Policies and Procedures
POLICY: Patient Choice and Meaningful Disclosure
Policy #6
Effective Date: January 1, 2015

Background and Purpose: The ILHIE Authority is committed to protecting and respecting the privacy of Individual's Protected Health Information. As part of its mission, the ILHIE Authority is statutorily required to create rules, standards, or contractual obligations that provide each Individual whose Protected Health Information is accessible through ILHIE Connect to have the option to opt out, opt in and revoke a prior decision to opt out or opt in. These rules, standards, or contractual obligations shall require written notice of an Individual's right to opt-out which directs the Individual to an HIE website. The Individual shall be provided meaningful disclosure regarding health information exchange (740 ILCS 14/9.6).

In accordance with the statutory requirements above, this policy describes how the participation decisions of Individuals to opt out of or to opt in to the ILHIE Authority's ILHIE Connect may be meaningfully exercised at the point of care. The policy also describes how an Individual may subsequently change these participation decisions. As used in this Policy and Procedure, "Participant" may additionally mean the Participant's Authorized User, as appropriate.

Terms used in this policy, but not otherwise defined in these Policies and Procedures, shall have the same meaning as set forth in HIPAA.

Policy:

1.0 **Patient Choice.** The ILHIE Authority will offer all Individuals a meaningful and informed way to decide whether to opt out of participation in ILHIE Connect. This Individual participation process will be governed by an opt-out policy and administered by each Participant at the point of care. Each Participant governs only the Protected Health Information held by that Participant. All Individuals that are patients of a Participant will be automatically enrolled in ILHIE Connect unless and until the Individual opts out in accordance with the procedures set forth herein. No affirmative action will need to be taken by Individuals to establish his or her participation, unless an Individual's medical record contains categories of Specially Protected Health Information requiring specific written Individual consent for disclosure under Applicable Law.

2.0 **Meaningful Disclosure.** To ensure that an Individual is able to make meaningful and informed choices about his or her participation in ILHIE Connect, each Individual will be offered the ILHIE Notice at the point of care at each Individual's first encounter with a Participant after it contracts to become a Participant. Each Individual will also be offered the ILHIE Notice at the point of care at each Individual's first encounter with a Participant for HIV-related care and first encounter with a Participant for genetic testing. In the event of a medical emergency that makes it impossible to offer the ILHIE Notice to the Individual at any such first

encounter, the ILHIE Notice will be offered as soon thereafter as is practicable, and then to Active Patients on an annual basis thereafter.

3.0 **ILHIE Connect Participation.** If an Individual's Protected Health Information is available for disclosure through ILHIE Connect, that Individual's Protected Health Information will be disclosed in response to a request, made by a Participant for a Permitted Purpose. These disclosures may include a notification of treatment or payment, or a summary of Protected Health Information related to treatment or payment as well as disclosures related to health care operations as allowed by Applicable Law. However, an Individual's Protected Health Information will not be disclosed in response to such a request when it contains Specially Protected Health Information unless necessary consent to disclose such Specially Protected Health Information, including through ILHIE Connect has been given by the Individual to the Participant that holds such data.

3.1 An Individual who does not want his or her health information to be disclosed to Other Participants may opt out by following the procedures below. If an Individual does opt out, the Individual's Protected Health Information will not be disclosed through ILHIE Connect for any purpose except as required or permitted by Applicable Law.

3.2 An Individual may decide at any time to change his or her preference to opt out or opt in to ILHIE Connect, including the revocation of a prior election to opt out of participation in ILHIE Connect.

3.3 An Individual's ILHIE Connect participation is specific to each Participant that maintains Protected Health Information about that Individual. An Individual who desires to opt out of ILHIE Connect participation on a State-wide basis must:

i) Submit an Opt-Out Form to each Participant that maintains Protected Health Information about that Individual; or .

ii) Submit an Opt-Out Form to the ILHIE Authority for each Participant that maintains Protected Health Information about the Individual. The ILHIE Authority may only opt an Individual out with respect to a health care provider that is a current Participant. If an Individual submits an Opt Out Form to or regarding a health care provider that is not a current Participant, the Opt Out Form will not serve to opt the Individual out of ILHIE with regard to that provider even if the provider becomes a Participant at a later point in time. A patient may submit an Opt-Out Form to a Participant that has not yet onboarded patient demographic information; however, Participant will not transmit the Opt-Out Form to the ILHIE Authority, and the opt-out will not become effective, until the Participant has onboarded the patient demographic information. An Individual can choose to opt out with some, and not all, Participants that maintain Protected Health Information about the Individual..

4.0 **Compliance.** Participants shall comply with these Policies and Procedures. The ILHIE Authority will monitor and enforce compliance with and adherence to these Policies and Procedures.

4.1 Participant shall cooperate with the ILHIE Authority in its monitoring and enforcement of the Participant's compliance with these Policies and Procedures.

