

From: susan israel <sisrael78@optonline.net>
Sent: Friday, March 6, 2020 10:21 AM
To: OHS.HITO <HITO@ct.gov>
Subject: Public Comment on the Draft Guiding Principles

March 6, 2020

To HITO and the Connecticut Office of Health Strategy:

Public Comment on the Final Report and Recommendations of the Consent Design Workgroup Guiding Principles for the Health Information Alliance/Health Information Exchange

Susan Israel, M.D., member of the Consent Design Workgroup

Thank you very much for this opportunity to give further comment for a wider regulatory process.

The Guiding Principles are fine in themselves for the overall exchange processes, but they do not specifically address, nor ask for comments on, the most crucial issue of moving medical data, which is the consent of the patient to do so. Any such discussion occurs in the Additional Considerations which are outside the body of the report. Thus, it remains unclear whether or not OHS will allow patients to control who can see their medical data and records or even be informed of all those who can access them.

Hopefully, there will be an opt-in (preferably) or an opt-out system installed in the Health Information Alliance so that no medical data will be moved into or through it without the *express* consent of the patient. Patient identifiers and provider matching lists must be a "use case" that requires consent, not entered automatically. This would follow the original HIE legislation for patients to list their providers, not for their providers list their names with the State of CT through the HIA.

Likewise, no medical records, including Clinical Care Summaries and Admission/Discharge/Transfers, etc., would be transferred through or into the exchange without the specific permission of the patient. This express consent of the patient could not be supplanted by any implied consent from just engaging in medical care where, without further consent and knowledge according to HIPAA since 2003, there can be the sharing of data between providers (covered entities) and their business associates for treatment, payment and health care operations.

The mandated, identified medical data sent by providers to the Office of Health Strategy and the Department of Public Health must require patient consent to be moved through any exchange or any system where business associates will see their identified data. The method of movement and handling of these identified, intimate data must be transparent to citizens, because they include infectious diseases, outpatient surgical and inpatient discharge summaries, tumor registry data, quality control metrics, CDAS and the All Payer Claims (health insurance) Data.

A discussion of the State of CT and medical data must include the HIA's consideration to include the Prescription Drug Monitoring Program, which besides opioids, includes some psychiatric medications, with the name of the prescribing provider and the date. This identified information is entered into a centralized data base to which many have access: business associates, providers, pharmacists, state

oversight, law enforcement, and even other states. It does follow the HIPAA rules for confidentiality, but this is not what most people would consider privacy to be.

Additionally, the HIA may incorporate a centralized data base which will include all of a patient's medications. But will this data base be created with or without the patient's express consent? Or will providers, pharmacies and business associates be allowed to share one's medications in such an expansive way, without further consent just because one engaged in treatment?

Hopefully, the Office of Health Strategy, through the creation of the HIA, will become a proponent of patient consent.

From: susan israel <sisrael78@optonline.net>

Sent: Monday, March 9, 2020 1:30 PM

To: OHS.HITO <HITO@ct.gov>

Subject: RE: Public Comment on the Draft Guiding Principles

Hi Tina,

Thank you for the acknowledgement.

I do not know if you can respond to this concern now. I would wish that all of what I wrote be communicated to the full IT Advisory Council in some way. I am concerned that just excerpts (as was done regarding APCD comments) might not convey adequately the issues I raised. Thanks.
