



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 the participation decisions of patients to opt out of or to opt in to the Illinois Health Information Exchange’s (“ILHIE”) EHR Connect may be meaningfully exercised at the point of care. The policy will also describe how a patient may subsequently change these participation decisions.

For the purposes of this Policy and Procedure, the following definitions apply:

“**Authorized Purpose(s)**” means purposes required or permitted by applicable Federal and Illinois law and made in accordance with the ILHIE Authority’s policies and procedures, including facilitating patient treatment, payment, and health care operations.

“**EHR Connect User(s)**” means the individual, organization, or other entity (e.g., “Subscriber” or “Participant”) with which the ILHIE Authority has a contractual arrangement for the participation of the individual, organization or other entity in EHR Connect. EHR Connect Users may include individual and institutional health care providers including but not limited to physicians, hospitals, clinics, laboratories, or pharmacies. In the future, EHR Connect Users may include public and private health insurance plans. In accordance with the terms of this Policy and Procedure or to the extent required by the EHR Connect User’s contract with the ILHIE Authority, this Policy and Procedure is applicable to each EHR Connect User’s “Authorized User” as defined in the EHR Connect User contract.

“**EHR Connect**” means the ILHIE’s EHR Connect, a State-wide bi-directional health information exchange.

“**EHR**” means electronic health record.

“**ILHIE Notice**” means written notice developed and approved by the ILHIE Authority for use by EHR Connect Users to provide patients with meaningful disclosure about EHR Connect and that explains the function of EHR Connect, the purposes for disclosure of a patient’s health information to other EHR Connect Users, the potential benefits and risks to an individual of participation in EHR Connect and any other information as required by law. The ILHIE Notice will further explain a patient’s right to opt-out of in EHR Connect and direct the patient to the ILHIE Authority’s 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 EHR Connect.

**“ILHIE Signage”** means signage developed and approved by the ILHIE Authority that briefly describes EHR Connect, patient opt-out rights, and that identifies the ILHIE Authority website.

**“Opt-Out Form”** means the “ILHIE’s EHR Connect Opt-Out Form” developed and approved by the ILHIE Authority for use to document a patient’s EHR Connect opt-out decision, and which may be updated from time to time.

**“Opt-In Form”** means the “ILHIE’s EHR Connect Opt-In Form” developed and approved by the ILHIE Authority for use to document a patient’s EHR Connect opt-in decision for patients who previously did not participate in EHR Connect, and which may be updated from time to time.

**“Specially Protected Health Information”** means certain alcohol and substance abuse treatment information, HIV test results and the identity of the tested patient, genetic testing and information, child abuse and neglect reports and records, sexual assault evidence and information, the identity of an individual in a mandated public health report, veteran’s homes resident records, and all other health information that requires patient consent for disclosure under Federal or Illinois law.

## II. POLICY

The ILHIE Authority will offer all patients a meaningful and informed way to decide whether to opt-out of participation in EHR Connect. This patient participation process will be governed by an “Opt-Out” policy and administered by EHR Connect Users at the point of care. All patients of an EHR Connect User will be automatically enrolled in EHR Connect, and no affirmative action will need to be taken by patients to establish their participation, unless a patient’s medical record contains categories of Specially Protected Health Information requiring specific written consent for disclosure under Federal or Illinois law. A patient will be included in EHR Connect unless and until the patient affirmatively opts out.

To ensure that patients are able to make meaningful and informed choices about their participation in EHR Connect, each patient will be offered the ILHIE Notice by his or her participating EHR Connect User during the first patient encounter after the EHR Connect User enrolls in EHR Connect, or as soon thereafter as is practicable.

If a patient does not opt out of EHR Connect, a summary of his or her health information will generally be disclosed in response to a specific request, or query, made by an EHR Connect User for an Authorized Purpose. However, a patient’s health information will not be disclosed in response to such a query when it contains Specially Protected Health Information unless consent has been given by the patient to the EHR Connect User authorizing that EHR Connect User to disclose such Specially Protected Health Information through EHR Connect.

