



Policies and Procedures
TOPIC: Patient Opt-Out Choice and Meaningful Disclosure
Policy #: TBD
Effective Date: TBD

## I. BACKGROUND AND PURPOSE

The purpose of this policy is to describe how at the point of care the consent decisions of patients to participate or not participate in the Illinois Health Information Exchange (ILHIE) may be meaningfully exercised. The policy will also describe how these consent decisions by patients may be subsequently changed.

For the purposes of this Policy and Procedure, “provider” means the party (i.e., “Subscriber” or “Participant”) with which the ILHIE enters a contractual arrangement for the provider’s participation in the ILHIE. A provider may be an individual or an organization.

## II. POLICY

The ILHIE will offer all patients a meaningful and informed way to decide whether to participate or not participate in its State-wide health information exchange. This patient consent process will be governed by an “Opt-Out” policy and administered by providers ~~and provider organizations~~ at the point of care. This means that all patients of a provider ~~or provider organization~~ that participates in the ILHIE will be automatically enrolled in the ILHIE, and no affirmative action will need to be taken by patients to establish their consent, unless a patient’s personal health information contains categories of “specially protected” health information requiring specific written authorization under Federal and State laws. A patient shall be deemed to have given his or her consent to participate unless and until the patient affirmatively opts-out of the ILHIE.

To ensure that patients are able to make meaningful and informed choices about their participation in the ILHIE, each patient will receive a written Notice from his or her participating provider ~~or organization~~ during the first patient encounter after the participating provider ~~or organization~~ enrolls in the ILHIE. This Notice will be developed and approved by the ILHIE and will explain the function of the health information exchange, the purposes for disclosure of the patient’s protected health information to other participating ~~providers-individual practitioners~~ or organizations, and the potential benefits and risks of participation in the exchange.

If a patient does not opt-out of the ILHIE, his or her protected health information will generally be disclosed in response to a specific request, or query, made by a participating provider ~~or organization~~ for a permissible purpose. However, a patient’s protected health information will not be disclosed in response to such a query when it contains “specially protected” health information unless specific written authorization is given by the patient to the participating provider ~~or organization~~ for the disclosure of such information in the ILHIE or the participating

provider ~~or organization~~ can ensure that no such information will be available through the ILHIE.

A patient who does not want his or her protected health information to be disclosed to other participating ~~providers individual practitioners~~ or organizations may opt-out by following the procedures below. If a patient does opt-out, his or her protected health information will not be disclosed through the ILHIE for any purpose except as permitted by law such as public health reporting.

A patient may decide at any time to change his or her consent preference to participate or not to participate in the ILHIE, including the revocation of a prior decision to opt-out of participation in the ILHIE.

### III. PROCEDURES

#### A. Patient Procedures.

1. No action is needed by a patient of a participating provider ~~or provider organization~~ if he or she wishes to participate in the ILHIE. A patient shall be deemed to have given his or her consent to participate unless and ~~unless-until~~ the patient affirmatively opts-out of the ILHIE. These alternatives shall be collectively referred to herein as the patient’s consent decision.

2. Every patient must receive a Notice about the ILHIE from his or her participating provider ~~or organization~~ during his or her first encounter with that provider ~~or organization~~ after ~~the provider it enrolls-joins~~ in the ILHIE. This Notice must be provided in writing, and in the form developed and approved by the ILHIE which explains:

- (i) the ~~purposes and~~ function of the ILHIE;
- (ii) the purposes for which a patient’s protected health information may be disclosed to other participating ~~providers individual practitioners~~ or organizations through the ILHIE;
- (iii) the types of protected health information which may be disclosed to other participating ~~providers individual practitioners~~ and organizations;
- (iv) the need for the patient’s specific written authorization to disclose certain categories of “specially protected” health information ~~in accordance with applicable law~~;
- (v) the fact that a patient’s personal demographic information will be included in a Master Patient Index maintained by the ILHIE to permanently record his or her consent decision;
- (vi) the potential benefits and risks of participation in the ILHIE; and
- (vii) the fact that a patient’s participation in the ILHIE is voluntary and subject to a patient’s right to opt-out, ~~including audio, visual, and written instructions on how to opt-out of participation in the ILHIE in whole or in part to the extent possible~~.

