

**MINUTES OF THE MARCH 29, 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 2:00 p.m. on March 29, 2012, at the Naperville campus of Northern Illinois University, 1120 E. Diehl Rd., Naperville, IL 60563, with a video conference location at Stratton Building, 401 S. Spring St., 3rd Floor, Room 349-C, Springfield, IL 62706 and webinar participation capabilities.

<p><u>Appointed Committee Members present in person:</u></p> <ol style="list-style-type: none"> 1. Jim Anfield 2. Elissa Bassler 3. Leah Bartelt 4. David Carvalho 5. Edward Mensah 6. Pat Merryweather 7. Nicholas Panomitros 8. Harry Rhodes 	<p><u>OHIT staff present:</u> Dia Cirillo; Krysta Heaney; Saroni Lasker; Saro Loucks; Mary McGinnis; Cory Verblen; Laura Zaremba</p> <p><u>Invited Guests present:</u> Walter Blumenshine; Eric Foster; Marilyn Lamar; Dr. David Trachtenbarg</p>
<p><u>Appointed Committee Members present electronically:</u></p> <ol style="list-style-type: none"> 1. Jennifer Creasey 2. Jud DeLoss 3. Carl Gunter 4. Tiefu Shen 5. William Spence 	<p><u>Invited Guests present electronically:</u> Robyn Luke</p> <p><u>OHIT staff present electronically:</u> Mark Chudzinski; Diego Estrella; Danny Kopelson</p>
<p><u>Appointed Committee Members absent:</u></p> <ol style="list-style-type: none"> 1. David Holland 2. Ron Isbell 3. Timothy Zoph 	

Call to Order and Roll Call

Dr. Nicholas Panomitros, DDS, MA, JD, LLM, a member of the Authority Board and appointed by the Board to chair the Committee, welcomed the appointed Committee members present in person and electronically. Krysta Heaney of the Office of Health Information Technology (“OHIT”) 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, Jud DeLoss, Carl Gunter and Tiefu Shen, who had advised the Secretary in advance of their attendance by electronic means necessitated by business or employment purposes.

Introduction

Dr. Panomitros noted that today's meeting is being held as part of the launch by the State of Illinois Office of Health Information Technology of the Behavioral Health Integration Project (BHIP). The BHIP project is focused on the integration of behavioral healthcare and medical healthcare and the role of health information technology to facilitate that integration. The privacy and security challenges that behavioral health and substance abuse treatment providers face in electronically exchanging patient data with other providers are topics that are of direct interest to the members of this Committee, who have been charged with making privacy and security policy recommendations to the Board of Directors of the Illinois Health Information Exchange Authority. The convening today by OHIT of behavioral health and substance abuse treatment providers in the State of Illinois provides a unique opportunity for the Committee to invite public testimony and comments that the Committee should consider in formulating its privacy and security policy recommendations. Today's meeting, therefore, is largely informational. On the Agenda for today is invited testimony from two emerging regional health information exchange initiatives, one centered in Central Illinois, the other in Metropolitan Chicago, as well as from three organizations which provide services to behavioral health and substance abuse patients.

Approval of Minutes

The minutes of the last meeting of the Committee, held on February 8, 2012, in Chicago were unanimously approved.

New Members

Dr. Panomitros confirmed his appointment of the following individuals as additional members of the Committee:

- Leah Bartelt, Reproductive Rights Staff Counsel, Roger Baldwin Foundation of ACLU of Illinois; and
- Jennifer Creasey, Associate State Director of the Illinois Legislative Office of AARP.

Invited Testimony

Dr. Panomitros welcomed the following individuals who had agreed to share with the Committee their valuable insights regarding data security and privacy concerns:

- On behalf of the Prairie Center Health System, Mr. Eric Foster, Chief Operating Officer of the Illinois Alcohol and Drug Dependence Association;
- On behalf of the Central Illinois Health Information Exchange, Dr. David Trachtenberg, its Chief Medical Informatics Officer and a practicing physician;
- On behalf of the Metro Chicago Health Information Exchange, Mrs. Marilyn Lamar, Legal Counsel;
- On behalf of the Mental Health Centers of Central Illinois, Mrs. Robyn Luke, Administrator; and
- On behalf of GROW in Illinois, Mr. Walter Blumenshine, Fieldworker for GROW in Illinois and a U.S. Armed Forces veteran.

