



OFFICE
FOR
CIVIL
RIGHTS

Office for Civil Rights

U.S. Department of Health
and Human Services

200 Independence Avenue, SW.
H.H.H. Building, Room 509-F

Washington, D.C. 20201

TELEPHONE

1-800-368-1019

E-MAIL

ocrmail@hhs.gov

TDD

1-800-537-7697

www.hhs.gov/ocr

COMPLIANCE REVIEW INITIATIVE:

Protecting the Civil Rights and Health Information Privacy of People Living with HIV/AIDS

“To be free of discrimination on the basis of HIV status is both a human and a civil right. Vigorous enforcement of the Americans with Disabilities Act, . . . the Rehabilitation Act, and other civil rights laws is vital to establishing an environment where people will feel safe in getting tested and seeking treatment.”

-- National HIV/AIDS Strategy for the United States¹

SUMMARY

Focusing on HIV testing, prevention and treatment services, the U.S. Department of Health and Human Services (HHS), Office for Civil Rights (OCR), conducted coordinated compliance reviews at twelve hospitals – one hospital in each of the twelve cities most impacted by HIV/AIDS: Atlanta, GA; Baltimore, MD; Chicago, IL; Dallas, TX; Houston, TX; Los Angeles, CA; Miami, FL; New York City, NY; Philadelphia, PA; San Francisco, CA; San Juan, PR; and Washington, DC. The compliance reviews examined the ways in which each hospital ensures: (1) equal access for HIV-positive individuals to programs and services; (2) meaningful access for limited English proficient (LEP) individuals; and (3) the privacy and security of individuals’ health information and their rights with regard to that information.

OCR evaluated each hospital’s policies and practices and found that all of the hospitals under review had implemented some policies and practices to promote equal access and protect health information. In addition, many of the hospitals had implemented evidence-based interventions to increase the number of newly diagnosed individuals entering or retained in care. However, OCR also found that in some of the hospitals, there were opportunities for improvement; and OCR provided those hospitals with technical assistance. This report summarizes OCR’s findings and identifies additional steps that hospitals and other health care providers can take to protect the civil rights and health information privacy of people living with HIV/AIDS.

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) estimate that 1.2 million people in the United States are living with HIV and nearly one in eight are unaware of their HIV status. Approximately 50,000 people become newly infected each year. Many individuals are at increased risk for HIV infection as a result of both recognized risk behaviors and socioeconomic factors. “Prevention efforts have helped keep the rate of new infections stable in recent years, but continued growth in the number of people living with HIV ultimately may lead to more new infections if prevention, care, and treatment efforts are not targeted to those at greatest risk.”²

For the period 2005 to 2014, HIV infection rates have increased significantly among racial and ethnic minority populations. For example, new HIV diagnoses among Latino gay and bisexual men were up 24% during this period; new diagnoses among African American gay and bisexual men were up 22%.³ A systematic review of 29 published studies showed that African American transgender women were most likely to test HIV positive, compared to those of other ethnicities: 56% of African American transgender women had positive HIV test results compared to 17% of white and 16% of Latina transgender women.⁴

Due, in large measure, to language barriers, immigration status, discrimination, stigma, homophobia, and higher rates of incarceration and poverty, many Latino and African American men who have sex with men and transgender women do not receive access to HIV testing, prevention and treatment. For example, when translation services are inadequate or nonexistent, language barriers often prevent LEP individuals from receiving the health care that they need.⁵

A “communication inequality” may exist, “whereby those with limited English language ability may not benefit from communications about HIV testing – contributing to the current HIV and HIV testing disparities in Hispanic communities in the U.S.”

-- AIDS Patient Care and STDs (2013)⁶

In addition to language barriers, people living with HIV often experience stigma and discrimination, resulting in denial of care, patient neglect and impermissible disclosures of HIV status.⁷ Fear of discrimination prevents many people from getting tested; individuals are afraid that if they test positive, their HIV status will be disclosed to their employers, friends or family members.⁸ Health care providers, however, can play a critical role in addressing the stigma and discrimination present in testing, prevention and treatment for vulnerable populations at risk for HIV.⁹

In 2010, the White House released the *National HIV/AIDS Strategy for the United States*¹⁰ (NHAS) and the corresponding *NHAS Federal Implementation Plan*.¹¹ The NHAS provides the foundation for a coordinated national response to the HIV epidemic, with three primary goals: (1) reducing the number of people who become infected with HIV; (2) increasing access to care and optimizing health outcomes for people living with HIV; and (3) reducing HIV-related health disparities. As part of the third goal, the NHAS calls for reducing stigma and discrimination against people living with HIV and vigorously enforcing federal civil rights laws to establish an environment where people feel safe getting tested and seeking treatment.

