these organizations, but that standards should not be determined by the state.
2. The committee's intent is not to hinder EHR adoption by clinicians and therefore legislation should not mandate how clinicians practice medicine.

3. The committee understands that the information sharing is crucial to e-prescription success and should not succumb to proprietary control by large pharmaceutical companies, pharmacy chains, pharmacy benefit managers (PBMs), insurers, or hospital networks**.**

4. The committee encourages the state to continue support of national studies and initiatives including Connecting for Health by the Markle Foundation and Health Information Security and Privacy Collaboration (HISPC).

5. The committee encourages the authority[b] to help stimulate, facilitate, and coordinate research for better understanding the implementation and use of EHR in the state.

Objective 2:

Overcome Barriers: Identify and overcome barriers that clinicians face when using electronic health records.

Specifically we want to decrease financial, regulatory, technical, workflow, and organizational barriers that arise with the implementation and maintenance of electronic health record systems.

Recommendations for Implementing the Objective:

To help overcome barriers to EHR adoption, funding is needed to help clinicians and programs that assist clinicians with EHR adoption. Funding also is needed for grants and low-interest loans to reduce the overhead expense required for EHR adoption especially in smaller practices and underserved areas. The investment in EHR is a shared one that will benefit patients, insurance companies, hospitals, state, and federal agencies. Funding sources should be sought from all who benefit. Creative funding sources may include monies from low-interest bonds, insurance companies, hospital organizations, other organizations that directly benefit from EHR adoption, private foundation, and state and federal grants.

Issues for Further Consideration:

1. The committee felt it most feasible for the state to provide assistance to clinicians who both requested assistance and were in need. The current need for EHR adoption should focus on solo and small group practices, rural practices, and underserved health clinics.

2. The committee recommends that the foundation fully assess any changes to legislation when decreasing legal barriers. While there are many proponents

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[b] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

who suggest loosening Stark laws and other anti-kickback legislation, these laws may protect small physician practices and smaller vendor companies.

3. The committee recommends that the foundation evaluate all programs that they will support financially.

Objective 3:

Educate clinicians: Engage clinicians and technicians to both learn from their experiences and to help others adopt EHRs.

Recommendations for Implementing the Objective:

To help educate clinicians and technicians, it is important to gain knowledge from programs already in place (DOQ-IT, current university programs, and clinicians with successful EHRs) to help educate clinician and technicians to successful EHR adoption.

Issues for Further Consideration:

1. The committee specified educational needs for clinicians in the selection of vendors, technical and workflow challenges. Most of all, education should inform clinicians to the benefits in EHR adoption by reducing medical errors and optimizing medical care.

2. The committee encourages the continual education of health information technicians and hope that many certify through accredited degree programs in health informatics.

Interconnecting Clinicians Committee Final Report

Adopted Nov. 13, 2006

The Interconnecting Clinicians Committee was based on *Strategic Framework Goal 2* of the four *Goals of Strategic Framework* described by David J. Brailer, M.D., Ph.D., National Coordinator for Health Information Technology, U.S. Department of Health and Human Services.[39] As stated in the goal statement, "without clinicians' ability to exchange information with one another electronically, whether it is across town or across the country, patients' information may not be readily available when and where it is needed." It further states "to remedy this, an interoperable system based upon a common architecture must be developed."

Strategic Framework Goal 2 lists three strategies for achieving an interoperable system. First is to foster regional collaborations where locally held patient information can be electronically accessible to those involved with providing care. These collaborations have been named Regional Health Information Organizations (RHIOs), or sub-network organizations or SNOs.[40]

The second strategy is the development of a common set of standards for sharing health information. Government commitment to using interoperable systems with common standards and architecture is the third strategy outlined in *Strategic Framework Goal 2*.

Within this context, the committee began its deliberations on April 18, 2006. One of the first issues noted by the members was that the word "clinicians" within the committee name should not be viewed as a limitation on the type of stakeholders needing to participate in health information sharing. Interoperable health information technology holds great promise for improving the health care system and population health. Stakeholders in these areas need to be involved in the process for developing the infrastructure for health information sharing.

The committee adopted the goal of creating a supportive environment in Illinois for sharing electronic health information to ensure that every resident's complete and accurate medical history, including test results and medication information, is available to provide optimal care by the treating physician, improve the health care system, and the health of the population.

The overarching recommendation of the committee was to create an entity to assume the leadership role in creating this supportive environment. This entity would be charged with the responsibility of fostering local collaborations and developing an infrastructure to facilitate health information sharing within the state. Stakeholder representatives would be on the entity's governing board to ensure the necessary commitment to health information technology. This and other taskforce committees agreed that the entity would be embodied as a state authority.[c]

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[c] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

The committee also adopted objectives for attaining the goal. Following is a restatement of the committee's goal and the objectives with recommendations for their implementation.

Goal

Create a supportive environment in Illinois for sharing electronic health information to ensure that every resident's complete and accurate medical history, including test results and medication information, is available to provide optimal care by the treating physician, improve the health care system and the health of the population.

Objectives

1. Eliminate barriers to sharing health information among persons authorized to receive the data within and outside of Illinois.

   Recommendations for Implementing the Objective:

   The committee recommends that the authority[d] review the report from the Health Information Security Privacy Collaboration (HISPC) – Illinois project and note those barriers identified by the project that have not been addressed by the General Assembly or other entities and develop a plan for their elimination. Unfortunately, the report of the HISPC – Illinois project is not due until after the due date for the taskforce's report and plan. The authority must take an active role in responding to barriers not identified by HISPC – Illinois or potential barriers that may surface, regardless of whether they are state or federal issues.

   Issues for Further Consideration:

   Financial barriers to infrastructure development for health information sharing were also discussed by the committee. Committee members suggested that the authority review funding opportunities as part of its role of fostering health information exchange.

2. Review and make recommendations to revise Illinois laws where necessary to facilitate the exchange of electronic health records in an accurate and secure manner while protecting or maintaining patients' rights and privacy.

   Recommendations for Implementing the Objective:

   The committee recommends that the General Assembly approve legislation creating the authority.[d] This legislation should provide for the transfer to the authority those Illinois Department of Public Health assets derived from it grants to the Illinois Health Network. Creation of the authority is critical to ensuring

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[d] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

that the continued development of health information technology in the state. An Illinois Department of Public Health grant supported the creation of an early stage electronic health information sharing network. As funder for the network, the Department retains ownership rights to the assets. The assets can serve as the foundation for the authority's[e] health information sharing infrastructure.

Once created, the authority[e] will assume the role of recommending legislative changes necessary to further the goal of health information sharing.

Issues for Further Consideration:

In developing the standards for participating in the state health information exchange, the authority[e] needs to consider whether it should require participating providers to obtain patients' consent to be listed on the record locator service (RLS) – See Objective 6 – or establish a policy where patients are listed unless they "opt-out" of the health sharing process.

The authority[e] also needs to consider patient involvement or accessibility to their records held by parties to an electronic exchange transaction.

3. Assure that standards in Illinois are consistent with the national standards for health information exchange.

   Recommendations for Implementing the Objective:

   The committee recommends that the enabling legislation for the authority[e] require it to develop standards consistent with nationwide standards where applicable. To ensure that vital health information can be shared with other states, it is imperative that the authority's[e] health information exchange use the same standards used by other exchanges.

   The committee also recommends that state agencies be required to adopt interoperable health information systems and require the submission of health information in a manner consistent with national standards.

4. Develop a plan to provide technology support to clinicians and guidance on how to connect with other organizations within Illinois.

   Recommendations for Implementing the Objective:

   The committee recommends that the authority[e] develop a plan to provide technical support for clinicians and local health information exchange organizations in areas or sectors where there is an unmet need (e.g., rural providers or providers with substantially uninsured practices).

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[e] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

Lack of information about how to develop and support interoperable health systems is a major barrier for health care providers. The authority[f] can address this role by developing a plan for support. This should not supplant support that needs to be provided by health information vendors.

Issues for Further Consideration:

The authority[f] should consider working with health information vendors to provide this support on a low cost/no cost basis.

5. Identify opportunities to foster electronic health exchange activities, especially in rural and underserved areas of the state.

Recommendations for Implementing the Objective:

The committee recommends that the authority[f] be empowered with the responsibility of fostering health information exchange activities. This may include the issuance of grants, and/or working with other state agencies regarding loan programs and providing assistance in pursuing other funding opportunities.

6. Propose an entity to assure implementation of health information exchange.

Recommendations for Implementing the Objective:

The committee recommends the creation of the authority[f] to perform the function of assuring implementation of health information sharing activities within Illinois.

Part of this assurance function is for the authority[f] to develop initiatives to foster interoperable health information technology. Another part is for the authority[f] to establish a state health information exchange. The state exchange would consist of the RLS to link health care providers with sources for patient information within Illinois and other states, and the mechanism to facilitate the data transfer from the data source to the caring provider.

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[f] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

Personalizing Health Care Committee Final Report

Adopted Nov. 9, 2006
Amended Dec. 18, 2006

The purpose of the Personalizing Health Committee was to recommend a strategic framework that will enable consumers in Illinois to participate in the management of their own healthcare through the use of a personal health record (PHR). Studies suggest that well-informed patients are better equipped to actively participate in their own health care and decision-making. Advancements in technology have enabled consumers to have electronic access to their health information and to gather specific information relating to their illnesses, chronic conditions and health characteristics.

The committee deliberated on several issues before formulating its recommendations. The issues discussed by the committee related to the following objectives:

1. Defining the characteristics of the PHR and identifying its key functionalities.
2. Promoting and adopting standards for data elements.
3. Recommending a certification process that ensures that PHR service providers will protect confidentiality, as well as maintain rights to privacy.
4. Suggesting policy that provides financial resources to broaden access to PHR.
5. Promoting incentives for sponsorship of PHR.
6. Supporting an infrastructure that mirrors the EHR for secure and reliable health information exchange.
7. Identifying and addressing the barriers for use of the PHR.
8. Educating consumers about the benefits and value of PHR.
9. Creating a business case for PHR
10. Identifying regulatory barriers to data exchange among PHR providers, individuals, and others.

While the committee recognized that enhancing consumer choices and promoting the use of Telehealth systems are important issues, these issues were discussed to a lesser degree because initiatives are already underway in the marketplace to address these matters.

Goal

Promote a secure environment in which all individuals in Illinois have access to a private electronic PHR that is interoperable with other systems for the purpose of broadening access to patient information and health education.

Objective 1

Promote adoption of standards for the PHR. Ensure that this objective remains worthy of implementation. Given the number of PHR initiatives throughout the state and at the private-sector level, it is not productive for the state to develop a separate definition at this time.

