

**MINUTES OF THE MARCH 25, 2014 MEETING OF THE
PATIENT CONSENT PREFERENCES & DATA SECURITY WORK GROUP
OF THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY**

The Patient Consent Preferences & Data Security Work Group (Work Group) of the Illinois Health Information Exchange (ILHIE) Authority, pursuant to notice duly given, held a meeting at 2:04 p.m., on March 25, 2014, at the offices of GOHIT, State of Illinois James R. Thompson Center, Room 2-201, 100 W. Randolph St., Chicago, IL 60601, with telephone conference call capabilities.

Roll Call

<p><u>Members Present:</u> Harry Rhodes (Co-Chair), American Health Information Management Association</p>	<p><u>Members Present:</u> Chuck Cox, MCHC/MetroChicago HIE Howard Lee, Wirehead Technology Reginald Ramey, Wirehead Technology Laura Martin, Advocate Health Care Estra Ali, Advocate Health Care Mikki Pierce, Atrium Advisory Services</p>
<p><u>GOHIT/ILHIE Staff Present:</u> Beth LaRocca, GOHIT Ivan Handler, ILHIE Authority Raul Recarey, ILHIE Authority</p>	<p><u>Members Present by Phone:</u> Sherri Devito, Illinois State Medical Society Nick Bonvino, Southern Illinois Health Information Exchange Elizabeth McKnight, Alliance of Chicago and Chicago Health Information Technology Regional Extension Center Chris Freeman, Pillars Steve Lawrence, Lincoln Land HIE/Illinois Health Exchange Partners Jennifer Routzon, Central Illinois Health Information Exchange</p>

Welcome

Beth LaRocca confirmed the presence of the Patient Consent Preferences & Data Security Work Group members and staff listed above with the exception of Steve Lawrence, Raul Recary, Estra Ali, and Mikki Pierce, who joined the meeting after it came to order. The ability of those participating by phone was confirmed. Notice of the meeting and an agenda were posted at least 48 hours in advance of the meeting.

Mr. Harry Rhodes, Co-Chair, gave an introduction and a rundown of the agenda. Prior to the meeting, invitees received various information (e.g. past work sheets, matrix examples, draft outline, persona model, data segmentation approaches analysis framework, copy of the charter, and work plan with dates and deliverables, etc.) which was discussed throughout the meeting.

Recommendations Report

The “Draft Outline for the 2014 ILHIE Authority Data Segmentation Recommendations Report (Version 1)-March 22, 2014” document was created by the Co-Chairs to facilitate the initial drafting of the Recommendations Report that the Work Group will present to the Authority Board in the Summer of 2014, in accordance with the Work Group’s charter. The Draft Outline proposed that the Recommendations Report begin with a technology review of the technological solutions that the Work Group examined in the past year (Consent2Share, Data Segmentation for Privacy (DS4P, the Veteran’s Administration solution), SHARPS, and Audit Trails). The Work Group discussed the analysis framework to evaluate the advantages and disadvantages of each solution for the purpose of establishing assessment benchmarks and baselines.

The Work Group will also document the capabilities of the ILHIE and EMR systems and how the capabilities interact. It will provide a summary of the current state of data segmentation. The Work Group Report will include a review and analysis of meaningful use on the HIE and medical records and privacy. The Work Group developed a persona to describe the impact of segmentation on the consumer. The reproductive health for minors persona has been received, and Ivan Handler indicated he would take the initial steps to develop additional personas for patients with sexually transmitted diseases, HIV testing results, behavioral health, and substance abuse.

The Recommendations Report will also include specific patient consent preferences and scenarios, as well as map elements in the information exchange and consumer preferences for those elements.

Finally, the Work Group Report will offer a recommendation to the ILHIE Authority Board reviewing the technical feasibility of data segmentation, assessment of potential population impact, and recommendations regarding the continued annual review of technology and population impact.

Summary of Current State of Segmentation Model - Data Segmentation Approaches Analysis Framework

The Work Group discussed the proposed Data Segmentation Approaches Analysis Framework worksheet, a framework to compare the various technological solutions that the Work Group examined in the past year including Consent2Share, Data Segmentation for Privacy (DS4P), SHARPS, and Audit Trails. A major Work Group concern is the difficulty in implementation and administration of the different models. The models should be logical, user-friendly, feasible, and affordable.