In 2015, the White House issued the *National HIV/AIDS Strategy for the United States: Updated to 2020*¹² (the NHAS Update) and an accompanying *Federal Action Plan*.¹³ The NHAS Update builds on past accomplishments, lessons learned, and scientific advances since the original NHAS was published. For example, the NHAS Update recommends that the federal government “review the methods used to distribute [f]ederal HIV funds and take steps to ensure that resources go to the [s]tates and localities with the greatest burden of disease.”¹⁴ The NHAS Update also designated a coordinated national response to HIV as a fourth goal.

ROLE OF THE HHS OFFICE FOR CIVIL RIGHTS

OCR enforces civil rights laws that prohibit discrimination by health care and social service agencies receiving federal funding from HHS and protects the privacy and security of individuals' health information under the Health Insurance Portability and Accountability Act of 1996¹⁵ (HIPAA). OCR accomplishes its mission through education, policy development, investigations, technical assistance, voluntary compliance efforts and enforcement. OCR works to ensure equal access to health and human services, advance the health and well-being of members of vulnerable communities, protect individuals' private health information, and provide the tools for full consumer engagement in decisions related to their health care.

As part of its work to address the HIV epidemic, OCR participates in the HHS National HIV/AIDS Strategy Implementation Group. Over the five-year period from FY 2010 to FY 2015, OCR opened 145 new matters to address allegations that people living with HIV suffered civil rights or health information privacy violations.¹⁶ The table below provides highlights of OCR's efforts, from FY2010 to FY2015.

Table 1: Highlights of OCR Enforcement and Outreach

DATE	ACTIONS TAKEN
October 2009	OCR and an Austin, TX orthopedic surgeon entered into a settlement, which resolved a Violation Letter of Finding where OCR concluded that the surgeon failed to comply with Section 504 of the Rehabilitation Act of 1973 (Section 504), ¹⁷ when the surgeon declined to perform knee surgery on a patient living with HIV. Section 504 prohibits disability discrimination in programs receiving federal funds. The surgeon agreed that in the future, he and his staff would not deny or withhold medically appropriate treatment from patients solely because of their HIV status.
March 2010	OCR entered into a settlement with Windsor Rosewood Care Center, a Pleasant Hill, CA skilled nursing facility which agreed to provide individuals living with HIV/AIDS equal access to its programs and services, as required by Section 504. The settlement resolved a Violation Letter of Finding, in which OCR determined that Windsor Rosewood failed to comply with Section 504 by denying admission to a Medicaid beneficiary because he was HIV-positive.
June 2010	OCR secured resolution of a complaint against a Los Angeles, CA hospital following allegations of civil rights and health information privacy violations. In this case, a patient alleged that a physician entered his room and discussed his HIV status in a loud voice. Following that discussion, the patient's roommate requested transfer to a new room because of the patient's HIV status and the hospital accommodated the roommate's request. To resolve concerns that the hospital violated Section 504 and HIPAA, OCR secured a commitment by the hospital to sanction the physician who made the comments, amend its policies to prohibit accommodation of patient room transfer requests based on prohibited discriminatory reasons, including HIV status, and provide staff training on the amended policies.
February 2011	OCR entered into a resolution agreement with the General Hospital Corporation and Massachusetts General Physicians Organization, Inc. (Boston, MA), which agreed to pay \$1,000,000 to settle potential violations of the HIPAA Privacy Rule. The incident involved the loss of 192 patients' health information, including patients living with HIV, when an employee left the documents on the subway train while commuting to work. In addition to names and medical record numbers, for 66 patients, the impermissible disclosure included names, dates of birth, diagnoses, medical record numbers, health insurer and policy numbers, and providers' names.
August 2012	OCR issued a Violation Letter of Finding, concluding that a Los Angeles, CA surgeon violated Section 504 by refusing to perform back surgery for a Medicaid recipient living with HIV. In August 2012, HHS terminated the surgeon's participation in the Medicaid program and the surgeon's eligibility to receive federal financial assistance. Following a settlement agreement with OCR in May 2014, HHS reinstated the surgeon's participation in the Medicaid program, as well as his ability to receive federal funds.
May 2013	OCR launched its "Information is Powerful Medicine" ¹⁸ national campaign, which encourages those living with HIV to be proactive in their medical care. The campaign explains individuals' rights under HIPAA, including how individuals can monitor and access a copy of their medical records. The campaign reaches African American men who have sex with men (MSM) and was featured at Black gay pride events in Atlanta, Chicago, New York City, Oakland and Washington, DC, as well as at the U.S. Conference on AIDS in New Orleans.
August 2014	OCR entered into a voluntary resolution agreement with Williamston House, a Williamston, NC assisted living facility. The agreement resolved a complaint alleging that the facility denied admission to an individual based on his HIV status, in violation of Section 504.

