Anti-Selection & Genetic Testing in Insurance: An Interdisciplinary Perspective

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Abstract: Anti-selection occurs when information asymmetry exists between insurers and applicants. When an applicant knows they are at high risk of loss, but the insurer does not, the applicant may try to use this knowledge differential to secure insurance at a lower premium that does not match risk.

Introduction

One of the fundamental principles of insurance is the law of large numbers, which makes a collective management of independent and similar risks more cost-effective and less risky than managing them individually. Private insurers collectively manage risk by creating homogeneous risk pools through underwriting and risk classification. Insurers therefore argue that they need information about major risk factors in order to appropriately allocate risk and set rates commensurate with an individual's likely losses. For some conditions, genetic testing can bring greater accuracy to the underwriting process, making it of particular interest to insurance companies. As artificial intelligence and big data gain importance in the business world, underwriting practices may become more granular. Against this background, we expect the question of how to handle genetic information to receive renewed attention in the forseeable future.

During risk classification, those categorized as high risk may be denied insurance or be charged a higher premium. Such negative consequences for individuals categorized unfavorably are endemic to any classification scheme, and genetic information is no exception in those jurisdictions where use of this information remains legal. Therefore, applicants may fear disclosing genetic information to insurers. This fear hinders some individuals from undergoing genetic testing or participating in genetic research — a choice that may have adverse consequences for public health.[1] However, if applicants are not required to disclose predictive genetic information, those at higher risks could apply for greater policy coverage without insurers being able to assess risk and set appropriately higher premiums, a concept known as anti-selection. Insurers argue that anti-selection may reduce available coverage levels and lead to increased prices for all consumers, even those without genetic predispositions.

These competing interests of consumers and insurers in individually underwritten insurance lines, such as life insurance, are often at the heart of regulatory

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activity in this area. Though different types of genetic tests may have distinct implications for both private and public insurance, regulations tend to focus on the privately issued, individual-underwritten policies and on predictive genetic tests. This paper does the same.

For any regulator contemplating whether to restrict insurers' use of predictive genetic information, an initial consideration may be: how much of an economic impact will restrictions have on insurance markets? If the economic impact is too dire, financial concerns may outweigh genetic privacy and non-discrimination concerns; if it is minimal, regulation may be justifiable to promote human rights and public health. The severity of the economic impact on insurers depends, in part, on whether individuals will change their insurance-purchasing behavior after receiving an adverse genetic test result.

This paper begins with a discussion of anti-selection theory and modeling, then explores regulatory approaches taken in four common law and one mixed (common and civil law) jurisdictions from around the world, and then turns to a discussion of how insurance purchasing behavior may be impacted by genetic testing. This section provides a robust bibliography of current literature across disciplines on the topic. Given that any potential effect of anti-selection depends on human behavior and practical realities, such as time, monetary, or knowledge constraints, we argue that there is a role for a broader, interdisciplinary community. Specifically, those researching the ethical, legal, and social implications (ELSI) of genetic testing can enrich the prevailing actuarial and economic perspectives about individuals' insurance purchasing behaviors following genetic testing. Additionally, in the ELSI community there has been extensive attention on genetic discrimination and its impact on individuals, but there has been far less research on the behavior of individuals regarding insurance uptake following a genetic test. We conclude by exploring why individuals who learn that they are at increased genetic risk may decide not to, or be unable to, purchase higher insurance coverage. These reasons fall into four domains: (1) internal barriers, (2) external barriers, (3) genetic dimensions, and (4) system dimensions.

I. Anti-Selection and Genetics

Broadly conceived, anti-selection results from asymmetric information between a prospective insured and the insurer, whereby the insured knows more about her risk than the insurer and this informational advantage leads to lower premiums.[2] With increasing rates of predictive genetic testing, there is now greater chance of such information asymmetry. The result may be that if insurers are unable to learn of this heightened genetic risk, they may not charge a sufficient premium to cover it.

Given that any potential effect of anti-selection depends on human behavior and practical realities, such as time, monetary, or knowledge constraints, we argue that there is a role for a broader, interdisciplinary community. Specifically, those researching the ethical, legal, and social implications (ELSI) of genetic testing can enrich the prevailing actuarial and economic perspectives about individuals' insurance purchasing behaviors following genetic testing.

One worry raised by insurers is if they set prices according to the average risk in the population, they could over-attract higher-risk customers, which may create a need to raise premiums.[3] If relatively better risks then drop out of the insurance market, premiums could rise anew, with the potential that in the end only very high-risk types will be insured. The worst-case perceived risk of anti-selection is that even high-risk individuals might find premiums prohibitively high, potentially leading to a complete 'unraveling' of the market.[4] In general, anti-selection is not a purely hypothetical scenario and there some existing evidence exists that shows it could be an issue in some insurance markets.[5] However, whether it is an issue for genetic information specifically is debated and some argue that this is unlikely.[6]

This is complicated by additional factors that can lead to information asymmetry outside of the anti-selection problem: the insurer's underwriting process could fail to identify, or an applicant could fail to disclose, risk that is known to the applicant; an insurer could incorrectly assess the weight of the information provided; or the insurer could be prohibited from considering certain risks if their country or jurisdiction restricts this by law or other policy. In this paper we

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focus on the scenario where information asymmetry is caused by regulation that prevents insurers from collecting or considering genetic test results.

