PROTECTING THE CONFIDENTIALITY AND SECURITY OF SENSITIVE HEALTH DIAGNOSES LIKE HIV IN NORTH CAROLINA\(^1\)

May 2012

WHAT WOULD YOU DO?\(^2\)

You enter a patient room or curtained area in the emergency department to discuss the patient’s care. The patient is HIV positive. The patient has two visitors and they are having a calm, friendly conversation.

Do you?

A) Ask the patient if it is okay to speak about her care with others present.

B) Ask the visitors to leave the room before speaking to the patient.

C) Start talking about her HIV medications with the visitors present.

I. Introduction

The Duke Legal Project has represented many clients whose HIV statuses were inadvertently disclosed by physicians in hospital settings. Although unintended, these unauthorized disclosures of HIV status have devastating consequences for our clients—your patients. Our clients have been shunned by their families, refused a hug or touch, and forced to use separate dishes and utensils. They have been thrown out of churches and fired from jobs. They have faced community harassment as word of their HIV status spread. This vilification happens all too frequently—even today.

For a physician, patients with HIV may seem like many other patients with a serious illness. But HIV is not just another serious disease. It carries with it a unique stigma that can insidiously affect almost every aspect of a patient’s life, often completely cutting them off from social and familial ties. As a consequence, most people with HIV keep their diagnosis a secret, hidden from employers, coworkers, members of their church, neighbors, family and friends.

This manuscript attempts to provide health care providers with the background to be effective, compassionate providers for people living with HIV/AIDS.

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\(^2\) Answer: (B)
II. Understanding HIV Stigma

This manuscript will first provide a conceptual framework for understanding the HIV/AIDS epidemic, the experience of people living with HIV/AIDS (PLWHA), and the pervasive stigma associated with HIV and assigned to PLWHA. It aims to convey the importance of maintaining the confidentiality of sensitive health information, HIV status in particular, in all patient settings.

“Stigma” is defined as “a mark of disgrace or infamy; a stain or reproach, as on one’s reputation.” Goffman defined “stigma” in 1963 as “an attribute that is significantly discrediting which, in the eyes of society, serves to reduce the person who possesses it.” Stigma can be the result of particular undesirable characteristics, such as physical deformities, or it can stem from negative attitudes toward an entire group and the behaviors associated with that group, such as homosexuals and prostitutes. “Under Goffman’s definition, stigmatization is the societal labeling of an individual or group as different or deviant.” Some HIV/AIDS related stigmatization research has focused on stigmatizing attitudes and the correlation between such attitudes and misunderstanding and misinformation about the modes of HIV transmission or the risk of infection through normal social behavior.

Social science researchers generally agree that HIV/AIDS-related stigma undermines public health efforts to combat the epidemic. AIDS stigma negatively affects preventive behaviors such as condom use, submitting to HIV testing, and seeking appropriate care following diagnosis, to name a few. This stigma also diminishes the quality of care given to HIV-positive patients and the perception and treatment of PLWHA by their communities, families, and partners. “Decreasing AIDS stigma is a vital step in stemming the epidemic.”

A. The Historical Underpinnings of the AIDS Epidemic

HIV/AIDS has been stigmatized since it was first diagnosed in the United States. AIDS was first recognized as an unexplained pattern of illness in 1981, and the American public has since undergone episodes of panic, witnessed the identification of HIV as the cause of AIDS, and experienced the development and dissemination of promising antiretroviral drugs. This illness

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6 Id.
7 Parker, supra note 2, at 15
8 Brown et al, supra note 3, at 3
9 Id.
10 Id.
11 Id.
12 Centers for Disease Control and Prevention, Thirty Years of HIV – 1981-2011, 60(21) MORBIDITY AND MORTALITY WEEKLY REPORT, at 689 (2011). http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6021a1.htm
has morphed from being initially associated exclusively with Caucasian men to having an increasing impact on blacks, Latinos, and women.\textsuperscript{14}

Despite this propagation of the disease into increasingly more communities, the Kaiser Foundation has found that the percentage of Americans reporting AIDS as the most urgent health problem facing the country declined from 68% in 1987 to 49% in 1990, to single digits in 2009, and 7% in 2011.\textsuperscript{15} Thus, the perceived urgency of AIDS has decreased, but stigmatizing perceptions of the disease remain entrenched.

Stigma toward people living with HIV has had a devastating impact on the HIV epidemic. The World Health Organization cites “fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose their HIV status or to take antiretroviral drugs.”\textsuperscript{16}

In North Carolina, AIDS continues to conjure thoughts of death and for many, embarrassment. Many HIV related deaths in NC have been hidden by families and explained away as cancer or other diseases because of possible shame to the family. This perpetuates HIV-stigmatization and leaves families with the burden of heavy secrets and questions unanswered for those family members who may want to openly discuss HIV.