In support of the NHAS goal of reducing stigma and discrimination, OCR initiated, in 2014 and 2015, coordinated compliance reviews at twelve hospitals – one hospital in each of the twelve cities most impacted by HIV/AIDS. The compliance reviews examined the ways in which each hospital ensures:

1. equal access for HIV-positive individuals to programs and services;
2. meaningful access for LEP individuals to programs and services; and
3. the privacy and security of individuals' health information and their rights with regard to that information.

This report summarizes OCR's findings and identifies additional steps that hospitals and other health care providers can take to protect the civil rights and health information privacy of people living with HIV/AIDS.

ENSURING ACCESS TO HEALTH CARE WITHOUT DISCRIMINATION

Hospitals and other health care providers that receive federal financial assistance from HHS, including Medicare Parts A, C, and D, are required to comply with federal civil rights laws that prohibit discrimination on the basis of race, color, national origin,¹⁹ disability,²⁰ age,²¹ or sex.²² In addition, health programs operated by state and local governments, including public hospitals and Medicaid programs, are prohibited from discriminating on the basis of disability, whether or not they receive federal funds.²³

To comply with Title VI of the Civil Rights Act of 1964²⁴ and Section 1557 of the Affordable Care Act,²⁵ covered entities – including most hospitals and health care providers – are required to take reasonable steps to provide meaningful access to each LEP individual eligible to be served or likely to be encountered in their health programs or activities.²⁶ Reasonable steps may include: (1) the provision of qualified interpreters to LEP individuals when oral interpretation is required to provide meaningful access,²⁷ and (2) the provision of qualified translators to translate written documents or web content.²⁸ Such language assistance services must be provided free of charge, be accurate and timely, and protect the privacy and independence of LEP individuals.²⁹ Healthcare providers, with limited exceptions, are prohibited from allowing children, family members or friends of the patient to serve as interpreters.³⁰ To ensure high quality care, hospitals and other covered entities must institute robust workforce training programs, advance interventions to increase health literacy,³¹ and provide culturally and linguistically appropriate services³² to diverse populations.

Under Section 504, no qualified individual with a disability shall be excluded from, denied the benefits of, or be subjected to discrimination in any program or activity that receives federal financial assistance. Individuals living with HIV or AIDS, including those without symptoms, are people with disabilities under Section 504 and Section 1557.³³ Individuals wrongly assumed to have HIV or AIDS are also protected under both laws.³⁴ To achieve compliance with these laws, hospitals and other health care providers must ensure that their programs are administered free of discrimination on the basis of HIV.

As part of its findings, OCR identified civil rights standards that hospitals were meeting or exceeding; examples are provided in the table below:

