

**IL HIE Legal Task Force  
Substance Abuse Workgroup  
June 1, 2011  
Meeting Notes**

In Person Attendees:

Theodora Binion-Taylor, Illinois Department of Human Services, Division of Alcoholism and Substance Abuse

Rachel Brady, Chicago Lawyer's Committee

Robert Bollinger, OHIT Legal Intern

Mark Chudzinski, General Counsel, OHIT

Amanda Fraerman, OHIT Legal Intern

Nate Inglesteinfeld, Chicago Lawyer's Committee

Embassie Susberry, Chicago Lawyer's Committee

Attended by Phone:

Bill Connors, Seaquest Technologies

Sara Howe, Illinois Alcohol and Drug Dependency Association

Rick Nance, Illinois Dept. of Human Services, Pharmacy & Clinical Support Services

Renee Popovits, Popovits & Robinson

John Radin, Seaquest Technologies

Allen Sandusky, South Suburban Council on Alcohol and Substance Abuse

Mike Simko, Walgreens Co.

Harrison White, Gateway Foundation

Renee Popovits, co-chair of the Substance Abuse Workgroup, opened the meeting at 2:00p.m., hosted by OHIT at the State of Illinois J.R Thompson Center in Downtown Chicago, with a telephone conference call-in number. It was noted that notice of the meeting and the agenda were posted on the OHIT website and at the Chicago meeting location no later than 48 hours prior to the meeting. Roll was taken, and the ability of those attending by telephone to hear and participate was confirmed.

The minutes from the April 14, 2011 meeting were reviewed and discussed. The minutes were approved by the members as amended.

Ms. Popovits provided several informational updates.

*HIE Survey.* A questionnaire was distributed by CBHA on Feb. 28<sup>th</sup> of this year to all of the community based healthcare providers. Of the 282 respondents, 77% were mental health services providers, 70% were substance abuse services providers, and 26% were developmental

disability services providers. The results indicate a preference (48%) of the respondents to providing patients an opportunity to opt-in (rather than opt-out) to a disclosure of their protected health information (PHI). It was noted that providers need education and training about electronic records, what they are, and how they can be implemented. A majority of the respondents (71%) indicated that PHI should be made available to providers in emergency situations (a/k/a “break-the-glass”), but the survey provided few details regarding the nature of the released information and the duration of the permitted disclosure. A majority of the respondents (85%) indicated that more consumer input is needed.

In the ensuing discussion it was noted that some of the comments in the survey reflect some confusion about what an HIE actually is and how it integrates or becomes a part of the health care network. Questions to be addressed include: What does an HIE do with PHI? Should the HIE have a comprehensive patient consent model approach (all PHI is subject to a single consent), or a granular one (specific categories of PHI are subject to separate consents), which would be more complicated to manage.

*CBHA Panel Discussion:* On May 10, 2011, Ms. Popovits participated in a panel discussion at the CBBA conference to educate providers about HIE. Most mental-health services providers are not using an EHR system, and have a long road ahead of them towards electronic clinical patient records.

*California Law Report:* Ms. Popovits shared with the group a report titled “Privacy and Data Security Issues Related to Electronic Health Information Exchange by Behavioral Health Service Systems in California,” by Paul Litwak. It is a lengthy legal memo that analyzes a number of privacy, security and DERSA issues under California and Federal law in proposing a model of patient consent that could be used in California for an HIE.

The next agenda item was the discussion of Consent Issues. It was noted that presently there are only two ways to exchange Substance Abuse treatment information: in the event of medical emergencies, or with written patient consent.

*Tiger Team Findings about Granular Consent:*

A recent finding of the Tiger Team suggests that when patients are given the opportunity to exercise their patient consent rights in a granular manner (selecting different consent options for specific categories of PHI), they don’t often exercise that right, preferring an all-in (or all-out) PHI consent approach. Such a finding may suggest that patients don’t want to focus on the details, or they don’t understand what they are consenting to, or the provider hasn’t done a good job of explaining to the patient what the patients are signing.

