Recommendations from Past Reports: Legislation

Recommendation	Report	Implemented?
We recommend the enactment of legislation establishing a Code of Fair Information practice for all automated personal data systems. • The Code should define "fair information practice" as adherence to specified safeguard requirements. • The Code should prohibit violation of any safeguard requirement as an "unfair information practice." • The Code should provide that an unfair information practice be subject to both civil and criminal penalties. • The Code should provide for injunctions to prevent violation of any safeguard requirement. • The Code should give individuals the right to bring suits for unfair information practices to recover actual, liquidated, and punitive damages, in individual or class actions It should also provide for recovery of reasonable attorneys' fees and other costs of litigation incurred by individuals who bring successful suits.	*Records, Computers and the Rights of the Citizens* (1973)	
Pending the enactment of a code of fair information practice, we recommend that all Federal agencies (i) apply the safeguard requirements, by administrative action, to all Federal systems, and (ii) assure, through formal rule making, that the safeguard requirements are applied to all other systems within reach of the Federal government's authority. Pending the enactment of a code of fair information practice, we urge that State and local governments, the institutions within reach of their authority, and all private organizations adopt the safeguard requirements by whatever means are appropriate.	*Records, Computers and the Rights of the Citizens* (1973)	

Recommendation	Report	Implemented?
Existing laws or regulations affording individuals greater protection than the safeguard requirements should be retained, and those providing less protection should be amended to meet the basic standards set by the safeguards. In particular, we recommend • That the Freedom of Information Act be amended to require, an agency to obtain the consent of an individual before disclosing in personally identifiable form exempted category data about him, unless the disclosure is within the purposes of the system as specifically required by statute. • That pending such amendment of the Act, all Federal agencies provide for obtaining the consent of individuals before disclosing individually identifiable exempted-category data about them under the Freedom of Information Act. • That the Fair Credit Reporting Act be amended to provide for actual, personal inspection by an individual of his record along with the opportunity to copy its contents, or to have copies made; and that the exceptions from disclosure to the individual now authorized by the Fair Credit Reporting Act for medical information and sources of investigative information be omitted.	*Records, Computers and the Rights of the Citizens* (1973)	
The CPRI should review federal and state laws and regulations for the purpose of proposing and promulgating model legislation and regulations to facilitate the implementation and dissemination of the CPR and its secondary databases and to streamline the CPR and CPR systems.	*The Computer-Based Patient Record: An Essential Technology for Health Care* (1997)	

Recommendation	Report	Implemented?
We recommend that all personal data in such systems be protected by statute from compulsory disclosure in identifiable form. Federal legislation protecting against compulsory disclosure should include the following features: • The data to be protected should be limited to those *used exclusively for statistical reporting or research.* Thus, the protection would apply to statistical-reporting and research data derived from administrative records, and kept apart from them, but not to the administrative records themselves. • The protection should be limited to data *identifiable with, or traceable to, specific individuals.* When data are released in statistical form, reasonable precautions to protect against "statistical' disclosure" should be considered to fulfill the obligation not to disclose data that can be traced to specific individuals. • The protection should be specific enough to qualify for non-disclosure under the Freedom of Information Act exemption for matters "specifically exempted from disclosure by statute." 5 U.S.C. 552(b)(3). • The protection should be available for data in the custody of all statistical-reporting and research systems, whether supported by Federal funds or not. • Either the data custodian or the individual about whom data are sought by legal process should be able to invoke the protection, but only the individual should be able to waive it. • The Federal law should be controlling; no State statute should be taken to interfere with the protection it provides.	*Records, Computers and the Rights of the Citizens* (1973)	

Recommendation	Report	Implemented?
We recommend specific, preemptive, Federal legislation providing: (1) That an individual has a legal right to refuse to disclose his SSN to any person or organization that does not have specific authority provided by Federal statute to request it; (2) That an individual has the right to redress if his lawful refusal to disclose his SSN results in the denial of a benefit, or the threat of denial of a benefit; and that, should an individual under threat of loss of benefits supply his SSN under protest to an unauthorized requestor, he shall not be considered to have forfeited his right to redress; and (3) That any oral or written request made to an individual for his SSN must be accompanied by a clear statement indicating whether or not compliance with the request is required by Federal statute, and, if so, citing the specific legal requirement. In addition, we recommend (4) That the Social Security Administration undertake a positive program of issuing SSNs to ninth-grade students in schools, provided (a) that no school system be induced to cooperate in such a program contrary to its preference; and (b) that any person shall have the right to refuse to be issued an SSN in connection with such a program, and such right of refusal shall be available both to the student and to his parents or guardians	*Records, Computers and the Rights of the Citizens* (1973)	

Recommendation	Report	Implemented?
The committee recommends that the U.S. Congress move to enact preemptive legislation that will: • establish a uniform requirement for the assurance of confidentiality and protection of privacy rights for person-identifiable health data and specify a Code of Fair *Health* Information Practices that ensures a proper balance among required disclosures, use of data, and patient privacy; • impose penalties for violations of the act, including civil damages, equitable remedies, and attorney's fees where appropriate; • provide for enforcement by the government and permit private aggrieved parties to sue; • establish that compliance with the act's requirements would be a defense to legal actions based on charges of improper disclosure; and exempt health database organizations from public health reporting laws and compulsory process with respect to person-identifiable health data except for compulsory process initiated by record subjects.	*Health Data in the Information Age* (1994)	
Congress should pass legislation to extend peer review protections to data related to patient safety and quality improvement that are collected and analyzed by health care organizations for internal use of shared with others solely for purposes of improving safety and quality.	*To Err is Human: Building a Safer Health System* (2000)	

Recommendation	Report	Implemented?
The NCVHS recommends that the Secretary of HHS encourage enabling legislation for use and exchange of electronic PRMRI, including: a. comprehensive federal privacy and confidentiality legislation. This would ensure that all health information in any medium, used for any purpose, and disclosed to any entity receives equal privacy protection under law. b. uniform recognition by all states of electronic health record keeping; and national standards for PMRI retention and electronic authentication (digital signatures).	*NCVHS Report to the Secretary on Uniform Standards for Patient Medical Record Information*(2000)	