A patient who does not want his or her health information to be disclosed to other EHR Connect Users may opt out by following the procedures below. If a patient does opt out, his or her health information will not be disclosed through EHR Connect for any purpose except as permitted or required by law, such as for purposes of public health reporting.

A patient may decide at any time to change his or her preference to opt out or opt in to EHR Connect, including the revocation of a prior election to opt out of participation in EHR Connect.

### III. PROCEDURES

#### A. EHR Connect User and Patient Procedures.

1. After an EHR Connect User contracts to join EHR Connect, that EHR Connect User must offer the ILHIE Notice at the point of care at each patient's first encounter with that EHR Connect User, or as soon thereafter as is practicable. EHR Connect Users are encouraged to post a copy of the ILHIE Notice on the EHR Connect User's own website, if any, and to record the delivery of the ILHIE Notice in the patient's medical record.
2. The EHR Connect User must prominently and consistently display the ILHIE Signage.
3. The EHR Connect User may display and make available any other materials about EHR Connect developed, approved and made available by the ILHIE Authority in a public area of the EHR Connect User's office or facility, or on the EHR Connect User's website.
4. If a patient asks questions about EHR Connect, the EHR Connect User or EHR Connect User's designee (e.g. HIPAA Privacy Officer) will respond to the patient, including responding to questions about the contents of the ILHIE Notice, including the potential benefits and risks of participation in EHR Connect.
5. No action is needed by a patient of an EHR Connect User if he or she wishes to participate in EHR Connect and the patient does not have Specially Protected Health Information in his or her medical record. A patient shall participate in EHR Connect unless and until the patient elects not to participate through proper completion of the Opt-Out Form.
6. A patient may elect to not participate in EHR Connect at any time by executing an Opt-Out Form. An EHR Connect User must allow a patient to opt-out of EHR Connect participation at any time, even after having already been enrolled in EHR Connect. However, any exchange of health information that may have occurred prior to a patient's decision to opt-out will not be reversed.
7. If a patient elects to opt out of EHR Connect at the point of care, and the patient's identity has been collected by the participating EHR Connect User, the EHR Connect User will require the patient to document his or her decision to opt out by utilizing the Opt-Out Form. A copy of this signed Opt-Out Form will be kept and maintained by the receiving EHR Connect User in the patient's medical record in accordance with the EHR Connect User's policies and applicable law governing health record retention. If the patient who is participating in EHR Connect fails or refuses to sign an Opt-Out Form at the point of care, the EHR Connect User will inform the patient that the patient will continue to participate in EHR Connect unless the form is properly completed.
8. If requested, an EHR Connect User will assist the patient in participating in EHR Connect. The EHR Connect User will supply the patient with the Opt-In Form. The receiving EHR Connect User will keep and maintain a copy of this signed Opt-In Form in the patient's medical record in accordance with the EHR Connect User's own policies and applicable law governing health record retention.
9. A patient may elect to opt out of EHR Connect by either of the following means:

- (i) Completing and submitting the Opt-Out Form to the patient's EHR Connect User during a patient encounter.
- (ii) Acquiring the Opt-Out Form on the ILHIE Authority website and submitting the completed, notarized form to the ILHIE Authority by U.S. mail, facsimile, or as a scanned attachment to an email.

10. A patient may elect to opt in to EHR Connect after not participating by completing and submitting the Opt-In Form to the patient's EHR Connect User during a patient encounter, and providing any appropriate consent.

11. If an EHR Connect User's EHR can ensure that Specially Protected Health Information will not be made available through EHR Connect, then the EHR Connect User must ensure that that the user's EHR does not make Specially Protected Health Information available through EHR Connect unless a patient with Specially Protected Health Information has given consent to the disclosure of the information to that EHR Connect User. If a participating EHR Connect User's EHR cannot ensure that a patient's Specially Protected Health Information will not be made available through EHR Connect, then the EHR Connect User must either (i) obtain the patient's consent to disclose the Specially Protected Health Information, or (ii) make the patient's entire medical record unavailable through EHR Connect.