Procedures

Patient and Participant Procedures

1.0 After a Participant contracts to join ILHIE Connect, that Participant must present the ILHIE Notice (i) at the point of care to each Individual at the Individual's first encounter with that Participant, or, in the event of a medical emergency that makes it impossible to offer the ILHIE Notice to the Individual at the first encounter, as soon thereafter as is practicable; (ii) to each Individual will also be offered the ILHIE Notice at the point of care at each Individual's first encounter with a Participant for HIV-related care and first encounter with a Participant for genetic testing; and (iii) to each Active Patient, on an annual basis thereafter. In the sole discretion of the Participant, the Participant may offer the ILHIE Notice to an Individual by any

reasonably appropriate means, including but not limited to by mail, email, or Individual portal. Participants are encouraged to post a copy of the ILHIE Notice on the Participant's own website, if any, and to record the presentation of the ILHIE Notice in the Individual's medical record.

2.0 The Participant must prominently and consistently display the ILHIE Signage.

3.0 The Participant may display and make available any other materials about ILHIE Connect that are developed, approved and made freely available by the ILHIE Authority to Participants in a public area of the Participant's office or facility, on the Participant's website, or both.

4.0 Participant may amend its current Notice of Privacy Practices ("NPP") to reflect its contemplated requests, uses, and disclosure of Protected Health Information through the ILHIE; however, amendment of a Participant's NPP will not satisfy ILHIE meaningful disclosure requirements. The ILHIE Notice is separate and apart from any requirements the Participant is obligated to comply with pursuant to HIPAA or the Participant's HIPAA NPP.

5.0 If an Individual asks questions about ILHIE Connect, the Participant or Participant's designee (e.g. HIPAA Privacy Officer) will respond to the Individual, including responding to questions about the contents of the ILHIE Notice.

6.0 No action is needed by an Individual who is a patient of a Participant if that Individual wishes to participate in ILHIE Connect and the Individual does not have Specially Protected Health Information in his or her medical record. An Individual shall participate in ILHIE Connect unless and until the Individual opts out through proper completion of the Opt-Out Form. If the Individual does not want to disclose his or her Protected Health Information held by a specific Participant, an Individual must:

i) Submit an Opt-Out Form to each Participant that maintains Protected Health Information about the Individual that the Individual does not want to disclose or

ii) Submit an Opt-Out Form to the ILHIE Authority for each Participant that maintains Protected Health Information about the Individual that the Individual does not want to disclose. The ILHIE Authority may only opt an Individual out with respect to a health care provider that is a current Participant. If an Individual submits an Opt Out Form to or regarding a health care provider that is not a current Participant, the Opt Out Form will not serve to opt the Individual out of ILHIE with regard to that provider even if the provider becomes a participant at a later point in time. A patient may submit an Opt-Out Form to a Participant that has not yet onboarded patient demographic information; however, Participant will not transmit the Opt-Out Form to the ILHIE Authority, and the Opt-Out will not become effective, until the Participant has onboarded the patient demographic information.

7.0 An Individual may elect to opt out of having his or her Protected Health Information disclosed throughILHIE Connect at any time by executing an Opt-Out Form with respect to each Participant which maintains Protected Health Information which the

Individual does not want disclosed. A Participant must allow an Individual to opt out of ILHIE Connect participation at any time, even after having already been enrolled in ILHIE Connect; however, any exchange of Protected Health Information that may have occurred prior to an Individual's decision to opt-out will not be reversed.

8.0 If an Individual elects to opt out of ILHIE Connect at the point of care, and the Individual's identity has been collected by the Participant, the Participant will require the Individual 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 Participant in the Individual's medical record in accordance with the Participant's policies and Applicable Law governing health record retention. If the Individual who is participating in ILHIE Connect fails or refuses to sign an Opt-Out Form at the point of care, the Participant will inform the Individual that the Individual will continue to participate in ILHIE Connect unless the Opt-Out Form is properly completed.

9.0 An Individual may elect to opt out of ILHIE Connect by either of the following means:

(i) Completing and submitting the Opt-Out Form to the Individual's Participant during an Individual's encounter with the Participant, or
(ii) Obtaining the Opt-Out Form from 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.

10.0 An Individual may elect to opt in to ILHIE Connect after not participating by completing and submitting the Opt-In Form to the Individual's Participant during an Individual's encounter with the Participant, and providing any necessary consent.

i) If requested, a Participant will assist the Individual to opt in to participation in ILHIE Connect after not participating and supply the Individual with the Opt-In Form.
ii) After an Individual has not participated in ILHIE Connect with respect to a specific Participant(s), an Individual must submit an Opt-In Form to each such Participant(s) that the Individual wishes to disclose the Participant's data about the Individual through ILHIE Connect.

11.0 An Individual with Specially Protected Health Information must elect to participate in ILHIE Connect at the point of care by providing any necessary consent to the Participant holding the Specially Protected Health Information and signing the Opt-In Form. The Participant obtaining the consent will keep and maintain a copy of the signed Opt-In Form and any written consent necessary for disclosing the information, including through the ILHIE in the Individual's medical record in accordance with the Participant's policies and Applicable Law governing health record retention. If the Individual who is requesting to participate in ILHIE Connect fails or refuses to sign an Opt-In Form and requisite written consent for disclosure of Specially Protected Health Information at the point of care, the Participant will inform the Individual that the Individual will not participate in ILHIE Connect for that specific Participant unless the forms are properly completed.

