

# **HISPC-Illinois II Implementation Project Summary and Impact Analysis Report**

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Submitted to:  
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# Notice

The HISPC-Illinois Steering Committee finalized the documents referenced in this report on December 17, 2007. These final documents are on the HISPC-Illinois Web site at:

<http://www.idph.state.il.us/hispc2/reports.htm#p2rpt>

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# HISPC-Illinois Implementation Project Summary and Impact Analysis Report

## *Executive Summary*

Health information technology (HIT) presents significant opportunities to improve the quality of the health care delivery system. Through mechanisms like a health information exchange (HIE), technology can enable patient health information to be available for clinicians no matter where the patient is being treated. It will improve patient safety by reducing medical errors, reduce costs from duplicative procedures and provide public health authorities with quicker data to respond to outbreaks or bioterrorism events.

There has been an increased momentum among the states and the federal government to capture these and other benefits by expanding HIT initiatives such as HIE and electronic health records (EHR).

Efforts to expand HIT in Illinois have increased over the last two years. In 2005, legislation was enacted to create the Electronic Health Records (EHR) Taskforce to recommend a plan for the development and use of EHRs in the state. The taskforce issued a report in December 2006 recommending the creation of a state-level health information exchange and the establishment of a program to foster the adoption of EHR systems by clinicians.

In July 2006, Governor Rod R. Blagojevich issued an executive order creating a division of patient safety within the Illinois Department of Public Health. The Governor gave this new unit an important HIT role as part of its patient safety mandate with respect to prescription drug safety.

The U.S. Department of Health and Human Service funded an initiative, the Health Information Security and Privacy Collaboration (HISPC), to enable states to address privacy and security challenges and barriers to the establishment of HIEs. In early 2006, Illinois was one of 33 states and one territory to join this collaboration.

The goals of this initial phase of HISPC were to: identify both best privacy and security practices and challenges relating to health information exchange; develop consensus-based solutions that protect the privacy and security of health information; and, develop plans to implement those solutions.

The priority for Illinois as HISPC entered an implementation phase was to work with governmental and private sector stakeholders - a public-private partnership - to move forward on privacy and security issues that need to be addressed by the governance structure of a state-level HIE. The **HISPC-Illinois II** project proposed to accomplish this task by establishing two work groups, each focusing on distinct privacy and security-related product.

A **Privacy and Security Work Group** was formed to develop draft privacy and security policies and recommendations for consideration by the governance structure of a state-level HIE. The work group developed a draft document, “Recommendations on Privacy and Security Policies,” that focused on 12 privacy and security areas.

A **Legal Work Group** was convened to draft a uniform model patient EHR/HIE consent form for possible use by the state-level HIE, clinicians, health care facilities and other providers. During its deliberations, the work group developed three forms after they determined that one form would not address the different issues faced by providers and an HIE under state and federal law. The three are the:

- ✎ Notices of Privacy Practices Insert
- ✎ Consent for Use and Disclosure of Certain Types/Categories Protected Health Information
- ✎ Authorization for Use and Disclosure of Protected Health Information for Research

The products of the two work groups were sent to interested stakeholders for review and comment on October 23, 2007. Comments were to be returned by November 7, 2007. Both work groups have met to discuss the comments that were received and made revisions to address many of the comments.

During December, these products will be finalized by the work groups and then be reviewed and approved by the HISPC-Illinois II Steering Committee. The “Recommendations on Privacy and Security Policies” document will be shared with the Illinois Health Information Exchange Advisory Committee – a committee that has been formed by the Departments of Healthcare and Family Services and Public Health to continue the implementation planning for the development of a state-level HIE. The Legal Work Group forms will be distributed to health care providers who will be encouraged to use the model forms or incorporate text from them into their existing forms.

Depending upon the availability of funding, HISPC-Illinois can enter a new phase in 2008 by participating in a collaboration of states analyzing the barriers to the interstate exchange of health information caused by varying state consent laws. This “Interstate and Intrastate Consent Strategy” collaborative would look at potential solutions to those barriers.

## ***Introduction and Overview***

### **Current HIT/HIE Landscape in Illinois**

The HIT/HIE landscape in Illinois has been evolving over the last couple of years. Planning for a comprehensive state-level HIT/HIE initiative began in 2005 when the Illinois General Assembly passed and Governor Rod R. Blagojevich signed legislation (Public Act 94-646) creating the Electronic Health Records (EHR) Taskforce. The primary objective of the taskforce was to create a plan for the development and use of EHRs 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 taskforce held over 40 meetings and issued its report on December 27, 2006. It recommended the creation of a state-level health information exchange (HIE) under the governance of a not-for-profit organization called the Illinois Health Information Network (ILHIN). ILHIN would also work with the Illinois Department of Public Health on a program to foster the adoption of EHR by health care providers.

Legislation to implement the recommendations of the EHR Taskforce, House Bill 1254, was approved by the Illinois General Assembly during the spring 2007 session. The Governor amendatorily vetoed the bill to change the ILHIN from a not-for-profit organization to an advisory body and shift responsibility for implementing the state-level HIE to the Illinois Department of Healthcare and Family Services (the state Medicaid agency). The bill died when the Illinois House of Representatives failed to act on the Governor's recommended changes.

Although there is some disagreement over the governance structure, there is widespread support for the creation of a state-level HIE. To continue this momentum, the Directors of Healthcare and Family Services and Public Health have established the Illinois Health Information Exchange Advisory Committee (HIE Advisory Committee). The mission of the HIE Advisory Committee will be to collaborate with the two departments in the implementation of a state-level HIE.

In addition to the activity related to the state-level HIE, Governor Blagojevich issued an executive order (Executive Order 2006-08) in July 2006 to create the Division of Patient Safety within the Illinois Department of Public Health. The purpose of the new division is to consolidate the state's efforts dealing with medical errors and focus on improving patient safety. The Governor 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 the new division 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.

Prior to the enactment of the Electronic Health Records Taskforce Act, Illinois had several ongoing HIT/HIE initiatives. The Illinois Department of Public Health developed a system to provide integrated data sharing and support for multiple health and human service programs. This system was transferred to the Illinois Department of Human Services when that agency was created.

Another initiative, the Illinois Health Network, offered the infrastructure to electronically transmit health information among hospitals and health care professionals. The creation of this entity was facilitated by a \$1.5 million grant from the state to the Illinois Hospital Research and Educational Foundation.

In the early 1990s a group known as the Chicago Health Information Network attempted to develop an HIE. Because of lack of governance and funding, however, the group disbanded. Although there has been no success in establishing a fully interoperable regional health information organization (RHIO), an organization known as the Northern Illinois Physicians for Connectivity (NIPFC) is working to fulfill the goals of a RHIO. NIPFC encourages and facilitates the use of health care technology among its members by maximizing economies of scale. Its vision is to ensure the privacy and security of confidential information yet allow health information to be shared by way of a patient index.

