

Privacy and Security Solutions for Interoperable Health Information Exchange

State Implementation Plan – Illinois

Subcontract No.
RTI Project No. 9825

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April 15, 2007



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I - Background

Purpose

The purpose of this report is to outline plans to implement the solutions proposed for addressing privacy and security-related issues that have been identified as significant barriers to the successful electronic health information exchange (HIE) within the state of Illinois. This report will outline the process used to develop implementation plans for the proposed solutions, including the organization and charge of the implementation planning work group (IPWG), the process used to formulate, propose and assess the feasibility of implementation plans, and the means by which the projects will be funded, staffed and governed.

The State Implementation Plan Report consists of eight specific implementation plans that correspond to each of the proposed solutions identified in the Final Assessment of Variations and Analysis of Solutions Report. Each of these implementation plans include a summary of the solution, scope definition, identification of key assumptions, a task plan, assigned resources, a projected budget, a project governance model and a projected timeline.

Report Limitations

Considerable effort was made to ensure that the solutions and corresponding implementation plans were practical, effective and achievable. Despite these efforts, there are still factors that must be taken into account that directly impact the report content. Many of the solutions and implementation plans outlined in the report depend on the existence of the Illinois Health Information Network (ILHIN). The creation of the ILHIN is part of the recommendations of the Illinois Electronics Health Records Taskforce (EHRTF) as part of its final report to the Illinois General Assembly (Appendix 1 – EHRTF Final Report). Set up as a not-for-profit organization, the ILHIN's primary objective would be to establish a state-level health information exchange. Given this charge and the level of multidisciplinary representation proposed for the ILHIN's governance structure, responsibility of these recommended projects would be a perfect fit for the ILHIN. The entity does not currently exist, the acceptance of these responsibilities has not been formalized, and the ILHIN remains a very critical assumption.

Even though technically still an assumption at the time of this report, in the 95th General Assembly of the Illinois legislature, the House Bill (Appendix 2, HB1254) which provides for the creation of the ILHIN was passed unanimously on March 22, 2007 and forwarded to the Senate for its consideration. Additionally, Senate Bill 0005, Illinois Health Care for All Act, contains one Article specific for the formation of ILHIN (Appendix 3 – SB0005, Article 35). As stated in both bills, the "primary mission of ILHIN shall be the following: (1) To establish a state-level health information exchange to facilitate the sharing of health information among health care providers within Illinois and beyond in other states; and (2) To foster the widespread adoption of electronic health records, personal health records and health information exchange by health care providers and the general public." The ILHIN is provided in both bills with the following ten powers and duties:

- Creation of a federated state-level HIE.
- Establish standards for access to ensure privacy and security.
- Identify and address barriers and gaps in electronic health record (EHR) adoption.
- Provide general public education on benefits and safeguards to HIE.

- Assure privacy and security of information in research requests for data via institutional review boards.
- Solicit funds to fulfill its duties.
- Collect fees in connection with its duties.
- Collect de-identified data in a central repository for public health purposes.
- Make de-identified data available for healthcare quality measurements.
- Encourage e-prescribing programs.

Whereas there exist some variations between these two bills in the governance of ILHIN, the functions and broad scope stakeholder representation for the entity remain as recommended by the EHRTF. It remains to be seen which, if either, of these two bills will become law. Their existence and the unanimous passage of HB1254 in the House indicates that the political will for the forward progress of EHR and HIE exists in Illinois.

Should it come to pass that the ILHIN is not created in the 95th General Assembly, progress in Illinois in EHR and HIE development as described in the Final Assessment of Variations and Analysis of Solutions Report will undoubtedly continue, albeit in the piecemeal fashion that has occurred to date. In the absence of a centralized authority as would be provided by the ILHIN, Illinois could seek and obtain support for coordination on a smaller scale as has been provided by the HISPC project. Such future support could facilitate one or more professional associations such as the Illinois State Medical Society or Hospital Association, or the Illinois Foundation for Quality Health Care to step into the breach and lead a more strategic effort for implementation. Although all the implementation plans set forth in this report are predicated on the assumption of the formation of ILHIN, they could just as easily be implemented by a less formal coordinating body as could be provided for by such an interim solution for planning.

Another important factor to consider regarding this report is that, because Illinois is just getting started in HIE, there is little information available to help determine costs and detailed plans for implementing these recommended solutions. The IPWG found that developing detailed task plans and budgets was extremely difficult as identifiable resources and costs that may be readily available in an existing, established infrastructure devoted to HIE development is not present in Illinois. Although effort has been made to review work done by others further along in the HIE development process, a concise confirmation of analysis is still pending.

II – Summary of Analysis of Solutions Report

The Solutions Working Group (SWG) members were comprised of experts in health information management and information technology systems. Other members included legal (risk management), physicians (emergency medicine) and a consumer advocate. The Illinois Electronic Health Records Taskforce (EHRTF) served as the reviewing body for the proposed solutions.

The SWG began with the task of developing a more comprehensive list of barriers than that which was derived by the Variations Working Group (VWG) as part of its review of business practices in Illinois related to the security and privacy of health information. The list of barriers generated through discussion by the SWG was based on their expertise and experience in their relative professional fields, rather than tied to a scenario-driven review as was the case for the VWG. The resulting analysis by the SWG yielded a list of eight basic types of barriers:

- **Organizational Culture Barriers**
 - For example, these are barriers which come about from business practices created due to an organizational culture of physical/paper records; actions based on risk aversion and/or comfort rather than standards; market competition; organization type such as clinics vs. hospitals, public vs. private, etc.; and/or ownership of data and not sharing it.
- **Technology and Standards Barriers**
 - These are barriers which come about from business practices related to the technical challenge to patient identification, secure and interoperable exchange protocols and vocabulary standards.
- **Staff Knowledge about Health Information Exchange Barriers**
 - These are barriers which come about from business practices related to a lack of emphasis in, standards for and established core competencies related to privacy and security in staff education programs.
- **Consumer Knowledge about Health Information Barriers**
 - These are barriers which come about from business practices related to patient education, privacy rights and message standardization and delivery.
- **In-house Resources for Information Management Barriers**
 - These are barriers which come about from business practices related to the relative availability of funds, staff, and professional and legal guidance.
- **Privacy and Security Leadership Development Barriers**
 - These are barriers which come about from business practices related to the relative availability of expertise in management staff for privacy and security of health information.
- **Global Market Barriers**
 - These are barriers which come about from business practices related to technical challenges of offshore access and user authentication, and competitive market forces in software development in the absence of required standards.
- **Legal Barriers**
 - These are barriers which come about from business practices related to fear of breaking the law, variations in law interpretation, lack of national guidelines for

interpretation, and relative availability of legal expertise in privacy and security of health information.

Following the identification of root causes for the barriers to implementation, the SWG then grouped the root causes into related areas for solutions development. The solution areas that were identified included:

- Benefits of regional exchange of health information
 - The desired outcome for solutions in this area is for the benefits for regional electronic exchange of health information to be demonstrated and promoted.
- Technology standards development
 - The desired outcome for solutions in this area is for technical standards for electronic health information exchange to be developed and adopted.
- Professional standards development
 - The desired outcome for solutions in this area is for professional standards specific for privacy and security leadership to be developed and promulgated.
- Consumer education
 - The desired outcome for solutions in this area is for consumer education in HIE and their rights to privacy and security to be provided as an essential element for implementation of HIE.
- Staff education
 - The desired outcome for solutions in this area is for staff education to be standardized for maximum competency in both the technical aspects of HIE as well as security and privacy protections.
- Inclusion of economically disadvantaged healthcare groups
 - The desired outcome for solutions in this area is for health care groups that are economically disadvantaged to be included in e-HIE and its development.
- Quality assurance for electronic information exchange
 - The desired outcome for solutions in this area is for quality assurance to be included as an integral part of organizational structure as developed for the implementation of HIE.
- Legislation and enforcement
 - The desired outcome for solutions in this area is for legislation developed and enforcement carried out to be clear, complete and timely.

From these solution areas a specific solution was chosen from each area through a detailed ranking methodology process as described in the Final Assessment of Variation and Analysis of Solutions Report. A summary for each solution chosen is found in IV – Implementation Plans in this document.

III – Review of State Implementation Planning Process

The Implementation Planning Working Group (IPWG) was formed as a continuation of the SWG. Membership and stakeholder representation are indicated in the table below.

Committee Members	Organization	Area/Industry of Expertise
Margret Amataykul, MBA, RHIA, CHPS, FHIMSS	Margret\A Consulting, LLC	EHR Consultant
Maria I. Ferrera	CCA Strategies LLC	Consumer Advocate
Steven Glass	Access Community Health Network	Healthcare/Ambulatory Information Technology
Joe Granneman, CISSP, CHSS, CNE, MCSE, CCA	Rockford Memorial Hospital	Healthcare/Inpatient Information Technology
Merida Johns, PhD, RHIA.	Bundling Board	HIM Expert
Vernel Johnson, MD	St. James Hospital	Emergency Medicine
Gary Nalley	University of Illinois Medical Center at Chicago	HIT Expert
Maria Pekar, MBA, JD	Loyola University Health System	Attorney/Risk Management
Lou Ann Schraffenberger, MBA, RHIA, CCS, CCS-P	Advocate Health Care	HIM Expert
Donna Schnepf, MHA, RHIA	Moraine Valley College	HIM Expert/Academic
Geraldine Smothers, MPA, RHIA, CSL, CPHQ	Professional Dynamic Network	HIM Expert/ILHIMA representative
Rachelle Stewart, DrPH, RHIA	University of Illinois at Chicago	Academic HIM
Neal Zeigler, MD	Baylor Medical Center	Emergency Medicine

Charge of IPWG: The Implementation Working Group (IPWG) was responsible for developing a detailed report on the implementation of the proposed solutions to privacy and security issues that impact the wide-spread electronic exchange of health information among organizations in and around the state of Illinois, focusing at a minimum on the nine domain areas of privacy and security.

Leadership of the IPWG: The project content development by the IPWG was lead by team members Joe Granneman, Maria Pekar, Geraldine Smothers and Rachelle Stewart, with assistance by the HISPC Steering Committee Chairman (HSC), Jonathan Dopkeen. The HISPC project management team provided facilitation for the IPWG.

Stakeholder Representation by the IPWG: A significant proportion of the members of the SWG are experts in health information management and information technology systems. Other members included legal (risk management), physicians (emergency medicine) and a consumer advocate.

Criteria for prioritization of the solutions for both the analysis in the Final Assessment of Variation and Analysis of Solutions Report, as well as for moving forward with implementation planning for this report, were obtained by facilitated discussion in a combined meeting of the HSC, Legal Working Group (LWG) and SWG. The criteria were then weighted by nominal consensus. Solutions were ranked as to the degree to which they met each criterion by nominal consensus in an online survey open for all members of the HSC, LWG and SWG. A final weighted score for each solution was obtained by taking the consensus ranking for each solution, multiplying each rank by its criterion weight and then summing all weighted rank scores. The solution with the highest consensus prioritization score for each solution area was selected for extended analysis in the Final Assessment of Variation and Analysis of Solutions Report and this report. Details on this process can be found in the Final Assessment of Variation and Analysis of Solutions Report. Feasibility was given the second-highest criterion weight and thus contributed significantly in each solution's final weighted priority score.

The criterion of feasibility for the implementation plans was determined with the use of the consensus-derived feasibility criteria developed at the joint meeting between the HSC, SWG and LWG and were as follows:

- Cost of implementation
- Lack of proven value of HIE
- Unidentified funding streams
- Complexity of systems and processes for implementation
- Change aversion
- Requirement for long-term organizational commitment
- Indeterminate consensus among stakeholders
- Unidentified resource availability

The SWG, during its deliberations for the selection of solutions to move forward for implementation, considered these eight aspects of feasibility for all proposed solutions, and ranked the solutions against one another by group consensus as to their overall feasibility during the prioritization process, as described above. Of the eight solutions selected for implementation planning, six of them were deemed to be the most feasible of all proposed solutions, one was the second-ranking most feasible, and one was third-ranking. The IPWG chose by consensus to move forward with all eight solutions proposed by the SWG for implementation planning.

The implementation plans are prioritized and discussed in order according to the hierarchy of influence for the eight solutions as determined by the SWG. This hierarchy was determined by inter-relationship analysis of all the solution areas by the SWG, and this analysis revealed that efforts to promote the benefits of regional exchange of health information would be a major driver for HIE development in Illinois. As information would become available to stakeholders concerning the cost effectiveness and positive impact on patient care and outcomes, this information would then act as a catalyst for the promotion of HIE developmental activities. Additionally, the adoption and promulgation of standards, for both technology and the professional development of leaders for security and privacy, would drive the development of HIE, because both the technical ability to exchange information would be enhanced by solutions in these areas, as well as the organizational ability and will to do so. The promotion of education of both healthcare staff and consumers on electronic health records would assist even further in

the development of HIE as familiarity with the technical processes developed, and trust of protections put in place became known and accepted. Major outcomes of efforts applied in benefit analysis, standards development and education would be the facilitation of the inclusion of the economically disadvantaged, enhanced quality assurance of the systems put in place, and the adoption and enforcement of clear and timely legislation in support of security and privacy. This approach of identification of drivers and outcomes of the process defined the structure for the discussion of the implementation plans, as focus for action should be put upon those driving activities most likely to leverage development, and major outcomes would become key indicators of successful development.

Standard project management methodology was applied to all solutions. This included the use of project managers, defined timelines and milestones, and communication plans for accountability. As the implementation plans were all predicated on the creation of a central lead agency and/or authority for HIE development in Illinois, an agency which currently exists only in proposal stage with the Illinois General Assembly (the proposed ILHIN), these plans were developed with the intention to forward on to the ILHIN as proposed recommendations for implementation. Should the ILHIN not be formed, these recommendations would be forwarded to any EHR/HIE coordinating project developed in its absence, as described in the Background section of this report.

Vetting of these implementation plans is scheduled to occur in May 2007 in a combined meeting with the EHRTF, the HSC and all work groups. In addition to review of these implementation plans, these stakeholders will also review the results of the Consumer Focus Group Summary conducted in March 2007 which assessed four focus groups of consumers in two age brackets (24-59 years of age, and 60-plus) on their:

- Current use of personal health records and their exposure to electronic health records.
- Perceptions about ownership of their records.
- Use of computers and their concerns related to the privacy and security of confidential information.
- Perceptions about the implementation of a national electronic health information exchange, including benefits and concerns about privacy and security of such a process, and the types of patient identification that could or should be used in such an exchange.