Recommendations for Implementing the Objective:

1. Support the national standard or other standard PHR that it is likely to evolve. Such standard should include the following characteristics:

    - It is in an electronic format.
    - The consumer has control over its content and rights of access.
    - It includes consumer-generated information in addition to information from health care providers, pharmacists and pharmacy benefits managers, health plans, and insurance companies.
    - It is private and secure.
    - It combines personal health data and knowledge-based tools.
    - It provides information about consumer rights and responsibilities.
    - It is portable and interoperable.

2. Monitor initiatives that are under consideration that could universally affect the PHR.

    - Given the number of PHR initiatives at the national, state and private sector level, it is not productive for the state to develop separate standards. However, anything offered in the state should meet at least minimum federal requirements.
    - The state should monitor initiatives at the state and national level for the purpose of influencing a PHR initiative in Illinois and aligning any such initiatives, as needed, with national efforts for the purpose of interoperability.
    - The authority[g] should monitor the state of PHR development in the marketplace and engage in educating the public regarding PHR availability and adoption.

3. Support a PHR framework that parallels the EHR for secure and reliable health information exchange.

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[g] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

Issues for Further Consideration:

1. The committee understands that ASTM International (originally known as the American Society for Testing and Materials) through HL7 and X12 has accepted the role of administering a national standard, therefore the state would not have to assume such responsibilities if it accepts the national standards.

2. The committee noted that development of the PHR is on a fast track for individuals with health insurance and those who are Medicare-eligible. The state's major role should be to focus on the uninsured, Medicaid and other state health program participants.

3. Although interoperability is currently not available in most PHR systems, it is an important goal in the development of a PHR in Illinois. The committee recognizes that in the interim development of a PHR system, data transfer is likely to be paper-based.

Objective 2

Reaffirm that existing processes for privacy and security of personal health information are in place and that the appropriate regulatory authorities can monitor non-compliance and breaches.

Recommendations for Implementing the Objective:

1. Establish a set of protocols and procedures to enable payers, stakeholders, and consumers to report breaches of privacy and security.

2. Ensure that complaints relating to privacy and security are handled by the Illinois Attorney General's Office and/or the Division of Insurance, Illinois Department of Financial and Professional Regulation.

3. The committee determined that privacy and security guidelines already exist under HIPAA and existing state law. While existing guidelines and laws may address privacy and security issues, the committee defers to the findings and recommendations of Health Information Security and Privacy Collaboration (HISPC) regarding privacy and security guidelines.

Issues for Further Consideration:

1. New Illinois regulation may be needed in the absence of any federal regulations, relating to privacy and security non-compliance. Defer to the findings of the HISPC project.

2. Recognizing that de-identified data may and can be sold, the committee suggests that the state regulate who should have access to de-identifiable data for research and marketing but not regulate how data can be sold.

Objective 3

Encourage PHR vendors wishing to do business with the state to adhere to industry standards relating to technology, security, confidentiality, privacy, and governance.

Recommendations for Implementing the Objective:

1. PHR service providers wishing to provide services in the state according to approved standards must meet industry-wide certification requirements identified by the authority[h].

2. The authority[h] should delegate or identify a certifying body that will certify PHR service providers wishing to provide services in the State according to approved standards.

3. The authority[h] should create a list of PHR service providers that have met industry wide certification standards and make the list available to the public.

Issues for Further Consideration:

1. The authority[h] should consider establishing a list of certifying bodies that are recognized by the authority[h].

2. The committee recognizes that certifying bodies do not exist at this time, but anticipates that such bodies will exist in the future.

Objective 4

Suggest policy that will provide financial resources to broaden access to PHR.

Recommendations for Implementing the Objective:

1. Ensure that the financial resources will be made available for PHR for the uninsured, Medicaid and other recipients of state programs, individuals in medically underserved areas (MUAs) and health professional shortage areas (HPSAs).

2. Ensure that appropriate financial resources are dedicated to adoption of PHRs and education of consumer and provider groups regarding the benefits of the PHR.

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[h] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

Issues for Further Consideration:

1. The committee acknowledges that the employers and health plans will play an important role in making PHRs available to employees and their family members, therefore state resources would not be directed to those populations where PHR is available.

2. The committee urges the state to address what happens to the PHRs of individuals who lose health coverage and/or access to a PHR vendor when they are no longer employed.

3. The committee discussed issues relating to fees for an electronic PHR, but ultimately decided that the decision regarding fees should not be determined by the state, but rather the state should allow the market to drive whether there should or should not be fees for access.

4. The committee agreed that the state should not create any tax credits or subsidies to broaden access of PHR.

5. The committee held several discussions as to the status of PHRs with regard to health benefit plans and specifically as to whether PHRs should be considered a "health benefit" or a "program enhancement." The committee determined that considering PHRs to be a "health benefit" had regulatory, as well as tax implications, for consumers and employers sponsoring PHRs. Therefore, the committee determined that PHRs should be considered as a "program enhancement" for the purpose of this project.

Objective 5

Identify and address the barriers that can limit access to PHRs for individuals in medically underserved communities to limit health disparities in Illinois.

Recommendations for Implementing the Objective:

1. The committee recognizes that the PHR combined with technology results in a powerful telehealth medical tool. Health care consumers can easily communicate with providers while also participating in their own healthcare. The state should promote and enhance telehealth activities by working with providers to educate, train, support and finance telehealth medicine opportunities in communities where it is deemed appropriate.

2. The state should develop strategies to ensure that all consumers in the state have access to a PHR and consumer information about benefits, rights, and responsibilities.

3. The state should explore opportunities to develop and distribute PHRs in collaboration with existing state programs.

Issues for Further Consideration:

1. The state should identify all government and other authorized Web sites and agencies involved in health advisory that will support PHR.

2. PHRs will bridge communication between the healthcare consumer and the provider. The committee believes that as health care consumers take more responsibility for their own health and begin to take part in decisions regarding their treatment, there exists a potential for improvement in the quality and efficiency of the care provided.

Improving Population Health Committee Final Report

Adopted Nov. 14, 2006
Amended Dec. 18, 2006

One of the critically valuable deliverables of the exchange of electronic health records (EHR) is the ability to improve the health of individuals, communities, state, and nation by ongoing disease surveillance systems, accelerating the speed of clinical research, and improving quality of care.

Background Information
Improving population health can be accomplished through a variety of public and private initiatives. Some of these initiatives may include bio-surveillance, disease tracking, clinical research studies, clinical performance measurement, environmental assessment of services, and access to care.

For ongoing public health activity governed by state law or regulation, government agencies could request providers to submit required information on a nightly basis to a public health agency's repository. Similarly, organizations that participate in health information exchange (HIE) with the written authorization of the patient and organizational participant may establish a de-identified data repository for usage by the organization at their own expense.

For clinical research and other studies, special requests would be submitted to the governing HIE governing body for consideration. Special studies would utilize the record locator service (RLS) approach to identify and link non-patient identifiable data for this purpose. Clinical research and other studies would adhere to the strict patient privacy and security provisions and be responsible for charges incurred in utilizing a RLS approach. The exception for special studies, in which a public health agency would need no permission to act, would be an emergency request by government public health services to monitor emergency activity or urgent disease conditions.

Goal

Support a patient privacy protected, streamlined approach for access to population health information to advance bio-surveillance capabilities, increase quality and outcomes of patient care, and propel clinical knowledge from the time of discovery to practice implementation.

Objectives

1. Ensure protection of patient privacy and confidentiality of information remains a top priority and consideration in every population health initiative.

Recommendations for Implementing the Objective:

The committee recommends the creation of a state authority[i] to establish a public-private state health information exchange and to foster the development of local health information exchanges. Furthermore, this authority[i] must promulgate rules governing those entities connecting to the state health information exchange and researchers using the exchange data. These rules must follow federal and state patient privacy and confidentiality protections and adhere to access rules developed by the state authority[i].

The committee also recommends that all organizations connecting to the state health information exchange provide assurances that it:

- complies with federal and state laws and regulations on patient privacy and health information confidentiality,
- has privacy and security protocols and operational guidelines in place, and
- reports instances of non-compliance with privacy and confidentiality guidelines to federal and state authorities.

The committee recommends that the authority[i], in collaboration with public and private organizations, educate the public on their patient privacy rights and the privacy and protection of their information under EHRs and HIE exchanges.

2. Ensure that an internal board reviews special study applications for the use of state health information exchange data.

Recommendations for Implementing the Objective:

The committee recommends all requests to the authority[i] for research be reviewed by an internal review board appointed or designated by the authority or governor.

3. Develop a multi-level approach for secure access to population health that protects patient privacy.

Recommendations for Implementing the Objective:

The committee recommends that the authority[i] identify regulatory and legislative barriers to accessing population health information based upon state HIPAA pre-emption analysis and HISPC – Illinois Project.

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[i] This refers to the initial legal structure proposed by the taskforce for the entity. The revised and final recommendation of the taskforce is for the entity to be legally constituted as a not-for-profit organization.

Issues for Further Consideration:

The authority[j] should look at establishing security access levels for different types of applications. This review should include:

- an information analysis of application types;
- the credentials required of an applicant for different applications;
- distinguish between ongoing and special studies; and
- whether patient identifiable repositories, such as in public health or public health related government organizations, should have access controls and audit trails.

4. Develop a stream-lined approach for secure, approved access to population health information.

Recommendations for Implementing the Objective:

The committee recommends that the authority's design of the state health information exchange include a mechanism to capture population health information and to permit using de-identified data for research by approved researchers following privacy and security guidelines.

Issues for Further Consideration:

The taskforce has adopted the "federated" model with respect to general patient records. Under that model, health care providers retain the records, but upload patient index information to an RLS. However, there is nothing to preclude Illinois, under state law and regulation, to require reporting of data to the state to fulfill its regulatory and oversight responsibilities.

Authority[j] staff should also look at RLS, or RLS Plus Tag, architecture to determine its effectiveness in collecting population health data (i.e. bio-surveillance, mandated public health reporting requirements) or for use in research. Related issues to be considered include:

- the cost and ownership of establishing and maintaining population health and a state repository containing de-identified data; and

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- the management of duplicate patient occurrences (i.e. one patient with multiple occurrences due to submission by physician, hospital, clinic, laboratory, etc.)

5. While patient information and reporting to public health is currently included and covered under HIPAA, an approach for inclusion of patient information for other studies needs to be addressed.

   Recommendations for Implementing the Objective:

   The committee recommends that the authority[k] review the issue of including patient information for other studies.

6. Encourage and enhance "quality" research involving quality of care and patient outcomes.

   Quality and patient outcomes can be used to:
   - Identify gaps in delivery of care and best practice outcomes
   - Patient and consumer decision-making for consumer guides, report cards, etc.
   - Payment decisions
   - Published studies
   - Regulatory and quasi-regulatory oversight
   - Identify disparities in health care

   Organizations needing this information may include:
   - Providers
   - Health plans
   - Regulators
   - Consumer groups
   - Researchers
   - Employers
   - News media

   Recommendations for Implementing the Objective:

   The committee recommends that the authority[k] work closely with the Illinois Department of Public Health's Division of Patient Safety on the design of the state health information exchange to ensure that it captures quality data to address patient errors and other safety issues.

