

**MINUTES OF THE FEBRUARY 8, 2012, MEETING  
OF THE DATA SECURITY AND PRIVACY COMMITTEE OF THE  
ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY**

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 2:15 p.m. on February 8, 2012, at the offices of McDermott Will & Emery, 227 West Monroe Street, in Chicago, IL 60606, with a telephone conference call and webinar participation capabilities.

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| <p><u>Appointed Committee Members Present in person:</u></p> <ol style="list-style-type: none"> <li>1. Jim Anfield</li> <li>2. Elissa J. Bassler</li> <li>3. David Carvalho</li> <li>4. Ron Isbell</li> <li>5. Edward Mensah</li> <li>6. Pat Merryweather</li> <li>7. Nicholas Panomitros</li> <li>8. Harry Rhodes</li> <li>9. William Spence</li> </ol> | <p><u>OHIT Staff Present:</u><br/>                 Laura Zaremba; Mark Chudzinski; Sunil Cherian; Robert Crane; Krysta Heaney; Danny Kopelson; Saroni Lasker; Mary McGinnis; Cory Verblen</p> <p><u>Invited Guests (Legal Task Force):</u> Bernadette Broccolo; Laurel Fleming; Mary Lucie; Renee Popovits; Wendy Rubas; Maia Thiagarajan</p> |
| <p><u>Appointed Committee Members Present electronically:</u></p> <ol style="list-style-type: none"> <li>1. Jud DeLoss</li> <li>2. Carl Gunter</li> <li>3. David Holland</li> <li>4. Tiefu Shen</li> <li>5. Timothy Zoph</li> </ol>  | <p><u>Invited Guests present by phone (InterSystems Corp.):</u> Verena Chan; So Ling Chiu</p> <p><u>OHIT Staff Present electronically:</u><br/>                 Diego Estrella</p>  |

*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 Jud DeLoss, Carl Gunter, David Holland, Tiefu Shen and Timothy Zoph who had advised the Secretary in advance of their attendance by electronic means necessitated by business or employment purposes.

*Introduction by Laura Zaremba, ILHIE Authority Acting Executive Director*

Laura Zaremba, Acting Executive Director of the Authority, welcomed the appointed Committee members and on behalf of the Authority thanked them for their volunteer service to the State of Illinois and the Authority. The privacy and security of patient health data raises important policy issues to be addressed by Authority, in connection with its development and implementation of a

state-wide Health Information Exchange (ILHIE). The policy recommendations which the Committee will present to the Authority will be significant in advancing the implementation of the ILHIE and the ultimate goal of achieving better health outcomes for the people of Illinois. The ILHIE also aims to control the cost of health care and enhance value for patients and payers, maximize federal health information technology funding to Illinois and its health care providers, enhance public health and disease surveillance, and reduce disparities.

*Proposed Committee Work Plan and Schedule*

Dr. Nicholas Panomitros, DDS, MA, JD, LLM, a member of the Authority Board and appointed by the Board to chair the Committee, welcomed the assembled Committee members, and confirmed his appointment of the following individuals as members of the Committee:

- Jim Anfield – Senior Director Strategic Relationships, Blue Cross Blue Shield of Illinois
- Elissa J. Bassler – CEO, Illinois Public Health Institute; ILHIE Advisory Committee member
- David Carvalho – Deputy Director Policy Planning and Statistics, Illinois Department of Public Health; ILHIE Authority Board ex-officio member
- Jud DeLoss – Attorney in private practice; ILHIE Advisory Committee member
- Dr. Carl Gunter – Director, University of Illinois Strategic Healthcare IT Advanced Research Projects (SHARPS) on Security
- David Holland - VP/CIO, Southern Illinois Healthcare; ILHIE Authority Board member
- Ron Isbell – Manager Network Infrastructure Data Security & User Access, Children’s Memorial Hospital
- Dr. Edward Mensah – Program Director Public Health Informatics, University of Illinois at Chicago School of Public Health; ILHIE Authority Advisory Committee member
- Pat Merryweather – Executive Director, Illinois Foundation for Quality Healthcare (IFMC-IL); ILHIE Authority Advisory Committee member
- Harry Rhodes – Director Practice Leadership, American Health Information Management Association (AHIMA)
- Tiefu Shen – Chief Division of Epidemiologic Studies, Illinois Department of Public Health
- William Spence – CIO, Roseland Community Hospital
- Timothy Zoph – Senior Vice President, Administration / CIO, Northwestern Memorial HealthCare

