

MINUTES OF THE AUGUST 20, 2013, MEETING OF THE PATIENT CHOICE AND MEANINGFUL DISCLOSURE WORK GROUP, AND THE MEANINGFUL DISCLOSURE AT THE POINT OF CARE SUBGROUP, OF THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY

The Patient Choice and Meaningful Disclosure Work Group, and the Meaningful Disclosure at the Point of Care subgroup, of the Illinois Health Information Exchange Authority (“ILHIE Authority”), pursuant to notice duly given, held a meeting at 1:30 p.m. on August 20, 2013, at the State of Illinois John R. Thompson Center, 100 West Randolph Street, Suite 2-025, Chicago, Illinois 60601 and at the State of Illinois Bloom Building, 201 South Grand Avenue East, 3rd Floor, Director’s Video Conference Room, Springfield, Illinois 62763, with video and telephone conference call capability.

Work Group Members Present	Organization	Subgroup
David Carvalho (Co-Chair)	Illinois Department of Public Health	Specially Protected Health Information
Marcia Matthias (Co-Chair)	Southern Illinois Healthcare	Point of Care
Crissie Anderson	Lutheran Social Services of Illinois	Specially Protected Health Information
Laura Ashpole	Popovits and Robinson	Point of Care
Elissa Bassler	Illinois Public Health Institute (via phone)	Point of Care
Alan Berkelhamer	Walgreens	Point of Care
Victor Boike	MetroChicago HIE	HIE Website
Lorie Chaiten	American Civil Liberties Union – Illinois	Point of Care
Charles Cox	MetroChicago HIE	Specially Protected Health Information
Jud DeLoss	Popovits & Robinson (via phone)	
Ramon Gardenhire	AIDS Foundation of Chicago	Point of Care
Mark Heyrman	University of Chicago Law School	Specially Protected Health Information
Cheryl Jansen	Equip for Equality (Springfield)	Point of Care
Mike Jennings	Walgreens (via phone)	
Beth Koch	Fayette Companies – Human Service Center (via phone)	
Sarah Koenig	APP Design	HIE Website
Marilyn Lamar	MetroChicago HIE	Point of Care
Steve Lawrence	Lincoln Land HIE/Illinois Health Exchange Partners	
Brigid Leahy	Planned Parenthood of Illinois (Springfield)	Point of Care
Howard Lee	Wirehead Technology	HIE Website
Tina Leeson	Association House (via phone)	
Marvin Lindsey	Community Behavioral Healthcare Association (via phone)	Specially Protected Health Information
Nancy Newby	Washington County Hospital (via	

	phone)	
Mikki Pierce	Atrium Advisory Services Inc	Break the Glass
Denise Pop	Rosecrance Health Network (via phone)	
Kathryn Roe	The Health Law Consultancy	Point of Care
Jodi Sassana	MetroChicago HIE	HIE Website
Meryl Sosa	Illinois Psychiatric Society (via phone)	Point of Care
Glenn Susz	APP Design	HIE Website
Rick Vander Forest	Ecker Center for Mental Health (via phone)	
Crystal VanDeventer	Lincoln Land HIE/Illinois Health Exchange Partners (via phone)	Point of Care
Michelle Ward	Anderson Hospital (via phone)	
Lauren Wiseman	Central Illinois Health Information Exchange	Point of Care
OHIT/ILHIE Staff Present		
Dia Cirillo	Office of Health Information Technology	Point of Care / Specially Protected Health Information
Krysta Heaney	Office of Health Information Technology	Point of Care
Danny Kopelson	Office of Health Information Technology	HIE Website
Beth LaRocca	Office of Health Information Technology	Point of Care
Raul Recarey	Illinois Health Information Exchange	Point of Care

Welcome and Call to Order. Ms. Elizabeth LaRocca, Office of Health Information Technology (“OHIT”) General Counsel, called the Patient Choice and Meaningful Disclosure Work Group meeting to order at 1:30 p.m.

Introductions. Ms. LaRocca confirmed the presence of the above Members of the Patient Choice and Meaningful Disclosure Work Group and the ability of those participating remotely to hear clearly and participate. There were no objections expressed to the participation of the Members by electronic means.

Comments from Co-Chairs David Carvalho and Marcia Matthias. Mr. David Carvalho stated the remaining scheduled meetings of the Work Group have been extended an hour to facilitate additional discussion in each Subgroup and meet Work Group deliverables. If necessary, the Work Group will convene for additional meeting(s) after the September 18, 2013 meeting of the ILHIE Authority Board.

