



ALCC

AIDS LEGAL COUNCIL of CHICAGO

**AIDS
FOUNDATION
OF CHICAGO**

A SOURCE OF HOPE. A FORCE FOR CHANGE

To: ILHIE Data Security and Privacy Committee
From: Ann Hilton Fisher, Executive Director, AIDS Legal Council of Chicago and
Ramon Gardenhire, Director of Government Relations
AIDS Foundation of Chicago
Date: 7/16/2012
Re: Patient Electronic Health Data Privacy and Security Policies – Oral and Written
Testimony With Regard to Panels 1-7

Thank you for the opportunity to provide testimony on protecting patient autonomy and confidentiality in the state-level Illinois Health Information Exchange.

Founded in 1985 by community activists and physicians, the AIDS Foundation of Chicago (AFC) is a local and national leader in the fight against HIV/AIDS. AFC collaborates with community organizations to develop and improve HIV/AIDS services; funds and coordinates prevention, care, and advocacy projects; and champions effective, compassionate HIV/AIDS policy.

The AIDS Legal Council of Chicago (ALCC) exists to preserve, promote and protect the legal rights of men, women and children in the metropolitan Chicago area impacted by HIV. ALCC provides direct legal services to people in need, educates the public about HIV-related legal issues, and advocates for social policies that ensure fair treatment for all people affected by HIV/AIDS.

There are approximately 38,000 people living with HIV in Illinois. Only half of them are in regular care¹. The ILHIE has the potential to improve access to care and retention in care for people living with HIV, but also has the potential to increase the fear and distrust that are already barriers to care for so many.

HIV is a uniquely stigmatizing disease

Since it was first identified 30 years ago, everywhere in the world people with HIV have been treated with suspicion and fear. United Nations Secretary General Ban ki-Moon recently said

1

Illinois HIV/AIDS Strategy: Background and Recommendations. Final Draft, July 2012. Illinois Department of Public Health, Office of Health Protection, HIV/AIDS and STD Sections.

"Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world."²

2

Ban Ki-moon op-ed (2008, 6th August), "The Stigma Factor", *The Washington Times*, as quoted in "HIV/AIDS Stigma and Discrimination", <http://www.avert.org/hiv-aids-stigma.htm>, accessed July 13, 2012.

It is also worth noting that many people with HIV come from marginalized populations, including the very poor, men who have sex with men, minority group members, illegal drug users, or sex workers, that are themselves stigmatized. Adding an HIV diagnosis to this only accentuates and increases the stigma that was already a part of their day-to-day life.

Even though HIV is no longer associated with a fear of certain and imminent death, the stigma remains. In a 2009 national survey by the Kaiser Family Foundation, more than one-third of parents said they would not want their child taught by someone with HIV, almost a quarter of the respondents said they would be uncomfortable having a co-worker with HIV, and more than half stated they would be uncomfortable eating a meal prepared by someone with HIV.³

Even too many health care providers share society's fear and distrust of people with HIV. A 2006 study of specific-service health care professionals in Los Angeles County found HIV discrimination to be prevalent. The researchers surveyed 131 skilled nursing facilities, 102 obstetricians, and 98 plastic and cosmetic surgeons to determine how many of these institutions practice a policy of blanket discrimination against people living with HIV. Of the institutions surveyed, 56 percent of the skilled nursing facilities, 47 percent of the obstetricians, and 26 percent of the plastic and cosmetic surgeons refused to treat people living with HIV.⁴ A 2012 survey found 5% of the dentists in Los Angeles County flatly refused to treat any patients with HIV, a number that rose to 10% if the patient's care was to be paid by Medicaid. The amount of discrimination also varied by neighborhood. In some areas the refusal rate was as high as 20%.⁵ In all areas there were additional providers who indicated that they would treat the person with HIV differently from their other patients.

In the last four years ALCC has represented Chicago-area residents who, because of their HIV status, have lost their jobs, been turned away at spas, sent to a different health care provider, or told to use a different bathroom. Even HIV-negative people who share a household with someone with HIV encounter stigma. Just this last week, a woman who shares her home with her HIV+ brother found her brother's HIV status used against her in a child custody petition.

Stigma interferes with access to health care

³ Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic, <http://www.kff.org/kaiserpolls/upload/7889.pdf> accessed July 13, 2012.

⁴ Sears B, Ho D. HIV discrimination in health care services in Los Angeles County: the results of three testing studies. 2006. <http://williamsinstitute.law.ucla.edu/research/health-and-hiv-aids/hiv-discrimination-in-health-care-services-in-los-angeles-county/> accessed July 13, 2012.

⁵ Sears B, Cooper C et al, HIV Discrimination in Dental Care: Results of a Testing Study in Los Angeles. Loyola Law Review - Symposium: LGBT Identity and the Law (Spring 2012). <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Sears-Cooper-Fariba-Younai-Donohoe-LLR-Spring-2012.pdf> . Accessed July 13, 2012.

HIV requires a life-long course of treatment, including rigorous daily adherence to a medication regime that may carry with it an array of adverse side effects, ranging from the uncomfortable (diarrhea, nausea, skin rashes) to the dangerous (heart disease, pancreatitis, diabetes).⁶ In addition to vigilant monitoring for side effects, people with HIV must also have regular viral load tests to ensure that they have not developed resistance to their medication regimen. All of this requires a close and trusting relationship between the patient and his or her health care provider.