The current consumer experience for these solutions is also important. Important questions include: 1) what sort of governance process is there in each model? 2) is this a practical solution? 3) what is the impact on the clinical workflow? 4) do EMR and HIE partners have the full capacity to implement the solutions? and 4) is there a possibility for phases or an integrated process? Some of these models are in development, so new functionalities will continue to develop.

A commentator noted that it is important to keep in mind how a particular solution fits into the national standards and trends. One of the goals of the ILHIE has been to be in general technological accordance with others across the nation in order to make it easier to interoperate with others. The Work Group generally agreed that the Framework should additionally assess “How the solution fits into national standards/trends?”

There was a general discussion about the solution implementation. It will be difficult to estimate an exact cost, but cost estimation is needed to achieve general idea of the economic impact of the solution. Cost estimation was recommended to be added as a factor in assessing the difficulty of implementation and administration of the solution section.

A commentator was unclear about the difference between the difficulty to administer section of the proposed Framework and the practicality section. It may be beneficial to add something to differentiate the two and provide clarity (e.g., is one from an operational standpoint and the other a user standpoint?). Something could be easy to administer, but impractical to implement.

The next step in developing the Report will be to sort through all the meeting minutes and notes for the four different solutions, and report them on the proposed Framework document that was shared with the Work Group. Ivan Handler indicated he make the first attempt at completing the Framework chart, and then open up completion of the document to a collaborative process.

The Work Group will also go back and create one page personas for other areas of concern: sexually transmitted diseases, HIV testing, etc. A commentator suggested that because minor reproductive is the only persona in place, the Work Group should create subgroups that write out what they think the requirements will be for the different personas. Doing so would help kick-start the creation of the personas.

There was a general discussion about improvement of the criteria for evaluation purposes. It may also be helpful to trade info with other HIEs in the state and nationally. Knowledge gained from creating the reviews can be used as a benchmark, allowing the Work Group to see what solution benchmarks have and have not been met.

It was clarified that neither the Authority nor the Work Group actively reaches out to vendors to give them the benchmarks and to show them what is expected of them. A commentator indicated that vendors seem to lack guidance and often have to guess at what their obligations are. Vendors need policy guidance. Even Consent to Share, which is developed around the C-32, lacks comprehensive standards. The issue is whether a particular tool works for a particular market. Currently there are essentially two technological options: 1) opt-in or 2) opt-out. If a technology is not available, it may be difficult to make a recommendation to the Board about what technology to use or pursue. The lack of standardization throughout the country is an issue.

There was a brief discussion about the various solutions presentations. A structure has been proposed that would use metadata tags. A commentator noted that no one has been chosen to pilot the structure.

One commentator noted that there is no clear guidance from SAMHSA. Therefore, implementation of Consent to Share may not fall within the bounds of the law. Further, the law has not been altered to encourage Consent to Share.

Another commentator noted that NIST, an organization that deals with federal privacy and security standards, just released a HIPAA toolkit User Guide. The toolkit User Guide contains a list of the different rules to follow in order to remain compliant with HIPAA as well as other considerations.

The Work Group agreed that the initial draft Recommendation Report will be drawn up and everyone will continue to monitor. A commentator volunteered to write a draft as he sees the requirements released for the different Personas. He will also look at and make comments on the criteria for Patient Consent Privacy. Following the comments, other Work Group members will respond to the comments.

There was a general discussion about the implementation capacity of EMRs. A commentator suggested something be written up regarding implementation capacity of EMRs. The write-up would address: 1) what an EMR can and cannot do; 2) how well EMRs work with HIE partners; 3) whether these solutions can be incorporated into existing EHR systems; 4) how feasible it is to attach it onto existing networks; 5) what sort of configuration issues will be faced; and 6) what steps will be taken if someone does not have an EMR system. One commentator mentioned that the final factor is out of scope.

A commentator asked whether the Work Group should project what percentage of the population will be able to employ a recommended solution. It may be helpful to note the part of the population that is not being included.

Public Comment

No public comments were offered.

Adjourn

The meeting was adjourned at 2:52 p.m.

Minutes Submitted by:

Brett Strickland, Esq.