Who Controls Your Medical Records?

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We had hoped that the 106th Congress would address the health care and HMO issue by giving more power to patients. Instead, the House Subcommittee on Courts and Intellectual Property has scheduled a hearing this week on a bill to lay the groundwork for corporations to control, manipulate, and market our most intimate medical records.

Quietly introduced as H.R. 354, the Collections of Information Antipiracy Act, this dangerous legislation would grant a new federal right to corporations that build databases of patients' medical records. It would protect the corporations' control of these databases by threatening to prosecute anyone who interferes with this new right.

These new federal crimes carry penalties of a $250,000 fine and five years in jail for the first infringement, and twice that for the second. H.R. 354 would subject the mere copying of a part of a corporation's database to the jurisdiction of federal judges with the power to seize assets without a finding of guilt, and impose huge fines and prison sentences.

This certainly wasn't what we had in mind when we heard politicians talk about "health care reform" or a "patient protection act." H.R. 354 is the product of behind-the-scenes dealmaking between a handful of powerful corporations and politicians.

The primary push for this bill comes from the American Medical Association (AMA), which is trying to get Congress to do a sidestep around a court decision the AMA lost in 1997 (Practice Management Info. Corp. v. AMA). At issue in that case was whether the AMA could control and charge fees for the sale of materials containing the Medicare codes that all health providers are required to use.

The marketing of databases is a very profitable part of the AMA's annual $230 million budget, since only a fourth of physicians are full dues-paying members and they provide less than a third of the AMA's revenue. In addition to its database of Medicare codes, the AMA has a database of all doctors, both

members and nonmembers, stored with all sorts of personal and professional information.

Six months after the court held that the AMA had "misused" its rights in the Medicare code database, the AMA turned its powerful lobbying apparatus on Congress to arrange a legislative fix. The AMA testified that the purpose of this bill is "to protect collections of information, including databases such as ours," and then followed up with well-timed PAC contributions.

But Congress should not make "collections of information" a new federal right enforced by the police and judicial power of the federal government! The Supreme Court correctly ruled in Feist v. Rural Telephone Service (1991) that, under the U.S. Constitution, copyright protection is granted only to authors who create new works, not to corporations that merely collect data, and the phone companies do not own their listings of phone numbers just because they spent money collecting them.

H.R. 354 is deviously designed to finesse the Feist decision by creating a new federal right called "collections of information," and by giving a special exclusion to telephone listings (as well as for stock quotes and the news media), but not for medical records. The AMA testimony makes clear that the Collections of Information bill will create new rights not constitutionally available under copyright laws.

The Collections of Information bill failed to pass the Senate last year and, when the sponsor, Rep. Howard Coble (R-NC), reintroduced it as H.R. 354, he said that medical information is one of the focuses of the bill and that its purpose is to get around "recent cases." His subcommittee rejected attempts to exempt medical records from the sweeping new powers created by the bill.

Databases of personal information are a tremendous financial asset because they can be used for so many commercial purposes such as targeted marketing and health insurance underwriting. Since the health care database market is growing by a billion dollars a year, corporations already have ample incentives to build databases and make big money off of them, and they don't need Congress to legislate any new incentives.

Ambiguous language in H.R. 354 preempts state laws that currently ensure legitimate access by patients and physicians to their medical records. HMOs would be able to deny access, impose delays, or charge huge fees before providing essential medical records to patients or their physicians.

Most states have laws that guarantee patients the right to access their own medical records, but H.R. 354 would preempt these even though it exempts certain other state laws. H.R. 354 purports to exempt state privacy laws, but that exemption would be overridden by another bill expected to pass, the Patient

Protection Act, H.R. 448.

By giving all these new rights in companies that build databases, H.R. 354 will make it difficult, expensive or impossible for individual Americans to access or restrict usage of their own personal information. We don't want the federal government to create new federal rights or incentives to encourage corporations to collect, manipulate, control, or market databases of medical records.