Public Comment for the December 17 meeting of the HIT Advisory Council - Susan Israel, MD

When deciding how the electronic health record will be handled, particularly consumer control over their intimate information, the following need to be considered:

There are such problems with hacking and cybersecurity that the processors of the data must obtain liability insurance. This would include employees of the vendor company and those of the health care oversight agencies who have access to identified EHRs as per PA 15-146, Section 23 (3)[(b)](c)(2) to "limit the use and dissemination of an individual's Social Security number..."and (3) to follow HIPAA 45 CFR 160, 164 which detail how identified medical must be handled.

Re-identification of the so called de-identified data given out to researchers and agencies cannot be prevented. Dr. Latanya Sweeney, who was quoted in the November meeting's article, has shown that even HIPAA compliant de-identified data has a .04% rate of re-identification and Deborah Lafky of Health and Human Services has shown a .22% rate, which would amount to over 7000 patients in CT. Latanya also has shown that 87% of patients can be re-identified just using the full date of birth, gender and ZIP code which are often given out as Limited Data Sets. All you have to do is merge those demographics with the publically available voter registration lists in CT which also contain the date of birth, name (gender) and address. And that is without using the actual accompanying medical information which might allow you to recognize your neighbor who broke her leg in a given year and has MS, etc.

Even de-identified data going to the Dept. of Public Health could potentially be re-identified because the DPH has so many identified patient data bases that it could merge with the HIE data. I do not believe people realize how much data the DPH has on all of us. It has identified hospital discharge data and wants to add out-patient data as well and hopes to obtain smoking and weight data additionally. The Tumor Registry is identified and the DPH can look at any of those patient records it wants. Then, of course, the DPH also has the identified infectious disease and newborn DNA databases, etc.

Additionally, there are plans to merge the EHR with the All Payer Claims Database – APCD which also threatens the privacy of the data in similar ways to merging it with the DPH data, as the APCD has identified enrollment data for example. It just is not possible to possess so much medical information on a person and keep the data from being re-identified. Thus CT citizens need to be accorded the same respect as the citizens of Rhode Island to make their own decisions as to whether or not they wish to take the risks of putting their medical information into the HIE.

References:

1. Health-Care Industry Spending More on Security But Not Ready for Cyberattack. Health IT Law & Industry Report: "... FBI Federal investigators also warned Nov. 9 that cybercriminals are increasingly using sophisticated techniques to gain access to health-care organizations' IT systems. Hackers are "doing their homework" on senior personnel before launching

phishing attacks or other campaigns aimed at accessing the troves of personal data health-care companies store, Donald Good, deputy director of the FBI's Cyber Division, said at the cybersecurity summit. These more targeted attacks can be harder to detect and are resulting in larger and larger breaches of data, he said. …."

2. Anderson N. "Anonymized" data really isn't—and here's why not. Law & Disorder/Civilization & Discontents. Ars Technica; Sep 8, 2009.

3. Sweeney L. Simple demographics often identify people uniquely. Carnegie Melon University Data Privacy Working Paper 3; 2000. & TheDataMAP. Matching known patients to health records in Washington State data; 2012-2013. & TheDataMap. All the places your data may go; 2012-2013. www.thedatamap.org/.

4. Kwok P. Lafky D. Harder Than You Think: A case Study of Re-identification Risk of HIPAA-Compliant Records. 8. Anderson N. "Anonymized" data really isn't—and here's why not. http://www.amstat.org/meetings/jsm/2011/onlineprogram/AbstractDetails.cfm?abstractid=302255.

5. National Committee on Vital and Health Statistics Ad Hoc Work Groups for Secondary Uses of Health Data. Hearing Proceedings; Aug 23, 2007. www.ncvhs.hhs.gov/transcripts-minutes/transcript-of-the-august-2-2007-ad-hoc-workgroup-for-secondary-uses-of-health-data-hearing/.