   The committee also recommends the authority[k] should establish a committee to provide and maintain guidelines on the quality of the health care information

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maintained by the state health information exchange, so that patients, providers, and researchers can be assured of the integrity of the data utilized.

To encourage greater participation in research, the committee recommends providers be notified of any potential patient candidates for clinical studies.

Issues for Further Consideration:

The authority[1] needs to consider methodologies for the removal of duplicate information utilized for both population health/de-identified patient data repositories and studies. This review should address who is responsible for the cost of assembling necessary data and managing duplicate patient occurrences.

Furthermore, the authority[1] will establish time frames and quality reporting requirements and develop participation or suspensions mechanisms for non-compliance.

7. Clinical and medical studies and practice knowledge will rapidly increase with access to EHRs for approved studies. This information needs to be shared with organizations where it will have the most positive impact.

Recommendations for Implementing the Objective:

The committee recommends that in developing its rules regarding research, the authority[1] should take into consideration how the results will be disseminated.

The authority[1] must work cooperatively with the Division of Patient Safety, other offices within the Illinois Department of Public Health, the Illinois Department of Healthcare and Family Services, the Illinois Department of Human Services, and various provider organizations to ensure that needed information is shared with its constituency groups.

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Appendix B

Electronic Health Records Taskforce Members

Electronic Health Records Taskforce
Members

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Special acknowledgment to the following people whose hard work and assistance were invaluable to the work of the taskforce:

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Member alternates: Hayes Abrams, Patrick Gallagher and Kathy Herold

Staff: Fee Habtes, Ph.D., Jeff W. Johnson and Ariel Katz, M.D.

Appendix C

Electronic Health Records Taskforce Act

Electronic Health Records Taskforce Act

Public Act 94-646
Effective August 22, 2005

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 1. Short title. This Act may be cited as the Electronic Health Records Taskforce Act.

Section 5. Electronic Health Records Taskforce established. There is hereby created the Electronic Health Records Taskforce, hereinafter referred to as the EHR Taskforce. The EHR Taskforce shall be convened by the Department of Public Health, in coordination with the Department of Public Aid and the Department of Human Services.

Section 10. Taskforce duties; membership.

(a) The EHR Taskforce shall create a plan for the development and utilization of electronic health records (EHR) in the State in order to improve the quality of patient care, increase the efficiency of health care practice, improve safety, and reduce health care errors. The EHR plan shall provide policy guidance for application for federal, State, or private grants to phase in utilization of EHR by health care providers.

(b) The Taskforce shall include representatives of physicians, hospitals, pharmacies and long-term health care facilities, academic health care centers, payors, patients and consumers, and information technology providers.

(c) The Taskforce shall prepare and submit a report on the EHR plan to the General Assembly by December 31, 2006.

Section 15. EHR plan. The EHR plan shall include, but not be limited to, a consideration of all of the following:

(1) key components of and standards for comprehensive EHR systems for recording, storing, analyzing and accessing patient health information, assisting with health care decision-making and quality assurance, and providing for online health care;

(2) consistent data elements, definitions, and formats that should be incorporated in EHR systems;

(3) analysis of costs and benefits in implementing EHR by various types and sizes of health care providers;

(4) survey of equipment, technical assistance, and resources that would be necessary to assist smaller health care providers with EHR implementation and utilization;

(5) standards, technology platforms, and issues related to patient access to their individual medical and health data;

(6) a potential phase-in plan for implementing EHR by health care providers throughout Illinois; and

(7) patient privacy, security, and compliance with applicable rules set forth in the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Appendix D

Electronic Health Records-related Acronyms

Electronic Health Records-related Acronyms

AHIC	American Health Information Community (The Community) - Federally-chartered commission to provide input and recommendations to the U.S. Department of Health and Human Services on how electronic health records
AHIMA	American Health Information Management Association
AHRQ	Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services
ANSI	American National Standards Institute - a non-profit organization that administers and coordinates the U.S. voluntary standardization activities
ASPE	Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
ASTM	American Society for Testing and Materials (ASTM) International -- founded in 1898, ASTM International is a not-for-profit organization that provides a global forum for the development and publication of voluntary consensus standards for materials, products, systems, and services.
CCD	Common Client Directory
CCHIT	Certification Commission for Health Information Technology - private, non-profit organization established to develop an efficient, credible, and sustainable mechanism for certifying health care information technology products
CCR	Continuity of Care Record - a standard specification being developed jointly by ASTM International (an SDO), the Massachusetts Medical Society, the Health Information Management and Systems Society (HIMSS), and the American Academy of Family Physicians (AAFP). It is intended to foster and improve continuity of patient care, to reduce medical errors, and to assure at least a minimum standard of health information transportability when a patient is referred or transferred to, or is otherwise seen by, another provider.
CDA	Clinical Document Architecture
CDC	U.S. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services
CDSS	Clinical Decision Support System
CHI	Consolidated Health Informatics Initiative - establishes federal health information interoperability standards as the basis for electronic health data transfer in all activities and projects and among all agencies and departments (ONCHIT Initiative)
CPOE	Computerized Physician/Provider Order Entry
DSL	Digital Subscriber Line
EHR	Electronic Health Record
EMR	Electronic Medical Record
GUI	Graphical User Interface
FHA	Federal Health Architecture - ONCHIT program to create a consistent federal framework to facilitate communication and collaboration among all health care entities to improve citizen access to health-related information and high-quality services
HIE	Health Information Exchange
HIPAA	Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191)

HIT	Health Information Technology – frequently associated with the OHCHIT Health Information Technology Adoption Initiative in partnership with the George Washington University, Partners/Massachusetts General Hospital Institute for Health Policy and Brigham and Women's Hospital
HITRC	Health Information Technology Resource Center, also known as the AHRQ National Resource Center for Health Information Technology (the National Resource Center), U.S. Department of Health and Human Services
HITSP	Health Information Technology Standards Panel
HL7	Health Level Seven - a standard development organization that supports the development and maintenance of a health data exchange protocol. Level Seven refers to the highest level of the International Organization for Standardization (ISO) communications model for Open Systems Interconnection (OSI) - the application level. The application level addresses definition of the data to be exchanged, the timing of the interchange, and the communication of certain errors to the application. The seventh level supports such functions as security checks, participant identification, availability checks, exchange mechanism negotiations and, most importantly, data exchange structuring.
HRSA	Health Resources and Services Administration
IHI	Institute of Healthcare Improvement
IOM	Institute of Medicine
ISB	Inter-SNO Bridge - term used by Connecting for Health to refer to the interface or point of contact between SNOs. From the publication, *The Connecting for Health Common Framework: Technical Issues and Requirements for Implementation.* Connecting for Health is a public-private collaborative of more than 100 organizations representing a diverse array of private, public, and not-for-profit groups.
ISO	International Organization for Standardization
LAN	Local Area Network
LHII	Local Health Information Infrastructure
NEDSS	National Electronic Disease Surveillance System - CDC initiative to advance the development of efficient, integrated, and interoperable surveillance systems at federal, state, and local levels
NCVHS	National Committee on Vital and Health Statistics - public advisory body to the secretary of the U.S. Department of Health and Human Services
NHII	National Health Information Infrastructure - ASPE initiative to improve the effectiveness, efficiency, and overall quality of health and health care through a comprehensive network of interoperable systems of clinical, public health, and personal health information. (Now incorporated into ONCHIT)
NHIN	Nationwide Health Information Network - a network linking disparate health care information systems to allow patients, physicians, hospitals, public health agencies and other authorized users across the nation to share clinical information in real-time under stringent security, privacy and other protections. Described in the Framework for Strategic Action: The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Health Care. As used by Connecting for Health, "(t)he NHIN is the sum of all SNOs. It is a network of networks whose participants agree to the Common Framework. The NHIN is not a separately funded entity; it is a framework of cooperation and compliance. If the individual SNOs externally facing interfaces work, the NHIN will work. There are no required "top level" services in the NHIN; at the national level, adherence to standards and policies, however defined and affected, are the key elements. All the actual infrastructure of the network is either hosted within the SNOs, or uses the existing Internet (*The Connecting for Health Common Framework: Technical Issues and Requirements for Implementation).* Connecting for Health is a public-private collaborative of more than 100 organizations representing a diverse array of private, public, and not-for-profit groups.
NIH	National Institutes of Health, U.S. Department of Health and Human Services

ODBC	Open Data Base Connectivity
ONCHIT or ONC	Office of the National Coordinator for Health Information Technology, U.S. Department of Health and Human Services
PHDSC	Public Health Data Standards Consortium
PHI	Personally Identifiable Health Information
PHIN	Public Health Information Network
PVRP	Physician Voluntary Reporting Program - U.S. Department of Human Services, Centers for Medicare and Medical Services sponsored quality of care reporting program.
RHIE	Regional Health Information Exchanges
RHIO	Regional Health Information Organization
RLS	Record Locator Service - an index that lets clinicians find out where the patient information they seek is stored so that they can request it directly from its source (*The Connecting for Health Common Framework: Overview and Principle)s.* Connecting for Health is a public-private collaborative of more than 100 organizations representing a diverse array of private, public, and not-for-profit groups.
RPMS	Resource and Patient Management System
SDN	Secure Data Network
SDOs	U.S. Standards Development Organizations
SNO	Sub-network organization - as used by Connecting for Health, "SNO is any group of entities (regionally or non-regionally defined) that agree to communicate clinical data with one another using a single Record Locator Service (RLS), using shared policies and technological standards, and operating together under a single SNO-wide set of policies and contractual agreements. A SNO has two sets of interfaces, one internal, which binds its member entities together, and one external, which is where traffic to and from other SNOs and outside entities come from" (*The Connecting for Health Common Framework: Technical Issues and Requirements for Implementation*). Connecting for Health is a public-private collaborative of more than 100 organizations representing a diverse array of private, public, and not-for-profit groups.
SQL	Structured Query Language
SRD	State and Regional Demonstration contracts (AHRQ funded)
THQIT	Transforming Healthcare Quality Through Health Information Technology grants (AHRQ funded)
URL	Uniform Resource Locator

Appendix E

Illinois Electronic Health Records (EHR) Activities

Illinois Electronic Health Records (EHR) Activities

Illinois hospitals, clinics, physicians, and public health professionals have been actively pursuing various electronic solutions to ensure the efficient, effective, and safe delivery of health care services. As expected, most of the early initiatives responded to the specific needs of the provider/organization. Early statewide efforts were spawned by the Illinois Department of Public Health's desire to better coordinate maternal and child health services.

