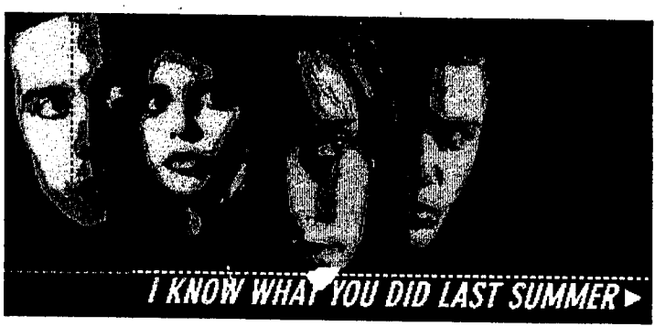
Congress of the United States
Washington, DC 20515



But What Did HHS Do Last Summer?

Weakened Privacy Rule Puts Your Health Information at Risk

September 11, 2002

Dear Colleague:

On August 14, the Department of Health and Human Services weakened vital protections in the medical Privacy Rule, creating dangerous loopholes that expand unauthorized access to the personal health information of millions of Americans. The attached editorial in The Boston Globe ("Patient Privacy," August 18, 2002) provides useful background information on this important issue. The modifications approved by HHS roll back strong privacy safeguards established during the Clinton Administration. Specifically, the HHS modifications:

- **Remove patients' right to consent to the release of their private medical information:** HHS has taken away your right to decide whether your medical information can be shared for health care treatment, payment, and so-called "health care operations," a category including commercial activities such as the sale or merger of an HMO. A patient's right to consent was at the core of the Clinton Administration's privacy rule. The Bush Administration hollowed out this core by removing the consent requirement for a wide range of activities, including a one-time initial consent for re-use of information for business purposes that have nothing to do with treatment of the patient.

- **Allow drug companies broad access to patient information without prior consent:** The Clinton Administration's rule contained a provision that allowed patient information to be disclosed to drug companies without consent for a limited list of public health related activities, such as for the purpose of reporting serious side effects from a prescription drug to the FDA. The Bush Administration replaced this narrow list with a broader exemption that allows nonconsensual disclosure of patient information to drug companies for a wide range of activities, which may include marketing campaigns. This change is especially troubling since once drug companies obtain a patient's medical information, they are not subject to any federal restrictions on using that information for other purposes.

- **Permit marketing schemes that turn your pharmacist into a secret agent for drug companies:** This loophole in the HHS rule allows drug companies to pay your pharmacist or doctor to make new treatment recommendations based on your medical history and send you unsolicited product mailers, without informing you of the fee the drug company has paid to your health care provider.

We are greatly disturbed by the loopholes created by the Department's recent modifications to the Privacy Rule. If you would like to join our efforts to close these harmful loopholes, please contact Mark Bayer with Rep. Markey (5-2836), Kristin Amerling with Rep. Waxman (5-5051), or Karen Folk with Rep. Dingell (6-3400).

Sincerely,

Edward J. Markey
Member of Congress

John D. Dingell
Member of Congress

Henry A. Waxman
Member of Congress

Boston Sunday Globe
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PATIENT PRIVACY

FINDING THE RIGHT balance on privacy of medical records is no easy matter. A policy that is too restrictive interferes with the exchange of information among providers that can be helpful, even life-saving, for patients. A policy of virtually unlimited access to records, especially in the computer age, can keep patients from being candid with their doctors — or from seeking treatment in the first place.

Earlier this month the Bush administration announced the final version of a privacy regulation that offers patients some protection but retreats from an earlier version of the rule drawn up by the Clinton administration. Senator Edward Kennedy and Representative Edward Markey, both critics of the Bush rule, should proceed with plans to strengthen patient privacy in Congress.

Under a health insurance law passed in 1996, Congress was supposed to come up with a privacy regulation by 1999 or cede that responsibility to the administration. Congress was unable to reach a consensus, so the Clinton administration unveiled its privacy regulation in its final weeks in office. The Bush administration quickly announced its intention to modify it.

The Clinton regulation required that health care providers get prior written consent from patients before disclosing a patient's health data. After hearing criticism of this provision from insurers and HMOs in particular, the Bush administration weakened it by requiring only that providers make a "good-faith effort" to get consent.

Medical privacy advocates consider this a huge loophole and say it would have been possible to maintain the basic principle of prior written consent while modifying it to head off inadvertent disclosure problems that could arise, for instance, when a friend tries to pick up a patient's prescription at a pharmacy.

Privacy advocates and members of Congress like Kennedy and Markey also fault the Bush regulation for provisions that would permit use of medical records for certain forms of marketing. While doctors and pharmacists would not be allowed to sell patient data to pharmaceutical companies seeking it for sales purposes, a drug company would be allowed, for instance, to pay a pharmacist to identify customers taking a certain drug and then have the pharmacist write them to persuade them to switch to the drug company's brand.

Massachusetts legislators could solve such problems with the Bush regulation by passing their own law, although a proliferation of conflicting state privacy laws could create chaos among providers and insurers. It would be far preferable for Congress to be alert to problems as they arise and to pass legislation that maintains an equilibrium between privacy rights and a constructive exchange of medical information.