



Adopted 08/07/13

JULY 24, 2013 MINUTES  
OF THE 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 Illinois Health Information Exchange Authority (“Authority”), pursuant to notice duly given, held a meeting at 10:00 a.m. on July 24, 2013, at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with video and telephone conference call capability.

✚ Meaningful Disclosure at the Point of Care Participant List

Participant Name	Participant Representation
Beth LaRocca	Office of Health Information Technology
Charles (Chuck) Cox	MetroChicago HIE
Dana Crain	Southern Illinois Healthcare
Danny Kopelson	Office of Health Information Technology
Deb Gory	Metropolitan Chicago Healthcare Council
Glenn Susz	APP Design
Howard Lee	Wirehead Technology
Kathy Roe	The Health Law Consultancy
Laura Ashpole	Popovits & Robinson
Lauren Wiseman	Central Illinois Health Info. Exchange
Lorie Chaiten	ACLU (IL)
Marcia Matthias	Southern Illinois Healthcare
Mark Chudzinski	Office of Health Information Technology
Matt Mann	Illinois Hospital Association
Melissa Picciola	Equip for Equality
Raul Recaney	Illinois Health Information Exchange
Sarah Koenig	APP Design
Shira Mendelsohn	Office of Health Information Technology
Brigid Leahy	Planned Parenthood of Illinois

✚ Introduction of Work Group Members. Open Meetings Act acknowledgement regarding notices posted online and at the meeting location more than 48 hours in advance of the meeting. Reiteration of plan to meet briefly as a large group, break into subgroups and reconvene to discuss workgroup progress. Acknowledgement from Work Group members that everyone had received their subgroup assignments.

- Work Group split into 4 subgroups per Agenda:
  - Meaningful Disclosure at the Point of Care (facilitated by Marcia Matthias);



- Meaningful Disclosure at HIE Website (facilitated by Danny Kopelson);
  - Specially Protected Information (facilitated by David Carvalho);
  - Break the Glass – Medical Emergency (facilitated by Mark Pellegrino).
- Reconvene at 11:45 to summarize subgroup progress.
  - Timeline: It is important for participants to be mindful of the strict timeline to accomplish Work Group goals. Acknowledgement that each subgroup participant received an Action Plan for his/her subgroup outlining objectives and deliverables.
- ✚ Meaningful Disclosure at the Point of Care Introduction: It is important to define the scope of patient opt-out choice at the point of care and to stimulate conversation with an objective review. Any policy recommendation should meet the statutory requirements.
- Agenda for today: Define the scope and content of meaningful disclosure and develop resources for disclosure use to ensure that patients do indeed receive meaningful disclosure. There will be four deliverables, including policy recommendation for patient choice and meaningful disclosure.
  - Participant Question: Will amendment to the Notice of Privacy Practices (NPPs) serve as the statutory notice?
    - Response: It will be a separate document.
  - Issues this subgroup will address: Does anyone have suggestions?
    - Participant Comment: Responsibilities of providing the notice to patients who opt out of the ILHIE or RHIOs.
      - This will be a separate group discussing these issues.
    - Suggest that we break into subgroups and discuss:
      - Subgroup: Content of the forms, revocation, opt-out forms, and the notice.
      - Subgroup: Collection, storage, and communication.
      - Policy: Document regarding retention
- ✚ Definitions: Meaningful disclosure should be defined. There is a tool kit on the ILHIE website that might reference meaningful disclosure such that we



ensure consistency with our language and we are not reinventing things or confusing the patient.