Dr. Panomitros noted that the input of each member of the Committee is greatly valued and important, and each member brings to the Committee personal knowledge of different areas of relevant expertise. The primary focus of today’s meeting is informational, to bring to the whole Committee an overview of Illinois law relating to the privacy and security and of patient data, and an overview of the HIE technology that is being initially deployed for the State-level ILHIE in respect of data privacy, security and patient consent management.

To place the work of the Committee in context, Dr. Panomitros noted that the core services of the ILHIE will begin to be rolled-out this coming April, and that all of the initial core services should be available for use by the end of this calendar year. Also relevant to the timing of the

Committee's deliberations is the fact several sub-State HIEs, particularly in Central Illinois and in the Metro Chicago area, have initiated some limited services or are planning to shortly.

Alongside the accelerating technical implementation of the State-level ILHIE, is the organizational development of the ILHIE Authority, which plans to employ a full-time Executive Director in the near future, finalize a budget for FY2013 and hire other ILHIE staff. In addition, the State of Illinois has recently received an additional federal grant to explore how electronic records exchange can promote the greater integration of behavioral health treatment with medical treatment. As one of the principal topics to be addressed in that Behavioral Health Integration Project (BHIP) initiative is the identification of legal and policy barriers to the exchange of patient data, the work of that BHIP initiative will complement the work of this Committee.

Dr. Panomitros proposed that the Committee work towards the attainment of two goals:

- Goal 1: Formulate recommendation on ILHIE consent management policy: no consent vs. opt-in vs. opt-out
  - Recommendation on specific General Assembly statutory initiatives and Authority regulations
- Goal 2: Formulate recommendation on ILHIE initiatives to increase public trust
  - Identify elements of desired public education/outreach effort
  - Identify desired skills of Chief Privacy Officer to be hired
  - Identify elements of desired ILHIE security monitoring and auditing

Dr. Panomitros proposed the following milestones in the timeline of the Committee's work plan:

- Mid-March, State-wide electronic BHIP project "town hall meeting" to be organized by OHIT, with invitation to public for addressing issues with respect to Illinois laws and regulations regarding (1) behavioral health and (2) substance abuse
- April 11, Committee progress report to Authority Board
- April 16, request written report from OHIT & ILHIE Legal Task Force with respect to all Illinois laws and regulations regarding the development and implementation of the ILHIE, including specific text of proposed statutory and regulatory amendments
- May 3 or 4, at ILHIMA convention in Bloomington-Normal, IL, solicit additional testimony regarding specific Authority regulatory and General Assembly statutory initiatives
- Mid-May, request OHIT to submit recommendation regarding items in Authority budget for FY 2013 to promote public trust
- May 30, Committee deliberations regarding specific Authority regulatory and General Assembly statutory initiatives
- June 6, presentation of Committee's recommendation to Authority Board

#### *Overview of ILHIE Authority Charter and Committee Charter*

Mark Chudzinski provided an overview of the Authority's governance structure, the development of the ILHIE (including its core functions services), and the formation by the Board of the Authority of the Committee on December 1, 2011. The Act creating the Authority expressly notes the importance of protecting patient privacy and security with respect to the ILHIE. The Act states:

“ILHIE shall be an entity operated by the Authority to serve as a State-level electronic medical records exchange providing for the transfer of health information, medical records, and other health data in a secure environment.”

“The Authority shall create and administer the ILHIE using information systems and processes that are secure, are cost effective, and meet all other relevant privacy and security requirements under State and federal law.”

“The Authority shall establish minimum standards for accessing the ILHIE to ensure that the appropriate security and privacy protections apply to health information, consistent with applicable federal and State standards and laws.”

The Board of the Authority created the Committee with the following duties:

“The ILHIE Data Security and Privacy Committee shall serve in an advisory capacity to the Board on the policies of the Board with respect to the use and protection of health information, medical records, and other health data in the possession or control of the ILHIE.”