Several EHR initiatives received federal funding from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services. These initiatives are:

- **The Enhancing Quality in Patient Care (EQUIP) Project** – Implements an electronic health records system in a network of community health centers and develops a data warehouse to monitor, aggregate, and provide data for quality improvement. **Sponsoring Organization:** Erie Family Health Center
- **Linking Rural Providers to Improve Patient Care and Health** – Develops a central electronic health record system to allow the sharing of health information between a hospital, medical group, county health department, and behavioral health organization for rural economically disadvantaged, ethnic/racial minority residents, the elderly, and persons with special/complex health care needs. **Sponsoring Organization:** Katherine Shaw Bethea Hospital
- **Sharing Patient Record Access in Rural Health Settings** – Develops an implementation plan for an ambulatory EMR in a medically underserved region that will electronically connect physician offices, the regional hospital, ancillary

services, and other community health services; identifies indicators to track measurable improvements in patient safety, quality of care, clinician and patient satisfaction, and operational efficiency. **Sponsoring Organization:** Sarah Bush Lincoln Health Center<sup>1</sup>

In the private sector, many hospitals are adopting EHR systems and working to link those systems with associated physicians. Specific plans to link the separate hospital based systems together do not yet exist.

### **Current Privacy and Security Landscape**

No formal governance structure for privacy and security has been established in Illinois. While the enabling legislation that would have created the ILHIN was not approved, state policymakers are still pursuing the creation of a “state-level HIE” and initiatives to “foster the widespread adoption of EHRs and local health information exchanges.” The work of the HISPC – Illinois II project to draft privacy and security policy recommendations and to develop a model forms to address the release of patient information to an HIE – will serve as important resources as the process for creating the state-level HIE continues. Illinois plans to ask stakeholders, including the Illinois State Medical Society, and the Illinois Hospital Association, to assume strategic leadership roles in a coordinating body to move forward with these privacy and security issues.

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<sup>1</sup> Illinois Electronic Health Records Taskforce Report and Plan: December 2006, page 57, [http://www.idph.state.il.us/ehrtf/Draft%20Report/EHR%20Taskforce%20Report\\_Plan%20Dec%202006.pdf](http://www.idph.state.il.us/ehrtf/Draft%20Report/EHR%20Taskforce%20Report_Plan%20Dec%202006.pdf)



## ***HISPC – Illinois II Update***

The priority for Illinois as HISPC entered phase 2 was to move the public-private partnership outlined in the Electronic Health Records Taskforce report and supported in the HISPC-Illinois State Implementation Plan forward in the areas of privacy and security. It is the intent of the project to expedite the development of a state-level HIE by bringing stakeholders together to lay the groundwork on privacy and security issues.

Adopting privacy and security policies that will satisfy national requirements for participation in the Nationwide Health Information Network and provide assurances to Illinois residents regarding the safety of their personal health information will be a major task during the development of the state-level HIE. HISPC-Illinois II set up a work group, the Privacy and Security Work Group, to help facilitate this task by developing draft privacy and security policies and recommendations for consideration by the state-level HIE governance structure.

The promise of EHR and HIE is to enhance the quality of health care provided to patients. Patient support is essential for this to become an effective tool. To receive this support, patients must be adequately informed as to the potential use of their health records and be assured of the privacy and security of that data.

The optimal goal is to provide all patients in Illinois with the same information regarding privacy protections under the law and the necessary education to understand how their records will be safeguarded in an EHR/HIE environment. To address this goal, the Legal Work Group was tasked with the development of a model uniform patient EHR/HIE consent form for possible use by the state-level HIE, clinicians, health care facilities and other providers. The Legal Work Group was also tasked with the development of a plan to disseminate the consent form and encourage its use.

The tasks of the work groups were complicated by some uncertainty regarding how HIE would be structured in the state. At the beginning of the project, the Steering Committee and work groups were responding to the structure recommended by the Electronic Health Records Taskforce. The taskforce recommended a federated architecture for the state-level HIE based upon the “Connecting for Health Common Framework.”<sup>2</sup> This was addressed by providing an overview of the process and responding to member questions regarding potential architecture issues.

### **Draft Privacy and Security Policies/Recommendations for ILHIN**

The Privacy and Security Work Group began its deliberations on September 21, 2007. Members discussed an outline of topic areas for the “Draft Policies and Recommendations document.” An outline of privacy and security topics used in the

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<sup>2</sup> Markle Foundation, *The Connecting for Health Common Framework*, ©2006, available at: [www.connectingforhealth.org](http://www.connectingforhealth.org).

HIMSS Privacy and Security Toolkit<sup>3</sup> was discussed. The members agreed to use this outline as the starting point for the document. (Figure 1)

During its October 4, 2007, meeting, the Privacy and Security Work Group discussed the first draft of the document.

Members felt that the state-level HIE's statement of philosophy on privacy and security should be as strong as possible without making any guarantee.

The draft also included a new "Remedies" topic area to recommend that the state-level HIE develop policies on how privacy and security violations are to be remedied.

On October 16<sup>th</sup>, the work group agreed to send the second version of the document to the Steering Committee for its review prior to the dissemination of all HISPC-Illinois II work products to stakeholders for comment.

The work group's November 20<sup>th</sup> meeting was focused on a discussion of the stakeholder's comments regarding the document. Most of the comments focused on the consistency between some provisions in the privacy and security policy recommendations document related and the draft forms proposed by the Legal Working Group. The Legal Work Group addressed some of these issues during its post-stakeholder comment meeting. The remaining consistency issues will be addressed in the final revision of the document. Another commenter suggested adding a provision granting patients the right to "annotate" their health information held by the state-level HIE to be consistent with HIPAA.

The final draft of the "Recommendations on Privacy and Security Policies" will be decided by the Privacy and Security Work Group in December.

**Figure 1**

- "Draft Policies and Recommendations document."**  
**September 21<sup>st</sup> Outline of Topics**
1. Philosophy for the Protection of Information
  2. Patient Rights with Respect to Information Security
  3. Protection of Caregiver Information
  4. The Privileges and Obligations of Researchers
  5. The Rights of Society
  6. Collection of Information
  7. Retention and Destruction
  8. Information Security Program
  9. Accountability and Responsibilities
  10. Access to Information
  11. Classification of Information
  12. Records of Access
  13. Disaster Recovery/Business Resumption Plans
  14. Information Security Awareness Training
  15. Monitoring and Auditing

<sup>3</sup> "Developing Policies, Procedures, and Practices - Introduction," By Ted Cooper, MD, part of the *HIMSS Privacy and Security Toolkit*, Healthcare Information and Management Systems Society, January 2007, page 2.  
[http://www.himss.org/content/files/CPRIToolkit/version6/v6%20pdf/D37\\_Introduction\\_to\\_P-Ps.pdf](http://www.himss.org/content/files/CPRIToolkit/version6/v6%20pdf/D37_Introduction_to_P-Ps.pdf)

## **Develop a Model Uniform Patient EHR/HIE Consent Form**

HISPC-Illinois found no Illinois law **yet** relating to privacy and security relating to health information exchange. It did find a variety of Illinois statutes with specific restrictions on the use of protected health information.

Within this context, the Legal Work Group met on September 26, 2007, to start the task of developing a model consent form for the release of PHI for HIE purposes. The primary consideration for the work group was to balance the privacy concerns of patients with the need to establish an efficient mechanism to share patient health information with treating clinicians.