- Qualifications of forms: We can have electronic notification and documentation. But we must determine capabilities of the system. From the ILHIE perspective, electronic forms on the ILHIE website about opt-out is not possible but it is something to aim form.
- Participant Comment: We want a signature from a patient to acknowledge that they want to opt-out.
  - Response: But are we describing signing on a screen that doesn't generate a piece of paper. Also, aren't we giving providers the choice of disclosure?
- Revisit the documents and definitions. We must understand that there are some important assumptions made about the process that everyone may not agree with this. Let's begin with collection of patient opt-out at provider point of care. What is the provider? Who is the provider? Is it an individual, an organization, is it part of the EHR? Any thoughts and recommendation regarding who the provider is and their responsibility?
  - Participant Response: To access the ILHIE, a participant needs a password and login, such that it boils down to an individual. Consistency needs to be maintained. For instance, the organization (provider/hospital) isn't going to record the opt-out of the patient, it will be an individual.
  - Participant Comment: Another thought is that a large organization, including hospitals or nursing homes will sign up to an HIE once. Would that mean every time a patient is seen at one of those places, the hospital or nursing home would go through the opt-out process again?
  - Participant Comment: Let's address how we opt-out. We should really narrow it down to an individual. It would be dangerous not to hold a person responsible. It might be helpful to have the organization document opt-out and then identify a person responsible for opt-out because a hospital or nursing home would not want an opt-out/meaningful disclosure happening too many times unnecessarily.
  - Participant Comment: From a legal perspective, there are probably community documents with independent logins



✚ Opt-Out Frequency Discussion: Participant Comment: Perhaps we should observe from a patient perspective. If I, the patient, get my ears checked and go through the opt-out process and then go to an abortion clinic at a later date, I might feel differently about being in the ILHIE system. If the patient's opt-out is perpetual until revoke, meaningful disclosure may only be presented once per provider and once per organization. A patient should be reminded every time he/she goes to the provider. The patient may not have thought about opt-out the same way at different offices or clinics. Meaningful disclosure/opt-out as a perpetual choice would deny the patient the opportunity to reconsider whether they want to participate in the ILHIE.

- Participant Comment: I don't think it is practical to have meaningful disclosure as part of the physician or the drug workflow each time.
  - Participant Response: The concern is when the patient hasn't considered other issues. If I were to go for an abortion, I might reflect differently regarding opt-out.
  - Participant Response: Providing meaningful disclosure too often can result in the loss of meaning of meaningful disclosure. Maybe meaningful disclosure can be provided again in special circumstances.
  - Participant Response: But this proposal is that the patient essentially gets nothing. Is that better? 45% of women have an abortion. Therefore, an abortion isn't a special population.
- Participant Comment: A balance is needed. Meaningful disclosure for every patient encounter is potentially too much and having meaningful disclosure once per provider may be too little. Consider a pharmacy --- there are thousands of encounters a day and the customer picks up prescriptions, which is very different than how hospitals and physician offices run. It is important to think broadly about how meaningful disclosure impacts everyone. I have been in places where they get HIPAA notices and when they are distributed all the time, patients don't seem to be as thoughtful about reading.
- Participant Comment: We see both perspectives. I personally deal with a population that has sensitive information. We see a woman who comes in often for follow up and would have been



provided meaningful disclosure just the week before. So, do we provide notices to that same individual coming in every time, knowing that she likely drops the notice in the garbage? But once is not necessarily enough. We need to establish a happy medium. Is there some kind of potential balance between once a year and on every visit?

- Participant Comment: Is it possible for the subsequent providers to know you have been given notice and in a specific time frame?
  - Participant Response: Notices of meaningful disclosure should get tracked. However, it has to be considered that every time the patient gets a notice, incurs a cost.
- ✚ Opt-out Discussion Location: A patient may need to discuss opt-out or meaningful disclosure in greater depth at a different location. A privacy officer or someone who understands meaningful disclosure should be available to explain opt-out.
  - Participant Comment: A pharmacy, a hospital, etc., doesn't have a privacy officer. We have to think more broadly. So you have to think broadly.
  - Participant Comment: At Central Illinois, we think about these issues.
  - Participant Comment: But each organization decides where in the workflow the meaningful disclosure occurs, whether be on-site or off-site.
  - Participant Comment: What about a public notice? Can't we have a place every patient can read it at the provider's office, like a plaque?
    - Participant Response: How effective are those plaques? A hotline to call for more information might be helpful. You can provide a plaque where the initial conversation occurs. However, a plaque can't just be hanging on the wall and be adequate. There should be a number for a patient to call if they are confused.
  - Participant Comment: The number to call is ILHIE. It is not in our budget and we don't have a way of knowing the volume. When someone has questions, it's difficult to get answers.



