Health Information Technology Exchange of Connecticut
Consent Committee Meeting
Minutes
April 12, 2011
3:00 – 4:30 PM

COMMITTEE MEMBERS PRESENT: Thomas Agresta, Ellen Andrews, Lisa Boyle, Daniel Carmody (phone), Peter Courtway, Brenda Kelley, and John Lynch.

DPH REPRESENTATIVES: Marianne Horn, Sarju Shah

CALL TO ORDER AND OPENING REMARKS:
Tom Agresta called the meeting to order at 3:10 PM. He provided an overview of the task assigned to the committee from the HITE-CT Board of Directors, acknowledged that this is a challenging issue and pointed to eight areas that needed to be addressed.

CONSENT POLICY DISCUSSION:
John Lynch provided an overview of the Consent Policy Model (Model) in the ONC approved HITE-CT Strategic and Operational Plan. There was discussion and clarification among the members about the Model and about current law governing exchange of protected health information.

Ellen Andrews expressed her support of an "opt-in" model because with "opt-out" there is no teachable moment. She distributed an article on a Massachusetts opt-in pilot launched in 2005 with a $50 million dollar contribution from BC/BS of Massachusetts. The pilot has a 90% opt-in rate in a patient population of 500,000. There was discussion of the complexities of an opt-in model. Ellen indicated that the language in the bill currently before the CT legislature that would require written consent from patients before a health care provider could release patient health information is currently being negotiated with CHA's legislative liaison. There was also a clarification about what Ellen and the groups she represents truly want in an HIE, that is allowance of all information to flow into an HIE, and written consent required once by a patient in order to allow retrieval of information. This would permit a "break the glass" scenario for emergencies.

Brenda Kelley indicated that AARP can live with opt-in or opt-out, the biggest concern with CT's current Model is that there is nothing on consumer choice. She is also concerned that patients have the ability to view their whole record and make corrections when and if appropriate. Additionally, she is troubled that the Plan does not ensure that there is a consistent message for patients in regards to HIPAA forms; every provider has a different HIPAA form.

There was substantial discussion about the risks / benefits to patients of not having either providers participate in an HIE because of administrative overhead challenges, or not having their data available at the point of care when needed. This was balanced against the risk of either inadvertent or malicious access and inappropriate use of Protected Health Information. Members of the committee had different perspectives on this risk / benefit ratio.

There was discussion about the need for an extensive education campaign of all stakeholders in the exchange process. Ellen Andrews said she was concerned because substantial, multi-modal education like this is most often the first thing to be cut in times of fiscal crisis

Peter Courtway stated that the way the RFP is structured, exchange will develop in layers. Many policies and procedures need to be developed.

Dan Carmody echoed the need for policies and procedures and stated that the education needs to include consumer benefits / risks, consumers' rights and an explanation of current law. He stated that from a

financial perspective, getting more people into the exchange is a good thing. The goal was to develop an exchange to connect providers, not to develop a lot of overhead. He agreed that there still needs to be a lot of education and that opt-out does give the patients choice. He described the Personal Health Record (PHR) as likely a required Stage 2 MU goal. The HIE could act as a router to allow patients and clinicians to populate a PHR. There also was discussion about patient's capacity to amend, or make comments on their medical records. Discussion occurred about not setting up the HIE as the place responsible to make corrections to patient records. Patients would have to return to the source of the data for corrections to be made. A recognition that these issues were future considerations that need further discussion was made by the group.

Lisa Boyle explained the concerns expressed in the HIPAA rule comments about wanting to get enough information in and to improve quality of care.

Tom Agresta clarified that the discussion is really about retrieval of information from the exchange and that this is enormously different than when opting in to the exchange itself. This was made clear by the fact that all members of this committee felt information should initially flow into the HIE in a secure and protected manner, yet some felt a written consent for retrieval, versus only allowing authorized clinicians to retrieve data under appropriate conditions should be the default policy. All agreed that if patients specifically chose not to participate in data sharing there should be a specific written denial of access that is developed.

RECOMENDATIONS:

The following recommendations were made:

1. Change language around consent and move away from utilizing "opt-in" and "opt-out" language to more defined language of authorization, attestation, etc.
2. Develop a process by which we explore retrieval of information that informs patients that their information is being retrieved from the HIE and give them a right to "opt-out".
3. Endorse and encourage the development of a robust educational plan and a team to be put in place to ensure that all stakeholders are informed.
4. Develop a strong framework for privacy, security and access that includes the workflow, audit trail, and access policies.
5. Develop a consumers' Bill of Rights explaining what data will be in the exchange, where it will be located, and what it would be used for (include everything from consent, to whom can access be given and what are the consumers' rights). This should be something standardized by HITE-CT to be given to patients as part of the HIE Agreement.

Tom Agresta motioned to endorse the current Consent Model and the additional recommendations. The motion was seconded by Peter Courtway. The motion was supported by Tom Agresta, John Lynch, Peter Courtway and Brenda Kelley*. Ellen Andrews voted against the motion. Lisa Boyle and Dan Carmody were not present for the vote.

PUBLIC COMMENT
None

ADJOURNMENT
The Committee meeting adjourned at 5:15 PM

*Brenda Kelley, through the HITE-CT Vice Chair, Tom Agresta, modified this vote at the HITE-CT Board of Director's meeting on April 18, 2011. Ms. Kelley indicated that her vote should reflect an abstention until such time as an acceptable consumers' Bill of Rights is developed.

DRAFT