

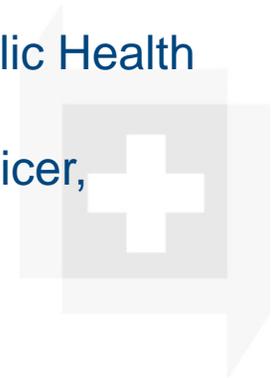


Patient Choices and Meaningful Disclosure Work Group

Illinois Patient Consent Management Workshop
Wednesday, June 26th

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Southern Illinois Healthcare
Co-Chairs



Agenda



- **Definition of Key Terms**
- **Directives**
- **Deliverables**
- **Major Activities**
- **Adoption Timeline**
- **Handouts**
- **Stakeholder Role**
- **1st Meeting Agenda**



Patient “Opt-Out” Choice



Consent policy adopted by the ILHIE Authority for the exchange of PHI through the ILHIE.

- Allows PHI maintained by health care providers and organizations participating in the ILHIE to be automatically accessible through the ILHIE unless a patient “opts-out” that is, exercises his or her choice to deny access to all such information through the Exchange.
- If patients do not exercise the right to opt-out, their PHI can be transmitted through the ILHIE.
- A patient can elect to opt-out or revoke the opt-out choice (that is, opt back in) at any time.

Meaningful Disclosure



The process and the content of the process by which patients are educated and informed by their providers at the point of care so as to make a meaningful and informed decision about whether or whether not to participate in an HIE. The content of this information will be about:

- Health information exchange (HIE);
- How and with whom their PHI will be shared in or through an HIE; and
- Their rights to expressly decline any further disclosure of their PHI by an HIE to third parties.



Regarding Patient “Opt-Out” Choice

- Define the form of patient opt-out consent;
- Recommend a set of appropriate rules, standards and obligations that the ILHIE and its participants shall adopt and implement to meet the statutory requirement that each patient or recipient whose health record is accessible through an HIE shall be provided a reasonable opportunity to:
 - Expressly decline the further disclosure to third parties of PHI by the HIE, except to the extent permitted by law; and
 - Revoke a prior decision to opt-out or decision not to opt-out.

Regarding Meaningful Disclosure

- Define the form and content of meaningful disclosure for HIEs in Illinois.
- Identify and recommend issues and topics that should be addressed by providers at the point of care
- Develop tools, materials and other resources for use by providers to ensure that patients receive meaningful disclosure about HIEs and their rights with respect to the disclosure of their PHI by an HIE to other providers or third parties.

Regarding Patient “Opt-Out” Choice

- HIE policies and procedures establishing best practices for patient opt-out consent management.
- Template patient opt-out and revocation forms for use by providers at the point of care.
- Regulatory language for use in the administrative rule making process around the issue of patient opt-out choice.



Regarding Meaningful Disclosure

- Template language for NPPs or other deliverables to be given to patients at the point of care around the issues of opt-out consent and meaningful disclosure, including written notice of a patient's right to opt-out of an HIE, which directs the person to an HIE website containing an explanation of the purposes of the HIE and instructions on how to opt-out of participation.
- Recommendations for HIE website content and audio, visual and written instructions regarding how to opt-out of participation in an HIE.
- Regulatory language for use in the administrative rule making process around the issue of meaningful disclosure to patients.

Major Activities

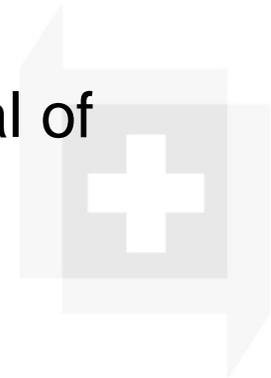


- Discussions with and data collection from ILHIE participants and other HIE stakeholders about opt-out consent management, policies, forms and the content of disclosures.
- Review and analysis of information gathered from ILHIE participants and other HIE stakeholders and from the ILHIE's comprehensive survey of other opt-out State HIEs.
- Identification of best practices to be incorporated into ILHIE policies, forms and disclosures.
- Drafting, discussion and revision of ILHIE's proposed policies, forms and disclosures.

Timeline



- July/Aug 2013 – Work Group’s Performance of its Major Activities
- Aug/Sept 2013 – Data Security & Privacy Committee and Regional HIE Work Group meetings and approvals of the ILHIE’s proposed policies, forms and disclosures for patient opt-out consent and meaningful disclosure
- Sept 2013 – Status report to the ILHIE Authority Board
- Nov 2013 – ILHIE’s Authority Board’s approval of ILHIE’s policies, forms and disclosures



Work Group Handouts



- Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure
- ILHIE's Draft Patient Opt-Out Choice and Meaningful Disclosure Policy
- Electronic Handouts (posted on ILHIE website) including:
 - Opt-Out State HIE Forms, Policies, Meaningful Disclosure Materials and Website Content
 - Opt-Out State HIE Survey Document
 - ILHIE Data Security and Privacy Committee's Links to Patient Consent Materials and Report of Preliminary Findings and Recommendations (September 19, 2012)



Stakeholders' Roles



- Collaborate with ILHIE Authority staff, Work Group members and other stakeholders in carrying out the Work Group's directives and meeting its major activity objectives.
- Lending each stakeholder's unique perspective, knowledge, training and experience to the task of creating the ILHIE's standards and policies around Patient "Opt-Out" Choice and Meaningful Disclosure.
- Attending Work Group meetings and undertaking tasks assigned by the Work Group Co-Chairs until such time as the Work Group's major activity objectives have been achieved.



Work Group Meeting Agenda



- Co-Chair Introductions
- Membership and Contact List Formation
- Distribution and Explanation of Handouts
- Assignments and Timeline Goals
- Discussion and Q&As