IV – State-level Implementation Plans

Solution 1

Development of a systematic, comprehensive approach to promoting the benefits of health information exchange (HIE)

Summary

A comprehensive, systematic approach to promoting the benefits of HIE was identified by the SWG as having the capability of significantly impacting the development of a robust infrastructure for HIE in Illinois. The specific solution to benefits promotion identified to be of highest priority for action was to determine the benchmarks for regional exchange of information, perhaps by a committee of industry (HIT and administrative) stakeholders, similar to that which was done for HIPAA transactions.

Barriers due to variations in information technology development from organization to organization could be alleviated by a standardized approach for information exchange. Variations in the organizational culture of physical/paper records, the culture of actions based on risk aversion and/or comfort rather than standards, the culture of market competition, the culture of organization type such as clinics vs. hospitals, public vs. private, etc., and the culture of ownership of data and not sharing it all would be affected by the creation of a level playing field brought about by benchmarking. Furthermore, benchmarked standards would by definition begin to create the infrastructure which does not exist currently in Illinois for the electronic exchange of information, such as a RHIO.

The establishment of benchmarks for regional exchange of information would impact all domains of privacy and security of information, as well as all stakeholders in HIE. Small pockets of exchange are occurring currently in Illinois, but efforts have been neither coordinated nor synchronized, so the development of standards for statewide applicability is essentially at a zero stage. Local standards, however, may prove to be productive starting points for the implementation of this solution.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 1:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Local standards will be readily available and appropriate
- Benchmarking health information exchange is possible

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN. The ILHIN will have both fiscal jurisdiction and task assignment responsibility for the project.

Project Scope

Implementation of Solution 1 will provide a method for effectively promoting HIE. The project will include developing ways of measuring the effectiveness of HIE and promoting these measures among people and organizations who are leading the development of HIE initiatives within the state of Illinois as well as with organizations who are not actively participating in HIE development activities but deemed to be key stakeholders. The deliverables include a consensus-based set of benchmark measures that will be used to measure the effectiveness of HIE projects, including regional health information development. The project will also produce a methodology for promoting these measures. This project will require the formation of a team of HIE experts to develop the measures.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	5 days	
Identify budget	5 days	
Develop project charter and detailed project plan	5 days	
Develop communication plan	5 days	
Identify project team	5 days	
Conduct project kickoff	1 day	✓
Benchmark Identification		
Identify and acquire subject matter experts	10 days	✓
Assess local HIE initiatives	15 days	
Acquire local standards	30 days	
Research national RHIO initiatives	20 days	
Analyze local and national standards	20 days	
Develop benchmarking standards for Illinois	10 days	
Conduct external review of standards	30 days	
Revise standards based on external review	5 days	
Publish Illinois benchmarking standards	20 days	✓
HIE Promotion		
Develop marketing strategy	15 days	
Promote benchmarking findings to key stakeholders	60 days	✓

Solution Timeline



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 1000 man-hrs)	\$100,000
Subject Matter Expertise (\$125 * 200 man-hrs)	\$25,000
Marketing Expenses	\$50,000
TOTAL	\$175,000

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to run the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓
6: Public Health agencies	✓
7: Community clinics	✓
8: Laboratories	✓
9: Pharmacies	✓
10: Long term care facilities	✓
11: Homecare and Hospice	✓
12: Law Enforcement	✓
13: Professional associations	✓
14: Academic research facilities	✓

Stakeholders	Impacted
15: Quality improvement organizations	✓
16: Consumers	✓
17: State government	✓
18: Homeless Shelters	✓

Feasibility Assessment

As part of the solution prioritization process, the SWG determined that ability to implement Solution 1 was very feasible. Although the cost of implementation is not insignificant, it is not daunting either. There has been significant work completed around the country regarding the establishment of RHIOs. As such, the needed information and expertise to complete this project is available. If the ILHIN becomes a reality accompanied by adequate funding, it will indicate that the political will to implement HIE is there. This is key to the successful implementation and proposed impact of Solution 1.

Potential Barriers

Barriers	Applicable to Solution 1
Cost of implementation	
Lack of proven value of HIE	✓
Unidentified funding streams	✓
Complexity of systems and processes for implementation	✓
Change aversion	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	✓
Delayed establishment or inappropriate governance structure of ILHIN	✓
Local standards are not readily available or appropriate	✓
Benchmarking health information exchanges are not possible	✓

Solution 2

Adopt universal standard for patient identification by all accrediting agencies, with official, verifiable means of identification defined, with both primary and secondary required (two factor identification).

Summary

The SWG determined that the single most important technical standard needed to move HIE forward in Illinois was for all accrediting agencies to adopt a universal standard for patient identification, with official, verifiable means of both primary and secondary identification defined.

This solution addresses, through standardization, the specific barrier of the technical challenge to patient identification. Furthermore, insufficient resources for language diversity to assure provision of information and the adequate comprehension of information given, is addressed via a technical solution for patient identification. By the creation of a universal standard for this data field, the cultural barriers of organization type and of ownership of data and not sharing it are reduced by the creation of a reliable means of patient identification.

The type of information to be exchanged addressed by this solution is focused specifically on patient identification, Domain 3. Many stakeholder institutions in Illinois have electronic information management systems, and therefore have a means of patient identification. The degree of standardization that exists currently for the identification algorithms and data fields in use throughout the state is unknown. Adoption of a universal standard would impact all stakeholders with health information management systems, as well as any stakeholder who would access health information, thus impacting all stakeholders.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 2:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Current electronic health information systems have the ability to store and utilize an additional patient identifier.
- Selection of a universal standard for patient identification is possible.
- There will be no nationally accepted unique patient identifier.

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN. The ILHIN will have both fiscal jurisdiction and task assignment responsibility for the project. The adoption of these standards will be the responsibility of the stakeholder organizations that engage in HIE.

Project Scope

Implementation of Solution 2 will provide a method for a universal standard of patient identification for adoption by organizations that participate in electronic HIE in Illinois. The project will include developing ways of securing and promoting this standard with verifiable means of both primary and secondary identification, auditing and repudiation. The deliverable is

a method for universal patient identification that includes confidentiality, integrity and availability. The universal patient identifier will include compatibility with existing legacy systems. It will include the ability to be implemented internally within existing systems or added on to systems without the capability to store this additional patient identification.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	30 days	
Determine budget including adoption incentive cost criteria	60 days	
Develop project charter and detailed project plan	15 days	
Develop communication plan	5 days	
Identify project team	20 days	
Conduct project kickoff	1 day	✓
Secure Identification Design		
Identify and acquire subject matter experts	15 days	✓
Research available secure electronic identification techniques available.	30 days	
Determine applicability of available secure electronic identification techniques.	15 days	
Analyze local and national standards	20 days	
Conduct external review of standards	30 days	
Revise standards based on external review	15 days	
Publish Illinois Patient Identification Standards	20 days	✓
Legacy System Compatibility		
Research major software vendors identifier capabilities	30 days	
Design system for legacy compatibility	180 days	
Develop methodology for stakeholders to achieve legacy compatibility.	30 days	
Provide methodology to stakeholder community	30 days	✓
Promote methodology adoption by stakeholder community by providing incentives for adoption	120 days	✓

Solution Timeline

Project Start-up



Secure Identification Design



Legacy System Compatibility



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 5000 man-hrs)	\$500,000
Subject Matter Expertise (\$125 * 3000 man-hrs)	\$375,000
Standards Promotion – Marketing	\$50,000
Adoption Incentives*	\$11,000,000
TOTAL	\$11,925,000

*Adoption Incentives are inducements that would encourage healthcare organizations to adopt the state-level recommendation for a patient identification methodology. This cost is based on each of Illinois’ 220 healthcare facilities (hospitals, psychiatric facilities, etc.) receiving an inducement worth \$50,000 in value. This incentive is meant to offset some of a facility’s cost of adopting the standard. The exact incentive is yet to be determined.

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to run the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓
6: Public Health agencies	✓
7: Community clinics	✓
8: Laboratories	✓
9: Pharmacies	✓

Stakeholders	Impacted
10: Long term care facilities	✓
11: Homecare and Hospice	✓
12: Law Enforcement	✓
13: Professional associations	✓
14: Academic research facilities	✓
15: Quality improvement organizations	✓
16: Consumers	✓
17: State government	✓
18: Homeless Shelters	✓

Feasibility Assessment

As part of the solution prioritization process, the SWG determined that ability to implement Solution 2 was feasible. The cost of implementation is quite significant. Also, the topic of the establishment of a unique patient identifier is very contentious. Despite these challenges, the IPWG felt that consensus could be garnered in Illinois for establishing a state-level standard methodology for identifying a patient. The IPWG also felt that technology currently exists to accomplish this, and that legacy systems could be retrofitted cost-effectively to handle this change. The state-level standard for patient identification would not necessarily supersede an organization's pre-established method. It will ensure that the organization has the data required to carry out the state-level patient matching methodology in order to effectively share information with another organization. This is key to the successful implementation and proposed impact of Solution 2.

Potential Barriers

Barriers	Applicable to Solution 2
Cost of implementation	✓
Lack of proven value of HIE	
Unidentified funding streams	✓
Complexity of systems and processes for implementation	✓
Change aversion	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	✓
Delayed establishment or inappropriate governance structure of ILHIN	✓
Local standards are not readily available or appropriate	✓
Assurance that participating facilities will consistently collect the required information	✓

Solution 3

Develop standards for consistent and available privacy and security expertise for organizations.

Summary

A recurring theme identified by the SWG was the impact of the inconsistent availability of privacy and security expertise in organizations. Privacy and security expertise are a critical element for the implementation and ongoing support of HIE. The solution proposed and prioritized by the SWG to address this was to define the professional qualifications for privacy and security officers. Included in the definition would be the requirement for such an officer within an organization, as well as that officer's specific roles and responsibilities.

By providing a standardized approach for organizations to assign roles and responsibilities for their privacy and security officers, this solution would address a number of barriers. Typically, organizations do not include privacy experts during the planning phase of an information technology implementation, therefore increasing the likelihood that IT solutions would not have the appropriate patient privacy and security protections. Organizations often assign dual roles to one individual, such as legal counsel and privacy officer. This tends to spread staff too thin for effectiveness. Furthermore, there are no mandated national standards for privacy and security officers, there is a general lack of security officers for information technology statewide, and there is a lack of credentialing in both privacy and security officers. All of these contribute to an overall lack of organizational infrastructure for information edit checks, audits and general quality assurance of health information and HIE.

The variations in information technology development from organization to organization, and resource availability from organization to organization both would be impacted positively by a delineation of roles and responsibilities for privacy and security within a specified individual. Legal expertise often resides in organizations outside of health information management staff. This division of responsibility would be alleviated by a joining of responsibilities under this solution. Variations in the culture of organization type would also be addressed by the creation of a standard approach to privacy and security leadership.

By adoption of this standardized organizational approach to privacy and security officers, the current lack of ongoing education for staff to understand the results and/or ramifications of the release of health information would be positively impacted by their role. This solution would provide for organizations a path to develop the adequate infrastructure and role delineation for the development and enforcement of all security, privacy and information management policies and procedures.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 3:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Organizations currently have individuals who possess knowledge of privacy and security guidelines.

- Professional organizations will provide privacy and security training along with validation exams.
- Organizations will require evidence of privacy and security training/knowledge for those who hold related positions.

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN; however, shared parties will make this project a reality. Internal resources will be managed by the organizations. Training and certification is currently available via multiple professional organizations, i.e. the American Health Information Management Association (AHIMA), the Health Information Management Systems Society (HIMSS), but may also be expanded to other entities.

Project Scope

Implementation of Solution 3 will include identification of those in organizations that have privacy and security knowledge, establishment of privacy and security competencies (or acceptance of existing ones), required validation exams and acceptance of such competencies for job descriptions of privacy and security positions related to health information and HIE. This project will require the formation of a team of privacy and security experts to develop the desired competencies.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	5 days	
Identify budget	5 days	
Develop project charter and detailed project plan	5 days	
Develop communication plan	5 days	
Identify project team	5 days	
Conduct project kickoff	1 day	✓
Model for Privacy and Security Officer Development		
Identify and acquire subject matter experts	10 days	✓
Assess level of available certification	15 days	
Determine if additional certifying groups are needed	15 days	
Develop model organizational privacy/security team	21 days	
Develop model security job description	21 days	
Develop model privacy officer job description	21 days	
Conduct review of models with field experts	30 days	
Revise job descriptions as needed	5 days	
Publish Privacy and Security Officer expertise standards to Illinois	20 days	✓
Model Promotion		
Develop marketing strategy	15 days	
Promote model to key stakeholders	60 days	✓

Solution Timeline

Project Start-up



Model Development



Model Promotion



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 500 man-hrs)	\$50,000
Subject Matter Expertise (\$125 * 160 man-hrs)	\$20,000
Marketing Expenses	\$50,000
TOTAL	\$120,000

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to run the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

Stakeholders most impacted would be those organizations which produce and maintain health information, not necessarily those that would just access it, as it would be the producing organizations that would be required to have an identified privacy and security officer.

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓

Stakeholders	Impacted
6: Public Health agencies	✓
7: Community clinics	✓
8: Laboratories	✓
9: Pharmacies	✓
10: Long term care facilities	✓
11: Homecare and Hospice	✓
12: Law Enforcement	
13: Professional associations	
14: Academic research facilities	
15: Quality improvement organizations	
16: Consumers	
17: State government	
18: Homeless Shelters	✓

Feasibility Assessment

Despite disparate and inconsistent expertise in the area of privacy and security, there are existing certification exams available for those who provide privacy and security advice to others. The major barrier is the lack of mandated training and certification. The solution to this problem would be impacted favorably if positive connections are made with professional groups and organizations. Experts in the field can help to define core competencies for privacy and security expertise, similar to those currently required for the Joint Commission on Accreditation of Healthcare Organizations or related organizations. There is precedence for a multidisciplinary approach to privacy and security expertise teams, as seen with patient care activity at all levels. Finally, general privacy and security guidelines are available at the national and state level. HIPAA regulations serve as the national template for such guidelines and are supplemented with more stringent state requirements.