When there is an overriding fear of stigma, denial and lack of communication are common. The very basic fear of rejection and loss of privacy can hamper a person’s ability to communicate effectively. This can lead to failure to negotiate condom use and failure to employ other methods of safer sex to prevent HIV transmission. The fact that many people are indeed ostracized after revealing their HIV-positive status makes disclosure a difficult step for many to take. Many PLWHA still find it challenging to tell new partners about their status and to negotiate sexual encounters, despite legal requirements to notify past and present partners.

For women around the world, stigma and the risks associated with disclosure can lead to blame for cause of infection, loss of reputation, fear of interference with childrearing, ostracism from family and in-laws, abuse and violence and in some countries even death. In the United States, several factors have been identified that increase transmission risk for African American women including gender dynamics, social status, and social roles.\textsuperscript{17} Factors related to stigma and fear may challenge a woman’s dialogue with her partners, safer sex negotiation with

\begin{itemize}
\item \textsuperscript{14} Id.
\item \textsuperscript{15} Id.
\item \textsuperscript{17} Hortensia Amaro. Love, Sex, and Power: Considering Women’s Realities in HIV Prevention, 50(6), AMERICAN PSYCHOLOGIST, June 1995, at 437–447
\end{itemize}
partners, and knowledge and disclosure of serostatus. Indeed, many HIV-positive women continue to practice HIV-risky behaviors including unprotected sexual acts.

Trauma is often another indicator of HIV incidence. Recent research suggests high rates of childhood sexual abuse and physical trauma influence health status, risk-taking behavior, and communication with family members. Childhood trauma results in strained relationships that challenge perceptions of and communication regarding healthy relationships. Histories of childhood abuse have been linked with disassociation during physical contact. Trauma, mental illness and substance abuse are intrinsically linked to sexual risk taking behavior. Whetten et al. (2006), examined prevalence and predictors of trauma among HIV-positive populations in the South and found that more than half of respondents experienced adult physical or sexual abuse in their lifetime. She also found a high prevalence of substance abuse and mental health symptoms among HIV-positive individuals living in the Southeastern United States. Sixty percent of the study participants reported symptoms of mental illness, 32% reported substance abuse, and nearly one-quarter identified symptoms of both mental illness and substance abuse.

### 1) Misconceptions About HIV-Transmission

Some of the stigma surrounding HIV stems from public misconceptions about HIV transmission. Although Americans have learned a great deal since the beginning of the so-called “AIDS Epidemic,” the learning curve appears to have flattened out since the early 1990’s, and the remaining myths about modes of transmission are stubbornly persistent. Over the past twenty years, roughly one in four Americans have continued to either believe or is unsure about whether one can get HIV from sharing drinking glasses with PLWHA. Similarly, one in six believes the same about shared toilet seats, and 12% either think you can get HIV by swimming in a pool with someone with HIV, or are not sure. Overall, in 2011, one in three gave an incorrect answer to at least one of these three questions about means of

<table>
<thead>
<tr>
<th>Activity</th>
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<tr>
<td>Swimming in same pool</td>
<td>12%</td>
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<tr>
<td>Touching a toilet seat</td>
<td>16%</td>
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<tr>
<td>Sharing a drinking glass</td>
<td>22%</td>
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<tr>
<td>Kissing</td>
<td>37%</td>
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18 Serostatus refers to the presence of antibodies in the blood in response to HIV.
22 Whetten et al., supra note Error! Bookmark not defined.
24 Id.
25 Id.
transmission. These charts (above and below) show percentages of people in the United States who have certain misconceptions about the transmission risk posed by common activities. HIV cannot be transmitted any of these ways.

Research with clinicians and patients has revealed knowledge deficits and misconceptions among PLWHA, as well as difficulty using the HIV knowledge they possess. One common misconception associated with risky sexual behaviors is the belief that having an undetectable viral load means that one cannot transmit HIV to others. Another misconception held by HIV-positive women is the belief that it is difficult for them to transmit HIV to an HIV-negative man during sexual intercourse.

2) Blameworthiness and Moral Condemnation as Stigmatizing Agents

The chart at right shows the public’s response to the following: “As I read each statement about AIDS, please say whether you agree or disagree with it...In general, it’s people’s own fault if they get AIDS.” Although these numbers have vacillated over the years, in the early 1990’s trending toward diminishing moral, the percentage of people who agree with that statement has increased since then, which has helped to maintain the stigma associated with this disease.

The reasoning fueling this stigma is multi-faceted, complex, and fluid. It is often layered atop other stigmas associated with the following groups: homosexuals, prostitutes, intravenous drug-users and those who engage in casual sex. “These layers of stigma have unfortunately helped to extend and deepen the AIDS stigma to many who are infected with...the disease.”

