

Strategies for Electronic Exchange of Sensitive Information: HIV, AIDS, and STDs

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Individual Choice is one of the guiding principles set out in the Privacy and Security Framework,¹ one of the guidance documents developed for implementation of electronic health information exchange (HIE) networks. The Individual Choice principle is especially applicable when an individual is being treated for a condition the individual deems especially sensitive whether because of fear of social stigma attached to having the condition, or because of fear of potential discrimination if having the condition becomes known to others. Both state and federal law address the need to protect health information that may be of an especially sensitive nature. For example, federal law prohibits disclosure of genetic information to employers or insurers,² while other federal regulations prohibit use or disclosure (including re-disclosure) of patient records maintained in connection with any federally assisted program of alcohol or substance abuse treatment.³ Texas law protects patients from disclosure of their medical records that contain information about testing for, diagnosis of or treatment for HIV, AIDS or sexually transmitted diseases.⁴ However, certain other sensitive health information, such as reproductive health issues, being the victim of domestic violence or other criminal actions, and gender identity issues, are generally not the subject of special statutory or regulatory protections, but patients may still wish to prevent disclosure of such information to other health care professionals who are not directly involved with the treatment of the patient related to the patient's sensitive health issues.⁵

HIV, AIDS, AND STDs DEFINED

HIV means human immunodeficiency virus.⁶ It is the virus that can lead to AIDS.⁷ AIDS means acquired immune deficiency syndrome as that term is defined by the Centers for Disease Control (CDC).⁸ The CDC uses CD4+T cell counts and HIV viral load levels to monitor the

¹ *Individual Choice*, The HIPAA Privacy Rule and Electronic Health Information Exchange in a Networked Environment; available at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/healthit/introduction.pdf>.

² Genetic Information Non-discrimination Act of 2008 (GINA), Publ. L. 110-223, 122 Stat. 881 (2008).

³ 42 C.F.R. §2.3. For a more complete discussion about managing substance abuse treatment information, see *Strategies for Electronic Exchange of Substance Abuse Treatment Records* available at HIETexas.org.

⁴ TEX. HEALTH & SAFETY CODE, Chp. 81.

⁵ Letter to the Sec. of HHS; National Committee on Vital Statistics, (November 10, 2010) available at <http://www.ncvhs.hhs.gov/101110lt.pdf>.

⁶ TEX HEALTH & SAFETY CODE §85.002(4)

⁷ Centers for Disease Control, *Basic Information About HIV and AIDS*, available at <http://www.cdc.gov/hiv/topics/basic/print/index.htm>

⁸ TEXAS HEALTH & SAFETY CODE §85.002(1)

prevalence of HIV infection and AIDS in the United States.⁹ STD refers to a sexually transmitted disease, which includes HIV and AIDS, but also includes other infections that produce a disease in, or otherwise impair the health of a person or that cause an infection or disease in a fetus in utero or a newborn.¹⁰ Some health care providers prefer the term STI, or sexually transmitted infection, to reflect the fact that a person may be asymptomatic, but still represent a potential for infecting others.

HIV and AIDS are notifiable conditions¹¹ which means that both testing for and diagnosis of these conditions *must* be reported to the local health authority, which then reports the information to the Texas Department of State Health Services (DSHS).¹² If there is no local health authority, then the report must be made directly to the DSHS.¹³ DSHS and the local health authorities report surveillance data to the Centers for Disease Control.¹⁴ Each of these entities may release de-identified data for certain statistical and reporting requirements.¹⁵ The test results for either AIDS or HIV infection, or antibodies to HIV, are confidential¹⁶ and may not be released without specific patient authorization except to the public health organizations listed above and to the following providers who might access the information through an electronic health information exchange: (1) the physician or other person authorized by law who ordered the test;¹⁷ and (2) a physician, nurse, or other health care provider who has a legitimate need to know the test result in order to provide for the patient's health and welfare.¹⁸ In addition, if personal health records are accessible in an HIE by a patient, then the test information may also be released to the person tested¹⁹ or a person legally authorized to consent to the test on the person's behalf such as a parent or legal guardian.²⁰ Texas law also allows for partner notification to those who may have been exposed to HIV or AIDS as well as to those who might be at risk for spreading the disease.²¹ Texas law also allows for disclosure of an individual's test results to certain emergency personnel, peace officers, detention officers, county jailers and firefighters who may have been exposed to HIV or AIDS through their work while on duty.²²

