



October 28, 2013

VIA EMAIL TO: Krysta.Heaney@Illinois.gov

Krysta Heaney, MPH
Office of Health Information Technology
100 W. Randolph Street, Suite 2-201
Chicago, IL 60601

Re: ACLU Comments on Work Group Recommendations

Dear Ms. Heaney:

The ACLU of Illinois ("ACLU") is in receipt of the October 24, 2013 submission of the Illinois Health Information Exchange ("ILHIE") Authority ("Authority") and the Office of Health Information Technology ("OHIT"), including Attachments A-G, and submit these comments prior to 5 p.m. on October 28, 2013, the time allowed for public comment. Please also consider this notification that the ACLU intends to present oral comments at the ILHIE Data Security and Privacy Committee ("DSPC") and working group meetings on October 30 and 31. In light of the short amount of time allowed for public comment, the ACLU submits these general comments rather than specific comments on each document.

The ACLU is appreciative of the substantial effort the Authority, the OHIT, the DSPC and the working groups have devoted to developing policies and procedures for the implementation of ILHIE in a manner that strives to protect patient privacy and security. The ACLU is pleased with much of what has come out of those efforts; however, we remain concerned about some fundamental aspects of how the ILHIE and EHR Connect will work and the risks to patient privacy that could occur because patients may not have the information they need to make fully informed decisions at each critical juncture in their care and that take into account their changed circumstances.

Specifically, the ACLU remains concerned that the Policies and Procedures Statement (Attachment F) and its implementing documents do not assure the seminal ILHIE policy of offering each patient the opportunity "to make meaningful and informed choices about their participation in EHR Connect."¹ To assure that patients can make meaningful and informed choices about their participation, the patient notice and information materials must be: (1) more specific and drafted in simpler terms understandable to the average patient, and (2) offered more frequently to ensure that patients appreciate, at critical junctures in their health care, the need to assess their ILHIE/EHR Connect election

¹ The implementing documents include: the Notice to Patients (Attachment A); the posted Notice to Patients (Attachment B); the ILHIE Website Content/Frequently Asked Questions (Attachment C); the Opt-Out Form (Attachment D); and, the Opt-In Form (Attachment E).

and consider changes in light of altered circumstances. This is particularly so as it relates to specially protected health information (“SPHI”).

1. Specificity and Simplicity.

As to specificity, the ACLU remains concerned that the policy statement, the notices, and the opt-out and opt-in forms do not adequately explain to patients that if they do not opt out of EHR Connect, all of their health information will be accessible through EHR Connect. The statement in the Notice to Patients (Attachment A) that “at this time EHR Connect cannot exclude specific information... from being shared” and that a patient is “either all in or all out” is necessary but not sufficient disclosure. This statement comes too late in the Notice and is not clear enough for the average patient. It should be stated up front and directly that if a patient does not opt out, all of the patient’s electronic health information may be accessible through EHR Connect and that if there is anything in a patient’s health records that the patient does NOT want each current and all future health care providers and insurers to have access to, the patient should consider opting OUT, because EHR Connect cannot exclude specific information from being shared.

This provision also must be supplemented with better information about SPHI. For example, the provision in the Notice (Attachment A) on page 1 entitled “**What Health Information Will be Shared through EHR Connect by EHR Connect Users? What Will Not be Shared?**” creates the inference that patients will be able to control segmentation of SPHI, while still allowing the sharing of other “diagnoses, test results, and other treatment information.” The more explicit statement on page 2 of the Notice (Attachment A) that “you are either all in or all” is too little and too late. To assure a meaningful and informed decision about whether to participate, all patients, but particularly those with SPHI, would benefit from an earlier and more explicit statement in the Notice to the effect that, if you do not opt out, all of your health information will be shared through EHR Connect; and, a further statement that if the patient gives consent to share SPHI, that SPHI may be shared with all the patient’s health care providers and, potentially, insurers, even if the patient does not want a particular provider, e.g., a podiatrist, to have access to health information concerning a sexual assault. Indeed, the meaningful disclosure working group discussed the possibility of a separate, brief document that would clearly and simply explain the issues related to SPHI; however, that is not one of the documents that came out of the working group. Such information is critical to patient understanding of how their health information will be shared, and, as we all know, once the information has been shared, there is no pulling it back.

Finally, the working group discussed on many occasions the need to have the patient notice in terms that are understandable by someone with a fifth grade reading level. The group was assured that others were working to make that happen. Unfortunately, the proposed documents attached to the DSPC submission (e.g., Notice, Opt-out Form, Opt-in Form) are not drafted in such terms.

