**From Susan Israel**:

"We were told at our meetings previous to yours that no data would be sent by the first use case. That is was just for identity and care mapping, meaning linking with one's providers. You seemed to be saying something different regarding different kinds of data. I am not sure if I heard you correctly to say that episodic care data would be exchanged without additional patient consent more than agreeing to receive care from a provider. And you mentioned that Public Health data would be sent without further patient consent to be in the HIE."

If this is a correct understanding of what Allan said, then I have the following questions/concerns:

What exactly does the first use case entail and what are the limits or not of its use? It does not seem that OHS has the intention that there would be any consent for patient identities to be included, linked to their providers and used to send data to OHS and other providers? (It needs to be worked out how discharge summaries and other mandated data will be sent & apparently without consent).

Is there really no complete opt-out of the HIE allowed? And which use cases would be subject to non-implied consent?

What is the difference between notification and consent? Because the HIPAA forms that patients are asked to sign are just to inform patients what can be done with their data without their consent and patients do not have to sign them because they are notifications? Is there the issue of implied vs specified consent?

Patients are the ones not to give their provider names to the HIE? (Allan said that for psychiatry, HIV, substance abuse, 42 CFR Part 2 may keep that information from being transmitted to the HIE for now.) But what if a patient does not want their dermatologist to know that they just had an abortion that could go through to providers as a care summary without consent?

Will there be a group of people who will be tasked with creating the identity key at the outset and then all data through the HIE will be transferred with the key and without the names?

Also, a clinical care summary is still very full data even if it is not the the longitudinal record, because it would probably include a problem list, medications and maybe past history information, etc.

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**From Pat Checko**:

1. For the most part I agree that the patient consent process should occur at the point of service (the provider) and be implicit, (i.e. with acceptance of service) for all use cases that are based on the three major HIPAA allowances. Any use cases that do not fall under these should have some mechanism for patient consent. TEFCA is releasing their new guidelines soon. Use cases should meet these conditions as they are created and adopted. The TEFCA discussion of Meaningful choice should also be considered.

2. A major reason for creating the HIE is to increase patient access to their EHR and to be able to share it with their loved ones, caregivers, etc. The recommendations do not address how that will be made possible, or even the patient's access to their own information (the longitudinal record).

3. A component of the recommendations address the "patient responsibilities". Given the dearth of information and discussion of that issue and the patient role in the EHR and HIE itself, it is not possible to comment on what that should look like. However, it needs to be taken into consideration before the first exchange of data occurs.

4. Under the HIE Governance Plan. The Privacy and Use Case deliberations and creation fall under the control of a special committee composed of users (sharers?) exclusively. I have concerns that while they will certainly take into consideration the important issues to data sharers and users, that the consumer and public health (not the agency) aspects of the use cases may not be addressed and have no advocates on the committee. I feel strongly that there either needs to be external members representing these groups within the governing body or through the HIT Advisory Board to serve this function.

5. We are at the infancy of the CT HIE and much will change as we progress to full implementation, but we need to keep in mind that we have set the patient as the North Star for our endeavors and not lose track of that commitment.

6. Would like to learn more and discuss how the HIE and Population Database fit together, including where data comes from to populate the later.