

July 24, 2013 MINUTES
 PATIENT CHOICE AND MEANINGFUL DISCLOSURE WORKGROUP:
 SPECIALLY PROTECTED INFORMATION SUBGROUP
 THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY

The Illinois Health Information Exchange Authority, pursuant to notice duly given, held a meeting of the Specially Protected Information Subgroup of the Patient Choice and Meaningful Disclosure Workgroup at 10:00 a.m. on July 24, 2013, at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with video and telephone conference call capability.

Participant Name	Participant Representation
David Carvalho	Illinois Department of Public Health
Charles (Chuck) Cox	MetroChicago HIE
Mike Jennings	Walgreens
Marvin Lindsey	Community Behavioral Healthcare Association of Illinois
Ann Fisher	AIDS Legal Council of Chicago
Susan Strange	Aetna Better Health
Amy Cullnan*	Monahan Law Group
Denise **	
*	Please help us to confirm the identity of this participant.
**	Please assist us in identifying this participant.

Call-In Participant Name	Participant Representation
Beth Cook	Human Service Center Peoria
Julie *** (represented Crissie Anderson)	Lutheran Social Services of Illinois
Kirby Shaw	Rosecrance Health Network
***	Please assist us in identifying this participant.

- Subgroup Introduction: Subgroup chair, David Carvalho, introduced himself to the Specially Protected Information Subgroup and asked the present members to do the same.
- Participant Introduction: Attendees in the conference room stated their names and the organizations in which they work. Participants via telephone stated their names and organizations as well.
- David Carvalho began discussion by reviewing the subgroup's deliverables (policy procedures) and summarizing the resources available to the participants: previous reports, an overview of consent management policies, the statute, etc.
 - David Carvalho described a scenario in which patient information could not be retrieved from the Health Information Exchange (HIE) because of a patient's preference to opt out of the system. Yet, he noted, there are situations in which the patient has no choice but to disclose certain information, such as the birth of a child.

- David Carvalho posed a broad question to the participants in order to help guide the subgroup's conversation: What are the critical issues/anticipations?
- Chuck Cox asserted that the subgroup had three objectives to consider when deciding on a policy: the law, obligations of providers in relation to the HIE, and HB1017's framework. In order to properly discuss data, it must be done within that context.
- David Carvalho prompted others to add their observations.
- Marvin Lindsey brought up the fact that mental health records and substance abuse data records are integrated. Therefore, it is difficult to separate specific data should be kept private. A drawback of the HIE is that its information is "all or nothing."
- Chuck Cox inquired into the state of the law. He proposed that obligation of protecting health records lies with providers, not the HIE.
 - David Carvalho posed a question in response: If providers share private patient information with the HIE, is the HIE legally protected?
 - Amy maintained that the law prohibits re-disclosure of mental health information, so the HIE may still have liability issues.
 - David Carvalho suggested that the first line of defense falls on the providers, and the second line of defense is on the HIE.
- Chuck Cox suggested that an indemnity agreement would protect the HIE.
 - David Carvalho stated that an indemnity agreement is insufficient and unreliable. The issue is too complex to be legally covered by such an agreement.
- Susan Strange acknowledged the fact that patient information is collected in various places in the medical world. In one case, mental health records may be reported in a patient's medical history and used by multiple providers.
 - David Carvalho reiterated that mental health records have been integrated (protected and unprotected records are grouped together). Also, information is not "silo-able" by provider; different providers may have mental health records of the same patients. Ironically, the current paper record system is not well done, which complicates the electronic transition process.
- Chuck Cox maintained that textual reports leak protected health information, which cannot be prevented. There needs to be a technical solution to this problem which currently does not exist with present technology.

- David Carvalho emphasized the need to acknowledge the current limitations of technology and organization in the healthcare industry. Although, he stated that the current system is not unchangeable, referencing how HIPAA took the status quo into account.
- David Carvalho asked the participants about the possibility of inadvertent disclosure of private health information.
 - Chuck Cox described that a provider cannot look up patients' private health information in the Metro Chicago HIE if the provider does not have an existing relationship with the patient. Therefore, even if there are multiple patients with the same name, a provider only has access to the patients he or she has treated previously.
 - David Carvalho inquired as to whether an emergency department can gain access to a patient's records even though the emergency department has never treated the patient before. In other words, since there is no existing relationship between the patient and provider in some emergency situations, how can the emergency department utilize information stored in the HIE?
 - Chuck Cox described that an emergency department would be able to search the Metro Chicago HIE by entering the patient's name. In this way, the emergency department could quickly establish a relationship with the patient and access his or her medical records using the aforementioned HIE.
 - David Carvalho suggested that even within hospitals themselves, due to lack of records and/or record confusion, there are situations in which providers receive the wrong patient data. Consequently, there could be situations in which the ILHIE would distribute incorrect patient data to emergency departments and/or confuse patient names because of limited knowledge of the actual patient.
 - Chuck Cox agreed and stated that incorrect patient data storage has implications within the Master Patient Index – imperfections in records lead to imperfect identification of patients. Therefore, policies must be flexible and not developed around specific technologies, allowing for further evolution.
- David Carvalho wrapped up the subgroup meeting in order to reconvene as a whole with the Patient Choice and Meaningful Disclosure members.