

AUGUST 7, 2013 MINUTES
 PATIENT CHOICE AND MEANINGFUL DISCLOSURE
 WORK GROUP, AND THE MEANINGFUL DISCLOSURE AT THE POINT OF
 CARE SUBGROUP, OF THE GOVERNING BOARD OF THE ILLINOIS HEALTH
 INFORMATION EXCHANGE AUTHORITY

The Patient Choice and Meaningful Disclosure Work Group of the Illinois Health Information Exchange Authority (“ILHIE Authority”), pursuant to notice duly given, held a meeting at 10:00 a.m. on August 7, 2013, at the State of Illinois James R. Thompson Center, 100 West Randolph Street, Suite 2-025, Chicago, Illinois 60601 and 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
Laura Ashpole	Popovits and Robinson	
Carolyn Bailey	Blessing Hospital (via phone)	Break the Glass
Elissa Bassler	Illinois Public Health Institute	Point of Care
Alan Berkelhamer	Walgreens	Point of Care
Victor Boike	MetroChicago HIE	Break the Glass
Charles Cox	MetroChicago HIE	Specially Protected Health Information
Dana Crain	Southern Illinois Healthcare	Specially Protected Health Information
Mary Dixon	American Civil Liberties Union-Illinois	Point of Care
Kristen Dome	Leyden Family Services & Mental Health Center (via phone)	
[NAME MISSING]	AIDS Foundation of Chicago [AFC]	Point of Care
Deb Gory	MetroChicago HIE (via phone)	Break the Glass
Mark Heyrman	University of Chicago Law School	Specially Protected Health Information
Beth Koch	Fayette Companies – Human Service Center (via phone)	
Sarah Koenig	APP Design (via phone)	
Marilyn Lamar	MetroChicago HIE	Point of Care
Brigid Leahy	Planned Parenthood of Illinois (via phone)	Point of Care
Howard Lee	Wirehead Technology	HIE Website
Marvin Lindsey	Community Behavioral Healthcare Association	Specially Protected Health Information
Matt Mann	Illinois Hospital Association	Point of Care
Nancy Newby	Washington County Hospital (via phone)	Break the Glass

Susan O'Keefe	MetroChicago HIE (via phone)	Break the Glass
Melissa Picciola	Equip for Equality	Point of Care
Mikki Pierce	Atrium Advisory Services Inc (via phone)	Break the Glass
Renee Popovits	Popovits & Robinson	Break the Glass
Kathryn Roe	The Health Law Consultancy	Point of Care
Jodi Sassana	MetroChicago HIE	HIE Website
Susan Strange	Aetna Better Health	Specially Protected Health Information
Glenn Susz	APP Design (via phone)	HIE Website
Lauren Wiseman	Central Illinois Health Information Exchange	Point of Care
OHIT Staff Present		
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

Welcome and Call to Order. Ms. Elizabeth LaRocca, Office of Health Information Technology (“OHIT”) General Counsel, called the meeting to order at 10:03 a.m.

Approval of Agenda. There were no proposed revisions to the meeting Agenda that was duly posted in advance of the meeting in accordance with the Illinois Open Meetings Act.

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

Subgroup Meetings - Breakout

Meaningful Disclosure at Point of Care Subgroup

Ms. Marcia Matthias, Meaningful Disclosure at Point of Care Subgroup Chair, called the meeting to order at 10:15am. Attendance was taken and the ability of those participating by phone to hear clearly and participate was confirmed. There were no objections expressed to the participation of the Subgroup members by electronic means.

Approval of July 24, 2013 Meeting Minutes

Copies of the July 24, 2013 draft meeting minutes of the ILHIE Patient Choice and Meaningful Disclosure Work Group and Point of Care Subgroup were circulated in advance of the meeting. Clarification was provided that the draft minutes reflect the full meeting of the Work Group and the Subgroup meetings. Ms. Brigid Leahy of Planned Parenthood of Illinois was added to the Member attendance list for July 24, 2013. The Work Group approved the minutes as amended.

Summary of Prior Consensus

A document identifying Subgroup objectives, deliverables and timelines was distributed to the Subgroup. Ms. Matthias provided a summary of the consensus discussion from the July 24, 2013 Subgroup meeting:

- Provider is responsible for providing Meaningful Disclosure at the point of care;
- A “provider” is the legal entity that contracts with ILHIE;
- Recognize there is a cost associated with providing Meaningful Disclosure;
- Appreciate that there is a difference between opting-out and consent;
- Recognize patient rights to Meaningful Disclosure and opportunity to opt-out;
- Recognize limitations in Electronic Medical Records (“EMR”) to track patient opt-out;
- Recognize the need to balance patient notice and provider responsibility;
- Subgroup goal is to set minimum requirements for Meaningful Disclosure.