This appendix provides a brief description of a number of interesting EHR initiatives in Illinois. It is not intended as an inventory of every EHR project in the state. Such an inventory poses the risk of overlooking the noteworthy efforts of many providers and organizations.

It can be noted without hesitation that hospitals throughout the state have been actively engaging in EHR projects. Seven of these facilities made the *Hospital and Health Network's* annual list of the "100 most wired hospitals and health systems." (July 2005) Hospitals on this list were judged on their use of information technology in "five key areas: business processes, customer service, safety and quality, workforce, and public health and safety."

Physician offices throughout the state also are engaged in EHR efforts. The federally funded Doctor's Office Quality – Information Technology (DOQ-IT) program, administered by the Illinois Foundation for Quality Health Care, is helping many physicians through the process.

State EHR Activities

Cornerstone

Data management information system developed to facilitate the integration of community maternal and child health services. Initially developed by the Illinois Department of Public Health, the system provides for integrated data sharing and support for multiple health and human services programs.

Sponsoring Organizations: Illinois Department of Human Services and Illinois Primary Health Care Association
Location: Statewide
Category: Public health support
Started: Planning started in 1992. System rollout in 1997.

Illinois National Electronic Disease Surveillance System (I-NEDSS)

I-NEDSS is a Web-based application that establishes a secure and real-time communication link between hospitals, laboratories, and other health care providers with state and local health department staff for the purposes of reporting and managing communicable disease information. I-NEDSS is designed to improve local health departments' abilities to identify and track reportable diseases and outbreaks, including those due to bioterrorist threats.

Sponsoring Organization: Illinois Department of Public Health
Location: Statewide
Category: Public health support
Started: Planning started in 2001. This assessment was completed in June 2001.

Illinois Comprehensive Automated Registry Exchange (ICARE)

Web-enabled immunization registry providing health care providers access from any PC with an Internet Browser. All immunization data maintained in a central database located at IDPH headquarters.

Sponsoring Organization: Illinois Department of Public Health
Location: Statewide
Category: Public health support
Started: Planning started in 2001. This assessment was completed in June 2001.

Tracking Our Toddlers' Shots (TOTS)

Network based immunization registry that currently houses more than 12 million immunization records. Health providers with dedicated PCs can access immunization records. The system also has voice response and fax back capabilities.

Sponsoring Organization: Illinois Department of Public Health
Location: Statewide
Category: Public health support
Started: 2000

AHRQ - Transforming Healthcare Quality through Health Information Technology (THQIT) Grants

In **September 2004**, the U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality (AHRQ) awarded $139 million in contracts and grants to promote the use of health information technology (health IT) through the development of networks for sharing clinical data as well as projects for planning, implementing, and demonstrating the value of health IT. Five Illinois projects were funded. These are:

Enhancing Quality in Patient Care (EQUIP) Project

Implements an electronic health records system in a network of community health centers and develops a data warehouse to monitor, aggregate, and provide data for quality improvement.

Sponsoring Organization: Erie Family Health Center
Location: Chicago
Category: Implementation Grants (THQIT)

Started: 2004

Linking Rural Providers to Improve Patient Care and Health

Develops a central electronic health record system to allow the sharing of health information between a hospital, medical group, county health department, and behavioral health organization for rural economically disadvantaged, ethnic/racial minority residents, the elderly, and persons with special/complex health care needs.

Sponsoring Organization: Katherine Shaw Bethea Hospital
Location: Dixon
Category: Planning Grants (THQIT)
Started: 2004

Sharing Patient Record Access in Rural Health Settings

Develops an implementation plan for an ambulatory EMR in a medically underserved region that will electronically connect physician offices, the regional hospital, ancillary services, and other community health services; identifies indicators to track measurable improvements in patient safety, quality of care, clinician and patient satisfaction, and operational efficiency.

Sponsoring Organization: Sarah Bush Lincoln Health Center
Location: Mattoon, Illinois
Category: Planning Grants (THQIT)
Started: 2004

Toward an Optimal Patient Safety Information System

Promotes and evaluates the interchange of patient safety information and the reporting of adverse events and close calls among public and private voluntary incident reporting systems being used at United States hospitals.

Sponsoring Organization: Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
Location: Oakbrook Terrace, Illinois
Category: Value Grants (THQIT)
Started: 2004

Value of Technology to Transfer Discharge Information

Assesses the value of software applications to facilitate information transfer during the high-risk transition from hospital to home at discharge and compares health information technology to usual care for benefits outcomes, adverse events, effectiveness, costs, and satisfaction among patients and physicians.

Sponsoring Organization: Board of Trustees of the University of Illinois
Location: Chicago, Illinois
Category: Value Grants (THQIT)
Started: 2004

2005 THQIT Grants

On Oct. 6, 2005, AHRQ awarded more than $22.3 million to16 grantees to implement health information technology (health IT) systems to improve the safety and quality of health care. The recipients were selected from a group of AHRQ grantees who received health IT planning funds in 2004. Following is a description of the Illinois grant recipient.

Implementing an Ambulatory Electronic Medical Record and Improving Shared Access

Description: Implements an emergency medical records system that will provide shared access to patient records across various community health care providers and incorporates electronic tools for prescription distribution and management.
Sponsoring Organization: Sarah Bush Lincoln Health Center
Location: Mattoon
Category: Implementation Grants (THQIT)
Started: 2005

Other Illinois Initiatives

Illinois Health Network

The Illinois Health Network offers a Web-based gateway solution that enables the secure exchange of health and business-related information and data. The gateway functions as a brokered peer-to-peer network, centralizing the security and communications functions while its users create and exchange files directly. Data can be stored centrally on the gateway or decentralized at the local source.

The Illinois Health Network offers the infrastructure that enables participation of Illinois' hospitals and health care professionals in the health information exchange and technology adoption movement that is underway nationwide. Hospitals and other health care facilities, such as skilled nursing and long term care facilities, physicians and health professionals of all disciplines, ambulatory medical clinics, public and private insurers, service vendors, public health and behavioral health agencies, education providers, and other key partners, regardless of location can benefit from the secure interactions supported by the network.

Sponsoring Organization: Illinois Hospital Research and Educational Foundation, an affiliate company of the Illinois Hospital Association
Location: Statewide

Category: Provider Initiative
Started: January 2005

Northern Illinois Physicians for Connectivity (NIPFC)

This is an initiative by physicians to fulfill the goals of a RHIO. NIPFC will encourage and facilitate the use of health care technology amongst its members by maximizing its economy of scale. This organization will ensure the privacy and security of confidential information, yet allow health information to be shared by way of a Patient Index. Medical practices that currently are not using an EHR. NIPFC will benefit from electronic access to emergency room, laboratory, radiology, surgery, and anesthesia notes, as well as hospital-generated clinical documents. Medical practices that have already embraced an EHR or electronic prescribing program, will be able to share clinical information and/or pharmacy data electronically in real-time. All members will benefit from a regional, team approach to improving quality of care in the community. Continued funding for NIPFC will come from provider subscription fees.

Sponsoring Organization: DuPage Valley Physicians
Location: DuPage, Kane and Kendall counties
Category: Provider Initiative
Started: Incorporated in December 2005

KCHAIN (Kane Community Health Access Integrated Network)

Electronic health data exchange is a major component of KCHAIN's mission to provide health care to low-income insured or underinsured Kane County residents

"Advocates" at partner health care providers electronically transmit information on eligible persons to KCHAIN. This referral process enables KCHAIN to more efficiently identify and serve clients. KCHAIN has a goal to expand information technology infrastructure to support a RHIO-type health record exchange among area providers.

It was funded primarily through a federal Healthy Communities Access Program (HCAP) grant.

Sponsoring Organization: Partnership of health providers comprised of the five Kane County hospitals, federally qualified health centers, free clinics, private practitioners, and the Kane County Health Department
Location: Kane County
Category: Public health support
Started: September 2004

Doctor's Office Quality – Information Technology (DOQ-IT)

The Centers for Medicare and Medicaid Services (CMS), U.S. Department of Health and Human Services, provides funding for this initiative to assist physicians adopt EHR. As the agent for CMS, the Illinois Foundation for Quality Health Care provides consultative services to physicians in assessing the need for and installation of EHR in their practices. The foundation is currently working with about 150 physician practices throughout the state.

Sponsoring Organization: Illinois Foundation for Quality Health Care as contractor for CMS
Location: Statewide
Category: Federal Initiative

Appendix F

Executive Order Creating the Division of Patient Safety within the Department Of Public Health

STATE OF ILLINOIS
EXECUTIVE DEPARTMENT
SPRINGFIELD, ILLINOIS

EXECUTIVE ORDER NUMBER 8 (2006)

EXECUTIVE ORDER CREATING THE DIVISION OF PATIENT SAFETY WITHIN THE DEPARTMENT OF PUBLIC HEALTH

WHEREAS , nearly 98,000 Americans die each year as a result of preventable medical errors and these patient safety errors cost Americans as much as $50 billion per year;

WHEREAS , thousands of Illinoisans die each year as a result of medical errors, costing Illinois citizens more than $1.5 billion per year in increased patient insurance premiums, hospital costs, co-pays, physician insurance rates, and prescription drug costs;

WHEREAS , current law, such as the Illinois Adverse Health Care Events Reporting Law and the Hospital Report Card Act, require the Department of Public Health to track medical errors and to create hospital report cards to apprise the public of existing problems;

WHEREAS , Illinois has created the Electronic Health Records Taskforce which is currently developing an electronic health records system in the State;

WHEREAS , the Illinois Health Network provides information technology upgrades for rural health care facilities to enable hospitals to quickly transmit information such as radiology images on-line;

WHEREAS , Illinois strives to remain at the forefront of health care and patient safety while reducing health care costs to Illinois taxpayers;

THERFORE, I, Rod R. Blagojevich, hereby order the following:

Creation of the Division of Patient Safety Within the Department of Public Health

There is hereby created a Division of Patient Safety (the “Division”) which shall be located within the Department of Public Health (the “Department”) that will consolidate the Department’s efforts to eliminate medical errors.

Powers and Duties

The Department shall work with existing advisory committees and additional persons, as necessary, to ensure that representatives of affected constituencies are informed of the work of the Division. The Division’s powers and duties shall include, but not be limited to, the following:

To encourage all medical providers to utilize e-prescribing programs by 2011. E-prescribing allows a physician to legibly write and electronically send prescriptions to reduce the risk of medication errors.

To evaluate the areas within Illinois in need of enhanced technology to support e-prescribing programs.

To determine the types of technology needed to implement the e-prescribing program.

To coordinate with the Illinois Department of Financial and Professional Regulation and the Department of Healthcare and Family Services to draft and issue recommended medication practices such as prescribing, dispensing, and maintenance to all health care providers.