Additionally, lingering misconceptions about how HIV is transmitted contribute to prejudice against PLWHA. “People who harbor misconceptions about how HIV is transmitted are much more likely to express discomfort about working with someone who has HIV or

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26 Id.
27 Kaiser, POS--Attitudes about Stigma, supra note 27, at 8.
30 Kaiser, POS--Attitudes about Stigma, supra note 27, at 8.
32 Id.
33 Kaiser, POS--Attitudes about Stigma, supra note 27, at 8.
Most people agree that it is important to educate all persons about HIV transmission and the importance of testing and treatment. Educating the public—particularly young people—about HIV, including its transmission and prevention, is a key part of the U.S. National HIV/AIDS Strategy. Putting this into action, however, is not simple. Obstacles include political and financial challenges, as well as HIV no longer being in the media spotlight and a lack of reaching out in ways that are effective with specific communities. Education and awareness for families is also important to lessening the burden of stigma.

It is important to note that HIV stigma is a complex part of a larger societal prejudice toward people who are other—those who are: HIV positive, of color, gay or lesbian, transgender, addicted to drugs or alcohol, homeless, or mentally ill. These prejudices contain deeply embedded external and internal racism, sexism and homophobia and affect how individuals adapt to hardships and the well-being of communities. The task now is to confront the negative messages—the biased attitudes toward marginalized populations—and to continue to saturate the community with information in ways that they can hear and that will call them to action.

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34 Id.
35 Id.
3) HIV/AIDS in North Carolina

North Carolina has one of the highest rates of HIV infection in the United States. “In 2009, 957 new AIDS cases were diagnosed and reported in North Carolina, up slightly from the previous year. According to the CDC, North Carolina ranked 10th among all states and the District of Columbia in the number of new AIDS cases diagnosed in 2008 and is ranked 11th in the nation for estimated number of persons living with an AIDS diagnosis.” In that same year, 1,710 new individuals were diagnosed with HIV. These new diagnoses added to the population already living with HIV made for an estimated 35,000 HIV-positive people in North Carolina, which includes those unaware of their status.

The following two charts show the breakdown in HIV disease cases by transmission category in North Carolina in 2009: MSM (men who have sex with men, transmission via sex), IDU (intravenous drug users, transmission via needle), MSM/IDU (men who have sex with men and also use intravenous drugs), and heterosexual (transmission via sex). It is apparent that the primary means of transmission for women in North Carolina is through heterosexual sex, whereas for men in North Carolina, it is through homosexual sex. The rates of transmission via intravenous drug use are small for both men and women.

African American adolescent and adult women in North Carolina represent the largest recent disparity with rates of new HIV cases at 38.7 per 100,000. This was more than 14 times higher than of white, non-Hispanic females at 2.7 per 100,000. Common reasons reported by HIV seropositive African-American women in North Carolina for engaging in risky behaviors include financial dependence on their male partners, feelings of invincibility, a need to feel loved by a man coupled with low self-esteem, and alcohol and drug use. Wingood and DiClemente have applied the theory of gender and power to identify and understand the properties that increase women’s vulnerability for acquiring HIV, suggesting that the sexual division of labor that results in economic inequities for women (lower incomes and education, occupational sex segregation, homelessness, and limited health insurance); sexual division of power that result in

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37 Id. at iii
38 Id.
39 Id. at 26
40 Id.
imbalances in control and power for women (history of sexual and/or physical abuse, history of alcohol and drug abuse, partner who disapproves of practicing safer sex, having a steady high-risk sexual partner, viewing sexually oriented media; limited access to HIV education, alcohol and drug treatment, and male/female condoms, and limited self-efficacy in negotiating and using condoms); and the structure of cathexis (in which affective attachments of partners, family members, and surrounding community perpetuate social norms that conflict with safer sex practices) are core to the increasing rates of heterosexual transmission among women.  

Another marginalized group impacted early in the HIV epidemic and more recently, are gay and bisexual men. In North Carolina, young African American men are particularly impacted by HIV as they are more likely to identify MSM (men who have sex with other men) as a risk factor than other groups. In 2009, MSM activity accounted for 74 percent of all new HIV reports (including MSM/IDU) in North Carolina. This represents a notable increase in MSM reports over the last five years (74% in 2009 compared to 67% in 2005). In addition MSM contact accounts for the highest new HIV infection for adolescent men. Specific risk factors for young African American male in North Carolina are homophobia, racism, and poverty (N.C. Department of Health and Human Services, EPI Profile, 2010). “Homophobia, stigma, and discrimination are social determinants of health that can affect physical and mental health, whether MSM seek and are able to obtain health services, and the quality of the services they receive. Such barriers to health need to be addressed at different levels of society, such as health care settings, work places, and schools in order to increase opportunities for improving the health of MSM.”

