

Ethics, Insurance Pricing, Genetics, and Big Data

Robert Klitzman

December 2018

PRC WP2018-15

Pension Research Council Working Paper

Pension Research Council

The Wharton School, University of Pennsylvania

3620 Locust Walk, 3000 SH-DH

Philadelphia, PA 19104-6302

Tel.: 215.573.3414 Fax: 215.573.3418

Email: prc@wharton.upenn.edu

<http://www.pensionresearchcouncil.org>

All findings, interpretations, and conclusions of this paper represent the views of the author(s) and not those of the Wharton School or the Pension Research Council. © 2018 Pension Research Council of the Wharton School of the University of Pennsylvania. All rights reserved.

Ethics, Insurance Pricing, Genetics, and Big Data

Robert Klitzman

Abstract

Insurers are rapidly gaining access to consumers' genetic information. In the US, federal law bars using genetic information in health insurance, but not in life, disability, or long-term care insurance. Accordingly, insurers may fear adverse selection: individuals could undergo testing, learn they have risky genes, and purchase insurance without revealing test results. While other countries have established moratoria on insurers' use of genetic information, there is no consensus in the U.S. regarding how to avoid 'unfair discrimination.' The chapter discusses alternative solutions, including government bans of insurers' use of genetic information, or limiting insurer information to only high-risk genes.

Keywords: Insurance, risk-management, genetic testing, healthcare, Genetic Information Non-Discrimination Act

Robert Klitzman

Columbia University Medical School

Dramatic technological advances in computers and genomics are radically transforming countless aspects of contemporary life, including health care, life expectancy, retirement and financial planning, posing opportunities, but also profound ethical and public policy challenges. In the future, genetic testing promises to affect many aspects of health care and estimates of life expectancy in ways that can significantly shape decisions about various aspects of financial planning. Data that include genetic information are, for instance, yielding new insights on how best to diagnose, prevent and treat many diseases, from cancer to Alzheimer's, and revealing factors associated with aging and longer or shorter lifespans. Such data can thus potentially influence perceived needs for, and pricing of, life, disability and long-term care insurance (Calloway 2019), and various other financial products and services. Individuals who have genes that increase risks for Alzheimer's, for example, may decide to retire earlier and/or try to purchase more insurance than they would otherwise, and have different investment goals or needs. Based on genetic information, individuals may also decide not to have children, or to try to screen embryos for certain diseases, which may or may not succeed.

As scholars and others probe how technologies may disrupt and alter financial services and pension planning, it is vital to consider how computer, genetic, and other technologies are combining and transforming each other to refashion these domains.

The Case of Life Insurers

The effects on life insurance raise many of these issues in stark relief, and are thus explored below, as a case-in-point. Critical questions emerge, for instance, regarding whether companies selling life, disability, and long-term care insurance should have access to consumers' genetic information, and whether certain individuals, due to their genetics, will consequently be denied

coverage or face unaffordable prices. In deciding whether to sell such insurance policies and at what price, insurers routinely consider applicants' risk factors such as smoking and obesity, but society is now beginning to ask whether genetic information should be treated differently.

Background Concerning Genetics

Genes consist of deoxyribonucleic acid (DNA) that in turn is composed largely of four nucleotides: guanine, cytosine, thymine, and adenine, (abbreviated GCTA). Sequences of thousands of these nucleotides (commonly described using these abbreviations of four 'letters') code particular proteins that have various functions in the human body. Periodically, one such letter mistakenly replaces another – a misspelling. Some such misspellings are benign, while others may selectively harm or help the organism, significantly increasing or decreasing morbidity and mortality.

Technological advances have yielded inexpensive genetic testing, including whole genome sequencing. Over the past two decades, the cost of sequencing one individual's genome has fallen dramatically from several hundred million to less than one thousand dollars (though that current cost does not include interpretation of the information). Yet questions of privacy, confidentiality, and potential stigma and discrimination emerge. Direct-to-consumer genetic testing companies such as 23andme have sold their files on one million customers' genomic information to pharmaceutical companies for \$60 million (Herper 2015). This raises additional ethical questions regarding ownership of such data. The rapid spread and expansion of big data have thus made genetic information more cheaply and easily shared, sold, and resold, either with or without individuals' knowledge, understanding, willingness or explicit permission. Questions surface

regarding how readily these data can identify individuals, whether the uses of these shared data sets should be limited in any ways, and if so, who and how they should decide.