It is important to note that not all genetic information is the same. Single gene disorders or diseases, which arise as a result of a single gene operating in isolation, are relatively rare. Examples of such diseases include Huntington's disease, a progressive neurological disorder, and Lynch Syndrome, a genetic predisposition to colon and endometrial cancer. Multifactorial diseases are more common and arise from a complex interaction of (often) multiple genes and environmental factors.[7] Examples of such diseases include some types of heart disease and some cancers, and the genetic basis of these diseases is somewhat less understood. At present, insurers are most likely to take into account predictive single-gene conditions. Even then, relatively few genetic tests are currently useful in insurance underwriting, in part given the relative rarity of genetic conditions and the ability for individuals to undertake preventive measures. Additionally, almost all currently known single-gene genetic variants have incomplete penetrance, meaning that not everyone with the genetic variant will develop symptoms.

Anti-selection as it relates to genetic information is most relevant for lines of insurance that underwrite on the basis of morbidity and mortality, like life, long-term care, critical illness, or disability income insurance. Health insurance is often offered through public insurance programs and/or is community rated, so can be less impacted. However, to the extent that a jurisdiction, such as the United States, has a private, individually underwritten health insurance market, this line of insurance can also be implicated.

A. Anti-Selection and Regulation

Since anti-selection largely arises from information asymmetry, the best protection insurers have against it is to ensure that all applicants fully disclose all relevant risk information. However, in some cases, in order to protect the human rights of individuals or to encourage uptake of medically necessary genetic testing and research, regulators have restricted insurers' collection or use of genetic test results under a variety of approaches,[8] each with likely different potential effects on anti-selection.[9] Policies span the spectrum from those that allow insurers to use genetic information to those that place restrictions, such as a benefits cap, to those that prohibit insurers' use.[10] This section focuses on five home countries of the authors as case studies.

1. UNITED KINGDOM (UK)

In the UK, the Code on Genetic Testing and Insurance (UK Code) binds insurers and prevents them from using predictive genetic test results to discriminate against applicants. The agreement sets a monetary benefit cap under which customers are not required to disclose the results of predictive genetic tests — £500,000 for life insurance and £300,000 for critical illness, income protection, and long-term care insurance.[11] Benefit caps are a relatively common policy approach, especially in Europe.[12] This prevents applicants from trying to take out large amounts of cover based on their knowledge about genetic risk, while still providing protections for amounts of cover regarded as reasonable.[13] The Code also bars insurers from asking applicants to take a genetic test.

However, the UK Code further limits insurers. Even if the amount of cover is above the prescribed cap, insurance companies are only allowed to require the disclosure of a genetic test whose relevance has been approved by an independent committee. The only test approved in the over 20 years that the policy has been in place is Huntington's Disease for life insurance policies.[14] Indeed, the committee has since been disbanded due to inactivity. Thus, for all practical purposes, the only benefit cap that exists in the UK applies to applicants for life insurance with a positive genetic test for Huntington's Disease.

2. AUSTRALIA

Health insurance in Australia is community-rated (via legislation) and thus not subject to genetic discrimination. The Disability Discrimination Act 1992 prohibits discrimination on the basis of genetic status, but makes an exception for risk-rated insurance underwriting. The Act requires life insurers to have actuarial justification for using medical information, including genetic test results in underwriting, but studies have shown this documentation is rarely produced or enforced.[15] However, after growing pressure from researchers and advocates, in 2019, the Australian life insurance industry adopted a Moratorium with a benefit cap, similar to the UK.[16] The Australian Moratorium is an industry policy as it does not change the legal or regulatory situation in the country. It only allows insurers to seek genetic test results for life insurance policies above $500,000 in lump sum death or total permanent disability coverage, $200,000 in trauma/and or critical illness coverage and $4,000 monthly in income protection, salary continuance or business expenses coverage. The Moratorium allows life insurers to take into account a favorable genetic test result an applicant chooses to disclose, irrespective of the amount of cover; for example, to show that

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they are not carrying a genetic variant associated with developing an illness that runs in their family. In general, an applicant must only disclose family history for first-degree relatives. Life insurance industry standards likewise prohibit insurers from asking an applicant to take a genetic test.[17]

3. CANADA

Canada's Genetic Non-Discrimination Act, passed in May 2017, prohibits "any person" from requiring another "to undergo a genetic test as a condition of (a) providing goods or services to that individual, (b) entering into or continuing a contract or agreement with that individual, or (c) offering or continuing specific terms or conditions in a contract or agreement with that individual."[18] It is also illegal to discriminate based on an individual's refusal to undergo a genetic test or decision not to disclose the results.[19] Despite efforts from the Canadian Life and Health Insurance Association (CLHIA) and the Canadian Institute of Actuaries (CIA) to get an exception into the law for the life insurance industry,[20] the Canadian Genetic Non-Discrimination Act passed with broad language capturing all lines of individually underwritten privately issued insurance policies and a broad definition of "genetic test," which, unlike the UK Code, is not limited to predictive tests. The law recently underwent constitutional review. In 2019, the Quebec Court of Appeal found the law to be invalid, but in 2020 the Canadian Supreme Court reversed the decision, holding that the federal government had jurisdiction to pass the law.[21]

4. UNITED STATES (US)

The United States' response to growth in genetic technology and increased access to genetic test results is the Genetic Information and Nondiscrimination Act of 2008 (GINA).[22] GINA prevents health insurers and employers from collecting and discriminating on the basis of genetic information, including test results, family medical history, and use of genetic services.[23]

In addition to GINA at the federal level, the states across the US provide varying levels of protection against genetic discrimination and genetic testing in insurance. While GINA protects applicants in the health insurance industry, several states extend protection against genetic discrimination in various ways to life, long-term care, and disability insurance.[24] This variation across states can create confusion, and in some cases even enforcers are unsure about the extent of the protections that they are tasked to implement.[25] In 2020, Florida became the first state to bar the use of genetic test results in all three lines of insurance.[26]

