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First Annual HIPAA Privacy Check-Up

Bush Administration Fails the American Public

Wednesday, April 14th marks the first anniversary of the landmark federal medical privacy regulation, as [mandated](#) by the 1996 Health Insurance Portability and Accountability Act (HIPAA). The HIPAA Medical [Privacy Rule](#), the [first](#)-ever comprehensive federal law to protect the privacy of Americans' health information, takes crucial steps towards building privacy into the U.S. health care system. **Unfortunately for health care consumers, the Bush administration has failed to make good on its promise to safeguard people's medical privacy.**

The Privacy Rule gives people **NEW RIGHTS**:

- ✓ **Access to medical records**—The Privacy Rule gives Americans the right to see, copy, and amend their own medical records.
- ✓ **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 foil hackers.
- ✓ **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 Department of Health and Human Services, which will forward it to the Department of Justice if criminal conduct is suspected.

BUT, the Bush Administration has:

- ✓ **FAILED to provide guidance to the industry and educate the public**—In the two years provided by HIPAA to implement the Privacy Rule, the Bush administration failed to provide effective technical assistance to health care providers and health plans. The administration continues to fail to educate health care consumers about their rights and health care providers about their responsibilities.
- ✓ **FAILED to provide adequate enforcements**—The Bush administration's insistence on relying solely on consumer complaints to enforce the Privacy Rule is inadequate. Despite over 5,000 consumer complaints filed, not one civil penalty has been imposed by HHS. And, dozens of criminal complaints have been referred to DOJ, with no known penalties imposed.

- ✓ **FAILED to uphold the principle of medical privacy**— In a stunning act of harassment and intimidation, the DOJ, in its defense of the Partial-Birth Abortion Ban Act, issued subpoenas for hundreds of women’s medical records. In court, DOJ **defended** the subpoenas, arguing that “individuals no longer possess a reasonable expectation that their histories will remain completely confidential.” Ironically, DOJ is charged with enforcing the new Privacy Rule, which gives people exactly such an expectation of privacy. Although a number of federal judges have ruled that the subpoenas are unjustified and overly intrusive, the Bush administration’s demand for the records is likely to frighten women away from certain health care services. In fact, a significant percentage of people are **afraid** to seek care or be honest with their doctors for fear that their sensitive health information will be used against them by employers, the government, and others.



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 complaints, but should aggressively monitor and oversee compliance with the rule.
- **Mount a vigorous public education campaign**—One year later, the Privacy Rule continues to be misunderstood and misinterpreted. The Bush administration should take the lead in clearing up glaring **errors** and clarify that doctors 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 of 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](#).