



Data Security & Privacy Committee Minutes

July 27, 2012 / 9:30 AM – 12:30 PM

The Data Security and Privacy Committee (“Committee”) of the Board of Directors (“Board”) of the Illinois Health Information Exchange Authority (“Authority”), pursuant to notice duly given, held a meeting at 11 a.m. on July 27, 2012, at the Thompson Center, 100 W Randolph, Chicago IL; the Stratton Building, 401 S. Spring St., Springfield, IL; with a telephone conference call and webinar participation capabilities.

<p>Appointed Committee Members Present in person:</p> <ol style="list-style-type: none"> 1. Leah Bartelt 2. David Carvalho 3. Jud DeLoss 4. Nicholas Panomitros 5. Harry Rhodes 6. William Spence 	<p>OHIT Staff Present: Igor Brusil; Mark Chudzinski; Krysta Heaney; Mary McGinnis; Sarah Nelson; John Saran; Cory Verblen; Laura Zaremba</p> <p>Invited Guest: Sonia Desai Bhagwakar</p>
<p>Appointed Committee Members Present electronically:</p> <ol style="list-style-type: none"> 1. Jennifer Creasey 2. Carl Gunter 3. Ron Isbell 4. Pat Merryweather 5. Tiefu Shen 	

Call to Order and Roll Call

Mark Chudzinski, Secretary of the Authority and General Counsel of the Office of Health Information Technology (“OHIT”), welcomed the appointed Committee members present in person and electronically, and confirmed the presence of the Committee members noted above. There were no objections from the members of the Committee to the participation by electronic means of Jennifer Creasey, Carl Gunter, Ron Isbell, Pat Merryweather, and Tiefu Shen who had advised the Secretary in advance of their attendance by electronic means necessitated by business or employment purposes.

Behavioral Health Report – BHIP Preliminary Findings

Dia Cirillo Project Manager of the Behavioral Health Integration Project gave a power point presentation explaining the preliminary findings of the BHIP Provider Summits.

Ms. Cirillo explained what BHIP is, the role of the BHIP Provider Summits and an analysis of the data gathered from the Summits. The implications, limitations and next steps were summed up and detailed information about the presentation can be found by using the link below;



<http://www2.illinois.gov/gov/HIE/Documents/v3%20DSPCBHIP%20Prelim%20Summit%20Findings%207.27.12.pdf>

Substance Abuse Legal Work Group Report

John Saran a legal intern for OHIT presented a power point summing up the Substance Abuse Legal Work Group's purpose and progress thus far.

The Work Group's purpose is to remove barriers to the exchange of sensitive information between Illinois substance abuse providers and physical health providers through the ILHIE.

This will be done using the 15 points:

1. Promote change at the federal level = Congress
2. Institute Safeguards and Penalties -AODADA
3. Broadly construe medical emergency exception in HIE legislation
4. Create an alert system
5. Develop a standard consent form
6. Rewrite the IMHDDCA
7. Use "Upon My Death" as Expiration Event or Condition -IMHDDCA
8. Inclusion of comprehensive list of disclosure purposes -IMHDDCA
9. Preserve stringent court orders
10. Limit Use of Information in Criminal and Civil Investigations
11. 11-13 Meaningful use incentive payment changes
14. Expand HIT incentives to Behavioral Health
15. Institute administrative and technical safeguards

Statutory Changes Preview:

AODADA: Recommendation 2

- Increased safeguards against discrimination, criminal/civil penalties, civil right of action and limited use of records in civil/criminal proceedings

IMHDDCA:

- Elimination of: (Recommendation 6)
 - a) requirements of patients to specify a calendar date as the expiration date of their consent, as opposed to an event such as "upon my death" as recommended by SAMHSA;
 - b) requirement that, in addition to the patient, a witness must also sign the consent;
 - c) requirement that, in addition to the patient, a witness must also sign a revocation, and that any revocation must be in writing;
 - d) ambiguity with respect to blanket consents in that the meaning of "unspecified information" is unclear; and
 - e) contains strict provisions with respect to advance directives.

Link to the power point

http://www2.illinois.gov/gov/HIE/Documents/16_Substance%20Abuse%20update%20DPS-7%2027%2012%20%282%29.pdf

Genetic Testing Work Group Report



Igor A. Brusil a legal intern for OHIT presented a power point summing up the Genetic Testing Legal Work Group's progress.

Mr. Brusil informed the Committee of the Work Group's main goals:

1. Retain protection of privacy of genetic information.
2. Allow health care providers access to genetic information to facilitate healthcare.
3. Retain consistency with Federal health information privacy law (HIPAA) and Federal Genetic Information Non-Discrimination Act (GINA).
4. Ensure practicality of implementation of the Illinois Health Information Exchange in light of the Illinois Genetic Privacy Act (GIPA).