3. An identical Notice about the ILHIE will be available to patients on-line at the ILHIE’s website.
4. The identity of each patient receiving the Notice must be verified by the participating provider ~~or organization~~, including the accuracy of all personal demographic information of that patient.
5. A patient may opt-out of participation in the ILHIE by any of the following means:
  - (i) completion and submission of the ILHIE opt-out form during a visit or encounter with his or her participating provider, through his or her participating provider or organization. Alternatively,
  - (ii) acquiring the opt-out form on the ILHIE website and submitting the completed, notarized form  
a patient may opt out upon the submission of a notarized opt out form available on the ILHIE’s website. The notarized form may be submitted to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic communication.
  - (iii) If available at a future date on the ILHIE’s website, the patient may opt-out by registering his or her opt-out decision on-line.
- ~~6.~~ A patient may opt out of the health information exchange during a visit or encounter with his or her participating provider ~~or organization~~.
- ~~7.~~ Prior to opting-out, a patient must first be presented with a copy of the ILHIE’s written Notice.
- ~~8.~~ After a patient’s identity has been verified by the participating provider ~~or organization~~, ~~and after the patient has been presented with a copy of the written Notice, then~~ a patient may opt-out of participation in the ILHIE by executing a standard opt-out form developed and approved by the ILHIE for use by participating providers ~~and organizations~~ to document the patient’s opt-out decision.
- ~~8.~~ A patient may choose to opt-out at any time, even after having already been enrolled in the ILHIE. However, any exchange of protected health information that may have occurred prior to a patient’s decision to opt-out will not be reversed.
- ~~9.~~ A patient may revoke his or her decision to opt-out of the ILHIE by any of the following means:
  - (i) completing a written revocation form available from his or her participating provider or organization. Alternatively, a patient may revoke an opt out decision upon the submission of a notarized revocation of opt out form available on the ILHIE’s website. The notarized form may be submitted to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic communication. If

- available at a future date on the ILHIE's website, the patient may revoke his or her decision to opt-out by registering his or her revocation decision on-line.
- i) completion and submission of the ILHIE revocation opt-out form during a visit or encounter with his or her participating provider.
  - ii) acquiring the revocation opt-out form on the ILHIE website and submitting the completed, notarized form to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic communication.
  - iii) If available at a future date on the ILHIE's website, the patient may revoke his or her decision to opt-out by registering his or her revocation decision on-line.

140. Once the revocation form has been executed by the patient and communicated to the ILHIE by the patient's participating provider ~~or the patient or organization~~, he or she will be enrolled in the ILHIE from that date forward.

121. A parent or legal guardian may express the consent decision of a minor child under the age of 18 to opt-out of the ILHIE ~~only by any of the following means: through the minor child's participating provider or organization or through the submission of a notarized opt-out form available on the ILHIE's website. The notarized form may be submitted to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic communication.~~

- (i) completion and submission of the ILHIE opt-out form during a visit or encounter with minor child's participating provider.
- (ii) acquiring the opt-out form on the ILHIE website and submitting the completed, notarized form to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic communication.

If deemed necessary by the participating provider ~~or the ILHIE or organization~~, a parent or legal guardian may be required to present the provider ~~or the ILHIE or organization~~ with a proof of legal guardianship or other legal authority to act on behalf of a child.

123. A minor may be presumed legally capable of making his or her own consent decision when seeking treatment for mental health and behavioral services, substance abuse, birth control, prenatal care, ~~or~~ a sexually transmitted disease, or other treatment or services that the minor is authorized to receive under the law without the consent of a parent or legal guardian.

134. Upon reaching the age of majority, a patient whose consent decision was previously expressed by his or her parent or legal guardian will be given the opportunity to exercise his or her own consent decision in accordance with the procedures outlined in paragraphs 1 through 11 above.

