

The Right to Know vs. the Right to Privacy

“Data is not information, information is not knowledge, knowledge is not understanding, understanding is not wisdom.”

Cliff Stoll & Gary Schubert

THERE'S BEEN A GREAT DEAL IN THE NEWS LATELY REGARDING PRIVACY ISSUES. Internet services have been criticized for selling personal information about their clients. Lawsuits are being brought against banks for allegedly disclosing financial data without proper authorization. Consumers have complained about doctors sharing their health information with drug companies, among others.

A major part of this debate involves federal government regulations dealing with the privacy of health information. The new rules, which were finalized in the closing days of the Clinton administration, cover “individually identifiable health information” held or disclosed by health plans, medical providers, and data clearinghouses. The secretary of the Department of Health and Human Services, Tommy Thompson, has indicated his agency will examine the rules and may change some of the provisions, although he was unwilling to push back the start date of the regulations.

It's understandable why the privacy of medical information is so controversial. People tend to be very protective about their health and the health of their family members. Someone getting treatment for AIDS or depression might not be willing to get help if they thought their medical condition would become public knowledge.

One problem is that it's often hard to accurately define what health information is. Other key issues are who should get access to your medical records and how that information can be used.

For example, let's say you have a chronic but treatable health condition. Should your employer know about the problem in order to make necessary changes to your workplace so you can do your job? Should this information be shared with your health plan's pharmacy benefit manager so the manager can recommend generic drug therapies that will treat your condition at

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a reduced cost? Does your company's workers' compensation insurer have the right to access your medical files if you file a claim involving your health condition?

What right do you have to access your medical file and correct what you believe is inaccurate information? Is doctor-patient confidentiality always waived in the case of minor children? How many people in the doctor's office, hospital, or health plan need to know about your health status in order to do their jobs? How much should we spend to deal with this issue? Are these expenditures justified, or is there an easier (and cheaper) way to protect people's health information?

At the heart of the debate over privacy is the question of who owns the information about a person's health. When does “my” case of the flu become public information? When I go to the doctor? When I file a claim with my health plan? Do I get to say who has the right to see my personal health data? Should my consent to outside access to my medical records be wide open, or do you need to ask me on a case-by-case basis?

It's a complex issue. The federal government received over 5,300 public comments on the proposed

health information rules. It's also probably why the new regulations take up more than 1,400 pages of print. Regardless of how you feel about the issue of personal privacy or the social and economic costs involved, it's clear that the actuarial profession needs to be involved in the debate.

Insurers and actuaries depend on comprehensive and accurate information in order to do their jobs. Health benefits are designed and priced with an understanding of the health status and utilization patterns of plan participants. Life insurers use mortality predictions to set rates and establish reserves. Personal injury claims under property and casualty policies are evaluated based on the injured party's medical records.

In fact, a number of the professional standards of practice refer to the actuary's responsibility to use the right kinds of information in the development of work products. Actuarial Standard of Practice No. 23, on "data quality," notes that users of actuarial reports "expect that actuaries

will seek and use appropriate data in their work, and that actuaries will make disclosures in the actuarial communications of any material imperfections in the underlying data"

If actuaries can't access the data they need, they won't be able to do their jobs. The cost estimates for health care providers and insurers to comply with the new federal regulations range from \$17 billion to \$22.5 billion. If our record-keeping systems become too complex or expensive to maintain, the delivery of health care may be compromised. If we need to get someone's permission every time a doctor or insurer wants to know his or her personal health information, it will considerably slow the treatment of medical conditions and payment of health claims.

Actuaries need to do a better job of explaining to policy-makers how they use data and why timely access to personal records, such as medical information, is important. The profession also must emphasize actuaries' obligation to respect the

confidentiality of such information. One of the reasons this issue of privacy is such a hot topic is that there have been instances of intentional or negligent release of private health information to the public. (Thankfully, these cases have not involved actuaries.)

The Academy has made some effort to respond to this issue. The Health Practice Council provided comments on the federal privacy regulation and will continue to monitor how the new rules are implemented. Other groups will be looking at congressional and regulatory proposals to control the use of personal data by financial services companies.

More than most, the actuarial profession understands that we live in an information age. Questions about privacy and the use of personal data are going to proliferate. All of us will be struggling to find the appropriate dividing line between private and public information.

It's up to actuaries to help establish those boundaries. ●