- Participant Comment: Public notice is an important component, but meaningful disclosure is where the patient is warned and the public is given the opportunity to ask questions. We can't just assume every person understands opt-out from the public notice.
- Participant Comment: If the provider would have to provide that information, it would be a huge cost. We don't want to create that kind of scenario either. Patients will say "what is this" 5 times too many if you make it too easy for them to ask questions. There is a real practical cost to a provider.
- Participant Comment: Maybe we should return to who is the provider? Within the scope of HB107, maybe there is something different for mental health than other providers? What is a mental health provider?
- Participant Comment: We are so concerned about ILHIE and provider costs but we need to consider the best interest of patients. I even have difficulty understanding opt-out because there is no one to answer my questions. How can we make information available to patients?
- Participant Comment: How often should the provider say, each time you go to the same provider for different treatment, there needs to be some reminder so the patient can sit and reflect about opt-out? Maybe the public notice is helpful or having the call center. Or maybe adequate information on the website would be more beneficial than a 10 minute in person, meaningful disclosure conversation.
- Participant Comment: When you consider HIPAA, you don't explain this every time to remind a patient.
- Participant Comment: But there also has to be a place where a patient can ask questions. It is not at the provider, it has to be at ILHIE, preferably a phone call because everyone does not have a computer.
- Participant Comment: If the plaque explains opt-out and someone has a concern that they don't want to opt-out, it is more of an exception to the rule.



- Participant Comment: It can't just be one time the patient is told about opt-out and forever more it is not explained again. Is the reminder a poster?
  - Participant Response: We can probably influence in this committee what goes on in that public notice.

✚ Liability: What happens if the provider or hospital hands the notice every time? What is the liability if the registration person does not provide that notice and something happens?

- Participant Comment: Are we going to provide everything at the local level or at the organizational level and then let each organization decide based on their business operations.
- Participant Comment: How prescriptive are we going to be and what sales job does that necessitate if we become too prescriptive?
  - Participant Response: There is some suggestion about a website a patient can go to. The provider maybe says, go to this website. However, each patient may not understand the content on the website. Maybe there should be an initial meaningful disclosure, a plaque, and a place to get heard.
  - Participant Comment: The idea of having a call-in service and someone to fund it might not be very practical
- Participant Comment: What is the goal? Patient safety and privacy? Taking it from a practical situation, if the patient does not want the physician to know they are HIV positive, then this new HIV diagnosis might change their desire to be opted-out.
- Participant Comment: HB1017 requires a website to go to in order to get more information which was an alternative to the call in line. If you have a plaque up, if there is no calling-in number, then the questions come to the provider.
- Participant Comment: The idea of a website can work because most people have access to computer. It is an issue but it can't stop us from moving forward. The website for the ILHIE and other HIEs are very user friendly and easy to understand. I have a concern with the plaque, for those who don't understand within the general population. If the website is worded for a 6<sup>th</sup> grade education level, that might be helpful.