B. Participating Provider ~~and Organization~~ Procedures.

1. Each participating provider ~~or organization~~ must provide every patient with a Notice about its, his, or her participation in the ILHIE during the patient’s first visit or encounter with that participating provider ~~or organization~~ after the provider joins it enrolls in the ILHIE. This Notice must be provided in writing, and in the form developed and approved by the ILHIE which explains:

- (i) the purposes and function of the ILHIE;
- (ii) the purposes for which a patient’s protected health information may be disclosed to other participating ~~providers individual practitioners~~ or organizations through the ILHIE;
- (iii) the types of protected health information which may be disclosed to other participating ~~providers individual practitioners~~ or organizations;
- (iv) the need for the patient’s specific written authorization to disclose certain categories of “specially protected” health information in accordance with applicable law;
- (v) the fact that the patient’s personal demographic information will be included in a Master Patient Index maintained by the ILHIE to permanently record his or her consent decision;
- (vi) the potential benefits and risks of participation in the ILHIE; and
- (vii) the fact that a patient’s participation in the ILHIE is voluntary and subject to a patient’s right to opt-out, including audio, visual, and written instructions on how to opt-out of participation in the ILHIE in whole or in part to the extent possible.

2. This written Notice ~~may will~~ be provided to the patient as a standalone document. Each provider is encouraged to provide additional information as an addendum or inclusion? to the participating provider’s ~~or organization’s~~ HIPAA Notice of Privacy Practices. The participating provider ~~or organization~~ is encouraged to record the delivery of the ~~amended?~~ written Notice in the patient’s medical record.

3. The participating provider will prominently display the ILHIE signage that briefly describes health information exchange, patient opt-out rights, and that identifies the ILHIE website.

4. The participating provider ~~or organization~~ is encouraged to ~~may also include post~~ a copy of the Notice on its own website, if any. ~~The provider may and~~ display and make available any other written ~~materials notice~~ made available by the ILHIE in a public area of the participating provider’s or organization’s facility.

45. The identity of each patient receiving the Notice must be verified by the participating provider ~~or organization~~, including the accuracy of all personal demographic information of that patient.

65. If the patients ask questions about the ILHIE, the participating provider ~~or provider's designee (e.g. HIPAA Privacy Officer)~~ ~~or organization~~ must verbally counsel the patient about the contents of the Notice. The goal of such counseling will be to educate the patient about the potential benefits and risks of participation in the ILHIE, while at the same time, to fully respect the individual consent decision expressed by the patient. ~~The provider may refer the patient to the provider's HIPAA Privacy Officer or other appropriate individuals.~~

67. Once a patient has been provided with a copy of the written Notice by a participating provider ~~or organization~~, it is not necessary for that provider ~~or organization~~ to repeat the process.

87. If a patient elects to opt-out of the ILHIE during the patient's visit or encounter, and the patient's identity has been verified by the participating provider ~~or organization~~, the provider ~~or organization~~ will require the patient to document his or her decision to opt-out by utilizing the standard opt-out form developed and approved by the ILHIE. A copy of this opt-out form will be kept and maintained by the participating provider ~~or organization~~ in the patient's medical record in accordance with the provider's ~~or organizations own~~ policies and applicable law governing record retention.

89. A participating provider ~~or organization~~ must allow a patient to opt-out at any time, even after having already been enrolled in the ILHIE. However, any exchange of protected health information that may have occurred prior to a patient's decision to opt-out will not be reversed.

109. If requested, a participating provider ~~or organization~~ will assist the patient in revoking his or her decision to opt-out of the ILHIE. The provider ~~or organization~~ will supply the patient with the standard revocation form developed and approved by the ILHIE. The participating provider ~~or organization~~ will keep and maintain a copy of this signed revocation form in the patient's medical record in accordance with its own policies and applicable law governing record retention.