With just a few other bits of data about an individual (e.g., date of birth and zip code), genomic data can be identifying, raising possibilities of discrimination (Erlich et al. 2014). Science fiction scenarios as in the film *Gattaca* highlight public fears of potential misuses of genetic data. In the US, the Genetic Information Nondiscrimination Act (GINA; US Equal Employment Opportunity Commission 2008) currently bars use of genetic information for health insurance underwriting decisions, but not for life, long-term care, or disability insurance.

The plummeting cost and widening use of genetic testing make these issues ever more pressing. Individuals at risk of serious diseases that are associated with genetic tests may fear loss of insurance coverage or higher costs, and thus avoid genetic tests that might aid the prevention, diagnosis or treatment of the disease. In the future, for instance, hospitals may sequence the genes of all patients who enter the institution, using left over blood samples, and store the information in large databanks. Questions therefore emerge of who should have access to such information – whether any researcher, pharmaceutical company, law enforcement official, school, insurer should potentially see the data and if so, to what specific information—for example, if certain identifiers should first be removed, and if so, which. US policymakers recently wrestled with a few of these dilemmas in revising the so-called Common Rule (Office for Human Resource Protections 2009; 2016), regulating human subjects research, including use of large biobanks. The revised Common Rule (2016) allows for broad onetime consent for unspecified future research uses, provided certain privacy protections are met. How exactly such regulations will be implemented, what unanticipated challenges may arise, what kinds of patient consent may be needed in other situations, whether any restrictions should be placed on data sharing, and how. Questions also

persist regarding whether all patients will find these situations acceptable or might avoid certain tests or medical care as a result.

Problems also arise of potential misinterpretation by both providers and patients of genetics, statistics (e.g., absolute vs relative risks), and genetic tests (concerning relatively large numbers of variants of uncertain significance). Levels of understanding of genetics are low among providers, including most physicians. Most internists rate their knowledge as very/somewhat poor concerning genetics (73.7%) and guidelines for genetic testing (87.1%), and most felt they need more training on when to order tests (79%), how to counsel patients (82%), interpret results (77.3%), and maintain privacy (80.6%) (Klitzman et al. 2013).

Concerns arise, too, given noted examples of hacking of data from major corporations and institutions. Violations of confidentiality have occurred through various means, both intended and accidental (Rouse et al. 2019).

Challenges Concerning Life Insurance

Life insurance permits pooling of the financial risks of unanticipated disability, chronic disease or premature death, providing a key social value, preventing survivors from becoming impoverished after a wage-earner dies. Large numbers of policyholders come to share these risks.

But as more consumers obtain genetic testing, often on their own, actuarial risk assessments will become more complicated (Klitzman et al. 2014). Consumers may discover that they possess genes that increase their risks of sudden cardiac or other premature death or Alzheimer's disease or other conditions that may require long-term care. These individuals may not disclose these test results to insurers, but buy insurance. People with highly penetrant genes for diseases that lack effective prevention or treatment report being advised to undergo anonymous testing, and if they

learn they have the mutation, to purchase life, disability and long-term care insurance (Klitzman 2012). Individuals who learn that they have genes associated with increased risks of Alzheimer's, for instance, are 2-3 times more likely to purchase long-term care insurance or to plan to do so (Taylor et al. 2010). Another study of individuals testing for genes associated with Alzheimer's disease found no significant differences in health, life, or disability insurance purchases, but individuals who learned that they had these genes were 5.76 times more likely to alter their long-term care insurance (Zick et al. 2005). Knowledge asymmetry can result if consumers have such information while insurers do not, causing 'adverse selection' and uneven playing fields.