To expand the Department's nursing home database to include information such as staffing ratios, medication distribution, on-site services, and citations issued against each facility, enabling consumers to make well-informed decisions.

To implement and expand the State's efforts at health care provider information transparency, such as the Hospital Report Card, the Consumer Guide to Health, and similar efforts to ensure that health care consumers and purchasers may make informed choices regarding the quality and cost effectiveness of medical care.

To implement the Illinois Adverse Health Care Events Reporting Law.

Savings Clause

Nothing in this Executive Order shall be construed to contravene any state or federal law.

Severability

If any provision of this Executive Order or its application to any person or circumstance is held invalid by any court of competent jurisdiction, this invalidity does not affect any other provision or application of this Executive Order which can be given effect without the invalid provision or application. To achieve this purpose, the provisions of this Executive Order are declared to be severable.

Effective Date

This Executive Order shall become effective upon filing with the Secretary of State.

Rod R. Blagojevich, Governor

Issued by Governor: July 13, 2006
Filed with Secretary of State: July 13, 2006

Appendix G

Privacy and Security Solutions for Interoperable Health Information Exchange

Interim Assessment of Variations Report

Privacy and Security Solutions for Interoperable Health Information Exchange

Interim Assessment of Variations Report

Subcontract No.
RTI Project No. 9825

Prepared by:

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Submitted to:

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November 6, 2006

Table of Contents

NOTE: THE PAGE NUMBERS FROM THE ORIGINAL REPORT WERE CHANGED TO FIT WITHIN THE PAGE NUMBER STRUCTURE USED BY THE EHR TASKFORCE.

Executive Summary

HISPC was formed through a contract between the Research Technology International (RTI) and thirty-four (34) other states, including Illinois. The goal of HISPC is to assess and provide solutions that address variations in organization-level policies and state laws that affect privacy and security practices, including those related to HIPAA, and may pose challenges to interoperability of health information exchange. Workable privacy and security approaches and business practices are imperative for comprehensive information exchange solutions to facilitate quality improvement, medical error reduction, timely surveillance, rigorous research, and improved efficiency and affordability of health care.

The Illinois HISPC Privacy and Security Steering Committee (HSC) will be the reporting body for Illinois' contract with RTI. In addition, the Steering Committee will receive oversight from the Illinois Electronic Health Records (EHR) Task Force. As part of their charge, the HSC will provide RTI and the EHR Task Force with the following:

- A comprehensive review of the privacy and security laws and business practices that pose a challenge to the proliferation of health information exchange within the state
- A review and examples of best practices and solutions within the state that maintain privacy and security protections while encouraging interoperable health information exchange
- Recommendations to improve both organizational business practices and state laws regarding privacy and security that currently adversely affect interoperable health information exchange
- Provision of a plan to implement the subcommittee's recommendations

The HSC will have under its purview several working groups to support its objectives. These working groups include a business variations working group (VWG), a legal working group (LWG), a solutions working group (SWG), an implementation plan working group (IPWG), and an ad hoc working group (AWG). HSC will determine membership of the working groups as well as review and approve all work products resulting from the groups. It is anticipated that the organization you represent will play an active role on at least one of these groups.

Illinois' HISPC has spent significant time capturing and assessing the business practices surrounding privacy and security of health information conducted by organizations in the state. Over one hundred (100) unique business practices among 30 representative organizations were discovered. The uses of technology to capture, maintain, and share patient information varies tremendously among Illinois' organizations. As would be expected, business practices surrounding privacy and security of health information vary based on the level of technology available to an organization. However, several common themes appear regardless of the level of technology available to an organization. The varying array of interpretation and sometimes misinterpretation of HIPAA is a common issue, sometimes even within the same organization. Also, for paper-based organizations, sharing of information has been based significantly on established trusted relationships. The level and method of sharing is based on familiarity between the existing parties more so than established business agreements. As such, a telephone call from a trusted person will garner the requisite information and perhaps more than required.

Silos of technology utilization are found throughout Illinois. Many health care organizations have been able to incorporate significant technological resources to maintain patient data. This is particularly true of the major urban health care facilities in the Chicago area. However, very little effort has gone into enabling organizations to share data electronically with one another. Chief among the reasons for this is that the culture in Illinois is not conducive to data sharing. Information is often deemed as propriety and a business asset as opposed to an opportunity to improve quality of care and patient safety. Although there is evidence that this trend is shifting, it has been a slow process. The cultural change and technical infrastructure necessary for sharing of information needs to come together before the policies and procedures necessary to facilitate health information exchange begin to become more commonplace.

Identifying viable solutions to these issues will be the next order of business for the HISPC project. Once identified and reviewed by the wider stakeholder community, a plan will be developed to implement these solutions in Illinois. Also, the business practice barriers, solutions and implementation plans will be shared on a national level.

1. Methodology Section

Upon award of the HISPC contract, the Illinois Foundation for Quality Healthcare, in conjunction with the Illinois Department of Public Health, determined the make-up of the HISPC Steering Committee (HSC). The HSC is comprised of several members of Illinois' Taskforce on Electronic Health Records (EHR). The primary goal of the Illinois EHR Taskforce is to promote and provide legislative guidance for statewide use of EHRs and improved health information exchange. The HISPC project will provide the Taskforce with needed information in the area of security and privacy to help achieve this goal. The HSC provides the leadership and oversight for the Illinois HISPC project. The HSC also provides recommendations of members for each of the working groups that make up the HISPC. The HSC has 12 members representing 11 organizations. The HSC roster and Committee Charter are included in the Appendix.

Meetings with the Variations Working Group (VWG) and facilitated individual calls to the larger stakeholder community were the two methods for acquiring business practices on security and privacy of health information. A healthcare market research firm was contracted to facilitate the meetings and calls. The Variations Working Group (VWG) was formed from the recommendations of the HSC. The VWG consists of 13 members representing 11 organizations. The VWG met six (6) times to discuss each of the eighteen (18) scenarios provided by Research Triangle Institute (RTI). During the first meeting, Patient Treatment (Scenario 1) and RHIO (Scenario 6) scenarios as they were deemed most applicable to the vast majority of work group members. Subsequent meetings only included members that were applicable to the scenarios that were to be covered during a given meeting. The meetings averaged two (2) hours in length.

Twenty-seven (23) one-on-one facilitated interview calls were made. On average these calls lasted thirty (30) minutes. The call participants represented twenty-three (23) organizations. Both during the VWG meetings and within the interview scenarios, participants were not asked only about their business practices, but also about the domains to which the practices related. They also were asked whether they felt the practices were barriers or aids to health information exchange (HIE). Meeting and interview notes were taken and analyzed by the project coordinators and the market research firm. Business practices were extracted from the notes and entered into the Assessment Tool provided by RTI. The project team reviewed the results and classification of the practices and made changes whenever appropriate.

The HSC, the VWG, and the broader stakeholder community were given the opportunity to review and confirm the validity of the identified business practices as well as add any additional practices that may have been omitted previously. The business practices are currently under review by the Legal Working Group to identify any legal drivers for the practices. Once determined, this document will be revised to include this information.

2. Summary of Relevant Findings Purposes for Information Exchange

2.1 Treatment (Scenario 1-4)

Scenarios 1 through 4 discuss the transfer of information in emergent and non-emergent situations, the amount of information that can be disclosed and the ability of providers to access protected-level (i.e. mental health and substance abuse) patients and their information, regardless of the provider's hospital admitting status.

2.1.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from third party payors, clinicians, behavioral health, law enforcement, public health and hospitals in both urban and rural settings. The hospital job functions included compliance, safety and privacy, risk management, health information and medical records.

2.1.2 Domains

The domains addressed in this scenario include:

- User and Entity Authentication
    - Mental health stakeholder stated that no verbal or written user or entity authentication is required for the release of patient information in cases where information is not protected or can't be released for legal reasons.
    - Pharmacy stakeholders stated the organization releases the minimum amount of data in an emergent situation with authentication occurring verbally, physicians would provide Drug Enforcement Agency (DEA) number and law enforcement would provide badge number and district. The authentication could also occur by requesting a callback number to confirm.
    - Hospital stakeholders stated that medical records department doesn't release any information during the first contact by the requestor. To authenticate requestor's identity they require a telephone number that they can call back.
    - All stakeholders stated that they request some form of identification from patients and physicians (with whom they are not familiar) before treatment or release of information.
- Information Authorization and Access Controls

    - Stakeholders stated that all users receive training before a user name and password is issued.
    - Hospital and Clinic stakeholders stated that all employees have to sign confidentiality agreements regarding disclosure of patient information.
    - Stakeholders with EHRs stated that access to patient information is based on role in the organization, with physicians having access to all patient information.
    - One hospital stakeholder stated it provides access via a secure portal to all credentialed physicians in the area, regardless if the physician has admitting privileges to that specific hospital or not.
    - Hospital stakeholders with an EHR stated that offsite access to patient files is allowed for physicians and some radiologists.
    - Some hospital stakeholders allow temporary access for non admitting credentialed physicians whereas other stakeholders don't allow access to non-admitting physicians to locked units and patient files.
    - One hospital stakeholder with an EHR that doesn't allow temporary access to non-admitting physicians will allow paper copies of pertinent patient information if it is critical to patient care.

- Patient and Provider Identification
    - Stakeholders from all groups stated in paper-only environments that patients are categorized by social security number and name.
    - Stakeholders with an EHR categorize patients using basic name and demographic information.

- Information Transmission Security or Exchange Protocols
    - Stakeholders from all groups stated that they exchange information either verbally or via fax with appropriate disclaimers in emergent situations. In non-emergent situations information can be transmitted verbally, fax or US mail. Very few of those interviewed had dedicated fax machines for specific information.
    - Physician stakeholders utilizing offshore or onshore transcription services access their transcribed encounter notes via a secure web portal. Most stakeholders stated they did not use any offshore services.
    - One hospital stakeholder stated that their policies strictly prohibit use of offshore transcription services.

  - Stakeholders, which transmit patient medical records and laboratory results in non-emergent situations, send these records by either internal mail or US mail, or release them directly to patient. Mammogram or ultrasounds are sent by Fed-Ex or other carrier for tracking purposes. One stakeholder provides an encrypted CD with any medical records that include protected information to requesters as long as a patient release form is signed.

  - All stakeholders utilize fax disclaimers that state, “If this transmission has been received in error please destroy.”

- Information Protections (against improper modifications)

  - All stakeholders with an EHR stated that electronic signatures are used to sign off on patient charts.

  - Stakeholders all stated that an addendum can be added to the original record with a date, time stamp and user’s name. Most stated that patient records can only be amended within 24 hours of initial documentation. In one organization, designated individuals only can amend an unsigned report. An audit trail has to be printed and attached to the record.

