

# On Medical-Privacy Issue, the Doctor Finally May Be In

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WASHINGTON—Congress is starting to get serious about one of the most neglected items on its agenda: enacting the first national law to protect the privacy of medical records.

Didn't I know there wasn't one? That is a leading reason the effort has spluttered for so long. Congress has been at the job for 28 years, and countless hearings, and at least 10 bills have come and gone since the mid-1990s. There was even a deadline—tomorrow—which lawmakers obviously will miss.

That means it will fall to the Department of Health and Human Services, beginning in February, to regulate the disclosure of electronic medical records, a small portion of the total information pool. Almost everyone, HHS Secretary Donna Shalala included, prefers comprehensive legislation as the best way in the new information age to contain the possible abuse and misuse of what can be the most sensitive details of a person's life.

So the department will go forward, according to a spokeswoman, but not so quickly as to pre-empt Congress if it takes action this fall. That turns up the heat on Capitol Hill. In a 1996 law, Congress set a goal of Aug. 21, 1999, for enacting medical-record privacy protections. Now, it calls the missed deadline a "tripwire," and support is galvanizing around a Senate bill and two efforts in the House.

Medical privacy is difficult terrain for federal lawmakers. They must navigate around a patchwork of popular state laws, many of them targeted to specific conditions such as HIV and genetic disorders. They are also bumping against two perennial controversies: abortion and liability (as in access to juvenile abortion records, and a patient's right to sue). And to cap it off, political pressure to prompt them into action so far has been low.

**Study of Fears**  
 Powerful consumer and health-care groups have called for national protections, but they are fighting bigger battles such as Internet privacy and managed-care reform. A single organization is solely devoted to the cause, the Health Privacy Project at Georgetown University. And as director Janet Goldman puts it, "How many doors can you bang on when you've got a couple of staff people?"

## Who Knows What About Your Medical History?

### INSURANCE COMPANIES:

If you've claimed it, they know it, from all laboratory tests you've taken to the number of times your kid has gotten stitches.

### BIG GOVERNMENT:

Requires medical records to verify claims made through Medicare, Medicaid, Social Security disability workers' compensation and state benefit programs.

### RESEARCHERS:

Doctors, hospitals and other organizations often operate data for scientific purposes, but they're not supposed to release names.

Source: Privacy Rights Campaign, San Diego

### MEDICAL INFORMATION BUREAU:

Hundreds of insurance firms use this database of 15 million Americans and Canadians to obtain information about applicants for life insurance and individual health insurance policies.

### EMPLOYERS:

If they provide insurance, they can receive copies of your claims or medical records.

### DIRECT MARKETERS:

Information can be used for marketing purposes when you participate in informal health screenings, such as for cholesterol or blood pressure at your local drugstore.

come a breeze to disseminate and hugely valuable to scientists, insurance companies, marketing concerns—even employers and creditors.

It is one thing for researchers to cull genetic information to cure breast cancer. But studies show that most people draw the line when pharmacies sell prescription records to drug marketers, bosses peruse results of fertility treatments, or a hospital accidentally posts thousands of patients' records on the Internet. All three cases were reported recently, and privacy experts say they are typical, except for one feature: Most abuses don't become publically known.

"The problem is people don't realize when their privacy is being violated," says Ari Schwartz, a policy analyst for the Center for Democracy and Technology, a Washington civil liberties group. "They feel strongly about the issue, but they won't speak up until something happens to them. For most people it's a vague concern. That makes it difficult to galvanize them."

On Capitol Hill, the Senate health committee is believed to be closest to producing a comprehensive bill with bipartisan support. The effort is headed by Sen. Jim Jeffords, the Vermont Republican who chairs the committee, and Sen. Christopher Dodd, a Connecticut Democrat. The two would carry on the committee are Sen. Sam Brownback, an anti-abortion Kansas Republican, and Democratic Sen. Ted Kennedy of Massachusetts, the committee's health-care activist whose support would give the bill instant cachet.

In the house, two efforts have emerged as front-runners, one backed by Rep. Bill Thomas (R-Calif.), who heads the Ways and Means health subcommittee, and the other by a group of Democrats that includes Reps. Henry Waxman and Gary Condit of California and John Dingell of Michigan. Mr. Thomas's staff has worked over the congressional recess to rally Democratic support, so a bill can be introduced once Congress reconvenes after Labor Day.

Meanwhile, HHS is proceeding with regulations to cover electronic records, which privacy advocates expect to function as a de facto standard for printed ones. That is unless Congress gets its act together. Ms. Goldman and others, though, say they will believe that when they see it. "There have been lots of bills and lots of hearings, where everyone pounds the podium and says 'Yes, we're going to have legislation,'" she says. "And then nothing. It just goes away."

will be easier to work through delicate issues like juvenile rights and produce a really good bill."

