

FOR IMMEDIATE RELEASE

JUNE 4, 2008

CONTACT:

Ashley Katz

Executive Director, Patient Privacy Rights

(512) 732-0033 or (512) 897-6390

[www.patientprivacyrights.org](http://www.patientprivacyrights.org)

PATIENT PRIVACY RIGHTS TESTIFIES BEFORE HOUSE ENERGY & COMMERCE ON  
“HITEC” DRAFT LEGISLATION

**Congress: Protect in statute what Americans assume happens when they visit their doctors: that what they “say in the doctor’s office stays in the doctor’s office.”**

Washington, D.C. -- Dr. Deborah Peel, founder and chair of Patient Privacy Rights and leader of the bipartisan Coalition for Patient Privacy testifies today before the House Energy & Commerce Committee, Subcommittee on Health, and makes privacy recommendations for the new draft Health IT bill, “HITEC.” We ask Congress to ensure both progress and privacy in revisions to the bill.

Patient Privacy Rights is urging Congress to include the definition of privacy and restore Americans’ right to consent to the use and disclosure of their personal information. The definition of privacy is “an individual's right to control the acquisition, uses, or disclosures of his or her identifiable health data.”

With electronic health records, the risk to patient privacy is real. Existing laws do not go far enough. Today, 4 million providers and their employees decide when, where, and who gets your sensitive health data, not you, and electronic systems are not secure. Meanwhile Americans’ personal health information is worth billions. It is the perfect storm for massive privacy violations that will ultimately lead to discrimination by employers, insurers, banks and more.

It has been puzzling to encounter opposition to privacy; it is a right that is centuries old. “It is not a radical notion,” remarked Peel. Privacy means control over personal information—without control, you have no privacy.

Including the right to control who can view and use your health information is another imperative for HITEC. “Getting consent to disclose your diagnosis of cancer, an STD, a Paxil prescription or even having the flu is not radical. In fact, obtaining consent is even easier with health IT,” said Peel. Some have argued that getting consent today is burdensome or impractical. Peel addressed this head on: “If you believe that you are saying it is O.K. for the health industry to *not even try* to communicate with their customers, and it is O.K. to let those who have the most to gain decide how personal information is used. Well, that’s not O.K. Destroying the bond of trust between physicians and patients that has worked for millennia is the one radical concept of this debate.”

Patient Privacy Rights also urges Congress not to delegate to committees the power to change Americans’ long-standing rights to health privacy. It is critical that Congress, the body accountable to voters, set the basic framework for Health IT and our fundamental privacy rights.

The lack of privacy is both harmful and deadly.

- According to HHS, **two million** mentally ill Americans do not seek treatment for this reason.<sup>1</sup>
- **600,000** cancer victims do not seek early diagnosis and treatment.<sup>2</sup>
- **Millions** of young Americans suffering from sexually transmitted diseases do not seek . . . treatment.<sup>3</sup>
- The California Health Care Foundation found that **1 in 8** Americans have put their health at risk for the sake of privacy: *Avoiding their regular doctor - Asking a doctor to alter a diagnosis- Paying privately for a test - Avoiding tests altogether.*<sup>4</sup>
- The Rand Corporation found that **150,000 soldiers** suffering from PTSD do not seek treatment because of privacy concerns.<sup>5</sup>

---

<sup>1</sup> 65 Fed. Reg. at 82,779

<sup>2</sup> 65 Fed. Reg. at 82,777

<sup>3</sup> 65 Fed. Reg. at 82,778

<sup>4</sup> CHCH Consumer Health Privacy Survey, June 2005

<sup>5</sup> "Invisible Wounds of War", The RAND Corp., p. 436 (2008)

These statistics are unacceptable. Patient Privacy Rights urges the House to protect the most sensitive information on earth, our health records.

**About Patient Privacy Rights:**

Patient Privacy Rights is a national organization that educates consumers about the importance of health privacy, champions smart policies, and holds industry accountable to protect what's most valuable—our health, our families and our reputation. PPR is headquartered in Austin, Texas. For more information visit [www.patientprivacyrights.org](http://www.patientprivacyrights.org)