Privacy Parsed

A national medical ID poses severe threats to HIV confidentiality

November 1, 1998 By Doug Ireland

Big Brother is about to destroy your medical privacy. That's the likely effect of a federal plan to assign every American a national medical ID number. The establishment of what's known in bureaucratic language as a "unique health identifier" was mandated by an obscure Republican amendment to the Kennedy-Kassebaum portable health insurance law passed by Congress (and signed by President Clinton) in 1996, requiring the Department of Health and Human Services (HHS) to come up with such a plan by the spring of 1999.

The creation of this gigantic database containing every bit of medical information on every American from the cradle to the grave ought to terrify anyone with HIV, since the potential for abuse of these records is enormous. With teenage hackers already breaking into the Pentagon's most secret computer files, it should be obvious that the confidentiality of the medical database will be almost impossible to protect—especially since Congress has failed to pass a meaningful medical-privacy law punishing disclosure of such information without your consent.

Privacy experts say that once this information is centralized, it can be accessed easily by individuals or organizations with basic technological ability. Employers could use the computer files to deny you a job or a promotion, insurance companies to refuse you insurance or raise your rates. Many PWAs are already paying for prescriptions on their own so as not to leave a paper trail—thereby preventing their insurers from knowing what drugs they're taking. But your national medical ID would be required to obtain or fill a prescription, which means that the government would know about every single pill you're popping, from Prozac to protease inhibitors.

It gets worse. As information-policy consultant Robert M. Gellman—one of the 17-member committee advising the HHS on how to set up the database—has pointed out, "Once everyone's required to use a government-issued health identification card, it may become impossible for any American citizen to walk down the street without being forced to produce that card on demand by a policeman. You won't be able to use a credit card, cash a check, fly on an airplane, check into a hotel, go to school or enter or leave the United States without showing that card." In other words, it'll be a scarlet letter on the breast of anyone with HIV—one which, if religious-right proposals to criminalize HIV transmission ever became law, could land some of you in jail.

The Clinton administration was moving full speed ahead to implement the plan until August, when

it announced a temporary delay. It would be nice to think that Bill has become more protective of people's privacy in recent months, but this administration has a dreadful record on such issues—among other jolly ideas it has put forward is a computer chip that would allow the government to tap into your e-mail without a court order.

No, the real reason for the delay is the cleverness of Vermont's liberal Democratic senator, Patrick Leahy. Leahy may be an uncharismatic mumbler, but he's one of our more intelligent solons and a ferocious defender of privacy rights. Author of a bill to repeal the requirement for a national medical ID, Leahy smartly rounded up some of the Senate's most conservative members to cosponsor it. Now known as the Leahy-Ashcroft bill (that's John Ashcroft of Missouri, a Christian Coalition poster boy), it seems quite likely to pass the Senate this winter. (A similar measure has been introduced in the House by Oregon Democrat Peter DeFazio.) Leahy-Ashcroft is what forced the administration to take a half step back.

Leahy rightly believes that Congress got it backward—rigorous medical privacy protections should be legislated *before*, not after, the creation of the national medical ID. There are a half dozen bills in the House and Senate on medical privacy, all of them bad. Most contain exemptions—for communicable diseases like HIV, mental health patients or minors—or blanket pre-emptions of existing state medical privacy laws. In some states—including California, New York and Massachusetts—those laws are stronger than the proposed federal legislation that would supersede them. Yet the lobby for a national medical ID is a powerful and greedy one—health insurers, HMOs, hospitals and existing medical database companies would save a fortune through more efficient billing and marketing procedures.

Time is running out. Write your reps in Congress today urging passage of the Leahy–Ashcroft and DeFazio bills. Otherwise you can expect the electronic equivalent of a knock on your door.

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