Rothschild and Stiglitz (1976) have suggested that asymmetric information could significantly affect insurance markets. Yet in analyzing data on annuities in the UK, Finkelstein and Poterba (2004) found that asymmetric information may affect certain aspects of consumer behavior, but not others. Specifically, individuals who expected to live longer tend to purchase more 'back-loaded' policies (that, over time, pay more per year), while people who expect to live for shorter periods tend to purchase policies that provide payouts to the consumer's survivors. Nevertheless, asymmetric selection did not appear to affect the size of the annuities purchased (Finkelstein and Poterba 2004). These results suggest the need to look at multiple aspects of life insurance policies that such asymmetric knowledge can affect. As one strategy for diminishing potential adverse selection, Brown and Warshawsky (2013) have suggested combining annuities and long-term care insurance policies, pooling these products. Whether such an approach will reduce adverse selection due to genetic testing is unclear.

If insurers decide to access genetic information, they could potentially do so in several ways: through family history, medical records, asking applicants if they or family members have had genetic tests performed, and asking applicants to undergo such tests. The growth of electronic

health records (EHRs) heightens the accessibility of such data. Genetic test results are increasingly becoming parts of EHRs, and insurance applications regularly request releases of medical records.

Indeed, insurers are currently debating how to address these issues. In the UK, life insurers have accepted a moratorium on using genetic information (Association of British Insurers 2011). In the US, one American life insurance executive has stated that his company would ask for such genetic information but did not wish to be the first to do so (Peikoff 2014). A group of Canadian and European authors (Joly et al. 2014) has articulated a set of broad questions requiring further examination along these lines.

In the US, however, life insurers remain uncertain what to do. Scientific understandings of genomics are rapidly evolving. Though some have argued that ‘genomic information about currently known common variants seldom substantially affects mortality risk estimation that is already based on phenotype and family history’ (Klitzman et al. 2014, p. 2), genomic risk assessments can be more accurate for highly penetrant disorders, than prognostications based on family history. Even in a family whose parents both had breast cancer and carry a BRCA gene, for example, a woman may be found to not have the mutation, thereby lowering her risk significantly. Many consumers’ genomic information may ultimately assist diagnosis, treatment and prevention, reducing risks. Knowledge of the presence of certain genes can motivate individuals to reduce their risk behaviors and pursue enhanced medical interventions. Insurers will need to appreciate how individuals without mutations for lethal disorders have lower risks than do the general population.

As seen in Table 1, nations differ considerably in how they confront these issues. For instance, France and Germany have established full moratoria on insurers’ use of genetic test results, while Australia and Canada have instituted partial moratoria (Knoppers et al. 2004).

Table 1 here

US federal legislation does not directly comment on life, disability, or long-term care insurers using genetic information, and state laws range considerably. Vermont and a few other states prohibit use of genetic information, while others bar use of genetic tests for certain conditions such as sickle-cell trait (e.g., in North Carolina). New York requires specific informed consent for genetic testing. Wisconsin requires that underwriting reflects actual risks (National Genome Research Institute 2018). States thus range from ‘strong’ to ‘no protection’.

Insurers should avoid unfair discrimination, but the meaning of this concept can differ, especially in the context of genetics (Klitzman et al. 2014). Definitions of ‘unfairness’ can involve weighing the competing interests of consumers vs. insurers. Insurance companies that know consumers’ genetic test results can stratify risks more accurately. At the same time, insurers may make conservative business decisions, overestimating risks in ways that lead to denials of coverage or significantly increased costs for certain consumers.

While scientific knowledge about the roles and predictiveness of many genes is rapidly advancing, many uncertainties persist. Studies suggesting that particular genes are highly associated with certain diseases have frequently failed to be replicated. Genetics research is often biased, selectively focusing on severely ill patients, rather than the general population, thus leading to overestimations of risks. Use of genetic information could thus result in many individuals unjustifiably being priced out of the life insurance market.

Possible Solutions

To address these concerns, several solutions are possible. First, government policies could prohibit all insurers from using any genetic information. In such a case, however, asymmetrical

knowledge and adverse selection could ensue. Presumably, insurance companies would then seek to amortize the effect, increasing rates for all consumers. And some consumers may object, wary of individuals with mutations who disproportionately buy insurance. Research is thus needed to gauge how potential customers would view these trade-offs.