- Information Audits

  - Stakeholders with an EHR stated that when files are accessed, printed, or copied an entry is created in the audit log. Those without an EHR didn’t have any way of tracking records.

- Administrative or Physical Security Safeguards

  - Stakeholders stated that access to patient information is restricted by user’s role within the organization.

  - Hospitals and pharmacies store all patient information in a locked room with restricted access.

  - Stakeholders stated that administrative personnel responsible for diagnostic coding of charts are responsible for noting the records with legally defined highly confidential information. Stickers, usually orange, are used on the charts to trigger careful handling of the record.

  - Stakeholders stated release of non-emergent health information that includes protected information has to receive specific authorization from the patient before disclosure.

- Information Use and Disclosure

- Hospital stakeholders stated in accident investigations test results for alcohol and barbiturates are released to law enforcement investigating motor vehicle accidents after the appropriate forms have been received. Patient authorization is not needed.

- Stakeholders release the "minimum necessary" information to requestors. The interpretation of "minimum necessary" is left up to the person giving the information.

- Stakeholders stated they would not release any treatment or medication information to other health care entities without patient consent or healthcare power of attorney.

- Hospital stakeholders stated that patient records that are received from outside of the hospital are included as part of the permanent records under a tab labeled "other" in the back of the chart and the information can't be disclosed. Those with an EHR scan the information into the patients record.

- Stakeholders stated that medical records for deceased relatives require a death certificate, consent of next of kin, or power of attorney.

2.1.3 Critical Observations

Based on interviews and discussions with the VWG, it was found that many healthcare provider organizations use the telephone and fax machines as their primary means of exchanging patient-level information with one another. Stakeholders tend to rely heavily on pre-established relationships when exchanging information. Often times, voice recognition alone is enough for authentication of the person receiving the information.

For organizations that utilize an EHR, significantly more procedures are in place to protect patient information. Users receive training and sign confidentiality statements before being allowed access to EHR systems; however, no reference was made to ongoing employee training on policy and procedure changes.

Some organizations indicated they distinguish protected patient information using colored stickers on the chart. This is a significant issue as this now means the information is no longer private.

Several stakeholders indicated that insurance cards or green cards used as identification are not always a reliable way to authenticate patient identity. Because of the fraudulent use and sharing of insurance identification cards to receive medical treatment, medical records may not accurately reflect the actual care received. A medical record could possibly include information of more than one individual. Conversely, one individual could have information spread among several medical records under different names.

In exchanging patient information for non-emergent treatment reasons, the stakeholders try to uphold the HIPAA "minimum necessary" guidelines. There is no clear definition of what “minimum necessary” should consist of in any given situation. The level of information provided varies not only from organization-to-organization but also between people within the same organization.

There are not standardized forms to request or disclose patient information. As such, organizations potentially share varying degrees of information for the same type of request. Furthermore, a general lack of standardization of information management inter-organizationally has created silos of development that will impede the transition from paper to electronic health record management. The overall culture of consideration of health information to be proprietary in nature has also contributed to the formation of these information silos. This change in culture is occurring, albeit slowly. However, culture change is a prerequisite to any technical infrastructure development with its concomitant policy, procedures, and practices.

2.2 Payment (Scenario 5)

Scenario 5 discusses the interaction of third party payors and health care providers. Insurance company caseworkers require access to patient information to properly manage cases of the patients in which insurance coverage is provided. In particular, caseworkers are required to approve/authorize inpatient encounters and thus need a certain level of access to patient information in order to properly make this assessment. Scenario 5 addresses the possible business practices that are required if a healthcare provider utilizes an EHR and provides access to the EHR to insurance company caseworkers.

2.2.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from commercial payors, and security officers and risk managers from hospitals in both urban and rural settings.

2.2.2 Domains

The domains addressed in this scenario include:

- Information Access and Access Controls
    - Payor does not request access to any provider’s EHR for approval or authorization.
    - Healthcare providers do not provide electronic access to any of their patient systems to external entities that are not officially affiliated with the healthcare provider.
- User and Entity Authentication
    - Payor authentication of patient requesting approval/authorization for inpatient encounters by verification of member identification number, name, birth date and address is done via a telephone call or letter from the patient to the payor.
    - Payors authenticate providers identity via the telephone or internet by verifying provider identification.

2.2.3 Critical Observations

Third party payor representatives stated that they would not solicit for nor take advantage of any access granted to a hospital’s EHR. This just is not part of their current procedure. If the carrier did not already have the information as part of their own data set (claims data), they would request information using a paper-based procedure for release of information.

In regards to healthcare providers, hospitals have not routinely provided access to their EHRs by external entities such as third party payors. There are specific policies and procedures in place for access to PHI by employees and physicians of the hospital. However, typically no electronic access is granted to PHI by non-employees of the hospital. And although this is against policy for provider and the insurer, a caseworker did share the fact that nurses in office-based physicians have shared information to caseworkers by allowing the caseworker to view pertinent decision-making data under the nurse's login. However, it was stated that the nurse did not share her login information and the nurse was present during the reviewing process.

Both healthcare providers and third party payors state that they share only the "minimum necessary" data with other entities. However, the definition of "minimum necessary" can vary widely among organizations and even within the same organization.

The existing business practices surrounding the authorization for inpatient admission can be considered as potential barriers to the widespread adoption of HIE. Criteria for inpatient admissions are determined by coverage eligibility, level of trauma, diagnosis, and lab test results. These data elements can easily be acquired through an EHR. However, if access for authorization is neither provided nor sought, then existing methods of requesting this information via paper will continue.

2.3 RHIO (Scenario 6)

Scenario 6 discusses the participation of stakeholders in a Regional Health Information Organization (RHIO) with participation by multiple organizations in electronic health information exchange.

2.3.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from commercial payors, and security officers and risk managers from hospitals in both urban and rural settings, public health, law enforcement, pharmacy, clinicians, laboratories, community and health centers.

2.3.2 Domains

The domains addressed in this scenario include:

- Information Authorization and Access Controls
    - Payor will not allow any access to any of their information.
    - Hospitals currently allow access to their EHR from physicians with admitting privileges.
- User and Entity Authentication
    - All stakeholders that allow any access from outside entities currently utilize user login and passwords. Pharmacy stakeholders have randomly assigned passwords.

2.3.3 Critical Observations

Currently, there are no operational RHIOs in Illinois. Several RHIO initiatives are in various stages of development. As is the case with most RHIOs in their infancy, issues such as the exact mechanisms, policies and procedures for sharing and accessing patient health information, defining who owns the data, and assigning responsibility for data validity, organizational-level privacy and security of data, appropriate use of data, and breach notification protocols have not been established. Among the stakeholders we interviewed, there aren't currently any business practices surrounding RHIO activities.

All of the provider stakeholders state that, in a hypothetical situation, they would share only the minimally necessary data with other entities unless required to do so by law. However, in the case of RHIO participation, payors state they would not share any of their proprietary data. Hospitals state they would be more likely to share information but only among the physicians that have admitting privileges and never with other hospitals. Public health officials say they would only share de-identified aggregated data.

2.4 Research (Scenario 7)

Scenario 7 discusses the collection of data for an Institutional Review Board (IRB) - approved research project at a medical center involving an investigational drug for children with behavioral health issues. A request is made for additional use of the data for research beyond the scope of the original study to include tracking of patients and use of raw data for a white paper.

2.4.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from public health agencies, hospitals and third party payors.

2.4.2 Domains

The domains addressed in this scenario include:

- Information Use and Disclosure
    - Hospitals have policies in place for researchers that request additional tracking outside of approved research protocols. Any request for additional data collection would constitute another study and therefore another IRB review. All clinical investigations require fully informed patient consent and the submission of all forms and consents to the IRB for study approval. The IRB has representatives from health care, medical practice, pharmacy, consumer, and religious advocates.
    - Public health agencies release only aggregated data without patient identification to researchers. Policy is in place for public health agency to institute patient contact if deemed necessary as result of research.
    - Third party payors may have policies in place which prohibit the release any of their data for research purposes, or they may have in place IRB approval processes as described for hospitals, with any changes or additions to studies requiring repeat of the patient authorization process.

2.4.3 Critical Observations

Federal and state statutory requirements for IRBs for the approval of all research involving human subjects provide a significant level of protection for the informed consent by participants for the use and disclosure of protected health information obtained during research activities. As a result, business practices developed for the implementation of research protocols have neutral impact on the implementation of electronic health information exchange, as those protections would be required to remain in place regardless of format of information. For entities such as third party payors who have made policy decisions to not allow their data to be used for outside research purposes, a more over-arching barrier is present in that such policies to protect proprietary information may prevent participation by such entities in the wider purpose of health information exchange for any reason, not just research.

2.5 Law Enforcement (Scenario 8)

Scenario 8 discusses the interaction of law enforcement and health care providers. Law enforcement requests a copy of a patient's blood alcohol test results to investigate an accident. It is believed that the patient may have been the cause of the accident so law enforcement would need this information to properly assess the situation. Scenario 8 addresses the possible business practices required in the exchange of health information between a health care provider and law enforcement agencies.

2.5.1 Stakeholders

The stakeholders solicited for input to this scenario included representatives from urban and rural hospitals and law enforcement. The hospital job functions represented included: compliance, safety and privacy, risk management, health information, and medical records.

2.5.2 Domains

The domain addressed in this scenario includes:

- Information Authorization and Access Controls
  - Health care providers do not provide access to patient information without patient consent, or, in the case of law enforcement, a subpoena. If a subpoena is provided, no patient consent would be required.

2.5.3 Critical Observations

Hospital providers stated they do not give access to parents of patients who are 17 years or older without that patient's authorization. The authorization could be verbal. The identity of the insurance guarantor is immaterial to the release of patient information, even if the guarantor is the parent of the patient. Patient information, when the patient is a minor and not pregnant, can be released to parents. In this particular scenario, parents can only be provided payment information. This policy would only change if the patient were incapacitated.

One provider indicated that documentation of what was released to law enforcement would be kept in the back of the medical records.

Appropriate law enforcement agencies can request information, but hospitals require a formal submission of a subpoena, which might include a copy of the traffic ticket with such a written request. If a subpoena were provided, patient authorization would not be required. Only the information specific to the subpoena would be released. Legal drivers for these practices include both HIPAA as well as the Illinois Motor Vehicle Act. The Illinois Motor Vehicle Act further defines when information can and cannot be released in an accident.

A law enforcement participant noted that “DUI packages” are often carried by police officers. These packages contain the appropriate paperwork law enforcement needs to request from providers for the release of test results for a patient involved in an accident when alcohol or drug use is suspected.

If the accident results in injury, law enforcement would be able to obtain patient test information without a subpoena to determine if the patient were under the influence of drugs or alcohol. Under Illinois statutes, if a patient is 17 years or older, law enforcement agencies would not be able to provide any of the patient’s test results to the parents.

