
Patient Choice and Meaningful Disclosure Work Group: Meaningful Disclosure at the Point of Care Subgroup

Action Plan

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Objectives: Define the scope of patient opt-out choice at the point of care and make a set of policy recommendations that HIEs and their participants will implement to meet the statutory requirement that every patient whose health record is accessible through a HIE shall be provided a reasonable opportunity to expressly decline the further disclosure of their PHI by the HIE, except to the extent permitted by law, and to revoke their prior decision to opt-out or not opt-out of a HIE.

Define the scope and content of meaningful disclosure regarding HIE at the point of care, identify issues about HIE that should be addressed at the point of care and develop resources for use by providers at the point of care to ensure that patients receive meaningful disclosure about HIE and their rights with respect to the disclosure of their PHI by means of HIE to other providers or third parties.

Deliverables: Policy Recommendations for Patient Choice and Meaningful Disclosure at the Point of Care
Statutory Notice Required under HB1017
Recommendations for Amendments to Notice of Privacy Practices
Opt-Out Form and Revocation of Opt-Out Form

Resources¹: ILHIE Authority Data Privacy and Security Committee Report (09/19/12)
HB1017 Amending the Mental Health and Developmental Disabilities Confidentiality Act
Multi-State HIE Opt-Out Survey Resources (zip file)
Patient Choice and Meaningful Disclosure Policy Draft

¹ Resources are available at: <http://www2.illinois.gov/gov/HIE/Pages/PCMDWorkGroup.aspx>.

Excerpts from “Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure”

DRAFT for August 20, 2013 Meeting

1. Collection of patient “opt-out” at provider point of care

Preference: The provider at the point of care is responsible for providing its patient with the opportunity to opt-out, including the distribution, collection and processing of opt-out forms.

“Provider” means the party (i.e., “Subscriber” or “Participant”) with which the ILHIE Authority enters a contractual arrangement for participation in the ILHIE. A provider may be an individual or an organization.

a. Frequency of collection

Preference: Once per provider, per patient.

b. Duration

Preference: A patient’s “opt-out” choice is perpetual until revoked or changed.

c. Documentation

Preference: Provider will distribute, collect and maintain documentation of a patient’s opt-out preference, including any written consents as may be required for “specially protected” patient health information, in accordance with the provider’s own policies for the collection and maintenance of patient opt-out preferences. ~~It is anticipated that t~~The ILHIE Authority, through its Patient Choice and Meaningful Disclosure Work Group, will facilitate the creation of template forms for distribution and use by providers in documenting patient opt-out preferences.

d. Transmission to ILHIE

Preference: An ILHIE participant will send an electronic message (IHE standard) notifying the ILHIE of a patient’s decision to opt-out, triggering an “electronic flag” for that patient in the ILHIE’s Master Patient Index (MPI). If the ILHIE participant’s system is unable to send an electronic message in the prescribed IHE standard, the provider will have access to a secure website that will enable the entry of a patient’s opt-out decision into the ILHIE’s MPI.

e. Reconciliation

Preference: The last in time (i.e., the most current) consent preference on record with the ILHIE will govern all disclosure of information by the ILHIE for any particular patient.

f. Revocation

Preference: A patient may elect to revoke a prior opt-out, that is, opt back in to the ILHIE at any time by requesting that any of his or her ILHIE-connected providers reverse the patient's last recorded opt-out choice. The provider will send an electronic message (IHE standard) or use the provider website provided by the ILHIE to notify the ILHIE of the patient's updated preference, thus reversing the consent flag for that patient in the ILHIE's MPI.

2. Collection of patient "opt-out" at HIE

a. Storage at HIE

Preference: The ILHIE will maintain its MPI as a central registry of patient consent preferences. The ILHIE will not collect or store opt-out forms, which documentation will be collected and maintained by a patient's provider at the point of care in accordance with the provider's own policies for the collection and maintenance of patient opt-out preferences.

b. Patient Access

Preference: Currently, there is no electronic patient portal for the communication and receipt of a patient's opt-out consent preference at the level of the ILHIE. The ILHIE Authority will consider the feasibility of enabling this functionality, including concerns regarding the authentication of individuals.

c. Revocation

Preference: The ILHIE will maintain its MPI as a central registry of patient consent preferences. Initially, access to the ILHIE's MPI will be available to providers participating in the ILHIE. Direct patient access to ILHIE's MPI for the management of their own consent preference may be made available at a future date. The ILHIE will not collect or store revocation of opt-out forms, which documentation will be collected and maintained by a patient's provider at the point of care in accordance with the provider's own policies for the collection and maintenance of patient opt-out preferences.