Adjourn for Subgroup Meetings

Meaningful Disclosure at Point of Care Subgroup

Ms. Marcia Matthias, Meaningful Disclosure at Point of Care Subgroup Chair, called the meeting to order at 1:45pm. Ms. Matthias confirmed Subgroup Members received all meeting documents. The Subgroup approved the minutes of the July 24, 2013 meeting as is.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item #1c. Collection of patient “opt-out” at provider point of care, Documentation.

Preference #1c. 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 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.

Ms. Matthias suggested “retention” is added to this section. Ms. Marilyn Lamar stated “maintain” reflects the concept of retention but suggested the revision would provide clarity. There was discussion regarding the length of time a provider should retain patient preferences, in particular because the opt-out is perpetual until revoked. The Subgroup discussed whether the policy should include specific guidance regarding the retention of patient preferences. Ms. Lamar suggested that, if the provider has transmitted the patient’s preference to the ILHIE, the ILHIE would maintain the patient preference in the ILHIE Master Patient Index, and that the provider may not need to keep the record indefinitely.

Ms. Elissa Bassler asked how providers become aware of a patient’s exiting consent preference, specifically their non-participation in the HIE. Mr. Recarey stated if a patient opts-out the ILHIE will respond to a query for that patient’s record with “no data available” or “no results;” it would not indicate the patients’ consent preference, which could itself be construed as protected health information. The ILHIE will maintain the patient’s preference in the MPI but it will not be visible to the provider. The provider requesting access to that patient’s data would need to have a discussion with the patient.

Ms. Lorie Chaiten asked whether and how the patient can verify if their preferences have been accurately recorded. Mr. Recarey stated there will be an audit record of all transactions based on that information. The patient can request access to that information from ILHIE. The request would be similar to a consumer request for their credit report.

Ms. Matthias stated the Subgroup’s recommendation regarding collection of patient opt-out documentation: Change “maintain” to “retain documentation ...” Ms. Lamar suggested including language addressing the provider’s responsibilities for record retention. The recommendation was made to add reference to providers’ legal obligations under Illinois medical records retention law. The Subgroup determined the reference to applicable Illinois law was not inconsistent with the ILHIE policy requirement that retention also be consistent with a provider’s own policies, because the applicable law requirement is specific to records retention, while the policy recommendation regards documentation and retention of opt-out preferences. The providers may elect to follow more stringent record retention policies, but not less. The Subgroup reached agreement on the providers’ responsibility.

Ms. Chaitan asked if the template forms were to be in an electronic format or paper format. Ms. Matthias stated if the provider can produce electronic forms that would be acceptable, further clarifying providers can employ various media (for example a handheld device) to document patient preferences.

Ms. Matthias updated the Subgroup on the progress made on developing recommended opt-out and revocation of opt-out forms. The OHIT Consumer and Education Work Group, at the request of the Point of Care Subgroup, reviewed other opt-out state's forms to identify best practices. The Consumer and Education Work Group met on the morning of August 20th. The Work Group identified five (5) form examples with varying degrees of content for consideration. Ms. Matthias summarized the recommendations of the Consumer and Education Work Group regarding the form and content of the opt-out and revocation forms: 1) one-sided document; 2) brief description of opt-out effect; 3) definition of opt-out; 4) use of "participation" language; 5) cautious of negative language; and 6) acknowledge global consent. The Work Group will draft ILHIE forms for review and consideration by the Point of Care Subgroup at its next meeting.

Ms. Lamar asked about if Illinois would require consent forms be notarized. Ms. Chaitan stated the notary requirement would present a significant burden for patients. Ms. Lamar noted it is very important to verify the identity of the individual making the request; and indicated it may be more necessary for the revocation form than the opt-out form. Ms. LaRocca clarified the notary requirement would only apply to patients that elect to submit their opt-out request directly to ILHIE. If a patient elects to opt-out at the point of care the provider could submit the request to the ILHIE, no notary required.

Ms. Cheryl Jansen stated many of the state opt-out forms were very positive towards health information exchange ("HIE"). Ms. Jansen stated one of the goals of the Subgroup is to consider and provide information on both the risks and benefits of participation in HIE. The Subgroup discussed giving specific consideration to "behavioral health" records and providing clear notice that a patient's decision to opt-out is global and would apply to the entirety of their record. The Subgroup discussed a desire to inform patients that there is a new framework for sharing of their mental health data.

Ms. Jansen recommended the addition of a sentence to the opt-out form: by participating in health information exchange all of your health records from all of your participating providers will be available through the exchange. Ms. Jansen noted several State non-participation forms indicate that access to patient records will be available to your provider and in an emergency situation. Patients may not make the connection that all participating providers will have access. There were no objections to adding language to the opt-out form indicating the global nature of opt-out. Ms. Bassler stated the Subgroup should be cautious of using negative language, stating it is important to strike a balance that does not "scare" patients away from participating and realizing the benefits of the HIE. Ms. Chaitan clarified the recommendation to include adding "neutral" language to the opt-out form indicated the global nature of opt-out.