Mr. Brusil then explained the GIPA issues that need to be resolved:

1. Clarify the scope of genetic information that is subject to GIPA.
2. Clarify rules for lawful disclosure of genetic information that is subject to GIPA (i.e. initial transmission of information to ILHIE).
3. Clarify rules for lawful re-disclosure of genetic information that is subject to GIPA (i.e. further transmission of information from ILHIE).
4. Underscore the need for state-wide uniformity of rules governing protection of genetic information that is subject to GIPA (i.e. home rule).

Link to the Genetic Testing Power Point;

http://www2.illinois.gov/gov/HIE/Documents/17_Genetic%20Testing%20Presentation%20Brusil.pdf

AIDS Confidentiality Act Report

Sonia Desai Bhagwakar, JD, presented a power point regarding the AIDS Confidentiality Act findings by the HIV/AIDS Legal Task Force Work Group. A description of the Act was given followed by a summation of the issues regarding the Act.

Issues:

- **Definition of test results**: results of a lab test or any record that is indicative of positive test results?
- **Designated recipient**: "Any person designated..." Can an HIE or HIE participants generally be designated.
- **Time-limited**: Amended rules eliminate specificity requirement but add durational requirement.
- **Ambiguity of treatment exception**: the Act permits disclosure to persons engaged in the patient's treatment
- **No express authorization for transmittal /disclosure to an HIE**: Revised regulations allow for HIV test results to be "transmitted in a confidential manner in an electronic medical record system, medical record or confidential fax."
- **No re-disclosure without consent or meeting an exception**
- **No medical emergency treatment exception**

It was then noted that Approximately 20 states have statutes that allow disclosure of HIV/AIDS data for purposes of treatment without consent and, approximately 25 states have a medical emergency exception.

Link to the AIDS Confidentiality Act Report;

http://www2.illinois.gov/gov/HIE/Documents/18_AIDS%20Confidentiality%20Act%20presentation.pdf



Public Testimony

Dr. David B. Graham, CIO Memorial Health System, Lincoln Land HIE stated that patient safety and improved quality of healthcare must be the primary objectives of our work. Dr. Graham addressed the following issues: HIPAA Treatment, Payment and Operations; Consent Policies and Meaningful Choice; Patient Access to and alteration of Data; and State-level unique identifier.

Dr. Tom Mikkelson, COO & Vice President for Medical Affairs, Touchette Regional Hospital, addressed four areas: technical limitations on sequestering sensitive data for transmission through an HIE, limits on disclosure of sensitive data and the impact on patient safety for emergency treatment and on coordination of care between multiple physicians in the care team, implications of meaningful choice and clinic workflows, and coordination of care with out-of-state healthcare providers.

Dr. Mikkelson gave a detailed testimony explaining his concerns about the limitations of the technology, the difficulties of accurately prescribing medication with limited medical history access, and areas of patient issues in regards to HIE.

Link to Dr. Mikkelson's testimony;

http://www2.illinois.gov/gov/HIE/Documents/4_Testimony_Mikkelson_v4_FINAL.pdf

Dr. Fred Rachman, The Alliance of Community Health Services, stated that HIE is seen as essential to improving their support of continuity of care, facilitate transitions and more cost effectively manage care across settings such as subspecialty, diagnostic, emergency and hospital services.

Dr. Rachman also stated that sharing information must be balanced with concern over unintended consequences through sharing of information in ways that can needlessly violate privacy, impair the sense of safety of disclosures within the context of healthcare provider/patient relationship, or lead to negative consequences.

Dr. Rachman believes that strategies and policies must be in place to protect the privacy and safety of protected health information, and that there should be clear consequences for violations.

He stated that it is also crucial that the office of HIT (OHIT) continue to work with the legislature to harmonize the current laws and rules regarding the exchange of this sensitive information, as these uncoordinated standards can lead to unwarranted gaps in critical information needed by caregivers to provide the most optimal and safe care.

Link to Dr. Rachman's testimony;

http://www2.illinois.gov/gov/HIE/Documents/5_HIE%20Testimony_Alliance%20of%20Chicago%20Community%20Health%20Services_2012%207%2021.pdf

Esther Sciammarella, Chicago Hispanic Health Coalition, stated that each patient should be assigned a unique patient identifier so that a patient's ILHIE record contains a complete record of a patient's medical background, including mental health (medications), substance abuse history, or HIV/AIDS. This unique identifier should comply with existing HIPAA (and other consumer privacy regulations') provisions and regulations.



All patients should have access to their ILHIE records because proper patient identification (race, ethnicity, gender, residence location, etc.) will be required to make meaningful and effective population-based medical decisions.