Potential Barriers

Barriers	Applicable to Solution 3
Cost of implementation	
Lack of proven value of HIE	
Unidentified funding streams	
Complexity of systems and processes for implementation	✓
Change aversion	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	
Delayed establishment or inappropriate governance structure of ILHIN	✓

Solution 4

Establishment of core competencies for staff education and training in electronic health information, privacy and security.

Summary

The SWG recognized that while education in privacy and security is a key function in health care, the current state of training is not sufficient for the demands and changes that will be necessary in an electronic environment. One of the greatest barriers to successful implementation of electronic HIE is the lack of defined and established core competencies in education and training to ensure staff knowledge and understanding in the overall goals of HIE. In addition to understanding HIE, these competencies should include understanding of their roles and responsibilities, as well as the consequences of their actions as they relate to privacy, security and confidentiality.

The SWG discussed variations in staff experience, knowledge, expertise and training in understanding key elements related to HIE, and how staff knowledge, or lack thereof, has an impact on the implementation of HIE and the protection of privacy and security. As a solution to the variations experienced in staff knowledge, expertise and training, the SWG recommended to establish core competencies for staff education, to include not only privacy and security training, but awareness of the technical issues relevant to their job responsibilities and electronic health information.

This solution addresses the perception that there is a lack of ongoing education for staff to understand the results and /or ramifications of the release of health information, that there is a lack of standardized educational materials that have been developed for sufficient evaluation of effectiveness, that there is a lack of understanding by staff of what is appropriate and what is not in the exchange of health information, and that there is a lack of ways to share educational materials. Defined core competencies would provide the educational foundation for effective training in all aspects of health information management and exchange. Organizations sometimes have a culture of diminished value of staff continuing education. Having core competencies defined will enable institutions to target their training funds effectively to help overcome this. In addition, there are not mandated national standards for privacy and security officers, and this solution would include the development of core competencies for these staff as well. The fear of breaking the law that persons involved in the exchange of health information have could be directly reduced by the providing staff with the sufficient and complete information they need in order to perform their functions.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 4:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Stakeholders will value core competencies as essential to the effectiveness of HIE.
- An assortment of educational material on core competencies will be available for research and review.
- Benchmarking for core competencies is available.

Project Ownership and Responsibilities

The ownership and responsibility for this project is expected to be ILHIN. The ILHIN will have the responsibility for fiscal jurisdiction and task assignment responsibility. Secondary ownership resides in all stakeholder organizations that will be expected to promulgate the competencies through their educational program development.

Project Scope

The implementation of education based on core competencies will promote standardized skills and knowledge that will foster patient, employee and customer satisfaction in the long term. The project will include defining core competencies for privacy and security, credentialing, policies and procedures, release of information, HIPAA compliance, standardization, information technology elements and other key components that may be identified in the future. The project will include development of educational materials to ensure consistency in curricula and inclusion of components in privacy and security, policies and procedures and methods for teaching core competencies. Deliverables will include, but may not be limited to: project team to ensure completion of the project; key documents, definitions and curriculum; core competencies for each function defined in the process of implementation, i.e., privacy and security; and templates of policies and procedures as applicable. This project will require organization of a collaborative team of experts to develop and promulgate the core competencies curriculum.

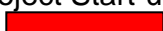
Project Timeline and Milestones

Task	Duration	Milestones
Project Start-up		✓
Confirm Project Scope	5 days	
Establish budget	5 days	
Develop project goals and objectives	5 days	
Develop detail project plan	10 days	
Develop Communication plan	5 days	
Establish an effective communication system to communicate plan	5 days	
Identify project team and team leader	10 days	
Conduct project kickoff	1 day	✓
Core Competencies Development		
Identify an acquire subject matter experts	10 days	
Assess local HIE initiatives	15 days	
Develop model competencies	15 days	
Develop model curriculum	15 days	
Develop model policies	15 days	
Research and analyze corporate/business core competencies in healthcare , non healthcare, accreditation and regulatory environments	15 days	
Establish benchmarks with key stake holders	10 days	
Define core competencies and methods of	20 days	✓

Task	Duration	Milestones
measurement involve stakeholders		
Get agreement on core competencies with stakeholders	20 days	
Publish core competencies	30 days	
Competencies Promotion		
Develop Marketing strategy	20 days	
Promote core competencies to users and key stakeholders	60 days	✓

Solution Timeline

Project Start-up



Competencies Development



Competencies Promotion



Projected Cost and Resources Required

Resource	Cost
Project Team Staffing (\$80/hr*1500 man-hrs)	\$120,000
Stakeholders expense	\$25,000
Supplies, Materials, Printing	\$30,000
Public Relations and Marketing	\$50,000
Total	\$225,000

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to manage the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

All stakeholders would be impacted, with the exception of QIOs, consumers and state government, as these stakeholders would not have staff directly involved in HIE.

Stakeholders	Impacted
1. Clinicians	✓
2. Physicians Groups	✓
3. Federal Qualified Healthcare Facilities	✓
4. Hospitals	✓
5. Payers	✓
6. Public Health Agencies	✓
7. Community Clinics	✓
8. Laboratories	✓
9. Pharmacies	✓
10. Long Term Care Facilities	✓
11. Homecare and Hospice	✓
12. Law Enforcement	✓
13. Professional Associations	✓
14. Academic Research Facilities	✓
15. Quality Improvement Organizations	
16. Consumers	
17. State Government	
18. Homeless Shelters	✓

Feasibility Assessment

The feasibility for implementation of Solution 4 was determined to be highly feasible by the SWG. There are multiple groups of experts in healthcare available to achieve the definitions for core competencies. The educational process required to facilitate core competencies is achievable. In addition, the concept of core competencies is well documented in the literature. While cost is a factor in all implementation processes, the cost for the implementation of Solution 4 would be outweighed by the impact of a potential negative patient outcome due to staff incompetence. Health care providers want no less than individuals who are competent and capable of performing their duties and responsibilities well. In addition, HIE done incorrectly is a risk with legal implications. Although there are privacy, security and confidentiality laws such as HIPAA, and institutional policies and procedures for privacy and security protection, defined core competencies to abide by these laws and follow these procedures are absent. Therefore, the positive impact that this solution would have on patient care is significant. The key to successful implementation of Solution 4 is a commitment to core competencies from ILHIN or the designated authority body.

Potential Barriers

Feasibility Barriers	Applicable to Solution 4
Cost of implementation	✓
Lack of proven value of HIE	✓
Unidentified funding streams	✓
Complexity of systems and processes for implementation	✓
Change aversions	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	✓

Solution 5

Develop educational materials for consumers to be distributed by providers and other stakeholder organizations.

Summary

This solution directly responds to the perceived lack of consumer knowledge about health information. The public fears discrimination from the use of patient identifiers, and therefore could be reluctant to allow HIE. There is a general lack of understanding by the public of electronic health records and personal medical records in general, which could contribute also to this reluctance. There is a perception by the public concerning the lack of security of electronic records, which has been made even more public through security of information breaches in other sectors, such as banking. Materials developed to allay these fears and misperceptions, as well as provide consumers with the information they need concerning their rights in the matter of their health information are critical to moving implementation of HIE forward.

There are no mandated national standards for privacy and security officers. The defining of the core competencies for professional staff identified as necessary in Solution 4, and the active participation of privacy and security officers in the development and delivery of consumer information for their organizations will ensure consumers are provided with clear and accurate assurances of their rights.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 5:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Providers will welcome well-developed, plain language materials to address patient fears about electronic information.
- Consumers will accept the wide-spread usage of electronic information with proper education

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN. The ILHIN will have both fiscal jurisdiction and task assignment responsibility for the project. Secondary ownership will reside with providers, whose responsibility it will be to deliver the patient education materials.

Project Scope

Implementation of Solution 5 will develop educational materials for providers that will be distributed by providers. Educational materials will include but not be limited to: pamphlets, CD's, videos and on-line modules. The portfolio of materials would be updated on a regular basis, as needed, and made available to providers at cost or minimal profit. Standard language templates could be maintained on a ILHIN website. Consumers from various populations will be involved in the development of the above materials for validation. This project will require the formation of a marketing team to develop the materials.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	5 days	
Identify budget	30 days	
Develop project charter and detailed project plan	5 days	
Develop communication plan	5 days	
Identify project team	5 days	
Conduct project kickoff	1 day	✓
Educational Materials Development		
Identify and acquire subject matter experts	10 days	✓
Develop and conduct survey of providers to determine needs	30 days	
Develop and conduct survey of consumers to determine needs	30 days	✓
Develop top three communication products	30 days	✓
Review products with sample providers	30 days	
Made necessary changes to products	20 days	
Decide best method of dissemination	5 days	
Education Promotion		
Develop marketing strategy	15 days	
Promote educational materials to key stakeholders	60 days	✓

Solution Timeline

Project Start-up



Materials Development



Education Promotion



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 1000 man-hrs)	\$100,000
Subject Matter Expertise (\$125 * 200 man-hrs)	\$25,000
Marketing Expenses	\$75,000
TOTAL	\$200,000

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to run the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, marketing team staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

Stakeholders impacted by the implementation of Solution 5 are those who would collect patient information for HIE, would directly provide services for patients and the patients themselves. Stakeholders who act primarily as consumers of health information data such as professional organizations and academic research facilities would not be impacted as directly. However, the quantity and quality of data available to these types of stakeholders would be indirectly impacted by the degree to which the educational efforts as a result of the solution would increase consumer participation in HIE.

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓
6: Public Health agencies	✓
7: Community clinics	✓
8: Laboratories	✓
9: Pharmacies	✓
10: Long term care facilities	✓
11: Homecare and Hospice	✓
12: Law Enforcement	
13: Professional associations	
14: Academic research facilities	
15: Quality improvement organizations	✓
16: Consumers	✓
17: State government	✓
18: Homeless Shelters	✓

Feasibility Assessment

As part of the solution prioritization process, the SWG determined that ability to implement Solution 5 was the most feasible of all solutions proposed. Although the cost of implementation is not insignificant, it is within the realm of feasibility, and the benefits to quantity and quality of information available for HIE could be impacted very positively by the implementation of consumer education. Barriers to consumer educational efforts include change aversion in both consumers and providers, the former of which would as expected be more comfortable with the known world of paper as opposed to the unknown world of electronic information, and the latter, who might prefer to continue to exert internal control over the information provided to their patients. Another barrier might be the need for long-term organizational commitment by providers to provide ongoing education to their patients in an ever changing and developing electronic world. Lastly, the consensus among stakeholders concerning what defines the recommended levels of participation in HIE, properly balanced with the patient right to secure and private information, is at this time indeterminate.

As a preliminary step to provide background information for the project team to develop and conduct a survey of consumers to determine their needs, a series of consumer focus groups were held in March 2007 (Appendix 4). Four groups of eleven to twelve participants in two age range groups (24-59 years of age, and 60-plus years of age) were led in discussions concerning their:

- Current use of personal health records and their exposure to electronic health records.
- Perceptions about ownership of their records.
- Use of computers and their concerns related to the privacy and security of confidential information.
- Perceptions about the implementation of a national electronic health information exchange, including benefits and concerns about privacy and security of such a process, and the types of patient identification that could or should be used in such an exchange.

In general, the consumers in the focus groups were relatively computer literate, and expressed comfort in the securities that are in place on the Internet. They expressed a desire for assurances about the safeguards that will be in place and enforced for the protection of health information. The focus group participants expressed a desire for information concerning who will be accessing their records, and whether or not they will be allowed to authorize and control access to their information. They also wanted to know if they would have access to their information. In one group queried concerning access to de-identified data for research, there was indication of some level of support for such activity, but a more thorough survey for this information is needed. Overall, it can be concluded that consumers are most likely quite prepared to participate in the electronic health information world, and any barriers in acceptance to materials to be developed as a result of this solution should not present significant impact to the feasibility of its implementation.

Potential Barriers

As with all the solutions developed for the protection of privacy and security in the implementation of HIE for Illinois, the creation of the ILHIN is key to the successful implementation and proposed impact of Solution 5. Without a central agency to develop and promote standardized consumer educational materials, a unified message is practically impossible. Non-standardized, or even mixed, messages to consumers about their rights to

private and secure health information and the functionalities of HIE will only serve to continue the current climate of fear and misunderstanding that could hamper the implementation of HIE.

Barriers	Applicable to Solution 5
Cost of implementation	✓
Lack of proven value of HIE	
Unidentified funding streams	✓
Complexity of systems and processes for implementation	
Change aversion	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	
Delayed establishment or inappropriate governance structure of ILHIN	✓

Solution 6

Extend and promote, in discussion with State's Attorney General, national Stark, e-prescribing and anti-kickback relief regulations, so those who are advantaged can support those who are disadvantaged.

Summary

The Stark, Anti-kickback relief and e-prescribing regulations allow for the donation of software and in some cases, hardware and training by hospitals to physician practices and other health care providers. In addition to this, it was proposed by the SWG that this federal relief be extended and promoted such that hospitals are allowed and possibly induced to provide physicians and other practitioners that are serving economically disadvantaged populations with not only hardware, software and training, but also additional technical resources to implement and support the technology.

This solution addresses the variations in resource availability from organization to organization. In particular those individuals/entities that are unable to afford an EHR system will not be able to effectively exchange health information and thus would not be able to contribute to or benefit from HIE. This solution helps ensure these individuals/entities are provided the technology that will serve as the necessary conduit to the ILHIN and ultimately the national health information network.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 6:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Taskforce members will gain an overall understanding of the applicable regulations and their existing limitations.
- Benchmarking optimal regulatory relief will be possible.
- Support from the federal government will be obtained.

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN. The ILHIN will have both fiscal jurisdiction and task assignment responsibility for the project.

Project Scope

Implementation of Solution 6 will provide a method for changing and/or creating new legislation that will provide for a means by which advantaged health care providers can contribute to the promotion of HIE capacity in disadvantaged providers.