Most, but not all, STDs are also reportable. The list of reportable diseases is maintained by the Department of State Health Services.²³ The CDC only maintains surveillance information

⁹ Institute of Medicine Issue Brief, *Monitoring HIV Care in the United States: Indicators and Data Systems*, (March, 2012).

¹⁰ TEXAS HEALTH & SAFETY CODE §81.003(11).

¹¹ *Id.* at §81.041(e).

¹² *Id.* at §81.043(e).

¹³ *Id.* at §81.043(c).

¹⁴ *Id.* at §81.043(c)(4).

¹⁵ *Id.* at §81.052.

¹⁶ *Id.* at §81.046(a) and (b).

¹⁷ *Id.* at §81.043(c)(3).

¹⁸ *Id.*

¹⁹ *Id.* at §81.043(c)(2).

²⁰ *Id.*

²¹ *Id.* at §81.051.

²² *Id.* at §81.048

²³ See <http://www.dshs.state.tx.us/idcu/investigation/conditions/>

on nationally notifiable conditions.²⁴ However, the CDC can and does monitor the prevalence of other STDs such as HPV by gathering information from specific sites such as STD clinics.²⁵

THE PRIVACY RULE, HIV AND AIDS

The Privacy Rule does not specifically address HIV or AIDS, but it does authorize disclosure of protected health information (PHI) without the patient's specific authorization for purposes related to public health,²⁶ law enforcement,²⁷ emergency management,²⁸ and with limitations, research.²⁹

Public health activities supported by the Privacy Rule include disease surveillance, public health investigations and public health interventions.³⁰ Public health disclosures include both mandatory reporting requirements under federal, state or local law, as well as collection of information for purposes of preventing or controlling spread of a disease. The Privacy Rule supports disclosure to persons who may have been exposed to a communicable disease or who may be at risk of spreading the disease if such disclosure is authorized under state law as it is in Texas.³¹

Uses and disclosures of PHI that may be required by law do not require authorization by an individual so long as the use or disclosure complies with and is limited to the relevant requirements of the law requiring disclosure.³²

The Privacy Rule gives patients the right to request restrictions on certain uses and disclosures of their health information,³³ including restrictions on how the patient's information is used or disclosed to carry out treatment, payment, or health care operations.³⁴ A provider is not bound to accept the requested restriction, but if the restriction is agreed to, it is binding.³⁵ The only mandatory restriction comes as a result of passage of the Health Information Technology for Economics and Clinical Health Act (HITECH).³⁶ The HIPAA Privacy Rule now authorizes

²⁴ Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance 2011*. Atlanta: U. S. Dep't of Health and Human Services.

²⁵ *Id.*

²⁶ 45 C.F.R. §164.512(b).

²⁷ 45 C.F.R. §164.512(h).

²⁸ 45 C.F.R. §164.510(a)(3)and (4).

²⁹ 45 C.F.R. §164.501.

³⁰ 45 C.F.R. §164.512(b)(1)(i)

³¹ 45 C.F.R. §164.512; see also *supra* at note 16.

³² 45 C.F.R. §164.512(a)(1)

³³ 45 C.F.R. §164.522(a)(1).

³⁴ *Id.*

³⁵ 45 C.F.R. §164.522(a)(1)(iii).