A patient should be able to allow the sharing of her-his health information to facilitate coordinated care. The ILHIE medical record should be available to the patient in his/her preferred language if needed. This will allow a patient the opportunity to amend or correct medical errors contained in the ILHIE record. In the event that the ILHIE medical record cannot be translated in a timely manner, it is important to have certified medical translators available to assist the patient in maintaining accurate medical information in the ILHIE records.

Link to Esther Sciammarella's testimony;

http://www2.illinois.gov/gov/HIE/Documents/6_CHHC_HealthCarerecords%20%28%29%20ES%207-2012.pdf

Harry Rhodes, HM Solutions, provided testimony outlining a patient's "Meaningful Choice" and what that means, what the current HIPPA privacy law permits and explaining and illuminating the various consent models in discussion Opt-in, Opt –in with restrictions, Opt-out, and Opt-out with exceptions. Mr. Rhodes also spoke of the steps that need to be taken to insure a "preferred future" in HIE, which involves addressing several key questions or barriers which are explained in Mr. Rhodes power point.

Link to Harry Rhodes testimony;

http://www2.illinois.gov/gov/HIE/Documents/7_Rhodes_July%2027%202012%20Invited%20Public%20Comment_FINAL.pdf

Link to Harry Rhode's Power Point;

http://www2.illinois.gov/gov/HIE/Documents/Invited_testimony_2012_july_27_HR.pdf

Ed Murphy, Director, Central Illinois Health Information Exchange (CIHIE) - Mr. Murphy's testimony was focused primarily on ethical issues, followed by economy, efficiency, and effectiveness regarding privacy, security and consent management. He spoke from the consumer's perspective.

Mr. Murphy stated that patients should have a choice whether their information be in the HIE or not, and strongly supports the Opt-out model.

He does not support "Breaking the Glass" for emergency medical treatment because the patient chose not to have their information shared.

Mr. Murphy also feels that patients having access to their data which is shared in the HIE is a "patient-provider" issue.

Adding HIE to the Notice of Privacy Practices including how to opt-out should be easy to integrate.

Consent should be valid indefinitely, unless superseded by a revised valid consent.

Mr. Murphy supports the use of de-identified, large population data for epidemiological studies.

Link to Ed Murphy's testimony;

http://www2.illinois.gov/gov/HIE/Documents/9_Consumer%20Testimony%20%28Ed%20Murphy%29.pdf

Dr. David Trachtenberg, (CIHIE) spoke from a physician's viewpoint. **He surmised that these were the key considerations regarding safety and privacy:**

- Comply with current standards for patient confidentiality.



- Support quality patient care.
- Laws that are easy to follow.
- Fair for patients and clinicians.

Dr. Trachtenbarg also spoke about patient choice, permitted uses for patient data, granularity of patient data, sensitivity toward patient data and safeguards for certain personal health information.

Dr. Trachtenbarg also shared ways of fostering public trust in HIEs by enforcement and mitigation properties and a potential framework for patient/clinician collaboration.

Link to Dr. Trachtenbarg's testimony;

http://www2.illinois.gov/gov/HIE/Documents/10_Physician%20Testimony%20-%20revised%20%28Doctor%20Trachtenbarg%29.pdf

Cynthia Bracy, Director for Advocacy, Illinois Health Information Management Association (ILHIMA), explained how Illinois state law prohibits the successful implementation of a comprehensive, Nationwide health information exchange to ensure complete patient medical history that is accessible across organization and state boundaries.

A streamlined patient consent model in Illinois will help achieve the full potential of the health information exchange. She asked the committee to take ILHIMA membership concerns to congress to change Illinois state law and support a comprehensive statewide health information exchange and, ultimately, a comprehensive nationwide health information exchange.

Link to Cynthia Bracy's testimony;

http://www2.illinois.gov/gov/HIE/Documents/11_Invited%20Testimony_Cynthia%20Bracy_ILHIMA_CB.pdf

Pat Schou, Director, Illinois Critical Access Hospital Network addressed the barriers critical access hospitals are having in connection with revising and developing new policies to meet the HIPPA requirements.

The critical access hospitals expect the security compliance standards for health information exchange to be used in Illinois to meet the requirements of the Office of the National Coordinator for Health Information Technology and the Office of Civil Rights at a minimum.

The critical access hospitals fully intend to achieve the new requirements, but because of the limited financial and personnel resources and the delayed ability of some EHR vendors to meet service needs of their clients, determining a timeline will definitely be a barrier to most.

Link to Pat Schou's testimony;

http://www2.illinois.gov/gov/HIE/Documents/14_IL_HIE_comments_icahn_july_2012.pdf

Adjourn

Submitted by:

Saro Loucks