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Should Life Insurers Have Access to Genetic Test Results?

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Should life insurance companies have access to consumers' genetic information? In deciding whether to sell life insurance policies and at what price, insurers routinely consider applicants' risk factors such as smoking and obesity. Should genetic information be exceptional? The Genetic Information Nondiscrimination Act (GINA) bars use of genetic information for health insurance underwriting decisions, but not life, long-term care, or disability insurance. These questions have received occasional attention in the past, but have become more salient with the rapidly decreasing cost and increasing use of predictive genetic testing. Individuals at risk of serious genetic diseases may fear loss of insurance coverage or higher rates, and thus decline genetic testing that could improve disease prevention, early diagnosis or treatment.

Life insurance allows people to share the financial risks of premature death. Its core social value lies in preventing the impoverishment of survivors after the death of a familial breadwinner. The larger the pool of policyholders who share the risk, the more fairly premiums can be calculated – so long as the pool reflects the risk of the population, or the ways in which it differs can be specified. However, the expansion of predictive genetic testing threatens to complicate actuarial risk assessments.

Insurance companies fear that individuals may undergo testing and learn they have a variant that confers substantial risk of death and/or disability (e.g., sudden cardiac death), and then purchase insurance without revealing the test results. Carriers of the *APO E4* allele associated with a moderate risk for Alzheimer's disease are 2-3 times more likely to buy long-term care insurance or plan to do so.¹ Persons at risk of highly penetrant genetic diseases without effective prevention or treatment have been advised to test anonymously, and if found to have the mutation, to buy life, disability and long-term care policies.² If these consumers know their genetic test results while insurers do not, an asymmetry in knowledge leads to "adverse selection" of high-risk applicants, and an uneven playing field.

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Insurers could access genetic information in several ways: through family history, reviewing medical records, asking applicants if they or family members have undergone genetic testing, or requesting that applicants undergo testing. The growth of electronic health records (EHRs) makes these data more accessible, since genetic testing results are increasingly entered into EHRs, and insurance applications routinely include blanket releases of medical information.

Life insurance companies are currently debating how to approach these issues. British insurers have agreed to a moratorium on the use of genetic information until 2017.³ One American life insurance executive has said that his company would request genetic information, but does not want to be the first to do so.⁴ A group of Canadian and European experts laid out several broad questions, suggesting more discussion and studies concerning use of genomic data by life insurers.⁵

However, in the US, no decisions have been made; and US life insurance companies seem unsure how to proceed. Genomic knowledge is rapidly evolving. While Joly et al. wrote that “genomic information about currently known common variants seldom substantially affects mortality risk estimation already based on phenotype and family history⁷,” genetic data for highly penetrant conditions should be more accurate than predictions based on family history alone. In fact, if results of genetic tests ultimately aid diagnosis, prevention, and treatment, testing could actually lower the risk for many insurance applicants. Indeed, all of us have genetic predispositions to disease, and many can be modified by lifestyle changes and medical interventions. Moreover, an individual found to lack the familial mutation for a potentially lethal disorder has a lower risk of that disease than the general population, something insurers may fail to appreciate.

Countries vary widely in their approaches. As of 2004, a few countries established moratoria – either full (e.g., France and Germany) or partial (e.g., Australia and Canada) – on insurers’ use of genetic information.⁶ In the US, no federal legislation directly addresses use of genetic information by life insurers and state laws are variable: a few bar use of genetic test results (e.g., VT), others prohibit decisions based on genetic information regarding specific conditions (e.g., sickle-cell trait, as in .NC)), and some merely require informed consent for genetic testing (e.g., NY) or that underwriting decisions reflect actual risk (e.g., WI).⁷ While some states have relatively robust protections, most have none.

Prior scholarship has concluded that insurers should avoid “unfair discrimination,”⁷ but questions then arise of how that should be defined. Notions of “unfairness” are not objective, but involve balancing the interests of stakeholders (e.g., insurers, consumers, and policymakers). Although insurers that know applicants’ genetic propensities could stratify risks more accurately, conservative business decisions may lead them to overestimate risks. Much of the genetic literature is skewed by selective ascertainment of the most severely affected patients, rather than reflecting population-based data, and may itself overestimate risk. Risk adjustment based on genetic data could price many people out of the life insurance market.

Several solutions are possible:

- Government policy could ban use of genetic tests by insurers. However, if individuals pursue genetic testing, and those at higher risk disproportionately purchase insurance, the fundamental business model would be undermined. Insurers would probably try to amortize the loss over all customers, leading to uniformly higher rates. Some consumers may object to these higher prices, knowing that individuals with mutations are disproportionately purchasing insurance (i.e., “free-riders”). Hence, the viability of this approach would depend on whether consumers would prefer to pay higher rates in return for restricting insurers’ access to genetic information.
- Insurers could be allowed to seek information only about certain defined sets of well characterized high-risk, high-penetrance genes and variants. Individuals who take medically effective measures to reduce their risk would have rates modified according. A list of predictive tests for unpreventable or untreatable genetic diseases—modest in number—could be developed. This approach would limit the number of persons denied coverage, while taking insurers’ strongest interests into account.
- A certain modest amount of insurance could be available to everyone, as in the UK (where life insurance is required for mortgages), with companies allowed to seek genetic information only from individuals who want to purchase additional coverage.
- Insurers could be permitted unlimited access to genetic information. Unfortunately, certain applicants might then be excluded from the insurance market.

If access to at least some life insurance is a social good, which we believe it is, public policy should seek to maintain the general availability of coverage. Hence, we favor universal availability of modest amounts of life insurance; for those desiring additional coverage, insurers would be allowed access to genetic information for a limited number of clinically well characterized high-risk, high-penetrance genes and variants. In establishing which genes should be included in the latter group, input from genetic and policy experts and public transparency are crucial and more data from population based studies to determine the unbiased natural history of these conditions.

Treating genetic information differently from other data with predictive value utilized by life insurers is warranted by a combination of factors: the desire to avoid disincentives for potentially valuable genetic testing in medical contexts; the extent to which genetic predispositions are out of a person’s control (in contrast, e.g., to smoking or obesity); and the concern about the implications of genetic information for family members. Similar considerations motivated the adoption of GINA and the various state laws protecting genetic data.

Scholars, physicians and policy makers need to consider these rapidly-evolving issues now, lest insurers’ make decisions on their own. The outcomes of these policy discussions could affect whether patients feel secure enough to undergo genetic testing.

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