1140. Once the revocation form has been executed by the patient and communicated ~~by the participating provider or organization~~ to the ILHIE, he or she will be enrolled in the ILHIE from that date forward.

124. Participating providers ~~and organizations~~ who have agreed to requests made by their patients for restrictions on the disclosure of "specially protected" health information under Federal and State law, such as information regarding mental and behavioral health, alcohol and substance abuse treatment, HIV/AIDS testing and genetic testing, will honor those requests and ensure that their EHRs, if capable, will not make such information available through the ILHIE. If a participating provider's ~~or organization's~~ EHR is incapable of ensuring that such information will not be made available through the ILHIE, then the provider ~~or organization would not be able to opt in the patient to the ILHIE~~ instead will require the patient to opt-out of participation in the ILHIE.

132. The participating provider ~~or organization~~ will comply with the consent decision made by a parent or legal guardian for his or her minor child to opt-out of the ILHIE. If deemed

necessary by the participating provider ~~or organization~~, a parent or legal guardian may be required to present the provider ~~or organization~~ with a proof of legal guardianship or other legal authority to act on behalf of a child.

143. A minor may be presumed legally capable of making his or her own consent decision when seeking treatment for mental and behavioral health, substance abuse, birth control, prenatal care, ~~or a sexually transmitted disease~~, or other treatment or services that the minor is authorized to receive under the law without the consent of a parent or legal guardian.

154. Upon reaching the age of majority, a patient whose consent decision was previously expressed by his or her parent or legal guardian will be given the opportunity to exercise his or her own consent decision in accordance with the procedures outlined in paragraphs 1 through 101 above.

156. Upon enrollment in the ILHIE, a participating provider ~~or organization~~ will electronically supply the ILHIE with personal demographic information about all of its patients so that other participating ~~providers individual practitioners~~ and organizations may access their protected health information, if available, for a permissible purpose in accordance with the ILHIE’s policies and procedures.

176. All decisions made by patients to opt-out of the ILHIE or revoke a prior decision to opt-out of the ILHIE will be immediately and electronically communicated by the participating provider ~~or organization~~ to the ILHIE to ensure compliance with each patient’s decision to opt-out. For purposes of this Policy and Procedure, the term “immediately” shall mean within one (1) the same business day or as soon thereafter as practicable or required by contract, but in no event longer than three (3) business days.

187. A participating provider ~~or organization~~ will not deny care to any patient solely because he or she elects to opt-out of the ILHIE.

C. ILHIE Procedures.

1. The ILHIE will provide outreach, educational information, and where requested, technical assistance to patients and participating providers ~~and organizations~~ to promote a consistent implementation of the consent procedures outlined above. At a minimum, the ILHIE’s educational information must include a written Notice developed and approved by the ILHIE which explains:

- (i) the purposes and function of the ILHIE;
- (ii) the purposes for which a patient’s protected health information may be disclosed to other participating ~~providers individual practitioners~~ and organizations through the ILHIE;
- (iii) the types of protected health information which may be disclosed to other p Participating ~~individual practitioners providers~~ and organizations;