5. IRELAND

In Ireland, use of genetic test results by insurers is limited. The Disability Act 2005 (Part 4) regulates and controls genetic testing in various third party contexts, including insurance.[27] Specifically, the processing of genetic test results is prohibited in relation to a policy of assurance, a policy of health insurance or health-related product, an occupational pension, a retirement annuity contract or any other pension arrangement, unless the consent of the person has been obtained,[28] thereby implying the necessity for informed consent.[29] Therefore, in insurance settings, insurers are not permitted to request, take into account or process the results of genetic tests without a person's consent.[30] For example, application forms or health questionnaires that ask health related questions of an insurance applicant should not include any question about genetic tests. Despite these protections, there is a gap in the legislation regarding the use and access to family medical history information by insurers and other third parties. The definition of 'genetic data' in the legislation is narrow does not include family medical history.[31]

The protection of genetic information in Ireland is further strengthened by the General Data Protection Regulation (GDPR) at European Union level.[32] Article 9 of GDPR identifies genetic data as a special category of personal data subject to additional privacy protection; providing that processing of this data is prohibited except in limited circumstances as set out in article 9 (for example, if the data subject has given their explicit consent to the processing of this data).

Although these are reasonably decent privacy protections, there are no legislative protections in Ireland against the discriminatory use of such genetic information by insurance companies.[33]

6. IMPACT OF REGULATION ON ANTI-SELECTION

These examples of international regulation and industry guidance highlight how insurers or government policy can impact the potential extent of anti-selection. In the context of genetic anti-discrimination, policies that largely bar insurers from considering genetic test results, such as in Canada or the US health insurance market, could theoretically increase anti-selection because insurers are prohibited from gathering information. Thus, the policy creates an asymmetric situation between insurers and applicants where the insurer cannot know potentially relevant genetic information about the individual they are insuring. This is sometimes referred to as regulatory adverse selection because the imposition of information asymmetry is stemming from government policy.[34] The benefit cap approach, such as in Australia, is a policy

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that protects individual interests for low to moderate levels of coverage but preserves the insurers' right to seek information symmetry for policies with higher benefit caps. The question remains, however, how much these industry guidances and regulations would lead to increased anti-selection and how this would affect insurance market outcomes.

II. Modeling Anti-Selection

Generally, we must rely on modeling to measure the potential impact of barring insurer collection and use of genetic test results because direct measurement of anti-selection in insurance markets is difficult. Take, for example, the UK Code on Genetic Testing and Insurance, and its precursor policy, the Concordat and Moratorium. Since this policy went into effect, there has not been evidence of greatly increased premiums or instability in the insurance market, despite insurers inability to consider predictive genetic test results in all but a very small handful of applications.[35] However, because UK insurers are unable to collect genetic test results, it is also impossible to measure the extent to which anti-selection is actually impacting markets. Given that the UK insurance markets are continuing to thrive, it is clear that an 'unraveling' has not occurred, but without data, it is unknown what potential anti-selection effects, if any, there were in the UK market following the moratorium. Thus, we can only model what the impact of a ban on collection of genetic test results would be, based on hypothetical scenarios.

Two primary disciplines model anti-selection in insurance broadly, and the impact of genetic testing specifically: actuarial science and economics. The two disciplines vary in methodology and focus, so the conclusions do not always align. Even within the disciplines, findings vary greatly as to the impacts of genetic testing, as is discussed further below. Ideally, in both disciplines, models attempt to approximate reality as best as possible—taking into account such evidence as may exist of insurance markets and human behavior. Sometimes, however, assumptions in the models may not capture true human behavior following a genetic test. As will be discussed further below, ELSI scholarship can help provide insight regarding human behavior to bolster assumptions about how individuals might react following a genetic test. Below we briefly summarize modeling of anti-selection across disciplines.

A. Actuarial Modeling of Anti-Selection and Genetic Testing

Actuarial modeling attempts to assess whether and to what extent anti-selection will impact premiums and whether this may change across lines of insurance. Such modeling poses two main challenges.

First, the risk of ill-health or premature death associated with a particular genetic variant must be estimated. All the major single-gene disorders now have a considerable epidemiological literature, so in principle these estimates can simply be taken from there. However, there are major traps for the unwary modeler: the rarity of genetic conditions, the testing setting, and the differences in manifestation and onset of genetic conditions.[36]

Relevant high-risk genetic disorders, such as hereditary breast and ovarian cancer or Huntington's Disease, are comparatively rare, which makes prospective studies of unselected populations (the gold standard of epidemiology) too costly. Therefore, study populations tend to be small and selected *because* they are known to be at risk, such as through manifested symptoms or family history.[37] Those with deleterious variants who do not meet the selection criteria are never studied. The result is that mortality associated with carrying certain variants can be overstated.

Genetic testing relevant for insurance has so far been largely confined to clinical settings. The tested population broadly coincides with the population selected for epidemiological studies, so such studies can, with caveats, be applied to persons who are tested. This is *not* true of any hypothetical extension of genetic testing to a larger population, for example by whole-genome sequencing at birth.

Some disorders manifest sooner than others with detectable clinical symptoms which are disclosable to an insurer. Compare breast cancer and cardiomyopathies (inherited heart disorders). Mutations in the *BRCA1* and *BRCA2* genes can indicate risk of breast cancer that may only develop decades in the future, while no cancerous tissue is present or detectable. Cardiomyopathies very often present major and detectable changes to the heart muscle at early ages.[38] In this case, barring insurers from using genetic test results does not deprive them from obtaining other health information about the early existence of a serious condition.