Another trend that is notable in North Carolina is the number of foreign-born HIV cases diagnosed. The chart at right shows the number of HIV cases of this type diagnosed from 1991 to 2009. It is apparent that there has been a sharp increase in these types of HIV cases being diagnosed since 1991. The prevalence of these cases has increased tenfold.

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In 2009, the estimated lifetime medical cost for a newly HIV infected person was about $367,000.\textsuperscript{45} This burden of disease and expense illustrate the critical need for adequate funding of HIV prevention and care efforts in the state because infected persons who receive proper care are less likely to transmit the disease and each infection prevented saves dollars.\textsuperscript{46}

### III. Protecting the Medical Confidentiality of Patients living HIV

PLWHA have certain rights and certain responsibilities with regard to their positive status. One of the most important rights is the right to confidentiality regarding their health status, while the foremost responsibility is to reduce the risk of transmission. The law in North Carolina provides some clear guidance on both issues.

Many of the problems facing individuals with HIV/AIDS “stem from the unnecessary disclosure of one’s HIV status -- a disclosure that might have been prevented had the individual been informed of his or her rights and/or been provided with preventative legal counseling at an earlier point in time. Indeed, it is widely recognized among AIDS experts that unnecessary disclosures serve to inflame the stigma and discrimination associated with HIV/AIDS. The stigma and discrimination, in turn, further deter vulnerable persons from getting tested for HIV and receiving prevention counseling. Thus, the disease continues to spread. In fact, of the roughly one million people living with HIV/AIDS in the United States, it is estimated that about one-third do not know they have the disease.”\textsuperscript{47}

“Virtually every complaint of AIDS discrimination begins with an unnecessary disclosure of AIDS or HIV information to someone without the training and understanding to handle it properly.”\textsuperscript{48} The next section discusses these particular confidentiality breaches and discusses the effects of unauthorized disclosure of seropositive status on the lives of PLWHA.

### A. Right to Confidentiality

#### 1) Confidentiality: What’s at Stake?

There is an old Jewish story that illustrates the difficulties of undoing a disclosure:

A man goes before his Rabbi and admits to having spread harmful information about his neighbor. He asks the Rabbi what he should do to repent. The Rabbi says, “You need to do the following: go home, find a feather pillow, and release the feathers into the wind.” The man follows the Rabbi’s instructions and returns the next day. The Rabbi then says, “Now, to gain forgiveness, you must go back to your home and retrieve all of the feathers.” “But Rabbi,” the man exclaims, “the feathers by now have scattered throughout the village!” “Precisely!” the Rabbi says. “And so too has the damage you have caused your neighbor’s reputation.”

\textsuperscript{45} Id.
\textsuperscript{46} Id.
\textsuperscript{47} American Bar Association’s Young Lawyers Division, \textit{Answering the Call: HIV Legal Check-Up}, American Bar Association, 1 (2005).
\textsuperscript{48} Id. at 5.
Persons living with HIV and other stigmatizing conditions have justifiably high levels of concern about confidentiality. They do not need to be told this story. Those of us who work with these clients need to be repeatedly reminded of just how devastating a careless disclosure can be. The Duke Legal Project has represented many clients who have faced discrimination after their HIV status was disclosed without permission. We have had clients fired from jobs in restaurants, nursing homes, health care facilities, a homeless shelter, and a poultry factory; we’ve had other clients who have faced adverse employment actions due to their HIV status—a nurse’s aide moved to the file room, a deli worker moved to the warehouse, for example. Other clients have been refused services by medical providers, hospitals, chiropractors, and others. Many others have been shunned by families, friends, classmates, and/or church communities because of unauthorized disclosures. A report by the ACLU AIDS Project documents how “[b]reaches of confidentiality can and do unravel people’s lives, forcing them to find new jobs, new schools, and new homes.”

Many professionals, especially in high stress situations like emergency departments or courtrooms, may be desensitized to the stigma that an illness like HIV or substance addiction presents. When a physician or an attorney talks openly about someone’s HIV status in the emergency room (ER) waiting area or during a trial, it is unlikely that s/he does so with malicious intent. The damage done to the patient or client whose friends and neighbors now know his or her health status is no less, however, than if the physician or attorney intentionally set out to breach his or her confidentiality.