Table 2: Protecting Civil Rights

ELEMENTS REVIEWED	COMPLIANCE ACTIONS AND PROMISING PRACTICES
<p>Establish Nondiscrimination Policies and Practices to Improve Access and Reduce Barriers To Quality Health Care.</p>	<ul style="list-style-type: none"> Committed to reducing the number of HIV transmissions and increasing the number of people living with HIV who are in treatment, a Dallas hospital partners with its school of health professions’ community prevention and intervention unit. The unit is one of several programs dedicated to outreach and targeted programs for vulnerable populations. At the hospital and a satellite testing clinic, the unit provides brochures in both English and Spanish, as well as free confidential and anonymous HIV testing. In addition to community outreach, the unit offers counseling and effective prevention programs tailored to reach high-risk communities. For example, the unit receives a grant from its state health department that funds prevention and outreach services to African American men who have sex with men. A District of Columbia hospital adopted a comprehensive policy prohibiting discrimination based on an individual’s race, color, national origin, sex, religion, age, marital status, personal appearance, sexual orientation, gender identity/expression, familial status, family responsibilities, matriculation (being enrolled in a college or secondary school), political affiliation, genetic information, disability, source of income, and place of residence or business. A San Francisco hospital established a clinic to specifically serve the needs of its Spanish-speaking LEP community. According to the hospital, Latinos make up 27% of all new HIV diagnoses in its service area, and approximately 50% of these cases involve LEP individuals. The role of the clinic is to ensure care coordination and provide culturally and linguistically appropriate services to enhance the quality of care that LEP patients receive. The clinic consists of an interdisciplinary, bilingual team of social workers, nurses, physicians and medical assistants, who have gained extensive experience working in the Latino community. The clinic holds monthly team meetings to coordinate services for patients who may require additional supportive services.
<p>Develop Comprehensive Language Assistance Services to Ensure Effective Communication and Meaningful Access for Individuals with Limited English Proficiency.</p>	<ul style="list-style-type: none"> A District of Columbia hospital posts signs and notices in intake areas and other points of entry to notify LEP individuals that free interpreter services are available. The hospital’s staff consistently demonstrates familiarity with the language identification tools and placards; and an LEP patient can select his or her primary language from among approximately 40 different languages. A Los Angeles hospital instituted a multi-level interpreter and translator program to ensure that no request for language services is denied. If a certified bilingual staff person cannot interpret because the patient’s primary language is rare or the request has a high level of complexity, the hospital has contracted with a professional telephone/video interpretation service to avoid or reduce service delays. In response to its determination that there is a prominent Spanish-speaking population in its service area, a New York City hospital makes available copies of many of its vital documents in Spanish, including: <i>7 Key Facts to Know Before Getting an HIV Test; HIPAA Request for Access; Notice of Privacy Practices; HIPAA Authorization to Disclose Information; Informed Consent for Transfusion of Blood and Blood Products; General Consent for Treatment; Informed Consent for Invasive, Diagnostic, Medical and Surgical Procedure; AIDS Institute Authorization for Release of Health Information and Confidential HIV-Related Information; Informed Consent to Perform HIV Test; Health Care Proxy; Informed Consent for Dental Procedures or Oral Surgery; Informed Consent Progress Note; Informed Consent for Anesthesia and/or Sedation Analgesia; and Consent for Prenatal and Obstetrical Services.</i> An Atlanta hospital published grievance procedures that provide for initiation, review, and when possible, prompt resolution of patient complaints concerning the quality of care or service received. The grievance procedures apply to concerns related to the provision of language assistance services and specifies that staff must inform patients of their right to file a complaint or grievance without fear of retaliation or barriers to service. If bilingual staff members are unavailable to interpret the grievance procedures, the hospital staff has been trained to use a telephone interpretation service.

ELEMENTS REVIEWED	COMPLIANCE ACTIONS AND PROMISING PRACTICES
<p>Implement Effective Training Programs to Ensure Equal Access to Quality Health Care.</p>	<ul style="list-style-type: none"> • A San Francisco hospital offers to its staff members, affiliated physicians and community health care providers a weekly conference series on the medical management of HIV. This series is part of a comprehensive provider education program developed in response to requests for educational seminars specific to the needs of clinicians and researchers. The program offers preceptor opportunities for local and visiting physicians, nurses, pharmaceutical companies, and other interested groups. As part of the program, the hospital organizes an annual three day continuing medical education course that includes the latest research on the long-term management of HIV. • Staff members at an Atlanta hospital receive training on their language assistance services program, which includes how to identify individuals with limited language capabilities and how to access language assistance services. The training is provided to each new hire and on an annual basis thereafter. The training includes an in-depth overview of cultural competency, patient rights, and the hospital's grievance process. • A large Los Angeles hospital identified 822 employees who have been certified as bilingual interpreters by their county government. Most of these individuals were also certified to read and write in the second language. The hospital also conducted advanced employee training, including a 40-hour "Introduction to Health Care Interpreting" course, which has been completed by 420 bilingual hospital employees. This course focuses on patient rights, with modules on health care interpreting, medical terminology, cultural competency, ethics, and consecutive and simultaneous modes of interpreting. Employees in the county program, or those applying for healthcare interpreter positions, enjoy priority enrollment in the course. Additionally, the hospital has one full-time interpreter who speaks both Mandarin and Cantonese and three full-time Spanish healthcare interpreters. The four interpreters are supervised by the hospital's Coordinator of Language Services. These interpreters provide face-to-face interpreting, video and telephonic interpreter services, and translation verification.