- (iv) the need for the patient’s specific written authorization to disclose certain categories of “specially protected”<sup>2</sup> health information; in accordance with applicable law;
  - (v) the fact that the patient’s personal demographic information will be included in a Master Patient Index maintained by the ILHE to permanently record his or her consent decision;
  - (vi) the potential benefits and risks of participation in the ILHIE; and
  - (vii) the fact that a patient’s participation in the ILHIE is voluntary and subject to a patient’s right to opt-out of participation in the ILHIE, including audio, visual, and written instructions on how to opt-out of participation in the ILHIE in whole or in part to the extent possible.
2. The ILHIE will develop and make available to providers template signage that briefly describes health information exchange, patient opt-out rights, and that identifies the ILHIE website. The ILHIE may prepare and distribute additional notices or materials for display by its participating providers ~~and organizations~~ in public areas that are designed to inform patients about the ILHIE and their right to opt-out of the ILHIE.
  3. The ILHIE will include the written Notice, as well as other information designed to inform patients about the ILHIE and their right to opt-out of participation in the ILHIE, on its website.
  4. The ILHIE will develop and provide its participating providers ~~and organizations~~ with templates of all standard opt-out forms, revocation forms, Notices, signage, and other educational materials for ~~purposes their~~ distribution and use in providing their patients with meaningful disclosure about the ILHIE and a patient’s right to opt-out of participation in the ILHIE. In addition, the ILHIE will include all of these forms, notices, signage, and other materials on its website.
  5. The ILHIE will make a standard opt-out form and a revocation form available on its website that a patient may complete, notarize and submit directly to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic communication. The ILHIE may, in the future, make available to patients on its website an electronic process available to enable patients to opt-out of participation in the ILHIE. Any such on-line process would be designed by the ILHIE to elicit sufficient personal demographic information from the patient to verify his or her identity and have to employ methodologies and technologies to ensure proper patient verification.
  6. If available, any such electronic on-line process would include access to the same information and materials as made available to patients by their participating providers ~~and organizations~~, including the written Notice developed and approved by ILHIE. Prior to opting-out on-line, a patient would be required to acknowledge electronically that he or she has been presented with and understands the Notice.

7. A patient’s election to opt-out ~~through submission of a notarized form available either through a participating organization, or if available in the future, on-line at~~ the ILHIE’s website, ~~and received by the ILHIE~~ will be ~~immediately communicated to the~~ implemented by ~~the ILHIE~~ within one (1) business day or as soon thereafter as practicable, but in no event longer than three (3) business days. The ILHIE will record the patient’s decision to opt-out in its Master Patient Index.

8. A patient may revoke his or her decision to opt-out of the ILHIE at any time by any of the following means:  
(i) ~~completion and submission of~~ a revocation form supplied by his or her participating provider or organization, ~~or if available in the future,~~  
(ii) ~~by completing~~ acquiring the revocation form on the ILHIE website and submitting the completed, notarized form to the ILHIE by U.S. mail, facsimile, or as a scanned attachment to an electronic ~~communication of an electronic revocation form on-line at the ILHIE’s website. This must be a standard revocation form developed and approved by the ILHIE.~~  
(iii) ~~if available in the future, a patient may revoke his or her decision to opt-out of the ILHIE by completing an electronic revocation form on-line at the ILHIE’s website.~~

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9. Once the revocation form has been executed by the patient and communicated to the ILHIE, he or she will be enrolled in the ILHIE from that date forward.

10. Upon enrollment in the ILHIE, a participating provider or organization will electronically supply the ILHIE with personal demographic information about all of its patients. The ILHIE will electronically maintain personal demographic information about all patients of participating providers and organizations in a Master Patient Index in order to record and maintain each patient’s consent decision. In addition, the ILHIE will utilize this personal demographic information to enable other participating providers ~~and organizations~~ to access the protected health information of patients for a permissible purpose in accordance with the ILHIE’s policies and procedures.

11. All decisions made by patients to opt-out of the ILHIE will be immediately and electronically recorded by the ILHIE to ensure compliance with each patient’s decision to opt-out.

12. For a patient who has not opted-out of the ILHIE, the ILHIE will generally share all of a patient’s health information that is available through the ILHIE in response to a query from a participating provider ~~or organization~~.

13. A patient’s protected health information will not be disclosed in response to a query when it contains “specially protected” health information for which a specific written authorization is required. Participating providers ~~and organizations~~ whose EHRs are incapable of ensuring that such information will not be made available through the ILHIE will ~~not be able to opt in~~ require their patients with “specially protected” health information ~~to opt-out-of-to~~ participation in the ILHIE.

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14. For a patient who has opted-out of the ILHIE, the ILHIE will ensure that no protected health information will be disclosed ~~except~~ for any purpose except as permitted by law such as public health reporting. Instead, ~~consistent with the patient's reasonable expectations,~~ a message will be sent to the participating provider ~~or organization~~ that submitted the query ~~that~~ to the effect there is “no information available.”