



Beyond the Genetic Information Nondiscrimination Act: ethical and economic implications of the exclusion of disability, long-term care and life insurance

The Genetic Information Nondiscrimination Act (GINA) was intended to protect individuals in the USA from discrimination based on their genetic data, but does not apply to life, long-term care or disability insurance. Patient advocates and ethicists have argued that GINA does not go far enough. Others express concerns for the viability of insurance companies if millions of potential customers know more than professional actuaries. Here we discuss the exclusion of certain insurance types from GINA. We explore the ethical and economic implications of this distinction, and potential paths forward. We suggest that because long-term care and disability insurance can be essential for well-being, there is no good reason to place them in a class with life insurance and therefore beyond GINA's reach.

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Background

As precision medicine advances, an increasing number of individuals will have some knowledge about their own genomic data. When ordered by a care provider, or obtained through direct to consumer (DTC) testing and shared with the clinician as part of a medical history, these data may be added to the electronic health record [1]. It is common practice for insurance companies offering life, long-term care (LTC) or disability insurance to gain access to a customer's medical records as a condition of providing the insurance. In contrast to employers and health insurance providers, there is no federal US legislation prohibiting purveyors of life, LTC or disability insurance from using that genetic data in evaluating an application, whether to charge a higher rate or deny coverage outright. Here we explore the reasons for, and implications of, this dichotomy in the USA between the status of employment and health insurance, and the lack of protections around other types of insurance.

Health insurance exceptionalism?

In late 2015, NIH Director Francis Collins was a guest on National Public Radio's Diane Rehm Show, a nationally broadcast US radio program [2], to discuss the NIH's Precision Medicine Initiative. During the show, Dr Collins fielded a question regarding privacy, namely, whether people should be concerned if they volunteer for the so-called 'million-person cohort', that their private health information could be used against them if obtained by the wrong party. Of course, the question is relevant for all of the different types of information collected, for use by any number of entities including the government, financial institutions and educational programs, among others. With regard to genomic data, Dr Collins cited the Genetic Information Nondiscrimination Act (GINA) [3], but also explained that it does not cover life, LTC or disability insurance. This raises the question whether, how, and why health insurance differs from these other types of insurance, such that only the former is covered under GINA.

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It has been argued that access to healthcare is a right, not a privilege [4]. Even if one accepts this argument, this right is not absolute. It must be balanced with other factors such as allocation of limited resources and economic burden on the provider, among others. Accepting healthcare access as a right, therefore, does not settle the matter, but rather raises a host of other questions, such as should the elderly receive liver transplants? How much healthcare access is enough? Who gets to decide? [4]. These nuanced cases and judgment calls share common ground with the questions raised here, namely, where should society draw the line?

Continuing with the assumption that healthcare access is a right, because of the fact that access to healthcare in the USA is effectively mediated through insurance, it would follow that healthcare insurance is also a right [5]. Passage of the GINA of 2008 took more than a decade of lobbying by patient advocacy groups, medical professionals and researchers [6]. In its current form, GINA does not apply to LTC, disability or life insurance. These other types of insurances are considered different, and not held out as ‘rights’.

‘Long-term care’ refers to a spectrum of services ranging from medical to social. It differs from acute medical insurance in that it is aimed not at healing a person and returning him or her to a healthy state, but rather to prevent decline, and to foster adjustment as decline occurs [7]. Disability insurance protects the beneficiary against lost wages should a disability prevent that person from performing his or her job, and thus earning his or her salary. Life insurance differs from both LTC and disability insurance in that the beneficiary is not the policy-holder. Rather, life insurance is meant to protect the policy-holder’s dependents in the event of the policy-holder’s death. But in all of these cases, one seeks to protect oneself or one’s dependents from financial misfortune or even catastrophe in the event of sickness, injury or death.

Compared with life insurance, long-term care and disability insurance are easier to regard as akin to health insurance and therefore deserving of both public support and inclusion in laws prohibiting genetic discrimination. There are several reasons for this. One is that LTC and disability are often needed as a direct consequence of the success – or failure – of medical care. There is no principled difference between LTC for a transplant patient and LTC for an elder who lived long enough to need it because of improved access to treatments that earlier would have been life-ending; at least, there is no principled difference that makes genetic information a salient criterion for discriminating against the latter. Second, many disabilities follow some medical intervention aimed at effecting a better outcome at the time the disability was caused or dis-

covered, and researchers are developing increasingly accurate tools to measure postoperative disability [8]. Third, insurance companies and other payers spend billions of dollars on aggressive treatments that might not work, or work well, while the benefits of long-term and disability care are easier to document [9].