One of the first actions of the work group was to define the limitations of a “model form.” These limitations are:

- The model form is NOT intended to be a universal consent;
- The model form is NOT intended to replace existing informed consents for treatment;
- The model form is NOT intended to replace Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) authorizations or consents/authorizations for use and disclosure of highly sensitive health information required by state law; and,
- The model form must NOT be inconsistent with those forms.

The work group then went over issues relating to a model form. These include:

### **Information to be Disclosed**

- What is the scope of the information to be disclosed to the HIE?
  - Medical information only?
    - Should definition differ from PHI under HIPAA?
  - Financial/payor information?
  - Other?
- Should the model form adopt an “all or nothing approach” or allow a patient to disclose only selected information under a “check the box” approach?
  - Should there be any consequences or disclaimers attached to limitations?

## Authorized Uses

- Should authorized uses be limited to treatment or, alternatively, to treatment, payment and health care operations (TPO) [as defined under HIPAA]?
- If the authorized uses are limited to TPO (and authorized users are limited to providers, health plans and health care clearinghouses), is any consent required for the disclosure of PHI to the HIE in anticipation of use for TPO?
- Should any use beyond TPO be authorized (e.g., research, outcomes measurement)?
- Might the state want to access the HIE for various public health or other purposes?

## Additional Provisions

- Revocation right and consequence?
- Expiration date or event?
- Patient Rights?
  - Is an individual entitled to an accounting of disclosures?
  - Should individuals be entitled to access and/or edit their data in the HIE?
- Who can sign?
  - “Personal representative?”
  - Can a minor revoke a parent’s or guardian’s prior consent?
- How should the contractors of HIE participants be handled?
- Acknowledgement of potential re-disclosure?

## Other Considerations

- Impact of health information confidentiality laws
  - HIPAA – Is the disclosure of health information to the HIE a disclosure for TPO?
  - Impact of other federal laws (e.g., FSAR)

- State law considerations
  - How does Illinois law affect the content of the model form (e.g., AIDS Confidentiality Act? Genetic Information Privacy Act? Medical Patient rights Act)?
  - Does the model form need to embody a HIPAA preemption analysis?
- Opt-in or opt-out process?
- Existing Templates
  - HIPAA authorizations
  - Forms developed by other states

The group's discussion focused on the point that the HIPAA Privacy Rule authorizes the use and disclosure of PHI without authorization or consent, for treatment, payment and health care operations activities. Members suggested that the privacy rule would apply to transactions processed by an HIE. Some concern was expressed that requiring a consent form for HIE transactions would create a potential backlash about the need for consent for current practices.

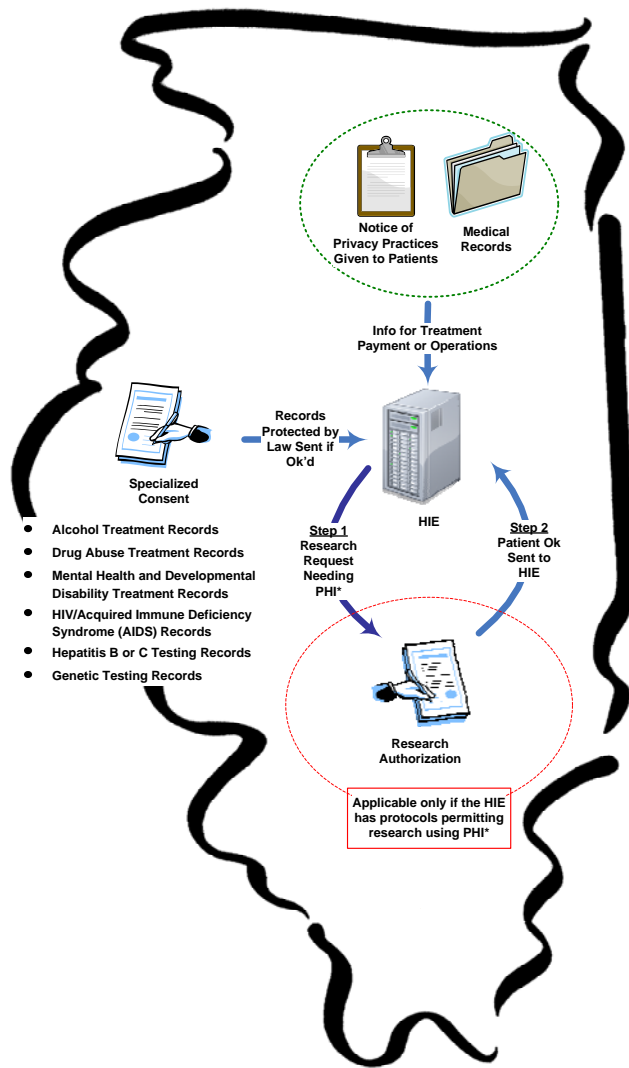
It was decided that the work group would proceed under the premise that the HIPAA Privacy Rule would cover HIE transactions. The group also decided that patients should be given information regarding the possible use of their health information.

The work group agreed that a consent form was necessary for the release of special categories of health information protected under state law.

At its October 10, 2007, meeting the Legal Work Group considered three draft forms. These were:

- 📄 Notices of Privacy Practices Insert
- 📄 Consent for Use and Disclosure of Protected Health Information to the Illinois Health Information Network
- 📄 Authorization for Use and Disclosure of Protected Health Information to the Illinois Health Information Network

There was some discussion as to whether the "Notices of Privacy Practices Insert" was voluntary as to its use by a provider. The concern was to avoid placing an additional



\*PHI = Protected Health Information

Diagram outlining the release of patient health information within the context of the forms developed by the Legal Work Group

meeting:

### Notices of Privacy Practices Insert

The health care provider would use this insert or incorporate the model language into their existing notice of privacy practices. It advises the patient that their PHI could be provided to a HIE.

### Consent for Use and Disclosure of Certain Types/Categories Protected Health Information

While the HIPAA Privacy Rule authorizes the use and disclosure of PHI without the patient's authorization or consent, written consent is required to disclose

burden on providers. It was noted that none of the forms would be mandated, but the goal is to encourage their use to provide consistent information for consumers.

Members also discussed whether the consent form was trying to accomplish too much. Further comments noted the difficulty in working with a long, complicated form and the challenges of educating the public. The work group decided to omit research from the form, since a separate document would need to be approved by an institutional review board (IRB) for any research project.

The group agreed to the draft "Notices of Privacy Practices Insert." It was also agreed that the consent and authorization forms be changed to provide that the consent form would focus on the release of health information within special categories protected by law. The authorization form would be changed to only address the release of PHI for research purposes.

The Legal Work Group agreed to present the following forms to the Steering Committee at its October 22

certain categories/types of PHI under Illinois law. This consent form would be used by the patient to grant permission for this information to be disclosed to the HIE.

### **Authorization for Use and Disclosure of Protected Health Information for Research**

The Legal Work Group recognized that there were additional requirements needed to use PHI for research activities. The Legal Work Group developed an authorization form to specifically allow a patient to allow the use and disclosure of PHI for research activities.

Stakeholder comments regarding the drafts were the focus of the work group's November 14 meeting. One of the main concerns was whether the wording of the forms would imply that mandated public health reports required patient consent prior to the release of PHI. It was agreed to revise the documents to clarify that PHI could be sent for mandated public health purposes without approval.