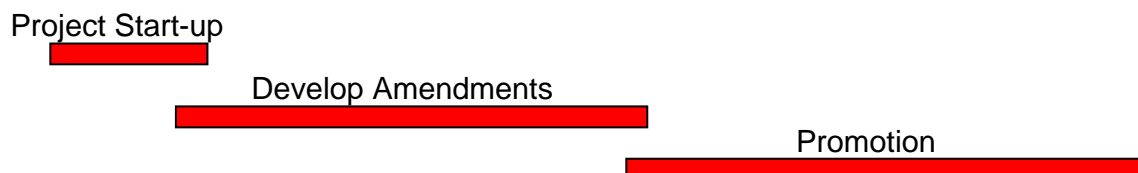
The purpose of the project is to enhance, where needed, existing HIE laws. The project's objective is to develop proposed ways to extend and promote, in discussion with State's Attorney General, national Stark, e-prescribing and anti-kickback relief regulations, so those who are advantaged can support those who are disadvantaged. The deliverables include proposed amendments to the above-stated regulations and others where appropriate. The project will also produce a methodology for promoting these amendments. This project will require the formation

of a team of legal experts to develop the amendments who can also understand contractual limitations that hospitals may have with existing software vendors regarding rights to sublicense, etc. The team should also include representatives from IFQHC, the affected industries (e.g., hospital, individual practitioner, lab), the federal and state Attorney Generals' offices, a HIT vendor and CMS.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	5 days	
Identify budget	5 days	
Develop project charter and detailed project plan	5 days	
Develop communication plan	5 days	
Identify project team	5 days	
Conduct project kickoff	1 day	✓
Develop Amendments		
Identify and understand existing laws & pending legislation	15 days	
Review literature on existing amendments to identify where they could be improved	15 days	
Research governmental relief mechanisms afforded to providers in other countries where HIT systems have matured to capitalize on knowledge already in existence	15 days	
Analyze laws, literature and other governmental relief mechanisms to identify keys to successful HIT initiatives	15 days	
Determine where inadequacies exist in current laws	15 days	
Develop suggested amendments	30 days	
Conduct external review of proposed amendments	30 days	
Revise amendments based on external review	5 days	
Publish Illinois suggested amendments	20 days	✓
Promote Amendments		
Develop marketing strategy	15 days	
Promote amendments to key stakeholders	60 days	✓

Solution Timeline



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 1000 man-hrs)	\$100,000
Subject Matter Expertise (\$125 * 200 man-hrs)	\$25,000
Marketing Expenses	\$50,000
TOTAL	\$175,000

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to run the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

Stakeholders impacted would include all those who provide healthcare and for whom the Stark, Anti-kickback and e-prescribing regulations apply, as well as consumers who have been historically underserved.

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓
6: Community clinics	✓
8: Laboratories	
9: Pharmacies	
10: Long term care facilities	
11: Homecare and Hospice	
12: Law Enforcement	
13: Professional associations	
14: Academic research facilities	

Stakeholders	Impacted
15: Quality improvement organizations	
16: Consumers	✓
17: State government	
18: Homeless Shelters	

Feasibility Assessment

As part of the solution prioritization process, the SWG determined that ability to implement Solution 6 was feasible. Although the legal hurdles to overcome are significant, they are conquerable. Individuals with the expertise needed to analyze the existing laws are readily available. Further, there has already been legislative and agency support provided, as evidenced by several recent legislative initiatives and some published safe-harbors. As such, the needed expertise and support to complete this project is available. If the ILHIN becomes a reality accompanied by adequate funding, it will indicate that the political will to implement HIE is there. This is key to the successful implementation and proposed impact of Solution 6.

Potential Barriers

Barriers	Applicable to Solution 6
Cost of implementation	✓
Lack of proven value of HIE	✓
Unidentified funding streams	✓
Complexity of systems and processes for implementation	✓
Change aversion	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	✓
Delayed establishment or inappropriate governance structure of ILHIN	✓

Solution 7

Provide recommendations for use of multidisciplinary teams in the acquisition of new information technology (IT) solutions. These teams should include at least the Chief Information Officer, end users such as the clinical department, finance, quality management and HIM, as well as the security and privacy officer.

Summary

As efforts to develop and implement HIE move forward, systems and procedures for quality assurance and data integrity will naturally evolve out of technical standardization and staff education. As a priority to further the development of quality assurance for HIE, the SWG proposed to provide recommendations for multidisciplinary teams for acquisition of new IT solutions to include at least the Chief Information Officer, end users (clinical department, finance, quality management, HIM) and the security and privacy officer.

This solution addresses an identified lack of organizational infrastructure for information edit checks, audits and general quality assurance of health information in Illinois. Ensuring a full spectrum of stakeholders for decision-making and choosing of information management solutions will enable organizations to acquire systems with the greatest capacity to meet all needs, including that of data integrity and quality assurance.

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 7:

- ILHIN will be established and have the necessary resources available to devote to this solution.
- Smaller stakeholder organizations will have sufficient diversity of personnel in an IT acquisition team, even when staff members perform multiple roles for their agency, to assure all aspects of data management and integrity are addressed in the acquisition process.
- Technical standards for recommendations will be available.

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN. The ILHIN will have both fiscal jurisdiction and task assignment responsibility for the project. Secondary ownership belongs to all health information management stakeholders who would acquire IT systems according to the standards promulgated by the ILHIN.

Project Scope

Implementation of Solution 7 will provide a method for stakeholders to develop a comprehensive team for the acquisition of IT for the implementation of HIE. The project will include assessment of current local methodologies for acquiring IT systems for HIE, and a consensus-based set of benchmark measures of best practices for data integrity technical standards. The project will also produce a methodology for promoting these measures. This project will require the formation of a team of HIE experts to develop the measures. This team will most likely be the same HIE experts identified in Solution 1, as the scope of these two solutions overlap to a degree due to role of data integrity issues in successful regional exchanges of information.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	5 days	
Identify budget	5 days	
Develop project charter and detailed project plan	5 days	
Develop communication plan	5 days	
Identify project team	5 days	
Conduct project kickoff	1 day	✓
IT Acquisition Standards Development		
Identify and acquire subject matter experts	10 days	✓
Assess local methods for acquisition	15 days	
Assess local and national standards for data integrity	20 days	
Develop benchmarking standards for Illinois	10 days	
Conduct external review of standards	30 days	
Revise standards based on external review	5 days	
Publish Illinois acquisition standards	20 days	✓
Standard IT Acquisition Promotion		
Develop educational tools and other resources	120 days	
Promote standardized acquisition team recommendations to key stakeholders	60 days	✓

Solution Timeline

Project Start-up



IT Acquisition Standards



Standards Promotion



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 500 man-hrs)	\$50,000
Subject Matter Expertise (\$125 * 100 man-hrs)	\$12,500
Educational Expenses	\$10,000
TOTAL	\$72,500

Method for Tracking, Measuring and Reporting Progress

A project manager will be assigned to run the project. The project manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The project manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. Weekly status meetings with the project team will be held. Also, staff members will provide weekly status reports to the project manager. In turn, the project manager will use these individual reports to generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities.

Issues and risks will be identified during weekly project status meeting. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the project manager.

Stakeholder Impact Assessment

Stakeholders impacted by the implementation of Solution 7 are those who would acquire IT systems for HIE. Stakeholders who act primarily as consumers of health information would not be impacted as directly.

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓
6: Public Health agencies	✓
7: Community clinics	✓
8: Laboratories	✓
9: Pharmacies	✓
10: Long term care facilities	✓
11: Homecare and Hospice	✓
12: Law Enforcement	
13: Professional associations	
14: Academic research facilities	
15: Quality improvement organizations	
16: Consumers	
17: State government	
18: Homeless Shelters	✓

Feasibility Assessment

As part of the solution prioritization process, the SWG determined that the ability to implement Solution 7 was very feasible. Although the cost of implementation is not insignificant, cost savings could be accomplished through joint development with Solution 1. The development of a standardized approach for IT systems acquisition could be hampered by the overall complexity of systems and processes for implementation, as well as a lack of long-term organizational

commitment by stakeholders to adopt the standards, and indeterminate consensus among stakeholders about the validity of those standards.

Potential Barriers

As with all the solutions developed for the protection of privacy and security in the implementation of HIE for Illinois, the creation of the ILHIN is key to the successful implementation and proposed impact of Solution 7.

Barriers	Applicable to Solution 7
Cost of implementation	
Lack of proven value of HIE	
Unidentified funding streams	
Complexity of systems and processes for implementation	✓
Change aversion	
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	
Delayed establishment or inappropriate governance structure of ILHIN	✓

Solution 8

Include in lead state agency/organization legal staff with expertise in privacy and security to guide integrated state efforts

Summary

In December 2006, the EHRTF recommended that the Illinois Legislature 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) and governed by stakeholders in the health care system. The EHRTF Report proposed that the first few years of ILHIN's existence 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. The ILHIN also will need to monitor and make recommendations to IDPH regarding the impact of state and federal legislation on Illinois EHRs. In conjunction with this proposal to establish a lead agency for HIE development in Illinois, the SWG proposed that legal staff with expertise in privacy and security to guide integrated state efforts be included in this lead state agency/organization.

The inclusion of privacy and security expertise at the highest level of HIE developmental efforts in Illinois will address a number of barriers identified in the Legal Barriers. These barriers include persons involved in the exchange of health information fear breaking the law, the interpretation of laws concerning health information varies from organization to organization, and there is a lack of national guidelines for the interpretation of laws concerning health information. If the ILHIN is formed as recommended, it will be authorized to provide technical and organizational assistance toward the expansion and adoption of EHR use.

Inclusion of legal technical assistance to organizations and state agencies with health information statutory responsibility will facilitate the development of consistent legislation, policies and procedures. Guidelines for interpretation and application would more likely be standardized with this central authority approach. There are no mandated national standards for privacy and security officers. There is also a lack of a centralized authority or organization for the privacy and security of health information. The creation of the ILHIN and the establishment of its legal expertise would directly impact these barriers.

A central authority with legal expertise will also impact barriers in Staff Knowledge About Health Information Exchange Barriers (There is a lack of ongoing education for staff to understand the results and/or ramifications of the release of health information) and Technology and Standards Barriers (There are no national requirements for information system interoperability; There is no standardization in security protocols and interfaces).

Planning Assumptions and Decisions

The following are key assumptions in the implementation of Solution 8:

- ILHIN will be established and have the necessary resources available to devote to this solution.

- Legal expertise in the health information security and privacy domain will be available to the ILHIN.
- Hiring can occur in a timely enough manner to impact the development of other activities related to the implementation of EHR.

Project Ownership and Responsibilities

Overall ownership of this solution will belong to the ILHIN. The ILHIN will have both fiscal jurisdiction and task assignment responsibility for the project.

Project Scope

Implementation of Solution 8 will provide a means to align HIE implementation efforts with privacy and security protection through the provision of legal expertise to the agency which will lead those efforts. The objectives of the project will be to define the legal counsel job, identify the knowledge, skills and abilities required to do the job effectively, and carry out the hiring process to select a candidate for the position. Once the candidate is hired, the project will also produce tasks and their priorities for the new position. The project will require the formation of a hiring team to assist in the interview and selection process.

Project Timeline and Milestones

Task	Duration	Milestone
Project Start-up		
Confirm scope	5 days	
Identify budget	20 days	
Develop job description	5 days	
Develop communication plan	5 days	
Develop knowledge, skills and abilities sought	5 days	
Identify hiring team	5 days	
Identify desired job advertisement venue(s)	5 days	
Post job	1 day	✓
Hiring Process		
Collect applications	30 days	
Review and screen applications	5 days	
Schedule interviews	5 days	
Conduct interviews with team	20 days	✓
Check references	5 days	
Select candidate	5 days	
Finalize hiring	30 days	✓
Privacy and Security Legal Expertise Inclusion in Development of Legislation, Policies and Procedures		
Develop reporting structure for legal counsel	5 days	
Develop task priorities for legal counsel	30 days	✓

Solution Timeline

Project Start-up



Hiring Process



Inclusion



Projected Cost and Resources Required

Resource	Cost
Project Team Personnel (\$100/hr * 250 man-hrs)	\$25,000
Job Advertising Expenses	\$5,000
TOTAL	\$30,000

Method for Tracking, Measuring and Reporting Progress

A hiring manager will be assigned to run the project. The hiring manager will be responsible for all aspects of the project including successful completion and delivery of all work products and communication of project status to the appropriate identified stakeholders. The reporting structure and mechanism will be outlined in the project communication plan.

The hiring manager will generate and maintain a comprehensive project plan that will be regularly reviewed with ILHIN leadership. The hiring manager will generate a project status report to ILHIN executive staff. The frequency of the report will be outlined in the communication plan. The status reports will include milestones achieved during the reporting period, progress towards upcoming milestones, list of issues and potential risks, risk mitigation strategies and a list of planned activities. Assignment of issue resolution and development of risk mitigation strategies will be the responsibility of the hiring manager.

Stakeholder Impact Assessment

Stakeholders	Impacted
1: Clinicians	✓
2: Physician groups	✓
3: Federal health facilities	✓
4: Hospitals	✓
5: Payers	✓
6: Public Health agencies	✓
7: Community clinics	✓
8: Laboratories	✓
9: Pharmacies	✓
10: Long term care facilities	✓
11: Homecare and Hospice	✓
12: Law Enforcement	✓
13: Professional associations	✓
14: Academic research facilities	✓

Stakeholders	Impacted
15: Quality improvement organizations	✓
16: Consumers	✓
17: State government	✓
18: Homeless Shelters	✓

Feasibility Assessment

As part of the solution prioritization process, the SWG determined that ability to implement Solution 8 was feasible. Comparatively speaking, the cost of implementation is fairly insignificant, and very much within the realm of affordability. There are several nationally recognized certifications focused on the privacy and security of electronic information. As such, the needed information and expertise to complete this project is available. If the ILHIN becomes reality accompanied by adequate funding, it will require the privacy/security expertise in order to be successful and promote the safety of electronic health information exchange. This solution is key to the successful implementation of ILHIN.

Potential Barriers

Barriers	Applicable to Solution 8
Cost of implementation	
Lack of proven value of HIE	
Unidentified funding streams	
Complexity of systems and processes for implementation	✓
Change aversion	✓
Requirement for long-term organizational commitment	✓
Indeterminate consensus among stakeholders	✓
Unidentified resource availability	
Delayed establishment or inappropriate governance structure of ILHIN	✓

V – Multi-state Implementation Plans

Aside from the eight solutions discussed in section IV, there were several solutions recommended by the SWG that had national implications and which could include possible multi-state interactions. However, these solutions require activity from the federal government rather than specific objectives that would require Illinois to establish solutions specific to its interactions with other states. The solutions fall into two areas: either they are recommendations for clarification of existing federal law, or they are requests for the development of new laws. State activity would include participation on any multi-state taskforce convened by the federal government to either develop model legislation for a new law or develop a response for clarification of an existing law. Neither task requires the development of a detailed implementation plan. The national-level solutions recommended by the Illinois SWG are listed in section VI below.