The goal for the meeting was to develop consensus on item #1. Collection of patient “opt-out” at provider point of care in the *Excerpts from Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure*.

Frequency of Collection

The HIPAA Notice of Privacy Practices (“NPP”) was offered as a model for the frequency of collection of patient opt-out. Mr. Matt Mann asked for clarification on the definition of Meaningful Disclosure, suggesting that the form of Meaningful Disclosure may have an impact on the frequency of collection of patient opt-out; there are different provider responsibilities if the disclosure is a provider-to-patient conversation versus providing the patient with a brochure. Ms. Marilyn Lamar noted that during the development of the legislation [HB1017] there was opposition to stringent provider requirements for Meaningful Disclosure. The legislation includes language that Meaningful Disclosure will include written notice of a patients’ right to opt-out and an HIE website with audio, visual, and written instruction on how to opt-out. Mr. Mann stated that providers want standard documentation that can be provided to patients explaining how the HIE works.

The Subgroup discussed workflow implications of the proposed collection process. Ms. Lauren Wiseman suggested a tiered approach to providing Meaningful Disclosure suggesting different roles and responsibilities at each level. The Subgroup recommended provider organizations consider tasking the HIPAA/Privacy Officer staff with responsibility for understanding the Meaningful Disclosure and opt-out process. In many provider organizations the HIPAA/Privacy Officer is responsible for answering provider privacy questions, the addition of HIE disclosure information would build off an existing framework.

Meaningful Disclosure

Ms. LaRocca stated there will be robust resources available to providers on the HIE website, developed pursuant to HB1017 requirements, that will allow providers to answer basic consumer questions. Ms. LaRocca clarified that the legislation does not require a hotline for provider or consumer inquiries.

Ms. Mary Dixon raised a concern that it may be unrealistic to expect patients to remember a website or that they have the opportunity to opt-out if they are only provided Meaningful Disclosure at the first encounter with a provider. Ms. Dixon indicated that at the past meeting there was general agreement there may be certain situations, e.g. sensitive diagnosis, that would trigger a need to provide Meaningful Disclosure at a subsequent visit. Ms. Dixon suggested including an additional opportunity to opt-out at a different setting/point of care. Ms. Matthias stated there is some responsibility on the part of the individual to read the documents that they have received.

AIDS Foundation of Chicago [AFC] reminded the Subgroup that a large part of the conversation at the prior meeting was to have a brochure, or placard at the point of care as an element of Meaningful Disclosure. Ms. Matthias asked: If the Meaningful Disclosure requirement would be to put up a sign at the point of care, what is the provider's legal liability if they do not have that information available or do not update that information? Mr. Mann indicated provider requirements cannot go beyond the scope of the legislation. AFC suggested a placard would fall under Meaningful Disclosure and is not an above or beyond requirement.

Ms. Matthias indicated the Subgroup is responsible for recommending minimum requirements for Meaningful Disclosure; providers can choose to go beyond the minimum requirement. AFC suggested there is an important distinction between Meaningful Disclosure for HIE and for HIPAA. A main concern for a patient accessing mental health care is that their general medical provider will now have access to that information, and vice-versa; therefore, the disclosure should be more meaningful.

A discussion ensued about having more robust Meaningful Disclosure requirements in particular care settings, e.g. behavioral health care settings. It was noted that it may be more manageable to classify Meaningful Disclosure requirements by provider type rather than category of service. This classification gives the provider the opportunity to self-classify themselves. Providers would recognize when they are providing services of a particularly sensitive nature and could decide the level of Meaningful Disclosure. The minimum would be establishing categories of providers that are required to provide additional information to satisfy Meaningful Disclosure.

Ms. Brigid Leahy recommended that patients be periodically reminded of their opportunity to opt-out. Patients need to understand the ramifications of their decision to opt-out or revoke a prior decision. Meaningful Disclosure does not need to be done every time but there needs to be a system in place so that it does not only happen once. You would not need to provide repeated Meaningful Disclosure to a patient over an episode of care for example, a woman with an abnormal pap requiring repeated follow-up visits. Ms. Lamar proposed an annual reminder, similar to federal credit requirements. There was a brief discussion about the feasibility of providers or the State using an annual mailing to provide Meaningful Disclosure to patients. There was agreement that it is the providers' responsibility to inform the patient that the provider has joined the ILHIE.

