Health Information Technology Exchange of Connecticut  
Special Populations Committee  
Meeting Minutes  
Thursday, September 1, 2011  

PRESENT: Mark Masselli (Co-Chair), Brenda Kelley (Co-Chair), Lori Reed-Fourquet, Matthew Barrett, Christine Bianchi (phone), Ellen Burkhart (phone), Matthew Cook, Cindi Delfavero, Sara Diamond (phone), Kate Galambos, Claudio Gualtieri, Pamela Higgins, Karen Joseph (phone), Catherine La Forza (phone), Ellen Makar (phone), John Merz, Sheila Molony, Kathy Null (phone), Mary Ann O’Brien, Nancy Shaffer, Catherine Wagner, Barbara Parks Wolf, Alicia Woodsby, Teresa Younger

CALL TO ORDER  
Mark Masselli called the meeting to order at 3:15 PM. Mark Masselli thanked everyone for attending and invited people to introduce themselves and identify their organization or agency.

Mark Masselli reviewed the meeting minutes from the August 3rd meeting and requested a motion to approve the minutes. Alicia Woodsby reiterated her concern that some key consumer issues (i.e. around “opt-out”) were decided before the committee began meeting and before some key stakeholders were involved in the process. She asked that the September minutes reflect that concern. Motion was properly moved and seconded. The minutes with this amendment were adopted by voice vote. **Motion Passed.**

STATUS UPDATE ON HITE-CT  
Lori Reed-Forquet, the HITE-CT interim Executive Director, provided a status update. Discussions with the proposed vendor continue; the area of focus is on a detailed implementation schedule. Lori Reed-Fourquet also met with a different vendor to discuss a product for immunization information which would be used to identify those in need of immunization.

Lori Reed-Fourquet informed attendees that the Legal/Policy Committee is drafting policies for the Health Information Technology Exchange of CT for stakeholder input.  

*There will be a 30-day comment period for the public and a meeting with the Legal/Policy Committee on September 20, 2011 from 8:30 – 10:00 AM where public comment will be received. She encouraged Committee members to inform their networks about this important comment period.*

*Ten policies have been drafted and will be posted in the Connecticut Law Journal on September 6, 2011 for a 30-day public comment period. Those policies are:*
1. Affinity Domain Policy. (Pending) “This document describes the statewide standard interoperability requirements and specifications including standard content, identification schemes, vocabularies, systems and their interactions to be supported by the Connecticut Health Information Exchange (HITE-CT).” This is a technical policy and will be discussed on September 22, 2011 from 1-3 PM by the Technical Committee.

2. Audit Policy. “The purpose of the policy is to ensure that the security and confidentiality of patient data transmitted through HITE-CT is protected through privacy/security audits.”

3. Identity Management Policy. “The purpose of the policy is to ensure that the identities of the persons and entities interacting with HITE-CT are assured through the performance of tests to enable a data processing system to recognize entities (individuals or machines interacting with the HITE-CT system).”

4. Authentication Policy. “The purpose of the policy is to ensure that systems and persons interacting with HITE-CT system are known through the process of reliable security identification of subjects by incorporating an identifier and its authenticator.”

5. Access Control Policy. “The purpose of the policy is to define who and how individuals and systems can access HITE-CT managed data through a means of ensuring that the resources of a data processing system can be accessed only by authorized entities (individuals or machines interacting with the HITE-CT system) in authorized ways.”

6. Consumer Authorization and Consent Policy. “The purpose of the policy is to define the circumstances in which a consumer can permit or withhold disclosure of HITE-CT accessible health information.”

7. Consumer Principles Policy. “The purpose of the policy is to define consumers’ and patients’ expectations that will govern the design and implementation of health information exchange and technology in Connecticut.”

8. Breach Notification Policy. “The purpose of the policy is to define policy surrounding identification, investigation, notification, and mitigation of a breach.”

9. Purpose of Use Policy. “The purpose of the policy is to define permissible uses of the HITE-CT information such as Patient Care, Public Health, and Quality.”

10. Information Security Policy. “The purpose of the policy is to ensure that the information security is conducted in a manner that protects personal health information and that supports the availability, confidentiality, integrity, and accountability of HITE-CT shared clinical information.”

(The above policies are quoted directly from the CT Department of Public Health web site: http://1.usa.gov/hitectpolicies)
Brenda Kelley introduced the Consumer Partnership for eHealth’s Health Information Technology Consumer Principles (2009) to help continue the dialogue around HITE-CT’s adoption of consumer principles. After some discussion about this document it was determined that the group would work directly off of the newly drafted HITE-CT Consumer Policy. The draft policies were posted on GoToMeeting.com for those attending via phone. However, the group later decided to use the Consumer Principles document for discussion because its language was more consumer friendly. All agreed that once consensus was reached, Lori would incorporate these decisions into the official policy document.