2.6 Prescription Drug Use/Benefit (Scenarios 9 and 10)

Scenarios 9 and 10 discuss Prescription Benefits Manager's (PBM) business practices and policies associated with the exchange of health information with providers. Scenario 9 discusses the interaction between a PBM and an outpatient clinic. In order for the patient to receive the physician-prescribed medication which is not on the PBM list of preferred antipsychotic the physician is required to complete a prior authorization. Scenario 9 addresses the business associate agreements that would need to be in place between the PBM and the provider.

Scenario 10 discusses the interaction of PBM1 with Company A who is considering switching services from PBM2 to PBM1 for costs savings purposes. PBM1 requires access to employee's prescription drug use and associated drug costs to review and effectively assess the situation to provide a cost savings comparison to Company A. Scenario 10 tries to address the business associate agreement that would need to be in place between Company A and the PBMs.

2.6.1 Stakeholders

The stakeholders that were solicited for input to this scenario included pharmacies.

2.6.2 Domains

The domain addressed in this scenario includes:

- Information Use and Disclosure
    - The PBM would only have access to de-identified patient data. The PBM would be required to have a business associate agreement with the provider in order to obtain this information. The information shared would be limited by the minimum necessary guidelines under HIPAA.
- User and Entity Authentication
    - The pharmacy system is set-up with limited access by job function. User ID and passwords are randomly generated and assigned.
    - Suspicion of fraudulent access will warrant physician verification. Pharmacies typically are able to authenticate physician identities by referring to a linked database, which includes physicians across the country.
- Administrative or Physical Security Safeguards
    - One pharmacy participant indicated that the physical access to pharmacy data is secured "between four walls and a locked door."

- Information Transmission Security or Exchange Protocols
    - Transmission of data between pharmacy and physician offices is often sent via a secure FTP website and is encrypted.

2.6.3 Critical Observations

HIPAA does not allow for any health information exchange between companies that do not have business associate agreements. In Scenario 10, the exchange of information would have to be between Company A and PBM1; the exchange could not be between PBM1 and PBM2. The information provided to PBM1 for analysis could only be de-identified data.

2.7 Healthcare Operations/Marketing (Scenarios 11 and 12)

Scenarios 11 and 12 discuss health care providers' policies on marketing services to targeted subsets of patients. Scenario 11 identifies an integrated health delivery system (IHDS) consisting of critical access hospitals and a large tertiary hospital. The IHDS would like to use patient identifiable data from the critical access hospitals to target market patients in need of the new rehab services available in the tertiary hospital. Scenario 11 addresses the possible business practices that are required if a healthcare provider conducts marketing using protected health information (PHI) with their consumers.

Similarly, Scenario 12 discusses the interaction of a hospital obstetrics department with the marketing department. The marketing department requests patient identifiable data for the following purposes: to be able to market new pediatric services; to solicit for parenting classes; to raise funds for a neonatal intensive care unit; and to sell to a local diaper company so they can market their products. Scenario 12 addresses the use and sale of identifiable patient data for marketing purposes.

2.7.1 Stakeholders

The stakeholders solicited for input to this scenario included representatives from urban and rural hospitals. The hospital job functions represented included: compliance, safety and privacy, risk management, health information, and medical records.

2.7.2 Domains

The domains addressed in this scenario include:

- Information Use and Disclosure Policies
    - Stakeholders reported that HIPAA allows providers to market or initiate fundraising efforts using only de-identified patient data (or only patient demographics) as long as patients receive a notice of privacy and are given an opportunity to sign an "opt-out clause."
    - Health care providers do not sell patient data under any circumstances.
- Information Transmission Security or Exchange Protocols
    - If an outside marketing service is used, a business associate agreement must be in place between the provider and the marketing organization.
    - When an outside marketing service is used, only de-identified or patient demographic data is exchanged. The data would be sent using a secure FTP server or through US mail on an encrypted CD.

2.7.3 Critical Observations

There seems to be varying interpretations on HIPAA guidelines for operations and marketing purposes even though providers often refer to HIPAA guidelines as the basis for their marketing practices and policies.

Under HIPAA, providers must obtain patient authorization and provide their notice of privacy practice that would include an “opt-out clause” before being able to use patient de-identified information for marketing and fundraising efforts. Only patient demographic data and/or dates of health care service could be used. These opt-out opportunities increase trust between patients and providers, but may represent a barrier to implementation of health information exchange, in that patients that opt out will impact the completeness of available health information.

If an outside organization were used for marketing, they would be required to be in a business associate agreement with the provider and adhere to HIPAA compliance issues. An outside marketing service would only be provided non-identifiable patient data and the data would be sent either using a secure FTP server or via US mail on an encrypted CD. The requirement for the development of business associate agreements presents a barrier for the implementation of health information exchange initially, but once executed, should facilitate the standardization of health information exchange.

If a patient indicates he/she would not like their contact information used for marketing purposes that is brought to the corporate compliance officer’s attention (these steps may differ by organization) who will inform the marketing department.

Providers never sell patient data to outside entities for marketing purposes.

2.8 Bioterrorism Event (Scenario 13)

Scenario 13 discusses the reporting of and response to a laboratory-confirmed case of anthrax.

2.8.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from hospitals, public health agencies, and emergency medical services.

2.8.2 Domains

The domains addressed in this scenario include:

- User and Entity Authentication
    - Initial reports by providers to local health departments of immediately notifiable conditions such as a case of anthrax are most often handled by telephone and fax.
    - Reporting of notifiable conditions is a routine part of providers' business practices, and telephone and fax numbers, as well as personnel involved on both the private and public side, are well known to those responsible for providing and receiving reports.
    - Telephone contacts between parties are used to notify intent and confirm receipt of fax.
- Information Authorization and Access Controls
    - State laboratory provides complete patient information results for patients with anthrax confirmation only internally to IDPH Communicable Diseases Section.
- Information transmission security or exchange protocols
    - Routine practices for assuring telephone numbers and fax machine security would be used. Use of e-mail would be restricted to information without patient identifiers included.
    - Encrypted messaging from the Illinois National Disease Surveillance System to CDC is in development, but not currently available.
- Information use and disclosure policy
    - Standard patient authorizations allow use and disclosure of all patient information for public health purposes.

- State statutes for response to public health emergencies such as incidents of bioterrorism allow the disclosure of patient information to law enforcement.

2.8.3 Critical Observations

Actual bioterrorism events are unprecedented in Illinois, and as such, no routine business practices exist for critical analysis. As a proxy for such a public health emergency event, routine practices for interacting with public health in time-sensitive situations were discussed for this scenario. One of the tenets of bioterrorism preparedness is that development of routine person-to-person contacts and relationships between providers and public health personnel will aid in the rapid dissemination of information in the event of a public health emergency precisely because those involved will know “who to call.” This relationship building for emergency preparedness is neutral with respect to the implementation of electronic exchange of health information.

Illinois has implemented an electronic disease reporting system (Illinois National Electronic Disease Surveillance System, or INEDSS) that is currently deployed to all local health departments, as well as to a significant proportion of large hospitals. It was developed to Public Health Information Network (PHIN) standards, and as such should be an aid to the implementation of electronic exchange of health information due to its compatibility to such standards. However, the module specific for the reporting of bioterrorism events in INEDSS is still under development. Providers stated that despite the availability of an electronic reporting medium such as INEDSS, an extreme public health emergency event such as possible bioterrorism would necessitate the use of telephone contact until time was available to perform data entry into the system. Rather than the business practices of telephone contact, it is this current state of disjointed information systems which require separate data entry which comprises a significant technological barrier for electronic health information exchange.

2.9 Employee Health (Scenario 14)

Scenario 14 discusses an employee's request for a return-to-work document after presenting at a local emergency department for treatment of a chronic condition and the mode of information transmission to the employer.

2.9.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from hospitals in both urban and rural settings, public health, clinicians and community and health centers.

2.9.2 Domains

The domains addressed in this scenario include:

- User and Entity Authentication
    - Stakeholders stated that identification of a patient who requests the return-to-work documentation via the telephone is authenticated by the patient providing their treatment date and social security number.
    - Employer stakeholders authenticate the source of the return-to-work document by the letterhead on which the document is printed.
- Information Authorization and Access Control
    - Employee personnel records are maintained in an information management system distinct from employee health records, and human resources managers do not have access to employee health records.
- Information protections (from improperly modifications)
    - Stakeholders do not take any specific steps to protect return-to-work documents from being improperly modified by employee.
- Information transmission security or exchange protocols
    - Stakeholders stated that return-to-work documentation is given directly to patient in person or faxed to number given by the patient. No stakeholder had transmitted a document via email.
    - Stakeholders with EHRs do not cut and paste clinical information, either a software-generated form is created, or a hand written form is given to the patient.

- Information Use and Disclosure
    - Stakeholders stated that only the patient can initiate a return-to-work request, employers couldn’t request the documentation without the employees consent.
    - Stakeholders will list only actual diagnosis on return-to-work statement if explicitly requested by the patient. Otherwise, the “minimum necessary” information for one organization included the dates of treatment, date allowed to return to work, and any physical limitations.

2.9.3 Critical Observations

Hospital stakeholders with an EHR stated that they would not cut and paste any information from the EHR; however, some EHRs have a software-generated letter on the hospital’s letterhead that contains the minimum necessary information that includes treatment date(s), return-to-work date and any physical limitations. Stakeholders without an EHR stated that they use standard forms with hospital logo that contain the minimum necessary information, treatment dates(s), return-to-work dates and any physical limitations.

All stakeholders stated that they use only one of two modes of transmission for the return-to-work document: handed to the patient, or faxed to a number provided by the patient. E-mail transmission has not been utilized by any of the stakeholders interviewed.

All stakeholders interviewed stated that a patient has to initiate the request for return-to-work documentation; employers are not able to directly request the information.

2.10 Public Health (Scenarios 15-17)

Scenario 15 discusses the public health response to an active tuberculosis carrier that has taken a bus trip across state lines. Scenario 16 discusses the public health response to a positive laboratory result in state-mandated newborn screening tests for genetic/metabolic or endocrine disorders. Scenario 17 discusses issues concerning the transfer of a homeless person from a county shelter to a hospital-affiliated drug treatment clinic.

2.10.1 Stakeholders

The stakeholders that were solicited for input to these scenarios included representatives from hospitals, a homeless shelter, public health agencies, and behavioral health services.