Ms. Roe asked if the information notice on the opt-out form would constitute the statutory written notice. It was clarified that there would be an independent notice given to the patient. It was further clarified that it requires an affirmative action on the part of patient to receive the opt-out form from the provider. Ms. Laura Wiseman stated it may be beneficial to include some information on the ILHIE on the opt-out form. Mr. Alan Berkelhamer stated this was consistent with the recommendation of the Consumer and Education Work Group.

Ms. Lamar asked whether information that is not available under query when the patient opts-out becomes available if the patient revokes their prior decision not to participate. Mr. Recarey indicated the system is “all-in or all-out”. Ms. Matthias suggested a sentence explaining the length of time affected by the opt-out be included on the revocation form under development by the Consumer and Education Work Group.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item #1d. Transmission to ILHIE.

Preference #1d. *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.*

Mr. Recarey stated the ILHIE will maintain the patient choice in its MPI. Providers that have an IHE enabled system will be able to transmit the patient’s preference electronically to ILHIE.

Ms. Lamar suggested the policy indicate ILHIE will maintain the flag indefinitely in an electronic format while it is in operation. The Subgroup recommended the policy preference be revised to *Transmission to and Retention by ILHIE*; there were no voiced objections.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item #1e. Reconciliation.

Preference #1e. *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.*

The Subgroup recommended the revision: *The most recent consent preference ...* There was verbal consensus.

Ms. Chaitan asked how quickly the ILHIE becomes aware of a patient’s opt-out. Mr. Recarey stated that, if the process is handed electronically using the IHE standard, the update occurs in microseconds. Ms. Chaitan asked if the Subgroup should establish guidelines for how quickly the provider transmits to ILHIE a patient’s opt-out. Patients have a strong preference for how quickly their preference is transmitted. There was clarity that the timeframe was between the provider and ILHIE, not how quickly the ILHIE processes the form after receipt of the form. Ms. Wiseman said the time frame should be on the form, e.g. CIHIE will process the form within 3-5 business days. Two categories 1) the provider receives the opt-out form and a) electronically transmits status to ILHIE or b) provider has alternate transmission; or 2) patient sends preference directly to ILHIE.

Ms. LaRocca noted the currently proposed policy Requires of the provider *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 provider 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 the same business day or as soon thereafter as practicable.*

Ms. Bassler agreed that patients should have some indication the timeframe in which their preferences will be recorded by the ILHIE. The Subgroup recommended adding to the transmission section that the provider will transmit opt-out preference to ILHIE within a defined period.

Ms. VanDeventer stated concerns that the provider will not transmit opt-out information to the ILHIE, especially if it takes the provider out of their workflow. Ms. Matthias stated that the policy does not indicate the mechanism for transmission. Ms. Meryl Sosa asked if the alternative was to require patients to send the form directly to ILHIE, e.g. via U.S. mail. Mr. Ramon Gardenhire stated the patient-only process would be very onerous. Ms. Recarey provided clarity to 2 options: 1) the provider wants to communicate consent electronically via an IHE compatible system or 2) the provider has the IHE-capability but chooses not to send the opt-out preference to ILHIE instead requiring the patient to execute their preference. Ms. VanDeventer stated that patient processing is a common practice in other states. Ms. VanDeventer indicated the provider will be unwilling to participate in ILHIE if the provider, including their office staff, is required to transmit the preference on the patient's behalf.

Mr. Recarey clarified that if the patient requested to opt-out and the provider cannot or will not send their preference, then the patient can verbally inform the provider that they do not have the authorization to access their record via the ILHIE. The Subgroup discussed the provider burden for faxing forms to ILHIE and the market penetration of EMRs with the capability to electronically collect, store and transmit consent preferences. Ms. Wiseman stated many EMRs are moving in that direction especially with the 2014 ONC EHR certification criteria.

The Subgroup discussed whether the technical mechanism for the Regionals communicating with the ILHIE is out of scope for the Subgroup. Ms. Chaitan suggested that in the interim, before a technical solution is developed, the Subgroup should recommend a standard for ensuring a patients' opt-out preference is reflected system-wide.