The concept of “opting in” versus “opting out” was discussed at length. Mark Masselli indicated that the HITE-CT Board of Directors decided on an “opt out” approach for “normal” circumstances, with exceptions for specific instances, and that the Committee may express its concern to the Board. Several individuals agreed that informed decision-making was critical, regardless of whether an opt-in or opt-out approach was ultimately adopted. The goal is to make sure that the consumer knows how their information will be used and accessed. Barbara Parks Wolfe suggested that some of the concern about opt-out might be mitigated by the fact that, at least at this point, HITE-CT was not going back and entering historical data. That means there will be a face-to-face opportunity to engage the consumer in the decision before data is included. Lori Reed-Fourquet, however, noted that the decision to include historical data in the future was not specifically precluded and if the Committee wanted to preclude inclusion of historical data in the future it should make that clear.

There was a discussion about whether personally identifiable data should be allowed for research purposes. The committee was split. Matt Barrett suggested that the policy establish a presumption against using personally identifiable data, but then clearly specify exceptions. For example, “personally identifiable information shall never be disclosed except in circumstances specified and those allowed by HIPPA rules” Others on the Committee also noted that completely restricting the use of personally identifiable information could significantly hamper important medical research, especially because things like admittance dates in a hospital and time of stay could be potentially, personally identifiable information.

Matt Cook reminded the Committee that the policy discusses notification of the subject of care, not how the information will be used. The consensus of the group was to revisit the substantive decisions in the future and focus their immediate attention on notification and disclosure policies.

Ellen Maker asked whether the Special Populations Committee would be commenting on the advance notice of proposed rulemaking (ANPRM) from 8/9/2011, metadata standards to support nationwide electronic health information exchange. The Office of the National Coordination for Health Information Technology (ONC) is soliciting public
comments to be submitted by Sept 2. Mark Masselli asked that we restrict discussion to developing CT’s Consumer Principles given tight timeframe under which we are operating. At the next meeting we will provide the members with more information on the federal standards that Ellen referenced.

In the interest of time, the Committee next agreed to limit discussion to the italicized Consumer Principles only, not the detailed sub-bullets within each principle.

**MOTION:** Teresa Younger moved to accept the italicized principles of the Consumer Partnership for eHealth Health Information Technology-Consumer Principles 2009, amended by the group as follows:

*Individuals should be able to access their personally identifiable health information conveniently and affordably.*

- Individuals should have a means of direct, secure access to their electronic health information that does not require physician or institutional mediation.
- Individuals should have access to all electronic records pertaining to themselves (except in cases of danger to the patient or another person).
- Individuals should be able to supplement, request correction of, and share their personally identifiable health information without fees or burdensome processes.

*A consumer shall be notified how their personally identifiable health information may be used and who has access to it.*

*A consumer shall have control over whether and how their personally identifiable health information is shared.*

*Systems for electronic health data exchange shall protect the integrity, security, privacy and confidentiality of an individual’s information.*

*The governance and administration of electronic health information networks shall be transparent, and publicly accountable.*

*Recognizing the potential of electronic patient data to support quality measurement, provider and institutional performance assessment, relative effectiveness and outcomes research, prescription drug monitoring, patient safety, public health, informed decision making by patients and other public interest objectives, systems shall be designed to fully leverage that potential, while protecting patient privacy.*
Implementation of any regional or national electronic health information network shall be accompanied by a significant consumer education program so that people understand how the network will operate, what information will and will not be available on the network, the value of the network, its privacy and security protections, how to participate in it, and the rights, benefits and remedies afforded to them. These efforts shall include outreach to those without health insurance coverage.

Alicia Woodsby seconded the motion. **Motion passed.**

It was agreed that at the next meeting, the Special Populations Committee will focus on developing the bullets under each of the italicized principles.

The issue of how the unique needs of various special populations would be reflected in the consumer principles was raised. Brenda Kelley indicated that California had adopted similar principles, but with more specific special population language. Teresa Younger requested that the Committee receive a copy of the CA document in advance of the next meeting. They are enclosed with these minutes.

**NEXT STEPS -- MEETING SCHEDULE**

Items for the next meeting: It was agreed that the meeting initially scheduled for 9/15 would be cancelled due to several schedule conflicts. The next meeting of the Special Populations Committee will be Thursday, 9/22 from 3 – 5 p.m. An additional half hour was added to the meeting at the request of the Committee. Agenda will include finalizing consumer principles, adding special populations principles, as needed, and addressing how sensitive health information will be handled.

**ADJOURN**

Meeting was adjourned at 4:45 PM