ENSURING INDIVIDUALS' MEDICAL PRIVACY

Hospitals and other health care providers that transmit individuals' health information electronically in certain healthcare transactions are required to comply with the Health Insurance Portability and Accountability Act of 1996³⁵ (HIPAA) and the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009,³⁶ and their implementing regulations, known as the HIPAA Rules.³⁷ The information subject to these requirements is defined as "protected health information" or "PHI".

The HIPAA Rules protect patients' medical records and other health information maintained by doctors, hospitals, health plans, and other health care entities. These standards provide patients, including those living with HIV, access to their medical records and control over how their personal health information is used and disclosed. Whether health information is stored on paper or electronically, hospitals and their business associates covered by the HIPAA Rules must keep PHI, such as HIV status, private and secure.

Individuals who receive treatment or health insurance from a HIPAA covered entity have legal rights to:

- keep their health information private, including information regarding their HIV status;
- share their health information with others, including a spouse, domestic partner, parent, sister, brother or friend;
- ask their doctors, labs, or pharmacies to not share their health information with a health plan, if the item or service is paid for out of pocket;
- say which phone number their doctors or pharmacies should call to leave a private message;
- see or request copies of their medical records, including electronic health records, and to direct a copy of their records to designated third parties;
- check to make sure their medical records are correct and complete;

- ask their doctors or pharmacies to fix items in their medical records that are wrong or missing, or make “amendments”;
- receive Notices of Privacy Practices explaining how their health information may be used and shared and their rights with respect to that information;
- know how their health information is used or shared by requesting reports, or “accountings of disclosures”; and
- file a complaint with HHS if they believe their rights are being denied or their health information isn’t being protected.

OCR recently released guidance to entities covered by HIPAA addressing the rights of individuals to access and obtain copies of their PHI, as well as new consumer videos that summarize this right, produced jointly with the Office of the National Coordinator for Health Information Technology. These tools are available at:

- *Your Information, Your Rights!* Video Series;³⁸ and
- OCR Access Guidance.³⁹

OCR’s compliance reviews examined and provided technical assistance regarding the hospitals’ policies, procedures and practices for ensuring the privacy and security of individuals’ PHI and their rights with regard to that information. OCR provided robust technical assistance to help these entities achieve more comprehensive compliance with the HIPAA Rules.

As part of its findings, OCR identified HIPAA standards that hospitals were meeting or exceeding; examples are provided in the table below:

Table 3: Protecting Health Information Privacy

HIGHLIGHTED ACTIONS	COMPLIANCE ACTIONS AND PROMISING PRACTICES
Designate HIPAA Privacy and Security Officials responsible for developing and implementing policies and procedures to protect health information.	<ul style="list-style-type: none"> • As required by the Privacy Rule, most hospitals identified a HIPAA Security and Privacy Officer responsible for specific HIPAA compliance and implementation activities. This level of administrative oversight facilitates patients’ access to their health information, including HIV status, and ensures that health care providers protect individuals’ data from being improperly disclosed. Designated HIPAA officials may also serve an important role when individuals pursue their rights to access or amend their PHI or to file a complaint about privacy violations.
Provide a Notice of Privacy Practices that describes how individuals’ medical information may be used and disclosed and how they can get access to this information, and develop policies and procedures to assure distribution of the Notice and to document individuals’ receipt of the Notice.	<ul style="list-style-type: none"> • As required by the Privacy Rule, most hospitals’ Notice of Privacy Practices provided information about how the hospitals may use and disclose an individual’s health information, as well as an individual’s rights and the hospital’s obligations with respect to that information. The Notice provided all patients, including people living with HIV, information about the right to access and amend their medical records and how to file a privacy complaint. • A Philadelphia hospital provided patients its Notice of Privacy Practices through multiple channels: on posters at key locations throughout its facilities, at patient registration sites, as an attachment to its patient consent form (with additional explanation of the Notice), and on its website. The Notice of Privacy Practices was provided as a pamphlet for patients to take with them with a tear-off portion that constitutes the Acknowledgement of Receipt form. These multi-modal forms of outreach demonstrated a commitment to inform patients of their information privacy rights and how they may be exercised.

