

Should life insurance firms have access to your genetic test results?

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So you're thinking you might like to check out one of those inexpensive new tests that would give you some insight into, say, the health implications of your ethnic heritage. It may, incidentally, turn up findings you may or may not want - say, on your Alzheimer's disease risk, or your risk of developing lung, breast or skin cancer.

And let's say in the next year or two that when you apply for life insurance (or long-term care or disability insurance), the insurance company demands to know whether you've had any genetic testing done, and if so, wants to see it. Or requires some genetic testing done as a condition of providing coverage.

Didn't see that coming, did you?

The [insurance companies](#) have - and, fortunately for us, so has a group of bioethicists from Columbia University, who in a recent commentary in the *Journal of the American Medical Association* pondered the not-at-all distant future in which insurers will seek access to applicants' genetic test findings before making their underwriting decisions.

Now that it can cost as little as \$1,000 to have a full-genome scan - more than 700,000 Americans have done it - the future is now.

Although the Genetic Information Nondiscrimination Act of 2008 bars the use of genetic information for health insurance coverage decisions, it does not do so when it comes to [life insurance](#), disability insurance or

long-term care insurance.

A few U.S. states have adopted some protections against such use by insurance companies, but most have none. Only Vermont outright bars its use by insurers. And some insurance companies have already started asking.

For starters, the authors of the commentary - Robert Klitzman, Paul S. Appelbaum and Wendy K. Chung, all of Columbia University's Medical Center - acknowledge that having one's genetic information scrutinized by an insurer opens an individual to being denied coverage - or offered coverage at inflated rates - for having acted in the interest of one's own best health: After all, aside from a few untreatable or unpreventable genetic diseases that could be turned up, many of the genetic variants currently being found interact with other factors in the environment, and with behaviors.

Knowing what those risks are, an individual can take steps to lower her risk of developing whatever disease she carries an elevated risk for developing. And clearly, our society is not bettered if knowing - and acting on that knowledge - is discouraged.

The conundrum is that people who suspect they carry a genetic variant that could affect their life span or their ability to care for themselves are - at least now - the ones who are most likely to get [genetic testing](#) performed. Those whose fears of premature death or disability are confirmed will disproportionately apply for health or disability insurance.

If insurers are kept in the dark about applicants' genetic risks, they respond to their increasingly sick pool of claimants by hiking their premiums to everybody. Insurance for people of average risk (or at least for people who don't know of any outsized genetic vulnerabilities they

may have) may be priced out of the market. And that's not good either.

The commentators suggest there may be ways to thread this bioethical needle: Give all people access to a certain level of insurance without any requirement to ante up genetic information; to get layers of coverage beyond that minimum, insurance companies may require genetic information.

"Scholars, physicians and policymakers need to consider these rapidly evolving issues, or insurers will make decisions on their own," the group wrote. And life and disability insurance companies should align their reading of genetic risk with scientific findings, and to make their assumptions transparent. As scientists deepen their understanding of the power of specific genetic variants, and of the interaction between genes and behavior, insurance companies will need to underwrite accordingly.

Either that, or insurers could be told, as they are in Vermont, that they're not entitled to consumers' [genetic information](#), whatever it says.

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