Second, anti-selection is a behavior, that can be represented in a model, but the empirical evidence varies by line of insurance and is not consistent across studies. A model must represent the (different) information available to the individual and the insurer. This is not confined to genetic test results, but includes family history, especially if this caused the genetic test to be taken (in a clinical setting, see above) and measures from non-genetic biomarkers.

Two studies can help shed light on the important role of informational and behavioral assumptions in

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actuarial modeling. Macdonald & Yu (2011) modelled a wide variety of scenarios, mostly resulting in anti-selection costs being a fraction of one percent of total premiums.[39] They acknowledged that these results could be scaled up if more disorders were covered, or if `adverse selectors' chose very large sums to insure. Howard (2014) modelled a single scenario, in which 75% of `adverse selectors' took out ten times the average sum insured.[40] This model projected life insurance premiums in Canada to increase by 12%, and male and female mortality (among insured lives) by 36% and 58% respectively. The great majority of these costs were accounted for by the inclusion of several cardiomyopathies and differences in assumptions about insurance purchasing behavior.

B. Economic Modeling of Anti-selection and Genetic Testing

Whereas actuaries use information about risk, the course of disease, and potential informational constraints to model the potential impact on insurance premiums, economists assess the potential consequences of anti-selection by looking at efficiency and measures of overall social well-being, or so-called 'social welfare' on insurance market outcomes.[41] When insurers face informational constraints, market outcomes are less efficient than if information was shared between insurers and policyholders. Models focusing on efficiency find that a ban on risk classification entails a loss in efficiency because full disclosure is always the most efficient system.[42]

Different conclusions may be reached when taking an ex-ante view that focuses on social welfare.[43] For example, if we consider two groups, people at high-risk and people at low-risk, there could be a policy change that benefits those at high-risk at the expense of those at low risk. A ban on risk classification can be beneficial if the advantage gained by those at higher risk outweighs the burden imposed on those at lower risk.[44] From an ex-ante view, a ban on risk classification can thus protect individuals from facing classification risk, which may otherwise deter them from genetic testing altogether. Therefore, there are arguments that policies that restrict certain types of risk classification may be preferable on distributional grounds. While there is a more efficient way to achieve these redistributive goals in principle, it is far from clear whether this could be achieved in practice. Recently, others have looked at anti-selection from a similar perspective called 'loss coverage' and found a comparable overall effect where even if there is some anti-selection, the benefit to those at high-risk can outweigh the extra cost to those at lower risks.[45]

The typical anti-selection models need to be modified in the context of predictive genetic testing because here the applicant has information based on a choice to take a genetic test and the outcome of that test. Early economic analyses concluded that a regulatory regime allowing insurers to use genetic test information is better than one which prohibits it.[46] Since then, this conclusion has held across other economic studies.[47] For example, other studies have incorporated psychological costs from testing, such as feelings of anxiety about the future[48] or tested the findings across genetic information that has decision-making value for the individual because preventive treatment options may be available.[49] A recent study, however, modeled that, when premiums are so large that access to insurance becomes an issue, policies that allow for use of genetic test information may not be as good in terms of social welfare as those that ban genetic information.[50] These models mostly apply to private health insurance and long-term care insurance where contracts are exclusive, meaning that individuals do not buy policies from multiple insurers. In the life insurance context, however, models predict varied outcomes for the impact of genetic testing on insurance,[51] in some instances finding that prohibiting insurers from using genetic information increases social welfare.[52]

Several additional studies that have analyzed anti-selection in life insurance specifically for genetic testing are of note. An early 1999 study predicted that, in the case of life insurance, failure of insurers to adequately obtain genetic test results related to breast or ovarian cancer could lead to "unbearable" costs related to anti-selection.[53] However, the study concluded that such costs could be manageable if family history is adequately taken into account.[54] Another study found only modest anti-selection welfare costs from banning life insurers' access to *BRCA1/2* test results, but point out possibly large efficiency costs, for family background groups who are at high risk for carrying the genes, should the test become widely adopted.[55] Another study also focused on the *BRCA1/2* genes and concluded that anti-selection due to genetic testing is a manageable problem for insurance companies as long as testing rates are low and only a few highly predictive genetic tests are available.[56]

III. Anti-selection, Genetic Testing, and Insurance Purchasing Behavior

When modeling the potential for anti-selection, economists, actuaries, and other researchers must make several assumptions to incorporate into their analysis. One such assumption is whether individuals will alter their insurance purchasing behavior after receiving the results of a predictive genetic test. If insurers can-

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not price-discriminate based on genetic test results, individuals with a positive test may opportunistically buy more coverage than they otherwise would — but the full extent of such behavior is unknown. Therefore, models must anticipate whether individuals who learn that they have an increased risk for a genetic disease and have no duty to disclose will subsequently purchase insurance, increase their coverage, or maintain the status quo.

So which assumptions regarding the percentage of individuals who may purchase insurance best approximate reality? The evidence is limited and seems to depend on the specific line of insurance and the type of genetic test.