HIGHLIGHTED ACTIONS	COMPLIANCE ACTIONS AND PROMISING PRACTICES
<p>Develop policies and procedures regarding individuals' right of access to inspect and obtain a copy of their medical records, both in paper and electronic form.</p>	<ul style="list-style-type: none"> • OCR's technical assistance prompted a hospital in San Francisco to revise its medical records access policy to require that workforce members respond to patients' access requests within 30 days of receipt, as required by the Privacy Rule, and to develop a procedure for workforce members to request additional retrieval time if the information requested is off-site. OCR's assistance also guided the hospital to include an access policy which would permit a patient to specify the time and manner of their access, and to establish a procedure for denials of access requests. Finally, the hospital learned the importance of providing individuals with a medical records fee schedule, showing the average amount, per unit, of these potential fees, when access is requested. • A Dallas hospital's policy protected individuals' rights to access all the personal health information that the hospital uses to make decisions about individuals. It outlined specific responsibilities for departments that maintain designated records and that receive individuals' requests for access to records. This ensured that patients, including people living with HIV, will not be denied segments of their medical records improperly and will not have to make repeated requests for their health information. The hospital's access policy also ensured that individuals attempting to establish disability benefits will not be charged a fee for a medical or mental health record requested by a patient or their representative.
<p>Evaluate the potential risks and weaknesses of keeping electronic health information confidential, secure, and available and apply sufficient security measures to protect the information.</p>	<ul style="list-style-type: none"> • OCR's provision of technical assistance prompted several hospitals to conduct a comprehensive, system-wide HIPAA security "risk analysis," overseen by information technology staff or consultants. This ensured that hospitals applied the full range of HIPAA security standards to sensitive health information. For example, these hospitals demonstrated the policies they applied to prevent improper access by employees and the technology used to deter and detect harmful intrusions, such as hacking of sensitive data. Specifically, organizations' HIPAA risk analysis should broadly encompass individuals' health information wherever it is used in a hospital to make decisions about patients, so that hidden threats to confidentiality are identified and addressed. • OCR's technical assistance resulted in a Baltimore hospital significantly improving its compliance with the HIPAA Security Rule which was vital to assuring that sensitive health information, and all individuals' health information, remained confidential and secure. The hospital assigned security responsibility to a specific individual, inventoried its valuable information technology and electronic health information, identified which data and IT systems were most critical, and secured them accordingly. The hospital also developed business continuity/recovery processes so that privacy and security can be maintained in the event of a disaster or unexpected system failure and individuals' sensitive PHI can be accessed when needed. The hospital also updated its training program and trained its workforce and management on becoming more security aware when handling electronic PHI. • OCR worked with a San Juan hospital to develop a process to review its Internet firewall, anti-virus, web filter, and email filter systems and strengthen its password configuration and security setting (to 8 minimum characters, changed every 90 days), enable password complexity, and establish login restrictions. These security safeguards are foundational to protecting all electronic health information, including HIV-related information. • A Dallas hospital with a robust information security program considered both traditional and emerging information technologies and services to ensure the privacy and security of individuals' health information, such as cloud computing, wireless connections, and mobile devices. • A hospital in Philadelphia conducted audits quarterly on various systems containing individuals' health information. For example, it reviewed physical access to its data center to see if security controls were operating and conducted a privacy walk-through of ambulatory centers.

HIGHLIGHTED ACTIONS	COMPLIANCE ACTIONS AND PROMISING PRACTICES
<p>Establish policies and procedures to ensure a notice of a health information breach is provided to affected individuals when needed, to OCR, and to the media (if necessary).</p>	<ul style="list-style-type: none"> • A Philadelphia hospital established an incident response team to respond to and investigate health information breaches and potential breaches, ensuring its employees are prepared to respond when health information, such as HIV status, is improperly disclosed, and to protect individuals' privacy rights. It also clearly provided multiple phone numbers and several email addresses that employees may contact to report breach incidents, including an anonymous tip line. Its policy also clearly stated it will notify affected individuals without unreasonable delay and no later than 60 days after breaches are discovered. • A San Francisco hospital revised its policy on responding to breaches of unencrypted health information so that it was consistent with requirements of the Breach Notification Rule, which requires notice to be provided to OCR, the individual, and the media, in some cases. • When personnel have the proper tools to address health information breaches, individuals with concerns about the improper use or disclosure of their information, such as people living with HIV, are more likely to receive the notice they need to protect themselves from further harm. A hospital in Atlanta provided designated workforce members a questionnaire assessing the privacy risks of each health information breach incident to determine when notification is required by HIPAA.