The work group then discussed the dissemination plan for sending the forms to providers. There was some debate as to whether the forms would be of use to providers. As written, the forms focused on the sharing of health information by a state-level HIE that has yet to be created. Currently, any HIE activity that is occurring in Illinois involves hospitals and their medical staffs. It was agreed to modify the forms so they can be of use by any providers participating in an HIE function. Members also advocated the development of a guidance document to explain their use to providers. It was also made clear that these forms were not a mandate, but models to be incorporated as appropriate within the provider's current practices.

There will be additional discussion of the dissemination plan at the Legal Work Group's December meeting. They will also vote on the final version of the forms that will be disseminated to providers.

### **Remaining Tasks**

Phase 2 of the project wraps up in December with the finalization of the work group deliverables. The Privacy and Security Work group will act on a final version of the "Recommendations on Privacy and Security Policies" document. After review by the Steering Committee at its December 17 meeting, this document will be shared with the interagency committee formed by Governor Blagojevich to move HIE forward in Illinois.

The Legal Work Group will be finalizing the notice, consent and authorization forms it has developed. It will then discuss and approve a plan for disseminating the forms to healthcare providers and to encourage their use.

The Steering Committee will review the Legal Work Group's forms as well as the dissemination plan. Upon approval, staff from the Illinois Public Health Institute will distribute the forms as outlined in the plan.



## ***Impact Analysis***

HISPC-Illinois has played an important role in addressing privacy and security issues relating to HIE. The legislatively mandated HIE study group, the EHR Taskforce, deferred to HISPC on privacy and security issues. The taskforce and HISPC-Illinois also shared a core group of members to maintain a link between the efforts of the two entities.

While the EHR Taskforce was laying out a blueprint for the development of a state-level HIE, HISPC-Illinois was identifying privacy and security challenges facing that effort. In its November 2006 “Interim Assessment of Variations Report,” HISPC-Illinois noted the following:

If the public does not feel its health information is safe and kept confidential, the movement towards HIE will be hampered at best and most likely impeded completely, no matter how great the possibilities are to improve quality of health care in the state.<sup>4</sup>

The variations report also noted an issue with the “wide-range” of different interpretations of HIPAA and its impact on HIE.

A public education program was one of the early solutions proposed by HISPC-Illinois work groups in the “Interim Analysis of Solutions Report” that was issued on January 16, 2007. It also figured prominently in the April 15, 2007 “State Implementation Plan – Illinois.”

To support the process of defining solutions, HISPC convened focus groups to gather consumer views on privacy and security issues, and HIE in general. While participants overwhelmingly supported having their records on an EHR system, there were concerns regarding privacy and security. Focus group feedback confirmed that to obtain consumer buy-in and comfort with an HIE process, consumers need assurances about the safeguards that will be put in place by the HIE governance structure.

Some of the questions about HIE that came up during the focus groups include:

- Who will have access to the health information?
- Will consumers be allowed to authorize and control access to their health information?
- Will consumers, at some point, be allowed to access their own health information records?<sup>5</sup>

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<sup>4</sup> HISPC-Illinois, “Interim Assessment of Variations Report,” p. 41, November 6, 2006, <http://www.idph.state.il.us/hispc2/phase1/IAVR.pdf>

<sup>5</sup> HISPC-Illinois, “State Implementation Plan – Illinois,” p. 115, April 15, 2007, <http://www.idph.state.il.us/hispc2/phase1/FIP.pdf>

Participant feedback also pointed to “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.”<sup>6</sup>

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.

Supported by the findings of the focus group, consumer education was one of the major solutions advocated by the HISPC-Illinois project. As HISPC moved into the implementation phase – phase 2, it was determined that a consumer education initiative would be premature given that the state-level HIE recommended by the EHR Taskforce and supported by the HISPC-Illinois project is still in the developmental stage.

In planning for phase 2, it was important to focus on efforts that would support the development of a state-level HIE and address issues of concern that consumers/patients have regarding the use and safety of their personal health information. It was agreed that this would best be accomplished by Involving stakeholders in providing guidance to the governance structure of the state-level HIE on privacy and security policies, and by developing a model consent form for the release of patient health information to an HIE.

The work groups of HISPC-Illinois II have made significant progress in completing the proposed deliverables. During the initial meeting of the Legal Work Group, it was determined that a single “model uniform consent form” would not work. The work group took the approach that three forms would be required. One form would be an informational notice informing patients that their PHI would be sent to an HIE. Another would be a consent form for the release of special categories of health information covered under state and federal law. The final form is an authorization form patients would sign to all the use of PHI by researchers – if research using personal identifiers is one of the permissible uses determined by the HIE governance structure.

The Legal Work Group is on target to complete these forms and adopt a plan to disseminate them to healthcare providers for their use.

Establishing a framework for the privacy and security policies of the state-level HIE is the task of the Privacy and Security Work Group.

The proposed “Recommendations on Privacy and Security Policies” document sets out recommendations for 12 focus areas that the work group felt the governance structure of the state-level HIE needed to address. These focus areas range from the privacy

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<sup>6</sup> HISPC-Illinois, “State Implementation Plan – Illinois,” p. 105, April 15, 2007, <http://www.idph.state.il.us/hispc2/phase1/FIP.pdf>

and security philosophy of the organization to remedies that may be imposed for privacy and security breaches.

Most importantly for consumer confidence in the state-level HIE, the current draft of the document contains a patient rights section to address patient privacy and security concerns expressed by participants of the focus groups convened by HISPC-Illinois.

The Privacy and Security Work Group and the Steering Committee will adopt the final version of the “Recommendations on Privacy and Security Policies” document in December.

Phase 2 of HISPC-Illinois wraps up with the state being better prepared to deal with HIE privacy and security issues. Because of the HISPC project, stakeholders have become more engaged in addressing privacy and security issues. The project has also brought a broad spectrum of stakeholders together to address barriers to HIE in Illinois. HISPC has also been instrumental in sharing the lessons learned by other states.

## ***Future Vision***

As the HIE implementation efforts continue, the state will be better prepared to address one of the remaining challenges identified during phase 1 of HISPC-Illinois – that challenge being the need to educate consumers regarding privacy and security issues. That mission will be taken up by stakeholders who participated in HISPC-Illinois as the structure of the state-level HIE takes shape.

### **Intrastate and Interstate Consent Strategy Collaborative**

Phase 2 of HISPC facilitated cooperative efforts by states to work on privacy and security challenges to HIE. A number of these “collaboratives” were created dealing with issue such as data standards and provider and consumer education. States joined these collaboratives to address needs and those needs naturally differed among the states based upon their level of HIE development. The immediate goal of each group was to develop a funding proposal for a 2008 project that addresses an identified challenge.

HISPC-Illinois II joined the “Intrastate and Interstate Consent Strategy Collaborative” because it complements the project’s current effort to address patient consent issues for release of information to an HIE. If federal funding is awarded, this collaborative proposes to study and evaluate various consent approaches and processes for obtaining patient permission to share PHI and to develop recommendations and tools for states to adopt to address barriers to intrastate and interstate exchange of PHI.