2) North Carolina Law

a) N.C. GEN. STAT. § 130A-143. Confidentiality of records (specific to HIV)

North Carolina law specifically protects HIV confidentiality. In the mid 1980’s, North Carolina passed a statute specifically protecting the confidentiality of records, whether publicly or privately maintained, that identify a person with “AIDS virus infection.” The statute is broad in scope and, on its face, covers breaches by any individual or entity in possession of such records. The statute allows disclosure in certain circumstances including release made with the person’s written consent, release to protect the public health under rules related to control measures for infectious diseases, release made for research purposes as long as no identifying information is released, or release made pursuant to subpoena or court order.

b) N.C. GEN. STAT. § 130A-12. Confidentiality of records

North Carolina law also has a specific provision protecting the confidentiality of HIPAA covered records maintained by local health departments, the Department of Health and Human Services and the Department of Environment and Natural Resources. This statute provides in relevant part:

50 N.C. Gen. Stat. §130A-143
51 Id. See Statute for full list of disclosure exceptions.
All records containing privileged patient medical information protected under 45 C.F.R. Parts 160 and 164 that are in the possession of the Department of Health and Human Services, the Department of Environment and Natural Resources, or local health departments shall be confidential and shall not be public records pursuant to G.S. 132-1. Information contained in the records may be disclosed only when disclosure is authorized or required by State or federal law. Notwithstanding G.S. 8-53 or G.S. 130A-143, the information contained in the records may be disclosed for purposes of treatment, payment, or health care operations.\(^{52}\)

c) Enforcement of Confidentiality Statutes

Each of the North Carolina statutes discussed here are contained in the Public Health Chapter 130A of General Statutes. Pursuant to N.C. Gen. Stat. 130A-25, it is a crime (a misdemeanor) to violate a provision of the Public Health Chapter.

d) Medical Malpractice

In North Carolina, an unauthorized disclosure of a patient’s confidential information constitutes medical malpractice. North Carolina courts have specifically held that “…a health care provider’s unauthorized disclosure of a patient’s confidences constitutes medical malpractice” under North Carolina law.\(^{53}\) Liability for medical malpractice is grounded in a deviation from the medical standard of care and subjects the health care provider to a civil action for damages.\(^{54}\)

3) Federal Laws

a) Health Insurance Portability and Accountability Act (HIPAA)\(^ {55}\)

A man is hospitalized for a medical emergency. His doctor discusses his HIV medications with the man’s wife within earshot of extended family members and others in the waiting room, none of whom knew the man’s HIV status. Another man is devastated when his doctor starts talking about the man’s HIV medications in front of his mother, whom he had not yet told about his HIV diagnosis. These are actual stories from clients that Duke Legal Project (DLP) represented. DLP has represented many clients who have had their HIV statuses disclosed in hospital settings. The consequences of these accidental disclosures can be far reaching and severe. Many of these disclosures could have been avoided by taking the reasonable precautions HIPAA requires.

\(^{52}\) N.C. Gen. Stat. § 130A-12.


\(^{54}\) N.C.G.S. 90-21.11.

Introduction to HIPAA.

HIPAA is the acronym for the Health Insurance Portability and Accountability Act of 1996, a federal law that provides individuals with certain rights and protections over their health insurance and health information. These rights and protections are particularly important to individuals with stigmatized conditions like HIV. As its name suggests, HIPAA is designed to improve the availability and portability of health insurance coverage, particularly employer-provided health insurance. HIPAA also contains privacy provisions that protect the confidentiality, integrity, and availability of patients' health information. When you hear about HIPAA, you may also hear about “the Privacy Rule.” The Privacy Rule is a set of federal regulations that set out standards for complying with HIPAA.

HIPAA adds another layer of privacy protection for patients. To be legal, any disclosure must also satisfy North Carolina law, even if HIPAA seems to give the green light. HIPAA gives way when state law is more protective of privacy.

Am I covered by HIPAA?

HIPAA applies to “covered entities,” which include:
- Healthcare Providers (for example, hospitals, doctors, psychologists, chiropractors, nursing homes, pharmacies, dentists);
- Health Plans (for example, HMOs, employer-provided health insurance plans, Medicare); and
- Health Clearing Houses that facilitate the processing of health information.

Many other organizations—such as life insurers or law enforcement agencies—are generally not covered by HIPAA.

What Does HIPAA Say?

HIPAA limits how and when you can use or disclose “protected health information” or “PHI”. PHI isn’t limited to “sensitive” information like a patient’s HIV status. PHI can be in any form or media—electronic records, paper charts, or conversations. Information you put in

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56 Title I. HIPAA limits employers’ abilities to exclude new employees for pre-existing conditions. This does not require employers to offer coverage, or guarantee that certain conditions will be covered. Additionally, there is a limit on the period for which imposing a pre-existing condition exclusion can be applied. HIPAA also contains anti-discrimination provisions related to eligibility for and pricing of employer-provided health insurance.

