Patient Privacy Hinders Research, Rules on Health Care Data Need Revising

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The federal rules created to protect your medical information have made it more difficult for universities and institutions to perform medical research, according to a report released yesterday.

The Health Insurance Portability and Accountability Act, or HIPAA, was designed, in part, to keep patient information confidential while allowing researchers to use this data to develop medical treatments and cures.

The report, released yesterday by the Institute of Medicine of the National Academies, said a number of problems create research roadblocks.

These problems include long, confusing consent forms patients must sign for medical studies, and patient fears that their personal health information somehow will be made public.

"The rule has made it more difficult for researchers to enroll patients in research studies," said Dr. Bernard Lo, professor of medicine at the University of California, San Francisco and the report's co-author.

"The rule has increased costs and times to conduct research and led researchers to abandon research."

The rule put a 25-year study on heart attacks and cholesterol-lowering drugs at the University of Minnesota on hold.

The Minnesota study depended on access to 40,000 patient records. After HIPAA was enacted, researchers were not able to get a waiver to continue and stopped seeking grant money.

Before the privacy rule went in effect in 2003, the University of Michigan was able to get 96 percent of its acute coronary syndrome patients to participate in a follow-up phone survey for a registry.

After HIPAA and its requirement for written consent, 34 percent of patients participated during a six-month period in 2005.

As far as security is concerned, patients have good reason to be hesitant.

The report cited 10 times in two years where patients' health information -- including data collected for research -- was lost, stolen or hacked.

In 2005, the Ohio State University Medical Center posted information about 2,800 patients on the Internet.

"The view now is that HIPAA was an imperfect solution," said Marc Boutin, executive vice president of the National Health Council, a nonprofit group in Washington, D.C.

The report calls on Congress to make consent forms simpler and to create either a new rule or strengthen HIPAA to ensure security.

The report said encryption software should be used in all portable computer equipment that researchers use to store patient information.