- Participant Comment: The patient should be offered more than one opportunity. They can get this information on the plaque and then go to the website. But then if they can't get information on the website, then you might want to have a brochure printed for those people. We can develop those things that the committee recommends.
  - Participant Comment: But there should be flexibility for the provider to choose the method of meaningful disclosure. It is important to be careful not to be too prescriptive or it won't be followed.
  - Participant Comment: If policy changes, will everything get updated? So if you have brochures and plaques and then things get changed, what happens? What about payment for brochures?
- ✚ Recap: Meaningful disclosure at provider point of care: The provider is responsible for giving meaningful disclosure. There are several preferences, including first encounter with the provider and meaningful disclosure. Template notices would provide notice of privacy practice and other materials for distribution.
  - Participant Comment: The divide we keep coming back to is where are plaques going to be. Plaques might need to be getting information from the exchange. Visuals instead of words are sometimes better.
  - Agreement: It sounds like the provider is an organization that has an agreement with the ILHIE and if the organization has multiple physicians then the information is distributed at the first interaction with the provider and not each subsequent physician at that organization. Then when we identify the responsibilities, we are recommending, these would probably be recommendations and not requirements. It may be costly to have posters if we keep updating as the law changes.
  - Participant Email: Patients are more concerned about family and employment disclosure than provider disclosure.
  - Participant Comment: There is no need to reinvent the wheel. Mark collected different forms from state agencies. They are up on the ILHIE website. I believe the regional health exchange was supposed to be posted on the website. Lincoln Land can send them and Southern Illinois also has forms.



- ✚ Do we have an agreement as to what is a provider? And then at the next meeting we can address the minimum responsibilities/recommendations or expectation.
- ✚ Reconvene as a group: Each subgroup will provide a minute or two to share information about the work group level and information that might be relevant for the other subgroups since so much of what occurs is interrelated
  - Meaningful Disclosure at the Point of Care
    - We had a lot of participation. We ran into difficulty, so make sure in future meetings that participants know not to place their phones on hold because music plays and participants can't hear others speak.
    - Had a great discussion regarding what is the provider? We have a conclusion: It is the organization who has the affiliation with ILHIE. We identified the minimum requirements and responsibilities of the provider as to what is meaningful disclosure. One of the concerns addressed was the cost involved in providing meaningful disclosure and how it should be done.
  - Meaningful Disclosure at the HIE Website
    - We had a great meeting about what would appear on the website. What is an HIE, HIT, and the benefits of them? Some of it already exists on the website and can be adapted. What is opt-out, changing your mind? We want the benefits of HIE and we are dependent on the technology workgroup as to how it will work and how forms work and point of care will need to be reflected on the website.
    - Next steps: We will look at the ILHIE website and look at what other states have done and we will outline how we see the website (how extensive or brief it should be).
  - Specially Protected Information
    - We spent a lot of time talking about the environment, the complexities of the environment, and other issues that should be addressed such as the current state of laws that affect health information. How the various RHIOs, ILHIE, interact with the data, what changes HB1017 made, and the fact that there are



multiple layers to complexity that information is protected and can exist in places you don't expect it. All the different ways the information may reside in the record make this complex to deal with. Accessing the records themselves discloses information. If the request for access is coming from a psychiatrist, does that infer that you are a mental patient which itself is protected? Who should have access? We discussed other environmental factors and other care coordination entities.

- Our takeaway: We need to be broad enough to anticipate that not every RHIO is identical. Our work will have to take into account the current environment and technology and the anticipated technology and environment. However, we don't want to make choices that constrain the way the technology might naturally evolve. We don't want to impede evolution.

- Break the Glass – Medical Emergency

- We discussed existing law in IL, e.g., the MHDDCA, and AIDS Confidentiality Act, regarding “break the glass” and separately, resources that could be made available to subgroup members via the Work Group webpage, in particular, those around substance abuse. We discussed the need to be mindful of the documentation requirements placed upon funded substance abuse programs and how these programs might receive information in the event of a break the glass occurrence. We also had a discussion around how nuanced this issue will be when dealing with general medical patients and patients with specially protected information or combinations of both and how break the glass will take place at the EHR or HIE level.

- ✚ Next scheduled meeting is scheduled for Wednesday, August 7, 2013, from 10:00 a.m. – 12:00 p.m. The same technology will be made available for those participating remotely. Anyone who may have a suggestion as to how we might better the process is welcome to contact us and we will continually try to make this a process better for everyone involved. Does anyone have any additional comments? We will adjourn the meeting.