57 Title II of HIPAA, also called the Administrative Simplification provisions.


60 Health care is defined as (1) preventive, diagnostic, rehabilitative, maintenance, or palliative care, and counseling, service, assessment, or procedure with respect to the physical or mental condition, or functional status, of an individual or that affects the structure or function of the body; and (2) sale or dispensing of a drug, device, equipment, or other item in accordance with a prescription. 45 C.F.R.160.103.

your patients’ charts and conversations you have with other healthcare providers about your patients’ health contain PHI. In fact, protected health information includes all individually identifiable health information that relates to:

- patients’ past, present or future physical or mental health or condition;
- the provision of health care to patients; and
- the past, present, or future payment for the provision of health care to patients.

Identifiable health information means the information could be used to recognize an specific individual, for example, a name, address, birthday, Social Security number, or demographic information.

HIPAA requires that covered entities:

1. implement written privacy policies that ensure that “reasonable safeguards” are in place to protect PHI, and
2. take reasonable efforts to use, disclose, and request only the “minimum necessary” amount of PHI needed to accomplish the purpose, use, or disclosure. This requirement does NOT apply when healthcare providers disclose information to other providers for the purposes of providing treatment.

Are any disclosures permissible under HIPAA?

HIPAA demands that “reasonable safeguards” be taken to protect privacy and that only the “minimum necessary” be disclosed. The Privacy Rule does not prohibit all disclosures of PHI. For example, a patient’s health care providers can disclose PHI for treatment and care coordination and to health insurance companies for claims documentation. HIPAA also permits disclosures made with the written authorization of the patient and disclosures to protect public health or to make required reports to law enforcement. De-identified PHI may be disclosed without restriction. De-identified health information neither identifies nor provides a reasonable basis to identify an individual.

Further, “incidental disclosures” that occur as a result of permitted disclosures (discussed below) and that cannot reasonably be prevented are permissible as long as reasonable safeguards are in place and only the minimum necessary is disclosed. For example, HIPAA does not prevent providers from calling out patients names in waiting rooms.

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62 "Individually identifiable” means there is a reasonable basis to believe the information can be used to recognize the individual. Id. at 3.
65 45 C.F.R. § 164.502, 164.514(d) (2010).
Are Disclosures to Relatives or Friends Permissible?

HIPAA permits limited disclosures of “directly relevant” information to relatives or friends involved in the patient’s care or payment.\(^6\) Physicians can’t assume, however, that someone accompanying a patient to the ED is involved in the patient’s care. Under HIPAA, if the patient is present, the provider must get the patient’s consent, give the patient an opportunity to object, or be able to “reasonably” infer, using “professional judgment” that the patient consents to having others present.\(^7\) If the patient can’t be consulted, disclosure must be in the patient’s “best interest.”\(^8\) Knowing how closely patients guard their HIV status, inferring consent is rarely if ever reasonable.

So how do I Comply with HIPAA? Keep PHI confidential!

It is important you know your institution’s specific privacy policies. Covered entities must designate a privacy official who is responsible for these policies and a contact person who receives complaints for violations and provides information about the covered entity’s policies. Covered entities also must ensure that employees receive training and comply with policies, including policies regarding the disposal of protected health information.\(^9\)

Interpreting “reasonable safeguards” is challenging and depends on the nature of the covered entity and the particular circumstances of the situation. For example, HIPAA and the Privacy Rule require you to speak quietly when discussing a patient’s condition\(^10\) but do not require that you to provide soundproof rooms. You are allowed to place patient charts on the exam room door, but you must take appropriate measures to safeguard private health information, like placing the front cover facing the wall.

Although HIPAA does not provide easy answers, there are established best practices for protecting patient confidentiality:

Waiting Rooms and Other Public Areas – Always assume other patients can hear you!

- **In public areas** like elevators, hallways, and reception, avoid discussing patient information. When conversations are necessary, speak quietly and avoid using patients’ names. Always assume someone else can hear you in waiting rooms or other public areas.
- Whenever possible, have discussions in a private, soundproof room.
- If a soundproof room is unavailable,
  - consider whether discussion of HIV is even necessary, and if it is,
  - make every effort to lower your voice so others cannot overhear.

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\(^6\) 45 C.F.R. § 164.510(b)(1).
\(^7\) 45 C.F.R. § 164.510(b)(2).
\(^8\) 45 C.F.R. § 164.510(b)(3).
\(^9\) See 45 CFR 164.306(a)(4), 164.308(a)(5), and 164.530(b) and (i).
• **At admitting windows or pharmacy windows**, ask that patients waiting stand back a few feet from the counter used for patient counseling.
• Do not display medical diagnoses on patient sign-in sheets.
• Put labeled prescription bottles in opaque bags.