Mr. Recarey clarified the ILHIE participant data sharing agreement states providers only query the system if they have a treatment relationship and authorization from the patient. Ms. Chaitan stated patients need an adequate explanation of any transmission and documentation of preference gap in the system. It was suggested that the explanation should be included in the Notice. The provider has the responsibility to explain to the patient that the patient needs to express their decision to opt-out at every provider until they confirm if their preference was recorded. Mr. Recarey stated it is common practice that the opt-out form indicating there is a lag time in processing. Mr. Gardenhire indicated this would be a burden for the patient.

Ms. Lamar asked if it is practical to say that the ILHIE will not allow providers to connect without the technology to electronically transmit patient preferences. There is currently only a small number of EMRs with the IHE protocols. Ms. Wiseman stated providers have an obligation to their patients, and should document their preferences, whether electronically or via the ILHIE provided website rather than place the obligation on the patient. Ms. Wiseman noted the rate of patient opt-out for the Central Illinois HIE is less than a tenth of a percent. Ms. Chaitan stated this is consistent with findings from across the nation. There are a very limited number of patients that would elect to opt-out thus having a very minimal impact of provider workflow. Mr. Recarey stated in practice the vast majority of providers will likely submit the consent preference on behalf of the patient.

Preference #1d was revised to include a timeframe for processing patient preferences to include transmission ... *within one (1) business day or as soon thereafter as practicable or required by contract, but in no event more than three (3) business days.*

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #1f. Revocation. *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 preferences, thus reversing the consent flag for that patient in the ILHIE's MPI. The provider will transmit a patient's cancelation of an opt-out election to the ILHIE within one (1) business day or as soon thereafter as is practicable or required by contract, but in no even longer than three (3) business days.*

The Subgroup agreed to add the timeframe language agreed upon with regard to transmission to the revocation policy. Ms. Matthias noted the Consumer and Education Work Group will provide a draft revocation form for review by the Subgroup.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #2 Collection of patient opt-out at HIE 2a. Storage at HIE. *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.*

Mr. Raul noted this preference was developed prior to the ILHIE Authority electing to accept paper opt-out and revocation forms directly from patients. The Subgroup recommended striking the above second sentence. Clarity was added to distinguish ILHIE responsibilities and provider responsibilities. The preference was amended to: *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 were received initially by the provider. If a patient provides an opt-out decision directly to the ILHIE, the ILHIE will retain a record of the patient's decision in accordance with applicable law governing record retention.* There were no objections from the Subgroup.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #2b. Patient Access. *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 Authority will consider the feasibility of enabling this functionality, including concerns regarding the authentication of individuals.*

Mr. Recarey stated the ILHIE is committed to enabling an electronic method; that method must fully address identify and authentication concerns. There were no objections from the Subgroup.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: #2c. Revocation. The Subgroup agreed to revisions to reflect prior consensus. The revocation policy recommendation was revised to the following: *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 available at a future date. The ILHIE will not collect or store revocation of opt-out forms which were received initially by the provider. If a patient provides an opt-out decision directly to the ILHIE, the ILHIE will retain a record of the patient's decision in accordance with applicable law governing record retention.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #3 Data filtering triggered by opt-out: #3a. 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.*

The Subgroup agreed this was not necessary as it is duplicative of prior policy. There were no objections to removing Preference #3a.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #3b. Data filtering triggered by opt-out: At ILHIE. *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".*

Ms. Lamar stated disagreement that ILHIE's MPI will be the central registry and thus the single source of information for applying patient consent. Ms. Lamar was comfortable with the remaining portions of policy preference #3b. There was clarification on the meaning of "a patient's reasonable expectations." Mr. Recarey stated the reference was intended to indicate patients have the expectation that there an opt-out will apply system-wide and there will not be conflicting opt-out scenario; the patient's preferences are not specific to one entity but rather transmitted through the entire system. Ms. Chaitan stated this issue speaks directly to the inter-relationship between ILHIE and the Regional HIEs in Illinois.

The Subgroup addressed questions about whether the patient needs to opt-out of every HIE until the technology allows for synchronization of preferences. Ms. Chaitan stated the language as currently drafted does not sufficiently account for what policies other HIEs will follow, nor does it help with the development of a policy that allows patient preference to be universally applied. While the Regional HIE Work Group is meeting to evaluate and identify mechanisms to ensure patient preferences are consistently applied, the Subgroup needs to develop policies to inform patients that currently their opt-out preference is not universal and what action the patient must take.

Mr. Recarey stated the ILHIE will make available its MPI service for free but an HIE may elect to not participate in the ILHIE statewide MPI project. Thus, the patient could opt-out of the ILHIE and not know they are included in the Regional. The Subgroup discussed the need for HIEs not willing to participate in the ILHIE MPI that there is an obligation of that HIE to provide information to the patient that their opt-out is not universal.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #3c. Data filtering

triggered by opt-out: At Regional HIE. *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 HIE in Illinois.* Ms. Lamar and Ms. Wiseman were in agreement with the policy preference. Ms. Chaitain there needs to be an interim policy while the technology solution is being developed.