With respect to intrastate consent issues, the collaborative’s goal is to identify model approaches to consent and then ask pertinent work groups in participating states to assess them by using two “use cases” to identify benefits and risks of each approach. Illinois’ primary role in this process will be to share information on lessons learned during the HISPC-Illinois II project to address the patient consent issues.

In addressing interstate consent issues, the collaborative will explore the viability of several statutory options that states could adopt by legislative action to resolve conflicts between state laws and regulations governing the exchange of PHI between states with conflicting laws governing consent. The HISPC-Illinois II Steering Committee and Legal Work Group will be asked to provide guidance on the proposed solutions and to analyze the potential solutions using an assessment tool developed by staff.

# **Appendix I**

## **HISPC – Illinois II Steering Committee**

## Steering Committee

### Purpose

The HISPC-Illinois Steering Committee will provide oversight and direction for the project. It will set the direction, monitor progress, solicit work group members and approve deliverables to ensure success of the project.

### Steering Committee Members

Member	Organization
David Carvalho	Illinois Department of Public Health
Patrick Gallagher	Illinois State Medical Society
Steven Glass	Access Community Health Network
Carolyn Guthman	Consumer, AARP
William Kempiners	Consultant
Louis Lazovsky	Midwest Business Group on Health, Vice President of Human Resources for the Jewish Federation of Metropolitan Chicago
Patricia Merryweather	Illinois Hospital Association
Randy Mound	SUPERVALU
Nancy Semerdjian, RN, MBA, FACHE	Evanston Northwestern Healthcare
Joyce Sensmeier	HIMSS

### Project Team

Stephanie Rizk, M.S.	RTI International Contact
Jeff W. Johnson	HISPC-Illinois Project Director
Elissa Bassler	Executive Director, Illinois Public Health Institute
Kathy Karsten	Program Associate, Illinois Public Health Institute

### Goals of the Committee

#### The HISPC-Illinois Steering Committee will strive to:

- Review, evaluate and analyze and approve contract deliverables produced by the working groups to ensure they are of the highest possible quality and truly reflects Illinois' current state and future needs relative to privacy and security of health information
- Provide organizational resources to help staff the working groups that will develop the contract deliverables

- Seek input and/or representation from as many stakeholder areas as possible in the creation and review of work resulting from HISPC activities
- Review progress and results of the project plan
- Identify opportunities for improvement
- Have members serve as a liaison between the Steering Committee and their organization/area of expertise, communicating HISPC activities to constituencies and soliciting their feedback

## **Time Frames**

The Steering Committee is expected to meet at least three times between August and December of 2007.

## **Ground Rules**

### **The Steering Committee will operate in the following manner:**

- A majority of the members on the committee shall constitute a quorum to have an official meeting.
- Consensus is the goal for approval of deliverables and committee recommendations.
- An agenda will be sent to members at least one week prior to scheduled meetings.
- Member suggestions for agenda items need to be sent to the project director no later than the two weeks prior to the scheduled meeting date.
- If a committee member cannot make a meeting, the member is encouraged to make every effort to find a replacement from your organization.
- Minutes will be taken by staff from the project team.
- Meeting times will be no longer than two hours unless special circumstances require extended time.
- Each member is expected to keep his/her constituent organization(s) updated on HISPC activities.

# **Appendix II**

## **HISPC – Illinois II Privacy and Security Work Group**



## Privacy and Security Work Group

### Purpose

In the next few years, Illinois will be focused on creating a state-level HIE that will connect the Nationwide Health Information Network (NHIN) with local/regional HIEs and health care providers.

“To participate in the NHIN, an organization will be required to use a shared architecture, adhere to adopted standards and provide certain core services. ... An NHIN health information exchange (NHIE) will be one that that implements the NHIN architecture (services, standards and requirements), processes and procedures and participates in the NHIN Cooperative.”

Adopting privacy and security policies that will satisfy national requirements and provide assurances to Illinois residents regarding the safety of their personal health information will be a major task during the development of the state-level HIE. In the spirit of the public-private partnership that came together during the work of the Electronic Health Records Taskforce, the purpose of the Privacy and Security Work Group is to help facilitate this task by developing draft privacy and security policies and recommendations for consideration by the state-level HIE governance structure.

### Work Group Members

Member	Organization
Ellen Brull, M.D.	Illinois Academy of Family Physicians
Julie Bryant	Director, Information Services and Medical Records Northwestern Memorial Hospital
Dan Budny	Capitol Community Health Center
Rafael C. Diaz	Chief Information Security Officer, CMS
Patrick Gallagher	Illinois State Medical Society
Carolyn Guthman	Consumer, AARP
Casey Kozlowski, RPh, MBA	Manager, Automation & Technology Development, Walgreens Co.
Louis Lazovsky	Midwest Business Group on Health, Vice President of Human Resources for the Jewish Federation of Metropolitan Chicago
Anne Mahalik, MPA, RHIA, FAHIMA	Illinois Department of Human Services, Director Health Informatics
Robert G. Nadolski	Chief Information Officer The Alden Network/LTC
Ted Nodzenski	Illinois Hospital Association

<b>Member</b>	<b>Organization</b>
Fred Rachman, M.D.	Chief Medical Officer, Chief Executive Officer Alliance of Chicago Community Health Services
Joyce Sensmeier	HIMSS
Nadine Zabierek	Blue Cross Blue Shield
Chase Zaputil	Manager of Pharmacy Systems, Supervalu

## **Project Team**

Stephanie Rizk, M.S.	RTI International Contact
Jeff W. Johnson	HISPC-Illinois Project Director
Elissa Bassler	Executive Director, Illinois Public Health Institute
Kathy Karsten	Program Associate, Illinois Public Health Institute

## **Goals of Work Group**

### **The Privacy and Security Work Group is responsible for:**

- Develop an outline of privacy and security issues to be included in the “Draft Policies and Recommendations document.”
- Prepare a draft of the “Draft Policies and Recommendations document” for review by stakeholders.
- Finalize the “Draft Policies and Recommendations document.”

## **Time Frames**

The Privacy and Security Work Group is expected to meet five times between August and December of 2007.

## **Ground Rules**

### **The work group will operate in the following manner:**

- A majority of the members on the work group shall constitute a quorum to have an official meeting.
- Consensus is the goal for approval of deliverables and work group recommendations.
- An agenda will be sent to members at least one week prior to scheduled meetings.

- Member suggestions for agenda items need to be sent to the project director no later than the two weeks prior to the scheduled meeting date.
- If a work group member cannot make a meeting, the member is encouraged to make every effort to find a replacement from your organization.
- Minutes will be taken by staff from the project team.
- Meeting times will be no longer than two hours unless special circumstances require extended time.
- Each member is expected to keep his/her constituent organization(s) updated on HISPC activities.

# **Appendix III**

## **HISPC – Illinois II Legal Work Group**

## Legal Work Group

### Purpose

The promise of electronic health records (EHR) and health information exchange (HIE) is to enhance the quality of health care provided to patients. Patient support is essential for this to become an effective tool. To receive this support, patients must be adequately informed as to the potential use of their health records and be assured of the privacy and security of that data.