**Family and Friends of Patients**

• **Always** assume the patient has not disclosed his or her HIV status to anyone.
• **Never** discuss HIV status in front of family and friends without the patient’s explicit authorization.
• When sensitive health information must be discussed, ask family or friends to leave the room before talking to your patient.
• **If a patient is incapacitated or unavailable**: you may share information about the patient with family and friends if you determine that it is in the best interest of the patient and.
  o You should ONLY share information that the person involved NEEDS to know about the patient’s care or payment for care.
  o You CANNOT talk about medical problems unrelated to the patient’s current condition.
• Providers may give family and friends, or anyone else, basic information such as patient room number, phone number, and general condition unless the patient objects.
• **Messages**: Providers may leave phone messages on answering machines or with family members. Do not include references to sensitive protected health information in phone messages. If a patient requests that the provider communicate with the patient in a more confidential manner, the request must be accommodated if it is reasonable.
• **Representatives**: People legally authorized to make healthcare decisions on behalf of your patient or a deceased patient’s estate are treated the same as the patient for purpose of use and disclosure of PHI.

**Medical Files**

• Providers should use or disclose only the minimum amount of PHI necessary to accomplish a task. For example, a payment officer may not need a patient’s entire medical file. It may be helpful to divide patient files into sections.
• **Folders** should not feature identifiable patient information on the outside, like a patient’s name or address.
• **Files** should not be reviewed in front of other patients. Files should be secured when not in use.\(^{71}\)

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\(^{71}\) U.S. Dep’t of Health & Human Servs., *Frequently Asked Questions*.  
• **Computers** should be locked with passwords when not in use.

• **Destruction of Records**: PHI in paper records should be disposed of by shredding, burning, pulping or pulverizing records so as to render the records indecipherable. Electronic PHI should be cleared using software, purged from the record with magnets, or the media should be destroyed.

The Security Rule specifically addresses electronic PHI. The Security Rule requires that covered entities “ensure the confidentiality, integrity, and availability of EPHI that it creates, receives, maintains, or transmits; protect against any reasonably anticipated threats and hazards to the security or integrity of electronic-PHI; and protect against reasonably anticipated uses or disclosures of such information that are not permitted by the Privacy Rule.”

It is important to note that HIPAA only establishes minimum guidelines for confidentiality. It may be necessary to do more in order to comply with North Carolina law on the confidentiality of a patient’s HIV status.

**What other rights does HIPAA give patients?**

All health plans and healthcare providers must provide members with copies of their Notice of Privacy Practices. Patients have the right to request copies of and or review their medical records. If a patient believes the information in his or her medical record is inaccurate, or that important information is missing, the Privacy Rule allows him or her to request the health care provider to amend the records. If the health care provider denies the request to amend, he or she must notify the patient. A health care provider can deny a request to amend if he determines the record is accurate and or complete or if s/he did not create the information the patient wishes to amend. A patient who believes his right to amend his medical records has been violated can file a complaint with the health care provider or the Office for Civil Rights within HHS.

**What happens if you violate HIPAA?**

Covered entities must maintain and submit compliance records to HHS, permit HHS to access records, and cooperate with HHS audits. Within HHS, the Office of Civil Rights is responsible for implementing and enforcing HIPAA. A client who believes his or her HIPAA rights have been violated may file a complaint with the Office of Civil Rights or the violating covered entity within 180 days of the HIPAA violation. After a hearing, the Office of Civil Rights has the authority to impose civil monetary fines of up to $100 per violation (paid to the government, not to the client) and a total amount of $25,000 for identical violations during a calendar year. Criminal penalties for HIPAA violations, such as intent to sell protected health information for commercial advantage or malicious harm, can be up to $250,000 and ten years imprisonment.

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HIPAA fast facts:

- As a healthcare provider, you are a covered entity. This means you have to comply with HIPAA.
- HIPAA protects protected health information (PHI), which includes your patients’ medical records and conversations you have about your patients’ health.
- HIPAA requires you to follow reasonable safeguards to protect PHI and to disclose only the minimum necessary amount of PHI to accomplish a task.

IV. Responsibilities of the HIV positive client

A. North Carolina Control Measures

When a person tests positive for HIV in North Carolina, his or her name and certain other demographic information is reported to the State Health Director. HIV positive persons are subject to certain legal requirements known as “control measures.” When a person tests positive for HIV they are informed of the control measures, usually by a state employee known as a Disease Intervention Specialist (DIS). By law, an HIV positive person shall:

(a) refrain from sexual intercourse unless condoms are used; exercise caution when using condoms due to possible condom failure;
(b) not share needles or syringes, or any other drug-related equipment, paraphernalia, or works that may be contaminated with blood through previous use;
(c) not donate or sell blood, plasma, platelets, other blood products, semen, ova, tissues, organs, or breast milk;
(d) have a skin test for tuberculosis;
(e) notify future sexual intercourse partners of the infection;
(f) if the time of initial infection is known, notify persons who have been sexual intercourse and needle partners since the date of infection; and,
(g) if the date of initial infection is unknown, notify persons who have been sexual intercourse and needle partners for the previous year.