CONCLUSION

Compliance with civil rights and health information privacy laws can build an environment of trust and inclusivity that supports access to quality health care for people living with HIV. OCR's *National HIV/AIDS Compliance Review Initiative* sets forth steps hospitals and other covered entities can take to comply with these laws. Covered entities must have strong compliance policies and procedures, robust workforce training, interventions to increase health literacy, culturally and linguistically appropriate services, and other measures to ensure adherence to civil rights laws and HIPAA standards. Covered entities can make a long term investment in their communities by implementing effective practices and ensuring compliance, and as a result, can significantly improve testing, prevention and treatment services, as well as health outcomes, for people living with HIV. The continued commitment of the hospitals in this compliance review to principles of nondiscrimination and the protection of health information privacy will increase access to care and reduce HIV stigma and discrimination for many people across the nation.

REFERENCES

- ¹ White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States* at 36 (July 2010), <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/strategy-history/original-strategy-documents/index.html>. For additional federal resources on HIV/AIDS, visit <https://www.aids.gov/> and <http://www.hhs.gov/civil-rights/for-individuals/special-topics/HIV/index.html>.
- ² U.S. Dep’t of Health and Human Servs., Centers for Disease Control and Prevention, *Today’s HIV/AIDS Epidemic* at 1 (Feb. 2016), <http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/TodaysEpidemic-508.pdf>. Individuals unaware of their human immunodeficiency virus (HIV) contribute to nearly one third of ongoing transmission in the United States. See Hall, H.I., An, Q., Tang, T., Song, R., Chen, M., Green, T. and Kang, J. *Prevalence of Diagnosed and Undiagnosed HIV Infection—United States, 2008-2012*. Morbidity and Mortality Weekly Report 2015, 64, 657-662, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6424a2.htm>.
- ³ U.S. Dep’t of Health and Human Servs., Centers for Disease Control and Prevention, *HIV Diagnoses Decline Almost 20 percent, But Progress is Uneven* (Dec. 6, 2015), <http://www.cdc.gov/nchhstp/newsroom/2015/nhpc-press-release-hiv-diagnoses.html>.
- ⁴ U.S. Dep’t of Health and Human Servs., Centers for Disease Control and Prevention, *HIV Among Transgender People* (Apr. 2016), <http://www.cdc.gov/hiv/group/gender/transgender>.
- ⁵ See, e.g., Burke RC, Sepkowitz KA, Bernstein KT. (2007). Why don’t physicians test for HIV? A review of the US literature. *AIDS*, 21(12):1617–1624, <http://www.ncbi.nlm.nih.gov/pubmed/17630557>.
- ⁶ Arya M, Amspoker AB, Lalani N, et al. (2013). HIV Testing Beliefs in a Predominantly Hispanic Community Health Center During the Routine HIV Testing Era: Does English Language Ability Matter? *AIDS Patient Care and STDs*, 27(1):38-44, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3545313/>.
- ⁷ See Brooks, R. A., Etzel, M. A., Hinojos, E., Henry, C. L., & Perez, M. (2005). Preventing HIV among Latino and African American Gay and Bisexual Men in a Context of HIV-Related Stigma, Discrimination, and Homophobia: Perspectives of Providers. *AIDS Patient Care and STDs*, 19(11): 737–744 (hereinafter, “Preventing HIV”), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1360177/>.
- ⁸ See Martinez, J., Lemos, D., Hosek, S., & the Adolescent Medicine Trials Network. (2012). Stressors and Sources of Support: The Perceptions and Experiences of Newly Diagnosed Latino Youth Living with HIV. *AIDS Patient Care and STDs*, 26(5): 281–290, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3335135/>; Sankar, P., Mora, S., Merz, J. F., & Jones, N. L. (2003). Patient Perspectives of Medical Confidentiality: A Review of the Literature. *Journal of General Internal Medicine*, 18(8): 659–669, <http://www.ncbi.nlm.nih.gov/pubmed/12911650>.
- ⁹ See Preventing HIV at 737-738.
- ¹⁰ See White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States* (July 2010), <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/strategy-history/original-strategy-documents/index.html>.
- ¹¹ See White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States: Federal Implementation Plan* (July 2010), <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/strategy-history/original-strategy-documents/index.html>.
- ¹² See White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States: Updated to 2020* (July 2015), <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update/index.html>.
- ¹³ See White House Office of National AIDS Policy, *National HIV/AIDS Strategy for the United States: Updated to 2020 – Federal Implementation Plan* (December 2015)(hereinafter “NHAS Update”), <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update/index.html>.
- ¹⁴ See NHAS Update at 45.
- ¹⁵ Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified in scattered sections of 26, 29, and 42 U.S.C.).
- ¹⁶ The 145 new matters include HIV-related civil rights complaint investigations, HIV-related health information privacy investigations and the 24 compliance reviews summarized in this report.
- ¹⁷ 29 U.S.C. § 794, and its implementing regulation, 45 C.F.R. Part 84.
- ¹⁸ See U.S. Dep’t of Health and Human Servs., Office for Civil Rights, *Information is Powerful Medicine* (2013), <https://www.aids.gov/privacy/>.
- ¹⁹ See Title VI of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000d – 2000d-7, and its implementing regulation, 45 C.F.R. Part 80.