The actuarial models discussed above approached this assumption in very different ways. The Howard model, for example, made a bold assumption: 75% of those who received a positive result for one of thirteen genetic conditions would opportunistically apply for as much life insurance coverage as they could get while everyone else would not apply for additional coverage.[57] A US Society of Actuaries (SOA) study ran the model several times, varying the estimated percentage of individuals purchasing insurance following a positive genetic test. These varied assumptions led to different predicted results for the life insurance industry.[58]

So which assumptions regarding the percentage of individuals who may purchase insurance best approximate reality? The evidence is limited and seems to depend on the specific line of insurance and the type of genetic test. For example, one retrospective study examining *BRCA1/2* in a cohort of women, found that 37 women (6% of those surveyed) changed their life insurance coverage after genetic testing, including 27 (4%) who increased their coverage.[59] Those women who chose to increase their life insurance policy were more likely to carry a *BRCA1/2* mutation, raising prospects of anti-selection.[60] While this small study highlights the possibility of some anti-selection, it is nowhere near the 75% assumption level incorporated into the Howard model described above. Additionally, another study found no influence from *BRCA1* research results on participants' purchasing of life insurance policies.[61]

Several studies have found potential evidence of anti-selection specific to long-term care insurance. For example, one found that those with a positive Huntington's Disease mutation are five times more likely to have long-term care insurance than the general public.[62] This study, however, did not assess when individuals took out insurance relative to their genetic test. So, it is possible that for some portion of these individuals, there was no information asymmetry regarding genetic testing between the insurer and the applicant at the time of their application for insurance. To address this, the study compared levels of long-term care insurance between those with a family history of Huntington's disease who were tested and did not carry the familial mutation versus those who did. Those with the familial mutation had rates of long-term care insurance ownership 20 to 30 percentage points higher than those without, although this observation comes from only 71 individuals who opted to get tested.[63]

Another study found those who tested positive for increased risk for Alzheimer's Disease reported making more changes and to have been thinking about making changes to their long-term care insurance policies (p-value of .0511), but found no significant changes in insurance purchasing behavior in health, life, and disability insurance.[64] Additional checks to ensure that these estimates were robust found that the results were 'only suggestive'.[65] Overall, the variance in the literature suggests no widespread agreement on the impact of genetic tests on insurance purchasing behavior and, therefore, anti-selection and that any evidence that there is an impact is based on studies with small sample sizes and focused on diseases with high penetrance and few preventive measures.

IV. Insurance Purchasing Behavior in the Real-World

Modeling and actuarial projections currently attempt to incorporate information about human behavior into predictions, but assumptions must be made in order to fill in evidentiary gaps. While some studies have explored how individuals react regarding insurance post-genetic testing, these studies have been relatively limited and focused on a small handful of severe genetic conditions. Greater ELSI research in this area can help support estimates of anti-selection by highlighting and empirically measuring the real-world complications that can affect individuals' insurance purchasing behaviors following a predictive genetic test.

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In this section we explore multiple factors that may contribute to insurance purchasing decisions and categorize them into four types: (A) internal barriers, which are those that are intrapersonal to the individual, (B) external barriers, which are the societal experiences that influence decision-making, (C) genetic dimensions, including different testing types and the information they produce, and (D) system dimensions, including alternative methods insurers may use to find information about the applicant.

A. Internal Barriers: Not Everyone Will Act 'Rationally' Following a Genetic Test

1. AVOIDANCE AND COPING MECHANISMS

Individuals react very differently to information about threats, including potential threats to their health. Self-regulation theory, for example, "refers to the processes through which individuals direct their thoughts, emotions, and actions to achieve desired outcomes and minimize harms."[66] The theory has been applied in the context of learning about future genetic risk to help understand individual reaction to risk information.[67] One aspect of self-regulation is that information that elicits fear or negative emotion can lead to coping behaviors such as avoidance.[68] Discussions of coping behaviors in the context of genetic testing highlight that individuals may avoid learning about genetic risk, may avoid discussion of risks with family members or medical care teams, or avoid recommended screenings.[69] Others could use coping mechanisms that minimize the importance or deny the accuracy of the risk information.[70] Generally, papers discussing avoidance and denial mechanisms following genetic test results do not specifically discuss insurance purchasing behavior. However, it is conceivable that individuals who are coping with negative or fearful information by ignoring, minimizing, or otherwise avoiding coming to terms with the information are unlikely to apply for greater insurance coverage as this would require direct acknowledgement of the risk information.

Studies also show evidence of information avoidance in the context of health information. Several papers model a patient's anxiety and fears arising from expectations about possible adverse health conditions.[71] In the context of genetic testing, individuals who are sensitive to "message uncertainty" associated with the taking of a genetic test may prefer to forego testing altogether and stick with their current belief despite the predictive value of genetic information.[72]

Some studies and modeling support this claim. First, in practice, take-up rates for existing genetic tests are low. When anonymous and costless genetic testing for Huntington's disease was offered, one study found that the percentage of individuals at risk who requested testing varied from 9 to 20%.[73] Similarly, another study finds take-up rates of 10%.[74] However, other studies related to hereditary breast and ovarian cancer have found high testing uptake rates of 78.2%.[75] These findings are notable given the differences between Huntington's Disease and hereditary breast and ovarian cancer. The former has no current clinical interventions, whereas knowledge of predispositions to breast cancer can lead to more intensive screening or preventive surgery. It is also important to note that public attitude towards genetic testing varies over time and may depend on the perception in the general population, experience by family members and peers, knowledge about prevention and treatment opportunities, and other factors. For example, after actress Angelina Jolie wrote an editorial in the *New York Times*, there was a measurable "Angelina-Jolie effect." One such measurement was conducted 15 days after the publication of the editorial and found a significant increase in daily *BRCA1/2* testing rates by almost 60%.[76]

2. UNDERSTANDING OF RISK

Individuals face another barrier when they do not know what to make of their genetic test results. Information about genetic risk is complex and difficult to fully understand, especially for those with lower health literacy. Even if individuals know the possible medical consequences of predictive genetic test results, many questions may linger about impact across other aspects of their lives, including financial ramifications.