“The Committee’s role is to review, evaluate and recommend ILHIE data privacy and security policies, and to oversee the development of new ILHIE data privacy and security policy recommendations with appropriate collaboration with State of Illinois stakeholders, policy developers and implementers.”

“The Committee may in its discretion, among other acts: solicit subject matter expert and stakeholder testimony on selected issues; document, track and maintain a list of relevant federal and state HIE and privacy and security laws that affect or may affect HIE privacy and security policies in Illinois, including law harmonization; propose HIE privacy and security policy priorities; and recommend HIE privacy and security policies for adoption as regulations by the Authority or for legislative action by the Illinois General Assembly.”

Illinois law applies to the Committee’s deliberation procedures to promote greater public transparency into the decisions made by State of Illinois bodies. They include the public posting in advance of meetings of meeting notices and agendas, the admission of the public to observe all meetings, and the publication of meeting minutes. The Board has adopted guidelines for the expression of public comment in connection with meetings of the Board, and these equally will apply to meetings of the Committee. The Chair can also invite testimony, and it is anticipated that the Committee will be offering stakeholders in the ILHIE ample opportunity in the near future to share with the Committee views on specific issues to be addressed in hearings convened by the Committee.

#### *Overview of Illinois Law*

##### *A. ILHIE Legal Task Force Overview*

Mrs. Bernadette Broccolo, partner with the law firm of McDermott, Will & Emery who serves as a co-chair of the IL HIE Legal Task Force, provided an overview of the formation and work of the ILHIE Legal Task Force under the auspices of OHIT, in which over 50 seasoned attorneys and health care professionals have been engaged in the identification of legal and policy challenges to the development and implementation of the ILHIE. The other co-chair of the Legal Task Force is Mark Deaton, General Counsel of the Illinois Hospital Association, whose professional experience includes substantial involvement in government relations initiatives.

Illinois health information confidentiality laws significantly predate Federal HIPAA. These various State laws are not harmonized with Federal law. While Illinois law and HIPAA contain similar concepts, there are gaps, giving rise to uncertainty, increased costs and delay in ILHIE implementation. Illinois statutes generally require consent for use and disclosure of “sensitive information”, including:

- Drug abuse/alcohol treatment
- Mental health/ developmental disability
- HIV/AIDs/sexually-transmitted disease
- Genetic testing
- Child abuse or neglect
- Sexual assault/abuse

Reflecting the divisions in Illinois law, the Legal Task Force was organized into ten Workgroups which address specific subject matter areas, including: General Protected Health Information; Behavioral Health; Substance Abuse; HIV/AIDS; Public Health & Abuse Reporting; Genetic Testing; Disclosure of Clinical Laboratory Test Results; Liability Issues; Patient Consent Management; and Interstate Issues. The preliminary conclusions of three of these workgroups, namely: Behavioral Health, Substance Abuse, and Genetic Testing, will be presented today in greater detail by the co-chairs of those workgroups. The co-chairs of the Task Force and of the ten Workgroups form an Executive Committee which has met nine times beginning on Oct. 27, 2010, to monitor the progress of the Workgroups, explore issues and challenges identified by Workgroups, and discuss common themes emerging across Workgroups and explore common legislative solutions. The various Workgroups will present their findings and recommendations in the form of “White Papers”, which will be shared with the Committee.

*B. Specially Protected Health Information (PHI)*

1. Behavioral Health

Laurel Fleming and Wendy Rubas, co-chairs of the Behavioral Health Workgroup, presented an overview of the findings of their Workgroup. The Workgroup has concluded that the Illinois Mental Health and Developmental Disabilities Confidentiality Act (“IMHDDCA”) presents a number of barriers to the establishment of HIE in Illinois. Its scope is broad and unclear. It arguably applies to behavioral health issues arising in non-mental health treatment scenarios (e.g., post-partum depression). It segregates behavioral health information (from medical treatment data) presenting challenges for patient data exchange. Currently, clarification of the IMHDDCA is essential in order to (1) facilitate proper administration of the ILHIE, and (2)

avoid excluding the behavioral health patients from the scope and patient care benefits of the ILHIE.