VI - National-level recommendations that would facilitate state-level activities

Requests for clarification of HIPAA Privacy and Security requirements. In exchanging patient information for non-emergent treatment reasons, stakeholders have stated that they 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. Further, it appears that HIPAA’s “minimum necessary” standard is being applied in practice to exchanges among providers for treatment purposes even though the HIPAA Privacy Rule does not require it. Similarly, it seems to be common practice to require the patient’s written authorization in non-urgent information exchanges even though HIPAA does not require it for exchanges among providers. It may be that the state law restrictions generally prohibiting disclosure of special categories of health information without consent (e.g., for mental health, substance abuse, HIV and genetic test information) have contributed to these precautions and practices which pre-date HIPAA. Clarifications at a federal level for “minimally necessary” guidelines and assistance in the promulgation of the guidelines are needed.

Documentation of Consent. Having a national uniform consent/authorization to release information would likely facilitate electronic exchange of information, both intra- and interstate.

Obtaining Consent/Authorization at Point of Service. Although HIPAA does not require health care providers to obtain consent or authorization to release information for treatment or payment purposes, a change to HIPAA requiring the provider to obtain the patient’s legal permission authorizing release and any future release at the time of hospital admission or other initial point of service would likely facilitate future requests for release of that provider’s information. Such practice would be consistent with what is viewed as an expanding practice among Illinois payors to obtain the individual’s “disclosure authorization form” authorizing future releases to the insurer at the time of application, as is permitted by Illinois law. Making this a federal recommendation or standard would facilitate the interstate exchange of information.

Jurisdiction and Enforcement Issues. Noting the extensive protections in existing laws governing health care providers, insurers and others, and noting the demonstrated commitment that stakeholders have to maintaining patient confidentiality, there is a need to have more stringent requirements and sanctions in place to address business associates and others who may not read, understand, or take seriously the requirements of a business associate or subcontractor agreement, and to otherwise deter other “bad actors” who may be outside the jurisdiction of existing laws. These concerns are amplified in the case of the overseas business partner who is not easily made subject to U.S. legal or contractual requirements. Providing additional deterrence on the federal level could facilitate and remove barriers to voluntary participation in an information exchange mechanism.

Maintaining Special Legal Protections and Ability to Segregate Different Categories of Information. A patient may be willing to authorize the release and future release of certain

types of health information (for example, general treatment records) but not other types of health information (for example, drug or alcohol abuse treatment records, abortion records, or genetic testing information). Therefore, having the ability to electronically segregate, store, retrieve and transmit different categories of information, while maintaining privacy and confidentiality protections, could facilitate electronic information exchange in several ways. First, patients may be more confident in participating in a RHIO or other exchange framework if special protections and the ability to exclude certain types of information from release are maintained. Second, having the ability to segregate or withhold information from general release may be required by laws that prohibit release of information unless certain circumstances exist (for example, a general subpoena or court order may permit release of some but not all information, as state law provides special requirements for mental health and developmental disabilities, alcohol/substance abuse, HIV and genetic testing information). Therefore, providers as well as consumers may be more willing to participate in electronic information exchange system if there are IT mechanisms that protect against unauthorized or illegal disclosures that could subject the provider to monetary or other penalties. Third, the ability to segregate and maintain special protections for categories of information that the federal and state legislatures and courts have found to require extraordinary protection is legally required absent wholesale preemption/revocation of such laws, and would also be necessary in order to be able to comply with new laws and changes to existing laws. The provision of model legislation for a national standardized approach to provide extraordinary protection would facilitate interstate exchange as well as compliance.

Changes to Stark and anti-kick back relief regulations. In order to expand the scope of the relief to target providers who serve the historically underserved, amend these regulations such that hospitals are allowed and possibly induced to provide physician practices that are serving economically disadvantaged populations with not only hardware, software and training, but also additional technical resources to implement and support the technology.

VII – Appendices

Appendix 1 – Illinois EHRTF Final Report

Executive Summary

Gov. Rod R. Blagojevich signed House Bill 2345,ⁱ 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.ⁱⁱ

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.ⁱⁱⁱ

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^{iv}*

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.^v*

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.

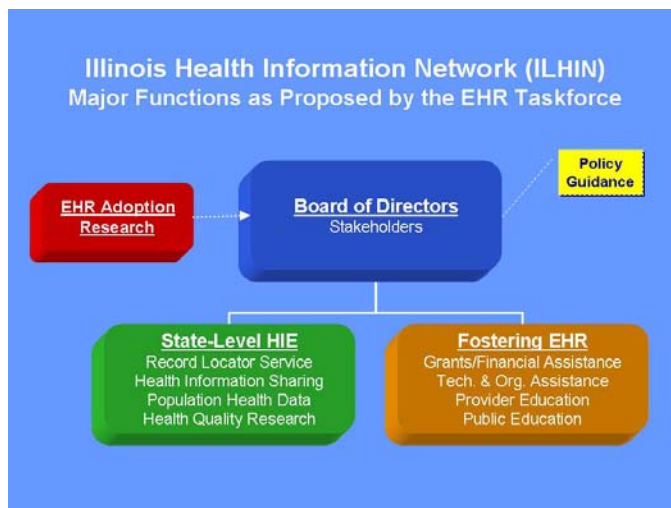
Governor Blagojevich and the General Assembly have already shown strong stewardship on this front with the passage and signing of the legislation creating this taskforce. Furthermore, the Governor demonstrated his continuing commitment to quality health care and the use of health information technology 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 statewide¹ health information exchange initiative as of March 2006.^{vi} 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^{vii}

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."^{viii} 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.

¹ 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.”^{ix}

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.^x

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.”^{xi} 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.^{xii}

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.”^{xiii}

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.^{xiv}

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.^{xv} 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.

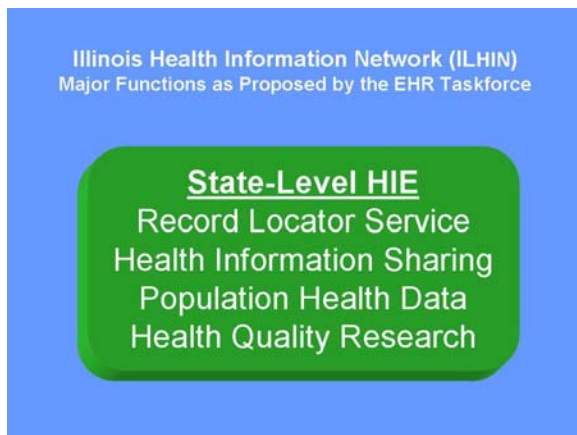
The taskforce identified the following functions for the **ILHIN**:

- 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).^{xvi}

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.



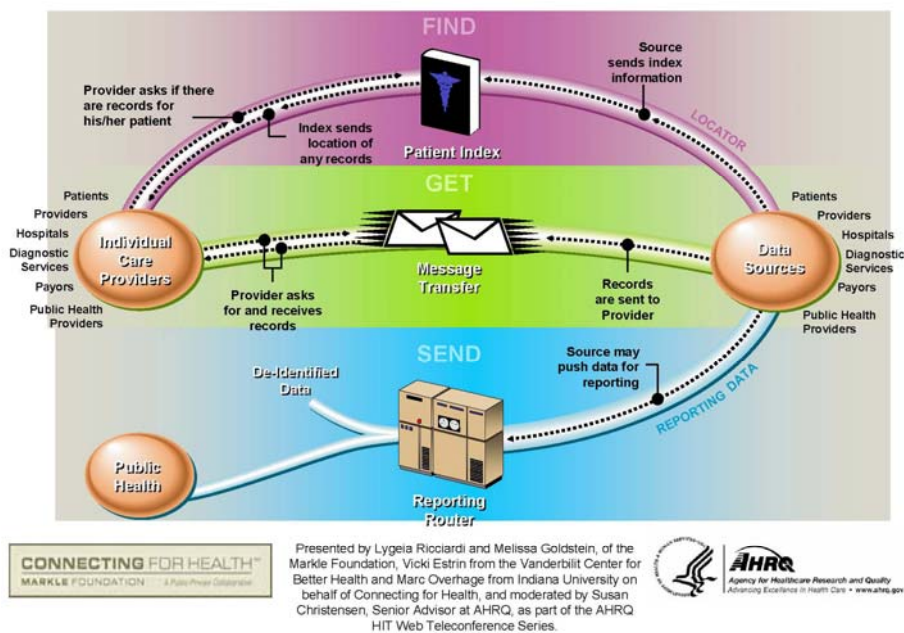
This function is adapted from one of the models reviewed by the taskforce, "**Connecting for Health Common Framework: Resources for Implementing Private and Secure Health Information Exchange.**" It was developed by Connecting for Health, a public-private collaborative convened by the Markle Foundation, 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."^{xvii}

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.



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.”^{xviii} 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

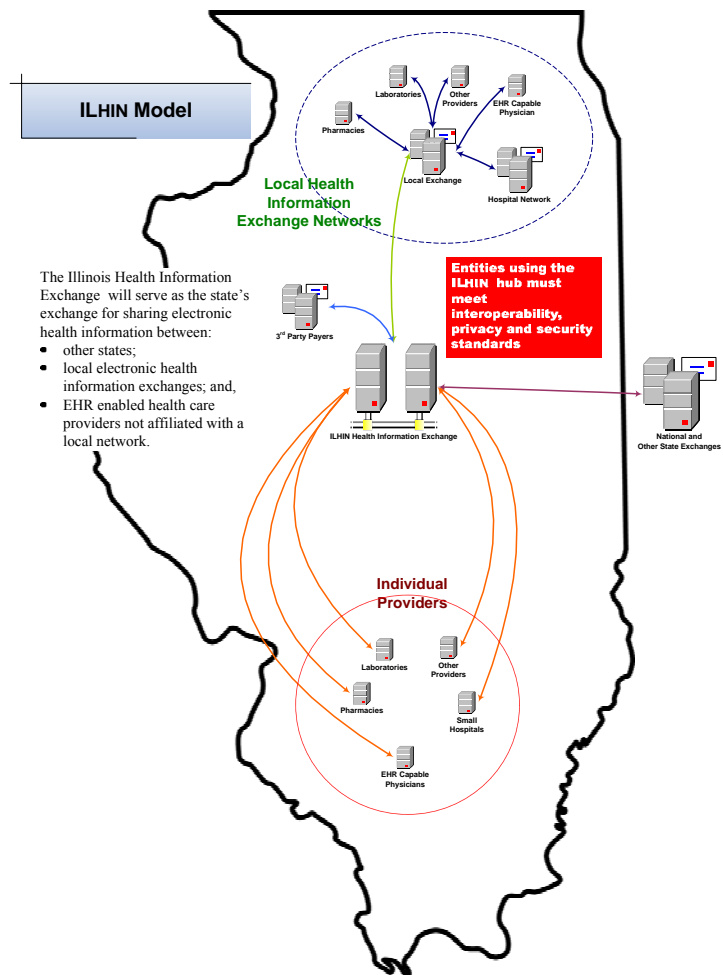
exchange (the highway) have interoperable systems to exchange data, use established data standards, and can be trusted to maintain the confidentiality of the information sent or received. For the purpose of meeting standards and efficiently transacting requests, the electronic requests must identify 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.

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.

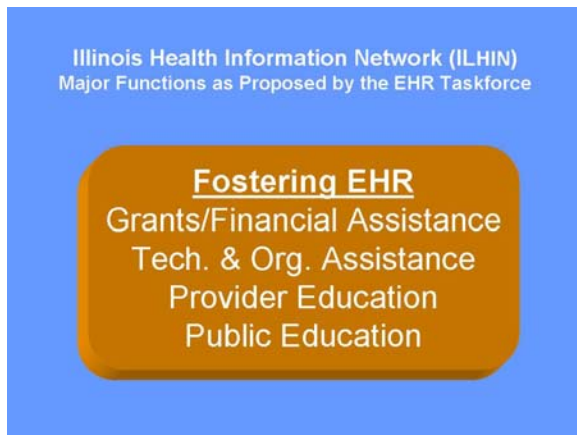
Fostering the adoption of EHR

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.^{xix} 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.^{xx}



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.^{xxi} 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.^{xxii} 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.^{xxiii}

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.^{xxiv}
- The Rhode Island legislature approved a \$20 million revenue bond to support the building of an HIE.^{xxv}
- In 2005, the Florida legislature appropriated \$1.5 million for the Florida Health Information Network grants program and another \$2 million in 2006.^{xxvi}
- 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.^{xxvii}
- 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.^{xxviii}
- 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.”^{xxix}

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.”^{xxx} 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.^{xxxi} 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.^{xxxii}

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.^{xxxiii}

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.^{xxxiv} 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.”^{xxxv} 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.^{xxxvi}

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.

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.”^{xxxvii} 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.^{xxxviii}

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 authority² 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 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.

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

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.³

³ 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 authority⁴ 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

⁴ 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's⁵ 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).

⁵ 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 authority⁶ 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.

⁶ 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 authority⁷ should monitor the state of PHR development in the marketplace and engage in educating the public regarding PHR availability and adoption.

⁷ 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.

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

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 authority⁸.
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.

⁸ 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 authority⁹ to establish a public-private state health information exchange and to foster the development of local health information exchanges. Furthermore, this authorityⁱ 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 authorityⁱ.

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 authorityⁱ, 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 authorityⁱ 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 authorityⁱ identify regulatory and legislative barriers to accessing population health information based upon state HIPAA pre-emption analysis and HISPC – Illinois Project.

⁹ 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 authority¹⁰ 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 authority¹¹ 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 authority¹² 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 authority¹ 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 authority¹ should take into consideration how the results will be disseminated.

The authority¹ 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.

¹² 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.

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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.

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).

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, <i>The Connecting for Health Common Framework: Technical Issues and Requirements for Implementation</i> . 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
LHI	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 (<i>The Connecting for Health Common Framework: Technical Issues and Requirements for Implementation</i>). 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 (<i>The Connecting for Health Common Framework: Overview and Principle</i> 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" (<i>The Connecting for Health Common Framework: Technical Issues and Requirements for Implementation</i>). 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

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



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;

THEREFORE, 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 2 – HB1254

**95TH GENERAL ASSEMBLY
State of Illinois
2007 and 2008
HB1254**

Introduced 2/15/2007, by Rep. Julie Hamos

SYNOPSIS AS INTRODUCED:

New Act

Creates the Illinois Health Information Network Act. Requires the Department of Public Health to establish a not for profit corporation to plan the creation of a state-level network for the electronic exchange of medical patients' records among health care providers. Effective immediately.

