

Oral Testimony
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Privacy & Security Tiger Team Hearing on Non-targeted Query

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Thank you for the opportunity to present to you today. Before I start my discussion regarding non-targeted queries, I wanted to give you some background on ClinicalConnect Health Information Exchange. ClinicalConnect is western Pennsylvania's first Health Information Exchange. It is a partnership of nine regional health systems which include 30 acute care hospitals and over 3000 physicians. Recent new participants include a post-acute care pediatric rehabilitation organization, three post-acute skilled nursing facilities and an independent fifty member private pediatric physician group. ClinicalConnect has been operational since June 2012.

Access to the information in ClinicalConnect is coordinated through a participant's electronic health record system (EHR). In order for a participant to make a request to ClinicalConnect for a patient's information, the patient must be registered in the participant's EHR. If not, then the request cannot be made to ClinicalConnect. Further, since the request is initiated through the participant's EHR, the individual requestor must be registered as a user of the participant's EHR. Once the user has logged into the participant's EHR and a patient has been selected, EHR can make a request to ClinicalConnect for information related to the patient. If there is information related to the patient, ClinicalConnect provides the information.

The Clinical Connect model has a number of advantages. Most notably, by requiring the participant to utilize its EHR to "front-end" requests to ClinicalConnect, there is a high level of assurance that:

1. The patient has a current relationship with the provider.
2. The patient has been informed of ClinicalConnect and has had the opportunity to Opt-Out (based on Pennsylvania law).
3. The user has the need to access the information in question (since the user must first access the patient's record within the EHR, consistent with the role-based access controls already implemented by the provider).
4. The EHR, other monitoring systems and processes implemented by the participant can monitor access to ensure that it is appropriate (based on the controls already developed by the provider).

With respect to the questions that you posed, I wanted to answer a number of them that I feel are particularly germane to how ClinicalConnect operates.

4. What additional limits are placed on non-targeted queries?

As noted above, who can query ClinicalConnect is controlled at the participant level based on a user having the appropriate security to view that patient record within the participant's EHR. Purpose and scope are defined in the ClinicalConnect Data Exchange Agreement as limited to treatment, payment and operations, public health activities and reporting as permitted by HIPAA, and reporting on quality measures as defined by "meaningful use" under ARRA and HIPAA.

5. What roles do patients have in limiting queries?

Under Pennsylvania Act 121, Pennsylvania is an Opt-Out state. A patient is given an opportunity to "opt-out" when he/she registers for services at a provider's facility. The patient's preference is then passed electronically to ClinicalConnect and managed centrally. Access to the patient information within ClinicalConnect is then blocked until/unless the patient later chooses to opt-in.

6. How do patients exercise "meaningful choice" as to whether their records are included in your "aggregator service"? Does this extend to the release of data or does that require additional consent?

ClinicalConnect requires that each participant make a standard "Notice of Privacy Practices Addendum" available to its patients. This addendum describes "ClinicalConnect" and how the patient's information will be managed and exchanged.

Regardless of whether the patient has "opted out", the patient's information is sent by each participant to ClinicalConnect. However, if the patient has "opted out", ClinicalConnect will not provide the patient's information in the event of a query. This model is based on ClinicalConnect being a business associate of each participant. This model is designed to ensure that patient information can be made quickly available, should a patient choose to "opt-in" after having previously "opted-out".

7. How do you address exchange of sensitive information in a non-targeted query model?

Currently, technical capability and standards within the industry that support the exchange of sensitive information are limited. As a result, ClinicalConnect instructs its participants not to send sensitive information to ClinicalConnect, especially where statutes impose additional restrictions on the disclosure of information. In light of these limitations, where the patient has concerns regarding access to their information, including sensitive information, the patient is advised of his/her ability to "opt-out".

10. What challenges/problems have been created by your approach? What adjustments have you or do you plan to make to your approach?

Our approach requires that each participant uses an EHR and has the technical support/resources necessary to integrate the previously described opt-out and record request processes into its EHR. No adjustments are planned at this time.