The optimal goal is to provide all patients in Illinois with the same information regarding privacy protections under the law and the necessary education to understand how their records will be safeguarded in an EHR/HIE environment. To address this goal, the task for the Legal Work Group is to develop a model uniform patient EHR/HIE consent form for possible use by the state-level HIE, clinicians, health care facilities and other providers. The Legal Work Group is also tasked with the development of a plan to disseminate the consent form and encourage its use.

### Work Group Members

Member	Organization
Matt Angela	COMP data, IHA
Rob Connor, J. D.	Deputy General Counsel, Illinois Department of Human Services
Steven Glass	Access Community Health Network
Robert John Kane, J. D.	Illinois State Medical Society
Anne Mahalik, MPA, RHIA, FAHIMA	Director Health Informatics, Illinois Department of Human Services
Michael A. Murer, J. D.	Executive Vice President and General Counsel, Murer Consultants, Inc.
Maria Pekar, J. D.	Loyola University Health System
Doug Polk, J. D.	Attorney, IHA
Frank Sears	Vice President, Information Technology, Southern Illinois Healthcare
Nancy Shalowitz, J. D.	Illinois Department of Healthcare and Family Services
Charles Sheets, J. D.	Foley and Lardner
Joel Shoolin, DO	Family Practice Medicine
Mary-Lisa Sullivan, J. D.	Acting General Counsel, Illinois Department of Human Services
Marilyn Thomas, J. D.	Chief Counsel, Illinois Department of Public Health
Darryl Vandervort	Katherine Shaw Bethea Hospital

## Project Team

Stephanie Rizk, M.S.	RTI International Contact
Jeff W. Johnson	HISPC-Illinois Project Director
Elissa Bassler	Executive Director, Illinois Public Health Institute
Kathy Karsten	Program Associate, Illinois Public Health Institute
Laura Keidan Martin, Partner, Katten Muchin Rosenman LLP	Legal Contractor
Brian D. Annulis, Katten Muchin Rosenman LLP	Legal Contractor

## Goals of Work Group

### The Legal Work Group is responsible for:

- Creating an outline of the issues to be addressed in the “Model Uniform Patient EHR/HIE Consent Form.”
- Preparing a draft “Model Uniform Patient EHR/HIE Consent Form” for review by stakeholders.
- Adopting a “Model Uniform Patient EHR/HIE Consent Form.”
- Preparing a plan that will address the dissemination of the “Model Uniform Patient EHR/HIE Consent Form” to health care providers and to encourage its use by those providers.

## Time Frames

The Legal Work Group is expected to meet five times between August and December of 2007.

## Ground Rules

### The work group will operate in the following manner:

- A majority of the members on the work group shall constitute a quorum to have an official meeting.
- Consensus is the goal for approval of deliverables and work group recommendations.

- An agenda will be sent to members at least one week prior to scheduled meetings.
- Member suggestions for agenda items need to be sent to the project director no later than the two weeks prior to the scheduled meeting date.
- If a work group member cannot make a meeting, the member is encouraged to make every effort to find a replacement from your organization.
- Minutes will be taken by staff from the project team.
- Meeting times will be no longer than two hours unless special circumstances require extended time.
- Each member is expected to keep his/her constituent organization(s) updated on HISPC activities.

# **Appendix IV**

## **Recommendations on Privacy and Security Policies**



## **RECOMMENDATIONS ON PRIVACY AND SECURITY POLICIES**

### **For Consideration by the Governance Structure of an Illinois State-Level Health Information Exchange**

The public-private partnership that came together during the work of the Electronic Health Records Taskforce (EHRT)<sup>7</sup> is intent on facilitating the creation of a state-level health information exchange (HIE) by providing recommendations on privacy and security policies to its governance structure. The Health Information Security and Privacy Collaboration (HISPC) – Illinois II project (hereafter referred to as HISPC – Illinois II) has been developed to accomplish this task.

HISPC – Illinois II determined that three overarching principles shall form the basis for the privacy and security policies of a state-level HIE. These principles are:

- A state-level HIE shall meet all applicable federal and state privacy and security laws.
- Privacy and security policies of a state-level HIE shall be understandable and clearly explain to the public how health information is to be protected.
- The governance structure of a state-level HIE shall adopt privacy and security policies consistent with privacy and security standards promulgated by the Nationwide Health Information Network (NHIN).

The first principle is an obvious and easily stated guideline, however, the governance structure of a state-level HIE will have to filter through a myriad of interpretations as to how state and federal law privacy and security laws are to be applied to HIE.

Public support of HIE is essential for it to become an effective tool to improve health care. That support cannot be achieved if the public does not understand or trust how the state-level HIE will safeguard of personal health information.

One of the major functions of a state-level HIE will be to connect local/regional HIEs<sup>8</sup> and health care providers with the NHIN. “To participate in the NHIN, an organization will be required to

**Draft pending approval by the Privacy and Security Work Group and the HISPC-Illinois II Steering Committee**

<sup>7</sup> Created by 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. Schoenberg. Report issued December 27, 2006

<sup>8</sup> Frequently referred to as a Regional Health Information Exchange (RHIE), Regional Health Information Organization (RHIO) or Sub-network organization.

use a shared architecture, adhere to adopted standards and provide certain core services.”<sup>9</sup> Ensuring the state-level HIE’s privacy and security policies are consistent with the NHIN standards will be a major task facing the governance structure. Because the NHIN has yet to establish such standards, HISPC – Illinois II can only focus on general issues.

Following are the suggestions and recommendations of HISPC – Illinois II on privacy and security policies that shall be considered by the governance structure of a state-level HIE.

### ***I. – Privacy and Security Philosophy***

The governance structure of a state-level HIE shall include a statement regarding its privacy and security philosophy. This philosophy statement is the first opportunity for the exchange to express its commitment to protecting patient health information. Building a level of trust with the public and providers will begin with a strong and clear statement from the state-level HIE. It is also important for entities connecting to the state-level HIE to understand the seriousness with which they shall address privacy and security.

- The philosophy shall convey a strong commitment to protecting information, but shall not imply a guarantee.
- To promote the goal of building trust, the philosophy shall include a statement of commitment to patient education and assuring that patients are fully informed with regard to the HIE.
- The philosophy shall apply to all information within the HIE, not just health information.

### ***II. – Patient Rights with Respect to Information Privacy and Security***

The EHRT recommended that the state-level HIE use a federated model in the development of the exchange process. Under this model, with the possible exception of data needed for public health or other governmental purpose, patient records are not uploaded into a central repository or database maintained by the state-level HIE. Participating providers only upload those data elements needed by the state-level HIE for entry into a master patient index. When a legitimate request for patient health information is received, the state-level HIE will search the master patient index to identify all locations where the patient has data. It will then request electronic copies from providers holding the records and transmits the information to the requesting provider. In the context of this model, HISPC – Illinois II recommends the state-level HIE adopt the following:

- The state-level HIE governance structure shall post a notice on its Web site of the rights send patients have under law and the policies of the HIE regarding their personal health

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<sup>9</sup> Gartner, *Summary of the NHIN Prototype Architecture Contracts - A Report for the Office of the National Coordinator for Health IT*, May 31, 2007, page 4, [http://www.hhs.gov/healthit/healthnetwork/resources/summary\\_report\\_on\\_nhlin\\_Prototype\\_architectures.pdf](http://www.hhs.gov/healthit/healthnetwork/resources/summary_report_on_nhlin_Prototype_architectures.pdf)

information notice of their rights on a periodic and regular basis.