12. A minor patient aged 12 years old or older has the capacity to consent to EHR Connect participation to the same extent as a person of legal age. An EHR Connect User will comply with the EHR Connect participation decision made by a parent or legal guardian for his or her minor child aged 11 or under. If deemed necessary by the EHR Connect User, a parent or legal guardian may be required to present the EHR Connect User with proof of legal guardianship or other legal authority to act on behalf of a minor child aged 11 or under.

13. Upon reaching age 12, a minor patient whose participation decision was previously expressed by his or her parent or legal guardian must be given the opportunity to exercise his or her own participation decision in accordance with the procedures outlined in paragraphs 1 through 12 above.

14. Upon enrollment in EHR Connect, an EHR Connect User will electronically supply the ILHIE Authority with personal demographic information about all of the user's patients so that other participating EHR Connect Users may access the EHR Connect User's patients' health information, if available, for Authorized Purposes.

15. All elections made by patients at the point of care to opt out of EHR Connect or to opt in to EHR Connect will be electronically communicated by the EHR Connect User to the ILHIE Authority within one (1) business day of receipt, or as soon thereafter as practicable or as required by contract, but in no event longer than three (3) business days.

16. Once a patient has been offered the ILHIE Notice by a participating EHR Connect User, it is not necessary for that EHR Connect User to repeat the process. However, an EHR Connect User may, in its discretion, offer the ILHIE Notice to a patient again, including if the patient's record contains new Specially Protected Health Information.

17. The EHR Connect User will not deny care to any patient because he or she elects to opt out of EHR Connect.

C. ILHIE Authority Procedures.

1. The ILHIE Authority will develop, approve, and make freely available on its website the ILHIE Notice, which may be updated from time to time.
2. The ILHIE Authority will develop, approve, and make freely available on its website the ILHIE Signage, which may be updated from time to time.
3. The ILHIE Authority will develop, approve, and make freely available an Opt-Out Form, an Opt-In Form, and additional materials and resources for use and display by EHR Connect Users in offering patients meaningful disclosure about EHR Connect and a patient's right to opt-out of EHR Connect.
4. All patient EHR Connect participation elections which are provided to the ILHIE Authority electronically will be immediately and electronically recorded by the ILHIE Authority to ensure compliance with each patient's decision.
5. A patient's election to opt out through submission of a complete, notarized Opt-Out Form directly to the ILHIE Authority will be implemented by the ILHIE Authority as soon after receipt as practicable, but in no event longer than three (3) business days. Once an Opt-In Form has been executed by the patient and communicated to the ILHIE Authority, he or she will be enrolled in EHR Connect from the date the ILHIE Authority processes the Opt-In Form.
6. Upon enrollment in EHR Connect, an EHR Connect User will electronically supply the ILHIE Authority with personal demographic information about all of the EHR Connect User's patients. The ILHIE Authority will electronically maintain personal demographic information about patients of EHR Connect Users in a Master Patient Index. The ILHIE Authority will also use the Master Patient Index to record and maintain each patient's EHR Connect participation decision. The ILHIE Authority will utilize patient personal demographic information to enable other EHR Connect Users to access the health information of patients for Authorized Purposes.
7. For a patient who is participating in EHR Connect, the ILHIE Authority will share a summary of all of a patient's health information that is available through EHR Connect in response to a query from an EHR Connect User.
8. For a patient who has opted out of EHR Connect, the ILHIE Authority will not disclose health information for any purpose except as permitted by law, such as public health reporting. Instead, a message will be sent to the querying EHR Connect User to the effect there is "no information available."
9. The ILHIE Authority will provide outreach, educational information and, where requested, technical assistance to patients and participating EHR Connect Users to promote the consistent implementation of the participation procedures outlined in this Policy and Procedure.