Disclosure of patient data subject to the IMHDDCA generally requires the collection of a very detailed patient consent. Currently permitted patient consents do not encompass disclosures for all contemplated ILHIE purposes. The IMHDDCA restricts behavioral health providers from disclosing the existence of patient records to the ILHIE. Disclosures allowed without consent for treatment, payment, and health care operations (including quality assessment and peer review) are more limited than under HIPAA.

The formal requirements for permitted patient consent were created without HIE electronic processes in mind, and will require additional administrative processes in order to be utilized in HIEs. The formal requirements that present challenges include: a high degree of granular specificity (i.e. no blanket consents), specific expiration dates, and execution procedures (e.g., witnesses).

The IMHDDCA erects several barriers to the establishment of the ILHIE, including:

- Limits the conduct of research. With few exceptions, individual patient consent is required. Consent is required in Illinois for types of research that HIPAA permits without an authorization such as: research using de-identified data and limited data sets, preparatory and retrospective chart reviews
- Outdated for application of an electronic medical record. No distinction between “use” and “disclosure”; no recognition of technical solutions and safeguards.
- Does not accommodate current business models. Limited role of a “records custodian” does not allow comprehensive services to be provided by a third-party vendor
- Establishes processes that are redundant with HIPAA’s, resulting in administrative inefficiency (e.g., amendment of records; accounting of disclosures).

Illinois’ individual licensure statutes for behavioral health treatment professionals often require that such professionals obtain consent for disclosure of patient information, unless an exception is provided. Exceptions are limited to only a few scenarios, and these scenarios cover far less than the IMHDDCA covers or that the ILHIE would need. Therefore, clarification of the interplay between these Illinois licensure statutes is also necessary.

The Workgroup’s preliminary recommendations include:

1. Clarify the scope of IMHDDCA so as to facilitate the identification of behavioral health information in the ILHIE.
  - Define mental health and developmental disability “services” as those either provided by defined mental health treatment providers or to defined diagnosed conditions (e.g., DSM-listed conditions)
  - Adopt HIPAA’s definition of “psychotherapy notes”
2. Make disclosure through the ILHIE an exception to written patient consent or modify the consent requirements to facilitate inclusion of mental health information in the ILHIE
3. Make IMHDDCA consistent with HIPAA with respect to:
  - Research
  - De-identification and limited data sets

- Business associates
  - Patient rights (amendment, etc.)
4. Centralize confidentiality requirements regarding behavioral health information in the IMHDDCA (in place of the licensing statutes)

In response to a question from a member of the Committee, Mrs. Fleming advised that currently electronic health record (EHR) systems generally do not allow for the easy identification and sequestration of behavioral health patient data elements from a patient's medical treatment data elements in the same record. Data generated by an entire hospital department, such as the psychiatry unit, can be identified and isolated (in its entirety) on the assumption that all of such data from such unit is protected behavioral health data, however with respect to the data generated by the remaining (medical) treatment units, the identification and sequestration of physician orders for psychotropic medications or of references in physician progress notes of potential or diagnosed behavioral health symptoms or conditions is much more challenging. The sequestration of an entire patient record because of one or more behavioral health data elements is also problematic for the treatment of a patient with non-behavioral health comorbidities, with medical treatment professionals in emergency situations being denied access to relevant patient data.

In response to a question from a member of the Committee, Mrs. Fleming advised that if a number of patient records are sequestered in their entirety because of the presence of one or more "illiquid" behavioral health data elements, such patients would be denied the benefits anticipated from health information exchange.

## 2. Substance Abuse

Renée Popovits, co-chair of the Substance Abuse Workgroup, presented an overview of the findings of the Workgroup. The Workgroup agrees with the strategic objective of ensuring that the behavioral health system fully participates with the general health care delivery system in the adoption of health information technology (HIT) and interoperable electronic health records (EHRs).