³⁶ American Recovery and Reinvestment Act of 2009 (ARRA), Pub. L. No. 111-5, H R. 1(2009) (*enacted as the Health Information Technology for Economic and Clinical Health Act (HITECH) in Title XIII, Div. A. and Title IV, Div. B.*)

patients to keep private information related to their care for which they, or someone not an insurance provider acting on their behalf, personally pays all of the expenses.³⁷

STATE APPROACHES TO CONSENT FOR DISCLOSURE OF SENSITIVE HEALTH INFORMATION IN AN HIE

States have struggled with how to create consent forms that will allow both patients and treatment programs to take advantage of the efficiencies of electronic exchange of health information while maintaining the now expected protections for confidentiality of those patients' PHI. A recent report from the Institute of Medicine notes that there is a variation across states for the threshold at which HIV viral loads and CD4 cell counts are reported. The report also notes the privacy barriers to sharing data for people with HIV across jurisdictions. These two factors influence the comprehensiveness as well as the accuracy of reported data. In addition, since most HIV/AIDS treatment support programs rely on federal funding, incomplete data can diminish a jurisdiction's access to funds for supportive services and treatment services for those within the jurisdiction.³⁸ Because the stigma from being diagnosed with HIV or AIDS remains prevalent, some states simply do not accept such information in their HIES because the technical issues are not fully resolved, while still others give notice to patients that they may not wish to consent to disclosure of their HIV/AIDS status through an HIE.

A regional provider in Connecticut, **eHealth Connecticut**, includes the following language in its notice to patients:

“Types of information included: Information accessed through the eHealthCT HIE includes ALL OF your medical information, including but not limited to, sensitive information related to HIV/AIDS, mental health, genetic disease or tests, sexually transmitted diseases and family planning. *Types of information NOT included:* Information as it relates to treatment for alcohol, substance or drug abuse received by [the patient] in any program or by any provider...³⁹

Utah, on the other hand, advises patients for its **Utah Clinical Health Information Exchange (cHIE)** that they may wish to opt out of participation by including this statement:

“The cHIE may also contain information about substance abuse, mental health conditions, and other conditions you may consider sensitive. ... Unfortunately the cHIE is not able to exclude specific tests, visit, or treatments. If you are concerned about some or all of your information being shared in the cHIE, you may want to consider opting out of the cHIE.”⁴⁰

³⁷ HITECH at §13405(a).

³⁸ *Supra* at note 9

³⁹ http://www.ehealthconnecticut.org/LinkClick.aspx?fileticket=Jq7hmvYy_WM%3D&tabid=100

⁴⁰ <http://mychie.org/support/fau>.

Conclusion

Whether HIEs in Texas follow an opt-in or opt-out approach for patient participation in electronic health information exchange, as reimbursement methods shift to rely more heavily on having patients' records accessible for defined meaningful use activities, physicians and other treatment providers for patients who are unwilling to participate in such networks will find themselves in an untenable position. The primary difficulty for health care professionals and facilities seeking to protect sensitive information on behalf of their patients is the degree to which Texas HIEs have the technical capability to sequester sensitive information, including behavioral health information. Michigan has recently authorized a separate network for behavioral health data to become a qualified data sharing organization for purposes of joining its Health Information Network which supports the sub-state health information exchange networks. This means that the existing networks that could previously only exchange physical health data will now be able to access behavioral health data on participating patients with patient authorization. If Texas were to pursue a similar option, it would first need to define what will constitute sensitive information for purposes of a separate system of sequester and then devise an acceptable protocol for accessing the system. Some privacy advocates are concerned that identifying patients using a record locator service to determine whether records sequestered because they contain sensitive information is in and of itself an invasion of the patient's privacy. The technical feasibility for how many layers of identification and authentication can be invoked is not addressed in this document. For example, is it practical for a record locator service to rely on utilizing unique identifiers to match a request from an authenticated provider with the correct patient data and also limit access to sensitive information only to a specific provider authorized by the patient? There will likely always be some condition a patient will desire to keep confidential from all but those directly involved in the treatment of the condition. As technical management of medical record networks continues to improve, patients and providers may find the trust necessary to take advantage of the benefits of more accessible records for patient care.