Mr. Eric F. Foster, AM, CADC, Chief Operating Officer, Illinois Alcoholism and Drug Dependence Association, presented testimony on behalf of Bruce Suardini, CEO, Prairie Center Health Systems. On March 21, 2012 Mr. Suardini conducted a focus group study with 25 substance abuse treatment clients. Overall, the clients would be hesitant to participate in an HIE if substance abuse treatment records were included. They voiced concerns about not having a say in who, specifically, would have access to their substance abuse treatment records if these records were part of a larger medical record. The clients were also apprehensive about re-release of substance abuse treatment records if they became part of a larger medical record. A major concern was stigma surrounding substance use disorders. Some liked the idea of limiting access to substance abuse treatment records to only life threatening situations. Others recommended that only certain parts of the substance abuse treatment record be included in the HIE record, excluding for example social and family history. In addition, some clients worried about how information in substance abuse treatment case notes would be used in a medical setting. Finally, clients felt an opt-out model would create a problem in that it would “red flag” people who chose not to participate in an HIE.

Dr. David Trachtenbarg shared with the Committee observations arising from his service as the Chief Medical Informatics Officer of the Central Illinois Health Information Exchange and as the Medical Director of the Methodist Diabetes Care Center in Peoria, IL.

- Physicians are taught the importance of maintaining patient confidentiality, but ultimately, privacy and security depend on the integrity of the individuals.
- For safest best care, physicians would like to see one high standard for all confidential patient information. Physicians believe HIPAA standards are reasonable. Ideally would like to see state law harmonized with HIPAA so we have one standard. With the rise of regional (multi-state) healthcare, this is even more important.
- To provide patients the safest best care, treating physicians need key patient information for best care of the patients, including HIV status, mental health problems and substance abuse. For patient safety and quality of care all appropriate health information must be available to treating clinicians.
- Physicians want to honor patient’s requests for privacy regardless of the legal status of the problem. Unfortunately, there is often a gap between what is safe for the patient and what a few patients want.
- When seeing multiple physicians, nearly every patient wants their medical condition to be communicated to their entire healthcare team. With hundreds of patients wanting their information to be communicated with other clinicians, has had only one patient express privacy concerns with a shared medical record.
- If any patient information requires extra levels of privacy protection, there should be uniform exceptions for disclosure. Coordination of care should be an exception permitting the disclosure of all patient information.
- If some patient information requires a higher level of privacy protection, he would like to see it apply to specialized psychiatric, developmental disability and drug treatment providers, not to primary care providers treating many conditions on one visit. The rationale for this is that primary care physicians see less severe problems than specialized providers.
- The laws requiring extra privacy protection in Illinois have different protections by for each medical problem. Unless physicians practice in a very narrow specialty such as a

drug treatment center, it is virtually impossible for them to know the law. In addition, attorneys give different interpretations of the laws. We need clearer laws written for the electronic age and less subject to multiple legal interpretations.

- Another looming problem is exchange of health information across state lines with different legislation. With healthcare mergers, this problem is now occurring within health systems using EHR software with a single database to store information for hospitals in different states.
- Current software EHR systems cannot handle the current law well. The intent of the physician's order is not documented in any standard way and thus impossible for a computerized record to handle properly. In addition, all EHR software is written to be HIPAA compliant; virtually no software is written to be compliant with state law.
- The sequestering of mental health visit notes can be done if the patient sees a mental health provider, but is virtually impossible to do if the patient is seen by a primary care physician for multiple problems.
- We also have problems because of changes in medical technology. Personalized medicine using a complete genome analysis is close to becoming generally available. On the average each of us has 100 genetic errors. In the future, proper treatment will require knowing this information for best treatment such as the best drug to treat high blood pressure. Consideration should be given to the future establishment of confidential testing centers where patients can anonymously obtain sensitive test results.