Knowledge gaps exist among patients and providers in the Illinois behavioral health community about the use of EHRs and the benefits of HIE. Legal barriers and confusion about privacy and exchange of sensitive patient data exist between Illinois behavioral and physical health providers. Illinois' confidentiality protection of substance abuse data is premised on protecting patients from the negative stigma historically associated with substance abuse, as is Federal law. Congress assumed individuals would be more motivated to seek treatment if they were assured their treatment remained confidential.

The Workgroup's preliminary recommendations include:

1. Revise Illinois laws to be consistent with HIPAA where possible and not in conflict with Federal substance abuse confidentiality law (42 CFR Part 2)
2. Work within parameters established by SAMHSA and ONC because of Federal law
3. Broadly construe medical emergency ("break the glass" exception) under State statute

4. Develop a State standardized consent form that meets requirements of Federal substance abuse confidentiality law and other Illinois laws
5. Modify Illinois MHDDCA consent provisions to create greater flexibility consistent with SAMHSA FAQs
6. There is a real need to institute safeguards to reduce stigma and discrimination. Preserving patient trust is paramount.
  - Neither Federal nor State laws expressly include non-discrimination prohibitions or protections. Additional patient protections addressing penalties for discrimination and improper use and disclosure of sensitive data should be added to the Illinois Alcoholism and Other Drug Dependency Act.
7. Strengthening Penalties and Remedies:
  - Legal remedies for violations of 42 C.F.R. Part 2 are limited to a \$500 criminal penalty, with additional violations allowing for increases up to \$5,000. Such amounts do not serve as a deterrent to improper use or resulting discrimination. Financial penalties and other remedies for improper use or disclosure of sensitive information should be strengthened in our State laws
8. Preserve Stringent Court Orders:
  - Addiction treatment information is of potential interest to law enforcement, child welfare, employers and attorneys in civil proceedings. Therefore, it is essential that any proposed changes to current law maintain strong confidentiality protections. Extensive due process provisions for court orders for substance abuse treatment information should be preserved consistent with 42 CFR Part 2.
9. Limit Use in Criminal and Civil Litigation:
  - Retain special due process protections of court orders required under 42 C.F.R. 2.61-2.66 and 20 ILCS 301/305(bb)
  - Prohibit use of treatment information in criminal and civil proceedings by the government without a specific court order and include exclusion of evidence as a remedy for illegally obtaining or wrongfully using confidential treatment information
10. Fund Behavioral Health EHRs:
  - Many small behavioral health providers in Illinois do not have the resources to purchase and implement EHR systems
  - Behavioral health facilities are not eligible to participate in the ARRA meaningful use incentive payment program
11. Expand HIT Incentives to Behavioral Health:
  - SB539 (Sen. Whitehouse D-RI) re-introduced a bill to expand federal health information technology payments to mental health professionals, psychiatric hospitals, mental health treatment facilities and substance abuse treatment facilities. Illinois should support this legislation.
  - Illinois should expand Medicaid incentives to substance abuse providers consistent with our detailed Workgroup recommendations.

### 3. Genetic Testing

Mary Lucie and Maia Thiagarajan, co-chairs of the Genetic Testing Workgroup, presented an overview of the findings of their Workgroup. The Workgroup had reviewed a number of Illinois and Federal laws that restrict disclosure of genetic testing data based on the sensitivity of the

information. The Workgroup has concluded that current laws would restrict exchange of such information through HIEs without patient consent. Revisions to the relevant Illinois laws should balance the need to protect the public against the need to promote exchange of information through HIEs. Amendments to the relevant Illinois laws should harmonize their provisions with HIPAA principles.

The Workgroup's preliminary recommendations include:

1. Genetic Information Privacy Act
  - Modify to facilitate ability of healthcare providers to share information for treatment purposes
  - Add exception for medical emergency of test subject
  - Modify to allow for the use for payment purposes as long as use for underwriting is prohibited
  - Modify to expand the use for healthcare operations
  - Add exception to address public health activities
2. Genetic Counselor Licensing Act/Mental Health and Developmental Disabilities Confidentiality Act
  - Modify to enhance disclosure for treatment purposes; incorporate a specific exception for HIE
  - Add exception for medical emergency of test subject
  - Modify to allow for the use for payment purposes as long as use for underwriting is prohibited
  - Expand use for health care operations and peer review purposes
  - Modify to allow disclosure for public surveillance and disease monitoring
3. Challenges – lack of consistency
  - Definitions vary between State and Federal statutes
    - “genetic information”
    - “genetic testing”
    - “genetic services”
    - “family member”
  - De-identification standards
    - Not addressed under current State law
    - Applicable to genetic information?
    - variations between providers
  - Research protocols
    - Independent Review Board (for ILHIE)