Second, insurers could be allowed access to all genetic information they seek. Unfortunately, some consumers might then be unable to obtain insurance.

Third, insurers could be permitted to obtain genetic information only about certain pre-defined, well-characterized, highly-penetrant genes. Consumers with certain genes who reduce their risks through effective treatment or prevention would have prices lowered accordingly. A list of such highly predictive tests could be determined, and clearly listed. The number of applicants excluded from coverage would thus presumably be reduced. Extreme care and caution would be needed, however, since most genes are not very penetrant, and environmental and other factors are involved in whether, when and how symptoms may occur. How much insurance prices would vary based on the presence or absence of these genes is also unclear.

Fourth, all individuals could be allowed to obtain a certain modest amount of insurance, with insurers able to obtain genetic test results from consumers who wish to buy additional coverage. This situation currently exists in the UK, for instance, since individuals there must have life insurance to obtain a mortgage.

Since life insurance provides a social benefit, public policy makers can seek to maximize its availability. Accordingly, the option of providing a certain modest amount of insurance to everyone may have certain advantages. Currently, in the U.S., social security offers some retirement annuity, disability insurance, and survivors' insurance to all who contribute. Medicaid and Supplemental Security Income also provide some long-term care coverage and disability

benefits, but they favor lower-income individuals and families. Moreover, the benefits provided for living expenses (as opposed to health care) are relatively limited for many individuals. Some employers also offer varying degrees of life insurance coverage, though policies range widely in generosity and cost.

If life insurers do access genetic information, input from genetic and policy experts and public transparency will be crucial in establishing which genes should be included. More population-based research is also vital to determine accurately the unbiased prevalence and natural history of these genetic markers and disorders. If insurers request information on results of genetic tests, significant caution is needed since patients may consequently be wary of undergoing such testing, even when it may potentially aid their health. Insurance policies could disincentivize patients from pursuing genetic testing that may be medically helpful, because of concerns about consequent diminished future insurability. Genetic test results differ from other medical data since individuals cannot alter their genes, as they can their weight, diet, and amount of physical exercise. An individual's genetic test results can also unfairly impede family members' insurability.

Key questions arise, too, regarding how companies allowed to access genetic information would or should do so. Insurers might only inquire whether individuals or family members have histories of certain specific conditions, or ever undergone genetic testing, and if so, to self-report the results. Alternatively, insurers might require potential customers to undergo genetic testing and submit the data.

Major challenges would also arise because many individuals have variants of uncertain significance. Given the thousands of letters in each DNA sequence, scientists remain unsure whether certain gene variants in fact impose major dangers, cause only slight impairments, are in fact benign, or even are protective against a disease. Thus genetic test sequencing yields high

amounts of uncertainty, and deep questions arise regarding how insurers will view and handle such ambiguities. Companies may want to drastically raise costs for, or exclude many consumers, but such decisions may be unwarranted since genetic risks may be minor, unlikely, and/or potentially offset by other biological or environmental factors.

Economic models of the impact of using genetic testing tend to show that outcomes depend on the assumptions imposed (MacDonald and Yu 2011; Howard 2014). One model, for instance, assumed that 100 percent of people with a particular high-risk gene will be tested over their lifetimes (Howard 2014). Yet this figure seems unrealistically high, at least presently, as well as in the near future. Indeed, rates of lifetime uptake of genetic testing in the US remain very low: no more than 20 percent of individuals at risk of HD have undergone testing, with only 14.7 percent of at-risk individuals doing so over 20 years in Northern Ireland (Morrison et al. 2011). For diseases such as breast cancer, the rates are below about 20 percent (Childers et al. 2017). Granted, such rates may increase if insurance company policies change, yet many people are wary of undergoing genetic tests, due to fears of stigma and discrimination. Moreover, the US has very few genetic counselors, making it unlikely that consumers could get the information needed when they are tested (Bureau of Labor Statistics 2018).

Conclusion

Federal and state policymakers, industry stakeholders, academic researchers, and others need to examine these questions carefully. Public policy in this area could influence whether patients opt to undergo genetic tests for medical reasons, ultimately helping or impeding individual and public health.