Mrs. Marilyn Lamar, on behalf of the Metro Chicago HIE, advised the Committee that the Illinois Mental Health and Developmental Disabilities Confidentiality Act contains patient consent requirements which in practice are difficult to satisfy in order to permit the transfer of certain patient data by a provider to an HIE. Specifically, the Act requires patient consent for the disclosure of a patient's behavioral health information, and requires that the patient's written consent specify not only the sensitive data at issue and the custodian who may disclose it, but also the identity of the permitted recipient of such data; no "blanket" consents are allowed. As HIEs which collect and store patient clinical data for later release are unable to identify in advance the eventual recipient(s) of the sensitive data, a provider can't forward behavioral health data to an HIE database for future release to yet-to-be identified data users. As a consequence, the MC-HIE has requested its participating health care providers to withhold from sending to the MC-HIE the behavioral health data of patients. In practice, the filtering out of behavioral health data from a patient's medical record has proven to be technically very difficult, and often the entire medical record of a patient with any behavioral health data will be sequestered. The net effect is that MC-HIE will not be as robust of a data repository and data exchange service as it otherwise could be, as the data of an entire category of patients with behavioral health issues, many of whom are Medicaid recipients, will be excluded from the MC-HIE, and in turn will not be available through MC-HIE to the State-level ILHIE. Mrs. Lamar advised: "this may ultimately result in the exclusion of a significant amount of data as an increasing percentage of the population takes medication for behavioral health problems. ...Unless it is changed, the current law will prevent behavioral health patients from receiving the benefits that an HIE will provide to other patients. Behavioral health patients will wind up on the wrong side of the digital divide."

A related problem noted by Metro Chicago HIE is that provider participants in the HIE may decide not to make available to the HIE general narrative text documents for any patient, as these documents are the most difficult to electronically screen for the presence of protected behavioral health data. Such documents include care summaries, discharge instructions and discharge summaries. Mrs. Lamar advised: “[this] would create huge gaps in the records of all patients – including those patients who don’t have any behavioral health issues. This is a situation in which the [Illinois law] could harm non-behavioral health patients, decreasing the value of HIE for all patients.”

Finally, the exclusion from HIE exchange of narrative text documents could disqualify eligible providers and hospitals in Illinois from receiving their Federal incentive payments for their adoption and Stage 2 meaningful use of electronic health record systems.

Mr. Walter Blumenshine, Fieldworker for GROW in Illinois, a provider of peer support mental health groups, stated that electronic exchange of patient information is long overdue and needed. In implementing health information exchange, professional and proper care must be the most important factor, followed by an economically driven system to perform the mission to save the taxpayers money. With respect to obtaining patient consent for disclosure of records, we must take that extra step to ensure that the clients know for sure what they are doing. Clients will be supportive of the sharing of records if it results in better care, and just and fair treatment. The extent of the behavioral health information that is shared should depend on its relevance to the medical treatment being received. The disclosure of current medications, to avoid adverse interactions with new prescriptions, may possibly be necessary. Patient information should be available only to those within the healthcare and social welfare system; law enforcement should be required to seek permission through judicial process for access to such information. Appropriate attention must be paid to the security of electronic patient data that is stored, and data breaches must be dealt with harshly but justly. Only true “life and death” emergency situations should justify access to patient records on emergency grounds. Different degrees of role-based access to patient records should be established, and no access should be allowed for commercial purposes. Safeguards are needed for persons with mental health conditions to not be treated and judged unfairly.

Robin Luke, Administrator of Mental Health Centers of Central Illinois, addressed the Committee through the video conference capability in Springfield, on behalf of Ben Yamnitz, a case manager at Mental Health Centers of Central Illinois and a consumer. Mr. Yamnitz sees multiple benefits to allowing providers to have timely electronic access to vital information of patients for the purposes of coordination of care. He is personally aware of an incident in which one of his clients did not receive optimal medical treatment because the hospital did not have access to the patient’s psychiatric medications. There are, however, concerns as well. Patients should have the right to determine who will have access to their records, for example excluding behavioral health information from providers of ancillary services without a need to know. Patients should also be able to choose which parts of their record that they want to share, such as excluding past treatment or social history that is not relevant to the current course of treatment.

Next Meeting

DRAFT 5/1/2012

Dr. Panomitros noted that the Committee is next scheduled to meet at 9:00 a.m. on Thursday, May 3 at the ILHIMA Annual Meeting at the Marriott Bloomington-Normal Hotel & Conference Center in Normal, IL.

Public Comment

There were no comments offered from the general public.

Adjournment

The meeting was adjourned at 3:15 p.m.

Minutes submitted by:

Mark Chudzinski
ILHIE Authority Secretary