THE LOSS OF MEDICAL PRIVACY

**Congress’ Instructions To Preserve Patient Privacy Rights Were Reversed by Dept. of HHS Regulations**

1996 Congress passed HIPAA, and instructed the Dept. of Health and Human Services (HHS) to address the rights of patients to privacy.

> “Not later than the date that is 12 months after the date of the enactment of this Act, the Secretary of Health and Human Services shall submit to [Congress]...detailed recommendations on standards with respect to the privacy of individually identifiable health information.”

2001 President Bush implemented the original HIPAA “Privacy Rule” recognizing the “right of consent”.

> “…a covered health care provider must obtain the individual’s consent, in accordance with this section, prior to using or disclosing protected health information to carry out treatment, payment, or health care operations.”

2003 Amendments to the “Privacy Rule” became effective eliminating “right of consent”.

> “The consent provisions...are replaced with a new provision...that provides regulatory permission for covered entities to use and disclose protected health information for treatment, payment, healthcare operations.”
The Health Insurance Portability and Accountability Act of 1996 (HIPAA) became a federal law on August 21, 1996. Through provisions in this law, Congress instructed the Department of Health and Human Services to address the rights of patients to privacy. HHS was directed to develop recommendations that would later become federal regulations.

Congress’ intent regarding medical privacy rights, as expressed in HIPAA:

- “Sec. 264 (a) Recommendations With Respect To Privacy Of Certain Health Information.

  "Not later than the date that is 12 months after the date of the enactment of this Act, the Secretary of Health and Human Services shall submit to [Congress]...detailed recommendations on standards with respect to the privacy of individually identifiable health information."

- “Sec. 264 (b) The recommendations under subsection (a) shall address at least the following:

  (1) The rights that an individual who is a subject of individually identifiable health information should have.
  (2) The procedures that should be established for the exercise of such rights.
  (3) The uses and disclosures of such information that should be authorized or required."

Original Privacy Rule

HHS promulgated “Standards for Privacy of Individually Identifiable Health Information” (i.e., “the Privacy Rule”) 65 Fed. Reg. 82,462. These federal regulations were implemented by President Bush on April 14, 2001.

In keeping with the intent Congress expressed in HIPAA, a federal right of consent was recognized in the Original Privacy Rule:

- Consent Provisions:

  164.506 “Consent for uses or disclosures to carry out treatment, payment, or health care operations.

  (a) Standard: consent requirement. (1) Except as provided in paragraph (a)(2) or (a)(3) of this section, a covered health care provider must obtain the individual’s consent, in accordance with this section, prior to using or disclosing protected health information to carry out treatment, payment, or health care operations.”
Congress’ intent to preserve medical privacy was expressed in the Preamble to the Original Privacy Rule:

- “Privacy is necessary to secure effective, high quality health care. While privacy is one of the key values on which our society is built, it is more than an end in itself. It is also necessary for the effective delivery of health care, both to individuals and to populations.” 65 Fed. Reg. at 82,467

- “Congress has long recognized the need for protection of health information generally, as well as the privacy implications of electronic data interchange and the increased ease of transmitting and sharing individually identifiable health information.” 65 Fed. Reg. at 82,469

- “This growing [public] concern [about the loss of privacy] stems from several trends, including the growing use of interconnected electronic media for business and personal activities, our increasing ability to know our genetic make-up, and, in health care, the increasing complexity of the system.” 65 Fed. Reg. At 82,465

- “…few experiences are as fundamental to liberty and autonomy as maintaining control over when, how, to whom, and where you disclose personal material.” 65 Fed. Reg. at 82,464-65

- “The right to privacy, it seems, is what makes us civilized.” 65 Fed. Reg. at 82,464-65

- “The right to be left alone is “the most comprehensive of rights and the right most valued by civilized men.” Justice Brandeis 1928.

- “Comments from individuals revealed a common belief that, today, people must be asked their permission before each and every release of their health information” 65 Fed. Reg. at 82,472

- Citizens “have strong expectations regarding consent for use and disclosure of health information.” 65 Fed. Reg. At 82,473

Amended Privacy Rule


HHS' stated intent was:

“…to propose changes that maintain strong protections for the privacy of individually identifiable health information while clarifying misinterpretations, addressing the unintended negative effects of the Privacy Rule on health care quality or access to health care, and relieving unintended administrative burden created by the Privacy Rule.”
However, HHS actually reversed the original intent expressed by both Congress and President Bush by eliminating the patient’s right of consent:

“The consent provisions...are replaced with a new provision...that provides regulatory permission for covered entities to use and disclose protected health information for treatment, payment, and health care operations.”
67 Fed. Reg. at 53,211

The Amended Rule eliminated the right of patients to control access to their identifiable health information in most situations, by granting federal “regulatory permission” to over 600,000 “covered entities” and millions of their “business associates” to use and disclose any identifiable health information for “routine” purposes. The definition of “routine” covers almost all conceivable uses of medical records, including uses for “health care operations” which are defined as business uses of interest to the covered entity rather than to the patient.

President Bush Supports Patient Right of Consent

• President Bush, April 27, 2004: “…there’s a lot of people in America who say… I want there to be good information technology in the health care field, I just don’t want somebody looking at my records unless I give them permission to do so. And I fully understand that. And your records are private, if that’s the way you want them to be.”

• President Bush, January 27, 2005: “I think my medical records should be private. I don’t want people prying into them, I don’t want people looking at them, I don’t want people opening them up unless I say it’s fine for you to do so.”

However, the 2003 Amended Rule eliminated patient “permission” when it eliminated “consent”.

Hippocratic Oath

“.....whatsoever I shall see or hear of the lives of men or women which is not fitting to be spoken, I will keep inviolably secret.”
The Amended Privacy Rule's Effects On Medical Privacy Rights

• Federal Court Findings – Citizens for Health v. Leavitt (03-2267 E.D. PA)

Federal District Court Judge Mary McLaughlin: “It is true that providers are permitted by the Rule to seek consent before disclosing [plaintiffs’] health information. They have chosen not to do so…..the Amended Rule has a sufficiently determinative and coercive effect on the action of the providers ….The Amended Rule has changed the landscape established by the Original Rule in which decisions will be made by providers as to whether they will seek consent or agree to patients’ demands for consent.”

• Dept. of Justice position in the Oral Argument, in Citizens for Health v. Leavitt (U.S. Court of Appeals for the Third Circuit, March 9, 2005):

In response to question from the Court regarding whether, under the HIPAA Amended Privacy Rule, patients may refuse to allow their identifiable health information to be used and disclosed: “…the short answer is you never had a right to absolutely prevent information that was necessary for the core functions of the healthcare system to operate from being disclosed to an insurer.” Transcript of oral argument at 21.

“Patients no longer possess a reasonable expectation that their medical histories will remain completely confidential.”

• Dept. of Justices position in 2004 regarding cases seeking to compel disclosure of medical records of women who had received abortions:

Federal law “does not recognize a physician-patient privilege…[patients] "no longer possess a reasonable expectation that their histories will remain completely confidential".