- A patient has the right to review their own health information contained in the HIE.
- Patients shall be informed of their rights with regard to mitigation in the event of a privacy or security breach.
- All participants in the state-level HIE shall guarantee that patients have the following rights.
  - ▶ A patient's personal health information shall only be released in accordance with state and federal law. Patients shall be informed of protections available under current law.
  - ▶ A patient has the right to request a restriction on the release of personal health information to the state-level HIE, except such information required to be reported under state or federal law.
  - ▶ The treatment of a patient shall not be conditioned on the release of the patient's personal health information.

### ***III. – Protection of Caregiver Information***

The information available through the state-level HIE should be used only for public health and patient care purposes. To encourage caregiver participation in the HIE, the state-level HIE should adopt practices, policies and procedures that limit the availability of HIE information exclusively to these purposes. Accordingly, the state-level HIE must adopt practices, policies and procedures that ensure the following:

- None of the HIE information made available to the public or a researcher may contain information identifying a patient or caregiver unless authorization has been given by the patient.
- HIE information shall not be available to anyone for use in any civil, criminal, or administrative proceeding against a caregiver.
- Under no circumstances shall the HIE disclose information to the public or a researcher that is confidential under Illinois Medical Studies Act.
- None of the HIE information shall be discoverable or admissible in any legal or administrative action for the purpose of establishing a standard of medical or health care practice.

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#### ***IV. – The Privileges and Obligations of Researchers***

The development of policies on researchers will require a better understanding of the architecture of the state-level health information exchange. At a minimum, HISPC – Illinois II recommends that these policies include:

- Defining “research” and “researcher.”
- Defining “de-identified” data.
- Whether When and how data that includes identifiers protected health information can be shared with made available to researchers and if so how that data will be shared a definition of “de-identified” data.
- Defining when a research request requires additional patients consent to sign an “Authorization for Use and Disclosure of Protected Health Information for Research.”<sup>10</sup>
- Requirements for how researchers shall protect the information in their custody.
- Defining researcher responsibilities to notify recipients of information of the protection requirements.
- The researchers’ expectation of accurate information. The policy for ensuring that researchers are made aware of the sources and the accuracy of information being provided shall be considered.
- Requirement relating to the disclosure of information resulting from the research.

#### ***V. – Retention and Destruction***

The state-level HIE shall adopt a retention and destruction policy consistent with state and federal law. The policy shall provide for preservation of the records during the migration to new technologies.

#### ***VI. – Information Privacy and Security Program***

The state-level HIE shall adopt policies describing the staff roles for a privacy and security program. This shall include responsibilities for the periodic review and maintenance of the information privacy and security policies.

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<sup>10</sup> Form recommended by the HISPC-IL Legal Work Group for use in obtaining a patient’s “authorization” for the use of protected health information.

- The approach to risk management shall be described in the policy
- The HIE shall have a staff position that is accountable for facilitating adherence to the privacy and security policies (e.g. privacy and security officer).

### ***VII. – Accountability and Responsibilities***

The state-level HIE shall define specific responsibilities and accountability for information privacy and security. These include:

- Who is responsible for oversight and monitoring of the program (see above).
- Who is responsible for reporting violations; at both the participant and state-level HIE levels.
- Who is responsible for imposing disciplinary measures on state-level HIE employees who violate privacy and security laws or policies.
- Who is responsible for imposing sanctions on participants for violations of privacy and security laws or policies.

### ***VIII. – Access to Information***

The state-level HIE shall define who has access to patient-specific information. These policies shall specify that access to the organization’s business recordspersonal health information will be based on assigned job responsibilities. These policies shall identify classes categories of information and specify who has access to information in specific classes of users.

### ***IX. – Records of Access***

For auditing and monitoring to assure information security, the state-level HIE shall maintain records/logs of who accesses patient information. The policies shall specify how long the access records shall be maintained.

### ***X. – Disaster Recovery/Business Resumption Plans***

The state-level HIE shall develop a policy for responding to disasters.

### ***XI. – Information Privacy and Security Awareness Training***

Policies shall be developed regarding information privacy and security awareness training for state-level HIE employees and participants.

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## ***XII. – Remedies***

The state-level HIE shall adopt policies on how privacy and security violations are to be remedied. To ensure the enforceability of these policies on participants in the HIE, the remedies need to be included in the participant agreements.

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# Appendix V

## Model Notice of Privacy Practices and Consent/Authorization Forms for Sharing Information with HIE

### **Notices of Privacy Practices Insert**

*To be used in conjunction with an Authorization to disclose “sensitive” health information. Presumes legal authority to otherwise disclose PHI for treatment, payment or health care operation purposes.*

[PROVIDER] also participates in a health information exchange (Exchange). The Exchange facilitates the electronic exchange of medical and other protected health information among health care providers that participate in the Exchange for patient treatment, payment and health care operation purposes. If applicable, add: “The Exchange does not house or store any data; rather, it merely facilitates exchange of data among participating health care providers.”

To the extent permitted by law, [PROVIDER] may disclose your protected health information to other health care providers who request that information, via the Exchange. In those cases where your specific consent or authorization is required to disclose health information to others, [PROVIDER] will not disclose that health information to other health care providers participating in the Exchange without first obtaining your written consent.

**Draft pending approval by the Legal Work Group and the HISPC-Illinois II Steering Committee**



## CONSENT FOR USE AND DISCLOSURE OF CERTAIN TYPES/CATEGORIES OF PROTECTED HEALTH INFORMATION

**PURPOSE AND INSTRUCTIONS:**

*The Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) and the HIPAA Privacy Rule authorize us to use and disclose your Protected Health Information, without your authorization or consent, for treatment, payment and health care operations activities. However, we do need your prior written consent in order to disclose certain categories/types of Protected Health Information under other state or federal laws. We will not deny you treatment or care if you refuse to sign this Consent, but we may not be able to share all of your relevant health information with other health care providers involved in your treatment and care. If you agree to allow us to disclose some or all of the requested Protected Health Information, please complete and sign this Consent.*

(Please Print Legibly)

Patient Name (Last, First, Middle)		Medical Record Number	
Street Address		SSN or other ID (Please indicate other by name)	
City	State	Zip Code	Telephone

I, \_\_\_\_\_ [Your Name], authorize  
 \_\_\_\_\_ (the “Provider”) to disclose the Protected Health Information  
 specified below to \_\_\_\_\_ [Identify recipient]

*[If the recipient is intended to be health care providers in the health information exchange, then insert the following language above—other health care providers, including but not limited other health care providers participating in the health information exchange (“Exchange”) who may request such information for treatment, payment and health care operation purposes. The Exchange facilitates the electronic exchange of medical and other individually identifiable health information among health care providers that participate in the Exchange for patient treatment, payment and health care operations].*

*[For use with the Exchange: I understand the purpose of the electronic disclosure of my medical and health information to other health care providers that participate in the Exchange is to facilitate my medical treatment (both primary and specialty care), arrange for payment for health care services provided to me and for other administrative purposes by the participants in the Exchange]. I understand the information to be disclosed includes the medical [and billing] records used to make decisions about me. For example, my record may include the following kinds of Protected Health Information:*

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- Demographic (name, age, address, etc.);
- Medical (diagnosis, treatment history, referrals to other providers, *etc.*); and,
- Encounter Data (description of services provided).