A promising sign for Ms. Goldman's camp is that despite the chaos and foot-dragging, the bills to emerge in recent months do adhere to a single framework. They grant that people should have access to their own records, that limits must be placed on the use and disclosure of information, that police access should be restricted, and that violations should be penalized. In the Senate in particular, several early obstacles have been overcome, including how often patients must sign waivers to release information.

But big controversies do remain. These include access to juvenile abortion records, whether patients will have the right to sue, and how the federal law will mesh with existing state statutes.

### A Breeze to Disseminate

Patients generally assume that their most embarrassing or devastating health problems are safe in a color-coded file. But the reality is, every note that doctors scribble or prescription they write may pass through dozens of hands and be typed into multiple computer databases. With the dizzying advances in communications technology, medical information has be-

But the oddest feature may be the contrast between fears ordinary Americans claim to have about medical privacy, and their failure to communicate that to Washington. Ms. Goldman cites a recent study for the California HealthCare Foundation showing just a third of U.S. adults trust health plans to maintain confidentiality. The study also found one of six people are so worried about leaks that they lie or ask their doctors to lie, or go to different doctors, or don't seek treatment at all, especially for sensitive conditions such as mental illness and communicable diseases.

Yet medical privacy is not a hot-button political issue, and few lawmakers bear from their constituents seeking protection for their medical records. Apparently, that is because an overwhelming majority of Americans presume there is already a law on the books to protect them.

"The lack of an outside force makes this a really difficult issue," says Joe Karplinski, spokesman for the Senate committee working on a privacy bill for action this fall. "No one says, 'When are you going to pass this?' No presidential candidates talk about it. Even the professional groups haven't really gotten engaged."

On the other hand, he says, "Perhaps if there isn't a visible political investment, it

*Health Care -  
 Medical Privacy*

# Bush's Answers On Drug Use Create Turmoil

By JOHN HARWOOD

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WASHINGTON—Texas Gov. George W. Bush's shifting answers to questions about possible drug use have generated the first significant turbulence for his high-flying GOP presidential campaign.

After refusing for months to respond to questions about drugs, Mr. Bush told a Texas newspaper that he hasn't used illegal drugs in the past seven years, as is asked on one background-check form that top White House officials must fill out. On a campaign swing yesterday, he extended his denial to a much longer period, volunteering that he "could have passed" a background check inquiring about drug use in the prior 15 years at the time his father became president in 1959.

But he and his aides wouldn't address whether he had used illegal drugs before 1974, when he was 28 years old. And by abandoning his earlier refusal to discuss specifics, the first-time national candidate stoked a brushfire of media attention that cheered his GOP rivals and undercut any momentum from his victory in last weekend's straw poll of Iowa Republicans.

"It's not helpful," said GOP pollster Whit Ayres, who isn't aligned with any candidate. He argued that the public's "nuanced view about personal behavior" would have allowed Mr. Bush to sustain his earlier silence without suffering political damage.

The controversy is all the more troublesome for Mr. Bush for two reasons. A centerpiece of his campaign is his call for a "responsibility era," and the contrast he

draws on issues of morality with the scandal-plagued Clinton administration. Moreover, the matter has burst into public view, from newspaper headlines to late-night TV talk-show jokes, just as he is becoming better known as something more than simply the son of the former president.

Mr. Bush and his aides have accused political opponents of fueling the controversy by circulating rumors of possible drug use. But some rivals insist it's Mr. Bush's own selective handling of personal-morality questions—he has categorically denied marital infidelity, for instance—that has put him in an untenable position.

"Why would you be so emphatic about marital infidelity . . . and be so reticent and so evasive about this?" asked Tony Fabrizio, Elizabeth Dole's campaign strategist. "If he continues this dance, he runs the risk of being labeled Clintonesque."

"Candor and honesty would probably be his best call," asserted Bill Dal Col, campaign strategist for Steve Forbes, adding that Mr. Bush has "created a perception of lack of maturity."

Drug-use questions have dogged baby-boom politicians for more than a decade. President Clinton and Vice President Al Gore, among others, have acknowledged having experimented with marijuana without sustaining significant political damage. The question of possible cocaine use represents uncharted waters; all major 2000 candidates except Mr. Bush—who concedes past "mistakes" but says he won't play the "gotcha game" on particular allegations—have denied ever using it.

Conservative publisher William Kristol observed that Mr. Bush has now placed himself "on a slippery slope" on the drug question. But Mr. Bush insisted his latest remarks have drawn a line.

"I've told the American people all I'm going to tell them," he said yesterday. "If they don't like it, they can go find somebody else to vote for."