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Second Annual HIPAA Privacy Check-Up

Bush Administration Fails Again to Protect Americans' Medical Privacy

Lack of Public Education, Inadequate Enforcement Stifle Impact of Privacy Rule

Thursday, April 14th marks the second anniversary of the landmark federal medical privacy regulation, the first-ever comprehensive federal law to protect the privacy of Americans' health information. The HIPAA [Privacy Rule](#), as mandated by the 1996 Health Insurance Portability and Accountability Act (HIPAA), built an important floor of privacy protection into the U.S. health care system. **Unfortunately, the impact of the Privacy Rule is dramatically weakened by rampant misunderstandings by both patients and providers and inadequate enforcement by the Bush administration.**

The Privacy Rule gives Americans IMPORTANT RIGHTS:

- ✓ **Access to medical records**—The Privacy Rule gives Americans the right to see, copy, and amend their own medical records. Americans also have the right to request an amendment to their medical record.
- ✓ **Confidentiality**—The Privacy Rule prohibits health care providers and health plans from disclosing identifiable health information to employers and others outside the health care system without patient authorization. Law enforcement officials must present some form of legal process (e.g., warrant, subpoena, summons) before a health care provider or health plan can disclose health information. States are free to enact stronger privacy laws.
- ✓ **Secure medical records**—The Privacy Rule requires that health care providers, plans, and “information clearinghouses” secure health information. The regulation requires security to prevent inadvertent disclosures and to foil hackers.
- ✓ **Limits on how much information is disclosed**—One of the most important concepts of the Privacy Rule is the “minimum necessary” principle, which stipulates that when health care providers do release personal health information, they generally must limit the information to the amount minimally necessary to accomplish the intended purpose.

- ✓ **Enforcement**—Criminal and civil penalties can be imposed on providers or plans that violate the Privacy Rule. If consumers believe their rights have been violated, they can file a [complaint](#) with the U.S. Department of Health and Human Services (HHS), which will forward it to the Department of Justice if criminal conduct is suspected.

Unfortunately, the Bush administration has:

- ✓ **FAILED to educate providers and patients about responsibilities and rights**—One year after the Health Privacy Project's 1st [HIPAA Privacy Check-Up](#) called on the Bush administration to provide guidance to the industry and educate the public, misunderstandings continue to dog successful implementation of the Privacy Rule. A strong education effort is needed to separate [myths from facts](#) and ensure that consumers, health care providers, and insurers understand the Privacy Rule. Especially as the Bush administration is actively lobbying for the development of an [electronic medical record system](#), it is critical to address consumers' privacy fears by both educating patients about their rights and providers about their responsibilities. If patients do not feel that their personal health information is being protected, they will simply withdraw from their own care—to the detriment of themselves and their communities. In fact, one in six Americans already withdraws from full participation in their own care because of fears that their information will be used without their knowledge or permission.
- ✓ **FAILED to adequately enforce the Privacy Rule**—The administration's insistence on relying solely on consumer complaints to enforce the Privacy Rule is impractical. Despite over 11,920 consumer complaints filed, not one civil penalty has been imposed by Department of Health and Human Services.
- ✓ **FAILED to protect the principle of medical privacy**— Just as the U.S. Department of Justice [subpoenas](#) of medical records did last year, many Bush administration policies continue to undermine the principle of medical privacy. With policies such as the Homeless Management Information Systems (HMIS) standards (which seek to collect highly sensitive health information about homeless persons), the administration continued to disable the fundamental standard of medical privacy. Recent security breaches with Choicepoint and LexisNexis Group—as well as the Kansas and Indiana Attorney Generals' [demands](#) for complete, unedited records of patients—will only bolster consumer concerns about the confidentiality and security of their sensitive health information.
- ✓ **FAILED to strengthen the Privacy Rule**—The Health Privacy Project's 1st [HIPAA Privacy Check-Up](#) called on the Bush administration to strengthen the Privacy Rule by limiting marketing to consumers and to mount a vigorous public education campaign. The administration did neither.



Prescriptions for Improvement

The Health Privacy Project's Call for Action

- **Strengthen enforcement**—The Bush administration must be more vigilant in enforcing the Privacy Rule and must insist on full and accurate compliance. HHS should not rely solely on consumer-driven complaints, but should aggressively monitor and oversee compliance with the rule.
- **Launch an aggressive public education campaign**—Two years later, the Privacy Rule continues to be misunderstood and misinterpreted. The Bush administration should undertake an immediate public education campaign to clear up misunderstandings and illustrate that doctors, for instance, can share health information with each other without a patient's consent and that family members can be informed about a relative's condition as well as participate in health care decisions.
- **Limit marketing**—The Bush administration made it easier for drug companies and others to use sensitive health information to market to consumers. At the very least, HHS should reinstate Clinton-era safeguards that required drug companies and others who perform marketing on their behalf to give consumers notice and the opportunity to opt out of such marketing.
- **Give consumers the right to sue**—People should be able to sue when their privacy rights have been violated. Congress must fix the Privacy Rule to include a private right of action. We urge the President to support this change. Without the ability to go to court if the Privacy Rule is violated, the law is a “right without a remedy.”
- **Conduct oversight**—Congress should hold annual oversight hearings, during which HHS will testify about complaints received, follow-up investigations, criminal referrals, public education, and enforcement. Congressional oversight will shed light on HHS's enforcement of the law, and provide a public record as we go forward.

The Health Privacy Project is a 501(c)(3) nonprofit organization dedicated to raising awareness about the importance of ensuring health privacy in order to improve health care access and quality, both on an individual and community level. Comprehensive medical privacy resources are available at our website – <http://www.healthprivacy.org>.

For more information about the HIPAA Privacy Rule, consult HPP's [Health Privacy: Know Your Rights](#) pamphlet and [Myths and Facts About the HIPAA Privacy Rule](#).