Health Information Technology Exchange of Connecticut
Legal and Policy Committee
November 17, 2011

Meeting Minutes

COMMITTEE MEMBERS PRESENT: John Lynch, Charles Covin (phone), Ellen Andrews (phone),

HITE-CT MEMBERS: Lori Reed-Fourquet (phone), Denese Sterling

PUBLIC: Susan Israel, MD

DPH REPRESENTATIVE: Marianne Horn

Call to Order
John Lynch chaired the meeting. The meeting was called to order at 8:35 a.m.

Review and Approval of Minutes from November 01, 2011
Upon a motion made by J. Lynch, seconded by L. Reed-Fourquet, the committee members adopted the minutes from November 01, 2011. **Motion passed**.

Review and Discussion of HIE Policies
J. Lynch reiterated that the ten policies are expected to become the version 1.0 documents once they receive final approval from the HITE-CT Board. He commented that minor paging information in the documents will be corrected before this happens.

Vote on Endorsement of HIE Policies
Upon a motion made by J. Lynch, seconded by L. Reed-Fourquet, the committee members recommended the policies to the HITE-CT Board of Directors. A roll call vote was taken as follows:

Policy Number	Policy Name	Ellen Andrews	Charles Covin	Lori Fourquet	John Lynch
1	HITE-CT PRIVACY AND SECURITY AUDIT POLICY	Abstain	Yes	Yes	Yes
2	HITE-CT IDENTITY MANAGEMENT POLICY	Abstain	Yes	Yes	Yes
3	HITE-CT AUTHENTICATION POLICY	Abstain	Yes	Yes	Yes
4	HITE-CT ACCESS CONTROL POLICY	Abstain	Yes	Yes	Yes
5	HITE-CT CONSUMER	No	Yes	Yes	Yes

	AUTHORIZATION AND CONSENT POLICY				
6	HITE-CT CONSUMER RIGHTS POLICY	No	Yes	Yes	Yes
7	HITE-CT BREACH NOTIFICATION POLICY	Abstain	Yes	Yes	Yes
8	HITE-CT PURPOSE OF USE POLICY	Abstain	Yes	Yes	Yes
9	AFFINITY DOMAIN INTEROPERABILITY POLICY	Abstain	Yes	Yes	Yes
10	HITE-CT INFORMATION SECURITY POLICY	Abstain	Yes	Yes	Yes

Discussion of Draft Business Association Agreement (BAA) and Draft Data Use and Reciprocal Support Agreement (DURSA)

- L. Fourquet will contact legal counsel to begin drafting a BAA contract.
- L. Fourquet will then send out the BAA to the full Legal & Policy Committee for review at the next Legal & Policy meeting.
- A recommendation will then be made to the full board that they authorize the executive committee to review and approve the interim BAA for early adopters for the test phase of the system.

Public Comment

Comments were made by Susan Israel, MD. Her comments are appended to the end of these minutes.

Schedule of Meetings:

- December 6, 2011

Adjourn

The meeting adjourned at 9:10 a.m.

Public Comment

November 17, 2011

Health Information Technology Exchange of Connecticut

The Legal and Policy Subcommittee has written "An opt-out consent model is generally recognized as the model most likely to result in a successful, viable HIE over time since requiring patients to take affirmative action in the form of consent before protected health information (PHI) can be collected by the HIE has proven to be a significant impediment in other states." (Though I believe some states have chosen an opt-in policy.) CT's statement seems quite correct to me, as I believe that if most of the citizens of CT knew the facts about the health care legislation, privacy laws and planned uses of their data, the line would be out the door.

In my view, the only ethical and perhaps constitutional option is an Opt-in model, with restrictions, for all patient medical records, that would allow patients, not doctors and hospitals, to retain ownership of their most intimate property and to have the choice of which data to risk for possible compromise. The pressure, of fulfilling the expectations of consumer choice, would be one of the best ways to ensure that privacy mechanisms are well maintained. Usually governments need a warrant for search and seizure, except it seems for our medical records. Unfortunately, it seems that government laws and regulations allow this and call for our medical data to be in its files.

I know that all those, such as yourselves, involved in deciding the fate of millions of citizens, have the best of intentions and believe you are acting in our best interests, to provide us with better and cheaper care in the most expedient way. However, the words of the privacy regulations and supposed technology innovations are used to obfuscate the fact that once data is sent out of a provider's office, particularly online, its privacy cannot be guaranteed. Not only will hundreds of authorized people have access to the data, there will be hackers and the inadvertent employee mistakes. Data can be re-indentified, and once it is "outed," it cannot be changed as a credit card number can be. Worse, once all these mechanisms of the HIE are in place, misuse of its data cannot always be stopped. We all know that knowledge about us can lead to power over us through decisions about employment, insurance coverage or even treatment options. Now we even have some states and the Federal government trying to get everyone's DNA, including newborns, in their data banks. With everyone's medical record for research, HHS or even our Dept. of Public Health, could decide that it is not cost effective to pay for certain treatments for people who are too old or too terminal.

Perhaps it is no accident that Clint Eastwood's Film J. Edgar, has just been released. It opens with Leonardo Di Caprio being thrilled by all the uses there could be of having a data base of fingerprints. The film details how J. Edgar misused the data he had on file. You might say well that was just one person, but future State or Federal administrations could do a lot of damage before being stopped.

Thank you very much for this opportunity to present comments.

Susan Israel, MD

Woodbridge, CT