2.10.2 Domains

The domains addressed in this scenario include:

- User and Entity Authentication
    - Public health personnel have established working relationships and corporate contact information for telephone, e-mail and fax machines is readily available.
    - Business practices for the reporting of newborn screening tests include only public health personnel, the hospital where the baby was born, and the attending physician. No Interactive Voice Response (IVR) system exists in Illinois.
- Information Authorization and Access Controls
    - Patient authorization is required for release of any protected health information that would be transmitted between homeless shelters and drug treatment facilities
- Information Transmission Security or Exchange Protocols
    - Facsimile transmissions are secured via telephone notice of intent to send and follow up call to assure receipt.
    - E-mail encryption is not used, so patient identifiers are excluded from e-mailed communications.
    - State laboratory results for newborn screening tests are maintained in a mainframe database and therefore can be transmitted only by extraction into another format or hard copy.
    - Commercial laboratory results for newborn screening tests can be supplied to hospital information systems via secured electronic laboratory

    reporting, which are then accessed by physicians according to attending role.

- Information Audits and Record and Monitor Activity
    - Communications from a health department to another entity that occur by facsimile transmission are confirmed by a follow-up telephone contact to assure transmission to the correct entity.
- Administrative or Physical Security Safeguards
    - Caseworkers who perform intake interviews of homeless persons entering shelters collect some protected health information required for the management of the cases. Such information is paper-based and secured in physically locked cabinets within a locked room to keep separate from facility and access by any others besides the caseworkers.
- Information Use and Disclosure
    - State statutes for disease control include procedures for the transmission of information to enforcement agencies outside of public health, such as the State’s Attorney’s Office.
    - Both state and local health departments stated they would not communicate with a private business entity, such as the bus company involved in the transport of the TB carrier, if obtaining any information helpful to the disease investigation was improbable. Information exchange could and would take place if such an entity could assist in the disease control investigation, e.g., an airline.
    - All disclosures of protected health information to relatives occur only with express written consent of patient.
    - Release of protected health information for payment of treatment services follows minimally necessary information guidelines.

2.10.3 Critical Observations

Stakeholders reported variability in interpretation of “minimum necessary” information for release between entities. Authorizations, when deemed necessary, are carefully sought, but not so carefully explained. Entities requesting information can be given wide latitude in what is being requested, such as with “fill-in-the-blank” forms, with patient allowing or disallowing by simple check boxes. This approach to authorization is neutral with respect to electronic health information exchange.

Professional relationships were reported by the stakeholders to be key to public health and to disease control and response activities. These relationships provide the platform for information exchange during a public health response. However key these relationships are to the success of public health response, they are neutral with respect to electronic health information exchange. On the contrary, it is widely regarded that functional electronic health information exchange will facilitate public health response.

Electronic, as opposed to paper, health information is developing in Illinois in a fragmented manner, with an apparent lack of planning for an overall strategic, statewide health information network. This fragmentation is major barrier for implementation of information exchange, as significant resources are being brought to bear at isolated institutions, creating more and more systems that may or may not be interoperable with respect to information exchange.

2.11 State Government Oversight (Scenario 18)

Scenario 18 discusses a request by a state governor for protected health information about immunization and lead screening of children to be supplied to researchers at a state university for analysis. There exists neither a legislated mandate for the consolidation of this data, nor a contract with the university to provide analytical services.

2.11.1 Stakeholders

The stakeholders that were solicited for input to this scenario included representatives from public health agencies and hospitals.

2.11.2 Domains

The domains addressed in this scenario include:

- Information Authorization and Access Controls
    - Information from the statewide immunization registry can be supplied to researchers, but only in aggregate form without patient identifiers.
    - Without statutory requirement for the provision of the data, collection and consolidation of such information would then be defined as a research protocol and subject to legal and IRB review and approval prior to participation.
- Information transmission security or exchange protocols
    - Blood lead screening laboratory test result information is provided currently by the state public health laboratory to other involved state agencies only by transfer to disk format and courier delivery.
- Information Use and Disclosure
    - All HIPAA guidelines on patient authorization for information use and disclosure would apply to the research protocols established to execute this scenario.

2.11.3 Critical Observations

This scenario was interpreted by working group participants as a theoretical research proposal, rather than legitimate governmental oversight function. This interpretation is due to the lack of a statutory requirement for the consolidation of data that would then be supplied to an agency external to the agencies that collected the data. Policies developed for business practices related to research which utilizes protected health information are generally neutral with respect to the implementation of electronic health information exchange (see Section 2.4), as the federal and state statutory requirements for the protection of research participants and their health information do not change with respect to format of the information.

3. Summary of Critical Observations and Key Issues

The assurance of security and privacy are critical to the successful proliferation of health information exchange in Illinois and throughout the country. If the public does not feel its health information is safe and kept confidential, the movement towards HIE will be hampered at best and most likely impeded completely, no matter how great the possibilities are to improve quality of health care in the state. Currently, Illinois is at the infancy of HIE development among its health care organizations. Major privacy and security-related barriers currently exist. For example, the wide-range of interpretation of HIPAA's "minimum necessary" clause for the same scenarios among organizations is a barrier to HIE as it will be difficult to exchange information if parties cannot agree on what is appropriate to exchange. Also, because of the competitive nature of the health care market in Illinois, the culture has not been conducive to data sharing. Silos of technology have formed, but there has been no real driving force promoting the sharing of data among organizations. As such, policies and procedures surrounding inter-organizational HIE are greatly lacking. By identifying issues like these and subsequently providing practical solutions, HISPC and efforts like it will have a positive impact on increasing HIE and ultimately improving the quality of health care in Illinois.

4. Appendices

HISPC Variations Working Group Roster

HISPC Variations Working Group Charter

ILLINOIS FOUNDATION FOR
QUALITY HEALTH CARE

HISPC Steering Committee (HSC) Charter

Team Focus/Purpose

The HISPC Steering Committee (HSC) will provide oversight and direction for Illinois' HISPC project. The HSC will set direction, monitor progress, solicit work group members, provide updates to the Illinois EHR Taskforce, and approve deliverables to ensure success of the project.

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Key Stakeholders

- IFQHC
- IDPH
- EHR Taskforce

Goals of Committee

The HISPC Steering Committee (HSC) will strive to:

- Review, evaluate and analyze and approve contract deliverables produced by the working groups to ensure they are of the highest possible quality and truly reflects Illinois' current state and future needs relative to privacy and security of health information
- Provide organizational resources to help staff the working groups that will develop the contract deliverables
- Seek input and/or representation from as many stakeholder areas as possible in the creation and review of work resulting from HISPC's activities
- Communicate current HIPSC status to the Illinois EHR Taskforce
- Review progress and results of the project plan
- Identify opportunities for improvement
- Have members serve as a liaison between HSC and its organization/area of expertise, communicating HISPC activities to individual members constituencies and soliciting their feedback

Time Frames

The committee will continue its function until the completion of the HIPSC contract. It is anticipated that all activities will be completed by May 2007.

Ground Rules

The HSC will operate in the following manner:

- Every committee member will participate.
- Organizational representation is required. If a committee member cannot make a meeting, every effort will be made to find a replacement from your organization. The Project Manager must be notified if a replacement cannot be found.
- A three-fourths (3/4) quorum of the committee is required to have an official meeting.
- Consensus is the goal for approval of deliverables and committee

recommendations.

- Each team member is expected to keep its constituent organization(s) updated on HISPC activities.
- Phones/Pagers should be put on vibrate
- If attending via conference call, the phones should be on mute unless the member is speaking.
- Only one committee member should be talking at a time (Don't talk over each other).
- Committee members will respect each other's time.
- The agenda will be adhered to.
- A chairperson will be elected at the first meeting
- The facilitator/project manager will monitor time.
- Minute taking will taken by committee staff.
- Meetings will be held at a set time each month and more frequently when required. A standing meeting time will be determined at the first meeting.
- Any agenda items should be presented to the project manager no later than the two business days prior to the scheduled meeting date.
- Meeting times will be no longer than 2 hours unless special circumstances require extended time.
- Given the time commitment and cost of face-to-face meetings, conference calls will be offered for all meetings.

ILLINOIS FOUNDATION FOR
QUALITY HEALTH CARE

Business Practice Variations Working Group (VWG) Charter

Team Focus/Purpose

The Business Practice Variations Working Group (VWG) will develop a detailed report on the variation of privacy and security practices at the organizational level in Illinois for the HISPC project.

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Key Stakeholders

- CMS
- AHRQ
- RTI
- IDPH
- EHR Taskforce
- IFQHC
- Illinois businesses involved in health information exchange

Goals of Work Group

The Business Practice Variations Working Group (VWG) is responsible for developing a detailed report on the variation of privacy and security practices at the organization-level focusing at a minimum on the following key domain areas:

- User and entity authentication for accessing electronic personal health information
- Information authorization and access controls to allow access to only people or software programs that have been granted access rights to electronic personal health information
- Patient and provider identification matching across multiple information systems and organizations
- Information exchange protocols for information that is being exchanged over an electronic communication network
- Safeguards to ensure electronic personal health information cannot be improperly modified
- Information audits that record and monitor activity of health information systems
- Administrative or physical security safeguards required to implement a comprehensive security platform for health IT
- State law restrictions regarding information types and classes and the solutions by which electronic personal health information can be viewed and exchanged
- Information and disclosure policies that arise as health care entities **share**

clinical health information electronically

Time Frames

The working group will remain intact until completion of the HISPC project in April 2007. However, this working group will serve as an advisory group after the submission of its assigned deliverable in October 2006.

Ground Rules

The VWG will operate in the following manner:

- Every working group member will participate.
- Organizational representation is required. If a working group member cannot make a meeting, every effort will be made to find a replacement from your organization. The Project Manager must be notified if a replacement cannot be found.
- A three-fourths (3/4) quorum of the working group is required to have an official meeting.
- Each group member is expected to keep its constituent organization(s) updated on HISPC activities.
- Phones/Pagers should be put on vibrate
- If attending via conference call, the phones should be on mute unless the member is speaking.
- Only one working group member should be talking at a time (Don’t talk over each other).
- Working group members will respect each other’s time.
- The agenda will be adhered to.
- The facilitator/project manager will monitor time.
- Working group staff will take minutes.
- Working group will be held at a set time each month and more frequently when required. A standing meeting time will be determined at the first meeting.
- Any agenda items should be presented to the project manager no later than the two business days prior to the scheduled meeting date.
- Meeting times will be no longer than 2 hours unless special circumstances require extended time.
- Given the interactive nature of the task, your onsite participation is highly encouraged. However, the ability to participate via conference calls will be offered for all meetings.

Appendix H

Endnotes

Endnotes

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[1] Public Act 94-646, effective Aug. 22, 2005. Sponsors: Representatives Julie Hamos - Elizabeth Coulson - Sidney Mathias - Paul D. Froehlich - Sara Feigenholtz, Mike Boland, Mary E. Flowers, Richard T. Bradley, Coreen M. Gordon, Elaine Nekritz, Karen May, Cynthia Soto, William Davis and Constance Howard; Senators William R. Haine - Steven J. Rauschenberger - Jeffrey M. Schoenburg.

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