2. Frequency and Timing of Notice.

The ACLU also is concerned that the policy stated in the Policies and Procedures Statement (Attachment F) at page 2 to the effect that “each patient will be offered the ILHIE Notice by his or her participating EHR Connect User during the first patient encounter after the EHR Connect User enrolls in EHR Connect, or as soon as practicable,” is not frequent enough and does not adequately reflect the multitude of changed circumstances that may cause a patient to be more concerned about the need to protect health information from being shared through EHR Connect, even if the patient is seeking care from the same provider who initially offered the ILHIE notice. For example, a patient with an uncomplicated health profile initially may choose not to opt out of ILHIE. If, however, circumstances change and the

patient, for example, has a genetic test, an HIV test or mental health care, generating particularly sensitive health information, the patient may have new concerns regarding discrimination and stigma, and may not recall that all health information potentially is shared in EHR Connect absent a decision to opt out. One-time notice simply will not suffice to assure that patients faced with changed circumstances understand the implications of sharing new health information through EHR Connect years after the initial notice is given. And, while special consent remains a requirement for the SPHI, a patient who, for whatever reason, was not initially participating in EHR Connect (because the provider did not include the patient, because the patient opted out initially because of general concerns about the system, etc.), and later signed the Opt-in Form (Attachment E), will have signed a broad consent to sharing of SPHI. Absent additional notice at the time of sensitive care that such health information will be shared through EHR Connect, the patient may not appreciate the need to reassess his or her circumstances. It is simply not reasonable to believe that patients will be focused on a notice they received at their first point of contact with the provider (defined broadly as the entity that contracts with ILHIE) when they access sensitive health care years later. Accordingly, the ACLU urges the DSPC to amend the policies and procedures to require that a clear patient notice be offered each time a patient seeks the type of care that may generate SPHI, and for all patients, annually.²

The ACLU also is concerned about the provision that allows the EHR Connect User to delay offering the ILHIE Notice until “as soon as practicable” if the Notice is not offered by the EHR Connect User during the first patient encounter after the EHR Connect User enrolls in EHR Connect (Attachment F, page 2). The only acceptable reason for not giving notice at the first encounter would be a medical emergency that made notice impossible. In all other situations, there should be no reason a provider cannot, at the very least, hand the patient a notice. This provision should be amended to instead state “or, in the event of a medical emergency that makes it impossible to offer the ILHIE notice to the patient, as soon thereafter as possible.” Without such an emergency limitation, patient health information may be shared before a patient even receives notice and has the opportunity to opt out. And, of course, once sharing occurs, there is no pulling it back.

Finally, the ACLU is supportive of the policy set forth in the ILHIE Policies and Procedures Statement (Attachment F), Section IIIA(12), (13) that requires that minors age 12 and older “must be given the opportunity to exercise his or her own participation decision (opt-out or opt-in) in accordance with the procedures outlined” for adults. A dual consent requirement (parent or guardian as well as the minor aged 12 and older), as advocated by some stakeholders, would be inconsistent with the provisions of Illinois laws that afford minors the right to self-consent – *without* involving a parent or guardian – to many different types of health care services. Those laws, which afford minors the authority to self-consent to such medical care as contraception, pregnancy testing, HIV testing, treatment and counseling, and substance abuse and mental health care, reflect determinations by the Illinois General Assembly that good health care policy is best served by allowing minors to access the medical care they need, even if parental notice or consent is not possible in each instance. In at least some circumstances, a dual consent requirement would result in a parent or guardian learning about the care the minor had

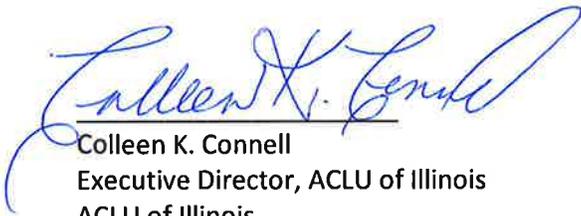
² In addition, it is critical that minors who seek care for which they can self-consent be given notice at the time of such care. For example, a 12 year old may choose to stay in EHR Connect when she turns 12 and is required to make an election about participation. However, when that same minor is 16, she may seek access to birth control or prenatal care. At that point, she should be given notice again to ensure that she reassesses her situation based on changed circumstance.

received, thus undermining the important public health bases for the self-consent statutes. We urge the DSPC to maintain this policy.

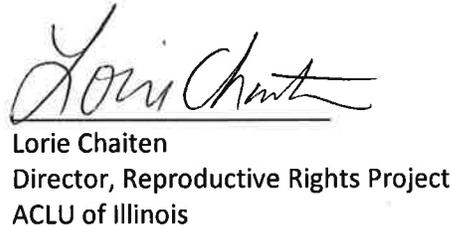
Again, the ACLU wishes to express its appreciation for the substantial effort that the Authority, OHIT, the DSPC and the working groups have dedicated to assuring that implementation of ILHIE and EHR Connect protect patient privacy and security. However, given the serious consequences that patients can suffer should their information be accessed too broadly, we think it imperative that the Policies and Procedures, as well as the Notices and Opt-Out and Opt-In Forms more explicitly and simply explain the concept of "all in or all out" as well as the current inability of EHR Connect to exclude specific information in a patient record from being shared. We also believe it is imperative that patients be offered the ILHIE Notice and a new opportunity to opt out whenever the patient seeks medical care that may generate SPHI and, in any event, annually.

Thank you for taking these concerns into consideration. We look forward to continued participation before the DSPC and in the working groups.

Sincerely,



Colleen K. Connell
Executive Director, ACLU of Illinois
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Lorie Chaiten
Director, Reproductive Rights Project
ACLU of Illinois