### C. *General PHI*

#### 1. Harmonization of Illinois law with HIPAA

Mrs. Broccolo advised that the October 28, 2011 Executive Committee Meeting resulted in a review of the findings and recommendations of the Workgroups, and the development of a “mainstream approach” to achieve an appropriate balance between removing the barriers to the implementation of an HIE and preserving the privacy rights of individuals. It concluded that a

threshold legal question is what kind of patient consent should be required to send health information through the ILHIE: No consent? Opt-in consent? Opt-out consent? The Executive Committee further developed a “Grid” for encapsulating the changes needed in current law to implement each of the three consent models.

The Executive Committee can offer the following preliminary conclusions regarding the principal concerns that have emerged from the deliberations of the Legal Task Force workgroups: (1) Illinois law needs to be harmonized to Federal HIPAA; (2) the Illinois MHDDCA needs to be revised; and (3) the Authority needs to take affirmative steps to facilitate the trust of Illinois’ residents that their interests will be appropriately protected when patient health data is entrusted to the ILHIE.

With respect to the harmonization of Illinois law with HIPAA, the specific recommendations would include:

- Expressly adopt HIPAA definitions for “Treatment, Payment, Operations”
- Expressly adopt emergency treatment exception (a/k/a “break-the-glass”)
- Substitute PHI as defined by the HIPAA Privacy Standards for “nature or details of services provided to patients” (in Illinois Patient Rights Act)
- Permit disclosures to “Business Associates”, as defined in HIPAA
- Permit disclosures “authorized or required by law”, as defined in HIPAA

The Task Force would recommend for the Committee’s consideration the following steps to facilitate public trust:

- Authority adopts pro-active approach to protecting patient PHI
  - Appointment of Chief Privacy Officer
  - Establishment of breach notification monitoring
  - Active field auditing of compliance of ILHIE participants
  - Independent Review Board (IRB) formation for considering requests for secondary use of ILHIE data
  - Coordination of enforcement among Illinois authorities of privacy and security violations
- Increased Illinois penalties for violations
- HIPAA security requirements

In addition, in connection with the operation of HIEs in Illinois, the Authority should consider requiring that HIEs:

- Provide notice to patients of participation in HIE
- Delineate patient rights in connection with HIE

## 2. HIE Consent Management Options: No consent, Opt-out, Opt-in

In connection with the operation of the ILHIE, the Authority will need to adopt a policy with respect to the right (if any) of patients to prevent the inclusion of some or all of the data in such patient’s health record from disclosure through the ILHIE. In selecting a patient consent management policy, a range of options exists, from providing that patients must affirmatively agree to the inclusion of their data (“opt-in”), or providing that patient data is by default included

in the ILHIE unless the patient affirmatively exercises a non-participation right (“opt-out”), or providing that patient data may be disclosed for “treatment, payment and operations” purposes without patient consent, as currently provided under Federal HIPAA. The following questions need to be addressed: Should each person have absolute control over his/her Personal Health Information (PHI)? Does society have a legitimate interest in having certain PHI disclosed? (against a patient’s wishes)

In order to succeed the ILHIE will need to achieve dual trust -- clinicians must be confident that the patient record delivered by the ILHIE is complete and reliable (no “digital Swiss cheese”), and patients must be confident that their PHI is adequately protected from unauthorized disclosure or use.

*Technical Demonstration*

Due to technical difficulties, the proposed presentation by InterSystems Corporation of an overview of the technology being initially deployed to protect the privacy and security of patient data within the ILHIE was postponed to a later date.

*Public Comment*

There were no comments offered from the general public.

*Adjournment*

The meeting was adjourned at 4:50 p.m.

Minutes submitted by: Mark Chudzinski, Secretary