LRB095 09220 JAM 29413 b

**FISCAL NOTE ACT
MAY APPLY**

A BILL FOR

HB1254

LRB095 09220 JAM 29413 b

AN ACT concerning State government.

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

Filed: 3/1/2007

09500HB1254ham001

LRB095 09220 JAM 32471 a

AMENDMENT TO HOUSE BILL 1254

AMENDMENT NO. _____. Amend House Bill 1254 by replacing everything after the enacting clause with the following:

Section 1. Short title. This Act may be cited as the Illinois Health Information Network Act.

Section 5. Establishment of the Illinois Health Information Network.

(a) In order to advance the effective implementation and use of electronic health records through public-private partnerships, the Illinois Department of Public Health shall establish a not-for-profit corporation, by November 1, 2007, under the General Not For Profit

Corporation Act of 1986 that shall be known as the Illinois Health Information Network, or ILHIN.

(b) The primary mission of ILHIN shall be the following:

(1) To establish a state-level health information exchange to facilitate the sharing of health information among health care providers within Illinois and beyond in other states; and

(2) To foster the widespread adoption of electronic health records, personal health records, and health information exchange by health care providers and the general public.

(c) ILHIN shall be governed by a board of directors as specified in Section 15 of this Act, with the rights, titles, powers, privileges, and obligations provided for in the General Not For Profit Corporation Act of 1986.

(d) Subject to the availability of public or private funds, the board of directors may employ an executive director, other staff, or independent contractors necessary to perform its duties as specified in Section 10 and to fix their compensation, benefits, terms, and conditions of their employment.

Section 10. Powers and duties of the Illinois Health Information Network.

(a) ILHIN shall plan for the creation of a state-level health information exchange using a federated model wherein patient electronic health records are stored, maintained, and updated by the treating health care provider, but access to key health data is provided to other providers of the patient, with patient consent if the patient is able to give consent, through secure interoperable record locator technology; provided that ILHIN may develop alternative or additional approaches to health information exchange to respond to advances in technology or the experiences of other states. To the extent possible, technical specifications and technology adopted by ILHIN for the state-level health information exchange shall have been tested in another state or states.

(b) ILHIN shall establish minimum standards for accessing the state-level health information exchange by health care providers and researchers in order to ensure security and confidentiality protections for patient information, consistent with applicable federal and State standards. ILHIN shall have the authority to suspend or terminate rights to participate in the health information exchange in case of non-compliance or failure to act, with respect to applicable standards, in the best interests of patients, participants of ILHIN, and the public.

(c) ILHIN shall identify barriers to the adoption of electronic health record systems by health care providers, including conducting, facilitating, or coordinating research on the rates and patterns of dissemination and use of electronic health record systems throughout the State. To address gaps in statewide implementation, ILHIN may, through staff or consultant support, contracts, grants, or loans, offer technical assistance, training, and financial assistance, as available and in accordance with federal law, to health care providers or associations representing health care providers, with priority given to providers serving a significant percentage of uninsured patients and patients in medically underserved or rural areas.

(d) ILHIN shall educate the general public on the benefits of electronic health records, personal health records, and the safeguards available to prevent disclosure of personal health information.

(e) ILHIN may appoint or designate a federally qualified institutional review board to review and approve requests for research in order to ensure compliance with standards and patient privacy protections as specified in subsection (b) of this Section.

(f) ILHIN may solicit grants, loans, contributions, or appropriations from public or private source and may enter into any contracts, grants, loans, or agreements with respect to the use of such funds to fulfill its duties under this Act. No debt or obligation of ILHIN shall become the debt or obligation of the State.

(g) ILHIN may determine, charge, and collect any fees, charges, costs, and expenses from any person or provider that uses the ILHIN, the health information exchange, or any electronic transaction in connection with its duties under this Act.

(h) The Illinois Department of Public Health may authorize ILHIN to collect de-identified health data from health care providers in a central repository for public health purposes and identified data for the use of the Department or other State agencies specifically to fulfill their state responsibilities. Any identified data so collected shall be privileged and confidential in accordance with Sections 8-2101, 8-2102, 8-2103, 8-2104, and 8-2105 of the Code of Civil Procedure and shall be exempt from the provisions of the Freedom of Information Act.

(i) The Illinois Department of Public Health may authorize ILHIN to make de-identified data available to health care providers and other organizations for the purpose of analyzing data related to health disparities, chronic illnesses, quality performance measures, and other health care related issues.

(j) ILHIN shall coordinate with the Illinois Department of Public Health with respect to the Governor's 2006 Executive Order 8 that, among other matters, encourages all health care providers to use electronic prescribing programs by 2011, to evaluate areas in need of enhanced technology to support e-prescribing programs, and to determine the technology needed to implement e-prescribing programs.

Section 15. Governance of the Illinois Health Information Network.

(a) ILHIN shall be governed by a 31-member board of directors, which shall be comprised of the following:

(1) The Directors of Public Health and of Healthcare and Family Services and the Secretary of Human Services, or their designees.

(2) The Regional Administrator, or his or her designee, of Region 5, Center for Medicare and Medicaid Services, U.S. Department of Health and Human Services.

(3) Three hospital administrators or 2 hospital administrators and a statewide hospital association representative, including one hospital administrator from a small rural hospital.

(4) Five physicians, including a primary care physician, a specialist, and one each from a small group practice, a rural practice, and a multi-specialty clinic, independent of other appointments in this Section who might also be physicians.

(5) Three representatives of payers, including the largest health insurance company serving Illinois, a large commercial insurer, and a local payer.

(6) Two representatives of employers, including a self-insured employer and an employer recommended by an employer trade organization that represents a broad base of employers in the State.

(7) Three pharmacists, including one employed by a large chain, one independent pharmacist, and one employed by a health care institution or a consultant pharmacist to health care organizations.

(8) Two representatives of federally qualified health centers as defined in Section 1905 (1)(2)(B) of the Social Security Act, one of whom is from a center in an association that represents a broad base of federally qualified health centers throughout the State.

(9) Two long-term care facility administrators, including one from a facility in an organization of 5 or more facilities located throughout the State and one from an independently-owned facility.

(10) One administrator of a home health agency.

(11) One administrator of a mental health clinic or facility.

(12) One administrator of a diagnostic center.

(13) One nurse.

(14) Three consumers.

(b) The 27 non-governmental board members shall be appointed by the Governor with the consent of the Senate to 3-year staggered terms as determined by the Governor. Persons may be 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. Initial nominees shall be submitted by the Governor to the Senate for its consideration by no later than January 1, 2008.

(c) The ILHIN board of directors shall elect its presiding officer from among its members and may elect or appoint an executive committee, other committees, and subcommittees to conduct the business of the organization.

Section 20. Health information systems maintained by State agencies.

(a) By no later than January 1, 2015, each State agency that implements, acquires, or upgrades health information technology systems used for the direct exchange of health information between agencies and with non-State entities shall use health information technology systems and products that meet minimum standards adopted by ILHIN for accessing the state-level health information exchange.

(b) In order to provide ILHIN with start-up capabilities to assist in the development of the state-level health information exchange, the Department of Public Health is authorized to transfer or license the assets of a State pilot program known as the Illinois Health Network to ILHIN as soon as is practicable.

Section 99. Effective date. This Act takes effect upon becoming law.

Appendix 3 – SB0005, Article 35

**95TH GENERAL ASSEMBLY
State of Illinois
2007 and 2008
SB0005**

Introduced 1/31/2007, by Sen. Emil Jones, Jr.

SYNOPSIS AS INTRODUCED:

New Act

Creates the Illinois Health Care For All Act. Contains only the short title provision.

LRB095 08883 KBJ 29070 b

A BILL FOR

SB0005

LRB095 08883 KBJ 29070 b

AN ACT concerning health.

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 Illinois Health Care For All Act.

Sen. Carol Ronen

Filed: 3/30/2007

09500SB0005sam001

LRB095 08883 DRJ 34787 a

AMENDMENT TO SENATE BILL 5

ARTICLE 35. IMPROVING PATIENT SAFETY AND PROMOTING ELECTRONIC HEALTH RECORDS

Section 35-1. Short title. This Article may be cited as the Health Information Exchange and Technology Act. All references in this Article to "this Act" mean this Article.

Section 35-5. Purpose. Health information technology improves the quality of patient care, increases the efficiency of health care practices, improves safety, and reduces health care errors. These benefits are realized through the sharing of vital health information among health care providers who have adopted electronic health record systems. To ensure the benefits of health information technology are available to the citizens of Illinois, the State must provide a

framework for the exchange of health information and encourage the widespread adoption of electronic health record (EHR) systems among health care providers.

Section 35-7. Definition. As used in this Article, "Department" means the Department of Public Health.

Section 35-10. Implementation of health information technology initiatives. In order to advance the effective implementation of health information technology, the Department of Public Health shall, subject to appropriation, establish a program to promote, through public-private partnerships, the development of a health information exchange framework and foster the adoption of electronic health record systems.

Section 35-15. Establishment of the Illinois Health Information Network.

(a) As part of its program to promote health information technology through public-private partnerships, the Department of Public Health is authorized in accordance with Section 10 of the State Agency Entity Creation Act to create a not for profit organization that shall be known as the Illinois Health Information Network, or ILHIN. The Department shall file articles of incorporation and bylaws as required under the General Not For Profit Corporation Act of 1986 to create the ILHIN.

(b) The primary mission of the ILHIN shall be the following:

(1) to establish a State-level health information exchange to facilitate the sharing of health information among health care providers within Illinois and beyond in other states; and

(2) to foster the widespread adoption of electronic health records, personal health records, and health information exchange by health care providers and the general public.

(c) The ILHIN shall be governed by a board of directors as specified in Section 35-25 of this Act, with the rights, titles, powers, privileges, and obligations provided for in the General Not For Profit Corporation Act of 1986.

(d) The board of directors may employ staff under the direction of the executive director appointed pursuant to Section 35-25, or independent contractors necessary to perform its duties as specified in this Section and to fix their compensation, benefits, terms, and conditions of their employment. Employees of the department may be deployed by the director to support the activities of the ILHIN.

(e) Funds collected by the ILHIN shall be considered private funds and shall be held in an appropriate account outside of the State Treasury. The treasurer of the ILHIN shall be custodian of all ILHIN funds. The ILHIN's accounts and books shall be set up and maintained in a manner approved by the Auditor General and the ILHIN and its officers shall be responsible for the approval of recording of receipts, approval of payments, and the proper filing of required reports. The ILHIN may be assisted in carrying out its functions by personnel of the department with respect to matters falling within their scope and function. The ILHIN shall cooperate fully with the boards, commissions, agencies, departments and institutions of the State. The funds held and made available by ILHIN shall be subject to financial and compliance audits by the Auditor General in compliance with the Illinois State Auditing Act.

Section 35-20. Powers and duties of the Illinois Health Information Network.

(a) The ILHIN shall create a State-level health information exchange using modern up-to-date communications technology and software that is both secure and cost effective, meets all other relevant privacy and security requirements both at the State and federal level, and conforms to appropriate existing or developing federal electronic communications standards. The ILHIN shall consult with other states and federal agencies to better understand the technologies in use as well as the kinds of patient data that is being collected and utilized in similar programs.

(b) The ILHIN shall establish, by January 1, 2010, minimum standards for accessing the State-level health information exchange by health care providers and researchers in order to ensure security and confidentiality protections for patient information, consistent with applicable federal and State standards. The ILHIN shall have the authority to suspend or terminate rights to participate in the health information exchange in case of non-compliance or failure to act, with respect to applicable standards, in the best interests of patients, participants of the ILHIN, and the public.

(c) The ILHIN shall identify barriers to the adoption of electronic health record systems by health care providers, including conducting, facilitating, or coordinating research on the rates and patterns of dissemination and use of electronic health record systems throughout the State. To address gaps in statewide implementation, the ILHIN may, through staff or consultant support, contracts, grants, or loans, offer technical assistance, training, and financial assistance, as available, to health care providers, with priority given to providers serving a significant percentage of uninsured patients and patients in medically underserved or rural areas.

(d) The ILHIN shall educate the general public on the benefits of electronic health records, personal health records, and the safeguards available to prevent disclosure of personal health information.

(e) The ILHIN may appoint or designate a federally qualified institutional review board to review and approve requests for research in order to ensure compliance with standards and patient privacy protections as specified in subsection (b) of this Section.

(f) The ILHIN may solicit grants, loans, contributions, or appropriations from public or private source and may enter into any contracts, grants, loans, or agreements with respect to the use of such funds to fulfill its duties under this Act. No debt or obligation of the ILHIN shall become the debt or obligation of the State.

(g) The ILHIN may determine, charge, and collect any fees, charges, costs, and expenses from any person or provider in connection with its duties under this Act.

(h) The Department of Public Health may authorize ILHIN to collect protected health data from health care providers in a central repository for public health purposes and identified data for the use of the Department or other State agencies specifically to fulfill their state responsibilities. Any identified data so collected shall be privileged and confidential in accordance with Sections 8-2101, 8-2102, 8-2103, 8-2104, and 8-2105 of the Code of Civil Procedure and shall be exempt from the provisions of the Freedom of Information Act.

(i) The Department may authorize the ILHIN to make protected data available to health care providers and other organizations for the purpose of analyzing data related to health disparities, chronic illnesses, quality performance measurers, and other health care related issues.

(j) The ILHIN shall coordinate with the Department of Public Health with respect to the Governor's 2006 Executive Order 8 that, among other matters, encourages all health care providers to use electronic prescribing programs by 2011, to evaluate areas in need of enhanced technology to support e-prescribing programs, and to determine the technology needed to implement e-prescribing programs.

Section 35-25. Governance of the Illinois Health Information Network.

(a) The ILHIN shall be governed by a board of directors appointed to 3-year staggered terms by the Director of Public Health. The directors shall be representative of a broad spectrum of health care providers and may include among others: hospitals; physicians; nurses; consumers; third-party payers; pharmacists; federally qualified health centers as defined in Section 1905(l)(2)(B) of the Social Security Act; long-term care facilities, laboratories, mental health facilities, and home health agency organizations. The directors shall include representatives of the public and health care consumers.