These issues also have critical implications for future research, underscoring needs to assess consumer attitudes regarding these tradeoffs. For instance, it is not yet known how much consumers would pay to avoid genetic testing. Additional research can elucidate views and attitudes in ways that might inform government and industry decisions. An examination of insurance company policies and decisions regarding genetics is also important. It may also be important to establish an independent ombudsoffice to receive and review claims of unfair discrimination, when they arise. Public trust in health care providers and institutions, government policymakers, and insurers is crucial, as the lives and welfare of countless individuals are at stake. Future research is also critical on how these technologies will affect other consumer and industry choices as well. For example, it would be important to learn whether and to what degree certain consumers will be more or less likely to seek certain kinds or amounts of financial products or services, and whether genetic data will affect decisions about financial portfolios and annuity pricing, and if so, how, and what challenges will emerge as a result.

In short, to understand the impact of new technologies on individual and company decisions regarding financial products, several complexities need to be considered. Computer technologies may alter not only the types of products offered, but also consumers' preferences based on information about themselves that technology provides. The term 'FinTech' should, arguably, thus be expanded from the way it is now sometimes used, to address how a wide variety of new technologies have financial implications for both individuals and financial institutions. Given how rapidly computer capabilities and analytics and genomic technologies are advancing and evolving, these domains will continue to be critical to monitor and examine.

Acknowledgements

This research was funded in part by a grant from the National Human Genome Research Institute: P50HG007257. The author has no financial conflicts of interest to disclose. The authors would like to thank Kristina Hosi, Charlene Sathi, and especially Patricia Contino, for assistance in preparation of this manuscript.

References

- Association of British Insurers. (2011). *Concordat and Moratorium on Genetics and Insurance*.
UK: Association of British Insurers.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216821/Concordat-and-Moratorium-on-Genetics-and-Insurance-20111.pdf.
- Brown, J. and M. Warshawsky (2013). 'The Life Care Annuity: A New Empirical Examination of an Insurance Innovation that Addresses Problems in the Markets for Life Annuities and Long-term Care Insurance.' *The Journal of Risk and Insurance*, 80(3): 677–703.
- Bureau of Labor Statistics (2018). 'Occupational Outlook Handbook Genetic Counselors.'
US Department of Labor. <https://www.bls.gov/ooh/healthcare/genetic-counselors.htm>.
- Callaway, J. (2019). 'FinTech Disruption: Opportunities to Encourage Financial Responsibility' in J. Agnew and O. S. Mitchell eds., *The Disruptive Impact of FinTech on Retirement Systems*. Oxford, UK: Oxford University Press, pp. xxx-xxx.
- Childers, C. P., K. K. Childers, M. Maggard-Gibbons, and J. Macinko (2017). 'National Estimates of Genetic Testing in Women with a History of Breast or Ovarian Cancer.' *Journal of Clinical Oncology*, 35(34): 3800-3806.
- Erlich, Y. and A. Narayanan (2014). 'Routes for Breaching and Protecting Genetic Privacy.' *Nature Reviews Genetics*, 15(6): 409-421.
- Finkelstein, A. and J. Poterba (2004). 'Adverse Selection in Insurance Markets: Policyholder Evidence from the UK. Annuity Market.' *Journal of Political Economy*, 112(1): 183-208.

