

**NOVEMBER 5, 2013 MINUTES
MINUTES OF THE PATIENT CONSENT PREFERENCES and
DATA SECURITY WORKGROUP of the GOVERNING BOARD
OF THE ILLINOIS HEALTH INFORMATION EXCHANGE
AUTHORITY**

The Illinois Health Information Exchange Authority (“Authority”), pursuant to notice duly given, held a meeting of the Patient Consent Preferences and Data Security Workgroup (“Workgroup”) at 2 p.m. on November 5, 2013, with telephone conference call capability.

<u>Members Present:</u> Peter Eckart (Co-Chair), Illinois Public Health Institute Harry Rhodes (Co-Chair), American Health Information Management Association	<u>Members Present:</u> Howard Lee , Wirehead Technology Victor Boike , MetroChicago HIE
<u>OHIT/ILHIE Authority Staff Present:</u> Raul Recarey Ivan Handler Krysta Heaney Beth LaRocca Kerri McBride Shira Mendelsohn Daniel Procyk Cory Verblen	<u>Members Present by Phone:</u> Julie Kovacin , Lutheran Social Services Christine Freeman , Pillars Community Services Steve Lawrence , Lincoln Land HIE Richard Thoreson , Invited Guest, SAMHSA

Welcome and Attendance

The Work Shop members were welcomed and the ability of members participating by telephone to hear the proceeding was confirmed. Notice and the agenda for the meeting were posted duly in advance of the meeting in accordance with the Open Meetings Act.

Consent2Share Presentation

Invited guest Mr. Richard Thoreson, SAMHSA Public Health Analyst, gave a presentation on Consent2Share regarding managing consent.

Mr. Thoreson indicated that SAMHSA wants to have something more than the all or nothing choice that is characteristic of current consent framework and to have the process fully automated. Consent2Share automates the consent process by creating rules using standard structured data, e.g. LOINC, SNOMED, ICD codes and RxNorm. SAMHSA provides the user interface so that the patient can manage their consent preferences at a granular level, for example to share alcohol data but not drug abuse data.

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When the relevant jurisdiction has the standards to enforce and the providers have their privacy standards, there is a policy decision point. Consent2Share takes all applicable policies and creates a single controlling policy. Through this pilot program, SAMHSA is hoping to minimize the cost for anyone who wants to implement and therefore significantly reduce the cost to entering the market. Consent2Share is open source.

SAMHSA wants to make the consent management process convenient for patients that have limited knowledge about their consent choices. SAMHSA fully support greater patient education and hopes that in the future patients can manage their consent preferences online.

Q&A with Mr. Thoreson

Question: What are barriers to the HIEs using this?

This solution is meant to be very low cost. Without automation, granular consent preferences management will be cost prohibitive.

Question: You mentioned this would be available to any entity that would use it. Will the service be available for major vendors?

Yes, that is desired. HIEs and vendors will respond to demand in the market.

Question: Are there alternative models for an open source or is this the obvious solution? SAMSHA has found this approach to have the most potential.

Question: How does this solution connect to existing EHRs?

The provider's EHR has to have the capability to produce a C32. The solution takes the C32 input, applies the policy rules and segments the data based on the policy rules. SAMHSA is actively working on a patient portal.

Discussion:

Work Group members suggested a live demo for future technology presentations. Mr. Handler explained Consent2Share, and segmentation more generally, requires a decision at what level to redact data. For example, the C32 has 17 sections; a decision could be made to redact data at a section level or further, at the field level. There are two main concerns. First, in order for patients to actually provide meaningful consent they need to understand the 17 sections and understand what redaction or data suppression is. This requires significant patient education. Second, state and federal laws identify information requiring specific patient consent at a high level, e.g. HIV/AIDS status versus all data indicative of HIV/AIDS. There is not clear alignment between what you can identify in a discreet fashion and the information a patient may want to suppress or protect from disclosure. For example, redacting HIV diagnosis, medications and other discrete data for a patient with HIV may meet legal requirements the fact that someone goes to a doctor 20 times a month, even with no other information, might allow the provider to infer that they have HIV.

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Mr. Handler expressed concern with data segmentation, namely that it does not specifically address who has access to information, a frequently cited concern among patients. Mr. Handler shared with Work Group members planned activities to use audit trails to determine the clinical relationship between a provider and patient. If there is no clinical relationship, the ILHIE could consider suppressing all information. Establishing clinical relationship also would allow ILHIE to implement role-based view and access rights, limiting access to an entire patient record. Mr. Handler indicated the ILHIE also has the possibility to let patients know who is looking at their record using the audit trail.

Public Comment:

It was noted that although Consent2Share is open source, suggesting relatively low cost, usually consultants are necessary to help design access controls, and this can drive up the overall cost. Another exciting aspect is that if there are a lot of users and the development of rules is shared by the open source community, a library of tools, rules and functions may become available. However, it is important to establish structure and governance processes and standards.

The meeting was adjourned.