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PRIVACY AT RISK. WHOSE? YOURS!

Your internist says you have high blood pressure. That information becomes part of your permanent record. A police officer gives you a speeding citation. Another entry. Academic achievements, credit ratings, armed service records, IRS returns, a refund to a dental patient. It's all on your ever-expanding personal ledger.

Such records present few problems if they remain under your control. Unfortunately, the massive storage capacities of computers have made it virtually impossible for the average citizen to keep track of who knows what about his or her past. Unable to determine or control who might access or use such personal records, many Americans are seriously concerned about invasions of privacy.

Consider the ramifications of being told you have high blood pressure. Life and disability insurers are interested in that information. They may want to extract higher premiums from you on future insurance applications. Even if the condition is being controlled successfully, you must respond in the affirmative to their question, "Have you ever been treated for hypertension?" And once you have answered yes, your response is shared with the entire insurance industry.

Such things happen in other industries as well. What you consider private becomes another routine entry in a growing dossier on you. Those troubled by this continual infringement on privacy seek protections that would give them access to their personal records but restrict public access. Their one major success—the Open Records Act—allows them to see what's inside their file. But

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the act doesn't prohibit others from seeing as well and from using the information.

This may change soon, spurred by grave concerns about those involved in genetic testing. It appears that genetic discoveries with the potential to predict diseases—some untreatable and eventually fatal—have caused the medical, legal and ethical communities to look for ways to protect those whose genetic makeup has been revealed.

The recent discovery of breast-cancer-related mutations in the BRCA1 and BRCA2 genes illustrates the need for immediate action. Women with these genetic mutations have a lifetime risk of breast cancer that approaches 85 percent.

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The most beneficial outcome of genetic testing would be preventive treatment for those with a genetic predisposition to breast cancer. But oncologists can't offer definitive treatments. It isn't even clear from the literature that "preventive mastectomies" are effective.

Knowing your genetic make-up in this case could be a problem. What you know can hurt you. A negative test, for example, might be falsely interpreted as a lifetime guarantee against breast cancer. It isn't. A positive test, without the promise of successful treatment, would lead to further concern and heightened emotional distress. For those who test positive, still more harm could come if the results are communicated to their employers, their health insurers or even to their family members.

Once insurers get the test results, higher premiums or denied coverage could be expected. Employers, wishing to minimize their financial risk, could compound the problem by choosing not to hire—or to dismiss—workers with positive test results.

Family complications are another possibility. Who, for example, speaks for the 8-year-old girl whose BRCA1-positive mother wants her daughter tested for the mutant gene? The mother's rationale: if the test is positive,

removing the child's breast buds could prolong her life.

Does a parent have the right to invade a child's privacy before the child has the knowledge and experience to make her own judgments? Does a child have the right of privacy, even if exercising that right may harm her in the future? There are no easy answers.

As a health professional, chances are that you will be drawn eventually into a confrontation that pits genetic testing against personal privacy. Would you, for example, hire a receptionist who has reported to you that she has the BRCA1 mutation? If your answer is yes, you risk increased health and disability insurance premiums for your entire office. Failing to hire, on the other hand, might make you the target of a lawsuit for discriminating on the basis of an applicant's predisposition to a disease.

At least 12 states have been sufficiently concerned about the right to genetic privacy to pass laws declaring that "genetic information is the unique property of the individual ... and that the intent of the statute is to prevent information derived from genetic testing from being used to deny access to health care insurance, group disability or long-term care insurance."¹

National legislation, similar in design, was introduced last spring. It failed to receive Senate attention before the session ended but is likely to be reintroduced during the next term.

Genetic discoveries continue at an accelerated pace. Within a few years, science will have mapped and sequenced the entire complement of human genes. And in the not-too-distant future, you may be asked whether you want to know about your DNA.

At a recent conference on genetic testing, a group of ethicists, health care providers and lawyers were asked to respond to this statement: "I would want to know about my DNA, but it should not become part of a central repository." Their answers: 27 yes, eight no.

There is a genetic test that can identify a very rare form of Alzheimer's disease, a form that accounts for about 1 percent of all existing cases. If your family has a history of Alzheimer's, would you want to be administered this test? And if you tested positive, would you want anyone besides yourself to know the results?

Whose privacy is at risk?
Yours is. ■

1. Colorado Senate Bill 94-058, Concerning Limitations on Genetic Testing; signed June 2, 1994, Gov. Roy Romer.

LETTERS

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THANKS

I have no profound or clever observations regarding the written contents of the JADA. I just wanted to say: Thank you, thank you, thank you! to whoever has been responsible for fixing the JADA continuing education answer sheet and envelope