Stigma interferes with health care not only because it causes direct discrimination, even by health care providers, but more significantly because it makes people with HIV reluctant to seek health care in the first place and more likely to drop out of care when stigma or discrimination, real or perceived, is encountered. Internalized stigma may cause feelings of depression and worthlessness. One third of all people with HIV report high levels of internalized stigma. Those individuals are *four times* as likely to report poor access to health care.⁷ Perceived stigma can also cause people to be more mistrustful of their health care providers, less willing to accept their recommendations, and more likely to fall out of care.

Confidentiality is the key to reducing the fear of stigma and discrimination among people with HIV and AIDS

Illinois has a strong AIDS Confidentiality Act. The link between confidentiality and public health is spelled out in Article 2 of the Act.

(2) Despite existing laws, regulations and professional standards which require or promote the informed, voluntary and confidential use of tests designed to reveal HIV infection, many members of the public are deterred from seeking such testing because they misunderstand the nature of the test or fear that test results will be disclosed without their consent.

(3) The public health will be served by facilitating informed, voluntary and confidential use of tests designed to reveal HIV infection.⁸

⁶ WebMD Side Effects of HIV and AIDS Drugs, <http://www.webmd.com/hiv-aids/aids-hiv-medication-side-effects> accessed July 13, 2012.

⁷ Sales J, Wong M et al, The Association of Stigma with Poor Access to Medical Care and Antiretroviral Therapy Adherence among people living with HIV/AIDS. *Journal of General Internal Medicine*, August 2009. <http://www.springerlink.com/content/71h5331844161x75/fulltext.pdf> accessed July 13, 2012.

⁸ 410 ILCS 305/2

The Act fulfills its promise to protect confidentiality by in nearly all cases leaving HIV disclosure solely up to the individual with HIV. The exceptions are very limited, including, for example, discretionary spousal or parental notification, limited use within a health care setting, or disclosure where a health care worker has been injured in an incident that might have the potential to transmit the virus. Any other disclosure requires “a legally effective release.”⁹ As further indication of the seriousness with which Illinois law protects the confidentiality of people living with HIV, the Act provides statutory damages for unauthorized disclosures. In 2008 those penalties were increased, so that there is now a minimum \$2000 penalty for a negligent release of information relating to someone’s HIV status, and a minimum \$10,000 penalty for an intentional or reckless disclosure.¹⁰

ILHIE must continue and reinforce Illinois’ long-standing commitment to assuring the strictest confidentiality of information related to an individual’s HIV status

We endorse and strongly urge the committee to adopt the specific recommendations made by the ALCU of Illinois. These include:

- 1. Patients must give specific opt-in consent to inclusion in the ILHIE.** The most effective way to protect patient privacy and autonomy, consistent not only with Illinois’ laws already protecting the confidentiality of HIV information, but also with other statutes, the underlying common law and constitutional foundations, is to adopt a system of requiring each patient to specifically consent to the inclusion of their name in the Illinois Health Information Exchange (opt-in) and to further require the development of policies (and technology) that allows each patient to segment and sequester sensitive health information, such that an additional specific consent of the patient would be required before sensitive health information could be exchanged through the ILHE (opt-in with reservations).¹¹

Only an opt-in consent requirement that preserves the patient’s right to segment and sequester sensitive health information would affirmatively protect patient privacy rights, assure greater patient participation in the ILHIE, promote more candid and comprehensive sharing of medical information with chosen providers, and ultimately best advance the statutory goals of improving a patient-centered health care system. This means that providers, prior to releasing patient names to the ILHIE, must advise each patient, individually, of the opportunity to be enrolled in the ILHIE, and of the right to consent to that enrollment (opt-in). ***A “ Notice of Privacy Practices” which effectively enrolls a person in the ILHIE, and which does not require specific consent to making one’s medical records accessible through the ILHIE, does not satisfy existing privacy policies or legal requirements.***

⁹ 410 ILCS 305/9

¹⁰ 410 ILCS 305/13

¹¹

2. **Patients must have the right to segment parts of their personal health record**, that the patient considers sensitive, including, not only information related to HIV, but also, for example, records pertaining to intimate partner violence, substance abuse treatment, or mental health diagnoses
3. **Providers who seek to distribute or to request segmented sensitive health information should be required to secure written consent** from patients before distributing or accessing sensitive segmented health information.
4. **The rights of patients to confirm or correct the accuracy of their electronic health records must be preserved in the ILHIE.** The most common HIV screening tests, like many other screening tests, not infrequently deliver “false positive” results. Although protocol dictates that no one be documented as HIV positive until confirmatory testing has been completed, ALCC has several times had to advocate for a patient whose medical record indicates they have HIV when in fact a confirmatory test returned a negative result. This right to correct records must be preserved.
5. **Patient data must be protected by prohibiting the sale of data and sanctioning the misuse of medical information.** In particular, it must be clear that the civil penalties of the Illinois AIDS Confidentiality Act apply to any information improperly disclosed to, or retrieved from, the ILHIE.

We appreciate this opportunity to offer testimony at this critical point in our state’s health care system. Please feel free to contact either of us for any further assistance we may be able to provide.