It is well documented that many individuals have low health and financial literacy and that this makes it difficult for them to process risk and decision-making in healthcare generally[77] and genetics specifically.[78] An individual who misunderstands their level of risk may make insurance purchasing decisions based on their personal perception of risk, not their actual risk. For instance, some applicants may perceive their risk to be higher than it actually is causing some to purchase more insurance than they need, which may then benefit insurers. For example, in the study of the rates of long-term care insurance and Huntington's disease, 27% of those who had a family history of the disease, but a negative genetic test result — and thus at no risk of developing Huntington's disease — had long-term care insurance compared to 10% in the general population.[79] Others may undervalue their risk and purchase too little insurance to cover their expected loss. In either case, misunderstanding of risk may make the insurance purchases of individuals appear irrational or unexpected compared to their actual risk.

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3. RISK PERCEPTION AND ENVIRONMENTAL FACTORS

The multidimensional interaction between genes and other factors such as environment and lifestyle choices (e.g., diet) must be taken into account when determining an individual's predisposition to disease.[80] Additionally, for some genetic conditions, there are a range of mitigating or preventive measures available to lower one's risk of developing disease. For example, women with a positive *BRCA1/2* test result may undergo prophylactic surgery or undertake more frequent cancer screenings. Individuals predisposed to heart disease may alter diet or exercise routines.

At this time, the predictive value of most genetic tests is therefore somewhat limited because they indicate the probability that an individual may develop a disease, and do not yet fully take into account how individual characteristics, prevention, and environment alter the risk. Although science and technology are advancing quickly, the predictive value and clinical utility of genetic tests vary.[81]

Individuals and their healthcare providers, therefore, may evaluate genetic risk differently depending upon how they view the relevance of environmental factors and the interaction with genetic factors. This, in turn, could affect whether and how much insurance an individual chooses to purchase. For example, an individual who learns of a genetic risk factor for heart disease may believe, accurately or not, that their lifestyle exercise and diet choices mitigate this risk enough so additional insurance is not necessary.

B. External Barriers: Not Every Opportunistic Individual Will Be Able to Access Increased Insurance

Insurance purchasing behavior is influenced by more than genetic testing results and an individual's understanding of their genetic risk. Many personal and societal factors weigh on an individual's calculus in deciding whether to purchase insurance. One important factor is the affordability of a plan. Even with a positive genetic test, applicants are unlikely to immediately seek out and purchase maximum coverage if they cannot afford the premiums.

1. FINANCIAL COST

The average life insurance premium across the countries examined in this paper are instructive. In the United States, the average monthly premium for a healthy 40 year old for a $250,000 term life insurance policy is approximately US$20.[82] A healthy 30-year-old in Canada can expect to pay an average of CAN$13 (US$10.23) per month per $100,000 of coverage.[83] In Australia, a healthy 40-year-old pays about AU$18 (US$13.60) per week for $250,000 in coverage. For women, this rate is cheaper at around AU$11 (US$8.70) per week for $250,000 in coverage.[84] In the UK, the average term life insurance premium is £30 (US$41) monthly. Unsurprisingly, these premiums vary by age and health status but the average premium demonstrates that the expense for just life insurance is one that could have an impact on an individual's or family's budget.

While some individuals or families could absorb these costs through budgeting, many families may not be able to afford additional insurance even if they desired it.[85] For example, one study found that individuals with a self-reported income of less than $49,000 had a higher frequency of Huntington's Disease diagnosis than those of a higher income.[86] One possible explanation for this is the inter-generational wealth effects of having a parent with a genetic illness.[87] Thus, individuals with a predisposition to Huntington's Disease may be less likely to be able to afford the costs of additional insurance. Additionally, even if the cost of a $250,000 life insurance policy could be affordable for many families, increasing this amount to greater coverage could begin to stretch budgets thin.

2. KNOWLEDGE OF A COMPLEX SYSTEM

Further, it is not clear that applicants know enough information from a genetic test to accurately predict the amount of coverage that they may need or want. Applicants may not even know the type of coverage available to them or they may assume that insurance costs are too high for their budget.[88] The impact of anti-selection may be significantly decreased if applicants do not know how to use their genetic test results to their advantage, since one key element of anti-selection is individuals 'exploiting' their informational asymmetry. Indeed, research in the UK has shown that only as few as 10% of applicants considered more than one life insurance policy while 59% relied on the advice of a broker.[89]

If anything, the taking of a genetic test might initiate a thought process to finally "get around" and obtain an adequate amount of life insurance for the household, as many people currently have insufficient life insurance holdings.[90] For example, Bernheim et al. (2003) argue that an insufficient purchase of life insurance is responsible for two-thirds of poverty among widows and over one-third of poverty among widowers.[91] Individuals may simply procrastinate on life insurance decisions to avoid thinking about the possibility of premature death and the hardship it would impose on the surviving family. Another obstacle encountered in practice is that people may not know how to determine an adequate amount of life insurance and do not feel comfortable taking financial advice. Acting upon the results of a genetic test may help overcome some of

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these cognitive hurdles and actually help improve the problem of insufficient life insurance holdings.

3. BARRIERS TO ENTRY

Applicants also incur opportunity costs to enter the insurance market. There exists a wide array of policy options, coverage types, and payouts that come with varying levels of complexity and work required to gain coverage. Some insurance applications, usually those for higher payouts, are complex and take significant time to complete and be processed.[92] This means that there is real opportunity cost to filling out applications, collecting required disclosure information, undertaking medical exams, and deciding which policy to purchase. Determining the best policy and coverage amount may be more difficult for those with lower financial literacy, a problem in populations across the globe.[93] Some applicants may find that the opportunity costs associated with purchasing insurance as a result of a genetic test are simply too high and forego it altogether.