(b) The Director of Public Health, the Director of Healthcare and Family Services, and the Secretary of Human Services, or their designees, shall be ex-officio members of the board of directors.

(c) The Director of Public Health shall designate the ILHIN's presiding officer from among the members appointed.

(d) The Director of Public Health shall appoint the executive director for the ILHIN. The executive director may be an employee of the Department of Public Health.

(e) The board of directors may elect or appoint an executive committee, other committees, and subcommittees to conduct the business of the organization.

Section 35-30. Health information systems maintained by State agencies.

(a) By no later than January 1, 2015, each State agency that implements, acquires, or upgrades health information technology systems used for the direct exchange of health information between agencies and with non-State entities shall use health information technology systems and products that meet minimum standards adopted by the ILHIN for accessing the State-level health information exchange.

(b) In order to provide the ILHIN with operational capabilities to assist in the development of the State-level health information exchange, the Department of Public Health is authorized to transfer or license the assets of the Illinois Health Network to the ILHIN as soon as is practicable.

Appendix 4

Illinois Foundation for Quality Health Care

Electronic Health Information Exchange Consumer Focus Group Summary

Sharp Research
March 2007

Objectives

- Assess consumers' current use of personal health records and their exposure to electronic health records
- Understand consumers' perceptions about ownership of their medical records
- Understand consumers' use of computers
- Discussion regarding concerns related to privacy and security measures involved with online exchanges of confidential information
- Assess consumers' perceptions about the implementation of a national electronic health information exchange (EHIE)
- Discussion of benefits and concerns regarding privacy and security of such a process
- Discussion of type of unique patient identification that should be used in an EHIE

Methodology

- Four (4) focus group sessions were conducted with consumers on Wednesday, March 7, and Thursday, March 8, at Home Arts Guild Research Center
- Participants were required to have visited a doctor or health care facility within the past 12 months (either for someone they care for or themselves)
- Focus group participants were recruited (12 participants were recruited per group):
- Two groups with participants aged 60 plus: One (1) group of 11 and one (1) group of 12 showed up
- Two groups with participants aged 24-59: One (1) group of 11 and one (1) group of 12 showed up
- Moderator Marybeth Sharp conducted the group with the assistance of a moderator's guide developed by Sharp Research and IFQHC

Organization of Results

- Executive Summary
- General Health Findings
- Healthcare Visits
- Personal Health Care Records
- Electronic Health Care Records
- Ownership of Health Care Data
- General Attitudes on the Safety and Privacy of Computers
- General Attitudes on Electronic Health Information Exchange
- Benefits and Concerns Regarding Health Information Exchange
- Patient Identification With Health Information Records
- De-Identifiable Health Care Data Used for Medical Research
- Conclusions

Executive Summary

General Health Care

Participants, in general, seem not to feel frustrated with the process of completing medical history forms when visiting a new physician's office. A little frustration was noted if they were required to complete these forms when they went to their primary care physician's office for annual check-ups; despite noted minor frustration, most saw this as a standard process. There was minor concern that the information they provide on medical history forms is inaccurate or incomplete.

Several participants maintain personal healthcare records. These can be copies of their actual health records, or another form of documentation they have developed on a computer to keep track of their medical procedures and medications. A few participants who provide care to others keep track of information that is necessary in caring for these people, such as medication records and some medical history.

When asked if they had heard of electronic health records, a few participants indicated they had and were even able to provide an accurate description of an electronic health record. Several participants indicated they have seen electronic health records in the offices of their own physicians. Many like the idea of electronic health records; they believe they will provide more accurate records and eliminate lost records. While many like and see benefits in electronic health records, they also want to ensure that these records remain part of the confidential "patient-doctor relationship." The use of a computer to record medical information leads some people to perceive that the medical visit itself will become automated and physicians will spend less time with patients.

The majority of participants currently receive hard copy prescriptions from their physicians' offices. A few have received a prescription generated by computer.

Participants were asked who was the owner of their healthcare data. The initial answer by most participants was "me." After discussing their actual access to these records, they soon changed their answer to the "hospital/medical facility were the owners" but they were able to get copies of this information when needed.

"Safety and Privacy" of Computers

Almost all participants use computers on a regular basis. Some are still a bit hesitant about "safety and privacy" when it comes to exchanging their personal and confidential information online, but the majority feel comfortable that the sites they use for online purchases and personal business are quite secure.

Electronic Health Information Exchange

Participants were provided with a definition of "Electronic Health Information Exchange" and asked to discuss concerns and perceived benefits related to the implementation of such a process. While the majority of participants reacted positively to an "electronic health record," many immediately expressed concern with an "electronic health information exchange" that would allow thousands of people to gain access to their healthcare information.

The perceived benefits of the process include immediate access to health information in the event of an emergency and a reduction in errors from lost or misplaced records.

The concerns associated with the process include increased access to personal/confidential healthcare information (a concern expressed especially by those who might have particularly confidential information such as mental illness) and hackers breaking into the system. There was also a concern that organizations, such as insurance companies and employers, may gain access to this information. The fear of insurance companies and employers obtaining this information made people believe that it could affect insurance premiums and coverage and also limit job opportunities.

While many participants see this process as being “inevitable” in the future of health care, they would still like to have some control over it. They would like to have the ability to provide authorization before any exchange of their health information is permitted.

Many participants would like to gain access to their own healthcare data via the electronic health information exchange. They felt that the ability to read their own records on line would be an appealing attribute.

When asked what type of patient identification number should be associated with electronic health records, the majority did not want to see their Social Security number used; they preferred having a “unique patient identification” number created.

Following each discussion, participants were asked how they would like to have their healthcare records maintained – in an electronic healthcare exchange process or in a paper copy. Thirty-nine of 46 indicated they would select the electronic process; four would like a paper copy; one did not care which format; one wanted both the paper and electronic format; and one was interested in electronic but wanted more information.

General Healthcare Findings

Healthcare Visits Findings:

- Out of forty-six participants, only one indicated he did not currently have a primary care physician.
- Participants were asked if they found the process of having to complete a medical history form upon entering a new doctor's office or updating their medical history when revisiting their current doctor's office frustrating.
 - The majority of participants felt this was a standard process when visiting any new doctor's office.
 - A couple indicated it was frustrating to have to complete the information every year for their annual visit with their primary care physician.
 - Those who have been going to the same physician for many years simply tell them "nothing has changed."
- Most participants were not concerned that they were forgetting information when completing medical history forms.
 - Several did not have a concern because they rely on their primary physician to forward copies of their medical records to any new physician.
 - A couple of participants indicated the form is so thorough that it usually addresses everything.
 - Only a few participants expressed concern regarding information they just did not know, such as the medical history of their ancestors or information pertaining to someone in their care, for example their parent or child.

Supporting Quotations:

"I switched practices and did not like the new doctor who took over the practice... so next time I have to go to a doctor I have some recommendations to follow up on for a new physician." (60+ Group)

"It is standard to complete these [medical history] forms every time you go to a doctor the first time." (60+ Group)

"I expect it each time that I go...it is something they want to know and maybe something came up since last time I went to the doctor's office." (60+ Group)

"I find it frustrating...I go once a year for an annual physical and I have to fill it out every time." (24-59 Group)

"When I am referred to a specialist, I have my primary care physician make sure they send over a copy of [my medical records] and I tell [the specialist] I do not need to fill out the forms because they already have a copy of my records from my physician. Why should I do something that is not worth my time?" (60+ Group)

"I always have my physician make a copy of my records and they give it to me to take to a new physician." (60+ Group)

"The questionnaire list [medical history form] is so long that if you follow it all the way through there is little chance that you are going to miss something." (24-59 Group)

"I filled out [medical history form] recently and it asked how old my grandparents were when they died. I had to call my parents because I would not have even gotten it close." (24-59 Group)

"The person I take care of is allergic to aspirin so I have to make sure I mark that down all the time." (24-59 Group)

Personal Healthcare Records Findings:

- A few participants in each group indicated they kept some type of personal healthcare records. In many of these cases, these personal health records are carried to the various doctor and health care appointments.
 - Several obtain actual copies of their physician/medical visits and referred to those as their personal health records.
 - A couple of participants developed a “simple” program on their computer (Microsoft Word was mentioned) and document all their visits, medical procedures, and a listing of all their medications.
- A few participants also maintain “pertinent” personal health information documents for someone they look over and assist to medical visits.
 - In many cases this was for a parent they were caring for and needed to maintain medication and medical treatment information.
 - Several participants also noted keeping copies of their children’s records, specifically immunization records.

Supporting Quotations

“I keep my [copies] of my files back from 1985.... I also ask for a copy of the [medical history] form that I fill out and [office visit information] because I want to keep track of my blood pressure and weight, so I ask for copies and I saved them all.” (60+ Group)

“On my computer...I keep track of all of my medical issues that I have had in my lifetime, like surgeries or problems that I had that did not require surgery. One side has my medications and supplements, and I take these with me and hand them this sheet. I have even done this in the operating room. I update the information and put a date on it to make sure it is the latest version.” (60+ Group)

“My mom was on a lot of medications so I kept a copy in my wallet [of all her medications] because we were in the hospital once a month and it was easier than carrying her bottles of medications with me. I kept the information on a little piece of paper laminated in my wallet.... It was easier to give it to them in the ER.” (24-59 Group)

“I keep copies of [my dad’s] records – photocopies of records and we keep all his medications documented.” (24-59 Group)

“I keep copies of my children’s immunization records.” (24-59 Group)

“It would probably be a smart thing to do [maintain personal health records] but I do not do it.” (24-59 Group)

Electronic Healthcare Records Findings:

- When participants were asked if they ever heard of electronic healthcare records, several provided a description of what they had already seen in their physicians’ offices and some indicated they had seen/read about electronic healthcare records on the Internet or in journals, or heard about it on television.
- A description of electronic health records was read to the group and they were asked to discuss the benefits and concerns regarding such a process. Many participants liked the idea of electronic health records and felt the medical field was late in getting this up and running. Perceived benefits to this type of process include:
 - Elimination of duplicate tests (X-rays, MRIs, etc.)
 - Elimination of lost/destroyed medical records (in cases of misplaced/misfiled records, securing files from damage such as water or fire, etc.)
 - More confidential than having hard copy file lying around the office or sitting by the examining room door

Supporting Quotations

“An electronic health record] is health information kept electronically in a centralized data file that is accessible, with firewalls, to specific individuals who are cleared to access that information. If they [physicians] had [electronic records] it would be easy to transfer medical records; instead of making a hard copy of the file, you could just pull it up on the computer.” (60+ Group)

“I never heard of [electronic health records] but I think we should have it because when I started treatment for cancer I started at one place and had to go to another place. ... I had a big folder and when I went to visit my primary doctor, they misplaced my folder.” (60+ Group)

“I heard of [electronic health records]...clinics and hospitals are on electronic systems, not all, but [electronic records] should be a better way to keep up with compliance and regulations – I think it is more confidential than having your medical record on the door so someone can walk by and look at it.” (24-59 Group)

“I read about electronic health records in journals and on the Internet.” (24-59 Group)

Electronic Healthcare Records in Physician Offices Today Findings:

- When asked if their physician’s office is currently using electronic health records, there was a mix of responses and confusion about whether their “actual health records” were electronic. Several indicated their physicians had computers in the examining rooms, others thought the nurses or staff entered data into a computer, and some indicated the healthcare records were still on paper.
- When asked how they feel about doctors using computers during an exam, there was concern from a few that it might eliminate any “personal touch” that is involved in a doctor-patient relationship, while others felt it would be the same if a doctor were taking notes during the exam – “What’s the difference if they are writing it down or typing it?”
 - Those participants who did not want a computer in the examining room did not seem to mind that the records were electronic as long as the physician was paying attention to them during the visit and putting the data in the computer afterwards.
 - More often participants in the 60+ group seemed to prefer the more “personal touch” component to an office visit versus participants in the 24-59 age group, who were more concerned with the accuracy and privacy of their records.
- Participants were asked about the type of prescriptions they receive from their doctor’s office, whether they are handwritten on a tablet of paper, electronic copy, or automatically sent via email to the pharmacist.
 - The majority of participants across all groups indicated they are receiving a handwritten copy of their prescription.
 - Only a few have received a computer printout of their prescription.
 - Those who have the prescription sent directly to the pharmacist could not determine whether it was via email, fax, or phone.
 - One participant indicated he receives a hard copy that he has to mail to his benefit plan.

Supporting Quotations

“I would be upset if my doctor was typing on a computer during the middle of my visit.” (60+ Group)

“A very important part of medicine is listening to the patient’s needs. If a doctor is on a computer, then he is not really focusing on what the patient is telling him – I think it is a distraction. If the person wants to make notes and go on computer after the visit that is fine.” (60+ Group)

“My doctor is a young doctor...he asks questions and types them in [the computer]. I would rather see what he is typing since you can’t read their handwriting.” (60+ Group)

“My only concern with it [electronic health records] is who would have access to that information.” (24-59 Group)

"I went to my doctor and he started typing on his computer with his back to me and that seemed a bit strange, so as long as he was facing me it would not be bad." (24-59 Group)

"I don't have a problem with my doctor typing his notes on a computer... my old doctor's office had a flood and all the records were destroyed so they should be up with the program on having files on a computer." (24-59 Group)

"I get my prescription called into the drugstore or a hard copy is given to me." (60+ Group)

"My physician [today at my visit] was putting something in the computer and when I checked out I was given a prescription [printed from the computer]." (24-59 Group)

"I was taken to the ER in Sweden...and they gave me a form printed [on a computer] in Swedish with my prescription." (60+ Group)

Ownership of Healthcare Data Findings:

- The initial perception of many participants when asked who was the owner of their healthcare data was "me." However, as the groups began to discuss the processes involved in getting copies of their health records, transferring their health information to other physicians' offices, and the inability to actually change this data, their viewpoints changed.
- Some believe ownership should have to do with who pays for the information.
- Participants noted they are able to obtain copies of their health records but cannot take the originals.
- Patients do not have the ability to make changes or add notes to their healthcare records; therefore, they are not owners of this data.

