EDITORIAL

Abbott and Costello Meet Frankenstein: 
Dueling Medical Privacy Horror Stories

BY HAROLD ALAN PINCUS, MD

A jumble of scientific, ethical, technological, political, clinical, and legal issues have crashed together in what may be the hottest controversy of the new millennium: privacy of medical records. Newsweek asks, "Naked Before the World: Will Your Medical Records Be Safe...?"

Horror stories abound regarding the actual (or potential) invasion of privacy: You’ve probably heard these already:
✦ Computer hackers break into an academic medical center’s computers and download patients’ files;
✦ Individuals with certain genetic risks may be excluded from health or life insurance plans because someone learned and amassed information about their conditions;
✦ Marketers directly contact patients by accessing pharmacy databases, so, a patient being treated for an STD will receive calls from telemarketers about purchasing condoms or other medicines. (This was reported in the Washington Post.)

Options, Options, and More Options?
What should be done?
The public demands that something be done.

Congress demands that something be done.
The Clinton Administration responds with several rounds of proposed Health Insurance Portability and Accountability Act (HIPAA) regulations.

Then, the Bush administration puts things on hold to further "review" these regulations.

Most recently, Secretary of HHS Tommy Thompson announces approval of the regulations, but states that the department will prepare "guidelines" that will elaborate further on potentially confusing aspects of the regulations.

USA Today editors — along with defenders of these regulations, many of whom work for consultant firms that can make millions providing advice to health care organizations on how to implement them — insist that another type of "horror stories" are being promulgated by opponents of the HIPAA regulations.

✦ Under the proposed regulations, family members would be unable to pick up prescription medicines for their sick relatives; and
✦ Doctors’ offices may not be able to send out reminder notices for preventive health care, such as immunizations and cancer or other screenings.

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Complex Rules, No Simple Answers

Clearly, we have competing "goods" at the heart of this controversy: personal privacy and the ability to effectively and efficiently conduct quality medical care and needed research. These laudable goals partially overlap and partially conflict. The fact is: rules such as the proposed HIPAA regulation are enormously complex and expensive to implement. Good clinical care requires that doctors know as much as possible — longitudinally — about a patient's care and assessments.

Society has reaped enormous benefit from its investment in medical research. The archive of clinical information in medical charts and other population-based records is an irreplaceable component in generating these scientific benefits and helping us understand patterns and mechanism of disease. Increasingly, such information is essential to address key health policy questions and conduct studies to improve the quality of health care.

We also must realize that no set of rules works 100% of the time, and attempting to legislate perfection will, ultimately, be unsuccessful. Much of the horror and mischief in the misuse of medical records and the invasion of privacy have been wrought by individuals with specific malintent or by attempts to "beat the system." Such purposeful effort is impossible to regulate, but should be severely punished. Furthermore, attempting to deal with privacy concerns through heavy-handed regulation is likely to be a losing battle — the incredible and continuing advances in technology simply create too many battlefronts too fast.

Horror stories of privacy invasion are popping up all over, well beyond the area of health care, from hotels installing tiny cameras in guest rooms (as reported in National Geographic Traveler) to busboys fooling around with the financial holdings of the wealthiest citizens, prompting the New York Times headline: "Paranoid Lately? You May Have Reason!"

No matter how well intentioned, the layer on layer of regulation is creating a mind-boggling complexity. When things already are too complicated, it is better to return to basic principles.*

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LETTERS TO THE EDITOR POLICY

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