C. Genetic Dimensions: Genetic Tests Are Complex and Variable

There is no single monolithic genetic test. Different types of genetic tests provide different information about risk. The type of genetic testing one gets, therefore, will greatly alter perceptions of risk and subsequent decisions about insurance purchasing. Many of the studies measuring insurance purchasing behavior focus on predictive genetic test results for adult or late-onset highly penetrant serious monogenic disorders, such as Huntington's disease and hereditary breast and ovarian cancer.[94] Even with these conditions, the situation is much more complex than it seems. For example, even in the case of Huntington's Disease, there is some reason to believe anti-selection would be less of a problem than foretold by insurers due to the rarity of Huntington's disease, the small group of those at-risk who opt for testing, insurer access to family history (in many countries), and the variation in progression and severity of disease.[95]

But not every genetic test is as predictive as these key examples. Modeling should, and often does, take into account a wide variety of genetic conditions in order to understand the potential impact on insurers. Assumptions of insurance purchasing behavior must also consider how individuals with less penetrant or less severe genetic conditions will react.

The field of genetics has evolved at a rapid pace in recent years giving rise to a multitude of tests and testing technologies that include: polygenic risk scores for multifactorial diseases, risk prediction models, whole genome sequencing, recreational genetic testing, low penetrance multifactorial gene panels, epigenetic clock, and pharmacogenetic tests.[96] While some of these technologies and tests appear particularly promising, they are mostly still at the research stage. The health impact of the few that have been translated into the clinic (mostly pharmacogenetic tests) is not sufficiently documented yet to support the conclusion that non-disclosure of results could lead to widespread anti-selection. However, given the fast progression of the discipline, careful monitoring of developments by actuaries and independent experts appears warranted.

It is also important to consider the distinction between diagnostic and predictive genetic testing. While this paper focuses on predictive genetic testing, some laws do also limit insurer use of diagnostic genetic tests. For example, while the UK Code covers predictive genetic testing, the Canadian Genetic Nondiscrimination Act applies to both predictive and diagnostic testing. Diagnostic genetic results serve to confirm or rule out a diagnosis based on existing symptoms, signs or abnormal non-genetic test results which indicates that the condition in question may be present.[97] Even if individuals who get a positive diagnostic test result were interested in altering their insurance purchasing behavior, the patient would still need to disclose to the insurer some information about the likely disease affecting him. In this case, the benefit to the insurer that can use the information is achieving greater certainty on the specific condition afflicting the applicant.[98] Such added certainty may also sometimes benefit the applicant. The proper premium will be easier to set for the insurer who may, in turn, be more likely to take on the risk and to make an adequate pricing assessment rather than overprice or reject an applicant because of a degree of uncertainty regarding his actual illness. Alternatively, if the insurer is unwilling to take on the risk, they could already identify that risk based on existing symptoms without reliance on the genetic test.

D. System Dimensions

1. TIMING OF PURCHASE

The timing of an individual's genetic test compared to when they purchase insurance also influences anti-selection. Some applicants, for example, already have existing policies that meet their needs well before they consider and take a genetic test. Others specifically choose to purchase an insurance policy directly before receiving a genetic test. Indeed, sometimes genetic counselors or other healthcare professionals recommend securing insurance prior to undergoing testing.[99] Here, the information balance between insurers and applicants who purchase insurance before receiv-

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ing a genetic test is no different than the information asymmetry between insurers and other applicants — as both would theoretically have access to information about family history and clinical symptoms. This scenario may bypass the anti-selection problem altogether since neither party could use information asymmetry to their advantage.

Sometimes, however, an applicant may know that someone in their family has received a positive genetic test and, depending on the jurisdiction, this information would not automatically come to light in an insurance application. In some jurisdictions disclosure would be required to the insurer, in other jurisdictions it would only be required if the insurer directly asks, in others no disclosure of genetic tests undertaken by family members is required. This may give the individual slightly more information about their risk than the insurer. However, the applicant still does not know her own genetic risk compared to that of the family member.

Timing is likewise important in the context of negative tests. It is not obvious that those who enroll in a life insurance plan before knowing genetic test results suddenly drop their plan once discovering they tested negative. In these scenarios, at the time of application, the individual would appear at higher risk due to family history and would be classified accordingly. Upon receiving a negative test result, some individuals may reapply based on the new information to obtain a lower premium, but others may not (due to the internal and external barriers described above), thus keeping more low risks in the risk pool, to the benefit of insurers.

2. 'GAMING THE SYSTEM'

When thinking about coverage amounts, there are two distinct pathways. In one, individuals are motivated to take out insurance to meet normal needs. In the other, individuals engage in a financial gamble by taking out abnormally large sums insured. A common approach to determining the amount of insurance to purchase is a needs analysis. For example, in determining the need for coverage for life insurance the applicant or financial planner on her behalf determines cash needs (e.g., funeral costs, installment debts, estate and inheritance taxes), income needs (for children and the surviving spouse during the readjustment and dependency period) and special needs (e.g., mortgage, emergency fund, college education). The total needs are then compared against available sources of recovery (e.g., checking and saving accounts, retirement funds, current group and other life insurance, etc.) to determine the additional amount of life insurance required to cover the gap. None of these calculations is affected if an applicant receives bad news about mortality risk.

Applicants may not always value life insurance as a key asset. A recent survey in the US by the Association of Life Insurance Underwriters reported that of individuals without life insurance only 38% believed they specifically needed the product.[100] Of course not all applicants place equal weight on the value of a life insurance policy, because the perceived need for life insurance depends on family circumstances, such as the number of dependents or existence of mortgages. For example, not all applicants who carry a life-threatening genetic variant or who know they have a family history of disease will view the need for life insurance policy the same. They will likely contextualize this need based on their family and financial circumstances.

