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RULES LET MARKETERS SEE PATIENT DATA CAMPAIGN AFOOT TO GIVE PATIENTS RIGHT TO BLOCK RELEASE OF FILES

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In an emergency, the hospital can't tell anyone except family that you're a patient. But it's free to use intimate medical details to forward marketing pitches to you from drug companies, insurers, and other "business associates."

That's a crack in the privacy wall established Monday, when new federal rules for health providers took effect, specialists said yesterday. They promise to try to block marketers' indirect access to patients and to reinstate a patient's right to withhold consent for the commercial use of health data by providers and their associates.

When Sally Scofield had knee surgery in January 2002 in Joliet, Ill., she had no idea a document-copying company would see her medical history. After the surgery, Scofield asked the hospital for a copy of her medical file. Instead, she received a letter from the copying company requesting a \$20 fee and a 75-cent charge per page.

"I thought when I talked to the doctor, it was just between me and him," said Scofield, 49. "I did not know a photocopy clerk could get it. The company had my Social Security number, my age, weight, and height, my credit card information - enough to steal my identity." Scofield is one of 11 individuals and organizations who sued April 11 in US District Court in Philadelphia. They are asking the court to strike portions of the federal rules that permit healthcare providers to sell indirect marketing access to their patients without the patients' consent.

US Representative Edward J. Markey, a Massachusetts Democrat, has filed a bill that would require consent.

"In the law that is now in effect, a drug company could pay a pharmacy to identify customers who are taking particular medications, and then those customers would start receiving recommendations that they switch brands - without any information about that drug company's financial ties to the pharmacy," Markey said.

The regulation drafted by the Clinton administration in 2001 would have allowed patients to decide who could see their records. In August 2002, the Bush administration revised the draft to eliminate the patient's ability to withhold consent. Under the rule that took effect Monday, a patient cannot stop a healthcare provider from sharing medical data. The revision also eliminated consent for sharing of medical files with insurers and billing companies.

On April 10, US Representative Ron Paul, a Republican and physician from Texas, filed a bill that would repeal the rule, as well as a section of the Health Insurance Portability and Accountability Act of 1996 that allows the federal government to form a medical data bank with government funds.

Bill Pierce, a spokesman for the US Department of Health and Human Services, said the criticism is overblown. "The final rule required consent on every single transaction," he said. "If you did not go into the doctor's office and sign

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the consent form, you could not get healthcare. You would have to go to the pharmacy and sign the form before the pharmacist could fill the prescription. That directly interfered with people getting healthcare."

He said the new privacy rule is the first to bar employers and institutions outside the health sector from acquiring personal medical data. For those organizations, consent is required.

Pierce also said that, conceivably, a manufacturer could pay a physician or a pharmacy to send letters to patients about a particular drug, but only the healthcare provider would have access to names and addresses.

Dr. Richard Sobel, an adviser to the plaintiffs in the federal suit, is still worried. "HHS is correct in saying that it is likely that a drug company would pay a pharmacy to market its product," he said. "But whether it will work like that is another question."

Sobel, a senior research associate at the Harvard Program in Psychiatry and the Law, said the sharing of information with business associates, even though the associate is bound to confidentiality, might lead to names leaking out. Diane E. Lewis can be reached at dlewis@globe.com.

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