One can anticipate two arguments for granting special status to health insurance as opposed to LTC or disability insurance. The first is that, as noted above, the acknowledged ‘right’ is actually healthcare, not health insurance. Health insurance is simply the *de facto* mechanism required to confer the right to healthcare in the USA. Given the need to balance a right to healthcare access with other factors such as limited societal resources, perhaps this is a convenient landmark at which to draw that line. Although arguably necessary to ensure human dignity, for public health, or to protect a human right, no such rights have been put forth regarding LTC or income in the event of disability. However, recall that GINA covers employers in addition to health insurers. There is also no acknowledged right to employment *per se*, and yet that protection is considered within the scope of GINA. An employer would not be allowed to factor a prospective employee’s genetic risk into hiring or compensation decisions. GINA asserts that people with genetic dispositions to disease must be given an equal opportunity to earn an income like anyone else. If a law is warranted to ensure that employers not discriminate based on genetic information, then should that law not extend to protect the person’s ability to ensure that income in the event of disability?

The second readily apparent argument is one of financial feasibility. It would be unsustainable for companies to insure high-risk people at average-risk rates (see below), and a single-payer system might be very expensive. Note, however, that there is a precedent for inclusion of these other types of insurance in anti-discrimination legislation. A number of individual states have passed their own laws regarding genetic discrimination, including Connecticut, Michigan, Ohio, California and Oregon. California’s GINA of 2011 (CalGINA) adds ‘genetic information’ to the list of protected classes for a number of different areas of law, including life and disability insurance [10]. Oregon’s law covers LTC, disability and life insurance, referring generally to ‘any policy of insurance’. [11] Though Oregon’s was one of the first such laws in the country, with the original version passed in 1995, little has been published regarding any resulting financial burdens. As with GINA until recently, there have been no notable court cases to test the law. This may reflect the law’s effectiveness; lack of awareness by consumers; the black-box nature of risk-assessment

by insurance companies; or some combination of these factors.

An uneven playing field

Although ancient Roman ‘burial clubs’ had subscribers who wanted to plan for funeral expenses, John Graunt’s early 17th-century ‘Bills of Mortality’ helped fledge actuarial science and laid the foundation for businesses that would collect premiums against a sum of money to be paid to deceased heirs. Life insurance emerged as an investment from which one could not benefit directly. Such a business, to be successful, is information intensive: if investors knew of mortality risks about which the companies were ignorant, payouts might not be covered by premiums.

In a world of precision medicine, life insurance companies must add genomic health risks to their calculations. Indeed, could insurance companies survive if millions of potential customers knew more about their health risks than did the firms’ actuaries? This is a key question because insurance companies are stakeholders who are most ardently going to argue against any proposals to extend GINA’s protections. In coming decades, precision medicine will become more advanced. People will know their risks with higher accuracy. Insurance companies would be foolish not to take age, lifestyle and dangerous hobbies into account. It could be argued they should add genetics as well. On the other hand, too little is currently known about the future costs of genetic risk, and too much depends on highly probabilistic and complex factors such as environmental and gene–environment interactions. Due to the highly stochastic nature of genetic causation, refusals to provide insurance or the imposition of onerous surcharges are not yet supported by adequate evidence.

Predicting an electronic & genomic future

Medical and nursing practice depend on better electronic health records [12]. The Health Information Technology for Economic and Clinical Health Act was signed into law in 2009 to promote the adoption and ‘meaningful use’ of health information technology, including electronic health records [13]. Adoption of electronic health records will, in the future, improve efficiency, safety, secondary use for research, and health outcomes. Genetic data serve as a prime example of how information technology can help clinicians provide better clinical care. As the sheer number of variables represented by genomic data quickly exceeds the human brain’s capacity for incorporation into decision-making, technology is required both to store the data and analyze it, factoring genomic data along with other clinical and lab data into a decision regarding treatment.