Supporting Quotations

"I should be the owner...I paid for it [health care records]." (60+ Group)

"Under the law, ownership has to do with custody and custody is in the hands of the institution – we as patients have a right to obtain copies...but we do not have custody so under the law we do not have ownership." (60+ Group)

"I think I can ask for my records to be transferred to a doctor and they may not physically give it to me but I know they have a set sent to the other office. I am the implied owner but I do not think I have rights to actually physically hold it." (24-59 Group)

"I would say the hospital is the owner because you do not get the originals." (24-59 Group)

"If we were the owner we would be able to change our records and we are not able to change it." (24-59 Group)

General Attitudes About the Safety and Privacy of Computers

Use of Computers Findings:

- All but one of 46 participants currently use computers; the one nonuser indicated he just enrolled in a computer class. The majority of participants use their computers and online services extensively. Only a few tend to use the computer infrequently, typically for email or to look up information on the Internet.
- The majority of participants who use their computers frequently also admitted they use the Internet for the exchange and transfer of personal and confidential information, such as product/service purchases, and online banking/financial business.

- Participants who are comfortable using the Internet for online purchases and financial transactions were comfortable because they know what to do or look for in terms of safety precautions
 - Most are comfortable making purchases online if it is with a reputable company or if they can determine it is a “secure site.” They determine it to be a secure site if it has a “secure lock” or “SSL encryption.”
- A few participants who purchase products online indicated they have a credit card designated for online purchases. In case fraud occurs, the credit card can be cancelled easily.
- In addition, many participants indicated they are always concerned about secure sites and fraud in general, so they make sure to monitor all purchases that show up on their credit cards, whether the purchases were made online or in a store.
- A few participants in the 60+ group expressed more concern that their Social Security numbers are tied to everything versus concern about safety on the Internet. One stated: “Our lives are really an open book tied to our Social Security number.”
- A couple of participants also expressed concern about the risk of identity theft, which can be associated with putting your personal information online.

Supporting Quotations

“I order online.... I do not keep financial records out there but I have a separate credit card that I use for online purchases.” (60+ Group)

“It’s our generation that is so concerned – young people put everything out there [on the Internet].” (60+ Group)

“I do not think twice about [using the Internet] as long as it is a real site and company.” (24-59 Group)

“I have not written a check in two years. Every bill is paid online by bank or their website.” (24-59 Group)

“I only use the computer for Internet and WebMD.” (24-59 Group)

“I take it for granted that major companies are secure and have a safe site. For smaller companies I am lucky—I am in the profession and know what to look for, like secure lock or SSL encryption. I buy stuff all the time online and I think it is more secure than paying in person in a restaurant.” (24-59 Group)

“I have a philosophy – if someone wants to get in [to data files], they are going to get in, no matter how secure you try to make yourself.” (24-59 Group)

“My purse was stolen and my bank account was wiped out. I always hear how easy it is for people to steal your identity.” (24-59 Group)

General Attitudes About Electronic Health Information Exchange

Electronic Health Information Exchange Findings:

- Participants were provided with a copy of the following definition of an electronic health information exchange and asked to discuss the benefits and concerns regarding this definition:
 - A “secure and private” electronic health exchange of health information (your medical history). This would allow healthcare providers to share personal health information and would include all healthcare providers such as hospitals, public health facilities, pharmacies, laboratories, and imaging centers who had the authorization to access this information. For example, if you went to another doctor’s within the state OR in another state and provided a piece of information, possibly a patient identification number, your medical history would come up electronically for the physician to review (e.g., it would show all recent physician visits, medications that you are and have been on, recent and historical medical conditions that you were treated for, etc.). This would allow doctors to

update your records at the time of each visit and this information would then be in your records for access.

- While many participants like the idea of having electronic health records in a physician's office, many became concerned about the notion that access to this information would now be expanded outside the physician's office or the hospitals/medical facilities to "thousands" of other people.

Supporting Quotations

"I do not like the idea [HIE] for privacy reasons but I think it is inevitable. The more people involved [in having access to health records] the more possibility information can get out. This secure access can be to 10,000 people." (60+ Group)

"I just think without adequate safeguards this would be a gross disservice to the privacy of the public. You certainly have to have the right computer experts to place safeguards in this system." (60+ Group)

"I don't think there would be anything in there [health records] that could be used against me and it is nice to know it is available in an emergency." (60+ Group)

"My mother-in-law is a retired nurse and I have two sister-in-laws that are nurses....There are things I do not want them to know. Who is going to have access?" (24-59 Group)

"I think we are trading a little bit of security for a whole lot of availability of medical information – it is a benefit but there is a tradeoff." (60+ Group)

"When we were on a trip, my son got ill and we had to go through all these things. It would have been nice to go someplace and allow them to pull up his records and give him the appropriate medication." (24-59 Group)

Electronic Health Information Exchange – Benefits Findings:

- Participants were able to identify many benefits associated with the implementation of an electronic health information exchange process. Some of these benefits include:
 - In an emergency, health information would be available immediately. This would be particularly beneficial if someone is traveling.
 - Elimination of lost or missing health records that are sent via fax or mail from one physician office to another. The files would be available immediately.
 - The long-term benefits would provide for a more efficient access to health information, a decrease in healthcare staffing needs, a decrease in manual errors (physician handwriting is not often legible), and potential for cost reductions in healthcare.
- If the health information exchange is electronic, it will be easy to track who accesses the data. When probed, participants agreed that it would be beneficial to know who has accessed their health information.

Supporting Quotations

"Wouldn't this be helpful if you are admitted to a hospital and they are able to pull up all your [health] information." (60+ Group)

"The medical industry is a high-cost industry and the reason we are charged so much is because information is not centralized or coordinated. We have everyone running around with their own information; and everyone is filling in their own information; and everyone has their own reports. The more we can eliminate some of these costs in terms of files and records would be good. But we definitely have to address the security issues involved in this process." (60+ Group)

"I had a situation when I gave birth on a holiday weekend and all my records were not sent to the hospital so both the baby and I had to redo all these tests.... If they had an electronic exchange, they could have just looked on the computer." (24-59 Group)

"I think this might reduce the costs...billing, administrative costs, and some of the overhead. I would need some Good Housekeeping Seal of Approval to make sure it is secure." (24-59 Group)

Electronic Health Information Exchange – Concerns Findings:

- The primary concern raised was a desire for assurance that the process of electronic health information exchange would truly be a "private and secure" exchange of health information.
 - The electronic health information exchange will allow more people access to extremely confidential information, such as mental illness situations.
 - The concern about hackers, who are always trying to get access to information and getting more successful in doing so. Electronic records would make it so much easier for someone to obtain information, as opposed to one hard copy.
 - More than "authorized healthcare professionals" will be able to gain access to this information, such as insurance companies and employers. Participants believe these various organizations will gain access to health information if it is electronic, and this, in turn, will affect the type of insurance coverage people get and provide employers reasons not to extend job offers.

Supporting Quotations

"I am always concerned about hackers and this takes it a step farther because it would be available worldwide." (60+ Group)

"I am not worried about who is accessing my banking information whereas patient health information is so much more interesting to look at...so I am sure hackers would love to get in there." (24-59 Group)

"If this information is out there... people will figure out how to get it." (60+ Group)

"I would not want to see someone access this outside the medical profession – especially psychiatric records." (24-59 Group)

"It might be easier for someone to access confidential electronic records, as opposed to shuffling through hard copies of medical records." (24-59 Group)

"You are talking about medical information – extremely confidential. My guess is someone who is managing IT at a high level will be able to see things because they will need to be able to get in the system to do things. Granted, there are different clearance levels, but you never know when there is a bad seed." (24-59 Group)

Electronic Health Information Exchange – Patient Authorization Findings:

- While many participants indicated the electronic health information exchange process would probably be "inevitable," it was important for patients to be required to give their authorization for other healthcare professionals to gain access to their health information.
- The majority of participants indicated the ability to view/access their own records would make the electronic health information exchange process even more appealing.
- Participants would like to see some type of limitations on who has access to data, a "role-based access," but they had difficulty providing the specifics in terms of "who" should access "what." While some discussed protecting the information by limiting the number of people who can access the information, others noted that in allowing more healthcare professionals access to the data, there may be less chance for medical errors.

Supporting Quotations

"Patients' rights have to be expanded just like the medical profession wants their rights expanded. There should be no instances of a transfer of records to any sources without the authorization of the patient." (60+Group)

"I think it would be good to have access to my own records and have it all in one place." (24-59 Group)

"In terms of data to be accessed, any hospital would be given access and clinics would have different levels of access. Maybe everyone has access or maybe not...or maybe some criteria need to be set up for access." (24-59 Group)

"There is a problem with that [role-based access] because I don't think a patient can determine who should have the information, whether it is lab, staff, or a nurse." (60+ Group)

"Here is the irony – all the safeguards we are discussing, and not one of us has failed to complain about all the red tape we have to go through now and all we are doing is adding more red tape to choke the whole system. I don't care who knows my medical records and the sooner they can get the information I need the better off I am." (60+ Group)

Patient Identification with Health Information Records Findings:

- Participants were asked what type of patient identification should be associated with their electronic health information records.
 - Many did not want to see their Social Security numbers tied to this electronic health information exchange since the access would be increased. Only a few felt it would be easier to use their Social Security number since it would be one less number for them to remember.
- Participants became very creative when attempting to think of ways to "safeguard" their data. They provided several different suggested "unique patient identification" options to allow access to their health data. Some of these suggestions include:
 - A "unique number" set up to be similar to the patient's driver's license or VIN number
 - A healthcare card similar to a credit card
 - A private PIN that can only be used with the scanning of a patient's thumb or eye
 - A couple of participants even suggested inserting a microchip into every person, similar to what is being done in animals.
- When participants were asked, if they had a choice of selecting electronic health records or paper copy, which would they select:
 - Thirty-nine would select electronic health records.
 - Four would like to keep paper copy.
 - One did not care, either electronic or paper.
 - One wanted both electronic and paper records.
 - One was interested in electronic but wanted more information.

Supporting Quotations

"I think there should be a separate number [not Social Security]...it would be an additional safeguard." (60+ Group)

"You should have your own private PIN.... It can only be accessed by scanning your thumb or your eyeball." (24-59 Group)

"Use Social Security number...I do not think too many people would be interested in my medical information...a unique password is just one more thing I need to remember." (60+ Group)

"Electronic with proper safeguards in place and communication from medical profession to the patients. Would also want the patient authorization before records were made available to others." (60+ Group)

"Electronic only because it is a 24-hour thing in the event of an emergency and I really feel that they should get more information to patients [about this process]." (60+ Group)

“I would like both [electronic and paper records]; the legal field needs to have everything documented.” (24-59 Group)

“Paper. I am not convinced about this and would have to think of process and security – I do not think this is a good idea.” (24-59 Group)

“Electronic and would like to be able to have a copy of my own files from the electronic file.” (60+ Group)

De-identifiable Health Care Data Used for Medical Research Findings:

- Participants in one of the groups were asked how they would feel if their health information, which would be de-identifiable, was used for medical research purposes. It was explained that having the information stored electronically would allow for access to a very large sample and could help in the advance of medical research.
- The majority of participants felt this was a good idea but some wanted more information about who was doing the research and how it would be used. There was concern from a couple of participants that the research was going to be done with “for profit” pharmaceutical companies and they did not like that idea.
 - Five participants would agree to having their health information used for research.
 - Three would want to know more about the use of the research before saying whether they would or would not agree to it.
 - Two would not agree to using their health information data for research.
 - One would do it only if he was paid for his information.

Supporting Quotations

“This amount of data could provide a warehouse of knowledge [for research purposes].” (24-59 Group)

“A lot of this research is done by pharmaceuticals and they do not do it for the good of us; they do it to sell us products for profit.” (24-59 Group)

“They are doing great things with research.” (24-59 Group)

Conclusions

- For the most part, consumers are very tuned in to today’s computer technology and quite comfortable with the securities that are in place on the Internet. In order to have consumer buy-in and comfort with an electronic health information exchange process, consumers need assurances about the safeguards that will be enforced .
- The electronic health information exchange process should also be explained to consumers: who will have access to the health information, will consumers be allowed to authorize and control access to their health information, and will consumers, at some point, be allowed to access their own health information records?
- Further research should be conducted on using de-identifiable data from an electronic health information exchange for medical research purposes. There seemed to be support for this effort, but it was tested in only one group.

ⁱ 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.

ⁱⁱ eHealth Initiative eHIssuebrief, *States Getting Connected: State Policy Makers Drive Improvements in Healthcare Quality and Safety Through Information Technology*, August 2006, available at: <http://www.ehealthinitiative.org/newsletters/IssueBrief.msp>.

ⁱⁱⁱ Robert Wood Johnson Foundation and the National Coordinator for Health Information Technology, *Health Information Technology in the United States: The Information Base for Progress*, page 2:6, October 11, 2006, available at: www.rwjf.org.

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^v Prepared for the Agency for Healthcare Research and Quality (AHRQ) by Avalere Health LLC, "Evolution of State Health Information Exchange/ A Study of Vision, Strategy, and Progress," page 2, January 2006, available at: http://healthit.ahrq.gov/portal/server.pt?open=18&objID=130379&parentname=CommunityPage&parentid=12&mode=2&in_hi_userid=3882&cached=true.

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^{viii} American Hospital Association, *Hospitals and Health Network Magazine*. July 2006, 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."

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^{xii} Office of the Governor, *Executive Order Creating the Division of Patient Safety within the Department of Public Health, Executive Order Number 8 (2006)*, July 13, 2006.

^{xiii} Office of the Governor, *Gov. Blagojevich announces sweeping reforms to improve patient safety; reduce costly medical errors - Governor proposes computerizing all prescriptions by 2011*, News Release, July 13, 2006.

^{xiv} The White House, *Executive Order: Promoting Quality and Efficient Health Care in Federal Government Administered or Sponsored Health Care Programs*, Section 3, August 22, 2006, available at: <http://www.whitehouse.gov/news/releases/2006/08/20060822-2.html>.

^{xv} State RHIO Consensus Project, “Table 1. State-Level HIE Initiative Governance Composition Comparison”, *State Level Health Information Exchange Initiative: Development Workbook – A Guide to Key Issues, Options and Strategies*, September 1, 2006, available at: www.staterhio.org.

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^{xviii} Markle Foundation, *An Overview of the Connecting for Health Common Framework*, Page 5, this is one of the component documents of *The Connecting for Health Common Framework: Resources for Implementing Private and Secure Health Information Exchange*, ©2006, available at: www.connectingforhealth.org.

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^{xxiv} National Association of State Chief Information Officers (NASCIO), *Profiles of Progress: State Health IT Initiatives*, November 2006, page 25, available at: <http://www.nascio.org/nascioCommittees/healthIT/members/#publications>.

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