Ms. Matthias referenced the Principles and Preferences document "form of disclosure" giving some leeway on how the provider chooses to give Meaningful Disclosure. The group discussed setting a minimum standard for Meaningful Disclosure, giving providers the flexibility to provide additional patient information if the provider deems it appropriate to their practice setting. Mr. Mann noted that all forms at the point of care should be available, at a minimum, in English, Spanish and in the language(s) for which that population represents 20%. There was clarification that Meaningful Disclosure notice is separate from the NPP but that the Point of Care Subgroup will recommend language that providers may choose to incorporate into their organization's NPP.

Ms. Wiseman recommended that ILHIE consider engaging in a public education campaign or public service announcement. Ms. LaRocca noted that the OHIT Consumer Education Work Group has created a number of provider and patient resources that are available on the ILHIE website. AFC suggested creating template provider notices that can be printed and posted in their provider setting.

Mr. Matt recommended that Meaningful Disclosure documentation be a part of ILHIE on-boarding. Ms. Wiseman indicated the Central Illinois HIE has a similar approach. Mr. Mann motioned to approve the language in *Excerpts from Principles and ILHIE Authority Preferences Regarding Patient Opt-Out Choice and Meaningful Disclosure #5b Principles Form of Disclosure for Meaningful Disclosure at Provider Point of Care*. There was clarification that references to provider is the legal entity contracting

with the HIE. Ms. Kathy Roe seconded the motion. There was discussion as to whether the Subgroup was holding a formal vote. The form of disclosure was approved by consensus, no formal vote was taken.

The Subgroup returned to a discussion of the frequency for the collection of patient opt-out at the provider point of care.

Ms. Dixon disagreed with the preference that patient opt-out only be collected once per provider per patient stating this collection was too infrequent. AFC proposed the Subgroup consider a more frequent collection timeframe; proposing annual collection. Ms. Matthias asked whether provider systems can handle tracking an annual patient opt-out collection. AFC suggested the policy could specify once per provider per patient, or at the next patient visit if that visit is longer than a year.

Once per provider is very provider friendly and not very patient friendly. The Subgroup needs to balance provider requirements and burden with providing adequate meaningful disclosure to enable patients to make informed decisions about their participation. There are many interactions a patient may have with a provider; it is the intervening conditions that are cause for concern from the patient perspective. A placard is not enough because it has not been considered as a requirement by this Subgroup. Ms. Wiseman noted that most providers would willingly choose to use a placard. Ms. Elissa Bassler expressed concern that having overly restrictive provider requirements may create disincentives to participate in the HIE. Without provider participation, patients will not benefit from the HIE.

It was recommended that the Subgroup recommendations reflect the principle that the provider will likely choose to display a placard and provide notice more frequently than once per provider per patient. Ms. Bassler suggested that the Subgroup recommend the ILHIE Authority encourage use of and that providers display prominently that the provider is participating in the HIE as well as have a resource locally to answer questions and to direct the patient to additional resources available on the HIE website.

Ms. Matthias proposed action on the following recommendation regarding frequency of collection: Once per provider per patient with further recommendation that the provider is encourage to prominently display materials about their participation in the ILHIE and patients' ongoing right to change their decision to opt-out or revoke a prior to decision to opt-out. Ms. Roe asked if there were any exceptions to the recommendations for example, children reaching the age of majority. Ms. Roe proposed that the ILHIE acknowledge legal requirements regarding consent requirements for minors and incorporate minors' consent rights extend to the right to opt-out of HIE. Ms. Bassler made a motion to accept the above recommendation. Mr. Mann seconded. Ms. Dixon and Ms. Leahy opposed, stating their opposition to only requiring notice once per patient per provider. AFC stated in a formal vote they would also oppose.

Ms. Dixon reiterated the position expressed by Ms. Lori Chaiten of the ACLU at the last meeting that a notice should be given for each patient/provider. Ms. Dixon noted that beyond the cost burden it is unclear that the distribution of a form is overly burdensome. The right to opt-out is very important and a significant change for the patient on the privacy end. The provision of notice at each encounter does not necessitate patient questions at each encounter. Ms. Matthias noted a significant cost associated with paper notices.