**EXCEPT AS OTHERWISE PERMITTED OR REQUIRED BY ILLINOIS LAW (E.G., FOR PUBLIC HEALTH REPORTING PURPOSES), YOU MUST INITIAL EACH OF THE FOLLOWING CATEGORIES/TYPES OF PROTECTED HEALTH INFORMATION THAT YOU AUTHORIZE US TO DISCLOSE FOR TREATMENT, PAYMENT AND HEALTH CARE OPERATION PURPOSES:**

- \_\_\_\_\_ Alcohol Treatment Records (please initial) (Your consent to disclose is valid for one (1) year from the date of date of this Consent)
- \_\_\_\_\_ Drug Abuse Treatment Records (please initial) (Your consent to disclose is valid for one (1) year from the date of date of this Consent)
- \_\_\_\_\_ Mental Health and Developmental Disability Treatment Records (please initial)(Your consent to disclose is valid for one (1) year from the date of date of this Consent)
- \_\_\_\_\_ HIV/Acquired Immune Deficiency Syndrome (AIDS) Records (please initial)
- \_\_\_\_\_ Hepatitis B or C Testing Records (please initial)
- \_\_\_\_\_ Genetic Testing Records (please initial)

**REVOCAION**

I understand that I may revoke this Consent, in whole or in part, by sending a written and dated notice to the Provider. Notice of your revocation of this Consent should be sent to:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Your revocation of this Consent will not affect any disclosures made prior to the acceptance of your revocation by Provider and you hereby acknowledge that Provider is released from any and all responsibility or liability for disclosure of the above information to the extent indicated and authorized by this Consent prior to Provider’s acceptance of its revocation.

**SIGNATURE OF PATIENT OR REPRESENTATIVE AUTHORIZED TO PERMIT DISCLOSURE**

I understand the purpose of the Network/Exchange and this Consent and agree to the disclosure of my medical and health information as set forth herein.

**Draft pending approval by the Legal Work Group and the HISPC-Illinois II Steering Committee**

---

Signature

Date

---

Authority of Personal Representative (if applicable): \_\_\_\_\_

Identify Verified by:  Photo ID,  Matching Signature,  Other, Specify  
\_\_\_\_\_

**YOU ARE ENTITLED TO A COPY OF THIS CONSENT AFTER YOU SIGN IT.**

**Draft pending approval by the Legal Work Group and the HISPC-Illinois II Steering Committee**

## AUTHORIZATION FOR USE AND DISCLOSURE OF PROTECTED HEALTH INFORMATION FOR RESEARCH

**PURPOSE AND INSTRUCTIONS:**

*The Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) and the HIPAA Privacy Rule authorize us to use and disclose your Protected Health Information, without your authorization or consent, for treatment, payment and health care operations activities. However, we do need your written authorization in order to use and disclose your Protected Health Information for research activities. We will not deny you treatment or care if you refuse to sign this Authorization, however, if you do not sign this Authorization you will not be able to participate in the research study described below. If you agree to allow us to use and disclose your Protected Health Information for research, please complete and sign this Authorization.*

(Please Print Legibly)

Patient Name (Last, First, Middle)		Medical Record Number	
Street Address		SSN or other ID (Please indicate other by name)	
City	State	Zip Code	Telephone

I, \_\_\_\_\_ [Your Name], authorize  
 \_\_\_\_\_ (the “Provider”) to use and to disclose the Protected Health  
 Information specified below to \_\_\_\_\_ [Identify recipient]

*[If the recipient is intended to be health care providers participating in the health information exchange, then insert the following language above—other health care providers, including but not limited other health care providers participating in the health information exchange (“Exchange”) who may request such information for research purposes and I hereby specifically authorize Provider to release my Protected Health Information to the Exchange and researchers for that purpose].*

**Protected Health Information to be Disclosed:** Specifically and meaningfully describe the Protected Health Information authorized to be disclosed for research:

---

My authorization to disclose Protected Health Information for research purposes specifically includes the disclosure of the following categories/types of Protected Health Information .  
**UNDER ILLINOIS LAW, YOU MUST INITIAL EACH OF THE FOLLOWING CATEGORIES/TYPES OF PROTECTED HEALTH INFORMATION THAT YOU AUTHORIZE US TO DISCLOSE FOR RESEARCH:**

**Draft pending approval by the Legal Work Group and the HISPC-Illinois II Steering Committee**

- \_\_\_\_\_ Alcohol Treatment Records (please initial) (Your authorization to disclose is valid for one (1) year from the date of date of this Authorization)
- \_\_\_\_\_ Drug Abuse Treatment Records (please initial) (Your authorization to disclose is valid for one (1) year from the date of date of this Authorization)
- \_\_\_\_\_ Mental Health and Developmental Disability Treatment Records (please initial) (Your authorization to disclose is valid for one (1) year from the date of date of this Authorization)
- \_\_\_\_\_ HIV/Acquired Immune Deficiency Syndrome (AIDS) Records (please initial)
- \_\_\_\_\_ Hepatitis B or C Testing Records (please initial)
- \_\_\_\_\_ Genetic Testing Records (please initial)

**EXPIRATION**

Except as otherwise specifically provided above, my authorization to use my Protected Health Information for research and to disclose my Protected health Information to other health care providers in the Network for research is valid for the for the time period between \_\_\_\_\_ (date) and \_\_\_\_\_ (date/event).

**RE-DISCLOSURE**

I understand that, except as otherwise specifically prohibited by Illinois or federal law, the Protected Health Information disclosed pursuant to this Authorization may be subject to re-disclosure by the recipient and may no longer be protected by the Health Insurance Portability and Accountability Act of 1996 or its implementing regulations. Participants in the Exchange, including Provider, are hereby released from any legal responsibility or liability for disclosure of the above information to the extent indicated and authorized herein.

**REVOCAION**

I understand that I may revoke this Authorization, in whole or in part, by sending a written and dated notice to the Provider. Notice of your revocation of this Authorization should be sent to:

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Your revocation of this Authorization will not apply to any uses and disclosures made prior to the acceptance of your revocation by Provider and you hereby acknowledge that Provider is released from any and all responsibility or liability for disclosure of the above information to the extent indicated and authorized by this Authorization prior to Provider’s acceptance of its revocation.

**Draft pending approval by the Legal Work Group and the HISPC-Illinois II Steering Committee**

SIGNATURE OF PATIENT OR REPRESENTATIVE AUTHORIZED TO PERMIT DISCLOSURE

I understand the purpose of this Authorization and agree to the disclosure of my medical and health information for research as set forth herein.

---

Signature

Date

---

Authority of Personal Representative (if applicable): \_\_\_\_\_

Identify Verified by:  Photo ID,  Matching Signature,  Other, Specify

---

**YOU ARE ENTITLED TO A COPY OF THIS AUTHORIZATION AFTER YOU SIGN IT.**

**Draft pending approval by the Legal Work Group and the HISPC-Illinois II Steering Committee**