12.0 If Participant's EHR can ensure that Specially Protected Health Information will not be made available through ILHIE Connect, then the Participant must ensure that the Participant's EHR does not make Specially Protected Health Information available through ILHIE Connect unless an Individual with Specially Protected Health Information has given consent to the disclosure of the information to that Participant. If Participant's EHR cannot ensure that an Individual's Specially Protected Health Information will not be made available through ILHIE Connect, then the Participant must either (i) obtain the Individual's consent to disclose the Specially Protected Health Information, or (ii) make the Individual's entire medical record unavailable through ILHIE Connect by on-boarding the Individual as opted-out.

13.0 A minor Individual aged 12 years or older has the capacity to elect to participate in ILHIE Connect to the same extent as a person of legal age. Participant must provide the ILHIE Notice to a minor Individual aged 12 years or older and provide such minors the opportunity to opt out. For minor Individuals aged 12 years or older, Participant will comply with the ILHIE Connect participation decision made by the minor Individual aged 12 years or older. A Participant will comply with the ILHIE 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 Participant, a parent or legal guardian may be required to present the Participant with proof of legal guardianship or other legal authority to act on behalf of a minor child aged 11 or under.

14.0 Upon reaching age 12, a minor Individual 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 Sections 1 through 13 above.

15.0 Upon on-boarding to ILHIE Connect, each Participant will electronically supply the ILHIE Authority with personal demographic information about all the Individuals who are patients of Participant so that Other Participants may request the Protected Health Information of Individuals who are patients of the Participant through ILHIE Connect, if available, for Permitted Purposes.

16.0 All elections to opt out of ILHIE Connect or to opt in to ILHIE Connect made by Individuals at the point of care will be electronically communicated by the Participant to the ILHIE Authority within one (1) business day of receipt or as required by contract, but in no event should communication take longer than three (3) business days.

17.0 Participant shall not deny care to any Individual because he or she elects to participate in, or opt out of, ILHIE Connect.

ILHIE Authority Procedures

1.0 The ILHIE Authority will develop, approve, and make freely available on its website the ILHIE Notice, which may be updated from time to time.

2.0 The ILHIE Authority will develop, approve, and make freely available on its website the ILHIE Signage, which may be updated from time to time.

3.0 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 Participants in offering Individuals meaningful disclosure about ILHIE Connect and an Individual's right to opt-out of ILHIE Connect.

4.0 Once an Opt-In Form has been executed by the Individual and communicated to the ILHIE Authority by a Participant, the Individual will participate in ILHIE Connect, with respect to that disclosing Participant, from the date the ILHIE Authority processes the Opt-In request. All Individual ILHIE 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 Individual's decision.

5.0 An Individual'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.

6.0 Upon on-boarding to ILHIE Connect, the Participant will electronically supply the ILHIE Authority with personal demographic information about all the Individuals that are patients of the Participant. The ILHIE Authority will electronically maintain personal demographic information about Individuals that are patients of each Participant in a Master Patient Index. The ILHIE Authority will also use the Master Patient Index to record and maintain each Individual's ILHIE Connect participation decision with respect to that Participant. The last participation decision received by the ILHIE Authority will govern the Individual's consent preference with respect to that Participant. The ILHIE Authority will utilize Individual personal demographic information to enable Other Participants to access the Protected Health Information of Individuals for Permitted Purposes.

7.0 For an Individual whose Protected Health Information is available for disclosure throughILHIE Connect through one or more Participants, the ILHIE Authority will disclose that Individual's Protected Health Information in response to a request, made by any Participant for a Permitted Purpose. These disclosures may include a notification of treatment or payment, or a summary of Protected Health Information related to treatment or payment as well as disclosures related to health care operations as allowed by Applicable Law.

8.0 For an Individual who has opted out of ILHIE Connect with one or more Participants, the ILHIE Authority will not allow disclosure of Protected Health Information from those Participant(s) for any purpose except as permitted by Applicable Law, such as public health reporting. Instead, a message will be sent to the requesting Participant to the effect that there is "no information available."

9.0 The ILHIE Authority will provide outreach, educational information and, where requested, technical assistance to Individuals and Participants to promote the

consistent implementation of the participation procedures outlined in this Policy and Procedure.

Associated Policies and References:
740 ILCS 110
Request, Use, and Disclosure of Protected Health Information
Emergency Access
Enforcement
Information Subject to Special Protection
Sanctions

Definitions
Applicable Law
EHR
ILHIE Connect
ILHIE Notice
ILHIE Signage
Individual
Master Patient Index
Opt-Out Form
Opt-In Form
Participant
Permitted Purposes
Policies and Procedures
Protected Health Information
Specially Protected Health Information