Ms. Lamar state the Regional HIEs want to maintain that patient may not feel comfortable having their data available at the state level but would still be willing to participate at the Regional level. Ms. Wiseman and Ms. Chaitan stated if the Regional chooses not to participate in the ILHIE MPI it becomes their obligation to inform the patient and their opt-out is not universal. Ms. Chaitain asked what the Subgroup should require the Regional HIE's tell their patients. Ms. Lamar stated the State may not have the authority to required specific action by Regionals that do not contract with the ILHIE.

Mr. Recarey stated the ILHIE would honor patient preferences made at the Regional HIE level and would like notification if a patient opts-out. Ms. LaRocca stated if a patient elects to not participate at the Regional HIE level the ILHIE will rely on good faith that the patient would elect to also not participate in ILHIE. Ms. Recarey stated it is ILHIE's hope that all Regional HIEs will share their patients' preferences. Ms. Lamar stated the issue MCHIE has is that the ILHIE's preference is to maintain its MPI as the central registry. Mr. Raul stated that because it is voluntary it in no longer the central registry.

Ms. Chaitan stated unless there is an assurance that the opt-out is universal the Subgroup should develop a policy that additional information be provided to patient and the limited scope of the opt-out. Ms. Lamar stated a discomfort legally that a patients' opt-out from a Regional HIE would also apply at the ILHIE. Mr. Recarey stated the underlying goal is to facilitate the communication between the Regional HIEs and the ILHIE and honoring patient preferences at the regional level.

There was consensus that at a minimum on the ILHIE from, the patient be informed their opt-out may not apply at the Regional level. Mr. Recarey stated the ILHIE wants to receive and will respect patient decisions from the Regional HIEs. Ms. Wiseman stated that the CIHIE form language notifies the patient that they are only exercising their choice within the region. Ms. Lamar will check with MCHC and provide a response to the Subgroup on their willingness to include notice that the opt-out is only for MCHIE.

Mr. Berkelhamer stated that the expectation is that, if patient opt-outs of health information exchange, the patient does not care what entity manages the HIE. Ms. Wiseman stated if the patient wants to only participate in the Regional HIE that is okay, but it still leaves the burden on the Regional HIE to explain to the patient the implications of their opt-out.

Ms. Matthias stated Southern Illinois Healthcare will provide both the ILHIE and the SIH opt-out but ideally would like to combine the forms. Ms. Lamar expressed reservations about information sharing by Regionals that do not participate in ILHIE. Ms. Wiseman stated CIHIE would be participating in the ILHIE so it makes its patients' consent preferences available to the ILHIE. Mr. Recarey stated ILHIE will work with CIHIE to enable a technical solution. Ms. Chaitan suggested the policy reflect strong encouragement that the Regional HIEs include in their notice an explanation to patients that their opt-out is specific to that HIE.

The Subgroup made the recommendation to remove the references to ILHIE's MPI as a central registry and indicated the Regional transmission of preferences would be addressed by the Regional HIE Work Group in a collaborative effort between ILHIE and the Regional HIEs.

The Subgroup began its review of the *Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure* with policy preference item: Preference #4a. Data filtered by opt-out. Global. Preference: Data filtering as a result of a patients 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.

Ms. Sosa noted a provision in HB1017 that allows that data be used for secondary uses for research purposes. Ms. LaRocca clarified that it is permissible under HB1017 yet not operational in ILHIE; Ms. LaRocca also referenced the inclusion of secondary uses for research purposes in the ILHIE's enabling language. Ms. Roe clarified the policy to say even if the patient opts-out to the extent the law allows, ILHIE can be used for submitting public health reporting or conducting research as authorized by law.

The Subgroup discussed how important it would be to notify patient about secondary data; is this more confusing to the patient when the patient should be focused on the decision to participate or not participate. Agreement was reached to not include on the opt-out form. Ms. Matthias noted that it is included in the providers' Notice of Privacy Practices.

Ms. Matthias requested Subgroup Members review Section 5 prior to next meeting. Ms. Matthias recommended two groups work off line to develop the statutory notice required under HB1017 and the language to be included as an optional amendment to the provider's Notice of Privacy Practice. The Subgroup identified members to serve on each subgroup.

Next Meeting Date: Wednesday, September 4th, 9:30am-12:30pm.

Public Comments: There were no public comments

Meeting Adjourned at 4:30pm.

Submitted by Krysta Heaney

Reviewed by Elizabeth LaRocca