*Script or Cover Sheet to Explain Consent:*

The group discussed whether it would be helpful to have a script or a cover sheet attached to the consent form or something that would explain to the patient exactly what they are doing in simplistic terms. It was noted that for there to be “informed consent”, the patient will have to understand what they are consenting to and what the consequences may be if they do or they do not consent. It was noted that uniformity of consent forms and materials would be desirable as patients may see multiple health professionals in multiple health care settings, and inconsistency could cause confusion and error, particularly if patients are given a granular consent option, which is reflected in different ways on different provider forms.

*Opt-in v. Opt-out feedback:*

The workgroup discussed the relative merits of having a patient’s information automatically subject to disclosure, unless the patient specifically chooses not to permit such disclosure (opt-out), compared to requiring the collection of patient to permit disclosures (opt-in).

Ms. Popovits noted that if the state-level HIE were to provide a record locator service (RLS), then all of the different providers, including behavioral health providers, would be invited to provide to the HIE information which identified which patient records were in a particular provider’s possession. Under the Illinois Mental Health and Developmental Disabilities Confidentiality Act, however, the disclosure that a person is a patient may require patient consent.

*Other Consent Issues:*

A participant described his recent discussion with Dr. Clark regarding current technology that can be used for collecting and managing patient consent, suggesting that technology is not the obstacle to establishing a granular patient consent system for sensitive PHI.

Ms. Popovits advised that Pam Hyde confirmed that the long-awaited by SAMHSA of FAQ 2 is in a format and close to release and expected for the end of this month. Any analysis prepared by the workgroup will need to reflect any eventual guidance from SAMSA.

*Specific suggestions in terms of consent:*

In the ensuing group discussion, the following matters were raised:

- Will patient consent need to be collected every time a patient is treated? It was noted that the HIE in operation in NY has patients agree to disclosure to the HIE, but that choice is re-authorized by the patient at each visit.
- Will patients be allowed to select which PHI is disclosed? It was noted that for treatment purposes other providers will expect to at least receive the basic information that is required for a CCD. The key elements of the CCD are: medication, labs, basic demographic information, and level of functioning. It was also noted that it would be

helpful if standards were adopted to reflect one set of data elements with agreed meanings so that providers could implement electronic health record systems that could interoperate. The selection of data elements that needs to be collected by providers is also influenced by the data that will be required to report provider outcome measurements by 2014. While most of the discussion of provider outcomes measurement has focused on Meaningful Use, its applicability to the substance abuse provider community is limited.

- Should HIEs have access to the entire treatment record, or just certain data elements like continuity of care, or something in between?

*Break- the- Glass Questions:*

- Will EHR systems alert ER room personnel that there is additional patient information “behind the glass”?
- Will all patient records have a “break-the-glass” option, some of which may have no further patient information behind them, or will alerts be provided only in respect of patient records that have concealed data?
- Once you “break the glass” how do you un-break it? When the substance abuse information is released as a part of a medical emergency exception, and consequently becomes part of the hospital record and can be re-disclosed, such data no longer enjoys 42 CFR non-disclosure protections for those disclosed medications or that treatment.
- Who provides the message that there may be some additional information in the patient record? Software that is running at the HIE? Who determines that there is undisclosed data? Is it simply a notice that a patient declined to have part of the patient’s record disclosed?
- Are patients in state government programs allowed to restrict information? Can a Medicaid patient restrict the same amount of information as anyone else? Mr. Chudzinski noted that under the current IL law regarding the confidentiality of substance abuse and behavioral health data, patient consents need to be obtained for disclosures. Legislation is pending (SB1234) which would change IL law to allow the disclosure of mental health PHI of patients in State programs to be disclosed without patient consent.

Ms. Popovits noted that the workgroup will probably focus additional attention on these “break the glass” questions.

*Tasks for next Meeting*

Ms. Popovits will be revising the workgroup’s draft report, and will continue to monitor the SAMHSA FAQs which we believe will come out before our next meeting. Ms. Howe and Mr. Nance will put together a consumer survey that asks questions to providers.

Mr. Chudzinski will request to get one of his OHIT colleagues from the technology side to present to the work group the latest thinking on how ILHIE is going to be structured. Mr. Chudzinski noted that OHIT is expecting to issue in the next 48 hours an RFP regarding the statewide HIE.

There was no public comment offered in response to the Chair's invitation. Ms. Popovits thanked everyone for continuing involvement and consideration.

The next meeting was set for Wednesday July 13, 2011.

The meeting was adjourned at 3:50p.m.