Ms. Leahy noted that the provision of a notice once in the lifetime of the provider patient relationship is insufficient for the patient to understand and remember what they have agreed to do, especially if no action on their part is required to participate. Annual notice requirements are a more balanced approach. AFC said that since providers will already be tracking their patients' opt-out status tracking annual notice does not seem like an additional burden. Ms. Matthias expressed concern that the provision of notice at each encounter could diminish the value of the notice and become overwhelming to the patient.

Ms. Bassler noted that there appears to be a difference between informing patients of a provider's participation in ILHIE versus providing patients an opportunity to opt-out. The Subgroup discussed alternative means, removed from the point of care, for providing notice to patients: patient portals, website postings, annual mailings. Mr. Berkelhamer indicated annual mailings would be cost prohibitive. There was agreement that relying solely on electronic communication either through patient portals or via website postings will not reach all populations.

Ms. Bassler motioned regarding the frequency of collection of patient opt-out and form of disclosure:

- The frequency of collection of patient opt-out at the point of care will be once per provider per patient. The provider is the legal entity or individual with a contractual relationship with the ILHIE.
- The provider will provide a patient with Meaningful Disclosure at the first patient visit following a provider's participation in the ILHIE. At a minimum, the form of the Meaningful Disclosure will include a written notice to the patient, *and* (emphasis added; amendment of prior motion) a prominently displayed poster/notification about the provider's participation in the ILHIE and a patient's ongoing right to change his or her decision to opt-out or revoke a prior to decision to opt-out.

AFC said at previous meeting there was agreement that the above motion was a minimum. The Subgroup further discussed whether the recommendation was a requirement or recommendation; consensus was reached as to the above minimum disclosure. ILHIE will develop the resources for providers to use. Ms. Dixon stated agreement with the recommendation. Mr. Mann affirmed the generally reasonableness of the recommendation. Ms. Bassler noted the motion strikes a balance in that it is less burdensome than once per year and does not discourage participation in the HIE as well as addresses patients' access to information on their rights to participation. It was noted that displaying the NPP is a requirement. Enforcement will occur through contractual relationships with ILHIE. AFC stated that it is important that the Subgroup create policy that sets a standard that establishes the floor as acceptable. Mr. Mann second. There was no Subgroup member present in opposition.

Duration

AFC recommended adding "or changed" to the proposed duration policy.

Ms. Matthias motioned regarding duration of patient opt-out:

- A patient's consent preference is perpetual until revoked or changed.

There was no Subgroup member present in opposition.

Document Creation

Ms. Matthias asked for members of the Subgroup to review the resources available on the ILHIE website. It was proposed to identify best practice Notice language at the next meeting. ILHIE/OHIT staff will draft proposed language based on best practices for review by the Subgroup.

Comments

Mr. Berkelhamer asked when exchange through ILHIE can begin; is the HIE Participant [provider] required to give Meaningful Disclosure to all its patients prior to going-live with the HIE? Regardless of the form of disclosure, can the provider begin participating in query prior to going live with ILHIE? ILHIE will report back to the Subgroup at its next meeting.

Adopted 8-20-2013

Subgroup Adjourned

Patient Choice and Meaningful Disclosure Work Group Reconvened

Meaningful Disclosure at the Point of Care Subgroup Summary: The Subgroup reached conclusions regarding the frequency of collection of opt-out, duration of the opt-out, and the form of disclosure.

Meaningful Disclosure at the HIE Website Subgroup Summary: The Subgroup reviewed other states website information and currently available ILHIE resources. The Subgroup reached consensus on the creation and posting of the following resources on the ILHIE website: HIE FAQs, audio PPT presentation, ONC video resources.

Specially Protected Health Information Subgroup Summary: The Subgroup focused its discussion on functionality at the provider and EMR level.

Break the Glass (Medical Emergency) Subgroup Summary: The Subgroup reviewed distributed resources, including the OHIT *Recommendations of the Substance Abuse Legal Work Group* White Paper and the SAMHSA FAQs Applying the Substance Abuse Confidentiality Regulations 42 CFR Part 2 to Health Information Exchange. The Subgroup will identify best practices for break the glass policies from other states, specifically in opt-out sates Indiana, Missouri and Michigan.

Next Meeting Date: Tuesday, August 20th, 1:30-3:30pm.

Public Comments: There were no public comments.

Meeting Adjourned at 12:00pm.

Minutes submitted by Krysta Heaney

Minutes reviewed by Elizabeth LaRocca