-
- ²⁰ See Rehabilitation Act of 1973, 29 U.S.C. § 794, and its implementing regulation, 45 C.F.R. Part 84.
- ²¹ See Age Discrimination Act of 1975, 42 U.S.C. §§ 6101 – 6107, and its implementing regulation, 45 C.F.R. Part 90.
- ²² See Section 1557 of the Affordable Care Act, 42 U.S.C. § 18116, and its implementing regulation, U.S. Dep’t of Health and Human Servs., *Nondiscrimination in Health Programs and Activities*, 81 Fed. Reg. 31376, 31410-31421 (May 18, 2016), https://www.federalregister.gov/articles/2016/05/18/2016-11458/nondiscrimination-in-health-programs-and-activities?utm_campaign=subscription+mailing+list&utm_medium=email&utm_source=federalregister.gov.
- ²³ See Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12131 – 12134, and its implementing regulation, 28 C.F.R. Part 35.
- ²⁴ 42 U.S.C. §§ 2000d – 2000d-7; 45 C.F.R. § 80.3(b)(2). See also U.S. Dep’t of Health and Human Servs., *Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons*, 68 Fed. Reg. 47311, 47313 (Aug. 2003)(hereinafter “HHS LEP Guidance”), <http://www.gpo.gov/fdsys/pkg/FR-2003-08-08/pdf/03-20179.pdf>.
- ²⁵ 42 U.S.C. § 18116; 45 C.F.R. § 92.201.
- ²⁶ 45 C.F.R. § 92.201(a)(1). See also HHS LEP Guidance at 47313-14.
- ²⁷ 45 C.F.R. § 92.201(d)(1); 68 Fed. Reg. 47315-47320.
- ²⁸ 45 C.F.R. § 92.201(d)(2); 68 Fed. Reg. 47315-47320.
- ²⁹ 45 C.F.R. § 92.201(c); 68 Fed. Reg. 47318.
- ³⁰ 45 C.F.R. § 92.201(e); 68 Fed. Reg. 47318.
- ³¹ See K Kalichman, S. C., Pope, H., White, D., Cherry, C., Amaral, C. M., Swetzes, C., Kalichman, M. O. (2008). The Association between Health Literacy and HIV Treatment Adherence: Further Evidence from Objectively Measured Medication Adherence. *Journal of the International Association of Providers of AIDS Care*, 7(6): 317–323, <http://www.ncbi.nlm.nih.gov/pubmed/19056866>.
- ³² See U.S. Dep’t of Health and Human Servs., Office of Minority Health, *National Standards on Culturally and Linguistically Appropriate Services* (2013), <https://www.thinkculturalhealth.hhs.gov/content/clas.asp>.
- ³³ See *Bragdon v. Abbott*, 524 U.S. 624, 631 (1998).
- ³⁴ 45 C.F.R. § 84.3(j)(iii)(Section 504); 45 C.F.R. § 92.4 (Section 1557).
- ³⁵ Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified in scattered sections of 26, 29, and 42 U.S.C.).
- ³⁶ Title XIII of division A and title IV of division B of the American Recovery and Reinvestment Act of 2009 (ARRA), *codified at* 42 U.S.C. §§ 300jj-11 – 300jj-51.
- ³⁷ The HIPAA Rules encompass the Federal Standards for Privacy of Individually Identifiable Health Information, the Security Standards for the Protection of Electronic Protected Health Information, and Notification in the Case of Breach of Unsecured Protected Health Information (45 CFR Parts 160 and 164).
- ³⁸ Available at: <http://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>.
- ³⁹ Available at: <http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/>.