Yet the worry about opportunistic purchasing can be seen in the Howard modeling described above.[101] Howard adduced no direct evidence for the financial-gambling behavior of 'adverse selectors.' However, statements in a document released by the Canadian Institute of Actuaries alongside Howard, and by Howard in evidence before a committee of the Canadian Senate, suggest that these assumptions were motivated by fears that viatical companies, legal in four Canadian provinces, would finance the purchase of policies with large sums insured by individuals with adverse genetic test results, who would then assign the benefits to the companies.[102]

Such activity, known as 'stranger-originated life insurance' (STOLI) did take place in the USA, especially before 2008. However its targets were extremely wealthy elderly persons with relatively short life expectancies.[103] There is no evidence that any population with adverse genetic test results, neither very old nor exceptionally wealthy, and with reduced but by no means negligible life expectancies, would prove profitable for viatical companies.[104] There is no published evidence of STOLI activity linked to genetic tests in the UK, where the Code has been in force for almost 25 years (and viatical companies are legal).

Moreover, if viatical companies were to make egregious profits from genetic tests, they would have to be better than clinical geneticists in discovering persons with deleterious variants, better than epidemiologists in understanding the clinical risk, and better than actuaries in understanding actuarial risk.[105] They would also be betting against any medical advances reducing mortality over several decades. It has been suggested that life insurers in North American have long-standing antipathy towards viatical companies because they are actually concerned with low lapse rates.[106] Current profit calculations assume that individual policyholders will have relatively high lapse rates, but policies purchased by viatical companies will likely not be lapsed — cutting into insurer profits.

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This, however, is a different matter entirely than problems with STOLIs.

V. What Does This Mean for Concerns about Anti-Selection?

Global discussions about whether insurers should be able to access and use genetic test results are inevitably intertwined with concerns of anti-selection. Different studies and models indicate the possibility for a variety of insurance purchasing behaviors—leading to a significant range in the estimated negative economic impact of any policies limiting insurers' use of genetic test results. If the impact of barring insurer use of genetic test results is so drastic as to significantly impact the insurance market, genetic anti-discrimination laws may face a tough road to enactment or new efforts may be undertaken to amend existing policy in favor of policy that is less restrictive. However, a more limited modelled impact suggests that a slight increase in premiums may be a viable policy choice in order to address fear of discrimination and other social concerns

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A. Use of Alternative or Complementary Strategies

In light of the complexity of the issues arising in this field, the novel nature of the challenges presented and their interdisciplinary nature, and in consideration of the fast pace of scientific and technological advances, it is questionable whether laws alone can adequately address the concerns presented in this area. There is arguably a potential for a lack of understanding of the realities and limitations of advancing genetic science, as well as a lack of awareness of the existence of relevant legal protections, on the part of medical and legal professionals, as well as the general public.[107] This may perpetuate further stigma and negative attitudes towards individuals with certain genetic susceptibilities and intensify the potential for discriminatory and other unfair treatment. Furthermore, legislation can take years to adopt and, once enshrined, can become static due to the difficulty of amending the law. This leads to outdated laws as scientific advance outpace the legislation.

In light of these challenges, some alternative strategies to address genetic discrimination and the use of genetic results in insurance merit consideration (in addition to any traditional legislative frameworks), including public-private agreements, public engagement, awareness raising and education, and multidisciplinary dialogue.

A multifaceted and well-informed awareness-raising and education campaign is needed, which targets the myriad of stakeholders in this field, as well as the public. Such a campaign should aim to ensure that individuals are aware, not only of the basic elements of genetic science (and the benefits and limitations of genetic testing) but also the potential for misuse of their genetic information (and any legal or other protections in place).[108] Awareness raising campaigns should similarly target scientists and medical professionals, and commercial third parties such as insurance companies and ensure that they are informed about the ethical and legal issues that may arise with use of genetic information, as well as any relevant protections or policies in place.[109] A number of international legal instruments have highlighted the need for such awareness raising and education in this area.[110]

In addition, ongoing multidisciplinary engagement and discussion is required in this area.[111] There is a need for in-depth and focused discussion and consultation with the various stakeholders involved, including scientists, insurance companies (and other third parties), lawyers and policy makers. This discussion is particularly necessary in the insurance industry, in light of the complexity of the issues arising regarding fundamental practices and principles of the industry, and with a view to achieving the correct calibration of competing interests (between the insurer and the customer). In conjunction with such measures, there also needs to be public consultation and engagement on these issues to ensure transparency and to gauge the public's attitude and perception of these issues.[112]

In light of these challenges, some alternative strategies to address genetic discrimination and the use of genetic results in insurance merit consideration (in addition to any traditional legislative frameworks), including public-private agreements, public engagement, awareness raising and education, and multidisciplinary dialogue.

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VI. Conclusion/Next Steps

From the insurer's perspective, allowing access to genetic test results for underwriting seems highly logical, maybe even obvious. But society must be concerned if many individuals choose not to undergo testing out of fear of genetic discrimination.[113] The competing interests between the need for insurers to have access to information known to applicants to accurately allocate risk and for applicants to be protected against unfair discrimination by insurers is at the core of regulation in this area. It also requires a deeper inquiry into whether anti-selection is actually as serious a problem as some insurers suggest. As we have laid out in this paper, the actuarial and economic models generally do not suggest wide-spread and severe anti-selection effects related to genetic testing. Further empirical evidence from ELSI researchers regarding individual purchasing and other behaviors following a genetic test will help to provide data for actuarial and economic modeling, as well as provide key research to underline any regulatory or policy response.

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Authors' Note

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Note

The authors do not have any conflicts of interests to declare.

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