- Herper, M. (2015). 'Surprise! With \$60 Million Genentech Deal, 23andMe has a Business Plan.' *Forbes*. January 6: <https://www.forbes.com/sites/matthewherper/2015/01/06/surprise-with-60-million-genentech-deal-23andme-has-a-business-plan/#40dc97f02be9>.
- Howard, R.C.W. (2014). *Report to CIA Research Committee: Genetic Testing model: If Underwriters Had No Access to Known Results*. Document 214082: Canadian Institute of Actuaries: <http://www.cia-ica.ca/docs/default-source/2014/214082e.pdf>.
- Joly, Y., H. Burton, B. M. Knoppers, I. N. Feze, T. Dent, N. Pashayan, N. S. Chowdhury, W. Foulkes, A. Hall, P. Hamet, N. Kirwan, A. Macdonald, J. Simard, and I. Van Hoyweghen (2014). 'Life Insurance: Genomic Stratification and Risk Classification.' *European Journal of Human Genetics*, 22(5): 575-579.
- Klitzman, R., W. Chung, K. Marder, A. Shanmugham, L. J. Chin., M. Stark, C.-S. Leu, and P. S. Appelbaum (2013). 'Attitudes and Practices Among Internists Concerning Genetic Testing.' *Journal of Genetic Counseling*, 22(1): 90-100.
- Klitzman, R., P. S Appelbaum, and W. K. Chung (2014). 'Should Life Insurers Have Access to Genetic Test Results?' *JAMA*, 312(18): 1855-1866.
- Klitzman, R. (2012). *Am I My Genes? Confronting Fate and Family Secrets in the Age of Genetic Testing*. New York: Oxford University Press.
- Knoppers, B. M., Godard, B., and Joly, J. (2004). 'A. Comparative International Overview,' in M. A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy (Basic Bioethics)*. Cambridge: The MIT Press, pp. 173-194.
- Macdonald, A. S., and Yu, F. (2011). 'The Impact of Genetic Information on the Insurance Industry: Conclusions from the 'Bottom-Up' Modelling Programme.' *ASTIN Bulletin: The Journal of the IAA*, 41(2): 343-376.

- Morrison, P. J., Harding-Lester, S., and Bradley, A. (2011). 'Uptake of Huntington Disease Predictive Testing in a Complete Population.' *Clinical Genetics*, 28: 1-6.
- National Human Genome Research Institute. Genome Statute and Legislation Database. <https://www.genome.gov/policyethics/legdatabase/pubsearch.cfm>
- Office for Human Research Protections. (2009; 2016). *Federal Policy for the Protection of Human Subjects* ("Common Rule", Revised January 15, 2009. Effective July 14, 2009. Content last reviewed February 16, 2016) <https://www.hhs.gov/ohrp/regulationsandpolicy/regulations/45-cfr-46/index.html>.
- Peikoff K. (2014). 'Fearing Punishment for Bad Genes.' *The New York Times*. April 7: <https://www.nytimes.com/2014/04/08/science/fearing-punishment-for-bad-genes.html>.
- Rothschild, M., and Stiglitz, J. (1976). 'Equilibrium in Competitive Insurance Markets: An Essay on the Economics of Imperfect Information.' *The Quarterly Journal of Economics*, 90(4): 629-649.
- Rouse, T., D. Levine, A. Itami, and B. Taylor (2019). 'Benefit Plan Cybersecurity Considerations: A Recordkeeper and Plan Perspective,' in J. Agnew and O. S. Mitchell (eds.), *The Disruptive Impact of FinTech on Retirement Systems*. Oxford, UK: Oxford University Press, pp. xxx–xxx.
- Taylor, D. H., Cook-Deegan, R. M., Hiraki, S., Roberts, J. S., Blazer, D. G., and Green, R. C. (2010). 'Genetic Testing for Alzheimer's and Long-Term Care Insurance.' *Health Affairs*, 29(1): 102-108.
- US Equal Employment Opportunity Commission (2008). *The Genetic Information Nondiscrimination Act of 2008*. <https://www.eeoc.gov/laws/statutes/gina.cfm>.

Zick, C. D., Mathews, C. J., and Roberts, J. S. (2005). 'Genetic Testing for Alzheimer's Disease and its Impact on Insurance Purchasing Behavior.' *Health Affairs (Millwood)*, 24(2): 483-490.

Table 5.1. Moratoria on the use of genetic information by life insurance companies

Yes	No	Partial
Canada	Austria	Australia
Finland ^a	Belgium	Canada
France ^a	Bulgaria	Greece
Germany ^a	Chile	New Zealand
Ireland ^a	Cyprus	South Africa
New Zealand	Czech Republic	
South Africa	Denmark	
Sweden ^a	Estonia	
Turkey	Georgia	
The United Kingdom ^a	Hungary	
	Iceland	
	India	
	Israel	
	Italy	
	Japan	
	Luxembourg	
	South Korea	
	Spain	
	Switzerland	

Note: ^a The amounts and expiration dates vary

Source: Knoppers et al. (2004)