The HIV positive person’s attending physician must ensure that the PLWHA’s spouse is notified of the test result. The physician can accomplish this by providing the spouse’s name to the North Carolina Division of Public Health which will then inform the spouse. Notification of past and future sexual or needle sharing partners is mandatory. That can be accomplished by the HIV positive individual or, by consent, by the Disease Intervention Specialist.

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75 Id.
76 10A NCAC 41A.0202 (2).
Failure to abide by these control measures is a misdemeanor in North Carolina subject to up to 2 years in prison.\textsuperscript{77}

1) HIV Positive Students

Parents or physicians of an HIV positive child in school or day care are not generally required to disclose the HIV status of the child to school administrators. North Carolina control measures provide that only when a child may “pose a significant risk of transmission in the school or day care setting because of open, oozing wounds or because of behavioral abnormalities such as biting.”\textsuperscript{78} is the physician required to notify the local health director. If such notification occurs, the local health director will go through a process to investigate and assess the transmission risk. If it is determined that a “significant risk of transmission” exists, the local director must notify the parents, determine whether an adjustment can be made to the school setting to eliminate the risk of transmission, or whether an alternative educational setting needs to be developed. The health director must also consult with the superintendent or private school director to decide whether school personnel working directly with the child need to be notified of the HIV infection in order to prevent transmission.\textsuperscript{79}

If the child is in day care and it is determined by the local health director that a significant risk of transmission exists, then the parents must place the child in an child care setting that “eliminates the significant risk of transmission.”\textsuperscript{80}

2) HIV Positive Health Care Workers

Only those HIV positive health care workers and dentists who perform “surgical or obstetrical procedures” or “dental procedures” that are exposure prone as defined in the North Carolina regulations\textsuperscript{81} are required to notify the State Health Director in writing. Pursuant to control measures, the State Health Director must investigate the medical practice of the HIV positive provider to assess the risk of HIV transmission. If the State Health Director determines that there may be a significant risk of HIV transmission to patients, s/he must appoint an expert panel to complete a comprehensive analysis of the risk of HIV transmission to patients, the provider’s practices and clinical condition, and the nature of the procedures performed by the provider.\textsuperscript{82} The State Health Director is not allowed to identify the HIV positive health care worker to the panel.

\textsuperscript{78} 10A NCAC 41A.0202(3)(a).
\textsuperscript{79} 10A NCAC 41A.0202(3)(b).
\textsuperscript{80} 10A NCAC 41A.0202(3)(c).
\textsuperscript{81} 10A NC ADC 41A.0207 (a)(1) “Surgical or obstetrical procedures” means vaginal deliveries or surgical entry into tissues, cavities, or organs. The term does not include phlebotomy; administration of intramuscular, intradermal, or subcutaneous injections; needle biopsies; needle aspirations; lumbar punctures; angiographic procedures; endoscopic and bronchoscopic procedures; or placing or maintaining peripheral or central intravascular lines. (2) “Dental procedure” means any dental procedure involving manipulation, cutting, or removal of oral or perioral tissues, including tooth structure during which bleeding occurs or the potential for bleeding exists. The term does not include the brushing of teeth.”
\textsuperscript{82} 10A NCAC 41A.0207(d). The expert panel must include “…an infectious disease specialist, an infection control expert, a person who practices the same occupational specialty as the infected health care worker and, if the health care worker is a licensed professional, a representative of the appropriate licensure board.”
After investigation and considering information provided by the health care worker, the expert panel will make recommendations to the State Health Director relating to any restrictions that may be necessary to prevent HIV transmission from the HIV positive provider to patients, identifying patients who may have already been exposed to a significant risk of HIV transmission, and future reviews of the provider's clinical condition and practice.\textsuperscript{83}

The State Health Director shall consider the recommendations of the expert panel and if s/he decides to impose practice restrictions on the provider, issue what is called an “isolation order,” which is a public health order setting out any necessary restrictions on the practice of the infected health care worker and any required infection control training.\textsuperscript{84} A copy of the isolation order is then provided to the appropriate licensure board.\textsuperscript{85}

\textsuperscript{83} 10A NCAC 41A.0207(e).
\textsuperscript{84} 10A NCAC 41A.0207(g).
\textsuperscript{85} 10A NCAC 41A.0207(j).