

Overview of the Workshop Process: What Does This All Mean?

Illinois Patient Consent Management Workshop

Wednesday, June 26th

10:00am – 3:00pm



Illinois Patient Consent Management Workshop



Why Are We Here (non metaphysically speaking)?

- The Illinois Health Information Exchange (ILHIE) Authority is beginning the process of developing the privacy, security and consent policies that will govern the exchange of patient data, utilizing health information exchange in Illinois.
- An immediate goal of this effort is to enable health care providers to electronically exchange patient health information in a secure environment that protects patient privacy and confidentiality.
- This Patient Consent Management Workshop is an opportunity for health care stakeholders to provide input and recommendations on possible privacy, security, and consent management policies to govern health information exchange in Illinois.
- These policies include those that the ILHIE Authority is required to consider pursuant to a recent amendment to Illinois' Mental Health Confidentiality Act.

Overarching Objectives



- Define the form of patient “opt-out” consent for the exchange of patient health information through the ILHIE and other Illinois HIEs.
- Establish a credible and reliable statewide consent process so that patients and providers have a clear understanding of how patient “opt-out” consent works and consent processes are implemented and administered seamlessly.
- Provide and promote ongoing consumer and provider education and foster ongoing constructive stakeholder engagement and support so that HIEs, in general, and the ILHIE, in particular, are widely used tools of health care.

This Workshop's Objectives



- Provide participants with an overview of:
 - The consent requirements in the Patient Choice and Data Sharing amendment to the Mental Health and Developmental Disabilities and Confidentiality Act (HB1017) and the relevant capabilities of the Illinois Health Information Exchange (ILHIE) technical platform.
 - The ILHIE's stakeholder engagement process for the development of a statewide approach to patient consent management.
- Foster participant engagement in the process of developing a statewide approach to patient consent
- Identify additional issues for consideration by ILHIE governance bodies and subject matter Work Groups.

Stakeholder Participation



- The ILHIE Authority has invited – and will continue to encourage - interested health care stakeholders to participate in any of three Work Groups that will be convened today to provide recommendations that will ultimately be proposed to the ILHIE Authority Board on the management and implementation of ILHIE privacy, security and consent.



Remainder of Today



Agenda

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| 10:15-11:00am | Patient Choice and Data Sharing – Overview HB1017
Q&A |
| 11:00-12:00am | ILHIE Technical Platform Overview & Demonstration
Strategic Health Advanced Research Projects (SHARPS) Presentation |
| 12:00-12:30pm | Overview – Patient Consent Protocol Work Groups
Patient Choice and Meaningful Disclosure
Patient Consent Preferences and Data Security
Breach Response Protocol |
| 12:30pm | Public Comment |

Adjourn/Lunch Break

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| 1:30pm | Break-Out Work Group Sessions |
| 2:30pm | Public Comment |

Adjourn



Key Responsibilities in relation to Patient Choice



Patient = Exercise choice

Provider = Meaningful Disclosure

Provider = Determine purpose of PHI

Provider = Register and transmit choice

ILHIE – Meaningful Disclosure

ILHIE = Register and transmit choice

ILHIE = Transmit PHI



A wise person once said ...



“Patients should have a choice about whether their health data should be in an HIE or not. I do not believe that most consumers are, or want to be, fully informed about data security and privacy issues and protocols for HIEs. I’m not saying they don’t want to know anything: I’m just saying they don’t want to know everything. They are not stupid or uncaring. They are smart enough to know that the details are many and complex. They care enough to want reasonable assurances that someone else understands the details and can be trusted.”

- Testimony of a self-described “Consumer guy” to the ILHIE Data Security and Privacy Committee on June 27, 2012.

Let the trust building begin ...