Our hope is for a future of high-quality interoperable electronic health records, capable of incorporating genomic data. When we achieve such a network of easy-to-use, well-organized and interoperable systems, the demands to obtain personal health information for nonmedical purposes will also be easier to comply with. What are called ‘compelled authorizations’ – for our purposes, demands for genetic information for risk stratification by insurance companies – may be predicted to expand. For several reasons, including erosion of privacy rights and adverse social consequences, these authorizations should be limited [14]. More broadly, as DTC testing and precision medicine science grow and evolve, there is a case to be made that the insurance industry should be regarded as having a role in public health [15]. The scope of that role, and any consequent duties, need to be addressed by the ethics and policy communities.

A darker future for personalized medicine would see insurers requiring genetic testing before LTC or disability policies are approved or priced. One might also imagine a kind of ‘redlining’ in which insurers make LTC or disability decisions for subpopulations, perhaps racial or ethnic. There is an increasingly urgent need to identify an acceptable compromise between the legitimate needs of insurers to enjoy some measure of profit from their risk taking, and the no less legitimate needs of consumers to avoid financial destruction caused by disability or the need for LTC.

One step might be to enforce some measure of information equity. Insurance companies in principle have plenary access to all patient health information – even as consumers have no such access to insurance actuarial-table calculation algorithms, threshold calculations, and so on. Currently, insurance companies enjoy take-it-or-leave-it power to compel patients to authorize disclosure of health information in medical records. If a DTC result has been validated by a clinically ordered test, or even if the result was simply discussed with the healthcare provider, that information might be a part of the medical record and therefore included in the information available to the insurer. From the insurers’ position, this is good business, despite the fact that DTC genetic testing might elicit no useful information. As a matter of transparency regarding an uncontroversial public good, it is necessary for patients, or future consumers of long term care and/or disability services, to have commensurate access to insurance firms’ actuarial tables, calculation algorithms, threshold determinations, and so on. We can even envision a market in which insurers competed on the basis of such transparency and the benefits available to subscribers.

Conclusion

The failure of GINA to prevent genetic discrimination in the context of disability or LTC was both the failure of moral suasion and the success of industry lobbying. It is an unhappy commentary that an uncontroversial public good could be impeded by protests that those who might otherwise have provided it would not be able to turn enough profit. To be sure, this observation would be weakened if there were evidence to support the notion that genetic information holds the difference between financial destruction and a fair profit. There is yet no such evidence – but it is certainly something that an industry would allege if it wanted to obtain legislative support for the exemption.

As a society, if our attestations of moral responsibility to older citizens, the disabled and other vulnerable populations are *bona fide*, it should be a straightforward matter to advance public support for such benefits. Indeed, under Social Security, the Americans with Disability Act and Medicare, there is already nearly universal support for these values. That the meeting of a moral obligation might prove costly for investors is perhaps a legitimate consideration in the marketplace. But it is far less legitimate when the goal is to minimize discrimination without evidentiary basis, and to celebrate and act on values that few, if any, would publicly disdain.

Future perspective

Beginning in the Roosevelt era and continuing into the 1970s, the USA acted on the realization that a civil society must – absolutely must – ensure that ordinary

people not face financial ruin caused by others' bad investments, and that elders and the poor were entitled to a basic level of healthcare. In this regard, the future of the republic was bright. Unfortunately, from our perspective, the future is now far less bright. A new America is ideologically split, not just by Democrats and Republicans, but by those who have acquired the belief that shared, mutual social commitments are to be disdained and actively opposed. The services provided by governments to protect people from catastrophic misfortune have mutated into something viewed as an oppressive infringement on individual liberty. If the next decade continues the moral meanness of the 2016 election campaign, we will need to wait for a re-emergence of the core values that once shaped policy in genetics, biomedical research and public policy before we see a change in policy regarding what is within GINA's reach.

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Executive summary

- The United States' Genetic Information Nondiscrimination Act covers health insurance and employers, but not disability, long-term care, or life insurance.
- Between precision medicine and direct-to-consumer genetic testing, an increasing number of people have knowledge of their genetic data.
- People's right to healthcare in America is effectively mediated through access to health insurance.
- An individual's desire not to be penalized for genetic make-up must be balanced with companies' desire to be profitable.
- Long-term care insurance and disability insurance ensure access to medical care and are thus more like health insurance than life insurance, which benefits one's dependents.
- Information equity and transparency may represent a good first step toward resolving this tension.
- As a society, we must be explicit in addressing these issues head-on, remaining grounded in our moral responsibility to all citizens, particularly the most vulnerable among us.

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