2007 Patient Privacy Principles

The Coalition for Patient Privacy developed the following privacy principles to serve as standards for legislation in Congress. Without these ironclad privacy protections, consumers will not trust or participate in any electronic health system.

- Recognize that patients have the right to medical privacy*
 - Recognize that user interfaces must be accessible so that health consumers with disabilities can individually manage their health records to ensure their medical privacy.
- The right to medical privacy applies to all health information regardless of the source, the form it is in, or who handles it
- Give patients the right to opt-in and opt-out of electronic systems
 - o Give patients the right to segment sensitive information
 - Give patients control over who can access their electronic health records
- Health information disclosed for one purpose may not be used for another purpose before informed consent has been obtained
- Require audit trails of every disclosure of patient information
- Require that patients be notified promptly of suspected or actual privacy breaches
- Ensure that consumers can not be compelled to share health information to obtain employment, insurance, credit, or admission to schools, unless required by statute
- Deny employers access to employees' medical records before informed consent has been obtained
- Preserve stronger privacy protections in state laws
- No secret health databases. Consumers need a clean slate. Require all existing holders of health information to disclose if they hold a patient's health information
- Provide meaningful penalties and enforcement mechanisms for privacy violations detected by patients, advocates, and government regulators

Definition: *Health information privacy is an individual's right to control the acquisition, uses, or disclosures of his or her identifiable health data. (Report of the NCVHS to Sec Leavitt dated June 22, 2006)