



# patientprivacyrights

## **Brief Summary Testimony by Deborah C. Peel, MD, Founder & Chair of Patient Privacy Rights**

As a practicing physician in the field of psychiatry for over thirty years, I know that effective treatment depends upon the trust established between a doctor and a patient. *The idea that your most embarrassing conditions should stay private, or that information about YOU should be in your control, is not a radical concept.*

Despite the fact that HIPAA requires more stringent privacy-protective state laws and medical ethics to prevail over the privacy ‘floor’ in HIPAA, the opposite has occurred. Today:

- 1) Individuals have no control over their personal health information.
- 2) Electronic systems are not secure.
- 3) Americans’ health data is worth billions.

*How do we address these threats? How do we progress with privacy?*

**First, define privacy.** NCVHS defined health information privacy as “an individual's right to control the acquisition, uses, or disclosures of his or her identifiable health data.” Privacy means control over personal information—if you have no control, you have no privacy.

**Second, restore Americans’ control over their personal health information.** At a minimum, any health IT legislation must codify in law what Americans assume happens when they visit their doctors: that what they “say in the doctor’s office stays in the doctor’s office.”

**Third, strengthen public participation significantly in this bill.** The proposed members of the HIT Policy and Standards Committees are dominated by conflicted appointees from the health industry; their recommendations will reflect their interests. These committees must include sufficient representation by those without ties to government or the private sector, including consumer advocates, privacy experts, scholars, and those with expertise in medical ethics.

I’ve been sitting face to face with patients for over thirty years. It is frankly heart breaking to see the real destruction caused when private, intimate information gets in the wrong hands. Patient Privacy Rights, in operation for just a few years, hears daily from patients from every state in this nation, desperate for help and looking for justice.

We will always have nosy neighbors. And we will always have security breaches at some level, regardless of the security standards we implement. The one thing you can do and must do is minimize what happens to our private information on a daily basis. Thank you.