

However, many other third parties did *not* need patients' consent before obtaining their medical records, including:

- FDA (for monitoring drugs and dietary supplements),
- law enforcement,
- researchers (in some instances),
- public health officials,
- federal government, and
- medical licensing boards.

### Bush Administration Eliminates Patient Consent

Some industries were strongly opposed to the consent provision as it appeared in the December 28, 2000 final rule. They lobbied the incoming Bush administration to *eliminate* patient consent.

In March 2002, HHS proposed to modify the rule so that health care insurers, hospitals and others could transfer medical information—*without* patients' consent—to pay claims, treat patients, and do other tasks.

The Bush administration published its final modifications to the federal medical privacy rule on August 14, 2002. The final rule can be found in the U.S. Code of Federal Regulations, see 45 CFR 160 and 45 CFR 164.

Consequently, for the first time in our nation's history, *the federal government is giving the medical industry full authority to decide for individuals whether personal health information can be released to others without individuals' consent.* Individu-

als will *not* get an accounting of when their medical records are disclosed for routine (most) purposes.

What's more, some powerful industry groups support pre-empting state laws regarding medical privacy. Given their past lobbying success, it's likely that state laws soon could be pre-empted by the federal rule.

### What Can You Do to Protect Your Medical Privacy?

The new federal rule applies to *all* citizens, even if you pay privately for health care.

If you want to restore *true* medical privacy and control who has access to your personal health and genetic information, you can: (1) get Congress to eliminate HHS's authority to decide for you who can access your medical records, (2) get Congress to repeal the Administrative Simplification provision of the HIPAA law, and/or (3) work with your state legislators and governor to make sure stronger state medical privacy laws are not pre-empted by the new federal rule.

*It's your personal health information and you should be the one to decide who has access to it. Big Brother and Big Business should not decide for you!*

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## What Every American Needs to Know about Medical Privacy

Did you know that under a new so-called federal "medical privacy" rule (effective October 15, 2002), your personal health information—including your **past medical records** and genetic information—can be disclosed to large organizations such as the following *without your consent*?

- Data-processing companies
- Insurers
- Researchers (in some instances)
- Hospitals
- Doctors (even those not treating you)
- Law enforcement officials
- Public health officials
- Federal government

That's right. Under the new federal rule (which will become fully effective on April 14, 2003 for most organizations), all of the above will be able to access your personal health and genetic information *without* your permission.

*How did this federal rule come about? Who was behind it and lobbied for it? What can you do to protect your medical privacy? Read on....*

## Why a New, Weak Federal Medical Privacy Rule?

Until recently, health privacy was considered a matter regulated by the states. Every state has some type of law to protect citizens' medical records. However, abiding by 50 different state privacy laws has proved difficult for the industries that want to create a national health information system.

Thus, leaders of medical, hospital, insurance, and other industries have been working for over a decade to nationalize standards for electronic medical records.

## Who was Behind the National Electronic Health Information System?

In 1991, the Workgroup for Electronic Data Interchange (WEDI) was established to foster the development of national electronic medical codes and electronic payment systems. WEDI succeeded in getting many of its goals incorporated into the Clinton health care plan. President Clinton's 1993 Health Security Plan included a provision titled "**Administrative Simplification.**"

That section of the plan called for establishing a national health information infrastructure. It required that unique identifiers be assigned to four groups for processing medical claims electronically, including every: (1) individual, (2) employer, (3) health insurer, and (4) health care provider. It also called for creating national codes for medical claims and for new, *federal* medical

privacy rules. The bottom line is that you can't create a national health care system without standardized information.

## HIPAA Law Includes Mandatory Unique Health Identifiers

The American people clearly rejected the Clinton plan to nationalize health care. However, the Administrative Simplification provision was tucked away in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which was signed into law on August 21, 1996 (Public Law 104-191).

Under the HIPAA law, the following four groups are required to have unique identifiers for tracking medical records and electronic claims processing, including every:

- individual,
- employer,
- health insurer, and
- health care provider.

## Unique Health Identifiers Put on Hold—but *Only* Temporarily

Due to public outcry, federal funding for assigning every individual a unique health identifier has been put on hold *temporarily* over the past few years.

But unless the Administrative Simplification provision of the HIPAA law is repealed, all Americans may soon be assigned a number for tracking their medical information from cradle to grave.

Also, aware that the American people were concerned about medical privacy, legislators included a provision in HIPAA requiring that a medical privacy law be passed by August 21, 1999, or the secretary of the U.S. Department of Health and Human Services (HHS) would have to draft such a rule.

Congress missed its self-imposed deadline, and the authority to establish federal regulations for medical privacy shifted to HHS under the Clinton administration.

## Clinton Administration Drafts a Federal "Medical Privacy" Rule

In November 1999, the Clinton administration proposed federal regulations relating to medical privacy. It proposed *prohibiting* doctors, hospitals, and others from obtaining *patients' consent* before releasing their medical information.

However, the public spoke out against the proposed rule. HHS received more than 52,000 comments during the public comment period. The issue most discussed was patient control of personal health information.

A final federal medical privacy rule was released on December 28, 2000, just before President Clinton's departure. It required that individuals give their consent before medical records could be used for health care treatment, payment, or "health care operations"—a broad term encompassing many activities.

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