3. Data filtering triggered by "opt-out"

a. At Provider EHR

Preference: Providers who have received a patient's opt-out preference will honor this preference and ensure that notice of a patient's opt-out has been communicated to the ILHIE.

b. At ILHIE

Preference: The ILHIE's MPI will be the central registry of patient opt-out preferences in Illinois. All HIEs in Illinois will use ILHIE's MPI as the single source of information for applying patient consent preferences when handling patient data so that the opt-out choice

applies to all providers. When a request comes in from a provider to the ILHIE for the purpose of obtaining an aggregated report about a particular patient, the MPI flag will be queried. If the patient has exercised an opt-out, an aggregated document will not be transmitted. Instead, consistent with the patient's reasonable expectations, a message will be sent to the requesting provider that there is "no information available."

c. At Regional HIEs

Preference: The ILHIE Authority, in collaboration with the Regional HIEs, will evaluate and identify mechanisms for ensuring that patient consent preferences are accurately and consistently applied and recognized across all HIEs in Illinois.

4. Data filtered by "opt-out"

a. Global

Preference: Data filtering as a result of a patient opt-out is global, meaning all data from all sources available through the ILHIE will be unavailable for disclosure, except as permitted by law, such as in the case of public health reporting.

5. Meaningful Disclosure at Provider Point of Care

Preference: The provider at the point of care is responsible for providing its patients with meaningful disclosure, ~~including the distribution of a provider's Notices of Privacy Practices containing consisting of~~ a description of the health information exchange ILHIE and a patient's opt-out choice. Providers will provide patients with meaningful disclosure at the patient's first encounter with a provider who has become a participant in the ILHIE. ~~It is anticipated that t~~The ILHIE Authority, through its Patient Choice and Meaningful Disclosure Work Group, will facilitate the creation of template meaningful disclosure notices, ~~sample language for Notices of Privacy Practices~~ and other best practice "tool kit" materials including sample suggested language for a provider's Notice of Privacy Practices for distribution and use by providers in providing patients with meaningful disclosure.

a. Content required

Preference: Providers will provide their patient with meaningful disclosure regarding (i) health information exchange (HIE); and (ii) a patient's right to opt-out of disclosure in an HIE. The ~~ILHIE~~ Authority will have resources available on its website to assist providers in meeting their meaningful disclosure obligations.

b. Form of Disclosure

Preference: Providers will provide patients with written notice, ~~which may be included in the form of a provider's Notice of Privacy Practices~~, describing health information exchange and a patient's right to opt-out. Written notice will be provided in the form of a standalone document, and providers are encouraged to include additional notice in the provider's Notice of Privacy

Practices. In accordance with their own policies for meaningful disclosure regarding health information exchange and patient opt-out rights, providers may will also provide patients with additional written notice materials of concerning health information exchange and a patient's right to opt-out which directs the patient to a health information exchange website containing (i) an explanation of the purposes of the health information exchange; and (ii) audio, visual, and written instructions on how to opt-out of participation a health information exchange. Providers will also prominently display signage that briefly describes health information exchange, patient opt-out rights, and that identifies the ILHIE website. The ILHIE Authority on its website will make available at no cost to providers sample signage translated into appropriate languages. Providers may also utilize additional written signs, posters, brochures, pamphlets, website postings, Q&As, audio-visual information and oral briefings to educate patients about health information exchange and patient opt-out rights.

c. Patient Acknowledgement

Preference: Providers may require their patients to execute an acknowledgement of receipt of meaningful disclosure for inclusion in the patient's medical record in accordance with the provider's own policies for meaningful disclosure regarding health information exchange and patient opt-out rights.

MAP:mp